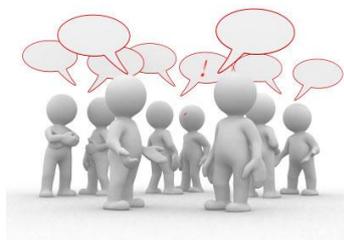


Public Face

An initiative of the



How to engage people as co-applicants for research funds



Introduction

Research funding bodies in the UK health sector are increasingly asking principal investigators to include a public representative as a co-applicant¹. This paper pools what we know about how to arrange things so that public co-applicants are appropriately engaged. It is written by Peter Bates and Evelyn Koon to fill a gap in the existing literature² following a group³ discussion hosted by the [East Midlands Academic Health Science Network](#) as part of its work on Public Leadership. Additional material has been provided via email⁴ and from relevant literature⁵. As readers provide feedback to peter.bates@nottingham.ac.uk, further insights will be used to update the paper. Please also let us know if you have made use of this document.

A note on language and the reach of this paper

In this paper, the term 'public' means patients, service users, carers and members of the public.

Most health research teams⁶ have the following:

- A principal or chief investigator who takes overall managerial responsibility for the entire project
- A team of co-investigators, who altogether might be called the 'research team' and they do all the work of designing and delivering the research.
- Some, but not all of the co-investigators are named on the funding application form as co-applicants. This means that while all co-applicants will be co-investigators, not all co-investigators are co-applicants.

Involving a member of the public as a research funding co-applicant is a hybrid that lies between two extremes – research that is entirely controlled by the university and research that is entirely controlled by the community. This is shown as the middle column in the table on the next page. More information is available on how the general public can influence the priority setting of research funders⁷ and conduct research themselves⁸, as well information on how specific community organisations can initiate and control research⁹.

Research that is entirely controlled and delivered by the university	The team includes a public co-applicant	Research that is done by the community
Q.1: Who decides on the research question and oversees the delivery of the project?		
Eminent researcher, perhaps with academic colleagues and clinical partners	Team of co-applicants, including the public co-applicant	Community group
Q.2: Who bears financial and legal responsibility¹⁰?		
University	University	Community group
Q.3: Who undertakes interviews and other data collection?		
Academic researchers	Negotiated	Four options: <ul style="list-style-type: none"> • The community group is trained to do this themselves • They commission and line manage academic researchers to do it on their behalf • Members of the research team work alongside academic researchers • Specialist, dual-identity 'user-researchers' are employed¹¹
Q.4: When can findings^a be shared with potential beneficiaries?		
After publication	As they arise, but only with the co-applicant and the advisory group who all sign a confidentiality statement	As they arise, bearing in mind that interim findings may be tentative if the dataset or analysis is incomplete
Q.5: Who retains the data after the research is over?		
University ¹²	University	Community group

A radical step forward

Involving a member of the public as a research funding co-applicant has the potential to be a radical step forward for health research. In the past, the vast majority of research was controlled by the academic institutions, rather than being co-produced in partnership with the public. Involving the public has the potential to challenge current practices at a number of levels:

- It begins to shift control of research from academia to the community, and it starts a conversation about how far we wish to travel in that journey¹³.
- It presses researchers to focus ever more strongly on patient benefit, which eclipses both personal career advancement and the publication of academic papers.

^a There are two qualifiers here. First, specific types of research, sometimes called action, emancipatory, or inclusive research are set up from the outset to share findings as they emerge with all potential beneficiaries. Second, the usual arrangements described here can be set aside for individual research studies by prior agreement with the funding body.

- It spotlights any tokenistic practices within academia, where only a few¹⁴ of the co-applicants are genuinely involved in the design stage of developing research proposals. By demanding that public co-applicants are fully involved and can evidence the impact of their involvement, the whole approach by which research is managed is called into question.

These are delicate matters, so it is unsurprising that, to date, there has been little guidance¹⁵ available – either for members of the public who are invited to become co-applicants or for the principal investigators who wish to engage them. We have been assured that the National Institute of Health Research is preparing an amendment to the online guidance for applicants¹⁶, and hope that this document will open the debate further so that everyone is clear about what is expected. This will also help research teams to avoid the three risks of undermining academics, exploiting the public or weakening research efforts.

When should the public co-applicant's involvement begin and end and what will they do in between?

It appears from the literature that the role of co-applicant is more probabilistic than categorical – in other words, there are a number of factors that are likely to be in place, but no one of them is a firm requirement for the title.

- The public co-applicant is likely to be involved in the early stages of thinking about the research question and potential approach¹⁷, and continue throughout the whole project to dissemination and adoption of the findings.
- They may attend all the meetings of the Steering Group, where reasonable adjustments to traditional routines may be made in order to help the person participate fully¹⁸. Evidence of participation combined with the declaration of other co-applicants will demonstrate that they have made a substantial contribution to the research design, delivery and dissemination.
- Interact between these meetings with the Principal Investigator or their nominated deputy so that the working relationship is maintained, difficulties can be quickly overcome and adjustments can be tailored to enhance the participation and contribution of the public co-applicant.
- Regularly interact with other patient or public representatives so that their personal experience is augmented by the views of others¹⁹. While the co-applicant would ideally be part of a wider group of research-active volunteers, it is not essential that they also serve as chair to such an advisory group of patients, carers and the public. Indeed, it may be better to share out such responsibilities between group members. On some occasions, it will be helpful for the public co-applicant to carry issues from the research steering group into this wider group for discussion and then carry the views of the group back into the steering group.

As a member of the research team, the public co-applicant might also help with the actual research work itself, such as by conducting interviews or recording data and analysing it²⁰. However, these activities are not an essential part of the role. The public co-applicant must be genuinely involved across the life of the project, but this does not mean that they have to be involved in a particular way.

What skills and experience are needed to be a co-applicant?

The following requirements should be read as a prompt for thought and reflection rather than an iron rule that cannot be changed. The circumstances of individual studies and diverse community groups are so varied that there will always be an exception to any fixed rules.

We are aware of the pioneering and innovative approach taken by some leading academics in this field, but note that engaging lay co-applicants remains the exception rather than the rule. In general, the principal investigator needs to:

- Consider the public co-applicant as a valued contributor to the process of the research, rather than as merely a means of obtaining funding approval or to meet politically correct expectations. Indeed, the co-applicant has been described as a ‘co-owner’ of the research project²¹, but in the case of public co-applicants, this does not extend to formal responsibility. Department of Health guidance²² requires people involved in research to be ‘appropriately qualified for their role’, which we here consider to mean having relevant lived experience and the ability to contribute to the overall research project.
- Think through the details of the research programme in order to identify areas where the public co-applicant and other public representatives will genuinely add value.
- Adapt their customary ways of working so that the public co-applicant can play a full part.
- Expect and welcome contributions to meetings and at other times, rather than try to confine the public co-applicant to the ‘PPI slot’.

The co-applicant needs to:

- Be online (or have access to someone who is) so that they can complete registration requirements with the funder, receive and send email communication and review documents²³.
- Have some prior experience of patient and public involvement in health research and have some knowledge of the aims and methods of health research.
- Be educated to degree level or have equivalent experience²⁴, alongside sufficient intellectual and social skills so that they can acquire a broad understanding of the activities of the research team, effectively participate in Steering Group meetings, ‘sense-check’ the work of the researchers and help to problem-solve in the event of difficulties. If these skills are not present, training²⁵ may help the person to develop them or the usual role of the co-applicant can be carved²⁶ into a new shape so that it does fit with the co-applicant’s strengths.
- Be in sympathy with the aims of the research project and to consider it a worthwhile undertaking if conducted effectively. Exercise your responsibility to be proactive and constructive.
- Be a person of standing within their wider public involvement community²⁷, so that the funder can be reassured that the oversight and governance of the study is in safe hands and there will be the best chance of patient benefit as a result of their investment.

- Be able to commit to involvement throughout the life of the study, and to make succession plans if they are obliged to resign due to unforeseen circumstances²⁸. This commitment requires the public co-applicant to be aware of the responsibility attached to the role and of the need for a rigorous approach.

Other requirements that might fall upon public co-applicants are in the table below.

Requirements for academic co-applicants ²⁹ (according to BBSRC ³⁰)	What this might mean for public co-applicants
Be resident in the UK	Public co-applicants should live near enough to the place where most meetings happen so that they can attend regularly. Alternatively, they should be able to effectively connect via the use of technology.
Be employed by the organisation submitting the application as a lecturer or equivalent or have an existing written formal arrangement with the eligible Research Organisation confirming <ul style="list-style-type: none"> • that the research will be conducted as if the applicant were an employee at lecturer level or equivalent • they will provide all necessary management and infrastructural support, and • the organisation will take full responsibility for the research and its proper governance; 	The organisation submitting the bid should bear responsibility for supporting the co-applicant's activity in relation to the project, including management, infrastructural support and governance. We can read this to mean: <ul style="list-style-type: none"> • access to a workspace, desk and computer and library as needed • opportunities for personal development and training
These arrangements must extend the end date of the funding.	The organisation needs to be able to demonstrate an ongoing commitment to the person that extends both before the project starts and after it is complete.
Confirm that any commitments they have to existing research projects can be satisfactorily completed before starting the new project ^b , and there is no conflict of interest between the investigator's obligations and to any other organisation or employer.	The organisation bears responsibility to ensure that the public co-applicant is not overloaded with other demands and has capacity to undertake the role of co-applicant and there is no conflict of interest with any other responsibilities that the co-applicant holds

Who has served as a public co-applicant?

A number of people have served as co-applicants in the East Midlands and beyond. One study³¹ obtained responses from 50 research projects, of which 33% had included lay co-applicants. We have not been able to find any evidence to show whether public co-applicants are drawn from diverse communities or not³².

Are patients considered vulnerable?

^b This may be a requirement that is peculiar to the BBSRC – many co-applicants work simultaneously on several projects. The key issue is that co-applicants have capacity to meet their obligations.

Some paediatric research studies³³ have included parents as co-applicants instead of the teenagers themselves, despite the fact that the young people's group have given advice to the project design team. We encourage principal investigators to pursue ambitious as well as safe options for engaging co-applicants who have direct, personal, lived experience of the issues under investigation.

The Research Ethics process is designed to protect people who might be vulnerable to an abuse of power, especially where research overlaps with treatment. The National Institute for Health Research has made it clear that public co-applicants do not need the additional protection of research ethics approval³⁴, but we note that the principal investigator has a duty of care to ensure that the public co-applicant is not disadvantaged by their participation.

Confidentiality

All co-applicants, including public co-applicants, have a responsibility to protect the confidential aspects of the research proposal, uphold intellectual property rights and ensure any personal information arising from the research is properly safeguarded³⁵. Additional guidance is available³⁶.

Does the co-applicant have any other formal legal or financial responsibilities?

Academic co-applicants carry some responsibility for the appropriate disbursement and use of the funds awarded to the research team, as well as the professional integrity of published reports. In contrast, public co-applicants have a general duty of 'lay vigilance' regarding the progress of the research study and the accuracy and honesty of research reports, but they do not have any formal liability.

How should a co-applicant be recruited?

The co-applicant will have had prior experience of involvement in health research and will ideally have been engaged in at least one meaningful discussion where the ideas behind the research proposal have been explored. After this, ideally a clear process is used to advertise the opportunity and select the candidate against fair criteria in an equitable manner.

Embedding the concept in your organisation

A good place to start is with the senior academics who are the most successful in winning research bids and those who shape popular opinion in the academic community, so that, as they embrace co-production and start to engage the public as co-applicants, they influence many other people in the organisation to do the same. At the same time, helping students and early career academics to recognise the value of public involvement will have continuing benefits for many years to come.

There are powerful forces at work that make it difficult to start well. The pre-submission phase of preparing a research bid is largely unfunded³⁷ and some senior academics feel that they are too busy to spend extra time on PPI activities. However, it is important to ensure that public voices are heard early in the process, and the co-applicant adds their perspective as soon as possible in the development of the bid.

Sometimes mythology grows up until the frontline staff believe ‘the Prof will never support this’, so change agents may need a robust communication strategy to spread the message that public co-applicants are crucial to successful bids. Stakeholders, including senior academics, research assistants, research nurses and other clinical staff, all share the responsibility of promoting effective patient and public involvement in the whole project. However, for some patient groups and public co-applicants, the amount of time and level of engagement given by the principal investigator is a measure of the commitment given to the involvement agenda.

It is important that public representatives understand³⁸ the need for cultural change in some parts of the academic institution and balance their persistent encouragement that promotes positive change with an acknowledgement of the difficulties of creating a culture that creates genuine and sustained service improvement.

Once the group of co-applicants has been identified, it is vital to allocate time for people to tell their stories. Each co-applicant has a blend of personal and professional experience that they bring to the team, and space should be made to share this, so that relationships can be formed and mutual respect engendered. Training in research methods³⁹ may help co-applicants to understand the process of research as well as specific training in the role of the co-applicant.

Budget

Effective consultation and co-design of the research project and bid writing requires involvement from the public. This is likely to need at least two meetings with a number of patients and carers prior to writing the proposal. Funding will be needed to host these meetings and perhaps offer a participation fee.

The public co-applicant bears substantial responsibility throughout the process, from writing the bid to disseminating the findings. NIHR Involve recommends that their committee rate is an appropriate offer for people who wish to claim this.

An example

One funding [application](#) wrote “Our leading lay member — who has extensive experience of PPI work in health-related areas — was a co-applicant on the funding application, and his early input contributed to formulating and refining the research proposal and to developing a meaningful PPI strategy as part of those research plans. We have now recruited a further six lay members, who are health service users, carers and members of the general public. In conjunction with the leading lay

member and a researcher co-applicant, this forms an eight-strong PPI team for our research Programme.”

Degrading the process

Where there is a poor understanding of the reasons for including a public co-applicant, or where the process is conducted with undue haste, the following problems may arise:

- The public representative may be asked to sign as co-applicant at the last minute with no explanation of what the role entails.
- The public co-applicant may be offered no help or guidance⁴⁰ about what to expect in relation to online registration requirements.
- Tokenistic involvement may be detected by the funding body, leading to the rejection of the application.

¹For example, this [paper](#) mentions five research projects that were funded by the National Institute of Health Research and include public representatives as co-applicants.

² The following documents make no reference to the role of public co-applicants:

<http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Guidance-for-involving-people-with-experience-of-mental-health-problems.pdf>. Also <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Good-practice-guidance-for-involving-carers-and-family-members.pdf>. Also <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Research-methodology.pdf>. Also http://www.gmc-uk.org/Good_practice_in_research_and_consent.pdf 52588149.pdf. Also <http://www.shapingourlives.org.uk/documents/BTUSReport.pdf>. Also The National Working Group on Evidence-Based Health Care (2008) *The Role of the Patient/Consumer in Establishing a Dynamic Clinical Research Continuum: Models of Patient/Consumer Inclusion*. Virginia, USA: National Working Group on EBH. See www.evidencebasedhealthcare.org

³ Zenn Athar, Peter Bates, Tony Locke, Jackie Parkes, Kate Sartain, Dave Waldram and Kirsty Widdowson met on 23 June 2014.

⁴ The following people have kindly responded to an email inquiry: David Ardron (UK), Dorothy Atkinson (UK), Peter Beresford (UK), Sarah Carr (UK), Jim Conroy (USA), Ann Davis (UK), Bob Drake (USA), Jennifer Durrant (UK), Anita Eley (UK), David Evans (UK), Daniel Fisher (USA), Mark Friedman (USA), Laura Gardner (UK), Bill Gaventa (USA), Anne Gill (UK), Rob Greig (UK), Naomi Halflett (UK), Helen Hamer (NZ), Margaret Hall (UK), Justine Hill (UK), Rosemarie Hutchinson (UK), Andy Imparato (USA), Nev Jones (USA), Thomas Kabir (UK), Helen Kara (UK), Anne Killeth (UK), Tom Lane (USA), Elspeth Mathie (UK), Katie McDonald (USA), Alex Mendoza (UK), John O'Brien (USA), Raksha Pandya-Wood (UK), Maggie Peat (UK), Vanessa Pinfold (UK), Sarah Rae (UK), Sian Rees (UK), Julie Repper (UK), Sally Robinson (Aus), Alison Rojo (UK), Diana Rose (UK), Julie Rowbotham (UK), Dawn Rudolph (USA), Jo Sartori (UK), Roger Steele (UK), George Szumukler (UK), Donald Shand (NZ), Fran Silvestri (NZ), Roger Steel (USA), Jane Stein-Parbury (Aus), Maryrose Tarpey (UK), Jerry Tew (UK), Liz Tilly (UK), David Towell (UK), Joanne Welsman (UK), Andrea Whitfield (UK), Caroline Whiting (UK), Kirsty Widdowson (UK), Jak Wild (NZ), Tracey Williamson (UK), Pauline Winship (UK) and Til Wykes (UK).

⁵ See <http://bjp.rcpsych.org/content/early/2014/03/31/bjp.bp.113.128637.abstract>, also <http://www.biomedcentral.com/1756-0500/7/37>, also Stack, E. and McDonald, K. E. (2014), Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up?. *Journal of Policy and Practice in Intellectual Disabilities*, 11: 83–91. doi: 10.1111/jppi.12074, also Helen Kara, (2013) "Mental health service user involvement in research: where have we come from, where are we going?", *Journal of Public Mental Health*, Vol. 12 Iss: 3, pp.122 – 135, also <http://bjp.rcpsych.org/content/early/2014/03/31/bjp.bp.113.128637#BIBL>, also

<http://bjp.rcpsych.org/content/181/6/468.full.pdf>, also <http://onlinelibrary.wiley.com/doi/10.1002/wps.20086/pdf> also <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/Advanced%20training%20report-April2014.pdf> also http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014_FINAL.pdf http://books.google.co.uk/books?hl=en&lr=&id=oUMbAgAAQBAJ&pgis=1&redir_esc=y.

⁶ http://www.lancashirecare.nhs.uk/media/Publications/R_and_D/SOP/SOP%2009%20-%20Roles,%20responsibilities%20and%20delegation%20of%20duties%20in%20trials_%20Final%20v1.0.pdf

⁷ The James Lind Alliance is one example – see <http://www.lindalliance.org/>.

⁸ For example, Nicholls V (2004) *Strategies for Living: Doing Research Ourselves*.

⁹ See Heaney et al (2007) The West End Revitalization Association’s Community-Owned and –Managed Research Model: Development, Implementation, and Action *Progress in Community Health Partnerships: Research, Education, and Action* Winter 2007, Vol 1.4, pp 339-349. Also Nicholls, V. (2001) *Doing research ourselves*, London: Mental Health Foundation, also <http://www.jrf.org.uk/sites/files/jrf/1861346662.pdf>.

¹⁰ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf

¹¹ Kara H (2013) op cit.

¹² Ideally and when consent is given, data are data stored in a repository that maintains confidentiality while enabling secondary analysis by other researchers.

¹³ <http://www.invo.org.uk/wp-content/uploads/2012/03/INVOLVEguidelinesformembersofthepublicP1updatedjul09.pdf>.

¹⁴ Kara H, (2013) "Mental health service user involvement in research: where have we come from, where are we going?" *Journal of Public Mental Health* Vol. 12 Iss: 3, pp.122 – 135.

¹⁵ One example is at <http://www.jrf.org.uk/sites/files/jrf/1861346662.pdf>

¹⁶ Personal correspondence from Philippa Yeales, NIHR CCF, May 2014.

¹⁷ General guidance on involving people in designing research is available [here](http://www.invo.org.uk).

¹⁸ See <http://www.scie.org.uk/publications/positionpapers/pp09.pdf> and <http://www.peterbates.org.uk/uploads/Havingyoursay.pdf>.

¹⁹ NWO say “Co-applicants need to be representatives of the external parties acting as partners in the research project.” http://www.nwo.nl/binaries/content/documents/nwo/algemeen/documentation/application/nihc/licht-cognitie-gedrag-en-gezondheid---vooraanmeldingsformulier/Pre-proposal+form_FCB.docx

²⁰ See, for example, http://www.mentalhealth.org.nz/file/downloads/pdf/file_496.pdf

²¹ See <http://www.wellcome.ac.uk/Funding/Biomedical-science/Application-information/WTDO04117.htm>

²² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf

²³ Where the right person meets the remainder of the expectations of a research co-applicant but does not have access to the internet, the principal investigator should make alternative arrangements to enable them to participate, such as through an amanuensis, or by printing and posting hard copies of documents. We include it here as a general requirement because it would make things much easier for everyone if the public co-applicant did have access to the internet and this highlights the need for adjustments to be made as necessary.

²⁴ This is not designed to put people off or unduly narrow the field of available candidates, but to recognise that specific skills are needed to effectively fulfil the role of co-applicant. As a result, the ‘or equivalent’ part of this specification should be taken very seriously and the role not unreasonably restricted to people with academic qualifications.

²⁵ Training might include familiarisation with the process of academic research, information about the topic being researched, multi-disciplinary approaches and the governance of the research project. As public co-applicants are expected to have prior experience of being involved in research, they will have learnt from their previous involvement in a variety of activities, such as membership of an advisory group, involvement in staff recruitment and evaluation of documents. Separate ‘How To’ papers cover several of these themes (contact peter.bates@nottingham.ac.uk for details). Most importantly, the public co-applicant will have access to a mentor. At first, the mentor may be an academic, but as the process of engaging public co-applicants becomes commonplace, more experienced public co-applicants will be able to mentor newcomers.

²⁶ Job carving involves bringing selected aspects of several people’s roles together to form a manageable and fulfilling role for someone who would otherwise be unable to satisfy the traditional job description. See further information on the website of the British Association of Supported Employment.

²⁷ The ‘personal involvement community’ may be a small and specialist community that closely matches the specific issue being researched. The co-applicant would have standing within this community, but may not be known beyond it.

²⁸ We note here that setting strict conditions and requirements moves the arrangement away from involvement as a voluntary act within civil society towards a formal contract of mutual obligation.

²⁹ <http://www.invo.org.uk/wp-content/uploads/2012/03/INVOLVEguidelinesresearchgrantapplicationsR1.pdf> offers a general description of the role, and the row headers in the table are drawn from a description given by BBRC.

³⁰ See <http://www.bbsrc.ac.uk/web/FILES/Guidelines/grants-guide.pdf>

³¹ See <http://www.invo.org.uk/wp-content/uploads/2013/03/Poster-74-Whitfield.pdf>

³² Patterson et al (2014, DOI: 10.1192/bjp.bp.113.128637) found 77% of 167 mental health ‘service user-researchers’ were white British, hence a more ethnically diverse group than the general UK population.

³³ These are supported by Kirsty Widdowson.

³⁴ <http://www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf>

³⁵ An example of a confidentiality agreement form for all those involved in research:

https://npdc.okstate.edu/sites/default/files/confidentiality_agreement.pdf

³⁶ See <http://www.ccf.nih.ac.uk/Documents/Confidentiality%20guidance.pdf>

³⁷ In the East Midlands, the Research Design Service offers grants of up to £300 to pay for patient and public consultation prior to submission of research funding bids.

³⁸ NIHR Involve have set out the training requirements for service user co-applicants [here](#).

³⁹ <http://www.jrf.org.uk/sites/files/jrf/1861346662.pdf> tells us that: “the Mental Health Foundation’s Strategies for Living programme, the User Focused Monitoring programme at the Sainsbury Centre for Mental Health (neither of which are survivor-led organisations) and Advocacy Really Works ‘Have trained service users to carry out research’.”

⁴⁰ An accessible guide to serving as a public co-applicant would be helpful to many.