Mid and South Essex Integrated Care System

NHS
Mid and South Essex
Integrated Care Board

Maternity and Neonatal Independent Advocacy Service: Pilot Phase

Document Control:

Guideline Name	Maternity and Neonatal Independent Advocacy Service: Pilot Phase
Guideline Number	G001
Version	1.0
Status	FINALLY APPROVED
Author / Lead	Sarah Paxman Maternity and neonatal independent senior advocate
Responsible Executive Director	Giles Thorpe ICB Executive Chief Nurse
Responsible Committee	Maternity and Neonatal Board
Date Ratified by Responsible Committee	22/03/2024 (LMNS Steering Board)
Date Approved by Board/Effective Date	08/04/2024
Next Review Date	31/03/2025
Target Audience	MSEFT, ICB and MNVP
Stakeholders engaged in development of guideline (internal and external) *In alphabetical order*	• Nicki Abbott, Managing Director of Care Group 5, MSEFT • Viv Barker, ICB Director of Nursing and Patient Safety • Rachel Bickley, Regional MNVP Lead • Deborah Goldsmith, Director of Midwifery, MSEFT • Gemma Hickford, Consultant Midwife and Lead Clinician, LMNS • Wendy Matthews, Regional Chief Midwife and Director of Nursing, East of England, NHS England • Martine Pringle, Maternity Quality Lead Midwife, East of England, NHS England • Jill Stoddard, MSE Advisor to the Board • Barbara Stuttle, Non-Executive Director and Safety Champion, MSEFT
Impact Assessments Undertaken *(State if not applicable)*	• Equality and Health Inequalities Impact Assessment • Data Protection Impact Assessment • Privacy Impact Assessment

Version History

Version	Date	Author (Name and Title)	Summary of amendments made
1		Sarah Paxman Maternity and Neonatal Independent Senior Advocate	A new guideline which describes participation in an NHS pilot scheme to provide senior independent advocate support for maternity and neonatal service users within Mid and South Essex ICB

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1. Introduction

1.1. This guideline sets out how Mid and South Essex Integrated Care Board (ICB) will implement the Maternity and Neonatal Independent Senior Advocate (MNISA) pilot programme.

1.2. The Maternity and Neonatal Independent Senor Advocate role is a new role being piloted NHS England (funded until March 2025) to support women, birthing people and families in England. This follows the essential actions identified in the Ockenden review into maternity care. The overall aim is to help ensure the voices of women, birthing people and families are heard by their maternity and neonatal care providers when they have experienced an 'adverse outcome' during their maternity and/or neonatal care. MNISAs are independent from the Trust that provided the care and the service is free and confidential. The MNISA has been employed by and reports to the Integrated Care Board (ICB).

1.3. Please read this guideline in conjunction with the following documents, published by NHS England to support the pilot programme (links to these documents can be found at the end of this policy):

- Operational Guidance for the MNISA Pilot Programme
- Standard Operating Procedure for Consent and Consent Form
- Communications toolkit

1.4. This guideline is intended to be used by;

- The maternity and neonatal independent senior advocate (MNISA) for Mid and South Essex
- Mid and South Essex Foundation Trust (MSEFT) maternity and neonatal team members
- Mid and South Essex Local Maternity and Neonatal System (LMNS) and Integrated Care Board (ICB) personnel
- Senior Responsible Owners (SROs)
- The Maternity and Neonatal Voices Partnership (MNVP) for Mid and South Essex.

2. Definitions and language

2.1. **MNISA** – Maternity and neonatal independent senior advocate

Adverse outcome – This term has been agreed to describe a range of traumatic and devastating outcomes which can occur during maternity

and neonatal care. It is difficult to select words which reflect the real impact on the people involved. Service users have been consulted by the NHS England team, and the words ‘adverse outcome’ were reported to acceptable.

Woman and birthing person - It is recognised that not all pregnant and birthing people identify as female, and therefore inclusive, additive language will be used in this document to be inclusive of everyone.

Partner – It is also recognised that partners, dads, fathers, co-parents, etc. may have different preferences for how they prefer to be referred to as a parent. In this document, the term ‘partner’ will be used to be inclusive of everyone.

Families - The word family is intended to be interpreted in its broadest sense, which could include a partner, parents, siblings, or wider family such as grandparents. The extent by which family is defined for the purposes of this process, will be individual to the person or couple who have been referred.

3. Maternity and Neonatal Independent Senior Advocate for Mid and South Essex

3.1. The MNISA employed by Mid and South Essex ICB has extensive clinical experience in maternity and neonatal services, and a sound understanding of the pathways that NHS services follow when there is an unexpected outcome and people are harmed.

3.2. To effectively undertake this role, the MNISA has completed a bespoke training programme commissioned by NHS England and delivered by Baby Lifeline, as well as a nationally recognised qualification in Independent Advocacy.

3.3. During the pilot phase, the MNISA will have access to clinical supervision, support and mentorship from an experienced professional advocate who is employed by Rethink Advocacy in Essex. This regular contact has been arranged by Mid and South Essex ICB to support effective independent advocacy for people who access the service. The contract and data protection agreement with Rethink Advocacy are available separately.

4. The role of the Maternity and Neonatal Independent Senior Advocate

4.1. The MNISA has a duty to comply with the Advocacy Quality Performance Mark Code of Practice. Ultimately, they have to be led by the needs and wishes of their service users, and can support women,

birthing people and families by:

- helping them to gather information that they need to understand more about what happened to them or to their baby.
- explaining medical, obstetric and neonatal terminology (or find someone who can explain this for them).
- attending meetings with professionals / inquests with them (or liaise with professionals on their behalf if they don't feel able to do so themselves).
- conveying their worries, concerns and feedback to professionals and the Trust board / ICB board, so that the impact of these can be properly acknowledged, and used to make changes that may help another woman, person, baby or family in the future.
- making a complaint about their care, either by supporting them with the process or by acting on their behalf as instructed.

4.2. The MNISA takes a person-centred approach, and works in partnership with service users to understand their needs and what they would like to happen after experiencing an adverse outcome.

4.3. The MNISA can signpost service users to other organisations that can help them to meet other identified needs (counselling, bereavement support, financial and housing, etc.).

4.4. The MNISA will comply with the ICB Safeguarding Policy.

4.5. MNISAs cannot:

- act as a mediator between care providers and service users to resolve a conflict or complaint.
- give advice to their service users about how they should proceed. They must support the service users to explore all of the available options, without bias, judgement or opinion.
- provide formal counselling or bereavement support to service users.

5. Scope

5.1. There is no time limit within which adverse outcomes have occurred. To remain sensitive to women, birthing people and families, the terms ‘historic’ or ‘live’ cases should not be used. Rather, the decision as to whether the MNISA will work alongside women and families will be based on the stage a family is at in any complaints or investigation process, not the time elapsed since their adverse outcome.

5.2. Some women and birthing people will give birth outside of the Mid and South Essex (MSE) area, for example where an in-utero transfer to a tertiary unit has taken place. Not all ICBs are taking part in the pilot phase for this new service, and therefore it may not be possible to link everyone with an MNISA. Support may be given by the MNISA for MSE to women, birthing people and families where their maternity and neonatal care was through a provider within MSE, regardless of where they live.

5.3. MNISAs should not routinely be involved where all avenues of investigation and complaint, including appeal to the Parliamentary Health Ombudsman have been exhausted.

6. Referral criteria

The MNISA should only be actively involved when there has been an adverse outcome. While there are many adverse outcomes which affect women, birthing people and families; to remain consistent with the Immediate and Essential Action in the Ockenden review, for the duration of the MNISA pilot phase, the criteria are as follows:

- Stillbirth after 24 weeks of pregnancy.
- Neonatal death in the first 28 days of life.
- Neonatal brain injury that has been diagnosed or suspected, including hypoxic-ischaemic encephalopathy (HIE).
- The death of the mother or birthing parent within a year of the birth or pregnancy ending.
- An unexpected or unplanned hysterectomy, within 6 weeks of birth or the pregnancy ending.
- The unexpected admission of a mother or birthing parent to a critical or intensive care unit, within 6 weeks of the birth or pregnancy ending.

7. Referral process

7.1. Referrals can be made by women, birthing people and families themselves, or on their behalf by health professionals and other people supporting them, providing that it is with the knowledge and permission of the woman or birthing person (or their partner in the event of maternal death).

7.2. An information leaflet is available which explains how an MNISA may be able to help, and how a referral can be made. The content of the leaflet has been co-produced with people who have lived experienced of adverse outcomes in maternity and neonatal care (led by the NHS England team), and an easy-read accessible version is also available.

7.3. Please visit the Mid and South Essex ICB website to access further information and make a referral. https://www.midandsouthessex.ics.nhs.uk/work/maternity/maternity-and-neonatal-independent-senior-advocate/

7.4. A referral does not commit the woman, birthing person, partner or family in any way to proceeding, and they can change their minds or withdraw at any time.

7.5. A response will be made to every referral, and this will be directed to the person who made the referral, to confirm safe receipt. If the family have given their permission, the MNISA will aim to contact the family within 7 working days of receiving the referral.

8. Supporting women, birthing people and families

8.1. Service contact and availability

8.1.1. The service will operate Monday to Friday (37.5 hours per week). An email mailbox and voicemail facility will operate outside of working hours. (See section 8.6 for arrangements in the absence of the MNISA).

8.1.2. Initial contact with women, birthing people and families will be via their preferred means as indicated on the referral form. Once in contact with the family, the MNISA will supply their email address and telephone number for subsequent communication.

Email	Phone or Text
mseicb-me.maternityandneonataladvocacy@nhs.net	**07934 106525**

8.2. Caseload and capacity

8.2.1. As a new service, it is difficult to predict the number of referrals that might be received. The aim will be to make early contact with each woman, birthing person or family, and initially meet them at a time and place that is acceptable and convenient to them. Subsequent contact will be led by their needs. At times of high activity, there may be a waiting period for this initial meeting, although the MNISA will still make contact to let them know this. Every effort will be made to keep waiting times to a minimum.

8.2.2. In the event of the number of referrals exceeding the capacity of the MNISA during the pilot phase, escalation should be via the ICB to the NHS England project team.

8.3. Consent and information sharing

8.3.1. NHSE has developed a standard operating procedure (SOP) document (see section 11) to be used by all MNISAs for gaining consent from women, birthing people, and families to record their information. They have also prepared a consent form (see section 11) which provides information to women, birthing people and families about the storage and use of their personal data. The purpose of the form is to gain consent from participants:

- To gather, store, use and share personal information (for example, name, address and health information), confidential information about them and their baby, and details of the contacts MNISAs have with the women and families.
- For MNISAs to work alongside women, birthing people and families to explore how their concerns might be addressed, for example by meeting together with clinicians in maternity services, by supporting them through complaints processes or by signposting to other services or sources of support.
- To use information about their case, which has had personal information removed, to help understand themes and trends raised, to be able to report progress of the pilot and to help understand the impact of the MNISAs work.

8.3.2. The consent form will be provided to the woman or birthing person, or their next of kin in the event of maternal death, by the MNISA after making initial contact.

8.3.3. The consent form is available as an electronic form which can emailed or sent electronically to the person to complete. Alternatively, a paper copy can be made available.

8.3.4. A data protection impact assessment has been conducted, and a joint controller agreement is in place between NHS England and MSE ICB. These are available separately from this document.

8.4. Accessibility and communication

8.4.1. Information about the service is available in multiple languages by using the accessibility tool (browser) on the webpage (see section 7.3). There is also an easy-read accessible version of the leaflet.

8.4.2. The referral form has been written in plain English, and is simple to complete. In the event that digital access or literacy may present a barrier to self-referral, the telephone contact number for the MNISA can be given (See section 8.1.3).

8.4.3. As long as the minimum details (name, contact details and preferred language and/or communication needs) are completed on the referral form, the MNISA will be able to make contact using an interpretation service.

8.4.4. The MNISA will explore any communication needs with people accessing the service, and these will be documented. As it will be necessary to discuss complex and sensitive information, professional interpretation services will be offered for every appointment for those that need them.

8.4.5. The MNISA will access the same interpretation and translation services used by Mid and South Essex Foundation Trust. This is being supported by the Interpreting and Translation Services Officer at MSEFT.

8.5. Case recording

8.5.1. All documentation by the MNISA will be recorded on a secure case recording management (CRM) system commissioned by NHS England for use during the pilot phase.

8.5.2. A privacy notice is in place alongside the online referral form, and this will be further explained as part of obtaining consent to proceed.

8.5.3. All confidential patient data gathered will be stored on the secure CRM system. The NHS England project team will have some access to the CRM but will only be able to view non-patient identifiable data for reporting purposes. Compliance with GDPR and Duty of Confidentiality regulations is set out in a joint controller agreement, which is available separately from this document.

8.6. MNISA absence and ‘buddy arrangement’ with neighbouring ICB

8.6.1. During periods when the MNISA is absent from work due to annual leave or sickness, the Outlook electronic diary and mailbox for the service can be accessed by another appointed member of the LMNS team, in order to screen for new referrals or enquiries that require an urgent response.

8.6.2. Generally, only the MNISA will have access to the CRM system for cases in Mid and South Essex. In exceptional circumstances, MNISAs may be granted access to a neighbouring ICB’s case record system to provide continuity of service in the event of unexpected or prolonged MNISA absence from work. This will be explained clearly to service users from the outset.

8.6.3. A SOP is in place which describes the reciprocal agreement between Mid and South Essex ICB and Suffolk and North East Essex (SNEE) ICB, and how the neighbouring MNISAs can provide support during periods of absence. This SOP and incorporated data protection agreement is available separately from this document.

8.7. Lone working

8.7.1. The MNISA will adhere to ICB lone working guidance when travelling and attending home visits or meetings in other locations with women, birthing people and families.

8.7.2. A lone working risk assessment has been completed, which includes mitigation of risks where applicable. This will be reviewed and updated annually, in line with ICB policy.

8.8. Conflict of interest

8.8.1. The risk of encountering a conflict of interest (COI) during the pilot is low because the MNISA who has been employed for MSE does not live in the ICB area and has never worked for any of the organisations within the ICB, or accessed care as a service user themselves. If the MNISA has previously had any personal involvement in the provision or review of care, this is regarded as a COI.

8.8.2. There is a small risk that a conflict of interest could be encountered through providing support for the ‘buddy’ LMNS Suffolk and North East Essex. This is because the MNISA for MSE has worked previously at one of the providers there.

8.8.3. In the event that a COI is identified, the MNISA for MSE will not be able to provide independent advocacy support in these cases. This is regrettable, but as this is a pilot and MSE and SNEE are the only two ICBs participating, there will be no alternative.

8.8.4. In the event that such a COI is identified, an explanation and apology will be offered to the service user/s affected, and their service will be resumed when the named MNISA for SNEE is available.

9. Reporting and escalation

9.1. Routes for reporting and escalation have been agreed by the ICB in consultation with Mid and South Essex Foundation Trust, and are detailed in the appendices of this policy.

9.2. The MNISA will regularly attend MNVP, Trust and ICB meetings and forums to report progress, and share feedback about care from women, birthing people and families who have given their permission for their experiences to be shared. See Appendix A.

9.3. There are a range of circumstances in which issues arising from the care that women, birthing people and families have received, or identified through the work of the MNISA may need to be escalated.

9.4. Some queries or issues may be able to be resolved without formal escalation, through discussion with the relevant team members at the provider Trust.

9.5. When formal escalation is required, the MNISA will follow the pathways detailed in Appendices B and C.

9.6. When formally escalating any issues or concerns, the MNISA will liaise with maternity and neonatal service leads. At each stage of escalation, everyone who was previously involved will be notified.

10. Evaluation

10.1. To take away maximum learning from this pilot phase, an external independent evaluation has been commissioned to help inform the decision about whether to adopt this model after the pilot, and if so how roll out of the MNISA role might take place. Details about the evaluation can be found in the NHS England operational guidance for the MNISA pilot.

11. Arrangements for Review

11.1. This policy will be reviewed in conjunction with the pilot evaluation which is expected to conclude in March 2025. An earlier review will be carried out in the event of any relevant changes in legislation, national or local policy/guidance, organisational change or other circumstances which mean the policy needs to be reviewed.

11.2. If only minor changes are required, the sponsoring Committee/Board has authority to make these changes without referral to the Integrated Care Board. If more significant or substantial changes are required, the policy will need to be ratified by the relevant committee before final approval by the LMNS Steering Board.

12. Associated Policies, Guidance and Documents

Advocacy QPM Code of Practice, Revised edition, 2014

Associated NHS England Policies for the pilot programme

- Maternity and Neonatal Independent Senior Advocate Pilot Phase – Operational Guidance
- Maternity and Neonatal Independent Senior Advocate Pilot Phase – Communications Toolkit for ICB's and Trusts
- Maternity and Neonatal Independent Senior Advocate Pilot Phase – Standard Operating Procedure – Seeking Informed Consent
- Maternity and Neonatal Independent Senior Advocate Pilot Phase – Women and Families Consent Form

Associated ICB Policies

- Lone worker policy
- Conflict of interest policy
- Reciprocal agreement with SNEE, including DSA (data sharing agreement)

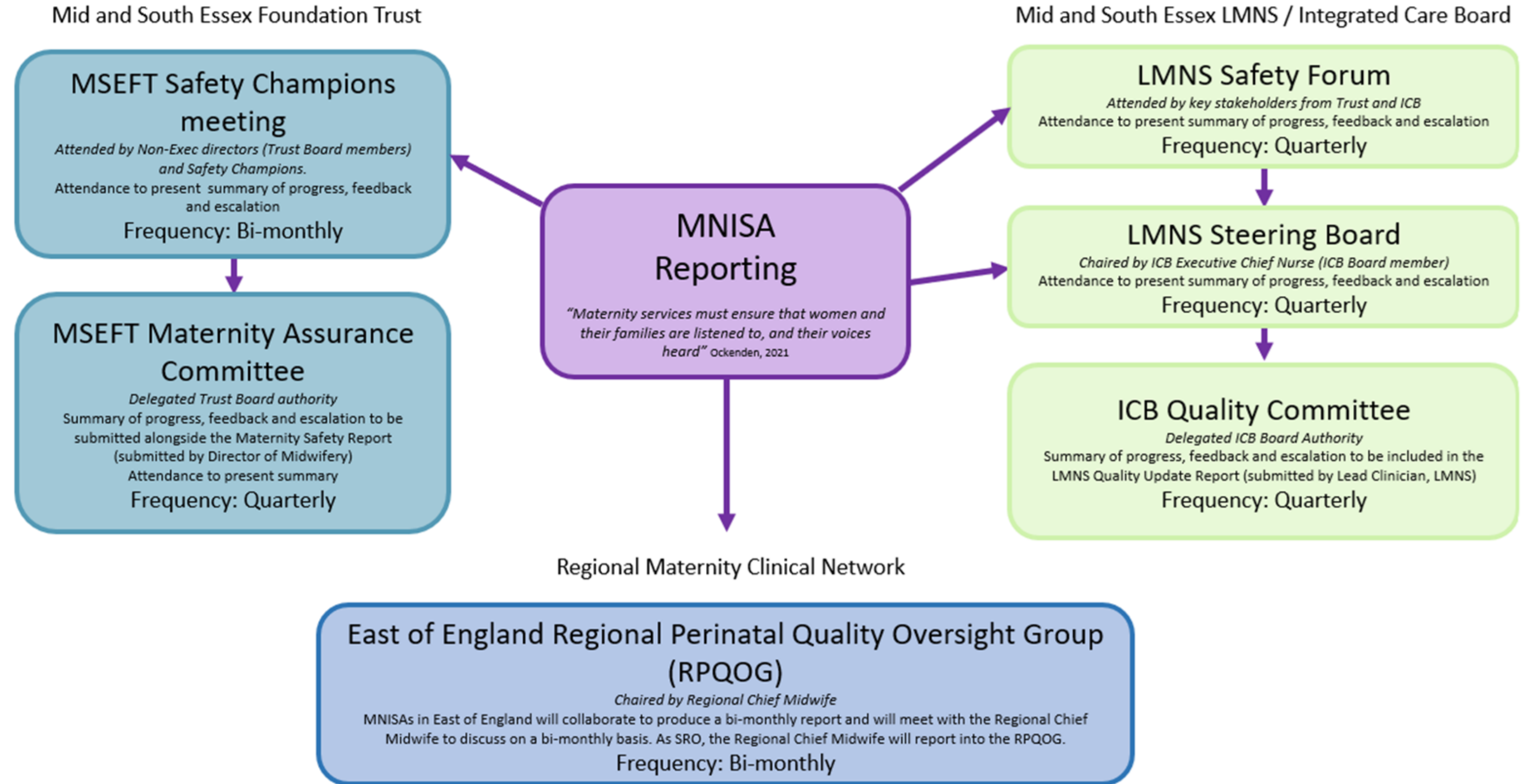
The above documents are available on request, please email s.paxman@nhs.net

13. Equality Impact Assessment

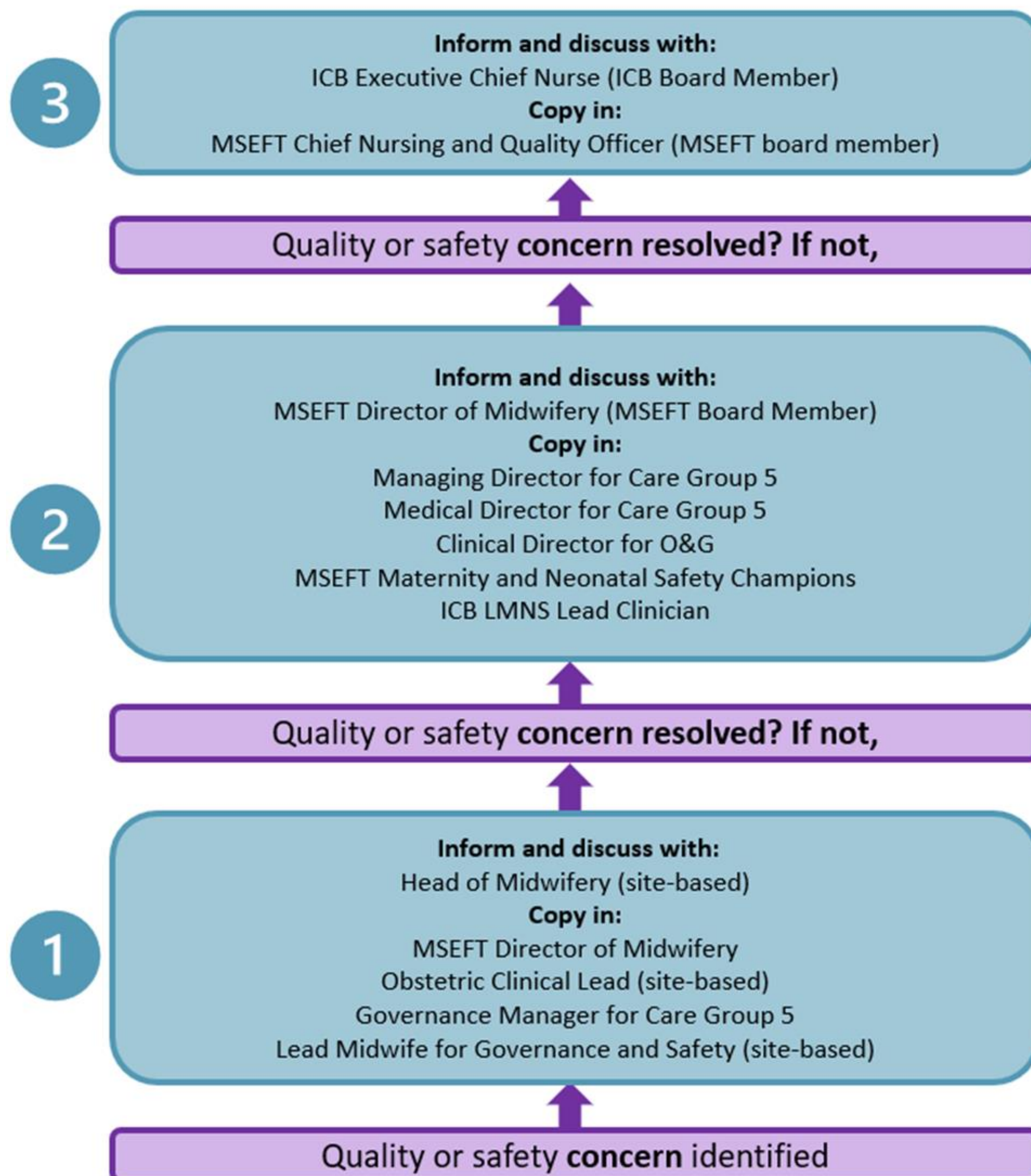
13.1. The EIA has identified no equality issues with this policy.

13.2. The EIA has been included as Appendix D.

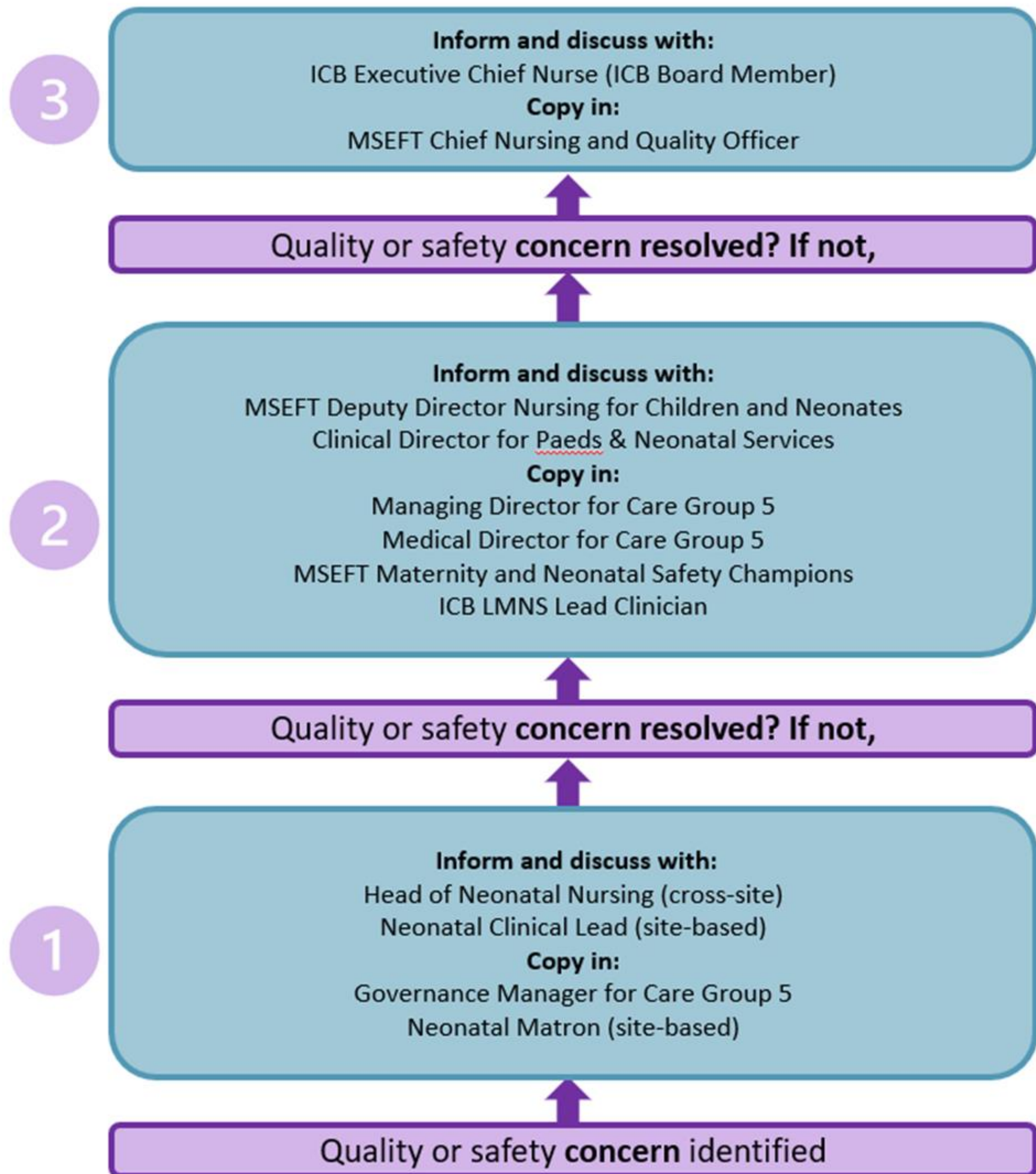
Appendix A – Reporting flowchart



Appendix B – Escalation flowchart (Maternity)



Appendix C – Escalation flowchart (Neonatal)



Appendix D - Equality Impact Assessment

INITIAL INFORMATION

Name of policy and version number: Maternity and Neonatal Independent Advocacy Service: Pilot Phase Version 1	**Directorate/Service**: Local Maternity and Neonatal System (LMNS)
Assessor's Name and Job Title: Sarah Paxman Maternity and Neonatal Independent Senior Advocate	**Date:** 28/02/2024

OUTCOMES
Briefly describe the aim of the policy and state the intended outcomes for staff

The aim of this policy document is to explain how Mid and South Essex are participating in an NHS England pilot. This policy helps Trust and ICB staff to understand specifically how the role will function in Mid and South Essex, introducing the appointment MNISA, detailing the referral criteria and describing how to make a referral, and how the MNISA will support women, birthing and families, and how the MNISA will report back and escalate concerns to the Trust and ICB.
EVIDENCE
What data / information have you used to assess how this policy might impact on protected groups?
As an organisation, the ICB regularly monitor the demographics of their workforce, including protected groups.
Who have you consulted with to assess possible impact on protected groups? If you have not consulted other people, please explain why?
• NHS England have co-produced this pilot with MNVP and service user representation, as well as consultation with representatives of minority groups. • MSE ICB Governance Leads • Chief Finance Officer • Human Resources • Director of Quality and Nursing

ANALYSIS OF IMPACT ON EQUALITY

The Public Sector Equality Duty requires us to **eliminate** discrimination, **advance** equality of opportunity and **foster** good relations with protected groups. Consider how this policy / service will achieve these aims.

N.B. In some cases it is legal to treat people differently (objective justification).

- ***Positive outcome*** *– the policy/service eliminates discrimination, advances equality of opportunity and fosters good relations with protected groups*
- ***Negative outcome*** *– protected group(s) could be disadvantaged or discriminated against*
- ***Neutral outcome*** *– there is no effect currently on protected groups*

Please tick to show if outcome is likely to be positive, negative or neutral. Consider direct and indirect discrimination, harassment and victimisation.

Protected Group	Positive outcome	Negative outcome	Neutral outcome	Reason(s) for outcome
Age			X	No impacts identified
Disability (Physical and Mental/Learning)			X	As above. ICB policies can be made available in alternative formats on request.
Religion or belief			X	No impacts identified

Protected Group	Positive outcome	Negative outcome	Neutral outcome	Reason(s) for outcome
Sex (Gender)			X	No impacts identified
Sexual Orientation			X	No impacts identified
Transgender / Gender Reassignment			X	No impacts identified
Race and ethnicity			X	As above. ICB policies can be made available in alternative formats on request.
Pregnancy and maternity (including breastfeeding mothers)			X	No impacts identified
Marriage or Civil Partnership			X	No impacts identified

MONITORING OUTCOMES
Monitoring is an ongoing process to check outcomes. It is different from a formal review which takes place at pre-agreed intervals.
What methods will you use to monitor outcomes on protected groups?
Relevant incident reporting data and Staff Survey results will be used to monitor the effectiveness of this policy.

REVIEW
How often will you review this policy / service?
Every 2 years as a minimum and earlier if there are any significant changes in legislation, policy or good practice.
If a review process is not in place, what plans do you have to establish one?
N/A