



Doeth am Iechyd
Cymru
HealthWise
Wales



Participant Summary Leaflet

Thank you for taking the time to consider registering with HealthWise Wales. This information leaflet contains all of the essential information that you need before registering.

What is HealthWise Wales?

HealthWise Wales hopes to involve everyone in Wales in improving the health and wellbeing of the population. By registering with HealthWise Wales, you are saying that you are willing to take part in research. You are saying that you are willing to spend a little bit of time every 6 months to contribute a small amount of information about your health, wellbeing and lifestyle. Also, by signing up to HealthWise Wales, we will tell you when there are opportunities to take part in studies that are relevant to you.

✉ www.healthwisewales.gov.wales
🌐 0800 9 172 172 or 02920 768090
☎ healthwisewales@cardiff.ac.uk



What will I have to do?

Taking part is voluntary: it's up to you to choose if you want to sign up. If you join, we will ask you to:

1. Give us your contact details.
2. Complete questionnaires about your lifestyle, health and wellbeing every 6 months or so.
3. Allow us to access and use your information in your NHS records.

We will not look at the actual notes that your GP or hospital consultant have written. Instead, we are given access to a dataset in which the purpose of each visit has been given a code. For example, if you go to your GP to have your blood pressure checked, and are given new tablets, the dataset might contain codes for "high blood pressure" and "new treatment given".



Will I need to agree to everything?

It is important to understand that to join HealthWise Wales you have to agree to give us your contact details, and to allow us to access and use your NHS records now and in the future. You'll need to agree that we can access and use your healthcare records in confidence for many years (even if you lose mental capacity and when you die) as the project will be ongoing. So, if you don't want us to do this, you will not be able to join the study. If you lose capacity, your relatives will be able to contact us to inform us of what we should do with your information. All of the other activities (questionnaires, new studies or events to which you are invited) are voluntary, so you will be able to choose which ones you would like to take part in.

How do I join?

You can register today through the online system on the website or through a paper-based system. You will have to read some information about what you are agreeing to. Please read this information carefully so that you fully understand what is involved before consenting to take part. If you are registering today, you will have to give us your consent (either by entering your email and selecting a password on the website or providing your signature on the paper-based consent form). Following this, you will be asked to provide registration details, such as your name, date of birth, gender, address, and contact numbers.

If you would like some more time to think about registering, we can provide you with information on how to register at a later time online through the website (www.healthwisewales.gov.wales) or by phone. We can also organise for someone to call you to complete the process over the phone.

How long does it take to join?

Once you have read these pages and decided you want to take part, joining will take about 5 minutes.

Will my information be safe?

It's important to us that all your information is safe. It will be held securely and anonymously. We will follow the standards set out in the Data Protection Act 1998, the Caldicott Review and Good Clinical Practice Guidelines for all data management and storage.

Will people outside of the research team know if I'm taking part in the project?

We will not share any of your personal information such as your name, address or anything you tell us in the questionnaires with your doctor or insurance companies. So, taking part will not have any negative effects on you (including your ability to work or get insurance). None of the information you give us will be used to make any decisions about your health or healthcare. If you are worried about anything to do with your health, you should speak to your doctor.

Who will have access to my information?

The study team will control access to your contact details, and only the study team will contact you directly.

Who is doing the study?

HealthWise Wales is a partnership between the public and the scientific community in Wales. It is funded by Health and Care Research Wales which has responsibility for research in the NHS in Wales. The day to day running of the study will be done by a team of researchers based in Cardiff and Swansea Universities. The study will be overseen by a Public Advisory Board and a Scientific Steering Group.

What will happen if I decide that I don't want to take part anymore?

You can withdraw at any time. However, HealthWise Wales will be of most benefit to the people of Wales if everyone who joins the study continues to be part of it. It would be helpful if you discuss any concerns that you might have with one of the study team before you decide to leave us (see contact details below).

What should I do if I have any questions?

You can phone us on 0800 9 172 172 (free from most landlines) or 02920 768 090.

Our office hours are 8.00 am to 7.00 pm Monday to Friday.

Or you can contact us by email on healthwisewales@cardiff.ac.uk. We will reply to your message quickly, unless you tell us that you would like us to phone you (and provide your telephone number).

Participant Consent Form

Taking part in HealthWise Wales is voluntary. If you join and then change your mind, you can leave the study at any time. If you don't want to take part, you don't have to do anything.

We will keep the information that you share with us. It will be held securely by Cardiff University and the NHS Wales Informatics Service. Names and personal details will be stored in a different place

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to all other study information. The study has been approved by the Wales Research Ethics Committee 3 (Wales REC3).

Please read the information overleaf before agreeing to take part in the study. If you would like further details, please ask the HealthWise Wales representative or see the 'About the Study' section on the website.

By taking part, you are agreeing to:

1. Provide us with your contact details (e.g. name, address, email address, phone number) and some personal details (e.g. sex, date of birth, ethnic group).
2. Answer some questions about your lifestyle and health.
3. Allow us to use your details to access and use the information in your routinely collected NHS records.
4. Be contacted every 6 months or so by the study team, to give us information about your lifestyle, health and wellbeing.
5. Be contacted to take part in events where we ask you about the topics we should be studying.
6. Be contacted by the study team about other studies that you may want to take part in.
7. Allow us to share anonymous information with other researchers if they have scientific and ethical approval for the questions that they would like to answer with the information, and have the right training.

By agreeing to take part, you also declare that:

1. You have read and understood the information about HealthWise that has been provided to you.
2. You are currently living in Wales, or using health services in Wales.
3. You are aged 16+.

If you do not understand any of the above information, you can contact us to discuss:

1. By phone on 0800 9 172 172 (free from most landlines) or 02920 768 090. Our office hours are 8.00 am to 7.00 pm, Monday to Friday.
 2. By email on healthwisewales@cardiff.ac.uk
- Now that you understand what is involved, do you agree to take part in the HealthWise Wales study? To join the study, please fill the form on the opposite page in and enter your signature and today's date.

Signature:

Date: DD / MM / YYYY

Participant Registration Form

Thank you for registering with HealthWise Wales.

Now that you've registered, we would like you to provide us with your contact details and some information about yourself. Please fill out each section below. If you have any questions, please ask the HealthWise Wales representative.

First Name:

Middle Name (Optional):

Surname:

Date of Birth (DD/MM/YYYY):

DD / MM / YYYY

Are you male or female?

Male

Female

Please enter your postal address:

Please enter your postcode:

Please enter your home phone number:

Please enter your mobile number:

Please enter your email address:

Please indicate how you would like HealthWise Wales to contact you in the future?

Email

Phone

Thank you for completing this form
