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Research Involvement and Engagement

Effective involvement: a report on the evaluation of a research awareness training package for public involvement in health research

--Manuscript Draft--

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Funding Information:	National Institute for Health Collaboration for Leadership in Applied Health Research and Care, Yorkshire & Humber	Dr Christine Smith
Abstract:	<p>Background As the role of Patient and Public Involvement contributors expands to all stages of the research cycle, there is increasing demand for training that meets the needs of this diverse population. To help meet this demand the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber, worked with members of the public to develop a bespoke training package. The University of Huddersfield's Public Partnership Group were invited to host the training and undertake an independent evaluation.</p> <p>Methods Participatory action research was used to structure the evaluation, such that participants in the training and public members of the evaluation team were co-collaborators with a robust, significant and visible share in the process. This is evidenced by their public team members' roles in undertaking the majority of data gathering, including surveys, non-participant observation and interviews, and analysis, engaging in all reflective discussions, leading on producing a formal report and contributing significant sections of this paper. The evaluation was approved by a University ethics panel. Public involvement consisted of the 13 participants who received the training, and 3 of the 6 members of the evaluation team. Data collection took place between November 2017 and March 2018.</p> <p>Results The evaluation found that participants understood more about the research process from attending the training, gaining greater confidence in their ability to volunteer to get involved. It also highlighted the difficulties of meeting the training needs of a diverse group with varying experiences and expectations. Skilful facilitation was needed to maintain pace, whilst engaging people with different levels of interest and knowledge. The management of the environment to maximise comfort and involvement was important. Early feedback to the delivery team enabled timely updating of the package. Involvement in the evaluation was initially daunting for the three public members of the team, but hugely enjoyable and fulfilling, as well as enriching the process and outcomes. In particular, public involvement in the analysis and interpretation stages increased the authenticity of the evaluation findings.</p> <p>Conclusions This evaluation validated the training package and demonstrated the value and impact of Public Involvement at all levels in research.</p>	
Corresponding Author:	Christine Smith University of Huddersfield School of Human and Health Sciences UNITED KINGDOM	
Corresponding Author E-Mail:	C.Smith4@hud.ac.uk	
Corresponding Author Secondary Information:		
Corresponding Author's Institution:	University of Huddersfield School of Human and Health Sciences	
Corresponding Author's Secondary Institution:		
First Author:	Catherine Richardson	

First Author Secondary Information:	
Order of Authors:	Catherine Richardson
	Ilyas Akhtar
	Christine Smith
	AMANDA EDMONDSON
	Alison Morris
	Janet Hargreaves
	Christine Rhodes
	Jo Taylor
Order of Authors Secondary Information:	
Response to Reviewers:	<p>Reviewer 1.</p> <p>The plain English summary is very clear. It would however be useful to add a final paragraph highlighting the value of public research team members collaborating in the study and the challenges that were encountered. The only other change I suggest to the plain English summary is to replace the phrase "care in selecting a nice environment" with "taking care to create a comfortable training environment". Maybe only a personal opinion but to my mind this reads better.</p> <p>Thanks for these useful suggestions – we have now incorporated these edits within the plain English summary. We have added the following fourth paragraph in the findings / recommendations section: 'The inclusion of public researchers in the evaluation team changed the way the work was managed and completed for the better. At times it was difficult; the public members needed to be assertive to get their views understood and the experienced researchers needed to allow others to lead'.</p> <p>The Abstract also gives a useful summary of study. However the first Methods paragraph is unclear on first reading when describing how public members of the evaluation team contributed to the study. Clarity would be improved by the following redrafts "...public members of the evaluation team were co-collaborators...." and "This is evidenced by public team members' roles in undertaking....".</p> <p>We have edited as suggested and agree that this makes clearer the role of the public members of the team.</p> <p>On page 10 readability would be improved by avoidance of the terms 'pedagogic' (line 23) and 'pedagogical' (line 55) which are not in common use. These should be removed altogether or replaced by plain English phrases.</p> <p>We have replaced these with 'learning' on line 55 and 'facilitation' on line 55.</p> <p>On page 13 line 35 readability may be improved by replacing the term 'heterogeneity' with 'diversity'.</p> <p>We have amended as suggested.</p> <p>On page 14 line 33 readability may be improved by replacing the term 'paradigm' with 'model' or 'pattern.'</p> <p>We have replaced with model.</p> <p>Reviewer 2</p> <p>This is an interesting article that highlights the issues of including PPI proper into research proper. I think the authors have addressed the comments by previous reviewers. However, I have a couple of questions/comments for the authors.</p> <p>6 Line 22 - participants were already known SUC's who had knowledge of research process. There is no justification for using these participants and no comment about how this might have affected the outcomes of the training. These participants found the training difficult and it sounds as though health literacy for research was not considered by the team. A research naive bunch would probably have been totally lost. This is a serious limitation of the evaluation.</p> <p>Although participants were known to the SUCs, they varied in their background, health state, literacy and health literacy, and research knowledge and experience. Their interests in research also varied. We have added this sentence in the section on Participants on page 6. Additionally, the content of the programme had previously been piloted with a group which included research naive participants. They expressed preferences to retain the content but recommended spreading it over two days. This became the structure of the programme which was formally evaluation.</p> <p>Page 14 Line 1 - There are always some participants that are more forthright than</p>

	<p>others and the facilitator needs to be very experienced to ensure everyone has a say. One limitation might be that there were two large groups - quite daunting for PPI. Having smaller groups would have helped with inclusiveness.</p> <p>We agree with this suggestion having since run the course with one smaller group on two occasions. We have added the following sentence to the end of this paragraph: 'Alternatively, working with one smaller group could have helped with inclusiveness, although this has implications for future sustainability and capacity of training.'</p> <p>Page 14 Line 22 - The authors comment on the "difficulty to unpick the deeply embedded power imbalances...", but fail to mention that research is difficult and complicated, especially for ethics and gaining approval of committees. There will always be power imbalance between people with knowledge and people without knowledge of a certain field.</p> <p>Thank you for this comment. Whilst this is outside the scope of the current paper, we have added to the end of the sentence on page 14 line 22 '...and the different understandings about research that may contribute to this.'</p> <p>Page 14 Line 50 - The authors make an interesting point about how PPI could be used effectively in research.</p> <p>We thank the reviewer for acknowledging this.</p> <p>Reviewer 3</p> <p>The Authors have adressed a challenge that all working with PPI will meet- have met. How to train lay participants, content , format ?? . The findings stress the diversity in the needs and outcomes of training for PPI for lay people. This may not be too exciting or new knowledge for those that for some years have worked within the PPI concept . The contribution from the this project is to documentation that this diversity. I wonder why the authors havent challenged the approach to PPI that is the basis for the evaluation: that lay people should become competent to participate and contribute to all steps in a research cycle . It seems to me that the authors must have had such discussions-the discussion section is the far most interesting part of this paper. Have the authors considered a conclusion from the project like this: - "that although training enables lay people to feel more confident as partners in research it does not support the individual participant to understand -what is in it for me ? how did I contribute ?.</p> <p>We agree that the paper does not fully engage with key debates about the extent of PPI and the growing argument that PPI members should contribute to all steps in the research cycle, and that the only barrier to this is lack of competence. However, although this is important to address, it is beyond the scope of the current paper, which aims to share learning about developing and evaluating a PPI training programme, and involving PPI partners in that process. The training programme itself, however, does engage with these debates, and also includes discussions about the benefits for PPI members and the importance of evaluating the impact of PPI on research and sharing this in research outputs and with PPI members.</p>
Additional Information:	
Question	Response
<p>Is this study a clinical trial? A clinical trial is defined by the World Health Organisation as 'any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes'.</p>	<p>No</p>

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Title page

Title: Effective involvement: a report on the evaluation of a research awareness training package for public involvement in health research.

Authors:

Catherine Richardson: Public member, Public Partnership Group, Human & Health Sciences, University of Huddersfield. C.Richardson@hud.ac.uk.

Ilyas Akhtar: Public member, Public Partnership Group, Human & Health Sciences, University of Huddersfield ily16@hotmail.co.uk.

Christine Smith [corresponding author]: Co -presenter and facilitator for the training package, Human & Health Sciences, University of Huddersfield. C.Smith4@hud.ac.uk

Amanda Edmondson: Academic member, Public Partnership Group, Human & Health Sciences, Centre for Applied Research in Health, University of Huddersfield, A.Edmondson@hud.ac.uk

Alison Morris: Service User/ Carer lead and administrator, Public Partnership Group, Human & Health Sciences, University of Huddersfield A.Morris2@hud.ac.uk

Janet Hargreaves: Academic member, Public Partnership Group, Human & Health Sciences, University of Huddersfield J.Hargreaves@hud.ac.uk

Christine Rhodes: Academic member, Public Partnership Group, Human & Health Sciences, University of Huddersfield C.A.Rhodes@hud.ac.uk

Jo Taylor: Training package design and presentation lead, Department of Health Sciences, University of York, jo.taylor@york.ac.uk

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Plain English summary:

Background:

The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber, worked with members of the public to develop a training package for members of the public to understand health research, and the ways they could be involved in doing it.

They collaborated to design an enjoyable and informative experience and then asked a university Public Partnership Group to host, and independently evaluate the package.

Method and design:

The evaluation team included three service users/ carers and three academics. We obtained ethical approval from the University, and consent from the participants to gather data. We used surveys, interviews and observation to find out about the participants' experience.

Findings and recommendations:

We found that the package was well designed, skilfully delivered, interesting and informative. All participants, despite different experience and expectations, felt they understood more about the research process and had greater confidence in their ability to volunteer to get involved.

Delivery was rushed at times and breaks were short because there was a lot of information. The venue affected how comfortable participants felt.

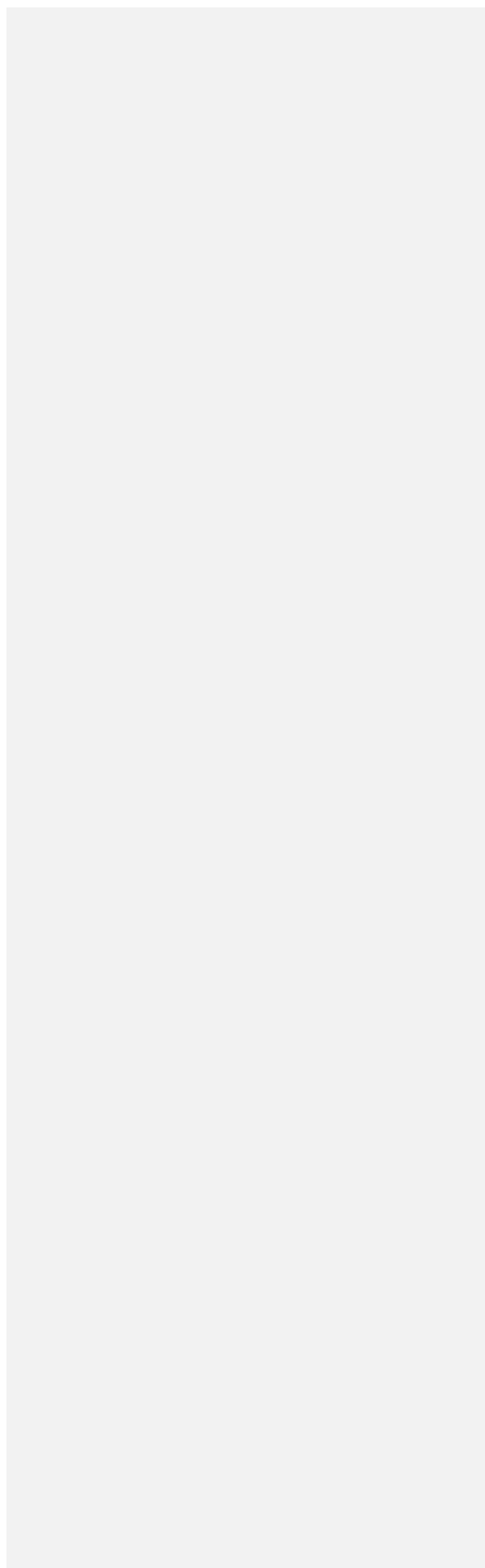
We recommend reducing or simplifying the material to allow a slower pace and more breaks, more time in introductions, different ways to gain group feedback, and ~~care in selecting a nice environment~~ taking care to create a comfortable training environment. A text book, or manual containing the materials in detail, would be a valuable addition.

The inclusion of public researchers in the evaluation team changed the way work was managed and completed for the better. At times it was difficult. The public members needed to be assertive to get their views understood and the experienced researchers needed to allow others to lead.

Conclusion:

The training package was enjoyable and did increase the participants' knowledge, understanding, skills and confidence. The experience of being involved with the evaluation was enriching for the team.

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Abstract

Background

As the role of Patient and Public Involvement contributors expands to all stages of the research cycle, there is increasing demand for training that meets the needs of this diverse population. To help meet this demand the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber, worked with members of the public to develop a bespoke training package. The University of Huddersfield's Public Partnership Group were invited to host the training and undertake an independent evaluation.

Methods

Participatory action research was used to structure the evaluation, such that participants in the training and public members of the evaluation team were co-collaborators with a robust, significant and visible share in the process. This is evidenced by their-public team members' roles in undertaking the majority of data gathering, including surveys, non-participant observation and interviews, and analysis, engaging in all reflective discussions, leading on producing a formal report and contributing significant sections of this paper.

The evaluation was approved by a University ethics panel.

Public involvement consisted of the 13 participants who received the training, and 3 of the 6 members of the evaluation team. Data collection took place between November 2017 and March 2018.

Results

The evaluation found that participants understood more about the research process from attending the training, gaining greater confidence in their ability to volunteer to get involved. It also highlighted the difficulties of meeting the training needs of a diverse group with varying experiences and expectations. Skilful facilitation was needed to maintain pace, whilst engaging people with different levels of interest and knowledge. The management of the environment to maximise comfort and involvement was important. Early feedback to the delivery team enabled timely updating of the package.

Involvement in the evaluation was initially daunting for the three public members of the team, but hugely enjoyable and fulfilling, as well as enriching the process and outcomes. In particular, public involvement in the analysis and interpretation stages increased the authenticity of the evaluation findings.

Conclusions

This evaluation validated the training package and demonstrated the value and impact of Public Involvement at all levels in research.

Keywords

Formatted: None, Space Before: 0 pt, After: 8 pt, Line spacing: Multiple 1.08 li

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7 Co-production; Public involvement; PPI; Participatory research; Research training
8 Service users and carers;
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10 **Background**

11 Research, particularly in the health field which preferences quantitative methods, has
12 traditionally seen the patients and public that research is intended to benefit as
13 remote from its design and delivery. There is a growing movement to challenge this
14 view which is endorsed within the UK by Government funded organisations. For
15 example, the National Institute for Health Research (NIHR) states:
16

17 “The suggestion that members of the public are ‘subjects’ or ‘silent partners’ in
18 research is no longer a tenable position to maintain for any research organisation
19 wishing to fund high quality research. Partnership, reciprocity and openness are now
20 fundamental to how research is done and to the successful translation of research
21 results into practice.”(National Institute for Health Research 2015)
22

23 The focus above on funding indicates the growing trend for Patient and Public
24 Involvement (PPI) to be embedded in any bid for monies. This parallels the
25 imperative from *Liberating the NHS*: “no decision about me without me” (Department
26 of Health 2010). Thus, any organisation offering health or social service, or
27 undertaking research in these areas is challenged to fully engage its service users,
28 or risk exclusion from funding.
29

30 Whilst user-led pressure groups and NHS activists may be heartened by this policy
31 shift, the ‘active’ Involvement in research, advocated by Involve (2012) often proves
32 hard to achieve. Oliver et al (2008) suggest ‘political mandate’ and the desire for
33 improved quality of research are the primary aims of Involvement. Political mandate
34 alone seems likely to lead to minimal, tokenistic involvement. However, Brett et al.’s
35 (2014) systematic review suggests growing evidence for impact of PPI at all stages
36 of the research process. For example, helping with design, ensuring language was
37 sensitive and enhancing data collection. In order to achieve this more engaged
38 approach, moving from tokenistic involvement to fuller participation, consideration
39 needs to be given to the preparation, training and support necessary for people to
40 make an effective contribution. Brett et al (2014) advise:

41 “offering service user training in research methodology may help maximize the
42 service user involvement and empower service users in their contributions to the
43 design of the study, providing service users with the tools to discuss outcomes and
44 formulate questions rather than limiting their involvement to accounts of their
45 experiences” (p.641).
46

47 Within this spirit and in order to promote, support and improve the scope and amount
48 of involvement of the public in health research, a public involvement team from the
49 Mental Health and Comorbidities Theme (DIAMONDS Programme,
50 <http://www.diamonds.nihr.ac.uk/home>) of the National Institute for Health Research
51 Collaboration for Leadership in Applied Health Research and Care, Yorkshire and
52 Humber (NIHR CLAHRC YH), worked with researchers to develop a bespoke
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7 training package for mental health service users and carers. This package was then
8 offered to the wider CLAHRC programme as a generic resource.
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10 The NIHR CLAHRC YH team initially piloted this awareness training package,
11 guided by best evidence to date and produced collaboratively with PPI members,
12 which was delivered in a one-day event. Feedback from participants led to a
13 restructure of the package and materials, creating a two-day training programme of
14 information sharing, discussion and group work.

15 Before offering the restructured awareness training package the delivery team
16 invited the collaboration of a University Public Partnership Group (PPG) who hosted
17 the training and designed and conducted a formal structured evaluation. The PPG is
18 a funded group within the university, chaired and led by Service Users and Carers,
19 with co-opted academic affiliations. It aims to influence health and social care
20 development through direct involvement with education and research.
21

22 **Methods**

23 **Aim**

24 The aim of the evaluation was to find out if the training would increase the
25 knowledge, understanding, skills and hence confidence of the participants regarding
26 their involvement in the research process.
27
28

29 **Design**

30 A Process Evaluation Methodology (Moore, Audrey et al. 2015) was employed to
31 explore implementation and participants' responses to and interactions with the
32 training, using a combination of qualitative and descriptive quantitative data. The
33 principles of collaborative participatory research (Minkler and Wallerstein 2008)
34 underpinned the design of the training package and the evaluation.
35

36 Initial planning meetings were held between the NIHR CLAHRC YH's training
37 implementation team, and members of the University PPG where they discussed
38 and agreed on an approach. All parties agreed that the evaluation should be co-
39 produced with the academic and service user/ carer (SUC) members of PPG being
40 equal partners. Three SUCs (one of whom was an administrator for the PPG) and
41 three academic staff with experience of educational and health research formed the
42 evaluation team. Although participants were known to the SUCs, they varied in their
43 background, health state, literacy and health literacy, and research knowledge and
44 experience. Their interests in research also varied. The training package evaluation
45 team were independent from the NIHR CLAHRC YH implementing team but worked
46 in close collaboration to ensure that the evaluation met expectations of the training's
47 agreed objectives.

48 Benchmarks for the training evaluation were identified through feedback from
49 researchers and service users. The discussion led to a decision not to include any
50 'testing' of participants' increased ability to engage in PPI. This was for two reasons:
51 firstly, adding a before and after measurement of skills and abilities risked turning an
52 event that what was intended to focus on awareness and confidence raising into an
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7 assessed course, which PPG members did not want, and would likely have changed
8 the dynamic of the evaluation. Secondly, although all participants had the potential
9 for Involvement over the weeks following the training, there was no guarantee that
10 this would be the case, so there was an uncontrollable variable. What it does
11 include relates to the expectations SUCs had of a training event and the goals that
12 health researchers thought could be achieved by a training event in terms of
13 enhancing PPI. This in turn led to the creation of four sets of data gathering:
14

- 15
- 16 1. Pre-training survey: to be completed after signing consent forms and before
17 the first session commenced.
- 18 2. Post-training survey: to be completed immediately after the end of the second
19 session.
- 20 3. Teaching observation: to be completed by two non-participant observers and
21 specifically including at least one SUC team member.
- 22 4. Individual interviews three months after training.
- 23

24 In addition, the training PowerPoint presentation was reviewed by a SUC evaluation
25 team member who was not a participant or observer at the training event.

26 **Participants and recruitment**

27
28 The training invitation went to an already known, purposeful sample of adult SUCs
29 who:

- 30
- 31 ▪ had some knowledge of the research process
- 32 ▪ were interested and committed to being involved in the training
- 33 ▪ were available on the two days of training.
- 34

35 Of the fifteen people who responded to the invitation to attend, thirteen attended on
36 day one and were included as evaluation participants.

37 **The training package**

38
39 The training days took place in November 2017 at the evaluation team's host
40 institution.

41 The day one venue was a small room situated at a part of the building that ensured
42 the minimum of external interruption. Participants sat round two circular tables which
43 meant that a few participants from each table had their backs to the screen, having
44 to turn around to face the front during the lecture presentations. Though the room
45 had air conditioning it became uncomfortably warm especially in the afternoon for the
46 group seated further from the exit.

47
48 The day two venue was in a large room with the tables arranged in two u-shaped
49 formations, allowing all participants to sit facing the screen throughout. The central
50 heating was difficult to regulate and the room became uncomfortably cold towards
51 the end of the day.

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7 On both training days, the teaching resources included a large screen with power
8 point slides, plus hand-outs, pens, post-it notes and writing material on the tables.
9 Two members of the evaluation team quietly observed the teaching process on both
10 training days by taking a back seat behind each group of participants.

11 Day one commenced with an opportunity for everyone to introduce themselves and
12 then the presentation focused on each stage of the research cycle. Day two
13 recapped understanding and focused on aspects of the research cycle where public
14 involvement was likely. One session specifically focused on introducing research
15 methods commonly used in health services research.

16
17 The presenter used a lecture technique followed by posing a question or by outlining
18 a group work task relevant to the topic just covered. The presenter then joined,
19 chaired and facilitated one group while the co-facilitator similarly worked with the
20 other group, as well as keeping time.

21
22 At the end of each group work task, the presenter and co-facilitator summarised the
23 group's findings. Finally, the presenter orally combined the two sets of findings into
24 one summary and moved back to the front to introduce the next topic.

25 **Data collection**

26
27 **Pre and post training surveys:** These were designed and piloted by PPG
28 members. The pre-training survey was completed by all participants after signing
29 consent forms (n=13) and before the first session commenced. The post training
30 survey was completed immediately after the end of the second session (n=12, one
31 participant could not attend day two). Questions aimed to understand the hopes and
32 expectations of participants, and their experience of the training. They included a
33 question asking them to rate their level of confidence on a scale of 1 -10 where 1
34 was low confidence and 10 was very confident. Whilst it is acknowledged that this
35 self-rating of confidence is limited in its significance, a decision was made not to
36 attempt to build in a measure of change, as this would introduce a perceived element
37 of 'testing' of their ability, which might be stressful and would run counter to the aims
38 of the training.

39 **Teaching observation procedure and measurements:** The teaching observation
40 were undertaken by one SUC and one academic, focus was mainly on the flow and
41 effectiveness of the training package, including:

- 42 • Course structure and delivery
- 43 • Content volume and quality/readability
- 44 • Pace and understanding/assimilation /checking understanding/ opportunity
45 for asking questions/clarification/ areas needing further development
- 46 • Group work discussions/balance between interaction participation
- 47 • Effectiveness of the delivery/methods

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50 **Post training individual interviews:** At around 3 months post-training, participants
51 who had consented to being contacted were invited to an interview either by
52 telephone, email or face to face. Two of the SUCs and one academic undertook the
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7 interviews. This was a structured interview, designed to mirror the questions and
8 areas of interest raised in the earlier surveys, allowed the opportunity to discuss any
9 areas of increased skills if this was appropriate and included an overall judgement of
10 their perceived level of confidence (n=11).

11 **Analysis and development of recommendations**

12
13 Analysis was conducted in two phases: immediately after the training, and 3 months
14 later after the follow-up structured interviews. Descriptive statistics were used to
15 explore perceived levels of confidence for Public Involvement among participants
16 before and after the training. The free text responses from the pre and post training
17 surveys, structured interviews and notes from the teaching observations were
18 analysed to identify themes (Newby 2014).

19
20 The first phase of analysis was undertaken by the three core researchers ensuring
21 inter-rater agreement. This analysis plus the review of training materials were the
22 basis of a series of four iterative, reflective discussions which helped to ensure a
23 collaborative approach, to ensure mutually derived findings and to provide early
24 formative feedback to the delivery team and to formulate recommendations:

- 25 • Discussion meeting 1 was between the two teaching observers [one a SUC
26 and one an academic] after the first training day to compare notes and review
27 the observation method. This established a spirit of enquiry and debate that
28 permeated the rest of the analysis. It affirmed the observation method and
29 indicated areas for follow-up.
- 30 • Discussion meeting 2 included a second SUC who had reviewed the teaching
31 materials, but had not been a participant or observer of the training. Each
32 person had undertaken initial analysis and coding of the survey findings. Their
33 analysis cross referenced with teaching observations and training materials
34 review led to refined coding and initial theme identification.
- 35 • Discussion meeting 3 included the three people as above but now included a
36 fourth SUC who had attended the training and completed the surveys, but was
37 also a member of the evaluation team. Initial themes were scrutinised, debated
38 and refined.
- 39 • Discussion meeting 4 was between the two teaching observers and the two
40 delivery team members. This meeting allowed the evaluation team to give
41 formative feedback to the delivery team to assist them in preparing for the roll-
42 out of the training regionally. The two observers agreed to produce a reflective
43 document prior to the meeting summarising the emergent findings, including
44 tentative recommendations. The delivery team lead had also reflected from her
45 perspective and these two documents formed the basis of the discussion.
46 There was a strong congruence between the different perspectives, but also
47 many points of debate.

48 Finally, following the three months gap between survey and interview data collection,
49 coding and analysis of the structured interview data was conducted by the same
50 analysts from phase one and incorporated into the findings. Two further discussion
51 meetings between the evaluation team reviewed and consolidated the themes and
52 recommendations.
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Results

Pre- training survey findings:

The pre-training survey feedback revealed a diverse group of 13 participants whose responses indicated a wide range of education levels and life experience.

The questions were intended to find out each participant's individual hopes and expectations, their current involvement, if any, future aspirations after the training and how they currently rated their level of confidence in their involvement in health research.

The three key expectations revealed for the majority of participants were to gain more knowledge and information in general about health research; to understand research methods and process; and to understand the workings of the PPI field better.

The participants' responses indicated that their expectations matched the training stated goals and objective. Two participants however reported having no specific expectations, adding that they hoped the training would address that.

Less frequently reported areas of interest were to learn more about consultation, co-production, collaboration, learning to navigate the system, addressing the 'tick box' culture, and working and dealing with staff in NHS organisations.

Potential areas of choice for future involvement identified by participants included:

- designing and / or evaluating research projects
- joining panels
- opportunity to sit in on student research training
- assisting students in choosing research topics for their dissertation
- getting more proactive in influencing services
- getting involved in more research work
- studying for further qualifications

Post-survey training findings:

The post training survey intended to find out whether the participants' expectations had been met, what sort of things they had enjoyed, things they understood better, suggestions for change and their current level of confidence in involvement in future research.

Out of the 12 participants who were able to attend the second day, 10 reported that their expectations had been met, that their knowledge and information around PPI had improved and that they now had a better understanding of the research process. They also stated that they looked forward to more engagement and involvement. Two reported that though they had no set expectations, they had learned a lot.

All the participants reported that they enjoyed the group discussions most. Some enjoyed the informal atmosphere while others appreciated the way the delivery team was approachable, which made them feel welcome and at home.

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7 Participants made a number of suggestions in terms of how the training package
8 could be improved:
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- 10 ▪ the length of the training be shortened
- 11 ▪ the training days could be brought closer
- 12 ▪ slower introductions session and participants should have name badges
- 13 ▪ better room arrangements so that everyone can see everyone else
- 14 ▪ pace to slow down so that group discussions are not rushed
- 15 ▪ participants to report their own group discussion findings

16 The main message was that participants had learned and understood a great deal
17 more about the research process and had a better understanding of PPI.
18

19 **Teaching observation findings:**

20 The teaching observation exercise focused on five main aspects of the teaching
21 session
22

23 a) Course structure and delivery:

24 The sessions were very well delivered with clear audibility and a good
25 communication style. The course content was of high quality and the presenter
26 demonstrated a high degree of skill and knowledge in both content and facilitation
27 techniques, with clear pedagogic-learning intentions.
28

29 b) Content, volume, quality and readability:

30 Although the content was of high quality, there was too much and so the central
31 messages were sometimes lost. Some slides were very busy and complex, while
32 some were too small to see clearly making readability difficult for the participants.
33

34 c) Pace and understanding/assimilation:

35 Participants were given opportunities to ask questions and seek further clarifications
36 but this was not taken up. The pace of the presentation was perceived to be speedy,
37 and at times there was an observable need to finish off group work in a rush and
38 move swiftly to the next topic and at such times, the opportunity for checking
39 understanding and assimilation was left unexploited.
40

41 d) Group work discussions/balance between interaction participation:

42 Group work sessions were observed to be well facilitated. The discussions were all
43 very lively and animated. However before answering the question posed or engaging
44 with the given task, participants regularly required the questions / group work tasks
45 to be repeated, rephrased and explained by the facilitators.
46

47 e) Effectiveness of the delivery/methods:

48 Some distraction of the group work discussions was observed as some participants
49 became focused and overinvolved in discussing deficiencies and challenges related
50 to PPI work or organisations. When this happened, the facilitators were observed to
51 tactfully use pedagogical-facilitation techniques to successfully guide the discussion
52 back to the topic under discussion. On both days, it was observed that participants'
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7 sensitivities were respected at all times and due respect and consideration given to
8 all contributions.
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10 A supplementary issue through both days was the extent to which the ambiance of
11 the room including lighting, heating and positioning of chairs, affected participants.
12 There was no clear consensus, with the same temperature being considered too hot
13 or too cold.

14 Although the observers felt that the central message was sometimes blurred, and
15 there were inevitable diversions and distraction, overall, the objectives of the training
16 were being addressed and met.
17

18 19 **Individual post training interview findings:** 20

21 Of the 12 participants who had completed the training, 11 took part in the individual
22 follow-up interview by telephone, email or face to face. The interview was focused at
23 establishing whether on reflection, the participants could give a snap shot of:
24

- 25 ▪ whether and how the training had helped
- 26 ▪ whether they had had a chance to use the new knowledge
- 27 ▪ what else could be included
- 28 ▪ overall feel of level of confidence in volunteering for involvement
29

30 In terms of main things learnt, most of the participants reiterated what they had
31 reported in the post training survey, which was that the research awareness training
32 was informative, very well structured and very well delivered and was beneficial,
33 even for new starters.
34

35
36 *“In order to exert some real influence public involvement does need some
37 understanding of the systems in which it operates” (participant 9)*
38

39
40 Participants also held that the group discussions made it possible for them to learn
41 more about research process from others who had had different life experiences and
42 perspectives which was beneficial. Two participants expressed surprise at the
43 complexity of research. One participant expressed concern about the level of
44 distraction, volume of particular participants and domination of group discussions.
45

46 Participants generally reported that the training had helped improve their levels of
47 confidence and had increased their scope of involvement.
48

49
50 *“...learning to formulate a topic [it] helps me with my presentation – I am
51 not very good with writing, and people are probably not very happy with my
52 pronunciation I am a more confident speaker now” (participant 8)*
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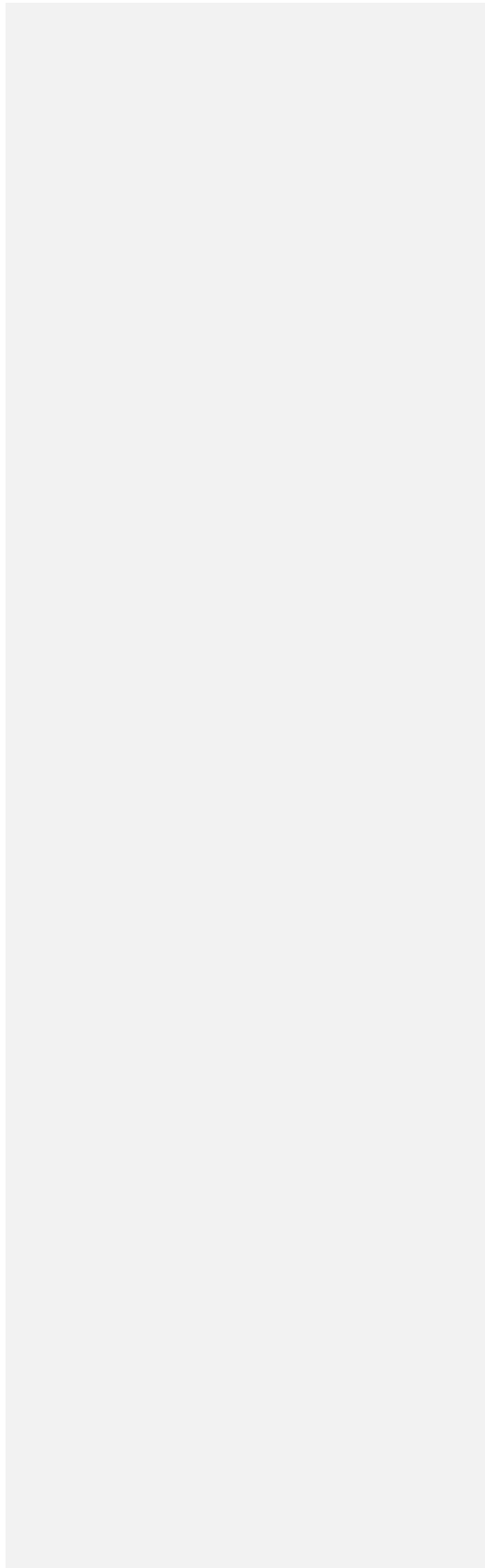
One participant now had time to think about other relevant issues that were not included in the survey or discussions. On reflection, the participant revealed a great sense pride, of achievement and enthusiasm for the future. These revelations show that the individual interviews brought out fresh feedback on aspects the participants had felt comfortable and free to report in a one to one interview.

Perceived levels of confidence:

In the pre and post training surveys, and again during the interview, participants were asked to rate their level of confidence, from 0-10, 0 being no confidence and 10, feeling very confident: see figure 1.

Initially none of the participants perceived themselves as having no confidence. The lowest rating was two and the highest 10. The majority of participants felt their confidence had improved post training, and this confidence level appears not to have diminished over time.

(Figure 1 about here)



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Discussion

The primary aim of the evaluation was to determine whether the training package increased the knowledge, understanding, skills and confidence of participants and to make recommendations regarding changes and improvements. This was achieved, with all participants taking new knowledge and confidence from the training, and the recommendations leading to an improved package that addressed the issues highlighted in the evaluation. This included taking greater care to securing an appropriate venue that offered physical and social comfort, which was identified as an important factor affecting engagement in the training in addition to the programme itself.

The discussion in this paper focuses on two areas of interest highlighted by the evaluation data and reflective discussions. Firstly, on the challenges of implementing PPI research awareness training and secondly on the insights gained regarding collaborative working between the public and academics from the training itself and the evaluation process.

The challenge of implementation:

One of the main items raised for discussion by the non-participant observers was the ways in which the main goal, despite being clearly articulated in the presentation, could be lost in the complexity of the content. This led to a reflection on the primary purpose of the training event: if it was, as understood, to help members of the public to understand the research process sufficiently to have the confidence to volunteer and contribute as part of a research process, then the theoretical content could be simplified to allow more time for their role to be foregrounded.

The informal conversations during breaks and group work plus analysis of the findings show a broad ~~heterogeneity~~ diversity in terms of age, sex, ethnicity, nature of service user/carer experience and educational and professional background. It is therefore unsurprising that pitching a standardised training package to them would be challenging: not dumbing down whilst avoiding jargon; allowing time to respectfully listen to individual participants' views, without losing pace and focus; stretching and inspiring those who want challenge, without offending those who are just enjoying an interesting day out.

Fawcett et al (2017), suggest that people with experiential knowledge make valuable contributions in forums such as these, but that in turn means that each person wants their particular narrative heard. An anonymised example from the group work is of one participant having a pertinent experience of an issue and taking some time to share it. The facilitator, anxious to use the anecdote effectively employed skilful group work techniques to incorporate the information but also keep the pace moving. Findings from the evaluation include comments about group work being a little rushed, some participants dominating the discussion and some feeling they had not been given enough time to speak. All of these comments could legitimately relate to this single example.

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7 The extent to which the different needs of individual participants could be
8 accommodated whilst maintaining the integrity, pace and flow of the training was a
9 significant consideration. The recommendation, to keep the intellectual level but
10 prune some of the more detailed content to allow more time for participant
11 interaction, was an attempt to address this. Supplementary materials, for example in
12 the form of a manual, workbook or textbook, might be desirable to help those
13 wanting more detailed information. Having a skilled facilitator for each group was
14 also essential, and this has implications for course capacity and the resources
15 required for future implementation. Alternatively, working with one smaller group
16 could have helped with inclusiveness, although this has implications for future
17 sustainability and capacity of training.
18

19 **The challenge of collaboration:**

20
21 In the early stages of planning the evaluation, the three evaluation team members
22 who were leading the work [two SUCs and one academic] met to plan. It took the two
23 SUCs an hour or more of determined, assertive dialogue to frame the evaluation into
24 a format they understood and felt empowered to actively undertake. This does not
25 reflect a lack of ability on the SUCs part, nor reluctance to engage from the
26 academic. Rather, it shows how difficult it is to unpick the deeply embedded power
27 imbalances that exist between researchers and SUCs and the different
28 understandings about research that may contribute to this. The exchange led to a
29 genuinely independent role for the SUCs, letting go of power by the academic, and a
30 lot of learning.

31
32 Similar tensions can be seen in the dynamics of the training in the findings from the
33 evaluation. There was no doubt that the training was sincere in its intention to
34 empower participants by presenting the full picture of the research cycle and the
35 places where they might be involved in it. However, the whole process remained
36 firmly within a paradigm-model where the research world invites the public to enter
37 and become involved on its terms. The content of the training honestly
38 acknowledged that PPI had a growing, and important role to play, but that it
39 remained limited in its ability to frame the focus, design and delivery of actual funded
40 research. The interactions and group work were respectful and warm, but tacitly
41 reinforced the notion that the repository of power and knowledge rests with the
42 research community.

43
44 Policy and practical guidance on PPI speaks positively of wanting genuine PPI
45 involvement, with detailed guidance on why, and how to get involved (National
46 Institute for Health Research). However, despite the espoused desire for authentic
47 involvement, the requirement to comply with policy (Oliver, Rees et al. 2008) remains
48 far easier to achieve than equal partnership. The paradox in Beresford and
49 Campbell's (1994) paper is contemporary despite its date: SUCs who have the
50 knowledge, background and confidence to challenge those in authority can be
51 dismissed as 'unrepresentative' and thus marginalised. In a research involvement
52 context, the 'expert by experience' may only be valued for their personal experience
53 of a particular health need, rather than welcomed as someone who could direct the
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research themselves. The Survivor Research Network manifesto (Omerod 2018) is one example of an alternative model of user-led research.

The difficulties of achieving authentic participation, when a consumer, or market led model of involvement is easier to achieve, and less likely to disrupt traditional power (Barnes and Cotterell 2012, Beresford and Carr 2012), is apparent in the evaluation. However, offering high quality training that opens up the research process did raise the participants' knowledge base and confidence to engage. Furthermore, the experience of undertaking this evaluation has demonstrated the possibilities of beginning to shift to a more collaborative position.

Conclusions:

The findings in this report underscore evidence that indicates that the PPI research awareness training package had indeed increased the knowledge, understanding and skills and that the participants' level of confidence had been raised. The training had already enabled some participants to get involved in different and new areas of research processes, and the package has been updated in line with the evaluation recommendations, further demonstrating that training and evaluation objectives had been met.

The evaluation highlights the challenges of delivering high quality training to the diverse PPI population, and of offering the public truly democratic involvement. However, it also demonstrates that it is possible to successfully deliver high quality, academically challenging training to members of the public, and adds to increasing evidence of the added value of including PPI contributors as partners in research.

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List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

DoH: Department of Health

NIHR CLAHRC YH: National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber

NHS: National Health Service

PPI: Patient and Public Involvement

PPG: Public Partnership Group

SUCs: Service users and carers

Declarations

Ethical approval and consent to participate

Ethical approval was gained from the University of Huddersfield, School of Human and Health Sciences Research and Enterprise Committee. Attention was given to informed consent, anonymity and confidentiality. Bearing in mind the participants' self-identified "service user / carer" status, emotional and physical safety through the training and gathering of data was of particular importance.

Participant consent was obtained prior to the first training session.

Consent for publication

Participants were informed on the Participant Information Sheet that: 'An evaluation report will be produced and at some point, and findings may be published in a journal or report. In both cases, your anonymity will be ensured'. All participants consented 'I give permission for my words to be quoted (by use of a number)' as part of the enrolment and consent process prior to the pre-training survey.

Availability of data and materials

The full report of this evaluation, including protocol, ethical documents and findings, can be found at: <http://clahrc-yh.nihr.ac.uk/ppi/training>. Data sharing is not applicable to this article as no datasets were generated or analysed during the current study. Other requests, please contact the corresponding author.

Competing interests

There are no competing interests to declare

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This output presents or refers to independent research by the National Institute for Health Research, Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber (NIHR CLAHRC YH). The views and opinions expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health. For more information visit www.clahrc-yh.nihr.ac.uk/

Authors' contributions / Authors' information

Ilyas Akhtar:

Is a graduate of the School of Human and Health Sciences, and now a public member of the PPG. Ilyas did not observe or participate in the two training days. He assisted in the design of the evaluation; analysed data from the surveys; reviewed the training materials; conducted telephone interviews; joined in reflective conversations about the findings, produced sections of the report and reviewed this paper.

Amanda Edmondson:

Is a health researcher in the School of Human and Health Sciences. She is a staff member of PPG. She did not attend or observe the training events. She reviewed the research protocol and ethics applications; she assisted in the information sharing and gaining of consent from participants at the commencement of day one; she read and commented on the evaluation report and contributed to the writing of this paper.

Janet Hargreaves:

Is a former academic staff member who was the Public Involvement academic lead for the School of Human and Health Sciences and who has retired during the process of completing this evaluation. Janet is now a public member of PPG. She collaborated with staff, PPG members and the CLAHRC YH team to produce the research protocol and ethics application; she assisted with the information and consent gaining, and generally with the smooth running of the training days; she observed the two sessions as a non-participant observer; she supported Catherine and Ilyas in their collation and analysis of data; she joined in with reflective conversations about the findings; supported Catherine and Ilyas in the production of the report, drafted some sections and contributed to the writing of this paper .

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Alison Morris:

Is the Public Involvement administrator for the School of Human and Health Sciences. She participated in the training and undertook the evaluation, but also assisted with aspects of the development of findings. She undertook the event management for both days and management of finances; she assisted in piloting the interview and conducted an interview herself; she joined in with reflective conversations about the findings; she offered practical and pastoral support to those involved and reviewed this paper.

Christine Rhodes:

Is now the Public Involvement academic lead for the School of Human and Health Sciences. She reviewed and commented upon the research protocol and ethical submission, the evaluation report and this paper.

Catherine Richardson:

Is a graduate of the School of Human and Health Sciences, and now a public member of the PPG. She led the information sharing and gaining of consent from participants at the commencement of day one; she observed the two sessions as a non-participant observer; she worked collaboratively with Ilyas in their collation and analysis of data; she joined in with reflective conversations about the findings; she led the formation, structure, writing and completion of this report and contributed to this paper.

Christine Smith:

Is Programme Manager and Public Involvement Lead for NIHR CLAHRC YH, she supported Jo Taylor in the iterative development of the training package as part of the formative evaluation; she facilitated group work during the training sessions; she joined in with the final reflective conversation about the findings and contributed to this paper.

Jo Taylor:

Is a Lecturer in Applied Health Research in the Department of Health Sciences at the University of York, and a member of the NIHR CLAHRC YH Diamonds research programme (www.diamonds.nihr.ac.uk). She designed the original training package in partnership with members of DIAMONDS VOICE (a service user and carer research panel for the programme). Jo led the delivery of the training package and worked with Christine to iteratively develop the training; she joined in with the final reflective conversation about the findings and contributed to this paper.

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Figure Titles and Legend

Figure 1: Reported Levels of Confidence

Figure 1 legend: pre training (blue), post training (orange), post training interview (grey)

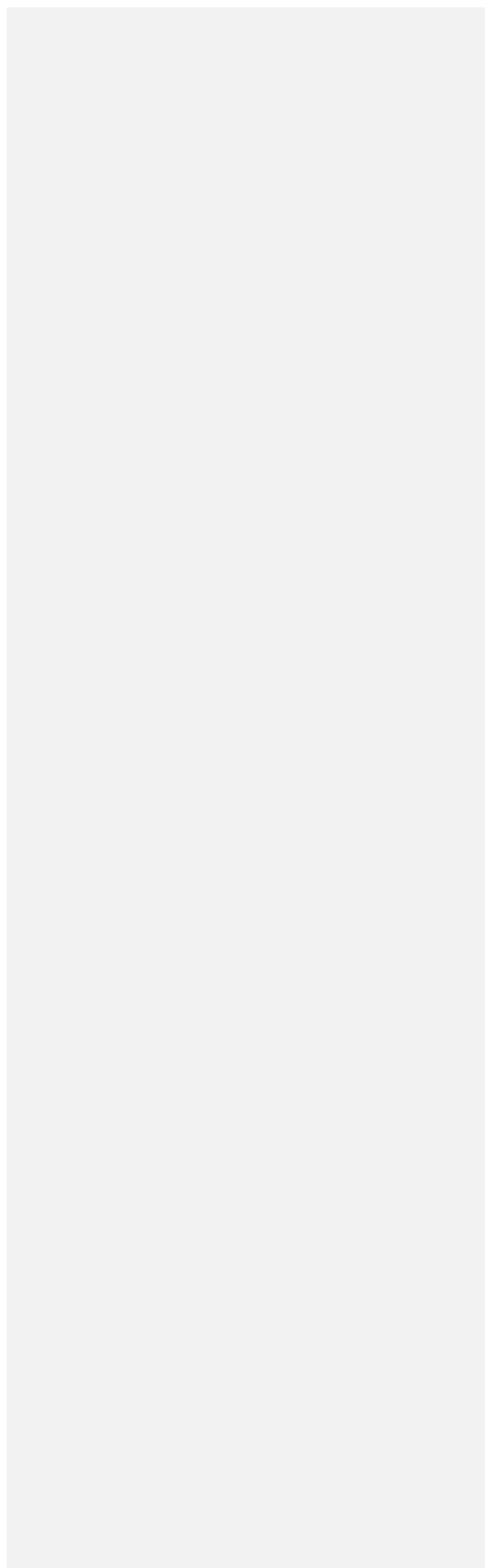


Figure 1. Reported levels of confidence

