



Patient Participation in Improving General Practice

Participant information leaflet: Observing meetings

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is doing this research?

We are a co-research group of patients, GPs, general practice staff, and researchers who are interested in making patient involvement in general practice have a real impact. The study is being led by Jessica Drinkwater, as part of a National Institute for Health Research doctoral research fellowship. Jessica is also a GP with an interest in how to support and develop patient involvement in general practice

What is the research about?

One role of patient participation groups (PPGs) is to be involved in improving general practice services. But there is little evidence about how to do this meaningfully. We have designed a process which aims to support patients and general practice staff to work together to improve general practice services for their whole patient population.

The process involves three stages. Firstly, we will work with PPG members and practice staff to identify five areas of your general practice where you would like to see change. Secondly, we will turn these into a survey specifically for your practice and help the PPG to distribute this. The survey will ask the wider patient population about their preference for change from the five areas identified in the first stage. Finally, we will meet with you to discuss the results, help you interpret them, and plan possible changes.

We would like to test this process with 3 PPGs and general practices to answer the following questions:

1. Does the process make sense to PPG members and general practice staff?
2. Is the process something PPG members, practice staff, and other patients want to get involved in?
3. What do PPG members and practice staff have to do to make the process work?
4. Overall what do PPGs and practice staff think of the process?

Why have you been chosen?

We will be working with 3 different PPGs and general practices in Leeds and Manchester. Your PPG and the staff in your general practice have shown an interest in being involved in this study.

**What will I be asked to do if I take part?**

We will be asking everyone in your PPG and the staff supporting them if they are willing to take part. If you all agree, Jessica Drinkwater and 1 or 2 other members of the research group would like to come and meet you all and explain the research in detail.

Once your PPG has agreed to participate, we would like you to take part in a series of meetings and activities as outlined below. The meetings will be similar to your normal meetings, but will involve structured activities and discussions. The process may involve more meetings than your PPG normally has. The process will go as follows:

1. There will be 2 separate meetings, one with patient PPG members and one with the general practice team. At both meetings we will discuss possible areas for change and group these depending on whether the group is interested in them or not.
2. A couple of weeks later we will hold a further meeting with PPG members and staff together. At this meeting we will ask everyone to vote for their top 5 areas for change. We will then discuss the results and agree the final 5.
3. After this we will develop three versions of the survey. A paper version which can be handed out, an online version, and a version where people vote in a box in the waiting room. We will then attend another meeting to show the PPG members how to help people complete the surveys. We will then expect the PPG and practice to distribute the survey. Jessica Drinkwater will analyse the results of the survey.
4. Once the survey is complete and analysed (usually 1-2 months later) we will hold a further meeting with PPG members and staff together. At this meeting we will explain the results and encourage you to develop a plan for acting on the results.
5. After this we would like to attend the next 2-4 normal PPG meetings to see what happens next. It will be up to the PPG and practice staff what happens in these meetings.

Jessica Drinkwater and one other member of the co-research group would like to attend each meeting and make notes of what happens during them. This will help us understand whether the process works and is useful to your PPG, and if there are improvements we can make. We would also like to look at any documents your group uses in these meetings for example agendas, minutes, and terms of reference. Finally, we would like to interview some of your group members about their experiences of this process (we will explain this in more detail if you are willing to take part).

We think that the first 4 steps (detailed above) will take approximately 4 months. The final part of the process (step 5) will depend on how often your PPG usually meets. The study will not last longer than one year. For more detail about the timeline please see flowchart of activities at the bottom of this form.

What happens to the data and how is confidentiality maintained?



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All information collected during this study will be kept confidential. Notes from the meetings and meeting documents will be anonymised so that any personal information (such as names, addresses, or places of work) will not be included in the research.

Anonymous notes from the meetings and meeting documents will be password protected and shared with the co-research group who are helping with the research. We will discuss these notes and documents to help us decide whether the process works in the 3 practices. To help us understand and interpret this research data further, Jessica Drinkwater will discuss it with her academic supervisors at the Leeds Institute of Health Sciences, University of Limerick and University of Hull. Sections of the anonymous notes may also be presented in reports, presentations, and scientific publications. We will send you a summary of the results at the end of the study.

During the study all the research data will be stored in a locked filing cabinet or in password protected computer files at the University of Leeds. The secure research data will be kept for 5 years after the study has ended. After the study has ended the anonymised data will be stored long term in the University of Leeds Research Data Repository. This anonymised data may be used to shape relevant future work by authorised researchers.

All information will be kept confidential unless there is evidence of actual or intended harm to others, for example criminal activity or patient-safety issues, although these are very unlikely to arise. In addition, in the unlikely event of concerns about quality of care being raised, under Jessica Drinkwater's professional code of conduct she will have to report the matter.

The University of Leeds is the sponsor for this study based in the United Kingdom. They will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for five years after the study has finished.

You cannot access, change or move your information, 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 information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at www.leeds.ac.uk/secretariat/data_protection.html

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to participate you can keep this information sheet, and will be asked to sign a consent form. Even after you have agreed to take part you can still withdraw at any time without giving a reason and with no consequences. If you withdraw after participating in a meeting the fact you attended will be on record and so this will still be used anonymously. If you do not wish to take part, or decide at a later date you no longer wish to take part, I will not observe your PPG any further and there will be no detrimental effects to your group.



What are the benefits and risks of participating in the research?

There are no immediate benefits or risks to taking part in this study. However, we hope that the process we have designed will help your PPG and practice to work together and may improve services at your practice. Data collected about this may help other PPGs and general practices to work together.

We understand that some people feel under ‘scrutiny’ when they are being observed. This study is not about making a judgment about how good or bad your group is, we are just trying to discover what happens during the process. Please talk to Jessica Drinkwater or another member of the co-research group if you feel uncomfortable.

Will I be paid for participating in the research?

You will not be paid individually for taking part in the research, although we will be very grateful. However, your general practice will be paid a one off fee of £750 to compensate them for any extra work or resources that they might have to use to help with the survey or having to put on extra meetings.

Who has given permission for the research?

This research has been approved by the University of Leeds School of Medicine Research Ethics Committee (SoMREC project number 18-009).

What if there is a problem?

If you are worried about the research or have any questions please speak to Jessica Drinkwater, a member of staff, or the chair of your PPG. Alternatively you can contact Jessica Drinkwater’s academic supervisor Professor Robbie Foy.

Jessica Drinkwater

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Thank you very much for taking time to read this information sheet.

Flowchart describing what is involved in the project

Timings	Expected activities of PPG and practice staff	Research team activity
Month 1	Meeting 0: Initial meeting Content: Meet each other. Explain project Outcome: Agree involvement	Meetings facilitated and observed by research team. Survey adapted for the practice by the research team.
	Meeting 1a: Agree priority short list Participants: PPG patients only Content: Card sort: 24 features of general practice Outcome: Short list of features to put in survey	
	Meeting 1b: Agree priority short list Participants: Practice staff Content: Card sort: 24 features of general practice Outcome: Short list of features to put in survey	
	Meeting 2: Vote on priorities Participants: PPG patients and practice staff Content: Combine both short lists & vote on final 5 Outcome: 5 features agreed for survey	
Month 2-3	Distribute survey Patient population to complete survey PPG attend training and help with distribution	Training to use survey & ongoing support.
Month 4	Meeting 3: Discussion of results Participants: PPG patients and practice staff Content: Discuss results and develop an action plan Outcome: Action plan	Results analysed, & meeting facilitated & observed by research team.
Month 5-12 Depends on how often PPG usually meet. Maximum follow up for 4 meetings or up to month 12.	Meeting 4: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	Research team will observe meetings. No Facilitation. Individual interviews with 3-5 members of PPG and 2-3 members of staff - may be at different time points.
	Meeting 5: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	
	Meeting 6: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	
	Meeting 7: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	