**£20 Amazon** **voucher** for taking part in an interview with us

# A box with the title of the study in black letter.  A black and white image in the shape of a light-bulb.

**Take part in our new research project, and help us to understand how assistive technology can affect health and quality of life!**

# We are doing a new research project called AdaptQoL.

# This is a national research study.

# We want to find out how assistive technology devices like wheelchairs, hearing aids, and other aids affect people’s health and quality of life



WHY HAVE I BEEN INVITED TO TAKE PART?

You have been invited to take part because:

* You are 18 years old or older
* You use assistive technology
* Your support service
thinks you can take part

WHAT IS THE ADAPTQOL PROJECT?

Assistive technology can help people do everyday things, like moving, talking or looking after themselves.

We want to find out how assistive technology can affect people’s health and quality of life. Quality of life can mean many things, such as:

* How happy you feel
* How satisfied you are with your life
* Your well-being

In this research project we want to find out:

* What quality of life means to you
* How assistive technology helps or changes your life

We will use what you tell us to create a new survey tool called AdaptQoL.

This survey tool will help the NHS and care services understand how well different assistive technology devices help people.

WHY IS THIS RESEARCH NEEDED?

Every year, the NHS and care services give out millions of assistive technology devices.

By developing the AdaptQoL survey tool, we will be able to measure how helpful these devices are.

With your help, we can make sure that the AdaptQoL survey tool is accurate and works well for everyone.

This will help the NHS and care services give the best support to people.

DO I HAVE TO TAKE PART?

No – it is your choice. You do not have to take part.

If you say yes, you can change your mind at any time, and it will not affect your care.

You can also ask a family member, carer, or friend to help or take part with you if you require help to communicate and/or take part.

WHAT WILL I HAVE TO DO IF I TAKE PART?

If you want to take part in this research, please fill in the questionnaire that came with this leaflet and post it back to us in the envelope provided.

You can also fill in the questionnaire online using the QR code on the front page of the questionnaire.

A member of the project team will then contact you to arrange a time for the interview.

The interview will last up to 1 hour.

In the interview, we will ask you:

* What ‘quality of life’ means to you
* How you think assistive technology affects
your health and quality of life
* Your thoughts on how to measure the
benefits of different assistive technologies

We will record the interview if you say it is ok.

You can do the interview:

* Online, by phone, or in person
* Alone or with someone you trust, like a friend, partner, or carer

Let us know if you need any support to take part in the interview – we are happy to help.

WILL MY DATA BE PROTECTED AND CONFIDENTIAL?

Yes, everything you tell us will be kept private and confidential.

We will only share information if we are worried about your safety or someone else’s.

All your information will be kept safely by Bangor University on protected computers.

We will follow UK data protection laws.

ARE THERE ANY RISKS OR BENEFITS TO TAKING PART?

We do not think there are any risks to you if you take part.

We may ask some personal questions about your health and quality of life. If any question makes you feel uncomfortable, you do not have to answer it.

There may not be any direct benefits to you, but as a thank you, you will get a **£20 Amazon gift voucher** if you take part in an interview.

WHO IS FUNDING THIS PROJECT AND HAS IT BEEN REVIEWED?

This project is funded by the Welsh Government through Health and Care Research Wales (Project number: 02-24-026).

It has been checked and approved by an NHS Research Ethics Committee (IRAS reference: 348110)

This committee made sure that the project was safe, fair, and respectful for everyone taking part.

This information sheet is also available online, as a video,
in large print, and in Welsh. Please scan this QR code to access other formats

**Do you want to know more?**

Please read the Frequently Asked Questions (FAQ) sheet below for more information about the project.

If you still have questions, you can phone us, write to us, or email us using the contact details below.

**Do you want to take part?**

If you want to take part, please fill in the questionnaire that came with this leaflet.

Send it back to us in the pre-paid envelope (or fill it in online using the QR code on the questionnaire)

Someone from the team will then contact you to arrange your interview.

These are the contact details for the project team:

**Website:** [**www.bangor.ac.uk/adaptqol**](http://www.bangor.ac.uk/adaptqol)

**Email:** **adaptqol@bangor.ac.uk**

**Tel: 07792670053**

**Post:** Write to us using the **prepaid envelope** sent with this leaflet

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**Please go to the next page for our Frequently Asked Questions (FAQs) section**

**Frequently Asked Questions (FAQs)**

**Please read the parts of the FAQ that are important to you**

If you have any other questions, please **contact us** using the contact details on the previous page

**What is the full title of this study?**

The full title is: *Adaptation and Quality of Life (AdaptQoL): Development of a patient-reported outcome measure for people who use assistive technologies and other adaptive interventions*



**What is the AdaptQoL project?**

AdaptQoL is a national research project.

We want to make a new survey tool to measure
how helpful assistive technologies are.

We will talk to people who use assistive technology
and use their answers to design the survey.

**What do you mean by ‘assistive technology’?**

Assistive technology means any tool or device that helps someone with an impairment to do something that might otherwise be difficult.

These devices fit into 5 categories:

1. *Mobility* (e.g. Wheelchair, walking stick, prosthetic limb)

2. *Cognition* (e.g. Memory aid, personal digital assistant)

3. *Communication* (e.g. Text-to-speech software, captioning app)

4. *Self-care and daily activities* (e.g. Shower chair, toilet frame)

5. *Sensory* (e.g. Hearing aid, screen reader, white cane)

**Why is the AdaptQoL project happening?**

Each year, the NHS and care services give out millions of aids and devices. These are called assistive technology.

Assistive technology help people do everyday things – like moving, self-care, and talking to others.

We want to understand how this technology can affect people's quality of life.

"Quality of life" means things like:

* Feeling happy
* Being satisfied with life
* Feeling well

We want to know what quality of life means to you.

We will use what you tell us to make a survey tool that helps care services understand what works best.

**Who is running this research project?**

The AdaptQoL research project is led by Dr Nathan Bray at Bangor University, and it is being carried out by experienced researchers.

Many organisations are supporting this research, including service users, NHS and care services, charities, and assistive technology teams.

Bangor University is in charge of the project and your information.

Bangor University hold appropriate insurance policies to protect against harm and offer compensation.

**Why do you need to hear from me?**

We want to hear from people who use assistive technology.

Your experience is important. We can only make a good survey tool by listening to people who use assistive technology, like you.

**Why am I being invited to take part in an interview for this project?**

You have been invited because:

* You are aged 18 or older
* You use assistive technology
* Your support service thinks you might be a good match
* We want to include people with different experiences and needs

We will check your answers on the questionnaire to make sure that you are eligible to take part. The criteria are:

* You have had a long-term impairment which resulted in you using assistive technology
* You are able to communicate in English or Welsh
* You are aged 18 or older, you are able to understand the project and you are able to provide consent

If you do not meet all of these criteria, unfortunately we will not be able to invite you to an interview.

**How long does the project last?**

This is one part of a larger project which will run for 2 years.

If you take part, we will only ask you to do one interview (unless you want to do more later).

**Who is paying for this project?**

The project is funded by the Welsh Government through Health and Care Research Wales (project number 02-24-026).

**Do I have to take part in the AdaptQoL project?**

No, it is your choice. You can say yes or no, it will not affect your care. You can ask someone else to help you take part if needed.

**What do I have to do if I want to take part?**

1. *Fill in a consent form and questionnaire*

First, you will need to fill in a consent form to say you want to take part in this research, this is at the beginning of questionnaire.

Then, you will need to answer the questionnaire, which asks about you, your health and the assistive technology you use.

You will then need to send this to us in the envelope that we have provided, or complete the online version of the questionnaire.

1. *Take part in an interview*

After we have received your consent form and questionnaire, a researcher will contact you to arrange an interview (in-person, online or phone).

The interview will last up to 1 hour.

We will ask about:

* What “quality of life” means to you
* How assistive technology affects your health and life
* How to measure the benefits of assistive technology

You can have a friend, carer or family member with you.

The interview will be recorded only if you agree.

If you need support (such as sign language), please let us know

**Will I get anything for taking part?**

Yes, you will receive a **£20 Amazon voucher** as a thank you.

**If I agree to take part, will you ask me to do more in the future?**

We will ask if you are happy to be contacted for future parts of the project, it is your choice.

**What if I change my mind?**

You can stop taking part in the research at any time for any reason, even after completing an interview.

This will not affect your care.

Any information you provide will remain confidential and will not be used for any other purpose than this research.

If you change your mind and would like to stop taking part, you can let us know using the contact details provided earlier in this leaflet.

**What will happen to the results of the project?**

We will:

* Share the results with everyone who takes part
* Share the results with health and care services
* Publish in scientific journals and conferences

You will not be named or identifiable in any report or publication.

**What should I do if I am not sure about taking part?**

We understand that you might need time to decide.

You can talk to us using the contact details provided earlier in this leaflet, or ask a family member, friend or health professional for advice.

**Who has reviewed and approved this research?**

The project has been approved by the NHS Seasonal Research Ethics Committee (IRAS ref no. 348110).

**What are the benefits of taking part?**

You may not get a direct benefit. But by taking part, you will help the NHS and care services to understand how to improve support for people using assistive technology.

**What are the disadvantages and risks of taking part?**

We do not expect any disadvantages or risks.

You might find that some questions are personal or sensitive. You do not have to answer anything that makes you feel uncomfortable.

**How will you protect my information?**

We will:

* Follow the UK’s data protection laws
* Keep all your data safe and secure at Bangor University

You can find out more about this by contacting us using the contact details provided earlier in this leaflet.

**Will my information be kept confidential?**

Yes. Everything you share will be confidential unless there is a safeguarding issue (more information in the next section)

Only the research team at Bangor University will see your name and contact details.

We will not share your details with the service or organisation that helped invite you.

**What are your rules for safeguarding and distress?**

Your safety and privacy are our top priority. But, there may be situations where we have to share your information with other services. This will only happen if:

* Something you say makes us believe that you or someone else is at risk of serious harm
* We become aware of a safeguarding concern (e.g. involving a child or vulnerable adult)

If it is appropriate, we will speak to you first and explain who we will inform and why.

You can pause or stop taking part without giving a reason at any time if you feel upset or distressed.

If you need additional support during or after the interview please tell us, our contact details are in this leaflet.

**How will you use information about me?**

We will need to use information from you for this research project.

This information will include:

* Your name and contact details
* The answers you give on the questionnaire
* The information you tell us in the interview

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Bangor University is the sponsor of this research and is responsible for looking after your information. We will not share your information related to this research project with other organisations.

We will keep all information about you safe and secure by:

* Storing your data on secure computer servers at Bangor University
* Not sharing your identifiable data outside of our organisation

Your data will not be shared outside the UK.

**How will you use information about me after the study ends?**

Once we have finished the study, we will keep some of the data so we can check the results.

We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your identifiable study data for a maximum of 1year. The study data will then be fully anonymised and securely archived for 10 years and then destroyed.

**What are my choices about how my information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

**Where can I find out more about how my information will be used?**

You can find out more about how we use your information:

* from our leaflet
* by asking one of the research team
* by sending an email to adaptqol@bangor.ac.uk
* by ringing us on 07792670053
* [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)

**What if there is a problem?**

If you have any concerns or would like to make a complaint, please contact Dr Diane Seddon (email: d.seddon@bangor.ac.uk). Dr Seddon is independent from the research team.