

# How To Effectively Engage Patients In Digital Health Technologies

**An Evidence Based Guide By:**



**UNIVERSITY OF  
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The transformation of  
healthcare should be  
**done with, not to**  
patients.

# WHY THIS MATTER.

Evidence shows that patients may **reject digital technology** if patients and the public have not been involved in its development.<sup>1</sup>

Therefore, patient and public involvement and engagement (**PPIE**) is **critical** for the development of digital health technologies that aims to improve the health and care of our patients.

This evidence-based guide is a **first-of-its-kind** review of best practice in PPIE, providing valuable advice and resources to digital health innovators.

1. Nicola Straiton, Robyn Gallagher, Prioritizing what matters most in digital health research, *European Journal of Cardiovascular Nursing*, Volume 21, Issue 6, August 2022, Pages 519–520, <https://doi.org/10.1093/eurjcn/zvab103>

# GUIDE DEVELOPMENT

This evidence based guide is the collaborative effort between the **University of Plymouth**, The **Academic Health Science Network (AHSN)** and **Boehringer Ingelheim**.

Development of the guide involved:

Systematic review of  
>10000 peer reviewed  
abstracts

Extensive Patient  
Input

A multi-stakeholder  
Workshop

6 months of  
Stakeholder  
Engagement

This guide contains real insights coupled with actionable advice for PPIE. To call it a definitive guide is **not an overstatement**.

# THE ENACT PRINCIPLES

Following a study led by the Centre for Health Technology at the University of Plymouth, these principles were co-designed and agreed by a range of stakeholders including **patients, clinicians, regulators, digital health innovators and academics.**



**Engage**



**Acknowledge, value and support**



**Communicate**



**Trust and Transparency**



# ENGAGE

## Principle 1:

Involve people **early** and **throughout**.

To do this successfully, it is helpful to consider your strategy carefully: **why are you conducting PPIE** and **how do you want people to feel** during the process?

Engaging with an intersectional cohort across the patient pool is essential – experiences of people with different employment status, ethnicities and genders will vary. Here, **selection bias** is a common challenge.

## Useful resources:

1. [Health Equity Assessment Tool \(HEAT\)](#) - help define which populations are affected by a particular condition and if any groups are under represented.
2. [Patient Involvement Volunteer Form](#) - whereby patients can express their interest in contributing to PPIE.
3. NICE's [Patient and Public Involvement Policy](#) is a great case of clear PPIE policies and transparency frameworks and provides a good example to innovators of how to involve patients.
4. NICE's [Public Involvement Programme](#) aims to help patients, carers, the public, and patient organisations involve themselves in NICE's work.

## Principle 2:

# Commit to **sharing power** and work in **equal partnerships**.

In this context, power-sharing means **equality of voice** for all stakeholders such as innovators, clinicians, managers, policymakers, patients and the public.

It is about **considering everybody's voice fully** and **being transparent as to why and how** decisions were taken, not patients and the public overruling decisions.

Patients have historically been passive participants, and **co-design is about empowerment and active engagement** – doing things with, not to, patients. Differing views are to be expected during the PPIE process.

## Useful resources:

- [Involving People and Communities in Digital Services](#), guidance published by NHS Transformation Directorate is a good example of diverse involvement best practice.
- [Shared Decision Making Guidelines](#), by NICE also house resources to help people in the process of power-sharing and shared decision-making.

## Principle 3:

Work in an **interactive, flexible manner**, learning how to be **openminded and receptive** to people's suggestions.

Many people may not think that accessing digital health systems is **relevant to them**, until they are in a situation where **they need to do so**.

Innovators and researchers should be mindful of this, and address the **'what's in it for me'**.

PPIE is a **dynamic and evolving process**, and digital technology means different things to different people at **different stages** of their healthcare journey.

Innovators should approach PPIE **empathetically** and be mindful of people's **individual circumstances** and the ecosystem around them, while recognising that these **may change over time**.



## Principle 4:

# Co-design engaging involvement activities and evaluation methods.

Developing evaluation frameworks, while remaining sensitive to how different people process motivation and purpose, may be challenging and **would benefit from expert input.**

Here, it is crucial that patients are involved as well, so that PPIE is partially evaluated **on what matters to all parties involved.**

Evaluation and PPIE processes should also **be aligned with evidence generation requirements** for innovators and their technologies. A strong evidence base aids **in the adoption** of technologies into the system.

## Useful Resource:

NHS England's **Innovation Service** acts as an 'information gateway' to support innovators in understanding the evidence standards and requirements needed for NHS procurement processes.



# ACKNOWLEDGE, VALUE AND SUPPORT

## Principle 5:

**Collaboratively discuss and agree intellectual property (IP) rights from the outset.**

**There are several challenges and concerns here:**

- Definition of IP is poorly understood.
- Concern over ownership of IP, particularly **if a patient provides rich insights** during the product development process.
- Concern around **sharing sensitive information** or trade secrets' with patients, particularly if competitors exist that may **tap into the same pool of patients**.

**These risks can be mitigated by :**

- Seeking advice on IP before starting the PPIE process, such as from **UK Research and Innovation (UKRI)**.
- Putting a commercial **non-disclosure agreement** in place.
- Having a **clear agreement on who owns the IP** from the beginning.

## Principle 6:

### Recognise, value and reward people's time

Some form of **reimbursement** and the existence of a **feedback loop** can express recognition for the contribution of patients and the public, and be helpful to maintain engagement **over the long term**.

Offering financial compensation is one way to do this. However, it is difficult to determine what a **fair compensation rate is**.

Furthermore, introducing financial incentives should not reduce PPIE to a transaction, or influence the feedback received.

### Useful Resource:

NHS England's **Expenses Policy and the Involve Framework**, used widely by the **National Institute for Health and Care Research (NIHR)**, provides **payment guidance** for researchers and professionals in this area, ranging from £12.50 to £300 pending on the nature of the activity.

## Principle 8:

**Support people** involved throughout the digital innovation journey and **allow enough time** for people to **familiarise themselves** with new technologies.

Formal support and upskilling mechanisms for patients involved in product development should **reduce health inequalities** and the **digital divide**.

Formal support mechanisms might include a -

**Material component:** giving access to the **basic hardware, connectivity, and infrastructure** needed to engage with digital interfaces.

**Training component:** such as reading materials, training sessions or physical demonstrations showing how to engage with digital technology.

## Useful Resource:

**ORCHA's Digital Health Academy** is an online training centre that aims to give all health and care professionals the knowledge, skills and confidence to safely use digital health in practice.

**The Digital Readiness Education Programme** aims to increase the digital skills, knowledge, understanding and awareness across the health and social care workforce.

## Principle 9:

Build in **sufficient time and resources** to conduct PPIE appropriately.

It is crucial to communicate internally about the **purpose and necessity of PPIE**. Having **senior buy-in** from the beginning can help set the tone for the project and relationships between different stakeholders moving forward.

Communicating clearly over the **budget and resources required** can help minimise the risk of underfunding or disruption to the project if priorities change.

## Useful Tip:

Having a **dedicated project manager** would be helpful to coordinate this aspect, ensure timelines are met and manage stakeholder relationships, such as with GPs, charities, and volunteers.



# COMMUNICATE

## Principle 10:

### Develop a **feedback loop**.

This should be an **iterative process** which entails communicating with participants often about **how and why their contributions** have been included (or not) and provides the foundation to **build meaningful relationships**.

One of the biggest **Thank You** innovators can offer is to keep in touch with participants after their initial engagement, showing what has happened with their feedback – **this is what you said, this is how we changed the product**, and this is why it was a meaningful change.

## Principle 11:

Communicate **clearly, regularly, and inclusively.**

Innovators undertaking PPIE must be mindful that different people like to be **approached in different ways.**

It is most effective to **tailor communication** approaches to **suit the audience** you wish to work with.

For example, when approaching someone who is **partially sighted**, it may be best to engage in-person or over the phone, or send emails with a very large font.

One NHS stakeholder reflected on **preparing for six months before starting PPIE**. The outputs and engagement rates were of much higher quality as a result.

## **Principle 12:**

**Create a safe space** where people feel supported in sharing their views.

Introducing a **whistleblowing mechanism** would allow the public to complain if an organisation has not engaged with them appropriately, and act as an **additional incentive** for organisations to get PPIE right.

It may be possible to have a more **informal Trustpilot-style approach**, where patients review the quality of engagement online.





# COMMUNICATE

## Principle 13:

Provide clear assurances and information about **patient confidentiality, data privacy and security.**

In order to **be transparent** and **maintain trust** during the whole PPIE process, it is crucial to be honest, realistic and manage stakeholder expectations.

This is particularly important when discussing patient concerns, such as information governance or data privacy. Organisations should not provide '**empty reassurances**' or make promises they are unable to keep. It is precisely this lack of transparency that can **damage trust**.

## Useful resources:

- **Data protection impact assessment (DPIA)** is a process designed to help systematically analyse, identify and minimise the data protection risk of a project.
- Appointing an **information governance officer** to ensure that data is stored and managed correctly is one way to establish trust.

# REFERENCES:



How to involve and engage patients  
in digital health tech innovation

An Evidence Based Guide



The **AHSN** Network



**Available at:**

<https://www.boehringer-ingelheim.co.uk/about-us/our-company-uk/principles-of-patient-and-public-involvement-and-engagement>

**Hope you all found  
this helpful!**



This is part of a series to help  
HealthTech founders access better  
resources for their projects.

**Just our small way of trying to help!**