

Introduction to Patient and Public Involvement (PPI) at Cambridge Clinical Research Facility

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Hello and welcome

This is an introduction Patient and Public Involvement (PPI) and Research Inclusion at NIHR Cambridge Clinical Research Facility (CRF).

My name is Caroline, and I am the PPI Lead here at the CRF (left). Together with Deepa, CRF Public Contributor (right), we hope you find this introduction informative.

If you have any questions, would like to know more or to get involved, please get in touch.

I am based on CCRC L3 and my email is: caroline.mcmahon3@nhs.net



We also have, 6 unit based PPI champions supporting the work of PPI and Inclusion across the CRF.

This presentation will help you understand PPI and the CRF, you'll learn:

- Know what PPI is and why it is important.
- Know the difference between patient and public involvement, engagement and participation
- Benefits to PPI
- Learn good practices of PPI
- Barriers to PPI
- Equality, Diversity and Inclusion (EDI) in Research
- Examples of PPI projects here at NIHR Cambridge CRF

What is Patient and Public Involvement (PPI)?

Public involvement in research is an active partnership between patients, carers and members of the public. It helps researchers shape and influence research.

'Public' includes patients, potential patients, carers and people who use health and social care services. It also covers people from specific communities and those with lived experience of health conditions.

Patient and Public Involvement, Engagement and Participation explained

Involvement: where members of the public are actively involved in research projects and in research organisations (Better ideas, experiences- better questions)

Participation: where people take part in a research study- providing the data to answer the research question

Engagement: where information and knowledge is provided and disseminated- raising research awareness and sharing our work.

[To read more, click here and visit peopleinresearch.org](https://peopleinresearch.org)

Why involve members of the public in research?



People who are affected by research have a right to have a say in it



Members of the public can provide a different perspective



Involving members of the public can tailor your research to the needs of specific communities



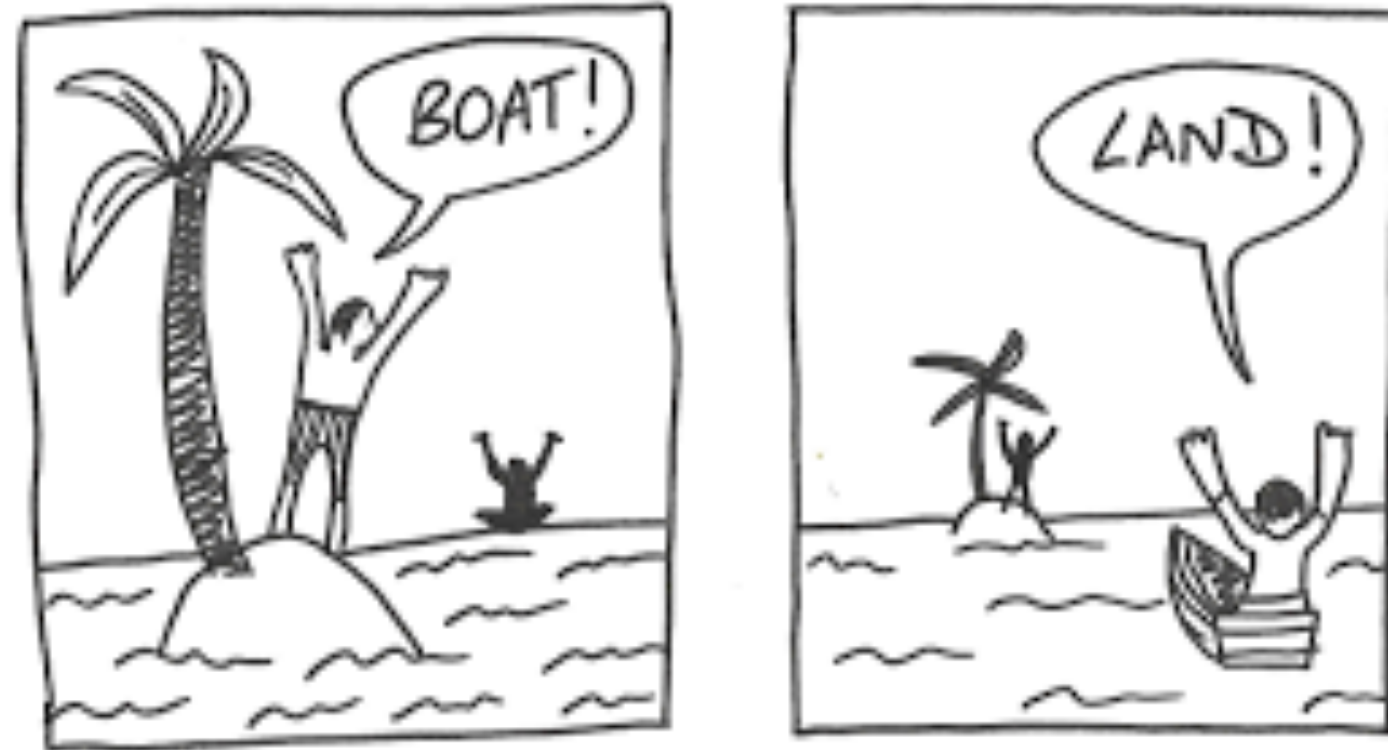
Public involvement can make research more relevant



Funding bodies and ethics committees will ask about your plans for public involvement

Read more about the benefits of PPI for researchers [here](#)

Perspective



different needs, have different perspective

UK Standards for Public Involvement

The UK Standards for Public Involvement are a description of what good public involvement looks like.

They encourage approaches and behaviours that are the hallmark of good public involvement such as: flexibility, sharing and learning, and mutual respect.

The Standards are for everyone doing health or social care research and provide guidance and reassurance for practitioners working towards achieving their own best practice.

Communications	Use plain language for well-timed and relevant communications, as part of involvement plans and activities
Governance	Involve the public in research management, regulation, leadership and decision making
Impact	Seek improvement by identifying and sharing the difference that public involvement makes to research
Working together	Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
Support and Learning	Offer and promote support and learning opportunities that build confidence and skills for public involvement in research
Inclusive Opportunities	Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

[Click here to read the UK PPI standards for Public Involvement](#)

What are the ethical considerations?

When involving patients and the public in research, key ethical considerations include:

- ensuring informed consent,
- respecting their autonomy,
- protecting confidentiality,
- managing potential conflicts of interest,
- ensuring equitable representation,
- guaranteeing that their involvement is meaningful and contributes directly to the research design and execution, not just used for tokenistic purposes



The [Research Ethics Service](#) will ask about the plans for public involvement in your research if you apply for ethical approval, and it will be part of their assessment process. They expect the involvement of the public in research, as it can help ensure that research planned is ethical, relevant and acceptable from a public perspective.

Find out more about the [impact of public involvement on the ethical aspects of research. \(.PDF\)](#)

Be Part of Research

Watch this short video by NIHR



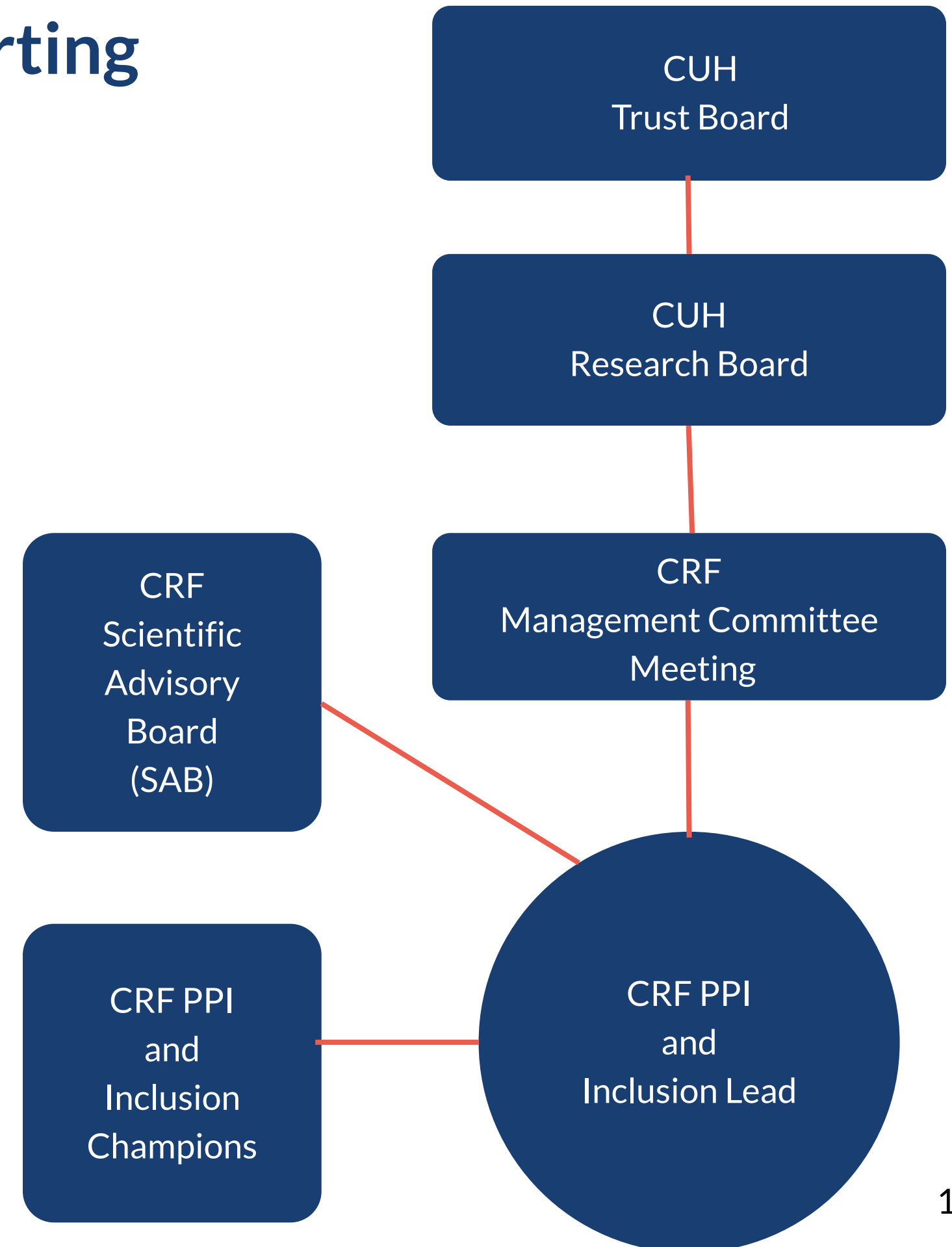
Our Commitment and Governance Reporting

In our commitment to Patient and Public Involvement, we produced a [joint NIHR Cambridge BRC and CRF PPIE strategy](#)

This strategy details; what we want to achieve in our short, medium and long term objectives, who the CRF PPI and Inclusion Lead reports to (governance structure, right), who we are working with and how we will measure our success in delivering our objectives.

Every year we submit an annual report to NIHR, this is where we detail our PPI and Inclusion activity.

BRC-Biomedical Research Centre
CUH- Cambridge University Hospitals



Equality, Diversity and Inclusion (EDI) in Research

One of the [NIHR's key priorities](#) is being committed to embedding equality, diversity, and inclusion (EDI) across NIHR's research, systems and culture. Helping to foster an inclusive environment and engage the talents and energy of diverse people in all areas of our work. [Read the full EDI strategy](#)

Five Strategic Themes



Our commitment to Equality, Diversity and Inclusion (EDI)

We have a joint [EDI strategy](#) with NIHR Cambridge BRC, our 5 strategic themes are:

1. Our participants
2. Our workforce
3. Our leadership
4. Training our workforce
5. EDI in PPI



- We are learning about the people who already take part in research here at Cambridge CRF,
- Working with our researchers to improve the inclusion of recruitment to research studies
- Going out meeting members of the local and regional communities, to raise research awareness.

We ask all our CRF colleagues to undertake NIHR INCLUDE training, to understand why its important to include those from underserved communities in research.

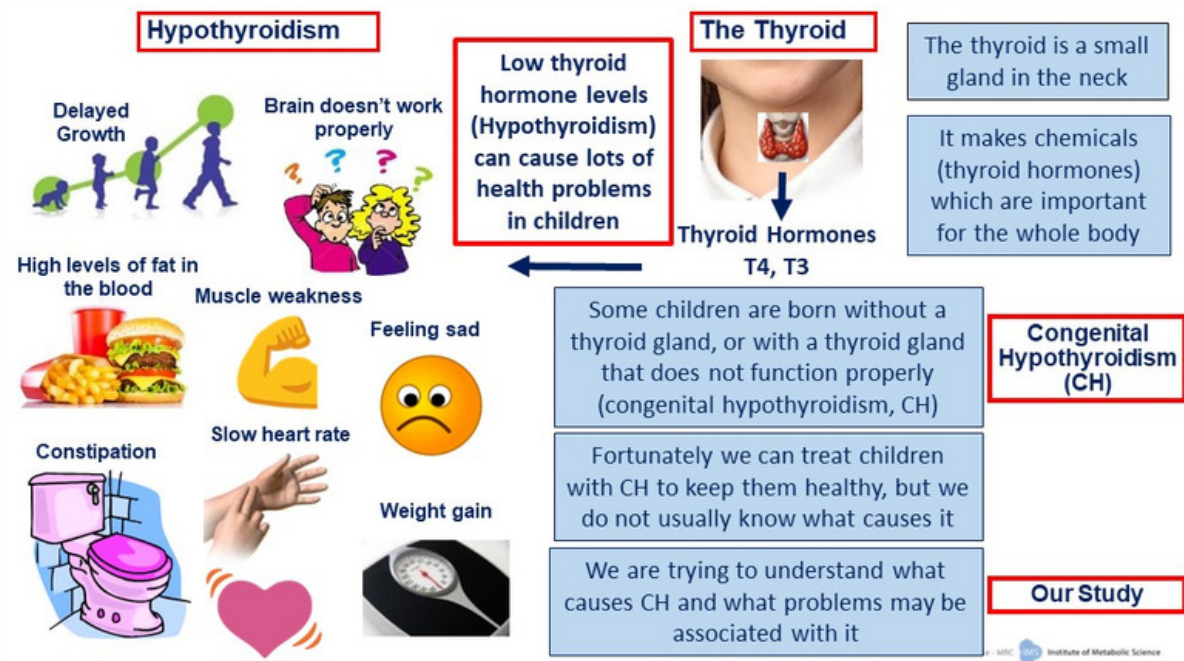
Other EDI Training and Resources, include:

- Local and national EDI training: CUH DOT, UKCRF Network and NIHR Learn
- Join CUH staff network groups- See connect

“No decision about me, without me.”

What does PPIE on the CRF look like?

We share our participant stories, hear participant feedback, celebrate the successes of our researchers and listen to the voices of others to improve health research. We also go out to different communities to raise research awareness.



A day in the life

Immy

Laura, Katie, Jen

I had a great time and learnt loads about my body, as well as helping the team with their research.

I took the picture of my skeleton home to show my dad and sister!

I'm proud to be part of research because...

- I am able to help others fight this terrible disease
- It gives me and my family hope in my fight against cancer
- It can help the future of medicine
- A sense of pride in being a part of something so important
- It can help save lives
- I love being looked after by such a professional team

Clint - NIHR Cambridge CRF research participant

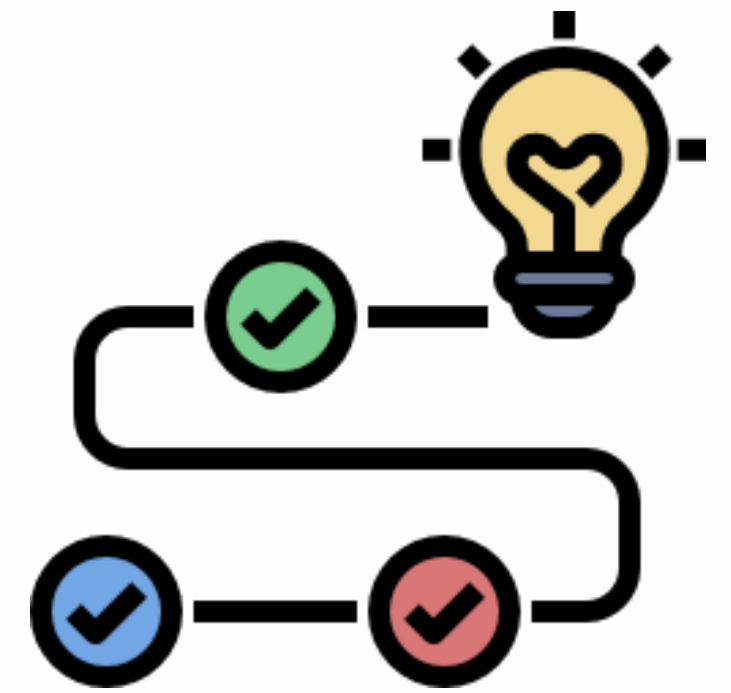


#BePartofResearch

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Research Facility

Conclusion

- Patient and Public Involvement and research inclusion is for everyone.
- Here at the CRF we are inventive and always willing to help raise research awareness.
- We're at the delivery end of research where we are uniquely placed to improve and influence research outcomes.
- We work collaboratively with the wider CRF team
- We couldn't do this without you!



If you are asked about how to find out how to take part in research, send them to: <https://www.peopleinresearch.org/>

Further reading

[NIHR | Best research for best health the next chapter](#)

[NIHR Patient and public pages](#)

[PPIE NIHR Definitions](#)

[UK PPI Standards](#)

[NIHR INCLUDE roadmap](#)

[INCLUDE training](#)

[UKCRF Network](#)

[NIHR equality, diversity and inclusion strategy](#)

[Be Part of Research](#)

[Merlin document- Equality, diversity and inclusion in employment- access for CUH staff only.](#)