



# HDBI PUBLIC ENGAGEMENT TOP TIPS

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This document is based on a workshop for HDBI researchers led by Georgie Ariaratnam (Public Engagement Manager, Francis Crick Institute) and Naomi Clements-Brod (HDBI Public Engagement Manager) in January 2023.

If you have any questions or would like to receive this document in a different format, please contact the HDBI PE manager: [hdbi-pe@bio.cam.ac.uk](mailto:hdbi-pe@bio.cam.ac.uk)



## Why does HDBI have a public engagement programme?

### IMPROVING RESEARCH

- Influencing grant applications
- Enabling outside-the-box thinking
- Reconnecting with motivations
- Developing essential skills
- Encouraging diversity in science

### RESPONSIBILITY AND RELATIONSHIP TO SOCIETY

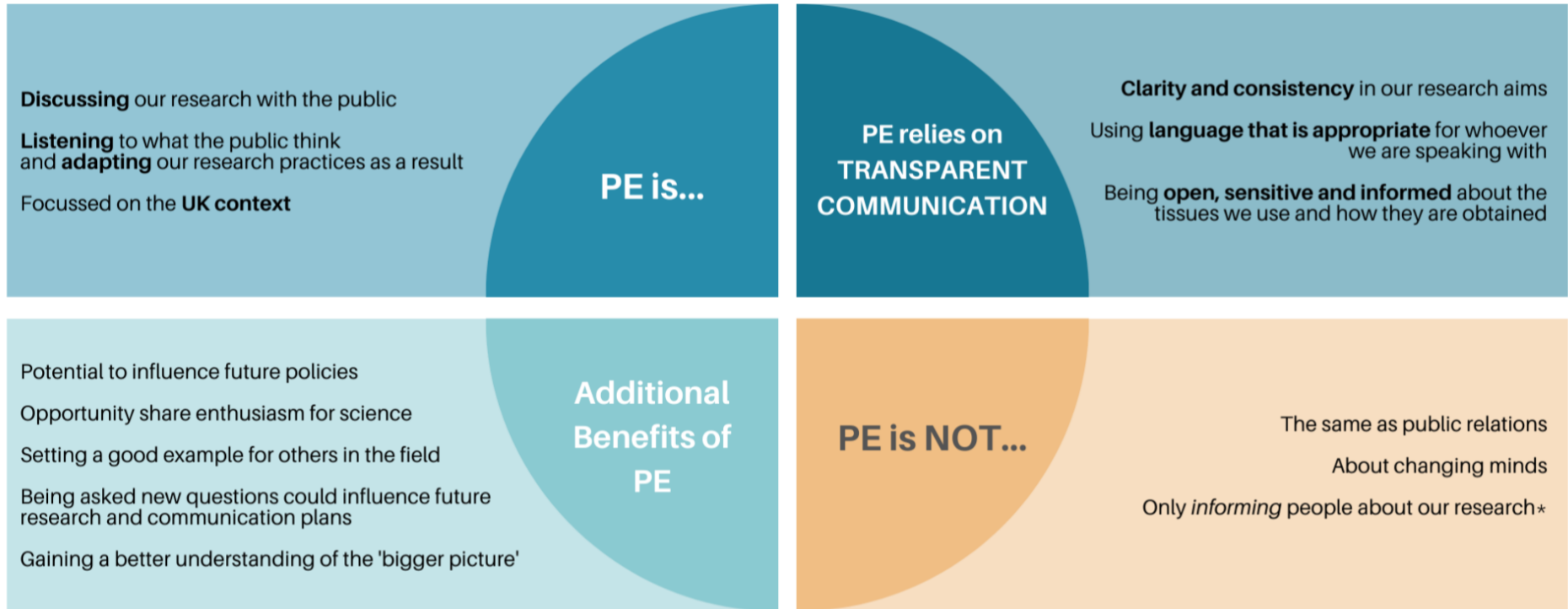
- HDBI research could have far-reaching implications for human health
- But there are historic and present-day inequities in accessing the benefits of scientific and medical advances
- Researchers are connected to the future outcomes of their work - which could be used (or misused) by others
- We must involve people who many one day be affected by our work
- Our research is possible because of tissue donations from the public so we must keep the public informed and involved

**ENSURING OUR RESEARCH IS RELEVANT AND MUTUALLY BENEFICIAL**

**GENERATING AND MAINTAINING TRUST IN SCIENCE**



## What is HDBI public engagement (PE)?



\*Because our research is not directly connected to most people's daily lives, we often have to do a substantial amount of explanation in order to have informed conversations.



## Who might I be engaging with? (relevant statistics from the UK population)

### Who are 'the public'?

- The public are not homogenous – people have different attitudes and beliefs and will interpret facts differently based on their values and experiences.

### General public attitudes

- [Progress Educational Trust](#) recently conducted [a survey looking at public opinions](#) on fertility, genomics and embryo research.
  - They found 41% of people were supportive of using human embryos for scientific and medical research, compared to 19% of people who opposed this type of research. 24% were neutral and 13% said they 'don't know'.
  - While there is considerable support for this type of research, a lot of people may not know enough about it to decide how they feel about it.
- The UK is overwhelmingly pro-choice - according to [data from YouGov in 2023](#), nearly 90% of UK adults believe people should be able to access abortion services in the UK.

### Common experiences – abortion

- According to [the University of Oxford Faculty of Law](#), about a third of women in the UK will have an abortion during their lifetime
  - [Government statistics](#) indicate that more than half of people having abortions have had one or more previous pregnancies which ended in live or stillbirth. This means many people who have abortions are already parents.
  - The same [government statistics](#) also indicate that people living in the most deprived areas of England are more than twice as likely to have abortions than people living in the least deprived areas.

### Common experiences – fertility challenges and treatment

- Over 3.5 million people in the UK experience some type of fertility challenge, according to [Fertility Network UK](#).
- [According to the HFEA](#), since 1991 there have been more than 1.3 million IVF cycles in the UK, with nearly 400,000 babies born as a result.
  - While many families have been completed through IVF, the majority of cycles are still unsuccessful and many people going through fertility treatment will not end up having children this way.
  - IVF through the NHS is funded in a 'post code lottery' system and according to [new research at Queen Mary University London](#), this means that not all aspiring parents receive the same access to fertility treatment and many have to pay for treatment privately, if they can afford treatment at all.
- [According to Tommy's](#), miscarriage is unfortunately quite a common experience.



- About 16% of known pregnancies end in miscarriage, generally within the first 12 weeks of pregnancy and about 1-2% of women have a late miscarriage (in the second trimester).
- About 1 in 100 women in the UK experience 3 or more miscarriages in a row and for about half of these women, the cause of the miscarriage is unknown.

## Inclusion & diversity

- Although the impact of advances in science and medicine has been widespread, there is still a lot of inequity in healthcare outcomes, especially among people from racialised groups. This means some people may be sceptical about benefits from healthcare advances extending to themselves or people in their communities. This view is unfortunately supported by historical and modern evidence. One recent example of inequity in healthcare outcomes: as recently as 2017, the UK government found that [White British babies have a 50% lower risk of perinatal mortality, compared to babies of other ethnicities](#). This is just one example - there are many reasons for distrust of science/medicine, and they vary among different communities.
- In the 2021 census, [over 262,000 people in England and Wales said their gender identity was not the same as their sex registered at birth](#) (or that they are transgender or 'trans')
  - [Young people \(age 16-24\) were the most likely to identify as trans](#)
  - So, not everyone with a uterus identifies as a woman and not all women have uteruses. Trans people have abortions and go through fertility treatment.
  - Therefore, 'donor' is a more inclusive term to use when referring to people who donate tissue to research, instead of words like 'women' or 'ladies'.



## How should I engage?

- **Understand where the public are coming from** –
  - ‘The public’ are not a homogenous group! You will encounter people with different values, beliefs and experiences which will affect how they interact and interpret any facts you share with them.
  - Try to understand other perspectives:
    - listen actively
    - avoid interrupting
    - ask open-ended questions (e.g. ‘what makes you think that?’)
  - Don’t take any disagreements personally, and it’s fine to agree to disagree.
  - Remember: you don’t need to change anyone’s mind
- **Use plain English** – this is not the same as ‘dumbing down’. It means speaking concisely and avoiding jargon.
  - Jargon may be hard to recognise because it’s become a normal part of how you communicate with other scientists.
  - Check your text/speech with a public engagement professional and/or the HDBI Insights Group.
- **Explain WHY you’re doing this research** – personal, scientific and societal reasons are all important.
  - In many cases, communicating why you do this research might be even more important than what research you do or how you do your research.
  - Be clear about who might benefit and manage expectations – if the anticipated benefits are a long way in the future, be sure to say that.
- **Know the facts** about key areas surrounding your research, for example, the regulations you work within (HTA and/or HFEA).
  - Check the HDBI FAQs before you engage to find out which facts might be important to know – [www.hdbi.org/faqs](http://www.hdbi.org/faqs)
- **Consider additional needs** – the person you are engaging with may require materials in a different format, or you may encounter with people who have physical disabilities or mental health difficulties. Consider this when planning your engagement and contact a public engagement professional for help.
- **Create a safe space where everyone feels comfortable and confident to engage** by
  - Using open body language (don’t cross your arms/legs)
  - Don’t stand behind a table
  - Make sure you’re standing/sitting on the same level as the person you’re speaking to
  - Share something about yourself (if you feel it is appropriate)



## What should I do if the conversation gets difficult?

Often, people really just want to feel they they've been listened to, so first try using active listening and avoid interrupting.

However, if you feel it's time to close the conversation (e.g. if you've already been speaking to the person for a long time), you can use the techniques below:

- **Close the conversation politely and sensitively**
  - You can suggest ways for the person to explore the subject elsewhere/online (e.g. 'Have you had a look at the HDBI website? The FAQs page might be of particular interest to you.')
  - If you're speaking with someone as part of a larger event with other activities taking place, you can encourage them to explore the rest of what's on (e.g. 'you might be interested in...')
  - Use a polite closer such as 'thank you for coming, it was lovely to meet you.'

**When the conversation gets more sensitive or difficult, to be used only if absolutely necessary:**

- **The ABC technique (Acknowledge, Bridge, Continue/Communicate)**
  - A should be empathetic
  - B should provide evidence or explanation
  - C should be hopeful, positive and future-focussed
- **Remember:** you don't have to change anyone's mind!

## Overall advice

Public engagement professionals (PEPs) are friendly and very happy to help with your engagement plans and preparations. We strongly recommend consulting with a PEP while planning or preparing for a public engagement event or scenario.

Make sure to read a risk assessment before going into any kind of public engagement scenario, or consult with your friendly PEP for help writing a risk assessment if you are organising an engagement event yourself.