



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



Health Research
Charities Ireland

MAKING A START: A toolkit for research charities to begin a PPI relationship



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**Health Research
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Contents

Foreword	07
Introduction	08
Engaging patients and members of the public.....	10
Developing the PPI relationship.....	12
Preparing for the workshop.....	16
The workshop.....	21
The process in depth	24
Where to from here?	46
Appendices.....	48



Foreword

Both Trinity College Dublin and Health Research Charities Ireland (HRCI) have, over many years, demonstrated a commitment to Patient and Public Involvement (PPI) that has helped to shape, encourage and champion health research. That commitment has also led to the development of strong working relationships between researchers and the people whose lived experience has proved invaluable in driving the research process.

Over many years, the Trinity Centre for Ageing and Intellectual Disability (TCAID), where TCD PPI Ignite is hosted, has proven the influence that PPI contributors with intellectual disabilities can have on the inception and development of long-term studies. This ground-breaking work was recognised when TCAID Director Prof Mary McCarron was awarded the inaugural HRB Impact Award. HRCI, through its own work and that of its member organisations, has ensured the ongoing involvement and importance of patient voices in many aspects of their work.

This toolkit, and the process that built it, are testament to the relationship that exists between the two organisations. It has been one of openness and willingness to experiment in the name of innovation. It is also thanks to the commitment of Prof Mary McCarron, Michael Foley and Sarah Bowman of TCD PPI Ignite and Bec Hanley, facilitator to the Charities Research Involvement Group in the UK who, together, created a dynamic co-design process that brought many aspects of PPI processes to light for those involved.

Most importantly, this collective co-design process could only happen with the energy and commitment of the PPI contributors and Irish research charities who were willing to become involved and contribute to the process: Tom Curran, Maureen Gilbert, Ann Leahy, Sile O'Connor - All Ireland Institute of Hospice and Palliative Care; Laura O'Philbin - Alzheimer Society of Ireland; Sinéad Hickey - DEBRA Ireland; Laura Brady, Caitríona Dunne, Susanne Grampe, Melissa Jones, Bernard King, Karen Lester, Paul Shield - Fighting Blindness; Rachel Bermingham, Claire Kilty, Deirdre Murphy, Eileen O'Sullivan - Irish Cancer Society; Aoife Kirwan, Willeke Van Eeckhoutte - MS Society; Alan Finglas - MSD Action Foundation; Isabella Bray - National Children's Research Centre; Sarah Boland, Aine Walsh, Lesley O'Hara - Saint John of God Hospitaller Services; Tara Raftery - Temple Street CUH; Anne Lawlor - 22q11 Ireland, along with our colleagues Clodagh O'Donovan and Michelle Gardner in HRCI and Gavin Dann in TCAID.

Generous sharing of training materials also came from a number of UK charities: Alzheimer's Society, Asthma UK, Autistica, Bowel Cancer UK, Breast Cancer Now, Building Research Partnerships, Cancer Research UK, Cystic Fibrosis Trust, Diabetes UK, Health and Care Research Wales, Marie Curie, MS Society, National Institute for Health Research, Parkinson's UK, Stroke Association, Tenovus Cancer Care and Versus Arthritis.

Finally, we wish to acknowledge the funding support provided by the Health Research Board (HRB) through its Knowledge Exchange and Dissemination Scheme for funding the project. We also wish to thank the HRB and the Irish Research Council for continuing to champion PPI through the Ignite scheme along with Pobal and the HRB for their ongoing support of HRCI.

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TCD PPI Ignite, Trinity College Dublin

Dr Avril Kennan

CEO

Health Research Charities Ireland

SECTION 1

Introduction

The purpose of this Toolkit

Patient and Public Involvement (PPI) is becoming increasingly important in how health research is conducted. PPI can influence research in many ways – how it begins, how it gets supported, how it develops and the impact the research can have.

As research charities and researchers become skilled in this area and as their research approaches adapt to fully incorporate PPI at different stages, there is a decreasing tolerance for any PPI which is tokenistic or badly managed. This is true for funders, for academics and, most importantly, for the people contributing to the research process.

This Toolkit has been written to help health research charities to develop an initial workshop with PPI contributors. Perhaps your organisation wants to develop a unified approach to PPI in research. Perhaps you are looking for some tips or new ways of approaching activities your organisation already does. Or perhaps you are looking to take your first steps in PPI. Whichever description suits best, it is hoped that there is something useful in this Toolkit for all research charities investigating PPI.

This Toolkit was developed through co-design workshops with a number of research charities who are members of Health Research Charities Ireland (HRCI). PPI contributors and staff from these charities worked with HRCI, Trinity College Dublin's PPI Ignite Team and UK PPI consultant Bec Hanley to develop this Toolkit, based on their own experiences and what they saw as the needs of people who may be unfamiliar with research. The design process involved three workshops with this Toolkit Development Group as well as the testing of some elements of the Toolkit at PPI workshops run by two of the health research charities among the Group: the Alzheimer Society of Ireland and Fighting Blindness.

In developing the Toolkit, the Group discussed the idea of 'the perfect workshop' to begin a PPI relationship and concluded that it doesn't exist. Every research project and every research charity have their own stakeholders who have particular needs, capabilities and preferences. This Toolkit should, however, provide enough context to build a bespoke workshop that is a 'perfect' starting point for your PPI contributors (and by 'perfect', this means a workshop that your charity can deliver, within the resources that are available, that will encourage contributors to come back for more).

What is Patient and Public Involvement (PPI)?

In an effort to clarify what is meant by involvement, Irish Universities Association's Campus Engage differentiates between three different ways in which people can become a part of the research process:

- Participation: Being recruited as study participants is defined as participation in research;
- Engagement: Efforts aimed at raising awareness among the public around research, such as newspaper articles, or outreach activities such as open days in research facilities can be described as engagement. Engagement activities are required for both participation and involvement;
- Involvement: Refers to co-created and co-produced research with a focus on collaboration.



The Irish Health Research Forum, a partnership of organisations and stakeholders that aims to influence health research in Ireland, has described PPI as:

...occurring when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge.

It is also useful to include the often-quoted definition of PPI developed by INVOLVE, an English organisation that supports PPI in research:

PPI is research carried out 'with' or 'by' patients/members of the public rather than 'to', 'about' or 'for' them.

Throughout this Toolkit, the term 'PPI contributor' is used for someone who contributes to a research process through some type of planned PPI process but who is not a researcher on the research team.

Why do researchers engage in PPI activity?

Researchers are increasingly recognising the fact that PPI has the potential to improve the quality and relevance of research. If PPI is done properly in an appropriate context, it can have a positive impact on all aspects of the research process.

In addition, both national and European public funding agencies are increasingly promoting the involvement of citizens in various aspects of the research process. This provides a level of public visibility for how public money is being spent. It is also seen as a way of counteracting a lack of public trust in research and in scientific findings more generally.

A misconception that some people have about PPI is that it is yet another hurdle to be jumped in the research process. While it might require investment, it is not a hurdle but a gateway: it is an opportunity to introduce into the project the helpful skills, contacts and perspectives that may not exist within the research team.

At a project level, research charities are inclined towards PPI due to the following:

Bringing in the lived experience

PPI contributors are experts in their own lives and their own experiences. They provide a holistic view of living with and through an experience. They are a living memory of a condition which can sharpen a research charity's sense of what is relevant to research and how research can make a difference.

These experts by experience can bring influential perspectives to research planning such as, for example, experiences of side effects from medication, a psychological perspective on growing up with a condition or the identification of practical barriers to participating in research as a subject.

Keeping it real

PPI contributors can challenge the stereotype of what a patient, a carer or a stakeholder can be. They can help the researcher question their own unspoken biases around health and healthcare use. Their presence can change the tone of a conversation from being practical and distant to one that is more empathetic to patient needs. They also have a stake in the success of the research that often goes beyond the researcher's motivation.

Keeping it going

Being in touch with the needs and perspectives of other patients or carers, PPI contributors can help to effectively and engagingly disseminate the results of research. They can also act as an advocate for the results in a way that many researchers may be reluctant to do.

Other practical skills and contacts

A PPI contributor may be able to assist with recruitment to research studies because of their understanding of the motivating factors and barriers that influence participation in research. They may also have skills that the research team do not have, such as experience with mainstream media, contacts within the public or the private sector, or access to a funder.

Is PPI a research methodology?

It is always useful to clarify how PPI is different from research methodologies, such as Community-Based Action Research, or research methods, such as focus groups.

As stated earlier, a participant is the subject of a study; they, or part of them, is what is being studied. Data which will later be analysed is, in some way, being gathered from them. A PPI contributor may be a participant, but their PPI contribution should not be their data.

Methodologies have a knowledge-making purpose (what researchers call an ‘epistemological’ purpose). Researchers choose a methodology because they believe that it will be the most useful way to create valid, reliable data that will answer the question that they are addressing. A research method is chosen as the most appropriate way to gather the data needed. PPI is different however, as it is about opening a dialogue that may go in many different directions and where all involved in that dialogue are equal.

A useful ‘rule of thumb’ is as follows: PPI activity is not a mechanism for gathering research data from the PPI contributors nor a way of validating qualitative data. If the PPI activity is being done for either of those purposes, then it is probably not PPI; it is an element of the researcher’s methodology.

Engaging patients and members of the public

Who are ‘Patients’ and who are ‘the Public’?

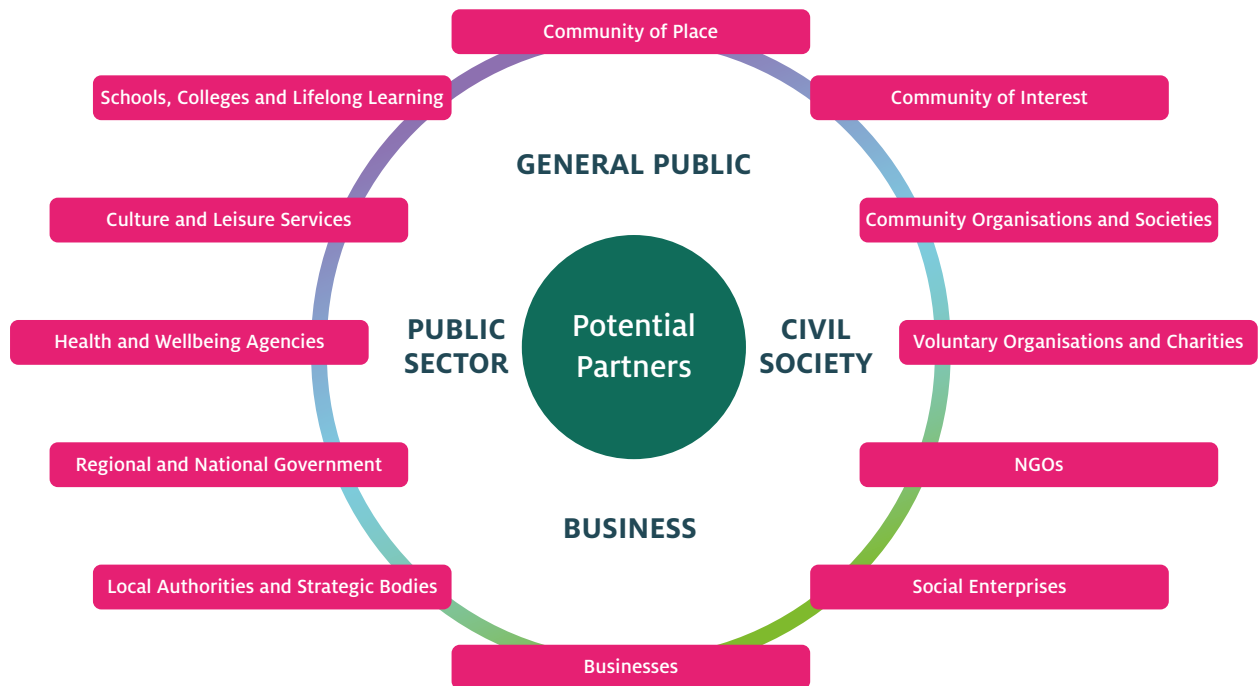
Misconceptions exist about what constitutes patients or public. Many people living with long-term conditions do not consider themselves ‘patients’ outside of the hospital setting. The ‘public’ is not a random group off the streets. On their website, the Health Research Board defines patients and public as follows:

By ‘public’ we mean everyone in Ireland who has an interest in health and social care as a public service including potential users of services. By ‘patient’ we mean people who use services such as patients, service users, clients or their carers.

Research charities and the researchers they engage with, must begin by asking the question: ‘Who needs to be part of a PPI group in order to add value to this research process?’. The answer to this question might be: a group of people with an experience of a particular condition; a person experiencing a disease; a carer for a family member experiencing some illness. In certain cases, it may even be a clinician or a manager in a hospital or care setting. It might be a mix of these different people. The criterion should not be ‘the person who is most like me’; the power of PPI is that it brings together different perspectives.

The first stage is to figure out who will be able to provide the patient or public perspective, what they will contribute to the research process and what benefit they might get from contributing to this research process.

The diagram below, from the UK's National Co-ordinating Centre for Public Engagement, provides a useful way of identifying relevant 'publics'.



Developing the PPI relationship

What does a good relationship look like?

If every relationship is unique, it can be 'good' in its own ways and on its own terms. Anyone seeking to build a PPI relationship should, however, have an idea of the type of relationship that they want to build. Otherwise, how do they know if they are attracting people who can help the research process and discouraging those who cannot?

Take a moment to consider the nature of the different relationships from your own life; not all of them are built to last. You may have an ex-colleague with whom you were very close when you worked together but now you only have Christmas Card contact. You may have someone you only see twice per year but have a great time with when you do. You may have come together with a group of people to run a festival, canvas for change or organise a fundraiser. These are all different types of relationships and, as long as people understand what they are getting themselves into at the start, these can be very healthy short-term or sporadic relationships.

This is also true with PPI relationships. For example, your research charity may need to work with a PPI contributor group quite intensely on a project in the full knowledge that, once this project is over, the relationship will also end. Alternatively, your research charity may need to convene a group twice per year but not have much connection to them at any other time during that year. As long as all sides are clear about the expectation on them from the beginning, it should not be an issue.

When the Toolkit Development Group were asked what makes a good PPI contributor, the top three characteristics were:

- Someone who has experience of their condition (or other useful experiences) and who is passionate;
- Someone who has time to devote to PPI activities; and
- Someone who can, and is willing to, communicate with the researcher or research charity.

When they were asked what, then, makes a good researcher in a PPI relationship, the top three characteristics were:

- A researcher who is a good communicator, e.g. someone who keeps in touch, is a good storyteller, a good writer, good in a group, a collaborator – whatever is appropriate to the activity;
- A researcher who can show respect, empathy and understanding; and
- A researcher who has time for the PPI contributors.

What mis-steps can a research charity or researcher make?

The list of issues below is based on the conversations of the Toolkit Development Group.

Not wanting to be there

Not every researcher or research charity is initially enthusiastic about PPI. Unfortunately, when PPI contributors get into the room, they often recognise that lack of enthusiasm pretty quickly. Regardless of any nerves or misgivings your research charity may have, once it has been agreed to involve PPI contributors, it needs to be done with commitment and enthusiasm. Otherwise, why would the PPI contributors want to be there?

Mismatched expectations

As mentioned earlier, not all relationships have the same purpose or function. If, however, everyone is clear about the nature of the relationship being built, they have a better idea of what to expect. They can also choose not to become involved, thereby saving both themselves and you time later on in the process.

Bad communication

Good communication is invisible but bad communication takes many forms. How we communicate and when we communicate are important. So, too, are the words we choose, how readable, legible, scannable our written communications are, how clear, understandable and engaging our spoken communication is. It is also important to consider what the people we are trying to communicate with would expect from good communication.

Fear of conflict

When people care about something, some conflict is often not far behind. Our ideal PPI contributor is passionate and motivated about playing a part in the research process, and this can lead to conflict. In order to reach a way of working together, research charities, researchers and PPI contributors may need to go through a 'storming' phase, where disagreements can be had and where compromises are reached.

This conflict is not a bad thing and can be vital in bringing to the surface issues that, if not addressed, could sink a research project or other research-related processes at a later date. While a lot is written about how to resolve conflict, please keep the following in mind:

- acknowledge that there may be disagreement during the process and that it is a healthy thing that needs to be dealt with in a healthy way;
- conflict must not be turned into a personal attack, the focus must always remain on the issue rather than the person;
- try to find where there is agreement on the issue; and
- work together on how best to resolve the conflict.

Trying to keep total control

It is common for research charities and researchers to act in a deliberate way, and for researchers to keep tight control of a research protocol. Too much control by one side of a PPI process, however, can stifle it. A commitment to PPI is a commitment to working with others and, therefore, a research charity or researcher may be bringing PPI contributors in on a dialogue about various aspects of the research process. Those PPI contributors may not envisage these elements of that process the same way as the research charity, but that is why they are involved.

At all stages, care must be taken to ensure that the research charity or researcher is not subtly trying to control the PPI contributors through activities like using jargon, only acknowledging the people they agree with, freezing out voices that are ‘not like us’, or dismissing contributions that might, on the surface, seem irrelevant.

Alternatively, including PPI contributors does not absolve a research charity from protecting the research process: the PPI contributors are not in full control and neither is the charity or the researcher. This is a relationship and, if it is a healthy one, it should not be about control. Establishing the parameters of that relationship will be built from the beginning and the first workshop is about the setting of those parameters. See Making an Agreement section for more detail.

Messing up on ‘hygiene issues’

Certain elements of a process, if they are done properly, are invisible; they are only noticeable if they are not. These elements, sometimes referred to as ‘hygiene’ issues, do not motivate people to do a good job but, if they are not dealt with, they really demotivate people. In every context and with every group, the hygiene issues are different. Hygiene issues could be things like the meetings being at an inconvenient time for the contributors, the room being too cold, the toilets being inaccessible, the reimbursement forms being very complex to fill in or an absence of vegetarian options.

Put yourself in the shoes of the contributors and then look again at whether you would or could attend this workshop. Dealing with hygiene issues is often learned through asking contributors about any dietary or accessibility requirements, through listening to contributors’ complaints during the tea break and, most importantly, through doing lots of work with different groups – experience is a great teacher when it comes to hygiene issues.

Forgetting to show and to expect respect

In the development of this Toolkit, there was a lot of discussion about respect. Research charities and researchers were worried that PPI contributors would not appreciate their specialist skills and knowledge and PPI contributors were worried that researchers would dismiss them and dismiss their lived experience as ‘not relevant’.

As with all relationships, people are often tentative about opening up and being honest with one another. This means that trust must be built. To build that trust, both sides need to show respect. In order for that respect to be shown, each side needs to understand the other. How can they do that without opening up? It is clear that this can end up in a deadlock.

As research charities and researchers are usually in a more powerful position, they need to take the lead on showing respect. This can be done by, for example, welcoming people, acknowledging people, verbally thanking them by name for their contribution. It can be done by giving different people the chance to speak, by using appropriate language and by not criticising. It can also be done by following up with each individual afterwards to thank them for a specific contribution that they made.

The research charity and the researcher also need to help the PPI contributors to understand the work of research, and how doing things a particular way can get results or answer questions. Most importantly, when contributors say things that might not be complimentary about research or researchers, often based on previous bad experiences, it is important to respond openly without taking offence, acknowledging why people might think that and, where possible, commit to not treating the contributors that way.

Not showing the PPI work

What is the point of doing all of this PPI contributing if it cannot be seen? While PPI work is a means to various ends, it is also important to show that it has taken place. Providing notes of meetings, taking pictures or shooting pieces of video at the meeting, crediting people in reports or publications: these are all potential ways in which people are acknowledged and can see that their work has made a difference – not all are suitable or appropriate to every group but you need to consider how you manifest the contribution that people make to the research process.

Rushing things

Relationships need time to develop. If a research charity thinks that it can achieve all of its PPI objectives in an afternoon, it is setting itself (and its PPI contributors) up to fail. The work needs to be able to move at a pace at which the contributors are comfortable; otherwise, they will be lost to the process.

The pace at which things move within a research process is dependent on a number of factors. If you are aware, however, that your potential PPI contributors are difficult to reach or if they require a lot of preparatory work before they can effectively contribute, then you must factor this into your overall approach to your research strategy. The timeline for the project should be understood by all concerned.

Expecting to know it all from the start

As a research charity involved with research, people expect you to have a lot of experience and to always know what you are doing; PPI contributors will probably also expect you to know what you are doing too. In the case of PPI activity, however, you are not going to know it all the first time around.

PPI activity is something that people can only master by doing it. Learning by doing means learning from inevitable mistakes. Give yourself a little slack and be honest that you do not know everything and that you may need to ask for forgiveness sometimes but that you are doing your best.

Ask your PPI contributors for help in getting it right for them. Build your process together so that it works for all.

Preparing for the workshop

Finding your PPI contributors

While this phase is often called a 'recruitment' phase, it is worth remembering that, if this is a relationship, it should be seen more as an invitation and a negotiation rather than some type of competition or screening process. This phase can take two forms for research charities:

- Research charities or researchers can seek out people to play a specific role within a research process;
- People with an interest can be invited to become part of a PPI network and, as roles and projects arise, can be offered the opportunity to become involved with research.

Either one or both can be used as a strategy to involve people. The benefit of the first approach is that the research charity is seeking specific people for a specific purpose. This should cut down on ambiguity and allow the research charity to train people up in that task. The benefit of the network is that the research charity can build a relationship over time and have people at hand when they are needed, with a mix of skills. They may also be available when work is taking place in advance of a funding application.

It should be kept in mind that reaching out and forming relationships should start sooner rather than later in any research process. The sooner people can be involved in a process, the more likely they are to feel like an equal partner who has helped to make and shape that process.

Writing a person specification

A person specification is a written statement about the types of skills and attributes that the research charity is looking for in a PPI contributor. In order to write it properly, the following needs to be considered:

- What types of people can contribute to this research process? A certain type of person may be needed with a particular type of experience.
- What skills does the role require? Will they, for example, be evaluating research proposals?
- What other circumstances or essential duties are relevant? They may need to be willing, for example, to travel to a particular city for meetings, to be able to join meetings that take place online or they may need to be available during a particular time of year.

Be sure that whatever is in the specification is actually relevant to the post and that people are not carelessly excluded by mistake, e.g. by stating that meetings must be during the working day because that time is more convenient for the research charity.

To interview or not to interview

In most cases, contributors are not interviewed because many researchers and research charities are grateful to get people to play an often-unpaid role within the research process. If the contributor is being paid, if they require Garda vetting or if the role is coveted, a formal process of selecting people may be needed, with explicit criteria and some type of evaluation process like an interview. Informal interviews can also be useful sometimes to help reach a shared understanding of what the role involves.

Digital and face-to-face engagement

Although addressed in Section 2 and Appendix C, it is not always possible to run workshops where participants can be together in a physical space. Rare disease groups, for example, often engage digitally due to their PPI contributors being geographically spread across the world. Other reasons to use online or digital platforms would be where a participant's health condition or caring duties may keep them at home or without access to appropriate transport.

This Toolkit encourages face-to-face group workshops as an effective way to build relationships. It is, of course, possible to run a workshop with multiple participants over a digital platform. Examples include web-based video-calling software such as Zoom, Facetime, Skype, Houseparty or Teams. These are not the same as face-to-face group workshops and are often not as compelling or as enjoyable. There can also be practical issues such as access to broadband or comfort with technology use that can impede it as a way of running the workshop.

Choosing the workshop size

Ideally, the workshop outlined in this Toolkit ought to have between eight and twenty people participating. Fewer than eight means that there is less experience within the room to draw upon. More than twenty means that keeping the group together becomes difficult and there is not enough time for everyone to play a full part.

If you have fewer than eight, however, focus on activities that allow for group discussion rather than games. If you have more than twenty, consider running a world café (<http://actioncatalogue.eu/method/7402>) where you have a number of tables set up like a café. Each table has a facilitator and a note taker. Each table facilitator will run an activity simultaneously with the other tables. These events can be enjoyable and festive but require a lot of preparation and facilitator support.

If on a digital platform, smaller rather than larger groups are best as they are more likely to give people an opportunity to interact.

Accessibility & inclusion

Creating accessible activities (i.e. those that do not unintentionally exclude certain types of people) is both good practice and is promoted in equality legislation. Having different voices and perspectives in the discussion is important at so many points within the research cycle. Diversity can lead to new and creative solutions to problems.

As a starting point, it is useful to clarify that equality is not equity: treating everyone the same way is not the same as everyone getting the same outcome; for example, while everyone may have permission to get on the bus, some people cannot physically get on because they use a wheelchair, or cannot afford the fare, or struggle to use public transport because of an intellectual disability. People may need different accommodations so that they can access the same services, events or workshops as everyone else.

There are useful guides that will help with running accessible events (https://www.tcd.ie/disability/assets/doc/pdf/Accessible_Events.pdf) but here are some points to keep in mind:

- Based on what you know about the characteristics of your PPI contributors, what is likely to help them to fully participate?
- Have you asked potential participants about any accessibility or dietary requirements?
- Have you put yourself ‘in the shoes’ of the potential participants and imagined the process from travelling to the workshop through to leaving the workshop. Have you figured out how and where you can help people to feel that they belong?
- Are the pictures you use and the examples you give relatable to the lives of potential participants? This is not about ‘blanding things out’; it is often about adding to the richness of images and examples.

Data protection implications

There is increasing awareness of the importance of data protection in health research. Health researchers must now, by law, ensure that participants have explicitly consented to their data being gathered and stored. Health researchers are now very clear that, for example:

- they must inform participants of their rights;
- they must ensure that participants’ data are stored safely; and
- they must only use that data in line with participants’ expectations.

What a researcher or research charity might forget, however, is that they also have data protection obligations to PPI contributors.

Generally, a research charity will need contact details for a PPI contributor, and they may take their picture or take a video of them at events. It is also possible that they may be gathering data from that contributor about their health status. If a research charity which represents people with a particular medical condition provides the names of some of their members to a research team, they are disclosing those people’s health status.

While it is beyond this Toolkit to explore data protection in depth, every research charity should have a clear data protection policy and should know its obligations under the law. If it is engaging with PPI contributors, it needs to ensure that its policy also covers the PPI activities that they will engage in and that any research team understands its obligations.

Setting up the room

In face-to-face workshops, this is a facilitated session rather than a training session. Your room should not look like a classroom or a training room. Try to have tea, coffee and water on hand and encourage participants to help themselves. If possible, ensure that there is space for people to move around if they wish without disrupting others. Creating a space where people can move around differentiates this from a school or training experience.

If possible, create a circle of chairs in the middle of the room so that it lessens the sense of hierarchy and allows every participant to see as many of the other participants as possible. If the room is ‘boardroom style’ and cannot be changed, try not to sit at either end but in the middle. If it must be ‘classroom style’, then work with what you have.

Regarding equipment, it may be necessary to have work-tables for certain activities. These may be in another part of the room or small side-tables may need to be placed within the circle. It may be useful to have a flipchart, depending on the activities chosen. It may also be helpful to have pens and post-its available on the chairs for people to be able to make notes or to write reminders about what was said.

Facilitating rather than training or teaching

Facilitation is about drawing out the learning and experiences that exist among the participants within the room so that they can learn from one another. It is also acknowledging their prior learning and experience and about validating participants' views while exposing them to others' views. As the name suggests, facilitation is supposed to make things easier for the people taking part, easier for them to contribute, easier for them to learn.

While it is beyond the scope of this Toolkit to outline the roles and behaviours of a facilitator, it is important for people who have not facilitated a workshop before to seek out more information on building facilitation skills and to facilitate groups and meetings in order to build those skills.

Please limit any presentations. This workshop is about building relationships; it is not about 'telling'. If you wish to present facts and statistics, provide them in a handout in advance of the workshop and provide some time at the beginning for people to read them if they wish.

Choosing your methods

This Toolkit provides a number of options for how you can approach each aspect of the workshop. Some require practice and planning while others are simple but, in the right hands, can be very effective. Choosing the correct method for you and your potential PPI contributors is dependent on a number of different elements:

- **How comfortable are you with facilitating a group?** Do you find it difficult to draw people out and encourage them to talk? How easy do you find it to change direction if something is not working? Could you co-facilitate with someone else? Is there someone who is already a PPI contributor who would also have facilitation skills?
- **Will the participants in the workshop feel satisfied at the end of it?** You may need to 'unpack' this question a little. For example, would playing bingo be seen by the group as fun and quirky, as an activity that they play regularly or as something frivolous and time-wasting? Alternatively, would being asked about how a research cycle might work be seen as something that is so beyond their own experience that they feel intimidated or disengaged?
- **How familiar are the participants with one another?** Do they already have a relationship built up or is this workshop an opportunity to bond as a group? Also, are they used to being facilitated in a group together and, if so, what techniques do they usually use?
- **Is the method in line with the mission and the identity of the research charity?** If a contributor reported back to the board of the charity about the workshop, would the members of the board be pleased?

Keep in mind that this Toolkit is not exhaustive. The methods described may inspire you to devise something that is very specific to your contributors. It is hoped that the purpose of, and mechanism within, each method is clear and that the tools here inspire you to tailor activities for your own group.

Reassuring the contributor

Finally, it bears stating explicitly that, as a research charity, the research process is likely to be clear to you: you understand it, know what will happen at each stage and you know the lingo and all of the 'rules' and why you follow them. You also understand your role and you know how you belong in the research process. This may not be the case for the PPI contributor.

A PPI contributor may not understand what is involved in research. They may be uncertain about what will be required of them. They may feel intimidated by the prospect of being involved and worried that they will be seen either as stupid or as an imposter. Alternatively, they may be very self-assured and clear from the beginning about what their role is and what they want from the process.

Uncertainty or anxiety can express itself as timidity, as reluctance, as condescension, as belligerence. None of these are particularly useful if you are trying to form a relationship with the participants. It is important to assure people during the early days that they belong and that their contribution will be important. This should become obvious in all of your interactions with them.



SECTION 2

The workshop

This section provides guidance on how to facilitate a workshop for PPI contributors as you begin a relationship with them. The workshop might be run by an individual charity or adapted to be run between a number of charities (or indeed research groups, funders, policy makers etc.).

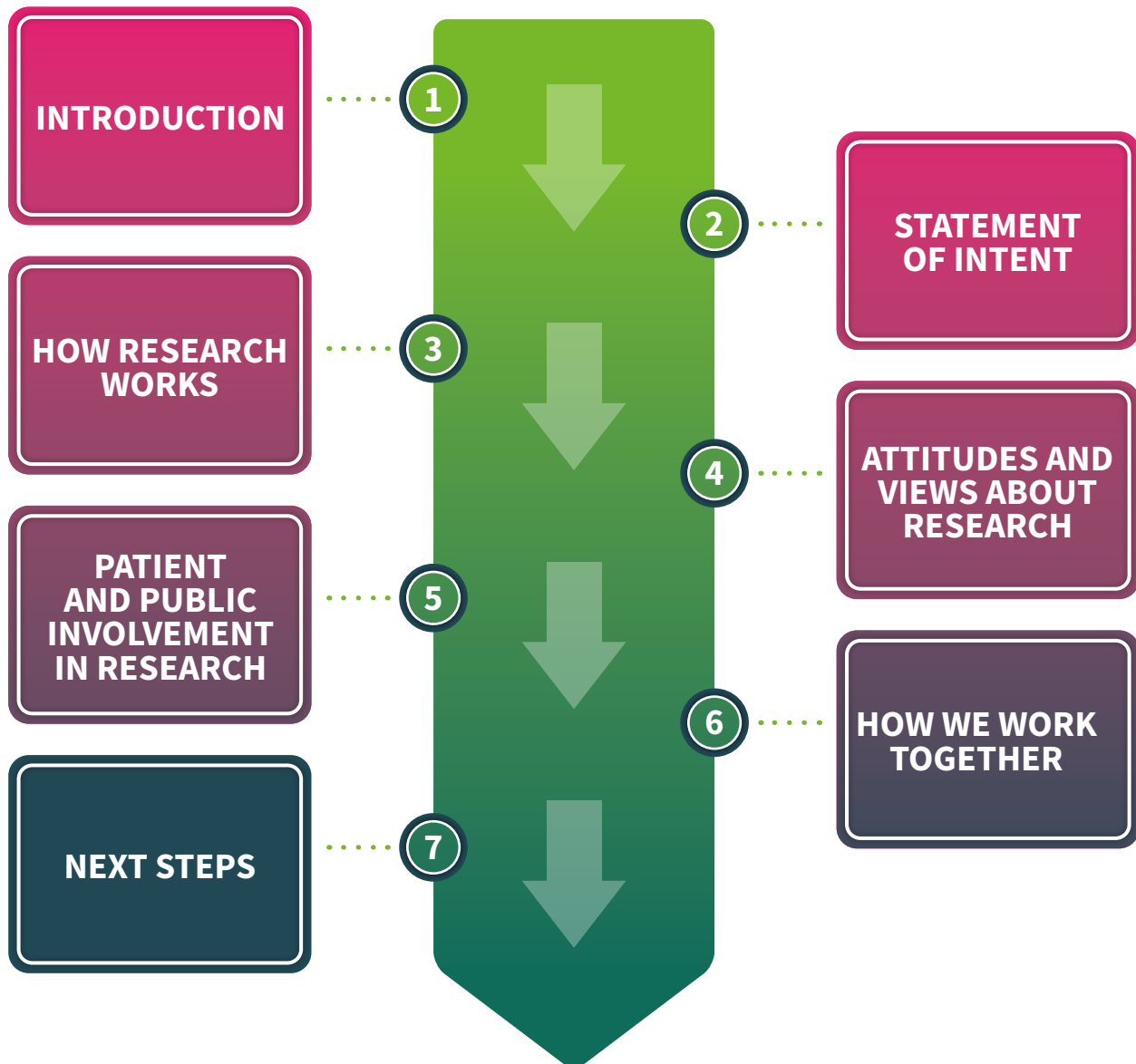
Objectives

This preliminary workshop has seven objectives:

1. Ensure PPI contributors feel welcome within the process;
2. Explain why you have brought people together and what you hope to achieve;
3. Help contributors to understand the research process;
4. Explore contributors' views and attitudes to research and PPI;
5. Discuss ways that contributors can help with PPI;
6. Draft an agreement for working together;
7. Plan next steps.

Process

The process to follow in the workshop is as follows:



Purpose of each process element

INTRODUCTION

- Introducing participants to one another
- Explaining who you are and introducing the charity
- Asking people what their expectations are

STATEMENT OF INTENT

- Explaining why you have asked participants here today
- Explaining what your intentions are
- Asking people for feedback on the stated intentions

HOW RESEARCH WORKS

- Telling participants something about the basis of research
- Explaining that this is about the whole research process rather than just 'data gathering'

ATTITUDES AND VIEWS ABOUT RESEARCH

- Discussing what people think about researchers and research
- Considering common misconceptions

PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH

- Discussing how non-researchers can get involved in research
- Providing examples of what is on offer
- Identifying what someone might be interested in (role profiles)

HOW WE WORK TOGETHER

- Considering the ideal working relationship, i.e. what would make the best contributor / the best researcher
- Discussing what makes a relationship go wrong

NEXT STEPS

- Thanking people for their involvement and answering any questions
- Giving them a contact name, phone number or email
- Identifying next steps and a timeline



The process in depth

This is not a protocol

Remember that this is a toolkit, not a protocol. It provides you with a structure that you can follow and that you may use in order to take your potential PPI contributors through a process. It is not a magic formula and you may find that, due to the nature of your attendees, certain aspects do not work or are not needed. You may also need to devise your own activity in order to better suit the participants and their circumstances. You should always be asking what your participants' needs are and be ready to adapt the workshop to meet those needs that are relevant to your objectives.

Alternative scenario

As stated above, the workshop process should work in a number of different contexts. It is written in this Toolkit as if there will be a group gathered together for a face-to-face workshop. We appreciate that this will not always be possible, so we have included a note for another scenario: a one-to-one workshop with a single PPI contributor or a single remote PPI contributor.

It may be necessary to do a face-to-face meeting with one other person to talk to them about this first stage of involvement. It may also be the case that this person is remote from the research charity and engaging digitally.

Alternatively, you may be using web-based video-calling software. For suggestions on running a group workshop online via video-calling, see Appendix C.

INTRODUCTION

- Introducing participants to one another
- Explaining who you are and introducing the charity
- Asking people what their expectations are

Aim: To get a sense of the group's expectations and to assure them that they are welcome

The need for this step:

First impressions matter. People may be coming to your workshop with some trepidation. This is particularly true if they are coming to your 'territory'. How can you make them feel welcome and assure them that they are in the right place, that they belong and that they won't be put into any awkward situations?

Task Time: 10 – 15 mins

Proposed activity:

A cup of tea/coffee and a chat is often a great start. It is your job to make people feel welcome, to serve them their tea, coffee or water with some nice biscuits, pastries or fruit.

For participants, this is the activity before the workshop begins but, for you, this is the start of the workshop. From now on, you are building the relationship with the participants, finding out what they are like, finding out their expectations for the workshop and other details that may come in handy later.

Playing the host also gets you over the awkward gap between the first person arriving and the last person arriving. If you can keep the tea, coffee and water flowing throughout the workshop, that helps to relax the atmosphere and to make it feel less like school.

At this point, you can ask people to write the name they wish to use on a label and stick it on. Most people can write their own name, even if they have low literacy levels, but always be willing to help with a comment like 'Oh, I can do it if you like; some people find these stickers very awkward'.

A one-to-one contributor or a remote contributor

This introductory step can be easier when it is one-to-one, even if it is over the phone. You can focus your attention on making them feel welcome and building trust by: thanking them for showing an interest in research; stating that you are looking forward to working with them; and expressing the hope that they find the work interesting and satisfying. Please keep in mind that, while this is less public and so not as intimidating, it can also feel more intense for both you and the PPI contributor.

Note that group video-calls are addressed in Appendix C.



STATEMENT OF INTENT

- Explaining why you have asked participants here today
- Explaining what your intentions are
- Asking people for feedback on the stated intentions

Aim: To clarify what will happen during the workshop

The need for this step:

Regardless of how much participants have been prepared in advance and how much reading material has been supplied, it is important to state what will happen during the workshop. This reassures people and provides an opportunity for people to clarify what they thought was about to happen.

Task Time: 10 – 20 mins

depending on the size of the group and whether you do an Icebreaker or not

Proposed activity:

By the time everyone sits down, you should have spoken to most, if not all, participants. If so, you do not need to do any 'icebreakers' because you have introduced everyone to one another over tea/coffee. If you would like to do an icebreaker, there are four suggested in Appendix D.

You might simply want people to go around the room to say their name. This means that they have all spoken out loud in the room in front of everyone else. Then you can tell them why they are here and what is going to happen. You can do this by talking them through the process and where things will end up at the close of the workshop.

You can ask them if this was what they expected and if there is anything else that they wanted to do today. If the group are a little shy, ask them to discuss that with the person beside them for a minute and then to feed back.

It is best to get all of this out in the open at the beginning. If someone makes a good suggestion, perhaps you can squeeze something else into the workshop. If you cannot, you must make another arrangement to answer that person's question or address their need in some other way. Do not dismiss anyone: you can say 'That's interesting. I don't think we will have time to get to that today, but I will speak to you about it at the break. We might be able to arrange something'.

A one-to-one contributor and a remote contributor

Checking in with an individual about their expectations is much easier and you are more likely to get instant, and ongoing, feedback from them.

With remote contributors, you may prepare a pack in advance to send to them through the post or you may have a video that explains the process in advance. By varying the formats that you use to engage with someone, it cuts down on the fatigue that can be felt during prolonged video-calls or phone calls. At the same time, take time to talk through any materials that you send as people may not have had the opportunity to take a look at them.



HOW RESEARCH WORKS

- Telling participants something about the basis of research
- Explaining that this is about the whole research process rather than just 'data gathering'

Aim: To introduce the group to both the research cycle and how research happens in practice

The need for this step:

Most researchers will acknowledge that there is a difference between how the research cycle should work, in theory, and how it really works in practice. For example, securing funding can be unpredictable and funder criteria may end up altering certain aspects of the research before it begins.

This section aims to bring people through both the theory and practice. This will help participants to understand the broad steps involved but it also humanises the process. By explaining what can go wrong, this can build empathy with those who engage in research and lessens the likelihood of participants being too judgemental about researchers.

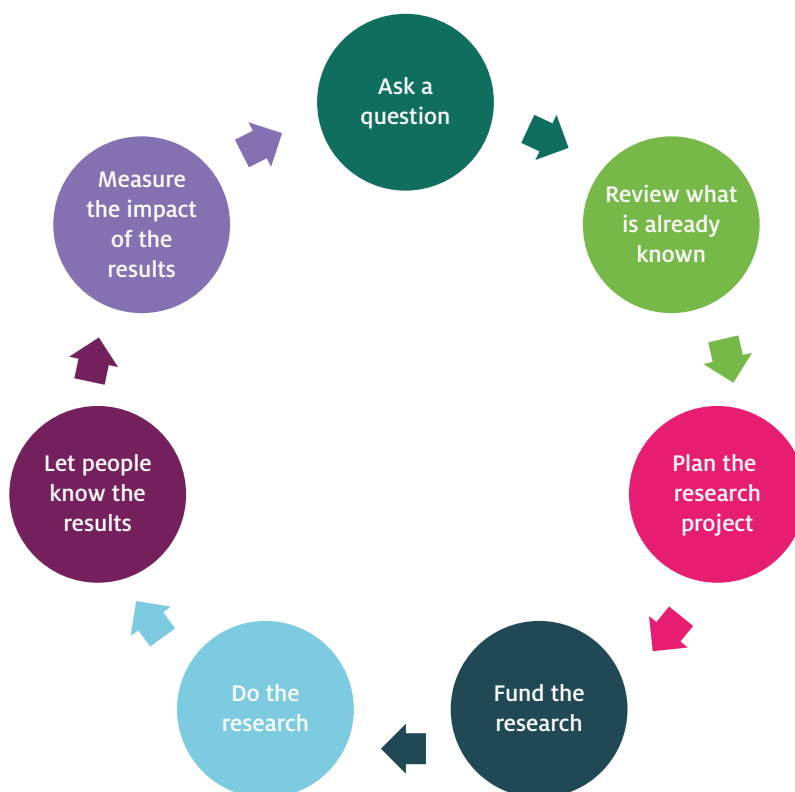
Task Time: 45 – 75 mins to cover how research works

Proposed activity:

The Research Cycle

Aim: To show that there is a cycle to research

Task Time: 15 – 30 mins



Provide cut-outs of the circles in the research cycle (see Appendix B) to a group of two or three people. You can, of course, modify this so that you can include things that are specific to your area.

Explain that each circle represents a stage in a research project. Ask them to put the circles in order. Give the group three to five mins to agree this. Explain to the group that, in reality, the stages are not distinct so there is usually some disagreement. It does not mean that the group's order is wrong but that there are differences.

Show the group the cycle as you have it set and ask them to talk about whether, how and why their order is different.

Alternatively, if it is not possible to do this, you can simply show the cycle to a group and talk through each stage, asking people at each stage if they have any experience of being involved in that part.

A one-to-one contributor and a remote contributor

With a one-to-one contributor, you can ask them to talk you through how they think the research cycle works. Assure them that there are no right or wrong answers but that you want to show them how a researcher thinks about research. If you are face-to-face with them, you could draw it out as they describe it. If they are remote, make a note of the sequence they describe.

Once they have talked through how they see the steps working, explain what extra steps a researcher would take or how the order might change slightly. When you are doing this, reassure them that their impression of how it works is understandable and that 'lots of people think it works that way'.

Aim: To show the realities of a research project

Task Time: 30 – 45 mins

The Realities of Research – Option 1

Using a testimony

It is strongly recommended to ask a researcher in the area of interest to your PPI contributors to come and tell their story about researching in a particular area. This will be a story about their own journey and how it felt, rather than a conference presentation on their research findings. The step is trying to get the participants to put themselves in the shoes of the researcher, so the researcher and the stories should be relatable to the participants.

If the person cannot do it live, you might Zoom them in or video them and upload it for the day. Be sure to brief the researcher in advance that this is a 'public' audience and so not to reveal any personal details about patients or anything about named colleagues.

Ask the group to form into smaller groups of three or four and to spend five minutes discussing what they heard. Was this what they thought research was all about? Did anything surprise them? What stood out for them?

Then, each group can ask two questions of the researcher if they are there in person or on Zoom.

A one-to-one contributor or a remote contributor

It may be best to have a video of a researcher telling their story in this case, as it would not be efficient to bring a researcher to each individual session. Engage the person about what they heard.

The Realities of Research – Option 2

Going on Holidays

If participants are unfamiliar with research, it is best to use a metaphor for something that everyone has some experience of. One useful metaphor for this purpose is about researching where to go on holidays. Try to use a real experience of going on an exotic or adventurous holiday. Use postcards, a sun hat, sunglasses, screenshots of exotic places, props that evoke holidays among the PPI contributors.

Get the group to discuss how do people decide where to go on holidays. If the group is large, split them into groups of three or four to discuss. This may be enough to get people going on the different ways in which they each choose their own holiday destinations. What this exercise hopes to draw out is the idea that, if someone is thinking of going somewhere new, they ask around, they gather information from friends who have gone before (or from guidebooks, or from online reviews). As with a literature review, they are finding out what is already known.

The hypothesis is that the traveller is going to enjoy themselves on this holiday. Draw out the idea that there is always uncertainty before going on holiday. Is there any way that the traveller can be sure that they will definitely enjoy themselves? Draw out the idea that research is always uncertain, and that part of the risk is that the hypothesis will be wrong.

It will be important to get the finances together. This may mean a trip to the Credit Union for a loan and the need to wait around for the results before proceeding. This is akin to the application for funding that many researchers experience. Draw out the idea that, even if the traveller gets the money, the trip may not go according to plan, and they still might not enjoy themselves.

The hypothesis is tested by going on the actual holiday and finding out whether going there is actually enjoyable or not. What happens if the traveller doesn't enjoy themselves? 'Draw the comparison of a mediocre holiday and a research project where the results proved either inconclusive or the hypothesis null.

Also, what is the impact of going on holiday? What are the consequences? Who benefits? Is anyone disadvantaged?

Throughout this process, you are using the metaphor to encourage people to consider the realities of the research cycle. Very quickly, it might emerge that people want to know more about the research cycle in itself; the metaphor is only there to help and, if it is not needed, you can abandon it.

A one-to-one contributor or a remote contributor

Talking through the steps of this metaphor with one other person is very effective as it provides time for the participant to recount particular experiences of good and bad holidays, so that they become emotionally connected to the activity. This conversation should flow back and forth.

The Realities of Research – Option 3

The Research Game

The Research Game is really an extended metaphor, but it is one where the ‘players’ have a stake and so can be more emotionally engaging than other methods. It is most suited to groups that already have some relationship to one another, e.g. a school group, a support group. It is intended to be fun and a little noisy and so is suited to some facilitators more than others. A lot of the learning occurs within the interaction between team members.

Please keep in mind that this is an opportunity to explore the realities of researching rather than a game for its own sake.

The game begins with splitting the group into two even teams. Each team is now a research team working on finding a cure for a new virus that is sweeping the world that makes your teeth turn green (you can change the symptoms here but just make sure that it is not something that is life threatening or similar to a symptom that the group may have experienced).

Each group is given a set of ‘literature’ cards to check (see Appendix B) and they must decide which of the cards is relevant to finding a cure. The group has three to five minutes to discuss which cards are important and they announce their results to the room and why they discarded the cards that they did.

Team 1 should realise that only the animal ones are relevant and that, for Team 2, the dietary ones are relevant. Once each team figures out the implications of their literature, they need to come up with a hypothesis to test. You will supply them with three hypotheses.

The team must discuss the hypotheses and say in order which they would test. These hypotheses serve two purposes. The first is to ask each team about whether there are hypotheses that they wouldn’t test. Each team has an ethically objectionable choice, i.e. killing rabbits or exposing someone to a virus. If they choose this as their top choice, tell them that they will not get ethical approval.

The second purpose is to show that there might be two or three equally valid choices that a researcher can make, and they have no way of choosing between them except to simply choose. The choice usually isn’t as stark as this, but choices do need to be made.

Once they choose their favoured hypothesis, the next stage is funding. You take the role of the research funder and you ask them about what they want to fund and that you are going to choose just one. Now is a good time to take a break. This is to replicate what happens in the research world where you must wait around for the results of your funding application to come through.

After the break, you announce, due to finding an extra pot of money, you will be funding both applications.

At this point, you tell each research team that they have to go off and do their research, which can take months or even years. Fast-forward to the end of the project and the results are now available of what they chose. You hand them the corresponding results of their tested hypothesis.

If nobody has a breakthrough, you can talk about the fact that all of this work is done but ‘it has come to nothing’ and how do people feel about that. This is an opportunity to talk about the usefulness of research to exclude possibilities and that research is never wasted. But that it is okay to feel disappointed if your results were unexpected or inconclusive. You can then show that the choice of Hypothesis 3 for Team 1 would have led to a breakthrough. It also shows Team 2 that, no matter what they chose, they weren’t going to make a breakthrough.

If Team 1 choose the breakthrough, you can show the other answers and that they could just have easily failed as succeeded in proving their hypothesis. You can also show the second team that they were not going to make a breakthrough, but one option is suggesting the need to find out more and that there is hope.

Ask people about who needs to know about what you have found out about rabbits? How are the teams going to tell those people or organisations?

What kind of impact will this have? Are there unintended consequences? Suggest that people, in trying to protect their health, release these animals into the wild and suddenly the disease spreads even faster because more people are exposed. Also, this increase in rabbits leads to an increase in foxes in urban areas.

Once the game is done, ask people for their feelings about the game and whether this was what they expected. Go back to the research cycle and show how the different stages of the game relate to the cycle

A one-to-one contributor or a remote contributor

This activity will only work live with a group and so should not be attempted with an individual or with a remote contributor.

Every person who had Green Tooth Virus also had contact with an animal in the last six months.

Green Tooth Virus caused large amounts of stress for women.

Over 85% of people with the Green Tooth Virus kept rabbits in their home or had rabbits on their land.



ATTITUDES AND VIEWS ABOUT RESEARCH

- Discussing what people think about researchers and research
- Considering common misconceptions

Aim: To surface any issues that PPI contributors may have about research and researchers

The need for this step:

PPI contributors may have a number of preconceptions about researchers and the world of research, so it is better to address them at this early stage. Some of these attitudes may come from their experience of bad PPI in the past or having not been shown respect as a participant in a research study.

People can, however, be reluctant to say what they think in front of a group. Alternatively, they may say these things in a way that feels very pointed or confrontational. As a research charity or researcher, if you get defensive, you are already losing, so this section is about finding safe ways to draw out these preconceptions and to address how they come about.

This is not about excusing bad behaviour on behalf of researchers or explaining away criticism. It should be a genuine attempt to bring attitudes to the surface, to acknowledge that bad behaviour can exist. More than that, however, it should be trying to understand how the attitudes were formed so that bad behaviour can be called out and guarded against when building an agreement.

Task Time: 30 mins

Proposed activity:

Your Views on Research – Option 1

Issues in a bag

Ask everyone to write down, on a set of three post-its, something that they think about research or researchers. It can be positive or negative, but it just needs to be clearly written. Explain that all of these post-its will go in a bag (or envelope) and you will draw out some of them and discuss them. State clearly that people can write anything they think or feel about research, researchers or anything related, and it will be read out. State also, in advance, that you are very grateful for both positive and negative comments because, if we cannot discuss negative things, then the PPI relationship will not get very far.

Give everyone three minutes to write their ideas down and then hand around the bag so that people can pop their ideas in. When the bag gets back to you, pick out a post-it and read it.

Once you have read it out, say 'Thank you to whoever wrote that. I can understand why people think...' and repeat what was written down. 'Is it an attitude that is widespread do people think?'. Try to keep this as a general discussion on what 'people' think or feel about research. Feel free to explore what comes up by asking people why they think those attitudes occur. Acknowledge bad behaviour for what it is, rather than explain it away, but it is also an opportunity to put it in context.

Be prepared to hear some comments that you might think are unfair or unwarranted. Please do not take offence. Do not criticise or deride the comment. Any comments are actually helping you to address issues; you need to be grateful for them.

Keep drawing out post-its until 30 mins is up. Remember that the activity is about the discussion,

rather than getting through the contents of the bag. Tell the group that you will hold onto the bag and email the other comments around with actions that might address those issues.

A one-to-one contributor or a remote contributor

As this is one-to-one, the person may feel comfortable enough to discuss their views openly. If not, it may be helpful to ask the person to provide you with one positive thing people believe about researchers and one negative thing people believe. That can be a starting point for the discussion.

Your Views on Research – Option 2

Researcher Bingo

This process is a little more dynamic than the bag. It is designed to be fun and to bring a light-hearted element to the workshop. It is important to judge carefully whether this will work, based on the spirit within the group, their familiarity with one another and their openness to doing something new.

Explain that you will be playing Researcher Bingo and that everything that you call out will be an attitude that you've heard about research.

Hand out the cards in Appendix B (each has eight squares). If you have more than eight players, ask some people to double-up.

You have a Caller Card which has all of the issues on it. Call out an item at random (not in order) from your card and if any of the players have it on their card, they can mark it off.

After each call, you ask people to raise their hand if they think that it is true. You keep a score of those attitudes that have the most hands until the game is finished, i.e. until someone has marked off all squares on their card.

Note that there must be a prize for the winner of the bingo, no matter how small.

You can now go back to the attitudes that had the greatest number of hands and ask people to talk about them. Take them one at a time and ask people where they come from and what their attitude is to them.

Remember, as above, do not take offence if someone agrees with one of the comments. Do not criticise or deride the comment. If someone genuinely believes, for example, that 'Researchers just go where the money is', this is an opportunity to find out why the person thinks that, as well as an opportunity to discuss how funding of research projects often works and how early-career researchers often need to move from project to project as they establish themselves. This is not an opportunity to explain away or excuse bad behaviour experienced by participants; that should be acknowledged for what it is, and they should be thanked for sharing that experience with you as a warning for what they do not want to happen again in the future.

A one-to-one contributor or a remote contributor

This activity will only work live with a group and so should not be attempted with an individual or with a remote contributor. Providing the contributor with a list of attitudes contained on the card, however, and asking them which they agree or disagree with, may begin a useful conversation and may draw out some experiences from the participant.

Researcher Bingo – Caller Card

Research takes years before there is any result	Research is very expensive	Researchers are smarter than me	Research needs at least 100 people
Science is a man's world	Researchers never tell you what they found	Researchers are well paid	Researchers always know what they're doing
Once you agree to take part in research, you can't back out	Researchers just go where the money is	Once researchers collect data, they keep it forever	Researchers are always objective
Lab research is better than surveys	Research is the answer to everything	Researchers are cut off from the real world	Researchers can't explain their research to real people

Research takes years before there is any result	Lab research is better than surveys	Researchers never tell you what they found
Science is a man's world	Researcher Bingo	Researchers just go where the money is
Once you agree to take part in research, you can't back out	Research is very expensive	Research is the answer to everything



PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH

- Discussing how non-researchers can get involved in research
- Providing examples of what is on offer
- Identifying what someone might be interested in (role profiles)

Aim: To get people thinking about how their own skills could contribute to research

The need for this step:

If potential PPI contributors feel remote from the research process, this is about helping them to see how their skills, knowledge and contacts can be beneficial to the research process. Before they can do that, however, they need to consider what those attributes might be. The first part is about identifying their own skills and the second part is about putting themselves into the process.

Task Time: 30 mins

Proposed activity:

PPI – Option 1:

Building a Role Profile

Ask contributors to write down on post-its some things that they are good at. People often struggle to think about what they are good at specifically, so it may be helpful to supply them with a list of skills. You can provide these as a handout or have them on posters on the wall:

- | | |
|--|---|
| • Tom has worked on committees | • Tara works well in a team |
| • Jackie knows a lot about research | • Alex knows a lot about her own condition |
| • Paula sticks with things and works hard | • Katerina is a good listener |
| • Kevin know a lot about medicine | • Hasan volunteers for lots of things |
| • Darren is a good storyteller | • Tina is good on details |
| • Niamh is passionate about her cause | • Eric loves to learn new things |
| • Terry has time to take part | • Róisín is good at giving feedback |
| • Rosa can talk in front of a crowd | • Shirley has some great ideas for research |
| • David has taken part in medical research | • Gerard is good at drawing |

Once everyone has written what they are good at, ask people to get into a group of three or four. Ask them to share, with the group, one skill that they have. Once people have done that, then ask them to stay in their groups.

Re-introduce the research cycle (see Appendix B). Ask people, in their group, to discuss where they think their skill might be useful in the research cycle and why.

While keeping people in their groups, show the room a role profile (see Appendix A), explaining its purpose in helping to build an expectation of what will be involved. Staying in their groups, ask the participants to build a role profile, using their group's collective set of skills and their interests, that would be perfect for them.

PPI – Option 2:

Letter from a Researcher

As above, ask participants to consider skills that they have which might be useful as a PPI contributor and to note them down, providing examples for inspiration.

Distribute a letter from a researcher who is doing research in the area of interest for the PPI contributors. Briefly explain what the nature of the research is and ensure that the researcher states that they would really like to have PPI contributors involved. The researcher states, however, that they have not done this before so would welcome any advice on what people would be interested in doing.

Ask the group to consider how they could use their skills to help this researcher. If someone suggests something, ask the rest of the group whether they could help with that too. Encourage the group to think beyond the project, through to helping with the funding proposal or promoting the results.

A one-to-one contributor or a remote contributor

With an individual, begin with asking the person to consider what words someone who knew them well would use to describe them. Give some examples like: ‘Would they say you were a good listener?’; ‘Would they say that you like to organise things?’.

After that, reintroduce the research cycle (see Appendix B) and discuss, section by section, where their skills might fit into the process. The person may be a little shy about this so suggest what kinds of activities people do and whether those would be of interest.

Show a role profile and then work with them on building the ‘perfect’ role profile that would suit their skills and interests.



HOW WE WORK TOGETHER

- Considering the ideal working relationship, i.e. what would make the best contributor / the best researcher
- Discussing what makes a relationship go wrong

Aim: To consider the conditions necessary for working together

The need for this step:

Agreements make for a great start to a PPI relationship. You have given the group a better understanding of the research process, a chance to flesh out preconceptions and a chance to consider what role they might play in the research cycle. Now it is about building an agreement on working together. This process also highlights that this is a two-way street: it is about the research charity and the contributor having their needs met and working together in ways that are mutually beneficial.

Task Time: 15 mins

Proposed activity:

On a flip chart, draw a T-shape, bisecting the sheet. In one column, write 'What I want' and in the other, write 'What I don't want'. Explain that, if we are to work together, we need to draw up some rules. The best place to start is to ask the group what they want from the relationship. As people make suggestions, write them down.

Then ask people what they don't want. Again, as people make suggestions, write them down. It is likely that people will call out things in one part for the other; if they do, write it into the other side. Once there is a full sheet, read them back to the group.

Then make a second sheet with the same T-shape. This time, ask what does the research charity want and what does it not want. Ask the group to suggest what the research charity would want out of the relationship. If they are reluctant, start them off with 'I want people to be honest with me' or 'I want the research to be successful'.

Tell the group that you will take that away and draw up an agreement or rules that everyone needs to abide by.

A one-to-one contributor or a remote contributor

Ask the person what they are hoping will happen from their experience of being a PPI contributor. Ask them what they really don't want to happen during the experience. Make a note of these. Ask them what they think the research charity wants and, then, what it doesn't want. Explain that you will draw this up as the start of an agreement about how you want to work as a PPI contributor.

What I want

What I don't want

--	--

What the
charity wants

What the charity
doesn't want

--	--



NEXT STEPS

- Thanking people for their involvement and answering any questions
- Giving people a contact name, phone number or email
- Identifying next steps and a timeline

Aim: To get people thinking about how their own skills could contribute to research

The need for this step:

At the end of a workshop, it is a good time to consolidate some of the learning, to refresh people's memories about what they achieved and to consider what they would like to do next. It is also a chance for you to reassure people that their input was valued and that their contribution is important.

Task Time: 10 mins

Proposed activity:

Go back over what you did during the session and how you did it, i.e. what each step was within the process.

Check in with people about how they are feeling at the end of the session and if there are any unresolved issues. One way to do this is to use a small ball and to gently throw it to someone; once they have caught it, they can say how they're feeling at the end of the workshop before they throw the ball to someone else to do the same.

Outline some of the PPI opportunities that may be coming up and explain how, for those who are interested in continuing to contribute, support and training will be provided for the particular activity required.

- Explain the circumstances around the next time you meet or the next time they will hear from you;
- Give people a contact name, number or email;
- Answer any final questions;
- Finally, thank everyone for participating in the workshop and for agreeing to play a PPI role.

A one-to-one contributor or a remote contributor

Go back over what you did during the session and how you did it. Explain the circumstances around the next time you meet or engage, provide them with contact detail, ask if they have any final questions and then thank them for their involvement.

Where to from here?

What is the very next thing I need to do?

The PPI workshop is finished so what do you need to do next? You need to do what you said you would do in the workshop. Perhaps people had questions you could not answer, and you promised to follow up with an answer. Perhaps you said that you would be in touch again next week with some follow-up details. You need to do these things as proof of your commitment to this process and to these PPI contributors.

You need to create a note of the first meeting, with a recap of what you covered and what came up, along with a draft of the agreement that the group devised for working together so that the contributors can read and comment upon them.

You need to process expenses quickly so that people are not left out of pocket.

Remember that all of this is part of a relationship, and you are now in the business of keeping it going.

Building a relationship over time

As with all of the relationships in your life, there are behaviours that promote the relationship and the feeling of connection: good communication, showing respect, not taking the other person for granted.

A relationship is two-sided so work with your PPI contributors on how you want to build the working relationship in the context of need, resources, geographical distance and other factors that can affect what can be done. Although beyond the scope of this Toolkit, there should be, at the very least, a commitment to cover out-of-pocket expenses of PPI contributors, if not some type of financial recognition for their contribution. As you build it together, you both also need to commit to it in order to make it work.

Feeding back to this Toolkit

Every time a version of this workshop is delivered, it becomes an opportunity for others to learn from what went well and what went badly. It may also inspire you to try something new as an activity which you would like to publicise. Please keep in touch with HRCI (hrci.ie/contact-us/) with both your positive and negative experiences so that this Toolkit can adapt and grow.

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Appendices

Appendix A: Agreements and Role Profiles

An agreement on how we work together

Each agreement should be forged with the group to suit their particular needs. What will be important for one group will not be as important for another. One example of an agreement created through a facilitated process with its PPI contributors is the Alzheimer Society of Ireland Dementia Research Advisory Team (DRAT). The full agreement is available here (https://alzheimer.ie/wp-content/uploads/2020/04/DRAT_Guidelines.pdf).

It states, for any researchers wishing to engage with the team, their preferred way of working and any conditions that should be in place when engaging with them. The agreement is designed ‘to make this easier for us and for you’. An agreement is not, and should not be, a ‘list of demands’; it should be an agreed set of conditions for optimal working. By stating them in advance, it should help researchers to plan their budget and research cycle more effectively.

The areas covered in the Alzheimer Society of Ireland agreement are as follows:

- Meetings – issues such as what time, where, which venues, whether support will be needed;
- Financial Considerations – issues such as the payment of expenses, financial acknowledgement of people’s time;
- Communications – issues such as how and when the contributors and the researchers will communicate and via what means, whether a contact person will be in place;
- Materials – issues such as what the style of the communication will be, how legible and readable it will be, how long it will be and how detailed;
- Recognition and Acknowledgement – issues such as how the contributors will be acknowledged in the research, in public events, in papers;
- Input – issues such as when, where and how within the research cycle the contributors will be involved;
- Support – issues such as the support that contributors may be required, which may include support in dealing with potentially sensitive or traumatic issues or may be around practical supports such as a translation of material.

This list is not exhaustive, but it does provide a useful sense of the issues that are often raised by contributors.

A role specification & person specification

It is often helpful to provide a role specification and a person specification which will highlight what the responsibilities of the PPI role are, the conditions under which that role operates and the types of knowledge, skills and experiences it would be hoped that the PPI contributor would have in order to fulfil that role. An example of a template for such a specification is available from INVOLVE (<https://www.invo.org.uk/be-clear-with-the-people-you-want-to-involve/template-two/>)

One note of caution in using this process, however, is that this needs to be written and communicated in a way that is appropriate for the audience. These can very quickly become officious and far more formal than the role will be. They may also be seen as something that will be adjudicated upon, even if the contributor role is self-selecting.

Areas that can be covered in a role specification are:

- The background to the role and the organisation;
- The expected responsibilities of the PPI contributor;
- The responsibilities of the organisation toward the PPI contributor;
- How long the role will continue;
- What training and ongoing supports will be supplied;
- Whether there will be a payment or reimbursement of expenses;
- Organisational contact details for further information.

Areas that can be covered in a person specification are:

- The experiences of the PPI contributor;
- The knowledge of the PPI contributor;
- The skills or personal attributes of the PPI contributor.

One example of a role specification was supplied by the Irish Cancer Society which they give to PPI contributors who may be reviewing funding applications.

Irish Cancer Society: What is involved in being a patient reviewer?

As the largest voluntary funder of cancer research in Ireland, the Irish Cancer Society is proud to have invested €25million in life-saving cancer research in Ireland since 2010.

It is our mission to ensure fewer people get cancer and those that do have better outcomes. To achieve this, we fund a broad range of research from basic laboratory research examining the underlying mechanisms of cancer, to population-based cancer research that examines the risk factors associated with cancer in the population, in addition to clinical research that investigates the benefits of new treatments or tests for cancer patients. Our Social Sciences and allied health research programmes are dedicated to survivorship research that seeks to improve the quality of life of those living with and beyond cancer. We have funded hundreds of projects over the years leading to many discoveries.

The Irish Cancer Society remain completely impartial to the research funding decision making process, which means that every eligible application that is submitted for these grant calls must be externally reviewed. Reviews are an important part of how decisions are made about what to fund or what not fund.

Reviews:

- ensure that only high-quality applications are funded,
- provide feedback to the applicants who have applied for funding.

In the past, these applications were only reviewed by independent international scientific reviewers who had a science background. They are independent reviewers because that they have no connection to the application or the applicant.

Since 2017, the Society has started including patient reviewers as part of the reviews process.

What is exactly involved for patient reviewers will vary between each grant call. However, in general, the following can be involved:

- Review a number of applications (the exact number depending on the grant call):
 - » This can be done through our online system or by hand if preferred.
- For some funding calls, patient reviewers will be required to attend an in-person meeting to discuss the reviews:
 - » This can be done over Skype or telephone if necessary,
 - » Generally, 1-2 meetings.
- For some funding calls patient reviewers may sit in-person on interview panels.

Support for reviewers

- Before any review begins reviewers will be given guidance and training by the Research team at the Society:
 - » This will be done in-person at the Irish Cancer Society Offices in Dublin and last approximately half a day.
- A member of the research team will be available at all times if you need support at any point in the review process.

Time commitment

- The time that you would need to commit to being a patient reviewer will be different for each grant call. When being invited to be a patient reviewer for the grant call, we will provide you with more of an estimate of how much time will be required.

Data protection and confidentiality

The Irish Cancer Society adhere to all data protection legislation, including the General Data Protection Regulation (GDPR) effective 25 May 2018.

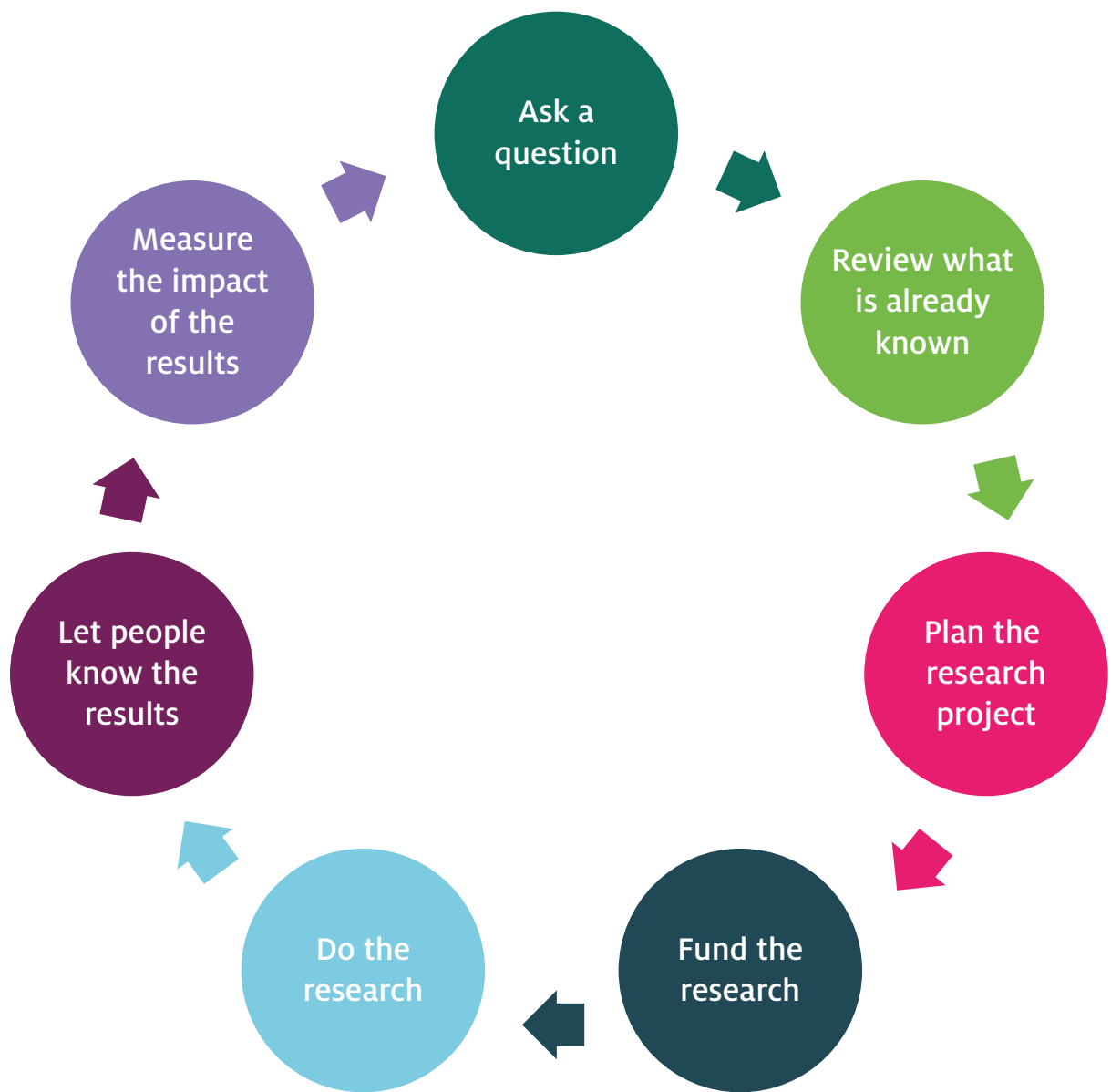
We will keep any personal information and details shared with us by our patient reviewers strictly confidential. The information you provide will be kept securely and used by the Irish Cancer Society in order to facilitate the grant review process and in improvements in patient care only. Your information will not be shared with any other organisation, other than with your permission, or where required by law.



Appendix B: Workshop Materials

The Research Cycle





The Research Game

Team 1 Cards - Literature Review

Every person who had Green Tooth Virus also had contact with an animal in the last six months.

Green Tooth Virus caused large amounts of stress for women.

Over 85% of people with the Green Tooth Virus kept rabbits in their home or had rabbits on their land.

30% of people with a family pet had Green Tooth Virus.

People with Green Tooth Virus find their teeth changing colour over a two-week period, on average.

Team 2 Cards - Literature Review

60% of people with Green Tooth Virus reported feeling stigmatised.

People with Green Tooth Virus find their teeth changing colour over a two-week period, on average.

Vegans in were more likely to get Green Tooth Virus than vegetarians at a ratio of 3:1.

People who ate yoghurt were much less likely to have Green Tooth Virus.

Employers in Ireland were discriminating against people with the Green Tooth Virus.

Team 1 Cards

Hypothesis 1

If we get rid of all the rabbits, we get rid of Green Tooth Virus.

Hypothesis 2

There is something in the rabbit hutch that is carrying Green Tooth Virus.

Hypothesis 3

The fleas on the rabbits are the way that Green Tooth Virus is passed on.

Team 2 Cards

Hypothesis 1

If you have a couple where only one has Green Tooth Virus, eating yoghurt will stop the other getting it.

Hypothesis 2

If someone stops eating yoghurt and gets exposed to Green Tooth Virus, they will develop the virus.

Hypothesis 3

If people eat yoghurt, their teeth will go white again.

Team 1 Cards

Results for Hypothesis 2

You check the hutch and analyse the bedding and the droppings. Green Tooth Virus is in the droppings.
CONGRATULATIONS - YOU'VE MADE A DISCOVERY.

Results for Hypothesis 3

Whether the rabbits had fleas or not does not appear to predict whether someone gets Green Tooth Virus or not. Your hypothesis was incorrect.

Team 2 Cards

Results for Hypothesis 1

It has been hard to recruit people, but you find that, in your small sample, that eating yoghurt is protective against getting Green Tooth Virus from your partner. This is promising but you need to do more research to figure out why this is happening.

Results for Hypothesis 3

You do a trial with people who have the virus, but their teeth do not go white. Yoghurt does not make teeth go white again. Your hypothesis was incorrect.

Researcher Bingo

Researcher Bingo – Caller Card

Research takes years before there is any result	Research is very expensive	Researchers are smarter than me	Research needs at least 100 people
Science is a man's world	Researchers never tell you what they found	Researchers are well paid	Researchers always know what they're doing
Once you agree to take part in research, you can't back out	Researchers just go where the money is	Once researchers collect data, they keep it forever	Researchers are always objective
Lab research is better than surveys	Research is the answer to everything	Researchers are cut off from the real world	Researchers can't explain their research to real people

Research takes years before there is any result	Lab research is better than surveys	Researchers never tell you what they found
Science is a man's world	Researcher Bingo	Researchers just go where the money is
Once you agree to take part in research, you can't back out	Research is very expensive	Research is the answer to everything

Researchers are smarter than me	Researchers are cut off from the real world	Research needs at least 100 people
Researchers are well paid	Researcher Bingo	Researchers always know what they're doing
Once researchers collect data, they keep it forever	Researchers can't explain their research to real people	Researchers are always objective

Research takes years before there is any result	Research is very expensive	Researchers are smarter than me
Research needs at least 100 people	Researcher Bingo	Researchers always know what they're doing
Science is a man's world	Researchers never tell you what they found	Researchers are well paid

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Research takes years before there is any result	Research is very expensive	Researchers are smarter than me
Research needs at least 100 people	Researcher Bingo	Researchers are always objective
Researchers never tell you what they found	Researchers are well paid	Researchers always know what they're doing

Science is a man's world	Once researchers collect data, they keep it forever	Researchers are cut off from the real world
Once you agree to take part in research, you can't back out	Researcher Bingo	Research is the answer to everything
Lab research is better than surveys	Researchers can't explain their research to real people	Researchers always know what they're doing

Research takes years before there is any result	Lab research is better than surveys	Researchers never tell you what they found
Science is a man's world	Researcher Bingo	Researchers just go where the money is
Once you agree to take part in research, you can't back out	Researchers are cut off from the real world	Research is the answer to everything

Research is very expensive	Researchers are smarter than me	Research needs at least 100 people
Researchers are always objective	Researcher Bingo	Researchers can't explain their research to real people
Researchers are well paid	Researchers always know what they're doing	Once researchers collect data, they keep it forever

Appendix C: Workshops using Video-Calling Platform

For a number of reasons, it may not be possible to bring all participants into a room to run a workshop. While this may mean that you are engaging with your participants one-on-one via telephone, email, instant messaging or video-call, another option may be video-calling with a group.

Using video-calling does have a number of advantages in that there is no travel involved for participants who have difficulty accessing transport or who are geographically dispersed. Using this platform is also cheaper and allows a number of shorter workshops to be run rather than one longer one.

At the same time, there are issues to keep in mind when running a group video-call:

Group video-calls are not the same as being in a room with people. While much easier and cheaper to organise, these group calls are no substitute for the type of dynamics that can occur when people can interact together in a room. For example, it is harder to make ‘small talk’ on a video-call; it is harder to have ‘side-discussions’; as only one person can speak at once, it is harder to encourage spontaneous comment.

Group video-calls can be tiring. You may want to split your workshop into a number of sessions. While it can be negotiated with participants, one helpful ‘rule of thumb’ is to take a break after 45 minutes of concentrated screen time. Also, breaks should be ten to fifteen minutes each rather than five. Remind people to switch off their camera and mic during breaks.

Group video-calls can be intimidating. If you have a number of people online at once, it can feel very intimidating for someone with no experience of doing these calls to speak to the group. This is especially true when they may not know the other people on the call. Keeping the numbers smaller may help with this. Really listening intently to every contribution, repeating back what a contributor said for emphasis and thanking them for their contribution are all even more important on a call like this where participants can feel even more isolated.

It can be hard to get everyone’s full attention. If someone is video-calling from home, they may be distracted by other things happening at home. Off camera, they may be checking their phone or, if calling in via their laptop, they may have something else open on screen that they may be looking at simultaneously. The more involved they are with your workshop, the less likely that is to occur but that means you must build in a lot of interaction.

Not everyone will join via a laptop. Some people will join via a tablet or their phone. This means that you won’t be able to show anything too complex on screen, e.g. slides with lots of writing or small detail on them.

Running the Workshop on a Video-Calling Platform

The structure for the workshop is still relevant but the process will need to take account of the restrictions within the platform:

- **Introduction:** Ensure that the first engagement that a participant has with you is a one-to-one session in the days or hours before the workshop. You should start to build your relationship with each participant as early as you can so that, on the group chat, each person at least feels that they know you. Remember that you can make your initial contact with people via telephone call, via a greeting card, via email, but the workshop should not be the first time they interact with you.

Contacting them on the platform in advance will help them to check whether their camera and microphone are working properly, whether the software is working and what will appear in the background when they are on a call. They may be using someone else's device or may be using their local library. A call in advance allows all of this to be worked out prior to the day itself.

Inform participants that you will be asking them to turn on their video for the start of the workshop and they are encouraged to keep it on after that, if at all possible.

- **Statement of Intent:** Apart from stating what the workshop will be, ask participants if they are used to doing these kinds of calls. Inform participants of both the structure and the timetable, including when the breaks will occur.
- **How Research Works:** Share an image of the research cycle and talk people through the various stages. Then, use either a researcher testimonial video or the extended metaphor of the holiday to take people through the realities of the research process.
- **Attitudes and Views about Research:** Instead of the issues in a bag, ask people to use the chat function to send comments to you only, both positive and negative, about researchers. Give people a few minutes to supply these. Once they have been sent, read those of a similar type out together and respond to them. If necessary, use some of the suggested attitudes from the bingo card. Ask people do they think those attitudes are fair and where do they come from.
- **PPI:** Ask participants to take a moment to write down some skills that they have. Once they have done that, screen-share the letter from the researcher who is asking for help with a research project and ask people to respond to that by suggesting ways in which they could help.
- **Making an Agreement:** Screen-share a Word document which has been split in two halves. Within this, ask the PPI contributors to suggest what they want and what they don't want from the PPI process. Repeat this using a similar Word document asking for suggestions of what they think the charity wants and what the charity does not want.
- **Next Steps:** Go through the group, checking in with everyone about how they felt that the session went and if there remains anything unresolved. Explain the circumstances around the next time you meet, provide them with contact details, ask if they have any final questions and then thank them for their involvement.

Appendix C: Icebreakers

An icebreaker is often used at the beginning of a facilitated workshop to put people at ease and introduce them to the rest of the group. It is debatable whether they put people at ease or make them more anxious. They do, however, often create an initial ‘no stakes’ task that everyone can do. This is why they appeal to some facilitators.

It is better to have a natural ‘icebreaker’, such as a sociable coffee break, hosted by the facilitator, as a way to introduce each person to the others in the group. This, however, is not always possible. If you must have an ‘icebreaker’ at the beginning of the session that goes beyond people simply saying their name to the rest of the group, try to make it a) something relevant to what you are about to do, but b) something that people don’t need any special knowledge to participate in or anything that will ‘put them on the spot’, c) fun or engaging and something that will help them to see the human side of the others present.

Most publications about facilitation include icebreakers, such as Seeds for Change’s Facilitation Tools for Meetings and Workshops (<https://seedsforchange.org.uk/tools.pdf>). Here are some examples of icebreakers, how they work and with what kind of audiences you might use them.

‘State One Thing’ Icebreakers

In this common Icebreaker, all participants are asked to state their name and one other thing specified by the facilitator. Examples might be: what is the first song you remember; tell us something about yourself that people don’t generally know; how did you travel here today; what did you have for breakfast; if you were an animal, what type of animal would you be?

The idea behind this is that it gives each person a chance to speak in front of everyone else and to say their name by way of introduction. The ‘one thing’ is often something that each person can answer due to their knowledge of themselves rather than any specialised knowledge.

While a simple and useful icebreaker, it can also lead to someone disclosing something they did not mean to or to someone’s attention drifting off to something else when the facilitator really wants them to be in the room.

‘Talk to Your Partner’ Icebreakers

Another common Icebreaker, each person is invited to turn to the person beside them and each person has two minutes to tell their partner about themselves. When the group comes back together, each person introduces their partner to the group, based on what they have been told.

This Icebreaker is useful when a group do not know one another as it creates a sociable moment and potentially forms a bond between two people who are sitting side-by-side.

In practice, however, some people will say a lot but do not listen and so do not report back very much to the group, and what they do report back may be incorrect. It is always useful to ask the person being spoken about ‘Is there anything you’d like to add to that?’

People Bingo

While this takes a little preparation, this is a useful Icebreaker to get people moving around. Each person is given a bingo card with a number of squares. Each square contains an attribute, characteristic of what might be expected would occur within a group of people. Squares may include items like the following: is left-handed; likes classical music; has lived abroad; speaks a second language; is wearing

brown shoes. For three minutes, everyone moves around the room, introducing themselves to one another and asking one another a question from the card, e.g. 'Hello Patrick. Do you like classical music?'. If the person says yes, they mark off that box on the card and move on to the next person. The person with the most boxes marked off is the winner.

This is dynamic and energising and tends to break through the reluctance strangers have to talk to one another.

Obviously, this does not work with groups where low literacy is an issue or where the group have difficulty moving around due to the room they are in or due to their own physical capabilities.

Sending a Clap around the Room Icebreaker

This Icebreaker is simply for energising a group. Everyone in the group stands in a circle, facing one another. The facilitator turns to the person beside them and claps their hands once. When they clap their hands, the person beside them claps one 'beat' after that and turns quickly to the person on the other side of them and claps the next 'beat'. That person claps the next 'beat' and quickly turns to the person beside them and claps the next 'beat'. This goes around the circle until it comes back to the facilitator.

This clap should be sent around the circle a few times so that everyone is comfortable. At this point, the facilitator can state some variations. A simple one is to make the clap go faster. Another variation is that the facilitator sends two claps in opposite directions around the circle. A third is that, when someone takes a clap, they can send it back in the direction from which it came. There is no winning or losing in this activity; it is about a group doing something together that is simple and fun.

As this is an energiser, it should be used when energy is needed. It should not, for example, be followed by a twenty-minute slide presentation. It tends not to be as effective when people have a vision or hearing impairment or are unable to clap effectively.



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