



Administrative Data
Research Network

An ESRC Data
Investment

Developing a Public Engagement Strategy

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Better Knowledge Better Society

Developing a Public Engagement Strategy

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1. Introduction

1.1. Description of ADRN

The Administrative Data Research Network (ADRN) is a UK-wide partnership between academia, government departments and agencies, national statistical authorities, funders and the wider research community that will facilitate new economic and social research based on routinely collected government administrative data.

The Network is establishing a new legal, secure and efficient pathway for the research community to access de-identified linked administrative datasets. This will potentially benefit our society by providing greater evidence-based research to inform policy.

The Administrative Data Research Network consists of:

- ▶ four Administrative Data Research Centres (ADRCs):
 - ▷ England: led by the University of Southampton
 - ▷ Northern Ireland: led by Queen's University Belfast
 - ▷ Scotland: led by the University of Edinburgh
 - ▷ Wales: led by Swansea University
- ▶ the Administrative Data Service, which is the co-ordinating body of the Network
- ▶ national statistics authorities (each in partnership with their country's Administrative Data Research Centre)
- ▶ government departments and agencies (the data custodians)
- ▶ the Economic and Social Research Council (the funding body)

The Network has commissioned this guide to support the development of knowledge and skills in the subject topic area.

1.2. Purpose of this guide and who it is aimed at

This guide is for researchers working with administrative data and requires no previous knowledge of Public Engagement. It may also be of interest more generally to a wider audience of researchers, policy makers and indeed the general public. The guide is designed to help the researcher build a strategy and plan for public engagement (PE) in their research that is appropriate and meaningful.

The focus of this guide is on PE for research that securely uses administrative data, although the principles may be applicable to other research areas. With this in mind, it is worth explicitly noting that PE is just as important for research using administrative data as it is for research where you interact with data subjects through questionnaires, focus groups or observation. The absence of 'live participants' in administrative data research does not negate the importance of public engagement as part of your research plan, not least because the data is collected for a purpose other than research.

The guide is split into two key parts: the five key questions you will need to work through in order to create your public engagement strategy and; the practical issues you will need to consider in order to plan the type of public engagement activity you will undertake.

Let's begin by exploring what is meant by the term public engagement and why it is important in the research process.

2. Public Engagement

2.1. What we mean by Public Engagement in research

Perhaps in the past Public Engagement was seen simply as a communication of science to a public audience. However, this simple one-way exchange of information is not how public engagement is now understood and enacted. Since 2005, the philosophy of public engagement (from a political, policy and research perspective) has shifted towards two-way engagement. This idea of dialogue is particularly important in emerging scientific areas, when using new scientific techniques or when undertaking science which has the potential to affect people's lives. It is the latter point which is relevant here; one of the drivers for using administrative data for research is the belief that it has the potential to influence social policy. This new 'dialogic two-way engagement' form of PE has at its core the belief that people should be brought into research as active participants.

The Economic and Social Research Council (ESRC) which funds the ADRN defines PE as involving:

"... activities that bring researchers and the public together. It is more than just meeting an audience and telling them about your research – effective public engagement is about two-way communication, with the researchers listening to and learning from participants." (Economic and Social Research Council¹)

This view of PE is also held by Research Councils United Kingdom (RCUK), which has, by including PE as a distinct activity for REF, underlined the importance of its role in research.

Different disciplines use different terminology to describe public engagement and this can make the landscape confusing. There are other terms which you may have come across in the literature on PE including: Patient and Public Involvement (PPI), user involvement, consumer engagement and so forth. All of these terms come under a wide umbrella of public engagement which is essentially about relationship building with members of the public and people affected or potentially affected by the outcomes of your research.

Developing a relationship with those likely to be affected by your research can be mutually beneficial – both you as a researcher and those you involve get something out of the process such as new insights, policy impact, community benefit. There are many academic and non-academic publications which demonstrate the impact of involving patients, members of the public and communities in research, and you may find it helpful to read some of these².

1 See ESRC PE Guidance (2018) <http://www.esrc.ac.uk/public-engagement/public-engagement-guidance/>

2 An example of research which has put publics at its centre is Hall's (2015) 'Everyday Austerity' project' which moved beyond academia and the media perspectives on austerity to engage directly with families and communities in Greater Manchester, <https://everydayausterity.wordpress.com/about/the-everyday-austerity-project/>.

2.2. When to engage members of the public

You can actively engage members of the public in all stages of the research process including:

- ▶ **Prioritisation of studies** – this is the stage where you define what research questions and issues are important to the public or communities who may have an interest in your research and its outcomes
- ▶ **Design and management of studies** – at this stage you can explore whether the members of the public involved are comfortable with your planned use of particular datasets and what information they feel you need to know in order to design your study appropriately to reflect their experiences?
- ▶ **Approvals, governance and permissions** – These are formal processes required before access can be granted to research data in controlled settings such as the ADRN. The ADRN's approval process requires that the researcher completes an Approvals Form and (in Scotland) a Public Benefit and Privacy Panel application to show evidence of potential public benefit and public engagement. At this stage, you may wish to talk to members of the public relevant to your research and listen to their opinions in order to explore the potential public benefits of your work.
- ▶ **Dissemination of findings** – PE commonly takes place at the dissemination stage once a research project has come to fruition. This is clearly an important stage at which to engage people to share your research findings and explain how they might benefit their community. This is also an important stage for those members of the public you may have involved already. Those you involve in your research will often be keen to know what impact their involvement has had and often find it rewarding to be involved at this stage.

The issue of when to undertake public engagement will be further explored in section 3.4.

2.3. The bigger picture – why public engagement is important

Since World War II, there have been many developments in science and technology and while these have been generally viewed as having the ability to improve society, the legitimacy of science and technology as an unquestioned public good is increasingly contested. Scientific developments, such as IVF and stem cell research, and controversies such as Bovine Spongiform Encephalopathy (BSE – or ‘mad cow disease’) and Genetically Modified (GM) crops, have led to the public questioning science and its advancement and calling for science to be accountable (Jasanoff, 2006, 2014).

This shift to involve the public as stakeholders is considered the right thing to do (for the purpose of transparency and accountability) and necessary to avoid situations where scientific and technological developments for public good are stopped in their tracks by a failure to garner public support (Wilsdon & Willis, 2004). This latter point is particularly pertinent for researchers working within the ADRN because the Network enables researchers to access linked administrative data (for research for public good) in a way that has not previously been possible.

The ADRN is a new initiative and coupled with this there is a lack of public understanding of the processes involved in using data that originates from individual public records, this creates a greater impetus for you to engage with members of the public who may be unfamiliar with this type of research. Indeed, both positive and negative scientific developments such as IVF and the BSE crisis, respectively, involved broad ranging public engagement to try to build public trust and ameliorate concerns. Your intention may be to undertake research for public good, but a lack of public awareness and understanding of research using administrative data, compounded with the fast-paced and technological nature of data linkage research, means the public need to be considered, valued and engaged. Researchers working with administrative data via the ADRN do so in a secure environment where the risk of re-identification is considered remote; however members of the public may not be aware of this and/or still have concerns. Public support should not be assumed – public engagement provides an opportunity for you to listen to members of the public or people potentially affected by your research and, if need be, to alleviate their concerns (if they have any).

2.3.1. The Policy Drivers for Public Engagement (PE)

There are four core policy drivers for PE in research in the UK, they are:

1. Responsible research and innovation
2. Economics
3. Socio-cultural
4. Political

A case example on administrative health data: the drivers to involve patients

The changing relationship between science and society resulted in calls for better public information campaigns, and for people to be included in the scrutiny and governance of science. Subsequent technological developments and computerising of the NHS resulted in the publication of the *Report on the Review of Patient Identifiable Information*, (“Report on the Review of Patient-Identifiable Information,” 1997) also known as the Caldicott report, which influenced the way patient identifiable information is processed, considered and subsequently used for research – and this report still influences the use of patient and administrative data today. At the same time as these developments in the 1990s, the UK witnessed a series of health scandals which changed the way patients interacted with the health system. The Bristol Royal Infirmary scandal (1995) resulted in a public inquiry in the UK. The Learning from Bristol report stated “The public are entitled to expect that means exist for them to become involved in the planning, organisation and delivery of healthcare” (Kennedy), 2001). This report placed patients at the centre of health policy and research, and shortly afterwards, the Consumers in Research organisation, now known as INVOLVE was created. INVOLVE supports the active involvement of patients and the public in health research. At the same time, the government commissioned Sir David Cooksey’s review of health research funding³ to make sure the UK was scientifically attractive and competitive in order to develop and sustain a thriving knowledge economy. Indeed, having robust and ethical research practices is important to attract research funding in all areas, and PE is viewed as a way of enabling high quality research. This view is also shared among European colleagues and funders.

The European Commissioner for Research, Innovation and Science, Máire Geoghegan-Quinn points out that:

‘The dialogue between science and the rest of society has never been more important... Science is the basis for a better future and the bedrock of a knowledge-based society and a healthy economy. After ten years of action at EU level to develop and promote the role of science in society, at least one thing is very clear: we can only find the right answers to the challenges we face by involving as many stakeholders as possible in the research and innovation process.’ (Geoghegan-Quinn, 2012)

It is clear that public engagement and involvement are crucial to both research and innovation, particularly in addressing social problems and issues, like many of the questions being addressed by those using administrative data in their research.

³ The review was titled: A review of UK health research funding, December 2016. HM Treasury on behalf of the Controller of Her Majesty’s Stationery Office. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/228984/0118404881.pdf

The 2010 [Concordat](#) on PE (which is led by RCUK) spelt out four expectations for all those involved in the research they fund, that:

1. UK research organisations have a strategic commitment to public engagement
2. researchers are recognised and valued for their involvement with public engagement activities
3. researchers are enabled to participate in public engagement activities through appropriate training, support and opportunities
4. the signatories and supporters will undertake regular reviews of their and the wider research sector's progress in fostering public engagement across the UK (Research Councils United Kingdom (RCUK), 2017)



3. Developing a strategy: key questions

When you begin developing a strategy for your project you need to consider your aims for engaging with people (other than it being a requirement of a funding application). Are there specific issues you are grappling with, such as whether people would be comfortable with your research topic, or maybe you are attempting to answer a particularly complex question and need some first-hand knowledge of the issues? What is your overarching aim? Once you know this, there are five key questions you need to ask yourself for the purpose of developing a PE strategy:

1. why do I want or need to engage the public at all?
2. who are the relevant people in my research?
3. where will I find the relevant people to get involved?
4. when (at what stage of the research) should I involve people in my research?
5. what methods or activities should I engage them in?

3.1. Question 1: Why do I want or need to engage the public in my research?

Your rationale for why and indeed how you involve the public in your research is likely to vary from project to project. There are, as I will consider in more detail now, many reasons for undertaking PE.

Authors such as Francisca Caron-Flinterman et al (2005), Jonathan Boote et al (2009) and funders such as the ESRC describe a range of reasons for undertaking PE; for researchers using linked administrative data in their research there are four particularly pertinent reasons:

1. the **policy imperative**: a requirement to include public engagement in one's research plan is currently a Research Councils UK, Wellcome Trust, National Institute for Health Research (NIHR) and ESRC policy.
2. the **consequentialist argument**: people have knowledge of their own illness, health condition, community and lived experience that can help bring insights to research which in turn have the potential to improve the quality, relevance and impact of that research. Engaging people with experience of the research issue you wish to address can help make sure you are answering the most pertinent questions. Your section(s) of the public may be able to help you develop research questions or identify solutions to ethical questions or concerns about the research.

Having already engaged with the public to understand their concerns about their communities, particular policies or a gap in services could help to make sure your research has impact with policymakers. Getting people and/or community organisations and charities on board can help you to demonstrate the utility of your research and its applicability to real challenges.

3. the **moral imperative**: it is generally considered the right and just thing to do to involve the public in the research process, and this is one of the rationales research councils have for making PE a requirement for funding. The ethical basis for this is particularly strong where research is publicly funded and or may have an impact on peoples' lives.
4. the **transparency and trust argument**: improving transparency in the research process and accountability to the wider community is an important reason for undertaking public engagement: in this way researchers can build good relations and trust with a vast range of stakeholders. As discussed in section 2.3, if innovation and scientific developments are to be fully realised, researchers need to have an honest dialogue with those affected by their research in order to develop positive science-society relationships. In the ADRN context, transparency in what it does and how it operates is a core principle on which the network is built. This principle is essentially about developing positive science-society relationships that allow the public to have confidence in the work of the ADRN.

3.1.1. Public trust and data linkage research

For researchers using linked administrative data, the transparency and trust driver is a particularly compelling one. This is because the ADRN research landscape is potentially highly sensitive – while data is lawfully linked together from different administrative data sources for research; the public may not understand the strict data security and governance in place within the Network. In addition the data itself or the topic area under study may be sensitive. It is therefore critically important for you to consider what the public trust issues might be for your research, such as concerns about data privacy or about who can access this type of data. I shall return to these points in a moment, but first let's look at some of the complex issues that may be raised from data sharing as well as linking data and from which we can learn some lessons.

There is growing evidence of what the public think about data linkage and sharing in health and social science. Two pertinent publications in this area are the work of Carter, Laurie, & Dixon-Woods, (2015) and Cameron, Pope, Clemence, & Institute, (2014).

Carter et al (2015) explored why the care.data initiative was so badly received by the public. Care.data was an NHS England initiative to link GP and Hospital data for the purpose of NHS commissioning, resource allocation, audit and research. Although the initiative had a seemingly good public interest case there was little consultation with the public about this and the public information campaign was generally considered unsuccessful: it consisted of

a leaflet (resembling junk mail) sent to all homes in England. It was also revealed that NHS England had previously sold data to insurance companies. After negative press coverage and concern voiced from both the medical profession and the public, the roll out of care.data in England was stopped and the initiative put on hold. Carter et al (2015) suggested that, while there are no legal barriers to (most of) our use of administrative data in research, something else was at play that raised concerns: a 'social licence' between the medical community and the public which in the care.data case was seen to be broken by the type of data share being proposed. This suggests that data given in one context i.e. a medical context cannot be unquestioningly repurposed to another (seemingly unconnected) context. Carter et al concluded that, 'legal authority does not necessarily command social legitimacy', (2015:408).

The second publication by Cameron et al (2014), 'Dialogue on Data', was commissioned by the ESRC. It involved a series of public engagement events undertaken to better understand people's views on the use and linkage of administrative data for research. These engagement events highlighted five issues of particular relevance to the ADRN:

- ▶ it was difficult to clearly explain de-identification and linkage
- ▶ it was difficult to get across messages that were both easy to understand and accurate
- ▶ the public wanted transparency (where possible)
- ▶ the public wanted to see very clearly articulated public benefits for using data in research
- ▶ there was strong opposition to the commercial use of linked administrative data

What we can learn from the work of Carter et al (2015) and Cameron et al (2014) is that it is necessary for researchers working with linked administrative data to be aware that they are working in a complex environment. There may be, for example, a lack of understanding among the public around terminology – such as what is meant by de-identified data – or about the technical and security processes used to protect data, or the governance processes for controlling who can access data through the Network. It is therefore vital to listen to public concerns and to provide clear and consistent messages.

3.2. Question 2: Who are the relevant people in my research?

One of the greatest difficulties researchers have is deciding who to engage with. Asking yourself four questions should help:

1. who does your research relate to?
2. who will be affected by the outcomes?
3. what conditions or social issues does your project explore?
4. do your findings have potential public impact?

Once you have identified who you need to engage, and if you are planning more than a one-off PE exercise, you should consider taking a layered approach to PE.

3.2.1. Layers of engagement

ADRN research could potentially affect discrete or even whole populations, so you need to decide who your research could affect, how you want to engage them and when in the research process you will do that. This may involve engaging with just one stakeholder using a one-off activity at the dissemination stage of your research, or it may involve engagement with multiple stakeholders using a variety of activities which take place at different stages. Relevant people may include:

- ▶ those affected by your research – patients, service users, carers, parents, community groups
- ▶ geographically specific groups, specific socio-economically identifiable groups, communities
- ▶ those with an assigned interest in your research – charities, advocacy groups, community groups

They may include but not be limited to:

- ▶ people with experience of your subject topic area (such as homelessness, social housing, welfare, education, social work or unemployment)
- ▶ recipients of a particular service such as those using social care or patients or carers
- ▶ charities involved in the area you are working in – which can also put you in contact with members of the public who may be interested in getting involved
- ▶ communities where location is key to the research
- ▶ general public – for wide perspectives or if your research is likely to affect the wider public

Determining who the relevant people are is essential and crucial to delivering a meaningful and clear public engagement event and strategy.

3.3. Question 3: Where will I find the relevant people to get involved?

Once you have decided who the relevant people or stakeholders are, it is important to think about how you find them, for example through:

- ▶ existing contact with you or colleagues
- ▶ a public or lay research group for your research topic or team – are there already public groups set up in a related area of research?
- ▶ previous research – have you undertaken research which involved charities, community groups, advocacy groups or know of any that may be relevant to this research?
- ▶ disease or topic-specific groups – are there any local organisations you already know related to your research, and would they know of anyone that could get involved?
- ▶ charities – which are the major or local charities in your area of research? Many are run or supported by members of the public and can help you find people who are interested. www.charitychoice.co.uk holds details of all registered charities in England and Wales, and most in Northern Ireland and Scotland
- ▶ community groups – use keywords to find local community councils, neighbourhood groups and other resources online
- ▶ people you know
- ▶ advertising your public engagement opportunity on research or volunteering websites
 - ▶ www.peopleinresearch.org
 - ▶ <https://do-it.org/>
- ▶ events such as a science festival or public lecture – these will, most often engage a science interested community but think about whether these events will engage or interest specific members of the public that you may wish to engage (people who could potentially be affected by outcomes related to your research or have experiences of health or social situations related to your research)

It may help to Google local or national groups, and charities – they may have a public engagement or contact person who can help you.

3.4. Question 4: When (at what stage) should I involve people in my research?

So far, I have considered why, who and where you might find relevant people to include in your engagement strategy – all of which should help you to think about when in the research process it is best to engage with your public. For example, you may decide that you want to engage the public throughout your research or you may decide that you would prefer to engage them as a one-off. Either can be appropriate depending on the aims and objectives of your PE strategy.

Let us look at the stages in a research cycle that you could potentially involve your public in, and the issues that can be addressed at each stage.

The research cycle

Most researchers will be familiar with the research cycle used here from work on developing their own research question through to the publication, dissemination and implementation of their research findings. This cycle provides the basic structure to most research projects. Although specifics will vary, all research projects from administrative data linkage projects in the social sciences to randomised clinical trials will follow this basic structure. While you may not think (at least in detail) about the different stages of the research cycle, it is useful to identify what they are in order to think through the potential impact of PE at each stage and the types of activity that can be carried out.

Below I present a diagram of the research cycle and consider what you can do and/or gain from undertaking PE at different stages of the cycle.



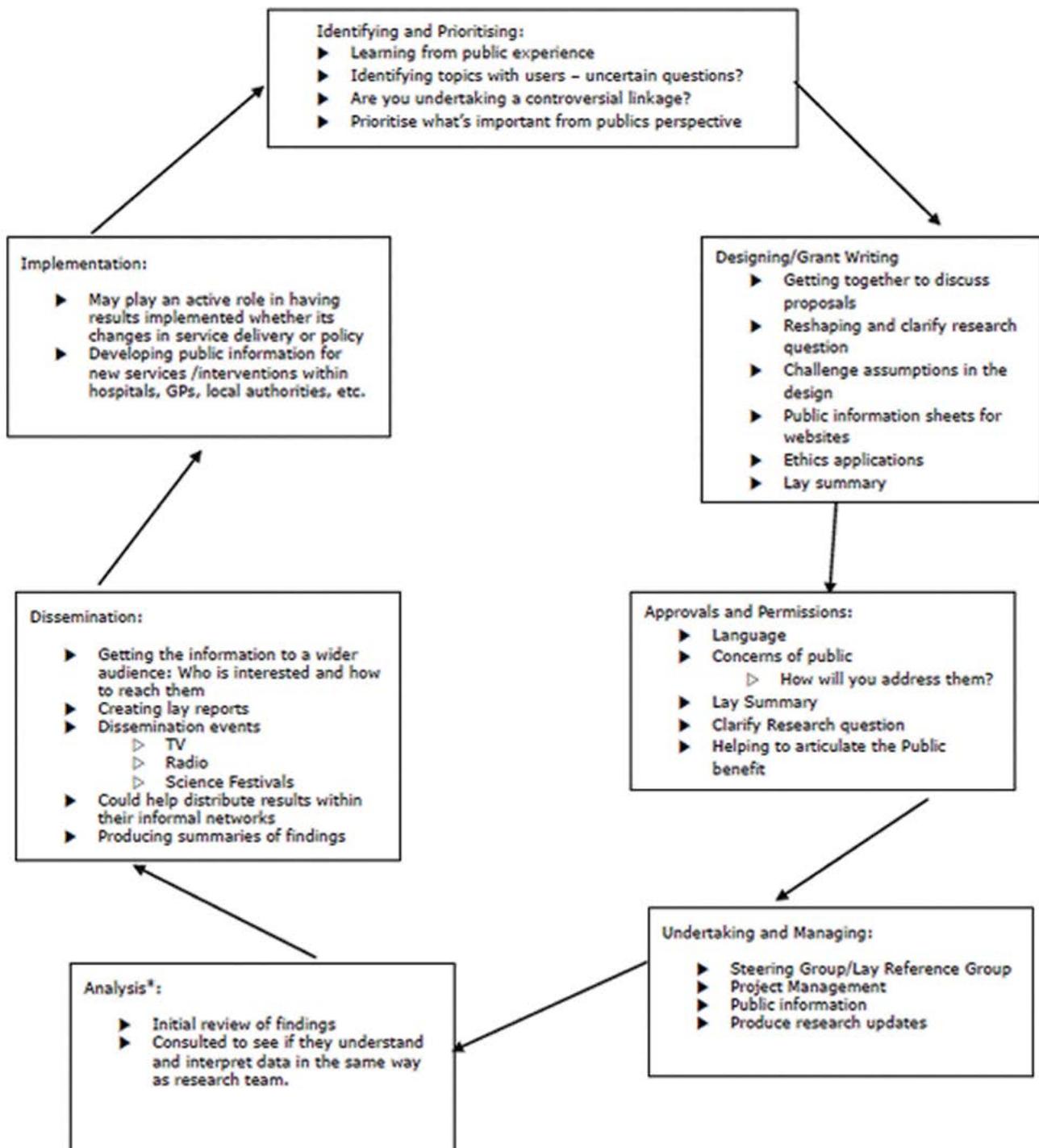


Figure 1 Public engagement in the research cycle

*This stage will be very difficult for those working with administrative data to engage people in, as the strict security and governance processes in place across the ADRN means only approved researchers who have passed SURE training can gain access to the data. Therefore, having members of the public involved at the analysis stage is not possible, although initial findings could be discussed.

3.5. Question 5: What methods (activities) can I use to engage people?

Now that you have thought about the research cycle and at what stage you may want to engage people, the next step is deciding what methods or activities to use. I will look now at the pros and cons of a range of activities.

Activity	Pros	Cons
Blog	<p>You can clearly articulate thoughts and ideas</p> <p>It has the potential for wide reach</p>	<p>It can take a lot of work to keep a blog updated</p> <p>You need to have a community that would know where to find your blog or you could use a shared blog platform such as 'The Conversation'</p>
<p>Bright Club</p> <p>This is a comedy event by scientists and academics, which aims to amuse and inform</p>	<p>It is an exciting and funny way to engage the public</p>	<p>You need to be able to communicate your research in a humorous way (training is usually available)</p>
<p>Café Scientifique</p> <p>This is usually informal science talks over coffee or wine in a café or bar</p>	<p>Often well attended</p> <p>Allows opportunity for dialogue</p>	<p>It will be a self-selecting audience</p> <p>It generally tends to be a science-interested community</p>
<p>Citizen juries</p> <p>This mimics an actual jury format – 12-20 people are selected to sit and hear 'evidence' from experts on a particular scientific or policy area. Jurors then have an opportunity to weigh the evidence and make recommendations</p>	<p>It is a good way to create dialogue and weigh up the positives and negatives in a project</p>	<p>These events can be particularly expensive</p> <p>They take very precise organising and buy-in from teams to run the jury</p>

Activity	Pros	Cons
Museum exhibits and event	<p>They have the potential for a large audience</p> <p>They are good for giving accurate information</p>	<p>Exhibits are static – little opportunity for dialogue</p> <p>There may be little opportunity for a continued presence once the exhibit ends</p>
Podcast	<p>A platform for you to clearly articulate thoughts and ideas</p> <p>The potential for wide reach</p>	<p>You will need to have a community that would know where to find your podcast</p>
Public lectures	<p>Discrete one-off activity</p>	<p>Unknown public attending – you may not get the people you have a specific interest in hearing from</p>
<p>Public panels</p> <p>Panels usually number 8-16 members and are created for a particular community, charity or research project. Panel members apply to be involved</p>	<p>Usually provides a breadth of experience</p> <p>Offers potential for broad discussion</p> <p>Offers potential for ongoing involvement</p>	<p>Limited control over panel selection (the organiser or originator of the panel will have been the one who selected participants)</p> <p>The panel may not have the experiences you are looking for</p>
Schools engagement	<p>Known age group</p> <p>Assistance in managing the activity from school</p> <p>Can inspire new generation of young people</p>	<p>May take a while for the young people to open up</p>

Activity	Pros	Cons
Science fairs/festival	<p>Advertising and costs are most often covered by the organiser</p> <p>They usually get large numbers of attendees</p> <p>They are good for giving accurate information</p>	<p>You will often be competing with other researchers on stalls for the attention of attendees</p> <p>Unknown public attending – you may not get the people you have a specific interest in hearing from (with specific lived experiences)</p>
TV/ radio appearance	<p>You can reach a wide audience</p> <p>They are good for giving accurate information</p>	<p>Very little feedback and dialogue</p> <p>May be difficult unless related to a science event or specific 'story'</p>
Twitter	<p>Useful for connecting with community groups and charities</p> <p>A good way to advertise your event</p>	<p>You are limited in what you can say</p> <p>You need to be careful what information you put out</p>
Workshop	<p>A good way to create dialogue around a topic</p> <p>You can select people to attend</p>	<p>You can usually only invite small numbers</p>

Figure 2: Public engagement activities

The activities you choose will depend on the aims and objectives of your PE strategy and on what activities take place locally to you. Try to engage groups or centres which undertake PE, as they have considerable experience, skills and knowledge in this area and may be able to support you. I have provided links to a selection of useful groups and organisations that run and/or advertise public engagement opportunities; please see Appendix A.

3.6. A worked example

Now that I have talked through the five key questions that you need to think about in order to develop your PE strategy, let us consider a worked example. Let us imagine that you are undertaking research looking at homelessness and its long-term impact on health.

Question 1: Why do I need to engage the public in my research?

You may have several reasons for wanting to undertake PE on this project, such as: you wish to learn from those directly affected by homelessness; your research focuses on a vulnerable group and you think listening to and involving them in the research is the right thing to do.

The topic is sensitive (i.e. it is likely to raise important social and political issues) and the data subjects are a vulnerable group, so there is a moral imperative to include them in your research – not least because they are often marginalised in society. In addition, people who have experienced homelessness are likely to have unique insights and knowledge that may help you – for example in refining your research question or contextualising your data analysis. Homelessness charities may also provide a useful and distinct view that could be helpful in providing context and insight into the policies related to your research.

You should try to make sure the language you use speaks to the communities related to your research, so their engagement and input is meaningful, and so your findings are understood and well received. It might be helpful to chat with those who have experienced homelessness and relevant interest groups about the potential public benefits of your research; do they understand the potential benefits in the same way as you?

Question 2: Who are the public in your research?

There are various people you can identify who are likely to be affected by your research, such as:

- ▶ homelessness charities and support groups will have a unique insight and may be able to put you in touch with people who are, or have previously been, homeless
- ▶ people who may be homeless or experience homelessness will be a group directly affected by your research
- ▶ the issue could affect anyone so a general view from a mixed public maybe useful – a public panel would be one way of getting a general overview.

Question 3: Where will I find the relevant people to get involved?

You could:

- ▶ make contact with the ADRC in your country (in the UK) to find out if they have a public panel or contacts in this research area (there are details of our public panels on the ADRN website www.adrn.ac.uk/public-engagement/supporting-research/public-panels/)
- ▶ contact homeless charities and local support groups. Charities can be found online at www.charitychoice.co.uk
- ▶ speak to colleagues who have done similar work – who did they contact and how did they go about doing that?

Question 4: When (at what stage) should I involve people in my research?

There are several stages you may wish to consider for this type of research project, including:

- ▶ designing and grant writing and approvals and permissions stages – this could help to make sure you use the appropriate language; identify any key concerns about data (re)use; and develop your approvals documentation, where you have to demonstrate public benefit and acceptable use of the data. Engaging with those relevant to your research can help with these tasks – and you can document what you have done to listen to and ameliorate any concerns they may have.
- ▶ Dissemination stage – at this stage, you should engage with those you worked with at the design and grant writing approvals stage to make sure the research is disseminated to the relevant stakeholders and through non-technical publications such as charity newsletters, website articles, blog pieces etc. As before, this is a very important stage at which you should and can acknowledge people's involvement.

Question 5: What methods (activities) can I use to engage people?

You could use a variety of methods to engage your relevant people, such as:

At the design and permission stages:

- ▶ Public panel – public panels are useful to engage with as they may already have direct experience of commenting on research and have a background understanding of some of the technicalities or research processes you are navigating. They may also have experience of social policy, circumstances or illness that you are researching.
- ▶ Workshop – when you first start, or at the planning stage of, your research, you may not know exactly how many contacts you will develop through your connections with homelessness groups and organisations, so you could hold a workshop. This has the advantage of providing an opportunity to bring together a range of stakeholders on the topic, such as homelessness charities, advocacy groups and academics as well as people who have experienced homelessness. Workshop participants may be able to provide advice on your research questions and relevant data sources.

At the dissemination stage:

- ▶ write for charity newsletters, give a public talk (e.g. at Café Scientifique) or organise a dissemination workshop with wider stakeholders to make sure policymakers are aware of the findings.

One thing to bear in mind is that it is an iterative process and plans may have to change. People may suggest a stakeholder or organisation they think you should engage with, and your plans may change and develop over time as you conduct each engagement activity – so be prepared to incorporate this into your PE strategy.

3.7. Evaluating public engagement

Evaluating PE is increasingly viewed as an important activity. There are many reasons why you will want to evaluate your PE activities. For example, you should be able to assess whether your original aims and objectives defined during question 1 – why do I need to engage? – have been achieved. Also, evaluating your PE activities can be important for those you have engaged, as it can be encouraging for them to understand what impact their contribution has had on the research and on their own development.

The impact of their contribution may be in 'soft' ways such as allowing you to tell their personal story or driving home the importance or relevance of the research. Given that public engagement is about relationship building, you should ask yourself: what did your public gain from being engaged?

You should try and build an evaluation plan into your PE strategy, even if it is a simple one. You should set aims and objectives to help define your evaluation. Evaluation may be a simple question asked of people at an event, or a short survey. The National Co-ordinating Centre for Public Engagement (NCCPE) has lots of evaluation resources and examples: <http://www.publicengagement.ac.uk/plan-it/evaluating-public-engagement>.

4. Practical considerations in public engagement

Now that you have a clearer idea of how to set out a PE strategy, we'll look at the practical issues to consider to plan your activities. There are many practical issues to consider before undertaking PE – not all of these suggestions will apply. The issues pertinent to your research will very much depend upon who you are engaging with.

Expectations

What are your expectations of the people you are engaging with?

- ▶ What contribution will they be expected to make?
- ▶ Are your demands on people's time reasonable?
- ▶ Do you expect them to have access to computer equipment, email etc.?
- ▶ What skills do they need?
 - ▶ research skills?
 - ▶ previous experience in research?
 - ▶ will you provide or find appropriate training for them?
 - ▶ or do they just need particular social experiences?

Organisational arrangements

- ▶ Do they know where the PE event is happening?
 - ▶ is the venue easy to find?
 - ▶ close to transport?
- ▶ Will your team arrange travel for people beforehand?
 - ▶ book trains, taxis etc. in advance.
- ▶ How will travel expenses be paid?
- ▶ Who will be the point of contact?

4.1 Costs and funding for public engagement

PE is not free, and you need to consider how to meet the costs. They include costs for the public engagement event and engagement activities (event and venue costs) and potentially payments for the public if you invite them to take part in your research (such as reimbursement of expenses). Remember to be clear about what will be included. For most public science events, there will be no direct payments, but ongoing payments are likely to include transport and out of pocket expenses at a minimum.

Cost considerations

Transport

(if inviting members of the public to be involved in an ongoing basis)

1. Do you need to pay for long distance train or petrol costs, and what will these costs be?
2. What will the costs for taxis be?
3. Do you need to account for any other travel costs?

Expenses

1. Do you have a system in place for paying public expenses?
2. Will members of the public be out of pocket?

Meeting room/venue hire

1. Are you paying to be part of a Science Festival or event?
2. Are you holding a public engagement event in an expensive venue, how much will this be?
3. Can you use a free room within the university?
4. Would it be better to use and pay for a community location e.g. a community centre or library?
5. How many times will you need this room/need to pay for a room?
6. Do you need rooms with wheelchair or disabled access and access to disabled toilets?
7. Are there any (potential) mobility issues, and should you hold the meeting close to local transport?
8. Does your venue come with all the IT equipment you need or will you need to hire this?

Refreshments

1. How many people are attending?
2. What catering should you order?
3. Roughly how much will this cost?
4. Do you need to cater for specific diets (diabetic patients, pregnant women etc?)

Carer or babysitting cover

(if inviting members of the public to get involved in an ongoing basis)

1. Are you inviting carers to get involved? Will you need to pay for professional carer cover?
2. Are you asking mothers or families to get involved? Will you need to provide a babysitter?
3. Will you need to pay for the costs of a personal assistant?

4.1.1. Funding for public engagement activities

The links below are useful when thinking about where to apply for funding for public engagement activities. These will usually be for much larger events or for large public engagement projects. Check with your own university, too – they may have funding available. Public engagement for individual projects should not typically require outside funding.

The National Co-ordinating Centre for Public Engagement Funding pages

<http://www.publicengagement.ac.uk/plan-it/funding>

The Royal Society Partnership Grants (STEM activity for 5-18-year olds)

<https://royalsociety.org/grants-schemes-awards/grants/partnership-grants/>

Scottish Government Talking Science Grants Scheme

<http://www.gov.scot/Topics/Business-Industry/science/Scienceengagement/engagement-grants>

The Wellcome Trust have several schemes

<http://www.wellcome.ac.uk/Funding/Public-engagement/Funding-schemes/>

5. Summary

If you have worked through this guide, you should have answered the five key questions:

1. Why do I want to/need to engage the public at all?
2. Who are the public (in this project)?
3. Where will I find people to get involved?
4. When (at what stage of the research) should I involve people in my research?
5. What methods or activities should I engage them in?

You should also have established the aims for your PE, identified who you will engage with and developed an idea about what kinds of event you can engage people in. You should also have considered the practical issues of funding. Bear in mind that one well-planned and run activity is better than an overly ambitious activity that doesn't fulfil your aims.

If you are engaged in the ADRN, you can also seek advice from the public engagement teams in each ADRC:

England: adrce@soton.ac.uk

Northern Ireland: adrcni@qub.ac.uk

Scotland: adrc-s@ed.ac.uk

Wales: ADRCWales@swansea.ac.uk

In the appendices you will find useful links and a glossary of terms for you to use with the people you engage with.

Other relevant guides for researchers working with linked administrative data include:

- ▶ Data quality issues in administrative data by David McLennan (2018)
- ▶ An introduction to data linkage by Katie Harron (2016)
- ▶ Legal issues for the ADRN user by Heather Gowan, Jessica Bell and Jane Kaye (2016)
- ▶ Ensuring the confidentiality of statistical outputs from the ADRN by Philip Lowithan and Felix Richie (2016)

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7. Appendix A

Links

Café Scientifique (find your local branch) <http://www.cafescientifique.org/>

Research Councils UK <http://www.rcuk.ac.uk/pe/>

Sciencewise <http://www.sciencewise-erc.org.uk/cms/>

The British Science Association <http://www.britishtscienceassociation.org/Pages/Category/our-work>

The national co-ordinating centre for public engagement <http://www.publicengagement.ac.uk/>

Wellcome Trust: <http://www.wellcome.ac.uk/Funding/Public-engagement/index.htm>

Science Festivals:

Edinburgh International Science Festival:
<http://www.sciencefestival.co.uk/>

Cheltenham Science Festival
<http://www.cheltenhamfestivals.com/science>

Cambridge Science Festival
<http://www.sciencefestival.cam.ac.uk/>

What you need to know about payment: An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research:
<http://www.invo.org.uk/wp-content/uploads/2011/06/INVOLVEpaymentdocument2011.pdf>
(Although this is intended for members of the public it is a useful document for researchers and research teams too).

8. Appendix B: Glossary of common terms used in administrative data research for the public

This common list of research terms and their definition should be useful for you when working with members of the public. It may help you describe your study to them or it may be something you copy and give to those you involve as a reference.

Abstract: a summary of a research paper.

Administrative Data: refers to information collected primarily for administrative (not research) purposes. This type of data is collected by government departments or by organisations on behalf of government for the purposes of registration, transaction and record keeping, usually during the delivery of a service.

Case study: in depth analysis and systematic description of one person or group of similar persons to promote a detailed understanding of their circumstances.

Causation: is when one factor necessarily alters the possibility of a second.

Cohort studies: (or follow up studies): Studies which begin with a group of people (the cohort) free from disease but who have been exposed to a potential cause of disease or outcome. The cohort is followed up to see the subsequent development of new cases of the outcome of interest. Cohort studies provide the best information about the causation of disease and the most direct measurement of the risk of developing disease. They can also be used to measure the outcome often treatments or exposure when, for ethical reasons, it is not possible to perform an RCT or to investigate the effects of a rare exposure.

Confidentiality agreement: is a legal agreement to protect confidential information revealed during discussions or negotiations with another party. It applies to both organisations and individuals and is likely to contain clauses covering protection of people against the copying or retention of confidential information, disclosing information that is not already in the public domain to a third party and remedy for a breach of the agreement.

Controls: is the comparison group in a random controlled trial. They receive the usual treatment (or a placebo) while the experimental group receives the treatment being tested.

Dissemination: the communication of research findings to a wider audience through, for example, publication in medical journals, the media, and voluntary organisations' newsletters.

Efficacy: refers to whether the intervention worked or not.

Empirical evidence: relates to collection of data in the real world and based on observation rather than through assumption and abstract development of an argument using reasoning alone.

Epidemiology: the study of populations or communities rather than individuals.

Ethics: is the name given to the code of practice based on a set of decent, fair and moral principles and guidelines that researchers should abide by. Research that will seek to gain personal confidential information or to test a new intervention on people must get ethical approval from an Ethics Research Committee (REC).

Ethics Research Committee (REC): groups of professionals and service users that review the ethical considerations of research studies.

Hypothesis: an unproven theory tested through research – rather like a hunch.

Incidence: the number of new occurrences of something in a population over a period of time.

Mean: the average value. The mean age of a group of people would be calculated by adding up all the ages and dividing the result by the number of people in the group.

Median: The middle result or mid-point when all the data values are put in sequential order.

Outcome: The result being looked for in a study e.g. stopping smoking.

Research question: defines the reason for the research. It describes the area of the study and what the researchers want to learn about it.

Safe haven: an environment for research and statistical analysis in which the risk of identifying individuals is minimised. A place where research can be done on sensitive data such that the risk of disclosure is reduced by controlling who can have access, what data they can analyse and what outputs can be taken away.

Significance: the difference seen between the control group and the treatment group will only be significant if it is unlikely to have occurred by chance. This is typically agreed to be the case if the likelihood of it having happened by chance are less than 5%.

Trusted third party: a trusted third party is an organisation with secure facilities for matching data (such as the Office for National Statistics or the National Records for Scotland).

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