PPH kits study: photo-based survey

Appendix 2 Participant information sheet

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**Key things to know**

* The aim of this study is to map the layout and contents of post-partum haemorrhage (PPH) kits in UK maternity units.
* We’ll ask you to take around ten photos of a PPH kit on your unit, both packed and unpacked. We then ask you to upload these photos via Thiscovery, a dedicated secure web platform, that you can access on a computer, mobile phone or tablet. You’ll also be asked a few questions about the PPH kit.
* We estimate that participation in this study takes up to an hour of your time. You can pause and continue the activity at any time.
* The study has received approval from the Health Research Authority (HRA) and the research and development office at your trust has been informed that this study is taking place.
* Your confidentiality and that of your unit will be maintained at all times.
* Participation in this study is entirely voluntary. If at any time you decide you no longer want to take part, just let us know.
* The University of Cambridge is the sponsor for the study.

**About this study**

* The aim of this study is to map the layout and contents of post-partum haemorrhage (PPH) kits in UK maternity units. These kits can have various layouts; some units use a box, bag or trolley, and sometimes they also have containers or compartments to group items within a kit. It’s also possible that drugs and other medical contents in PPH kits may vary from one unit to another.
* We’d like to ask maternity professionals from various units to share photos of their PPH kits. We will use these data to learn more from and about the range of kits in use and how these might vary across different units.
* This survey forms part a wider study that aims to develop guidance on how various units could further improve how they design and organise PPH kits. Your insights as a maternity professional, who may use or be familiar with a PPH kit as part of your clinical work, are critical to inform future guidance.
* This study is organised by an independent team from the Healthcare Improvement Studies Institute (THIS Institute) and maternity professionals affiliated to the PROMPT Maternity Foundation. THIS Institute is an independent research institute co-created by the University of Cambridge and The Health Foundation (an independent charity). The PROMPT Maternity Foundation is a charity that aims to reduce preventable harm to mothers and babies in maternity care.

**What would taking part involve?**

* If you choose to take part, you’ll be asked the following:
	+ Log in to Thiscovery (if you already have an account) or register on Thiscovery by providing your name and email address, and agreeing to the terms and conditions and privacy statements (see <https://www.thiscovery.org/#terms-of-use>). In short, Thiscovery is a secure online platform – originally developed by THIS Institute at the University of Cambridge – that enables the health and care system to improve and innovate through collaboration.
	+ Take around ten photos with a mobile phone or tablet of a PPH kit on your unit, both packed and unpacked, guided by a set of instructions.
	+ Upload these photos via your Thiscovery account. When you upload them, you’ll also be asked a few questions about the PPH kit and the type of unit that the kit is used in.
* We estimate that participation in this study takes about an hour of your time. You can pause and continue later at any time.

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

* Although there may not be direct benefit to you from taking part in this study, your contribution will be used to inform guidance on how various units could further improve how they design and organise PPH kits. The aim of that guidance is to facilitate the work of maternity professionals and help improve the care for maternity service users.

**Are there any risks?**

* There are no risks for you associated to participation.
* Your confidentiality and that of your unit will be maintained at all times. No one outside the project team will know the name of the unit where the photos were taken.

**What do I do if I want to withdraw from the study?**

* If you change your mind about taking part in the study, you can withdraw at any time without giving a reason. However, it may not be possible to remove research data that have already been submitted through your Thiscovery account. To withdraw please email PPH-kits@thisinstitute.cam.ac.uk
* Personal data used to register for Thiscovery will be securely stored on Thiscovery, as set out in the Thiscovery [terms and conditions](https://www.thiscovery.org/#terms-of-use). If you decide at any point after registering with Thiscovery that you no longer want your contact details kept by Thiscovery, you can de-register by emailing help@thiscovery.org
* **How will we use information about you?**We will need to use information from you for this research project.
* This information will include your name, email and name of the maternity unit you are based at. People will use this information to do the research or to check your records to make sure that the research is being done properly.
* 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.
* We will keep all information about you safe and secure.
* 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
* Your confidentiality will be maintained at all times. The only personal data collected will be your name and email address. These personal data will be separated from the other research data, so that individuals will not be identifiable in the research data. The data will be used only by the project team and will be stored on the secure networks of the University of Cambridge.
* The University of Cambridge is the sponsor for this study and is based in the United Kingdom. The research team from the University of Cambridge will be using information from you in order to undertake this study and will act as the data controller for this study. This means that the research team is responsible for looking after your information and using it properly. University of Cambridge will keep identifiable information about you for two years after completing the study.
* Any links between the personal data held in Thiscovery and the data generated by the study (research data) will be destroyed two years following the end of the study. This will be done by deleting your project-specific user ID in the Thiscovery database.  Your personal data used to register for Thiscovery will remain in the Thiscovery personal data stores, as set out in the Thiscovery terms and conditions (see <https://www.thiscovery.org/#terms-of-use>).
* Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the research data about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
* You will also be asked if you would like the research team to notify you about the results of the study and/or possible future projects run by THIS Institute that could be of interest to you. If you consent to these options, the researchers will store your contact details in the safe haven only for as long as needed to carry out those options.

**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.
* We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**Where can you find out about how your information is used?**

You can find out more about how we use your information

* <https://www.medschl.cam.ac.uk/research/privacy-notice-how-we-use-your-research-data/>
* by asking one of the research team.
* by sending an email to **PPH-kits@thisinstitute.cam.ac.uk** or
* by ringing the University of Cambridge Clinical Research Governance Office on 01223 769291.

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

* The results of this study will be reported in peer-reviewed journals and presented at conferences. It will not be possible to identify any individual from any reports produced.
* Public study updates will be provided at the study web page at: <http://ths.im/pph-kits>

**For any complaints or concerns**

* Contact Dr Jan van der Scheer (Chief Investigator) on jan.vanderscheer@thisinstitute.cam.ac.uk
* If you are still not satisfied, you can contact the Data Protection Officer at dpo@admin.cam.ac.uk
* If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioners Office (ICO) at [www.ico.org.uk](http://www.ico.org.uk) or telephone 0303 123 1113.

**Research team and important details**

* This study is led by a team from The Healthcare Improvement Studies Institute (THIS Institute) based at the University of Cambridge, including Dr Jan van der Scheer (Chief Investigator), and Matthew Woodward (Research Associate). Other research team members include Professor Tim Draycott, Cathy Winter, Dr Katherine Lattey and Dr Chloe de Souza from the PROMPT Maternity Foundation.
* This study is funded by The Healthcare Improvement Studies (THIS) Institute - an independent research institute co-created by the University of Cambridge and The Health Foundation (an independent charity committed to bringing about better health and health care for people in the UK).
* This study has received ethics approval from University of Cambridge Psychology Ethics Committee Ref. PRE.2024.037
* To get in touch with the research team, please email to PPH-kits@thisinstitute.cam.ac.uk
* For technical problems or questions about the platform, please contact the Thiscovery team using the chat or email at help@thiscovery.org

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