

VOCAL

**Public involvement
in research survey**



Appendix 6

“When we talk about public involvement, we mean all the ways in which the research community works together with people including patients, carers, advocates, service users, and members of the community. Excellent public involvement is inclusive, values all contributions, ensures people have a meaningful say in what happens and influences outcomes, as set out in the UK Standards for Public Involvement.”

The Shared Commitment to Public Involvement

**This work was commissioned by the
Medical Research Council**

VOCAL



Medical
Research
Council

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Introduction

Vocal was commissioned by the Medical Research Council (MRC) to undertake a review of public involvement in research (February–September 2022), with a specific focus on non-clinical health and biomedical research. This Appendix shares the findings of a survey which gathered the experiences and views of people working in or with the MRC.

The survey questions were developed by Vocal and the MRC Project Team and approved by the Public Involvement Project Oversight Group (PIPOG). It was promoted by the MRC and Vocal to researchers, public partners, public engagement/ involvement practitioners and members of the public and hosted on the UKRI Engagement Hub. The survey ran from 6 to 27th May 2022, and achieved 332 responses.

The survey had two possible routes; one for respondents who selected that they work in a research environment, and another for members of the public, or public/patient contributors to research. The split of the routes happened after respondents answered question 2, and the two routes joined back together at question 14. The respondents for each question are shown in brackets after the question number.

Unfortunately, there was an error in the survey route for members of the public, and public/patient contributors which was rectified part way through the survey period. Therefore, we have approximately half of the possible responses to the survey questions 9–13. Throughout the data below, unanswered categories show all survey respondents even if they were not asked the question because of routing.

For questions 5 and 15, we have amalgamated data with that collected from MRC Head Office staff during the Research Programme Managers' Forum on 28 April 2022. This is indicated below.

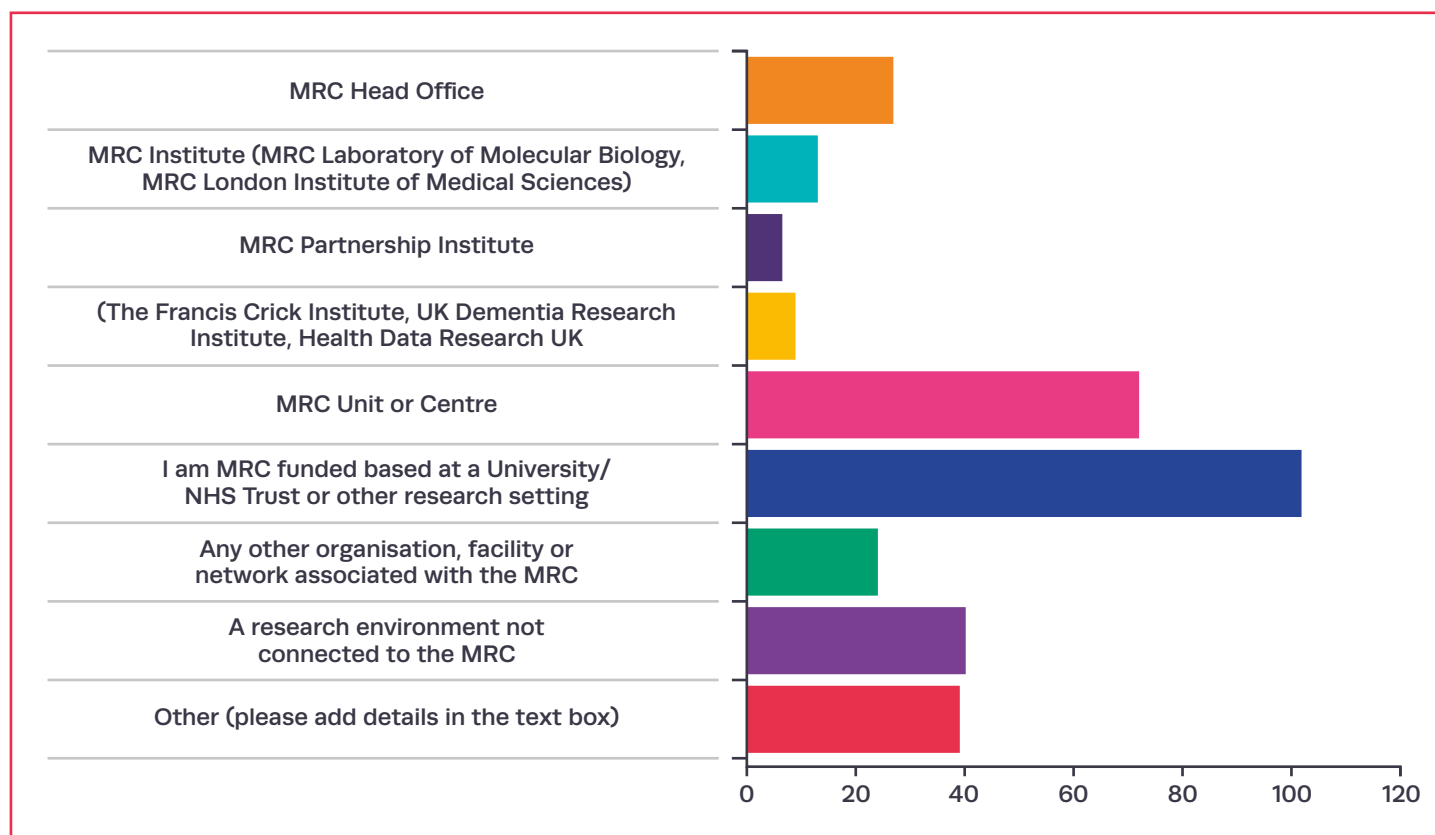
Percentage figures have been rounded to the nearest whole percentage, or tenth of a percentage as appropriate.

Free text responses are provided in full (p23–41).

Survey questions and data

Q1 (All): Which of these are you connected with?

There were 332 responses to this part of the question.



Option	Total	Percent
MRC Head Office	27	8%
MRC Institute (MRC Laboratory of Molecular Biology, MRC London Institute of Medical Sciences)	13	4%
MRC Partnership Institute	6	2%
(The Francis Crick Institute, UK Dementia Research Institute, Health Data Research UK)	9	3%
MRC Unit or Centre	72	22%
I am MRC funded based at a University/NHS Trust or other research setting	102	31%
Any other organisation, facility or network associated with the MRC	24	7%
A research environment not connected to the MRC	40	12%
Other (please add details in the text box)	39	12%
Not Answered	0	0.00%

If other, please give details

Of the 39 respondents who selected 'other', 27 were members of the public or public contributors. 12 worked in research environment not affiliated to MRC.

Overall, this is a useful distribution of respondents across the categories.

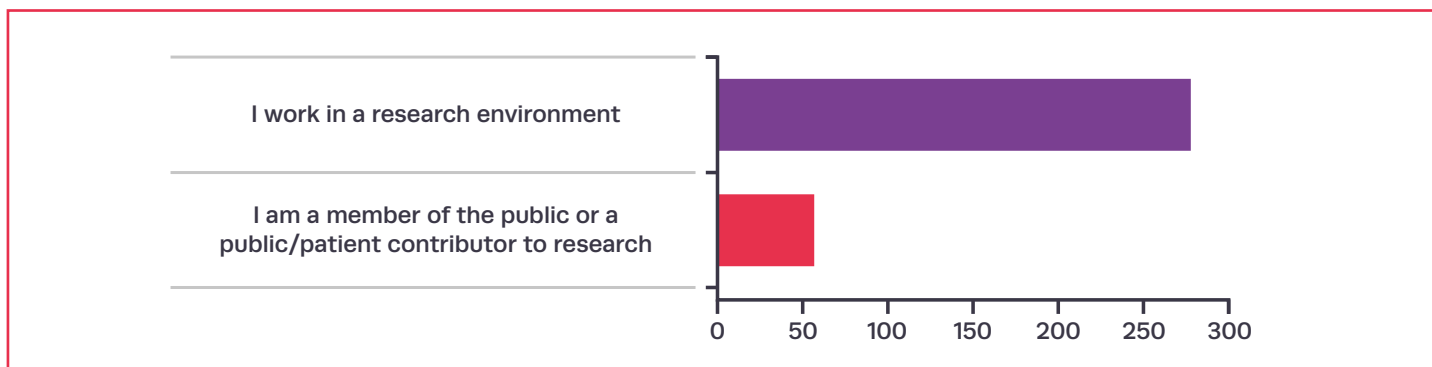
Survey questions and data

Q2 (All): We welcome all responses

You may choose to respond to the questions for people who work in a research environment or as a member of the public or patient/public contributor to research.

Please select below.

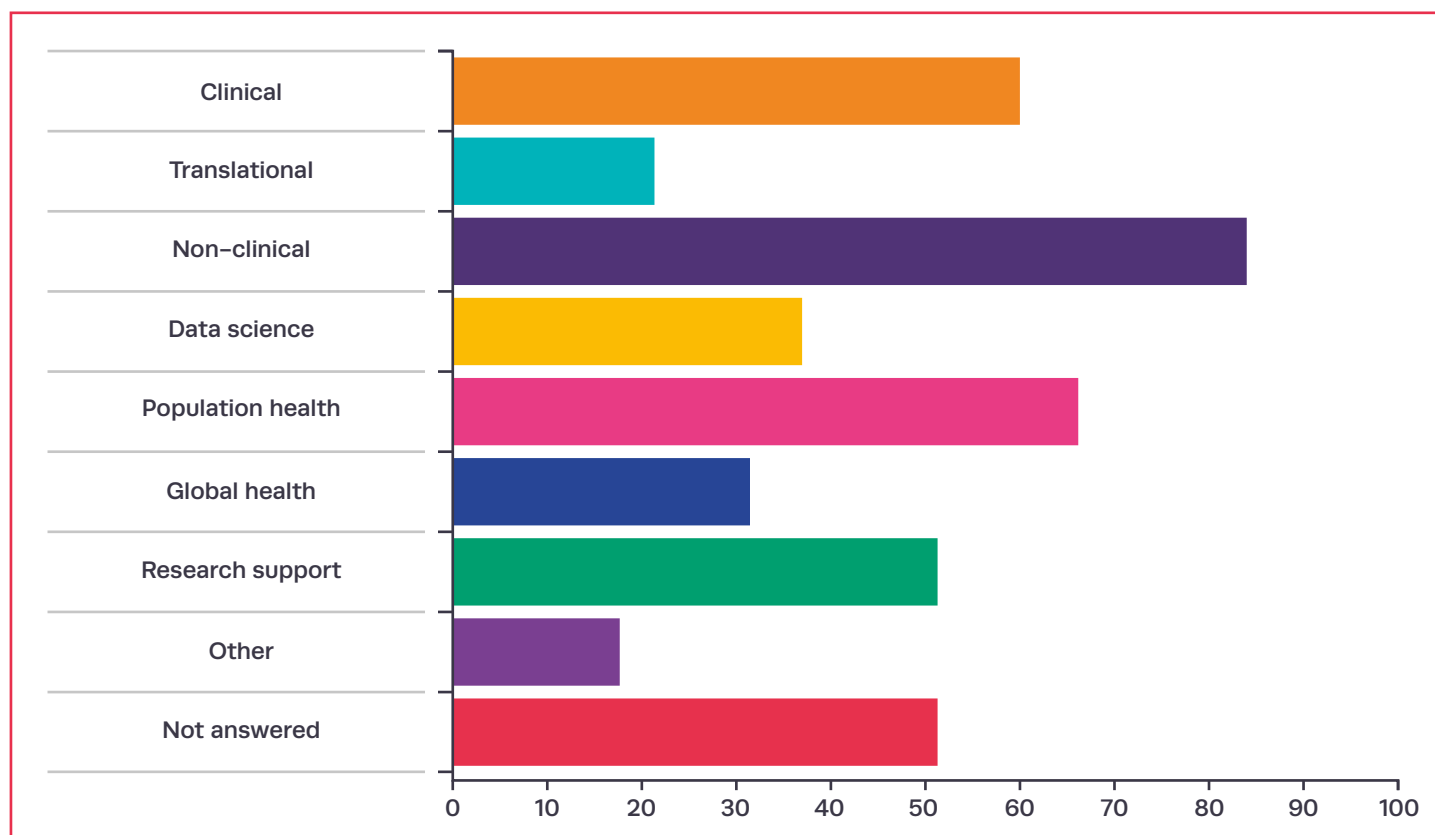
There were 332 responses to this part of the question.



Option	Total	Percent
I work in a research environment	277	83%
I am a member of the public or a public/patient contributor to research	55	17%
Not Answered	0	0%

Survey questions and data

Q3 (Researchers): Which of the following best describes the main focus of your research or work? There were 281 responses to this part of the question.



Option	Total	Percent
Clinical	60	18%
Translational	74	22%
Non-clinical	86	26%
Data science	35	11%
Population health	65	20%
Global health	31	9%
Research support	52	16%
Other	17	5%
Not Answered	51	15%

If other, please give details

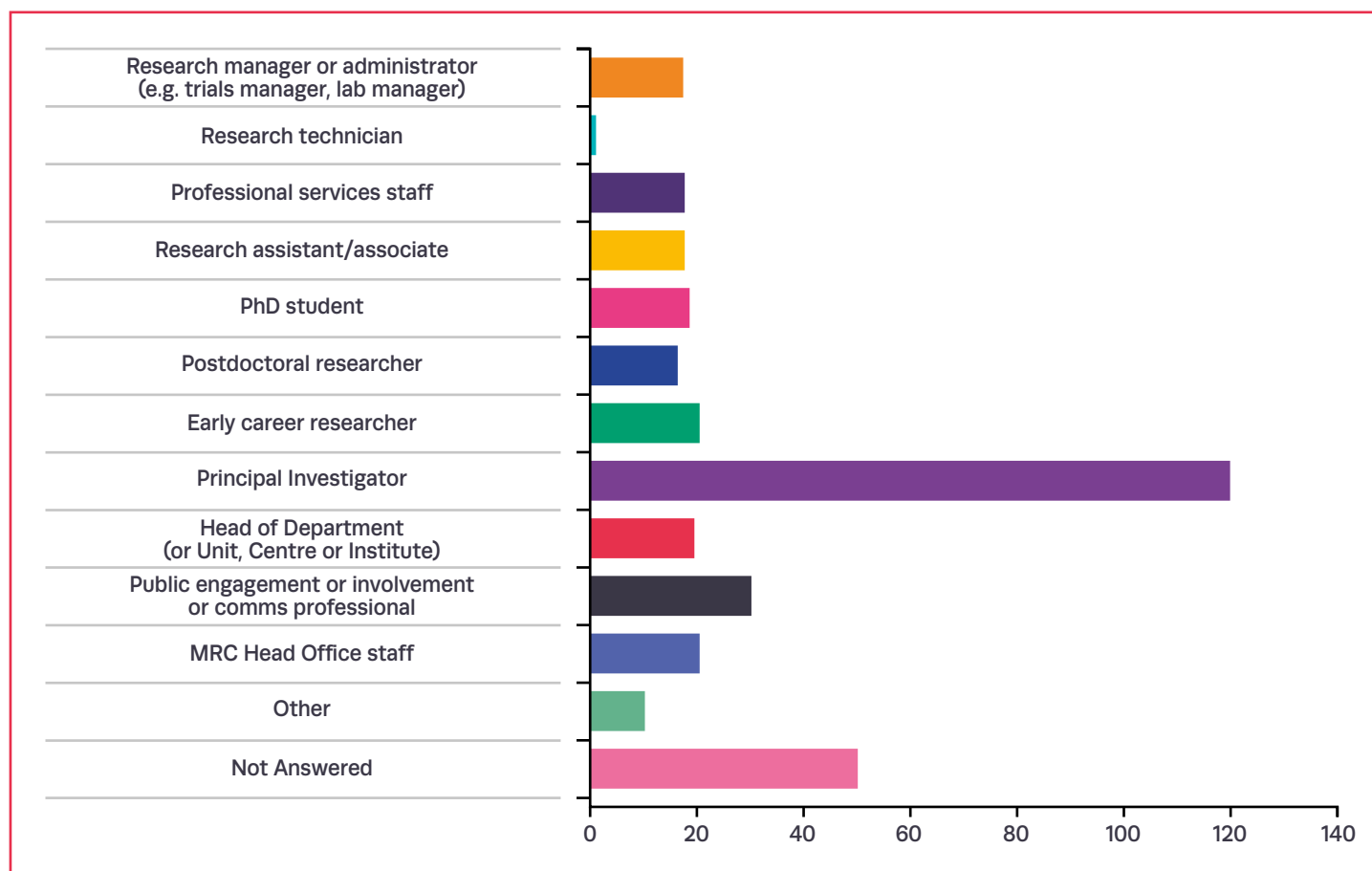
Of the 17 people who selected 'other' 6 of them were involved in engagement, involvement, knowledge exchange activities. Interestingly, they did not view their role to be part of research support.

The remaining 'other' answers were spread across multiple categories, with some respondents describing roles which cut across several areas of research.

Survey questions and data

Q4 (Researchers): Which of the following best describes you?

There were 284 responses to this part of the question.



Option	Total	Percent
Research manager or administrator (e.g. trials manager, lab manager)	17	5%
Research technician	2	1%
Professional services staff	18	6%
Research assistant/associate	18	6%
PhD student	19	6%
Postdoctoral researcher	6	5%
Early career researcher	21	6%
Principal Investigator	120	36%
Head of Department (or Unit, Centre or Institute)	20	6%
Public engagement or involvement or comms professional	34	10%
MRC Head Office staff	21	6%
Other	8	2%
Not Answered	48	14%

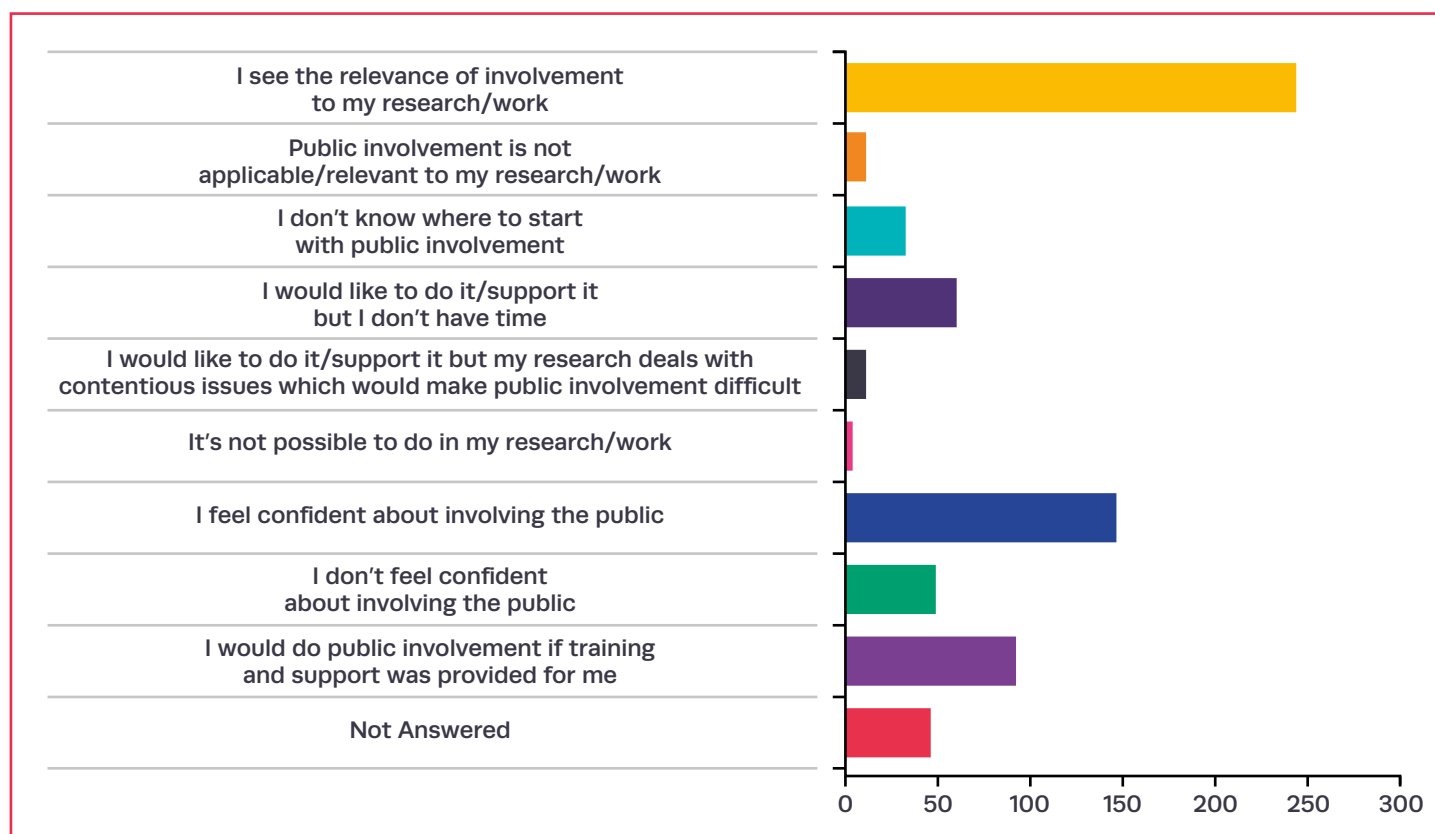
If Other (please specify)

There were eight responses to this part of the question. Three of these were members of the public.

Survey questions and data

Q5 (Researchers): Which of the following statements do you agree with? Please select all that apply.

- MRC Head Office.
- MRC funded researchers/research environment.
- Non MRC funded researchers/research environment.
- Public Engagement and/or Communications Professionals (PEPs).
- Where it is of interest, we have further looked at subsets including Principal Investigators, and whether the PEPs are MRC funded/affiliated or not.



Option	Total	Percent
I see the relevance of involvement to my research/work	242	73%
Public involvement is not applicable/relevant to my research/work	14	4%
I don't know where to start with public involvement	31	9%
I would like to do it/support it but I don't have time	67	20%
I would like to do it/support it but my research deals with contentious issues which would make public involvement difficult	12	4%
It's not possible to do in my research/work	5	2%
I feel confident about involving the public	145	44%
I don't feel confident about involving the public	46	14%
I would do public involvement if training and support was provided for me	88	27%
Not Answered	48	14%

Survey questions and data

Q5 Further breakdown of Q5 responses by role/funder

PLEASE NOTE we have added in data collected from the Research Programme Managers' Forum in this question.

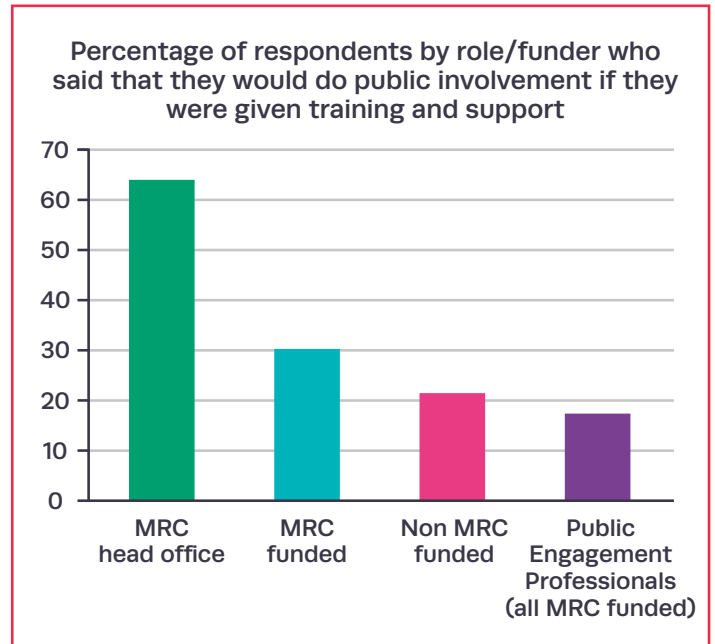
There are no evident trends from those who selected 'Public involvement is not applicable/relevant to my research/work'. Five respondents who chose this had selected non-clinical as their main focus of work in question 3, and five selected research support as their main focus.

Interestingly, more respondents (25%) from MRC Head Office selected 'I don't know where to start with public involvement' than the other categories, which were evenly spread at between 7-10% of respondents.



20% of all respondents selected the option that they would do or support public involvement if they had more time. Interestingly, there are differences between MRC and non MRC funded staff within the research environment, with only 7% of non-MRC funded researchers selecting this option.

Responses to question 6 (see below) show that dedicated time for public involvement was the most selected factor in encouraging more public involvement, with 49% of respondents selecting this option.



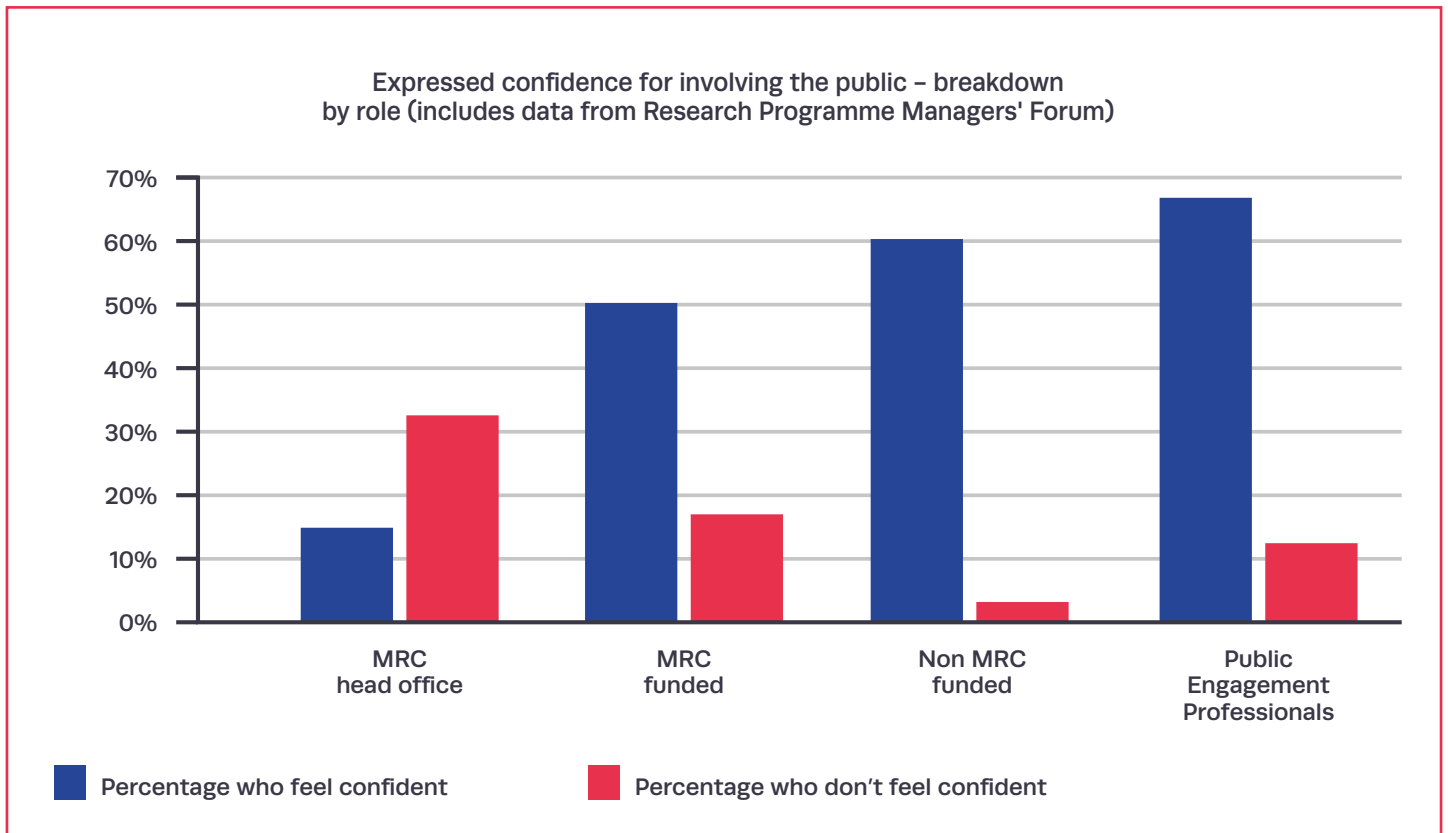
27% of respondents overall selected 'I would do public involvement if training and support was provided for me'. Notably, 65% of staff from MRC Head Office (consistent across both surveys) selected this option.

The respondents within MRC research environments were above the average in their response. Interestingly, all responses from Public Engagement Professionals (PEPs) were affiliated to MRC research environments.

Survey questions and data

Q5 Further breakdown of Q5 responses by role/funder.

PLEASE NOTE we have added in data collected from the Research Programme Managers' Forum in this question.

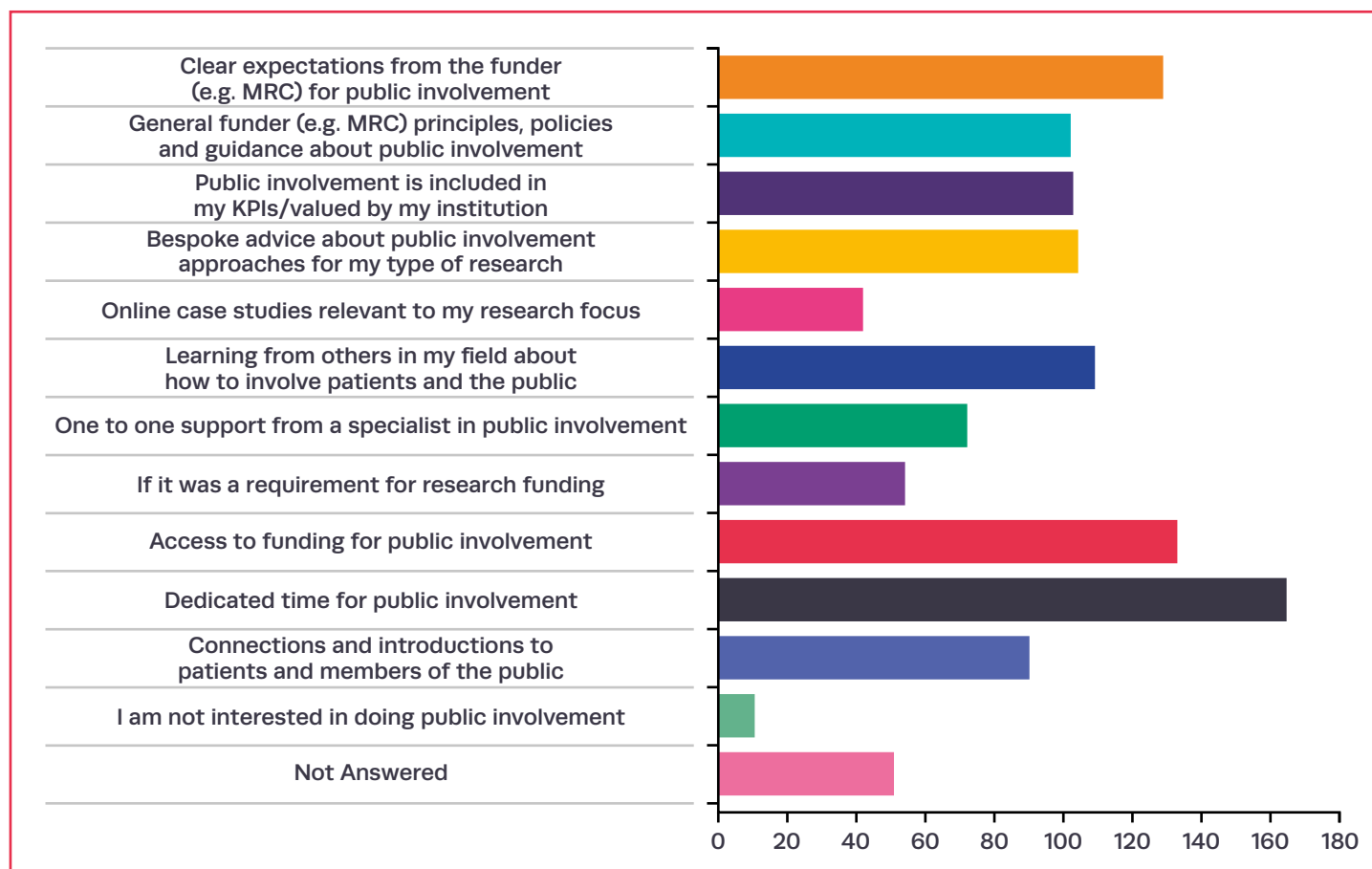


Data from staff at MRC Head office shows that they feel less confident about involving the public than funded researchers and PEPs.

9 out of 17 MRC funded PEPs feel confident to involve the public, whereas 4 responded that they don't feel confident. For PEPs who are not MRC funded, 11 out of 13 feel confident to involve the public, with 2 responders not answering.

Survey questions and data

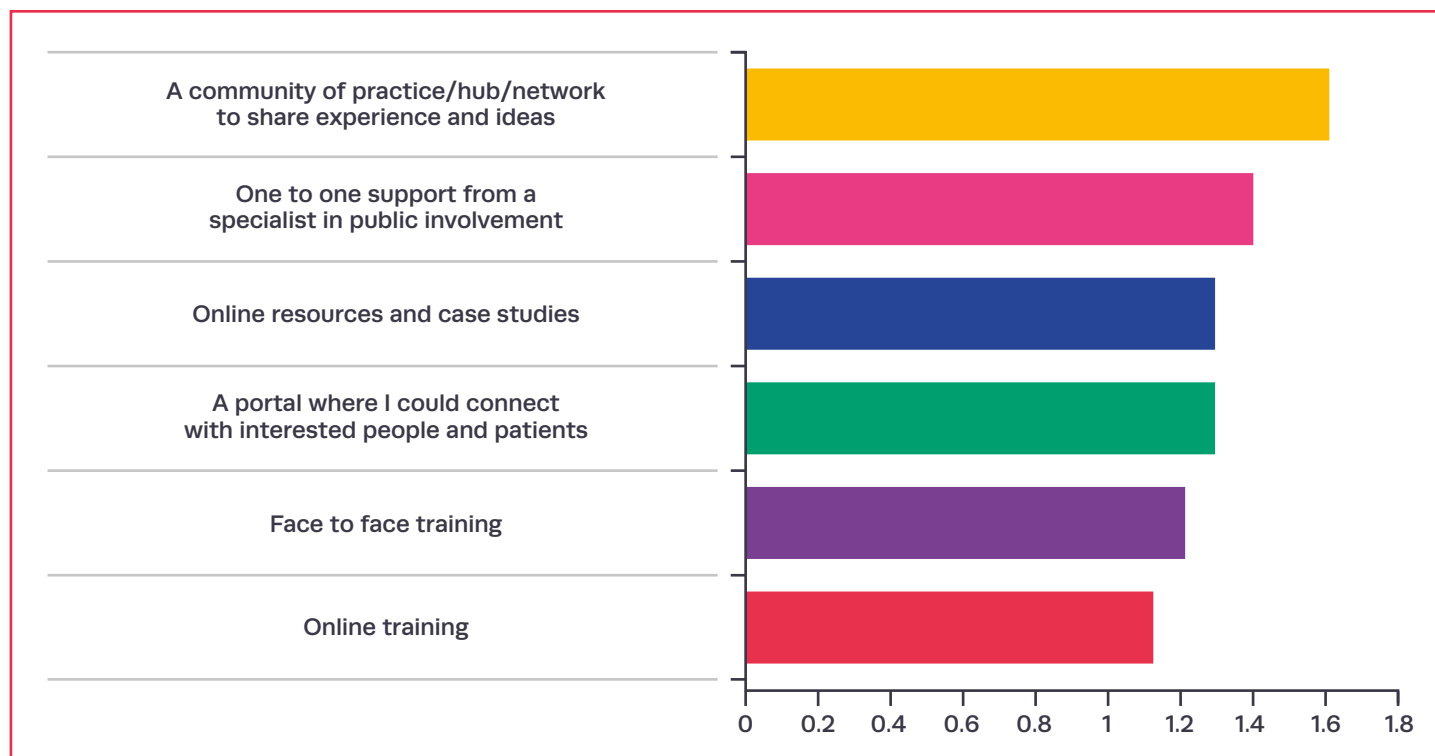
Q6 (Researchers): What would encourage you to involve the public more in your research or work? Please select up to 4 of the following that are most important to you. There were 282 responses to this part of the question.



Option	Total	Percent
Clear expectations from the funder (e.g. MRC) for public involvement	127	38%
General funder (e.g. MRC) principles, policies and guidance about public involvement	104	31%
Public involvement is included in my KPIs/valued by my institution	105	32%
Bespoke advice about public involvement approaches for my type of research	110	33%
Online case studies relevant to my research focus	44	13%
Learning from others in my field about how to involve patients and the public	113	34%
One to one support from a specialist in public involvement	70	21%
If it was a requirement for research funding	52	16%
Access to funding for public involvement	135	41%
Dedicated time for public involvement	164	49%
Connections and introductions to patients and members of the public	91	27%
I am not interested in doing public involvement	9	3%
Not Answered	50	15%

Survey questions and data

Q7 (Researchers): What kind of support would you find most useful? Please rank up to 4 of the choices below in order of priority (1=most important)



Option	Ranking
A community of practice/hub/network to share experience and ideas	1.6
One to one support from a specialist in public involvement	1.4
Online resources and case studies	1.3
A portal where I could connect with interested people and patients	1.3
Face to face training	1.2
Online training	1.1

Please note: We have removed the ranking information from this report as there was broadly even spread of ranking across all of the options.

Q8 (Researchers): Is there anything else not on the two previous lists that would be important to you?

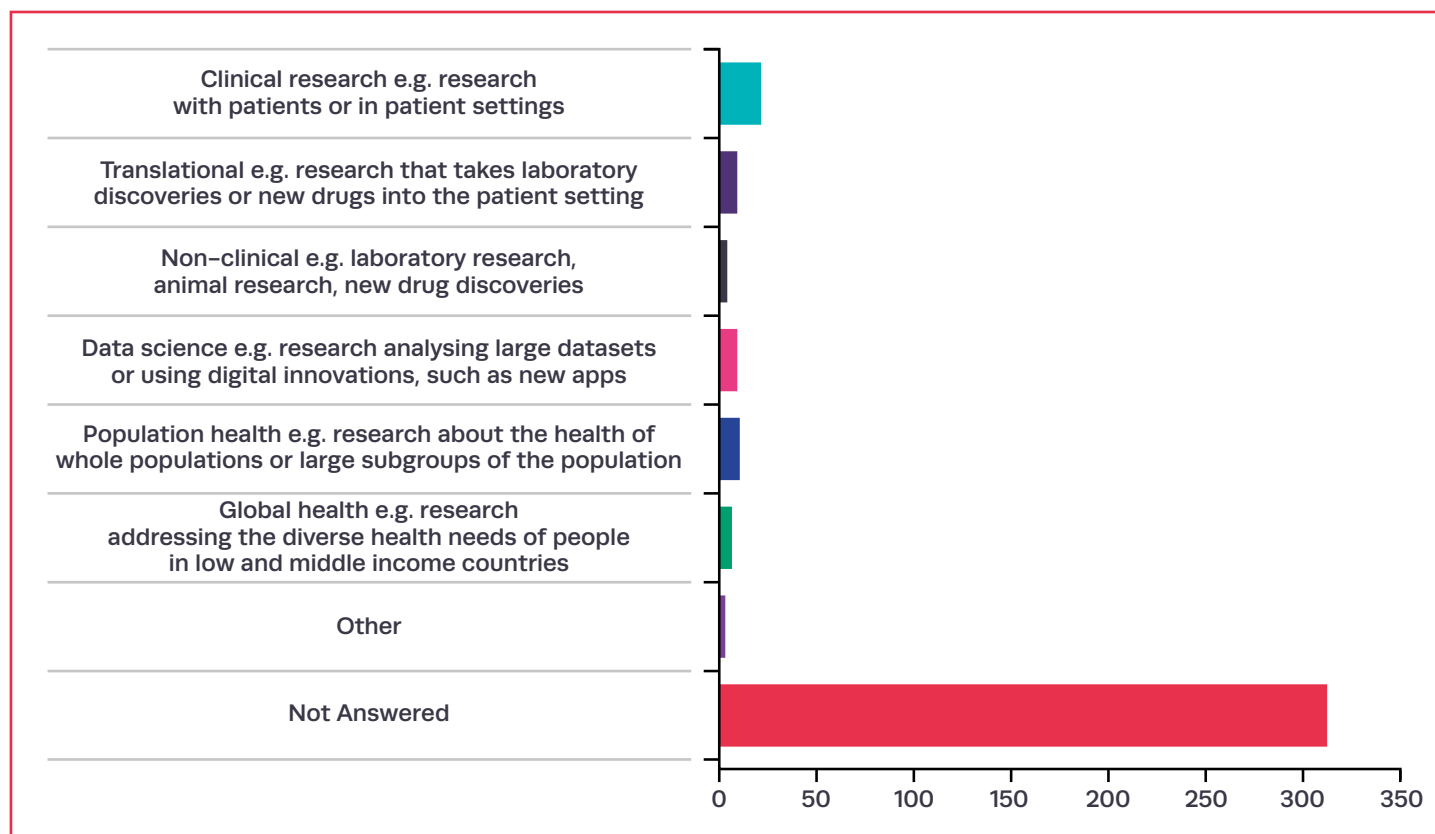
There were 69 responses to this part of the question. All free text responses to this question are listed from p23.

Survey questions and data

Q9

(Public): Which of the following are you most interested in:

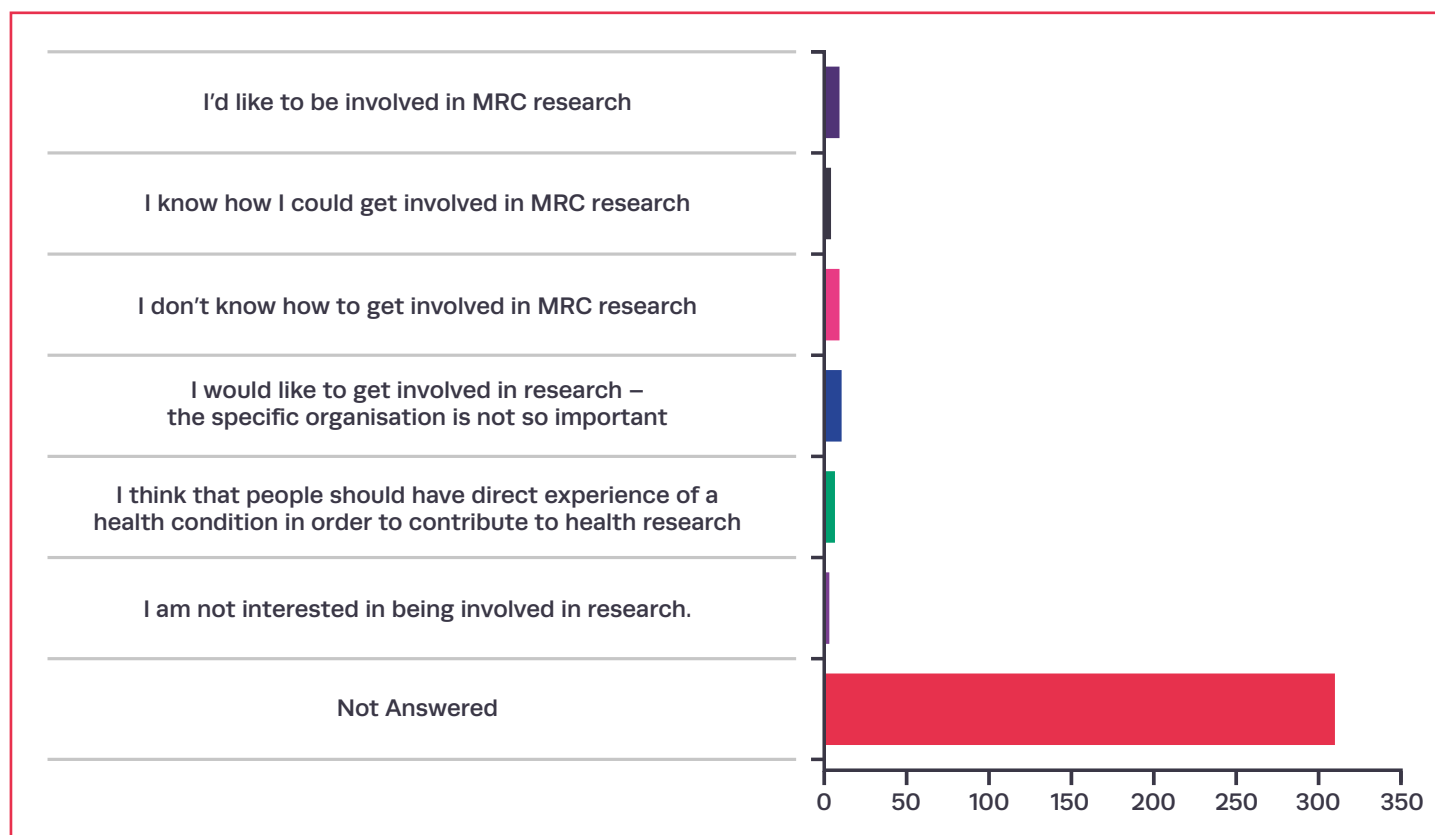
There were 21 responses to this question.



Option	Total	Percent
Clinical research e.g. research with patients or in patient settings	17	5%
Translational e.g. research that takes laboratory discoveries or new drugs into the patient setting	9	3%
Non-clinical e.g. laboratory research, animal research, new drug discoveries	4	1%
Data science e.g. research analysing large datasets or using digital innovations, such as new apps	10	3%
Population health e.g. research about the health of whole populations or large subgroups of the population	12	4%
Global health e.g. research addressing the diverse health needs of people in low and middle income countries	8	2%
Other	1	0%
Not Answered	311	94%

Survey questions and data

Q10 (Public): Which of the following statements do you agree with? Please select all that apply. There were 21 responses to this part of the question.



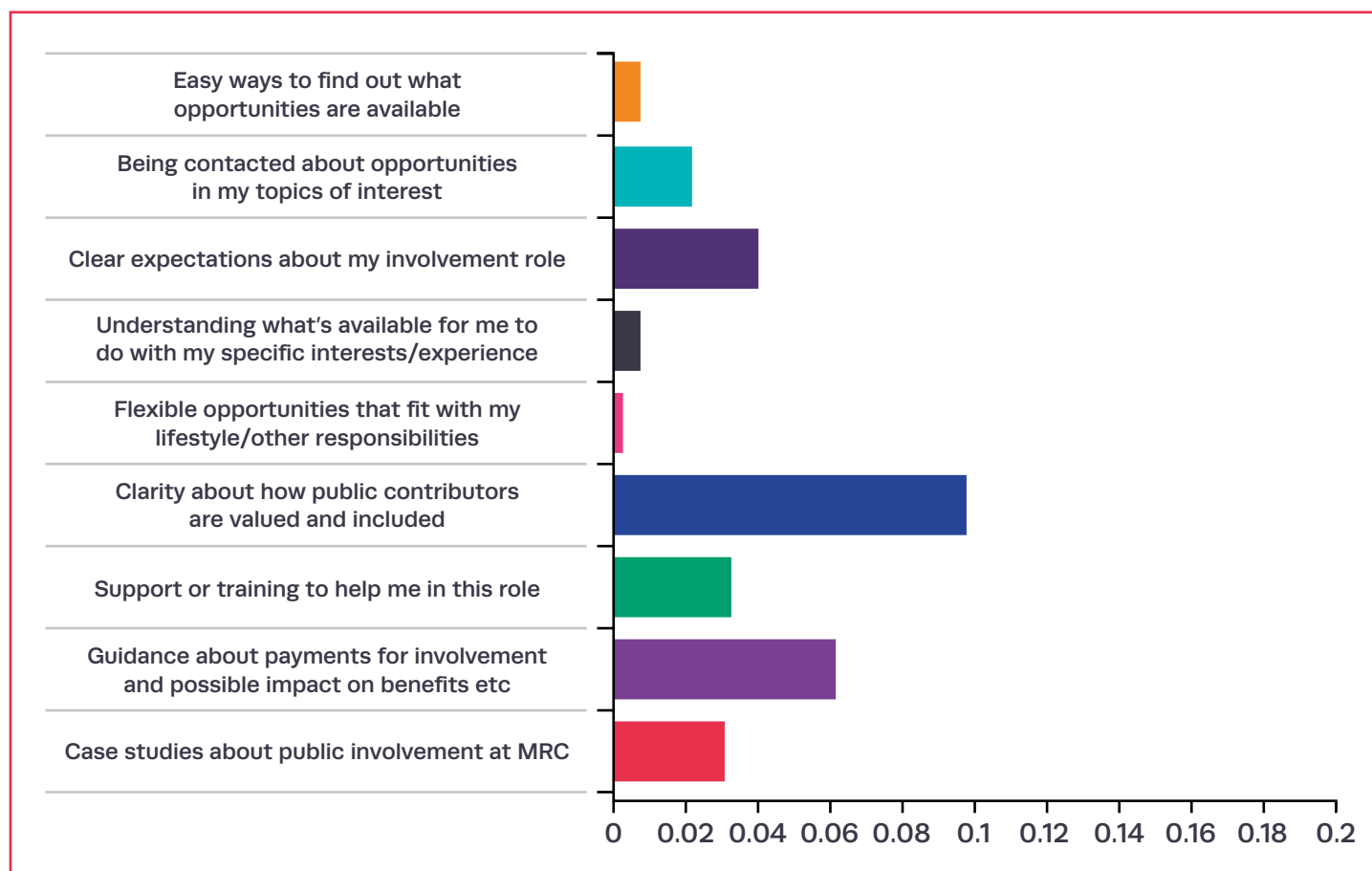
Option	Total	Percent
I'd like to be involved in MRC research	15	4.5%
I know how I could get involved in MRC research	1	0.3%
I don't know how to get involved in MRC research	11	3.3%
I would like to get involved in research – the specific organisation is not so important	13	3.9%
I think that people can contribute to all types of research	14	4.2%
I think that people should have direct experience of a health condition in order to contribute to health research	4	1.2%
I am not interested in being involved in research	0	0%
Not Answered	311	93.6%

Is there anything you would like to add that isn't included above? (Free text)

There were 4 responses to this part of the question. These are provided on p31.

Survey questions and data

Q11 (Public): What would encourage you to become involved with research at MRC? Please rank up to 4 of the choices below in order of priority (1=most important).



Option	Ranking
Easy ways to find out what opportunities are available	0.18
Being contacted about opportunities in my topics of interest	0.10
Clear expectations about my involvement role	0.08
Understanding what's available for me to do with my specific interests/experience	0.06
Flexible opportunities that fit with my lifestyle/other responsibilities	0.06
Clarity about how public contributors are valued and included	0.05
Support or training to help me in this role	0.03
Guidance about payments for involvement and possible impact on benefits etc	0.02
Case studies about public involvement at MRC	0.02

Is there anything else that would be important to you?

There were 2 responses to this part of the question.

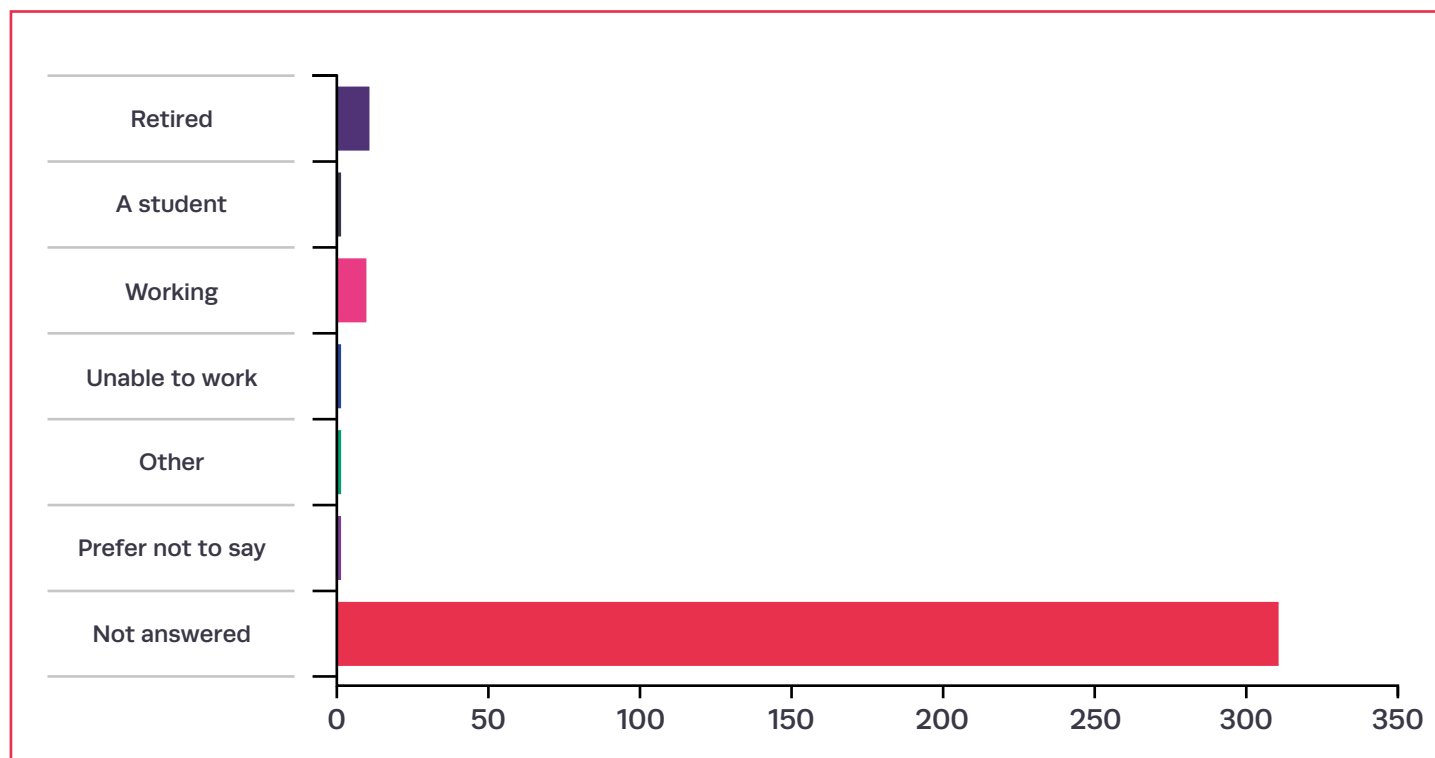
"I think all of the above are important. I often speak to people about my involvement in research and the general public's awareness of health research has undoubtedly improved since Covid. This is a great opportunity to engage with more people. I'm saddened that PPIE groups are not more diverse in terms of age as well as ethnicity and also educational background. Communication is key and there is just not enough of it. Using charities and support groups more to engage with groups of people would be beneficial. People often tell me they don't know what opportunities there are to get involved."

"Being told when my contributions are no longer required and why."

Survey questions and data

Q12 (Public): As part of our Diversity Monitoring we would like to know: Are you currently any of the below? Please select one.

There were 21 responses to this part of the question.



Option	Total	Percent
Retired	9	2.7%
A student	1	0.3%
Looking after home or family	0	0.0%
Working	8	2.4%
Unable to work	1	0.3%
Unemployed	0	0.0%
Other	1	0.3%
Prefer not to say	1	0.3%
Not Answered	311	93.7%

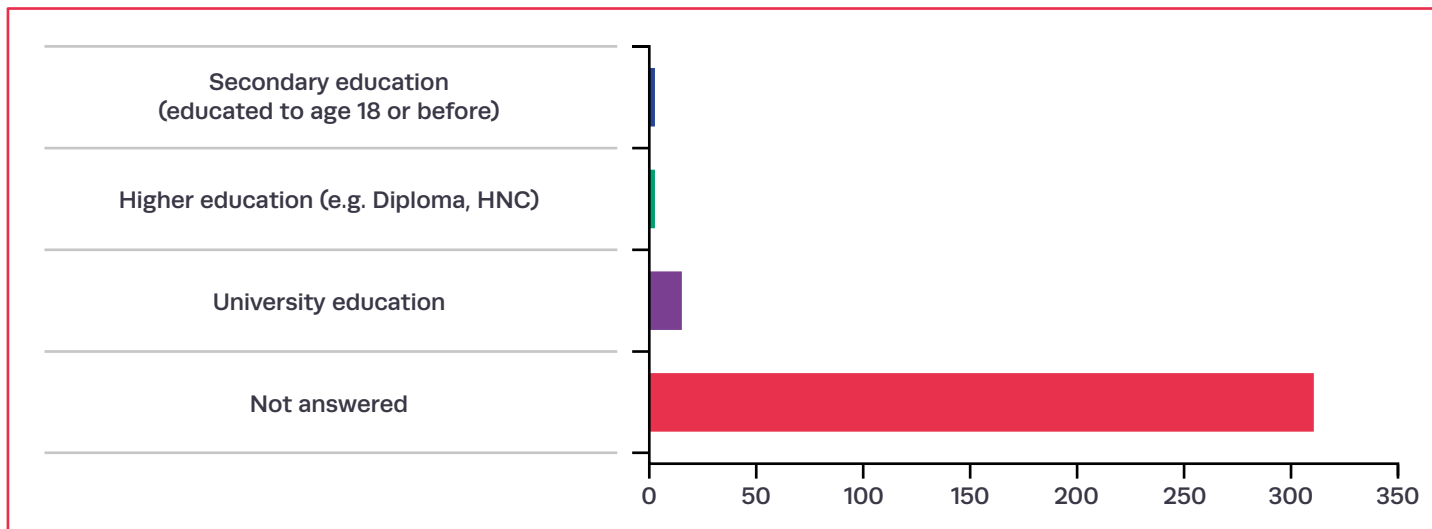
If Other (please specify)

There were 2 responses to this part of the question. One suggested the survey should allow multiple categories to be selected. The other provided further details about working patterns.

Survey questions and data

Q13 (Public): As part of our Diversity Monitoring we would like to know: What is the highest education level you have attained?

There were 21 responses to this part of the question.



Option	Total	Percent
No formal education	0	0.0%
Primary education (educated to age 11 or before)	0	0.0%
Secondary education (educated to age 18 or before)	3	0.9%
Higher education (e.g. Diploma, HNC)	3	0.9%
University education	15	4.5%
Prefer not to say	0	0.0%
Not Answered	311	93.7%

Survey questions and data

Q14 (All): In your opinion, what are the most important reasons for public involvement in research? Please select up to 4 of the following:

There were 332 responses to this part of the question.



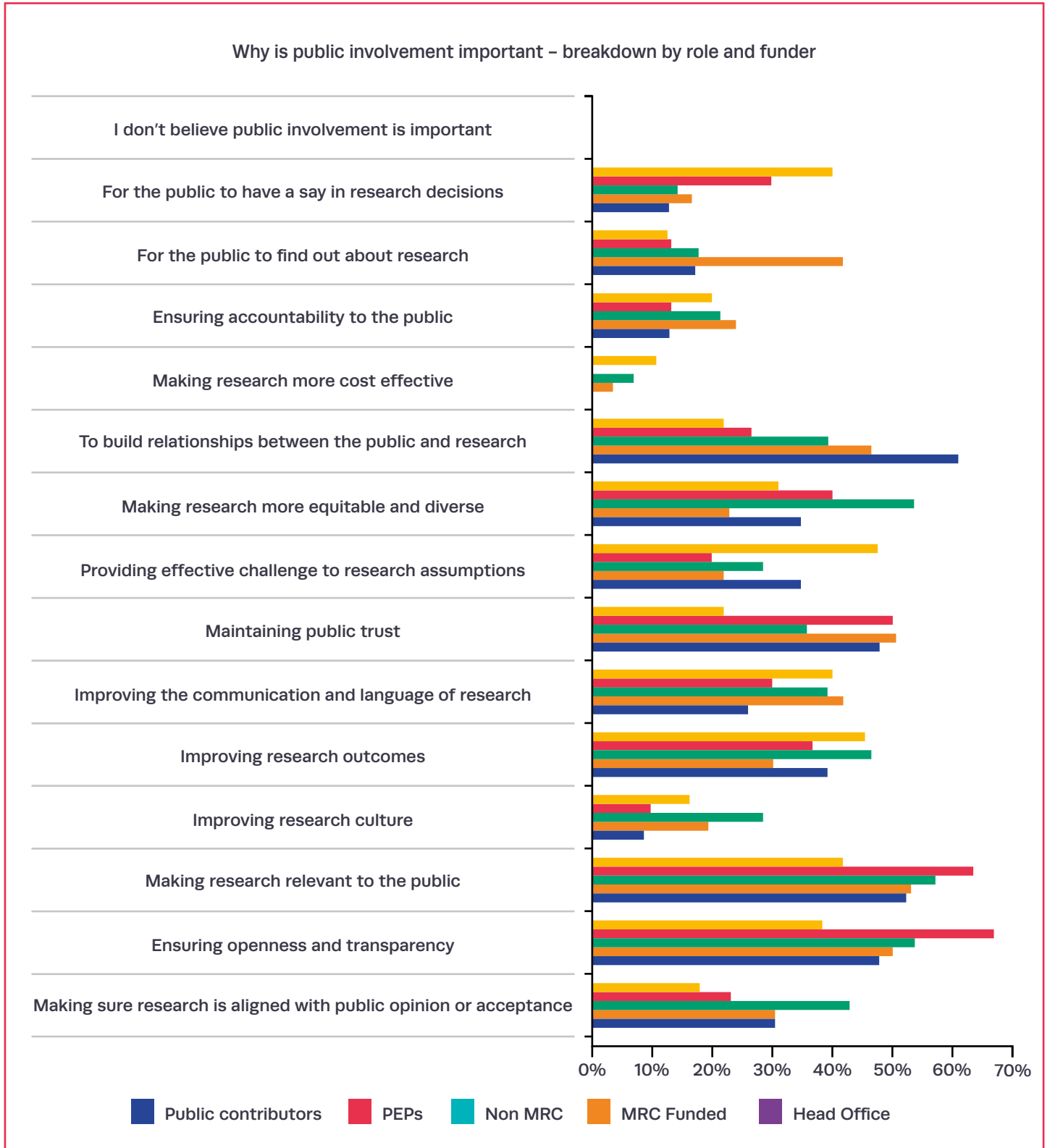
Option	Total	Percent
Making sure research is aligned with public opinion or acceptance	96	29%
Ensuring openness and transparency	165	50%
Making research relevant to the public	174	52%
Improving research culture	60	18%
Improving research outcomes	117	35%
Improving the communication and language of research	130	39%
Maintaining public trust	147	44%
Providing effective challenge to research assumptions	91	27%
Making research more equitable and diverse	97	29%
To build relationships between the public and research	136	41%
Making research more cost effective	15	5%
Ensuring accountability to the public	71	21%
For the public to find out about research	102	31%
For the public to have a say in research decisions	71	21%
I don't believe public involvement is important	2	1%
Not Answered	0	0%

Survey questions and data

Q14

Q14 Continued: Breakdown of responses by role/funder.

There were 332 responses to this part of the question.



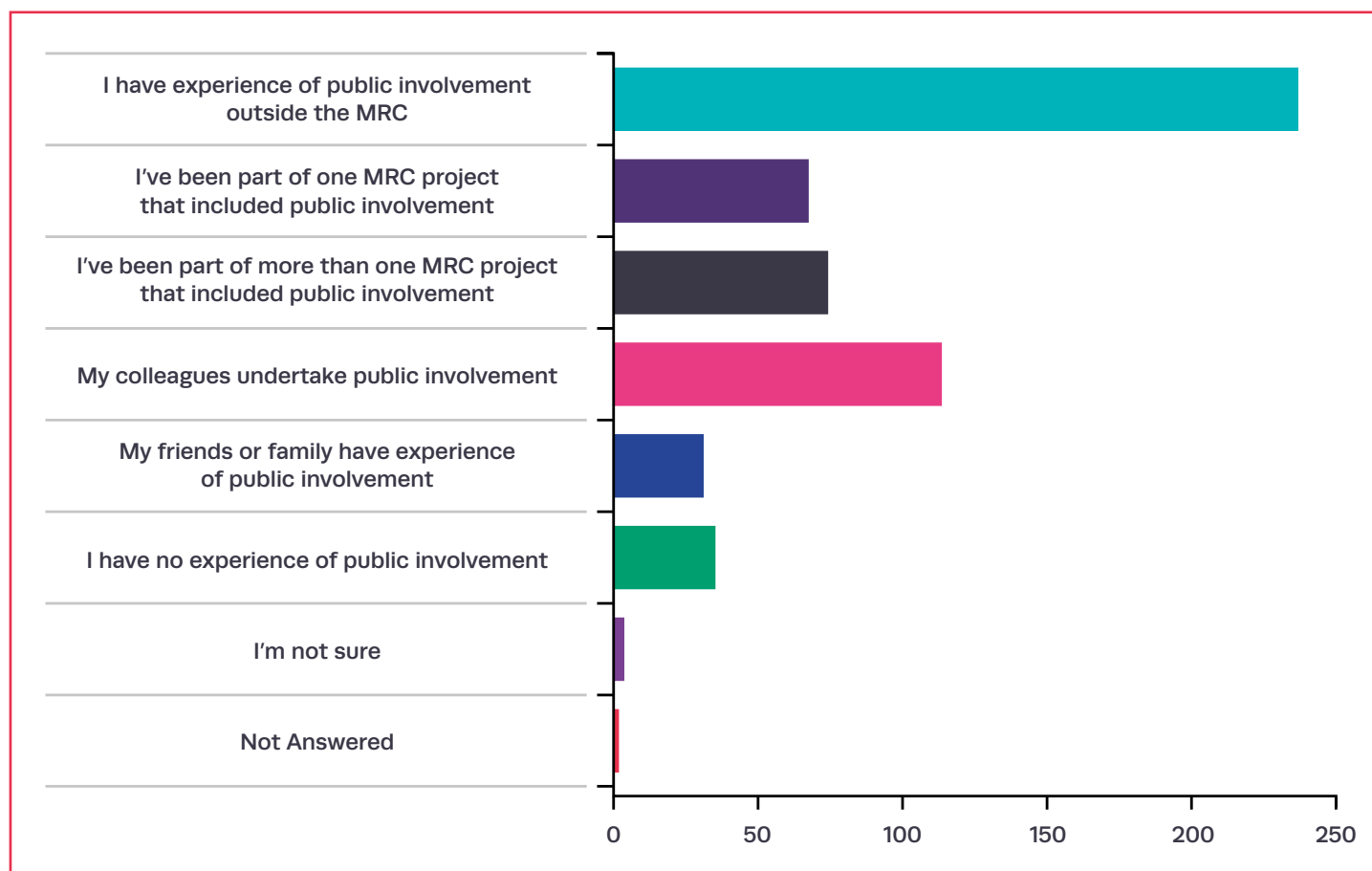
Is there anything you would like to add that isn't included above?

There were 39 responses to this part of the question. These are provided from p31.

Survey questions and data

Q15 (All): What is your experience of public involvement so far? Select all that apply.

There were 329 responses to this question.



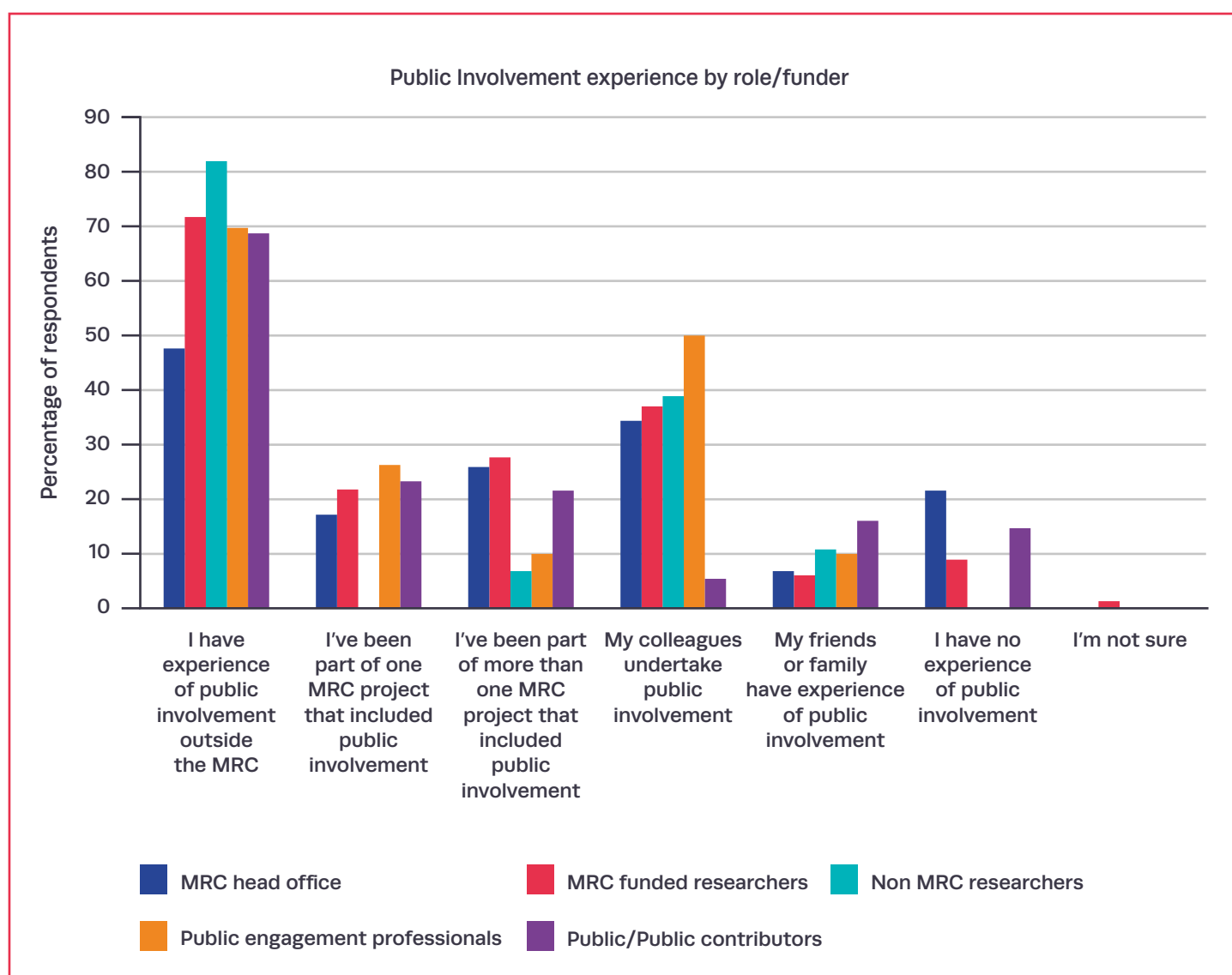
Option	Total	Percent
I have experience of public involvement outside the MRC	234	70%
I've been part of one MRC project that included public involvement	69	21%
I've been part of more than one MRC project that included public involvement.	77	23%
My colleagues undertake public involvement	110	33%
My friends or family have experience of public involvement	29	9%
I have no experience of public involvement	33	10%
I'm not sure	5	2%
Not Answered	3	1%

Survey questions and data

Q15 (All): What is your experience of public involvement so far? Select all that apply.

There were 329 responses to this question.

	I have experience of public involvement outside the MRC	I've been part of one MRC project that included public involvement	I've been part of more than one MRC project that included public involvement	My colleagues undertake public involvement	My friends or family have experience of public involvement	I have no experience of public involvement	I'm not sure
MRC Head Office	48	17	26	35	9	22	0
MRC funded researchers	72	22	28	37	6	9	2
Non MRC researchers	85	0	7	39	11	0	0
Public Engagement Professionals	70	27	10	50	10	0	0
Public/ Public Contributors	69	24	22	5	16	15	0



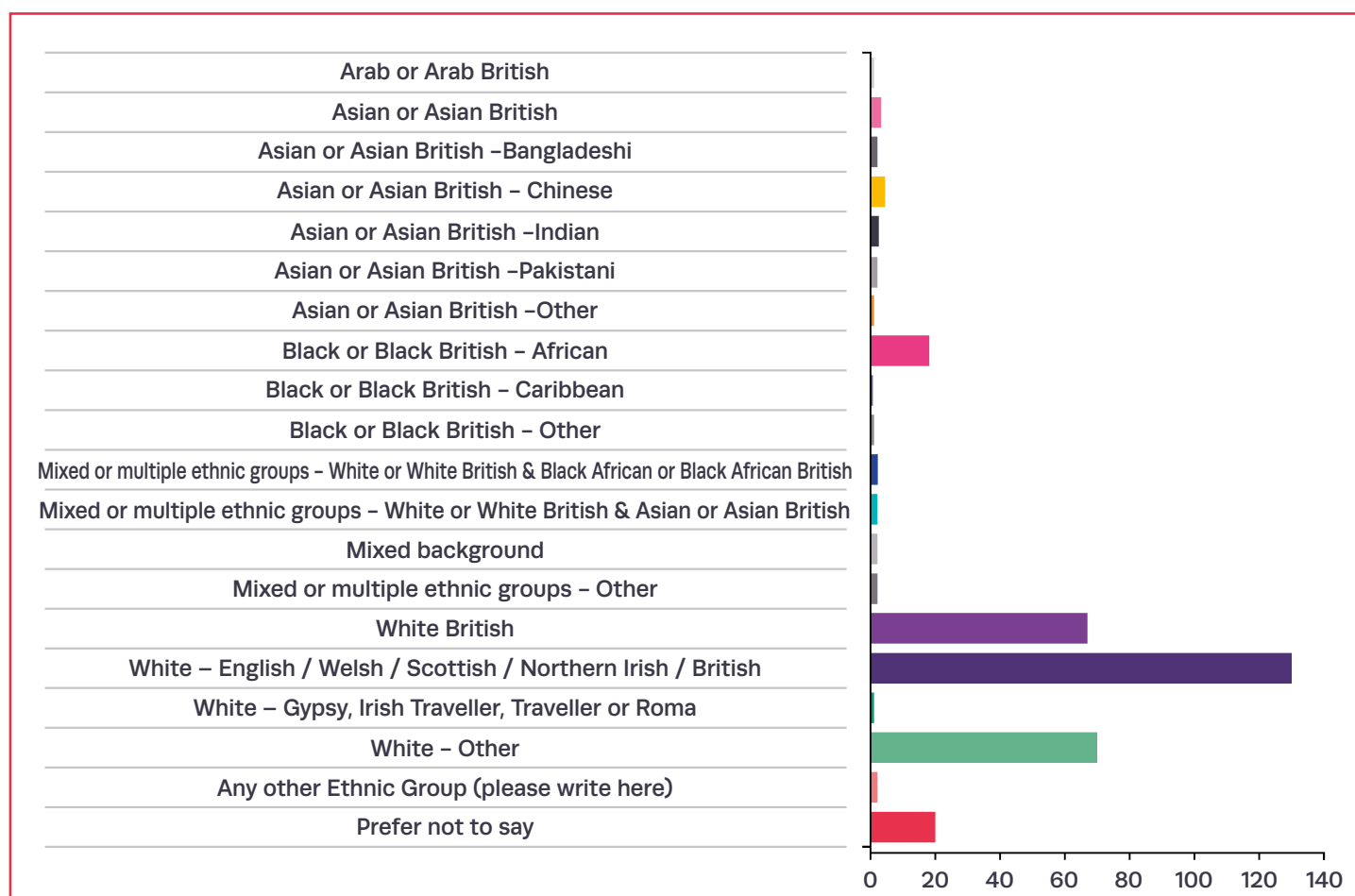
Survey questions and data

Q16 (All): Is there anything else you'd like to add about public involvement?

There were 62 responses to this question. These are provided from p35.

Q17 (All): How would you describe your ethnic group?

There were 332 responses to this question.



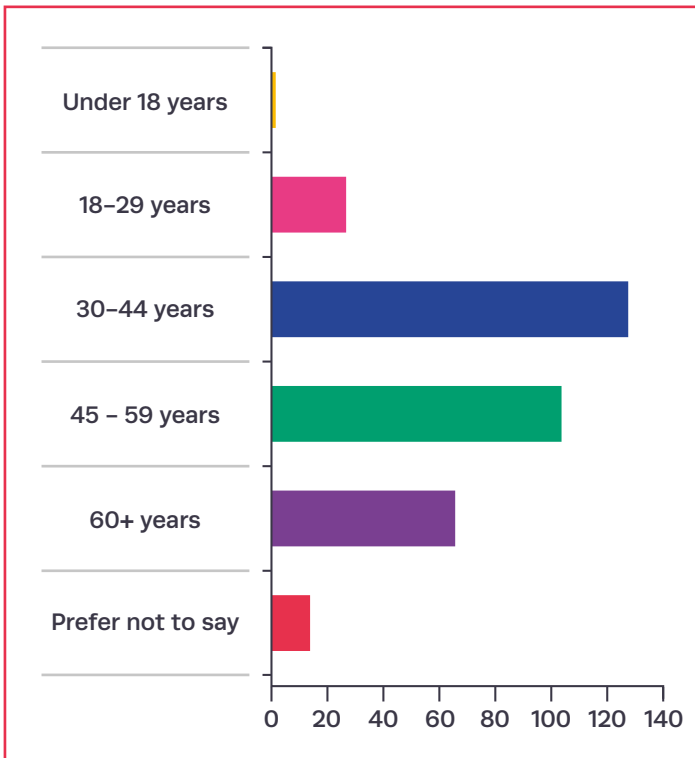
Option	Total	Percent
Arab or Arab British	1	0.3%
Asian or Asian British	3	0.6%
Asian or Asian British - Bangladeshi	2	0.6%
Asian or Asian British - Chinese	4	1.2%
Asian or Asian British - Indian	4	1.2%
Asian or Asian British - Pakistani	2	0.6%
Asian or Asian British - Other	1	0.3%
Black or Black British	0	0.0%
Black or Black British - African	14	4.2%
Black or Black British - Caribbean	1	0.3%
Black or Black British - Other	1	0.3%
Mixed or multiple ethnic groups - White or White British and Asian or Asian British	2	0.6%
Mixed or multiple ethnic groups - White or White British and Black African or Black African British	2	0.6%

Option	Total	Percent
Mixed or multiple ethnic groups - White or White British and Black Caribbean or Black Caribbean British	0	0.0%
Mixed background	2	0.6%
Mixed or multiple ethnic groups - Other	2	0.6%
White British	65	19.6%
White - English / Welsh / Scottish / Northern Irish / British	129	38.9%
White - Gypsy, Irish Traveller, Traveller or Roma	1	0.3%
White - Other	74	22.3%
Any other Ethnic Group (please write here)	2	0.6%
Prefer not to say	20	6.0%
Not Answered	0	0.0%

Survey questions and data

Q18 (All): Which age group are you in?

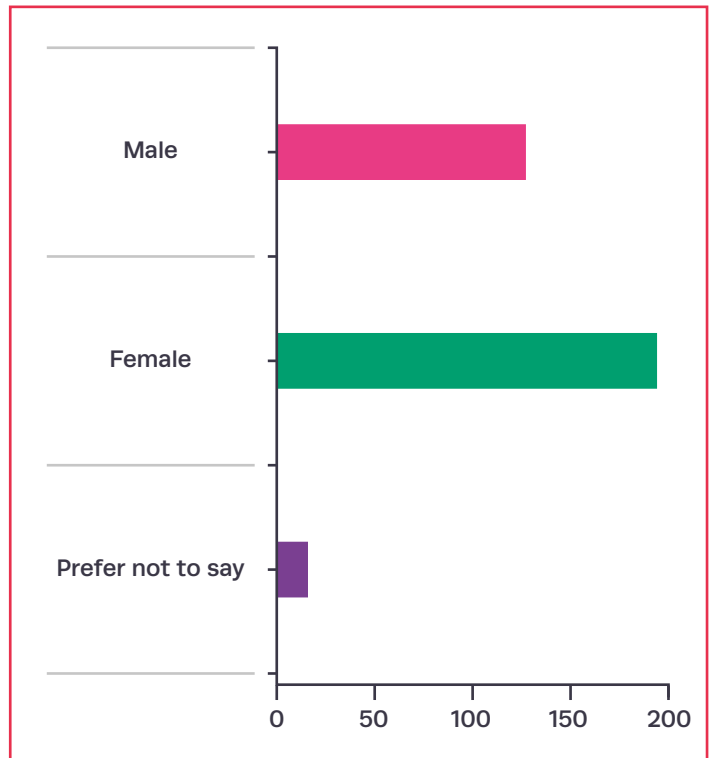
There were 332 responses to this question.



Option	Total	Percent
Under 18 years	1	0.3%
18-29 years	24	7.2%
30-44 years	127	38.3%
45 - 59 years	104	31.3%
60+ years	63	19.0%
Prefer not to say	13	3.9%
Not Answered	0	0.0%

Q19 (All): What is your sex?

There were 332 responses to this question.

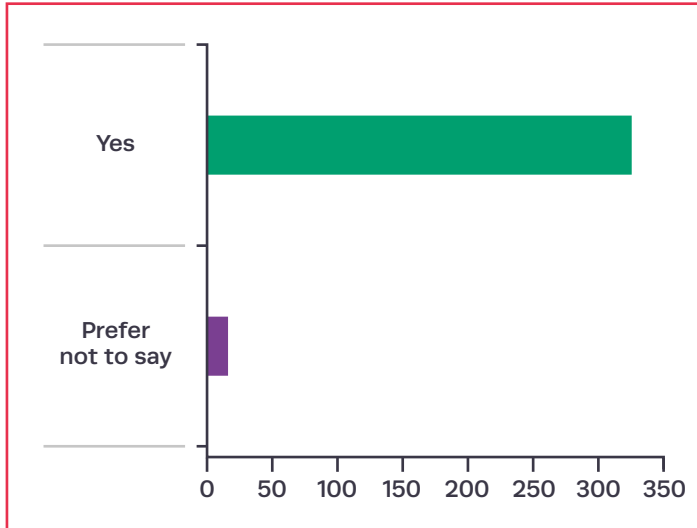


Option	Total	Percent
Male	128	38.6%
Female	190	57.2%
Intersex	0	0.0%
Other	0	0.0%
Prefer not to say	14	4.2%
Not Answered	0	0.0%

Survey questions and data

Q20 (All) : Is the gender you identify with the same as your sex registered at birth?

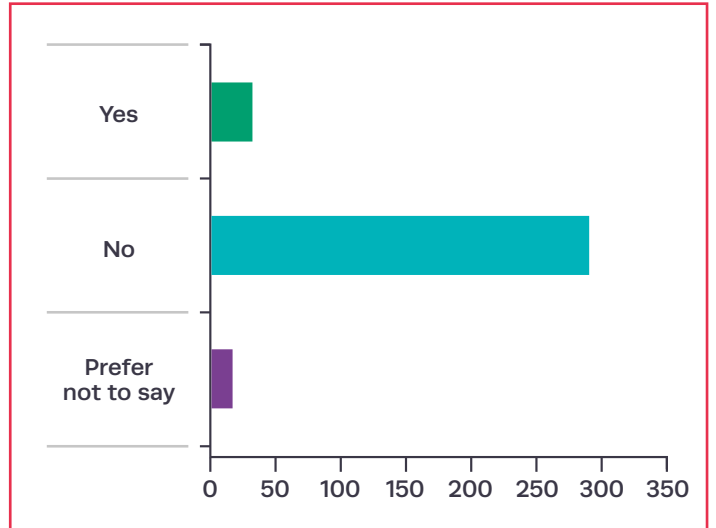
There were 332 responses to this question.



Option	Total	Percent
Yes	319	96.1%
No	0	0.0%
Prefer not to say	13	3.9%
Not Answered	0	0.0%

Q21 (All): According to this definition¹, do you consider yourself to have a disability?

There were 332 responses to this question.



Option	Total	Percent
Yes	30	9.0%
No	287	86.5%
Prefer not to say	15	4.5%
Not Answered	0	0.0%

1

Under the Equality Act 2010, the definition of disability is "if you have a physical or mental impairment that has a substantial and long term adverse effect on your ability to carry out normal day to day activity".

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

Question 8:

Following the two previous closed questions:

- what would encourage you to do more public involvement?
- what support would you find most useful?

This question asked researchers and those working in research environments 'Is there anything else not on the two previous lists that would be important to you?'

The responses have been directly quoted and categorised into headings below. Where appropriate, some quotes have been placed into more than one category.

8.1. Strategy/policy

Clear steer from funders about whether involvement or and engagement is expected if you are MRC funded.

Clear processes and guidelines. I have completed public engagement and would have felt more secure interacting with members of the public if there were clear codes of conduct.

Information on guiding principles but also best practice.

Clear guidance and training for MRC PMs on what MRC expectations are in this space, incl. e.g. eligible costings.

Guidance and a PPIE panel.

Guidance on dealing with sensitive information provided by patients/public even if not requested.

Funders at least Europe-wide should connect and devise a strategy together, if true improvements are the target.

When no clear expectations are set, women are often disproportionately involved in public engagement initiatives. This is then seen as an unnecessary "soft" skill to develop, and perceived as time spend unproductively.

There is an enormous gender discrepancy, and in my opinion the only way to overcome it is to set clear expectations for the contributions we make: e.g. a certain number of hours spent speaking to the public and other stakeholders every year, or developing online resources, etc. It would then be essential to report these within our institution, and to effectively encourage / require people to cover that minimum.

Clear guidance to public especially if they want to access high level primary data.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.2. Staffing

The main limiting issue is finding the correct patient/public group and then the administration that goes into setting up the event, delivering the event is, for me, an enjoyable, rewarding experience, which is really not much work.

For early career researchers it's difficult to find ways to involve with the public, so support from senior researchers in their area of expertise would be needed to move public involvement further.

Need greater support for public engagement professionals. We are often forgotten both from a funding and supporting research perspective. We have experience and knowledge, help researchers see how we can help.

Recognition of time trade-offs. We cannot be asked to do everything and do everything at world-leading quality. Ideally without funding. For me, there need to be people who are good grant or paper writers, others who are good analysts, or ideas developers or networkers and also people who do public engagement. And each of these needs to be valued by universities and funders.

8.3. Public involvement as a gendered issue

When no clear expectations are set, women are often disproportionately involved in public engagement initiatives. This is then seen as an unnecessary "soft" skill to develop, and perceived as time spend unproductively.

There is an enormous gender discrepancy, and in my opinion the only way to overcome it is to set clear expectations for the contributions we make: e.g. a certain number of hours spent speaking to the public and other stakeholders every year, or developing online resources, etc. It would then be essential to report these within our institution, and to effectively encourage / require people to cover that minimum.

8.4. Reward and recognition

Value by my institution would be key. PPIE is not in our metrics or promotion criteria, yet the organisation is happy to recognise journal impact factor and other academic outputs (which may not even require any PPIE).

KPIs to measure PPI.

Value given to achievements in this area broadly across the sector, such that time spent on this enhanced career prospects, not harmed them.

Guidance on how to include public involvement on my CV as a skill/output.

Currently someone who is a really good public communicator but has fewer papers and less income will struggle – so proper resourcing and incentive structures for me are the most important thing if we want this to happen properly and not as an afterthought.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.5. Training

I think some training would be useful, but I could only select 4 options so had to drop this, and was going to select online training as it would make it more accessible to a wider audience.

8.6. (Dedicated) time for public involvement

It is also important to allow researchers sufficient time to collate strong PPI for their research, so dissemination with timelines when grants are due is helpful.

One of the difficult things at my research Institution is that the MRC funded scientists have very little time to take on PPI beyond the scope of their current work.

Time and funding to support this work.

Protected time. It would be great to do more of this – but this would have to come at the expense of other priorities and not be an add on as we are already stretched.

In the global “up-or-out” system of academic science where research output is the primary measure it appears impossible to dedicate time for anything else.

Time and space to do this the hardest thing.

8.7. Time trade offs

Proper recognition that it is important and that by doing this, less of another thing will happen (week still the same length– what do funder wish to see less of, what do you want people to stop doing).

Recognition of time trade-offs. We cannot be asked to do everything and do everything at world-leading quality. Ideally without funding. For me, there need to be people who are good grant or paper writers, others who are good analysts, or ideas developers or networkers and also people who do public engagement. And each of these needs to be valued by universities and funders.

I would like to note that I already suffer from a workload that requires far more than contractual hours and therefore I ask you to consider how I should be expected to add yet more to that workload? The most realistic way to ‘encourage’ me to take part in PPI is actually to relieve me of other less important responsibilities or duties to make space for this new one. I don’t regard ‘dedicated time’ as sufficient for this given my current situation – it sounds like it would simply occupy some of my contractual hours and displace further activities to outside hours.

Pressure on time is the biggest factor preventing people getting involved in PI. Even though the focus of evaluations is still the quality of the science, more and more time needs to be devoted to other important activities, data management, knowledge transfer, public engagement, training, diversity/inclusivity, etc. For a small unit it becomes difficult to manage all of these different streams of activity. Better guidance and support centrally, but also a smaller set of achievable and well-defined goals would really help.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.8. Expert support

An organisation who organised the PPI for us.

Links to organisations experienced in delivering PPI who can design and deliver involvement activities that reduce bias in communication from the research community.

Given the diverse range of research activity and infrastructure supported by MRC, tailored support would be most valuable. For example, public involvement for a large and established population cohort needs to be seen within the context of participant communication, involvement and engagement activities.

Dedicated professional support staff to aid with organizing the basic logistics.

Appointed PPI coordinators in the research organisation.

Guidance from experts in specific areas of how to engage successfully in PE.

For me, there need to be people who are good grant or paper writers, others who are good analysts, or ideas developers or networkers and also people who do public engagement. And each of these needs to be valued by universities and funders.

8.9. Funding for Public Involvement

In terms of accountability and transparency, PPIE should be given considerably more resource, but it tends to be seen as housework/women's work that gets outsourced by white male PI's.

Funding!

None of the items offered in q7 would be of benefit. The main problem is being time-poor and with little admin support. Therefore it is staff we need to take up this part of the challenge.

Dedicated funding to support activity.

More dedicated funding to PPI.

Funding is also majorly important. I have received a small pot of money, but the rest of the money I need will come from my PhD budget.

Just to note, I think without question that funding is the most critical element. There is sometimes a narrative that researchers are unsure/not interested in public engagement/involvement. That is undoubtedly true for some, but there are also a very large number of people who are keen, trained, enthusiastic and brilliant. However, the funding support for this work is very limited, and with recent strategic changes at Wellcome, appears to be getting smaller. This is an opportunity for UKRI to lead and set a huge example by committing resources to this as a priority, not a nice to have/add on also need resource to talk to relevant people, not the same already over represented, well served groups who have the time and lucky position in life to get to these events. we need to access areas of greatest need.

Financial compensation for the time spent on public engagement.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.10. Public involvement as a requirement of funding

PPI compulsory requirement for funding even in pre-clinical studies.

Funding involvement is great and critical part of what research is all about – most of research is funded by the taxpayer so they should definitely know what is going on.

However, I would add the caveat that ‘public involvement’ does not become a blanket term for increasing the demands on what research groups need to do during a grant in order to get the funding – public involvement should be something managed/supported by the research institutions themselves and the funders themselves in collaboration with the PIs (and not limited do the duration of grants themselves).

It is also something that might come across as easy as a box ticking exercise – “yes we have done public involvement” but gauging how effective or good this is can be tricky and would just add one more element to detract from what the main aim of funding is – to support world class research into X Y Z.

It is key to ensure that there is sufficient time (consider longer timelines for applications), PPIE training (before submitting funding applications) and resources (time and money) to consult patient and public partners on funding applications prior to submission.

8.11. Systems and processes and infrastructure

access to digital tools to facilitate PPI is one thing but evaluation another.

Guidance and a PPIE panel.

More University support e.g., resources, funding, and an expectation that we do more of this.

The big problem for me is that funders in my world (NIHR) expect it and will pay for it in a grant (payment for involvement once you get going), but are less keen to pay for the required infrastructure to make it routine (a PPIE coordinator working across multiple studies). It is transformational to have that kind of infrastructure in place (which we now do but funded from a very large commercial programme grant, so not clearly sustainable in the long run). Different possible models for this, but I don't need expert advice, I need resource to support public partner recruitment and support.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.12. Connecting with communities

Value of commissioning third parties organisations to engage often ignored communities, who can then deliver uncomfortable messages back to the commissioning organisation is underrated.

A list of schools or other community groups + contacts who are keen to hear from researchers e.g. for STEM or other events that we could reach out to.

In my case, I see the value and importance of public involvement, have lots of ideas and methods in place for outreach and other types of involvement. But the main bottleneck is connecting with patients/people/public especially in or after times of social distancing. Social media just doesn't cut it (bubbles, science-only audience). A portal to connect and introduce with interested people and patients would be the most helpful and much appreciated.

A portal where I could connect to people/patients from groups who are currently under-represented in research. I am not interested in being connected with 'professional' PPI contributors.

8.13. Understanding communities

Advice on the cultural context of public involvement (as well as the ethics). Not all members of the public are the same and any advice and support should explicitly consider the needs and interests of different potential cohorts.

Community engagement and community empowerment models in research that are associated with improved health are poorly understood. Clearly articulating and outlining the steps involved in each of these models would be very useful and important.

8.14. Equality, Diversity and Inclusion

The reason that I am hesitant about a portal to connect with interested patients/the public is a concern about the representativeness of the portal (as I often work with underserved and socially marginalised populations).

Also need resource to talk to relevant people, not the same already over represented, well served groups who have the time and lucky position in life to get to these events. we need to access areas of greatest need.

A portal where I could connect to people/patients from groups who are currently under-represented in research. I am not interested in being connected with 'professional' PPI contributors.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.15. Knowledge and experience of general public/ public contributors

Access to patient experts not lay people that understand clinical trials methods.

Advice and training could be worthwhile. But more important is a serious discussion of when public involvement is likely helpful and when it is not. For example, if I'm interviewing research scientists for a focused area of research, what do we expect a non-specialist member of the public to contribute to the process? Likewise if I'm assessing complex research proposals for possible funding. And what do we expect the cognitively impaired to contribute?

I would like recognition from both funders and Universities that it is OK for academics, professional practitioners and scientists to be experts in our field and that we are sometimes the people best able to set a research agenda. The mantra that 'the public' or 'the community' *always* know best is becoming problematic. It will lead to 'tick box' engagement/involvement.

I think some of my research is too technical, i.e. requires too much background knowledge/ literature to be easily explained to public in a reasonable amount of time.

8.16. Knowledge and impact of public involvement

A formative rapid assessment.

Developing evaluation framework for community engagement activities.

Strategies which look to the recent role of public/research interaction (pandemic) in advancing science. A clear address of the opportunity afforded to population health science as a result of pandemic response.

Research that showed the need for public engagement (i.e. is my research compromised or misdirected by not having a public engagement component).

8.17. Non-clinical

Case studies are mentioned, but in order to be useful they would need to specifically include examples of patient and public involvement with non-clinical/non-translational/fundamental research.

Advice on specific steps on the research process e.g. how to involve the lay public in statistical data analysis.

Good examples of the different ways that public involvement can augment fundamental "basic-science" research.

Survey free text responses

Q8 What else would encourage/support you to do more public involvement?

8.18. Terminology

Proper definition of what is meant by PI, including who the 'p' is. When the NCCPE was set up in 2008 they came up with a definition. Unfortunately, the RCs were not able to quickly adopt that definition. Latest example is the KEF that didn't have a definition for Community Engagement. How do all these practices sit with Knowledge Exchange? For me and many other practitioners KE is an umbrella term, and one engagement/involvement practice should not be overemphasised over another. The only guiding principle is the question 'who is the stakeholder that is key to making a particular impact?', then engage with them. We call it outcomes-focussed engagement. Today it could be patient involvement, tomorrow it's policy engagement.

8.19. Other

As a rhetorical question, would specialised training be given concerning animal rights activists, religious dogma, individuals who may have a one in a million condition who become upset and problematic if their condition is not immediately researched/resolved, e.g. there have been very emotive and highly publicised cases of parents who wished for their children to be kept artificially alive, and doctors who wanted to turn off the life support.

Perhaps some issues would be easier to deal with after a sound teaching of philosophy and ethics. (Often overlooked in day-to-day research).

Survey free text responses

Question 10 (Public)

This was an open question for public/ patient or public contributors to write anything they wished to about public involvement.

Responses:

Members of the public struggle to contribute to research, or conduct research themselves.

I think there should be more of the public involved in research but many do not feel they have the ability/ knowledge to take part.

I used to be on the database of the brain research department of the MRC many many years ago (maybe 20 odd) and came to the MRC laboratories in Cambridge to sit in front of a screen and take part in experiments, but at some point I was no longer invited to help – no idea why. Nobody told me why I wasn't ever invited again. Disappointing but there we go.

Whilst it is vital that people with lived experience of a condition are involved, there are also roles for others who can perhaps offer a more objective view.

Question 14

This question asked all survey respondents 'In your opinion, what are the most important reasons for public involvement in research?' and asked them to select up to 4 options. This was followed by an open question; Is there anything you would like to add that isn't included above?

The responses have been directly quoted and categorised by role/funder.

14.1. Quotes from MRC Head Office staff

An obvious question, not directly addressed in the above list, is whether there should be greater public involvement in the prioritisation of research funding.

14.2. Quotes from MRC funded researchers/staff within MRC research environments

There are many areas of research where public involvement can be valuable. For example, public input can help in the design of devices and services aimed at helping patients and their caregivers, the public can help with messaging and language, they can help prioritise research into care and support service in the community, and they can help basic researchers understand the patient perspective and why we do research. But it is difficult to see how the public could contribute to a decision on whether to support project A or project B when those projects are highly specialized basic research.

Survey free text responses

Q14 Other important reasons for public involvement in research

To learn from patients lived experience.

I think the general public needs to be educated in science in order to make meaningful decisions at elections with respect to public and legal policy on questions related to science. e.g. nuclear power, stem cell research, abortion.

It can be important to include PPI to ensure that your research is feasible/appropriate, depending on what information you already have.

Members of the public have different expertise/sense making, e.g. lived experience or insider perspectives.

As a basic scientist, it's clear that the public isn't educated on the value of basic science to research. While that case is made clearly for physics (e.g. no one questions the value of research in astronomy or particle physics), in biology, the emphasis is too much on providing immediate tangible benefit, and not enough on pure discovery research and its benefits. A good (recent) example is the discovery of CRISPR which has so many applications but would never have been funded if only research of immediate benefit was prioritised. This case needs to be made strongly so that the public understands the huge value produced by fundamental research, and that important advances can only come by funding basic science.

Improving trust in scientific analysis.

'The public' do not speak as a single voice.

Most of these reasons are focussed on the benefit to the public, but good engagement is a dialogue, and there are just as many benefits for the researchers, which are not listed above. Public involvement can shape research directions, but it also has other huge impacts on those involved, making them think about their work in a different way, building creativity and communication skills, and enhancing their work/life balance. This seems a very one-sided list.

To create awareness and thus minimize misconceptions.

I feel that P.E/ PPI training should be available to all researchers, and make the training mandatory if you want to include as many researchers as possible in PPI.

There will always be those who are reluctant to get involved with PPI, but there needs to be some degree of humility between researchers and public collaborators to connect with the people whose outcomes they are trying to improve. It is a great opportunity to grow knowledge and maintain the trust of participants with regard to retention of participants – for example. It enables the public to make a difference too.

The most important reasons in my field are to better understand the phenomena we study and to gather data.

A key feature is the need for the whole population – researchers and the public – to be involved in research through the provision of data and samples.

The set of research questions that are funded or pursued may be biased. i.e. They may support a particular demographic of the population without addressing more pressing needs. I am interested in whether our research is 'colonised', and whether there are mechanisms that can objectively assess public need and feed that into study designs at their conception. The BMJ has

Survey free text responses

Q14 Other important reasons for public involvement in research

had several editorials that show that we as researchers are failing to address the racial health gap for example.

Public trust that we know what we are doing, and that we are doing it properly, without necessarily needing to know the detail.

Educating the public in an easy to understand way how research is benefiting society. This will make it easier for the public to accept public health policies and advances in new treatments.

Encouraging children to pursue subject that can lead to research careers.

Another benefit for public involvement is faster uptake of new evidence.

14.3. Quotes from non-MRC funded researchers/staff within MRC research environments

By public involvement we mean when members of the public work with researchers to help shape research (e.g. providing input about research priorities and research design or advising on research project). I strongly disagree with that – I think certainly members of public should play a role in being aware of what research is taking place, but “providing input about research priorities and research design or advising on research project” is not something that members of the public are best equipped to contribute to esp. as re MRC as they may not necessarily have the education/expertise/information needed to understand what the issues are today but also where they will lead to tomorrow.

Choosing outcomes that are relevant to them.

To encourage the underserved groups or communities to get interested & involved in research participation.

14.4. Quotes from public engagement and communications professionals

Starting the conversation, many of the publics don't actually know about the research to start with (at least in the research I promote), so raising awareness and starting the two-way conversation is vital. This allows them to make more informed choices.

Making sure research is designed in the best possible way to meet the needs of those to take part and benefit from it in future.

I find it very difficult in the non-clinical research space to understand when it's best to do PPI. It seems to more obvious to me in clinical research. I think my answers would change if this was considering clinical research.

Survey free text responses

Q14 Other important reasons for public involvement in research

14.5. Quotes from members of the public and public/patient contributors

We save money, time, manpower resources and make for a better quality application provided we are listened to.

PPI will help to make the research more amenable to help recruitment of participants.

To help researchers think about what has been overlooked and may affect outcomes.

Making research more aligned CROS to PROS and PREM so that you get less dropout rates in trials and better adherence.

Encouraging the public to allow data-sharing for research purposes.

If it affects us, we should have a say.

It would be beneficial to use co-production in determining research topics and how the trials are organised.

A wide range of patients with diseases should be consulted regularly to assess the suitability and progress of publicly funded research for their illness. If, as with mecfs, there has been constant disquiet and challenge, not just from a few but most patients and their representatives, this should be taken on board, not overridden. No patient group should have research models imposed on them or their calls for more help just casually dismissed. MRC need to publish clearly how much each disease is getting per year so evaluation and comparisons can be made.

If research can only cover a certain number of areas of an illness, the most relevant are included.

To ensure the most relevant patients are included in research & not selected on the bias of results wanted i.e. The PACE trial for M.E never included patients who were chronically ill and/or bedbound/housebound.

Many of the above are good reasons for the public to be involved in research. To ensure that any health research is going to benefit the patients it must include patients/pubic in the decision about the research question.

The breadth of knowledge and experience that the public can bring in order to reshape research is invaluable.

PPI can help researchers to see and design their proposed projects in a more practical/feasible way and that is more acceptable to the public and potential participants.

Making better science.

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

Question 16:

This question asked all survey respondents 'Is there anything else you'd like to add about public involvement?'

The responses have been directly quoted and categorised by role/funder.

16.1. Quotes from MRC Head Office staff

I think it is important to differentiate between public involvement and participant (or patient) involvement, particularly where the research involves direct human participation. These are different constituencies and will have different views; for example, about the prioritisation of research questions.

I think there are some really good examples from charities – from the German and UK MS societies setting their research priorities through public involvement to CRUK's involvement of publics/patients in funding decisions.

There are also some great examples of how the lack of public engagement has shut down initiatives (care.data) and is really hurting public discourse around science.

The MRC has one of the least prominent public involvement and engagement strategies of anywhere I have worked. It would be great if this could be done more – but this also feels like a bit of a stretch if we are cutting opex budgets?

16.2. Quotes from MRC funded researchers/staff within MRC research environments

Public involvement definitely has its place and can be genuinely useful. But there is risk that when it is applied to ALL research processes, projects or decisions, some of it will tokenism. That is worse than not doing it all.

Because of their clinical situation, cognitively impaired patients may not be able to contribute in a meaningful way.

I think it is essential and have incorporated it into my research for over two decades.

It is important to acknowledge that by 'public involvement' what you actually mean is 'involvement of a tiny number of highly motivated and highly educated members of the public'. Involving a handful of individuals, or even 10s of individuals will never be representative of the general population. The people who volunteer for public involvement tend to be (like clinical research volunteers) of above average socioeconomic status and education. I have frequently met retired professionals including retired researchers volunteering in this capacity – which is appreciated, but they are a very unrepresentative group. Even when a study involves people from their target population, typically this is only a very small number of people so again is not representative. I feel there is a lot of fiction generated about how public involvement in research means we are representing our country's population and serving their wishes in terms of research priorities etc. It really, really does not.

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

Yes there is. This survey starts with the assumption that PPI is inherently a good thing, that there are no side effects nor downsides to it, that it perhaps doesn't always work, but we can continue to improve it. In my opinion like everything else – be it a drug treatment, a new service, a new therapy, an NHS reform, a university reform, a funding review, a CQC visit etc etc there is a balance of good on harm. During my career I have been involved in excellent examples of this, and also one's which are totally disastrous. I think that public engagement can be very beneficial, but also is sometimes totally dreadful, and a major threat to the progress of medical research and improving the health of the public.

This survey unfortunately is further evidence that we are turning a blind eye to the downsides and dangers of PPI. I have seen it manage to destroy good research – and I am not talking metaphorically. I have seen it close down research projects, prevent good research from being funded, lead to intimidation of researchers, prevent professionals from being truthful, and also actively encourage bad research that is harmful to the public. I have also witnessed organisations and regulators being bullied into taking rash and unfortunate decisions that I know they regret. I have also seen it at its best. But whilst everyone, including myself, acknowledge the potential benefits, I detect a reluctance or indeed fear of even hinting at the problems and risks, which is already causing harm, and I am afraid this survey is a perfect example of this group think.

There was literally nowhere until this open question at the end that even hinted at the possibility that people might have been deterred by bad experiences of this, and the dangers of the underlying assumption that PPI is always “a good thing”. Nothing in life is always a good thing, everything that we do has risks and benefits, and we should always look at the balance of the two. Except in this survey.

Making it an essential component of a research grant application only works if there is clear evidence for applicants that it genuinely impacts on the funding outcome. Otherwise it breeds resentment at the requirement to do it for those who are not willing, frustration for those who put effort into it but see no reward for having done so, and ultimately devalues it.

There should be an expectation to include it where is/can be appropriate / integral and opportunities for additional linked funding for less integral PE post research grant award.

I think University's need to value the need for public involvement and have mechanisms which support PPI activity and efforts to establish ongoing public involvement to support research.

I think it is placing too much pressure on young investigators to tell them to do public engagement. Research is more than a full-time job and they are starting their careers in science as many of them also start their families. To tell them that they should prioritise doing public engagement (like talking with school children) when they struggle to see their own children is NOT helpful. It is great that some people enjoy public engagement, but it is wrong to make the exceptional the norm.

I think it is being taken too far honestly. There are projects where it can be really useful to ensure feasibility and appropriateness. But I think asking PPI groups what research should be conducted and/or to evaluate research proposals can be highly inappropriate. I wish the MRC would think carefully about what knowledge someone with lived experience for example can honestly bring to a project. I also have serious concerns about the validity of relying heavily on PPI input as PPI groups don't tend to be highly representative/typically capture those willing to engage even more than actual research projects. The whole paradigm is often biased/weighted towards a vocal minority and can be of limited value for this reason. The requirement for a lived experience representative (typically non-MRC schemes) seems borderline offensive for this

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

reason – how can you expect one individual to represent the views of a large and diverse group? If one MRC employee was asked to represent the experiences of your entire organisation you would be rightly insulted. We should be working towards more robust research standards than this. Public involvement can be highly appropriate, and certainly we should be engaging more widely in disseminating our findings, but I am strongly opposed to blanket requirements for public engagement at all project stages and think we need to be really considered in how we approach wider elements of engagement to ensure that it is necessary and that its value is fully realised.

In terms of EDI agendas, the addition of PPIE can be a corrective for narrow perspectives, and can help with the application of knowledge, e.g. implementation, or scale up and spread.

The principle is great but time/resources to do this are often stretched. Thus good if it's better recognised AND funded by MRC and other funders.

I have mostly engaged through invitations from schools, and found this well-appreciated by the students.

PIs are overwhelmed by life in Academia. The percentage of successful grant applications is very low in the UK for the level of science we have. Although most people agree that public engagement is very positive for science, only more public engagement will work efficiently if the implementation does not require excess paperwork and duties.

The biggest barriers are public understanding of what we are doing, and understanding the context – especially in more basic science this can be difficult to get across in a meaningful way. It is also the case that 'lay people' who take part are not necessarily entirely representative of the wider population. Whilst small focus groups are easier, large-scale projects such as those undertaken by specialist societies (in partnership with organisations such as James Lind Alliance) can be really helpful in getting more representative views.

I tend to do more public engagement as member of a charity committee and receiving charity funding as there is a closer relationship with people in specific charities than UKRI funding.

I'm all for it. The main problem is the time commitment – difficult along with all of the other things we are expected to do.

Think could be very strong but needs to ultimately increase quality of research and help communicate research findings optimally to the public.

The two big barriers for the fundamental research I do are:

1. time.
2. difficulty of speaking with the public about using human embryonic/foetal material in research.

I currently have a large grant (Wellcome) for public involvement in a fundamental research project. This requires time and effort. However, I am also well aware that my next research grants and promotion at my university will be assessed based on my scientific outputs, not on how well I have involved the public in my research. This is a significant barrier for many researchers who already feel over-stretched.

Perhaps most critical in the sphere of health data science, for transparency and to build trust.

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

We must be a bit wary of the 'professional' patient / public contributor whose views might be forcefully expressed but not necessarily representative of the wider population.

I have experience in public engagement, but it would be useful to find out ways to involve the public and any related ethical issues.

I believe that public involvement, in a real sense of dialogue and two-way communication, is a fundamental part of the academic research project. We shouldn't be simply sharing our research with each other – we are funded by society and accountable to society. The last two years have made clear what happens when there is distrust in science and in the scientific process. As stated earlier, I think that UKRI should lead this by committing resources, not just to training (which many academic institutions do very well, adding more will not have a big impact) but also to funding directly, and emphasising the importance of this work.

I do feel that public involvement can be beneficial to some types of research (e.g. translational research), but it should be targeted at research areas/types where it is useful and relevant, not across the board. The same goes in the other direction: not all research is of interest/direct relevance to the public, so public involvement/public outreach should be focused on research projects/types that are of most public interest. Making public involvement/public outreach a condition of all types of grant funding would, in my opinion, be counterproductive.

It is not relevant for most of my work and so I would be unhappy about requirements for public involvement. I think the best science will often be done without concern for possible public perceptions: historically, what we consider some of the most important advances in science were (and in some places still are) publicly unpopular (e.g. evolution). However, when it is appropriate (e.g. in my work, engaging with rare disease patients and their foundations) some funding or support would be appreciated and could help the research.

In a previous working life I had worked in transplant immunology.

During open days the public did not want to know details of the research.

But patients and families were impressed and reassured by a friendly chat with us and experiencing tours of our facilities.

Conducting research gets much easier with public involvement.

The MRC should sign up to the NIHR PPI National Standards.

Building insight of the public about research.

I was involved earlier in my career when it was possible to find time for it.

I think MRC talks a lot about how this is important, but doesn't really do anything to formally encourage or facilitate public involvement, or engage with the public itself, or create actual opportunities to involve its researchers with the public.

I think there are many ways in which public involvement can contribute to research, but it would be interesting to quantify this in some way to convince other researchers how this can have a positive impact.

It's very hard to understand quite what is expected from PPI for research topics that are very much at the discovery end of the pipeline. It is great to have the public exposed to cutting edge

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

research, but it is hard to envisage how their feedback can substantively influence the questions proposed for research or the nature of the research at very basic/discovery level. Yet, this is something that is becoming increasingly expected from researchers and takes a considerable amount of researchers' time, energy and resources.

16.3. Quotes from non-MRC funded researchers/staff within MRC research environments

The title of the survey is "What are the benefits and challenges of public involvement?" but so far there is very little on the "challenges" but mostly just on the "benefits", so this is not very balanced.

Vital for research and needs to be managed better.

I feel strongly that research need to be more ethnically diverse and fair to the public.

Should be core to what we do.

16.4. Quotes from public engagement and communications professionals

I think a blanket expectation for involvement in all MRC research will be unrealistic, particularly for basic and blue skies research. For this, I think engagement approaches to enable dialogue can be more effective. I wouldn't want to involve for the sake of involving...

It needs promoting! It needs teasing out from the broader umbrella of public engagement.

The following issues need fixing (1) funding for public involvement in preparing funding applications; (2) in NIHR, more £ is spent on studies that have no public involvement than on studies that do, so make it a condition of MRC funding approval; (3) give public contributors access to academic libraries; (4) admit that commercial interests affect some public contributors willingness to engage and establish safeguards; (5) create ethical approach to payments for involvement and participation.

PPI in lab-based and pre-clinical research is important to build early connections and ensure research is designed needing the target populations needs e.g. is the medical product being developed acceptable or are there any other considerations, concerns or worries that need to be addressed and taken into account.

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

16.5. Quotes from members of the public and public/patient contributors

Question is too broad – I have many things to say. one of the most important is that our influence is less impactful than we or anyone else in the system would like. It is definitely difficult to define and unless there are very good feedback mechanisms from researchers, it is difficult for PPI individuals to gain a sense of their worth.

PPI is really part of complying with the public sector equality duty which is a legal requirement. PSED is only possible when working with the nine protected groups as well as the public at large.

As a member of the public I find it immensely interesting and enjoyable getting involved in research.

The public is a very general term. In my area it is often practitioners and other expert or active groups who we want to connect with.

Have a look at PFMD patientfocusedmedicinedevelopment.org

The quality varies hugely but this is rarely acknowledged let alone tackled.

How do we get a more diverse involvement from the public and regions especially rural areas of the country?

The neglect of ME/CFS has been a scandal and disaster. The way the MRC has been indifferent to our sizeable and highly disabled population, the way they there's been no accountability for the disastrous decisions made by those who had power but wrongly saw ME/CFS as a psycho / behaviour disorder, the fact that there is not anyone the public can complain to when public funding bodies are acting in a way suggestive of bias and prejudice and leading to neglect... it has to all change. Attitudes to mecfs and gulf war syndrome have been repugnant and cost lives. The medical profession need humility and should always have listened to and respected the patient voice. MRC are there to facilitate progress for all diseases and yet it left some to stagnate whilst it bragged about your high achievements for more prestigious areas. The fact that MRC are only now considering "the public" in 2022 says it all.

I have a PhD, and am a trained genetic epidemiologist. I have become involved as a member of the public because I cannot work due to my M.E but I wish to still use my knowledge to help in a more low key way.

I have an illness that has been poorly researched, where bad and unethical "science" has been allowed e.g. outcome swapping, bias, publishing unfavourable data in future buried papers rather than the main paper, info in abstract presented in a dishonest way, raw data hidden from independent view, adverse events not recorded as such or taken seriously... I could go on. If I as a patient could have any impact or involvement in research, it would simply be to say, "Do better." Go back to basics, refresh your 1st year methodology lecture notes, act with integrity, and when bad science is called out, stop closing ranks...

Survey free text responses

Q16 Is there anything else you'd like to add about public involvement?

My background was in the pharma industry and clinical trials of new medicines as well as the business side of manufacture and supply. I see an additional side to research and understand the high compliance and regulatory requirements that are necessary. The public have many attributes to bring to the research table including but not limited to personal experience of actual medical conditions.

I have been working on a MRC grant application where it was intended that I would be a co-investigator but the process is not set up to easily accept a lay person in this role. If you wish to encourage members of the public to be co-investigators it would be helpful to look at how this can be achieved. Also, when I looked on the MRC website it was not obvious how I could apply to be involved in MRC PPIE activities.

I think that for it to be valued more, it should move away from being a volunteer role and be paid.

I was involved in research during my working life and am aware of the work of the MRC. I was also involved in clinical research during my working life and therefore have quite a wide breadth of knowledge. I have also worked with different groups of people in the community and hospital setting as well as being a long-term patient. I therefore enjoy working in patient/ public involvement, but I think it is something that many people would feel unsure about getting involved in.

We give added value to a project and where it is about for example new drugs or therapies for particular conditions, those affected by that condition bring insight and common sense to researchers.

MRC Review of public involvement in research (2022)

Complete list of documents

Looking forward: Working with the Medical Research Council towards a public involvement strategy (Main report & Executive Summary)

Appendix 1 Methodology of the MRC public involvement review

Appendix 2 Landscape review of public involvement in non-clinical research

Appendix 3 Tweetchat #Involvement_Preclinical

Appendix 4 A patient's desktop review of public involvement at the MRC

Appendix 5 Examples of MRC public involvement

Appendix 6 Public involvement in research survey

Appendix 7 References and toolkits about public involvement in research

Please see full list of acknowledgements in Main report

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This work was commissioned by the Medical Research Council

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