

## How to guide

# How to engage people as research co-applicants

Last updated 4/06/18.



### Introduction

The National Institute of Health Research expects patients and the public to be involved in every stage of the research process, and some research teams have taken up this challenge by inviting a member of the public to be a co-applicant<sup>a</sup>. 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 literature<sup>1</sup> following a group<sup>2</sup> discussion hosted by the [East Midlands Academic Health Science Network](#) as part of its work on Public Leadership. Additional material has been provided via email<sup>3</sup> by a range of people from across the world, academics, public contributors and people who 'live in both worlds' as well as from relevant literature<sup>4</sup>. As readers provide feedback, further insights will be used to update the paper. Please also let us know if you have made use of this document by contacting [shahnaz.aziz@nottingham.ac.uk](mailto:shahnaz.aziz@nottingham.ac.uk).

<sup>a</sup>Examples are given in INVOLVE (2009) *Senior Investigators and Public Involvement*, INVOLVE, Eastleigh, sections 6.3 and 7 which gives several examples of projects that have engaged with public co-applicants. To date, NIHR Involve has 'asked researchers to involve the public in the design and planning of their research but has not asked them to include the public as co-applicants' (Sarah Buckland, personal communication 5 Feb 2015).

## 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 teams<sup>5</sup> have the following:

- A principal investigator 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 just one of the ways in which the public can contribute to the whole process of research and service delivery. Including a public co-applicant does not mean that the research will be co-produced<sup>6</sup>, that the voice of patients will be heard in every decision forum throughout the research journey, or that the results will be of benefit to patients. But if a public co-applicant's role is set alongside a range of other ways in which patients and the public are involved in the research process, they may contribute to the accomplishment of these goals.

## Some questions to start with

When designing a piece of research, the following questions may form a useful starting point, especially for people who are new to the role of co-applicant. The answers to these questions will vary according to the nature of the funding body, the research group, the research method and the preferences of the individual research team.

- **Who decides on the research question and oversees the delivery of the project?** This question really presses home the question of whether the public contributor will have real influence at the start of the research process.

- **Who bears financial and legal responsibility?** The Research Governance Framework<sup>b</sup> sets out general responsibilities, and within this, we think that academic co-applicants bear some responsibility for these formal matters – for stewardship of time and money, for keeping to timetables and for reporting. To what extent do you expect a public co-applicant to share in these responsibilities?
- **Who undertakes data collection and analysis?** There are several ways in which public contributors can be involved in these activities<sup>c</sup>, but this is not an essential component of the co-applicant's role, so it is worthwhile to clarify expectations before you begin.
- **When can findings be shared with potential beneficiaries?** In traditional approaches to research and publication, findings tend to be confidential until the full story is told through the academic press<sup>d</sup>. When and how might the public co-applicant share the research findings with other members of the community?
- **Who retains the data after the research is over?** Will the public co-applicant, patient groups or others have access to the original data after this analysis is complete?
- **What is the role of a public co-applicant?** This of course, is the subject of this document. An early issue to resolve is to decide to what extent the public co-applicant is viewed as bearing similar responsibilities to the other co-applicants. Most of this paper is based on the idea that the public co-applicants' role should be as similar as possible to the role of other co-applicants, making adjustments to facilitate this for co-applicants who do not have a background in health research. This means that they share in meetings to shape the direction of the research, oversee its progress, contribute to its

<sup>b</sup> The Research Governance Framework for Health and Social Care does not define the role of the co-applicant but rather sets out general principles. It is available [here](#).

<sup>c</sup> There are at least four options: (1) public contributors are trained to do this themselves; (2) They commission and line manage academic researchers to do it on their behalf; (3) public contributors are trained to work alongside academic researchers; and (4) specialist, dual-identity 'user-researchers' are employed. For an example of option (4) see 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. Available [here](#).

<sup>d</sup> Specific types of research, sometimes called action, emancipatory, or inclusive research will share emerging findings with all potential beneficiaries from a very early stage in the process.

delivery, represent it to external agencies and disseminate its findings.

More information is available on how the public can influence the priority setting of research funders<sup>e</sup> and conduct research themselves<sup>7</sup>, as well as information on how specific community organisations can initiate and control research<sup>8</sup>.

## **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 journey<sup>9</sup>.
- It presses researchers to focus ever more strongly on patient benefit.
- It spotlights exclusive practices within academia, where sometimes only a few<sup>10</sup> 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.
- It highlights the gaps in administrative and practical provisions where research organisations have an expectation that the public will be involved, but have not worked out how to provide office facilities and library access, obtain research passports and ethics approval or make payments.

These are delicate matters, so it is unsurprising that, to date, there has been little guidance<sup>11</sup> 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

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

for applicants<sup>f</sup>, and hope that this document will open the debate further so that everyone is clear about what is expected.

Our impression is that many stakeholders share a positive determination to avoid the tokenism that would arise if public co-applicants were engaged simply to tick boxes, meet 'politically correct' expectations or secure funding. We hope that this paper will help research teams to avoid the three risks of undermining academics, exploiting the public or weakening research efforts and instead strive for genuine coproduction.

### What is the role of the public co-applicant?

It is difficult to be dogmatic about the precise requirements for the role of public co-applicant, but the following elements are likely to be present.

- **Involved throughout.** The public co-applicant is likely to be involved in the early stages of thinking about the research question and potential approach; and continue throughout the whole project to dissemination and adoption of the findings.
- **An active member of the Steering Group.** The public co-applicant may attend all the meetings of the Steering Group. Evidence of participation combined with the testimony of other co-applicants will demonstrate that they have made a substantial contribution to the research design, delivery and dissemination.
- **Connected to a wider group of patients and the public.** The public co-applicant will regularly interact with other patient or public contributors so that their personal experience is augmented by the views of others<sup>g</sup>. On some occasions, it will be helpful for the public co-applicant to carry issues from the research steering group into a

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<sup>f</sup> Personal correspondence from Philippa Yeales, NIHR CCF, May 2014.

<sup>g</sup> Interestingly, the Netherlands Organisation for Scientific Research says "Co-applicants need to be representatives of the external parties acting as partners in the research project." (see their notes for submitting a funding application, accessed 2 March 2015 at [http://www.nwo.nl/binaries/content/documents/nwo/algemeen/documentation/application/nihc/licht-cognitie-gedrag-en-gezondheid---vooraanmeldingsformulier/Pre-proposal-form\\_FCB.docx](http://www.nwo.nl/binaries/content/documents/nwo/algemeen/documentation/application/nihc/licht-cognitie-gedrag-en-gezondheid---vooraanmeldingsformulier/Pre-proposal-form_FCB.docx)). In considering this in relation to public co-applicants, we think that the public co-applicant would ideally be part of a wider group of research-active volunteers, but we do not think it is 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, rather than overburden the public co-applicant.

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 it<sup>12</sup>. However, such 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 are the responsibilities of the principal investigator?**

The following suggestions 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 communities 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:

- **Communicate value.** Consider the public co-applicant as a valued contributor to the process of the research.
- **Point out the crucial issues.** Think through the details of the research programme in order to identify areas where the public co-applicant and other public contributors will genuinely add value.
- **Be flexible.** Adapt their customary ways of working so that the public co-applicant can play a full part. This may require reasonable adjustments to traditional routines to be made in order to help the person participate fully<sup>13</sup>.
- **Welcome contributions.** Expect and welcome contributions to meetings and at other times, rather than try to confine the public co-applicant to a 'PPI slot', placed at the foot of the agenda. Whilst this is a general point that applies to public involvement in all settings, it is helpful to get it right for the public co-applicant and not just rely on their commitment and tolerance.
- **Maintain contact.** The public co-applicant will interact between Steering Group meetings with the Principal Investigator or their

nominated deputy so 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.

### **What skills and experience do public co-applicants need?**

Again, there are no hard and fast rules, but in general, the public co-applicant needs to:

- **Have relevant lived experience and the ability to contribute to the overall research project.** These twin expectations are rooted in two quotations. The first comes from Department of Health guidance<sup>14</sup> which requires people involved in research to be ‘appropriately qualified for their role’. This statement was not originally made in respect of public co-applicants, but we like to apply it to them and suggest it might be interpreted as having relevant lived experience and the ability to contribute to the overall research project. The second quotation comes from the Wellcome Trust who describe a co-applicant as a ‘co-owner’ of the research project<sup>15</sup>. Again, this was not originally referring to public co-applicants in particular, but we believe that all co-applicants, including public co-applicants, do bear some responsibility for the research project as a whole. In the case of public co-applicants, we think that this responsibility is real, but does not extend to formal responsibility.
- **Have some prior experience of patient and public involvement** in health research and some knowledge of the aims and methods of health research. As a public contributor, there are many ways for newcomers to get involved in health research, and we feel that the role of public co-applicant needs someone with prior experience.
- Be educated to degree level or have equivalent experience<sup>h</sup>, alongside sufficient intellectual and social skills so that they can

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<sup>h</sup> 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 seriously and the role not unreasonably restricted to people with academic qualifications. Nor is it meant to be an inflexible barrier, as the aim is to match the ability of the co-applicant to the task they face in understanding and overseeing the whole research project. We note that acting as a public co-applicant is not the only way to be involved in a research project and so people without the skills set out above can have a substantial influence through other roles. Other objections to this guidance that have been suggested include: (i) all the duties requiring

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, training<sup>i</sup> may help the person to develop them or the usual role of the co-applicant can be carved<sup>j</sup> 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 responsibility and be proactive and constructive.
- Be a 'fit and proper person'<sup>k</sup> and a person of standing within their wider public involvement community<sup>l</sup>, 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.

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academic ability can be jettisoned while retaining the title of public co-applicant; (ii) academic training engulfs lived experience, so the only authentic Experts by Experience are non-academic.

<sup>i</sup> 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@ndti.org.uk](mailto:peter.bates@ndti.org.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.

<sup>j</sup> 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](http://www.basem.org.uk).

<sup>k</sup> To be strictly accurate, this phrase relates to directors of healthcare organisations, rather than those who govern healthcare research, but it may be relevant to consider how the spirit of these regulations impacts the proper governance of research. We suspect that these regulations are not used to select people very frequently, but rather form the basis for deselecting people who are found to be unsuitable for a specific reason, such as a particular criminal offence. Moreover, such rules should not lead to indirect and unjustified discrimination. See Care Quality Commission (2014) Regulation 5: Fit and proper persons: directors and Regulation 20: Duty of candour – Guidance for NHS bodies. Available at [http://www.cqc.org.uk/sites/default/files/20141120\\_doc\\_fppf\\_final\\_nhs\\_provider\\_guidance\\_v1-0.pdf](http://www.cqc.org.uk/sites/default/files/20141120_doc_fppf_final_nhs_provider_guidance_v1-0.pdf).

<sup>l</sup> The goal here is to make the most of the public co-applicant's potential role in interaction with others who share their lived experience of the health condition being researched. If they are well known and respected, then it will be much easier to obtain a wider range of views to augment their own, and it will also be much easier to disseminate messages about the research, than it would for an isolated individual with no standing or reputation. We note that the phrase 'personal involvement community' may refer to 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.



- 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 circumstances<sup>m</sup>. 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.
- It is helpful if the public co-applicant has access to the internet so that they can complete registration requirements with the funder, receive and send email communication and review documents<sup>n</sup>.

The following table highlights a number of other potential requirements for a public co-applicant. The left hand column comes from a research council and sets out what they require for co-applicants in general. We have reflected on this list and suggested a few ideas about how these things might be applied to public co-applicants, and listed them in the right hand column of the table. They are merely prompts for reflection that may be helpful in your own circumstances.

Requirements for academic co-applicants (according to BBSRC <sup>o</sup> )	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.

<sup>m</sup> 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 which may come to be regarded as a contract of employment. This will have consequences for both the employer and the employee, and implications in respect of welfare benefits and tax liabilities.

<sup>n</sup> 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.

<sup>o</sup> See the Biotechnology and Biological Sciences Research Council's online guide at <http://www.bbsrc.ac.uk/web/FILES/Guidelines/grants-guide.pdf>

<p>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</p> <ul style="list-style-type: none"> <li>• that the research will be conducted as if the applicant were an employee at lecturer level or equivalent</li> <li>• they will provide all necessary management and infrastructural support, and</li> <li>• the organisation will take full responsibility for the research and its proper governance;</li> </ul>	<p>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:</p> <ul style="list-style-type: none"> <li>• access to a workspace, desk and computer and library as needed</li> <li>• opportunities for personal development and training</li> </ul>
<p>These arrangements must extend beyond the end date of the funding.</p>	<p>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.</p>
<p>Confirm that any commitments they have to existing research projects can be satisfactorily completed before starting the new project<sup>p</sup>, and there is no conflict of interest between the investigator's obligations and to any other organisation or employer.</p>	<p>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</p>

### Who has served as a public co-applicant?

A number of people have served as co-applicants in the East Midlands and beyond. One study<sup>16</sup> 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 not<sup>17</sup>.

### Are patients considered vulnerable?

Some paediatric research studies 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

<sup>p</sup> 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.

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<sup>9</sup>. A joint statement from INVOLVE and the National Research Ethics Service has made it clear that public co-applicants do not need the additional protection of research ethics approval<sup>18</sup> as they are working alongside researchers rather than participating in the research. However, we note that the principal investigator, and indeed the whole team, has a duty of care to ensure that the public co-applicant is not disadvantaged by their involvement in the research. Pastoral care may be especially relevant if the bid fails, as the public co-applicant may have made a considerable emotional investment in the success of the project and have fewer distractions in comparison to their battle-hardened academic colleagues.

## 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 safeguarded<sup>19</sup>. Additional guidance is available<sup>20</sup>.

Some public co-applicants have lived experience that is relevant to the research that is being undertaken, but which they may not wish to be publicly known. Principal investigators should exercise a duty of care in respect of this and ensure that the personal and perhaps private history of the public co-applicant is not inappropriately divulged.

Where the intended research topic involves matters that may evoke responses of embarrassment, discrimination or danger, then the public co-applicant's personal details should be held by the immediate team and obscured in the application form, perhaps by use of a pseudonym and office address, rather than home address, while the narrative in the funding application should explain that these details have been changed

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<sup>9</sup> There is a possibility that someone who is a participant in research may wish to engage in patient and public involvement activities. We would advise against overlapping clinical, research and involvement activities as this would multiply the risks.

for reasons of safeguarding<sup>21</sup>. Funding bodies may wish to check that the person can be contacted via the Principal Investigator.

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

Academic co-applicants who are employed by a university or similar body 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. To be precise, they are responsible to their employer, who bears the formal responsibility.

Where the Chief Investigator and the majority of co-applicants are employed by a university or a similar body, then the formal responsibility lies with this body. The 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 do not hold any formal liability.

Where a group of public co-applicants form their own independent research organisation and apply for research funding, that group are deemed 'jointly and severally liable' for meeting the obligations set out in the research contract – to deliver the product to the expected standard in exchange for the funds provided. Such groups are advised to address this risk via a formal structure (such as through becoming a company limited by guarantee) and appropriate insurance.

### **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 early explorations of the ideas behind the research proposal – so they may well be already known to the principal investigator or their colleagues.

Common practice in the academic community is to recruit academic co-applicants by informal means, based on the principal investigator's knowledge of individual interests and expertise. If applied to the public co-applicant, such an approach would achieve parity of approaches, and work well if the principal investigator and colleagues had a rich network of connections with public contributors. On the other hand, if such a network has not yet matured or there is a clear wish to widen the field,

then an alternative would be to define the role, 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. INVOLVE has produced guidance on the leadership role of senior investigators<sup>22</sup>.

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 unfunded<sup>r</sup> and some senior academics feel that they are too busy to spend extra time engaging with the public. 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 contributors understand<sup>23</sup> the need for cultural change in some parts of the academic institution and balance their persistent encouragement that promotes positive change with an

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<sup>r</sup> 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. Similar arrangements are available elsewhere.

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. Although we have suggested that public co-applicants have some prior experience in involvement with health research, there may be some gaps in their knowledge and so training in research methods<sup>24</sup> may help them understand the process of research. We have not located any examples of training that is specific to the role of being a public 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 research process, from involvement in writing the bid at the start to disseminating the findings at the end. The NIHR Research programmes have agreed the rates that they pay people and have published these figures, but they stop short of recommending them to others. Advice from INVOLVE is that “the rate for involvement of people as co-applicants will depend on a variety of factors and in many cases they are likely to be employed by the host institution and so would be paid a salary.”<sup>s</sup>

## **An example**

One funding application<sup>25</sup> included the statement, “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.

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<sup>s</sup> Sarah Buckland, INVOLVE, personal communication, 5 February 2015.

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 contributor may be asked to sign up 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 guidance<sup>t</sup> 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.

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<sup>1</sup> It was encouraging to see that NIHR INVOLVE will be working with the NHS R&D Forum and INVOLVE-RDS in 2018 to publish some official advice on public co-applicants (see the announcement at <https://www.rds-se.nihr.ac.uk/newwordpress/wp-content/uploads/INVOLVE-RDS-UpdateWinter18.pdf>). Gary Hickey forwarded this document to their group for reference on 9/2/18. The previous gap is illustrated by the fact that the following documents make no reference to the role of public co-applicants: NIHR Mental Health Research Network (undated) *Good Practice Guidance for Involving People with Experience of Mental Health Problems in Research*, London, MHRN (accessed on 2 March 2015 at <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Guidance-for-involving-people-with-experience-of-mental-health-problems.pdf>). Also NIHR Mental Health Research Network (undated) *Good practice guidance for involving carers, family members and close friends of service users in research* London: MHRN (accessed on 2 March 2015 at <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Good-practice-guidance-for-involving-carers-and-family-members.pdf>). Also NIHR Mental Health Research Network (2012) *Research Methodology Guide* London: MHRN (accessed on 2 March 2015 at <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Research-methodology.pdf>). Also General Medical Council (2013) *Good practice in research and consent to research* (accessed 2 March 2015 at [http://www.gmc-uk.org/Good\\_practice\\_in\\_research\\_and\\_consent\\_to\\_research.pdf\\_58834843.pdf](http://www.gmc-uk.org/Good_practice_in_research_and_consent_to_research.pdf_58834843.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](http://www.evidencebasedhealthcare.org) accessed 2 March 2015.

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<sup>t</sup> An accessible guide to serving as a public co-applicant would be helpful to many.

<sup>2</sup> Zenn Athar, Peter Bates, Tony Locke, Jackie Parkes, Kate Sartain, Dave Waldram and Kirsty Widdowson met on 23 June 2014.

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<sup>4</sup> Such as Gupta E & Roberts B (2014) User and researcher collaborations in mental health in low and middle income countries: a case study of the EMPOWER project *BMC Research Notes* 2014, 7:37 doi:10.1186/1756-0500-7-37 (accessed 2 March 2015 at <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 Trivedi P & Wykes T ( ) From passive subjects to equal partners: Qualitative review of user involvement in research *British Journal of Psychiatry* 2002, 181, 468-472 (accessed 2 March 2015 at <http://bjp.rcpsych.org/content/181/6/468.full.pdf>), also Wykes T (2014) Great expectations for participatory research: what have we achieved in the last ten years? *World Psychiatry* Volume 13, Issue 1, Article first published online: 4 FEB 2014 (accessed 2 March 2015 at <http://onlinelibrary.wiley.com/doi/10.1002/wps.20086/pdf>) also NIHR CRN: Mental Health Growing a service user and carer research resource London: NIHR (accessed 2 March 2015 at <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/Advanced%20training%20report-April2014.pdf>) also NIHR CRN: Mental Health (undated) *Good practice guidance for the recruitment and involvement of service user and carer researchers* London: NIHR (accessed 2 March 2015 at [http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014\\_FINAL.pdf](http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014_FINAL.pdf)), also Stadden P (2013) *Mental health service users in research* Policy Press (see [http://books.google.co.uk/books?hl=en&lr=&id=oUMbAgAAQBAJ&pgis=1&redir\\_esc=y](http://books.google.co.uk/books?hl=en&lr=&id=oUMbAgAAQBAJ&pgis=1&redir_esc=y)).

<sup>5</sup> Lancashire Care NHS Foundation Trust (2013) Roles, responsibilities and delegation of duties in clinical trials or medicinal products (accessed 2 March 2015 at [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](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))

<sup>6</sup> See The Social Care Institute of Excellence webpages on coproduction at <http://www.invo.org.uk/scie-talking-and-walking-co-production/> (accessed 2 March 2015)

<sup>7</sup> For example, Beresford P (2013) *Beyond the usual suspects* London: Shaping our lives (accessed 2 March 2015 at <http://www.shapingourlives.org.uk/documents/BTUSReport.pdf>). Also Nicholls V (2004) *Strategies for Living: Doing Research Ourselves*.

<sup>8</sup> 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 Faulkner A (2004) *The ethics of survivor research* Bristol: The Policy Press (accessed 2 March 2015 at <http://www.jrf.org.uk/sites/files/jrf/1861346662.pdf>).

<sup>9</sup> NIHR INVOLVE (2009) Getting involved in research grant applications: Guidelines for members of the public (accessed 2 March 2015 at <http://www.invo.org.uk/wp-content/uploads/2012/03/INVOLVEguidelinesformembersofthepublicP1updatedjul09.pdf>).

<sup>10</sup> 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.

<sup>11</sup> One example is Faulkner A (2004) *The ethics of survivor research* Bristol: The Policy Press (accessed 2 March 2015 at <http://www.jrf.org.uk/sites/files/jrf/1861346662.pdf>).

<sup>12</sup> See, for example, Hamer, H. P., Clarke, S., Butler, R., Lampshire, D., Kidd, J. (2014) *Stories of Success* Auckland NZ: Mental Health Foundation (accessed on 2 March 2015 at [http://www.mentalhealth.org.nz/file/downloads/pdf/file\\_496.pdf](http://www.mentalhealth.org.nz/file/downloads/pdf/file_496.pdf)

<sup>13</sup> See Doel M, Carroll C, Chambers E, Cooke J, Hollows, A, Laurie L, Maskrey L & Nancarrow S (2007) SCIE Position paper 09: Developing measures for effective service user and carer participation (accessed on 2 March 2015 at <http://www.scie.org.uk/publications/positionpapers/pp09.pdf>).

<sup>14</sup> Department of Health (2005) Research Governance Framework for health and social care (accessed on 2 March 2015 at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/139565/dh\\_4122427.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf))

<sup>15</sup> See the Wellcome Trust's online guidance at <http://www.wellcome.ac.uk/Funding/Biomedical-science/Application-information/WTD004117.htm>

<sup>16</sup> See the online poster summarising their work at <http://www.invo.org.uk/wp-content/uploads/2013/03/Poster-74-Whitfield.pdf> uk (accessed 2 March 2015) or contact the lead researcher at [andrea.whitfield@uwl.ac.uk](mailto:andrea.whitfield@uwl.ac.uk).

<sup>17</sup> Patterson S, Trite J & Weaver T (2014) Activity and views of service users involved in mental health research: UK survey *British Journal of Psychiatry* DOI: 10.1192/bjp.bp.113.128637 Published 10 April 2014 (accessed on 2 March 2015 at <http://bjp.rcpsych.org/content/early/2014/03/31/bjp.bp.113.128637.abstract>). They found 77% of 167 mental health 'service user-researchers' were white British, hence a more ethnically diverse group than the general UK population.

<sup>18</sup> NIHR INVOLVE and National Research Ethics Service (2009) *Patient and public involvement in research and research ethics committee review* <http://www.invo.org.uk/wp-content/uploads/2011/12/INVOLVENRESfinalStatement310309.pdf>

<sup>19</sup> An example of a confidentiality agreement form for all those involved in research has been supplied by Oklahoma State University – accessed on 2 March 2015 at [https://npdc.okstate.edu/sites/default/files/confidentiality\\_agreement.pdf](https://npdc.okstate.edu/sites/default/files/confidentiality_agreement.pdf).

<sup>20</sup> See NIHR (2014) *Confidentiality and disclosure: A guide for applicants, reviewers and commissioning panels* Accessed on 2 March 2015 at <http://www.nihr.ac.uk/ccf/confidentiality-guidance.pdf>

<sup>21</sup> This approach was discussed with Gary Hickey at NIHR INVOLVE (personal communication 24/05/2018).

<sup>22</sup> INVOLVE (2014) *NIHR Senior Investigators: Leaders for patient and public involvement in research*. INVOLVE, Eastleigh

<sup>23</sup> Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J. (2004) *Report Summary - Training for service user involvement in health and social care research: a study of training provision and participants' experiences* Eastleigh: INVOLVE.

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Accessed on 2 March 2015 at <http://www.invo.org.uk/wp-content/uploads/2012/01/TRUEsummary2004.pdf>.

<sup>24</sup> There are some resources to help in designing training materials (although they do not focus specifically on the role of public co-applicants), including INVOLVE (2012) *Briefing notes for researchers: involving the public in NHS, public health and social care research*. INVOLVE, Eastleigh (accessed on 2 March 2015 at <http://www.invo.org.uk/resource-centre/resource-for-researchers/>) Also INVOLVE (2012) *Developing training and support for public involvement in research*. INVOLVE, Eastleigh (accessed on 2 March 2015 at <http://www.invo.org.uk/wp-content/uploads/2012/11/INVOLVETrainingSupport2012.pdf>).

<sup>25</sup> *Investigating the implementation, adoption and effectiveness of ePrescribing systems in English hospitals: a mixed methods national evaluation* (accessed 2 March 2015 at <http://www.cphs.mvm.ed.ac.uk/projects/eprescribing/patientInvolvement.html>)