



PARTICIPANT INFORMATION

WELCOME TO PILOT TESTING SIBLING CIRCLES: a privacy-preserving, local peer-discovery app for the daughters and sons of absent mums and dads

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siblingcircles.com, sisterhoodearlymotherloss.co.uk

Invitation

If your mum or dad passed early, or if you're estranged or they're absent for other reasons, (before you were 21), we'd like your help to test an early-stage app, (a minimum viable product).

The app is privacy-preserving and designed to allow you to safely find people around you with exactly the same experience, connect and chat. Participation is confidential, anonymous and no personal identifiers are shared on the app. Some anonymised information will be shared with City [St.George's](#), University of London to support the studies of the app's developer.

Before deciding whether to take part please read the below information and ask us if you have any questions using the contact details below.

Background

Sibling Circles is a social start up on a mission to create local networks around early parent loss or absence. Our founder's mother died when she was 13 and her father when she was 23. Studies have shown that around one in 20 young people lose a parent before they're 16 and up to one in four experience some form of parental absence. We know it isn't something to hide – it's something to share with the people around who get it.

Why are we doing this?

Our aim is to obtain proof of concept for the app and its possible benefits, as well as to test its usability and design so we can refine it. Our broader aim is to reduce the isolation around our experiences by strengthening community, so as well as creating connections, in the future the app will also signpost to local social events, peer support groups.

Who is invited to take part?

If you're over 18 and your mum or dad passed early, or if they were absent for other reasons before you were 21, you're invited. This is a closed pilot and the app will only be available to vetted users. If you're a student, choosing to take part or not will have no effect on study, employment or any involvement with us.

Can I pull out?

Taking part is voluntary. You can choose not to take part in any or all of the project. If you provide your consent to take part, you're still free to withdraw any time without giving a reason.

How do I take part?

Provide your consent and fill out the sign-up form, which includes your contact details, a multiple choice question concerning your family circumstance and your age at loss or separation from your parent(s) so you can find relatable connections. You can preview the questions [here](#). Identifying information won't be shared on the app or with the university or researcher.

What does taking part involve?

OPTIONAL Pre-Test Focus Group (45 minutes)

We'll send an invitation asking if you want to take part in a small focus group to ask about your expectations for the app and reasons for taking part. We'll also test usability by asking you to think out loud and share your thoughts as you navigate the app.

PHASE 1: Test the app

The app will be turned on in the evenings between 7pm to 9.30 pm for four sessions during the course of a week.

Receive a link and instructions to download it. Chose an icon and create a quick anonymous profile (2 minutes). Look for the people who share your experience or similar, make a few connections and test the app's features. Please jump on it a few times during that week to get a feel for it and see if you want to make more connections. If there's anything that's broken or needs urgent improvement please put it in the feedback box. After the last session we'll text you a link to complete a feedback survey online (see below).

PHASE 2. 5 MINUTE ANONYMOUS SURVEY ONLINE

Take a few minutes to complete an anonymous survey online asking what you liked, didn't like, how it may have benefited you and for any suggested improvements. You can preview these questions [here](#) and below.

OPTIONAL POST TEST FOCUS GROUP Dates to be confirmed

If you'd like to give us more feedback and meet your peers you can also take part in a 45-minute, informal focus group at City's Clerkenwell Campus and/or online. Confidentiality and anonymity will be maintained. Please indicate your interest in the consent and sign up form.

What are the possible benefits and risks of taking part?

This is an opportunity to find people around you who could potentially become life-long, loyal friends! You'll also be helping to co-design a product which can help younger users and has the potential to strengthen local networks on the ground. Your feedback will also help us obtain funding so we can develop this product fully.

There may be occasions when somebody shares something distressing, or something that concerns you about their safety. If this happens please make this known to the administrator immediately by using the chat's report feature or emailing hello@siblingcircles.com.

How am I safeguarded?

We want everyone to have a great experience and that means keeping things safe.

This is a small, closed pilot not available to the public. If the link to the app is shared it can't be used by anyone who hasn't signed-up. Everyone taking part is eligible and vetted

and we may ask you to provide additional information to verify you. We're only recruiting users over 18 via admin approval. We implement privacy-by-design on the app (minimal data collection, encryption, anonymisation and privacy-preserving location). We also operate a reporting system and escalation protocol. The app also provides community guidelines promoting kindness and inclusion and provides a feedback loop. This helps us make sure everyone is supported and looked after.

What is the role of City St.George's, University of London?

The app was developed by Mariyahbanu Memon, an undergraduate student at City St. George's, University of London. In support of her studies an amount of anonymised information will be shared with her. The use of this material within the University will be subject to proportionate ethical review and will comply with their data handling and ethical procedures.

What personal information do you collect and how is it stored?

We collect the following personal information; name, contact details, gender, broad location and basic information concerning your family circumstance so that we know you're eligible to take part and can onboard you onto the app. Only the administrator at The Sisterhood for Early Motherloss / Sibling Circles has access to this information. No directly identifying information will be shared on the app itself or with the researcher or City St George's University. These records will be stored on an encrypted device and kept for two years until June 2028 before before destroyed. We keep these details so we can contact you with the results or invite you to take part in further research. You may withdraw this data anytime inline with your GDPR rights. (see our data privacy statement below).

How will I be anonymous?

No direct identifiers such as name and contact details are shared on the app or with the researcher or City St.George's University and no identifiable information will be recorded in the study itself. Personal information disclosed on the sign up and consent survey will redacted before being transferred to the researcher or City/St/George's University. Focus group sessions will be audio-recorded by the Sisterhood and screened so that only anonymised quotes are transferred to the student or to City St George's University. Data which is anonymised may not be withdrawn.

Data privacy statement

The data collector and data controller for this Sibling Circles pilot is The Sisterhood for Early Motherloss Association (the Sisterhood), based in the United Kingdom. This means that we have a duty to oversee the confidentiality, integrity, and appropriate use of your information and we're fully responsible for looking after it.

Your personal data will be processed only for the purposes outlined in this information page. The legal basis under which we process your data is our public task and legitimate interest in establishing a charitable network of like-minded individuals. For ethical reasons we ask for your consent to take part in this research project by completing a consent and sign-up form.

Data Sharing

As data controller and in line with our legitimate interest, we have the lawful authority to transfer data to academic partners, which in this case is City St George's, University of London. No identifiable personal information, such as names, contact details, or any information that could reasonably re-identify participants will be received by the researcher or City St George's. The data City St George's receive will consist solely of anonymised survey outputs and selected feedback from focus groups, processed and anonymised by The Sisterhood before any transfer takes place.

City St George's will only use the anonymised information for the specific and proportionate purpose of evaluating and improving the performance of the project, in line with the research purpose. We will not share data with any other organisations but there may be occasions when regulatory authorities need to access research data in accordance with their statutory powers.

Your Rights

To safeguard your rights, we will collect the minimum personally identifiable information possible. You have the right to request access under the General Data Protection Regulation (GDPR) and may withdraw this data anytime. Anonymised data cannot be withdrawn. You can find out more about how we handle your data and your rights under the General Data Protection Regulation (GDPR) by visiting:

<https://siblingcircles.com/privacy>

If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (ICO) directly here: <https://ico.org.uk/>.

By email: casework@ico.org.uk

By phone: 0303 123 1113

What if there's a problem?

If you have any problems, concerns, or questions about this study, please contact hello@siblingcircles.com

How do I Sign Up?

Consent and sign up by visiting: <https://siblingcircles.com/sign-up>

Support organisations which maybe helpful

- EACES: for estranged and care experienced students www.instagram.com/eaces
- Stand Alone; supporting estranged adults, www.standalone.org.uk
- Breakaway; supporting estranged adult children, <https://breakaway.org.uk>
- Lads Need Dads; supporting the sons of absent fathers with male role models, <https://ladsneeddads.org>
- Sister System; a north London charity for care affected women and girls (13-24), sistersystem.org
- National Youth Advocacy Service; supporting care leavers, www.nyas.net
- The Sisterhood for Early Motherloss; supporting families in north London affected by early motherloss, sisterhoodearlymotherloss.co.uk
- Winston's Wish; online grief support for young people, www.winstonswish.org
- Grief Encounter Helpline; 0808 801 0111
- Young Minds; a mental health charity for young people, www.youngminds.org.uk