



**British Heart Foundation
Data Science Centre**

Led by Health Data Research UK

Patient and Public Involvement and Engagement Strategy (PPIE) 2024 to 2025

How we want to include patients and the public in our work



Easy read booklet

Who we are and what this booklet tells you about



We are the **British Heart Foundation Data Science Centre**, called **BHF DSC** for short.



BHF DSC is a **partnership** between the **British Heart Foundation**, called **BHF** for short, and **Health Data Research UK**, called **HDR UK** for short.

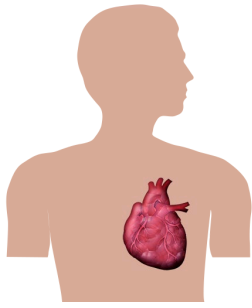


A **partnership** is when 2 or more organisations work together.

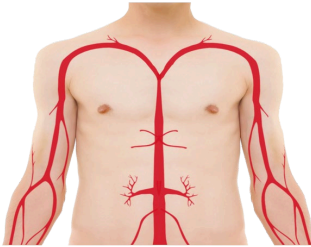


We work with people and organisations to help them do **research** into health problems

Research is work done to find out new information about something.



Some of this research is about health problems that affect the heart and **circulation**.



Circulation means how the heart pumps blood around the body.



Health problems that affect the heart and circulation include diseases called

- heart attacks
- stroke
- vascular dementia.



We want to include **patients** and the **public** in our work.

A **patient** is anyone who is ill and gets help or treatment from a health service.



The **public** means all the people in an area, like a country.



This is called **patient and public involvement and engagement**, or **PPIE** for short.

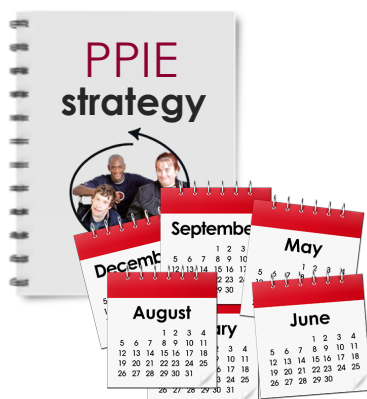
It means we want patients and the public to be part of what we do and give us ideas and help us make decisions.



The patients and public we include are called our **public contributors**.

Our public contributors might be

- people who have or have had health problems that affect or are connected to the heart and circulation
- family or friends of people who have or have had health problems that affect the heart and circulation.



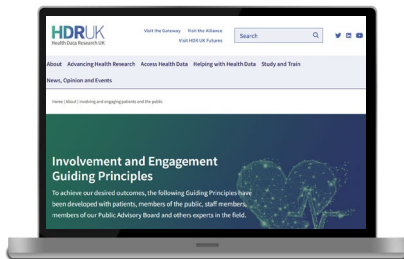
This booklet tells you about our PPIE **strategy**.

A strategy is a plan about how to make something happen over time.



We follow **guidelines** for the work we do.

Guidelines are information you can follow about how to do something.



Go to this website to read our guidelines

[www.hdruk.ac.uk/about-us/
involving-and-engaging-patients-
and-the-public/patient-and-public-
involvement-and-engagement-
guiding-principles](http://www.hdruk.ac.uk/about-us/involving-and-engaging-patients-and-the-public/patient-and-public-involvement-and-engagement-guiding-principles)

Why we want to include patients and the public in our work



When people and organisations work with us to do research, **health data** is used.



Health data is information about a person's health.



Sometimes, health data is used without the **consent** of the person it is about.



Consent is when you say you understand and agree something can happen.



We want to include patients and the public in our work so that



- health data is used in a good way that is open and clear



- our research is done in a good way that is open and clear



- our research is good quality and follows guidelines



- our research can have a good effect on the health of the public



- the public can trust our research.

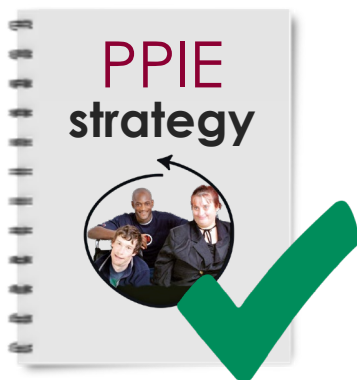
How we will include patients and the public in our work



We have 6 **objectives** about how we will include patients and the public in our work.



Objectives are things that need to be done to make something happen.



Our objectives are what we need to do to make our PPIE strategy happen.



We tell you about our 6 objectives in the next part of this booklet.

Objective 1

Make sure patients and the public are included in everything we do



We will

- ✓ include the public in all parts of our work
- ✓ meet our public contributors often and listen to what they tell us
- ✓ find more public contributors
- ✓ make sure people who work for us know about and follow guidelines for PPIE
- ✓ follow official rules when we work with the public
- ✓ look at our projects and see what chances they offer for PPIE
- ✓ tell people about and support BHF DSC and HDR UK activities that involve the public
- ✓ tell people about our PPIE work at events that happen in person and online.



Objective 2

Make sure equality, diversity and inclusion is part of everything we do



Equality means everyone is treated in a fair way.



Diversity means including people who might not get treated the same way as other people, like people who are old, disabled, a different gender or from a different background.



Inclusion means everyone is included and no one is left out.

EDI

Equality, diversity and inclusion is called **EDI** for short.



We will

- ✓ make EDI objectives for our organisation and think about what we do now and how we can make it better



- ✓ work with HDR UK to go to events outside of towns and cities so more people can be included in our work



- ✓ make sure there is diversity in our **Public Advisory Group**, called **PAG** for short

- ✓ start partnerships with organisations that can help us have more contact with diverse groups of people



- ✓ work with local groups to make sure diverse groups of people are included in our work

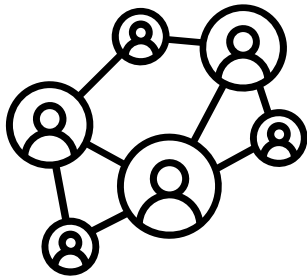
- ✓ make sure what we do is **accessible** so more people can be included in our work.



Accessible is when something can be used or understood by everyone.

Objective 3

Have good partnerships and networks and use them to get better at what we do

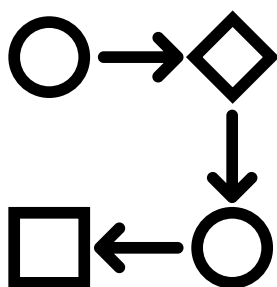


Networks are groups of people who share ideas and support each other.



We will

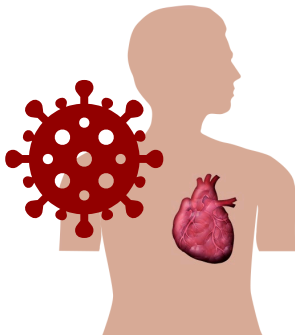
- ✓ grow partnerships we already have and look for new partnerships to start
- ✓ share what we learn about PPIE with our partners to make information better for everyone
- ✓ take part in PPIE networks
- ✓ take part in work to make PPIE guidelines better
- ✓ work with our public contributors to make a **framework** for partnerships that includes information about PPIE.



A **framework** is a guide for organisations to follow about the best way to do something.

Objective 4

Make sure anyone who is part of what we do knows about our PPIE work and trusts that it is good



We will

- ✓ give good training and support to our public contributors
- ✓ give good training about PPIE to researchers
- ✓ support people who work for us and our partners to include PPIE in new projects
- ✓ share information we find out about PPIE with other organisations to show how important it is
- ✓ work with public contributors and researchers who are part of a group called the **CVD-COVID-UK consortium** to make sure PPIE is included in new projects and training is given every year.

The CVD-COVID-UK consortium do research about COVID-19 and health problems that affect the heart and circulation.

Objective 5

Monitor and evaluate our PPIE work



Monitor means watch and check something.

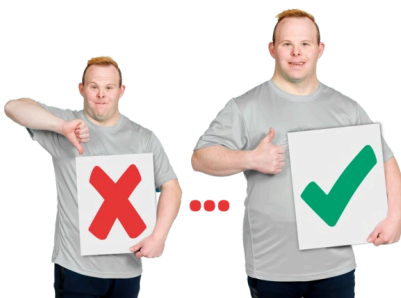


Evaluate means look at information about something and work out how important it is and what effect it will have.



We will

- ✓ monitor our PPIE work so we know what happens and can think about what effect it has
- ✓ send a newsletter to our public contributors every month that talks about ways they have affected our work
- ✓ write things, like blogs, with our public contributors to show how our PPIE work makes a difference
- ✓ evaluate our PPIE work and think about ways we can make it better.





We will

- ✓ share information about our PPIE work so that good things we find out can be used by other people
- ✓ **review** our PPIE work every year
- ✓ write 2 or more **case studies** about our PPIE work every year and share the case studies in our organisation and with our partners.

Review means look at how good or bad something is.

A **case study** is when something, like a person or a group, is looked at closely and written about.

Objective 6

Make sure information about our PPIE work is included in our communications



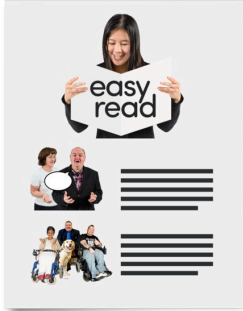
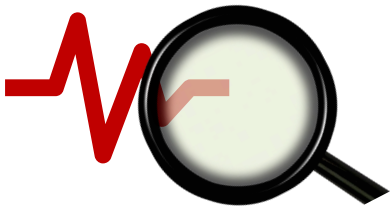
Communications are how an organisation shares information about what it does, to people inside and outside of the organisation.



We will

- ✓ have a **Writing Club** where our PAG can be part of writing communications for people outside of our organisation
- ✓ run workshops to check our website is good
- ✓ ask our public contributors to help run some events, like our monthly online events or networking events
- ✓ make communications about our PPIE work better inside our organisation so people who work for us know more about it.





We will

- ✓ find new ways to include more people in health data research
- ✓ make our communications accessible
- ✓ work with partners and community groups to find ways for more people to see our communications
- ✓ work with our public contributors to include stories about real lives in our communications.

How to contact us



If you want to find out about what we do or how you can get involved, contact our friendly PPIE team.



Send an email to

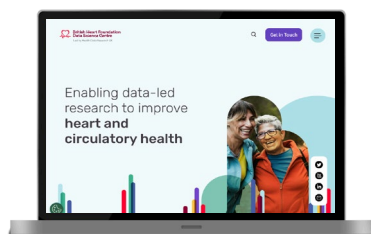
- Jemma Austin
jemma.austin@hdrug.ac.uk
Jemma has a job called **PPIE Officer**.



- Amy Hodgkinson
amy.hodgkinson@hdrug.ac.uk
Amy has a job called **PPIE Manager**.



- Samaira Khan
samaira.khan@hdrug.ac.uk
Samaira has a job called **Senior PPIE Manager**.



Or go to our website
www.bhfdatasciencecentre.org

Thank you to A2i for the words.
www.a2i.co.uk (reference 40237)