

LONDON BOROUGH OF CAMDEN	WARDS: All
REPORT TITLE Living With Endometriosis in Camden 2024	
REPORT OF Director and Projects Lead of Healthwatch Camden	
FOR SUBMISSION TO Health and Adult Social Care Scrutiny Committee	DATE: 16 th December 2024
SUMMARY OF REPORT Healthwatch Camden (HWC) have produced a report which provides a snapshot of the health impact of a condition called endometriosis on women and young girls. Endometriosis is a chronic inflammatory disease related to a woman’s reproductive and menstrual health. HWC coproduced their research and findings through a series of in-depth one-to-one interviews with 16 women, all of whom were either diagnosed or were currently obtaining a diagnosis of endometriosis from their health providers. This report includes personal lived experiences of endometriosis and the services that support women’s health in Camden. The report is summarised with a set of recommendations aimed at existing services as well as outlining the urgent need for additional provisions which HWC would like the committee to consider for endorsement and action. NB: For the purpose of this report, the term ‘Woman’ is used throughout to refer to anyone assigned female at birth (AFAB), i.e., people who menstruate of average menstruating age (12-49 years old), girls of pre-menstrual age, and women post menopause age. Local Government Act 1972 – Access to Information No documents that require listing have been used in the preparation of this report. Contact Officer: Stephen Heard 85-87 Bayham Street Camden, London NW1 0AG Stephen.heard@healthwatchcamden.co.uk 020 7383 2402	
RECOMMENDATIONS	

That the Committee note the contents of the report which can be found in Appendix A and agree to revisit women's health at a future meeting.

Signed:



Stephen Heard, Director Healthwatch Camden

Date:28/11/24

1. Purpose of Report

- 1.1. This report is presented at the request of Healthwatch Camden to inform the board of Healthwatch Camden's recent work with female sufferers of endometriosis. Healthwatch Camden aims to share their multi-agency, collaborative approach to tackling health inequalities in the female population of Camden, and how the findings can be best addressed to the board. The full report is attached as Appendix A.
- 1.2. Healthwatch Camden aims to highlight the consequence of gender-based health inequalities playing a significant role in endometriosis patients having extremely poor physical, mental, social and economic health outcomes.
- 1.3. This report comes at a time of increasing focus on the health and wellbeing of women, especially in relation to their gynaecological health. A recent report¹ by the Royal College of Obstetricians and Gynaecologists has revealed over three quarters of a million women in the UK currently waiting for months and years with serious gynaecological conditions. Healthwatch Camden hopes that by highlighting the patient voices in their report, it will provide further insight into the devastating impact of these long waiting lists on quality of life beyond health outcomes.
- 1.4. Healthwatch Camden would like the committee to support the recommendations in the report which outline amendments or additions to services that can greatly improve endometriosis care and outcomes in Camden.

2. Report Background

- 2.1. Healthwatch Camden conducted 16 deep dive one-to-one interviews with 16 women in Camden, to explore their experience of living with endometriosis and its impact on the quality of their lives. Through this report, HWC set out to understand women's perceptions around their own health and wellbeing, their perceptions of the gaps in current provisions, and their outlook on health inequalities as well as on measures to reduce it in the borough.
- 2.2. Endometriosis² is a debilitating disease affecting 1 in 10 women in the UK. That's over 1.5 million women living with this condition, a similar number to

those affected by diabetes. Despite being a serious chronic disease, it takes an average of 8 years 10 months from the first GP visit to get a diagnosis. It costs the UK economy £8.2bn a year in treatment, loss of work and healthcare costs.

2.3. The impact of improving endometriosis care for women in Camden cuts across all aspects of public health, for e.g., improved health outcomes, mental health support for women and girls, supporting women to obtain and remain in meaningful employment, reduced burden on primary care repeat appointments and A&E emergency admissions as a result of continuous care pathways, healthy outcomes for children and direct family members, social cohesion and participation in community. Healthwatch Camden's report highlights changes which can be implemented locally alongside national strategies in order to increase awareness of endometriosis, reduce diagnosis times, improve the management of symptoms in a holistic manner, and ultimately reduce health inequalities for women in Camden.

2.4. Key findings from women's feedback in the Healthwatch Camden report:

- Gaslighting and dismissal of their condition by health providers, family and people around them made women feel extremely isolated and unsupported in their endometriosis journey. Experiencing this from an early age led to normalisation of their own pain and subsequent poor health-seeking behaviour which worsened outcomes. Pain-related stigma and cultural perceptions around menstruation played a huge role in women's pain being ignored, which in turn caused women to harbour widespread mistrust and lack of confidence in the health system not just for endometriosis but for all other health conditions. The feeling of being 'second class citizens' was echoed in the women's experiences of the lack of care pathways, referrals, research, and holistic support for endometriosis.
- The impact of endometriosis on women's physical, mental and socio-economic health is unacknowledged by current care models in Camden and beyond. Anxiety and depression are highly common symptoms as well as consequences of living with the condition without any support, causing women to exhibit low self-esteem, isolation and withdrawal from society. Intense feelings of loneliness expressed by the women caused psychological strain not only on themselves but also on their partners and family members, and women described a non-existent social life as a result. The negative impact of the condition on women's ability to obtain, maintain, or develop in a job has direct implications on the NHS and the wider economy, as demonstrated by the recent NHS confederation report³.
- There is a lack of awareness about endometriosis among young girls, members of the public, and medical professionals, which makes it more difficult for endometriosis related pain to be recognised and taken seriously by the health system. The Endometriosis UK inquiry in 2020 found that women from global majority communities experience additional complexities and barriers to accessing menstrual health support. This is reflected in the disparity in care and understanding women experience during their

interactions with health professionals. Women described doctors not believing them, misdiagnosing them with other common conditions, and not referring them on to specialist gynaecology until they went into A&E with complications from the condition. Opportunities for improving menstrual health education in schools is crucial since this condition has a negative impact on the education and attainment of young girls, and improved awareness can lead to better outcomes at a young age.

- The need for holistic treatment pathways, especially the establishment of a local support group for this condition, aligns with the growing recognition of the importance of addressing women's health issues holistically and informatively. Ineffective pain management strategies, lack of compassionate communication, and disparate healthcare provisions exacerbate the immense physical and psychosocial toll of this condition.

2.5. Healthwatch Camden's recommendations for endometriosis care in Camden:

- Establishment of a women's health hub by the North Central London Integrated Care Board.
- Formation of a women's health steering group or forum in Camden. Set-up local endometriosis support session with support and leadership by this steering group.
- Increase public awareness campaigns to destigmatise conversations surrounding menstrual health, and to promote health literacy and self-advocacy skills for women.
- Improve menstrual health education and support in schools.
- Improve diagnosis of endometriosis locally by establishing clear guidelines for primary care to recognise and escalate care.
- Establish continuous care pathways and initiate greater coordination between health partners in the borough to develop endometriosis care models that encompass primary care, sexual health, gynaecology, mental health, nutrition, physiotherapy, as well as alternative pain-management therapies.
- Improve management of symptoms through expanded access to treatments so that they can be made universally accessible.
- Enhance training for healthcare professionals to include more compassionate and empathetic care around women's health, integrating lived experiences.
- Publish a women's health strategy for Camden and conduct further research locally on health outcomes for endometriosis and related conditions.

3. Finance Comments of the Executive Director Corporate Services

- 3.1. The Executive Director of Corporate Services has been consulted on the contents of the report and has no comments to add to the report.

4. Legal Comments of the Borough Solicitor

- 4.1. Under the Local Authority (Public Health, health and Wellbeing Boards and Health Scrutiny) Regulations 2013 a Local Authority may review and scrutinise any matter relating to the planning, provision and operation of the health services in its area. The Local Authority must invite interested parties to comment and take account of relevant information provided by Healthwatch.

5. Environmental Implications

- 5.1. There are not identified environmental implications related to this report.

6. Appendices

Appendix A: Full report with Healthwatch Camden recommendations

REPORT ENDS