

“You Said, We Did”

Working together to improve the research experience

Pen Awards 2026



Why does research matter?

Research gives people opportunities to directly contribute to improving diagnosis, treatment and care for the future, changing lives through the power of research.



Better outcomes

It is well known that patients treated in research-active organisations tend to have better health outcomes

Research helps us understand what works, improve care and support better outcomes for patients and communities.



Supporting others

Taking part in research gives everyone the chance to improve health and care for everyone

People who take part in research contribute to knowledge that can benefit others now and in the future.



Access to innovation

Every treatment or intervention used in the NHS was once discovered through research

Participation can provide access to new medicines and treatments that may not yet be routinely available via the NHS.

Participants make health research possible

Who we are

We are an NHS commercial research team based at the Royal Devon University Healthcare NHS Foundation Trust, covering a large geographical area.

Participants are at the heart of everything we do!

630,000

People served across Devon, Cornwall, and the Isles of Scilly

Rural & coastal

We serve some of the most rural and coastal communities in the UK

Barnstaple

is home to North Devon District Hospital, the most rurally remote hospital in England

Royal Devon CRC

bespoke facility for delivering commercial research

- Our role is not simply to recruit participants, it is to support them throughout their research journey
- Retention is one indicator of a good research experience, alongside what participants tell us directly

You said, we did - why did we do it?

We wanted to hear directly from the people who experience research with us

- Research participants are volunteers
- They give their time, sometimes over several years
- PRES survey tell us what people think- focus groups let us hear the detail behind it
- We wanted to understand the experience first-hand, and then act on what we heard



We listened

The first focus groups brought together a broad range of participant experiences



Who?

People at different stages of their research journey, different studies, communities and experiences



Open conversation

Space to share what worked and what did not



Senior leaders

Direct conversations with senior research leaders



**We listened for themes
- but also for the
practical changes that
could make a
difference**

What people told us



Make it easier

Appointments, reminders and directions should be simple and clear



Make costs simpler

Travel, reimbursement and insurance can create unnecessary barriers



Use the right language

Call us “participants”, not “patients”



Keep us informed

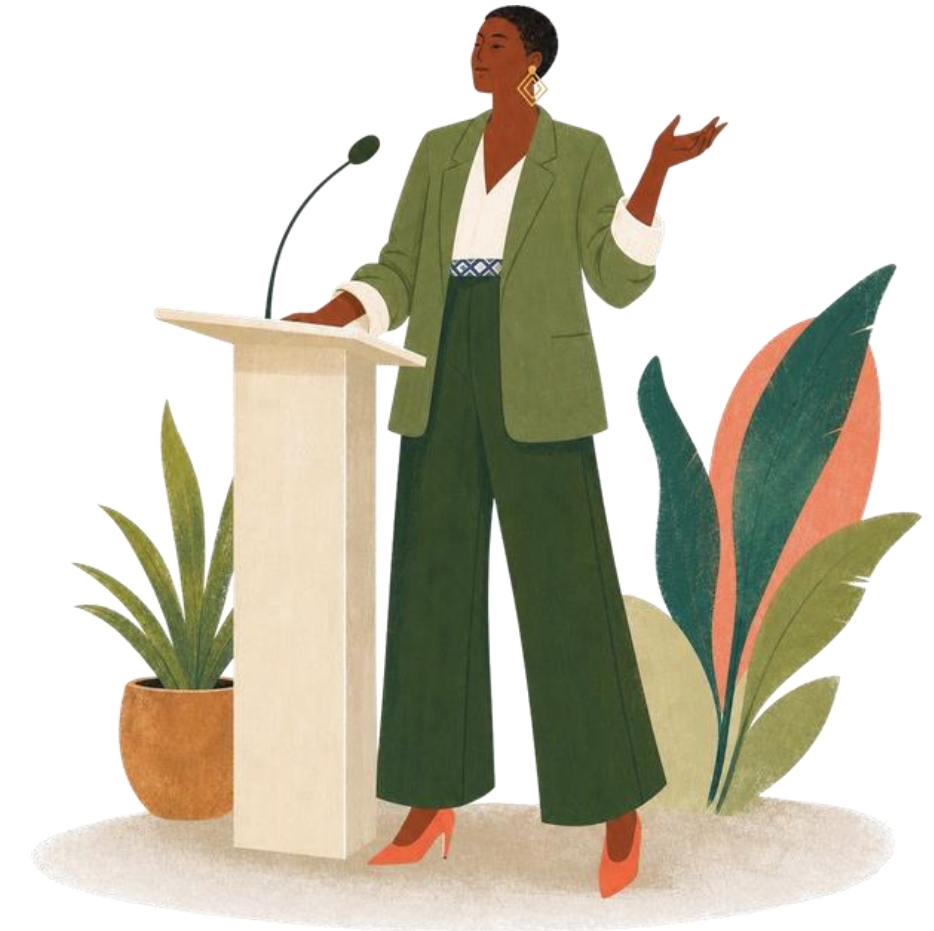
Tell participants clearly what has changed and what to expect



Close the loop

Share study results where possible

Together, these themes became our practical plan for improvement



You said → We did

We made the feedback visible, tracked actions and reported back.

“Make it easier to find us”

New maps and clearer directions.

“Remind us before appointments”

Better appointment reminders and communication.

“Help with the practical stuff”

Travel insurance discussed earlier; reimbursement processes reviewed.

**“Tell us what has changed
when we have to re-consent”**

Explanation around reconsent forms made clearer, so participants know where changes have been made

“Let us know the outcome of a trial”

Better information and a clearer way to share study results.

“See us as participants, not patients”

Staff encouraged to use the word “participant”.

And where something could not be changed, we explained why

Focus group feedback

You said	We did
You would like appointments scheduled further in advance to help with planning	This may be dependant on the complexity of the visit we will endeavour to book the visit as far in advance as possible.
You appreciated receiving an email or text reminder the day before your appointment, especially when you could simply reply YES to confirm attendance.	We are sending an appointment Email the week before you visit. We are looking to implement a new system call snapboard that will send a text message the day before.
Patient information sheets (PIS) documents were often too long and detailed:	Regarding PIS:
• You suggested adding an index to quickly find important information. • You asked for a “key facts” summary that clearly explains what you actually have to do.	• Unfortunately for commercial trials we are not permitted to change or create study documents. All documents have gone through ethics prior to the opening of the trial. • We will look to see if it is possible to create an index for the PIS that we are given.
When consent forms are updated, you would like changes highlighted, so you don’t need to re-read everything and re-sign unnecessarily.	In commercial trials we are not permitted to change or create study documents. All documents have gone through ethics prior to the opening of the trial.
	We will send the updated consent form prior to your visit, we can highlight “ ☞ mail.



We kept people in the loop



Embedding this in practice

The focus groups are now an annual conversation - not just a one-off exercise

We didn't just ask participants what they thought, we showed them that what they said mattered

16

People joined the second-year focus groups



Some returned

Participants who had taken part before could see the process continue.

40

Participants engaged over two years

99%

Participant retention in clinical studies



Some were new

New voices added different perspectives and experiences.



"It's been nothing but a pleasure – the staff are the ultimate professionals and charming. I've enjoyed every single moment of it and I look forward to coming!

Absolutely they go the extra mile, worth every penny they are. The materials provided are exceptionally good and I am well informed."

Barbara, Research participant



But don't just take our word for it

