

Participant Information Sheet for Parents

The title of this research study is: Mapping multiple birth care during the first 1,001 critical days: a World Café method study

What is this research aiming to find out?

Our previous research has led us to understand that parents of twins, triplets or more (multiple birth families) face unique emotional and practical challenges in the first year after birth. We have noticed that the specific needs of multiple birth families are often overlooked and research exploring their needs is missing. Without a good understanding of parents needs and experiences it is very difficult to make sure professionals get effective education on how to advise families.

This research aims to listen to families and learn from their experiences. We also want to hear from professionals at the same time so they can also listen to families, and together we can create knowledge and develop practical ideas about what could be improved and how.

What is a 'World Café' event?

A World Café is a commonly used approach that brings groups of people together in small groups at several tables, like in a café, to have conversations. There will be professionals and different families sitting down together to talk about different topics at each table and people will be free to move around.

The topics where conversations will be encouraged are;

- Pre-conception and early pregnancy
- Antenatal care, going for scans etc
- Preparing for birth and birth choices, experiences of birth
- First days with the babies in hospital (neonatal units or wards)
- First days and weeks at home (up to 3 months of age)
- Caring for your babies from 3 months to 2 years of age

Why have I been invited to participate?

You've been invited to join this study because you are a parent of twins, triplets or more and you had your babies in the last 10 years.

Do I have to take part in this research?

While you are warmly welcomed to join, it's completely up to you. Your participation is entirely voluntary. This leaflet aims to provide you with all the details about the project, to allow you to make an informed decision.

If I decide not to take part, what happens?

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Choosing not to take part is completely up to you. If you choose not to take part, it will not change anything about any healthcare you receive or your access to services.

If I do decide to participate, what can I expect?

If you choose to take part in the study, we will let you know the date, time and location of the World Café event that is nearest to you. We plan to have two events, one in central Birmingham and one in the Burnley area. The venues have been chosen because they offer a family and child friendly environment so you can choose to bring your children with you. You would also be welcome to come with another parent or with a family member or friend who could help you take part while still caring for your children. We aim to create a relaxed and comfortable environment for the event.

We can provide you with additional information about the location of the World Café event which will include detail on access, accessibility and how to contact us about any special needs to support your attendance and participation. We will be able to provide you with a refund on your travel expenses (up to £15) and a £20 shopping voucher to say thank you for your participation.

Once we have confirmed your attendance against the registration list at the event, we will ask you to wear a sticker with a name on it in order for people to address you in conversation. The sticker will be coloured to indicate if you are a parent or professional. It is up to you if you choose to use your name or a nickname of your choosing.

During the World Cafe, we will ask you to write your thoughts and ideas on paper tablecloths and sticky notes and we may also take handwritten notes as the conversations are happening. As the Café is happening some of the notes will be passed to an artist who will draw out some of the issues and comments and this will give everyone the opportunity to see the ideas created—in words, images, and colour—while being part of the event.

After the event we will send you a summary of the key observations from the day via email or phone call and give you an additional opportunity to provide feedback.

What good might come from joining this research?

By taking part, you will have a chance to explore your parenting journey from pregnancy through to 2 years of age with other multiple birth parents/families as well as professionals who work within the services that support families. Our vision is that we take away the key learning from this event and use it to inform the way we provide education to health professionals on how to support multiple birth families. We would also use the learning from the events to develop ideas for future research

and to inform health and social care policymakers. We will provide you with information on how you can follow our future work.

What are the possible difficulties that may come from joining this research?

There is a risk that, in having conversations about what may have been a particularly sad or upsetting time in your pregnancy or parenting journey, unexpected emotions could be brought up. If you feel upset at any point, feel free to let us know how you are feeling, or you can leave the event for a break or choose to leave altogether. We will provide you with information on where you can seek support for any issues that arise. Remember, your well-being matters most.

What happens if my children need my attention during the World Café?

To ensure parents can attend and provide us with the valuable information we are asking for, we appreciate that some children will need to come too. In making these events family friendly we fully expect them to get a little noisy and perhaps a bit messy and have chosen locations that will provide some activity for your children to engage with which may give you more opportunities to contribute.

Please do not feel that you must bring your children, for example if you have routine childcare or they are in school etc. We have tried to accommodate the timings of the school run but please just let us know if you need to arrive late or leave early. We also appreciate that there can be on the day issues such as illness and so just let us know if you are no longer able to attend but still want to be involved.

There may be different ages of children and children with different needs and so we appreciate it might be challenging to keep everyone happy and ask for your patience with others in attendance. We also accept that your children are the priority and only ask for your time and attention if you feel able to give it.

We will provide information on where you can find a quiet space throughout the event if you or your children need it, and you are free to come and go as necessary with no explanation needed.

We will require no photography during the events and all the research staff involved have been through safeguarding checks with their employer.

N.B. There will be a venue limit on the number of people attending the events and so places will be allocated on a first come first served basis until capacity is reached.

What if I want to withdraw from the research?

You have the option to withdraw from the study at any point before or during the World Café event. Once the data is anonymised and analysed, it becomes very difficult to identify contributions from individual participants but please talk to us if there is any specific information you would like withdrawn and we will do our best to identify and remove it.

Who is funding the research?

This research is funded by The Wellcome Trust through the British Academy/Leverhulme Small Research Grants Scheme.

Who makes up the research team?

The research team is jointly led by Dr. Elizabeth Bailey and Professor Fiona Cowdell, both experienced researchers. Elizabeth is a midwife and Fiona is a nurse. Other members of the BCU team are researchers from the Elizabeth Bryan Multiple Births Centre and are not only knowledgeable about multiple births but some have lived experience of multiple births too. The team also includes members of staff from the UK-wide multiple births charity Twins Trust and Vicky Gilroy who works at the Institute of Health Visitors.

We will employ additional team members to help support the World Café events to run smoothly and these will be employed through BCU for the project and could be existing members of staff or healthcare students (student nurses, health visitors or midwives) who will be provided with training and guidance and will be supervised through the events.

How do you keep my information safe and private?

Your privacy matters to us, so we take steps to keep your details safe. We will ask you to register for the event so that we have your name and contact details (email or phone number) to let you know further information and to make sure you are able to attend. Your data will be stored securely on a password-protected device within Birmingham City University's (BCU's) 'Office 365' application, using Multi-factor Authentication to make sure only authorised people can access it.

The data that is collected from the conversations may be tagged to indicate if it has come from a parent or a professional but otherwise will be anonymised. Any paper documents, like consent forms, will be scanned and kept safe on Birmingham City University's secure online storage, locked behind passwords.

We will use your contact details to send you an online link to a feedback form for after the event which you can complete electronically and anonymously.

What will happen to the research data after the project is finished?

The research team are required to retain the data generated by the project within our own record systems for 3 years following the end of the study after which time it will be securely digitally archived. Overall findings of the research will be submitted to research journals for publication.

After the end of the project, we will make the data collected available to other researchers as part of an approach known as 'Open Research'. This means that a fully anonymised version of the data will be made available to other researchers via

an online platform called the UK Data Service (<https://ukdataservice.ac.uk/>). The data shared here it will not contain any detail that could identify individuals or services who have taken part. This is something that has been agreed with our funders and means that the value of the data we collect is of greater public benefit as it could support other researchers learn about multiple birth families.

Who should I contact if I wish to raise concerns about how my personal data is used?

If you wish to raise concerns about how your personal data is used. You can contact BCU's Data Protection Officer on informationmanagement@bcu.ac.uk

or

Telephone +44 (0)121 331-5288

or in writing to:

Data Protection Officer,
Information Management Team,
Birmingham City University, University House,
15 Bartholomew Row, Birmingham,
B5 5JU.

You can complain directly to the Information Commissioner at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF, further information available at www.ico.org.uk

What about my rights?

Your rights are important throughout the research process. You have the right to know what is being asked of you before you agree to it, which is called informed consent. If you decide you do not want to be part of the study anymore, that is okay, and it will not affect you in any way. We will keep everything you tell us private and safe, that is your right to confidentiality and data protection.

Once we have finished gathering all the info and made it anonymous, it's not possible to take it out of the study. But do not worry, your privacy still stays protected throughout the whole process.

Who can I contact for more information?

If you have any further questions and would like to know more, please email us on multiple.births@bcu.ac.uk and let us know if you would like us to email you or contact you by phone.

Who do I contact if I want to raise concerns or complain about this research?

If you wish to raise concerns or complain about the research, please contact the chair of the ethics committee at BCU, this is a person outside of the research team.

hels_ethics@bcu.ac.uk

