

# Campaigns for 2024

## *Forward Planning*

# Background

Healthwatch Lincolnshire has strategically chosen to prioritise **menstrual health, respiratory conditions, neurological conditions,** and **mental health** in its upcoming 12-month focus.

This decision is driven by a commitment to amplify the voices of individuals and communities that are often underrepresented or unheard in healthcare discussions.

By addressing these specific themes, Healthwatch Lincolnshire aims to broaden its engagement across diverse areas and populations, fostering a more inclusive dialogue on health issues.

Moreover, this targeted approach aligns with the organisation's overarching goal of addressing health inequalities, allowing them to proactively contribute to a more equitable and comprehensive healthcare landscape in Lincolnshire.

This approach will also allow us to reach diverse population groups as outlined in our Annual Plan, hearing the voices of Health and Social Care Staff, those with physical and/or sensory impairment, young people, Veterans and those impacted by social isolation and digital exclusion.

# Overview

## RESPIRATORY

- Asthma (All)
- COPD (LW&AW)

## FEEDBACK TOPICS

## MENSTRUAL HEALTH

- Endometriosis & PCOS (SW&LW)
- Menopause (LW)

## NEUROLOGICAL

- Fibromyalgia (All)
- MS (All)
- ME (All)
- Migraines (All)

### KEY

- SW = Start well 0 - 19
- LW = Live well 20 - 64
- AW = Age well 65 and over
- All

## MENTAL HEALTH

- New fathers (SW&LW)
- Military personnel/veterans (All)
- Farmers (All)

# Menstrual Health

**Main conditions:** Endometriosis, Polycystic Ovary Syndrome (PCOS) and Menopause.

**Timings:** Jan – Mar 24

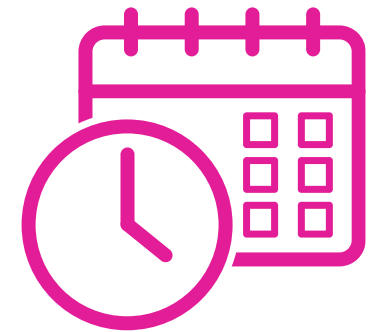
## *Why focus on menstrual health?*

As part of the Government's Women Health Strategy, each ICB will have a Women's Health Hub. One aim and hope is that these hubs will improve diagnosis times, treatment and support for a range of conditions including Endometriosis, PCOS and the Menopause.<sup>1</sup> However, currently, little is known about the experiences of those in Lincolnshire who have or are going through these conditions.

## **Endometriosis**

1 in 10 women have endometriosis. This is the same as number of people who have diabetes. Symptoms of endometriosis include chronic pain, fatigue, depression and fertility problems. There is currently no cure and on average women have to wait 7.5 years to be diagnosed.<sup>2</sup>

Endometriosis costs the UK economy £8.2 billion a year in treatment, loss of work and healthcare costs.<sup>2</sup> NHS Lincolnshire ICB is one of only seven ICB's to not to have an accredited Endometriosis Centre.<sup>3</sup>

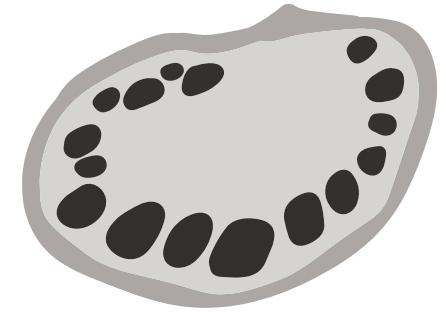


**It takes 7.5 years on average to be diagnoses with endometriosis <sup>2</sup>**

## Why focus on menstrual health?

### Polycystic Ovary Syndrome (PCOS)

Around 1 in 8 women have PCOS, but 70% are undiagnosed. It is the single most common cause of infertility. Those with PCOS have a higher risk of cardiovascular disease, hypertension, diabetes, depression and anxiety. They are also at higher risk of pregnancy complications and endometrial cancer. There is no cure. <sup>4</sup>



### Menopause

Menopause is when periods stop. It usually affects women aged 45 to 55 but can happen after certain surgeries or cancer treatments too. Perimenopause refers to when you have symptoms of menopause, but your periods have not stopped. Symptoms can have a huge impact on daily life and include mood swings, brain fog, hot flushes, and joint and muscle stiffness. 8 out of 10 experience some symptoms, for around 4 years after the last period. <sup>5</sup> Indeed, 1 in 10 women working during their menopause have left their job due to symptoms. <sup>6</sup>

The main medication used to help menopause symptoms is hormone replacement therapy (HRT). <sup>7</sup> A study by the Fawcett Society highlighted, only 4 in 10 are offered HRT in a timely fashion. Nationally and locally there have been shortages of HRT. <sup>8</sup>

# Respiratory Conditions

**Main conditions:** Asthma and Chronic Obstructive Pulmonary Disease (COPD).

**Timings:** Apr – Jun 24

## *Why focus on respiratory conditions?*

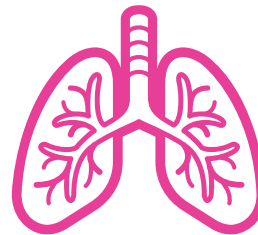
In Lincolnshire, Asthma and COPD are one of the top causes of years lived with disability for children & young people and those aged 65 and over, respectively. Both conditions are key areas of interest in the Lincolnshire Joint Strategic Needs Assessment (JSNA).<sup>9</sup>

The Asthma + Lung UK as part of the Taskforce for Lung Health produced a summary document outlining respiratory health in Lincolnshire. In 21/22, according to the quality and outcomes framework (QOF) in Lincolnshire: <sup>10</sup>



**7.3%**  
of those aged 6+  
have Asthma

*England average = 6.5%*

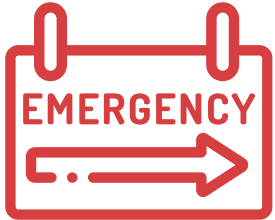


**2.3%**  
have COPD\*

*England average = 1.9%*

*\*This number is likely to be higher.*

## Why focus on respiratory conditions? Continued.



In 2020/21, there were **5,695 emergency admissions** for respiratory conditions. [10](#)



In August 2022, **3,841** people were on a waiting list for respiratory care. This figure is **1.7x higher than the average for England.** [10](#)



Also, in June 2022 there were 1,070 doctors in Trusts in **Lincolnshire**. Out of those, there were **3.0 respiratory specialists per 100,000** people, **compared to 5.0 per 100,000 across England.** [10](#)

# Neurological Conditions

**Main conditions:** Fibromyalgia, Multiple Sclerosis (MS), Myalgic Encephalomyelitis (ME), Migraines.

**Timings:** Jul – Sep 24

## *Why focus on neurological conditions?*

Neurological conditions are a key priority in the Lincolnshire JSNA. Headache disorders are one of the top causes of years lived with disability for children & young people and those aged 20 – 64 in Lincolnshire. [11](#)

Before the introduction of the Integrated Care System (ICS) earlier this year, NHS Lincolnshire asked Healthwatch Lincolnshire to conduct a survey to explore people's views about health and care services. Within this work were especially keen to hear from people who had fibromyalgia, MS and ME.

Overall, the feedback provided about services/support for these conditions in Lincolnshire was poor. Concerns were raised around access to services, quality of care and not being taken seriously (especially by those with fibromyalgia and ME). For many with these conditions this survey was the first time they had been asked for their thoughts on services.





## Why focus on neurological conditions?

### Fibromyalgia

Fibromyalgia affects about 2.5 million people in the UK and the condition can have a huge impact on daily life. <sup>12</sup> Symptoms can include widespread pain, stiffness, fatigue, poor sleep and 'fibro-fog'. There is no cure and symptom management focuses on non-drug treatments. <sup>13</sup>

Research shows that healthcare professionals do not always follow treatment guidance and people with fibromyalgia report being unhappy with the care they receive. <sup>14</sup> Via our ICS survey, we also have evidence of this in Lincolnshire.

### Multiple sclerosis (MS)

Multiple sclerosis (MS) is the most common (non-traumatic) cause of neurological disability in people under 40. Roughly, 100,000 people in the UK have MS. <sup>15</sup> It can lead to a range of issues such as fatigue, spasticity, tremor, pain, mental health, mobility and visual problems. There is no cure. <sup>16</sup>

As part of the ICS survey, 45 people with MS shared their views. They highlighted mixed experiences of care in Lincolnshire with many having to receive care outside of the county.



**2.5 million people  
had fibromyalgia in  
the UK <sup>12</sup>**



**100,000 people in the  
UK have MS <sup>15</sup>**

## Why focus on neurological conditions?

### Myalgic Encephalomyelitis (ME)

Myalgic Encephalomyelitis (ME) affects about 250,000 people in the UK. It can cause flu-like symptoms, sleep difficulties and profound tiredness. It can be a mild illness or severely disabling, leaving people housebound. As it is similar to other conditions, the journey to an ME diagnosis can be long. There is no cure and treatment needs to be highly personalised. <sup>17</sup>

As part of the ICS survey, 117 people with ME shared their views of services in Lincolnshire. They too highlighted not being taken seriously, unempathetic healthcare professionals and a lack of care and support.

### Migraines

Headaches are one symptom of migraines along with feeling sick, dizziness and sensitivity to light, sounds and smells. <sup>18</sup> Roughly, 10 million people live with migraines in the UK, making them more common than diabetes, asthma and epilepsy combined. The information on how children are affected is limited, despite migraines being the third leading cause of years lived in ill health in the UK. <sup>19</sup>

3 million workdays are lost every year due to migraines, costing £4.4 billion. Headaches are one of the most common reasons for A&E attendance. <sup>20</sup>



**250,000 have ME in the UK** <sup>17</sup>



**10 million have migraines in the UK** <sup>19</sup>

# Mental Health

**Focus groups:** New Fathers, Military Personnel/Veterans and Farmers.

**Timings:** Oct – Dec 24

## *Why focus on mental health for these groups?*

### **New fathers**

Maternal Mental Health is a focus of many national and local strategies including the NHS Lincolnshire Joint Forward Plan, Better Lives Lincolnshire and the JSNA for the county. [21](#), [22](#), [23](#)  
However, new fathers are not often included.

An evidence review by Bringing Baby Home, revealed a "dad-shaped hole" in perinatal NHS Services. [24](#) **1 in 10** men experience anxiety and depression in the first six months after birth. Studies have also shown that fathers with mental health problems during the perinatal period are up to **47 times** more likely to be classed as a suicide risk than at any other time in their lives. [25](#)



# Why focus on mental health for these groups?

## Military Personnel/Veterans

The 2021 census highlighted there were **44,811** veterans **living in Lincolnshire** with **22% living in North Kesteven**.<sup>26</sup> 38% of veterans nationally have/had a code on their medical record for a common mental health disorder. The conditions were in order of prevalence depression (18%), alcohol misuse (17%), anxiety (15%), PTSD (3%) and dementia (2%).<sup>27</sup> In 21/22 1 in 8 UK Armed Forces were seen in military healthcare for a mental health-related reason.<sup>28</sup>



## Farmers

The Lincolnshire farming industry produces 1/8 of the UK's food, generating over £2 billion in crops and livestock. 30% of the UK's food passes through south Lincolnshire which dispatches over 1,000 of lorry loads of food daily. The industry supports 56,000 people in agriculture, processing, marketing and logistics.<sup>29</sup>

The Farm Safety Foundation revealed “**92% of UK farmers under the age of 40 rank poor mental health as the biggest hidden problem facing farmers today**”.<sup>30</sup> 44 suicides were registered in England and Wales in 2020 for those working in farming. Farming is associated with poor sleep, work-life balance, physical and mental health. It is also affected by traumatic events: extreme weather, epidemics, crime and subsequent financial damages. Furthermore, mental health is often still a topic surrounded by stigma in this community.<sup>31</sup>

# What will we do with the experiences shared?

We act as a critical partner to health and care service providers and commissioners across Lincolnshire, using what people have told us as the basis for this relationship.

We want the views and experiences of local people to shape the services they provide and influence the decisions they make.

To do this, we analyse what local people are telling us to identify trends and issues. We then talk to commissioners and service providers about what is working well and what could be improved.

Our unique powers under the Health and Social Care Act 2012 mean we are involved in decision-making, and commissioners and service providers should listen to what we say. We have a seat on the Lincolnshire Health and Wellbeing Board and are involved in various other local health and care boards and working groups so that people's views can influence the work of these groups.

We will continue to champion the meaningful involvement of users and carers in the design, delivery and decision-making of health and care services and will encourage providers to use co-production approaches to design and develop their services. The introduction of the Lincolnshire Integrated Care System will result in significant changes to how the NHS is managed. We will continue to play an active role in this to ensure service users' voices are heard at all levels of NHS decision-making.

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