

Participant Information Sheet

What are the physical and psychological health perceptions and support needs for adults born preterm?

You are being invited to take part in a research study. Before you decide, it's important that you understand why the research is being done and what it will involve. Please take the time to read this information carefully, and feel free to discuss it with others if you wish. If anything is unclear or you'd like more information, don't hesitate to get in touch.

Thank you for considering this opportunity.

- **Do I have to take part?**

No. Taking part in this study is entirely voluntary. If you do choose to take part, you will be given this information sheet to keep and asked to sign a consent form. You are free to withdraw at any point during the survey without giving a reason, and this will not affect your rights or any services you receive. The survey is anonymous, and therefore, once you have completed the survey, we are unable to remove your data because it cannot be linked back to you.

- **What is the purpose of the study?**

Each year, around 13.4 million babies are born early (before 37 weeks of pregnancy). Thanks to advances in medical care, most now survive into adulthood. However, some adults born preterm, especially those born very early or with complex medical needs, may face long-term health challenges.

Even though more people born early are now living well into adulthood, we still know very little about how they feel about their health, what support they might need, or how being born early has shaped their lives, especially for people from diverse backgrounds across the UK.

- How adults born preterm perceive their health and well-being
- What kinds of support do they need
- How being born early has shaped their lives

The study will focus on people aged 18 and over and will pay particular attention to how ethnicity, disability, and early birth may affect their experiences.

As part of the project, I am inviting adults born preterm to take part in a UK-wide survey. This UK-wide survey will help us gather a broad range of perspectives from adults born preterm, and identify key patterns, priorities, and areas that need further exploration in interviews.

This project is being developed in collaboration with adults born preterm to make sure the research reflects real experiences and priorities. By taking part in an interview, you'll be helping shape future research and services for a growing but often overlooked group.

- **Why have I been invited?**

You have been invited to participate in this research because you were born before 37 weeks of pregnancy. We aim to involve approximately 150 adults from across the UK.

- **What will happen to me if I take part?**

If you choose to take part, you will complete an online survey which will take around 15–20 minutes. The survey is anonymous — no names or identifying information will be collected.

Some of the questions may feel personal or sensitive. You do not have to answer any questions you don't feel comfortable with, and you can exit the survey at any time.

- **What are the possible disadvantages and risks of taking part?**

There are no known risks associated with taking part, but some of the survey questions may feel personal or bring up difficult memories. On the study website, you can find a list of resources to contact for support.

- **What are the possible benefits of taking part?**

There is no direct benefit to you, but your views will help build a better understanding of the needs and wants of adults born preterm. This could help improve support and raise awareness in healthcare and wider society.

- **What will happen to the results of the research study?**

The findings from this study will be published in academic journals and shared through social media and public events.

Summaries of the results will also be shared with participants and the wider public in easy-to-understand formats, including videos and infographics via the study website.

- **Who is organising and funding the research?**

The research is led by a PhD student at Imperial College London and funded by the NIHR Imperial Biomedical Research Centre (BRC).

- **Who has reviewed the study?**

This study was given a favourable opinion by Imperial College Research Ethics Committee (ICREC) and approval by Azeem Majeed, Head of Department of Primary Care and Public Health.

Contact for Further Information

If you would like any further information or to discuss your participation in this project at any time, please contact:

Jo Craddock

Jo.craddock25@imperial.ac.uk

Thank you very much for your time and consideration.

Transparency notice

How will we use Information about you?

Research Study Title:

The physical and psychological health perceptions and support needs of adults born preterm.

Study number 7862395

Imperial College London is the sponsor for this study and will act as the Data Controller.

Being a Data Controller means that we are responsible for looking after your information and using it appropriately, plus we are responsible for explaining this to you. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has been completed in relation to primary research data.

The study is expected to finish in February 2028.

For more information / confirmation regarding the end date, please contact the study team. See **'WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED'** for contact information.

We will need to use information (including personal data and data created as part of the study) from you for this research project.

This information will include your

- Initials
- Name
- Date of birth
- Ethnicity
- Health conditions

People within the College and study team (see section 'Sharing your information with others') will use this information to do the research or to check your records (see information to be collected) to make sure that the research is being done properly and the information held (such as contact details) is accurate.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Imperial College London is the sponsor of this research and is responsible for looking after your information. We will keep this information about you safe and secure by

- Data management plans have been created and reviewed in line with Imperial's Information Governance Policy Framework. This covers the collection, movement, processing and storage of the data.
- Data to be stored in a dedicated secure environment which underpins security measures.
- Robust pseudonymisation has been implemented to prevent identification
- Access controls have been implemented to ensure only key personnel can access the data.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

LEGAL BASIS

As a university, we use personally identifiable information to conduct research to improve health, care and services. As a publicly funded organisation, we have to ensure that it is in the public interest when we use personally identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Our legal basis for using your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

- Imperial College London - "performance of a task carried out in the public interest"; Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#).

Where special category personal information is involved (most commonly health data, biometric data and genetic data, racial and ethnic data etc.), Imperial College London relies on "scientific or historical research purposes or statistical purposes".

INTERNATIONAL TRANSFERS

We may share data about you outside the UK for research related purposes to:

- Where necessary to provide access to a data processor / service provider who will utilise your personal data as instructed by us.
- Where necessary to share with a third-party organisation / collaborator (as listed) who is also involved in the study.
- Where data has been collected from outside the UK and requires additional transfer(s) as part of the study activity.

If this happens, we will only share the data that is needed. We will also make sure you can't be identified from the data that is shared where possible. This may not be possible under certain circumstances – for instance, if you have a rare illness, it may still be possible to identify you.

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- (some of) the countries your data will be shared with have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK
- We use specific contracts which stipulates that personal data must maintain the same level of protection when outside the UK as it has within the UK. For further details visit the Information Commissioner's Office (ICO) website - www.ico.org.uk
- We do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says
- We need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing
- We have procedures in place to deal with any suspected personal data breach. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website - [Personal data breaches: a guide | ICO](#)

SHARING YOUR INFORMATION WITH OTHERS

We will only share your personal data with certain third parties for the purposes referred to in this participant information sheet and by relying on the legal basis for processing your data as set out above.

- Other Imperial College London employees (including staff involved directly with the research study or as part of certain secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third-party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study (such as contact details) may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

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- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information:

- by asking one of the research team
- by sending an email to jo.craddock25@imperial.ac.uk or

COMPLAINT

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to jo.craddock25@imperial.ac.uk or by ringing us on 07966386923

Following our response, if you are not satisfied, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building, Level 4, London SW7 2AZ.

If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)- via www.ico.org.uk. Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.