**Public Involvement Support Pack**

Promoting successful inclusion in research



**Contents:**

**SUPPORT NEEDS:**

1. Introduction
2. Communication Impairment
3. Support needs prior to meetings
4. Support needs during meetings
5. Support needs for participation
6. Other important information

**Appendices:**

1. PI role description
2. Terms of reference Research Team
3. Terms of reference Critical Friends Group / Advisory Board
4. PI Payment guidance
5. INVOLVE Top Tips for PI research
6. I-ASC examples

**Definition of Public Involvement (PI):**

The National Standards for Public Involvement in Research defines PI as the following groups:

Patients, Service Users, Survivors, Family Members and Carers (Support Workers or Personal Assistants)

1. **Introduction**

This pack focuses on people who have communication impairment or family members with experience of communication impairment and who want to be involved in research. View this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+1/0_htvvaiw2) to learn more and meet someone who uses an electronic communication aid to substitute for the fact that his own speech production is unintelligible.

Communication impairment can present in many ways, for example, the individual may have difficulty finding words and expressing ideas but they have no difficulty understanding words or situations; other people may have difficulty processing language and communication at typical conversational speed but given some more time, they can understand everything. Others may have particular difficulty understanding communication and conversation but plainly written summaries may improve their understanding. See the Stroke Association [website](https://www.stroke.org.uk/effects-of-stroke/communication-problems) for more information.

The forms included in the appendices of this pack might be completed by anyone considering PI research, to see if it is feasible for them to participate before a project begins.

If a research project carries on for a number of years, the information might be revisited every 6 months to check that information is still current and relevant to the current situation of the PI co-researcher.

The completion of these forms by the PI co-researcher, and where they use them, can be decided between the PI co-researcher and the Chief / Principal Investigator. Where needed Personal Assistants (PA) will facilitate conversations about the responsibilities involved in the research project and who will be doing what.

Where a PI co-researcher employs PAs, this document may also facilitate a conversation about which PAs would like to be involved in supporting the research and which PAs are less interested.

If the PI co-researcher has care commitments of their own, such as a disabled child or spouse, or needs the support of a PA, then care provision or staff shift patterns need to be discussed. This discussion may also include conversations about who is willing to travel and stay away from home should it be needed.



1. **Communication Impairment**

When a person has a communication impairment it is important to make sure you know how they get their message across and what you can do to help them achieve success.

It may be useful to have a discussion with the person and also a discussion with the person in the presence of their Personal Assistant.

The type of questions that would be useful to ask are outlined below:

**What methods of communication do you use?**

This may include using an electronic communication aid, signing, pointing to symbols in a communication book or using eye gaze to select letters on a computer screen. These are often collectively described as Augmentative and Alternative Communication ([AAC](https://communicationmatters.org.uk/wp-content/uploads/2019/02/What-is-AAC.pdf)).

**How easily can someone with a communication impairment get their contributions heard?**

In meetings, it is useful to know when the person with a communication impairment wants to contribute to the meeting e.g., by using a gesture like raising their hand, or speaking one word using their electronic communication aid. It may also be useful to know if the person uses some speech or vocalizes, at times.

As aided communication takes longer, one useful strategy that AAC users often use in this context is to compile their message whilst the meeting carries on. When the AAC user is ready, the meeting stops and can return to the earlier point that the individual wants to comment on. This maintains the flow of meetings. Another strategy may be for the person to use a quicker system that their Personal Assistant understands, e.g., signing or being able to understand the person’s impaired speech.

Some people also use body language or signs to indicate what they want to say. It is worth checking this out with an individual as there may be signs that are personal to them. It would be useful to tell people in the research team whether to look out for an arm or leg movement so they are ready for this.

Eye pointing (looking) can also be very powerful and easy for individuals with a communication impairment to use to indicate what they want or who they are talking about.

People with communication impairment may also have physical challenges that make the ways in which they say or indicate Yes and No rather subtle. It is vital to make sure that the Yes and No response of the individual is clearly understood by all the research team members. This could be a head nod or shake, a vocalization or a hand gesture. Ask the person to show you how they indicate Yes and how they indicate No.

For some people the use of a sign language interpreter means they can keep up with all the discussions taking place in the meeting. Additional funding may need to be found to provide this service if it was not included in the initial bid for research funding for the project.

Good practice would be to share this information with all team members.

1. **Support needs prior to meetings**

Things to check in terms of supporting or prompting an individual with a communication impairment might include:

* A member of the team reminding them to read and reply to emails or to read documents sent as attachments to prepare a response ready to deliver in the next meeting.
* Checking if a hard copy of the reading material needs to be sent in the post before the meeting, or whether a digital version would work.
* Checking if they use a text reader on a computer to support access to literacy. If so, are documents being made available in a format that enables them to be read out effectively? If not, the research team needs to alter the format of documents.
* Checking if the individual being included in the meeting has any visual impairment. Do they need access to Braille, large print or other supports?
* Deciding if it would be helpful to have a meeting (such as Skype) prior to any meeting with a member of the research team that will be providing support to the PI co-researcher in the meeting. The aim of this would be to clear up any misunderstandings before the meeting. This could take the form of an email conversation.
* Finding out how much preparation time they need for meetings. How long before meetings should they receive materials, to allow them enough time to read them and construct a response for the meeting? We suggest one week’s preparation time as a minimum. See this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+5/0_mpio3c4a).
* Asking if they need to read through documents with a familiar support worker who can read and discuss the documents with them and ensure they understand all of them.
* The research team member supporting the PI co-researcher needs to liaise regularly to ensure support for all meetings will be covered. Holidays also need to be planned around.

1. **Support needed in meetings**

This could include where the assistant sits in relation to the PI co-researcher in the meetings. Their disability may lead the person to prefer for papers to be held up and the pages turned on one side of their body, to make them easier to read.

If a person uses an electronic communication aid, it can be useful for them to turn off the speech at times during a meeting to ask questions of the person supporting them, silently. The person would read the question from the screen and have a quiet conversation with the PI co-researcher and hopefully answer the query without stopping the meeting. This would mean that not everyone would have to know that the PI co-researcher had a query, which is less embarrassing for them. See this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+4/0_5zpfoqmz).

Electronic communication aids can sometimes break down. It would be useful for the person supporting the PI co-researcher to know what back-up systems they have and how to use them. This may include putting the individual’s mobile phone on their knee to allow them to use text on their phone. Alternatively, a paper-based letter board could be used to spell out words, which the person supporting is then asked to read out. If this problem happens in a meeting it would be useful for the support person to be able to explain this difficulty to the rest of the meeting.

At times research teams can get carried away with discussions and they can carry on well after everyone is tired and very hungry. The person supporting the PI co-researcher needs to recognise this and suggest that the meeting breaks for all to have a drink and some food.

1. **Support needed for participation**

This section includes some practical and logistical factors that are worth considering in the bid development stages or delivery stages of a project.

* Does the PI co-researcher have their own Personal Assistants who are willing and able to support them during the meetings? Sometimes a PI co-researcher has specially trained medical Personal Assistants who will have to be with them at all times. In this situation, this person will be the one providing the support to the PI co-researcher and not a member of the research team.
* If not, how will the research team recruit suitable Personal Assistants for the PI co-researcher to enable them to complete their research commitments to the project?
* What training will the assistants need for general support of the PI co-researcher? If relevant, what experience do they have of supporting people with swallowing and eating challenges, and providing personal care etc. How will they be trained, and what insurance may be necessary? See this [video](https://mmutube.mmu.ac.uk/media/Public+Involvement+Powerpoint+Clip+3/0_ku55eejm).
* How long does it take to eat a meal/snack? This may affect the timetable for an all-day meeting. If not managed effectively, the person who helps the PI co-researcher with their lunch may still be eating theirs as the meeting starts again after lunchtime.
* What personal care facilities do they need to use? An accessible toilet or a changing place (with a plinth and hoist) may be required. The location of these may determine where the meeting can take place within the building.
* Medication may be needed if working a full day. This may change the requirements for a PA during meetings to someone who has the professional background to allow them to administer medication.

1. **Other important information**

This section covers some additional considerations, when involving PI co-researchers who have communication and physical challenges.

* How will the PI co-researchers travel to the research location? This may be in their own transport or with their own Personal Assistants. Alternatively, this may be on public transport either on their own or with Personal Assistant support.
* How long is the journey from their home to the place where the research meetings happen? Is it feasible to do this journey on a regular basis?
* Will they need parking reserving or are they Blue Badge holders?
* What is the best time to start meetings? Factor in acceptable times for leaving home to arrive relaxed. If the same Personal Assistant is driving and supporting in meetings, how long do they need so that they are relaxed and able to support the PI co-researcher effectively from the start of the meeting. Consider when staff shifts start and finish, or at what times care cover is available. This can impact on the travel time to and from meetings. It can also affect which members of support staff are able to attend which meetings. Some days may be better for meetings, for example consider the PI co-researcher’s other regular commitments.
* If the PI co-researcher’s own support staff are not able to stay for meetings, will they be escorted to the meeting room or do they need to be met at the front door?
* If the PI co-researcher’s own support staff are unable to stay, what help will be needed throughout the duration of the meeting/day?

**Appendices**

The following appendices provide blank templates to support effective PI informed research.

These forms are followed by some examples of how they were used within the I-ASC research project.

For additional information, video and other media, check the Public Involvement area of the I-ASC website (<https://iasc.mmu.ac.uk/public-involvement/> ).

**Role Description: Public Involvement Co-researcher**

Drafted:

Approved:

Revised:

Owner:

**Co-researcher on [Research project name]**

**Summary:**

To be an integral part of the research team for an average of [days, hours, weekly, monthly] during the life of [name] research project.

**Background:**

* The [name] project will run from [date] to [date] and is investigating [brief description of project name/objectives].
* The research team are based in [name and address of research project].
* The co-researcher(s) may work alongside the research team on every aspect of the project: from conceptualising the project, contributing to the funding bid, pre-planning the activities, designing data collection tools, collecting data and undertaking analysis. In addition, the co-researcher(s) may create the project outputs and disseminate the project findings (delete or amend as needed).
* The outputs will be shared through a series of dissemination events that could be led by the co-researchers.
* Other members of the research team are:
  + The Chief / Principal Investigator: [name]
  + Research fellows and associate researchers: [names]
  + Partners / collaborators: [Example: other organisations/institutions]

**Matters for consideration by co-researchers:**

Conflicts of interest: As a representative you will be asked to disclose any involvement you may have with other organisations, government bodies or corporate / commercial interests which could result in a conflict of interest.

Confidentiality: As a co-researcher on the [named] project you are asked not to share confidential information you have received as a result of your position. This should be discussed with [Chief / Principal Investigator or PI Lead].

**Roles and responsibilities:**

* Duties:
  + To commit to an average of [time specified as hours or days] across the life of the project to attend face to face meetings, read project reports, collect data etc.
  + To represent the views of those people who [specify type of experience, eg. use Augmentative and Alternative Communication], based on your lived experiences, at the meetings you attend.
  + To contribute to discussions at project meetings.
  + To contribute potentially to all stages of the research process from conceptualising the project, contributing to the funding bid, pre-planning the activities, designing data collection tools, collecting data and undertaking analysis. In addition, you may create the project outputs and disseminate the project findings.
* Qualities:
  + Co-researchers should have direct experience and knowledge of [topic / area of research] as a service user or a family member. Specific experience for this project would be [Example: using an AAC device as a child, undergoing assessment for AAC as a child or supporting a child who uses AAC].
* Essential criteria:
  + Understanding the issues relating to [Example: having a complex communication impairment and benefiting from using AAC].
  + Being able to maintain confidentiality.
  + Being able to commit to attend meetings and activities for approximately [Example: 2 days a month for 3 years].
* Desirable criteria:
  + Having access to a computer and email.
  + Having worked with professionals in the field [Example: of AAC].
  + Having an understanding of research processes and procedures.
* Remuneration:
  + Co-researchers on this project are paid a fee for their involvement.
  + There is a public involvement payment policy and all fees and expenses will be in accordance with that guidance. This includes reimbursement of travel expenses, provision of refreshments, etc.
* Support:
  + The co-researchers are able to access support and advice from the Chief / Principal Investigator, or their designate [name, email and phone number].
* Where appropriate a personal assistant or support worker (or a contribution to the cost of your own member of staff).
* A named individual will help you to understand technical terminology and jargon both before and during meetings.
* You will receive any training deemed necessary, either alongside other team members or as an individual, to support effective working as part of the team.
* You will receive mentoring from a named team member.

Further information:

Chief/Principal Investigator (or named PI Person): [Name, email and phone]

[Organisational website]

**Terms of reference:**

Drafted:

Approved:

Revised:

Owner:

**[name] Research Team**

1. **Purpose / role of the research team**

The research team is the group of individuals working on the project on a day to day basis.

The team was established on [date] and will work on the project until [date] or completion, whichever is the earlier date. This date may be extended if there is a contract variance or extension.

Some people will work full time and others part time.

The aim of the team is to deliver the [name] research project on time, against the agreed outcomes and measures, and within budget. The project protocol gives full details of the work packages, deadlines and lead for each element of work.

1. **Membership**

The research team is made up of those people working on the project.

Individuals may be academics employed by the University or employed in various capacities by partner organisations. They also include Public Involvement co-researchers or research advisors, or team members employed to facilitate a PI contributor who needs additional support.

Membership can start and finish at any time during the life of the project but will conclude no later than the end of the project as outlined in 1.

1. **Accountability**

All members of the research team are ultimately responsible to the Chief / Principal Investigator; however, they may have a line manager who provides day to day management and support.

The research team will report on their work to [add information about specific project steering / advisory / Critical Friends group and frequency of reporting].

1. **Working methods / ways of working:**

All individuals in the team will work independently, in small groups or as a wider team to deliver the project outputs on time.

The team can use the most effective methods of working suitable for each task they engage in, including but not limited to: face to face meetings, telephone, conference calls, conference videoing, emails.

Formal meetings will be held a minimum of quarterly, at [venue/host organisation]. These will be organised and chaired by the Chief / Principal Investigator, or designate. The agenda will be circulated prior to the meeting along with relevant papers for discussion. Visitors may be invited to attend. [Add name / job title] will take responsibility for the minutes.

An important part of evaluating progress both during and at the end of the project is reflective practice. Individually and collectively there will be regular opportunities to discuss opportunities and challenges relating to ways of working, progress, individual and team development.

1. **Sharing of information and resources**

All team members will have access to the host organisation / project shared drive where information and resources will be stored.

Confidential material is subject to the procedures outlined in the approved ethics applications and will be adhered to at all times.

1. **Definition of terms**

Public Involvement representatives: patients, service users, survivors, carers and family members (National Standards for Public Involvement in Research, NIHR 2018. Available from: <https://sites.google.com/nihr.ac.uk/pi-standards/home>)

Co-researcher: A public involvement representative undertaking active research as part of a research team on an ongoing basis.

Research Advisor: A public involvement representative actively engaging with a research project on an adhoc basis (specific activities).

Critical Friends Group: An individual invited by the project team to act as a sounding board on activities and progress, providing feedback and support either as individuals or as a group. This may include research advisors, but has PI representation.

Advisory Board: A group of individuals approached and appointed by the Research Funding Agency. The will act as a sounding board on activities and progress. They will report to the Research Funding Agency.

**Terms of reference:**

Drafted:

Approved:

Revised:

Owner:

**[Research Team Name] Critical Friends Group**

**And/or**

**[Research Team Name] Advisory Board**

1. **Purpose/role of the Critical Friends Group**

The Critical Friends Group are Research Advisors who are individuals invited by the Research Team to provide verbal and written feedback at different stages of the project on progress and outputs.

The Advisory Board are Research Advisors who are individuals invited by the Research Funding Agency to provide verbal and written feedback to the Research Team at different stages of the project on progress and outputs. The Chair of the Advisory Board provides written feedback to the Research Funding Agency on an annual basis.

The groups were established early in [date] and will remain in operation until [date]. This date may be extended if there is a contract variance or extension.

All members of the groups are involved on an adhoc basis.

The aim of both groups is to support the research team by providing critical feedback to the [named] research project. This will assist the team to deliver the project on time, against the agreed outcomes and measures, and within budget. The project protocol gives full details of the work packages, deadlines and lead for each element of work.

1. **Membership:**

The members of the Critical Friends Group will be individuals with appropriate expertise and lived experience to advise on specific or a diverse range of activities and outputs.

Individuals may be public involvement representatives (see PI definition below), academics, practitioners, commissioners, or other relevant people.

Members may be asked to take part in individual activities such as reading materials or testing an output and/or to attend group meetings to give collective feedback.

Membership can start and finish at any time during the life of the project but will conclude no later than the end of the project as outlined in 1.

An Advisory Board may be comprised of individuals with appropriate research, work and lived experience.

1. **Accountability**

All members of the Critical Friends Group are ultimately responsible to the Chief / Principal Investigator; however, they may from time to time be asked to participate by a designated research team member.

The Advisory Board is impartial and its feedback and questions are welcomed as part of a healthy dialogue and working relationship. They are ultimately responsible to the Research Funding Agency.

1. **Working methods / ways of working:**

All individuals on the Critical Friends Group will work independently, in small groups or as a wider team to support the research team to deliver the project outputs on time. Formal meetings will be held twice a year, at [add location name].

The Critical Friends Group and research team can use the most effective methods of working suitable for each task they engage in, individually or as a group, including but not limited to: face to face meetings, telephone, conference calls, conference videoing, emails.

Formal meetings of the Advisory Board will be held once a year, at [add location name]. These will be organised and chaired by the Chief / Principal Investigator, or designate. The agenda will be circulated prior to the meeting along with relevant papers for discussion. Visitors may be invited to attend. [Add name / job title] will take responsibility for the minutes.

1. **Sharing of information and resources**

The data shared with the groups will be anonymised. All draft and finished outputs should remain confidential until the launch of materials.

1. **Definition of terms**

Public Involvement representatives: patients, service users, survivors, carers and family members (National Standards for Public Involvement in Research, NIHR 2018. Available from: <https://sites.google.com/nihr.ac.uk/pi-standards/home>)

Co-researcher: A public involvement representative undertaking active research as part of a research team on an ongoing basis

Research Advisor: A public involvement representative actively engaging with a research project on an adhoc basis (specific activities)

Critical Friends Group: A group of individuals invited by the project team to act as a sounding board on activities and progress, providing feedback and support either as individuals or as a group. This may include research advisors, but has PI representation.

Advisory Board: A group of individuals approached and appointed by the Research Funding Agency. The will act as a sounding board on activities and progress. They will report to the Research Funding Agency.

***This is a worked example for the I-ASC project – this is how this document would appear for this specific project.***

**Role Description: Public Involvement (PI) Co-researcher**

Drafted: 30 01 16

Revised: 20 12 16

Owner: Chief Investigator / PI co-researchers

**Co-researcher on Identifying Appropriate Symbol Communicaiotn (I-ASC) project**

**Summary:**

To be an integral part of the research team for an average of 2 days per month during the life of the I-ASC research project.

**Background:**

* The I-ASC project will run from 01 01 16 to 30 12 18 and is investigating symbol communicaiotn aid recommendations for children who are non speaking: enhancing clinical decision making.
* The research team are based in Manchester Metropolitan University.
* The I-ASC PI co-researcher(s) work alongside the I-ASC team on every aspect of the project: from conceptualising the project, contributing to the funding bid, pre-planning the activities, designing data collection tools, collecting data and undertaking analysis. In addition, the I-ASC PI co-researcher(s) have co-created project outputs and have led on the dissemination logistics of the project findings.
* The outputs will be shared through a series of dissemination events. The I-ASC PI co-researchers have led the set up and delivery of these events.
* Other members of the research team are:
  + The Chief Investigator: [Murray]
  + Research fellows and associate researchers: [Lynch, Goldbart, Whittle]
  + Partners / collaborators: [Leeds University: Webb, Meads, Hess; Barnsley Assistive Technology Service: Judge, Randall]

**Matters for consideration by co-researchers:**

Conflicts of interest: As a representative you will be asked to disclose any involvement you may have with other organisations, government bodies or corporate/commercial interests which could result in a conflict of interest.

Confidentiality: As a co-researcher on the I-ASC project you are asked not to share confidential information you have received as a result of your position. This should be discussed with the Chief Investigator.

**Roles and responsibilities:**

* Duties:
  + To commit to an average of 2 days per month across the life of the project to attend face to face meetings, read project reports, collect data etc.
  + To represent the views of those people who use Augmentative and Alternative Communication, based on your lived experiences, at the meetings you attend.
  + To contribute to discussions at project meetings.
  + To contribute to all stages of the research process from conceptualising the project, contributing to the funding bid, pre-planning the activities, designing data collection tools, collecting data and undertaking analysis. In addition, you may create the project outputs and disseminate the project findings.
* Qualities:
  + Co-researchers should have direct experience and knowledge of Augmentative and Alternative Communication (AAC) as a service user or a family member. Specific experience for this project would be for example, using an AAC device as a child, undergoing assessment for AAC as a child or supporting a child who uses AAC.
* Essential criteria:
  + Understanding the issues relating to having a complex communication impairment and benefiting from using AAC.
  + Being able to maintain confidentiality.
  + Being able to commit to attend meetings and activities for approximately 2 days a month for 3 years.
* Desirable criteria:
  + Having access to a computer and email.
  + Having worked with professionals in the field of AAC.
  + Having an understanding of research processes and procedures.
* Remuneration:
  + Co-researchers on this project are paid a fee for their involvement.
  + There is a public involvement pay policy and all fees and expenses will be in accordance with that guidance. This includes reimbursement of travel expenses, provision of refreshments, etc.
* Support:
  + The co-researchers are able to access support and advice from the Chief Investigator, or their designate Whittle [+ email, + phone number].
* Where appropriate a personal assistant or support worker will be funded, or a contribution to the cost of your own member of staff.
* Whittle will help you to understand technical terminology and jargon both before and during meetings.
* You will receive any training deemed necessary, either alongside other team members or as an individual, to support effective working as part of the team.
* You will receive mentoring from Murray & Whittle.

Further information:

Chief Investigator (or named PI Person): Murray & Whittle + email, + phone.

***This is a worked example for the I-ASC project – this is how this document would appear for this specific project.***

**Terms of reference:**

Drafted: 30 01 20 16

Revised: 30 02 2017

Owner: Chief Investigator

**I-ASC Research Team**

1. **Purpose/role of the research team**

The research team is the group of individuals working on the project on a day to day basis.

The team was established on 4-1-16 and will work on the project until 31-12-18 or completion, whichever is the earlier date. This date was extended for some team members to include a contract variance (30-04-19).

There is one full time member of the team, all other people are part time.

The aim of the team is to deliver the I-ASC research project on time, against the agreed outcomes and measures, and within budget. The project protocol gives full details of the work packages, deadlines and lead for each element of work.

1. **Membership:**

The research team is made up of those people working on the project. The project has three collaborative partners (Manchester Metropolitan University, Leeds University and Barnsley Assistive Technology Service).

Individuals include academics and research staff employed by Manchester Metropolitan University and Leeds University and practitioners employed by Barnsley Assistive Technology Service.

The Chief Investigator facilitated the inclusion of Public Involvement co-researchers based at Manchester Metropolitan University, and negotiated the employment of a research assistant to facilitate the PI contribution where additional support was needed.

Membership started for some team members, including the PI co-researchers, during the development of the funding bid. Membership formally commenced on 04-01-16. Changes to staffing occurred across the life of the project.

1. **Accountability**

All members of the research team are ultimately responsible to the Chief Investigator, however, some team members have a line manager who provides day to day management and support.

The research team will report on their work to two different groups:

* The NIHR Advisory Board: once a year during the life of the project (3 times)
* The Critical Friends Group: every 6 months during the life of the project (6 times)

The Chief Investigator reports on the work to the Research Funding Agency

* NIHR 6 monthly reporting

1. **Working methods/ways of working:**

All individuals on the team will work independently, in small groups or as a wider team to deliver the project outputs on time.

The team can use the most effective methods of working suitable for each task they engage on, including but not limited to: face to face meetings, telephone, conference calls, conference videoing, emails.

Formal meetings will be held a minimum of quarterly, at Manchester Metropolitan University. These will be organised and chaired by the Chief Investigator, or designate. The agenda will be circulated prior to the meeting along with relevant papers for discussion. Visitors may be invited to attend. The Research Fellow will take responsibility for the minutes.

1. **Sharing of information and resources**

All team members will have access to the University / project shared drive where information and resources will be stored. Access to this will be provided to individuals.

Confidential material is subject to the procedures outlined in the approved ethics applications and will be adhered to at all times.

1. **Definition of terms**

Public Involvement representatives: patients, service users, survivors, carers and family members (National Standards for Public Involvement in Research, NIHR 2018. Available from: <https://sites.google.com/nihr.ac.uk/pi-standards/home>)

Co-researcher: A public involvement representative undertaking active research as part of a research team on an ongoing basis.

Research Advisor: A public involvement representative actively engaging with a research project on an adhoc basis (specific activities).

Critical Friends Group: An individual invited by the project team to act as a sounding board on activities and progress, providing feedback and support either as individuals or as a group. This may include research advisors, but has PI representation.

Advisory Board: A group of individuals approached and appointed by the Research Funding Agency. The will act as a sounding board on activities and progress. They will report to the Research Funding Agency.

**I-ASC informed training and mentoring to support effective PI co-researcher activity**

The evaluation of PI activity within the I-ASC project highlighted a number of ways that effective PI and co-creation could be supported. These are summarised below.

***I-ASC research methods training*** was provided over a number of sessions and in different ways. This enabled productive involvement across aspects of the project that went beyond advisory. This included training on:

* an overview of types of research methods;
* specific methods on the I-ASC project;
* Thematic / Framework Analysis (TA/FA);
* TA / FA coding procedures;
* Systematic Review processes – specifically, quality appraisal procedures;
* survey methodologies and their interpretation.

***Data collection preparations.*** I-ASC PI co-researchers were involved in many aspects of data collection. This necessitated some training, some support, some listening and collaborating / co-creating. Activities included:

* Participant Information Sheet (PIS) – alternative media delivery: see You Tube [video](https://www.youtube.com/watch?v=GWL1pFVVIlE).
* collaborative discussion and preparation of interview processes, procedures and materials;
* interview preparation and practice;
* field note construction and purpose;
* team briefing and debriefing during data collection.

***Heuristic synthesis.*** The key translational output from the I-ASC project was to provide an on-line resource, conceptualised as a heuristic that would be accessible to all stakeholders. This required some team debate, analysis and synthesis training as well as collaboration on the development of resources that would be meaningful to all stakeholders. Training and mentoring activities for all team members including PI co-researchers comprised:

* defining the I-ASC heuristic and its construction;
* synthesis of the collective findings to support heuristic development;
* exploring resource development based on findings.

***Social media platforms.*** I-ASC PI co-researchers were nominated to lead on dissemination aspirations for the project. This included a social media presence. One PI co-researcher was keen to lead on the in-project (now archived) website presence. This worked well but benefitted from a joint approach between the nominated PI co-researcher and one of the Co-Investigators to work on website developments. Outputs included:

* early project website (not current I-ASC site), mentoring collaboration on structure of the (3-year) project site (now archived).

***Staffing support.*** PI co-researchers who fit the ***hard to reach/difficult to include*** groups may come with additional support needs. These needs are never insurmountable if the team ethos is positive and open, with a ‘can do’ attitude. I–ASC findings suggest that it may take more time and require more resources but successful inclusion in the research team remains possible. These additional considerations may include time to develop and deliver on:

* job descriptions / advertising / interviewing / selection of Personal Assistant (PA) support for a PI contributor with additional support needs;
* training of project appointed PA (with training support from existing PA staff) – role, activities, reporting, support;
* preparation for meetings, research activities, and delivery of agreed project actions.

**Budgetary considerations – informed by the I-ASC experience**

Awareness of the financial implications, and attempting to offer informed suggestions for future bid construction, leads us to suggest the following considerations for any future bid submission attempting the level of PI involvement the I-ASC project delivered:

* For the lead organisation: consideration of time from the Chief / Principal Investigator in the bid development, pre-project set up phase, i.e., during the period of contract confirmation, employment of Research Fellow staff, etc., to support PI co-researchers in their contributions.
* For the lead organisation: consideration of how they will remunerate the PI-co-researchers / bid developers during the bid preparation phase and also during the pre-project set-up phases, i.e., outside of the funding award.
* For the research funders: additional time from the Chief Investigator to support methodological rigour, training and support (half day per week for the entire project delivery phases).
* For the research funders: a project manager role to support all administrative necessities, e.g., research passports, occupational health processes, HR processes (half day per week).
* For the research funders: additional time from Research Fellow staff to support logistical, theoretical, analytical and delivery and dissemination processes (a total of one day per week).
* For the research funders: appropriate budget to support reimbursement of PI contributors / researchers, e.g., vouchers for those who cannot be paid directly without jeopardising state benefit provision.
* For the research funders: appropriate budget to identify a research assistant role to support anyone who needs it. For example, someone with a severe communication disability can be effectively supported to deliver research objectives when given adequate support by a well-informed RA.

**Guidance for PI co-researchers about payment**

This document provides guidance for co-researchers about payment for their time. Organisations could use it to develop policies about payment for PI contributions.

**Important things for you to know**

1. [Add name of host organisation] values the input of all public involvement contributors to research. You should not be out of pocket by being actively involved in research. This means we will cover your expenses and offer payment for taking part.
2. [Add name of host organisation] should not ask you to be involved in a research project without discussing this policy with you. You do not need to say yes if you do not want to take part.
3. Receiving payment of a fee for involvement may have implications if you are on state benefits, unemployed or employed. This is because all payments will be treated as earnings.
4. [Add name of host organisation] will provide you with clear guidelines about the nature of your involvement, what amount we will pay you and what expenses we will cover - see below.
5. If you are receiving benefits, you must seek advice from a benefits advisor or from Jobcentre Plus about your personal circumstances.
6. Reimbursed expenses can, in some circumstances, be viewed as benefits. Again, it is important to take advice before agreeing to undertake any project work.
7. Receiving payments may also have implications for you if you are liable for income tax or national insurance, receiving a pension, pension credits or tax credits.
8. You can choose whether or not to accept payment for involvement in research, or whether to accept a lower amount so this does not affect your benefits. Taking expert advice is important. Other rewards might be available in lieu of payment, such as training, trips or visits, or meeting with other people.
9. If you are claiming benefits there is a maximum number of hours you may volunteer weekly. Please check with your benefits officer or Jobcentre Plus for more information

**Important questions to ask the research team**

1. What is the host organisation’s payments policy, and can you have a copy?

Check whether the payment policy is in line with the guidance from INVOLVE: <https://www.invo.org.uk/wp-content/uploads/2016/05/CCF_Public_Payment_Guide-1.pdf>

This would mean that they would cover where appropriate:

* All travel costs by public transport or car (mileage allowance)
* Overnight accommodation and subsistence (i.e., food and drink)
* Childcare or replacement carer costs
* Costs of a Personal Assistant or Support Worker
* Conference fees
* Administration costs, e.g., use of ‘phone, postage, stationery and other equipment
* Training
* A fee for your involvement.

1. How much does the organisation offer for involvement activities?

The INVOLVE recommendation is:

<https://www.invo.org.uk/wp-content/uploads/2016/05/CCF_Public_Payment_Guide-1.pdf>

Not all projects are funded to the same level. This means the fee may vary depending on the project. Not all roles need the same contribution. This means the fee may vary, depending on the complexity of involvement.

1. How much time will you be expected to give? (week, month, year)

Involvement varies by project. This will be discussed with you at the time.

1. Will the organisation pay for expenses and what will they cover?

See section 1 above. Depending on your role, the organisation may pay for you to attend meetings, prepare for meetings, attend training events, interview others, analyse data, review documents or present your findings. This may be on a one off basis, on an hourly rate or a day rate.

1. What expenses will the organisation cover directly or in advance?

The organisation may purchase in advance train tickets and pay for accommodation. They may also pay costs directly to a personal assistant or a replacement personal assistant/carer when agreed with you.

1. How do you claim back expenses you pay out yourself?

It is important that you keep your receipts for any expenses (e.g., travel tickets) as the organisation will require these to reimburse you. All claims for expenses need to go through the organisation’s finance procedure. The organisation may reimburse your expenses by making payments into your bank account. This can take a few days to a few weeks. If needed, the research team may be able to give you a float to cover initial costs until your payments start to come through (e.g., to cover tram or bus fares).

1. If a fee is offered, how do you claim this?

Depending what role you are undertaking, you will be asked to either complete a timesheet, submit an invoice or send your contact an email about the time you have spent working on the project. If your fee is for attending meetings, the person responsible will sort this with you each day that you are involved.

1. Who in the organisation is responsible for dealing with payments and expenses on your behalf? And how do you contact them?

Your contact is:

Their email is:

Their phone number is:

They are based at: