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# 1 Executive Summary

This report provides a comprehensive overview of the state of women's health in Leeds. By exploring the wider social and economic circumstances women and girl's experience, as well as the physical and emotional health challenges they face, we have created a picture of women that has been lacking up to now. What the study reveals is that despite the city taking very positive steps towards improving the health of women, there are still many whose health is poor and who are living in difficult circumstances. In part, this is due to a society that has under-appreciated the significant health challenges women face, leaving many women struggling with complex needs well beyond the point where support should have been available.

## Demographic profile of women in Leeds

There were 437,946 females living in Leeds in January 2018, with 15.9% aged 0-15 years, 66.1% aged 15-64 years and 17.8% aged over 65 years. The age profile of localities within Leeds can vary considerably, with some having nearly a third of their population over 65 years and others a greater proportion of younger women. The female population of Leeds is growing, with the biggest increase (34%) set to be in the over 65's by 2038. Leeds is a diverse city, with 20% of its female population from the Black and minority ethnic (BME) community, although this varied by area. In 7 MSOAs over half the population was from the BME community. It is estimated that women may live nearly 22 years with some form of disability. Within Leeds there are 5,000 women who report themselves as Lesbian, 4,000 as Bisexual, and 2,000 as Other.

## Social determinants of women's health

#### Education

Girls tend to do better overall in education than boys, with an increase in those achieving a good level of development in their early school years. Over 40% of girls, compared to just under 37% of boys achieved a GCSE in English and Maths, with 82% of girls achieving at least 2 substantial A-level grades. Although women have greater educational attainment there are fewer qualified women in the workforce. There is a growing recognition that more girls have un-diagnosed Autism and attention deficit hyperactivity disorder (ADHD). Across Leeds there are 176 year 11 and 12 girls not in employment, education or training (NEETs), of these 52 females were not available for work due to illness (10), pregnancy (15), through being teenage parent (26) or being a young carer (1).

### Housing

There is a higher proportion of younger women in council housing (15,438 women under the age of 45 as compared to 9,094 men). Nearly 60% of council tenants are female, with more older women in sheltered accommodation than men. There are currently 5 women sleeping rough in Leeds, but there may be many more who are affected by homelessness.

## Marital status and relationships

Men are more likely to be living alone in their adult years, whereas the proportion of women over 65 years living alone is higher than for men (66.5%). There has been an increase in same-sex couples and an increase in single sex couples with dependent children. Nationally there are 1.6million women and 179,000 men with dependent children in lone parent households.

## Carer

More females than males have carer responsibilities, with females in Leeds comprising nearly 60% (10,117) of those devoting more than 50 hours per week to caring for another, with a poorer gender balance in the more deprived areas.

#### Employment

In Leeds, there are more economically active men than women (79.9% men aged 16-64 years as compared to 69.2% of women), but female participation in the labour market has increased year on year. This is set to increase as the raising of the retirement age for women takes more effect. Unemployment rates are almost the same for men and women in the city (4.7% females, 4.8% males). Women are more likely to work part-time and although there has been an almost levelling of pay gap in

part-time work, full-time occupations still see an inequality with a median pay for a female full-time worker of £24,072 compared to £30,315 for a male worker.

## Poverty

23% of women (98,556 women) live in the most deprived areas of Leeds, with only 8% in the wealthiest. Women from ethnic minority backgrounds are more likely to be living in the poorest areas (nearly 74% of all Bangladeshi women and 68% of all Black Africans).

## **Benefit claimants**

Across Leeds 4,185 working age women (7,230 men) are claiming benefits of one form or another. There is a greater proportion of women in receipt of housing benefits (60% female, 40% male), with 37% of women with some level of arrears in their rental payments, with a higher proportion in the higher arrears banding.

## Asylum seekers and refugees

Currently there are 824 asylum seekers/refugees receiving support under Section 95 of the Immigration and Asylum Act 1999 in Leeds. It was not possible to find out how many of these are female. It is recognised refugee women and their children require support to get the care they need when living in their host county.

#### Sex work

Women engaging in sex work come from a broad spectrum of society for a wide range of reasons. They are more likely to experience mental health problems and stigma than other sections of society and find difficulty accessing services. Leeds is taking a proactive role in supporting sex workers through the introduction of a managed approach.

## Prison and offending

There is not a female prison within Leeds, however there were 132 women released back into Leeds in 2018. There is a new secure children's home at Adel Beck, catering for girls and boys aged 12 to 15 years. Two thirds of young women who commit crime have been in statutory care and have complex needs. There is a call

for young female offenders to be given community-based sentences rather than being sent to prison.

#### Health status of women in Leeds

Women's health has generally been improving; life expectancy for both men and women was increasing up until 2012-2014 but then remained static since 2012-2014 and is now starting to fall. Life expectancy for women in Leeds is 1 year below the national average. Deprivation has a major impact on the health of the population, with the mortality rate in women in the more deprived areas of Leeds 40% higher than that in the wealthiest areas.

#### Cancer

Cancer is the greatest overall cause of mortality for women in Leeds, accounting for 26% of all female deaths in the city. Deprivation has a marked effect on the risk of dying of cancer with a 30% higher mortality rate in those living in the poorest areas. There has been an overall fall in cancer deaths over the past 10 years, however lung cancer mortality is still rising, as is ovarian cancer. Big reductions in cervical cancer are being seen as a result of the HPV vaccination programme.

#### Diseases of the Circulatory system

Diseases of the circulatory system are the second largest cause of mortality in women in the city. The rates have been decreasing, with a 27% reduction in deaths over the last 10 years. There is great variance depending on where women live, with those in the poorest areas having a 50% higher mortality rates than those in the wealthy parts of the city. Women tend to develop cardiovascular disease later in life, unless they have type 2 diabetes, where the rates are the same as for men.

#### **Respiratory disease**

Respiratory diseases account for the third highest cause of death in the city for women. In the poorer areas of the city, women have over twice the death rates of women who are non-deprived. Chronic obstructive pulmonary disease (COPD), is the cause of more female deaths than breast cancer, with the prevalence of asthma greater than that in men. Women have higher levels of cystic fibrosis than men and a higher mortality.

#### Diabetes

Although more men are diagnosed with diabetes, the implications for women getting the disease are important, with effects on fertility, pregnancy and cardio-vascular health. Across Leeds there are 3,032 females with Type 1 and 16,018 females with Type 2 diabetes, with a rate of 37.3 per 1,000 births of gestational diabetes. It is important that women with diabetes seeks advice if they are planning a pregnancy, and if they are pregnant, they are carefully monitored. Type 2 diabetes incidence increases with deprivation, mostly due to the higher levels of obesity.

## Mental ill health

There is an increasing number of young women who are developing mental health problems. Black women, Asylum seekers and refugees, and Gypsy and Traveller groups have higher rates of common mental health disorders and are less likely to receive mental health treatment. Recently available data from services in Leeds suggest that a higher proportion of females than males have a diagnosed mental health condition when they first access treatment for substance misuse. Self-harm rates and eating disorders are more common in girls and women and suicide is the leading cause of death in women up to 34 years of age. Sexual abuse, violence and trauma are important causes of mental health difficulties in women.

There are an increasing number of women being diagnosed with dementia, which is now the single largest cause of female death, with 741 female and 402 male deaths in Leeds in 2016.

## Long term conditions, frailty and end of life

In Leeds there are 151,435 women living with one or more long term conditions (36.2% of the female population), with 19,818 women registered within the frailty cohort (4.73% of the female population). More women than men are registered onto the end of life cohort (1,214 women, 797 men).

#### Sexual Health and Contraception

#### Contraception

Leeds has a larger proportion of its population at childbearing age than seen regionally and nationally, with 44.8% of the female population aged 15 to 44 years of age. There has been a recent decline in the use of long acting reversible contraception, but rates are still higher than the national rate. There is greater use of Emergency Hormonal Contraceptives in areas of higher deprivation. 12.1% of girls in years 9 and 11 reported having had sexual intercourse (13.4% of boys), with 5.1% of the girls feeling pressurised into having sex (3.9% of boys). Only a small percentage (8.5%) report using any form of contraception. There were 330 conceptions in teenagers aged under 18 years in 2016, with the rate decreasing.

#### Sexually transmitted infection (STI)

There has been a rise in women diagnosed with gonorrhoea (245 women diagnosed in 2017/18) and chlamydia (1,683 women in 2017/18), with a decrease in women attending for screening. However there has been an increase in on-line requests for testing kits. In Leeds, there is a high positivity rate, indicating that despite a reduction in those tested, improved effectiveness of targeting is identifying those most at risk.

#### Human Immunodeficiency Virus (HIV)

Deaths from HIV/AIDs are now rare in the UK. Across Yorkshire and The Humber there were 1,121 females diagnosed with HIV, of which the majority were Black African. In Leeds 53.4% of HIV diagnoses were made at a late stage of infection (41.1% nationally).

#### Healthy Lifestyles

#### Tobacco use

There has been a year-on-year decline in women smoking, but Leeds levels are still higher than the rest of Yorkshire and England. More men than women smoke, but Leeds girls are more likely to smoke than similar-aged boys, with White girls smoking more than other ethnicities. There are 9.8% of women in Leeds smoking during pregnancy, which is lower than the national average. Women find it harder to quit smoking than men.

#### Alcohol use

The risk of developing health problems through excess alcohol is greater in women than men. Chronic liver disease is now the 5<sup>th</sup> commonest cause of death and morbidity in women across the UK. School girls are more likely to drink alcohol than boys, but boys have a higher consumption. Female alcohol intake overall is higher in the wealthier parts of the city, with 63.6% of women consuming alcohol in IMD10 as compared to 28.5% in IMD 1. However, mortality is higher in the poorest areas at 26.9 per 100,000 compared to 7.6% in the wealthiest areas.

#### Drugs and substance abuse

There has been a recent rise in female deaths as a result of drug and substance abuse, with Leeds rates higher than England. Women can get addicted at a lower rate of usage than men and are increasingly using alcohol and detox rehabilitation. Sexual minorities are at greater risk of substance abuse.

#### Gambling

Problem gambling is still predominately seen in men, but there are an increasing number of women that are becoming addicted. There are important links between problem gambling and offending behaviour, with 23% of female prisoners having a pre-sentence history of at-risk gambling.

#### Obesity/Overweight and Underweight

Across Leeds 7.1% of the adult female population are classed as obese, but this rises to over 30% in some MSOAs, with a strong link to poverty. 8.5% of reception aged girls are overweight compared to 9.2% of boys. By year 6, this has increased to 18.1% of girls and 21.0% of boys. Obesity has significant health consequences for women, including increasing the risk of diabetes and cardiovascular problems along with implications for fertility and problems during pregnancy. More than twice as many women as men have a hospital admission for obesity treatment.

There are a greater number of women diagnosed with underweight than men, which has implications for its own health risks.

### Physical activity and sedentary behaviour

Women have lower activity levels than men and higher rates of being inactive, with the rates lower in deprived areas, with South Asian girls having the lowest levels.

## Use of health services

## Cancer screening

Leeds has lower than the national average of breast cancer screening (with 74% of eligible women screened), but it is improving. Cervical cancer screening is also falling with a 73.6% uptake in 2017. On a more positive note, bowel cancer screening is increasing, with 58% of eligible women tested in 2017.

## NHS Health Check

Over 90% of those eligible to have the NHS Health Check have been invited, with women from deprived areas more likely to take up the opportunity.

## Mental health service uptake

Twice as many women as men in Leeds access the Improving Access to Psychological Therapies Service. For acute mental healthcare, the difference between the sexes is not as great. There are slightly more men admitted to mental health inpatient wards than women, though a greater number of women are referred to Community Mental Health Teams. In Leeds, hospital admissions for self-harm are almost exclusively for females. Similarly, the majority of people seeking help for 'eating disorders as a primary diagnosis' within the IAPT service are women.

#### **Smoking cessation**

There were 944 women who set a quit date to stop smoking, of which 453 reported stopping and 378 were confirmed quitters on CO<sub>2</sub> testing. There are important issues in relation to women's difficulty in stopping smoking.

#### Weight loss

Access to weight loss services is greater in women, with 5,994 women (2,868 men) having a hospital admission due to obesity.

#### Reproductive health

Women have complex needs related to their reproductive health, which can impact on the 222,820 women in Leeds aged between 11 years and 51 years. These can include a significant proportion suffering monthly due to premenstrual syndrome and dysmenorrhoea, which can affect schooling, work and relationships. There are many disorders linked to women's reproductive health that can significantly affect their quality of life and yet are under-recognised by the wider society and the health services. The menopause affects every woman and yet remains poorly understood.

#### Maternal health and motherhood

Approximately 10,000 babies are born in Leeds every year. It is important to engage more women in preconception care, to ensure both the mother and father's health are optimal for future generations. Teenage conception rates are higher in Leeds than the UK but are falling. More women are conceiving over the age of 30 years. Fewer women in deprived areas are attending for a 10-week booking in appointment (68.2% as compared to 76.4%). Leeds has the lowest level of home births in the country (1.34% compared to 2.4% nationally) and is declining. There has been a reduction in the number of babies taken into care, but it is still higher than the national average of repeat care proceedings.

Across Leeds there were nearly 3,000 abortions in 2016, with a national increase in females aged under 30 years. For those women who lose a child through miscarriage or stillbirth, or through abortion due to fetal anomaly, support and guidance is needed, with a multi-disciplinary multi-organisational group taking this work forward in Leeds.

Breast feeding numbers vary greatly across the city, from 73% initiating breast feeding in the non-deprived areas down to 65.5% in deprived areas, and with just

19.5% of White British women living in the most deprived areas maintaining breast feeding.

There are long term consequences of pregnancy and childbirth, such as incontinence and pelvic organ prolapse that can have a marked effect on a woman's physical and emotional health and quality of life.

Between 10 – 20% of all women will experience a mental health disorder in the perinatal period. Whilst there has been a significant focus upon post-natal depression, there is increasing recognition that the whole of the perinatal period is a time during which women may experience a range of mental health disorders including: obsessive compulsive disorder, phobia, anxiety, depression and psychosis. Mental health problems experienced during this period can have a significant impact on women and their infants, some of which can be long-lasting. However, there are a number of interventions, such as peer support, community-based interventions and referral to IAPT services, which can reduce the likelihood of developing a perinatal mental health disorder or reduce its impact. Certain groups of women appear to be more at risk of perinatal mental ill health, including young women, women with a previous history of mental illness and women without social support.

#### Violence and abuse against women

There are still significant risks girls and women face with regard to their safety, both within the home and in the wider society. In 2018, 799 women and girls reported that they were the victim of a sexual assault and 858 the victim of rape. It has been estimated that 11,777 girls may have experienced sexual abuse at some point in their live. For the period 2017/18, 77% of Leeds domestic violence victims were female. Sexual assault, child sexual abuse and exploitation, domestic violence, bullying, female genital mutilation (FGM), forced marriage and sexual exploitation of women, are all great cause for concern.

## Conclusion

Leeds seeks to be at the forefront of addressing the issue of gender in public health. This report is an important step towards that important goal.

This first detailed report on the state of women's health in Leeds demonstrates that there are many positive changes to the lives of women, with decreases in cancer and cardiovascular disease. There are also excellent examples of good work being done within the city to support the needs of girls and women, which is showing dividends. However, there are still many areas of women's lives that are negatively affected by prevailing socio-cultural factors that have limited women in many ways. The rise in mental health difficulties, the emerging range of hidden and underrecognised reproductive health conditions, the challenge of increasing addiction, mostly compounded by poverty and complex home circumstances, and the risk of physical or sexual abuse have to be recognised and acted upon within the City.

# 2 Introduction

Leeds is doing well and continues to prosper. It is a great city to live and work, with diverse and thriving communities. It has a strong economy that has enabled the city to recover well from the recession. All of this positive progress is testament to the hard work and cooperation of people, organisations and sectors over many years.

Leeds is also a city marked by inequalities, including health inequalities, and has similar challenges to other large cities across the county in responding to the impact of austerity on public services. A House of Commons report showed that 86% of the burden of austerity has fallen on women (Stewart 2017). Just as important as identifying areas of deprivation is assessing change over time and responding appropriately. In line with national trends, there has been a worsening life expectancy for women and a static life expectancy for men in Leeds. One of our key challenges is to deliver gender sensitive services that meet the changing needs of people and communities.

In Leeds, we have two significant strategies that will enable this. The first is the Joint Health and Wellbeing Strategy, which aims to improve the health of the poorest the fastest. Closely linked to this is the Inclusive Growth priority in Leeds City Council's Best Council plan, which aims to enable as many people as possible to contribute and benefit from growth.

The City has an aspiration that by better understanding the health and wellbeing of our male and female population it can provide more effective gender sensitive services<sup>1</sup>.

This report is being written at a time of great change in society, with a recognised decade long age of austerity that has been most severely impacting on women (Stewart 2017). Although Leeds is a prosperous city, it has amongst the poorest areas of deprivation in the UK, with the localities affected increasing. We are now

<sup>&</sup>lt;sup>1</sup> This report includes references to trans women, but it is not possible to do full justice to the complex needs of the trans population in this report. It is anticipated these will be covered in a report at a later date.

also seeing people struggling with zero-hours contracts and in-work poverty, where despite having one or more jobs there is still not enough income to pay for essentials.

In the Leeds Director of Public Health report for 2017 (Cameron 2018), Dr Cameron recognised the differing effects of austerity on the lives and the health of men and women. For women there was the slowing down in improvements in life expectancy, a worrying increase in women suffering the effects of alcohol and an increase in the number of women who were experiencing mental health problems. One of the main recommendations from this annual review was for Leeds City Council to undertake a comprehensive health needs assessment for women.

Therefore, this exploratory study presents high level evidence on women's<sup>2</sup> health and wellbeing in Leeds for use by commissioners and key stakeholders across the city. This report has been be co-produced by Women's Lives Leeds and their partners<sup>3</sup>.

There have been significant advances in the medical treatment of many femalespecific diseases, with huge steps forward, for instance, in the diagnosis and treatment of breast cancer and cervical cancer. In Prof Dame Davies' 2014 Chief Medical Officers annual report (Davies 2015) which was focused onto the health needs of women, she noted that many health problems women face are still the subject of stigma and taboo, with women suffering hidden morbidity in silence.

In addition, what is increasingly recognised is that the health of a woman is more than the sum of female-specific illnesses or diseases. There is a *cumulative effect* where there is a greater impact as a result of complex anatomy and biological processes which are affected by social, cultural and economic circumstances. Although women are not defined by their biology, they can be significantly affected

<sup>&</sup>lt;sup>2</sup> In this report women's health also includes the health of girls

<sup>&</sup>lt;sup>3</sup> Women's Lives Leeds is a unique partnership of eleven women and girls organisations from across Leeds. They have specialisms in domestic violence, mental health, sexual health, sex work, trafficking, substance misuse, child sexual exploitation and education. The project launched on 1<sup>st</sup> November 2016 and has funding from the Big Lottery Women and Girls Initiative for 4 years.

by it. Each individual health problem is also influenced by, and influences, women's experience of an ongoing gender inequality, which can lead to constant levels of stress and its detrimental effect on wellbeing. Locally, in this era of austerity the context within which women's services operate has become increasingly challenging, with cuts to funding, wider reforms across welfare and housing services, and structural barriers to access, all having a disproportionate impact on vulnerable communities.

Part of the challenge of this report is in recognising the unique health and social challenges of being a woman, without becoming hooked into trying to find some sort of medical 'cure'. Such an approach creates a sticking plaster for the current health issue, rather than an opportunity to explore the underlying causes of the problems.

This report is also not trying to create more female victims but is aiming to demonstrate that there are unique health concerns that women experience as a result of their biology and the way they experience their lives. Most importantly, it is not meant to increase the pressure on women to somehow improve their lives, which for many are complex and a struggle.

The report is designed to highlight to commissioners and those with a statutory responsibility for the health and wellbeing of the women in the city, the need to seek new ways of reaching out and supporting the female population of Leeds. It also offers insight for those working with women and girls in the voluntary and charitable sectors to help them identify how and where they can further their greatest efforts in their work.

Nevertheless, the report is also a resource for girls and women themselves, along with the boys and men of the city. Health is everyone's concern and it is important for all to know the health risks women face and the struggles that can result. Health is *all* our responsibility, and as such we need to ensure that we all play a part in trying to make Leeds the healthiest city to live and work.

# 2.1 Aim of the study

The aim of the study is to provide an overview of women's health in Leeds to help inform commissioning decisions, through an analysis of the key routine data and academic research.

# 3 Research approach

The research approach adopted for the study comprised:

- A review of existing literature on women's health and service interventions.
- A general analysis of routinely collected health, socio-economic and serviceuse data.
- Interviews with key stakeholders, including councillors.
- Interviews with women across Leeds to hear their voices.
- Case studies from the 11 partner organisations of Women's Lives Leeds

The study was given ethical approval by Leeds Beckett University.

## 3.1 Literature review

A review of the literature was undertaken to identify key issues relating to the health of women in Leeds. This was a broad ranging review that focused on trying to identify the research and insights that lay behind the data. It could not be fully comprehensive, as each topic covered has been the subject of much discussion and research elsewhere but has attempted to give an overview of the most recent and relevant studies (up to the end of the census period –  $31^{st}$  January 2019).

## 3.2 Analysis of health, socio-economic and service use data

A descriptive analysis was undertaken of the available data relating to the health and social lives of women in Leeds.

The review covered the following areas:

- Demographic data.
- Mortality and morbidity data.
- Lifestyle data.
- Service use data.

Data sources used for the study were:

- The Leeds Public Health Intelligence service.
- Local GP audit data.
- Office for National Statistics.
- Public Health England.
- Nomis official labour market statistics.

Where available, data were analysed using the 2011 MSOA<sup>4</sup> classification across Leeds.

Disease prevalence taken from GP audit data represents individuals who had received a diagnosis from their GP and therefore may not represent the total number of males and females in Leeds who have undiagnosed conditions. Thus, the term 'known' prevalence is used where these data are presented throughout the report.

For each category of lifestyle prevalence (e.g. smoking, alcohol, physical activity), prevalence was calculated as a proportion of males and females who had been asked for this information by their GP (and therefore not as a percentage of the complete GP registered population). The proportion of males and females in Leeds who had not been asked for this information was calculated as a percentage of the complete GP registered population.

For the majority of the health data the Direct Standardised Rate (DSR), which is per 100,000 of the population, was used. Age standardised rates were also used where relevant, standardised to the European cohorts. It is important to note that disease prevalence and mortality and other data, were not always present in every MSOA.

Tables, histograms, bar graphs, line graphs and pie charts are used to present the data. Where possible, the top three MSOAs with the greatest concerns were identified for each topic.

More detail on the data can be found in the separate supplementary data report (Seims and White 2019).

<sup>&</sup>lt;sup>4</sup> Leeds is broken down into 107 Middle Super Output Areas (MSOA), each representing a population of about 5,000

#### 3.3 Interviews with key stakeholders

Key stakeholders of health and social care services from the Council and NHS were interviewed to determine their perspective on the state of women's health in Leeds. Their views were captured on how women use services and what information they needed in order to develop and improve services for the future. A pragmatic analysis was undertaken of the interview data to extract the key topics and issues and to identify any cross-cutting themes, which were used to help inform the scope of the review. The findings from the interviews are integrated into the narrative within this report and not included as a separate section.

## 3.4 Hearing the voices of the women on Leeds

Alongside this report there has been a separate study on Women's Voices in Leeds undertaken by Camille Thomas, from Women's Lives Leeds (WLL), and Dr Louise Warwick-Booth, from Leeds Beckett University (Thomas and Warwick-Booth 2018). This study comprised a series of 9 focus group interviews with women representing the characteristic-specific Equality Hubs managed by Leeds City Councils and other key demographics. The findings of this report are reported separately, but with some of the main findings also integrated into this report.

#### 3.5 Case Studies

A series of case studies have been included, representing key aspects of the report from the 11 partner organisations of Women's Lives Leeds. These are integrated within the report.

#### 3.6 Limitations

With the MSOAs being of a small population it is possible to see large year-on-year fluctuations. It is important that Commissioners need to be questioning the data before deciding to focus resources on an area.

It was not possible to locate current data on all the areas covered in the report. In part this was due to a decision to not use the Census data, which was completed in 2011 and may not reflect the current position of women in 2019. Where local data was not available the national data was used to give an indication of the scale of the issues covered in the report for women, or approximate numbers where research indicates the proportion of women that may be affected.

### 3.7 Abbreviations

ACE	Adverse Childhood Experiences
AIDS	Acquired immune deficiency syndrome
ADHD	Attention deficit hyperactivity disorder
APMS	Adult Psychiatric Morbidity Survey
BHI	Black Health Initiative
BMI	Body mass index
BME	Black and Minority Ethnic
CCG	Clinical commissioning Group
CVD	Cardiovascular disease
COPD	Chronic obstructive pulmonary disease
CRC	Colorectal cancer
CMHD	Common Mental Health Disorders
CSE	Child sexual exploitation
DFLE	Disability-Free life expectancy
eFl	Electronic Frailty Index
EoL	End of Life
EYFSP	Early years foundation stage profile
FASD	Fetal alcohol spectrum disorder
FEP	First episode psychosis
FGM	Female genital mutilation
FM	Fibromyalgia
FM	Forced Marriage
GAD	Generalised anxiety disorder
HRT	Hormone replacement therapy
HIV	Human immunodeficiency virus
IAPT	Improving Access to Psychological Therapies

IBS	Irritable bowel syndrome
IMD	Index of Multiple Deprivation (1 = most deprived, 10 = least deprived)
IPV	Intimate partner violence
LARC	Long acting reversible contraception
LCC	Leeds City Council
LCP	Local Care Partnerships
LGBTQ+	Lesbian, Gay, Bisexual, Trans, Queer and other forms of sexual expression
LTC	Long Term Condition
MBI	Mindfulness Based Interventions
MSOA	Middle Super Output Area
MUS	Medically unexplained symptoms
NEET	Not in education, employment or training
OA	Osteoarthritis
OCD	Obsessive compulsive disorder
POP	Pelvic Organ prolapse
PNM	Perinatal mental health
PMD	Perimenopausal depression
PMDD	Premenstrual dysphoric disorder
PMS	Premenstrual syndrome
PPFP	Postpartum family planning
PTSD	Post Traumatic Stress Disorder
SARS	Support after rape and sexual violence
SMI	Severe mental illness
WLL	Women's Lives Leeds

# 4 Understanding women and their health

#### 4.1 Being born a female

From conception there are important biological differences between females and males that impact on their health and wellbeing for the rest of their lives. The difference between males and females is based on whether they have the female XX chromosome or the male XY chromosome. This has an effect on the basic anatomy and physiology of the body and has an influence on nearly every aspect of how the body functions.

The girl embryo has a greater chance of surviving to birth and tends to have less congenital abnormalities (Sokal et al. 2014). Girls are more mature than boys at birth, both physically and cognitively and have a more rapid growth into independence than boys, with better self-help skills (such as dressing themselves), fine motor skills (such as turning pages in a book), and overall movement skills (such as moving around without bumping into things). Although boys are better at gross motor skills, such as running and throwing a ball (Moser and Reikerås 2016). Girls tend to have better language performance than boys from early childhood, both written and verbal, with links made to different inherent neural pathways in younger girls as compared to boys (Burman et al. 2008; Özçalişkan and Goldin-Meadow 2010) [see also (Alexander and Wilcox 2012)].

Although boys are more likely to suffer from developmental disorders, such as autism and attention deficit hyperactivity disorder (ADHD), there is now a growing awareness of how these conditions materialise in girls. With better screening, many more girls (and previously un-diagnosed women) who are affected are being identified as in need of support (Henry and Hill Jones 2011; Gould 2017; Kanfiszer et al. 2017; Parish-Morris et al. 2017; NICE 2018). NICE (2018b) has recognised that girls and women with ADHD can have poor social skills, with resulting social isolation leading to a negative impact of their self-esteem and well-being.

Historically there has been a lack of research that exploring disease states and their management in women, tending to rely on young, mostly White, males for

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pharmacological studies and working on an assumption that any results could be extrapolated to women, older men and different ethnic groups. We are only just starting to understand the female form, with early researchers being reluctant to explore female anatomy resulting in a very limited knowledge being gained of the female sex organs (Ah-King et al. 2014; Pauls 2015; Puppo and Puppo 2015).

What is emerging is that there are important differences between the anatomy and physiology of men and women that go beyond reproductive issues. The structure of the heart differs between the sexes - women have a smaller heart and coronary artery vessels, which is more sensitive to changes and reacts differently to cardio-vascular disease states than men (Papakonstantinou et al. 2013; EUGenMed et al. 2016; Regitz-Zagrosek and Karaigas 2017). Women's smaller lungs, different ventilation patterns and the effects of sex hormones can impact on the development of respiratory problems, such as asthma and COPD (Townsend et al. 2012; Pinkerton et al. 2015). Fat deposition is mostly in women's hips and thighs, which is actually beneficial for health, but obesity in women leads to visceral fat, which has a more damaging effect (Kapoor et al. 2017a; Wu et al. 2018).

Women have a stronger immune response through their sex hormones being immune-enhancing, whilst testosterone is immunosuppressive. The process by which this occurs appears to be mostly a result of hormonal influence, but also through the X chromosomes (Rubtsov et al. 2010; Ortona et al. 2016). This enhanced immune response can be of benefit, with a decreased risk of some cancers through swifter and more efficient removal of pathogens (Dorak and Karpuzoglu 2012), but it can also lead to an increased risk of autoimmune related disorders when the system malfunctions, including rheumatoid arthritis, multiple sclerosis, ulcerative colitis, Crohn's disease, and thyroid disease (Klein and Flanagan 2016; Roved et al. 2017). Women are at greater risk of both under active thyroid (NHS 2018a) and over active thyroid (NHS 2016a), both of which can be a result of disordered immune system activity. Fibromyalgia (FM), is also linked to problems with the immune system (Zhang et al. 2018), with over 7 times more women affected than men (NHS 2016b).

There has been a wide debate on whether there are structural differences in the brain, with some studies suggesting greater linkages between the right and left hemisphere. However, other studies explain such differences as being the result of brain plasticity and the effect of socio-cultural conditioning (Vidal 2011; de Vries and Forger 2015; Mills et al. 2016; Dean et al. 2018). What has been shown is that the female brain matures more quickly, with the neural pruning required to remove the unnecessary linkages developed through childhood to allow for more processed thought patterns happening earlier in women (Lim et al. 2015).

There are other biological differences that are not covered in the report, such as migraine, which is three times more prevalent in women, with more severe symptoms (Vetvik and MacGregor 2017). Urinary tract infections (cystitis) are also more common in women due to the shorter urethra, and can cause chronic long term problems as well as more frequent acute episodes (Katz et al. 2017). It is estimated that 1 in 3 people over the age of 65 years will suffer from dry eye syndrome / disease (NHS Choices 2016), as a result of reduced tear production, this is 1½ to 3 times more common in women and is mostly seen in menopausal and post-menopausal women as a result of hormone changes (Baig et al. 2018).

#### 4.2 Growing up as a girl and living as a woman

The socio-cultural implications of being a female has a powerful influence on the life of a girl from birth onwards. The toys that are focused onto boys and girls, the gender stereotypical clothes, and the way we interact with the girl and boy child can affect how they see themselves and how they come to realise their place in the world. This continues through stories, film and TV, and is pervasive across cultures and ethnicities (Halim et al. 2013, 2014; Coyne et al. 2016; Halim 2016).

It is very important to note however, that there are problems discussing social development, as there will always be exceptions as each generation meets a new world order. What is acceptable now might not have been in the generations that have gone before, and we are all affected in one way or another by the social determinants of health and those intersectional factors such as ethnicity and

sexuality that can have a powerful effect on how girls and women see their life. However, this section is included to give an idea of the powerful social processes that impact on our children and continue through our lives.

From pre-school onwards children are exposed to pressures to conform to existing stereotypes of boyhood and girlhood, with family, peers and teachers acting as powerful influencers (Riley 2014; Muntoni and Retelsdrof 2018). Studies with pre-school children already reveal girls and boys are aware of these messages, girls and boys have been found to play differently from early pre-school, with boys and girls tending to stay in their own same-sex groups and being wary of the opposite sex (Martin and Ruble 2004; Halim et al. 2017). Boys tend to be more engaged in activities, such as football, and be more 'boisterous' and physical with each other. Girls play is more likely to be based around communication and emotions, building intimacy through shared secrets (Al-Attar et al. 2017).

This socialisation process has also been found to result in girls believing that boys have gendered power over their bodies and that heterosexual relationships are 'normal' (Myers and Raymond 2010; Gansen 2017). These early experiences can feed into girl's aspirations and their willingness to do things that boys do, including school subjects such as mathematics and sciences.

Girls enter into puberty at an earlier age than boys, often whilst still in primary school, with 56% of girls (41% boys) starting puberty by age 11 and 10% also starting menstruation (Mayhew and Bradshaw 2014). This means they are past their main growing phase before they reach high school, but also means they have to come to terms with their new bodies and emotions at an earlier age than boys. It has been suggested that puberty and the onset of the menarche should be regarded as a public health issue, as many girls are negatively affected by what they experience, including feeling ashamed and afraid. This impacts on their self-confidence and willingness to engage in activities, which is especially the case when they are unprepared, or face significant physical discomfort (Sommer et al. 2015; Maphalala 2018; The Lancet 2018; You Gov UK 2018). The effects are also more pronounced when puberty occurs early, which is more likely to occur in socio-economically deprived girls and from some ethnic groups (Belsky et al. 2015; Kelly et al. 2017).

Earlier puberty and a more rapid maturation process than seen in boys also means that they are always a step ahead of their peer group boys, resulting in girls tending to socialise with other girls and be attracted to older boys (if hetero/bi sexual). Sexual problems can originate during adolescence and have a longer term impact, with girls as likely to experience problems as boys (O'Sullivan et al. 2016).

There is some evidence that girls and women are more attuned to non-verbal cues and are quicker at determining the emotional state of others compared to men (Gulabovska and Leeson 2014; Thompson and Voyer 2014; Wingenbach et al. 2018). They are also more likely to have longer eye contact and take a wider appraisal of another person than seen in men (Hall et al. 2010; Heisz et al. 2013). It is difficult to tell whether this emotion processing skill is a result of biological differences or female socialisation (Wingenbach et al. 2018), but it can result in women being quicker at making a judgement, and may also explain why men may be seen to be slower at responding to cues.

The socialisation process continues through adolescence, through peer pressure, and the influence of parents and school (Kågesten et al. 2016). The Global Early Adolescent Study<sup>5</sup>, which explores the experiences of children from age 10 through to 18, has found almost universal gendered pressure on girls and boys to conform to social stereotypes, which include:

- The hegemonic myth: There is a global set of forces from schools, parents, media, and peers themselves that reinforce the hegemonic myths that girls are vulnerable and that boys are strong and independent.
- Pubertal girls are the embodiment of sex and sexuality: Messages such as do not sit like that, do not wear that, do not talk to him, boys will ruin your future—support the gender division of power and affect while promote sex segregation to preserve girl's sexuality.
- Cover up and do not go out: As a consequence of adult perceptions of female sexual vulnerability, girls' mobility is far more restricted than for boys.

<sup>&</sup>lt;sup>5</sup> <u>http://www.geastudy.org</u>

- Boys are trouble: Because of adult concerns about their sexual vulnerability, girls are repeatedly told to stay away from boys and there are sanctions if they do not—punishment, social isolation, sexual rumour, and innuendo.
- Both boys and girls are aware of gender nonconforming peers: Young people (as well as a number of parents) spoke of peers whose interests, appearance, dress, and/or appearance was more typical of the opposite sex than their own. (Blum et al. 2017) (p53-54)

However, change is happening for young girls in a way that is not being seen with boys, with girls able to engage in male sports and pastimes, having a wider selection of clothes to wear (that might have been classed as 'boyish') and adopting 'laddish' lifestyles (Dobson 2014; Yu et al. 2017). This is bringing new opportunities, but also introducing new challenges as increasing levels of harmful alcohol intake, for instance, is presenting new health risks. In part, the one-sided wish to change is an effect of girls having greater curbs on their freedom than boys, so boys are not as motivated to challenge gender stereotypes and inequalities, particularly as boys also risk facing more severe consequences from their peers if they try and move away from the norm (Kågesten et al. 2016; Blum et al. 2017).

Despite, these advances social pressure continues on women though their adulthood, with stereotypical expectations of being the ideal mother and partner and care giver, whilst maintaining the home and being successful in the workplace (Henderson et al. 2016; WHO 2016; Meeussen and VanLaar 2018; Thomas et al. 2018). Living with the reality of violence also blights many lives, bring with it both personal risk and also limitations on activities through fear of what might happen (FRA 2014).

There are significant socio-cultural implications for women as they age. For those women whose working years were restricted due to caring responsibilities and parttime work, they are now entering into their older years with limited savings and pension, and a greater likelihood of poverty. Women are also exposed to negative representations of older women and ageist and sexist stereotyping that can
negatively impact on their self-esteem and willingness to fully engage in activities (Quéniart and Charpentier 2012).

For many, these pressures are the result of living in a very gender-unequal world, where women are faced with trying to match their expectations for a fulfilling life in a society that is still driven by a patriarchal dominance. This is harmful to both women and men as it creates undue pressure on both sexes. Nevertheless, many girls and women in Leeds are proving that change can happen and that we can have a different vision of a gendered society. Much can be done to help re-shape the social order, such as seen when gender-transformative policy changes are adopted, for example the Inclusive Growth Strategy in Leeds. It also requires schools and workplaces to be more vigilant in how they portray gender stereotypes and how they support opportunities for change and alternative life-ways. Case study 1 Clare

Clare<sup>1</sup> was referred to the Women's Lives Leeds Complex Needs Service in October 2017.

The young woman was identified as being a risk to herself as well as at risk from others, particularly around Child Sexual Exploitation (CSE). She was on a Child in Needs (CIN) plan and had a Children's Social Care Worker (CSWS) worker. The young woman identified that she used alcohol and drugs but did not have a good understanding of their effects. She also recognised that she needed support to increase her knowledge of sexual health and to develop her confidence, selfesteem and managing her mental and emotional health. She identified that she was not very happy in school or in her community and wanted to learn how to better resist peer pressure.

The young woman's attendance at school had deteriorated over the past 12 months and she would regularly run away or stay out without notifying her family therefore the Police became involved. She had witnessed domestic abuse in the family home and work has been ongoing with the parent around positive parenting. The Women's Lives Leeds worker and young woman identified what needed to go in the support plan and over the following year addressed the areas within the plan, until Clare exited the service 1 year later.

The young woman engaged well with the worker from the beginning and was happy to receive support. Other workers supporting the young woman commented on what a positive experience it had been:

"Your work with X is the first time she has engaged meaningfully with any service we have offered her, so it's really positive that she is participating with you."

"The young woman has engaged positively with the WLL worker and agreed to attend their sessions, this is brilliant for her"

The young woman engaged well with the sessions and said: "*I do stuff my own* way and not how other people tell me. *I listen to everything. My worker has* encouraged me to think for myself and be myself."

The young woman identified that it was important for her to have a female worker. I can talk to a woman more. It's just weird talking to a boy about stuff that you don't want to talk about.

<sup>1</sup> Name change

# 5 Intersectional factors and social determinants of women's health

### 5.1 Introduction

This report has taken an intersectional and life course perspective, which allows us to avoid the narrow vision of all girls and women being the same. An intersectional approach recognises that we all have different experiences that can be based on our sex, ethnicity, disability, sexuality and age. It also recognises the huge impact the social determinants of health, which include our relationships, educational achievements, socio-economic circumstances, and employment have on a woman's life (Wilkinson and Marmot 2003; McCall 2005; Hankivsky 2012).

The life course of each individual is shaped by how age impacts on the health challenges they face, but also the generational changes that influence the kinds of social and cultural environment, both that we have lived through and are experiencing today (WHO 2015). A woman who has experienced significant health challenges through her life or has endured domestic violence or discrimination in the workplace, will also have a perspective on her physical and emotional health and wellbeing that has been shaped by her past.

How these all mesh together creates each women's unique experience that may or may not be defined by any one factor, for instance a black women may have a different lifeway as a result of her skin colour, but equally may not (Bowleg 2012).

### 5.2 Age

As of January 2018, there were 437,946 females and 441,367 males living in Leeds. Of the female population in Leeds, 78,105 are aged 1-15 years, 289,657 aged 16-64 years and 70,184 are aged 65 years or older. This means that approximately two-thirds of the female population in Leeds is of working age (16-64 years), with the remainder of the population equally split between children and younger people (0-15) and older people (65 years or over) (Figure 1). Compared to males there are 11,822 more females than males over the age of 65 years. In those over 80 years of age there are 6,957 more females than males (Figure 2).



Figure 1 Age distribution of the female population in Leeds

The age distribution across the MSOA's<sup>6</sup> in Leeds varies considerably, with the highest proportion of females over the age of 65 years found in Wetherby East, Thorpe Arch and Walton (32.9% of the female population in that MSOA) and the lowest proportion of older women found in City Centre (0.6% of the female population in that MSOA). It is important to note that the MSOA 'City Centre' has mostly a working age population (97.4% of its female population).

With Leeds being an important provider of tertiary education, including four Universities and other colleges there is a big student population supporting the demographic profile of the city, which is reflected in the size of the 19 to 22 year old population (33,823 females, which is 7.8% of the female population).

It is projected that the population of Leeds will grow by nearly 10% over the next 20 years, with 6.1% more girls aged 0-14 years, 4.3% more women aged 15-64 years and 34% more women aged over 65 years by 2038 (ONS 2016a).

<sup>&</sup>lt;sup>6</sup> MSOA – Middle Super Output Area – Leeds is broken down into 107 local areas, each with a population of about 5,000, which are known as MSOAs



Figure 2 Population pyramid for Leeds, 2018

## 5.3 Ethnicity

Ethnicity was only known for 384,837 females in Leeds (90.4% of the female population). Figure 3 shows that approximately 80% of that female population are of white ethnicity, with nearly 20% being of another ethnicity, largely Asian/Asian British.



Figure 3 Females, by ethnic group for Leeds, 2016

The Romany Gypsy and Traveller community are also identified as a protected race under the Equality Act of 2010. Across Yorkshire and the Humber it is estimated there are around 25,451 within the Romany Gypsy and Traveller community, with a significant number living within Leeds (Warwick-Booth et al. 2017).

#### 5.3.1 Ethnicity by age

Across age groups we have a growing ethnic minority population, observed by the higher percentage among children and working age adults compared to older age (Figure 4). Among the youngest age group, over 25% are of non-white ethnicity, with nearly half of these children being of Asian/Asian British ethnicity.



Figure 4 Ethnicity by age group, females, Leeds, 2018

### 5.3.2 Ethnicity by local area

For those who have stated ethnicity, 7 MSOAs have a non-white<sup>7</sup> female population greater than 50% (including Harehills Triangle (75.2%), Beeston Hill (61.6%) and Chapeltown (60.3%)). At least 40% of the population in the top five of these MSOAs are from Asian/Asian British and Black/African/Caribbean ethnic groups, with nearly 52% of the female population in Harehills Triangle being of Asian/Asian British ethnicity (*Figure 5*).



Figure 5 Top five MSOAs in Leeds with the highest proportion (%) of females in non-white ethnic groups, 2018

Fourteen MSOAs have a non-white British population greater than 50%, with Harehills Triangle having the greatest female ethnic population at 90.6%. When exploring where different ethnic minorities are clustered, 59.0% of Bangladeshi or British Bangladeshi females live in three MSOAs (Harehills Triangle, 31.0% of all that population; Beeston Hill, 17.2%; and Chapeltown, 10.9%); 23.2% of all Black Caribbean females live in Chapeltown; and 60.5% of Chinese women live in three MSOAs (Little Woodhouse, 21.9%; Little London Sheepscar, 21.9%; and City centre, 16.7%).

<sup>&</sup>lt;sup>7</sup> Excludes white British, other white and white Irish

#### 5.4 Disability

The average life expectancy across England for females was 83.2 years in 2012-2014, with a Disability-Free life expectancy (DFLE) of 63.2 years, meaning a woman might live for 20 years with some form of disability. In Yorkshire and the Humber, the life expectancy is 82.4 years with a DFLE of 61.4 years, which is significantly lower than the national average. A woman in this region may live 20.7 years with a disability (ONS 2016b). For Leeds the latest data was for 2012-14, where the life expectancy was 82.4 years for women with a DFLE of 60.6 years, with the possibility of a woman living 21.8 years with a disability or 26.5% of her total life (ONS 2016c).

Women who are living in the most deprived environments (Decile 1) have a higher level of disability than those in the most affluent areas (Decile 10) - see Figure 6 (ONS 2018a).



Figure 6 Prevalence of disability for women and level of deprivation, England, 2014 to 2016

It is not known how many women are wheelchair users in Leeds, but they can experience many difficulties accessing health services, such as screening services and maternity care.

With age hearing can become increasingly impaired, with the menopause being a 'starting point' for many women's hearing difficulties (Oghan and Coksuer 2012). There are about 71% of men and 59% of women aged 85 and over reporting hearing difficulties (Scholes and Mindell 2014). Visual impairment is more common in women; globally two out of three blind people are women (Zetterberg 2016). This is due to women living longer than men and therefore endure more age-related vision defects, inequity in access to health services in many parts of the world and biological susceptibility (such as the role of oestrogen in cataract formation) (Zetterberg and Celojevic 2015; Zetterberg 2016; Ulldemolins et al. 2018). Visual impairment can have a marked effect on the quality of life, with issues, amongst others, relating to accessing services, such as cervical screening (Fang et al. 2016), increased risk of falls and other accidents (Lopez et al. 2011), negative well-being (Harada et al. 2008) and a greater risk of premature mortality (Zhang et al. 2016).

In Leeds as of February 2019 there were 2,318 women registered as having a visual impairment. This breaks down into 1,046 women who are registered Blind (51.0% of the whole cohort) and 1,272 women who are Partially Sighted (55.6%).

Nationally there are about 1.1m people with a learning disability, equivalent to about 4.4 people per 1,000 population registered with a GP (Hatton et al. 2016). This number is rising as there are a greater number of people with learning disabilities surviving into adulthood and older adulthood, although a women with a learning disability still has an 18 year lower life expectancy than the general population (NHS Digital 2017a). However, there are many more women with learning disabilities growing into older age as many of the life-limiting factors have started to be tackled. This means there is a growing need for more focused support to tackle issues of ageing in this population (Power and Bartlett 2018). There are many challenges facing women with a learning disability with their health, and they face particular issues relating to making decisions relating to the way they live their life and what support is needed to help them remain as autonomous as possible (BIHR 2016).

## 5.5 Sexual and gender minorities

According to the data collected by the ONS on sexual identity for Leeds there are estimated to be 263,000 who report themselves as heterosexual or straight, 5,000 as lesbian, 4,000 as bisexual, 2,000 as 'other', and 19,000 who 'don't know or refused

to answer' (ONS 2019)<sup>8</sup>. More women identify themselves as bisexual than men, and more men identify themselves as gay.

Usually the term LGBTQ+ is used to denote the Lesbian, Gay, Bisexual, Transgender and Queer community, but this does not limit those who might also have a sexual identity they do not recognise as heterosexual<sup>9</sup>. There are also those women who have sex with other women, but do not consider their sexual identity as either lesbian or bisexual (Armstrong and Reissing 2013).

There are important health and social implications as a result of one's sexuality and gender identification, including the increased risk of stigma and mental health issues, and engaging in risky lifestyles (Curmi et al. 2015; Westwood 2016; Ybarra et al. 2016; Pennay et al. 2018). A 2018 mapping report on the LGBT+ community in Leeds conducted by Forum Central (Stewart 2018) found that there was a growing need for support, but many of the organisations were struggling to find the necessary resources for their work. The report also notes that the community is more affected by identity than geography, such that locality-based services which have boundaries, may be inaccessible.

A key finding from the Woman's Voices study (Thomas and Warwick-Booth 2018) was for a separation of the needs of lesbian and bisexual women from gay and trans men. There was an anxiety that services tend to focus on the male rather than the female perspective, which puts up a barrier to accessing services. There should also be a better appreciation of the intersectionality that exists, rather than grouping all lesbian and bisexual women as the same.

<sup>&</sup>lt;sup>8</sup> It is important to note that these are estimates based on an Office for National Statistics survey and may not full represent all those who identify as LBT+

<sup>&</sup>lt;sup>9</sup> LGBTTTQQIAA - Lesbian, Gay, Bisexual, Transgender, Transsexual, 2/Two-Spirit, Queer,

Questioning, Intersex, Asexual, Ally, + Pansexual, + Agender, + Gender Queer, + Bigender, + Gender Variant, and + Pangender (OK2BME)

Within the report, reference will be made to sexuality<sup>10</sup> where it is possible, but often this is limited due to the lack of routinely collected data on sexuality.

## 5.6 Education

There is an increase for both girls and boys achieving a good level of development at the early years foundation stage profile (EYFSP), both nationally and in Leeds, with the gap between boys and girls achieving a good level of development narrowing (Figure 7). Of the 5,001 girls and 5,320 boys entered in 2017, girls had an average score of 35.3 vs. 33.1 for boys, with 71.3% of girls and 56% of boys achieving at least the expected level across all areas, and 72.2% girls and 57.9% boys achieving a good level of development (DoE 2017).



Figure 7 Percentage achieving a good level of development at EYFSP, Leeds, 2013-2017

In all areas of assessment girls are more likely to meet the 'at least expected' stage of development, with technology being the only area where boys are close to girls (94% of girls compared to 93% of boys in Leeds in 2017) (Figure 8) (DoE 2017).

Of the 3,640 Leeds girls who were at the end of key stage 4, 40.6% achieved a 9-5<sup>11</sup> pass at GCSE in English and maths, and of the 3,816 boys, only 36.9% achieved the same grades.

<sup>&</sup>lt;sup>10</sup> There are very specific issues relating to the trans community that are beyond the scope of this report, it is planned to address these separately.

<sup>&</sup>lt;sup>11</sup> New GCSEs are now graded 9 to 1, rather than A\* to G. Grade 9 is the highest grade, set above the current A\*. Grade 5 is known as a 'strong pass'



Figure 8 Percentage achieving 'at least expected' across all prime areas of learning, Leeds, 2017

Of the 2,719 girls aged 16-18 years, the percentage of students achieving at least 2 substantial level 3 qualifications in 2017 for Leeds was 81.9%, (compared to the 2,464 boys and 79.4%) (DoE 2018). However, nationally the number of boys who undertake A-Level maths and science subjects is still greater than girls (DoE 2018b) (Figure 9), which is an important consideration when increasing the number of girls entering science based employment and higher education.



Figure 9 Students entered for mathematics and science A levels. England, 2017/2018

Although boys have overall higher levels of developmental disorders, there is growing recognition of girls having un-diagnosed autism and attention deficit hyperactivity disorder (ADHD) that will also be impacting on their educational and social development (Halladay et al. 2015; Supekar and Menon 2015).

Among economically active adults in Leeds, women are more likely to have higher qualifications than men, however among the workforce there are a greater number of men with A-levels and a degree or equivalent or who have other qualifications (NOMIS 2018a) (Figure 10). This may be due to educated women being excluded from work, either on a voluntary basis, through child care, or involuntarily through lack of opportunity or suitable support.





This effect is seen nationally, where more women are achieving first degrees and postgraduate degrees in STEM subjects than men, but only make up 41% of the science workforce (Parliament 2016). With a greater attention to changing working practices and the way women's careers are viewed rather than just getting more girls and women to take STEM subjects.

### 5.6.1 Not in employment, education or training (NEET)

For those who are not in education, employment, or training (NEET) from Oct to Dec 2017 nationally there were 134,000 women and 197,000 men aged 16-24 years who

were unemployed (actively seeking work), and 251,000 women (212,000 men) economically inactive (not in employment who have not been seeking work within the last four weeks and/or are unable to start work within the next two weeks) (ONS 2018b).

Across Leeds in February 2018, there were 124 females of school years 12 and 13, who were not in employment, education or training and available for work (218 males). In addition, there were 52 females who were not available for work due to illness (10), pregnancy (15), through being a teenage parent (26) or being a young carer (1). The areas with the most NEET females were City and Hunslet (23), Gipton and Harehills (22) and Killingbeck and Seacroft (17).

## 5.7 Housing

There has been a marked increase in the rental market, with fewer people able to buy their own homes. This has implications for older age, as renting is a significant additional expense compared to home owners who have paid off their mortgage. In Leeds there were 33,000 female tenancy holders (59.7%) in council housing in March 2018, as compared to 22,316 males (40.3%). In the last 5 years (April 2012 to April 2017) Leeds has seen a fall of 1,120 local authority owned properties and an increase of 10,990 private sector properties (Ministry of Housing, Communities and Local Government 2018). As a result of this decrease in social housing, more women are at risk of being forced into private rented accommodation, which often has a higher rent and a greater risk of being of poorer quality.

There is a higher proportion of female tenancy holders in the younger age groups (16-45) (15,438 women, 9,094 men), whereas there is a higher proportion of males in the older age groups (Figure 11).



Figure 11 Housing Leeds Tenants, by age and sex, March 2018

Female tenancy holders are mainly living in houses or flats, but males more likely to be placed in flats (Figure 12). With a larger older female population there are more women living in sheltered accommodation.



Figure 12 Housing Leeds Tenants, by type of property and sex, March 2018

### 5.7.1 Homelessness

Currently there are 23 males (82%) and 5 females (18%) who are recognised as rough sleepers within the city of Leeds. The female proportion is higher than across the regional area (only 10%) and still greater than for England (14%). Periods of squatting and rough sleeping were only slightly less likely among women than men,

and both women and men were equally exposed to risks of violence and harassment in the process.

There are an increasing number of people made homeless through failure to keep up with private landlord rents. Since the introduction of the Benefit Cap and the forthcoming Universal Credit, it is anticipated that many more women will find themselves homeless. This was recognised by The Leeds Homelessness Strategy for 2016 to 2019 (Leeds City Council 2015a), which is seeking to put in place measures to increase housing advice and support, and to protect families in this situation.

Around half of both men and women who are now homeless have suffered the bereavement of a close relative or another major trauma in their lives. A recent study reported that a quarter of the women who were homeless and slightly fewer men had been in local authority care, and two thirds of both genders had a mental illness (Bowpitt et al. 2011a, b). Three quarters of both genders attributed their homelessness at least in part to family or relationship breakdown, with a background of violence in the home a common experience in the lives of both men and women (Bowpitt et al. 2011a). Men and women were evicted by other householders in roughly equal numbers.

In this study, women gave the main reasons for their homeless as relationship breakdown, domestic violence and the pressing need to escape abusive relationships, with many fleeing abuse and seeking safety (Bowpitt et al. 2011b).

### 5.8 Marital Status and relationships

Across the UK in 2017 there were 19 million families, of which 12.9 million were married or cohabiting couples, with an average household size of 2.4. Of the 3.9 million living alone, the majority of those aged 16-64 years were male (58.5%) and the majority of those aged 65 years and over were female (66.5%). Of those aged 20 to 34 years that were still living at home, 20% were female and 32% male (ONS 2017a); this is mostly because women are more likely to cohabit with an older man (Figure 13).

There are marked changes occurring within society that are affecting how and where people are living. A growing number of younger people are staying at home for longer as the age of forming partnerships increase and the cost of renting and buying goes up. There has also been an increase in multi-family households.



Figure 13 England & Wales population estimates (aged 16 years and over) by marital status, age group and sex, 2018

In 2017, across England and Wales (ONS 2018c) the majority of the people aged over 16 years were living as a married couple (Figure 13). Females were less likely to be single than males (31.1% compared with 37.8%), but more likely to be divorced or widowed. Around 0.3% of the married couples were same sex (of which 56.8% were male and 43.2% females), which is an increase since 1996 and is thought to be because more people are now identifying themselves as lesbian, gay or bisexual. There has also been a rise in single-sex couples with dependent children.

Across the UK there are 2.4 million lone mothers and 386,000 lone fathers, of which 1.6 million women and 179,000 men have dependent children, representing 21% of dependent children living in lone parent households across the UK in 2017 (ONS 2017b).

In 2016, those who identified themselves as lesbian, gay or bisexual (LGB) were most likely to be single, never married or never civil partnered (70.7%). This could be as a result of:

- The young age structure of the population that identify themselves as LGB.
- Legal unions available to same-sex couples being relatively new.
- Those with a legal marital status of single being in same-sex cohabiting couples. (ONS 2016d)

With an increase in the life expectancy of men, there are fewer women living alone into their older years. There has also been a big increase in those over the age of 65 years getting married (silver splicers) and also in divorces (silver separators) (ONS 2017c).

### Case study 2 Sonia

Sonia<sup>1</sup> 29 year old woman was referred into Women's Lives Leeds (WLL). She was assessed as needing support with life skills; parenting/dependents and family relationships; personal safety; and welfare – accommodation, benefits, and money management.

There were concerns from Sonia's social worker that she was unable to recognise unhealthy relationships, but the female showed desire to attend an appropriate group to make positive changes.

As a result of WLL's interventions all goals identified in the original support plan have been met and mutually they agreed that the case can be closed as Sonia is now attending a healthy relationships group. WLL also supported her to write her statement for a court hearing and ensured that it met the court specifications and she felt confident to attend court to submit her statement.

Communication between Sonia and her daughter has improved with regular texts and phone calls.

*"I was supported through court when I was fighting for \*\*\*\*\* (her daughter) back and the WLL Complex Needs Worker gave me advice to help me move forward".* 

"The WLL worker came to court with me and gave me all the information what I needed. She gave me the list of solicitors that I can contact and stuff. She's helped me a lot. I don't know if I could have stayed in court all day by myself – it was too much. But I did it."

"I've felt a lot more confident about stuff. I feel I can do more stuff cos I've had support & someone saying to me 'it's alright, you can do it". It's been positive cos I've achieved all, well, most of my goals. It's helped me get a job and secure my housing situation"

<sup>1</sup>Name changed

### 5.9 Carer

It is still the case that woman have the greater carer responsibility through their working years (ONS 2013a; Carers UK 2015, 2016), with an estimated 58% of the 74,419 carers in Leeds female (43,168). Based on the 2011 Census, women also devote more of their time to caring responsibilities, with an estimated 10,117 female carers in Leeds devoting more than 50 hours a week on caring (Table 1).

	1-19 hours per week	20-49 hours per week	50+ hours per week	Total
Male	20,228	4,214	6,972	31,415
Female	27,256	5,632	10,117	43,004
Total	47,484	9,846	17,089	74,419

Table 1 Proportion of week devoted to a caring responsibility, Leeds

In Leeds, more women are claiming a carers allowance (in May 2018, 6,563 females, 2,707 males), with the majority being of working age (DWP 2018).

Trying to balance multiple roles has big implications for women's physical and emotional health, and also for their opportunities to engage in education and work, with the economic value of unpaid care by women estimated at £77bn per year (Carers UK 2016). An American study (Erosa et al. 2017) suggests that a more equal distribution of household tasks would make an 14% improvement in women having more time to devote to their careers. They also note a misalignment of talent, as capable women are held back by home responsibilities.

Many school-age girls and boys (aged 8 years and older) have carer responsibilities, with girls providing more adult care than boys, both for their own household and for members of another household (ONS 2017d).

Nationally women were providing 74% of child care (ONS 2017d). In households with a lower income, women are still providing the majority of child care (80% mother, 20% father), but in higher income households there is a more even distribution of primary childcare (60% mother, 40% father) (ONS 2017d).

With increasing longevity, many women now find they have older infirm relatives to care for whilst also having young children – this is especially the case for those who had their children later in life. This "sandwich caring" is leaving many struggling to cope, both financially and emotionally, with a toll on family life (Carers UK 2012; Brown et al. 2014). It is estimated that women are four times more likely to have to give up work due to multiple caring responsibilities (Carers UK 2012).

Increased caring responsibilities in the over 50's can also lead to a breakdown of social networks and a risk of social isolation, especially in the elderly (Leeds City Council 2015b). Spending more than 10 hours caring for parents or grandchildren a week is associated with poorer health and self-rated quality of life and, among women, a lower probability of being in full-time work (Brown et al. 2014).

Some 42% of grandmothers (32% grandfathers) provide regular childcare for an average of 10 hours a week (8 for grandfathers), with one in ten offering over 35 hours a week (Brown et al. 2014). There are benefits to grandparents to looking after their grandchildren, including improved mood, increased social inclusion and cognition, but highly frequent caring can result in stress and negative health effects (Campbell et al. 2016). For some family and friends this develops into more formal relationship as a Kinship Carer (Wellard et al. 2017), where children are living with them either full-time or most of the time, including as foster parents or under a Special Guardianship Order.

There can be a tension between women's expectations of caring and a new reality where more now is being done by either her partner or others. With women under the burden of social and personal pressures to be seen as capable in all roles, their health can be affected by a feeling of guilt if they perceive they are not carrying their 'fair share' in the home (Thomas et al. 2018).

It is notable that the 'Leeds Carers Strategy 2015-2018' (Leeds City Council 2015b) (p13) breaks down some demographics, but does not talk about gender split among carers. We recommend that there is a gender breakdown in future reports by the City.

## 5.10 Employment

Models of family life have changed radically over the last century, with it now being much more likely that households have a dual income or that the woman is in the higher paid job. There is also a greater chance that the male partner will be taking on the role of stay-at-home parent. However, there is still a larger number of women who are working part-time and are economically inactive (Figure 14) (Nomis 2018).



Figure 14 Leeds employment (percentage), 16-64 years, July 2017 – June 2018

Nationally there has been a big increase in the number of women employed, with a rate of 71% (80% for men) in Dec 2017- Feb 2018. However, in part this is due to the changes in the retirement age of women from 60 to 65 years, meaning more women are remaining in the workforce longer (ONS 2018d). In Leeds, female employment has risen from 55% to 69.6% between 2012-13 to 2017-2018, whilst unemployment has fallen from 13.2% to 3.6% in the same time period.

There are more women working part-time than men, both as employees and selfemployed, but what is not known is how much of this is by choice or necessity (Figure 15) (ONS 2017e). The choice of moving into self-employment has been found to be affected by the availability of support within employment, with the availability of sick, leave, maternity pay, childcare services, etc., being greater factors for women avoiding the self-employment option (Klyver et al. 2013). The improved pay within low-pay employment has also added to women staying in employment, with the state of the economy, house prices, and access to finance also important factors in whether a woman takes up a self-employment option (Saridakis et al. 2014).

Women's participation in the labour market is influenced by many factors, which include caring responsibilities, availability of work and also commuting time. Many women tend to be the main caregiver for children and not the main wage earner in the household, which impacts on their job choices and also how far they are willing to travel to work, as time is a greater factor in managing their day. This limits opportunities, this is especially the case for women with pre-school children (Munford et al. 2018).



Figure 15 All in employment (thousands), Leeds, by sex, Apr-June 2017

Commuting time has been found to be greater for men. A study on the impact of commuting time (Munford et al. 2018) found married or cohabiting women working full-time in managerial or professional roles report the greatest negative effect. This has implications for enticing women into the City, especially if there are issues with reliability of transport routes or public transport options.

Ethnicity has been to be a limiting factor for women with regard to their employment opportunities. A local interview based study on Muslim women in the workplace (Tariq and Syed 2017) found many issues in the way their ethnicity impacted on their careers. These included an expectation that despite gaining University degrees they were expected to settle down and have a family. They were also exposed to prejudices against their religious dress and for those in leadership positions faced more discrimination than their White counterparts, they also noted a lack of access to network and mentoring support. However, despite these difficulties they are making progress due to an unwillingness to be discouraged and their own endeavours to improve their opportunities.

### Case study 3 Chro

My name is Chro<sup>1</sup> I'm married. I came to UK in 2010. I live in Leeds. I live with my husband. I have two boys. I like gym, I like working and earning money. When I came to England, my English was not good, my confidence was low and I had some health issues. I felt very lonely and isolated. I dropped into the Asha Neighbourhood Centre to find out about their services. The Health Development worker invited me to join the cooking and walking groups. I was also referred to an ESOL class run by a college in Asha centre.

The ESOL teacher was very good and I benefitted from attending the ESOL classes. She helped me to boost my language skills and confidence. I took up another course named Child Care. I asked for childcare volunteering placement at the Asha centre and now Asha have offered me sessional hours, now I am working in the preschool. I'm so happy with my job also with everyone working around me, especially the workers they always help me to improve my language. I found working and staying with children a very difficult task in terms of educating them, despite this the children are happy with my volunteering work. After finishing my courses, I decided to continue working in Asha centre to improve my future. Although I'm a woman like others, I do all my daily work by myself even the works of children.

I found about Asha Neighbourhood through a family friend. I heard about the Health Project activities and the volunteering project. I wanted to do occasional volunteering to give me a focus in life after numerous miscarriages. I was experiencing mild depression and anxiety. I received lot of support in the beginning from the Asha Project. I was signposted to mental health workshops. I also joined a women's social group. I took part in a confidence building course during a weekend residential through Asha. When there was a mental and physical I conceived. I had a premature baby girl. I attended breastfeeding and baby massage sessions in Asha and bonded well with my baby.

I am asylum seeker. I have been suffering from mental health issues. I lived with the fear of being deported to a place where there was a risk to my life. Number of time I attempted to suicide because I couldn't cope with the conditions I was living with. My child self-harms and despite intervention I am unable to help him. The Health worker encouraged me to join the Health activities. I benefitted a lot from the mental health workshops. The Asha staff went beyond their duty to look for free funding to pay for my child to attend the play scheme so he could make friends. I wanted to study English to improve the quality of life and improve my communication skills but because of my immigration status I did not meet the financial criteria set by colleges. However, I was able to attend Health activities such as the cooking and exercise classes.

ESOL – English for Speakers of Other Languages

<sup>1</sup>Name changed

#### 5.10.1 Inequalities in pay

Women tend to leave education with higher educational attainment than men, yet are still over-represented in lower paid work and under-represented in higher paid work, with gender gaps in terms of participation (employment rate and hours worked) and pay widening with age (European Commission 2018). This can have a long-term effect, with a lifetime 'pay-penalty' and the possibility of poverty and social exclusion into retirement through poorer pension provision.

In April 2017, across the UK the gender pay gap based on median hourly earnings for full-time employees decreased to 9.1%, from 9.4% in 2016. This is the lowest since the survey began in 1997, with growth in women's earnings stronger than for men, but for a woman working full time this still represents a £100 difference in gross weekly earnings (ONS 2017f). In Leeds, a female full-time worker's median pay (gross) in 2017 was £24,072 compared to £30,315 for a male worker (ONS 2017g). Since 2013 there has been a steady increase in salary for men, yet relatively little change for women, resulting in a widening gap (Figure 16).



Figure 16 Full time workers pay, Leeds, male and female

Nationally, women's part-time pay is narrowly greater than males up until the age of 50+ years, and then men's pay is greater than women's (Table 2).

	Pounds (£)		
Age (years)	Male	Female	
16 to 22	7.42	7.48	
22 to 29	8.46	8.50	
30 to 39	9.13	9.85	
40 to 49	9.91	9.92	
50 to 59	10.23	9.63	
60+	10.50	9.45	

Table 2 The median gross hourly pay (excluding overtime) for part-time employees by age group, UK, April 2017

Source: Annual Survey for Hours and Earnings (ONS 2018e)

Across the UK, women are more likely to be working on a zero-hour contract (3.3% women in employment vs. 2.4% men in employment in October to Dec 2017) (ONS 2018f). The reality is that some women (especially those who are a single parent) are having to take on a number of different jobs to earn enough.

For the Leeds council, 61% of its workforce is female, with their mean hourly rate 8.6% lower than men's and their median hourly rate is 13.1% lower than men's (Leeds City Council 2017a). In comparison, Doncaster Council have produced a report on the issue of the gender pay gap within the council (Doncaster Council 2017). They note that they have a 70% female workforce covering many different sectors, with no significant pay gap evident when like-for-like jobs and hours worked were considered (-0.44% overall, -0.12% for part-time workers and -0.03% for full time workers).

The gender pay gap is not just about equality of pay, but about the way women's work is valued in society and their employment opportunities and progress at work (Grimshaw and Rubery 2007). These have been found to be influenced by:

- gendered education and career choices.
- occupational segregation with women confined to lower grades within organisations and concentrated in lower paid occupational sectors.
- devaluation of work deemed a 'female' occupation.
- non-continuous employment and a shift to part time work due to caring responsibilities, especially when children are young.

- occupational downgrading resulting from women working below their potential due to lack of quality part-time jobs and the absence of flexible career paths.
- an unexplained gap sometimes attributed to direct or indirect sex discrimination and systemic disadvantage (Metcalf 2009).

A Parliamentary group (Parliament 2016) looking into gender and pay argued that there needed to be a range of actions needed including:

- Addressing the part-time pay penalty and flexible working.
- Supporting parents to share childcare equally.
- Supporting women back into the workforce after time out of the labour market
- Tackling low pay in highly feminised sectors.

The European Commission report on Equality (European Commission 2018) has taken this further, advocating that there needs to be a profound structural change in labour market to achieve equality of opportunity for women. They suggest that changes in work organisation, general work culture and working time flexibility is needed, and that a career break for a family is not an indication of lack of ambition or commitment. To help achieve this there must be increased support for fathers to take longer paternity leave and to have flexibility to look after their children up to the age of 12.

There is also a need to radically re-think how women are enabled to combine work with their other commitments without losing the opportunities for progression and also for support within their wider roles.

## 5.11 Poverty

In 2015, across the UK a higher proportion of women (8.2%) were persistently poor<sup>12</sup> than men (6.3%) with the gap between women and men the largest it has been since they started collecting data in 2008. The recent period of austerity has also been found to have had a disproportionate impact upon women, with a study conducted for the House of Commons (Stewart 2017) showing that 86% of the burden for

<sup>&</sup>lt;sup>12</sup> Persistent poverty is defined as being in relative income poverty in the current year and at least two of the three preceding years.

recent cut-backs has fallen upon women. The recent introduction of Universal Credit as a system to replace the many existing benefits has increased poverty for many, with a recent study of its impact in Newcastle and Gateshead demonstrating how the complex system is pushing many towards distress and increasing suicide risk (Cheetham et al. 2018).

Those with low educational attainment are more than twice as likely to experience persistent poverty, with higher rates for single parents and single adults, and those over the age of 65 (ONS 2017h). A study of older single women in Australia reported that those who had caring responsibilities, lower savings and a lack of affordable housing, were at high risk of poverty and homelessness (Anglicare 2015).

Across Leeds there are 98,556 women (105,766 men) in the lowest decile on the Index of Multiple Deprivation (IMD) (which is a scale of relative deprivation that takes into account a number of different parameters (DCLG 2015)<sup>13</sup>). IMD 1 comprise the biggest across all the deciles (Figure 17). The number of women living in deprivation decile 1 is equivalent to 23% of the female population and a total of 57.4% of all females reside in deprivation decile 5 or below. Only 8.01% of females resided in the most affluent areas of Leeds.

- Employment Deprivation (22.5%)
- Education, Skills and Training Deprivation (13.5%)
- Health Deprivation and Disability (13.5%)
- Crime (9.3%)
- Barriers to Housing and Services (9.3%)
- Living Environment Deprivation (9.3%)

<sup>&</sup>lt;sup>13</sup> The Index of Multiple Deprivation is a score based on a number of different parameters:

<sup>•</sup> Income Deprivation (22.5%)



Figure 17 Number of males and females in each decile of the Index of Multiple Deprivation, Leeds. Leeds GP Audit data, 2018

### 5.11.1 Deprivation by ethnicity

It is important to note the higher proportion of ethnic minority women who are living in the poorest areas of the city, with 73.3% of all Bangladeshi women living in the lowest decile of the Index of Multiple Deprivation (IMD) (Table 3).

When ethnic groups are considered, females in the Black/African/Caribbean or other black ethnic group are most likely to be living in deprivation, with 63.6% living in the most deprived decile and 90% living in the most deprived half of the city (Figure 18). In summary, females in non-white ethnic groups are overly represented in the most deprived areas. However, when considering the absolute numbers, there are a greater number of females in the white ethnic group living in the most deprived decile.

Ethnic Group	Females in Decile 1	% of total ethnic group population
Bangladeshi or British Bangladeshi	1,476	73.3
Black African	7,522	67.1
Black Caribbean	1,399	51.3
Chinese	619	9.8
Indian or British Indian	1,373	14.7
Mixed - White and Asian	500	23.8
Mixed - White and Black African	1,474	55.3
Mixed - White and Black Caribbean	1,196	42.1
NK	7,171	17.2
Other Asian Background	2,295	30.7
Other Black Background	1,907	59.6
Other Ethnic Background	2,912	41.5
Other Mixed Background	850	32.3
Other White Background	11,629	31.2
Pakistani or British Pakistani	5,769	45.1
White British	50,006	17.6
White Irish	458	19.4

#### Table 3 Females in Decile 1 (IMD) by Ethnic Group, Leeds, 2018



Figure 18 Spread of ethnic groups across deprivation deciles. NB N.B. Values have intentionally only been provided by the most five deprived deciles

### 5.11.2 Benefit claimants

Across Leeds 4,180 working age women (7,230 men) are claiming benefits of one form or another (Figure 19).



Figure 19 Number of benefit claimants, by age and sex, November 2016, Leeds

There is a greater proportion of women in receipt of housing benefits (60% female, 40% male). There are 37% of women with some level of arrears in their rental payments, with a higher proportion than men in the higher arrears banding.

## 5.12 Asylum seekers and refugees

There are currently 824 asylum seekers/refugees receiving support under Section 95 of the Immigration and Asylum Act 1999 in Leeds (Home Office 2018a). It was not possible to get more detailed breakdown by locality or by sex for this report. It is important to note that migrant women can experience difficulties navigating the UK health system and can find themselves missing out on screening, vaccinations and appropriate maternity care, and they are also at greater risk of social exclusion and isolation (Mengesha et al. 2018; Schmidt et al. 2018).

#### 5.13 Sex Work

Women in Leeds involved in sex work operate across a varied and diverse sector including; online, clubs, from premises and on street. Basis Yorkshire<sup>14</sup> work with women from across sectors, with 8% of women accessing services working on street and 92% working off street, with street work comprising 15-20% nationally (House of Commons 2016). Women involved in sex work are reflective of the diverse population in Leeds with a significant proportion of women from BME backgrounds with additional issues in terms of ability to access culturally specific services.

The reasons for women engaging in sex work are varied and diverse and reflect both life histories/experiences and economic motives. Recent research identifies 'push and pull' factors for those engaging in or exiting from selling sex i.e. debt, poverty, homelessness and flexibility, freedom and good earning potential (Steffan et al. 2015). Furthermore, key to women accessing services is the importance of a non-conditional approach to delivering services, which enable better health and wellbeing outcomes for women (Bimpson 2018). In addition, the experiences of UK student sex workers were captured in the Student Sex Work project (Sagar et al. 2015).

Stigma is a significant factor in women's experience of selling sex (Benoit et al. 2015; Carlson et al. 2017; Zehnder, MaraRufer et al. 2019). In Leeds 60% of outdoor street workers, and 79% of indoor workers were less likely to declare to their GP that they were sex workers. Triangulated by further data featured later in this evaluation found that a key factor that consistently emerged was the fear of becoming stigmatised by health workers via labelling within the health and welfare systems (Basis Yorkshire 2018).

Mental health was identified as an extremely important issue for both indoor and street workers. 88% of street workers expressed their mental health to be of concern with 73% confirmed through diagnosis. Indoor workers identified this issue at much lower levels at 41%. However, this is a significantly higher incidence than that

<sup>&</sup>lt;sup>14</sup> https://basisyorkshire.org.uk

experienced by women generally within the Leeds population (Basis Yorkshire 2018).

The government recognises that of key importance is that 'those involved in prostitution and sex work are safeguarded, that traffickers and those who exploit vulnerable people can be effectively targeted, and ensuring that community concerns about prostitution and sex work can be addressed' (Home Affairs Select Committee 2016)(p1). Leeds has made a significant step in helping reduce the risks sex workers face through the introduction of a managed approach<sup>15</sup>.

This initiative aims to;

- reduce the problems caused by street prostitution to residents, and businesses which currently suffer from such nuisance;
- better engage with street sex workers to improve their safety and health, with a view to enabling them to exit this way of life
- reduce the prevalence of street sex working

A key element of the Managed Approach is to work with sex workers in the area to encourage more reporting of offences against them, increase their safety and also provide targeted support and services to improve their health and wellbeing and with a view to assist them to exit street based sex working. This initiative has seen a significant increase in the reporting of crime and support for the women engaged in street based sex work (Sanders and Sehmbi 2015; Basis Yorkshire 2018; Howard 2018).

# 5.14 Prison and offending

There is not a female prison in Leeds - the nearest are New Hall Prison at Flockton, near Wakefield and the young offending unit at Wetherby. There is now the newly opened Adel Beck secure children's home<sup>16</sup> in Adel, Leeds, which caters for children aged 12 to 15 years.

<sup>&</sup>lt;sup>15</sup> https://www.leeds.gov.uk/saferleeds/managed-approach

<sup>&</sup>lt;sup>16</sup> <u>http://www.securechildrenshomes.org.uk/east-moor-secure-childrens-centre/</u>

There have been two recent reports by the Prison Reform Trust that have focused onto the specific needs of women (Prison Reform Trust 2016, 2018) and one on the impact of a mother's incarceration on a child (Beresford 2018). They all highlight that urgent attention needs to be given to supporting young women with complex needs to avoid entering into the custodial system.

The Transition to Adulthood (T2A) Alliance (T2A 2016) have noted some key issues with regard to young adult women in the criminal justice system:

- Two thirds of women in custody aged 16-21 have recently been in statutory care.
- They have very particular and complex needs that relate directly to both their age and gender, which services rarely take into account. In this sense, they are likely to fall between services, and can therefore be considered to be the 'forgotten few'.
- The majority have had multiple traumatic experiences such as domestic abuse (more common for younger women than older women), sexual exploitation, and bullying, at levels usually far higher than for young men.
- These and other traumatic experiences are likely to have been very recent, and therefore raw in the mind of each young adult woman. They are also far more likely to have recently been in statutory care, and many are young mothers whose children are more likely than older women to be taken into state care.

They suggest that the needs of young women leaving custody has been largely ignored, as they make up a relatively smaller proportion of the prison population and they are more likely to be mixed in with older women in custody. There is a need to have better support as young women with complex needs move from childhood services into adulthood, as at present there is a risk their lives become more complex and harder to manage, increasing their likelihood of offending behaviour.

Although Leeds does not have its own prison for women, there are those women who are in custody elsewhere and are then returning to Leeds and requiring support. Though the course of 2018 there were 132 women released back into Leeds (41 low risk, 51 medium risk, and 30 high risk<sup>17</sup>). To help improve rehabilitation female service users in Leeds there are a number of different services, including the Interserve<sup>18</sup>, and Together Women<sup>19</sup>.

The Ministry of Justice has just published their Female Offending Strategy (MoJ 2018), which has called for a different approach to women who offend, or are at risk of offending. They have proposed a reduction in custodial sentences and much greater use of community-based initiatives supporting women into employment, and secure accommodation. With this in mind, the work in Leeds by the Together Women Project (Together Women 2018) which supports women in custody and on their release, should be encouraged and developed.

<sup>&</sup>lt;sup>17</sup> Data from HM Prison and Probation service and Leeds Community Rehabilitation Company (probation)

<sup>&</sup>lt;sup>18</sup> https://www.interserve.com/latest-insight/2017/improving-offenders-skills-and-opportunities-in-leeds

<sup>&</sup>lt;sup>19</sup> <u>http://www.togetherwomen.org</u>

### Case study 4 Karen

Karen<sup>1</sup> was in a relationship with Steve<sup>1</sup> and since breaking up with him she has been the victim of ongoing stalking by means of unwanted contact. He does not live in the local area. Her main fear was that his stalking would escalate and he would attend at her address.

In October 2018 he was convicted at court of harassment due to his behaviour and was issued with a Community Order. A Restraining Order was granted which stated he could not contact her directly or indirectly and could not attend in the local area where she resided.

Despite this order being granted, a month later he was sending her a large number of text and social media messages as well as phoning her on a withheld number. This was absolutely terrifying for her and she reported them all to the police; and he was charged with Breach of Restraining Order. He was granted conditional bail with conditions mirroring the Restraining Order. He pleaded not guilty to this new offence.

## Support

The Independent Domestic Violence Advocate (IDVA) team supported Karen all the way through from the first time she reported to the police. This included assessing her risk and needs, tracking the progress of the case, advocating on her behalf with the police and CPS, referring to other agencies and attending court to support her.

Karen was assessed as high risk and was given MARAC status; and her case was subsequently heard on a number of occasions due to the increasing number of repeat incidents. The IDVA has continued to liaise with other agencies to ensure appropriate support has been put in place for the family and has acted as the 'victim voice' during this process and has completed safety planning with the victim and completed Sanctuary Referrals.

The support included liaison with the CPS prior to the trials to ensure special measures were available and granted and on the day of the trial Steve pleaded guilty.

The case went to Crown Court for sentencing, of which the final sentence was a custodial sentence of over a year, suspended for 2 years and granted an extension to a Restraining Order for a further 5 years.

<sup>1</sup>Name changed
# 6 Health status of women in Leeds

#### 6.1 Introduction

The overall health status of women is most often related to life expectancy as this indicates the average age that death can be expected, a healthier population should mean a longer life expectancy. Knowing the causes of death (mortality) and the trends that are occurring can give useful indication as to the health challenges facing women in society. As seen in Section 5 there are many factors that can impact on health and wellbeing, with deprivation seen as one of the most important contributor to the risk of premature death.

#### 6.2 Life expectancy

Life expectancy for women and for men has been increasing year on year, however, the rate of improvement has been decreasing across the UK (Figure 23). For Leeds we are now in a position where the life expectancy for both women and men has been static since 2012-2014, and in 2013-2015 actually fell for women and men but has since slightly risen for women and fallen further for men.

Life expectancy is currently 82.1 years for women in Leeds and 78.2 for men (Figure 20) (ONS 2018g). For men this is 1.4 years below that across England and for women 1 year, with the difference greater than seen in 2001-2003 (0.1 years females, 0.3 years males).



Figure 20 Life Expectancy at birth, by sex, England and Leeds, 2001-2003 to 2015-2017

The life expectancy at age 65 has also seen a divergence from the national figures, with the gap growing to 0.7 of a year between 2014-2016 and 2015-2017. In 2015-2017, a woman in Leeds would expect to live another 20.3 years from her 65<sup>th</sup> birthday (17.9 years for a man) (Figure 21). This is lower than the national average – 21.1 years for a woman and 18.8 years for a man (ONS 2018g).



Figure 21 Life Expectancy at age 65, by sex, for England and Leeds, 2001-2003 to 2014-2017

As the majority of deaths occur in older age, the most common age of death for those born in 2014 to 2016 for a woman will be 88.9 years and for men 86.4 years (ONS 2017i).

Healthy life expectancy is the length of time an individual can expect to live in good health, and for a child born in Leeds in 2014-2016 a female can expect to live 63.0 years in good health (60.3 years for males) (ONS 2017j). However, with the longer overall life expectancy this means women tend to live longer but not with good health (19.2 years women, 17.9 years men).

## 6.3 Mortality

The biggest overall cause of death for women of all ages in Leeds is cancer at 243.5 deaths per 100,000 women, followed by deaths as a result of circulatory disease (217.9 deaths per 100,000) (Figure 22).



Figure 22 Mortality rate by cause (DSR) for females (all ages) in Leeds (2014-2016)

This has changed in the last 6 years, as before 2010 cardiovascular disease was the main cause of female death and there has been a welcome reduction of 27% in mortality from cardiovascular disease over the last 10 years (Figure 23).



Figure 23 All Ages Mortality for cancer and circulatory disease, 2006-2008 to 2014-2016, Females, Leeds

For women under the age of 75 years, the greatest cause of mortality is cancer at 124 deaths per 100,000, with cardiovascular disease (the next highest) being less than half that at 49.5 deaths per 100,000.

For women, dementia is most common cause of mortality, with a rate of 942.8 per 100,000 deaths in females and 856.1 per 100,000 in males across Leeds in 2016, with 741 female deaths in 2016 (as compared to 402 males) - dementia is now recognised as the highest single cause of female deaths across England and Wales (ONS 2018h).

## 6.3.1 Effect of deprivation on mortality

The mortality rate in females living in the more deprived areas of Leeds was 40% higher than that for those living in the wealthier areas. For females under the age of 75 years, the mortality rate was nearly double (Figure 24).

The biggest differences in mortality between women living in deprived vs. nondeprived areas are among Chronic Obstructive Pulmonary Disease (COPD) at 2.6x higher rate of death, falls (2.5x) and accidents (2.5x) (Figure 25).



Figure 24 All-Cause Mortality Rate for Females (U75) Compared by Deprivation



Figure 25 Mortality rate by cause (2014-2016, DSR) for females (all ages) ranked by deprivation ratio

# 7 Physical health

#### 7.1 Introduction

There are a wide range of health issues that can affect women either uniquely as a result of their reproductive biology or have a significant impact on their overall state of health. This section explores the impact of cancer, cardiovascular, respiratory disease, diabetes, falls and accidents, and issues relating to bone and joint health. Health conditions relating to reproductive and maternal health are discussed in Sections 15 and 16.

## 7.2 Cancer

Cancer (neoplasms) resulted in 69,930 deaths in women across England and Wales in 2016 – 26% of all deaths (ONS 2018i). In Leeds, over the three-year period 2014-2016 there were 2,614 female deaths as a result of cancer (which is a similar proportion of 26% of all deaths over this period). The rate of death as a result of cancer over this period in Leeds was 243.5 per 100,000, but 30% higher in deprived areas (303.8 per 100,00) as compared to non-deprived areas (232.1 per 100,000). Between 2006-2008 and 2014-2016, there has been an 8% decrease in mortality across the city for women of all ages and 16% in women under the age of 75 years (Figure 26), nevertheless, cancer is still the principal cause of death for women in Leeds.



Figure 26 Female mortality rate (DSR) for cancer in Leeds from the period of 2006-2008 to 2014-2016

In 2012-2014 there were 521 female deaths in the most deprived quintile in Leeds as a result of cancer, of which 239 have been calculated to be the excess caused by deprivation (PHE 2016a).

With advances in cancer detection and cancer treatment, there are more women survivors, which brings new challenges in dealing with the aftermath of the condition and the treatment. The quality of life of breast and cervical cancer survivors is very dependent on the level of pain and residual disability experienced, especially when it is coupled with financial difficulties as a result of prolonged absence from work (Huang et al. 2017). A longer-term plan of rehabilitation and support is therefore needed for those with complex multi-therapy.

Cancer risk has been found to be higher in lesbian, gay, bisexual, and transgender (LGBT) individuals (Margolies and Brown 2018), as a result of a greater proportion who smoke, have a higher alcohol intake than the heterosexual population, greater incidence of obesity and eating disorders as a result of poor body image and depression, and greater recreational drug use.

The Women's Voices study (Thomas and Warwick-Booth 2018), identified the specific needs of the BME community with regard to cancer, with a lack of awareness of the signs and symptoms, along with the awareness of services, especially where language and culture are an issue. There was also a recognition of the challenge overcoming stigma and fear, where it is seen as a curse:

"Some people believe that if we don't talk about it, it won't happen"

## 7.2.1 Lung cancer

Lung cancer is the leading cause of death for women aged 50-79 years of age across England and Wales (ONS 2018i), with 12,952 deaths across England in 2016. This is the same picture in Leeds, with 690 female deaths over the three-year period covering 2014-2016 – a rate of 65.7 per 100,000. This ranged from 7.3 in Bardsey, East Keswick, Collingham, Linton and Harewood, to 185.1 in City Centre, which was nearly three times the rate observed across the city. For women under

75, lung cancer was a cause of mortality in 98 out of 107 MSOAs (92%). For women of all ages, lung cancer mortality (2014-2016, DSR) across Leeds was 65.7, however this ranged from 7.3 in Bardsey, East Keswick, Collingham, Linton and Harewood to 185.1 in City Centre, which was nearly three times the rate observed across the city.

Rates of smoking have been falling faster and for longer in men than for women. Post war there was a steady decline in men smoking, whereas for women the rates were still on the increase. This is reflected in the greater decrease in lung cancer in men, with women still seeing the effects on their higher rates with rising lung cancer rates. In Leeds a symptom awareness campaign aimed at both the general public and Primary Care staff had a marked effect on the number of community-ordered chest X-rays, with nearly 81% more being screened in 2015 as compared to 2008. There was also a significant increase (p>0.0001) in the number of people diagnosed with earlier stage cancer (Kennedy et al. 2018). However, despite this being successful with men (with a growing difference between mortality nationally and in Leeds), the rate of mortality in women rose slightly over this time period, with no fluctuation during the campaign (Figure 27). It is important to note that in 2017 women's mortality in Leeds was the same as the national average for men.

Women are more likely to develop adenocarcinoma (non-squamous cell lung cancer) (Lortet-Tieulent et al. 2014), which develops in the outer regions of the lung. These don't have the same effect on coughing as the male type, and therefore tend to be more advanced before being identified. Women are also more likely to experience fatigue, shortness of breath (due to the size of the growing tumour) or chest or back pain due to metastatic spread. However, once symptoms emerge there is a similarity between men and women in seeking help, with an equal likelihood of delay as a result of culturally-embedded moral frameworks of stoicism and responsible service use (MacLean et al. 2017).



Figure 27 Rate of death (per 100,000) for lung cancer, by sex, for Leeds and England & Wales, 2001 – 2017

Lung cancer is strongly linked to smoking and to deprivation (Figure 28), with more women being identified with lung cancer in decile 1 (most deprived) than men (83.8 per 100,000 as compared to 65.2 per 100,000) – this rate is also much higher than for women in the most affluent parts of the city (29.4 per 100,000).



Figure 28 Lung cancer prevalence, rate per 100,000, by deprivation, Leeds, 2018

There is emerging data from the Dutch-Belgium NELSON lung cancer trial, showing that women are more likely to benefit from lung cancer screening, with mortality in women decreasing by 61% compared to a decrease of 26%, in men (ACR 2018). A Lung cancer screening programme is currently being trialled in Leeds<sup>20</sup>.

## 7.2.2 Breast Cancer

Breast cancer resulted in 9,613 deaths across England in 2016 and is the leading cause of death for women aged 35-49 years in England and Wales (ONS 2018i). Across England, the 1 year survival for breast cancer is 95.6% and 84.9% for 5 years; in West Yorkshire it is 95.3% and 84.7% respectively for patients diagnosed 2008-2010 (ONS 2017k). There has been a welcome decrease of 27.6% in mortality rate across Leeds from 39.5 per 100,000 in 2006-2008 to 28.6 per 100,000 in 2014-2016 (Figure 29). Most recently, the mortality rate ranged from 6.6 in Alwoodley West to 105.7 in Belle Isle North, which was over three times the rate across the city. For Leeds, over the 2014 to 2016 period there were 306 deaths.



Figure 29 All Ages Breast Cancer Mortality DSR, Leeds - Females

It is estimated that about 27% of cases of female breast cancer in the UK are linked to lifestyle and environmental factors, such as obesity, smoking, alcohol consumption, and lack of physical activity (Parkin et al. 2011). Family history has

<sup>&</sup>lt;sup>20</sup> <u>https://yorkshirecancerresearch.org.uk/news/mobile-lung-health-checks-launched-in-leeds</u>

also been shown to be associated with an increased risk of developing breast cancer (Kartal et al. 2018), with an important role for health professionals to counsel women with first degree relatives with the disease. What is notable is that although breast cancer mortality is higher in the more deprived communities the prevalence is higher in the more affluent areas of Leeds (Figure 30). This may be due to increased screening uptake and the identification of an increased range of cancers and an increased survival. The biggest inequalities in screening uptake are found in women from lower socio-economic backgrounds (Douglas et al. 2016).



Figure 30 Breast cancer prevalence by deprivation decile, Leeds, 2018

#### 7.2.3 Colorectal (Bowel) cancer

Colorectal cancer is the third most common cancer in women, with a prevalence rate across Leeds of 168.4 per 100,000 women. Bowel cancer is a widespread disease for women of all ages in Leeds, with mortality in 91 out of the 107 MSOAs (85%). Bowel cancer mortality (2014-2016, DSR) across Leeds was similar to the national average with 21.9 as compared to 21.4 per 1000,000 across England in 2016 (CRUK 2016a) (Figure 31). The rate of mortality deaths has decreased in males over the past decade but has seen a slight increase in females. In the Hyde Park, Burley MSOA, the rate was 120.0 per 100,000, which was nearly six times the rate





Figure 31: Mortality from malignant neoplasm of colorectal cancer, Leeds, 2006-2008 to 2014-2016

The risk of developing colorectal cancer is increased with diets high in consumption of red and processed meat (Bates et al, 2016) and alcohol (Schütze et al, 2011); with smoking (Wei et al. 2017) and low levels of physical activity (Shaw et al. 2018) and excessive visceral fat (Moghaddam et al, 2007; Bassett et al, 2010; Marino et al, 2011) – all of which are amenable to preventative action. Women do have a biological advantage over men with regard to cancer as a result of the protective effect of oestrogen (Micheli et al, 2009; Murphy et al, 2011; Caiazza et al, 2015; Lavasani et al, 2015). However, women tend to develop colorectal cancer a decade older than men, when there are more co-morbidities to contend with that can mask the signs and symptoms of the disease (Chacko et al. 2015; White et al. 2018a) – this highlights the importance of engaging in bowel screening (see section 15.1.3 on bowel cancer screening).

#### 7.2.4 Cervical cancer

Cervical cancer is 4<sup>th</sup> most frequent malignant cancer globally (Small et al. 2017), and the 13<sup>th</sup> most common cancer in women in the UK (CRUK 2017a) resulting in 682 deaths across England. In Leeds, the rate of death over the 2014-2016 period was 2.1 per 100,000 (24 deaths).

Across England the 1- and 5-year survival is 82.5% and 65.3% respectively; in West Yorkshire it is 83.9% and 67.5% (ONS 2017k). Cervical cancer is one of the few cancers that is a result of a preventable infection. The human papillomavirus (HPV), is a contagious infection, mostly transmitted via sexual intercourse, and is very common, meaning that most sexually active people will be at risk. This virus can also cause cancer of the vulva, vagina, anus and rectum (Williams et al. 2017). It is also an important cause of oral cancer in women who have sex with women (Saunders et al. 2017). There have been marked reductions in cervical cancer as a result of the introduction of the human papillomavirus (HPV) vaccination.

Women from ethnic minority backgrounds have a higher share of cervical cancer, and as there is an issue in getting young ethnic women to take up the HPV vaccination, the gap is set to increase (Batista Ferrer et al. 2016; Chan and So 2017; Johnson et al. 2017).

There is a growing literature on the risk of cervical cancer in lesbian women and women who have sex with women (WSW), with an urban myth that they are not at risk as they don't have sex with men. As the HPV virus can be passed between women, with unscreened women left at an increased risk (Eaton et al. 2008; Waterman and Voss 2015; Margolies and Brown 2018). A review of lesbian and bisexual women's gynaecological conditions found that bisexual women were more likely to have cervical cancer than the heterosexual population (Robinson et al. 2016).

There is a need to keep the public's awareness of cervical cancer high, as this is a mostly preventable and treatable cancer. The WHO have recognised that it is important that men are better informed of women's risks of cervical cancer and have

created a practice sheet on their role in prevention (WHO 2014). There have been few studies that have explored men's awareness of cervical cancer A recent study from Korea, reaffirms the need to ensure men understand the risk women are under, as in this study they seem very un-informed, either about its causes or how it can be detected etc. (Kim et al. 2018).

## 7.2.5 Ovarian Cancer

Ovarian cancer is the 6<sup>th</sup> most common in females, with over half diagnosed in women over 65 years of age, with the numbers expected to increase by 15% by 2035 (CRUK 2017b). In 2016, there were 3,492 deaths as a result of ovarian cancer across England. In Leeds, the prevalence rate for ovarian cancer is 114.9 per 100,000 women, with a mortality rate of 7.26 per 100,000 in 2017 (England 11.6 per 100,000) (Figure 32), with a steady decline in mortality rate.



Figure 32 Mortality rate, ovarian cancer, Leeds and England, 2013-2017

There is uncertainty about the possible causes of ovarian cancer, but the ones most usually cited (CRUK 2016b; Reid et al. 2017) include older age, inherited faulty genes, hormone replacement therapy and having previous history of breast cancerenvironmental factors such as exposure to asbestos, the use of talcum powder and cigarette smoking may also be risk factors. Protective factors have been found to include breast feeding, childbirth, and taking the contraceptive pill. There is a need for greater symptom awareness in the community, and increased GP dexterity with differential diagnosis. It is also worth remembering that a surprising number of women under 30 develop ovarian cancer, and women with two or more relatives on the same side of the family typically develop the disease under the age of 50. A recent meta-analysis from America (Henderson et al. 2018) supports the low benefit of a screening programme for ovarian cancer.

#### 7.3 Diseases of the Circulatory system

Diseases of the circulatory system, which include cardio-vascular and cerebrovascular disease, account for 64,849 female deaths across England and Wales; 24% of all deaths (ONS 2018i). Across Leeds (2014-2016) for women of all ages, circulatory disease mortality rate was 217.9 per 100,000, with a steady decrease in women dying from coronary artery disease between 2006-2008 and 2014-2016 - a 27% reduction in deaths in women of all ages and a 32% reduction in deaths in women under the age of 75 years (Figure 33).



Figure 33: Female mortality rate (DSR) for circulatory disease in Leeds for the period of 2006-2008 to 2014-2016

There is a great variance across the city, ranging from zero deaths in City Centre (with a predominantly younger population) to a rate of 661 per 100,000 in Headingley Central. In 2012-2014 there were 524 female deaths in the most deprived quintile in Leeds as a result of circulatory disease, of which 228 have been calculated to be the excess caused by deprivation (PHE 2016a).

There is important new research emerging with regard to sex and gender differences in cardiovascular disease, with differences in epidemiology, clinical manifestation, pathophysiology, treatment and outcomes being seen between men and women (Papakonstantinou et al. 2013; EUGenMed et al. 2016; Regitz-Zagrosek and Karaigas 2017). These impact on women's risk of developing coronary heart disease, heart failure and cardiomyopathies, hypertension, aortic valve stenosis, and mitral valve problems (EUGenMed et al. 2016). Many of these sex differences are under-recognised within the medical community and by women themselves, leaving them vulnerable to missed diagnosis and appropriate treatment.

## 7.3.1 Hypertension

High blood pressure (hypertension) is the largest single known risk factor for cardiovascular disease and related disability (PHE 2017a). It increases the risk of heart failure, coronary artery disease and stroke; it can also increase the risk of kidney disease, peripheral arterial disease and vascular dementia. In the UK, it is the third biggest risk factor for disease after tobacco smoking and poor diet.

Women can be younger when they develop high blood pressure and it can have serious implications for their health, especially if they are overweight and are smokers. Blood pressure can increase during pregnancy, leading to gestational hypertension, and pre-eclampsia (NHS 2018b), which can have important implications for both mother and child.

Although men are more likely to be hypertensive during their adult life, after 65 years more women have the condition, with 31% of men and 26% of women affected across the UK (PHE 2017a). Across Leeds there were 14,705 per 100,000 females and 15,637 per 100,000 males diagnosed with hypertension in 2018. There is a strong link between hypertension and deprivation (Figure 34), with a higher prevalence in the most deprived areas of the city, with the highest rates found in

Middleton and Westwoods (20,226 per 100,000), Harehills Triangle (19,928 per 100,000) and Lincoln Green and Ebor Gardens (19,817 per 100,000).



Figure 34 Prevalence of hypertension (DSR) in women, by deprivation decile, 2018

It is important to get more of the population tested, as it is estimated that half of the population do not know their blood pressure (PHE 2017a). Leeds is running 'Blood Pressure Wise'<sup>21</sup>, which is study funded for two years by the British Heart Foundation. It is being delivered within the Council, primarily within the manual workforce, but also in Community Pharmacies where they are engaging mostly women.

At the moment 300+ women have engaged out of 740 and out of those women, about 10% of them were found to have hypertension which means they would have been offered home monitoring equipment and told to get a formal diagnosis from their GP.

<sup>&</sup>lt;sup>21</sup> https://www.leedsccg.nhs.uk/health/campaigns/lbpw/

#### 7.3.2 Coronary Heart Disease

Coronary heart disease tends to occur later in women's lives, but is the second highest cause of female deaths (after Dementia and Alzheimer's disease), accounting for 22,359 deaths across England and Wales (ONS 2018i).

In the top ten ranked MSOAs in Leeds for coronary heart disease mortality, Headingley Central (256.1 per 100,000), Holbeck (220.9) and Burley (214) were the highest, and well above the city rate of 90 per 100,000. For women under 75, circulatory disease was a cause of mortality in 105 out of 107 MSOAs (98%). Circulatory disease mortality (2014-2016, DSR) across Leeds was 49.5, however this ranged from 7.4 in Wetherby West to 184.2 in Halton Moor, Wykebecks.

Pre-menopausal women have a higher resistance to coronary heart disease, generally developing the disease 10 years after men (Regitz-Zagrosek and Karaigas 2017). This is also seen in Leeds, where the CHD mortality rate was 21.8 per 100,000 in the under 75 year female population (with Headingley Central again being the highest at 129.8 per 100,000).

In those aged under 75 years, women's risk of dying as a result of cardiovascular disease increases with poverty, but not to the same extent as men's (NHS Digital 2018a). Despite this advantage, across Leeds women living in deprived areas still had a 50% higher risk of dying of circulatory disease.

## 7.3.3 Cerebro-vascular disease

Cerebro-vascular disease covers a range of conditions, including cerebral infarction, stroke, subarachnoid haemorrhage, and occlusion. Overall, women have a higher mortality in their older years. In 2016, there were 209 female deaths and 155 male deaths in Leeds (ONS 2018h) (Figure 35).



Figure 35 Deaths due to Cerebro-vascular disease, Leeds, 2016

Across Leeds stroke mortality was 33.4 per 100,000 female population, but this rose to 93.7 in Belle Isle South and 92.6 in Thornbury.

#### 7.4 Respiratory disease

Across Leeds, mortality for all respiratory diseases (excluding pneumonia and influenza) accounted for 853 female deaths – a rate of 77.5 per 100,000, with an overall rate of 139.6 in deprived areas compared to 65.3 per 100,000 in the non-deprived areas. The lowest mortality was seen in Alwoodley West (12.5) and highest in Little Woodhouse (275.7), having a rate which was over three times the rate observed across the city.

In 2012-2014 there were 328 female deaths in the most deprived quintile in Leeds as a result of respiratory disease, of which 206 have been calculated to be the excess caused by deprivation (PHE 2016a).

Sex differences are evident in some of the main respiratory disorders including asthma, chronic obstructive pulmonary disease (COPD), cystic fibrosis (CF) and non-CF-related bronchiectasis. The main causes of this are genetic predisposition, sex hormones and comorbidities (including a poorer nutritional status and increased incidence of anxiety and depression, which can affect poor asthma control and quality of life) (Raghavan and Jain 2016).

# 7.4.1 Bronchitis, emphysema and other chronic obstructive pulmonary disease (COPD)

With 12,743 deaths in women across England, this is a bigger cause of mortality than breast cancer but does not tend to get the same attention. For women of all ages, COPD was a cause of mortality in 103 out of 107 MSOAs (96%). In Leeds, 579 deaths were from COPD over the 2014-2016 period (a rate of 53.7 per 100,000), with a range of 110.8 in deprived areas through to 42.6 in the non-deprived areas by deprivation decile, and the mortality rate in Cross Green, East End Park and Richmond Hill being over three times the rate observed across the city at 189.9 per 100,000. For women under 75, COPD was a cause of mortality in only 85 out of 107 MSOAs (79%). COPD mortality (2014-2016, DSR) across Leeds was 21.2 however this ranged from 7.4 in Wetherby West to 132.3 in Little Woodhouse, which was over six times the rate observed across the city.

Women are developing COPD earlier despite a lower dosage of smoking (Sansores and Ramírez-Venegas 2016; Jenkins et al. 2017). With as many girls as boys smoking, there may be a more negative effect on a girl's lung function due to their smaller size.

## 7.4.2 Asthma

For women of all ages, asthma was a cause of mortality in 27 out of the 107 MSOAs (25%). Asthma mortality (2014-2016, DSR) across Leeds was 2.9 however this ranged from 3.4 in Ireland Wood, Lawnswood to 21.2 in East Ardsley, which was over seven times the rate observed across the city. For women under 75, asthma was a cause of mortality in 12 out of 107 MSOAs (11%). Respiratory disease mortality (2014-2016, DSR) across Leeds was 1.3 however this ranged from 7.6 in Swarcliffe to 23.3 in East Ardsley, which was almost eighteen times the rate observed across the city.

Boys tend to have higher levels of asthma pre-puberty, but following puberty the numbers of girls affected is greater, with adult women having more severe asthma and a later onset than men (Fuseini and Newcomb 2017) (Figure 36). This may be the result of the female sex hormones impacting on allergic responses in the airways.



Figure 36 Ratio of female to male rate of death, Asthma, England, 2016

An American study (Lu et al. 2016) found that being overweight and obesity was associated with greater risk of prevalence of asthma in adolescent girls, but not for boys. They also found there was no difference in the severity of asthma in girls who had a high level of fitness, which was the converse as seen in boys, which suggests that as boys get fitter their asthma improves, but this is not the case for girls.

There is evidence that asthma may get worse during pregnancy and is associated with problems to both the mother and also has implications for the risk of asthma in their offspring (Charlton et al. 2016; Ali et al. 2018; Liu et al. 2018). It is important that women who suffer from asthma are monitored and have good control through their pregnancy. Rates of asthma are also increased over the perimenopause period and in post-menopausal women who were using menopausal hormone therapy (Zemp et al. 2012; Triebner et al. 2016).

## 7.4.3 Cystic fibrosis

Cystic fibrosis is a metabolic disease of the lungs that is a life limiting disease, and is more severe in females, with peak exacerbations coinciding with the monthly menstrual cycle (Raghavan and Jain 2016).

## 7.5 Diabetes

There are three forms of diabetes: type 1, which is a result of the body not being able to make the hormone Insulin which is required for normal sugar control; type 2, in which the body cannot make enough Insulin for the body's requirements or doesn't work properly; and Gestational diabetes, which occurs in women whilst they are pregnant, but may clear up after birth (NHS 2016c).

## 7.5.1 Type 1 diabetes

Across Leeds there are 801 females and 1041 males with type 1 diabetes, with the prevalence increasing by deprivation (Figure 37).

Type 1 diabetes usually starts during childhood and unlike type 2 diabetes (which is mostly a lifestyle related disease) is a result of the body not being able to produce insulin. It has important consequences for the health of women, with those women affected having a marked increase in the risk of developing cardio-vascular disease and other health conditions. Women with type 1 diabetes have a roughly 40% greater excess risk of all-cause mortality, and twice the excess risk of fatal and nonfatal vascular events, compared to men with type 1 diabetes. (Huxley et al. 2015). It also has important implications for a women's fertility and pregnancy risks.



Figure 37 Prevalence of type 1 diabetes, by index of deprivation, Leeds, 2018

Girls developing type 1 diabetes in childhood tend to be more severely affected physiologically than boys, with more vascular problems in early adulthood (Samuelsson et al. 2016). Teenage girls are found to have poorer glycaemic control of diabetes, which has been attributed to depression and psychological problems (Forsander et al. 2017), but may also be a consequence of a more pronounced autoimmunity factor or hormone related (Samuelsson et al. 2016; Turtinen et al. 2018). The guidance would seem to suggest that girls (and boys) need more targeted support when they are first diagnosed, and as they go through their teenage years with diabetes.

Type 1 diabetes has a detrimental effect on young women's bone density and increases the risk of fractures in young women (Mastrandrea et al. 2008). However, the longer-term effect may be less than thought, as better control of type 1 diabetes is resulting in more women surviving into older age. A recent study of older American women who have had a diagnosis of type 1 diabetes for over 50 years, found there were actually fewer fractures than the control, non-diabetic population; this suggests that those women who are reaching old age have had better control of their diabetes and other health risks (Maddaloni et al. 2017). Despite this improvement, there are still many women whose control is not optimal, which opens up the possibility of longer term health problems (Swasey et al. 2018).

Type 1 diabetes can have a negatively impact on pregnancy, increasing the risk of having a large baby or a baby with birth defects, as well as potential health risks for the mother. There is a need for women to be given specialist advice both pre-conceptually and throughout the pregnancy (NHS Choices 2018).

## 7.5.2 Type 2 diabetes

In Leeds there are 4,566 females and 6130 males diagnosed with type 2 diabetes, with a strong link to deprivation (Figure 38).

There are sex and gender differences in the risk, pathophysiology and complications of type 2 diabetes, with significant consequences for women developing the disease through obesity. Pre-menopausal women have a higher level of protection against cardiovascular disease than men (due to the action of the sex-hormones on the circulatory system), with diabetes this is lost, opening women up to a greater risk of myocardial infarction and stroke mortality than that seen in men (Kautzky-Willer et al. 2016). The risk of developing diabetes is also increased in post-menopausal women by the loss of lean body mass and a decrease in total energy expenditure (Kautzky-Willer et al. 2016).



Females Males

Figure 38 Prevalence of Diabetes type2, by deprivation, Leeds, 2018

Both type 1 and type 2 diabetes can have a negative effect on fertility for both men and women-for women there can be problems with the fallopian tubes, ovaries, uterus and menstrual disorders leading to faulty ovulation (Basmatzou 2016). Conversely, higher parity is linked to greater risk of developing type 2 diabetes (Guo et al. 2017).

Type 2 diabetes is a major health risk for people of South Asian origin, who are between three and six times more likely to develop type 2 diabetes when compared to white Europeans (Hanif et al. 2014). They tend to develop the disease at an earlier age, with an increased prevalence of diabetes-related conditions. There are strong links to traditional South Asian culture that can also impact the management of diabetes. This was an important point raised as part of the Women's Voices in Leeds study (Thomas and Warwick-Booth 2018), in relation to culture and diet:

"A health professional came to deliver a health session and used a standard NHS questionnaire to calculate how healthy the women's lifestyle was. The questions around food asked if they ate chocolate and crisps etc. From the women's answers they should have been the picture of health because the questionnaire didn't consider cultural differences-although the women don't eat chocolate and crisps they eat a lot jalebis (deep fried sugar-coated flour)." (p26)

Women generally tend to have poorer control of their diabetes and experience more psychosocial stress (including economic, environmental, and behavioural components), which is often linked to their obesity (Ding et al. 2009; Kautzky-Willer et al. 2010; Franzini et al. 2013; Rossi et al. 2017). Teenage girls have been found to be the most affected (Forsander et al. 2017), especially if they had an anxiety that their parents were not able to manage their diabetes.

With diabetes being linked to visceral (abdominal) fat, waist size is a key factor in the link between diabetes and overweight (Seo et al. 2017), with a waist size at or above 88cm (35") in Caucasian women being a more positive indicator of diabetes risk than men's increased waist size (102cm 40"). For women of Asian origin the waist size

where risk increases is lower (80 cm 31.5" women and 90cm 35" for men) (Alberti et al. 2007).

# 7.5.3 Gestational diabetes and diabetes during pregnancy

The rate per 1,000 births of gestational diabetes calculated over 10 years (2007-2016) was 37.3 across the city and ranged from 21.7 in Pudsey ward to 69.5 in Gipton and Harehills ward, which was nearly double the rate observed across the city.

The impact of gestational diabetes mellitus (type 2) includes a higher risk for:

- Primary caesarean section.
- Preeclampsia.
- Premature delivery.
- Stillbirth, and perinatal mortality.
- Diabetic embryopathy (abortus, congenital anomalies).
- Diabetic fetopathy (macrosomia, birth weight, and body fat above the 90th percentile, fetal hyperinsulinemia) (Kautzky-Willer et al. 2010).

There is also a possibility that existing problems associated with diabetes may be worsened through pregnancy (NHS Digital 2016; NHS Choices 2018). Although it is possible to have a normal pregnancy and a healthy child, diabetes can cause serious issue for both themselves and their child that need to be carefully considered and managed (Bradley et al. 2016).

Key findings from the Pregnancy and Diabetes Annual report (NHS Digital 2016) for 2016 were:

- 24% of women with type 1 diabetes and 42% women with type 2 diabetes did not present to the joint diabetes antenatal team before 10+0 weeks gestation.
- Delivery by caesarean section was more common in diabetics (65% of type 1 and 57 per cent of type 2).
- Almost one in 10 women with type 1 diabetes had at least one hospital admission for severe hypoglycaemia.

• Ketoacidosis, a high risk for mother and fetus, occurred in 2.7% of women with type 1 diabetes.

In 2016 there were 3,304 pregnancies in 3,297 women with diabetes across England and Wales; of these, 1,608 women had type 2 diabetes, with nearly half being of Black, Asian or mixed ethnicity. Women with Type 2 diabetes also more likely to be older, be more overweight, with a shorter diabetes duration, and more likely to live in areas of social deprivation (NHS Digital 2016). These risks can be reduced, but it requires careful management through the pregnancy, which can put additional emotional and economic cost onto the parents, often when they are facing other financial pressures.

Diabetes UK (Diabetes UK 2018) offer the following advice to women with diabetes who are pregnant:

- Get to know the risks involved and how to reduce them.
- Talk to your GP or nurse.
- Keep your blood sugar to your target levels.
- Check what medication you're taking, as some can harm the baby.
- Take folic acid every day.
- Get your eyes and kidneys checked.
- Make healthy lifestyle choices like eating well, cutting down on drinking. alcohol, quitting smoking and getting active.

## 7.6 Accidents and Falls

For women of all ages, accidents were a cause of mortality in 88 out of 107 MSOAs (82%). Mortality from accidents (2014-2016, DSR) across Leeds was 15.8, however this ranged from 4.3 in Garforth to 111.9 in Little Woodhouse, which was approximately seven times the rate observed across the city. For women under 75, accidents were a cause of mortality in 56 out of 107 MSOAs (52%). Mortality from accidents (2014-2016, DSR) across Leeds was 8.3 however this ranged from 5.5 in Broadleas, Ganners, Sandfords to 79.0 in Little Woodhouse, which was over nine times the rate observed across the city.

Women are at greater risk of falls in their older years, with this being the leading cause of their loss of functional ability, independence and quality of life, and of injury-related death (Kenny et al. 2017). In 2016, across England 2,376 women (2,273 men) died as a result of a fall over the age of 65 years (ONS 2018i). Mortality from falls across Leeds resulted in 96 deaths over the three-year period 2014-2016, a rate of 8.2 per 100,000 population.

For women of all ages, falls were a cause of mortality in 67 out of 107 MSOAs (63%). Mortality from falls (2014-2016, DSR) across Leeds was 8.2 however this ranged from 4.5 per 100,000 in Middleton and Westwoods to 70.3 per 100,000 in Little Woodhouse, which was over eight times the rate observed across the city. For women under 75, falls were a cause of mortality in only 22 out of 107 MSOAs (21%). Mortality from falls (2014-2016, DSR) across Leeds was 2.4, however this ranged from 4.9 in Middleton and Westwoods to 34.9 in Armley, New Wortley which was over fourteen times the rate observed across the city.

Women are at greater risk of emergency admission due to a fall over the age of 65 years (2,000 Leeds women as compared to 926 Leeds men for the year 2017/2018). The 3 year aggregated rate (2015/16 to 2017/18) gives a rate of 2,696.65 per 100,000 for women and 1,833.85 per 100,000 for men across the city. The rate of falls varies by Local Care Partnership (LCP) (Figure 39), with the Leeds Student Medical Practice (LSMP) seemingly having the higher rate, but this is due to the small number of women over the age of 65 years skewing the data.



Figure 39 Emergency admissions due to falls, females, 3 year aggregate rate (2015/16 to 2017/18), DSR per 100,000, Aged 65+, Leeds Local Care Partnerships

Those women with a history of falls have a greater chance of mortality following a stroke (Foster 2017). Falls also have a very negative effect on an individual's confidence and willingness to mobilise or to socialise – this can compound the effects of immobility and lead to increasing social isolation and depression.

Many falls are as a result of chronic disease and pain, with the sex-specific factors more associated with falls being women's incontinence and frailty, and multimorbidity (Afrin et al. 2016; Gale et al. 2016). Increasing frailty, with its associated unsteady gait, lack of energy and weakness, is recognised as a consequence of ageing, but does not occur in everyone and can be avoided by preventative action in earlier years (Harmsen et al. 2016). The Australian Longitudinal Study on Women's Health (White et al. 2018b) found that obesity was a statistically significant cause of falls in middle-aged women (50-64 years), along with impaired vision, poor physical functioning, depression, leaking urine, stiff/painful joints, severe tiredness, osteoporosis and hormone replacement therapy. They note however, that it was often not one single cause, but a "woman's overall physical and psychological health and well-being reflected in the risk factors, with their risk of falling associated with a dynamic integration of these risk factors" (p 61).

There are also environmental factors (Fenton 2014) that impact greatly on how independence can be maintained as you get older, with ease of getting around reducing the risk (and the fear) of falling.

#### 7.7 Osteoarthritis

Osteoarthritis is recognised as a major cause of chronic pain, associated with exhaustion, social isolation, depression, obesity, and many other serious conditions (Barnett 2018). It is a common condition with over 8.75 million people across the UK seeking treatment, of which over 5 million are women (Figure 40). Osteoarthritis is more prevalent in women than men at every age, but the sex-difference magnifies after the menopause, with over 49% of women and 42% of men over 75 years being affected, demonstrating the effect of the sex-hormones on the disease (Pan et al. 2016; Jin et al. 2017).

In Leeds, there are 28,688 women (21,543 men) with knee osteoarthritis, and 19,864 women (10,472 men) with hip osteoarthritis (Arthritis Research UK 2013). More women than men claim disability living allowance as a result of arthritis (2,490 female claimants compared to 1,150 males in 2018) (NOMIS 2018b). Women working in health care, child care, and cleaning have an increased risk of sick leave and disability pension due to knee osteoarthritis (OA) (Hubertsson et al. 2017).

Osteoarthritis was predominately seen as a disease caused by the erosion of the joints due to hard wear and tear, but it is now recognised as being a much more complicated disease with a higher prevalence in women (Pan et al. 2016; Jin et al. 2017; Barnett 2018; Bortoluzzi 2018). Although there is not yet a full understanding of the causes of osteoarthritis, there is growing evidence that there is a strong immunity-related factor (Kalaitzoglou et al. 2017). The immune response has been found to be different in male and female sufferers (Kriegova et al. 2018), which could explain why more women develop the disease and have a more aggressive form. A link has also been made to the metabolic syndrome (Bortoluzzi 2018), which helps explain the higher incidence of osteoarthritis in obese women and men. There are links to levels of socio-economic deprivation, but this is possibly due to higher levels

of obesity in deprived communities, with a Spanish study (Reyes et al. 2015) suggesting up to 50% of the increased risk is due to this weight factor. Vertebral disc degeneration and other causes of low back pain are more common and more severe in elderly women than in elderly men, most likely as a result of oestrogen deficiency (Wang 2017).



Figure 40 Number of people (millions) who have sought treatment for osteoarthritis, UK, 2013

The higher incidence of OA has also been associated with a greater number of physical limitations, with a fear of falling, an increasing number of chronic conditions and poly pharmacy (French et al. 2016) – all of which are more prevalent in women, especially in their older years.

With the same degree of radiographic damage, OA is also more symptomatic in women with osteoarthritis compared to men (Tonelli et al. 2011). Women have significantly more pain, greater pain sensitivity and reduced function than men (Tonelli et al. 2011), even when controlling for variables such as depression, anxiety, pain catastrophising, social support, and physical activity. In addition, they have poorer perceived function, and more impairment on specific functional tasks.

There has been thought to be an association between smoking and osteoarthritis (Felson and Zhang 2015; Kong et al. 2017), but it is now recognised as more of cause of increased musculoskeletal pain than increasing the risk of the condition.

## 7.8 Osteoporosis

Osteoporosis is a condition that is caused by changes to the bone structure and strength leading to an increased fragility and fractures (NHS 2016d). It is estimated that over 3 million people across the UK have osteoporosis (Arthritis Research UK 2018), with over 40% of White post-menopausal women having the condition - with an ageing population the numbers affected are expected to increase (Rachner et al. 2011). Across England, 655 women died as a direct consequence of osteoporosis, but many more are affected by the impact of fractures and the subsequent frailty and loss of confidence that ensues. In Leeds 11,802 women have a diagnosis of osteoporosis (4,290 men) (Figure 41).

Osteoporosis can occur throughout adult life as a consequence of pre-existing disease, such as high dose oral corticosteroids, family history, some medical conditions and medications and being underweight, but is also a result of lifestyle factors including being a heavy drinker and smoking (NHS 2016d). However, for women the most rapid bone loss occurs whilst they are transitioning from pre- to post-menopause (Bjørnerem et al. 2018), with post-menopausal women losing an average of 2.5% of their bone per year over the first 5 years due to the loss of oestrogen production (Arthritis Research UK 2018). Many women (and men) suffer more than one fracture before they are diagnosed, leading



Figure 41 Prevalence of osteoporosis, by age and sex, Leeds, 2018

to an advancement of the disease when prevention could have been initiated.

Early treatment should be the goal of primary care to reduce the consequences of fractures (Rachner et al. 2011; Nguyen 2017; Ferrari 2018), but prevention should also be seen as important. Fractures can occur anywhere, at any time, with only hip fractures seeming to have a seasonal effect (most in the spring), suggesting that fall prevention should be aimed at all at risk (Costa et al. 2013).

There is also a lack of awareness in adolescent girls as to the risk and the need to build bone strength and avoid smoking etc. (Anderson et al. 2005), with great importance in getting bone density as great as it can be in early years (Chastin et al. 2014) as maximal bone density is acquired by the age of 30 and 90% of bone mass accrued in girls by 18 years of age (NIH 2015).

Although exercise is seen to be very beneficial for good bone health, female athletes are at risk of a problematic triad of osteoporosis, eating disorders and amenorrhea that can leave them with long term bone problems (along with other health issues) (Nguyen et al. 2014).

There is a high prevalence of dementia in women with osteoporosis, which might be a consequence of dementia being diagnosed in women who have fallen (Amouzougan et al. 2017). This cannot account for all the increased prevalence and whilst the exact reason is not known there should be an effort to ensure women with dementia are assessed to help prevent fracture, with all its negative consequences in this cohort of vulnerable women.

The National Osteoporosis Society (NSO 2015) in their Agenda for England recommends that there should be both national and local action, including the improvement of local services to increase provision for those affected and a need to raise awareness of the condition.

## 8 Mental Health

#### 8.1 Introduction

The Adult Psychiatric Morbidity Survey (APMS) is a population survey of mental health disorders in adults, carried out every 7 years in England. The most recent report (McManus et al. 2016) highlights a number of key issues concerning women. Rates of common mental health disorders (CMHD) across England have remained relatively stable over last 10 years, however, proportional rates of moderate/severe CMHD have increased – this is driven by the deteriorating mental health of women. Young women (aged 16 – 24 years) were identified in the APMS as a group particularly 'at risk' of a range of mental health problems. Rates of self-harm amongst young women have tripled since 1993, and today's young women are three times more likely than young men to experience post-traumatic stress disorder and eating disorders (McManus et al. 2016).

The percentage of women and men with serious mental illness (schizophrenia, psychosis and bipolar disorders) is similar in the population overall, although the pattern across the life course may be different, with men tending to develop psychosis at a younger age and women later on in life (McManus et al, 2016).

Some women appear to be at greater risk of mental illness and may struggle to access treatment and support that meets their needs. Black women have significantly higher rates of CMHD than White British groups, but as a group are less likely to receive mental health treatment (McManus et al. 2016). Asylum seekers and refugees, Gypsy and Traveller groups, women who are homeless and street sex workers are also at significantly increased risk of mental ill health (Davies 2015; McManus et al. 2016).

The reasons for the poor mental health of women is complex but may include: increasing levels of domestic violence/abuse and the pressures associated with online culture, social media and pornography. Austerity has also had a disproportionate impact upon women, with 86% of the burden for recent cut-backs falling on women (Stewart, 2017). The apparent deterioration of women's mental health occurs within a context of a reduced national policy focus on the mental health of women and girls. The Mental Health Foundation, in its report '*While your Back was Turned: How mental health policymakers stopped paying attention to the specific needs of women and girls*' (MHF 2017) recommends increased attention to gender across mental health policy including:

- Clearly identified government structures for sustained leadership and action to improve young women and girls' mental health.
- Action for young women and girls' mental health using a whole community's approach.
- Systematic collection of disaggregated (gender, age and other protected characteristics) data on mental health outcomes.

Local analysis of the experiences of specific groups of women in Leeds highlighted high levels of mental ill health/morbidity in some parts of the city's female population.

- Of the 126 people who took part in the LGBT Leeds LGBTQ+ Mapping Project, 30% said they had a 'mental health condition such as depression, schizophrenia or anxiety disorder' and 90% reported having a mental health experiences(s) that impacted severely their day to day functioning in the last five years (Stewart, 2017).
- A recent health needs assessment of sex workers (commissioned by BASIS in Leeds), found that over 85% of the 63 women involved had a mental health disorder (Finnigan, 2015).
- A qualitative survey carried out by Leeds Beckett University into the mental health needs and experiences of Black women born outside of the UK found that's stigma, loneliness, language barriers, previous trauma and stress associated with asylum process impacted significantly upon their mental health and that his was compounded by: *'limited access to culturally appropriate mental health services'* (Woodward et al. 2016).
- University counselling services note the increasing levels of emotional distress in the student population (Erskine, 2018).
## Case study 5 Mary

I came to Women's Counselling and Therapy Service (WCTS) after a recommendation from my CPN. I had been hospitalised for a physical illness from which I was not recovering as expected, luckily my GP realised that there was not only an underlying physical cause but also a psychological one.

I was diagnosed with a form of PTSD and gradually admitted that for the last five years of my marriage I had been physically, mentally and emotionally abused. I didn't realise this at the time as it was 'normal' for me, I abhorred such things when I heard of it happening to other people but could not recognise it in my own life.

When I first came to WCTS I was awaiting surgery to repair the physical damage that had been done and thought that this would be the panacea, unfortunately I had to have operations that have left me with constant physical reminders.

Counselling not only got me through this time but took me back through previous relationships and taught me that there had been a pattern of abuse going back to my childhood. I learnt that it wasn't me hiding what was happening in these relationships I expected this behaviour because I have never known any different. Now I choose to be single and I'm actually happy finding out who the real me is. I was made redundant last year and this has been a great opportunity to leave the past behind. I have gone back to study to do counselling in community settings; this will be my way of giving something back to those people who enabled me to start my life.

<sup>1</sup>Name Changed

## 8.2 Common Mental Health Disorders

Common mental health disorders (CMHDs) cause marked emotional distress and interfere with daily function. They comprise different types of depression and anxiety including: generalised anxiety disorder (GAD), panic disorder, phobias, and obsessive compulsive disorder (OCD). Symptoms of depression and anxiety frequently co-exist, with the result that many people meet criteria for more than one CMHD. If left untreated, CMHDs can lead to long term physical, social and occupational disability, and premature mortality. Locally, twice as many women are recorded as having a CMHD in Primary Care as men. When individual CMHDs are considered, this pattern remains, with the exception of Post-Traumatic Stress Disorder (PTSD) where rates are similar, and OCD where differences are less marked.

There has been an increase in the number of males and females affected by depression and anxiety across the city over the past year (Figure 42), with the biggest increase seen in anxiety for females.



Figure 42 Trends in anxiety and depression for females and males 18+ years, 2017 - 2018, Leeds

## 8.3 Serious Mental Illness

Serious Mental Illnesses are usually defined as Psychotic Disorders (including schizophrenia, schizoaffective disorder, and affective psychosis) and Bipolar Disorder. Psychotic disorders produce disturbances in thinking and perception severe enough to distort understanding of reality. People with a psychotic illness can make a full recovery, although some will have repeated psychotic episodes over their lifetime and/or some degree of persistent disability. There is significant comorbidity between these types of mental health problems and physical health conditions such as diabetes. Mechanisms for this comorbidity are complex, although are broadly

related to: lifestyle factors, medication side effects and barriers to healthcare. Evidence shows that people with Serious Mental Illness (SMI) die, on average, 15 – 20 years younger than the general population (Davies 2014).

The APMS did not report variation in rates of psychotic disorder across other ethnicities or between the sexes that met statistical significance – this does not mean that these differences might not exist, but rather that the sample size was too small to be able to detect them. Locally, recorded rates of SMI within Primary Care are broadly comparable.

## 8.3.1 First Episode Psychosis

First episode psychosis (FEP) is defined as the first time someone experiences disturbances in thinking which may include delusions or distort reality. Early intervention in psychosis is a key service/intervention which can reduce the early negative impacts of FEP and improve longer term outcomes.

National incidence modelling of FEP via <u>www.psymaptic.org</u> underestimates local service need consistently in the North of England – for reasons that are not entirely clear. Therefore, NHS England has advised local areas to review service use and pathways and use a specific formula to inform decisions about likely future incidence. Mental Health Service providers, NHS Leeds Commissioners and Public Health have worked together to agree an incidence in Leeds of 32/100,000, which is much higher than the figure of 24/100,000 estimated by <u>www.psymaptic.org.uk</u>. The onset of psychotic disorders in women tends to be later in life than in men, with a peak post menopause. Reasons for this are unclear, although there is developing consensus that decreasing levels of oestrogen (which operate protectively on the brain) around the time of the menopause increase the risk of psychosis (Ochoa et al. 2012; Falkenburg and Tracy 2014).

## 8.3.2 Dual Diagnosis

Dual diagnosis is defined as co-morbid severe mental illness and substance misuse. People with dual diagnosis often have other co-existing physical health problems. Forward Leeds data indicates that a higher proportion of women than men have a diagnosed mental health condition when they first access treatment (Table 4).

		Yr 16/17		
	Dual	No Dual		Total with
	Diagnosis	Diagnosis	Total	DD
Female	613	1367	1980	31%
Male	970	3213	4183	23%
Total	1583	4580	6163	26%

Table 4 Episodes in Treatment for dual diagnosis: Forward Leeds

	Yr 17/18				
	Dual	No Dual		Total with	
	Diagnosis	Diagnosis	Total	DD	
Female	611	1464	2075	29%	
Male	917	3404	4321	21%	
Total	1528	4868	6396	24%	

(Source: Forward Leeds)

The relationship between having a substance use disorder and a mental illness is complex. Studies have shown that co-morbidity varies by substance type, severity of substance use and psychiatric disorder. There is often a relationship with trauma which can lead to an increased likelihood of someone experiencing substance use/mental ill health. In turn, having a 'dual diagnosis' increases risk-taking behaviour and risk of harm (Schulte and Hser 2014). Young women in particular have been shown to be more susceptible to comorbid substance use and mental illness, rates.

In a primary care population of young people aged 14 – 18 years old, girls with substance use problems or substance use disorder had increased odds of reporting

symptoms of mania, attention deficit disorder, and conduct disorder (Shrier et al. 2003). Girls with substance use disorder were also at increased risk for symptoms of depression, eating disorders, and hallucinations or delusions

In comparison with men, women with co-occurring substance use/misuse and mental health disorders are more likely to stay in treatment for longer (Choi et al. 2015).

## 8.4 Eating Disorders

Eating disorders are a group of serious mental health conditions, characterised by persistent food intake disturbance. They can cause people to adopt restricted eating, binge eating and compensatory behaviours (such as vomiting and excessive exercise). They are associated with high morbidity, and sufferers have a significantly higher mortality rate than those without the disease from malnutrition, suicide and physical issues (such as electrolyte imbalances) (NICE 2017a).

Eating disorders predominately, but not solely, affect women, and commonly develop in teenage years. They are often comorbid with other physical and mental health disorders (including anxiety disorders) that are reported to affect the wellbeing and recovery of people with an eating disorder and raise the cost of treatment (NICE 2017a).

The 2007 national Adult Psychiatric Morbidity survey (APMS) highlighted the likely gap in epidemiological data due to under-reporting and under-diagnosis of eating disorders (McManus et al. 2009). In the 2007 study the 'SCOFF' survey tool<sup>22</sup> was therefore used in order to detect attitudes and behaviours associated with possible eating disorders in a large population sample. 20.3% of young women (6.1% of men) aged 16 - 24 years scored two or more (the clinical threshold for diagnosis of an eating disorder) on the SCOFF scale within this survey. The APMS reports that the

<sup>&</sup>lt;sup>22</sup> The SCOFF questions (Morgan F et al. 2000)

<sup>•</sup> Do you make yourself Sick because you feel uncomfortably full?

<sup>•</sup> Do you worry that you have lost Control over how much you eat?

<sup>•</sup> Have you recently lost more than **O**ne stone (14 lb) in a 3-month period?

<sup>•</sup> Do you believe yourself to be Fat when others say you are too thin?

<sup>•</sup> Would you say that Food dominates your life?

prevalence derived from this tool likely to be an overestimation. Applying this percentage to the female Leeds resident population aged16 – 24 years suggests there may be 13,000 young women with a possible eating disorder in the city.

## 8.5 Self-Harm and Suicide

Self-harm (non-fatal intentional self-poisoning or self-injury, irrespective of degree of suicidal intent or other motivation) is a key risk factor for suicide. It is suggested that at least half of people who die by suicide will have engaged in self-harm at some stage in their lives, often shortly before death (Davies 2015). However, the relationship between suicidal ideas, self-harm and suicide is not straightforward. The overall profile of people reporting suicidal thoughts, attempts and self-harm is very different (in terms of age and sex) from that of people who take their own life, and the great majority of people who engage in these thoughts and behaviours do not go on to die by suicide (McManus et al. 2016).

## 8.5.1 Self-Harm

The National Institute for Healthcare and Clinical Excellence (NICE) define self-harm as any type of self-poisoning or self-injury irrespective of motivation (NICE 2013). A range of behaviours constitute self-harm, including cutting, burning, punching, swallowing objects, head-banging, pulling out hair or eyelashes, and inhaling harmful substances (Laye-Gindhu and Schonert-Reichl 2005; Stänicke et al. 2018). As a behaviour, self-harm is associated with a range of mental health problems, including borderline personality disorder, depression, and schizophrenia (NICE, 2013).

The APMS (2016) reports a sustained increase in reported self-harm between 2001 and 2014. This increase was evident in both men and women across all age groups, however, young women were noted as a particular risk group. 25.7% of women in this population survey reported 'ever' self-harming,

Using this rate and applying it to the Leeds female population aged 16 – 24 suggests there may be 16,000 young women who have 'ever' self-harmed.

#### 8.5.2 Suicide

Suicide is considered as mainly a male issue, but it is still a significant cause of premature death in women and is just as devastating for all concerned (Mallon et al. 2016). Suicide is the leading cause of death in women aged up to 34 years (ONS 2018i), and in Leeds resulted in 30 female deaths between 2014-2016 (a rate of 2.4 per 100,000). The Leeds Audit of Suicide and Undetermined Deaths (Everitt et al. 2016) assesses coroner's records every three years for the previous triennium. Results indicate that since 2008 there have been more male (176) than female suicides (37). The rate of male death has increased from the 2008-10 audit; however, the rate of female death has not changed.

Data from the ONS show that Leeds has a female suicide rate of 10.3 per 100,000 for the years 2012 to 2014; this is comparable to both the Yorkshire and Humber rate (10.3 per 100,000) and the rate for England as a whole (10.0 per 100,000). For females in England and Wales, between 2001 and 2007, poisoning was the most common suicide method. In 2017 it is now hanging (42.8%), with poisoning at 36.8%, then drowning (5.2%), fall and fracture (3.1%), and other causes (12.1%) (ONS 2018j).

There are a number of key factors which increase the risk of a woman taking her life. Women most at risk are those who have been abused, either as adults (Trygged et al. 2014; Wolford-Clevenger and Smith 2015; Palm et al. 2016; MacIsaac et al. 2017) or as a child (Bedi et al. 2011). Bereavement, and motherhood (Mallon et al. 2016) have also been associated with suicide in women, with a specific link found between suicide and motherhood, especially for those with existing mental illness (Mallon et al. 2016; Gressier et al. 2017).

Women with gynaecological cancer are at greater risk as compared to women with other forms of cancer (Ward et al. 2013). There are also lifestyle associated risks, including alcohol (Gomberg 1989) and substance abuse (Foster et al. 2016; Stenbacka et al. 2017). Sexual minority women are at greater risk of suicide than heterosexual women (Tabaac et al. 2016), as are those who are trans (Barboza et al. 2016). Ethnic minority women are less visible in the suicide data, but evidence from America suggests that Asian women are less likely to seek help with emotional difficulties (Augsberger et al. 2015).

Whilst women may have borne the financial impact of austerity, there is no clear link between the recent recession and suicide in women (Coope et al. 2014).

# 8.6 Adversity and Mental Illness

There is increasing recognition of the link between adverse childhood experiences (ACEs) and the harmful effects that these have on health have throughout life. ACEs include: having parents with mental health problems and/or substance abuse disorders; having experienced violent, abusive or neglectful relationships as a child; bereavement; and divorce. Individuals with multiple ACEs are at increased risk of poor health outcomes, with the strongest associations being between multiple (defined as four or more) ACEs and sexual risk taking, problematic alcohol use and mental illness (Hughes et al. 2017).

A summary of recent research (Sara and Lappin 2017) on trauma concludes:

- Trauma is a common risk factor for a broad range of mental health disorders. These include personality disorders, bipolar disorder, mood substance misuse and psychosis.
- It is associated with reduced responses to treatment in mood disorders.
- Childhood adversity is associated with a 1.5 3 x increased likelihood of psychotic experience.

The Centre of Expertise on Child Sexual Abuse Scoping Report 2017 (Kelly and Karsna 2017) reports that 15% of girls (compared to 7% of boys) experience sexual abuse before the age of 16. Modelled Leeds estimates based on this prevalence figure and Leeds GP Registered Populations Mid-2018, suggest that 11,777 girls may have experienced sexual abuse in the city.

There are evidenced, causal relationships between, unemployment, debt and financial strain, having caring responsibilities, being in a violent or abusive relationship, living in built up areas and mental ill health (FPH/MHF 2016).

The Power Threat Meaning (PTM) Framework published by The British Psychological Society (Johnstone et al. 2018) goes further than reviewing such associations. It suggests that: 'emotional distress and troubling behaviour are intelligible responses to social and relational adversities and their cultural and ideological meanings' (p8). It foregrounds the central role that power and narrative play in the development of coping strategies or survival mechanisms, which are often termed mental illness within a psychiatric diagnostic system. The PTM framework may be a useful resource/perspective to employ when considering levels of distress in the female population given its focus upon understanding inequality and the effects of trauma and abuse.

The Visible partnership is a project in the city that brings together a number of key organisations to 'make visible' the impact of child sexual abuse on adults. The focus has been to support organisations in Leeds to be more trauma (or psychologically) informed, this includes statutory, third sector and others within the business community. The partnership has developed a policy statement for organisations to use in order to enable them to better support adults who have experienced childhood sexual abuse, this has now been approved and is being considered for adoption or already implemented by organisations across the city. The project is also achieving wider outcomes including improved information for the public and training/networking events for practitioners.

There is a broad consensus in the city amongst practitioners and commissioners that there is both *a gap in practice* – with mental health services needing to improve how they respond sensitively to trauma, and *a gap in provision* for people who have levels of need above that met by IAPT, but who may not have a psychiatric diagnosis.

## Case study 6 Sonia

Sonia<sup>1</sup> referred herself for counselling to address difficulties dating back to her childhood. She had grown up in poverty, being forced to beg round her neighbours as a child. She had been raped as a young child, then sexually abused by a family member until he died when she was an older teenager. After this she was also emotionally and sexually abused by her older brother. She had been in a physically and emotionally abusive relationship with the father of her children for twenty years.

At the initial meeting Sonia was shaking, hyper-ventilating, and barely able to speak. She gave little eye contact. She spoke fast when able to, was in frequent physical pain, and was too afraid to visit a doctor, due to what later emerged was shame. She had poor ability to make choices or ask for anything for herself. She spoke of having no capacity to set boundaries, was constantly exploited by others, particularly her neighbour, and manipulated by her adult children. She rarely left the house and was terrified of anything new.

# *"I mean nothing to my family and friends. I am never able to say no. Put up and shut up was my way of being a child"*

The work of counselling involved establishing a sense of safety, stabilisation and slowing down, working through breath, relaxation and art making. Sonia became able to voice her internal critical voices, learning to manage them and to make better choices for herself. Gradually she began to face her history of multiple abuse, fully understanding the impact this had had on her life, processing the trauma and associated shame. She overcome her fear of doctors, and developed a good relationship with her GP practice, receiving much needed treatment.

Due to concerns regarding the extent of exploitation Sonia was experiencing from her neighbour and the numerous practical difficulties in her life, she was referred to Women's Lives Leeds receiving support from a complex needs worker.

Through this partnership work, her practical needs, including debt management, multiple housing crises, social and medical needs were met in parallel with the psychotherapeutic work supporting gradually increasing self-awareness, esteem and assertiveness.

By the end of counselling Sonia's confidence had increased significantly, she was saying "no" appropriately to her exploitative neighbour and children and could identify abusive behaviour and protect herself from it. She was about to move house and planning to find work.

## Sonia's feedback

If hadn't been able to come I don't know where I'd be to this day. That's scary to say. I can't praise it highly enough. I could open up in trust and security and I have never been able to do that before. It lifted the guilt and shame I'd carried around with me for SO many years. I learnt how to respect myself from within. I realised it's not my fault what happened to me. I understand now why people took advantage of me. "My sense of being cared for. Now I have learnt to take help and this is HUGE. Once I get my house move, I want to look to the future and go back to work."

## 8.7 The Mental Health of Girls and Young Women

It is estimated that 75% of mental health problems in adult life (excluding dementia) start by the age of 18 years (DH 2015). The APMS (McManus et al. 2016), identified young women (16 – 24 years) as a high-risk group, with high rates of common mental disorders, self-harm, post-traumatic stress disorder and 'likely bipolar disorder'. Young women in the survey had the highest score of any demographic group in terms of prevalence of common mental disorders, with over 25% reporting symptoms in the last week. The gap between young women and men is growing significantly. In 1993, 16 to 24 year old women (19.2%) were twice as likely as men of the same age (8.4%) to have symptoms of CMHD (CIS-R score 12 or more). In 2014, CMHD symptoms were three times more common in women of that age (26.0%) compared to men (9.1%) and a report on student mental health reveals similar findings (Thorley 2017). In 2009/10 first-year male and female students were equally likely to report a mental health condition (0.5% of students surveyed). By 2015/16 this had risen to 2.5% of women but only 1.4% of men.

Research suggests that rates of self-harm in the UK have increased over the past decade within the younger cohort of girls and are thought to be amongst the highest in Europe. An analysis of hospital self-harm presentations reported a 68% increase in 13-16 year old girls between 2011 (45.9 per 100,000) and 2014 (76.9 per 100,000 (Morgan et al. 2017).

Patterns of self-harm in Leeds reflect the national picture. Self-harm hospital admissions data for Leeds indicates that young women aged 15-19 have the highest incidence of self-harm admissions: 297 young women were admitted in 2016–17 compared to 78 young men (Cameron, 2018).

There is evidence to suggest that there is a link between mental illness and social media exposure (Primack et al. 2009) and that excessive use of computers and mobile phones maybe linked to a higher risk of mental disorder in young women, possibly mediated by sleep loss (Thomée 2011). The notion of the 'idealised' body image has also been shown to have detrimental impacts on self-esteem. This is most notable in young women (RSPH 2017). There are also robust associations

between cyber-bullying and mental health, specifically in terms of suicide and selfharm (Daine et al. 2013).

Two local Third Sector organisations (Women's Health Matters<sup>23</sup> and The Marketplace<sup>24</sup>) worked with young girls aged 13 – 19 years old in the city during 2011 - 12 to gather insight about their self-harming behaviour (WHM 2012). It was found that this behaviour was an alternative way of coping with what was happening to the girls. Workers observed that many of the girls experienced low self-esteem and complex emotional situation in their home lives. The WomenSpace service, which is funded by Leeds NHS CCGs, works with those with severe and enduring self-harming behaviours. An evaluation of their services interviewed 12 users of the service (aged 18-60 years) and found that although they did not ask specifically about the nature of their trauma that some spoke of abuse in childhood and experiencing domestic abuse as key factors in their self-harming behaviour (Beckett et al. 2016).

## 8.8 Social isolation

Social isolation and loneliness are problems that exist across all ages and can have serious health impacts, both physical and emotional. The Government recently launched their first loneliness strategy and appointed a Minister for Loneliness (HM Government 2018), which is following on from the Jo Cox Loneliness Commission (Jo Cox Commission on Loneliness 2017). There are differences that exist between being socially isolated and suffering from loneliness, with social isolation "usually characterised as an objective lack of meaningful and sustained communication, while loneliness more often refers to the way people perceive and experience the lack of interaction" (Poscia et al. 2018); one can live alone and not feel lonely and yet others can feel lonely even when living with a partner.

There are a number of different reasons for feeling lonely, but the main factors include (ONS 2018k):

<sup>&</sup>lt;sup>23</sup> http://www.womenshealthmatters.org.uk

<sup>&</sup>lt;sup>24</sup> https://www.themarketplaceleeds.org.uk

- Widowed older homeowners living alone with long term health conditions.
- Unmarried, middle-agers with long term health conditions.
- Younger renters with little trust and sense of belonging to their area.

Being socially isolated and lonely have been shown to be linked to both physical and mental health problems and an increased risk of mortality (Zebhauser et al. 2014; Courtin and Knapp 2017; Leigh-Hunt et al. 2017; ONS 2018k). One of the largest studies undertaken in the UK on mortality and social isolation and loneliness (Elovainio et al. 2017) found that for loneliness, there was no excess mortality other than those mostly associated with depressive symptoms. However, the higher numbers of deaths in those socially isolated as compared to non-isolated individuals could mostly be attributed to differences in lifestyle, socioeconomic factors, and mental health problems. In a study by Liu & Floud (2017) they also found that excess mortality in socially isolated and lonely individuals was associated with socioeconomic status, unhealthy behaviours such as smoking, mental health problems and self-rated health. When social isolation is linked to food insecurity, the risk of mental health problems increases, with women more affected than men (Martin et al. 2016a).

With women generally living longer than men, there are many more women who are at risk of social isolation as with increasing age comes the risk of greater morbidity and multiple morbidity that can lead to difficulty mobilising and retaining old social networks (Pettigrew et al. 2014). Women report more loneliness than men, but this may be because they are more willing to report their experiences (ONS 2018k). There is also an increasing number of divorces over the age of 60 years (ONS 2013b).

## Case study 7 Maymoona

Maymoona<sup>1</sup> was a 70 year old Indian woman referred to the Leeds Women's Counselling & Therapy Service by an Asian women's support organisation for individual counselling in the community. She presented with anxiety and memory problems, difficulties sleeping, feeling confused, overwhelmed, tearful and frightened.

Maymoona attended regularly. Her anxiety gradually decreased and her memory appeared to be less debilitating as she told me her fears of growing older without anybody she could depend on. She had four adult children with their own families, and with sadness she told me how she had become separated from them when her husband took a 16 year old wife from India and she was made to leave the family home. Her children remained with their father, and she was ostracised by the community as the divorced woman. Whilst she had recovered contact with some of her children in their adult lives these relationships remained fragile. When she retired she had become isolated and depressed, made several suicide attempts and ended up in psychiatric care. Again, she was considered to have brought shame on the family for having mental health issues.

She explored her fears of growing old on her own, with her increased dependency needs and sense of vulnerability. She gradually became more active, contacting friends, accepting neighbour's invitations, going back to Temple and attending GP and hospital appointments for a range of physical health issues. As her confidence and sense of self- worth increased she initiated more contact with two of her children and although the contact was minimal she started to appreciate the relationships that were still possible.

<sup>1</sup>Name Changed

## 8.9 Dementia

Dementia is an increasingly common condition that has a major impact on the lives of those affected and those who care for them. It predominantly affects those over the age of 65 years but can occur in earlier life. It was estimated that approximately 850,000 people was affected with dementia across the UK in 2015 and this is projected to rise to over 1 million people by 2025, costing over £26.3billion (Prince et al. 2014).

It is not one disease, but has many different forms, including vascular dementia and Alzheimer's disease, with the common feature of causing memory problems, difficulty with planning, thinking things through, struggling to keep up with

conversations, and sometimes changes in mood or behaviour (Alzheimer's Society 2017). It is a most debilitating disease and a significant cause of mortality and morbidity, with dementia and Alzheimer's disease the overall highest cause of death in women across England and Wales, with 44,532 deaths in 2017 (a sixth of all female deaths) (ONS 2018i). In Leeds the mortality rate in 2016 was 942.8 per 100,000 for women and 856.1 per 100,000 for men, with the rate increasing over time (Figure 43). The rate is also higher in deprived areas, where men have the highest death rate.



Figure 43 Alzheimer's diseases and dementia mortality DSR per 100,000, Aged 65+ years, by sex and deprivation category, Leeds, 2010 to 2016

Across England the number of people over the age of 65 years with dementia was estimated to be 645,507 in March 2018 (NHS Digital 2018b), with 450,509 actually diagnosed (284,661 females, 165,848 males) (Figure 44). Across Leeds, in July 2018, the rate of dementia in women aged 55+ was 3,096 per 100,000 population and for men 2,463. In 2016 there were 741 female deaths as a result of Alzheimer's diseases and dementia as compared to 402 male deaths.



Figure 44 Observed prevalence of recorded dementia, by age group and gender, England, March 2018

There is a link between dementia and deprivation (Figure 45), with the highest prevalence rates found in Harehills (8,185 per 100,000), Meanwood 6 Estates (6,705 per 100,000) and Hunslet Green, Stourton, and Thwaite Gate (6,385 per 100,000). In part this higher prevalence is due to the higher incidence of risk factors in the more deprived areas, such as depression, hypertension, physical inactivity, diabetes, obesity, hyperlipidaemia, smoking and lower educational attainment (Beydoun et al. 2008; Deckers et al. 2015; Chatterjee et al. 2016; Neergaard et al. 2016; Albanese et al. 2017; Sabia et al. 2017; Cadar et al. 2018; Schiepers et al. 2018; Singh-Manoux et al. 2018). There is also a link between being more cognitively active during the working years and the rate of cognitive decline, which is again linked to socio-economic status (Rusmaully et al. 2017).



Figure 45 Prevalence of dementia, by deprivation, Leeds, July 2018

Those women with osteoporosis were found to have a higher incidence of dementia (although this might be that a fall in this group of women results in a diagnosis) (Amouzougan et al. 2017). There is also a risk of more advanced cancer at the point of diagnosis in women with dementia through difficulty in seeking help and their recognition of the warning signs and symptoms (Hopkinson et al. 2016; McWilliams et al. 2017).

Age-related hearing loss has been found to be a possible warning sign of further cognitive decline, cognitive impairment, and dementia (Loughrey et al. 2018), with hearing loss being a cause of depression in older women (Li et al. 2014). It is also associated with a greater risk of falling which can add to a woman's fear of frailty and unwillingness to socialise and to maintain important networks (Viljanen et al. 2009).

Women with Alzheimer's tend to have a worse outcome as compared to men across a range of cognitive outcomes (including language and semantic abilities, visuospatial abilities, and episodic memory) (Laws et al. 2016), possibly as a result of the loss of oestrogen in post-menopausal women or a greater protective cognitive reserve in males. In addition to these two factors, there is a growing appreciation of the possible sex and gender differences in Alzheimer's disease that warrant further attention (Nebel et al. 2018). These include lifestyle risk factors such as education, exercise, and marital status, along with biological risk factors and a result of disease states such as cardiometabolic risk factors, depression and sleep patterns.

For some, there is a steady decline into dementia; for others a more rapid process, but for all there is a marked change in the person who once was, which can put a huge strain on the individual and those now having to take a care-giver role. This can lead to a high level of care-giver stress in those looking after the affected individual, which can impact negatively on their own health and wellbeing and also affect their ability to offer longer-term support.

Lesbian and bisexual women can experience specific difficulties if their partner has dementia, especially in relation to stigma, social marginalisation, and if residential care is required (Westwood 2016; Butler 2017; Fredriksen-Goldsen et al. 2018). A very moving local account of the realities of being a lesbian with dementia and the impact it has on her partner can be found in Rachael Dixey's book (Dixey 2016) "Our dementia diary: Irene, Alzheimer's and me".

Currently Leeds has a relatively small population of elderly women from the BME communities (5.5% of all women over the age of 65 years), but they are at a high risk of developing dementia and the BME population in Leeds is ageing. In a recent national study (Pham et al. 2018), Black women were found to have a 25% greater chance of receiving a dementia diagnosis as compared to White women. Prevalence in the South Asian community was found to be lower, but there was uncertainty as to whether this was a reporting issue.

It is important to recognise that with advances in care, more women and men with learning disabilities are living longer and increasing their likelihood of developing dementia (Alzheimer's Society 2015), with an estimated 1 in 5 over the age of 65 affected and a third affected whilst still in their 50's. This can be particularly challenging for them and their carer's.

# 9 Long term conditions, frailty and end of life

## 9.1 Introduction

Currently in Leeds there are 70,184 women in Leeds over the age of 65 years and 11,095 aged 85 years and older, with a projected 34% increase in women aged over 65 years by 2038 (see section 8.1). As the population ages there is a greater risk of developing multiple health problems and becoming increasingly frail. There is a national recognition of the importance of improving health outcomes for this cohort of patients, with Leeds selected as one of four national sites to develop services aimed at those people who are recognised as being in most need.

The population of Leeds has been split into four categories in order to better serve those populations who have broadly similar needs at a population level enabling delivery of health and well-being outcomes (Leeds City Council 2017b). These population cohorts are long term conditions (LTC) (anyone with 1 or more LTC who doesn't fall into the end of life or frailty category), frailty, and end of life (people on a palliative care register), and healthy. LTCs are not limited to the aged, with the young affected as well as the old, with the need to support people living with frailty and at end of life (EoL) palliative care throughout the lifespan.

## 9.2 Long term conditions

There are some illnesses that are curable or amenable to positive support and are resolved within a short period of time, however there is an increasing number of health issues where full recovery is not possible. These long term conditions (LTC) (or chronic illnesses) can be both physical and mental, and affected individuals can often have more than one LTC. Those with co-morbidity (or multimorbidity) can create significant health challenges for those affected (Barnett et al. 2012; Schäfer et al. 2012; Li et al. 2016; Xu et al. 2018), with costs reaching an estimated 70% of the NHS health service budget (NHS 2014).

There are 151,435 females living in Leeds who have one or more long term condition, which is 36.2% of the female population. This number excludes those who are included on the frailty and end of life registers, so the overall number of women

with long term health problems will be greater. There is a strong relationship between long term conditions and deprivation, with the Yorkshire Health Study showing that 46% of those living in deprived areas experienced multiple morbidity as compared to 27% of those in non-deprived areas (Li et al. 2016).

# 9.3 Frailty

LTCs are not necessarily life limiting, but multimorbidity (especially when linked with frailty), increases the risk of poor health outcomes (Barnett et al. 2012; Li et al. 2016). According to NHS England, frailty exists "where someone is less able to cope and recover from accidents, physical illness or other stressful events. It should be treated as a long term condition throughout adult life." (NHS England 2018).

The early identification of an individual who is frail, or at risk of becoming frail, can enable services to offer support and guidance such they can be more resilient to changes and have better health outcomes (NHS England 2018). Leeds uses the electronic frailty index (eFI), which comprise 36 deficits<sup>25</sup> (Clegg et al. 2016), which are weighted to identify older people with mild, moderate and severe frailty.

A total of 19,818 females and 11,936 males (total of 31,754 people) are within the Leeds Frailty cohort, which equates to 2.35% and 1.42% of the overall Leeds population respectively (and 4.73% and 2.82% of the female and male population respectively). Figure 46 highlights that almost two thirds (62%) of the Frailty cohort are older women.

Leeds opened a Frailty unit last year at St James's Hospital (NHS Leeds 2017), which is providing a more focused service for older frail patients admitted as an emergency, with 63% now being discharged home on the same day.

<sup>&</sup>lt;sup>25</sup> eFI deficits: Activity limitation, Anaemia and haematinic deficiency, Arthritis, Atrial fibrillation, Cerebrovascular disease,

Chronic kidney disease, Diabetes, Dizziness, Dyspnoea, Falls, Foot problems, Fragility fracture, Hearing impairment, Heart failure, Heart valve disease, Housebound, Hypertension, Hypotension/syncope, Ischaemic heart disease, Memory and cognitive problems, Mobility and transfer problems, Osteoporosis, Parkinsonism and tremor, Peptic ulcer, Peripheral vascular disease, Polypharmacy, Requirement for care, Respiratory disease, Skin ulcer, Sleep disturbance, Social vulnerability, Thyroid disease, Urinary incontinence, Urinary system disease, Visual impairment, Weight loss and anorexia

In the next few months Leeds will be publishing a new vision for delivering better outcomes for those living with frailty (Leeds City Council 2019). This will provide a framework of action that will be adopted by all the main services in Leeds to provide comprehensive care for those identified as being frail.



Figure 46 Frailty cohort, Leeds, percentage distribution by sex and age

## 9.4 End of Life (EoL)

Being able to identify those people who are coming towards the end of their life can enable additional support to be put in place for a better quality of life in their final year (Ingold and Hicks 2013). To this end, all patients who are identified as being within one year of death are registered for End of Life Care, which can include palliative care, but also offers a wide range of support for the patient and their carers (NHS 2018c). A total of 1,214 females and 797 males (total of 2,011 people) are registered within the EoL cohort, which equates to 0.14% and 0.09% of the Leeds population respectively (and 0.29% and 0.19% of the female and male population respectively) (Figure 47).



Figure 47 End of Life cohort percentage distribution by sex and age

In addition, Leeds is using the Electronic Palliative Care Coordination Systems (EPaCCS) to record and share individuals end of life care preferences across all the main services across the city (NHS Leeds 2018).

# 10 Sexual health and Contraception

## 10.1 Introduction

There have been great changes and advances in sexual health services since the publication of the 'Framework for sexual health improvement' in 2013 (DH 2013). This new policy directive saw the move to bring the commissioning of many sexual health services into local authorities to ensure local people can receive comprehensive services focused onto their needs. A further important development has been in the way services are delivered. Whereas previously genitourinary medicine (GUM) Services were separate from contraceptive services these are now integrated (DHSE / PHE 2018), allowing greater opportunity for women to have a 'one-stop' approach to their sexual health needs.

Leeds has made a big commitment to ensuring sexual health services have been protected over the recent years of austerity, which has resulted in no cuts to the services provided. The new integrated Sexual Health Service for Leeds; Leeds Sexual Health was commissioned by Leeds City Council in 2015 and is a partnership between Leeds Community Healthcare Trust, Leeds Teaching Hospital Trust and Yorkshire MESMAC. Leeds Sexual Health<sup>26</sup> has developed a hub and spoke model with regard to its sexual health services, with the hub in the city centre, and 4 spoke clinics spread across the city in the areas of greatest need; this is complimented by specialist outreach nurses who provide community based services to sexually vulnerable communities within the city including outreach work with commercial sex workers in partnership Basis Yorkshire<sup>27</sup>, specialist services for people from LGBTQ communities in partnership with Yorkshire MESMAC as well as a specialist contraception outreach for HIV+ women delivered in partnership with BHA Leeds Skyline.

Responsive sexual health services are imperative for a city like Leeds, whose unique demographics present additional challenges in regard to meeting the sexual health needs of the population. Leeds has the largest number of young people in the region, with 65,262 women aged 16 to 24 years. In addition, there is a larger

<sup>&</sup>lt;sup>26</sup> https://leedssexualhealth.com/

<sup>27</sup> https://basisyorkshire.org.uk/

proportion of women of childbearing age in Leeds than seen nationally and regionally with 196,420 women aged between 15 and 44 years of age (44.8% of the total Leeds female population). There are also important links between deprivation and poor sexual health, which in Leeds is particularly problematic as the number of women living in poverty is increasing (see section 8.10).

In Leeds, the most at risk female populations (MARPs) are women under 25 years, women from Black African communities, commercial sex workers, women with learning difficulties and/or additional needs, and women living in areas of deprivation.

For England, the definition of sexual health includes the provision of advice and services around contraception, sexually transmitted infections (STIs), HIV and termination of pregnancy (DH 2013).

# 10.2 Contraception

Contraception offers protection against unwanted pregnancy and some can also reduce the risk of sexually transmitted infections. There are now many different forms of contraception and it is important that sexually active women are informed of the effectiveness of contraceptive methods and are empowered to have the maximum protection they require.

For those who are the most vulnerable to the risks of an unwanted pregnancy LARC (long acting reversible contraception) methods, such as implants, the intra-uterine system (IUS) or the intrauterine device (IUD), are recommended as they do not rely on daily compliance and are more effective than condoms and the pill. LARC can be accessed through Leeds Sexual Health and also via the LARC scheme which is commissioned by Leeds City Council and delivered in primary care settings.

Despite a recent decline in the number of women opting for LARC methods, the number of LARCs fitted in Leeds remains higher than the national rate. There has been a more marked decline in women under the age of 18 years opting for LARC

methods, with the reasons why unclear and warranting further investigation (Swift 2019).

The number of women accessing NHS Sexual and Reproductive Health services is declining nationally, with a similar drop in numbers in Leeds. This may be because more services are available over the counter at pharmacies. In 2016-2017, 7% of women aged 13-54 years used the service as compared to 1% of men (NHS 2018d). Women from areas of higher deprivation are more likely to use the services, with girls aged 13-15 from deprived areas also more likely to access Emergency Hormonal Contraceptives (EHC).

Free EHC is available via primary care, Leeds Sexual Health and also via the Leeds City Council commissioned Enhanced Sexual Health Pharmacy Scheme (ESHPS). The ESHPS operates across 39 pharmacies based with areas of deprivation and/or in areas where under 18 conceptions and termination rates are highest as well as areas that are geographically more isolated from city centre services. Many of the sites had extended opening hours (i.e. evenings and weekends) to increase accessibility, removing the need to wait for a GP appointment or access a sexual health clinic. Uptake of the ESHPS has been high, with the majority of consultation requests being for EHC after unprotected sex or contraception failure. The reclassification of EHC has resulted in it being available for purchase in pharmacies (data unavailable for this report).

There is an important ambition within the city to reduce the number of unwanted under 18 conceptions and teenage pregnancy and to reduce the number of removed children (which is covered in section 14.4 of this report). In 2016 there were 330 conceptions in teenagers aged under 18 years, which is a reduction of over half those seen in 2006 (718) (see also Figure 67 in section 14.2 for falling teenage conception rates in Leeds). Although the conception rate is decreasing it is still above both the national average and that of Yorkshire & The Humber (Table 5), with higher maternity rate, although the abortion rate is lower than the national average(ONS 2018I). Across Leeds there is a strong relationship between deprivation and teenage conception rates (Swift 2019). Nationally it is recognised that the strongest empirical evidence for the reduction of teenage conceptions exists between access to good quality Relationship Sexual Health Education (RSE) in schools and accessible sexual health services.

	Conception rate per 1,000 women	Maternity rate per 1,000 women	Abortion rate per 1,000 women	Percentage of conceptions leading to abortion
England	18.8	9.1	9.8	51.8
Yorkshire & The Humber	22.0	12.3	9.7	44.3
Leeds	27.9	14.7	13.2	47.3

The Teenage Pregnancy Midwifery Team in Leeds support young parents to make informed choices around their contraceptive choices with the aim of preventing future unwanted pregnancies.

There is also an important need for girls & young women to be provided with nonjudgmental support, advice and comprehensive relationship and sex education (RSE) in order to make informed choices from an early age. It is important to note that there will be mandatory RSE by 2020, which will ensure all schools are delivering consistently and inclusively.

The Leeds My Health, My School survey<sup>28</sup> (Leeds City Council 2018a) found that 12.1% of girls in years 9 and 11 that responded to the survey had had sexual intercourse, as compared to 13.4% of boys. Of those that had engaged in sexual intercourse, 5.1% of the girls (3.9% of the boys) felt they were pressurised into sex. Of those that had engaged in sexual intercourse only a minority reported using contraception (Table 6).

	Female	Male
Use a condom(s) and another form of contraception	2.1%	2.5%
Use a condom(s) only	3.7%	4.5%
Use another form of contraception/protection only	2.7%	1.4%
We didn't use anything	3.5%	4.8%
(blank)	88.0%	86.8%

Table 6 Sexual Intercourse contraception, Years 9 and 11, Leeds

<sup>28</sup> Years 9 and 11 only - 3 Years Aggregate (15/16, 16/17, 17/18)

Leeds City Council run the 3 in 1 scheme, where frontline workers in community settings are trained and resourced to provide a range of sexual health services including C-Card (free condom scheme), pregnancy testing & chlamydia/gonorrhoea screening as well as support and advice around subjects such as self- esteem, consent, peer pressure, pregnancy choices, as well as spotting potential safeguarding issues and/or child sexual exploitation (Leeds City Council 2018b).

A recent report on late abortions by the British Pregnancy Advisory Service found that a quarter of the 28 women surveyed were using hormonal or long acting reversible contraception, with more than half having used some form of contraception, and therefore had not thought they were at risk of pregnancy and had missed the signs (BPAS 2017; Mayor 2017). This suggests that women need to be better informed of the need for continuing vigilance, despite taking precautions. With so many physiological changes occurring over the perimenopause, it is important that those women who are receiving hormonal contraception have the right advice (Batur and McNamara 2015).

A key ambition of the Leeds City Council Public Health; Sexual Health Team is to prevent all unwanted pregnancies. The provision of contraceptive support and services following the birth of a child (postpartum family planning - PPFP) is seen as an key to achieving this ambition: reducing the risk of unwanted pregnancies as well as reducing the risks to both mother and child through an early repeat pregnancy (RCOG 2015; FSRH 2017a). A pilot is currently taking place between LCC, Leeds Sexual Health and Leeds Teaching Hospitals Maternity Services offering women the opportunity to be fitted with LARC before they are discharged from hospital.

Contraceptive decision-making for women with learning disabilities is often made by others and not the women themselves, which takes away some of their rights to determine their own reproductive lives (Ledger et al. 2016). It has been recommended that there should be more accessible information on contraception and safer sex, and support for young people with learning disabilities and for their parents (DH 2013).

#### 10.3 Sexually transmitted infection (STI)

In Leeds we have a highest rate of new diagnoses for STIs across the region and higher than the UK average (Swift 2019). The number of cases of gonorrhoea has risen in both women and men; syphilis has risen in men, but not in women (Figure 48).



Figure 48 Number of diagnosed cases of gonorrhea and syphilis, by sex, 2013/14 to 2017/18. Leeds

There has also been an increase in the number of cases of Chlamydia, from 1,369 women diagnosed in 2013/14, up to 1,683 in 2017/18 (Figure 49).

Nationally the number of women being tested for gonorrhoea, chlamydia and syphilis has declined in the past five years by approximately 14% for gonorrhoea and chlamydia, and by 17% for syphilis. Similar to many cities, lags behind the national target for Chlamydia testing rates. However, what appears to be happening is that although our overall rates are down, the positivity rates for identifying new cases is far higher than the national figures, suggesting we are targeting those most at risk more effectively (Swift 2019).



Figure 49 Diagnosed cases of chlamydia, by sex, 2013/14 to 2017/18, Leeds

Those who are young experience the highest diagnosis rates, most likely due to the greater rates of partner change amongst 16 to 24 year olds (PHE 2018a). With young women more likely to be diagnosed with an STI than young men – this is thought to be due to their greater chance of being identified through testing for chlamydia and also due to them being more likely to have an older (male) partner (PHE 2018a). PHE (PHE 2018a) advocate that anyone that is under the age of 25 years, who is sexually active should be screened for chlamydia annually and on change of sexual partner.

Lesbian and bisexual adolescent girls report more lifetime and past-year sexual partners and are least likely to use any form of condom or barriers (Ybarra et al. 2016; Doull et al. 2018). Young (18-26 years) lesbian, bisexual, and women who have sex with women (WSW) are at a greater risk of sexually transmitted diseases and yet may be less aware (Kaestle and Waller 2011; Doull et al. 2018), with the suggestion that they need to be specifically targeted to raise awareness of the need for appropriate protection.

Worryingly there has been an 8% decrease nationally in the number of chlamydia tests being carried out, but Leeds seems to have managed to increase both the

number of females and males being tested (4,535 per 100,000 females, 2,372 per 100,000 males in 2017) (Swift 2019).

With the advent of the HPV vaccination there has been a 90% reduction in genital warts in girls aged 15 to 17, since 2009.

There are a number of important gynaecological health implications for women who contract a sexually transmitted disease - these include Pelvic Inflammatory Disease, and Chronic pelvic pain (which are covered in the report below in section 13.7)

Nationally there have been cuts to specialist Genito Urinary Medicine (GUM) clinics, which is problematic at a time of increasing need (Robertson et al. 2017). There is a move to an Integrated Sexual Health Service (PHE / DoH 2018), and in Leeds women are now seen in one appointment for both contraception and GUM, whereas previously they would have had to attend two services. There is emerging evidence that this is working from an opportunistic view - those women attending for contraception get offered a full screen, and likewise those women attending for a full screen get their contraception needs addressed.

Public Health England advocate that anyone under the age of 25 who is sexually active should be screened for chlamydia annually, and on change of sexual partner. They also advise that black ethnic minority men and women should have an STI screen, including an HIV test, annually if having condomless sex with new or casual partners (Shew et al. 2006).

On-line STI testing is now becoming more available and popular; offering the option to request testing kits delivered to people's homes. Leeds Sexual Health offers access to Preventx Chlamydia/Gonorrhoea Screening Smartkits via their website (under 25's only). In 2017, 96% of the kits were ordered on-line in Leeds with 70% of the kits returned by females and 30% by males, with the average age of the users being 21 years (Swift 2019). The use of the kits has been limited to 16-24 year olds, with those areas of the city with the greatest student populations having the greatest usage, however the highest positivity rates have been found in the more deprived areas of the city.

## 10.4 Human Immunodeficiency Virus (HIV)

Deaths from the human immunodeficiency virus (HIV) have decreased dramatically in the UK over the last 20 years, with 121 men and 31 women dying of HIV and HIV related conditions in 2016 across England, and no deaths registered in Leeds over the past 4 years (ONS 2018h).

Free and effective antiretroviral therapy (ART) in the UK has transformed HIV from a fatal infection into a chronic but manageable condition. People living with HIV in the UK can now expect to live into old age if diagnosed promptly. With progressive strengthening of combination prevention (including condom use, expanded HIV testing, prompt ART and availability of PrEP), HIV transmission, AIDS and HIV-related deaths could be eliminated in the UK.

Across England there were 1,121 females diagnosed with HIV (3,569 males), with 57 females with a diagnosis of acquired immune deficiency syndrome (AIDS) at HIV diagnosis. Across Yorkshire and the Humber there were 1,840 females receiving care for existing HIV, with the majority aged 35-49 years. The most probable exposure route for women (1,737 females) is via heterosexual contact. The majority of women affected are Black African (PHE 2017b), with an American study also suggesting that Trans women are at heightened risk of HIV and drug use than the general population (Hoffman 2014).

Knowledge of HIV status, particularly early diagnosis, increases survival rates, improves quality of life and reduces onward transmission. Late diagnosis of HIV is the most important predictor of morbidity and mortality. In Leeds, between 2015 and 2017, 53.4% of HIV diagnoses were made at a late stage of infection (CD4 count =<350 cells/mm<sup>3</sup> within 3 months of diagnosis – when ART should begin) compared to 41.1% in England. Ideally, the percentage of late diagnoses should be below 25%. Leeds' percentage has remained steady since 2011-2013.

## 10.5 Abortion

Across England and Wales there were 185,596 abortions in 2016, with the highest rate in women aged 22 years (27.9 per 100,000), with a rate of 1.7 per 100,000 for those under 16 years and 8.9% in those under 18 years. 38% of abortions are for women who had one or more previous abortions (ONS 2017I). Nationally over the last 20 years there has been an increase in abortions in those aged under 30 years, a decrease in those aged 35 years and over and stable for those aged 30-34 years (ONS 2018I).

Across Leeds there were 2,957 abortions in 2016, (581, Leeds North; 1,137, Leeds South and East; and 1,239, Leeds West), with the greatest number in those aged 20-24 years (ONS 2017m) (Figure 50).





When a fetal anomaly is found, a termination may be necessary. To support the women and their partner there is a nationally agreed pathway of support that should be followed (NBCP 2018a) and this pathway is available for all those affected across Leeds.

# 11 Healthy Lifestyles

## 11.1 Introduction

Although the data here is presented as for each lifestyle issue there are important links between them, such as there can be a marked difficulty quitting smoking alongside quitting other substances such as alcohol, with women more likely to cite anxiety as the main barrier (McHugh et al. 2017). Participants with a primary alcohol use disorder were almost 30% less likely than those with an opioid use disorder to be current smokers, despite similar lifetime smoking rates (p52). This clustering of lifestyles can also have an important impact on the overall consequence, for instance as seen in the risk of developing cancer (Kerr et al. 2017), such that most services are now moving to tackle these multiple issues at the same time, as seen in the Leeds Integrated Healthy Living Service (Ingold et al. 2015).

## 11.2 Tobacco use

Across England 14.1% of women smoke (17.7% of men), with an average of 11 cigarettes a day for women (12 for men), with a steady year-on-year decline up until 2015 – 2016, when it slightly increased in men, but remained static in women. The age group with the biggest decline in numbers is 18-24 years, with another big recent decline in the 25-34 years group which is the age bracket most likely to smoke (ONS 2017n). School aged girls are more likely to smoke than boys (4% vs 3% boys), but these represent the lowest level of smoking prevalence since the national survey began in 1982 (NHS 2017a).

In Leeds more men smoke (18.2% as compared to 17.5% for women), but there is a greater proportion of women smoking in Leeds than in the rest of Yorkshire and Humber and for England (Figure 51). Across Leeds smoking is greatest in the more deprived areas, with 35.3% of women in Middleton and 34.3% of women in Belle Isle North smoking as compared to 5.6% in Alwoodley.



Figure 51 Prevalence of smoking (percentage), for females and males, 18+ years, 2016

In 2016, 3% of all admissions to hospital by women across England were a consequence of smoking, with 22% of admissions for conditions that can be caused by smoking, and 31,600 women (47,400 men) losing their life through tobacco related diseases (NHS 2017a). It is estimated that women who smoke lose at least 10 years of lifespan, with the hazard of continuing smoking over the age of 40 years 10 times higher than for those that quit (Pirie et al. 2013).

Women are more likely to smoke packeted cigarettes (62% vs 49.3% male), than hand-rolled (27% vs 37.3%) (ONS 2017o). Smokeless tobacco (paan, beel quid, snus, chewing tobacco) and non-cigarette tobacco (bidi, shisha) use is more prevalent within the South Asian community and is more common amongst women (Katie Wright, Colin Brodie and Gayan Perera 2013), but can be just as harmful as cigarettes, leading to mouth, oesophageal and pancreatic cancer along with other respiratory cancer, heart disease, respiratory disease and periodontal disease (NICE 2009; Cancer Research UK 2016). It is important to note that smokeless tobacco use during pregnancy can also lead to health problems for the child (England et al. 2010), including an increased risk of stillbirth, and may impact on fetal growth and an increased risk of pre-term delivery.

School children who are White or from Mixed backgrounds were more likely to smoke than those from Asian or Black backgrounds (NHS 2017a). In Leeds, the 'My

Health, My School' survey data (Leeds City Council 2018a) demonstrates that like most lifestyle factors, smoking becomes more prevalent as children get older. The prevalence of experimenting with cigarettes increases across the older age groups (Year 7 to 11) for both girls and boys but is higher among older girls compared to boys, however, for smoking prevalence (using more than 1 cigarette per day) is higher in boys compared to girls (Figure 52).



Figure 52 Children's smoking history in Leeds, - Percentage "ever smoked" and Percentage smoking over 1 cigarette per day by school year, 2015/16 to 2017/18

Girls have been found to be more likely to smoke because they feel it makes them look cool in front of their friends and are more likely to take up smoking if their close friends or siblings smoke (McGee et al. 2015). There is also the perception that it will help them to lose weight (Atenstaedt et al. 2016a). Smoking prevalence in girls is higher in those with low aspirations, with those that can envisage a more positive life and career being less likely to take up smoking (Atenstaedt et al. 2016b). What is promising is that the biggest reduction in smoking since the introduction of the smoking ban in public places has been observed among girls, with a reduction of 4.3% in regular smoking by 15 year old girls (Katikireddi et al. 2016).

In young adult women the motivation for smoking is influenced in some by a greater level of body dissatisfaction and eating pathologies, leading to both a drive for thinness (by smoking) and a fear of fatness (if they stop smoking) (Kendzor et al. 2009; Duncan et al. 2010; Copeland et al. 2016). This fear of gaining weight postcessation was also found in a study of female smokers from a deprived community (Memon et al. 2016). The group of women interviewed also felt that hormonal fluctuations during the menstrual cycle and greater levels of stress were also significant barriers to stopping smoking and reasons for relapse.

Smoking prevalence is higher in sexual and gender minorities, with an earlier initiation in young girls (Watson et al. 2018). Across England, smoking prevalence in heterosexual / straight women was 16.7% in 2014 as compared to 25% in Lesbians, 22.7% in bisexual women and 18.8% in 'others' (ONS 2016e), with smoking prevalence in lesbian women higher than heterosexual men and gay men. In another study (Fallin et al. 2015), bisexual women were found to have the highest rates of smoking, which was attributed to greater internal stressors of not belonging to any group. Higher rates of smoking in the sexual and gender minorities have been attributed to greater sense of identity and fitting in with others, rather than just a craving, and as a result of higher levels of stress and discrimination (Nguyen et al. 2018; Watson et al. 2018).

In 2016/17 only 10.5% of pregnant women in England were smokers at the time of delivery in , which was below the national ambition of 11% and a big reduction from 15% in 2006/07 (NHS Digital 2017b). Across Leeds there were 9.8% of women still smoking at the end of their pregnancy in the first quarter of 2017/2018, down from 12.3% in the fourth quarter of 2014/2015. Smoking during pregnancy can cause serious health problems including complications during labour and an increased risk of miscarriage, premature birth, still birth, low birth-weight and sudden unexpected death in infancy (NHS Digital 2017b). The effect of smoking can still be seen in the grandchildren of women who smoked during pregnancy (Ding et al. 2017) with higher birth weight, higher risk of overweight, and higher BMI through adolescence and young adulthood. Women who smoke during pregnancy have also been found to be less likely to initiate breast feeding, even after adjusting for socio-demographic factors usually associated with this cohort of women (Simpson et al. 2019).
## 11.2.1 E-cigarettes (vaping)

There has been an increase in the use of electronic cigarettes (E-Cigarettes, or Vaping) in preference to smoking cigarettes. The most recent review from Public Health England has found that vaping poses a small fraction of the risk of smoking and is an important aid in smoking cessation (McNeill et al. 2018). There is no available data on vaping use in women across Leeds.

Women have been found to use e-cigarettes for stress or mood management and for weight control, whereas men are more likely to do it for enjoyment or to quit smoking due to health concerns (Piñeiro et al. 2016).

The advice relating to the use of e-cigarettes during pregnancy is that there has been little research done on the long term effects of vaping on the child's health, and it is better not to use them. However, they are significantly less harmful than smoking and so their use is a much better option than ordinary cigarettes (Smoking in Pregnancy Challenge Group 2017).

### 11.3 Alcohol use

The current guidance (DH 2016) on alcohol intake for women is the same as for men – not more than 14 units a week, avoiding heavy drinking sessions and taking several drink-free days a week. The majority of women do not drink to excess, with 22% claiming to be non-drinkers or having not had a drink in the last 12 months and 62% stating that they had not had more than 14 units per week according to the Health Survey for England 2016 (NHS Digital 2017c). However, for those that have higher levels of consumption, their risk of developing health problems is greater than for men for the same level of consumption. The health consequences for women drinking are now a great cause for concern in Leeds and elsewhere (Cameron 2018). Chronic liver disease is the 5<sup>th</sup> commonest cause of death and morbidity in the UK and it is the only cause that is increasing, with chronic alcohol dependency responsible for the majority of emergency admissions related to alcohol (Vardy et al. 2016).

An analysis of the economic and social costs of alcohol-related harm in Leeds in 2008-09, (Jones et al. 2011) came to £480m, spread across health and social care (13%), criminal justice system (29%), workplace and lost productivity (27%) and the wider social and economic costs (31%).

Alcohol intake in school children in Leeds (Leeds City Council 2018a) shows that girls from a lower start in year 7 (27.5%) have a higher rate of the catch-all category "drink at all" than boys by year 7 and year 11 (77% as compared to 73%) (Figure 53). However, boys have the higher "drink weekly" and "drink monthly" rates by year 11, with 1% of year 11 girls drinking daily as compared to 2.1% of boys.



Figure 53 Three Year aggregate rates of school age alcohol consumption (percentage), Leeds, by sex and category: split by school year group

In adulthood there is a decreasing male-female gap in the use of alcohol, which is most evident in younger adults, where often females have overtaken males in their drinking levels. But for above the recommended limit (14 units), males still have the higher levels of consumption in Leeds (Figure 54).



Figure 54 Consumption of over 14 units of alcohol per week, Leeds, 2018 (Percentage of total)

Audit data for Leeds was collected for 115,082 females aged 15 years and older. Of these, 3,242 had scored positive for 'excess alcohol' which is equivalent to 2.8% of those recorded. By ward, prevalence of excess risk among those recorded ranged from 0.7% in Garforth and Swillington to 11.3% in Headingley and Hyde Park and 9.8% in Little London and Woodhouse. Both of these areas have high student populations.

The threshold where alcohol becomes dangerous is lower in women than it is in men, so for the same level of consumption the health effects are more pronounced in women (Milic et al. 2018a). This is because women process alcohol at a slower rate due to having less body mass, more fat and a lower body water content, which leads to a higher concentration in their body and alcohol staying in a women's system longer before being metabolised than it does in a man's. In addition, women generally have lower levels of alcohol dehydrogenase (AHD), which is needed to metabolise the alcohol.

Regular consumption above the recommended levels of alcohol can lead to an increased risk of:

- Liver disease.
- Infertility (through the disruption of the menstrual cycle).
- Altered sexual performance.

- Breast cancer and other fat related cancers.
- Menopausal symptoms and osteoporosis.
- Higher levels of stress.
- Heart disease and hypertension.
- Loss of mental function. (Drinkaware 2017)

There is some evidence that alcohol is protective against ischaemic heart disease and diabetes in females (Griswold et al. 2018), however, these protective effects have been found to be offset by the risks associated with cancers, which are increased with consumption.

There has been a year-on-year increase in women dying of liver cancer as a result of alcohol (GBD 2016). This increase in the rate of death as a result of liver disease, has especially been seen in the older population, with the rate increasing from 30.9 per 100,000 in 2003 to 45.7 per 100,000 in 2016 in 70-74 year old females (55.5 to 76.2 for men) (NHS Digital 2018c).

Alcohol intake is higher overall in the wealthier areas of Leeds (Figure 55). However, the mortality rate is higher in poorest, with a mortality rate of 26.9 per 100,000 for women in the lowest decile in Leeds, as compared to 7.6 per 100,000 in the most affluent areas. This is thought to be a consequence of a greater susceptibility to the damaging effects of alcohol, the quality of the alcohol consumed, the interaction with other risky lifestyle factors such as smoking and access to health care (Jones et al. 2015).

Females account for a steadily increasing proportion of referrals into the Leedsbased St Anne's alcohol detox and rehab centre rising from 28% in 2014/15 to 33% in 2015/16, to 35% in 2016/17 and to 41% in the first half of 2017/18. The young persons' service of Forward Leeds shows a very distinct sex difference with regard to the primary substance of young people accessing the service. For young men the primary substance is cannabis but for young women it is alcohol.



Figure 55 Consumption of any alcohol, by deprivation (IMD decile 2015)

It is important to understand the meaning of alcohol for women if we are going to make progress in helping women reduce dependency. Alcohol is often tied to women's identity, giving them a sense of freedom and a way of avoiding their everyday roles and responsibilities (Emslie et al. 2014). In addition, for many women there are stressors in their lives that are a trigger to drinking, such as on-going interpersonal violence (Becker et al. 2017). Women are also more likely to drink more alcohol during the premenstrual phase of the menstrual cycle, especially those with premenstrual dysphoric disorder (Becker et al. 2017). There may be an effect of increasing alcohol intake in younger women caused by women being older at childbearing (Slade et al. 2016), such that they have less restrictions on their drinking behaviour.

Low levels of drinking during pregnancy is still a contested area, with some studies suggesting there is little long term effect on the child, whilst others are suggesting abstinence (Mamluk et al. 2017; McCormack et al. 2018). Heavy drinking through a pregnancy increases the risk of serious health effects that comprise the fetal alcohol spectrum disorder (FASD). Children with FASD can have growth deficiencies, facial and other disfigurement, cognitive delay, and often significant behavioural problems, with girls having more disfigurement and neuro cognitive impairment. Affected boys are less likely to survive to start school (May et al. 2017). There is a recognition that advice on cutting out alcohol completely during pregnancy is unlikely to be effective, with many women continuing to drink despite the warnings (Gupta et al. 2016).

### Case study 8 Bee

Women's Health Matters "Breathing Space" is a domestic violence project offering input to support "stabilisation", and increase understanding of abusive relationships and preventative strategies

Bee<sup>1</sup> self-referred to Breathing Space Project. Previously 4 of Bee's children had been adopted due to abusive relationships and her consequent problematic drug use. At the point of referral she had a baby and was pregnant. She had Children's Social Care Service involvement, Family Drug and Alcohol Court involvement, and was in a foster placement, being monitored to ensure she didn't relapse or have contact with the abusive ex-partner.

At times Bee didn't feel heard or fully acknowledged for the changes she was making. Breathing Space provided Bee with a place where she could talk things through from her own perspective and gain support to maintain sobriety. On several occasions Bee told us that in the past she would have self-sabotaged and used drink or drugs again as a reaction to the stress of the assessment.

Bee says "If it hadn't have been for Breathing Space opening my eyes to the different types of abuse there are I probably wouldn't have cut contact with my ex and I wouldn't have been allowed to keep my children if I'd stayed with him. It's put me in a different headspace because it's about wellbeing as well as domestic abuse. I have made a lot of progress since I've been at Breathing Space."

Bee has recently been told that she is allowed home with her child and will be allowed full custody of her baby once it is born.

<sup>1</sup>Name changed

For post-menopausal women, ageing can mean psychological distress as a consequence of social impairment, fatigue, physical ill-health, depression, loss of loved ones, and a general feeling of loss, which can all add to the need for alcohol (Milic et al. 2018b). Unfortunately, with the menopause the impact of alcohol use disorder becomes more severe with both physical and emotional health consequences (Milic et al. 2018b). Post-menopausal women are also more likely to find it more difficult to recover from dependency in their older years than for men

(Milic et al. 2018b), due to the social stigma they experience and difficulty in accessing services.

Lesbian alcohol use is significantly higher than the general population and is higher than bisexual women (Shahab et al. 2017). In part this is due to perceived sexual minority discrimination and stress, and is aggravated when linked to low socioeconomic status and social isolation (Lewis et al. 2016). This same study also found that race was a factor, with White lesbian women more likely to drink to cope than Black participants. Treatment aimed at lesbian, bisexual and queer women should ensure that identity is acknowledged and services framed accordingly (Pennay et al. 2018).

Ethnicity can also be an issue with regard to both alcohol risk and also rehabilitation, with Sikh women with drinking problems resisting seeking help due to the fear of stigma and shame (Gill 2017).

Leeds has developed a robust strategy (Leeds City Council 2014) to help combat the problem of alcohol and drug abuse within the city. It sets out the priority action points, which includes greater work within schools and more outreach activity into communities most at risk. It is focused onto four key outcomes:

- People choose not to misuse drugs and / or alcohol.
- More people to recover from drug and alcohol misuse.
- Fewer children, young people and families are affected by drug and alcohol misuse.
- Fewer people experience crime and disorder related to the misuse of drugs and alcohol.

There is a new Drug and Alcohol Strategy and Action Plan currently being written. Working groups for each of the four overarching outcomes have been developing it and is likely to be published April 2019.

#### 11.4 Drugs and substance abuse

The death rate as a result of drug misuse has been fairly steady since 2001, but there has been an increase over the last 6 years in both women and men, with Leeds rates approximately 40% higher for women and 50% higher for men compared to the data for England (ONS 2017p) (Figure 56).



Figure 56 Age-standardised mortality rate for deaths related to drug misuse, by sex, England and Leeds, 2001 and 2016

The 'My Health, My School' survey data (Leeds City Council 2018a) asked high school children in Leeds about their use of illegal drugs and found that it was more of a problem for boys, with usage increasing with age (Figure 57).

There are important sex and gender differences between men and women with regard to substance abuse and response to treatment and rehabilitation (Greenfield et al. 2010; Becker et al. 2017). Women can find themselves addicted with lower levels of drugs taking and over a shorter time frame than when addiction occurs with men (Greenfield et al. 2010). Childhood adversity generally has more of an effect on male vulnerability to substance abuse, but if that abuse is persistent and on-going then women's risk grows to surpass the levels of alcohol, drug and polysubstance abuse seen in men (Evans et al. 2017).



Figure 57 Used Illegal Drugs, 3 Year Rates by Sex and Year Group (2015/16 to 2017/18)

Biological research has been limited on women, but the studies that have included women in structural neuroimaging studies have found significant sex effects on pathophysiology (Lind et al. 2017). This could be the result of sex hormones or menstrual cycle, endophenotypes that predate disease, neurobehavioral mechanisms associated with socialized gender roles, co-morbidities, or stress responses known to differ in women compared to men [p97].

Sexual minority women are at greater risk of substance abuse as compared to heterosexual women (Feinstein et al. 2017) mostly as a result of heightened risk of sexual abuse and trauma leading to post traumatic stress disorder (PTSD) (Dworkin et al. 2017).

Drug dependency is both a route into sex work, and also a cause of over 64% of Leeds' street working prostitutes staying in sex work due to the need for money to fuel their addiction (Martin 2017).

A study on women with learning disabilities with substance abuse (Slayter 2016) found that they were an under-researched group, but they were less likely to receive

treatment than men with learning disabilities or than other women, suggesting both a gender and disabilities discrimination.

## 11.5 Gambling

According to the 2018 Gambling Commission survey, excluding the national lottery, 38% of women have gambled in the previous year (46%% of men)(Conolly et al. 2018). Men are more likely to be classified as low risk and moderate risk gamblers (low risk - 3.9% men, 1.1% women; moderate risk 1.9% men, 0.4% women). Men are also more likely than women to be classified as problem gamblers (1.0% and 0.2% respectively). Age is an important factor, with women aged 25-34 more likely to be low risk gamblers, women aged 35-44 at greatest risk of being a moderate gambler, with the risk of problem gambling being similar at all ages under 65 years of age, then increasing for those aged over 75 years (Conolly et al. 2018).

A study undertaken by Leeds Beckett University (Kenyon et al. 2016a) and funded by Leeds City Council has estimated that there are 40,000 people at risk of gambling-related harms in Leeds, with 10,000 'problem gamblers'. Problem gambling is gambling to a degree that compromises, disrupts or damages family, personal or recreational pursuits (Lesieur and Rosenthal 1991). Unfortunately, the Leeds Beckett study did not give a breakdown of data by gender. However, as problem gambling impacts on around 6 to 10 individuals close to the problem gambler, it is also worth noting that many women will be on the receiving end of the negative consequences of gambling. They will be affected by harm to relationships, resources (such as money and debt) or health (including psychological distress and physical health risks) - and a combination of all three (Wardle et al. 2018).

Interestingly there is a strong link between women who have gambling disorder and compulsive buying behaviour (Díez et al. 2018) and the treatment approaches should take into account gender-related factors.

It is very telling that 23% of female prisoners (37% male prisoners) were identified as at-risk gamblers prior to their prison sentence. The female prison population

generally are more vulnerable than the general population to problem and pathological gambling (GamCare 2018), with a strong link to pre-existing mental health problems (Mestre-Bach et al. 2018). There is a need to have recognition of how vulnerable these women can be:

" Lastly, from an ethical standpoint, it is crucial that public policy be accompanied by an effort to minimize the risk of stigmatization, especially since it is dealing with a particularly vulnerable population – both as a result of the particular risk-factors highlighted in this article and of other well-known gender-sensitive variables associated with wrongful discrimination against women" p128 (Mestre-Bach et al. 2018).

The feeling of stigma associated with gambling is a barrier to both men and women seeking help, however an Australian study (Baxter et al. 2016) found that there were gendered differences in the cause of the stigma. Both men and women felt shame about their financial difficulties, but men were more greatly affected by the feelings of embarrassment from being addicted and the need to gamble to cope and the sense of failure. For women their stigma was more focused onto admitting that they were seduced by the 'bells and whistles' of the gambling venue where they felt important, their denial of their addiction; their belief in luck and that the casino can be beat; and the shame of being dishonest – these were all perceived as barriers to help- seeking.

# 11.6 Obesity/Overweight

Obesity is recognised as a major public health problem, with significant consequences including poor emotional and physical health and a risk of premature death (North Yorkshire County Council 2016). For women, there is the added burden that obesity can have a negative effect on their chances of childbirth and on the health of their offspring, both in the short- and longer-term.

Women tend to lay down fat in their hips and thighs (gynoid fat distribution) as compared to men who tend to deposit fat within their abdomen (android); this results in the female pear shape and the men's apple shape when overweight (Tchernof and Després 2013). This form of fat for women is relatively inert and does not lead to health problems, and here is evidence that a higher body mass index is actually good for women, helping to develop stronger bones (Salamat et al. 2016) and is protective during pregnancy and post-menopause. It is only when the fat is deposited abdominally that it becomes much more dangerous to women, with visceral fat being a major cause of type II diabetes and increases the risk of cardiovascular disease and premature death (Tchernof and Després 2013; Song et al. 2014; Elffers et al. 2017; Wu et al. 2018) and the fat-related cancers (Kapoor et al. 2017a, b).

Overweight and particularly very overweight is of great concern in very young children. The School Health Survey for Leeds (Leeds City Council 2018a) five-year rate data (2012/13 to 2016/17) shows that 8.5% of reception-aged girls are overweight compared to 9.2% of boys, and by year 6, this has increased to 18.1% of girls and 21.0% of boys. Again, this varies across the city, with some areas of Leeds seeing over a quarter of female reception class children either overweight or very overweight, including Beeston Millshaw, Elland Road and Cottingley (28.6%), Halton Moor, Wykebecks (28.4%), and Cross Green, East End Park and Richmond Hill (28.0%). For girls in year 6 there was a range of 14.2% in Roundhay to 43.9% in Gipton North. Girls of reception age classed as 'very overweight' ranged from 2.4% in Arthington to 14.5% in Little Woodhouse. In year 6 overweight was higher with a range of 0.0% in City Centre to 30.9% in Gipton North.

In the Leeds Women's Voices study (Thomas and Warwick-Booth 2018), there was concern over the availability of cheap unhealthy food, which was recognised to be a factor in poor diets and the likelihood of becoming unhealthy. As one of the respondents noted:

"...cheap foods, there's a lot of cheap food which is really unhealthy food and it's about educating people really. I suppose also it's with regards the suppliers. You know, two pieces of chicken and chips for 99p...That's what, the way we want people to go don't we to eat healthy but, it's the price. So, that's what I find it's what people can afford."

There are significant health consequences for girls and young women with obesity, including earlier sexual maturation, reproductive dysfunction, infertility, contraceptive failure and a range of diverse obstetric, perinatal, and neonatal complications, such

as spontaneous abortion and congenital abnormalities (Catalano and Shankar 2017; Elizondo-Montemayor et al. 2017). Obese women have higher risks of developing gestational diabetes, venous thromboembolism, depression and difficulty with breast feeding (Catalano and Shankar 2017) and obesity in post-menopausal women is a risk factor for chronic liver disease (Trembling et al. 2017).

Being obese pre-pregnancy also has long term implications for the offspring, as a result of the mother's high fat content leading to changes to the child's genetic structure. This can result in a higher risk in their children becoming obese themselves and having a shorter lifespan (Ojha et al. 2013; Reynolds et al. 2013; Catalano and Shankar 2017).

Across England 27% of women and 26% of men are classified as obese, with 4% of women and 2% men morbidly obese (Conolly and Saunders 2017). It is estimated that by 2050 obesity is predicted to affect 60% of adult men, 50% of adult women and 25% of children across England (North Yorkshire County Council 2016).

In Leeds, prevalence of adult obesity ranges from 7.1% of the female population in the City Centre to over 30% of the female population in other areas, including Swarcliffe (35.5%), Middleton and Westwoods (34.7%) and Belle Isle North (34.0%).

There is a counter-intuitive link between poverty and overweight and obesity, with women (but not men) living in poorer socio-economic circumstances more likely to be obese (Conolly and Saunders 2017). It has been suggested that food insecurity is linked to mothers risk of being obese as they are more likely to consume high-calorie but nutritionally-poor food to avoid feelings of hunger, especially in single mothers (Martin and Lippert 2012). The recession has also led to more women being obese (Jofre-Bonet et al. 2018). Poverty can also impact on the emphasis placed on health promotion and positive health interventions, such as weight loss as they are competing with a different set of everyday priorities (Audet et al. 2017). There is also a link between lower educational attainment and overweight (Wells et al. 2012), which is much stronger in women than in men, mostly as a result of poorer quality meals, early life under-nutrition, adversity and stress.

Managing weight for health is a major problem for people with learning disabilities, with 45% of women compared to 27% of women without a learning disability being classified as obese (PHE 2017c). The key causes are high levels of sedentary behaviour (Harris et al. 2018) and a greater risk of poorly balanced diets and having insufficient physical activity (Hallawell et al. 2012; PHE 2017d). Conversely, being underweight is twice as common in people aged over 64 with learning disabilities, compared with patients with no learning disabilities.

## 11.6.1 Psycho-social implications of overweight and obesity

Weight is a very contentious issue for women, with women and girls facing a double dilemma with regard to their weight, with a long-standing socio-cultural pressure to be thin and the impact of the obesogenic society.

The Health Survey for England for 2016 reveals that more normal weight women (13% vs 5% male) see themselves as too heavy, and only 4% of obese women thought they were the right weight as compared to 13% of men (Figure 58) (NHS Digital 2017d). This effect is also seen in school-aged girls and boys, where normal weight girls tend to see themselves as overweight, whilst normal-weight boys see themselves as underweight (Frisco et al. 2010).



Figure 58 Perception of own weight, by BMI category and sex, England, 2016

For obese women there is a much lower opportunity for employment and to prosper within an organisation, in a way that weight is not as much of a barrier for men (Caliendo and Gehrsitz 2016; Nickson et al. 2016; Hiilamo et al. 2017). In part, this is due to the way overweight men and women are perceived, with the wider social stigma overweight and obese women face within society being reflected in the prejudices experienced in the workplace. Even for women who are slightly overweight there might be repercussions, especially where physical appearance and beauty are seen to be the important parameters (Caliendo and Gehrsitz 2016).

Overweight school girls can find themselves stigmatized and ostracised, and the victim of fat-shaming, especially when linked with social media. The way the girl views her body can have a marked effect on her self-esteem and self-confidence, with childhood obesity resulting in a greater level of psychological distress through into their adolescence and adulthood, and girls being more affected than boys (Gibson et al. 2017). Pressure on girls to be thin can lead to further eating difficulties including eating disorders such as Anorexia Nervosa and Anorexia Bulimia and other depressive symptoms (Frisco et al. 2010). Conversely, calorie dense comfort food has been found to be more likely to be used as a coping mechanism by women, (Tomiyama et al. 2011).

There is a higher prevalence in obesity amongst lesbian women with the suggestion that there should be culturally tailored components into an obesity intervention for lesbian women (Mason and Lewis 2014; Mereish 2014; Haynes 2016).

# 11.7 Underweight

Approximately 2% of the female population of England is classed as underweight – [BMI <18.5kg/m<sup>2</sup>] - the same proportion as for males (NHS Digital 2017d). In Leeds, there are 41,503 females (37,775 males) over the age of 15 years identified as underweight. Underweight has been linked to eating disorders, but also to other disease processes, such as depression; cancer; digestive tract problems and cardiovascular disease; and to food poverty. In the elderly, it can be an indication of an inability to self-care or other health problems, such as heart disease, cancer or

depression; and poses a greater health risk than being overweight (Lorem et al. 2017).

Being underweight has its own risks, especially when linked to other health problems or lifestyle risks (such as smoking), including a higher risk of premature death. Low BMI has a negative effect on female hormones with amenorrhoea and increases the risk of premature menopause (Szegda et al. 2017; Zhu et al. 2018b). There is also an increased risk of maternal mortality, delivery complications, preterm birth, and intrauterine growth retardation (Girsen et al. 2016; Abarca-Gómez et al. 2017).

Low BMI can also impact on healthy bone growth, which can lead to osteopenia in later life (Tatsumi et al. 2016). Recovery from major illness can be affected by being underweight, with an increased risk of death following an acute myocardial infarction (Bucholz et al. 2016).

## 11.8 Physical activity and sedentary behaviour

In the Women's Voices study (Thomas and Warwick-Booth 2018) there was an acknowledgment that Leeds is fortunate in having a lot of green spaces that can be used for free physical activity. Nevertheless, despite this apparent opportunity women have lower activity levels than men, and deprived women have the lowest activity levels of all. It is important to note that there are health consequences of having a low level of physical activity (i.e. exercise) and also high levels of sedentary behaviour (i.e. sitting).

Sedentary behaviour is a significant cause of ill-health, both physical and mental (Dogra et al. 2017) and women who had the most sedentary lives were found to be at an increased risk of all-cause mortality, irrespective of other health concerns (Seguin et al. 2014). Prolonged sitting time has been found to be predictive of cardio-vascular disease, irrespective of leisure-time physical activity in post-menopausal women (Chomistek et al. 2013) and has a negative effect on bone health (Braun et al. 2015), especially in younger women. Decreasing the amount of time sedentary

has a more positive effect than increasing physical activity in older women (Braun et al. 2015, 2017).

As of July 2018, Leeds GP audit data for physical activity levels (measured using the GP Physical Activity Questionnaire) showed that of those females measured, only 41% were classed as 'active' or moderately active, with 42.2% classed as 'inactive' and 16.9% classed as 'moderately inactive'.

There are strong links between the levels of activity and inactivity between those living in deprived areas and the non-deprived areas (Figure 59), with 67,689 inactive female residents in the deprived areas as compared to 53,208 non-deprived females. However, both these levels are far higher than for males.



Figure 59 Combined Inactivity Status Rates by Sex and Deprivation, Leeds, 2018. GP Physical Activity Survey

Sedentary behaviour has been found to be greater in deprived neighbourhoods, but only by 15%, with positive perceptions of neighbourhood quality and high levels of neighbourhood social networks associated with decreased sedentary behaviour. Interestingly higher levels of social networks was associated with reduced sedentary time in men, but increased in women (Watts et al. 2017).

The health benefits of being physically active are many and include both short and long term effects, but it remains the case that girls and women are less likely to meet the national guidelines (Sport England 2018a). Getting girls and women engaged in activities is very important as there is increasing evidence that being physical active has both a preventative function on reducing the risk of developing cardiovascular disease (Chomistek et al. 2013), breast and colorectal cancer (Loprinzi et al. 2012a; Kerr et al. 2017), and osteoporosis (Chastin et al. 2014). There is also evidence that increasing physical activity has a positive effect on those women with health problems, with improved recovery, reduced risk of recurrence and decreased risk of death (Loprinzi et al. 2012b, 2013; Ballard-Barbash et al. 2012; Gonçalves et al. 2014). Strength and balance exercise programmes can be very therapeutic in preventing falls in the elderly (NICE 2015a). Reducing sedentary behaviour during pregnancy, can have a positive impact on both mother and child (Fazzi et al. 2017).

The Women's Voices study (Thomas and Warwick-Booth 2018) found three specific issues with regard to women's barriers to being more active in Leeds:

- Expensive public transport was identified as a barrier to women accessing green spaces.
- Dogs (fear of) were identified as a reason why some women don't use green spaces (particularly BME women)
- Lack of access to groups (free or low cost) when not wanting to exercise alone.

"...and one of the things that lifts my spirits and makes me feel healthier is going to the park or being by water or getting out into the countryside that has a massive impact on me and I think when that's - then that's made really tricky for a lot of people isn't it [in reference to the cost of public transport]."

Why women are not more active has been explored widely, with 'a fear of being judged' being identified as a key barrier (Sport England 2015a). There is an historical issue in the way that physical education is provided within schools that has had a detrimental effect on the way many girls view sport, with embarrassment, pressure to

succeed, or a self-perceived lack of ability in PE lessons coupled with other competing obligations being key factors for girls dropping out. The encouragement from teachers for girls to overcome the stereotype that sport is a 'manly' thing to do is a very important motivator (Wetton et al. 2013). Craike et al. (2009) also found that Year 11 students made a shift from competitive sport being for fun towards physical activity as a way of avoiding putting on too much weight, managing anger and finding relief from schoolwork.

The Women's Sports Foundation, (Women's Sport Foundation 2016) found those women who were previously active drop out of sport due to:

- Lack of access to the kinds of sports they want to do.
- Safety and transportation issues in getting to and from sports facilities.
- Social stigma of being associated with sport that has a 'gay' stereotype.
- Decreased quality of the experience, with more facilities and money associated with boys' sports and a greater sense of injustice.
- Cost of providing their own specialist coaching, equipment and travel.
- Lack of positive female role models in sport.

Ethnicity has been identified as potential barrier for women engaging in sport and physical activity. South Asian women may need to engage in more exercise than that advised to the White population due to having a different cardio-metabolic risk than white Europeans (Iliodromiti et al. 2016). They are also at greater risk of disordered glucose metabolism, leading to an increased risk of diabetes at a higher level of physical activity and lower levels of sedentary behaviour than western populations (Waidyatilaka et al. 2013). Despite this need, women from Asian backgrounds are the least likely to engage in sporting activities (Sport England 2017).

A worrying finding from the Women's Voices in Leeds study (Thomas and Warwick-Booth 2018) was that "some BME participants felt that provision for physical activity is targeted to and dominated by a white middle-class demographic e.g. charity runs cater for white middle-class elite runners. One participant described how she didn't feel welcome and many of her friends reported the same" (p28). There has been some useful research done on South Asian girls to identify how they perceive sport and physical education in Yorkshire. The Leeds Research Insight report on increasing rates of South Asian girls engaging in physical activity (Leeds City Council 2017c) found that South Asian girls levels of activity (41.2%) were lower than for any other ethnic group. The report made a number of recommendations, which included raising awareness of why physical activity is so important; making culturally appropriate clothing permissible; increasing after school activities and involving the local Mosques, cultural leaders and community groups. They also recommend that Asian women should become the leaders and role models for the younger girls. A further study (Stride 2014, 2016; Stride and Flintoff 2016) suggests that the girls have very similar aspirations as the White population, however although they may experience different challenges, these can be overcome by schools listening to their concerns and being more adaptable.

Schools are recognising the important of sport and physical activity for girls, with a new endeavour to sell it as beneficial for health. This has helped some girls to take a wider look at what activities they would like to do (Walseth et al. 2017), but it can create problems for those girls who could not, or did not wish to engage, leading to additional levels of guilt and discrimination. As noted, however, by Clark (2018) "'Health' as an enactment of successful girlhood thus seems to set up winners and losers since it is unequally attainable to different girls." (p490)

'This Girl Can' is a national campaign run through Sport England to get more girls and women engaged in sport and physical activity - there is a growth in women taking part in physical activities across the country (Sport England 2016) and Leeds is no exception. Park Runs, swimming, cycling, and an increase in High Intensity Interval Training (HIIT) have all seen increases over the last decade, however, this increase in participation tends to be within the more affluent areas of the city, with women from more deprived areas being less represented, reflecting the national picture (Sport England 2018b). This requires greater attention to attracting women who are currently considered to be 'hard-to-reach' (or unreached), such as those facing socio-economic disadvantage or from the ethnic minorities (Brook et al. 2017). There is also an issue with a 'forgotten age' of 25-60 years, with most focus being on school-age girls and the transition to adulthood, and then older women over 60 years (Stride et al. 2018).

According to Sport England's insight report (Sport England 2015b) into women and sport there are 7 key principles to follow:

- Change the offer to suit the women you are targeting don't expect women to change to fit sport and exercise.
- Don't just talk about 'sport' for many women, sport has baggage.
- Differentiate sport and exercise from other interests by promoting (not preaching) the additional benefits sell what your audience is asking for.
- Seeing is believing. Making sport the 'norm' for women relies on local women of all ages, sizes and faiths not only becoming active but celebrating it and encouraging others to join in.
- Use positivity and encouragement to drive action stimulating action through fear of consequences will have little traction.
- Make it easy for women to act: right time, right place, right welcome, right company, right gear.
- People make or break the experience ensure your audience are appropriately supported along the way.

The use of smart phone exercise tracking technology has been suggested as a way of increasing levels of activity, but it is not favoured by all women and tends to be avoided by those who see it as creating unnecessary competition and introducing the idea of hierarchy (Copelton 2010). There has been some evidence that it does not increase physical activity, but can act as a motivational factor for women to prevent stopping activity (Farnell and Barkley 2017). Such technology may also be a more effective in the younger generation (Toscos and Faber 2006).

It is important to remember that at the other end of the extreme there is a health risk of the Female Athlete Triad. This is a syndrome that comprises eating disorders, irregular or absent menstrual cycles and osteoporosis (Nguyen et al. 2014; De Souza et al. 2017) and is due to prolonged periods of physical activity and restricted diet as women try to reduce body weight as they train. This creates hormonal imbalance and the reduction of calcium in the diet causing a decrease in bone density. This can also occur in dancers and other activities that stress leanness and aesthetics coupled with heavy training regimens. Often suffers are only picked up after repeated stress fractures and there needs to be greater awareness of the risk in young females.

# 12 Use of health services

#### 12.1 Introduction

Leeds is well supported by health care services, with one of the largest teaching hospitals in Europe, dedicated teams of primary health care professionals and a thriving 3<sup>rd</sup> sector. The Health and Wellbeing Board is continually striving to improve the health of the city, through its Leeds Health and Care Plan and its Health and Wellbeing Strategy (Leeds City Council 2016; Dannhauser 2018).

Despite this high level of commitment to providing a people-centred health and social care provision the Women's Voices in Leeds study (Thomas and Warwick-Booth 2018), identified many barriers to accessing services within the City that included financial, language, childcare, timing, location, confidence, cultural and physical (such as building design for disabled women). A common theme from people's experiences was that services were not designed with them in mind, coupled with a lack of awareness of what is available. This also came out of the evaluation of the Women's Lives' Leeds (WLL) initiative (Warwick-Booth et al. 2019), where even really helpful services were just not getting the right sort of uptake, either due to people not knowing they were there, or a lack of confidence or ability in being able to access them effectively.

A further important finding from the Women's Voices study and the WLL evaluation (that has been supported elsewhere), is the need for an option on female-only services. In part this may be a cultural requirement but is also a real need for women who have experienced abuse at the hands of a man or simply do not feel confident or comfortable with men.

'... pretty much unanimously it is, 'Yes. I feel safer. I feel more confident communicating. I feel that I can share things with her that I wouldn't share with a male worker.' ... I think that's a really big thing, particularly with these women that we're working with, the really vulnerable women, a lot of whom will have negative experiences of men as well.' [CT1] quote from Women's Lives Leeds Evaluation (Thomas and Warwick-Booth 2018) p 26 Women are generally greater users of health services, mostly as a result of their reproductive health needs such as contraception, and screening tests, however contrary to popular believe, this does not mean they are always better users of services.

In the Cancer Awareness Campaign lead by the Department of Health and evaluated by Cancer Research UK (Moffat et al. 2016) found that on average, women reported more barriers to reporting symptoms than men. Women were more likely than men to report that finding it difficult to get an appointment with a particular doctor; disliking having to talk to the GP receptionist about their symptoms; and having a bad experience at the doctor's in the past, would put them off going to the doctor. Women were also more likely to report being worried about what they might find wrong, worried about what tests they might want to do, and were more worried the doctor wouldn't take their symptoms seriously.

The difficulties in using GP services was evident in the Women's Voices study (Thomas and Warwick-Booth 2018), with difficulty getting an appointment, the short time to explain complex problems and the lack of home visits, which are structural issues. There were also concerns over doctors lacking a 'human approach' and more focused onto computer notes or held stereotypical views about older women.

"I found that when I was going through the menopause that's probably when I had the least relationship with my Doctor's...I didn't feel like they connected very well with me about that. I didn't wanna take drugs or HRT I didn't want any of that. And that's **all** they could offer. And then other symptoms that I felt were happening because of the menopause they just didn't recognise they were- they weren't, interested in..." (p20)

There are a greater proportion of women as compared to men that are given a diagnosis of 'medically unexplained symptoms' (MUS) (NHS 2018e), which is where a person can experience physical symptoms but it is difficult for the GP to identify a specific cause. It can be the case that these symptoms are a result of conditions that have previously been difficult to diagnose, such as fibromyalgia or are a result of emotional difficulties creating physical symptoms (psycho-somatic or somatoform diseases) (RCP 2015; Razali 2017; Rosendal et al. 2017; NHS 2018e). Whatever the underlying problem, it can cause distress for both the patient and the doctor and

unless managed well, can exacerbate the problem and make the relationship with the GP more difficult (Stone 2014; Sowińska and Czachowski 2018). It has been proposed that GPs should adopt a more empathetic approach and that better communication can lead to better outcomes for both the patient and the GP (Chew-Graham et al. 2017; Houwen et al. 2017; Rosendal et al. 2017).

There were also concerns over hospital-based services, especially around the issue of communication, in terms of patient's frustrations of having to repeat their history to many different practitioners (which can also be traumatic when dealing with sensitive issues) and also when communication was poor between departments and staff.

This section explores the issues facing women with regard to health screening, the NHS health check, the use of mental health services, dental registration, smoking cessation and weight loss.

# 12.2 Health Screening

Screening offers an invaluable opportunity to identify early cancers, to pick up on cardio-vascular health problems (such as hypertension and high cholesterol levels) and diabetes; all conditions which benefit greatly from early detection and management. Currently across the country, women are offered breast cancer, cervical cancer, and bowel cancer screening (Leeds City Council 2017d) and the opportunity to have the NHS Health Check (Leeds City Council 2018c).

The Million Women study (Floud et al. 2017) found women with disabilities were 36% less likely to attend breast screening and 25% less likely to participate in bowel screening than women who were disability free. Those with self-care difficulties, mobility disabilities and vison disabilities had the lowest compliance

For some groups within society, the take up of screening is more problematic than for others (PHE 2013), with specific attention required to help address their needs. These include:

- Individuals who have hearing problems or are deaf.
- Individuals with a visual impairment.

- Individuals who have a physical disability.
- People from ethnic minority backgrounds who have no or poor understanding of the English language.
- Travelling communities.
- Lesbian and bisexual individuals.
- Transgender individuals.

In addition women with learning disabilities have been found to be underrepresented in screening up-take (Osborn et al. 2012; Connolly 2013; Willis 2016), with less than half of the eligible national population taking up the NHS Health Screen, 1 in 3 engaging in cervical cancer screening, 52% completing breast screening and 3 in 4 completing bowel cancer screening (NHS Digital 2017e). A Canadian study (Willis 2014, 2016) found a key factor in improving access is the role of the paid carer and better information to the whole family. There are some excellent initiatives that are supporting women with learning disabilities. Tenfold<sup>29</sup> is a forum that runs within Leeds to support third sector organisations working with or for people with learning disabilities. 'Through the Maze'<sup>30</sup> is an information and support service for people with learning disabilities in Leeds. "Bee together" <sup>31</sup> is a Leeds Time to Shine community development project aimed at supporting older women and men with learning disabilities at risk of social isolation.

People who are born profoundly deaf have specific health needs (Emond et al. 2015), with higher than the general population's levels of obesity, hypertension, diabetes, mental health difficulties, and with low health literacy. The main causes of hearing loss in the elderly are noise-induced hearing loss (working environment, loud music etc), hypertension, diabetes, genetic factors and hormonal changes post menopause (Oghan and Coksuer 2012). Hearing loss tends to be greater in men than in women, but there are still a substantial number of women who are missing out on hearing aids (Scholes and Mindell 2014), with hearing loss most pronounced in those from lower socio-economic areas and those most in need of social support. Those who are blind or partially sighted can also experience difficulty with regard to

<sup>30</sup> <u>http://www.through-the-maze.org.uk/</u>

<sup>&</sup>lt;sup>29</sup> http://www.tenfold.org.uk/

<sup>&</sup>lt;sup>3131</sup> https://timetoshineleeds.org/projects/learning-disability-community-development

being aware of screening opportunities or the mechanics of screening, such as needed for the bowel cancer faecal occult blood test (FOBT) stool sample (RNIB 2015).

Women with sight impairment accessing to health services can experience difficulties in a number of different ways. Reminders for general health screening such as breast screening are often sent by letter which is difficult if not impossible for some to read/access. People generally with a visual impairment can lack confidence going to new places without assistance and can in fact avoid going for fear of not finding places or finding their way around. Some medical staff forget or don't know how to audio described an environment making the woman unsure what is excepted or needed. Transport is also an issue as there is an anxiety catching a bus because they are not sure which bus to use, cannot see the numbers, don't know what stop etc. There may also be issues in the way that services call the next patient in for screening – if it is done on a screen then there is the possibility they will be missed.

There can be particular problems for Wheelchair users to access health services due to a lack of suitable adjustments both relating to structural barriers, such as poor street design and inaccessible buildings; physical barriers, such as narrow doors, poor toilet access and difficulty getting onto examination tables etc.; systemic barriers, such as appointments that are too short, or lack of planning to cater for their needs; and attitudinal barriers, such as stereotyping and stigmatizing or failure to deliver the same kind of care as given to an able-bodied women (Hanlon and Payne 2018). Similar findings were found in an American study (Stillman et al. 2017) of wheelchair users' experiences of accessing health care, where along with the practical difficulties, there was a perception that they received incomplete care and the physician only had a partial understanding of their needs.

"I've known some people who use wheelchairs who've had to struggle on to the bed, with help, and been very uncomfortable and very, very... and had an awful experience. But they wanted to go through with it and that was the only way they could. Because there was no facilities to help them, within their GP surgery. And I don't know whether you can get referred to hospital where they have facilities, but at that point they hadn't." quote from participant in the Women's Voices study (Thomas and Warwick-Booth 2018) Ethnic minorities have been found to have lower uptake of screening opportunities, leading to later presentations and poorer outcomes (Macmillan 2014). The sex of the practitioner for cervical cancer tests, language barriers, heath literacy, lack of awareness of religious requirements can all be significant factors in accessing screening opportunities (PHE 2013; Macmillan 2014). Women from the Romany, Gypsy and Traveller community also have access issues with regard to health care, in terms of structural factors, such as not being registered with a GP, cultural factors in relation to perceptions of health, language issues and the ability to understand messages, (Thompson 2013; Warwick-Booth et al. 2017; McFadden et al. 2018).

Lesbians are still at risk of cervical cancer, yet their uptake of PAP screening has been much lower than for heterosexual women (Tracy et al. 2013; Curmi et al. 2014, 2015), in part due to a belief that they are at a lower risk as they are not engaging in heterosexual sex, but also due to a fear of discrimination and other anxieties relating to the procedure. A further study by Johnson et al., (2016a) explored the experiences of lesbians, Bisexual women and transgender men, which found that those who were routine screeners felt more welcome in the health care setting, but for others who did not attend there was a fear of discrimination based on their sexual orientation and gender expression.

The transgender community have specific issues relating to their screening needs specifically trans men and their risk of cervical cancer. For instance the invitation system used for cervical screening is set up automatically to only invite the correct eligible patients, which may exclude male trans who still have a cervix (PHE 2013). In addition, women with a male history, or men with a female history that have developed breast tissue, still need breast screening.

Women who are from the Gypsy and Traveller community have also been found to miss out on screening opportunities, either through problems with access, health literacy, or lack of registration on the appropriate lists (PHE 2013).

#### 12.2.1 Breast cancer screening

Breast cancer screening is offered to women aged between 50 and 70 years every three years. Over England, 75.4% of those eligible for the screening took up the opportunity (2.2 million women), with 41.5% of the cancers detected being too small to have been picked up without the x-ray (7,635 women). Detection is highest in women aged over 70 years (14.6 per 1,000 women tested) and lowest in the 50-54 age bracket (6.2 per 1,000 tested) (NHS Digital 2018d). In Leeds we fall below the national average, with 74% of eligible women screened, but this an improvement on previous years and the most current data shows that across Leeds there has been an increase in breast screening uptake, from 66.9% in April 2012 to 70% in August 2017 (Figure 60).



Figure 60 Change in breast screening uptake in Leeds from Apr 2012 to Aug 2017

Cancer screening has been found to be lower in women with mental health problems (Howard et al. 2010; Aggarwal et al. 2013; Woodhead et al. 2016) and in those from ethnic minority backgrounds (Crawford et al. 2016; Hirth et al. 2016). Uptake of breast screening opportunities is also lower in women with intellectual disabilities (Collins et al. 2014) through a complex range of issues, with the role of the carer being of prime importance (Willis 2016).

### 12.2.2 Cervical Cancer Screening

Cervical cancer screening is effective at reducing advanced cancer in the population (Castle et al. 2017), with regular screening associated with a 67% reduction in stage 3 cancer and preventing 70% of deaths (Landy et al. 2016). Of the ~6% of women across England who tested positive, women aged 25-29 were most likely to have a high-grade abnormality, which reinforces the need for an active marketing programme for this age group (NHS 2017b). There has been a recent push by PHE to improve access to cervical cancer screening, as they recognise the national figures are at a 19 year low (PHE 2017e).

Across Leeds, of the 209,200 women eligible for the test, 45,000 have been screened, of which 96% were negative, 1.5% had borderline changes, and 1.1% having moderate to high grade changes (495 women) (NHS 2017c).



Figure 61 Change in cervical screening uptake in Leeds from Apr 2012 to Aug 2017

There are still women who do not attend screening and there has been a steady reduction in uptake across Leeds with a drop from 76.8% in April 2012 to 73.6% in August 2017 (Figure 61), however this is still above the national average of 72%. Analysis of screening activity tends to suggest that younger women are less aware of the test and older women have decided not to attend (Marlow et al. 2017). Older women that do not take up screening have been found to be affected by embarrassment and logistical issues (Hope et al. 2017). Those at risk of social

isolation (non-English speakers, alcohol abusers, heavy smokers, receiving treatment for psychiatric disease) and those less well educated (Myriokefalitaki et al. 2016; Labeit and Peinemann 2017) are also poor at taking up screening opportunities.

A study of women who did not attend (Marlow et al. 2018) found that they were more likely to be fatalistic and more focused onto the moment rather than thinking about potential future problems; these women were also more likely to avoid information about cancer and be less informed. The role of good quality, focused, and ethnically appropriate information has been suggested as key to getting more women to attend screening (Ghanouni et al. 2017).

There is also a strong argument that for women who have been sexually assaulted, the way the smear test is advertised and the language used to promote the test creates barriers to participation (Cosgrave 2018). With greater awareness of the needs of vulnerable women, the service could be more sensitively promoted and delivered. This work is being promoted by the My Body Back project<sup>32</sup>, which is supporting women a year onward following sexual assault.

It is proposed that the current PAP screening be replaced with HPV screening, which would result in an estimated 23.9% reduction in the current cases invited for screening and an estimated reduction of 19% in cervical cancer by 2023 (Castanon et al. 2017). There are worries that the self-sampling required for HPV screening may not be effective due to lack of knowledge, low self confidence in ability to self-sample and a worry over its efficacy amongst other factors (Williams et al. 2017). However, a recent meta-analysis of identifying precancer risk and reaching underscreened women by using HPV self-testing (Arbyn et al. 2018) has found it to be as effective as clinical samples, which may be a positive way forward.

<sup>&</sup>lt;sup>32</sup> <u>http://www.mybodybackproject.com</u>

### 12.2.3 Colorectal Cancer Screening

There has been a national bowel cancer screening in place since 2006, aimed at all men and women aged between 60 and 74 years of age. In Leeds this is mostly based on the bowel cancer screening test, which requires the return of three samples of stool (Leeds City Council 2017d).

In Leeds those women taking up bowel cancer screening has increased from 55% in April 2012 to 58% in August 2017 (Figure 62).



Figure 62 Change in Bowel screening uptake in Leeds from Apr 2012 to Aug 2017

In a review of the national data relating to colorectal cancer (White et al. 2018a) a higher proportion of women were found to have taking part in screening (60.9% women as compared to 55.5% of men), with the gap narrowing with age. This review also found that more women are diagnosed through emergency presentation, which was thought to be a consequence of the greater chance of co-morbidity as women tend to be older when they develop the disease.

There are also issues with the way women develop colorectal cancer that can impact on how they are diagnosed and the risk this cancer poses. Women are more likely to develop the disease in the caecum and ascending colon, which is not viewed in the standard Bowel Scope assessment, and are more likely to develop sessile serrated polyps, which are more likely to be missed via colonoscopy and can lead to more aggressive forms of cancer (Hansen and Jess 2012). Women's bowel cancer has also been found to have a lower level of haemoglobin in the faeces, resulting in a lower pick up on screening (Steele et al. 2012).

Women are as likely as men to prevaricate over screening due to the faecal sampling required (Lo et al. 2015; Clarke et al. 2016) and are embarrassed and have difficulty in reporting symptoms to their GP (Moffat et al. 2016). Greater attention needs to be paid in getting women to be screened, as many think this is a male disease (Friedemann-Sánchez et al. 2007).

One participant from the Leeds Women's Voices study (Thomas and Warwick-Booth 2018) noted that for people with a visual impairment, bowel cancer screening creates difficulties.

# 12.2.4 NHS Health Check Uptake

The NHS Health Check is a national initiative aimed at preventing Cardiovascular Disease (CVD), through inviting those aged between 40 and 70 years to complete the check every five years. The Leeds approach was to roll out the Health Check in stages, starting in 2009/10 with those most at risk, which included those practices with more than 30% of their population living in the 10% most deprived areas nationally and males.

The latest audit of uptake in 2017 (Turrell *et al.* 2017) shows that between 2011/2012 and 2015/2016, over 90% of those eligible had been invited to be tested. The report notes that women, especially those from deprived areas, are more likely to attend an NHS Health Check than men. It also notes that in Leeds, uptake across ethnicity groups is in proportion to the ethnic composition of local communities and is greater in the older population than the young.

## 12.3 Mental Health service usage

The primary delivery framework for NICE-recommended psychological treatments for Common Mental Health Disorders is the Improving Access to Psychological Therapies (IAPT) programme. This brings together evidence-based treatments informed by clinical guidelines with the delivery of interventions, in a stepped-care model. Validated patient-reported outcome measures (including GAD7 and PHQ9) are used to assess, monitor and evaluate treatment.





Figure 63 IAPT data by gender. Leeds, CCG Leeds Annual IAPT data return 2017/18

Acute mental health services provide community-based and inpatient treatment for people with moderate to severe mental health disorders, including psychosis. Admissions to acute mental health wards are broadly comparable between males and females, however a greater number of women are referred to community-based mental health teams/primary care mental health than men.

# 12.3.1 Eating Disorders

Treatments for mild to moderate eating disorders are delivered via the IAPT Service and in Primary Care settings. Information about eating disorders in Primary Care is not consistently recorded. The number of referrals to IAPT between 2016 /17 and 2017/18 with a primary or secondary diagnosis of an eating disorder were at least 15 times more for females compared to males (Table 7).

Table 7 Referrals with a Primary or Secondary Diagnosis of F50 – Eating Disorder

	Female	Male	Total
2016-17	91	6	97
2017-18	143	7	150

Admissions to hospital for physical health conditions related to eating disorders show a similar pattern with at approximately ten times more female patients admitted than males, and nearly 15 times more admissions for female patients than male patients (Table 8).

Table 8 The number of admissions for eating disorders (2013/14 to 2017/18), age 10+ resident in Leeds<sup>33</sup>

	Female	Male	Total
Admissions	721	49	770
Patient Count	346	34	380

The relationship between eating disorders admissions and deprivation appear random, however this may be related to the small overall number of admissions (Figure 64).

Services for severe eating disorders in Leeds are provided by LYPFT via the CONNECT service. This includes a community-based treatment service, inpatient service and FREED (First Episode and Rapid Early Intervention Service). In October 2018 there were 50 Leeds women on their caseload.

<sup>&</sup>lt;sup>33</sup> Eating Disorders Hospital Admissions (*Admissions data Copyright* © 2018, re-used with the permission of the Health and Social Care Information Centre (HSCIC) / NHS Digital. All rights reserved.)



Figure 64 Female admission rates (and confidence intervals) for eating disorders (2013/14 to 2017/18) by Index multiple deprivation deciles, 2015

### 12.3.2 Self-Harm

Information about self-harm is obtained by collecting data on hospital admissions. It is important to note that this data has limitations - self-harm hospital admissions data does not provide a comprehensive picture about self-harming behaviour in the community.

There are a higher number of admissions for women living in the most deprived two deciles of Leeds, with Leeds rates higher than the national average and greater for women in the deprived areas of the city (Figure 65).



Figure 65 Emergency Admissions for Deliberate Self-Harm All Ages, Persons
#### 12.4 Dental registration

Tooth decay is more of an issue for women than men and has been linked to sexdifferences in the composition of saliva, the effect of pregnancy, and different eating habits, especially relating to food production in the home increasing snacking (Lukacs and Largaespada 2006; Ferraro and Vieira 2010). Data was not available for Leeds, but this section has been included as dental health is an important aspect of overall health as women have specific issues to consider.

Obesity is linked to dental caries in children, with more decayed, missing, and filled permanent teeth among obese 18 year old girls than boys (Li et al. 2017). Children from lower socio-economic communities are more at risk of lower oral health quality of life, irrespective of their actual oral health status (Kragt et al. 2017), with the suggestion that self-esteem and self-perception about oral health and body image may be a factor..

A Swedish study (Ericsson et al. 2012) suggests that adolescent girls have more favourable perceptions, attitudes and behaviour with regard to their oral hygiene, which may be influenced, both by a better awareness of the health benefits, but also for cosmetic and aesthetic reasons.

Through pregnancy and whilst breast feeding, it is important to have good oral health as inflammatory gum disease, gingivitis or periodontitis are common problems faced during pregnancy. Increasing midwifery intervention to offer oral hygiene education and guidance on using dental services can improve women's up-take of services (George et al. 2018).

Mental illness can have a negative effect on dentition, as a result of a higher proportion of women smoking, the effect of medication, and anxieties relating to dental services and dental hygiene. There may also be issues relating to competing priorities in their life and difficulties accessing services, especially if there is a felt stigma to using the services (Kisely et al. 2011; Brondani et al. 2017). Eating disorders can damage the enamel of the teeth and result in a poor oral health status due to vomiting (Lourenço et al. 2017). Women with breast and other cancers can be at increased risk of dental problems (Lo-Fo-Wong et al. 2016) due to the effect of chemotherapy on normal mucosal replacement and also due to use of anti-oestrogen therapy.

Tooth loss in older women may be as a result of osteoporosis and warrant further investigation (Martínez-Maestre et al. 2010). Treatment with bisphosphonates can have a negative effect on oral health and affect bone healing after dental treatment (Grgić et al. 2017).

An Australian study (Riggs et al. 2014) found that migrant women and their children were more likely to access dental services through emergency care as they faced many barriers to using primary dental services.

## 12.5 Smoking cessation

Across Leeds, between April 2017 and March 2018 there were 944 females and 740 males setting a quit date to stop smoking, of those there were 453 female and 360 male successful self-reported quitters (or approximately 49% of both male and female quitters), with 378 female and 233 male quitters confirmed by CO validation (which is 83% females and 65% of males). There were more women than men attempting to quit and more whose outcome are not known or lost to follow up.

Women usually tend to be less successful at quitting smoking than men (Martin et al. 2016b), with especially older White women rating barriers to quitting (such as the risk of weight gain) more difficult to overcome than men. Interestingly a study of nicotine withdrawal showed that although women reported greater negative affect, psychological withdrawal, and sedation after overnight abstinence than did men, they were not influenced by the amount of nicotine in a cigarette when it came to its 'restorative' effect (Faulkner et al. 2018). This suggests it was the psychological and affective aspects of withdrawal rather than the nicotine that is the main barrier to cessation.

In part this may be due to women who smoke facing a greater burden of stigma, both from others and 'self-stigmatizing' their own behaviour by being very aware of the risks they face,, especially if they are mothers or pregnant (Triandafilidis et al. 2017). This can lead to feelings of shame and having to deal with the emotional bullying that men may not have to endure. With smoking being most prevalent in women from lower social backgrounds and in women with mental health difficulties, this negativity can make their lives all the harder. Focusing on the positive aspects of not smoking may be a more beneficial approach (Triandafilidis et al. 2017), including the effects of smoking on physical appearance, oral hygiene and the health benefits for their children (Memon et al. 2016).

It's also important to note that attempts to stop smoking during the pre-menstrual period are limited due to increased tobacco dependency and the negative effect of the withdrawal symptoms on top of those experienced by those with elevated affective PMS (e.g. irritability, anger) (Pang et al. 2017).

The Smoking Insight Evaluation carried out in the Leeds East and South CCG areas did not differentiate between male and female smokers, apart from specific reference to pregnant women who smoke (Trigwell et al. 2015). They did note that practitioners felt less successful at reaching into BME Communities.

Lesbian, bisexual, and other sexual minority women have been found to be more resistant to smoking cessation efforts, with the suggestion that they need more targeted interventions that work with them on overcoming the causative factors (Baskerville et al. 2017).

The Stop Smoking Services for Pregnant Women (SSSP) run by the NHS have found that by focusing their services on clinics rather than trying to reach out to the women in their own homes was more effective (Vaz et al. 2017). They also found that they should focus their attention onto the more deprived communities and those with lower educational attainment as they were the most likely to smoke and be the hardest to influence. The sex and gender differences seen between men and women with regard to tobacco consumption and with regard to problems of cessation warrant more gender aware policies and strategies (Amos et al. 2012).

#### 12.6 Weight loss services

In Leeds 5,994 women (2,868 men) had a hospital admission with a primary or secondary diagnosis of obesity, with 27 females (8 males) having Bariatric surgery in 2016/17 (NHS Direct 2018).

There is evidence to suggest men are more successful at losing weight than women (Stroebele-Benschop 2013). For women there tend to be multiple attempts with a boomerang effect, where weight loss is followed by weight gain. There is a higher proportion of women offered medicinal support by their GP to lose weight, with an increasing number of women are seeking surgical solutions to their weight difficulties, such as stomach bands.

Social stigma and discrimination as a result of obesity has been found to have a greater negative impact on women's ability to lose weight, through many different effects. These include the unwillingness to join exercise groups due to poor self-image, and a lower sense of self-esteem and self-efficacy restricting effort as there is a fear of failure. The stress and depression caused by the stigma can also lead to poorer eating habits. Changing social networks, with the lower likelihood of joining active friends can also be limiting, as can the life-limiting effects of obesity (Brewis 2014), such as reduced job options, lower income and poorer living environments, which limit life choices.

An American study (Ford et al. 2017) found that postmenopausal women with high adherence to a reduced-carbohydrate diet, with moderate fat and high protein intake, were at decreased risk for postmenopausal weight gain.

# 13 Reproductive health

#### 13.1 Introduction

The reproductive anatomy and physiology of a women's body is more complex and has a greater overall impact on their physical and emotional wellbeing than seen in men. The female reproductive system is designed for a difficult task – that of enabling conception, carrying a child to birth, and then providing sustenance to the baby. This involves complex anatomy and physiology that has the greater potential for disorders and difficulties than that seen in the male. There is also a huge emotional aspect to reproductive health, with an important power and control aspect to procreation and the implications of pregnancy and becoming a mother.

And yet despite the widespread issues that are associated with women's reproductive health, this is still a stigmatising and taboo area, and the Chief Medical Officer for England and Wales recognises that this leaves many women suffering in silence with hidden conditions (Davies 2015). Since her report in 2014 there have been two other important reports from Public Health England (a consensus statement on 'Reproductive health is a public health issue' and 'What do women say?: Reproductive health is a public health issue) (PHE 2018b, c) that are drawing attention to the need for a more public debate on women's reproductive health issues. These reports question whether that the issues women face with the regard to their reproductive health should be considered public health issue (see also Sommer et al. 2015). Two quotes from the completed survey (PHE 2018c p10) are important in this regard:

"...I look back and I think how much of my life I've lost to my periods...It's only when you step back and think other women don't go through this every month..."

"...it's been an atrocious, ferocious and frightful experience (menopause)..."

They also highlight the high level of misunderstanding that exists across society with regard to reproductive health, with both women and men lacking knowledge and awareness of what is normal and abnormal. This can create delay in seeking help,

and a lack of compassion from others for those affected. In part this originates during schooling where periods and reproductive health are still not seen as a topic for boys, and girls are left unprepared for the challenges they are to face. The lack of education was seen as a particular problem, with some schools doing a good job, but there was a feeling that for many girls they are left frightened and bewildered by the whole process, with this lack of knowledge extending throughout their lives. This issue came up in the Women's Voices study (Thomas and Warwick-Booth 2018) where many commented on the challenges they face, both personally and also professionally through inflexible workplaces.

#### 13.2 Premenstrual Syndrome (PMS)

The premenstrual syndrome (PMS – and also known as premenstrual tension) usually occurs usually in the 2 weeks prior to the monthly period and can cause bloating, backache, headaches, anaemia, nausea, vomiting, breast pain, mood swings, feeling irritable and loss of interest in sex (Sammon et al. 2016; Gunn et al. 2018; Maphalala 2018; Yonkers and Simoni 2018). Delayed gut motility can lead to constipation as a result of hormonal changes during the menstrual cycle (McCrea et al. 2009; EI-Tawil 2011). PMS can be a severe form – premenstrual dysphoric disorder (PMDD) (NHS 2018f) - where the emotional disturbances and physical discomfort can be disabling.

Assuming periods start at about 11 years of age and the menopause at 51 years of age this accounts for 222,820 women in Leeds that may be experiencing some form of monthly PMS. With an estimated 3-8% of women experiencing PMDD on a monthly basis (Halbreich et al. 2003), this could mean that between 6,684 and 17,825 women in Leeds are severely affected over a period of 40 years. If the disability adjusted life years (DALYs) were calculated, then this would mean sufferers have a greater burden than for many major recognised disorders (Halbreich et al. 2003). The impact of PMS and PMDD has gone mostly unrecognised and greater attention needs to be given to the effect this can have on the lives of nearly the whole of the female population of Leeds.

PMS can be caused by a number of different factors, including hormonal changes, obesity, sedentary behavior, high stress levels, certain foods (high salt can increase bloating), alcohol, caffeine and a diet poor in vitamins and minerals (NHS 2018f; Yonkers and Simoni 2018).

PMS has been found to have a negative effect on smoking and alcohol cessation attempts (Becker et al. 2017; Pang et al. 2017), with some evidence that those women with PMDD have a higher alcohol intake, possibly as a way of relieving their symptoms (Fernández et al. 2018). Premenstrual women can also experience worsening asthma symptoms, which can be helped with increased medication in the lead up to menstruation (Raghavan and Jain 2016).

PMS and PMDD can cause disruption to schooling (which can impact on overall educational attainment) and work and be a major disruption to life on a monthly basis (Maphalala 2018). Relationships can be strained, with a fear of rejection or through the effect of monthly mood swings.

The management of PMS can include prescription medications, cognitive behavioural therapy (CBT), exercise and dietary changes, through to total abdominal hysterectomy and bilateral oophorectomy and Hormone replacement therapy (HRT) (Chin and Nambiar 2017).

Women with mild PMS can also be helped with

- Small frequent meals rich in complex carbohydrates.
- Regular exercise.
- Regular sleep.
- Stress, alcohol and smoking reduction or cessation (Chin and Nambiar 2017).

There is a need to ensure that there is a societal recognition of the impact this can have on the lives of women and greater sensitivity to those suffering, with a push to tackle the 'taboo' around menstruation (The Lancet 2018). There should also be more support and guidance for fathers (Girling et al. 2018) and mothers so that they understand the challenges faced by adolescent daughters who are struggling with the effect of the menstrual cycle.

## 13.3 Dysmenorrhoea / Period Pains

Painful periods have been estimated to affect between 45 and 95% of menstruating women, with marked impact on pain sensitivity, mood, quality of life and sleep (lacovides et al. 2015). It is most often found in women who have a heavy menstrual loss, premenstrual symptoms, irregular menstrual cycle and below the age of 30 years. It can be linked with endometriosis and is also more common in women who have suffered sexual abuse (Osayande and Mehulic 2014).

In a Belgium study 41.6% of 13 year old girls experienced painful menstruation, with girls who have their menarche at a younger age most affected (Hoppenbrouwers et al. 2016) – if this were the case locally then this would affect nearly 1,600 of 13 year old girls in Leeds.

## 13.4 Iron-deficiency / Anaemia

There is a high prevalence of iron deficiency in adolescent girls due to heavy bleeding, which can be associated with anaemia, but not always (Johnson et al. 2016b; Cooke et al. 2017). This can cause fatigue, poor cognitive function, irritability and inability to concentrate, which can have a negative effect on a girl's quality of life, her educational attainment, and willingness to engage in physical activity. Girls from South Asia and African American Women have been found to be at a high risk (Bernardi et al. 2016).

In America anaemia has been estimated to affect between 9 and 16% of adolescent girls aged 16-19 years, which in Leeds could therefore impact on up to 3,351 girls

#### 13.5 Period poverty

Over 170,000 people in Leeds are estimated to be in relative poverty after housing costs. In 2015, 19.6 per cent of children under-16 in Leeds were estimated to live in poverty (28,000 children). Poverty is a gendered experience, with women having a higher incidence of experiencing poverty (Chant, 2006). The impact of poverty on women and children is something that is being increasingly recognised, and period poverty is one aspect of this.

Experiencing poverty can impact on all aspects of individual's life, and it is associated with stigma and societal exclusion (Ridge 2002). Social exclusion can be defined as the 'inability to participate effectively in economic, social, and cultural life and, in some characteristics, alienation and distance from mainstream society (Duffy 1995).

Period poverty is one area of poverty led social exclusion which has had raised national attention over the last two years. Period poverty refers to a lack of access to sanitary products due to financial constraints. Experiencing period poverty in school can cause severe embarrassment and distress, limiting social interaction and for some girls preventing them from engaging in their school work and in physical activities.

The National Union of Students have campaigned for University students to get free sanitary products and have launched a #FreePeriods Toolkit (NUS 2016). Aberdeen now supplies free tampons and sanitary towels to the most deprived areas of the city (Freeman 2017). Leeds are creating a city wide, sustainable approach that both tackles the stigma around periods and poverty and that provides sanitary products to all schools and community hubs. Working with internal and external partners, and led by young people, the Leeds scheme aims to normalise periods and eradicate period poverty.

#### 13.6 Infertility

Infertility is 'a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse' (Zegers-Hochschild et al. 2009). Across Britain it is estimated that one in eight women and one in ten men have experienced infertility, with prevalence higher in women aged 35-44 years (17.1%) and lower in younger women. Those women who were trying for their first child over the age of 35 years were more affected, as were those who were more highly educated and in managerial, professional and technical employment compared with those in routine occupations (Datta et al. 2016).

There are many reasons why a woman is not able to conceive a child. Smoking has been linked to a woman's infertility and risk of early menopause (Hyland et al. 2016), as has obesity (Broughton and Moley 2017) through its effect on female sex hormones. Women who are diabetic can also find it difficult to conceive (Basmatzou 2016). Sometimes it can be found to be a result of a specific cause, like pelvic inflammatory disease, endometriosis, or scaring after surgery for women, but for 25% of cases of infertility it is not possible to determine the cause (NHS Choices 2017). The impact of infertility can be profound, with higher rates of depression and dissatisfaction in their sex-life reported by affected women (Datta et al. 2016).

It is also important to note that total male sperm count has decreased by nearly 60% between 1973 and 2011 (Levine et al. 2017). In addition, older men have a decreased sperm count with a greater risk of damaged sperm, which can cause problems with conception, and for the longer term health of their offspring (Yatsenko and Turek 2018).

Approximately half of those affected by infertility actually seek medical help, and of those there is a marked socio-economic divide, with women from more deprived areas less likely to seek professional guidance (Datta et al. 2016).

#### 13.7 Menopause

Despite every women going through the menopause, there is still a lot of uncertainty as to what it is and what it entails, with a general lack of coverage of the issues women face through what been referred to as 'a window of vulnerability' (Dennerstein and Soares 2008). The menopause was an area of long discussion in the Women's Voices study (Thomas and Warwick-Booth 2018), indicating that this is an important issue for women across Leeds and warrants more consideration:

"So people who are coming in with menopausal symptoms or, whatever- you know, we get very misdiagnosed...thinking we've got depression or we've got this or it's the time of your life but actually- it's a real thing that happens to you and it's nasty and it's horrible and... people would rather have their periods back than go through the menopause and I've spoken to a lot of women about this." (p13)

There is a difference between the effect of getting older per-se and the pathophysiological changes that occur as a result of the menopause. For some the menopause can occur earlier, either through surgical removal of the ovaries, though treatment for other conditions (such as for cancer), or spontaneously through premature ovarian insufficiency (NICE 2015b). Those women who are taking tamoxifen for breast cancer suppression can also experience an early and dramatic menopause (Moon et al. 2017), with effects going on past its completion. In the UK, the menopause usually occurs between the ages of 45 and 55 years, which in Leeds accounts for some 54,679 women in this age group.

Due to there being many different signs and symptoms that women can experience during the menopause, other conditions may be missed, leading to a delay in diagnosis and commencement of treatment (Smith et al. 2005; Macleod et al. 2009; Hope et al. 2017). This is especially the case in women with learning disabilities (Willis 2007a), who have particular challenges when going through the menopause.

Menopause symptoms over the transition (perimenopause or climacteric) can last around 4 years from the last period (NHS Choices 2015), but it can go on for longer and can include:

- hot flushes short, sudden feelings of heat, usually in the face, neck and chest, which can make your skin red and sweaty
- night sweats hot flushes that occur at night
- difficulty sleeping this may make you feel tired and irritable during the day
- a reduced sex drive (libido)
- problems with memory and concentration
- vaginal dryness and pain, itching or discomfort during sex
- headaches
- mood changes, such as low mood or anxiety
- palpitations heartbeats that suddenly become more noticeable
- joint stiffness, aches and pains
- reduced muscle mass
- recurrent urinary tract infections, such as cystitis

These can have a marked effect on the quality of life and be a significant limitation on daily living for many women as they go through 'the change' (Greer 1992). The meaning of the menopause can vary across cultures, which may impact on the way the symptoms are perceived and the woman's perception of the overall experience (Hall et al. 2007).

The menopause effects a woman's risk of cardiovascular disease (CVD), including heart disease and stroke. Pre-menopause it is thought that women's lower levels of CVD, as compared to men, are due to a protective effect of the sex hormones, reducing atherosclerosis and a better lipid profile and a reduced risk of hypertension (EUGenMed et al. 2016; Regitz-Zagrosek and Karaigas 2017). Following the menopause this protection is lost and rates of disease start to follow and then overtake those seen in men. Early menopause (before 45 years of age) greatly increases the chances of developing coronary heart disease and overall mortality as compared to those women who have a normal or late menopause (Muka et al. 2016; de Kat et al. 2017; Ley et al. 2017; Savonitto et al. 2018). These negative CVD effects are compounded when linked to being obese and having diabetes (type 1 and type 2).

In a study exploring the impact of weight on when the menopause started found that underweight women had over twice the likelihood of starting early and overweight, obese women had a 50% chance of a late menopause (Zhu et al. 2018b). This relationship between underweight and early menopause was also found in the Nurses' Health Study II (Szegda et al. 2017).

The Genitourinary Syndrome of Menopause (Portman et al. 2014; Farrell 2017) relates to a collection of symptoms that affect women as a result of the changing levels of sex-hormone as they go through the menopause and can affect more than 50% of women. These include vaginal dryness, dyspareunia, urinary urgency and frequency, urge urinary incontinence, and recurrent urinary tract infections. Although these problems are common, women seem reluctant to seek treatment or are not asked about the possibility of such problems at consultation (Farrell 2017; Hull and Fournace 2017).

Changes in the levels of sex hormones during the menopause are also thought to be behind the increase in asthma and respiratory symptoms that occur during the transitional period or post-menopause (Zemp et al. 2012; Triebner et al. 2016; Fuseini and Newcomb 2017). This includes an increase in new-onset asthma attacks and other respiratory symptoms (wheezing, tightness, attack of shortness of breath), irrespective of smoking habits. This is thought to be as a result of hormonal changes affecting the immune system within the lungs increasing inflammation of the airways (Triebner et al. 2016; Fuseini and Newcomb 2017). A rise in the risk of developing sleep apnoea has also been reported (Jordan et al. 2014), which could be due to the re-distribution of fat after the menopause.

There can be important changes in bone health following the menopause, with a steep increase in the number of women developing osteoporosis (Bjørnerem et al. 2018). Oral health is also affected over the menopause, with a number of conditions associated with the changing hormonal environment in the body, including xerostomia, viscous, saliva, increased caries, altered or unpleasant taste, ulcerations, burning mouth syndrome, trigeminal nerve pain, periodontal

disease, osteoporotic jaw, and loss of alveolar bone height (Rothmund et al. 2017; Prasanna et al. 2018) – many of which create oral pain and further adding to a general reduction in the quality of life.

Women who smoke tend to undergo the menopause about 2-3 years earlier than non-smokers (IARC 2012). After the menopause, although smokers are at reduced risk of breast cancer (Dossus et al. 2014) they much greater risk of a number of conditions, including COPD (Sansores and Ramírez-Venegas 2016). How women manage alcohol is also affected by the menopause, both physiologically and psychosocially (Milic et al. 2018a).

The menopause is associated with hormonal mood swings, which have been associated with an increased risk of migraines (Vetvik and MacGregor 2017) and can cause additional difficulties for those with existing mental health problems. Women going through the menopause have been found to have a 2-3 times higher risk of developing depression than those women who are pre-menopausal or postmenopausal. This perimenopausal depression (PMD), impacts on quality of life, their need for social support and increased complaints of disability (Wariso et al. 2017) and may be due to an interaction between metabolic and hormonal factors influencing emotion regulation (Berent-Spillson et al. 2017).

A study of women with bi-polar disease (Perich et al. 2017) found that women experienced their bi-polar symptoms more frequently and more intensely during the menopause, with the women having difficulty in determining how much was a result of life events or the actual menopause, which may suggest some women are missing out on possible support. Sex differences have also been noted with regard to schizophrenia (Falkenburg and Tracy 2014), with women being more protected against developing the condition in their early life, but following the menopause (with a presumed drop in oestrogen), there is an increased risk of late-onset schizophrenia.

Women with learning disabilities going through the menopause, which can occur earlier, require support to understand the changes they are experiencing (Willis 2007b).

Premature menopause can also have marked psychological effects due to a feeling of loss, relating to sexuality, youth and the possibility of motherhood. This was evident in a study on the experiences of women who went through the menopause as a result of cancer treatment (Parton et al. 2017). The three key themes that emerged: 'I don't feel like a whole woman': The incomplete woman; I often feel frumpy and depressed': The abject asexual woman; and 'I feel old before my time': Out of time and social isolation, which reflect an additional burden on women who are already experiencing the stress of the cancer diagnosis and treatment.

There is general advice that can be given to women to help manage the perimenopausal period, which include (NICE 2015b):

- hormonal, for example hormone replacement therapy (HRT).
- non-hormonal, for example clonidine.
- non-pharmaceutical, for example cognitive behavioural therapy (CBT).

Many women turn to alternative and complementary medicine to try and find relief from their symptoms (Tonob and Melby 2017), but NICE warns that many of these are untested and may have serious interactions with other medications (NICE 2015b).

Keeping physically active has been seen to reduce reporting of menopause symptoms, but this may be due to feeling psychologically better able to cope with them, rather than actually decreasing the problems (McAndrew et al. 2009).

Improving the education of women so they better understand the menopause and how the symptoms can be managed has been found to be beneficial, with a Swedish initiative using group sessions at the local primary health care clinic to good effect (Rindner et al. 2017). More women are also turning to the web and other social media as a way of understanding their menopausal experience (Im et al. 2017), with a number of different web-based interventions now evident, but their effectiveness is not yet proved. There is now a dedicated Menopause Pathway being set up in Leeds to support women and health professionals to get an early diagnosis and appropriate support. In addition, the Leeds Centre for Women's Health<sup>34</sup> has a menopause clinic, which women can be referred to.

## 13.8 Other Gynaecological conditions

There are a number of important gynaecological health problems that women face that can have a marked effect on their physical and emotional health. Many of the these can cause high levels of pain and discomfort as well as being significant causes of obstetric complications and can result in a very poor quality of life.

## 13.8.1 Fibroids

Fibroids (Uterine leiomyomas) are benign tumours that occur within the womb and are very common in women of reproductive age, with an estimate of over 70% of women affected by the time of the menopause (Stewart et al. 2017). Many women have fibroids without symptoms, but they have been described as a major public health concern due to the large numbers of women affected and their widespread negative effects (AI-Hendy et al. 2017). In America it has been thought that annual cost of fibroids (including medical costs, lost work-hours and obstetric outcomes) could be as high as \$5.9-34.4 billion annually (Cardozo et al. 2012).

There are many possible causes of fibroids, but they seem to be most strongly linked to oestrogen and are 2-3 times more common in women of African-Caribbean origin, those with a family history of fibroids, and in women who are overweight and had their menarche at an early age (Baird et al. 2003; Stewart et al. 2017; NHS 2018g).

Not all women develop symptoms, but those that do can be affected by a wide range of debilitating health problems, including abnormal bleeding with subsequent anaemia, fatigue, painful periods, painful intercourse, pelvic masses leading to bowel and bladder problems, pelvic pain, abdominal pain, fertility problems and obstetric

<sup>&</sup>lt;sup>34</sup> http://www.leedsth.nhs.uk/a-z-of-services/leeds-centre-for-womens-health/

complications (Lisiecki et al. 2017; Stewart et al. 2017; NHS 2018g). Those women affected can have marked emotional and psycho-social health problems with a poor quality of life (Ghant et al. 2015). Having a higher number of children, oral contraceptives and smoking have all been found to reduce the risk of developing fibroids (Stewart et al. 2017).

## 13.8.2 Endometriosis

Endometriosis is a condition which occurs when the tissue (endothelium) that is normally found in the uterus grows in other parts of the body. This growth can occur on the peritoneum lining the pelvis, the fallopian tubes, or ovaries and can also be seen invading the bladder, bowel and ureter and, rarely, the eye and brain. This tissue goes through the same monthly cycle as found in the womb, including engorgement with blood and then bleeding, and can cause pain and discomfort and abnormal functioning of affected organs. It can have a physical, social, psychological and sexual impact, resulting in a reduction in quality of life and has been estimated to be a cost to the national economy of £8.2bn (Laganà et al. 2017; Morotti et al. 2017; NICE 2017b; Parazzini et al. 2017).

It is estimated that endometriosis affects between 5 and 10% of women aged 15-49 years, which in Leeds could account for between 11,190 and 22,380 women; of those affected, approximately 5 and 30% have a severe form of endometriosis. Despite this high prevalence and debilitating nature of the disease there are still many women suffering for years before a diagnosis is made and treatment commenced (Moen 2017; NICE 2017b).

Women with endometriosis can have difficulty conceiving (Saraswat et al. 2017) and those that do are at an increased risk of early pregnancy complications, miscarriage and ectopic pregnancy, haemorrhage and other serious risks to the mother and the offspring.

Endometriosis should be suspected in women (including young women aged 17 and under) presenting with 1 or more of the following symptoms or signs (NICE 2017b) :

- chronic pelvic pain.
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life deep pain during or after sexual intercourse.
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements.
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine.
- infertility in association with 1 or more of the above.

Women with endometriosis may find their symptoms persist into the menopause (Gemmell et al. 2017), which can be difficult to manage and can turn into a malignant form, including endometrioid adenocarcinoma.

Despite the severity of the symptoms and the disruption to life there is an under – recognition of fibroids and endometriosis and their implications. The newly formed All Party Parliamentary Group on Women's Health (APPG 2017) had endometriosis and fibroids as the subject of their first report which included a survey of 2,600 women and found:

- 42% of women said that they were not treated with **dignity and respect**.
- 62% of women were not satisfied with the **information** that they received about treatment options for endometriosis and fibroids.
- Nearly 50% of women with endometriosis and fibroids were not told about the short term or long term **complications** from the treatment options provided to them.

The APPG have made five recommendations:

- 1. Improved information resources.
- 2. The creation of an endorsed best practice pathway.
- 3. Education to include menstrual health at secondary schools along with wider awareness.
- 4. Multi-disciplinary teams and clinicians working together.
- 5. Where it exists, NICE Guidance should be followed.

In Leeds there appears to be clinical consensus that a specialist endometriosis pathway is not required, due to the volume of cases which would require surgery, but Leeds Teaching Hospitals NHS Trust are developing a new complex pelvic pain pathway, which will include the care of women who suffer from moderate to severe endometriosis, with onward referral where necessary. In addition, there is third sector support for women, for instance the local Northern Endometriosis Sisters Support (NESS)<sup>35</sup> group and via national organisations: Endometriosis UK<sup>36</sup> and MyEndometriosis<sup>37</sup>.

## 13.8.3 Pelvic inflammatory Disease

Pelvic inflammatory Disease (PID) is an inflammatory disease of the womb, fallopian tubes and ovaries caused by bacterial infection, such as through a sexually transmitted infection (i.e. chlamydia or gonorrhoea) (NHS 2018h). Symptoms include fever, vomiting, back pain, dyspareunia, and bilateral lower abdominal pain, as well as symptoms of lower genital tract infection such as abnormal vaginal odour, itching, bleeding, or discharge (Manoharan 2018). It is mostly found in younger women and is a leading cause of both tubal factor infertility and ectopic pregnancy.

In Leeds the prevalence rate in 2016/17 is 201.5 per 100,000, which is up from 139.2 per 100,000 in 2008/09 (Figure 66) but is better than the national average. The low rate is thought to be a result of the high chlamydia screening coverage resulting in more women being treated for the causative factors (Swift 2019).

<sup>35</sup> https://www.facebook.com/NESS.ENDO/

<sup>&</sup>lt;sup>36</sup> https://www.endometriosis-uk.org/

<sup>&</sup>lt;sup>37</sup> https://www.myendometriosisteam.com



Figure 66 Trend in Pelvic inflammatory Disease, females 15-44 years, Leeds

## 13.8.4 Polycystic ovarian syndrome (PCOS)

Polycystic ovarian syndrome (PCOS) can lead to irregular periods, physical signs of high levels of male androgens (excess facial hair or body hair), weight gain, thinning hair, oily face/acne, and polycystic ovaries (NHS 2016e).

It is an under-recognised condition that can cause a number of physical and emotional difficulties for the women affected. The overall prevalence of PCOS is estimated to be about 2%, and higher in the 30-34 age group and in those from socially deprived areas (Ding et al. 2016). It is thought that there could be 50% of affected women not diagnosed and therefore not getting the support they need (Ding et al. 2016).

## 13.8.5 Chronic pelvic pain

Around 6 to 27% of women worldwide suffer a persistent, non-cyclic chronic pain in their pelvis, (Speer et al. 2016). It is mostly associated with endometriosis or chronic pelvic inflammatory disease, or can be a result of other gynaecological problems and other causes which included irritable bowel syndrome, and chronic urinary tract infections (NHS 2016f).

#### 13.8.6 Vulvodynia and Vestibulitis

Vulvodynia and Vestibulitis cause chronic pain in the vulvar and on intercourse which are difficult to diagnose due to the often lack of specific external signs, but can have a significant impact on a woman's quality of life (Black et al. 2015; NHS 2016g).

## 13.8.7 Bacterial vaginosis and vulvo-vaginal candidiasis (Thrush)

Bacterial vaginosis (BV) is the most common form of microbiological syndromes in women of childbearing age (Verstraelen et al. 2010; Dirani et al. 2018). It is mostly caused by a disruption in the normal vaginal microbiota and though not seen as solely a sexually transmitted disease it is associated with sexual contact (Dirani et al. 2018). Lesbian and bisexual women are found to be at a greater risk, with estimates at 25-50% affected, most likely as a result of the sexual transfer of vaginal fluids (Marrazzo et al. 2005; Forcey et al. 2015; Vodstrcil et al. 2015; PHE 2018d). Bacterial vaginosis has been found to increase the risk of adverse pregnancy outcome, pelvic inflammatory disease (PID) and to an increase the risk of acquiring sexually transmitted infections (Dirani et al. 2018)

Vulvo-vaginal candidiasis, which is more often referred to as Thrush, is a common yeast infection of the vulva and vagina. It can be caused by having sex but again isn't classified as a sexually transmitted disease as it is carried by the majority of the population and only becomes problematic if other bacterial changes occur (i.e. through pregnancy, the menopause, or diabetes) (Lopez 2015).

Recurrent vulvo-vaginal candidiasis (RVVC) is when there are 4 of more episodes of infection in a year, which can cause significant discomfort and has a negative effect on the quality of life (Adolfsson et al. 2017).

# 14 Maternal health and motherhood

#### 14.1 Introduction

Each year in Leeds about 10,000 babies are born, for many women the birth will go well and the mother and family can move on, but for some women, the transition to motherhood can be very challenging, both physically and emotionally (Erskine 2014).

The Maternity Strategy for Leeds 2015-2020 (NHS 2015), recognises that for both the health of the mother and to give the child 'The best start in life' (PHE 2016b), there needs to be a concerted effort to reach out to all potential mothers (and fathers) to improve their health from pre-conception through to motherhood. This builds on the importance of the first 1001 critical days<sup>38</sup> of life – from conception to 2 years – where the child is undergoing its most important growing phase and getting it right here can have a lifetime of benefit for the child and even their offspring.

The Leeds strategy seeks to ensure that all women have personalised care and feel respected and supported. This is important as for many women and men, this is the most significant event in their life, and one where they can feel the most vulnerable.

The Leeds Women's Voices study (Thomas and Warwick-Booth 2018), suggests that some women felt the maternity service lacked an appreciation of the women's concerns:

"I understand they must see lots of... women coming and giving birth all the time but you have to treat people like they're human not like they're- on a conveyor belt of... birthing."

Leeds has set up a reference mechanism to get continuous feedback on their services through the Maternity Voices Partnership<sup>39</sup>. It's also important to note that the Care Quality Commission, which surveys users of services, found in their 2018 review of maternity services that Leeds Teaching Hospitals NHS Trust was doing better than expected as compared to other Trusts<sup>40</sup>

<sup>&</sup>lt;sup>38</sup> <u>https://www.1001criticaldays.co.uk</u>

<sup>&</sup>lt;sup>39</sup> https://www.mvpleeds.com

<sup>&</sup>lt;sup>40</sup> <u>https://www.cqc.org.uk/sites/default/files/20190129 mat18 outliers.pdf</u>

This section will outline the current health status of women with regard to their maternal health and the challenges they face.

#### 14.2 Pre-conception health

Pregnancy is one of the most physically and emotionally challenging times for the mother, bringing great anatomical and physiological changes. As the body adapts to cater for the developing embryo it requires substantial resources, which are best met in a healthy mother (and father).

A series of studies are reported in the Lancet on the importance of preconception health (Barker et al. 2018; Fleming et al. 2018; Stephenson et al. 2018). They report the significant negative consequences of poor maternal and paternal health on their offspring, with an increased risk of their children developing life-limiting and chronic ill-health. The health of the mother and father also has an impact on their grandchildren, as any health issues may be passed through to the eggs developing in the ovaries of their daughter as well.

The health of the father has been previously overlooked as a key factor in a healthy pregnancy, but it is now recognised as also being very important, to ensure their sperm is optimal. The most significant health risks occur when the mother or father are obese or underweight, has a poor diet that is low in macro and micronutrients, is a smoker, has a high alcohol intake or substance abuse (Dean et al. 2014; Lassi et al. 2014; King 2016; Hemsing et al. 2017).

Both the mother and the baby are also at increased risk if they have had a short period between pregnancies, such that postpartum family planning (PPFP), or the immediate implementation of contraception after delivery, is most important (RCOG 2015; FSRH 2017b). A study conducted in Edinburgh found that 1 in 13 women who required an abortion or were giving birth were doing so within one year of their previous pregnancy (Heller et al. 2016). The body needs time to recover from the stress of pregnancy and it is advisable to have a two-year gap. The important of PPFP is outlined by the RCOG (2015):

- PPFP can save mothers' lives family planning can prevent more than onethird of maternal deaths. PPFP can also save babies' lives – family planning can prevent 1 in 10 deaths among babies if couples space their pregnancies more than 2 years apart.
- Closely spaced pregnancies within the first-year postpartum increase the risks of preterm birth, low birthweight and small-for-gestational-age babies.
- The risk of child mortality is highest for very short birth-to-pregnancy intervals (i.e. less than 12 months).
- The timing of the return of fertility after childbirth is variable and unpredictable
   women can get pregnant before the return of menstruation.

In Leeds the teenage pregnancy midwives are pioneering the delivery of postnatal contraception based on the guidelines of the Faculty of Sexual and Reproductive Healthcare (FSRH 2017). The Leeds Sexual Health Service have also started doing in-reach clinics on the postnatal wards to improve rapid access to contraception post-natally. There are also plans in Leeds of a trial of offering coil insertion at elective caesarean section.

From a biological perspective the most critical time are the weeks around conception, which is the time the embryo is most sensitive to environmental factors such as the availability of a good diet, and the effect of smoking, alcohol, drugs and other teratogens (Stephenson et al., 2018). The 6 or more months prior to conception are therefore seen as an opportunity to make specific preparations for a pregnancy, such as losing (or gaining) weight, cutting back on alcohol, ceasing smoking etc. (for both the female and male). The benefits of having a longer-term public health perspective from adolescence onwards, is that healthy behaviours are in place prior to conception, even if pregnancy is not anticipated or planned for.

Younger women from the deprived areas of Leeds are more likely to be smokers at the point of conception and throughout their pregnancy (Erskine 2014). They also have a greater chance of being overweight at conception (25% with a BMI >30, compared to 20% in the not deprived areas), and underweight (4% BMI < 18.5, compared to 2.7% in the not deprived). This is important, as once the pregnancy has

started lifestyle interventions for obese women unfortunately have little effect on lowering the prevalence of gestational diabetes, or lowering the prevalence of caesarean delivery, large for gestational age fetus, or birth weight (Oteng-Ntim et al. 2015).

A study from America (Squiers et al. 2013) found that women who were planning a baby had a very different perception of pre-conception care than those who were not considering parenthood. They also found that the women saw it more as a way of creating a healthy baby, rather than avoiding an unhealthy birth outcome. They advocated a different approach to health promotion depending on segmenting the audience on their plans over the following 2 years using a social marketing approach. There is also a worry that trying to get all women (and men) to change their lives on the basis of a hypothetical baby that they may or may not want could be counter-productive for many and may increase intransigence to change (Thompson et al. 2017).

For those women who are planning a pregnancy there is greater receptivity to the need for health changes and it is a good opportunity for parents to be advised on delaying stopping contraception until health improvements have occurred.

There are studies underway to try and find the best approach to provide preconceptual care, including the mHealth programme 'Smarter Pregnancy' (van Dijk et al. 2017).

## 14.3 Pregnancy support

Across England there have been a recent decline in conception rates across all ages, except in the over 40's (ONS 2018I) (Figure 67). Across Leeds the rate of teenage conceptions was 28 per 1,000 women aged 15-17 years in March 2017, as compared to a national rate of 18.5 for England and 21.3 for Yorkshire and the Humber as a whole (ONS 2018m). The numbers of teenage pregnancies in Leeds have been falling, from 631 in 2000 to 330 in 2016.

The reasons for an increased number of women conceiving at ages 30 and over include increased participation in higher education, increased female participation in the labour force, increased importance of a career, the rising opportunity costs of childbearing, labour market uncertainty and housing factors (ONS 2018I).



Figure 67 Relative changes in age-specific conception rates, displaying change from a 1990 base through to 2016, England & Wales,

Booking in for antenatal services is an important opportunity to receive support and guidance for the pregnancy, safe delivery and care of the infant. Mothers in deprived areas of Leeds are less likely to attend clinic after 10 completed weeks since conception (with 76.4% of not deprived women attending within 10 weeks of conception, compared with 68.2% in deprived areas) (Figure 68). Although this has been improving, the gap between the deprived and those not deprived has stayed about the same.

There are important sex and gender differences between men and women with regard to substance abuse and response to treatment and rehabilitation (Greenfield et al. 2010; Becker et al. 2017). Women can find themselves addicted with lower levels of drugs taking and over a shorter time frame than when addiction occurs with men (Greenfield et al. 2010). Childhood adversity generally has more of an effect on

male vulnerability to substance abuse, but if that abuse is persistent and on-going then women's risk grows to surpass the levels of alcohol, drug and polysubstance abuse seen in men (Evans et al. 2017).



Figure 68 Percentage of mothers attending within 10 weeks of conception by deprivation status and year, Leeds

Underage pregnant girls are also in need of support:

'[teenage pregnancy] creates feelings of uncertainty and insecurity that generate anxiety, insomnia, intense feelings of ambivalence and confusion, as well as certain symptoms of depression, feelings of sadness, suicidal thoughts and irritability' (Trandafir et al. 2016).

Around 7 out of every 10 pregnant women will experience some form of sickness during their pregnancy, which usually passes at around the 14<sup>th</sup> week, however there are some that have continual sickness throughout their pregnancy. This is known as hyperemesis gravidarum and can result in hospitalisation and a very negative quality of life (NHS 2016h). It has been estimated to affect up to 1 in 100 women, and with 10,000 pregnancies a year in Leeds relates to 100 women across the City.

#### 14.4 Birth choices and support during labour

The National Maternity Review (National Maternity Review 2016) made a recommendation that all women should be given the choice as to what support they

needed during their birth and where they would prefer to give birth, based on a full discussion on the risks and benefits associated with each option. NICE, guidance for intrapartum care for healthy women and babies (NICE 2014) advocates:

- Advise low-risk multiparous women that planning to give birth at home or in a midwifery-led unit (freestanding or alongside) is particularly suitable for them because the rate of interventions is lower and the outcome for the baby is no different compared with an obstetric unit.
- Advise low-risk nulliparous women that planning to give birth in a midwiferyled unit (freestanding or alongside) is particularly suitable for them because the rate of interventions is lower and the outcome for the baby is no different compared with an obstetric unit. Explain that if they plan birth at home there is a small increase in the risk of an adverse outcome for the baby. (p5)

Voluntary Action Leeds (VAL 2018) undertook an engagement exercise to explore the influencing factors in regard to choice of birthplace and the perceptions of information preferences in regard to birthing choice. The study comprised a survey and interviews and their main findings were:

- Hospital birth was commonly framed as the default option for families, with some participants indicating that homebirth was not an option for them.
- Choice of birth place was perceived to be informed by a number of factors, with advice from medical professionals, advice from family members and peers, and past experiences the most often cited, however concerns about risk and safety appeared to underpin much of the discussion.
- Awareness of homebirth across the engagement was variable. There
  appeared to be inconsistent provision of information around homebirth, with
  some participants stating that they had received little or no information about
  homebirth from health professionals.
- 'Advice given by health care professionals' and 'positive or negative stories about types of birthing' were seen as key mechanisms for influencing opinion change.
- Groups with different cultural and religious backgrounds may present with additional information and support needs which need to be recognised.

The review of birthing choices in Leeds undertaken by Bennett (2017), found that Leeds was below the national average of homebirths, with 0.7% of all births in February 2017 and declining. Since that review there has been a communications campaign across Leeds to support home births alongside the development of a model of care to increase awareness of options<sup>41</sup>. There is also now a dedicated team 'Leeds Loves Homebirths' that are promoting the benefits of homebirths in Leeds and supporting those women who wish to make that choice<sup>42</sup>. This has resulted in a steady increase in homebirths to 3.1% in December 2018, with the aim of reaching 5% by the end of 2021.

## 14.5 Child removal into care

In 2014 there were 103 children under 1 year of age removed from their parental home into care, with Leeds having amongst the highest percentage of repeat care proceedings (national average 29%, Leeds 37%) (Leeds City Council 2017e). Since 2014 there has been a reduction in the number of babies taken into care, but this is still above the national average.

A study conducted at Lancaster University (Broadhurst et al. 2017) into vulnerable birth mothers found that there was a pattern of repeated care proceedings for some women. This has a profoundly negative effect on both the mother and the child, with the grief leading to mental health difficulties and a greater likelihood of further negative life events. In their study, many of the women were already very vulnerable, with 40% having been in care, often aged 10 years or older, and had experienced multiple placements. They were mostly under the age of 20 years, and the pregnancies were unplanned. These women have the most complex lives; the study found that that 66% of recurrent mothers had experienced neglect in their childhood,

<sup>&</sup>lt;sup>41</sup> http://www.leedsth.nhs.uk/a-z-of-services/leeds-maternity-care/what-we-do/care-during-your-birth/having-your-baby-at-home/

<sup>42</sup> https://www.facebook.com/leedsloveshomebirths/

67% emotional abuse, 52% physical abuse, and 53% sexual abuse, with an ACE<sup>43</sup> score of 4 or more.

The Department of Education independent evaluation (McCracken et al. 2017) into the services offered by Pause<sup>44</sup>, an organisation that works with vulnerable women at risk of having their children removed at birth, found good results, but the initiative has strict criteria to follow for women and families to be accepted onto the programme, including mandatory use of long-acting reversible contraception. In Leeds, a new service called 'Futures' is being developed to work with young women and men who have experienced the removal of a baby (Leeds City Council 2017e). This service is based on the Leeds Practice Model (Leeds City Council 2017f), and is focused onto providing intensive support to those most vulnerable. This initiative is closely linked with the Broadhurst study at Lancaster to help find the most effective way of helping vulnerable birth mothers.

## 14.6 Maternal death

A maternal death is defined internationally as a death of a woman during, or up to six weeks (42 days), after the end of pregnancy (whether the pregnancy ended by termination, miscarriage or a birth, or was an ectopic pregnancy) through causes associated with, or exacerbated by, pregnancy (World Health Organisation 2010). Across England the number of women who die during their pregnancy or as a result of childbirth has fallen over the decades, but still 42 women died in 2016 (ONS 2018h). Of the 973 maternal deaths in the UK that occurred between 2009 and 2013, over 90% occurred post-delivery (Davies 2015). In Leeds there were less than 5 deaths between 2013 and 2015, so thankfully it is rare, but devastating for all concerned (NHS Digital 2018e).

<sup>&</sup>lt;sup>43</sup> ACE - Adverse childhood experiences score is based on (a) physical abuse, (b) sexual abuse, (c) removal from a single-parent household, (d) exposure to community violence, (e) number of caregiver transitions, and (f) number of school transitions.

<sup>44</sup> https://www.pause.org.uk

Nationally two thirds of mothers died from medical and mental health problems in pregnancy and one third from direct complications of pregnancy such as bleeding. Three quarters of women who died had medical or mental health problems before they became pregnant. Women with pre-existing medical and mental health problems need pre-pregnancy advice and joint specialist and maternity care. Sepsis and the Flu are important causes of maternal death with the advice that the Flu vaccination can save the lives of both mother and child (Knight et al. 2014).

# 14.7 Miscarriage and stillbirth

Losing a baby<sup>45</sup> is both physically and emotionally traumatic and is a time of great need for the mother and her partner (Wonch Hill et al. 2017; Cullen et al. 2018). The wider family and friends can also be greatly affected by the loss (Murphy and Jones 2014). Helping the family through this difficult time is very important (Bakhbakhi et al. 2017).

Across England and Wales there were 3,112 stillbirths in 2016, with the numbers falling each year (ONS 2016f). In Leeds (Draper et al. 2018) there were 4.08 stillbirths per 1,000 births, 1.78 neonatal deaths per 1,000 live births and 5.85 deaths per 1,000 births in the extended perinatal period in 2016. In 2018, there were 122 deaths before 24 weeks, 41 later than 24 weeks, with 19 neonatal deaths.

When there has been a diagnosis of threatened miscarriage, there is an increased risk of antenatal depression in both the women and her partner (Zhu et al. 2018a), which can have an impact through into subsequent pregnancies and require additional monitoring and support (Lee et al. 2017).

Women who have had a miscarriage or stillbirth can have a range of after effects, including pain, bleeding, hormonal imbalances and psychological trauma (Cullen et al. 2018). Relationships can break down and longer-term mental ill-health can occur

<sup>&</sup>lt;sup>45</sup> Miscarriage is classed as a death before 24 weeks, after this time a death is classed as a stillbirth (delivered after 24 weeks, but showing no signs of life) or a neonatal death (NND) (born alive, but died before 28 completed days after birth) (Draper et al. 2018).

(Heazell et al. 2016; Murphy and Cacciatore 2017). Nationally there is an agreed pathway of support available for women and their partner who have experienced a miscarriage, stillbirth, neonatal death, or sudden infant death (NBCP 2018b). There is a multi-disciplinary multi-organisational group taking this work forward in Leeds.

Leeds has a specially designated Bereavement Midwife<sup>46</sup>, who can offer immediate and long term support to those affected by a miscarriage or stillbirth. The Maternity Strategy for Leeds also recognises that all staff should have training in the support of women experiencing a stillbirth or perinatal death (NHS 2015). In addition there is a bereavement support service for women from ethnic minorities provided by Haamla (Leeds Maternity Care 2018). In Leeds there is also the Stillbirth and Neonatal Death Society (SANDS) group that offers support to both parents (SANDS 2018), and a dedicated service offered by MindWell for parents who have lost a baby or young child<sup>47</sup>, which also lists other organisations offering support and guidance to those affected by miscarriage and stillbirth.

The bereavement project has recently had an engagement event to seek the views of all those involved in the support of women and their partners following a death (Butters 2018), with the feedback from the day being used to help develop the service.

It is worth noting that a baby's death after 24 weeks allows the parents to have maternity, paternity or shared parental leave and pay to help get over the loss, if the death occurs before the 24<sup>th</sup> week any time off is classed as sick leave. However, it is important that women know that sick leave for a miscarriage may be protected in the same way as sick leave for a pregnancy-related illness, such that you are not limited in how much you can take and it must be recorded as such and does not count towards your overall sickness record (Working Families 2017).

<sup>&</sup>lt;sup>46</sup> http://www.leedsth.nhs.uk/a-z-of-services/leeds-maternity-care/what-we-do/bereavement-support/ <sup>47</sup> https://www.mindwell-leeds.org.uk/myself/feeling-unwell/i-am-pregnant-or-a-new-parent/i-have-losta-baby-or-young-child

#### 14.8 Breastfeeding

It is internationally recognised that there is a benefit to breastfeeding, including better infant health, better long term maternal health (including increased protection against breast and ovarian cancer), and improved relationship building with the child (Victora et al. 2016; Unicef 2019). The WHO and UNICEF recommend<sup>48</sup>:

- Early initiation of breastfeeding within 1 hour of birth;
- Exclusive breastfeeding for the first 6 months of life; and
- Introduction of nutritionally-adequate and safe complementary (solid) foods at 6 months together with continued breastfeeding up to 2 years of age or beyond.<sup>49</sup>

Despite these advantages there is a recent acceptance by the Royal College of Midwives (RCM 2018) that 'the decision of whether or not to breastfeed is a woman's choice and must be respected'. Women who are not able to breastfeed can experience higher levels of stress and anxiety and face unhelpful stigma (Fallon et al. 2018; Símonardóttir and Gíslason 2018). UNICEF offer guidance on how best to promote and deliver responsive bottle feeding, and set out the importance of this approach if bottle-feeding is chosen as a method in terms of attachment and infant mental health<sup>50</sup>.

Across Leeds 73% of new mothers initiate breast feeding but this depends on locality, with this dropping to 65.5% in the more deprived areas of the city (the lowest rates of initiation of 40.6% within White British mothers) and rising to 86.2% in the most affluent areas of the city. (The same is seen for maintenance of breast feeding<sup>51</sup>, which stands at 48.5% across the city and below 40% in the deprived areas in the first quarter of 2018, as compared to over 60% in the not deprived areas -only 19.1% of White British mothers from the most deprived areas are still

 <sup>&</sup>lt;sup>48</sup> <u>https://www.who.int/en/news-room/fact-sheets/detail/infant-and-young-child-feeding</u>
 <sup>49</sup> There is a useful video relating to this at: https://www.unicef.org.uk/babyfriendly/about/call-to-action/

 $<sup>^{50}\</sup> https://www.unicef.org.uk/babyfriendly/wp-content/uploads/sites/2/2018/02/Infant-formula-and-responsive-bottle-feeding.pdf$ 

<sup>&</sup>lt;sup>51</sup> Which is defined as still breast feeding at 6 to 8 weeks

breastfeeding at this time point (Figure 69), which is a pattern reflected nationally (Simpson et al. 2019).



#### Figure 69 Breast Feeding at 6 to 8 week check, 2016/17 (White British), by deprivation

Women's Health Matters in Leeds ran a study exploring young, white, working-class mothers views on breastfeeding (WHM 2010). The study found that they needed targeted personal support to help them both initiate breastfeeding and also to continue. They found issues relating to the women's confidence in asking for information and support, and their ability to understand current advice and guidance.

The Leeds Breastfeeding Plan 2016-2021 (Best Start Strategy Group 2016) recognises the importance of breast feeding, and there has been a national push for mothers to breast feed. The intention is to support mothers and fathers, such that breast feeding can be initiated and continued, with a reduction in the gap between the deprived and non-deprived areas of Leeds for breast feeding rates. This plan is seeing an increase in the number of businesses and venues across Leeds signing up to be Breastfeeding friendly<sup>52</sup>, with support for breast feeding mothers to return to work.

<sup>&</sup>lt;sup>52</sup> https://familyinformation.leeds.gov.uk/professionals/breastfeeding-friendly

Leeds runs a breast feeding peer support service, which operates to give local women a forum for meeting other mothers who are breastfeeding (Leeds City Council and NHS Leeds 2018). These run in different localities across the city and on different days, so support is available all week if needed.

A trial, conducted in Sheffield and surrounding areas, of giving breastfeeding mothers vouchers was found to be successful in motivating those mothers who wished to breast feed until 6 months. For those mothers who were not in favour of breastfeeding the initiative did not increase up-take. There was, however a feeling amongst the women that this scheme could raise awareness of breastfeeding and encourage its normalisation (Johnson et al. 2018).

# 14.9 Long term physical effects of pregnancy and childbirth

Pregnancy and childbirth can exert a significant toll on a woman's body, which can affect their health and wellbeing well after the child has grown up. This was raised in the Women's Voices study (Thomas and Warwick-Booth 2018):

"I had three kids you know I- my anatomy is not what it was before I had them, and I- it's only when you- only maybe takes one or two women, to start speaking openly about, what's going on down there, you know for other people to go "oh actually you know for ten years I've had this but I didn't wanna mention it..."

Many of the problem's women experience post pregnancy, including prolapse and incontinence can be reduced through greater pelvic floor education, including support for exercises and a more proactive approach to protecting the pelvic floor during the birth. The Leeds Teaching Hospitals have an aim to reduce Obstetric Anal Sphincter Injuries (OASI) by 50% within one year through ensuring all practitioners have undertaken the PEACHES<sup>53</sup> and episiotomy training and there is an ambition

<sup>&</sup>lt;sup>53</sup> PEACHES: Position (birthing position can have an impact on stress to the perineum) Extra midwife (present at birth), Assess the perineum (throughout), Communication Hands-on technique, Episiotomy if required, Slowly

within the NHS long-term plan to improve access to postnatal physiotherapy, which should contribute to improved care in this area. The Women's Institute (TheWI 2018) is campaigning to ensure women have greater awareness of what is normal and what can be improved through treatment and access to specialist practitioners.

In Leeds there is campaign being launched soon in relation to pelvic floor exercises and healthy food and nutrition during pregnancy in Leeds in conjunction with 'Best Beginnings'<sup>54</sup>, which also links to the Baby Buddy App and Express Magazine<sup>55</sup>.

## 14.9.1 Haemorrhoids, anal fissures and constipation

It Is estimated that 2/3<sup>rds</sup> of pregnant women will have some form of anal symptoms during their pregnancy and as a result of childbirth, including haemorrhoids, anal fissures and constipation. They are a common cause of pain and discomfort during pregnancy, and for some women they do not resolve so can be a continuing case of distress (Poskus et al. 2014; Åhlund et al. 2018; Ferdinande et al. 2018). There is a national organisation (MASIC<sup>56</sup>) now working to reduce damage to the anal sphincter and to support affected women.

#### 14.9.2 Urinary and bowel leakage / incontinence

It is estimated over 5 million women over the age of 20 years are affected by stress urinary incontinence, overactivity of the bladder (+/- urgency urinary incontinence) or voiding dysfunction with resultant overflow incontinence, mostly as a result of childbirth (Davies 2015).

#### 14.9.3 Pelvic organ prolapse

Pelvic organ prolapse is the downward descent of the female pelvic organs (vagina, uterus, bladder, and/or rectum) into or through the vagina, and is thought to affect about one in 12 women living in the UK (Barber 2016). Although this is mostly as a

<sup>&</sup>lt;sup>54</sup> https://www.bestbeginnings.org.uk/news/embedding-with-leeds-maternity-care

<sup>55</sup> https://familyinformation.leeds.gov.uk/families/baby-buddy

<sup>56</sup> https://masic.org.uk/
result of pregnancy the effects are often not seen until after the menopause and can often occur alongside other pelvic floor problems such as incontinence.

"Prolapse and incontinence affect women's sex lives and relationships and cost the health service and individuals millions of pounds each year in pads, catheters, medication and other treatments ... This is morbidity, not mortality, but the number of women affected is enormous. Because these subjects are still taboo, greater public awareness is needed to empower women to access self-help resources and treatment pathways" (p15) (Davies 2015)

There is currently an investigation into the use of a surgical mesh that has been widely used as a treatment for incontinence and prolapse of the uterus. The mesh has been found to cause excruciating pain and long term health problems and has been the cause of fatalities as a result of sepsis. It is estimated that over 100,000 women have had the mesh fitted, with around 10% very badly affected. This has been debated in Parliament (House of Commons 2018) and there is now a suspension of its routine use. It is not known how many women are affected in Leeds.

The preferred approach to management is through a better awareness of pelvic floor strengthening before pregnancy and pelvic floor muscle training both during and after pregnancy, which has a positive effect on all pelvic floor conditions (Moossdorff-Steinhauser et al. 2015; Barber 2016; Hagen et al. 2017).

### 14.10 Perinatal mental health

During pregnancy and in the first year after birth, women can experience a range of mental health problems. These problems are collectively termed 'perinatal mental illnesses', and are estimated to affect between 10 - 20% of all women in the perinatal period (Hogg, 2013).

It is estimated that nationally, perinatal depression, anxiety and psychosis cost £8.1 billion for each one year cohort of births – with nearly 72% of this cost related to the

adverse impact upon the child (Bauer et al. 2014). Perinatal mental illness remains a significant cause of maternal death (Draper et al. 2018). Perinatal mental illness can also have important and far-reaching affects on babies and children, with the causal pathways that lead to poor outcomes not straightforward, involving both direct and indirect factors (Hogg, 2013).

Whilst there has been a significant focus upon post-natal depression, there is increasing recognition that the whole of the perinatal period is a time during which women may experience a range of mental health disorders. Rates of anxiety disorders in the postpartum period have been shown to be at least as prevalent as depression (Hogg 2013; Fairbrother et al. 2016). There is also a risk of post-traumatic stress disorder in women (and men) associated with birth, especially if the birth has been traumatic (James 2015; Zerach and Magal 2017). However, in practice, the range and prevalence of anxiety disorders (including generalised anxiety disorder, obsessive-compulsive disorder, panic disorder, phobias, post-traumatic stress disorder and social anxiety disorder) and depression are under-recognised throughout pregnancy and the postnatal period, with many women and men not receiving treatment (NICE, 2014).

Risk factors for antenatal anxiety and depression include: a lack of partner or of social support; history of abuse or of domestic violence; personal history of mental illness; un-planned or unwanted pregnancy; adverse events in life and high perceived stress, present/past-pregnancy complications and pregnancy loss (Biaggi et al. 2016).

Risks of both ante and postnatal depression are higher in women who are obese (Steinig et al. 2017), in younger women (Reid and Meadows-Oliver 2007; Hogg 2013), in women who have pre-existing mental health disorders such as bipolar disorder, and in those who have experienced a previous perinatal psychosis or postpartum depressive episode (Di Florio et al. 2018). Postnatal depression in particular has been shown to have far-reaching and long lasting effects on both mothers and their children (Myers and Johns 2018) Men are now recognised as 'at risk' of postnatal depression (Smith et al. 2013; Tuszyńska-Bogucka and Nawra 2014; Edward et al. 2015; Zerach and Magal 2017). This has implications not only for men, but for women and families. Men and same sex partners are vital to the wellbeing of mothers in the perinatal period-functioning as both protective and risk factors for maternal and infant wellbeing (Biaggi et al. 2016).

There are a wide range of interventions that are designed to reduce the risk or impact of perinatal mental illness. These include peer support, community-based interventions, talking therapies (such as those provided by IAPT) and intensive psychiatric/psychological treatment delivered both in the community and via inpatient settings by perinatal mental health services and Mother and Baby Units.

NICE guidance recommends screening for current and previous mental health disorders at the first maternity booking appointment (NICE, 2014). For treatment of anxiety and depression NICE recommends facilitated self-help or talking therapies. Cognitive Behavioural Therapy has the strongest evidence base for the prevention and treatment of mild perinatal anxiety and depression (Easter et al. 2015). However, web-based interventions show promise in reducing depressive symptoms (Lee et al. 2016) and Mindfulness Based Interventions (MBI) have been shown to lead to significant reductions in perinatal anxiety, and moderate, if less consistent efficacy in reducing depressive symptoms in the perinatal period (Shi and MacBeth 2017).

For women with more serious or complex mental health disorders, intensive, structured psychological therapy (including talking therapies) is recommended, alongside management with medications (NICE, 2014).

Community based and/or peer interventions can also provide significant support for women and families. A randomised control trial of offering lay support to women with a social risk of poor psychological health through pregnancy (Kenyon et al. 2016b), found that in women with two or more risk factors their mental health was significantly better than the control. It also resulted in improved mother-to-infant bonding.

Public Health England(PHE 2018e) has produced the following estimates of numbers of women in Leeds who may experience different types of mental health disorders in the perinatal period, over the course of one year (Table 9). The analysis applies population estimates of mental health disorders to the local birth rate in Leeds. Women may have more than one illness, so may be counted twice.

TH OD IN IN						(0040)
Table 9 Public Health	England Perinata	i Mental Health	Population	Estimates:	Leeds	(2016)

Estimated number of women with postpartum psychosis		
Estimated number of women with chronic SMI		
Estimated number of women with severe depressive illness	290	
Estimated number of women with mild-moderate depressive illness and anxiety (lower estimate)	955	
Estimated number of women with mild-moderate depressive illness and anxiety (upper estimate)	1,430	
Estimated number of women with PTSD	290	
Estimated number of women with adjustment disorders and distress (lower estimate)		
Estimated number of women with adjustment disorders and distress (upper estimate)		

It is possible that these nationally derived estimates for perinatal mental ill health underestimate levels of need in Leeds as they are not adjusted for deprivation (Erskine 2017).

Local and national data regarding mental health service use and perinatal mental health is limited. In part, this is due to the fact that within IAPT, there is no current national mandate to record whether a woman is pregnant or is accessing the service in the 12 months postpartum. Recording in Primary Care records is also inconsistent. Work is ongoing to 'link up' the national mental health service data set (which records acute care episodes) and the maternity data set.

### 14.11 Maternal and child nutrition

Having the right nutrition before and through pregnancy and during early life can have a marked impact on the health and wellbeing of both mother and child.

The Leeds Maternal and Child Nutrition Health Needs Assessment (Moores 2016) notes that there has been a general trend in healthier diets and more awareness of the need for supplements for women before and during pregnancy. However, it also recognises that some groups of women are still at risk of low intakes of the micronutrients necessary for a healthy baby. It is mostly young mothers that are most at risk of having diets below the recommended intakes of iron, fibre, oily fish, red meats, folic acid, calcium, Vitamins A and D and higher than recommended intakes of sugar, fat and alcohol.

Those women of childbearing age who are an unhealthy weight (both underweight and overweight) were found to be at risk of having below recommended intakes of dietary fibre, oily fish, fruit and vegetables, low level supplement use of folic acid and Vitamin D.

The health needs assessment calls for a greater role out of the Health Eating Nutrition for the Really Young (HENRY) training programme to all those groups and individuals who work with vulnerable families to help improve early life development. This is being offered in Leeds as part of Public Health priority based training<sup>57</sup>.

A study on infant feeding in the Gypsy and Traveller community in Bristol (Condon and Salmon 2015) found that it was important to work carefully with the community to ensure culturally sensitive health promotion was provided. In Leeds, Haamla (Leeds Maternity Care 2018) provides a weekly drop-in clinic at the Cottingley Springs site and there is a specialist maternity pathway for Gypsy and Traveller women (Erskine 2014).

<sup>&</sup>lt;sup>57</sup> https://www.leeds.gov.uk/phrc/public-health-training/public-health-priority-based-training

## 15 Violence and abuse against women

### 15.1 Introduction

"Violence against women and girls is one of the most wide-spread and devastating human rights violations across the globe. It takes place every day regardless of social background, whether at home, at work, at school, in the street, playing sports or online." P36 (European Commission 2018)

The extent of violence and abuse against women<sup>58</sup> requires all services in Leeds to be sensitive to the possibility that they are working with a victim. The Leeds Women's Voices study (Thomas and Warwick-Booth 2018) that was conducted in conjunction with this report identified domestic violence as a significant factor in the lives of women in Leeds.

As is often the case, the most vulnerable experience the most risk, and those with multiple disadvantage are more likely to face more extreme domestic violence and to have experienced sexual and physical abuse (McNeish and Scott 2014; Scott and Mcmanus 2016). However, the recent #MeToo movement<sup>59</sup> has highlighted that sexual exploitation of women exists in all walks of life. That it has affected internationally recognised women through to the weakest, demonstrates the extent of the challenges still facing women in contemporary society.

The experiences some women and girls who are now living in Leeds have faced are horrifying (Whitehouse 2017). Such victims may have arrived in Leeds as a refugee from a war zone, or from a country that has failed to protect those at risk. Often these women feel powerless to seek justice, are embarrassed or fearful of reaching out to services, and need careful support and guidance.

<sup>&</sup>lt;sup>58</sup> Doing full justice to issue of violence and abuse against women is beyond the scope of this report a separate study on the safety of women in Leeds is being conducted by Women's Lives Leeds over 2019/2020.

<sup>59</sup> https://metoomvmt.org

The UN Declaration on the Elimination of Violence against Women (DEVAW) defines gender based violence as:

"Any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivations of liberty, whether occurring in public or in private life." (Article 1) The declaration encompasses all forms of gender-based violence against women (physical, sexual and psychological), no matter in which context or setting they occur:

- in the family (such as battery, marital rape; sexual abuse of female children; dowry-related violence; female genital mutilation/cutting and other traditional practices harmful to women);
- *in the general community (such as rape, sexual harassment and intimidation at work, in school and elsewhere; trafficking in women; and forced prostitution), and*
- violence perpetrated or condoned by the state, wherever it occurs (Article 2)."

It is also important to recognise that violence against women can also be by other women, either through the intimate partner violence within same-sex couples, bullying, or the support of FGM and forced marriage.

Across Leeds in 2018, there were 2,204 serious sexual offences, and 485 other sexual offences, of which there were 954 sexual assaults and 953 rapes, with the majority having a female victim (Table 10)<sup>60</sup>. These are reported crimes, and in addition it must be noted that there are a significant number of women who do not feel able to come forward to the authorities when they have been a victim. It has been estimated that only about 15% of those who have experienced sexual violence report it to the police (MoJ 2013) and when asked why they hadn't, the Ministry of Justice review notes women's responses included: "… that it was 'embarrassing', they 'didn't think the police could do much to help', that the incident was 'too trivial or not worth reporting', or that they saw it as a 'private/family matter and not police

<sup>&</sup>lt;sup>60</sup> Crime data for 2018 is provisional information provided by West Yorkshire Police to Safer Leeds as statutory duty for a community safety partnership.

business'" (p17). This suggests that many women do not feel they will get the appropriate support.

	Female	Male
Sexual assault (aged 13 years and over)	679	117
Sexual assault (under 13 years)	120	38
Rape (aged 16 years and over)	615	53
Rape (under 16 years)	130	8
Rape (under 13 years)	113	34

Table 10 Reported sexual assaults and rape, Leeds, 2018

There is also an issue of whether the crime will be recorded. A report by Her Majesty's Inspector of Constabulary found that under-recording rates for sexual offences nationally stood at 26%, and even when crimes are correctly recorded, too many are removed or cancelled for no good reason (HMIC 2014).

There are many victims of violence that have never personally been abused but have lived a life in fear. This can emerge as a reluctance to go out in the evening, taking a taxi, being anxious when alone with an employer or client, and unwillingness to open the door to strangers, with younger women being most affected (FRA 2014). This can have a negative effect on women's freedom of movement and can impact on their work and social life.

At the Leeds Centenary Event to celebrate the 100 years since the suffrage won the vote for women, table discussions were held to identify the key issues facing the women of Leeds. One issue that came up was the anxiety caused by the lack of female drivers for taxis and a call for all taxi drivers to be given more training on gender and disability.

#### Case study 9 Donna

"I thought after leaving my ex life could move on, but I was wrong! The more I tried to separate from him, the more controlling he became. After visiting my GP for anxiety, I received information about Behind Closed Doors, and everything started to change.

I found their Prevention and Recovery Service (PARS) so easy to access, which was integral in enabling me to make the first step. Any more difficult to access, I might have been too scared, talking myself out of getting support.

For years I had maintained a strong 'I'm okay' mask. Now it was okay to not be okay and I was able to release my emotions in a safe space. Eventually, I trusted my worker enough to open up to her about things I hadn't told anyone, because she gave me the time and space I needed.

My worker helped me take control of my anxiety; admit and start to finally understand the abuse I had suffered for 11 years, giving me the tools to identify the cycle of abuse, so I could predict future behaviour of my ex.

My children are now happy and flourishing at school. In the last year I have finished my qualification and obtaining a promotion; more than I could have dreamt of achieving whilst in my abusive relationship. Without BCD, I think I would have given into the pressure to go back to my ex due to self-doubt, fear and confusion.

BCD have changed my life, saying thank you will never be enough"

<sup>1</sup> name changed

The Hazlehurst Centre Sexual Assault Referral Centre (SARC)<sup>61</sup> is part of Mountain Healthcare and serves West Yorkshire to support victims of sexual assault. In 2016-2017, 1,381 clients were referred to their service from across the region with 92% female, 7% male and 1% where gender was not known or transgender (Mountain Healthcare 2018), with the majority of those referred being White British and referrals on the increase.

There are other organisations supporting victims within Leeds. Support after Rape and Sexual Violence Leeds (SARSVL)<sup>62</sup>, offers counselling, advocacy and a helpline

<sup>&</sup>lt;sup>61</sup> https://www.hazlehurstcentre.org/

<sup>&</sup>lt;sup>62</sup> http://supportafterrapeleeds.org.uk

for those affected. The Women's Counselling and Therapy Service<sup>63</sup>, (established in 1982) offers free or low-cost support for women on low income; 52% of their clients have experienced child sexual abuse (CSA), 47% have experienced sexual assault / rape as an adult, and 72% experienced CSA and/or sexual violence as an adult.

### 15.2 Child sexual exploitation and abuse

The level of child sexual exploitation (CSE) is not known, but it is possible that 11,777 girls may have experienced sexual abuse in the city (see Section 11.5). Sexual exploitation of children is recognised as a serious crime and one that is feared to be on the increase. Certain groups of children are seen to be at particular risk, including children with learning difficulties or disabilities, looked after children, care leavers, migrant children, unaccompanied asylum-seeking children, homeless children, and children who run away from home and care and/or are missing from education (Leeds City Council 2017g).

The sexual abuse of girls and boys leaves a lifelong legacy of damage that can impact on both their mental and physical health and their ability to form relationships. Unlike sexual exploitation, this can occur in every home and for many remains hidden due to the controlling nature of many of the perpetrators.

The Leeds Safeguarding Children Partnership (Leeds Safeguarding Children Partnership 2017) is working with agencies across the city to provide a comprehensive range of statutory and third sector interventions to help protect children at risk. Nearly half the users of the Support after Rape and Sexual Violence Leeds (SARSVL)<sup>64</sup> service are victims of child sexual abuse. Basis Yorkshire<sup>65</sup>, is a charity working with children and young people who have been sexually exploited in Leeds, it originated as Genesis Leeds, which was set up in 1989.

<sup>63</sup> https://www.womenstherapyleeds.org.uk

<sup>64</sup> http://supportafterrapeleeds.org.uk

<sup>65</sup> https://basisyorkshire.org.uk

### Case study 10 Sarah

Sarah<sup>1</sup> was referred to Basis when she was 15 years old. Sarah was going missing for periods of time and reported excess use of drugs and alcohol, had made friends with young people from a local residential care home and was becoming increasingly known to the police due to Anti-Social Behaviour reports; she was not attending the Alternative Education Provision she was enrolled at. Initially, Sarah had sporadic engagement with Basis and was struggling to understand risk; however, the worker was persistent and support continued, including a referral for support from Forward Leeds to address drug and alcohol use. Sarah was also diagnosed with PTSD as a result from witnessing domestic abuse as a child. She had recently begun living with her mother again after over ten years being in the care of her father, which had resulted in a fragile relationship.

After the residential care home associated with Sarah's risk was shut down, she became more engaged although she was still going missing and accepting drugs and alcohol from older males and expressed that *"she wouldn't learn unless something really bad happened"*. Nonetheless she did enrol in the entry level course at College with support from Basis after a few months. Basis then also facilitated a meeting with a woman who Basis had previously supported and who had been exploited for many years as a child including into adulthood, so Sarah could hear first-hand the potential outcome of long term exploitation.

This meeting gave her a very different experience of risk and since then she has made changes in her peer group, her drug and alcohol abuse has reduced and she is being supported by CAMHS. She has been spending more time at home, has an improving relationship with her mother and receives glowing reports from College. Sarah is now at low risk of sexual exploitation and has joined our Lionesses group (peer support group for young people with similar experiences).

<sup>1</sup>Name changed

### 15.3 Domestic violence

The Home Office (2013) defines domestic violence and abuse as any incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members, regardless of gender or sexuality. This can encompass, but is not limited to, the following types of abuse:

- Psychological.
- Physical.
- Sexual.

- Financial.
- Emotional.

On International Women's Day 2018, the Prime Minister Theresa May (Prime Ministers Office 2018) outlined plans for an overhaul of the domestic abuse legislation in the UK. The new Bill will provide a new statutory definition of domestic abuse that includes economic abuse and other non-physical abuse, as well as making sentences tougher when children are involved. They are also planning to increase support for victims of abuse.

It is hard to determine the exact extent of domestic violence within society, as much remains hidden within the home, but It has been estimated that 1 in 4 women will experience domestic violence in their lifetime (ONS 2016g). According to the West Yorkshire Police Performance Unit, there were 20,434 domestic incidents in Leeds during 2017/2018, of which 18,770 had a victim identified;

- 77% of incident victims were female, 21% were male.
- 32% of incident victims were aged between 20 and 29 years, 26% were aged between 30 and 39 years, 17% were aged between 40 and 49 years (these were the greatest proportion age groups).
- 37% of incident victims were defined as 'White', 3% were defined as 'Asian', 3% were defined as 'Black', 56% 'Not Stated' or 'Unknown'.

Of the 21,830 where a suspect was identified

• 26% of incident suspects were female, 74% were male.

Crime survey data (ONS 2016g) tends to show that both men and women who were separated and in lone parent households were more at risk, as were those with low - educational status and those with long term illness or disability.

The term 'intimate partner violence' (IPV) is being used more widely as it reflects the view that violence does not only occur within a marital relationship where the husband is the abuser and the wife was the victim; violence can occur in any type of

personal intimate relationship (Ali et al. 2016). The effect of IPV on the victim can result in physical harm and severe psychological distress and ill-health, with long term consequences (Matheson et al. 2015; Ali et al. 2016; Hamberger et al. 2017; Pickover et al. 2017).

There is an assumption that domestic violence is mostly an issue relating to men and women within a heterosexual relationship, but studies and the available data suggest that intimate partner violence is also prevalent within homosexual couples. With similar types of abuse taking place in both heterosexual and homosexual relationships and many missing out on support due to lack of recognition of the problem (Blosnich and Bossarte 2009; Frankland and Brown 2014; Lewis et al. 2015; Reuter et al. 2016; Register 2018; Rollè et al. 2018).

Women with learning disabilities have marked difficulties in dealing with domestic violence as they may not be aware of the support that is available, and seeking refuge may be very problematic (McCarthy et al. 2017). Nevertheless, it is also important that they are recognised as being autonomous agents and should be supported to make their own decisions (Dixon and Robb 2016).

The Leeds Domestic Violence Service (LDVS 2018) comprises a consortium arrangement, bringing together all those working to help prevent domestic violence occurring and supporting those affected. The Best Council Plan 2018/19 – 2020/21 includes "*tackling and working to prevent risks, threats and harms, including domestic violence*". Progress will be measured by the number of "*Increased self-reporting of domestic violence and abuse incidents*."

### 15.4 Bullying

Bullying has always been an issue within the school years, with girls more likely to be the victims of indirect bullying (such as verbal bullying), as compared to boys who tend to suffer more physical bullying. Most often it is girls bullying other girls, and has complex causes, both for those bullied and those doing the bullying, often tied up with gendered identities and power imbalances (Forsberg 2017). With the advent of social media, this has created another level of potential victimisation – cyberbullying. The rise in social media has enabled the bully to enter into victims' homes and can create an ongoing attack on a young girl's identity and feelings of self-worth, and in extreme cases, can lead to suicide. Girls who more intensively searched for and had contact with strangers while online, were more strongly involved in cyberbullying, both as perpetrators and as victims, with girls starting to use cyberbullying earlier as an advanced aggressive social tactic to position themselves within their peer group (Festl and Quandt 2016).

Girls are now also involved in sexting – the sending of sexually explicit photos and videos, which can lead to further risks of cyberbullying (Ybarra and Mitchell 2014; Cooper et al. 2016; Sullivan 2016; Wilkinson et al. 2016; Van Ouytsel et al. 2017).

The negative effects of social media are not always the result of bullying, with negative comparisons with the lives of others leading to potential increased body dissatisfaction and distorted body image (Fardouly et al. 2015; Fardouly and Vartanian 2016; Burnette et al. 2017). This is also being found in girls who access pornography, resulting in sexual uncertainty, sexual preoccupation, the sexual objectification of women and the likelihood of early sexual activity (Koletić 2017).

The power of social media to influence young girls is further demonstrated by the role it plays in their emotional development, with immediate positive feedback on comments or photos being seen as key indicators of worth and the formation of identity and their perceptions of self (Ging and O'Higgins Norman 2016; Jong and Drummond 2016).

### 15.5 Female Genital Mutilation

Female genital mutilation (FGM) is mostly carried out on girls aged from infancy to 15 years, with the majority between the ages of 5 and 8 years. Unlike male circumcision (which can reduce HIV risk in vulnerable populations and may be necessary for other medical reasons) there are no medical reasons for FGM and is a criminal offence, identified as child abuse and a form of violence against women and girls (HM Government 2016).

Thankfully there is a global reduction in FGM (Kandala et al. 2018), nevertheless it is estimated that there are 137,000 women living in England and Wales aged 15-49 that may have been affected by female genital mutilation (FGM), with urban areas having the highest proportion of women from countries where FGM is still practiced (Macfarlane and Dorkenoo 2015).

Within Leeds it is calculated that there are 1,787 women with FGM, of which 197 are aged 0-14, 1,461 aged 15-49 years, and 130 aged over 50 years. There are more at risk, with 5,260 women born in FGM practicing countries and permanently resident in Leeds in 2011 (Macfarlane and Dorkenoo 2015). The hidden nature of this practice was seen as a concern in the Women's Voices study (Thomas and Warwick-Booth 2018).

A report by the Black Health Initiative (BHI) in Leeds North East area in 2015 recognised that Leeds, Bradford and Sheffield were major dispersal centres for asylum seekers, many of which are fleeing FGM and other forms of violence (Garrod 2015). The report identifies good practice within Leeds to support female victims of FGM, especially through Haamla (Leeds Maternity Care 2018), but warn of the complex physical and emotional health problems these women face and the need for greater cultural competence and training in FGM.

### 15.6 Forced marriage

Forced marriage (FM) is recognised as a form of domestic / child abuse and a serious abuse of human rights (Home Office 2013b). Although arranged marriages are a custom in some cultures, when the women or man is forced (including emotional coercion) into marriage, either in the UK or through being tricked into an overseas visit, then it has moved from being voluntary into a form of abuse. In a study of British Asian youths it was found that women tended to be more compliant regarding their parent's wishes as compared to the men, who were motivated by a

sense of pride and masculinity, but both could be the victims of emotional blackmail (Gill and Harvey 2017). Both males and females suffer as a consequence of FM, but women and girls often facing disproportionate harm, impacting on their life chances, including access to education, employment, and financial and personal autonomy.

Across the UK there were 1,196 cases (930 females [77.8%] and 256 males [21.4%]) reported to the Forced Marriage Unit (Home Office 2018b), with 152 being in Yorkshire and The Humber. The victims are most often from the Pakistan community (36.7%) followed by Bangladeshi (10.8%), Somalian (7.6%) and Indian communities (6.9%). Of those reported cases, 1.8% of the victims identified themselves as lesbian, gay, bisexual or transgender and 12.1% had a learning disability (female 47.2%, male 52.8%).

# 16 Concluding thoughts

The lives of women have changed considerably since the success of the suffrage movement 100 years ago. There is high level representation of women in the city council and health sector, with female leads for the Health and Wellbeing Board (Cllr Charlwood), and the leader of the council (Cllr Blake), with Paula Dillon the first female President of the Leeds Chamber of Commerce and the election of Rachel Reeves MP (only the second women to represent a Leeds constituency). Despite these advances there still exists marked gender inequalities that seep into nearly all aspects of women's lives.

Women are now protected through the Equality Act (Equality Act 2010) in a way that the sex-discrimination laws could not. There is now a legal responsibility of statutory bodies and employers etc. to prevent inequality from policy level through to women's (and men's) experiences on a day-by-day basis. Despite this protection, some women find they are still not paid the same as men for the same work or can find themselves penalised for pregnancy or for taking career breaks for children.

In the same way, what emerges time and time again from the studies and the articles relating to women and their health is the difficulty they have in getting their problems recognised as serious, and getting early help and attention (APPG 2017; Kiesel 2017). Many of the health challenges women face are uniquely female biological disorders/conditions that women often struggle to have acknowledged/diagnosed. What came out of the Leeds Women's Voices study (Thomas and Warwick-Booth 2018) was the need for women to feel listened to and for their perspective to be taken into consideration when services are planned and delivered.

"Listening to women and what they have to say first and foremost"

In part, this requires greater responsibility within the statutory bodies to treat women with more respect and to be more sensitive to the challenges they are facing, with regard to both their health and social wellbeing. We need to be faster at recognising when problems exist and striving to have a more responsive health service – as seen in the development of the menopause pathway and the new complex pelvic pain pathway. We also have to be careful that the city gives space for women's

needs to be met. An anxiety from one of the stakeholder interviews was that with the push for gender neutral commissioning, it may have left more women vulnerable through the loss of female-focused services.

For services to be effective, they need to ensure that they are targeting the right group in the right way. This depends on the prior knowledge of the risk the women face, as well as the values, attitudes and beliefs that can impact on the likelihood of engagement (Zainuddin et al. 2011; Kippen et al. 2017). It must also recognise the wider implications, as well as the practical limitations of what is being asked, including aspects of financial cost, the safety implications, the preferred place of any proposed health intervention and any sensitivities, such as whether a female only staff is required. To this end, stakeholders must be engaged in the process of service development (Buyucek et al. 2016).

Services also need to be more focused onto specific groups to help facilitate engagement as it is seen as personal and meaningful. Greater attention should be given to girls and young women, with more youth work. It's also especially important for those women who normally feel excluded from mainstream provision, including BME women, sex working women, lesbians, trans women, women from the gypsy and traveller community and women with disabilities. More services should be focused onto clustered care when supporting women with long term chronic health problems or those with complex needs. This is especially the case for women who have multiple morbidities at an earlier age.

There is an important group of women that need specific attention - these are young women with multiple social needs, who are in the transition between childhood services and adult services. It is in this period that many find their lives becoming more complex with the higher risk of unwanted pregnancy, removal of children, addiction and a greater risk of domestic violence. By breaking the cycle, it may lead to an overall healthier population in years to come and save these women and their children from much hardship and sadness.

The Leeds inclusive Growth Strategy (Leeds City Council 2018d) recognises the importance of Leeds as a city, both in the UK and internationally, but it also

acknowledges the challenges faced by such a diverse metropolis. Having a large proportion of the population living in deprived circumstances requires dedicated support through local initiatives working within communities. Leeds benefits greatly from having a thriving and very effective Third Sector, with committed workers providing much needed succour to those most in need. However, what is also needed from the Inclusive Growth strategy is the macro level of regeneration, where we see greater investment into providing work and opportunities for women to enable them to move out of poverty into a more positive future.

What is emerging from across the globe is that the more gender equal societies become, the healthier it is for both women and men. This is reflected in personal wellbeing, the education and happiness of children and improved productivity. What is significant is that most men's health organisations recognise the importance of tackling the 'restrictive societal norms of manhood' (Ragonese et al. 2018) that create so many problems for men and for women and the need to engage men in gender equality (Scambor et al. 2013, 2014). This requires a concerted effort for the whole population and each sector of provision, including the schools and the judiciary, to enable the kind of social re-engineering needed to foster change in attitudes, values and beliefs.

In a similar way we need to be striving to support women to have a more positive perspective on themselves and their role in the city. In a study of a deprived community in Sheffield (Peacock 2012), the women felt shame that they were not able to provide for their family and experienced a lot of negative social comparison. This was compounded by self-criticism, blaming themselves for the position they were in and not seeking help, rather than seeing themselves as being in impossible situations, where dependency should not be seen as a sign of failure.

Funding was raised as a specific issue within the Women's Voices study (Thomas and Warwick-Booth 2018), with an anxiety voiced that insufficient resources were being made available for meeting women's specific needs or were being limited to the most extreme cases.

"Where you're talking about domestic violence when you're talking about sex it feels... where you're talking about rape where you're talking about things like that, again thinking you know the gender specific areas are very, very important, you kind of support - and the peer support, that we've just talked about. And, when I've been to meetings with groups like that we talked about underfunding, again... they've talked about cuts again, they've talked about the fact that they feel, that they're the last priority not the first ..." P22

The 11 women centre partners delivering Women's Lives Leeds<sup>66</sup>, the Women and Girls Hub, Getaway girls<sup>67</sup>, Women Friendly Leeds<sup>68</sup> and the Black Health Initiative<sup>69</sup> amongst others are doing ground breaking work in reaching into vulnerable communities of women to enable growth and development. This work needs to be supported, but also their knowledge and experience has to act as a catalyst for other organisations to recognise their role in promoting the health of women across the city.

The important work undertaken by the council on men's health within Leeds (White et al. 2016a, b), coupled with the gender focused Director of Public Health report (Cameron 2018), these current reports on women's health (Thomas and Warwick-Booth 2018; Seims and White 2019) and the promise of a report on Trans health, demonstrates that Leeds is striving to be an inclusive city that recognises the importance of gender in health and wellbeing. With Leeds having almost the same pattern of social and cultural diversity as England as a whole, this study creates the opportunity for Leeds not only to change the lives of our population, but also to be a role model for other cities across the country, and also internationally.

<sup>66</sup> https://www.womenslivesleeds.org.uk

<sup>67</sup> https://getawaygirls.co.uk

<sup>68</sup> https://www.facebook.com/womenfriendlyleeds

<sup>69</sup> http://www.blackhealthinitiative.org

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