



**National Institute for
Health Research**

Public Co-Applicants in Research – guidance on roles and responsibilities

This guidance was developed jointly by the NHS R&D Forum,
the Health Research Authority and INVOLVE.



This guidance is intended to help:

- Researchers wanting to include public co-applicants in a study
- Public contributors wanting to become a co-applicant
- Research staff who coordinate public involvement activities or advise on funding applications
- Those working in or with research organisations to review or process research applications.

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This guidance can be read in conjunction with the NHS R&D Forum's Guidance on Public Co-Applicants for R&D Managers. www.rdforum.nhs.uk/content/2019/01/19/suc-co-applicancy-project-lead-collaborator-guidelines/

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Definitions:

- When using the term 'public' we include patients, potential patients, carers and family members, people who use health and social care services, as well as people from organisations that represent people who use services
- When using the term 'co-applicant' we mean an individual who is involved in the development of a funding application and, if funded, has some responsibility for the management and/or delivery of the study.

1. Introduction

Public involvement is an essential part of the research process. With increasing numbers of public contributors helping to shape and deliver research, there has been a rise in the number of public co-applicants joining research teams. While this had been a positive and productive experience for many, others have had a disappointing experience and there is a need for clarity about the role of public co-applicants and how they might be supported.

The inclusion of public co-applicants can increase the breadth of experience, knowledge and skills within a research team, and public co-applicants offer a different perspective from other members of the team during the development and delivery of a study. For many, becoming a public co-applicant is an achievement, and a recognition of expertise, that offers individuals the chance for personal development while making a valuable contribution.

A public co-applicant has the same level of responsibility as other co-applicants, and should be considered an equal member of the team. In many cases, this will be a level of responsibility not expected of other public contributors, such as advisory group members. It may require a greater commitment in terms of time and responsibility as, for example, public co-applicants will help to develop, approve and sign the research application ahead of submission for funding, before the study even begins.

“When I did become a co-applicant for the first time, it made everything fit together. You make the application, you become involved in all aspects of the preparation and people do take note of what you have to say. You are totally involved.”

Public co-applicant

“I became a co-applicant to gain experience in that role because I had already got a fair bit of experience in research, but also because of an interest in the particular research study as well. But the experience has been quite mixed.”

Public co-applicant

“Much of my work involves sensitive topics and a public co-applicant is therefore vital in ensuring the study is undertaken carefully.”

Researcher

“I wouldn't do research without one. They are part of the team anyway. They have an important role and add value.”

Researcher

Do NIHR funding programmes require public co-applicants?

No. There is no formal requirement to include a public co-applicant as part of the research team. However, where a public co-applicant is included in a study, most funders will ask for a clear description of their role and the reasons why a public co-applicant is joining the team. This should express the differences in their role from that of other members of the public involved in the study. Without this information, the presence of a public co-applicant can be seen as tokenistic.

2. Roles and responsibilities

Public co-applicants

There is no definitive list suggesting what tasks a public co-applicant might carry out as part of a study. This is for public co-applicants and researchers to discuss and agree before an application is submitted, and may form part of any written agreement between the public co-applicant and the lead applicant. The exact type and nature of the role will depend on:

- the requirements of the study
- the skills, interests and wishes of the public co-applicant
- the make-up of the study team
- the requirements of the funding body.

For many public co-applicants, their role will be helping to develop the study and the funding application. If the study is funded, then they will have a role in delivering some aspects of the study, or overseeing its conduct and progress. For others, a combination of these roles might be appropriate. However, it should be recognised that the majority of research funding applications are unsuccessful.

In some cases, a public co-applicant's role may include the coordination and delivery of the study's public involvement activities, or linking with wider communities. For other public co-applicants, this may not suit their particular skills, experience or available time, and they may prefer to focus on their lived experience.

Studies that also include a dedicated staff member to coordinate the public involvement activity should be clear about the public co-applicant and involvement coordinator roles, and whether they interact. Clear remits for both should avoid any confusion of the two roles.

The inclusion of a public co-applicant should not be the only contribution from members of the public. Good public involvement includes of a diverse range of views, rather than a single perspective.

A public co-applicant can expect appropriate support from the research team and / or the host institution, so that they can fulfil their role (see 'Support' on page 13). As with other co-applicants, they will be accountable for any agreed duties or work areas. Ways of assessing and reporting progress should be agreed, along with ways of raising or dealing with any challenging situations.

“On the whole, it has been a positive experience – filled with new opportunities, learning and development, networking, and much more. There have been a couple of occasions where it has felt as though I've been used to secure funding and/or make it look good – though through experience, I have learned to become more assertive in holding researchers to account.”

Public co-applicant

“I would never just give a co-applicant a role description. You need to negotiate with them and align the role to their skills. You also have to be flexible, as things will change.”

Researcher

“It gives me a sense of purpose, trying to help people who are struggling. It was also a positive experience to help me get further into research.”

Public co-applicant

Information required by funders about public co-applicants

Many funders, including the National Institute for Health Research (NIHR), do not require public co-applicants to complete a standard CV, but they may ask for a summary of any knowledge, skills or experience that is relevant to their role in the study. This might include:

- previous or present work (paid or unpaid) with any relevant organisations
- links with any relevant groups, committees, networks or organisations
- experience of particular health conditions, treatments, use of services - or as a member of a particular community
- knowledge and experience of research, including previous research undertaken
- knowledge and experience of patient and public involvement, including previous involvement activities
- skills from any other roles that are transferable
- relevant qualifications, training and learning.

Some funders prefer public co-applicants with relevant experience or an understanding of the research process, so it is best to check any guidance notes associated with the funding programme.

Researchers

At the earliest opportunity, researchers should consider how a public co-applicant would add value to the development and delivery of a study, and which perspectives and experiences might offer the greatest benefits. A clear role description should be developed and agreed with the public co-applicant, along with a budget that includes support and training for the public co-applicant in their role. These will be essential during the application process.

Developing and maintaining good working relationships between the research team and public co-applicants is crucial. As part of the research team, public co-applicants should be included in communications that are circulated to the rest of the team and other co-applicants. Although there may be no formal line management role for the researcher (or the research team), good practice principles for public involvement should be applied.

“When we first started we did not have a clear role description, but I was immediately pulled up by the public co-applicants and we did one!”

Researcher

“I had no role description at all and had no real discussion about what I was expected to deliver. I was told I would be a member of the management committee, but what that involves was not defined in any sense.”

Public co-applicant

See Values and principles framework for PPI:

www.involve.nihr.ac.uk/posttypepublication/public-involvement-in-researchvalues-and-principles-framework/

See National Standards for Public Involvement:

www.involve.nihr.ac.uk/wp-content/uploads/2018/03/71110_A4_Public_Involvement_Standards_v4_WEB.pdf

Budgeting for public co-applicants

Funding applications should include a well-costed budget for all public involvement activities, including appropriate budget for any public co-applicant, which should cover:

- payment of fees for public co-applicants' time
- expenses for public co-applicants
- support for public co-applicants (including extra costs, such as training or additional staff time to provide support).

Some funding programmes request costs for co-applicants as a percentage of salaried time. Often this is not appropriate for public co-applicants, and a budget to cover their activity and expenses should be clearly expressed in other ways.

Budgets for public co-applicants should be monitored regularly to ensure sufficient resource is available for the duration of the study.

See INVOLVE Cost Calculator:

www.involve.nihr.ac.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/

“No, I didn't develop the budget, as this was done before I started as a co-applicant.”

Public co-applicant

“My involvement in setting the budget has been mixed. There have been occasions where I have never been consulted, engaged or informed in this process. And others where I have been involved, commenting on, and suggesting the need to appropriately cost for my role, the involvement of other public partners, costs to cover travel, childcare and other expenses, and the need for appropriate resources and training.”

Public co-applicant

“When the Principal Investigator developed the bid, I did help with the budget. She drafted it, came to me and asked my advice: ‘Was that sufficient for the PPI?’ and we looked at how many people we would have on the Advisory Group, how many meetings per year, paid at the INVOLVE rates. We looked at how else we might involve users in the study for analysis, things like that. So yes, that was all done properly.”

Public co-applicant

“Our budget was developed using the INVOLVE guidelines, based on the time agreed with the co-applicant.”

Researcher

Contracts for public co-applicants

Whether a contract is required will depend on the role being performed and the approach taken by the host institution. In most cases public co-applicants are not employees, but the HR department of the host institution may consider the role more like employment than other involvement activities. Clarifying this with the local HR department at an early stage is essential, as this may have consequences for the public co-applicant and might determine whether they wish to take on the role.

In some cases, public co-applicants may be offered the opportunity to become an employee, with a contract for the duration of the study. For others, an agreement that outlines the role and responsibilities can be sufficient.

For public co-applicants who receive welfare benefits, there may be implications when accepting a contract and advice should be taken before anything is agreed or signed. For those involved with NIHR organisations, or NIHR funded studies, a Benefits Advice Service can provide free advice. For others, a local Citizen's Advice Bureau can offer support.

See Benefits Advice Service:

www.involve.nihr.ac.uk/resource-centre/benefits-advice-service/

“I had a short brief contract when I was self-employed. It was actually done through a user-led organisation that I was part of at that time.”

Public co-applicant

“Yes, we had to arrange contracts in order to be able to pay the co-applicants.”

Researcher

“No contract was offered. I didn't think about it at the time, and I don't know whether I would have wanted one at the start. But I would have liked to have known more about what being a public co-applicant means, what is involved and what time commitment is required. But not necessarily in the form of a contract.”

Public co-applicant

Legal responsibilities

Overall legal responsibility for the study rests with the lead investigator and study sponsor, often the host institution or organisation. Any legal requirements for public co-applicants will differ depending on the role and nature of the research. However, all co-applicants are responsible for the proper management of confidential information and study data. This can be covered by a confidentiality agreement, which all co-applicants may be asked to sign.

It is essential that researchers check with host institutions that indemnity insurance is in place to cover public co-applicants. Some insurers will cover named public co-applicants under existing policies. Researchers should advise public co-applicants about whether or not this is available, and what the consequences might be if indemnity cover is not in place.

“As I had a contract, it was covered by the standard university insurance.”

Public co-applicant

If the public co-applicant's role includes direct contact with study participants (for example, if they will interview participants), risk assessments will be required to ensure the safety of the co-applicant, similar to those used for research staff. The institutional lone working policy should be shared with the public co-applicant and followed. Public co-applicants who will have direct contact with participants should also receive appropriate research governance training (this covers the various principles of good practice, and the requirements and standards when conducting health and social care research).

Research protocols often limit access to any patient identifiable data to individual researchers, and all data handling needs to comply with current General Data Protection Regulations. Any breach of the study protocol or data regulations by anyone in the study team will be investigated, and in these circumstances any public co-applicant involved in such an investigation will be offered support and advice by the research team and host institution.

3. Who can be a public co-applicant?

Anyone can be a public co-applicant. Some level of knowledge, experience or certain skills may be needed to add value to the study and the research team. Research benefits from the inclusion of diverse communities and perspectives, and reasonable adjustments may be required to encourage the inclusion of some seldom heard communities.

Many researcher funders (including parts of NIHR) will accept paper rather than on-line submissions of applications from public co-applicants with disabilities or specific needs. Researchers and their host institutions will be expected to support public co-applicants during the application process.

Occasionally, researchers or healthcare professionals appear on a grant application to offer their experience of a health condition or service, rather than their professional role. This may have value for the research, but without wider public involvement in the study some funders may perceive this as a failure to engage with or involve the wider public.

“On a study with elderly co-applicants we went to them rather than the other way round, and made sure we phoned them so it didn’t increase their phone bill.

And when working with co-applicants who have learning difficulties we made sure literature was in easy-read format and helped sort out their transport.”

Researcher

“From my experience so far, it is difficult for researchers to arrange meetings outside of normal 9-5 working hours. I’m lucky that I’m able to shift my working hours around now, but I know when I move into full-time employment again that I will struggle to make these meetings.”

Public co-applicant

“This is integral. It’s not an add-on, it’s there. So whatever you do, if you have a disability, they make every allowance for that and they make sure you are supported and assisted to do the job properly.”

Public co-applicant

4. Support

Public co-applicants should consider the points raised in this guidance before agreeing to take part as a public co-applicant. It is especially important to seek clarity:

- about the role, with an agreed role description that should specify the tasks that the public co-applicant will undertake, and whether these link to any wider public involvement activities in the study. It is important to gain a sense of how much work will be involved before approving the research application prior to submission
- regarding payment and expenses policy and processes
- about what guidance, mentoring or learning opportunities will be made available to the public co-applicant during the development and delivery of the study.

Good practice for public involvement applies to all public co-applicants, so researchers and host institutions should ensure that adequate and appropriate support is offered to public co-applicants throughout the study.

This should involve:

- providing an appropriate induction into the team and / or organisation
- ensuring all reasonable accessibility and dietary needs are met
- offering appropriate training and development opportunities, as identified and agreed with the public co-applicant (including health and safety training). This may include attending conferences or seminars, departmental or institutional events
- ensuring clarity about payment of fees and expenses, and how these can most easily be claimed by the co-applicant
- encouraging shared feedback between the public co-applicant and the research team, and jointly reviewing progress at regular intervals.

See Guidance for researchers on PPI Feedback:

www.clahrc-oe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf

See Briefing Notes for Researchers:

www.involve.nihr.ac.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

“I use Elspeth Mathie’s feedback tool, which was really helpful.”

Researcher

“Feedback has been very limited. I tend to ask for feedback on ideas and contributions, though this is systematically not approached. Feedback should be given and sought by all co-applicants – public or not, and I think this culture is one we need to cultivate moving forward.”

Public co-applicant

Payment

One of the principles of public involvement is to offer payment for an individual's time. The process for paying a public co-applicant should be discussed with the host institution and align with their policies (such as who is responsible for deducting or declaring tax and National Insurance contributions). A copy of the institutional payment and expenses policy should be shared with the public co-applicant at the start.

For public co-applicants who receive welfare benefits, advice should be sought about how payment might affect them. For those involved with NIHR organisations, or with studies funded by NIHR, a Benefits Advice Service is available to offer support.

See Benefits Advice Service:

www.involve.nihr.ac.uk/resource-centre/benefits-advice-service/

See Guidance on Payment and Recognition:

www.involve.nihr.ac.uk/resource-centre/payment-and-recognition-for-public-involvement/

“The process of claiming payments and expenses is often long and difficult – initially requiring documents such as passports, birth certificates etc. to be shown in person. The processes have been mixed, with some universities making it very easy, while others require you to input in timesheets every time you conduct a piece of work.”

Public co-applicant

Expenses

All reasonable out-of-pocket expenses should be covered, ideally in advance (for example, travel tickets purchased by the research team for the public co-applicant). Where expenses need to be reimbursed, it should be made clear to public co-applicants that original receipts will be required as part of the claims process. Any limits on expenses should be clarified at the start.

“I had to fight the university to get them paid in the correct way!”

Researcher

“I did have a clear method of claiming – in fact, I only have to claim occasionally as I was paid a standard amount over the programme, which is what we agreed in advance. This seemed to balance out well.”

Public co-applicant

Learning and development

Good support includes the offer of training, as well as opportunities for public co-applicants to learn or develop knowledge and skills. Training should be focused on the needs of the individual and their role. A learning needs analysis tool may help with this.

See Learning Needs Tool:

www.involve.nihr.ac.uk/resource-centre/learning-and-development/learning-needs-and-tools/

Good Clinical Practice (GCP) training is not a requirement for any co-applicants, but GCP training may be offered to public co-applicants who will have direct contact with study participants.

Support offered by host institutions

Host institutions have a legal and financial responsibility for all co-applicants. This includes management and infrastructure support, and governance training. Where appropriate, the host could also provide:

- indemnity insurance that covers public co-applicants for the duration of the role
- a security pass or ID card (to cover all sites)
- an institutional email address
- a workspace with a computer
- access to project shared drives and internet
- membership of library membership
- staff development and training events.

“Training sessions were provided on analysis and research methods. But a whole team approach was used.”

Researcher

“I’ve never been offered any training opportunities as a public co-applicant. I’ve typically gone for this independently, in attempts to further my own knowledge and skillset. The chief investigators have typically provided an induction, though if I’ve been involved in writing the grant applications, I’m familiar with the project.”

Public co-applicant

“At the first full PPI group meeting, there was an induction that covered expense claims and payment, and all processes were covered. Training was raised, but wasn’t asked for as many were experienced PPI contributors.”

Public co-applicant

If the public co-applicant is to have direct, unsupervised contact with children and young people, or with vulnerable adults, they will need a Disclosure and Barring Service (DBS) check. This should be arranged through the host institution or organisation, and the cost covered by the research team.

See Disclosure and Barring Service:

www.gov.uk/db-check-applicant-criminal-record

Many institutions have a public engagement and involvement officer (or department) who may be able to offer support or guidance.

Where to get support if things go wrong – public co-applicants

If a public co-applicant is unhappy about the involvement plan or their experience, they can:

- talk to the project lead in the first instance
- talk to the group co-ordinator, if appointed as representative of a patient group
- request information about the host institution’s complaints procedure, if they feel unable to talk to the project lead, or if the situation does not improve. This could be a discussion with the local HR or Research & Development office, or could include bringing in an independent mediator
- contact the funding body to report any issues
- if all else fails, consider withdrawing from the study.

In any of these circumstances, it is important to consider whether any confidentiality agreements are in place, and whether reporting issues elsewhere breaks these agreements.

“When things went wrong and others in the study weren’t responding, I went to the funders and INVOLVE. The team had stopped sending me minutes and inviting me to meetings so I didn’t know what else to do. I didn’t know if I was still a co-applicant or whether they had removed my name without my knowledge. I didn’t know if I still had responsibilities for the study. They stopped my involvement, citing a lack of funding, even though the study hadn’t finished. I didn’t know if reports had been sent to the funders (NIHR), or if my name had been included - I certainly didn’t see any reports. It was hard to know what to do about it all.”

Public co-applicant

“If there is a problem with the team or the work, I have the back-stop of talking to the Principal Investigator, as we have a good relationship. When there have been issues, he has been very responsive. And I have built a good working relationship with the study administrator, who I would probably go to first instance if anything went wrong. But there does need to be a back-stop beyond the PI.”

Public co-applicant

Where to get support if things go wrong – researchers

All co-applicants are expected to act in the best interests of the project, including public co-applicants. If they do not, the project lead should discuss this with the co-applicant to find out why.

If a public co-applicant is appointed as representative of a patient group, the researcher might also talk to the group co-ordinator if problems arise.

Other members of the research team should raise any issues with the project lead. Project leads should look for advice and support from their host institution.

Links for guidance on support:

see Guidance on Payment and Recognition:
www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/

see Guidance on Learning and Development
www.invo.org.uk/resource-centre/learning-and-development/

“We have been reflecting on this, as we have always thought that people would know where to go if they were unhappy, as they are aware of the course of action outlined to participants (such as listed in patient information sheets).”

Researcher

“We were probably a year into the project when my line manager went off long-term sick, and that is exactly when things started to go wrong. It seems to me that PPI is over-dependent on a champion, and if they go everything goes to pot. I am all for champions, but they need to spread that knowledge and experience to ensure that there isn't just one of them there who is going to support PPI.”

Public co-applicant

5. Reflections...

...on being a public co-applicant:

“For me, co-applicants need to be in the full management line and have ‘authority’ to help make decisions. As an advisor, you can offer your views, which the team can use or ignore, as they see fit.”

“It’s just made me feel very valued.”

“A sense that you have actually contributed to something, that you have been listened to, that you have made a difference, and a sense of personal satisfaction that you are making something happen.”

“I did get a lot of grief, hassle and upset. And I do worry that user carers get flattered that they’ve been asked to be involved, and as a result they won’t think about what it is poor practice and they’ll go along with it. There is something about being a co-applicant where people get more flattered because it might be seen as a higher level form of involvement.”

“If researchers are including a public co-applicant in their application, justify it. There is a view among some researchers that we must have a public co-applicant, as it means a better chance of funding. But I feel more involved with other studies I’m involved in than the one I am on as a co-applicant.”

“A lot of learning experience, and I like to give something back to benefit that patient group positively in the long run.”

“I’ve learned an incredible amount through being a co-applicant. I’ve been able to make a real and valid contribution to advancing topics which are close to my heart, and above all, bringing the patient voice into research is something which matters a great deal to me. I’ve also been able to develop new skills, reflect on my interests, and have outputs acknowledged to my name, which have supported my patient advocacy work, and indeed evolving career.”

“The first time I went in, it was quite daunting in the sense of ‘What am I doing?’ ‘Am I going to say the right things?’ It’s something new, it is like putting your toe into the water. Every time I have gone it has been fabulous. I now feel part of their team. They do listen to what I have got to say, it’s really good.”

...on working with public co-applicants:

“Public co-applicants are part of the team and integrated as such. They provide a sense check and a different insight. They have added to the rigor of the research. Their personal experience has been so important especially when working in sensitive areas.”

“Public co-applicants contributed depth and understanding to the study, and helped develop the advisory group.”

“Initially the Principal Investigator felt that she didn’t want to overburden the public co-applicants with information, but she was told not to worry about this. They have responded positively to being included in all communications.”

6. Frequently Asked Questions

Do NIHR funding programmes require public co-applicants?

No. There is no formal requirement to include a public co-applicant as part of the research team. However, where a public co-applicant is included in a study, most funders will ask for a clear description of their role, and the reasons why a public co-applicant is joining the team. Without this information, the presence of a public co-applicant may be seen as tokenistic.

Is ethical permission required to include a public co-applicant?

Ethical approval is not needed unless the public co-applicant is likely to come into direct contact with study participants. In these instances, information about the public co-applicant should be included as part of the study's application for ethical approval, including a role description that clearly states what duties the public co-applicant will undertake.

See Health Research Authority's Top tips for public involvement in your research application:

www.hra.nhs.uk/planning-and-improving-research/best-practice/best-practice-in-public-involvement/top-tips-public-involvement-your-research-application/

Does having a public co-applicant mean this is co-produced research?

Co-production is an approach to public involvement in research that sits alongside other approaches, such as consultation or collaboration. Having a public co-applicant indicates that the research may be co-produced, but it is not by itself sufficient to conclude this. There are several principles that need to be followed before research can be deemed to be co-produced, as outlined in INVOLVE's Guidance on Co-production.

See Guidance on Co-producing a Research Project:

www.involve.nihr.ac.uk/posttypepublication/guidance-on-co-producing-a-research-project/

What happens if a public co-applicant leaves during a study?

As with any other co-applicant or team member, a public co-applicant may leave during the period of the study. This should be considered when developing any agreement that defines the public co-applicant's role and should address who is responsible for what at this time (for example, by stating who will identify any replacement, or what notice should be given, if any). As for changes to other core members of the study team, this should be reported to the funding body.

Can public or patient groups be included as co-applicants?

In many instances, where an existing patient or public group is involved in a study, a representative of the group will be nominated to be a co-applicant. This representative may act as a link between the study team and the rest of the group, as part of their role. But in some cases, where all group members wish to be co-applicants, it is wise to check at an early stage whether this would be considered appropriate by the funding body. This is likely to have implications for host institutions, who may provide support (such as indemnity insurance cover) for public co-applicants, and cost implications for the research budget in terms of payment for time and reimbursement of expenses. In many cases, this may not be practical.

Can children and young people become research co-applicants?

Children and young people should be able to be actively involved in research. Article 12 of the United Nations Convention on the Rights of the Child states that all children and young people who are capable of forming their own views have a right to express those views freely in all matters affecting them. These views should be given due weight in accordance with their age and maturity, both of which need to be considered when recruiting children and young people as co-applicants. However, a number of other considerations will need to be taken into account when working with children and young people as co-applicants.

See Involving children and young people in research – top tips:

www.involve.nihr.ac.uk/wp-content/uploads/2016/01/involvingcyp-tips-keyissues-January2016.pdf

Can public co-applicants be co-authors of papers or presentations?

It is important that public co-applicants' contributions are acknowledged. Co-authorship of publications (including journal articles, reports, abstracts, posters and press releases) and presentations should be agreed at the start, and any changes during the study agreed with the public co-applicant. Care should be taken when reporting research on sensitive topics, which may inadvertently link public co-applicants to a condition. Publishing guidelines for journals do not allow submissions that include anonymous contributors or pseudonyms.

INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

If you would like to know more about what we do, please contact us:

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