Getting the best from your NHS

Participant Information Sheet

You are being invited to take part in a research study to explore the use of Patient Reported Outcome Measures (PROMs) in your NHS care. Before you decide to take part 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.

Thank you for reading this.

Background

Aneurin Bevan University Health Board is leading the way to improving NHS care for patients. The Health Board is asking patients to fill out Patient Reported Outcome Measures (PROMS).

What are Patient Reported Outcome Measures (PROMS)?

Patient Reported Outcome Measures (PROMS) are a group of questions created for you to tell the Health Board about your health, experiences and quality of life. You may have been asked to complete PROMS using the methods listed below:

☎ A phone call from a member of staff

🗨 A text message

✉ A letter sent via the postal service

➤ An email

What are Patient Reported Outcome Measures (PROMS) used for?

PROMs are used as an assessment tool to make sure those who need urgent medical treatment are seen as soon as possible. PROMs also help the Health Board monitor your progress and symptoms from the comfort of your own home.

Who are we?

We are a team of experienced researchers at Bangor University in partnership with the Aneurin Bevan University Health Board (ABUHB).

Who is organising and funding the research?

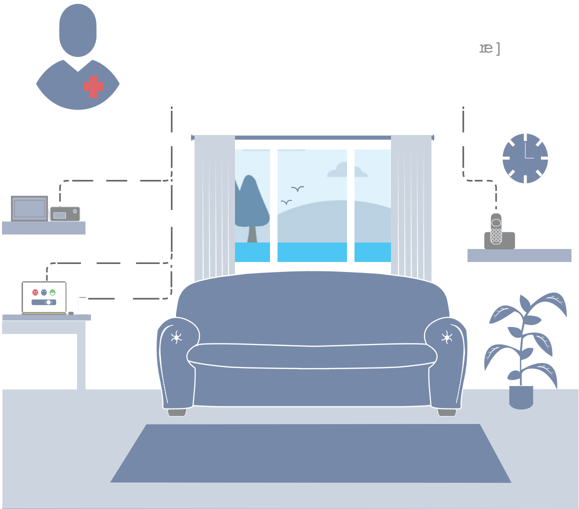
Welsh Government are funding this study. Aneurin Bevan University Health Board are the sponsor.

What is the purpose of the research?

We want to find out how Patient Reported Outcome Measures (PROMs) are working for patients and clinicians in Aneurin Bevan University Health Board.

Why are we asking for your help?

We have contacted you because we want to hear about your experiences of filling out and using Patient Reported Outcome Measures (PROMs). You may be a patient or family member. Sharing your views and experiences will



help us learn more about the use of Patient Reported Outcome Measures (PROMs). Your lived experiences will help us find out whether and how Patient Reported Outcome Measures help drive up standards of NHS care.

How can I help?

By participating in an interview over the phone, online video call or in person as a patient or family member (you can take part either separately or together).

What does taking part involve?

We would like to listen carefully to you. Interviews normally last around an hour and we will arrange the interview to fit around your schedule and needs. With your permission, our conversation will be audio-recorded.

If you agree to participate or would like further information, please fill out and return your contact details on the Consent to Contact Form.

What are the possible benefits of taking part?

Many people welcome the opportunity to share their stories to help us learn. The information we gain will help us understand more about the use of Patient Reported Outcome Measures (PROMs). This will help the NHS in Wales to improve patient care and support in future.

What are the possible disadvantages and risks of taking part?

We will ask about your experiences of care and specifically your views on Patient Reported Outcomes Measures (PROMS). Although it is unlikely this will be distressing, be reassured you do not have to answer any questions you do not want to and can stop at any time.

Do I have to take part?

No, it is entirely up to you.

What if I have concerns about this study?

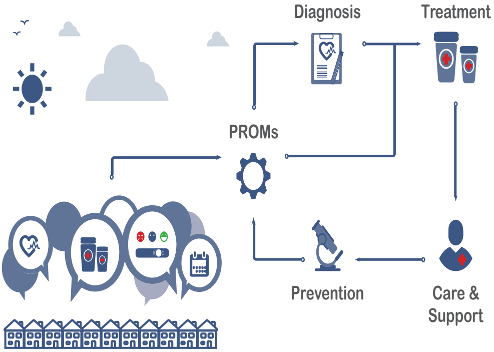
If you have a concern about any aspect of this study, you should ask to speak to a member of the research team who will do their best to answer your questions. The Chief Investigator is Dr Gareth Roberts, email hayley.lewis@wales.nhs.uk. If the research team are unable to resolve your query and/or you would like to speak to somebody outside of the research team you can contact the Aneurin Bevan Research manager on ABB.RandD@wales.nhs.uk.

What do I do next if I want to take part?

Thank you. Please send your consent to contact form back via the digital link. We look forward to hearing from you.

Data protection information: What will happen to the information I give?

Your contact details (name, email, telephone, address) will be logged by members of the research team on a secure database held in Bangor University. We will use these data to contact you to tell you more about the study and arrange an interview. The interview data you provide will be transcribed by an approved service in Bangor University, anonymised and analysed by members of the research team at Bangor University. We will not share any of your identifiable details unless you tell us something that makes us seriously concerned about you or another person's safety such as a child or vulnerable adult. We will publish findings, including anonymised quotes from the study in academic articles, reports and lay summaries. Your identifiable data will be destroyed at the end of the study.



What are your choices about how your information is used?

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. 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 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:

- by asking the research team
- by contacting the Data Protection Officer Jonathan Meredith at DPO.ABB@wales.nhs.uk

We would love to hear from you.

Value Based Healthcare study
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