

PROMs / PREMs Privacy Notice

Our commitment to privacy

Your privacy is important to us and we want you to let us know if we are not protecting your privacy to the best of our ability. Please also let us know if you have any other comment or complaint about the way we use personal data. We always try to work within the law, especially the UK General Data Protection Regulations (GDPR) and the Data Protection Act 2018 (DPA).

What does 'personal data' mean?

Personal data includes basic details about you, including your name and address. It also includes a range of other data about your physical or mental health, or data about your involvement with health and social care services.

What are PROMs and PREMs?

We would like to ask you some questions about your health and quality of life. These questions are designed by scientists and are known as Patient Reported Outcomes Measures (**PROMs**) and Patient Reported Experience Measures (**PREMs**). We would also like to ask you these questions at different times in your treatment and (in some cases) even after your treatment has finished.

The things we would like to ask you depend on your circumstances. We might want to ask you about a specific health condition, or we might have more general questions about you and your general health. We may also ask you about your experience of receiving care in your local hospital or clinic.

We want to ask you these questions to help us understand how your health condition and quality of life changes over time. It will help your clinical team check in on your well-being and also to make decisions with you about your care. Your answers will also help the NHS to understand what treatment works best for people.

The information you provide about your health will be stored by NHS Wales to allow your care team to see it alongside other medical information we use in healthcare (such as tests results and letters from your GP).

We want you to know that answering these questions this is **optional**. While we would very

much like you to take part in PROMs or PREMs activities, you may prefer not to take part. If so, we will respect your decision and we will continue to work with you as before. There will be no negative consequences for deciding not to take part.

Who are we and how will we collect this information?

We are Cardiff and Vale University Health Board, a part of NHS Wales. We collect data from you with PROMs / PREMs questionnaires which you will complete online. We protect your personal data and follow all the laws that are made to protect personal data.

We have asked Promptly to provide a secure website for you to answer the questions we have. We have worked closely with Promptly to ensure they have data security arrangements that will protect your data. Under GDPR, we are the data controller and Promptly is the data processor, and we have an appropriate formal agreement in place between us.

You will need to register for an online account with Promptly in order to provide your answers to the PROMs / PREMs questions. Please note that there is an additional privacy notice and website terms of service which are separate to our relationship with you. We encourage you to check out the Promptly privacy policy and terms of service before you decide to take part.

What data is being collected?

The data that is being requested from you is as follows:-

- Personal data about you: your name, gender, address and date of birth;
- Details of the clinic / hospital referring you;
- Answers provided by you in response to PROMs / PREMs questionnaires;
- Contact information provided to set up and maintain your account on the Promptly website.

All this data is recorded by Promptly and they will send the answers you provide and your personal data to the Health Board so that we can make sure the right doctors and other clinicians see your

responses. We will not receive the contact details you use to set up and maintain your account on Promptly.

Who will see my data?

The doctors and other clinicians who referred you to the PROMs / PREMs program will be the only staff who see your individual answers to the questions. Anyone who has access to your personal data will do so only when:-

- They need to see that data to do their job;
- They must follow any relevant laws and rules of their profession which protect data from being seen by anyone who does not have the right to see it;
- They can lose their jobs and careers if they misuse the data.

We may also use the data from your answers for management or administrative tasks which are

What are my rights over the personal data you hold about me?

The GDPR gives a series of rights to citizens in regard to their personal data. These rights are slightly changed because our work on PROMs / PREMs is a 'public task'.

Your rights over this personal data have changed in the following ways:-

GDPR Citizen Right	Applies?	Notes
The right to access data	Yes	People have a right to see personal data but we can only provide data to an individual entitled to see it. We will seek to maximise the amount of material we can share with you within the relevant law.
The right to erasure	No	This right does not apply to data gathered within a 'public task'.
The right to correct inaccuracies	Yes	Each request will be considered individually. The law allows us to refuse if it would be against the law or would harm the service. Only factual mistakes can be corrected. Changes to professional opinions are only allowed if the opinions are based on inaccurate facts.
The right to restrict processing	Yes	Each request will be considered individually. The law allows us to refuse if it would be against the law or would harm the service.
The right to object to processing	Yes	We do not use any automated decision making processes. Each request will be considered individually. The law allows us to refuse if it would be against the law or would harm the service.
The right to data portability	No	This right does not apply to public task data. However, where exercising rights to access data, we can provide data to you in an electronic format.

Additional rights include:

- The right to be informed about the regulator to whom complaints can be made (see below);
- The right to be informed about any transfers of data overseas: no data gathered from you will leave the United Kingdom;

allowed by GDPR / DPA. Data used in this way would not contain any individual's personal data.

Does the law allow you to do this?

We have to tell you what laws we are relying on to use your personal data. To allow the use of your personal data under [UK GDPR](#), we are using the provisions known as 'public task', [Article 6 \(1\) \(e\)](#) which means we are carrying out our duties set out in law. For health services, this law is found in Section 3(1) of the [National Health Service \(Wales\) Act 2006](#)

To allow sharing of more sensitive data, such as your answers to PROMs / PREMs question, [Article 9\(2\)\(h\)](#) of the UK GDPR tells us we can share personal data to provide health care or social care to an individual or for the management of health or social care systems and services.

- The right to be informed of how long data will be kept: for your personal data and your answers to PROMs / PREMs questions, your data will be kept in line with your medical records.

How do I ask a question about my rights over my data or complain about how my rights have been handled?

Please contact us if you wish to apply any of the rights set out above or if you wish to discuss any issues relating to personal data used to support our work with LAC.

You may contact us using the following details:-

Cardiff and Vale University Health Board	PROMPTLY HEALTH
Information Governance Department, Woodland House, Maes-y-Coed Road, Cardiff, CF14 4TT Uhb.Dpo@wales.nhs.uk	Promptly Health 53 1495-092 Algés , Lisbon, Portugal www.promptlyhealth.com

We will respond to your request within a month to explain what we intend to do.

How do I contact the regulator?

If you remain unhappy with the way we have processed your personal data, you may also wish to contact the national regulator.

You can also find out more about your personal data rights by going to the Information Commissioner’s Office (ICO) website at <https://ico.org.uk/your-data-matters/>.

For further independent advice about data protection, and your personal data rights, you can contact:-

Information Commissioner’s Office – Wales

2nd Floor, Churchill House

Churchill Way

Cardiff

CF10 2HH

Tel: 02920 678400 Fax: 02920 678399

E-mail: Wales@ico.gov.uk

Web: <https://ico.org.uk/>

In addition, if you remain unhappy, you may request a Court to assert your rights.