

**WELCOME TO OUR WEBINAR SERIES:**  
Exploring learnings from MNSI safety investigations

We will be starting shortly

*WELCOME*

# Sudden Unexplained Death in Epilepsy (SUDEP)

*Wednesday 29 January, 2025*



**Dr Louise Page**  
*MNSI*



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*Imperial College Healthcare  
NHS Trust*



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*West Middlesex  
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Hospital NHS Foundation Trust*



**Dr Emily Barrow**  
*ST7 Obstetrics  
& Gynaecology*

# Housekeeping

- *We welcome your questions, please put these in the Q&A box, not the chat*
- *Please use the chat box to engage in the webinar and with one another*
- *Your sound and video will not be visible during the webinar*
- *The session is being recorded and will be sent a short while after the session*
- *If you want to discuss anything further, please email [enquires@mnsi.org.uk](mailto:enquires@mnsi.org.uk)*
- *The chat is moderated, please use kind and respectful language*
- *We will share slides, resources and a recording after the session*

# MNSI overview

## Purpose

- *To provide independent, standardised and family focused investigations of maternity patient safety events*
- *To provide learning to the healthcare system via reports at local, regional and national level*
- *To analyse data to identify key trends and provide system wide learning; be a system expert in standards for maternity safety investigations and to collaborate with system partners to escalate safety concerns*
- *MNSI focus on systems and processes that impacted on care, we do apportion blame or liability*

**HSIB maternity  
investigation  
programme**

**Started 2018**

**Ended 30 Sept 2023**

**Maternity and Newborn  
Safety Investigations  
(MNSI) programme**

**Born 1 October 2023**

# MNSI investigation criteria

- *Babies*
  - *Term, following labour*
  - *Intrapartum stillbirth*
  - *Early neonatal death*
  - *Severe brain injury*
- *Maternal deaths*
  - *During pregnancy or up to 42 days from the end of a pregnancy*
  - *Direct & indirect deaths*
  - *Excludes accidental, homicide and suicide*

[The Care Quality Commission \(Maternity and Newborn Safety Investigation Programme\) Directions 2023 \(publishing.service.gov.uk\)](https://publishing.service.gov.uk)

# Maternity referrals: summary

01 April 2018 – 31 December 2024

Programme to date  
01 Apr 2018 – 31 Dec 2024



Referrals  
submitted

Rejected

Progressed to  
investigation

Investigations  
completed  
In period

Year to date  
01 Apr 2024 – 31 Dec 2024



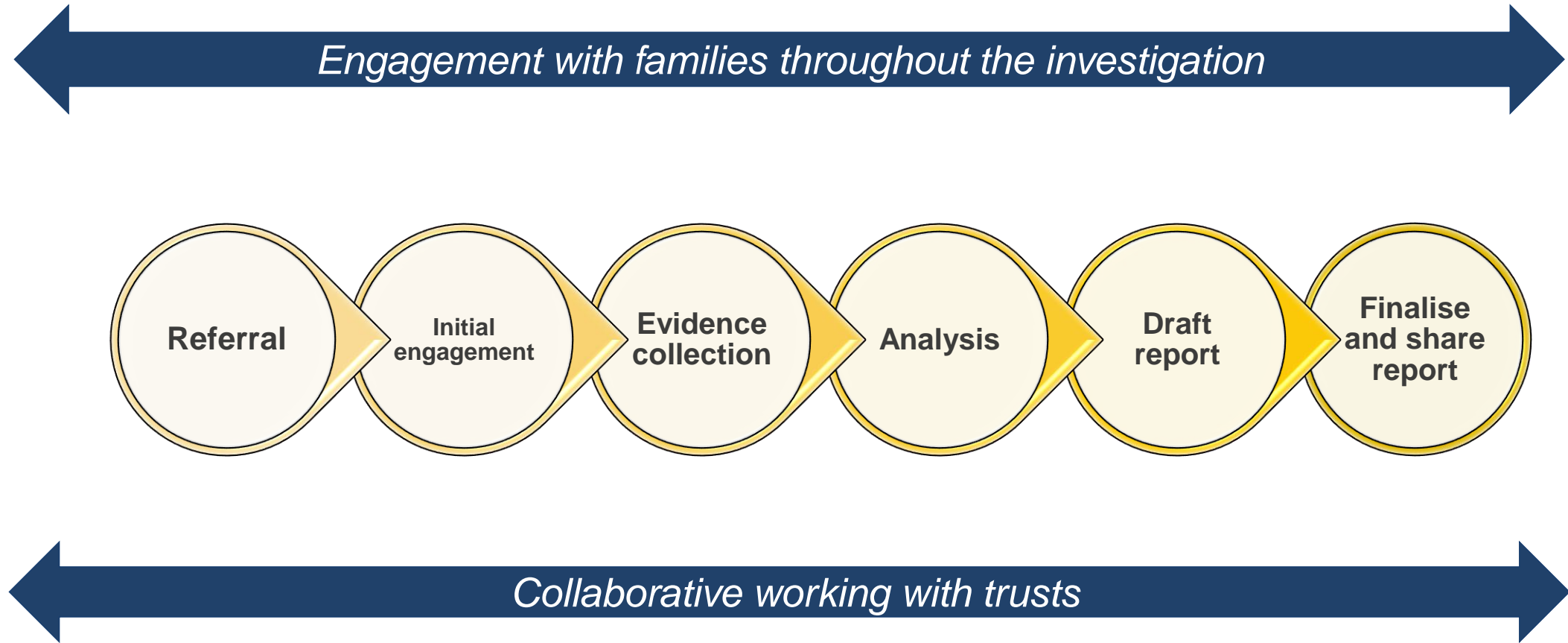
Referrals  
submitted

Rejected

Progressed  
to  
Investigation

Investigations  
completed  
in period

# Maternity investigation approach



*Dr Emily Barrow*





# Learning from maternal Sudden Unexpected Death in Epilepsy (SUDEP): Thematic analysis of safety investigations in England

Barrow E, Frise C, Biswas C, Hawes K, MacLennan K,  
McIntyre G, Palmer K, Perkins S, Page L.

# Background – SUDEP

- *Sudden, unexpected death of someone with epilepsy*
- *No other cause found*
- *>1/1000*
- *Leading cause of death in people with uncontrolled seizures*

**We need to talk about SUDEP**

**Act on:**



Night-time seizures



Uncontrolled seizures



Ineffective treatment

# Background – SUDEP and Pregnancy

**Key messages**  
from the report 2020

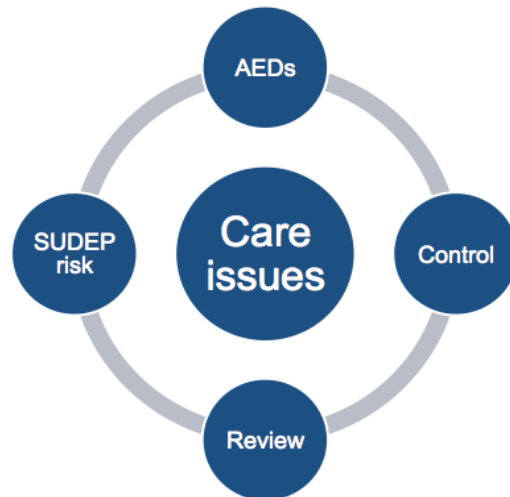


**Key messages**

**Epilepsy and pregnancy: we need to talk about SUDEP and epilepsy risk**

- *22 women died from causes related to epilepsy*
- *18 women died from SUDEP*

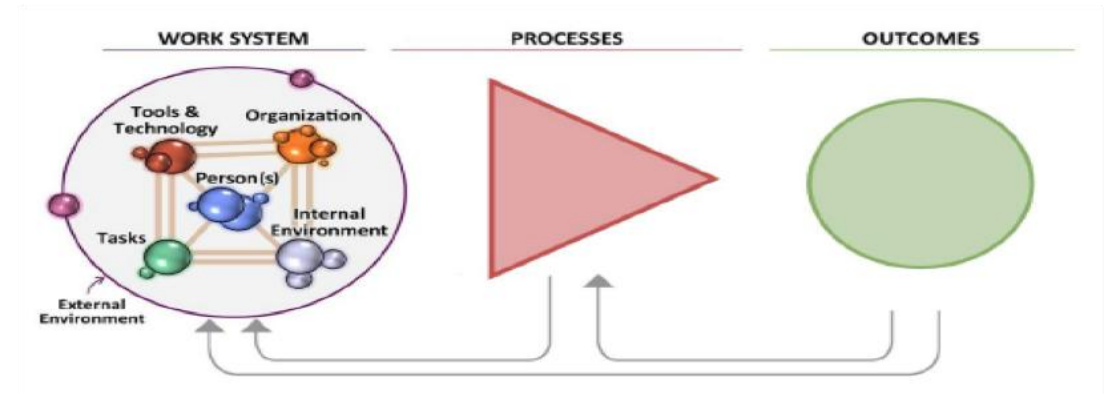
- *SUDEP awareness and risk assessment*
- *Clear standards of care for joint maternity and neurology services*



**We reviewed MNSI-investigated maternal deaths from SUDEP, using a systems-focus, with the aim to add to existing recommendations from MBRRACE-UK.**

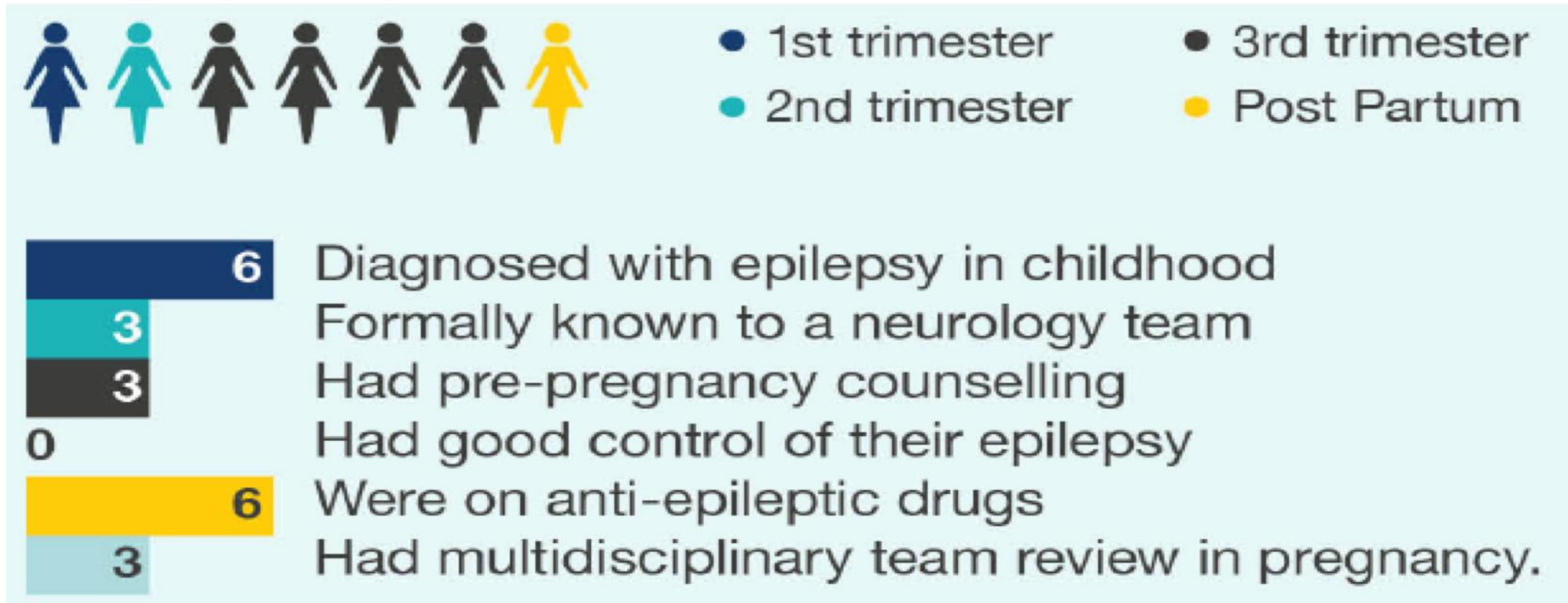
# Method

- *8 investigations into maternal deaths from SUDEP between 2020 and 2023*
  - *1 excluded*
- *Deductive, systems-focussed thematic analysis*



Holden, RJ et al. (2013)

# Results





**Delivery of  
individualised specialist  
multidisciplinary care**



**Communication across  
multiple providers**



**Communication with  
healthcare professions**

# Theme 1

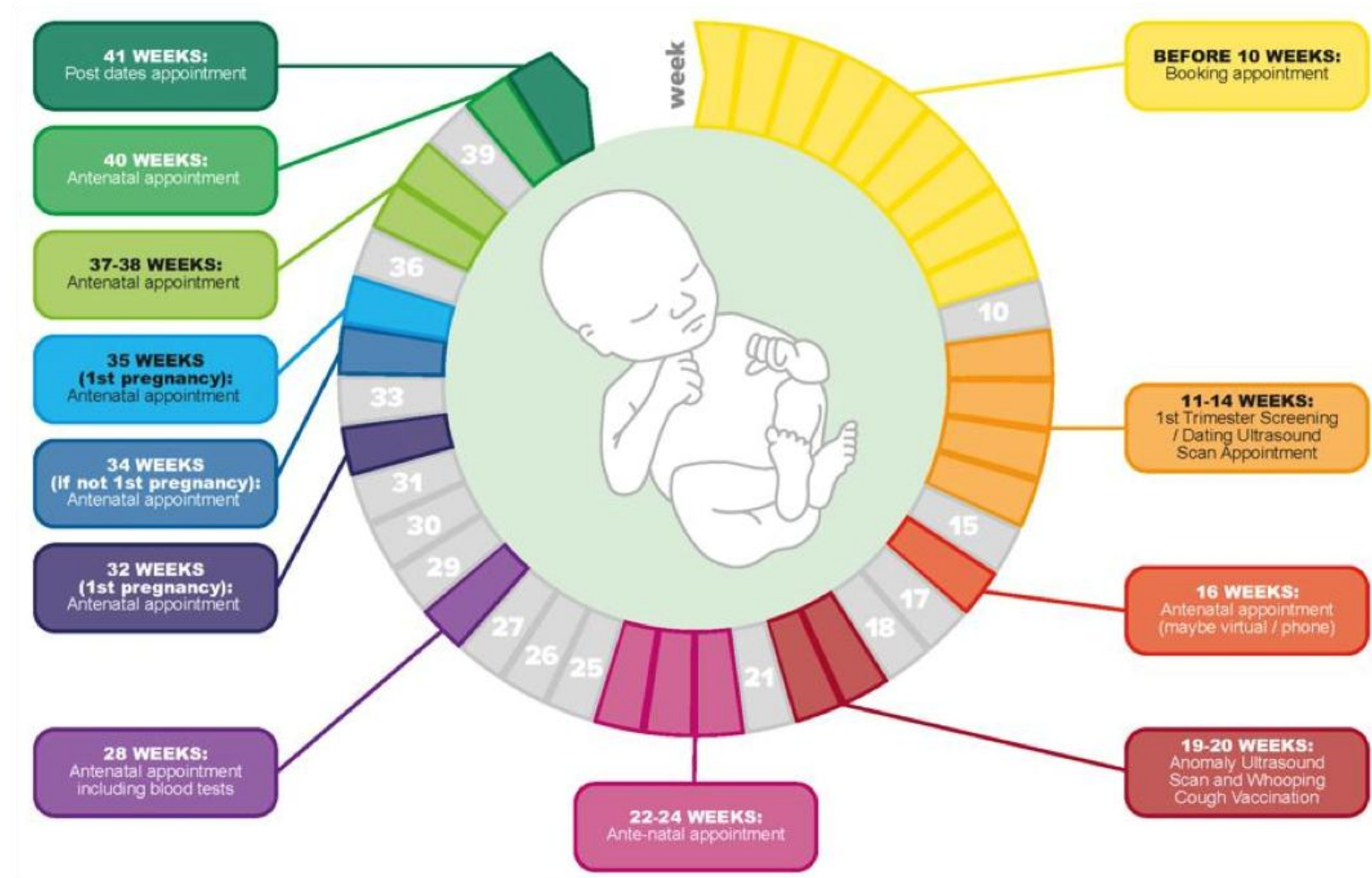


## Delivery of individualised specialist multidisciplinary care

*“There was no multi-disciplinary shared mental model, and the pathway did not provide opportunities for care decisions to be reached in a collaborative way, drawing on different spheres of expertise.”*



# 1. Delivery of individualised specialist multidisciplinary care



# 1. Delivery of individualised specialist multidisciplinary care

## Medical

Obesity

Mental health diagnoses

Smoking

Substance misuse

Previous preterm birth

## Social

Homelessness

Social services involvement

Multiple moves

Care between trusts

Living alone / limited social support

Relationship difficulties

## Epilepsy-related

Not on anti-epileptic drugs

Decision to stop medication

Frequent seizures

Nocturnal seizures

# Theme 1

*“She shared that she had experienced a seizure in the week.”*



*“The clinicians recalled that they explored the Mother’s seizure frequency and it was ‘normal for her’.”*



*“They understood that her recent seizure was more related to her housing needs and an inability to get a continued supply of medication.”*

# Theme 1

*“... it was unusual for a mother to be seen in different obstetric clinics...staff considered the four clinics the Mother was expected to attend was excessive... [this] contributed to her non-attendance and resulted in the Mother’s antenatal care missing key elements.”*

# Theme 1



## **Delivery of individualised specialist multidisciplinary care**

**Women's multiple risk factors required care to be delivered in an individualised way, with holistic oversight. Women with complex pregnancies require antenatal care co-ordinated by a named clinician, with expertise in their specific condition/s, with the care wrapping around the mother.**

# Theme 2



## Communication across multiple providers

*“... there was no obstetric or neurological oversight of the Mother in the last few weeks of her life... Other members of the team were aware of the Mother’s seizures ... there is no evidence that this information was shared.”*

## 2. Communication across multiple providers



## Theme 2

*"The investigation learnt that Trust A considered that they had oversight of the Mother's pregnancy and that Trust B would manage the Mother's epilepsy."*

*"... some staff had assumed that the Mother's GP was managing her epilepsy care."*



## 2. Communication across multiple providers



## Theme 2

*“The investigation learnt that there was no pathway or expectation for the obstetric and midwifery team at Trust A to share the Mother’s worsening seizure activity with the epilepsy team at Trust B and that there was a reliance on the Mother to communicate this information to the epilepsy team.”*

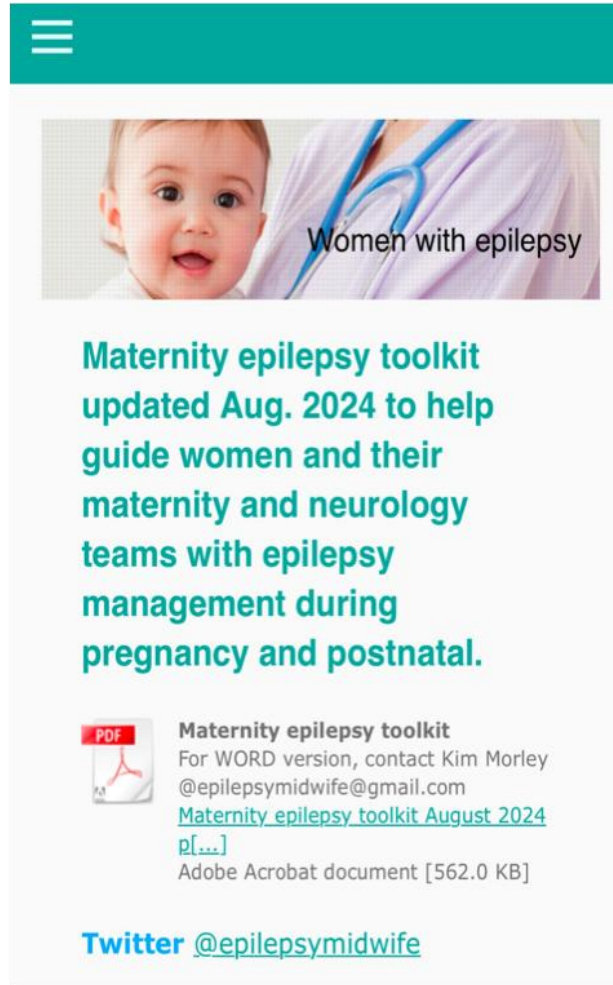
# Theme 2



## Communication across multiple providers

**Collaborative working and communication between providers would be enhanced by having shared access to information through IT systems and shared care toolkits.**


# Shared care toolkit



The image shows a screenshot of a social media post. At the top is a teal header with a white hamburger menu icon. Below the header is a photograph of a baby's face on the left and a person's chest with a blue stethoscope on the right. The text "Women with epilepsy" is overlaid on the right side of the photo. Below the photo is a teal text block: "Maternity epilepsy toolkit updated Aug. 2024 to help guide women and their maternity and neurology teams with epilepsy management during pregnancy and postnatal." Underneath this is a PDF icon with the text "Maternity epilepsy toolkit". To the right of the PDF icon, it says "For WORD version, contact Kim Morley @epilepsymidwife@gmail.com" and provides a link "Maternity epilepsy toolkit August 2024 p[...]" with "p[...]" in blue. Below the link is "Adobe Acrobat document [562.0 KB]". At the bottom of the post is the text "Twitter @epilepsymidwife" in blue.

Women with epilepsy

**Maternity epilepsy toolkit updated Aug. 2024 to help guide women and their maternity and neurology teams with epilepsy management during pregnancy and postnatal.**

 **Maternity epilepsy toolkit**  
For WORD version, contact Kim Morley  
@epilepsymidwife@gmail.com  
[Maternity epilepsy toolkit August 2024 p\[...\]](#)  
Adobe Acrobat document [562.0 KB]

[Twitter @epilepsymidwife](#)

# Theme 3



## Communication with healthcare professions

*“... the Mother found it difficult to navigate the healthcare system when she had seizures during the pregnancy.”*

### 3. Communication with healthcare professionals



## Theme 3

*“In the three years leading up to her death, the Mother had changes in her home circumstances which led to her changing address several times. During this time, the Mother accessed care through three different GP surgeries, with different doctors for most appointments...Throughout these interactions her epilepsy remained uncontrolled.”*

## Theme 3

*“the Mother experienced nausea and vomiting during her pregnancy. The organisational pathways in operation for mothers with epilepsy do not support timely and early access to additional information and monitoring of their epilepsy.”*



# SUDEP Education



*“The investigation learned that SUDEP is not routinely mentioned to mothers and there was a perception this may be frightening for them to hear as “there’s lots of anxiety anyway around pregnancy.”*”

# Theme 3



## Communication with healthcare professions

**Pathways need to be flexible, to allow women to easily access care in early pregnancy and when they need help. Women need to be partners in their care and be educated about their condition and its risks. This requires collaboration between women and care providers. Shared care toolkits could empower women in this way.**

# Conclusion

- *The systems-focused approach to both MNSI investigations and this review can support the development of recommendations for improving the safety of care for women with epilepsy throughout the NHS.*
- *Whilst there is evidence of progress in epilepsy care since the MBRRACE-UK 2020 report, our thematic review of deaths from SUDEP echoes their findings.*

# Recommendations – Beyond MBRRACE-UK 2020

- *Epilepsy care in pregnancy is complex and is optimised when delivered in a bespoke, flexible way informed by individual risk factors.*
- *Collaborative working, between care providers and with women, is essential.*

# Recommendations – Beyond MBRRACE-UK 2020

- *Shared access to information is required, as well the allocation of a lead professional with holistic oversight.*
- *Shared IT systems and a shared care toolkit would promote collaboration and empower women.*

# References

*Maternity & Newborn Safety Investigations. Home: The Maternity & Newborn Safety Investigations Programme [Online]; 2024 [Accessed 24 May 2024]. Available from: <https://www.mnsi.org.uk>.*

*Knight M, Bunch K, Tuffnell D, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2016-18. Oxford: National Perinatal Epidemiology Unit, University of Oxford; 2020.*

*Holden RJ, Carayon P, Gurses AP, et al. SEIPS 2.0: a human factors framework for studying and improving the work of healthcare professionals and patients. *Ergonomics*. 2013; 56(11):1669-86. doi:10.1080/00140139.2013.838643.*

*Dr Charlotte Frise*



# *How should this impact physicians in non- maternity specialties?*

**Charlotte Frise**

*Consultant Obstetric Physician, Queen Charlotte's and Chelsea  
Hospital*

*Lead Consultant Obstetric Physician, NWL Maternal Medicine  
Network*

*Senior College Lecturer in Clinical Medicine, Keble College, Oxford*

*Honorary Senior Clinical Lecturer, Imperial College London*



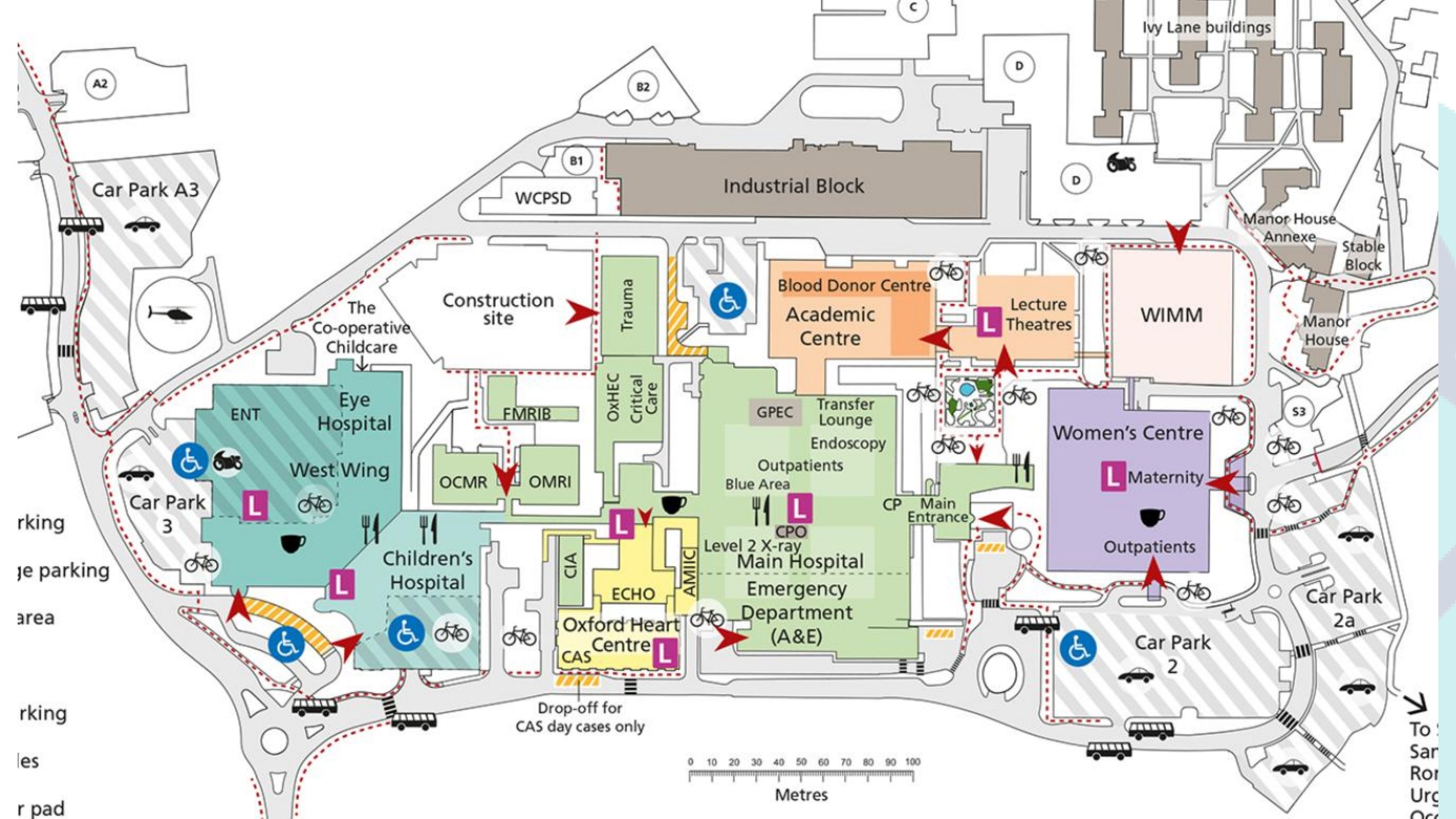


# Objectives

- 1. Women of childbearing age (not pregnant) with epilepsy*
- 2. Pregnant women with epilepsy*
- 3. Women with epilepsy after delivery*



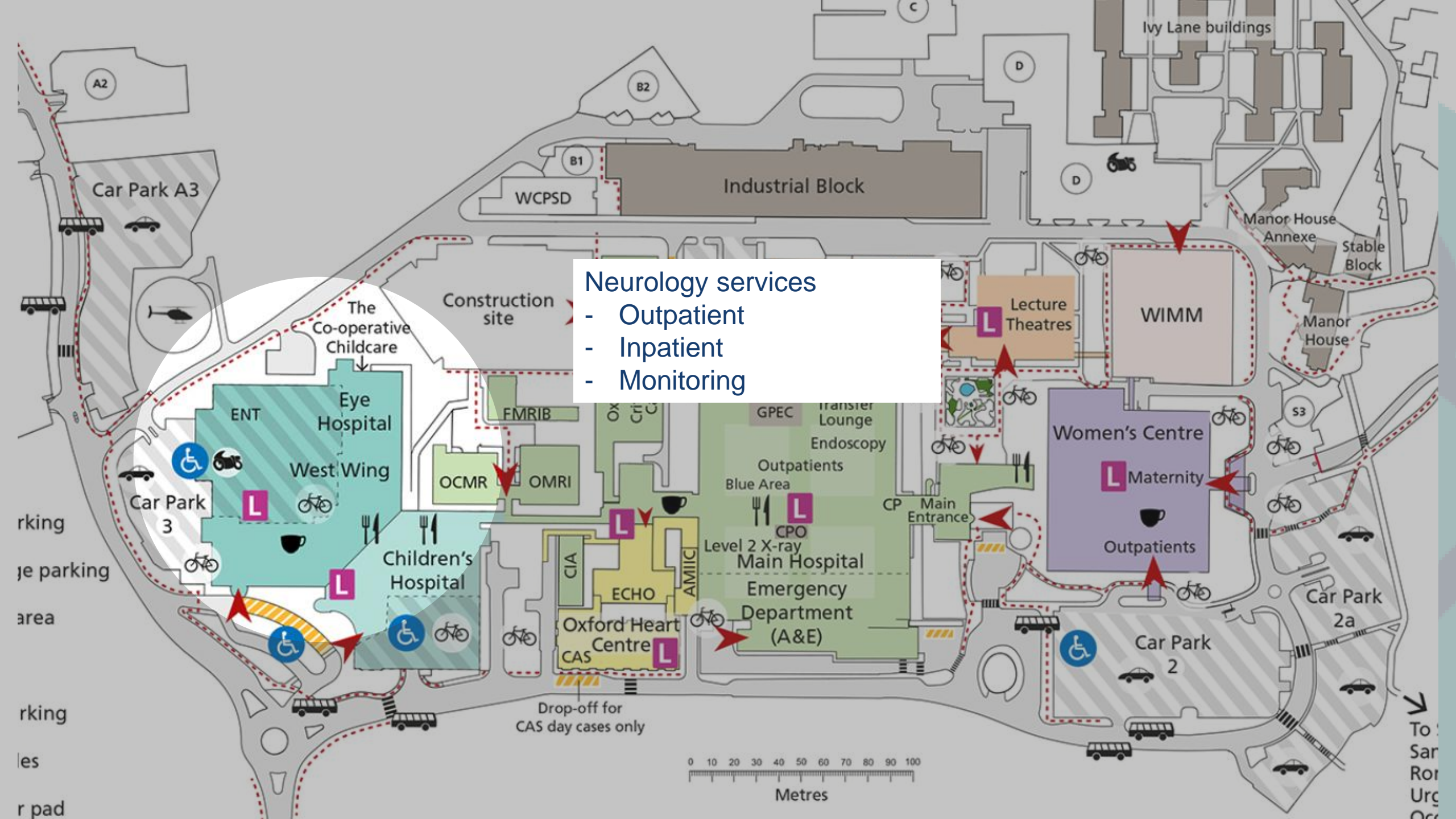
**Who is this relevant to?**



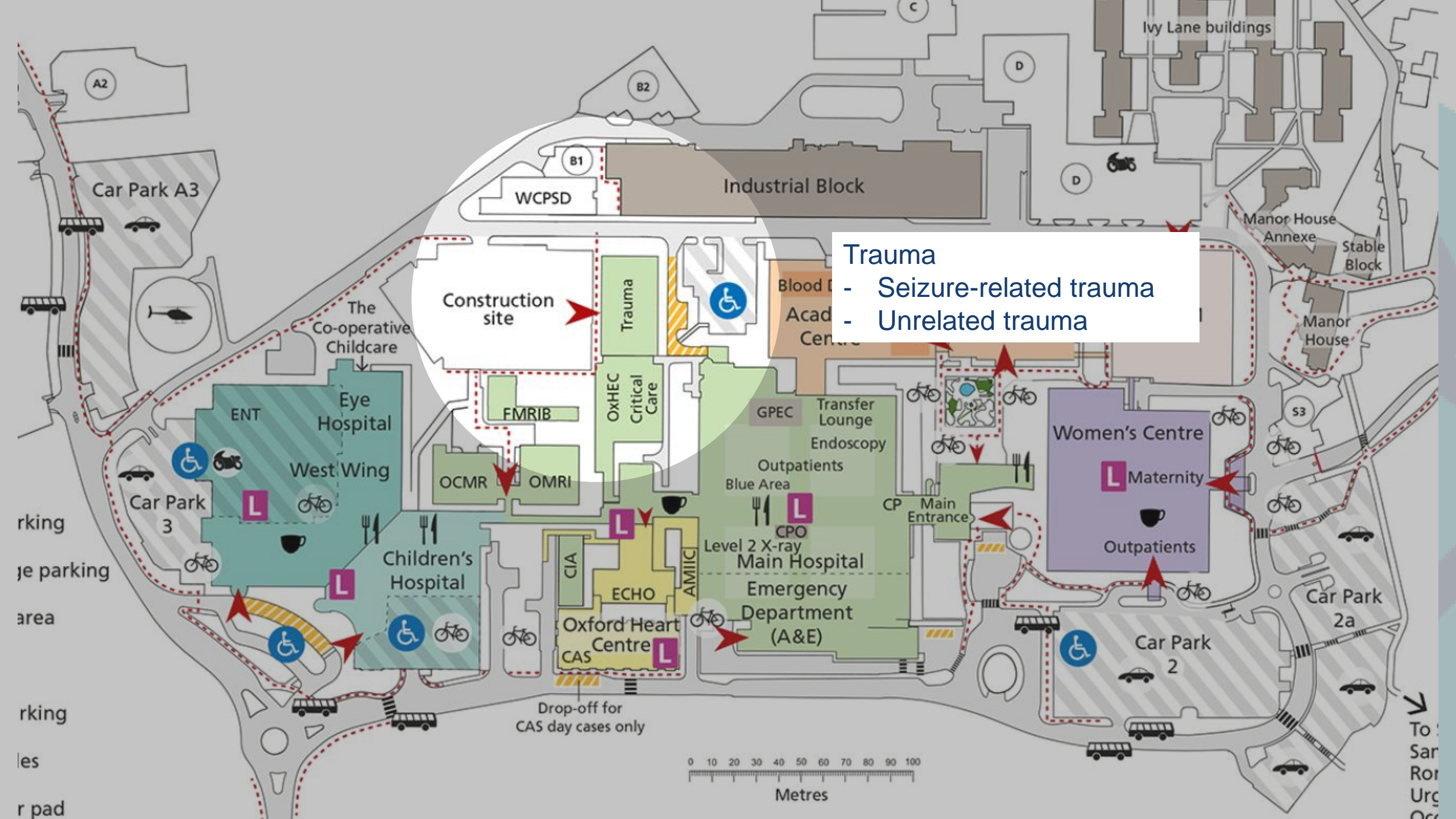


Neurology services

- Outpatient
- Inpatient
- Monitoring







**Trauma**

- Seizure-related trauma
- Unrelated trauma

Construction site

Trauma

Blood  
Acad  
Centre

ENT  
Eye Hospital

West Wing

FMRIB

OxHEC  
Critical Care

GPEC

Transfer Lounge

Endoscopy

Outpatients

Blue Area

CPO

Level 2 X-ray

Main Hospital

Emergency Department (A&E)

Women's Centre

Maternity

Outpatients

Children's Hospital

CIA

ECHO

AMIIC

Oxford Heart Centre

CAS

Drop-off for CAS day cases only

Women's Centre

Maternity

Outpatients

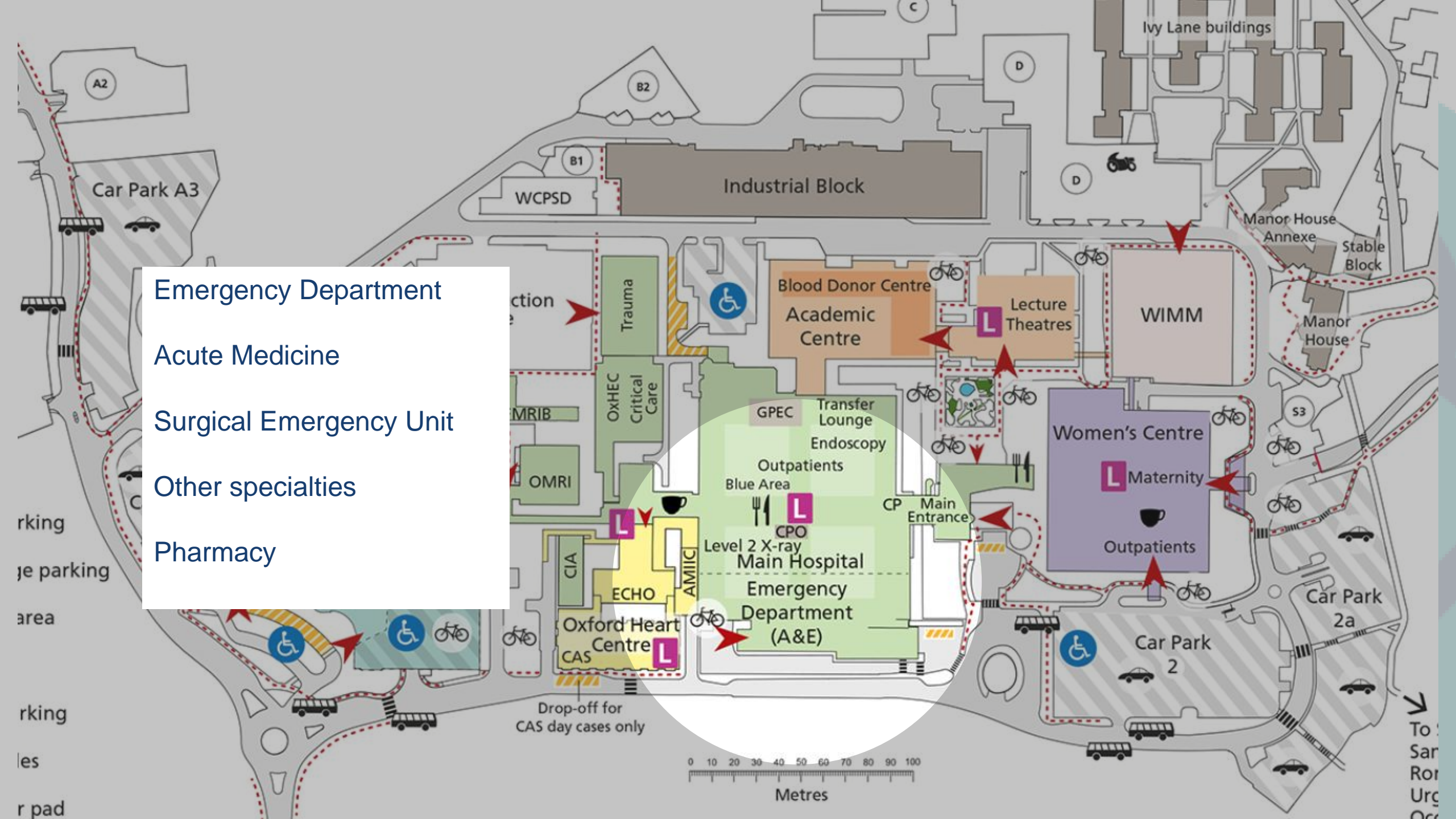
Car Park 2

Car Park 2a



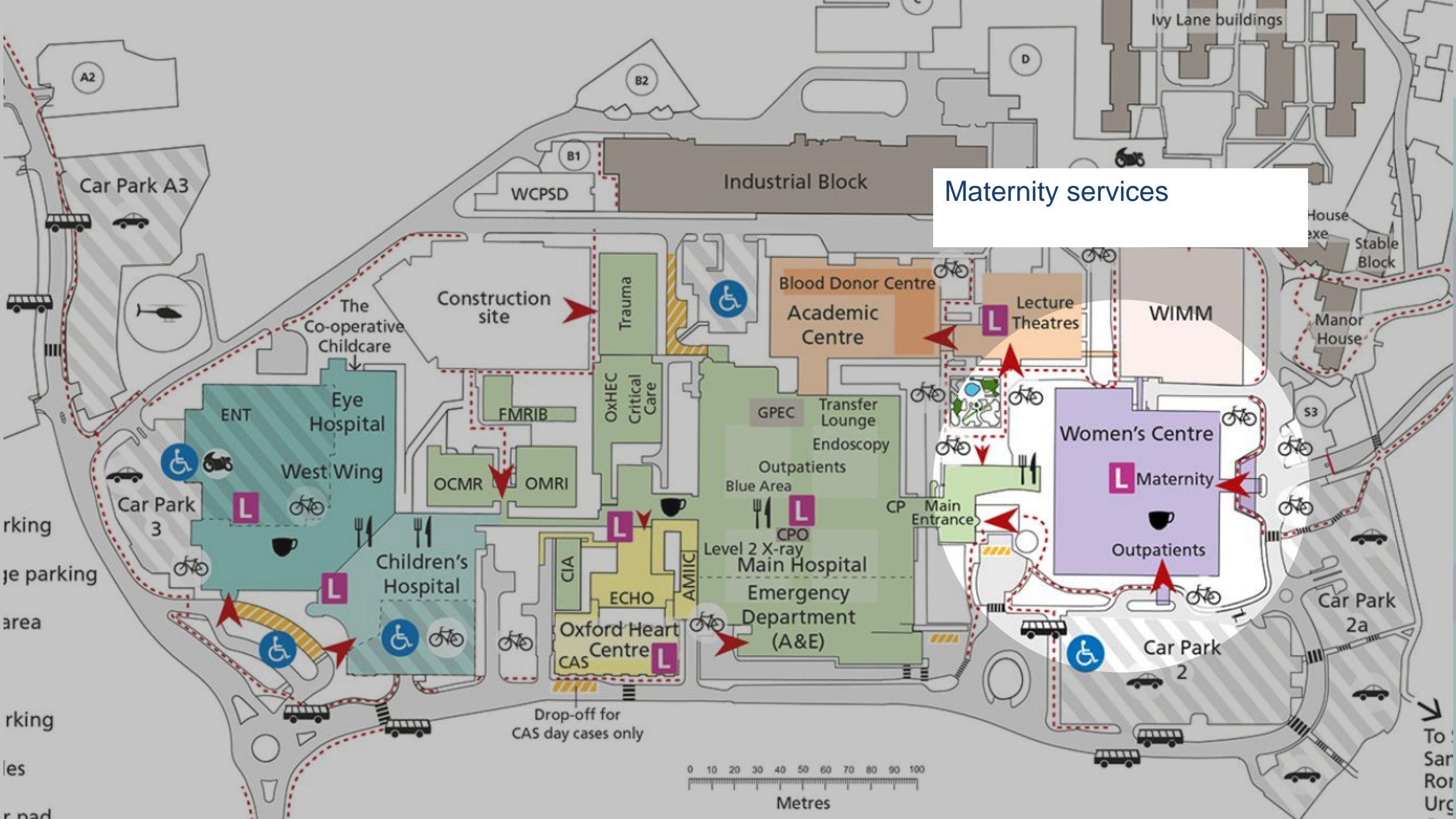


- Emergency Department
- Acute Medicine
- Surgical Emergency Unit
- Other specialties
- Pharmacy





Maternity services



# Women of childbearing age + epilepsy

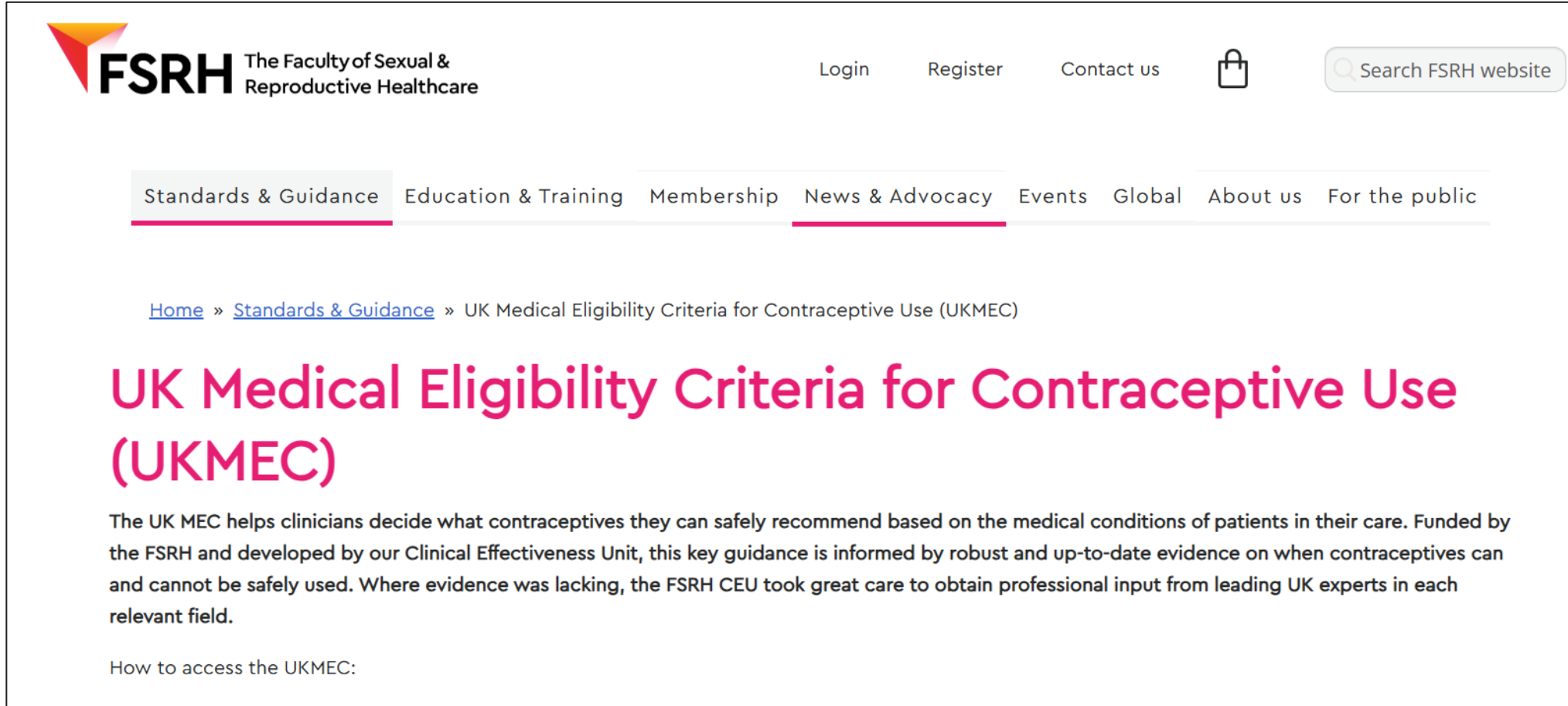
Even if not relevant to the presenting complaint

- *Could they be pregnant?*
- *Are they on any potentially teratogenic medications?*
- *Are they following the appropriate safety advice for contraception e.g. if on valproate or topiramate?*
- *Are they aware of their contraceptive options?*
- *Are they taking folic acid 5mg daily if trying to conceive?*
- *Have they received pre-pregnancy counselling? Do they want it?*






# Contraception



The screenshot shows the FSRH website header with the logo and navigation links. The main navigation menu includes 'Standards & Guidance', 'Education & Training', 'Membership', 'News & Advocacy', 'Events', 'Global', 'About us', and 'For the public'. The breadcrumb trail is 'Home » Standards & Guidance » UK Medical Eligibility Criteria for Contraceptive Use (UKMEC)'. The main heading is 'UK Medical Eligibility Criteria for Contraceptive Use (UKMEC)'. The introductory text states: 'The UK MEC helps clinicians decide what contraceptives they can safely recommend based on the medical conditions of patients in their care. Funded by the FSRH and developed by our Clinical Effectiveness Unit, this key guidance is informed by robust and up-to-date evidence on when contraceptives can and cannot be safely used. Where evidence was lacking, the FSRH CEU took great care to obtain professional input from leading UK experts in each relevant field.' Below this, it says 'How to access the UKMEC:'.

**FSRH** The Faculty of Sexual & Reproductive Healthcare

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[Home](#) » [Standards & Guidance](#) » UK Medical Eligibility Criteria for Contraceptive Use (UKMEC)

## UK Medical Eligibility Criteria for Contraceptive Use (UKMEC)

The UK MEC helps clinicians decide what contraceptives they can safely recommend based on the medical conditions of patients in their care. Funded by the FSRH and developed by our Clinical Effectiveness Unit, this key guidance is informed by robust and up-to-date evidence on when contraceptives can and cannot be safely used. Where evidence was lacking, the FSRH CEU took great care to obtain professional input from leading UK experts in each relevant field.

How to access the UKMEC:

UKMEC	Definition of category
Category 1	A condition for which there is no restriction for the use of the method
Category 2	A condition where the advantages of using the method generally outweigh the theoretical or proven risks
Category 3	A condition where the theoretical or proven risks usually outweigh the advantages of using the method. The provision of a method requires expert clinical judgement and/or referral to a specialist contraceptive provider, since use of the method is not usually recommended unless other more appropriate methods are not available or not acceptable
Category 4	A condition which represents an unacceptable health risk if the method is used



Intrauterine Contraception (IUC)		IUC does not protect against STI/HIV. If there is a risk of STI/HIV (including during pregnancy or postpartum), the correct and consistent use of condoms is recommended, either alone or with another method of contraception. Male condoms reduce the risk of STI/HIV.	
Copper-bearing IUD (Cu-IUD) Levonorgestrel-releasing IUS (LNG-IUS)			
CONDITION	CATEGORY	CLARIFICATION/EVIDENCE	
*See additional comments at end of section	I = Initiation, C = Continuation		
	Cu-IUD	LNG-IUS	

NEUROLOGICAL CONDITIONS			
Epilepsy	1	1	
Taking anti-epileptic drugs	<p>Certain anti-epileptic drugs have the potential to affect the bioavailability of steroid hormones in hormonal contraception. Additionally, hormonal contraception may affect the levels of certain anti-epileptic drugs with potential adverse effects.</p> <p>For up-to-date information on the potential drug interactions between hormonal contraception and anti-epileptic drugs, please refer to the online drug interaction checker available on Stockley's Interaction Checker website.<sup>98</sup></p>		

## Lamotrigine and contraception

### Other formats

If you need this information in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated into another language, please contact the PALS desk. Please see page 2 for contact details.

### Introduction

Lamotrigine is a medication which is taken for seizure control, prescribed by a neurologist, or as a mood stabiliser, prescribed by a psychiatrist. Some contraceptives and lamotrigine can affect each other. New guidance has been released relating to contraception and lamotrigine, which may affect your contraceptive choice. This leaflet is available to help you make the right decision for you about your contraception.

### Combined hormonal contraception

These are contraceptives which contain the hormones oestrogen and progesterone. Combined hormonal contraception includes certain pills, the contraceptive patch and the vaginal ring. These are not recommended with lamotrigine as they may change the levels of lamotrigine in your blood, increasing the risk of seizures or mood changes. If you are unsure if your contraceptive falls into this category, please check with your doctor.

### Progesterone only contraception

These are contraceptives which contain the single hormone progesterone, such as the progesterone only pill (POP), the contraceptive injection and contraceptive implant. These may interact with lamotrigine in different ways.

- In theory with the progesterone only pill (POP) and the contraceptive implant, there may be an increase in the chance of pregnancy when also taking lamotrigine. However, the evidence for this is limited and the risk is likely to be small. If you wish to use these contraceptives, the advice is to use condoms along with them.
- The effectiveness of intrauterine contraception (coils) and the injection are not changed by lamotrigine.

# Pregnant women + epilepsy

Even if not relevant to the presenting complaint

- *Are they under the correct services?*
- *Are they on appropriate medications?*
- *Are they being appropriately monitored?*

Are the clinicians familiar with what to do if 'no' to any of these questions?



# How at risk are they?

Risk of a seizure

Risk of SUDEP

## Box 3.1 SUDEP Risk Awareness (adapted from <https://sudep.org>)

Known risk factors:

*Seizure-related factors:*

- Uncontrolled seizures
- Tonic clonic seizures
- Nocturnal seizures
- Epilepsy starting before the age of 16
- Increasing frequency of seizures

*Treatment factors:*

- Infrequent epilepsy reviews and engagement with an epilepsy clinician
- Ineffective AED treatment
- Frequent medication changes
- Sub-therapeutic doses of AEDs

*Individual factors:*

- Living alone or sleeping alone
- Not taking medication as prescribed
- Sleep deprivation
- Stress
- Alcohol or substance misuse
- Learning disability

# Women with epilepsy after pregnancy

- *Perfect storm of sleep deprivation/hormonal changes/changes in routine*
- *Wide range of healthcare professionals involved*
- *Who has oversight of the epilepsy care?*

*Recovery from one pregnancy ---- planning for the next!*

# Conclusions

- *Relevant to majority of clinicians in wide range of specialties*
- *Asking if they are pregnant is not sufficient*
- *You are not expected to know all the answers!*
- *Find your local and network team*

*Joanna Girling*





# *MDT approach to epilepsy care within a network setting*

*Joanna Girling*

*Consultant in Obstetrics, Obstetric Medicine, Preterm Birth prevention &  
Gynaecology at West Middlesex and Chelsea Westminster Hospitals*

*Clinical Director NW London Maternal Medicine Network*

*Obstetric Assessor for MBRRACE*



Royal College of  
Obstetricians &  
Gynaecologists



NW LONDON  
Maternal Medicine Network







**MNSI**  
Maternity & Newborn  
Safety Investigations



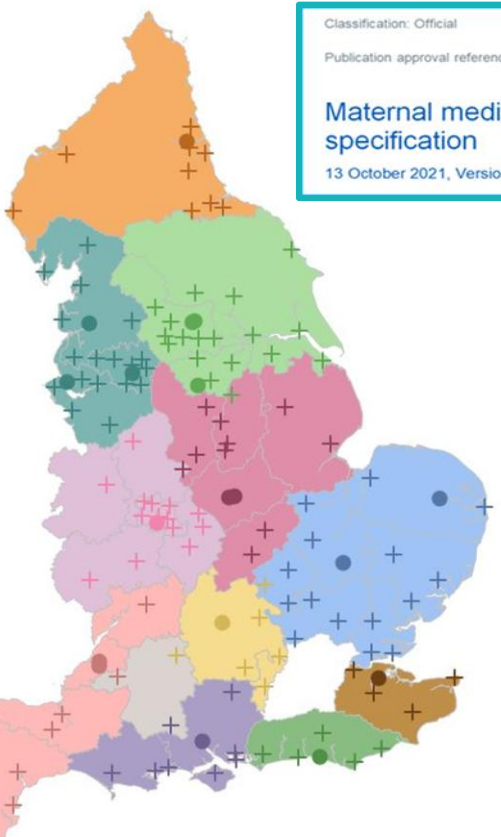
**Network (England map)**

- East Midlands
- East of England
- Kent and South East London
- North East and North Cumbria
- North West
- South West
- Sussex and South East London
- Thames Valley
- Wessex
- West Midlands
- Yorkshire and Humber

**Maternal medical centre**

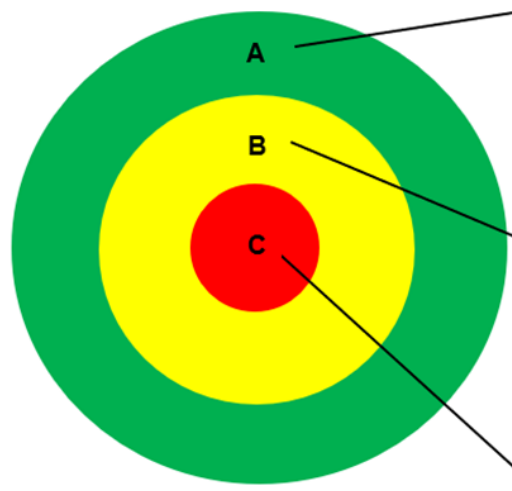
- + No
- Yes

Shaded areas of the map approximate the network



Classification: Official  
 Publication approval reference: PAR709  
**Maternal medicine network service specification**  
 13 October 2021, Version 1

**MATERNAL MEDICINE NETWORK**



**Category A**  
 Medical conditions that can be managed using **local expertise** and evidence based maternity care

**Category B**  
 Complex medical conditions where *consideration is given to* a Maternal Medicine Centre clinical review (either virtually or face-to-face according to clinical need) and on-going **advice and guidance** to a local maternity unit

**Category C**  
 Highly complex medical conditions where care in pregnancy is *usually led by the Maternal Medicine Centre* during pregnancy and includes plans for delivery

Increasing complexity of medical condition

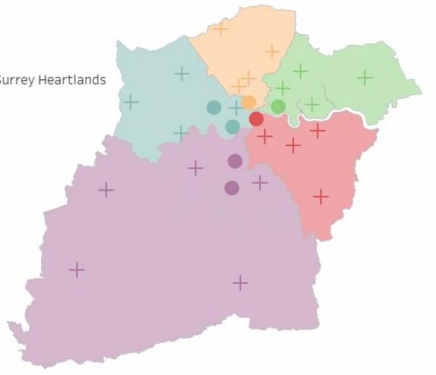
**Network (London map)**

- North Central London
- North East London
- North West London
- South East London
- South West London and Surrey Heartlands

**Maternal medical centre**

- + No
- Yes

Shaded areas of the map approximate the network



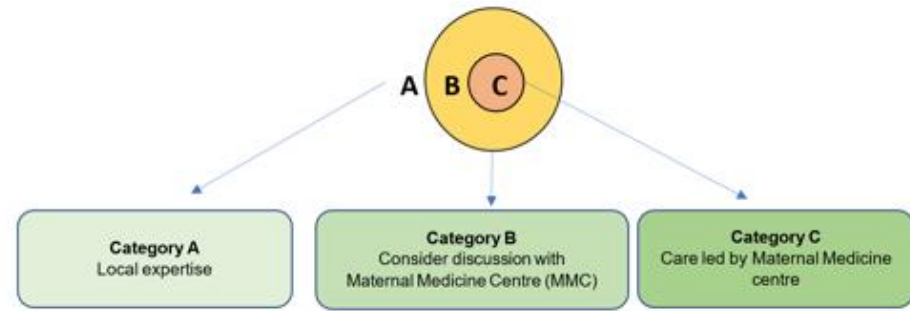
Category Local  
 Epilepsy managed jointly with neurology and obstetrics

North West London Integrated Care System  
 Working together for better health and care

**NW LONDON**  
 Maternal Medicine Network

Medicine  
 access including

**NW London Maternal Medicine Network: Obstetric Neurology**



Epilepsy managed jointly with neurology and obstetrics  
 Epilepsy without local access to joint neurology and obstetrics input

# Barriers, challenges, goals



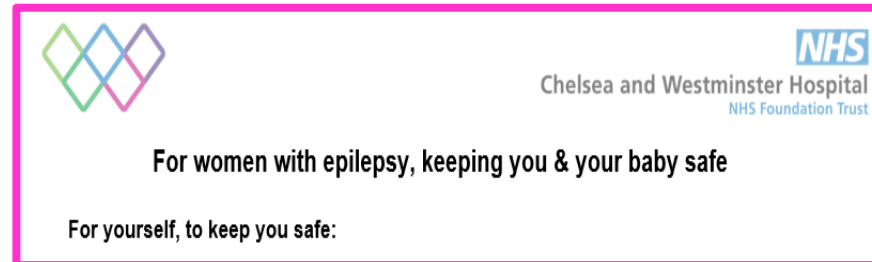
- *Pre-pregnancy → pregnancy → post birth → contraception*
- *Access to care*
- *Fragmented IT*
- *Local geography*



# Barriers, challenges, goals



- *Pre-pregnancy → pregnancy – post birth – contraception*
- *Access to care*
- *Fragmented IT*
- *Local geography*



[Contraception | Information, Methods, Tools and Advice | SH:24 \(sh24.org.uk\)](https://sh24.org.uk)

Emergency alerts on your phone: have **you** set these up?  
(this takes under 5 minutes and might just save your life)



**ANDROID**

- 'Settings'
- ↓
- 'safety and emergency'

**APPLE**

- 'Settings'
- ↓
- 'Health'
- ↓
- 'medical ID'

We suggest, at a minimum:

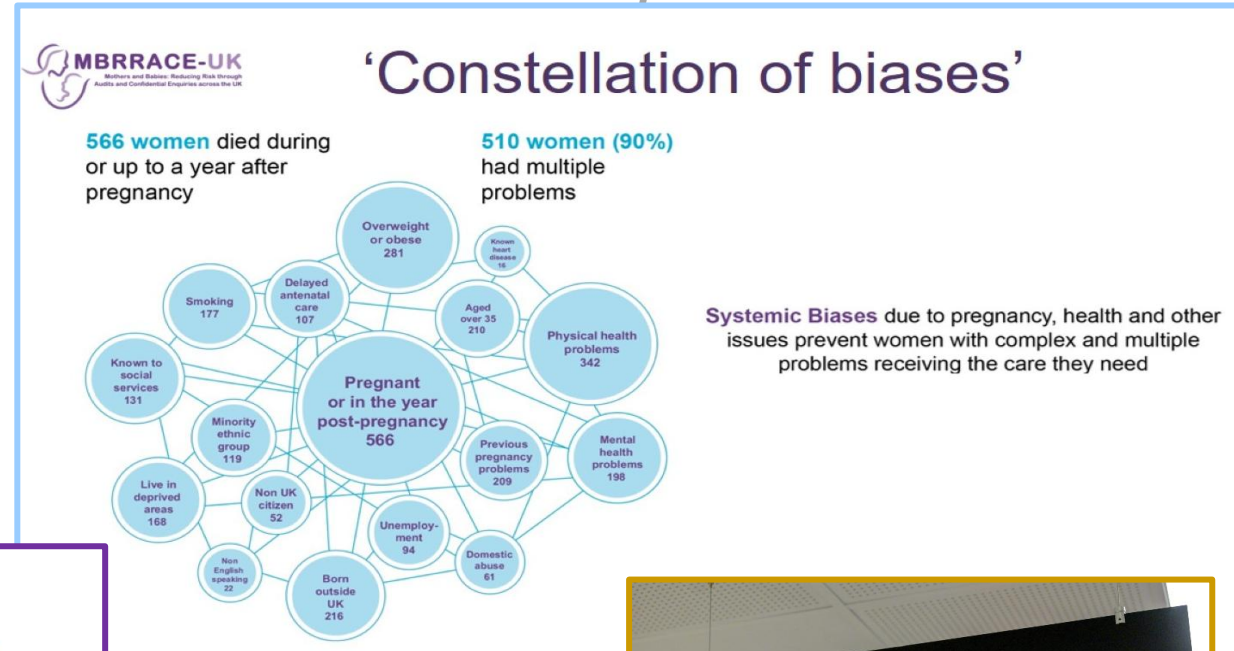
-  The date your baby is due
-  The hospital where you are planning to have your baby
-  Details of any medical conditions
-  Details of regular medications
-  Up-to-date emergency contacts

V2 10/24

# Barriers, challenges, goals



- *Pre-pregnancy – pregnancy – post birth – contraception*
- **Access to care**
- *Fragmented IT*
- *Local geography*



Alternatives to neurology opinion





# Barriers, challenges, goals



- *Pre-pregnancy → pregnancy – post birth – contraception*
- *Access to care*
- *Fragmented IT*
- *Local geography*



# Barriers, challenges, goals



- *Pre-pregnancy → pregnancy – post birth – contraception<sup>n</sup>*
- *Access to care*
- *Fragmented IT*
- *Local geography*



# Ways forward

- *Good epilepsy care for pregnancy needs a multiprofessional and multidisciplinary approach*
- *Get involved with your local and regional networks – or set them up*
- *Speak up for women with epilepsy*



## **Develop clear standards of care for joint maternity and neurology services, which allow for :**

- Early referral in pregnancy, particularly if pregnancy is unplanned, to optimise anti-epileptic drug regimens**
- Rapid referral for neurology review if women have worsening epilepsy symptoms**
- Pathways for immediate advice for junior staff out of hours**
- Prompt postnatal review to ensure anti-epileptic drug doses are appropriately adjusted.**

**Regard nocturnal seizures as a 'red flag' indicating women with epilepsy need urgent referral to an epilepsy service or obstetric physician**

## **Develop clear standards of care for joint maternity and neurology services, which allow for :**

- Early referral in pregnancy, particularly if pregnancy is unplanned, to optimise anti-epileptic drug regimens**
- Rapid referral for neurology review if women have worsening epilepsy symptoms**
- Pathways for immediate advice for junior staff out of hours**
- Prompt postnatal review to ensure anti-epileptic drug doses are appropriately adjusted.**



# Alternatives to neurology opinion

Urgent neurology services are not provided at most hospitals.

- Epilepsy Nurse Specialist
- Specialist Epilepsy Midwife.
- Obstetric physician

With development of maternal medicine networks, all maternity units should have access to advice from an obstetric physician.

- Ability to manage epilepsy in pregnancy is a core competence for obstetric physicians.
- Obstetric medicine credential includes training in this area.

# Questions & answers

Please only use the Q & A box to input your questions





*NEXT WEBINAR:*

# First trimester deaths in England from venous thromboembolism associated with hyperemesis

*Thursday 13 February, 1pm – 2pm*



**Dr Louise Page**  
MNSI



**Dr Charlotte Frise**  
Imperial College Healthcare  
NHS Trust



**Chandrima Biswas**  
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