# Management of Surrogacy

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| **Summary statement: How does the document support patient care?** | To ensure good planning for surrogate parents and the children of surrogate parents and a robust sensitive plans in place for antenatal planning, labour and postnatal period. |
| **Staff/stakeholders involved in development:** | Safeguarding midwives |
| **Division:** | Women and Children's |
| **Department:** | Maternity |
| **Responsible Person:** | Chief of Service |
| **Author:** | Safeguarding Midwife |
| **For use by:** | All healthcare professionals irrespective of grade, level, location or staff group involved in caring for patients where a surrogacy is planned. |
| **Purpose:** | To ensure there is a robust sensitive plan in place for antenatal planning, labour and postnatal period for surrogacy pregnancies. |
| **This document supports:** | https://portal.hfea.gov.uk |
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| Version | Date | Author | Status | Comment |
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| 1.0 | June 2023 | Sarah Barwick, Safeguarding Midwife (SRH&WH) | Archived | New Trust wide guideline adopted from Legacy East's Surrogacy Guideline. |
| 1.1 | September 2023 | CE Team | Live | Merged approval with Legacy East. Replaces:<br>• MP029 Management of Surrogacy (Legacy East)<br>• CG15022 Surrogacy (legacy West) |

**The interpretation and application of clinical guidelines will remain the responsibility of the individual clinician.**
**If in doubt contact a senior colleague or expert.**

## Contents

# Management of Surrogacy

## 1.0 Aim

The purpose of this guideline is to ensure good planning for surrogate parents and the children of surrogate parents and to ensure there is a robust sensitive plan in place for antenatal planning, labour and postnatal period.

## 2.0 Scope

All healthcare professionals irrespective of grade, level, location or staff group involved in caring for patients where a surrogacy is planned.

This guidance is relevant to:

- Obstetricians
- Gynaecologists
- Paediatricians
- IVF Practitioners
- Midwives
- Neonatal nurses.

## 3.0 Responsibilities

In the event of a request for surrogacy all staff should be aware of the law regarding surrogacy, the Department of Health guidance and the rights of the parties involved.

Midwives and Obstetricians are expected:

- To access, read, understand and follow this guidance.
- To use their professional judgement in the application of this guideline.

Midwifery management are expected:

- To ensure the guideline is reviewed as required in line with Trust and National Recommendations.
- To ensure the guideline is accessible to all relevant staff.

## 4.0 Abbreviations used within this guideline

| | |
|---|---|
| **IPs -** Intended Parents | **PO -** Parental Order |
| **HFEA -** Human Fertilisation and Embryology Authority | **PR -** Parental Rights |
| **NIPE -** Newborn & Infant Physical Examination | **NHSP -** Newborn Hearing Screening |
| **TMBU -** Trevor Mann Baby Unit | **SCBU** - Special Care Baby Unit |
| **MIS -** Maternity Information System eg Badgernet | |

## 5.0 Principles

Offer care in a non-judgmental and supportive manner: with an overarching approach to understand that surrogacy is unique maintain accurate and contemporaneous records of discussions and decisions reached.

Confidentiality is vital and disclosure should be made on a need to know basis. Any reference to the surrogacy arrangement in the medical notes should only be made after discussion with and permission from the surrogate person.

The needs of the surrogate person should always be a priority and all (final) decisions rest with them. Information requested by the commissioning parents must be sanctioned by the surrogate and documented in the medical notes.

## 6.0 Definitions

### 6.1 Surrogacy

Surrogacy is the practice whereby one woman and person (the surrogate person) becomes pregnant, carries and gives birth to a child for another person(s) (the commissioning couple). This is as the result of an agreement prior to conception that the child should be handed over to that person after birth.

There are two types:

- **Straight Surrogacy:** Also known as genetic or traditional surrogacy is when the surrogate provides her own eggs to achieve the pregnancy. One of the IPs provides her own eggs to achieve the pregnancy. One of the IPs provides a sperm sample for conception either by home-insemination away from a licenced setting or artificial insemination with the help of a fertility clinic. Home-insemination does carry risks if the sperm has not been screened for infections. Embryos may be created in vitro and transferred into the uterus of the surrogate through a UK clinic.
- **Full Surrogacy:** Also known as host, gestational surrogacy is when the surrogate doesn't provide her own egg to achieve the pregnancy. In such

pregnancies, embryos are created invitro and transferred into the uterus of the surrogate using the gametes of at least one IP, plus the gametes of the other IP or a donor, if required.

### 6.2 Commissioning couple (Intended parents)

The commissioning couple are the people who wish to bring up the child after his or her birth. They may both be the genetic parents, or one of them may be, or neither of them may be genetically related to the child. The woman and person for whom the child is to be carried (the 'commissioning mother') may be the genetic mother in that she provides the egg. The genetic father may be the husband or partner of the commissioning mother, or he may be an anonymous donor. (DOH 1998). Intended parents who have no genetic connection to the child are not able to access the parental order and therefore extinguish the surrogate legal responsibility. It is therefore important for the surrogate/IP to seek legal advice.

## 7.0 Accountabilities and responsibilities

Whilst the confidentiality of the commissioning and surrogate parents should be upheld there will need to be certain communications to ensure staff are not complicit in any illegal act and that all health staff, who need to know, are informed. Please see flowchart in Appendix 1.

## 8.0 Surrogacy and the law

The legal framework for surrogacy is the Surrogacy Arrangements Act of 1985, amended in the Human Fertilisation and Embryology Bill of 2007. The intentions of the Surrogacy Arrangement Act of 1985 are summarized below:

8.1 Surrogacy is an agreement arranged before the pregnancy begins, with intent for another person to assume parental rights. Pregnancy is determined to begin at the time of insemination or embryo transfer.

8.2 No person with any commercial interest in the surrogacy arrangement may initiate or negotiate any part of the surrogacy proceedings.

8.3 It is illegal to advertise to seek or become a surrogate, through any form of the UK media.

8.4 Any person breaching (8.2) and (8.3) above is liable for punishment, either a fine or by imprisonment.

8.5 Should staff become suspicious that the parties are involved in a commercial arrangement, they should contact the Lead for Safeguarding children for further advice and guidance.

The 2007 amendments clarify that non-profit making organisations (such as the agencies which have a strong prevalence in many agreements today) are allowed to take part in the

negotiations necessary for a successful surrogate pregnancy. Non-profit making organizations are allowed to advertise their services.

Surrogacy UK website provides detailed advice on all aspects of surrogacy: http://www.surrogacyuk.org/ http://www.surrogacyuk.org/Downloads/Guide to Surrogacy UK for Healthcare Professionals.pdf

## 9.0 Parental responsibility: Who are the child's legal parents?

The Human Fertilisation and Embryology Act 1990 (2) section 27, states that the legal mother is always the surrogate mother regardless of genetic makeup and she is legally responsible for the child until such time as the intended parents seek a parental order.

The surrogate has the legal right to keep the child, even if it is not genetically related to her. Surrogacy arrangements are not legally enforceable, even if a contract has been signed and the expenses of the surrogate have been paid.

The surrogate will be the legal mother of the child unless or until parenthood is transferred to the intended person through a parental order. This is because, in law, the surrogate who gives birth is always treated as the mother or person.

There are two methods through which parental responsibility may be transferred.

1. A parental order can be made if the case satisfies section 30 of the Human Fertilisation and Embryology Act. The criteria for accessing the PO are based on an enduring relationship not on marriage. It can also be accessed for solo parents via a remedial order.

2. An application may be made to adopt the child under the Adoption Act 1976.

UH Sussex staff should ensure that if there is any cause for concern that they take advice from the Safeguarding children's named doctor or nurse / midwife.

### 9.1 Same sex couples:

Marriage (same sex Couples) Act 2013 set up a framework to allow same sex couples to achieve legal recognition of their relationship. Therefore same sex couples are able to apply for the parental order.

### 9.2 Foreign commissioning parents and British Surrogate

If neither commissioned parents is domiciled in the UK, they will not be eligible to apply for a parental Order. It would be critical that the parents and the surrogate obtain legal advice as adoption could contravene international adoption rules. Adoption would therefore be the only

available option to obtain legal parenthood. It would be important to get legal advice on the legal status of any child born through surrogacy by non-domiciled intended parents.

## 10.0 Procedures and actions to follow

The immediate postnatal period is a time of great emotional upheaval, which may be compounded in a surrogacy arrangement and great sensitivity is required in handling both the surrogate and commissioning parents. Where there is conflict the midwife must focus their care on the surrogate person and baby.

- A child born to a surrogate must be registered as her child.
- The commissioning parents, having assumed care of the child, have no legal relationship with it and no rights in law until a parental order has been made or unless the commissioning father is named on the birth certificate.
- The HFEA advises that, until the parental order comes into force, strictly speaking it is the legal surrogate who should give consent for screening of the newborn.
- Commissioning or intended parents will apply for a parental order (if the genetic makeup of the baby comes from either or both of them) or an adoption order where gametes from either of the commissioning parents have not been used. Until this time (6 weeks – 6 months) the legal mother is the surrogate.
- Handing over the baby will take place following discussion and agreement with the surrogate mother as the birth plan guide.
- The surrogate is cared for as per routine postnatal care guidelines. The woman and person's GP is notified of their discharge home.
- The commissioning mother/person and baby are notified to the appropriate community midwife, health visitor and GP. They may be prescribed Metoclopramide 10 mg tds from 27 weeks of the host surrogate pregnancy to be able to breast feed the baby. The commissioning mother can also start to double pump from 26 weeks of the host surrogate pregnancy.

As the Surrogate Mother and person is the legal mother at birth, the baby cannot be removed from the hospital by the commissioning parent(s) without her consent. The arrangements will have been made by the surrogate and IPs during the antenatal period and ideally a birth plan is will be in place for staff to follow. This ensures that Staff should consider whether the Duty Social Worker should be informed of the Surrogacy arrangement to ensure that both the Surrogate Mother and the commissioning parent(s) are able to receive support and advice in the post natal period where appropriate.

The commissioning parent(s) should not be admitted as a patient of the Trust. If the surrogate mother requests that the commissioning parent(s) be permitted to stay with her until the baby is discharged, this should be accommodated and recorded on MIS.

Where, following birth, the Surrogate Mother delegates responsibility for the child to the Intended Parents, this should be written clearly in the medical notes. If this is the case, wherever possible, the intended mother may be accommodated separately with the baby in

a side room on the postnatal ward. Parenting support and advice will then be provided to the commissioning parent(s) until the baby is discharged. This arrangement must be recorded in the surrogate mothers notes on MIS and also the baby's notes on MIS, stating that this is the request of the surrogate mother. The commissioning parent(s) presence on the ward should then be recorded in the ward day book. If this is not possible, owing to capacity, the baby will be transferred for care in TMBU /SCBU where the commissioning parent(s) may visit in place of the surrogate mother.

### 10.1 Community midwife

- The midwife should be informed of the status of the pregnancy this will be documented on MIS.
- It is important for the midwife at booking to ascertain who are the baby's biological parents, including where relevant, details of the donor sperm and / or egg. This will be relevant in order to assess relevant family history and risk assess for inherited diseases. For combined screening and the quadruple test, risk assessment is based on the age of the biological mother.
- The midwife should establish whether the surrogate mother is married. If she is married then she and her husband hold parental responsibility until the legal process of transfer PR is complete.
- If the surrogate mother is not married the midwife should establish that the (commissioning donor) father is registered on the baby's birth certificate when the baby is born. Only then will he hold parental responsibility.
- The midwife should notify the health visitor and GP of the baby's status as above so that any consents required will be requested from the person holding parental responsibility (see section 8 & section 9). This is particularly important for the early immunisations which are due before the legal process may have been finalised or if the baby requires immediate/ early surgery or treatments.
- It may be relevant for the midwife to complete safeguarding procedures.
- It is important to recognise that the Trust's duty of care is to the Surrogate Mother. The Trust owes no duty to the commissioning parent(s). All applicable antenatal care should be provided to the Surrogate Mother in the usual way. The commissioning parent(s) can be involved in this process provided that the Surrogate Mother consents to this" and "The Surrogate Mother has the right to make all decisions relating to her antenatal care. It is important to remember that the child is not recognised as a "person" until birth and therefore, the rights of the mother should take precedence over the interests of the unborn child.

### 10.2 Medical Staff / Nursing and Midwifery

When a baby is to be discharged and transferred to the commissioning parents who live in another part of the country, staff should ensure that the health staff in the new area are aware of the status of the baby and that there is full communication with the new area midwife and health visitor.

If any staff identify that the due legal process has not been followed they should notify the police.

If any staff have concerns for the safety or welfare of the baby they must follow the Sussex Safeguarding and Child Protection Procedures and make a referral to the appropriate local Children's Social Care and notify the Safeguarding Children's Named Doctor/ Nurse/Midwife.

The Consultant Midwife can be contacted for support and/or a referral made into the Consultant Midwife Clinic for review, with complex care planning within pregnancy and birth.

## 11.0 Mental capacity of the surrogate mother to make decisions

Should staff have any concerns regarding the mental capacity of the Surrogate Mother to make decisions about her pregnancy, a formal assessment of capacity should be performed (staff are advised to follow the Trust's consent policy).

In the event that the Surrogate Mother lacks capacity to make a particular decision, treatment should be given having regard to the best interests of the Surrogate Mother – however, staff are advised to consult the Trust's Lead on the Mental Capacity Act prior to administering non-emergency treatment in such circumstances.

## 12.0 Termination of pregnancy

A surrogate has the right to a termination. The intended parents have no right to prevent a termination taking place. The intended parents should not be informed about a termination unless the surrogate has given consent for this information to be shared.

## 13.0 What if the surrogate mother changes her mind?

If the Surrogate Mother changes her mind and wishes to keep the baby, the Trust must respect her wishes. In this situation, the Courts will usually allow her to keep the baby. If there is disagreement between the Surrogate Mother and the commissioning parent(s), the Lead for Safeguarding Children should be contacted.

## 14.0 What if the intended parents change their mind?

If the intended parents change their mind about taking the child for whatever reason, the surrogate (and her husband/wife) will be legally responsible.

## 15.0 What happens if there is a dispute between the intended parents and the surrogate?

The trust should attempt to work with the surrogate and the intended parents at all times. Should a dispute arise, the surrogate's wishes should be respected at all times and staff may wish to consider contacting the Lead for Safeguarding children for further advice and guidance.

If the intended parents attempt to remove the baby from trust premises against the surrogate wishes, staff should consider informing the Police, subject to the consent of the surrogate.

**Should staff have any concerns about the welfare of the baby staff should follow standard safeguarding procedures.**

## 16.0 What if the child becomes ill and is in need of treatment?

Where possible, decisions about the baby's treatment should be made jointly, by the Surrogate and the commissioning parent(s) in conjunction with the health professionals. In most circumstances, the Surrogate will hand over responsibility to the Intended Parents on an informal basis, at birth. However, the surrogate remains legally responsible for the baby until a Parental Order has been confirmed or the baby has been legally adopted by the commissioning parent(s). The commissioning parent(s) have no legal rights over the baby until this time.

Therefore as a matter of law, even where the surrogate has delegated the care of the baby to the intended parents, this does not mean that she relinquishes all legal rights or responsibilities to the baby or that the intended parents automatically assume the legal right to make decisions about the baby.

In the event of any dispute between the surrogate and the attended parents, it is the surrogate mother who has parental responsibility in law to consent/refuse treatment on behalf of the child. One of the intended parents may share parental responsibility if registered on the child's birth certificate.

Typically there is a good relationship between the surrogate and IPs and this will have been discussed in the antenatal period (birth planning meeting) and the IPs will be part of that decision making.

## 17.0 Further information and support

Further information for surrogates and intended parents is provided in the Department for Health and Social Care guide- Surrogacy: legal rights of parents and surrogates: Overview - GOV.UK (www.gov.uk)

Information on surrogacy, previous and current research and updates on the legal guidelines for surrogacy is accessible via the Surrogacy Solicitors - Surrogacy Lawyers & Legal Advice - NGA Law and Brilliant Beginnings - Surrogacy in the UK and abroad websites

## 18.0 Monitoring

To provide annual audit reviewing any surrogacy cases for the year to determine if correct pathway was followed.

## References

Arrangements for Payments And Regulation. DH 1998
Surrogacy guidance for intended parents: pre-surrogacy, pre-birth and post-birth - GOV.UK (www.gov.uk)

Human Fertilisation and Embryology Authority. Code of Practice
https://portal.hfea.gov.uk

Surrogacy UK http://www.surrogacyuk.org/ Home - SurrogacyUK

www.hfea.gov.uk/399.html#guidanceSection3945: Legal parenthood: surrogacy **Appendix**

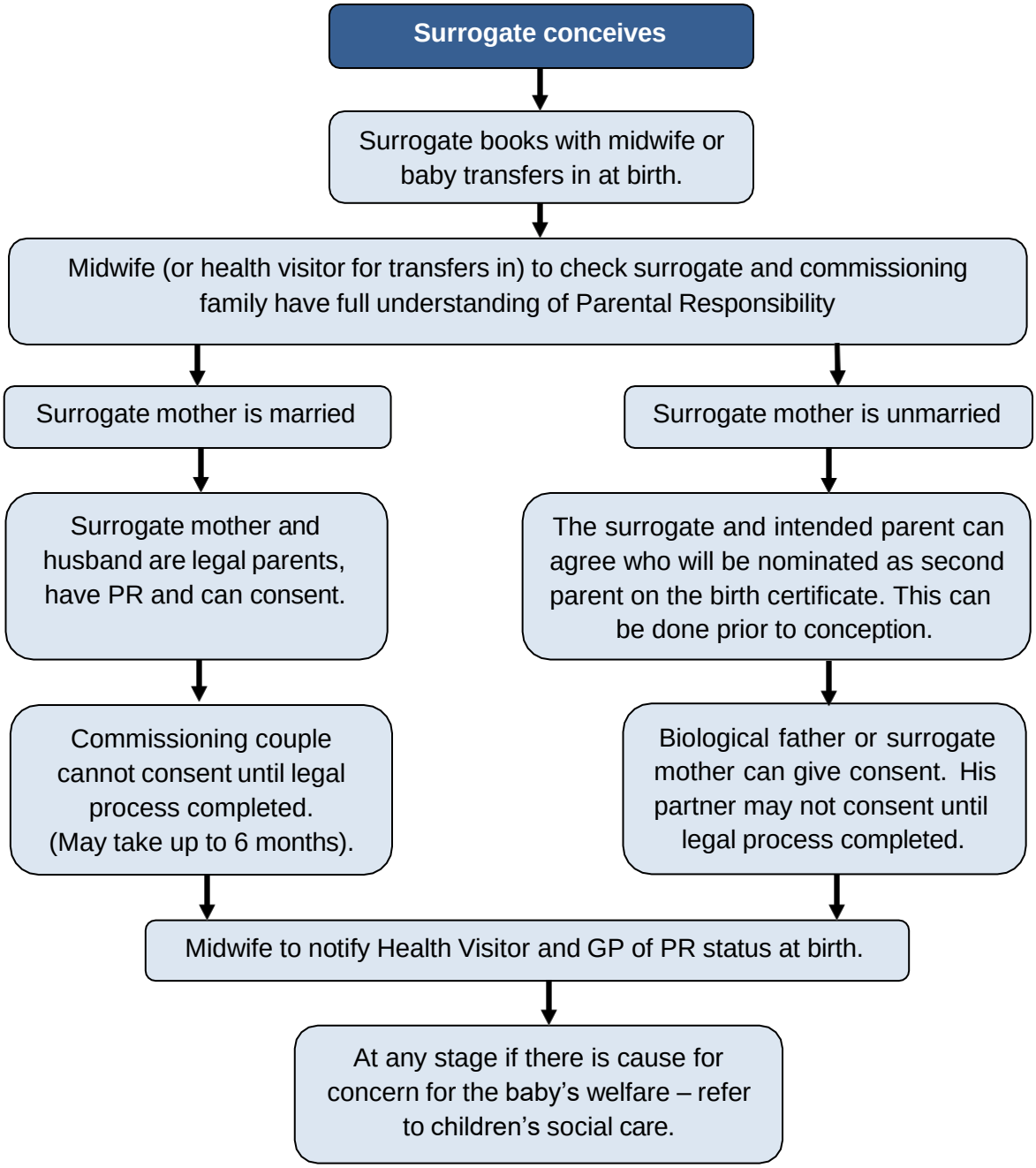
COTS Surrogacy in the UK. www.surrogacy.org.uk
The Adoption & Children Act 2002

Reame, N E & Parker, P J (1990) surrogate pregnancy: clinical features of 44 cases. American Journal of Obstetrics and Gynecology 16(2): 1220-1225 Civil partnership act 2004

Cafcass, G. T. (2021). *Cafcass Parental Order Applications FOI.* London: Cafcass.

*NGA Law, Parenthood and parental orders*. (2019). Retrieved from Nga Law: https://www.ngalaw.co.uk/knowledge-centre/parenthood-and-parental-orders-surrogacy-law
*Protected Characteristics*. (2020, December). Retrieved from Equality and Human Rights Commission: https://www.equalityhumanrights.com/en/equality-act/protected-characteristics
Care in surrogacy: guidance for the care of surrogates and intended parents in surrogate births in England and Wales - GOV.UK (www.gov.uk)

## Appendix 1: Staff responsibilities in surrogacy flowchart



## Appendix 2: Surrogacy checklist

| **Booking appointment or when clinician becomes aware of surrogacy** | | | |
|---|---|---|---|
| Date Documentation related to surrogacy commenced | | | |
| Surrogate mother is married | | Yes | No |
| Names of the commissioning parents | | | |
| Who are the biological parents for screening purposes | | | |
| Is there a children's guardian allocated? | | Yes | No |
| HV informed of the surrogacy | | Yes | No |
| GP informed of the surrogacy | | Yes | No |
| **At birth & postnatal** | | | |
| The surrogate mother is cared for as per routine postnatal care guidelines. | | | |
| As the Surrogate Mother is the legal mother at birth, the baby cannot be removed from the hospital by the commissioning parent(s) without her consent. | | | |
| Does the surrogate mother agree the commissioning parents can visit/stay? (record in the notes) | | Yes | No |
| Does the surrogate mother delegate responsibility for the child to the commissioning parents … record on MIS | | Yes | No |
| Staff should ensure they have written consent from the Surrogate Mother before handing over the baby and that this is done, wherever practicable, in the presence of the Surrogate Mother and the commissioning parent(s). | | Yes | No |

| | | | |
|---|---|---|---|
| If the surrogate is not married the midwife should establish that the (commissioning donor) father is registered on the baby's birth certificate when the baby is born so he can have parental responsibility. | | Yes | No |
| HV informed of the birth | | Yes | No |
| GP informed of the birth | | Yes | No |
| Check address where baby is being taken to so the new HV/GP can be alerted. | | Yes | No |
| The commissioning mother/person and baby are notified to the appropriate community midwife, health visitor and G.P. | | Yes | No |
| New address | | | |

**Once completed scan form into MIS**

## Appendix 3: Surrogacy inclusive language in perinatal services

**Author** Teresa Coote- Brilliant Beginnings
**Internal reviewer** Caro Townsend- BSUH Maternity Voices Partnership Chairperson
**External reviewer** Natalie Gamble- NGA Law Director/Brilliant Beginnings co-founder

### Purpose of the Language Guide

This guide has been developed to accompany the trust policy for management of surrogacy. The guide seeks to clarify the dynamics between a surrogate and intended parents, so that perinatal care is inclusive for all, and acknowledges each person's position with regards to any child/children born through surrogacy under the trust.

### Significance of the Different Pathways to Parenthood

Childbirth is a period of significant vulnerability and growth, and we value all the intersecting identities that contribute to a person's experience of this, including but not limited to race, gender identity, sexuality, age, religion and ability. The people experiencing childbirth and the transition into parenthood, either as the birthing person, or as an intended parent, require care from midwives and fellow health professionals that is both inclusive and individualised, reflecting the pathway they have followed to this point.

A key legal aspect of surrogacy is the application to the courts for a parental order, completed by the intended parents of any child/children born. The parental order transfers the legal parenthood for the child from the surrogate (and her spouse if married) to the intended parents. (NGA Law, Parenthood and parental orders, 2019)

Parental order applications are one of the most reliable ways to track surrogacy births, both in the UK and internationally. The data is managed by Cafcass (Child and Family Court Advisory and Support Service), who are an independent advisory organisation that works with families and courts to ensure the safety and wellbeing of children in the UK on a range of cases, including surrogacy.

Since the Cafcass case management system was introduced in 2008, the number of parental orders, for both domestic and international surrogacy has continued to increase. During the first year of using the management system to record data, there were just 67 applications made. By 2018 this number had risen by four times the amount to around 280, with the majority of them relating to domestic surrogacy within the UK (England having the highest number of cases). Additionally, recent data shows that parental order numbers have continued to grow to above 300 applications in 2020, including 100 applications from same-sex couples and more than 20 from single parents who have pursued surrogacy as a route to parenthood. (Cafcass, 2021)

Until 2018 Surrey and Sussex recorded the third highest number of surrogacies, exceeded only by London and the Avon, Gloucestershire, Wiltshire and Thames Valley service area group (both of which have higher population figures). For the past three years, Surrey and Sussex have exceeded Surrogacy Inclusive Language in Perinatal Services the Avon, Gloucestershire, Wiltshire and Thames Valley service area group in the number of parental order applications granted by the courts.

## Legal Frameworks in Relation to Perinatal Care

### Equality Act

The Equality Act 2010 prohibits discrimination, harassment and victimisation of in the workplace and in wider society. It is designed to ensure people with certain 'protected characteristics' are not disadvantaged or subjected to unwanted conduct because of that characteristic. Public bodies (such as local authorities and NHS trusts) have an active duty to eliminate discrimination, harassment, and victimisation of anyone who is protected under the Act, and foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

One of the characteristics protected by the Equality Act is pregnancy and maternity. The care of any pregnant or birthing person should, at all times, meet standards as set out by wider Government and internal guidance and should seek to acknowledge the individual circumstances of the person being cared for.

### Specific Language Replacements

The following examples have been sourced from current documentation relating to perinatal care of surrogates and intended parents, and also from feedback on lived experiences from care provided within Surrey and Sussex health trusts.

**TABLE 1 when referring to the surrogate**

| Previous Term | New Term | Previous Example | New Example |
|---|---|---|---|
| Surrogate mother | Surrogate | "The midwife must focus her care on the surrogate mother" | "The midwife must focus her care on the surrogate" |

**TABLE 2 when talking to the surrogate**

| Previous Term | New Term | Previous Example | New Example |
|---|---|---|---|
| Your baby | The baby | "Plans need to be made for the birth of your baby" | "Plans need to be made for the birth or the baby" **or** "plans need to be made for your labour" |

**TABLE 3 when referring to the intended parent(s)** (where a biological link **is** present)

| Previous Term | New Term | Previous Example | New Example |
|---|---|---|---|
| Sperm donor | Biological father/dad | "We are able to test the sperm donor's blood" | "We are able to test the biological father's blood" |
| Egg donor | Biological mother/mum | "..... details of this surrogacy pregnancy by egg donor" | "…details of this surrogacy pregnancy using the mother's egg" |

**TABLE 4 when referring to the intended parent(s)** (where a biological link is **not** present)

| Previous Term | New Term | Previous Example | New Example |
|---|---|---|---|
| Intended mother/intended father Commissioning parent | Mother/mum Father/dad parent | "parenthood is transferred to the intended mother" | "parenthood is transferred to the parent through a parental order" |

**Note**: the use of the collective term "intended parents" in documentation is acceptable.

**TABLE 5 when speaking to the intended parent(s)**

| Previous Term | New Term | Previous Example | New Example |
|---|---|---|---|
| The baby | Your baby | "post-natal checks are recommended for the baby" | "post-natal checks are recommended for your baby" |

**Appendix 4: Surrogacy and newborn screening consent (SRH&WH only)**

# NEWBORN SCREENING CONSENT

Three newborn screens are offered, all details of these screens can be found in 'Screening Tests for you are your baby' which was issued to you antenatally. This booklet can also be found by scanning this QR code:

## 1. Newborn & Infant Physical Examination (NIPE).

The screening elements of the NIPE programme are:

- Eyes: approximately 2 or 3 in 10,000 babies have problems with their eyes that require treatment. The prime purpose of screening is to identify congenital cataracts.
- Heart: approximately 4-10 in 1,000 babies have a heart problem.
- Hips: approximately 1 or 2 in 1,000 babies have hip problems that require treatment.
- Testes: approximately 1 in 100 baby boys have problems with their testes that require treatment.

## 2. Newborn Blood Spot (NBS)

The screening elements of the NBS programme are:

- Sickle cell disease (SCD),
- Cystic fibrosis (CF),
- Congenital hypothyroidism (CHT)
- Phenylketonuria (PKU),
- Medium-chain acyl-CoA dehydrogenase deficiency (MCADD),
- Maple syrup urine disease (MSUD),
- Isovaleric acidaemia (IVA),
- Glutaric aciduria type 1 (GA1)
- Homocystinuria (pyridoxine unresponsive) (HCU)
- Severe combined immunodeficiency (SCID)

## 3. Newborn Hearing Screening (NHSP)

The screening element of the NHSP programme is:

- Permanent Hearing Loss: 2 in 1000 babies are born with a permanent hearing loss. This increases to 1 in 100 if baby has spent longer than 48hrs on a neonatal unit. No Clear Responses can be obtained from this screening due to a hearing loss, fluid/debris in the ear, baby was unsettled or it was too noisy. If a No Clear response is obtained from the AABR screen baby will be referred to Audiology for further testing. If there is a contraindication to screening, baby will be referred directly to Audiology. Contraindications are: Microtia, atresia, confirmed cCMV, bacterial meningitis, PVP shunt
- Information about your baby's visit to the audiology clinic can be found by scanning this QR code:

## Consent

For each screening programme the details of baby, the screening results and, if required, any tests following the screen will be kept on the NHS screening information system used by the NHS Newborn Screening Programme. The information will be shared with babies doctor, health visitor and other health professionals directly involved with the screening and with any subsequent investigations and treatment if required.

All staff that work in or with the NHS are required as a matter of law to keep information about you and your baby confidential.

An anonymised version of this information will be used for monitoring the success and evaluating the benefits of the screening programmes. All requirements of the Data Protection Act 2018 will be met during the storage and use of the data.

You may request and receive a copy of the information held about baby at any time.

If you choose not to take up this offer of screening, we will keep a record to show that we have contacted you and that you have declined the screen, and we will let babies GP and Health Visitor know that baby has not been screened.

**Please complete**

| | | | | |
|---|---|---|---|---|
| Surrogate Name | | | | |
| Surrogate Hospital number | | | | |
| Estimated due date | | | | |
| If completed postnatally | | | | |
| Babies Name | | | | |
| Babies Hospital number | | | | |
| Babies NHS number | | | | |
| | **YES/NO** | | **Signed** | **Date** |
| **NIPE screen consented** | | | | |
| **NBS screen consented** | | | | |
| **NHSP screen consented** | | | | |

**Midwife/doctor completing form:**

| **Date** | **Printed Name** | **Signed** | **NMC/GMC Number** |
|---|---|---|---|
| | | | |

**If completed antenatally please email a copy of the form to the postnatal screening failsafe clerk.*