

Resource Survey for Public Involvement and Engagement Activities in Data Driven Research



HDRUK
Health Data Research UK

 **ADRUK**
Data-driven change

NHS
England

 **Research
Data
Scotland**

 **Office for
National Statistics**

DARE UK

 **CANCER
RESEARCH
UK**

PEDRI

 **British Heart Foundation
Data Science Centre**
Led by Health Data Research UK

Content

Executive Summary.....	3
Background	4
What is PEDRI?	4
Aim	4
Methods	5
Design	5
Analysis	5
Sample	5
Findings	9
Summary	16
Strengths and Limitations	19
Appendix	20
Appendix.A: Resource survey questions	20
Appendix B: Question response rate	24

Glossary

PEDRI – Public Engagement in Data Research Initiative

PIE – Public Involvement and Engagement

Executive Summary

The Public Engagement in Data Research Initiative (PEDRI) has completed a resource survey about public involvement and engagement in data research and statistics. The survey aimed to identify the resource needs of public, researchers, and public engagement professionals to effectively complete their roles. The survey was disseminated through PEDRI partner's public communication channels from the middle of December 2022 to the end of January 2023. The survey was completed by 123 respondents.

The key findings of the survey are:

- There is a lack of existing resources for researchers and PIE professionals to support them in their involvement and engagement activities.
- Responders were not aware of some existing resources that may meet their needs.
- Members of the public expressed a desire to see plain language and jargon free descriptions of data.
- Researchers and PIE professionals described challenges providing jargon-free descriptions with the need for greater standardised descriptions of data and data terminology.
- Members of the public requested a greater quantity and depth to the information provided to them, with responders conducting their own additional research into topics.
- Members of the public favoured more interactive support, such as presentations and guidance. While researchers and PIE professionals showed a preference for video supported resources.

This report contains a series of recommendations that can be found on page 17 in summary this report suggests:

- Creating additional targeted resources to support PIE activities in consultation with members of the public.
- Researchers, PIE professionals, and supporting organisations should collaborate to create an open access resource hub to reputable data research PIE resources.
- When creating PIE resources, they should be in plain language with limited jargon. When technical language is required, its meaning should be explained.
- There should be a collaborative effort to create consistency and clarity in descriptions of data terminology in PIE activities, including the creation of a glossary of data and statistical research terms.
- Researchers and PIE professionals should be aware of the needs of their audience and provide more detailed information when required.
- Emphasis must be placed on the accessibility of resources in style and design that suit their needs and different learning styles.

Background

What is PEDRI?

The Public Engagement in Data Research Initiative or PEDRI is an initiative founded by statistical, health, and administrative research organisations to collaborate on the best ways to communicate to and with the public. PEDRI is a sector-wide partnership bringing together organisations who work with data and statistics to generate insights that can inform policy and practice. Our goal is to collaborate on establishing and driving forward best practice for public involvement and engagement with data research, to bring the views of the public to policymakers and data holders together in a more meaningful way.

To enable us to do this, PEDRI conducted a survey to understand the resource needs of members of the public, researchers, and public involvement and engagement professionals.

In this document the term public involvement and engagement (PIE) refers to the variety of activities including members of the public for involvement/engagement purposes. The decision was made to not use the term patient and public involvement and engagement (PPIE) more commonly used in health research. This is to create consistency across PEDRI partners' activity, as we are an initiative that includes administrative and statistical research, and the term patient is not appropriate in all instances.

Aim

This survey was designed and distributed by the Resource Working Group of PEDRI. The working group members were Ben Thomas(PEDRI) Ester Bellavia (HDR UK), Jan Speechley (Public Representative), Matt Howard-Murray (Cancer Research UK), and Samaira Khan (BHF Data Science Centre).The aim of the survey was:

To identify the requirements of public members, researchers, and public involvement and engagement professionals to effectively fulfil their role.

To achieve the survey aim, the following objectives of the survey were:

- To identify what good PIE resource provision is
- To identify what resources members of the public use and would like to see
- To identify what resources researchers and PIE professionals need

Methods

Design

The PEDRI Resource Working Group produced an online survey through the Survey Monkey platform from the middle of December 2022 to the end of January 2023. The survey design contained a mixture of open and closed questions, with a greater weighting to open questions to allow for freedom of responses from participants. The full survey questions can be seen in Appendix A. The survey question path split for members of the public and for researchers/PIE professionals, to gather the most relevant information.

Analysis

The closed quantitative survey responses were analysed in simple univariate analysis through the Survey Monkey professional online platform. The open qualitative survey responses were analysed through thematic analysis and presented in this report as a collective narrative of responses.

Sample

The PEDRI resource survey was completed by 123 people, including members of the public, researchers, and public involvement and engagement professionals between the middle of December 2022 and the end of January 2023. The survey sample represents a wide range of ages, with peaks in 30-39 and 60-69 ranges representing researchers/PIE professionals and members of the public respectively, see figure 1. The survey sample also has varied representation from members of the public in particular, see figure 2, while still having a strong enough response rate from researchers and PIE professionals to draw substantive conclusions.

The weighting of the type of data by both members of the public (see figure 3) and researchers/PIE professionals (see figure 4) they work with skews heavily to health data. There is still strong representation from administrative data and statistics particularly from researchers/PIE professionals.

This survey asked participants where they reside in the UK, see figure 5. From the results in figure 5 it can be seen the survey contain an over representation from people residing in England over other UK nations. This should be taken into consideration with the application of this report's findings.

Age of responders

Answered: 123 Skipped: 0

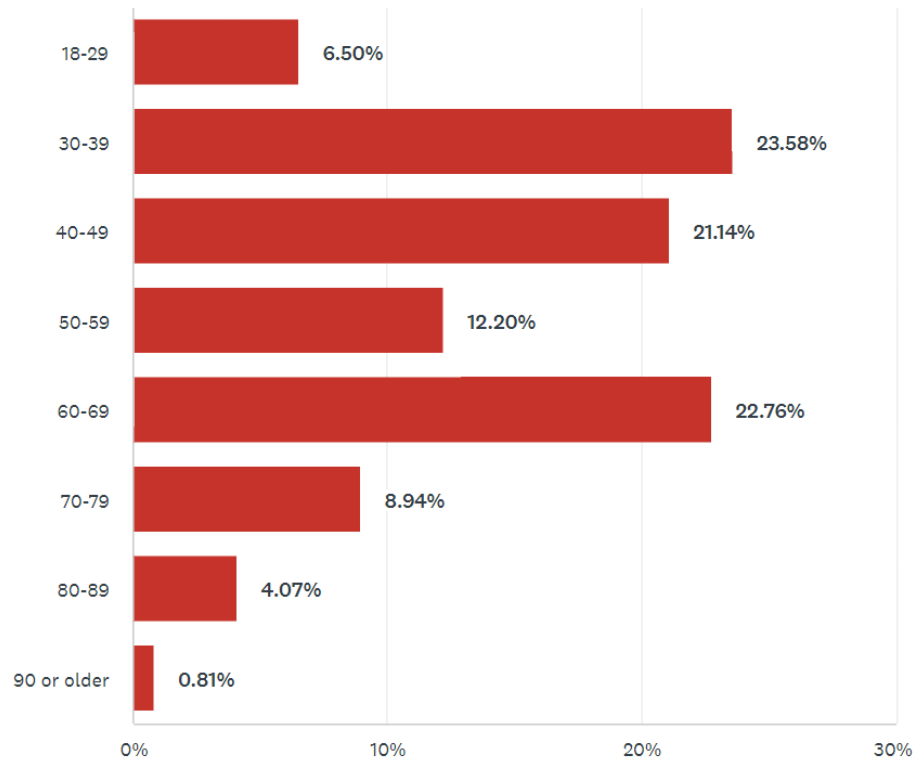


Figure 1

Main role of responders in data driven research or statistics

Answered: 120 Skipped: 3

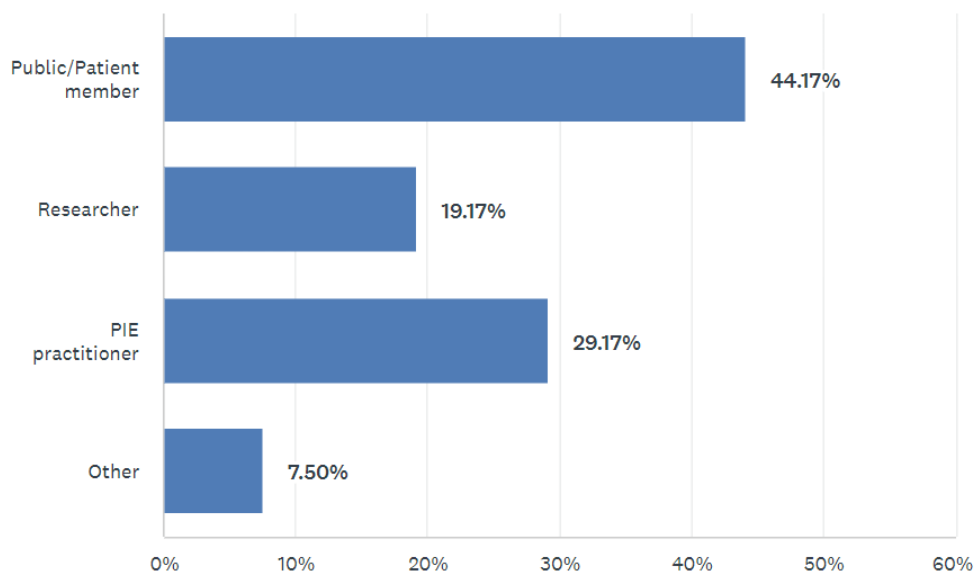


Figure 2

Type of data public/patient worked with

Answered: 48 Skipped: 75

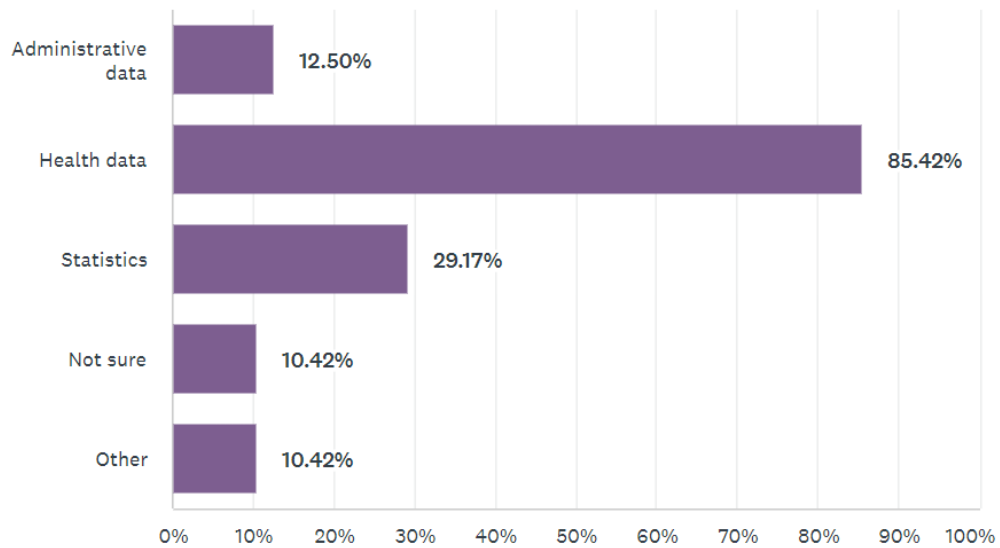


Figure 3

Type of data researchers and PIE professional worked with

Answered: 66 Skipped: 57

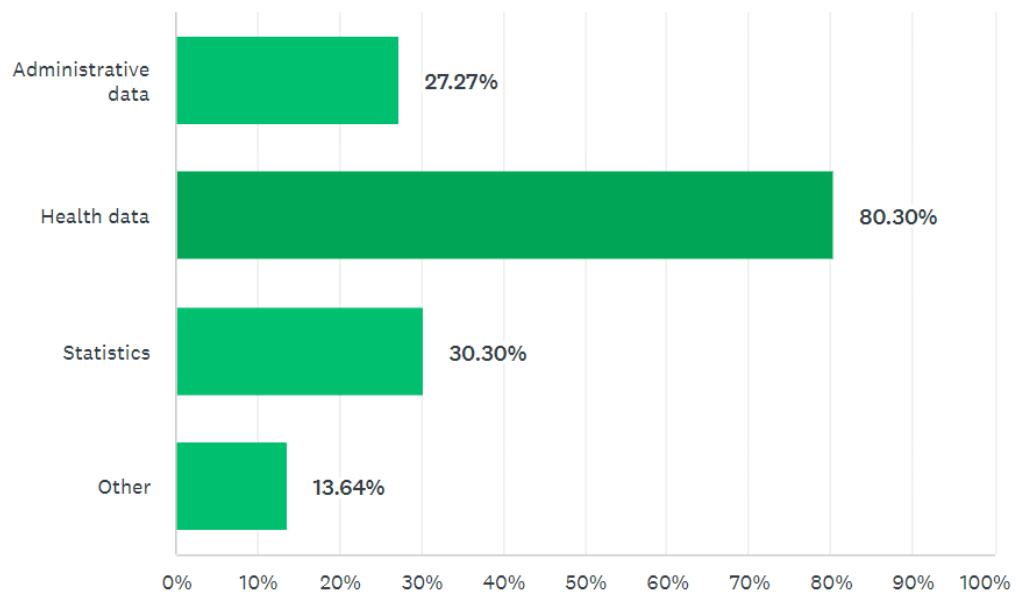


Figure 4

Where responders lived in the UK

Answered: 123 Skipped: 0

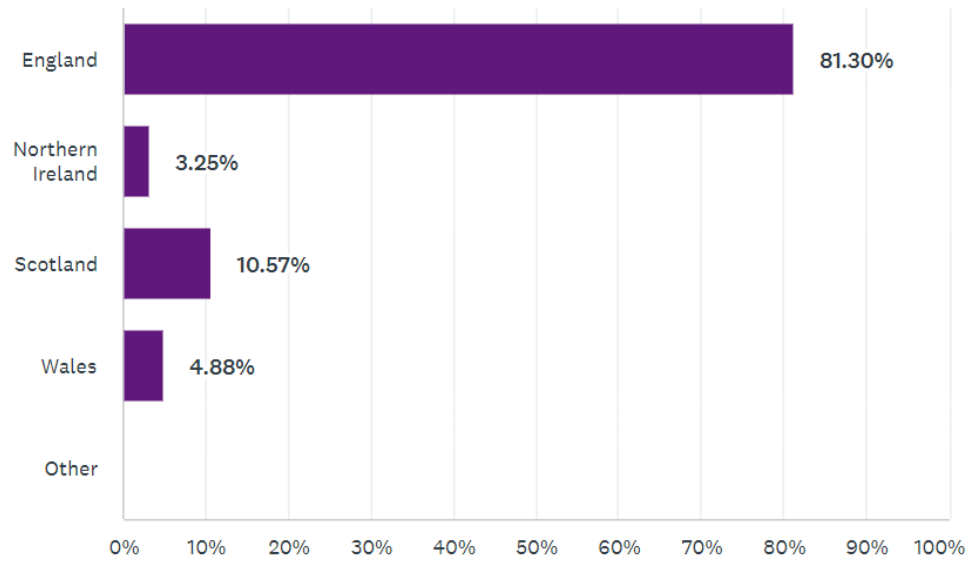


Figure 5

Findings

Researchers and PIE professional responders to this survey strongly expressed that they currently do not have enough access to PIE resources to support this role. Figure 6, below, illustrates a breakdown of responses to the level of support PIE professionals perceive to have in their role. It shows that no responders strongly agreed they had enough resources to support their role.

Researchers and PIE professionals: I have enough resources to support my role

Answered: 33 Skipped: 90

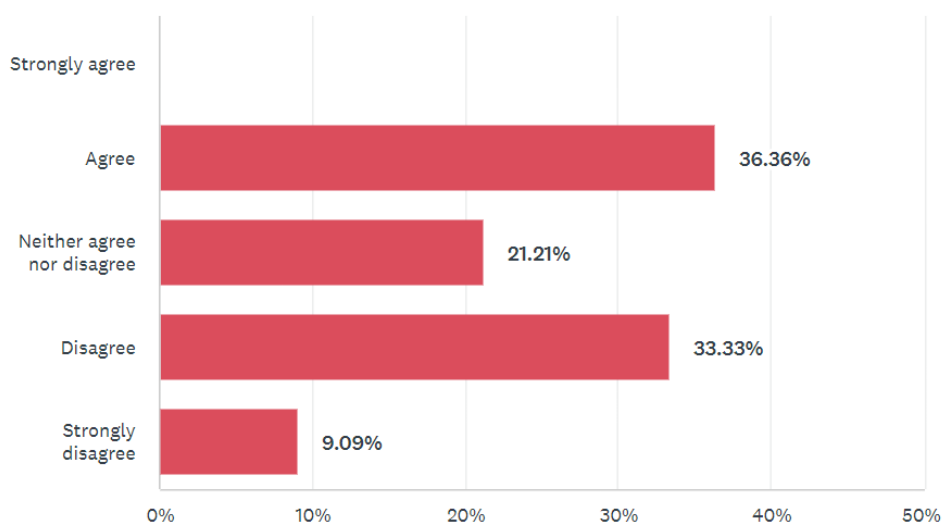


Figure 6

For members of the public what do good and bad explanations look like?

“too much jargon or complicated spreadsheets with no explanation”

Member of the public

When discussing what good explanations of data-driven research and statistics look like, responding members of the public highlighted the use of clear information formats, a good range of resources, and appropriate language. Conversely, poor explanation was described as having challenging language or jargon, providing limited information, and poorly explained statistical concepts. It should be noted there was a wide range of experiences and underlying knowledge from responding members of the public.

Good practice for responding members of the public entailed using different formats in the development of materials. Responding members of the public highlighted the importance of clear design of provided material such as tables or graphs to foster a greater understanding of the study messages. Additionally, for several responding members of the public, there should be particular importance placed on using plain language and real-world examples to explain technicalities of research.

Good explanation for responding members of the public is when “data assessment is explained and presented in simple lay person's language with clear statement on how the data was sourced and assessed”. Conversely, explanation was described as poor when information was too “academic or clinical style with language not understood by non-professional.” It was a common theme in responses to avoid “jargon without explanation or providing a simplified plain language explanation”.

In data research, members of the public described poor explanation of the value and reliability of data and its access, linkage, and use, in addition to the lack of information related to the context, methods and impact of data research. Some respondents also discussed receiving limited detail on technical aspects, such as data protection and sample characteristics, underscoring the lack of diversity and inclusion that can often characterise data-sets. The responders expressed a general desire for greater depth of information.

“[We] “need very clear explanation on the WHY data is needed and HOW it moves from data to action”

Member of the public

A barrier to public understanding of the value of data-driven research for public benefits is lack of information, either outright or in relation to inaccessible language. To overcome poor explanations of data research, some respondents admitted having independently looked for information online. As one public responder said if information is not effectively “explained I Google data .. facts”.

Concerning statistics, a few respondents highlighted the importance of sharing statistical information, to improve understanding of data research. However, these are rarely shared in an accessible way or not at all. These included the theoretical underpinnings informing decision-making on specific aspects of statistics such as forecasting; the reasoning behind the choice of specific statistical tests (e.g., correlation or causation); the process of gathering relevant statistics and their meaning for the purpose of the research; and the interpretation of findings, referring to statistical significance in particular. A few respondents indicated the need for a better explanation of percentages that are in the public domain but perhaps not fully understood because they are not contextualised.

Importantly some respondents admitted that their knowledge or professional background may have contributed to their better engagement with both topics, others revealed the challenges experienced mainly due to accessibility issues.

What aspects of data research or statistics would members of the public like to know more about

“All that is available”

Member of the public

When asked, members of the public showed a strong desire to learn about a wide array of data research and statistical processes. From our respondents there was a common desire to have a greater understanding of the data access process either what data is available or ways to support data availability, e.g. “Most effective ways of making data accessible”. Respondents also described a desire to know more about data security and protection processes such as “How anonymity is assured when linking data sets”.

Along with subject specific requests for training, e.g. “machine learning and improving diagnostics and treatment”, a common response from members of the public is for basic data research and statistics training, a “dummies guide” for instance. This is something we should make sure is signposted to members of the public. A less common theme, but noteworthy, is several public respondents asking for greater evidence of “data which will impact our everyday activities or capabilities”.

What aspects of data research or statistics do researchers and PIE professionals find challenging to explain to public members?

A wide range of aspects of data research or statistics were found to be challenging to explain to members of the public or groups. Statistical terms and principles commonly featured, including calculating years of life lost, pseudonymisation, estimation, randomisation, inference, probability, and prediction modelling. One researcher cited the “fact that most statistics are misleading; The fact that people use statistics to support narratives rather than inform them” as a barrier.

The technical aspects of data research and the many different processes or systems used by researchers were also cited as a barrier to public understanding. Some of these related to specific areas of research or infrastructure, for example data linkage, machine learning, federation, and legal vs ethical requirements.

“limited shared vocabulary (because there is no consensus) about data subject rights and governance structures. Without these we cannot secure equity in health data management and decision making, pre-defined engagement will take precedence over involvement”.

Public involvement and engagement practitioner

Researchers sometimes also cited the difficulty in explaining to the public why data or infrastructure like Trusted Research Environments (TREs) should be trusted and struggled to talk about ethical issues like ‘privacy’ or in addressing concerns about data re-use for commercial purposes.

Some researchers reported a lack of capacity to provide clear-language explanations whereas some bemoan a lack of easy-to-find resources to share with the public. It was also reported that it is difficult to describe how people can be involved in data research. One researcher said: “Sometimes it is difficult not to use technical jargon and describe findings in a simple to understand way”. 15% of respondents, however, reported that there were no aspects of data research which they found challenging to explain.

The role and expectations of PIE professionals

“I think the challenge is not communicating to small groups of engaged individuals but how to inform national debate”

Health data professional

How and who are involved and engaged in research was another common theme. Many cited difficulties in explaining what PIE is and why it matters, particularly given inconsistent terminology between funders. The time required to get public contributors to a point of understanding where they can meaningfully contribute to the research is also cited due to the amount there is to learn.

Several PIE Professionals and researchers also referenced the lack of power that professionals have to deliver what the public wants or needs. PIE Professionals in particular described feeling limited in their ability to affect change that public members want.

“Public contributors can sometimes find it difficult to distinguish the influence/knowledge that members of staff have e.g. they might ask a data analyst why a specific care pathway can't be changed in light of research results, but data analysts don't have this knowledge or power to change care”

Public involvement and engagement practitioner

“How much power we have (or don't have) as PPI professionals to deliver what the public wants or needs.”

Public involvement and engagement practitioner

As well as difficulties in explaining the role of public members and the scope of their influence over data research, one respondent also found it hard to explain to public contributors the roles, influence and knowledge that different members of staff have over how research is conducted. Managing expectations of the public by explaining the limitations that researchers face, the lengthy and cumbersome processes, as well as the necessity for things to be done a specific way was also cited as important.

What do good PIE resources look like?

“clear and accessible, created with a strong public involvement”

Public involvement and engagement practitioner

When asking researchers and PIE professionals about their preferred resources, the medium used to train the public a common theme was the use of visual learning such as videos and infographics. Some responders said the availability of additional generic training videos would be useful. Preferred resource sources for researchers and PIE professionals included GDPR Expert check, ONS, NIHR, Cancer Research UK, and INVOLVE. Interestingly, some responders said they had ‘developed in house tools to develop accuracy of data’ some for specific projects and also some said ‘time to train [public] members’.

Members of the public responding to the survey have expressed differing views on their preferred medium of resources, see figure 7. Members of the public put less emphasis on narrated videos and more emphasis on electronic guidance and presentation. Whilst videos and recorded presentations can be useful to members of the public, researchers and PIE professionals should be mindful of the preferred mediums of members of the public. Members of the public seem to prefer a more interactive medium with the opportunity to ask questions.

Preferred resource formats for patient/public responders

Answered: 36 Skipped: 87

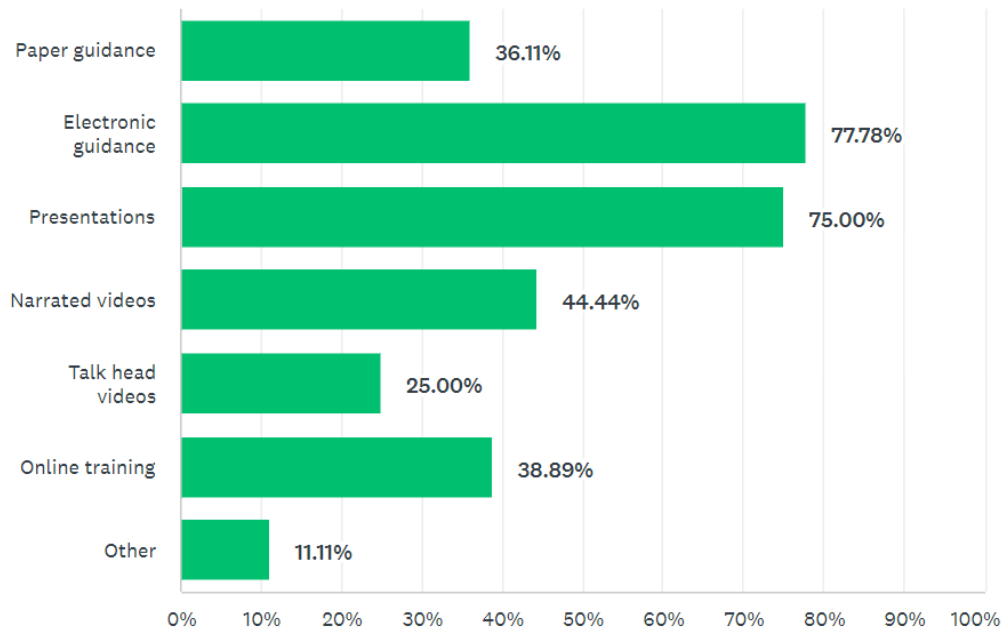


Figure 7

Researchers and PIE professionals stated that the most helpful and supportive resources were written in plain language, free, relatable, accessible, and reusable. Additionally, some respondents identified that good resources gave them ideas and motivation when working with PIE groups. Resources written to improve public understanding were described as helpful and supportive to their role. Notably, responders felt consistency across the sector in the use of language and terms would assist their roles.

Researchers and PIE professionals: What resource support do you need?

“Where would I find a list of resources available?”

Public involvement and engagement practitioner

As shown in figure 6 researchers and PIE professionals did not feel they had enough resources to support their role in public involvement and engagement. The results initially suggest there is a substantial need for additional resources that are

necessary to support the respondents' roles in data research and statistics. However, for some people good resources are already available, perhaps requiring signposting. Additionally, when describing what resources were needed there was a range of detailed responses. This highlights the diversity of need in the research and PIE community.

The findings of this survey did highlight a desire for a central website “to signpost the public to for simple explainers”. Simple explainers for members of the public was a recurring theme, such as to reach the “difference between evidence and opinion” and resources for promoting wider data literacy. Responders also requested resources to describe data research terms in research methods, such as Trusted Research Environments, federation, and anonymisation.

A less common theme but of note is a request for resources/guidance setting “out what is administrative data”. Additionally, further public explainers on how administrative data interacts and how it is linked to other forms of routine data, e.g. health data.

There were also specific requests from researchers and PIE professionals for resources to support public members' understanding of:

- Cross sectoral linkage
- UK Standards for data protection
- Trusted Research Environments
- Limitations of routinely collected data
- Research ethics process
- Resources to support/improve public levels of trust in data
- Specific health conditions.

Respondents highlighted the importance of these resources being accessible online, kept up-to-date, and available in one place. The results of this survey suggest that additional resources are necessary to support the respondents' roles in data research and statistics. It should, however, be noted that for many of the topics highlighted by respondents, resources already exist. In some instances, there may be a need for improved signposting to existing resources.

Summary

Lack of PIE resources

The results from this survey indicate researchers and PIE professionals do not have enough resources to support their role in involvement and engagement activities. Figure 6 shows that no responder strongly agreed that they had the required resources.

- Both members of the public and researchers/PIE professionals requested a wide range of additional resources, from data research introductions to subject specific guidance, such as on TREs. For some responders' requests, resources already exist to meet their needs.
- Responders may not be aware of these resources, or they are not of high enough quality for their needs. Members of the public and researchers/PIE professionals should be sign posted to available resources that would support their roles.

Wording and terminology in resources

The wording and terminology of existing PIE resources was a point of concern from members of the public and researchers/PIE professionals alike, but from different perspectives.

- Responding members of the public expressed a desire to see clear jargon free descriptions of data, in plain language.
- Several responding researchers and PIE professionals described it as very challenging to provide clear jargon-free descriptions, in part due to a lack of consensus on technical language.
- Responding researchers and PIE professionals showed a clear preference to providing greater standardised and consistent descriptions of data and data terminology for engagement with the public.

Style and content of resources

In terms of the content of PIE resources, members of the public showed clear preferences to the quantity, depth of information, and style of presentation.

- Responding members of the public requested a greater quantity and depth to the information provided to them.
- Several members of the public reported doing their own research into topics, when they thought they had not been provided with appropriate depth of information. The survey also showed differing resource style preferences, with members of the public favouring more interactive support, such as presentations and guidance, against researchers and PIE professionals favouring video supported resources.

Recommendations

Summary statement	Recommendation
Researchers and PIE professionals do not feel they have enough resources to support the PIE role	Researchers, PIE professionals, and supporting organisations could create additional targeted resources to support their work with members of the public
	Members of the public should be involved/consulted in choosing topics, creating, and approving resources to support PIE
There is a need to sign post to existing resources	Researchers, PIE professionals, and supporting organisations should collaborate to create an open access resource hub to provide links to reputable data research PIE resources
	Researchers and PIE professionals should continuously review existing resources to maintain their accuracy and relevance
Members of the public would like to see clear jargon free descriptions of data	Plain language and limited jargon should be used whenever creating public facing PIE resources
	Where technical language is required, researchers and PIE professionals should provide explanations / definitions
	When there is technical language, check that all public members have understood its meaning
Lack of consensus in description of data and data terminology for engagement with the public	Researchers and PIE professionals should collaborate across the data and statistical research communities to create consistency and clarity in descriptions of data terminology
	A glossary of data and statistical research should be created to support public members' ease of understanding
	Use real world examples to describe data related concepts, wherever possible, when creating public facing PIE resources
Provide the correct quantity and appropriate detail of information to members of the public	Researchers and PIE professionals should be aware of the needs of their audience and regularly check public members have the correct level of detailed resources. When required additional relevant information should be provided

Summary statement	Recommendation
Differing perspectives on the 'best' formats for PIE resources	<p>Where possible the preference of public members for more interactive resources, e.g. presentations, should be integrated into PIE activity</p> <p>When creating resources they should be created to be as inclusive and accessible as possible for their audience, such as using large print and if online meeting screen reader requirements</p> <p>Researchers, PIE professionals, and supporting organisations should aim to create resources that support different learning styles and preferences, this could include podcasts, videos, written articles etc.</p>

Strengths and Limitations

This report, like all studies, contains both strengths and limitations to its methods and applicability to the target audience:

- A strength of this survey is it has captured both views of the public and professionals with a good mix of respondents from members of the public, researchers, and PIE professionals.
- The participants in this report represent a good age range as seen in figure 1.
- The participants, both members of the public and researchers/PIE professionals are working across multiple sectors of data research, see figures 3 and 4. Though health data, as could be expected, is the largest represented sector, researchers/PIE professionals have, in particular, good representation when working with administrative and statistical data.
- The responses received have had a good depth of reflection on the lived experience of participants in data research. This builds a degree of confidence in the findings from this survey.

However,

- A note of caution that these preferences are from a limited number of responders (n=123) that will likely represent the more engaged individuals from the community.
- The survey has limited responses from Northern Ireland, Wales, and to a lesser extent Scotland, see figure 5. This has to be taken into account when implementing any findings.

Appendix

Appendix A: Resource survey questions

About you

1. What is your current age?

- Under 18
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90 or older

2. Where do you reside within the UK?

- England
- Northern Ireland
- Scotland
- Wales
- Other (please specify)

3. What main role do you have in data driven research or statistics?

- Public/Patient member
- Researcher
- Public involvement and engagement practitioner
- Other (please specify)

4. What type of data do you work with? (tick all that apply)

- Administrative data, e.g. housing, education, or policing data etc
- Health data
- Statistics
- Other (please specify)

Resource Survey for Public Involvement and Engagement Activities in Data Driven Research

5. What type of data do you work with? (tick all that apply)

- Administrative data, , e.g. housing, education, or policing data etc
- Health data
- Statistics
- Not sure
- Other (please specify)

6. When being told about data research or statistics, what do you think has been explained to you well? Please feel free to explain why it was explained well.

7. When being told about data research or statistics, what do you think has been explained to you poorly? Please feel free to give an example

8. What aspect of data research or statistics would you like to know more about to help you in your work?

9. Are there any aspects of data research or statistics you find challenging to explain to public members/groups?

10. Are there any other aspects of your work or role you find challenging to explain to public members/groups?

Resource Survey for Public Involvement and Engagement Activities in Data Driven Research

11. Do you agree with the statement "I feel I have enough resources to support my public involvement and engagement role"? {select one}

By resource we are referring to guidance or support material in any format which is not staffing, budgets or honorariums.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

12. Are there any resources that you find helpful or supportive when you conduct public involvement and engagement with data research or statistics? *These can be resources for you or those given to members of the public*

13. Why has this resource been helpful or supportive?

14. Are there any subjects or aspects within data research or statistics you would like to have additional resources to support your public involvement and engagement activities? *These can be resources for you or those given to public members*

15. Do you have any other thoughts on resources supporting public involvement and engagement in data driven research or statistics? {free text}

Resource Survey for Public Involvement and Engagement Activities in Data Driven Research

16. Which format(s) do you prefer to receive resources in, when you get information about data research or statistics? (all that apply)

- Paper guidance
- Electronic guidance
- Presentations
- Narrated videos
- Talk head videos
- Online training
- Other (please specify)

17. Which topics or aspects within data research or statistics do you feel would benefit from additional resources to support your role?

18. Do you have any other thoughts on resources supporting public involvement and engagement in data driven research or statistics?

Appendix B: Question response rate

Question	Number of responses	Number of responses removed	Number of valid responses
When being told about data research or statistics, what do you think has been explained to you well? Please feel free to explain why it was explained	26	1	25
When being told about data research or statistics, what do you think has been explained to you poorly?	30	3	27
What aspect of data research or statistics would you like to know more about to help you in your work?	33	0	33
Are there any aspects of data research or statistics you find challenging to explain to public members/groups?	40	0	40
Are there any other aspects of your work or role you find challenging to explain to public members/groups?	27	2	25
Are there any resources that you find helpful or supportive when you conduct public involvement and engagement with data research or statistics? These can be resources for you or those given to members of the public	10	0	10
Why has this resource been helpful or supportive?	22	0	22
Are there any subjects or aspects within data research or statistics you would like to have additional resources to support your public involvement and engagement activities? These can be resources for you or those given to public members	17	0	17
Do you have any other thoughts on resources supporting public involvement and engagement in data driven research or statistics?	15	1	14
Which topics or aspects within data research or statistics do you feel would benefit from additional resources to support your role?	30	3	27
Do you have any other thoughts on resources supporting public involvement and engagement in data driven research or statistics?	15	1	14



To get involved please email contact@pedri.org.uk

HDRUK
Health Data Research UK

 **ADRUK**
Data-driven change

NHS
England

 **Research
Data
Scotland**

 **Office for
National Statistics**

DARE UK

 **CANCER
RESEARCH
UK**

PEDRI

 **British Heart Foundation
Data Science Centre**
Led by Health Data Research UK