

PRIME-RU Patient and Public Involvement: Information Sheet

Greater Manchester Mental Health NHS Foundation Trust (or, “we”) have set up a new research unit to carry out research into the mental health and wellbeing of parents during pregnancy and after childbirth. We call this unit ‘PRIME-RU’, which stands for ‘Perinatal Mental Health and Parenting Research Unit’. Members of PRIME-RU have previously researched a wide range of topics, such as:

- Women’s and men’s experiences of pregnancy
- Understanding the bond, interaction, and relationship between a parent and a baby, and how to assess, support and strengthen it
- Understanding or exploring the experiences of parents when their child has a health condition
- Understanding the experiences of parents with mental health difficulties
- Developing psychological and psychosocial interventions to support such parents

As we are a new unit, we are planning lots of exciting new research studies. We are now looking for members of the public, who are **parents or carers of children**, to help us shape our research.

We are inviting you to join our **Patient and Public Involvement (PPI) group**. The group’s members will be asked to give their opinion on our research and help us make it better and more relevant to families. We may ask your views on research materials, like leaflets and information sheets, as well as your input on funding applications. **You do not need any experience or knowledge of research**. We are interested in your views as a member of the public.

Please see some Frequently Asked Questions (FAQs) and answers about joining the PPI group below. We hope you find them helpful.

What is this ‘PPI group’?

This is a group of people (members of the public) who have agreed to be contacted about getting involved in PRIME-RU activities. Being in the group means that you have agreed for our researchers to contact you directly about suitable opportunities as they arise. **However, this does not mean that you must participate in every (or any) opportunity that we share with you.** The decision would be up to you. You are welcome to get involved in activities that personally interest you and/or are convenient for you.

What will my involvement entail?

We are currently planning a range of studies. Typical requests for your views and involvement may include the following:

- Telling us whether a new research idea is relevant and/or acceptable
- Giving feedback on resources aimed for the public, such as our website, summaries of research, information leaflets, etc.
- Sharing your views on how we could best include people’s lived experiences in our work

- Planning how to best communicate research findings to the public
- Depending on your interest in research, assist us with analysing information

Please note that these are just a few examples. The specific tasks will depend on the research study/activity. A researcher will always support you with any activities you sign up for.

Why do you want to work with members of the public?

We know that working with members of the public or 'Experts by Experience' makes research better. When people's views are considered throughout a project, research is more relevant to the public, health services, and to wider society. This way, people get much better value for their money, because health research is funded mainly by public money.

Who are you looking for?

We are looking for (biological and adoptive) parents or other carers of children, such as grandparents and foster carers. We are particularly interested in parents/carers with mental health difficulties, but this is not necessary. We would love to hear from different types of parents and carers of children. We would like to hear from parents of children of different ages. We also welcome parents who are expecting a baby.

Please note you must be **at least 18 years old to join the group**. There is no upper age limit.

We are very keen to involve people from different backgrounds. **We encourage parents from any ethnic/cultural/religious/disability/gender/sexual orientation/age and other communities to get in touch with us.**

How much time do I need to commit?

How much you want to get involved is completely up to you. **Signing up to our PPI group does *not* obligate or commit you to take part in any of our activities.** As mentioned earlier, there are various opportunities or tasks you can get involved in and this may inform how long an activity may take. We may ask you to review materials and that may not take longer than 10-20 minutes. We may also like to discuss an idea with you in more depth and that may take 30-60 minutes. We would always discuss timing with you and try to accommodate you. For example, as parents you may be busy with many tasks and commitments and we would consider this when arranging a time to meet.

Do I need previous experience?

You do *not* need to have previous research experience or qualifications to join our PPI group. We are interested in the views and experiences of all parents and carers of children.

Where will my involvement take place?

For now, our activities will be remote. Activities can be done using different methods, such as via a video call using MS Teams, a phone call, email, or post. This depends on the needs of each activity and what you personally are comfortable with. Please note that you do *not* need to have any video call application or software to attend a video call and we would support you in setting this up.

Will I be by myself or in a group?

This can vary, depending on the activity. If you feel uncomfortable with attending a group meeting/call, please do not let this put you off. We can arrange you to meet or speak 1-1 with a researcher instead. You can also choose to get involved in activities that are done in a way that makes you comfortable. If you prefer meeting new people but do not enjoy doing a task on your own, or vice versa, that is completely ok with us.

What will happen in the meetings?

Group meetings are led by one or two researchers. The other attendees are people like you, who have signed up to receive information about our activities. We plan to invite only a small group of people (under 10) to our meetings so that everybody can contribute. You can also meet 1-1 with one of our researchers.

What is the sign-up process to join the PPI group like?

To sign-up to the PPI group to be contacted about opportunities in our unit, we ask everyone to complete a survey. The survey has questions about how you would like to be involved in our activities, as well as some basic questions about you and your family. You do not have to answer all the survey questions if you do not want to. The purpose of the survey is to make sure that our activities are likely to be relevant to your personal experiences, and that we can contact you about opportunities that you will most likely find suitable. For example, if you told us that you have experience of mental health difficulties, we will contact you about activities relating to it.

The survey can be [completed online](#). When you have submitted your responses, a researcher will contact you to welcome you to the PPI group and tell you more about our work. Alternatively, you can complete the survey with a researcher over the phone or a video call.

Will I have to share personal information?

Signing up and completing the survey are totally up to you. You do not have to answer all the questions if you do not want to. However, we would like to have some kind of an idea of the kinds of life experiences you may have (such as whether you are a parent). This way we can assess whether our activities are relevant to you. We will also need to collect some contact information so that we have a way of getting in touch with you.

Any information you tell us is collected and stored in a way that complies with the law (Data Protection Act 2018). The PPI group, the survey, and information storage have been assessed and approved by the GMMH Information Governance department. This means that we will store your information on a safe GMMH computer system, which follows strict safety standards. Only authorised researchers at PRIME-RU will have access to your information. Your information will only be used for contacting you about our activities. We will delete any information we hold about you upon your request at any time. You do *not* need to explain why you want your information to be deleted. We will also contact you annually to confirm

that you are still interested in being part of the group on the list. If you say no, or if we cannot get in touch with you, we will remove your information from our computer system.

Will I be reimbursed?

Yes, you get reimbursed for your time. This reimbursement can vary because each study/project can have a different amount of money for this in the budget. The minimum amount you will receive is £10 per hour. If you are asked to prepare for a meeting (for example, by reading a report), you will be reimbursed for your preparation time. If the activity involves travelling to a meeting, we will reimburse you for public transport, taxi, or parking. We can also reimburse you for childcare costs while you attend a meeting if you discuss this before each meeting/activity with us. We will always let you know how you will be paid for each opportunity before you decide whether an opportunity is for you. You can find more information about your right to reimbursement for your involvement on the '[NIHR INVOLVE](#)' website.

I'm interested! What do I need to do now?

Fantastic! To sign up to the PPI group, please [complete the survey online](#) or get in touch with us to arrange a call with a friendly researcher. If you answer all the questions, the survey takes about 10-15 minutes and we will be in touch with you after your completion.

I have another question/I'm still not sure. How do I get in touch with you?

We would love to hear from you. You can contact us by:

Email: prime@gmmh.nhs.uk

Telephone: 0161 271 0028

Twitter: @PRIMERU3

The sign up survey: tinyurl.com/1jdo5znd