Role Description for the “Parent and Public Involvement Virtual Group” for the GBS3 Trial

Title: Routine testing for GBS in pregnancy: the GBS3 Trial

Background

What is the GBS3 trial?

Group B Streptococcus is also known as GBS, Strep B or group B Strep. It is a common bacterium that normally causes no harm. In the UK, about 1 in 4 women carry GBS in their vagina and rectum (back passage) and are unlikely to know that they carry it. If they have GBS and are pregnant, the baby may be exposed to it around labour and birth. Whilst most babies won’t be affected, there is a small chance of their baby becoming seriously ill or even dying.

Researchers in Nottingham and around the UK, in collaboration with the National Childbirth Trust (NCT) and Group B Strep Support (GBSS) charities, are looking at whether routinely testing pregnant women for group B Streptococcus (GBS) carriage reduces the risk of infection in newborn babies compared to the current policy in place in the UK.

The current policy in the UK is to offer antibiotics during labour to women whose newborn babies are considered to be at a raised risk of developing GBS infection, but not to offer pregnant women testing for GBS carriage. We will be comparing the current policy against two different strategies each of which uses a GBS-specific test to guide the offer of antibiotics:

- Laboratory Test at approximately 3-5 weeks before expected due date or planned induction of labour (Enriched Culture Medium or ECM Testing)
- Bedside Test at start of labour (Intrapartum Rapid Testing)

Each hospital involved in the trialwill be randomly allocated to undertake one of the three strategies. This means that all women who are pregnant and give birth at that hospital will, unless advised otherwise by their doctor or midwife, will follow the same strategy throughout the hospital:

- Current 'risk-based' strategy (usual care in the UK)
- Enriched Culture Medium (ECM) testing (Laboratory Test)
- Intrapartum rapid testing (Bedside Test)

We are hoping to involve 320,000 women and babies in 80 hospitals across England, Scotland and Wales. We also want to speak to about 50 new mothers and 30 healthcare professionals about their experience and thoughts about the actual testing process.

All information needed by the trial will be come from the health care records of the mother and baby, from hospital laboratories and from the interviews.

The trial is being funded by the National Institute of Health Research (NIHR), which is the research arm of the NHS.

What is the role of the virtual Parent and Public Involvement (PPI) Group?

The aim of the virtual PPI group is to provide a public perspective on the trial in order to obtain a range of knowledge, perspectivesand expertise that can contribute to the research.

The PPI group will advise the research team on:

a. Documents and participation leaflets aimed at the public and for healthcare professionals (midwives, doctors)
b. Specific aspects of the research relevant to their expertise, experiences and knowledge
c. Using information routinely collected during pregnancy and childbirth and about the baby's health

Your views will help shape this work and you don't need to have medical knowledge or an academic background to take part. We simply need you to help us understand how we can make our research parent and baby-friendly. Your experiences of pregnancy, GBS and your treatment will help us understand what it might be like for any parents involved in our trial. We also want to hear your thoughts about the information we need to collect on mothers and babies, and how we plan to use it. We want to make sure that parents can easily understand and support this trial and your experiences will help us to do this. To help facilitate discussions in an open and supportive environment for parents, there are two separate GBS3 Facebook groups.

The first group is for pregnant women and parents who have been directly affected by illness in their babies caused by group B Strep and the second group is for pregnant women, their partners and for parents who have no previous experience of group B Strep.

Who else will be in the group?

Other parents, representatives from the trial team, and representatives from the National Childbirth Trust (NCT) and Group B Strep Support (GBSS) charities.

What would I need to do if I was part of this group?

We would like you to tell us what you think of our trial. The GBS3 team will ask specific questions within the virtual group. This will include things like what we should include in any leaflets or questions about how we can support any parents involved. From time to time, we may also ask for your views and feedback on other research or trials related to the GBS3 trial.

We will conduct all the discussion using a closed Facebook group. This means that the group is visible to the public, but only members can see the posts. To join the group, you would need a Facebook account. You can use any existing account or set up a new profile. We will need to know your profile name in order for you to be involved in the group. Apart from the researchers and representatives from GBSS and NCT, only people who have consented to join the group will be invited to join.

We understand that life is busy and that your time is precious so you are welcome to provide your opinion and feedback to the questions as often or as little as you would like. Your participation is voluntary and you are free to leave the group at any time, without giving a reason.

What would I need to talk about?

We want to understand what parents and expectant parents might think about our research. When we ask for your feedback we would like you to think about it from your experience and tell us what might be more or less helpful.

We aim for the group to be a safe space that will enable interesting and positive conversations. However, during our online discussions we might be talking about topics that may bring back memories and you might find this difficult or upsetting. It is important for you to think about how comfortable you are talking about these topics before you apply to be a member of the group.

Even if you think it will help our trial, it is important to put yourself first. If any of the topics of the meetings are upsetting for you, get in touch with one of the group administrators and they will signpost you to other services that might be able to provide support.

Can I tell my family/ friends about my role on the PPI group?

It is okay to tell your family and friends that you’re taking part in a panel for a research project about testing for GBS in pregnancy. However, we ask that what is discussed in the online discussion group is not shared with anyone else. This includes anything relating to which hospitals might be taking part in the trial and information contained in any documentation you read.

What support will we give you?

You can talk to us at any point if you need any support. If you find any of the topics discussed upsetting, please get in touch with one of the administrators of the group. The GBS3 Facebook group will be a space for members to share their views and we aim for this to be a positive experience. Because issues around Group B Strep can be sensitive, we are aware it is possible that comments could trigger traumatic or unwelcome memories or thoughts. If this is the case, please get in touch with one of the administrators and we will do our best to help.

While we think it is unlikely, it is possible that there may be offensive or inappropriate comments on the group. The group admins will monitor the group for such comments and will delete them and potentially remove the member who posted such comments. We cannot guarantee to remove any such comments before anyone sees them, but you will be able to help us by flagging inappropriate comments.

How will my privacy be maintained?

The platform for sharing your views will be a closed online Facebook group, which means that other members of the group can see what you have written. Non-members can see that you are part of the group, but not what you have written. This is to protect your privacy, although you are responsible for your overall privacy settings on your profile. In addition, all data shared on Facebook is governed by the terms of contract between yourself and Facebook.

Quotes from the group may be used by the researchers but your name and any other personally identifying details about you will not be linked to these comments.

You can find out more about how we use your information and read the University of Nottingham privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx. The GBS3 trial specific privacy notice is available to view on our website www.GBS3 trial.ac.uk.

Payment and expenses:

There will be no payment or expenses for taking part in the virtual PPI group.

Next Steps:

Thank you for taking the time to read this information sheet. If you would like to become a member of the group, please complete the GBS3 Trial Parent and Public Involvement Group Agreement. Once you have submitted the agreement, please request to join one of the groups on facebook which is most suitable for your situation (links to both groups will be provided upon completion of the agreement) and a member of the team will be in touch.

If you have any questions please contact us: GBS3@nottingham.ac.uk