**Researcher Guidance: Involving people with lived experience as co-applicants on research projects**

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**Introduction**

This handbook is a resource for researchers who involve people with lived experience of diabetes as co-applicants on grant applications. It aims to guide you through setting up and maintaining the relationship with your Patient and Public Involvement (PPI) co-applicant. The handbook covers expectations, how Diabetes UK can support researchers, and provides example role descriptions and agreements which can be tailored for your project. The items set out in this handbook are for reference and not considered mandatory.

# **Definition**

**Patient and Public Involvement Co-applicant -** When using the term ‘patient and public involvement co-applicant’ we mean an individual who is involved in the development of a funding application and, if funded, has some responsibility as part of the team for the management and/or delivery of the project These would be specific to the patient and public involvement activities outlined in the project.

**Developing your application and setting up the PPI relationship**

At the beginning of the relationship, it is important to:

* Ensure you have enough PPI co-applicants built into your project. We recommend minimum two members; this allows them to support each other in their PPI co-applicant journey.
* Define roles and responsibilities of the PPI co-applicant(s) - be clear what is and isn’t within the role. It is important to be specific about the activities they will support.
* Consider any other policies and procedures the PPI co-applicant(s) needs to sign (e.g. Terms of References, Confidentiality Disclosure Agreements).
* Decide who is the named contact within the research team responsible for supporting the PPI co-applicant(s).
* Agree how your PPI co-applicant(s) works with the individual responsible for PPI in the research.
* Decide if/how your PPI co-applicant(s) will link with other public contributors or study management groups (such as community organisations or a study steering group).

**Congratulations on getting funded…what next?**

We recommend that within the first 3 months you should induct the PPI co-applicant(s) into the research team. You should discuss:

* The role description, terms of references and any other policies and procedure.
* The importance of confidentiality - research can often be sensitive and has the potential to lead to exciting findings. Consider whether there is a need for written agreement within your institution. Diabetes UK strongly encourages you to agree what information can and cannot be shared with people outside of the research team.
* Any learning and support needed for the role.
* Ways of working, including how and when to communicate with each other.
* Whether the host institution requires indemnity insurance for the co-applicant, and any related implications.
* Policies and procedures for making incentive payments and for claiming expenses.
* A process if the PPI co-applicant(s) leaves the study.
* A process for the PPI co-applicant(s) to provide feedback – we recommend informal check-ins to see how they are getting on in their role.
* A process for how issues or complaints will be addressed, and the support available to the co-applicant(s).

**Line management and support for the PPI co-applicant**

It isn’t necessary to have formal line management, but research teams are encouraged to follow [**UK standards for Public Involvement**](https://sites.google.com/nihr.ac.uk/pi-standards/home).

Here are some examples of facilities that may be available for a PPI co-applicant. While not all are essential, it is beneficial to consider whether any of the following are required or available for PPI co-applicant(s) at your institution:

* Indemnity Insurance
* Security pass or ID card
* Institutional email address
* Workspace with a computer
* IT support for remote working
* Access to protected shared drives or intranet
* Membership of host library
* Staff development training or events

**Maintaining the PPI relationship**

Diabetes UK are developing ways of supporting PPI co-applicants and researchers to make the relationship as effective as possible. This ensures involvement is meaningful and ultimately leads to higher quality research with greater impact.

The PPI relationship can be most beneficial and impactful if it is tied to key dissemination points throughout your research. It can be helpful to plan PPI in a structured way, ensuring the activities are specific and tangible, to make sure you are getting the most benefit from lived experience expertise, and that involvement is a positive experience for everyone sharing their time and experiences.

Keeping a record of PPI activities can be useful for evaluating PPI to make sure it is meaningful and useful for your research. Marie Curie and Cardiff University have produced a toolkit to help with planning, recording, and evaluating PPI. It is called the Public Involvement in Research Impact Toolkit (PIRIT). They can be downloaded using the links below:

* [Public Involvement in Research Impact Toolkit (PIRIT) - Marie Curie Research Centre - Cardiff University](https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit)
* [Public involvement in research impact toolkit (PIRIT) - Learning for Involvement](https://www.learningforinvolvement.org.uk/content/resource/public-involvement-in-research-impact-toolkit-pirit/)

The toolkit includes a PPI planning tool and an Excel spreadsheet to record PPI activities. It is designed to reflect the [UK Standards for Public Involvement](https://sites.google.com/nihr.ac.uk/pi-standards/home). Using the toolkit can support you to report on your PPI activities and their impact in your quarterly and annual reviews with Diabetes UK.

**How can Diabetes UK can support you?**

We understand that PPI can often feel overwhelming at times, despite it being critical to high quality impactful research. If you are a Diabetes UK funded research, the Research Team can help by:

* Acting as a sounding board for any ideas you have for PPI in your research.
* Listen and provide guidance on dealing with any PPI challenges you are be experiencing in your PPI journey.
* We can connect you with local Diabetes UK groups.

# **Stay in touch**

If you have any comments or questions about PPI, please get in touch research@diabetes.org.uk.

**Appendix A: Example Role Description**

|  |  |
| --- | --- |
| **Project title**  |   |
| **PPI role title**  |   |
| **Lead researcher**  |   |
| **Project background**  |
| *

In plain English:* Project aims
* Why the research is important
* How the research will be carried out
* What is the potential impact
 |
| **What does the role involve?**  |
| * How PPI co-applicant(s) will work with research team - include with tangible activities and be specific about whether they will be consulted or be involved in co-creating
* Give details of research team member responsible for PPI (point of contact) and how the co-applicant(s) will work with responsible team member
* Specify if or how PPI co-applicant(s) will communicate with other contributors (such as steering group)
* Describe how lived experience perspective will be important in the research, such as feasibility/acceptability of long-term developments, or how to show relevance to clinical practice and people with diabetes

  |
| **What skills are required?**  |
| Below is an example of what you might include but this should be adapted based on the role.   |
| **Essential**: * Confident in reviewing documents and taking part in email correspondence with other steering group members
* Good computer skills
* Ability to join video conference meetings and one face to-face meeting
* Enthusiasm to contribute to all aspects of the project as appropriate

 **Desirable** * Experience of participating in research
 |
|  **What is the time commitment?**  |
| Include length of project and role, number of meetings, length of meetings, format (in person/video conference) and preparation time for meetings.  |
|  **When will the role begin?**  |
|  |
|  **What support is provided?**  |
| E.g. training opportunities, support using technology, support understanding technical aspects of project, main contact for PPI contributors.  |

**Appendix B: Example Code of Conduct**

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| --- |
| **Code of Conduct** |
| **Research teams will:** * Induct the PPI co-applicant(s) into the research team within 3 months of funding.
* Discuss and sign the role description and agreement within 3 months of funding.
* Identify a team member responsible for supporting the PPI co-applicant(s) and communicate this to the PPI co-applicant(s).
* Identify and explain any relevant organisational policies such as confidentiality, professional behaviour standards, or grievance/disciplinary procedures.
* Notify Diabetes UK if there is a change of PPI co-applicant(s) or any issues that arise.
* Recruit a replacement if a PPI co-applicant(s) leaves the study.
 |
| **PPI co-applicants will:** * Attend induction with the research team within 3 months of funding.
* Discuss and sign the role description and agreement within 3 months of funding.
* Participate in activities with the research team agreed in the role description.
* Give 3 months advance notice if leaving the study to allow time for finding a replacement.
* Raise any concerns with your main PPI point of contact.

  |
| **Lead Researcher** **Name** **Signed** **Date**  |
| **PPI Co-applicant** **Name** **Signed** **Date**  |

**Appendix C: Example Non-Disclosure Agreement**

**Name**

**Address**

**Date**

**Non-Disclosure Agreement**

**Project title:**

Thank you for your interest in working with [principal investigator name at institution name] on the project [add title] funded by [add funder].

Your appointment as a patient and public involvement co-applicants may require us to disclose confidential information to you. Accordingly, we would first like to agree the terms on which any such confidential information is to be disclosed and held. These terms are set out in the schedule attached to this letter.

Please confirm your acceptance of the terms set out in the schedule by signing, dating and returning the enclosed copy. This letter of agreement will become legally binding upon your acceptance.

Yours sincerely,

**[Name]**

**For and on behalf of [organisation]**

I agree to the terms set out in the Schedule to this letter.

Signature:

Print Name:

Date:

**SCHEDULE**

1. **Background**

[principal investigator] has requested that you become a PPI co-applicant on project [title]. In consideration of your agreeing to accept such appointment and to provide services from time to time in connection with that appointment, [principal investigator name at institute] has agreed to disclose Confidential Information to you in connection with the Purpose. You agree to use such Confidential Information in accordance with the terms of this Agreement.

1. **Definitions**
	1. The following definitions shall apply in this Agreement:

**Confidential Information:** all confidential information (however recorded or preserved) disclosed or made available to you, directly or indirectly, by [principal investigator] or its employees, officers, agents, representatives or advisers including but not limited to:

1. your appointment as [add role];
2. the terms of this agreement;
3. any information disclosed to you in connection with your appointment as

[add role];

1. any discussions you have with any other [add role];
2. any information relating to [institute], its personnel and operations which a reasonable person would regard as confidential.
3. Confidential Information shall not include any information that is or becomes generally available to the public (other than as a result of its disclosure by you in breach of this agreement), or which was, is or becomes available to you on a non-confidential basis from a third party who you reasonably believe is not bound by a confidentiality agreement with [institute], or otherwise prohibited from disclosing the information to you.

**Purpose**: the services you will be asked by [principal investigator] to undertake from time to time in connection with your appointment as a [add role].

1. **Your Obligations**

3.1 You will keep Confidential Information confidential and, except with the prior written consent of [principal investigator]:

(a) use the Confidential Information only for the Purpose and not use or exploit the Confidential Information in any way for any other purpose; and

(b) not disclose or make available the Confidential Information in whole or in part to any third party other than other [add role] in connection with the Purpose, except as expressly permitted by this agreement.

3.2 You may disclose Confidential Information if and to the extent such disclosure is required by law, by any governmental or other regulatory authority, or by a court or other authority of competent jurisdiction. Where you are legally permitted to do so, you will promptly notify [principal investigator] of such disclosure.

**4. Return of information and Announcements**

4.1 At the request of [principal investigator, you shall promptly:

(a) destroy or return to [principal investigator all documents and materials (and any copies) containing, reflecting, incorporating, or based on Confidential Information;

(b) erase all Confidential Information from any computers owned or controlled by you to the extent possible.

4.2 You will not make any public announcement concerning your appointment or this agreement without our prior written consent (such consent not to be unreasonably withheld or delayed) except as required by law or any governmental or regulatory authority (including, without limitation, any relevant securities exchange), or by any court or other authority of competent jurisdiction.

**5. Conflict of interests**

* 1. You will inform [principal investigator if you are conflicted from any discussions due to direct interests. A direct interest applies to any of the following situations:
1. [Add any potential conflicts]

**6. Reservation of rights and acknowledgement**

6.1 [principal investigator] reserves all rights in the Confidential Information. No rights in respect of such Confidential Information are granted to you and no obligations are imposed on [principal investigator] other than those expressly stated in this agreement. In particular, nothing in this agreement shall be construed or implied as obliging [principal investigator] to disclose any specific type of information under this agreement, whether Confidential Information or not.

6.2 Except as expressly stated in this agreement, [principal investigator] does not make any express or implied warranty or representation concerning its Confidential Information, or the accuracy or completeness of the Confidential Information.

6.3 The disclosure of Confidential Information by [principal investigator] shall not form any offer by, or representation or warranty on the part of, [principal investigator] to enter into any further agreement.

6.4 You acknowledge that damages alone would not be an adequate remedy for the breach of any of the provisions of this agreement. Without prejudice to any other

rights and remedies, [principal investigator] shall be entitled to the granting of equitable relief (including without limitation injunctive relief) concerning any threatened or actual breach of any of the provisions of this agreement.

**7. General**

7.1This agreement constitutes the entire agreement between the parties and

supersedes and extinguishes all previous drafts, agreements, arrangements and

understandings between them, whether written or oral, relating to its subject matter.

No variation of this agreement shall be effective unless it is in writing and signed by

each of the parties (or their authorised representatives).

7.2 No party may assign, sub-contract or deal in any way with, any of its rights or

obligations under this agreement or any document referred to in it.

7.3 Any notice or other communication required to be given under this agreement,

shall be in writing and shall be delivered to the addresses set out at the beginning of

this agreement.

7.4 Nothing in this agreement is intended to, or shall be deemed to, establish any

partnership or joint venture between any of the parties, constitute any party the agent of another party, nor authorise any party to make or enter into any commitments for or on behalf of any other party.

7.5 This agreement and any dispute or claim arising out of or in connection with it or its subject matter or formation (including non-contractual disputes or claims) shall be governed by and construed in accordance with the law of England and Wales. The parties irrevocably agree that the courts of England and Wales shall have exclusive jurisdiction to settle any dispute or claim that arises out of or in connection with this agreement or its subject matter or formation (including non-contractual disputes or claims).

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