

**Prevalence and risk factors for prescription medication sharing in the UK general population**

**Participant Information Leaflet**

We would like to invite you to take part in our research project. Before you decide whether or not to participate, we would like you to understand why the research is being conducted and what it would involve for you. Talk to others about the study if you wish. Please ask us questions if anything is unclear.

What is the purpose of the study?

We wish to talk to members of the public and healthcare professionals about their experiences of prescription medication sharing. Prescription medication sharing means giving some of your prescription medicine to someone, such as a family member, friend, work colleague or neighbour to use or someone giving you some of their prescription medicine for you to use. Some studies have shown that around 50% of adults have shared prescription medicines. Medications are often shared with friends or family for good reasons such as to help relieve symptoms, make people feel better or to save time visiting a healthcare professional. There has been no research in the UK on prescription medication sharing. This study will help us understand why people share their medication, the types of medication they share, when they share, and who they share with. Knowing the reasons why people share their medicines will help us to make recommendations for improvements in patient care and how people access prescription medications.

**Why have I been asked to take part?**

You are being invited to participate because you have recently taken part in a telephone survey regarding prescription medication sharing and expressed an interest in being involved in an interview in this topic area or you are a healthcare professional with a role in medicines management.

Do I have to take part?

It is up to you to decide whether you wish to participate in the project. We will describe the study and go through this information sheet with you before you participate in the interview. We will answer any questions you might have. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason and without affecting the quality of health care you receive.

What happens to me if I take part and what will I have to do?

If you decide to take part, we would like to interview you. The interview will last up to 60 minutes and will be carried out by a researcher from the University of Bristol. The interview can be either face-to-face at a time and place that is convenient to you or via telephone or video call (e.g., using MS Teams) if you prefer. During the interview the researcher will ask you about your experiences of sharing prescription medication (e.g., giving some of your prescription medicine to someone, such as a family member, friend, work colleague or neighbour to use or someone giving you some of their prescription medicine for you to use.). You can stop the interview at any time without giving a reason if you wish.

The interview will be audio-recorded using an encrypted digital recorder. After the interview the recording will be transcribed (e.g. typed up) by a company approved by the University of Bristol and made anonymous. Recordings will be encrypted in accordance with the University of Bristol Information Security Policies when transmitted electronically to the transcription service. Encrypted typed transcripts will be electronically returned to the University of Bristol. Recordings and the typed transcripts will be stored securely at the University of Bristol.

If you decide after the interview that you do not wish your interview recording to be used within the study, you will need to notify the researchers that you would like to withdraw via email or telephone, within two weeks of the interview taking place. After a period of two weeks your recording will have been anonymised for analysis and it will not be possible to withdraw your interview after this point.

Apart from the research team, the only people who can see your information are authorised individuals whose job it is to monitor and check the conduct and quality of the research. In certain exceptional circumstances, confidential information that is recorded during an interview, may need to be disclosed. For example, if the researcher has concerns about your well-being or safety, this may need to be reported to your GP or other appropriate agencies. The researcher will however discuss this with you first.

If you would like to take part in an interview, please contact Debbie McCahon or Shoba Dawson via email on deborah.mccahon@bristol.ac.uk or shoba.dawson@bristol.ac.uk. If you would prefer to speak with one of us, please contact us via telephone on 0117 455 5081 or 0117 455 4310.

# What are the benefits and disadvantages of taking part?

You will not benefit directly from participating. The answers you give to the research could help other people in the future**.** There should be no disadvantages from taking part. Participation in an interview will mean giving up some of your time.

**What will be done with the findings of the research?**

We will hold workshops with patients, GPs, and community pharmacists to review the findings of this research. These workshops will be used to develop resources for use by patients and healthcare professionals to help reduce unsafe sharing practices, to improve care and access to prescription medication.

# Will my participation in this project be kept confidential?

The University of Bristol is the sponsor and data controller for this study. All information collected about you will be kept strictly private and stored securely at the University of Bristol. Your name and other personal details will only be used to help improve care. Universities in the UK have a duty to ensure that it is in the public interest to collect and use person details from people who have agreed to take part in research. This means that when you agree to take part in a study, we will only use your data in the ways needed to carry out and analyse the study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible.

All personal information collected (including audio recordings) will be kept separate from your study records and consent form so that you cannot be identified. All personal information and the audio recording from the interview will be securely destroyed within 3 months of the analysis being completed. Your study consent form and anonymised interview transcript will be securely stored for 5 years in line with the University policies.

We will use anonymous quotes and extracts from interviews in written reports and presentations to researchers, health professionals and health service managers. These quotes will not use your real name. We may also use them in public presentations and for training purposes.

If you wish to make a complaint or raise any concerns with this research, you can contact the Research Governance Team via research-governance@bristol.ac.uk.

If you wish to make a complaint about how the researchers handle your personal data, you can contact our Data Protection Officer who will investigate the matter. You can contact our Data Protection Officer at the University of Bristol on data-protection@bristol.ac.uk or you can complain to the Information Commissioner’s Office via telephone on 0303 123 1113. Please see [www.ico.org.uk](http://www.ico.org.uk) for further information about making a complaint.

**What will happen to my data?**

Your involvement in the study will remain confidential. This information will only be available to research staff and national bodies which monitor whether research studies are conducted properly. Your study data will be anonymised (e.g. your personal details will be removed). This means that it will be given an identification number and any identifying information about you will be removed. Therefore, it will not be possible to identify you by name from any aspect of documentation or reporting for this research study. At the end of the study, we will make study information, with the personal details removed available on request to authorised researchers who are working on other related studies. Anonymised information will only be shared with researchers who request access, pass checks to show that they are genuine researchers and have ethical approval for use of research information. Authorised researchers will also be required to sign a data sharing agreement before they can have access to any data.

**Will my data be used by any other authorised people?**

In addition to the research team, people from regulatory authorities whose job it is to check the conduct of research will be allowed to see your study information to carry our monitoring for the research sponsor.

Who is funding this study? Who has reviewed it?

The study is funded by the National Institute for Health and care Research School for Primary Care Research. This study has been reviewed and approved by the Faculty of Health Sciences Research ethics committee (REF 12522).

What if I have questions or want to know more about the study before deciding?

We are happy to answer any questions you have. Just use the contact details below to get in touch.

**Contact details:** Debbie McCahon, Tel: 0117 455 4310, Email: deborah.mccahon@bristol.ac.uk

 Shoba Dawson, Tel: 0117 455 5081, Email: shoba.dawson@bristol.ac.uk

**Address:** Bristol Medical School, Population Health Sciences, Canynge Hall,

39 Whatley Road, Bristol, BS8 2PS

**Thank you very much for taking the time to read this information. Please get in touch if you have any questions or would like to take part.**