

# Patient and public involvement strategy feedback questionnaire - public version

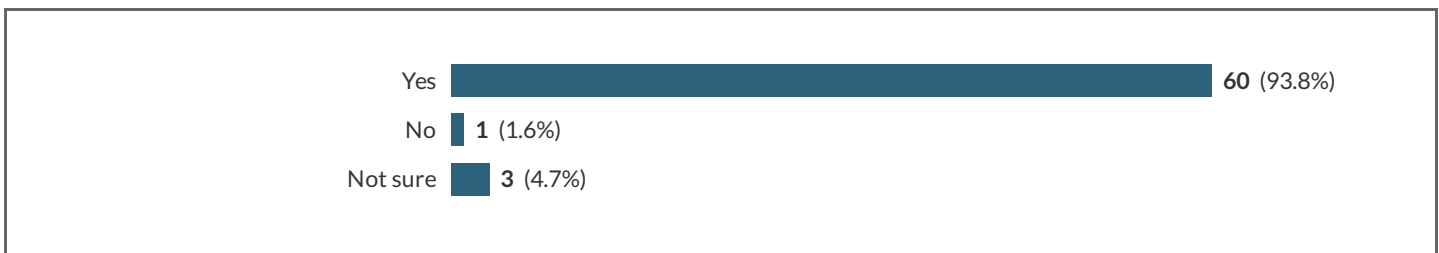
Showing 67 of 67 responses

With **1 response excluded**

Showing **all** questions

Response rate: 67%

## 1 Do you agree with the vision?



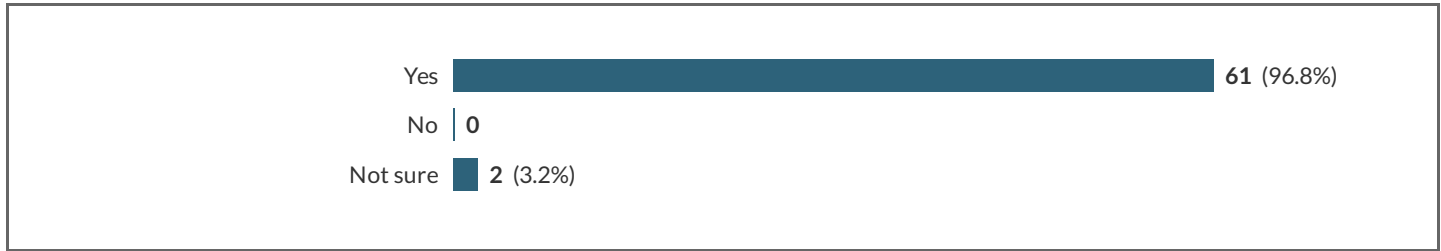
## 2 Please give your views on the vision. Is there anything that should be added or changed? If so, please give your reasons.

Showing all 49 responses	
there has been quite a bit of discussion of late on twitter about the use of 'empower' - in general it was disliked as there is general agreement that you can't empower people as it comes from within, however you can share your power or make the system better etc so people feel able to take part - if you want to keep the words in it might be better to add feel to the sentence eg 'communities feel enabled and empowered to work...'	<a href="#">782554-782545-82327336</a>
Give some examples of under-served groups.	<a href="#">782554-782545-82338041</a>
What do you mean by 'enabled' and 'empowered'? What will this look like and what will you do? What outcomes will you monitor. What about Patients, etc, will have equal standing in terms of numbers involved, diversity, involvement from the very start of projects, financial remuneration (budgetary considerations), etc	<a href="#">782554-782545-82339598</a>
Not an easy read version for inclusion of those who should be included but may need help to give their views	<a href="#">782554-782545-82361493</a>
First things first and I think priority 3 has to be understood and adequately set up for the others to have a chance so that should be number 1. One of the weaknesses in the health care system has been that in sharing experiences and particularly innovation. Maybe Covid19 has promoted improvement in this. Nevertheless I don't think this document promotes this directly enough - just by implication.	<a href="#">782554-782545-82367947</a>

I think it is brilliant.	782554-782545-82369234
The vision document seems very comprehensive and I have nothing to add.	782554-782545-82371153
I'd expect nothing less of a PPIE vision. But perhaps to give it more meaning and distinguish it from other (dare I say) standard PPI visions, it would be worth saying that your vision is that every one of your researchers fully understands the benefits of PPIE and how to undertake value-adding PPIE, and that they incorporate it [automatically] as an integral part of all research they do.	782554-782545-82372641
Perhaps more emphasis on the wider societal benefits of health research.	782554-782545-82377308
Yes, please add words to the effect that PPIE contributors will get feedback from researchers for whom they work.	782554-782545-82378782
A good ideal but not easy to achieve	782554-782545-82379833
I would only ask: Is "all communities" strong enough to highlight the need to reach out and engage more vigorously with non-white (BAME) communities?	782554-782545-82381467
Projects should be transferable to all parts of the NHS, Scotland, Wales and NI.	782554-782545-82394154
Seems clear and comprehensive	782554-782545-82398120
Very comprehensive	782554-782545-82402665
Concise and to the point, I like it	782554-782545-82403668
Good vision scope. For more general uptake, a more succinct version would be more engaging.	782554-782545-82420539
I agree that everyone is an equal and should be treated as such.	782554-782545-82424143
partners suggests equal weight but that cannot be, because some are much more informed	782554-782545-82425031
Good. Maybe - ..partners to improve the quality of research and the health and wellbeing of all society.	782554-782545-82451773
I think it is very comprehensive and addresses the wide range of people which it targets.	782554-782545-82476443
Looks fine	782554-782545-82489024
this review should include all ethnic backgrounds, patients families and carers	782554-782545-82490592
It might be helpful in attracting PPI, if you could give examples where PPI/E has made a difference and how	782554-782545-82493884
We need to look to the future, this project will be of great advantage to all.	782554-782545-82494707
No, perfectly sensible vision	782554-782545-82521135
In terms of wording, I would add "members of" before the final word "society", otherwise the vision is spot on. I particularly like the phrase "valued partners", it is key to PPIE.	782554-782545-82531888

I think this is very comprehensive.	782554-782545-82539118
It's quite a grand vision that is more appropriate to a national body, and should be more relevant to OBRC	782554-782545-82594455
Who is this for? If the public - simplify. E.g. 'To involve the public in helping with medical research. To seek the widest possible representation.	782554-782545-82596989
Agree	782554-782545-82596838
'from all communities and age groups'	782554-782545-82643842
It covers everything I would expect in a good vision statement	782554-782545-82694823
I personally think that enabled has become a cliched term, that is used to often and has lost meaning and impact to a lot of the population (politicians are always bandying it around). I think the statement is concise and covers what is needed, but I would replace enabled with involved, as we want people to be involved.	782554-782545-82695673
How will people be chosen?	782554-782545-82704011
Nothing to add	782554-782545-82708179
Might it be worth adding something about being sought out? It might shift the burden of responsibility slightly from patients to the BRC, which is perhaps as it should be?	782554-782545-82747913
It's brief, clear and comprehensive.	782554-782545-82756126
I found it a difficult read to get a full understanding and had to read 3 times. From what I understand the priorities are far ranging so its difficult to be specific about changes or additions. My worry would be about control of implementation which may come later.	782554-782545-82775113
I like the word partners. Could you add the word encouraged?	782554-782545-82818177
Is it worth saying something about what you hope participants will get out of this or can get out of this. E.g. improve their own understanding...	782554-782545-82986238
As there is a struggle to get people involved, the statement could be stronger, maybe the word encouraged should be added along with welcomed, so that it is friendly, non-threatening.	782554-782545-83090244
It is a longwinded way of saying that the vision is for the best interests of all those involved in type 1 diabetes research.	782554-782545-83145057
I think the vision should also say the PPIE engagement is essential to improve the quality, relevance and cost-effectiveness of the research	782554-782545-83183076
Perhaps Include in communities something like from all communities and abilities / disabilities?	782554-782545-83249233
looks good to me and appropriately inclusive	782554-782545-83248725
it is comprehensive. Feedback is included. But not feedback on the feedback - this is what's missing for me - closing the loop	782554-782545-83258506
I think sometimes it is not very clear and visible how patients can be involved. Perhaps you could make people more aware like asking GP surgeries to cooperate?	782554-782545-83378116

**3** Do you agree with Priority 1?



**4** Please give your views on Priority 1. Is there anything that should be added or changed? If so, please give your reasons.

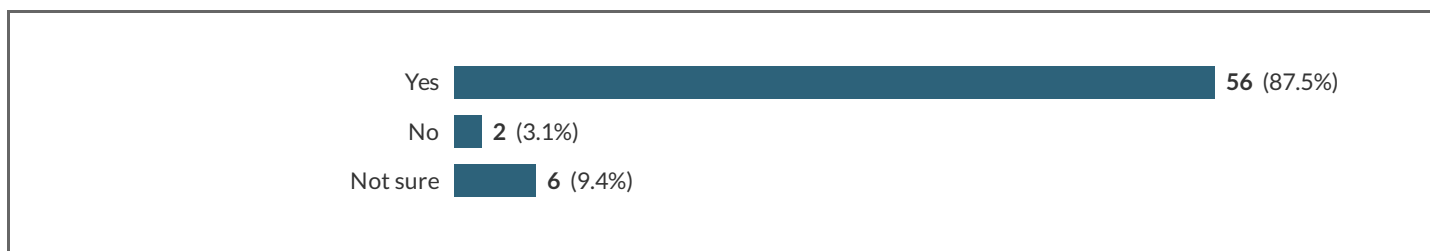
Showing all 50 responses	
Should this be broader than health research ie social care and public health?	782554-782545-82327336
good.	782554-782545-82338041
There also needs to be a budget for PPI and review of how this was spent. Also a review of how, what POI has contributed and how this was acted upon.	782554-782545-82339598
No mention of how this will be done not all can manage or have facilities for on line ,phone or paper should be added	782554-782545-82361493
But see above that it should be number 2	782554-782545-82367947
I think it's fine.	782554-782545-82369234
I am pleased to see that you are promoting the PPI opportunities more widely, as there have been several occasions when I would have liked to take part in projects but was excluded because I live outside a designated area	782554-782545-82371153
First bullet point is vague: "more widely". Lacks anything by which to measure success/ effectiveness.	782554-782545-82371278
Similar to my comments on the vision, aren't these the obvious things that any research organisation should have already been doing for a while and should be doing henceforth. On the other hand, I can understand that these are the essential basics that you may need to state - but that then raises the question about what they actually mean in practical terms. So, you plan to "promote PPI opportunities more widely and communicate the value and relevance of health research': more widely than what? with what objective in mind? any measurable outcome? And you have a priority to support researchers to produce understandable and engaging materials: but my experience as someone with a keen interest in this issue, is that researchers who can produce plain language text and (more fundamentally) to take themselves out of the research bubble and seek to understand their 'audience', is in the minority, so how are you going to	782554-782545-82372641

deliver on this priority. On a point of detail, there seems to be some overlap between priorities 1 and 3: both talk about materials being giving support to researchers on PPIE materials.	
It seems good to me as it is.	782554-782545-82377433
Need to promote general benefit of health research to society, rather than just project specific. Help involved public become champions for health research and public involvement.	782554-782545-82377308
I am only aware of chances to get involved by email this needs to be greatly expanded to get people from all walks of life and ethnic groups	782554-782545-82379833
These aims are written in very broad strokes. What does 'engaging' mean? Do you mean 'relevant'? An issue that is unimportant to a white community might be critical to an Asian to African community, And will 'understandable' mean the issue is presented in a format that non-white communities will accept?	782554-782545-82381467
With remote conferencing, there is no reason why views should not be sought from all over the UK	782554-782545-82394154
ensure that language is fully understood by minority groups	782554-782545-82398120
Again, very easy to understand	782554-782545-82403668
a small explanation on what PPIE is	782554-782545-82407707
Clarity of language is very important. Perhaps useful to add that information is provided in languages other than English that are known to be used in the communities to whom the communications are addressed	782554-782545-82411831
No changes	782554-782545-82420539
That all spoken languages are considered and translated for minority groups. That images can be clearly understood by all groups.	782554-782545-82424143
the outcomes of consultations are also important to everyone if their contribution is felt valued	782554-782545-82425031
This may be more meaningful when we see how PPIE opportunities will be more widely promoted?	782554-782545-82451773
Train those researchers from all sectors to use the materials and be able to answer questions related to the images and languages used.	782554-782545-82476443
No problem	782554-782545-82489024
reporting of evidence found should also be a priority of any research programme	782554-782545-82490592
Wherever, acronyms are used they should always be preceded with the full description of the letters used. Having served on OUHFT committees, clinical trial steering groups, there is a growing list of acronyms (currently 12+ pages for one committee. How are staff expected to remember them all let alone PPI/E members?	782554-782545-82493884
No, perfectly sensible approach	782554-782545-82521135
In BP1, "more widely" is vague and may be more useful if defined and clarified with examples of what "more widely" might look like. BP3 is key to	782554-782545-82531888

PPIE. Regardless of their backgrounds, people learn and assimilate information in different ways e.g. some respond to pictures or diagrams, some like information as prose, others like bullet points and key facts highlighted etc. It is important, therefore, that PPIE materials are presented in different ways to have the most wide-ranging effect. BP4 - I am unsure as to what the 2021 website review is. BP5 (and the use of plain English) is very important. BP6 - this is important because lay people tend to perceive public involvement in research as trialling new drugs but, of course, it can be much more than this.	
This makes sense.	782554-782545-82594455
Leave out 'more' in first sentence. ( smacks of breastbeating)	782554-782545-82596989
Nothing needed to be added or deleted	782554-782545-82596838
'all communities and age groups'	782554-782545-82643842
I couldn't have said it better!	782554-782545-82694823
in addition: Provide feedback to researchers to aid them in future development of PPIE materials.	782554-782545-82695673
Who will be reviewing the readability of the contributors' materials?	782554-782545-82704011
Nothing to add	782554-782545-82708179
This priority rightly focuses on the need to involve and engage more widely.	782554-782545-82756126
Items 2, 3 and 5 are all about variations around activities and materials and possibly could be consolidated maybe. I have no idea around the process of 2021 website finding implementation is this really a given and all findings are implemented?	782554-782545-82775113
Develop an expectation that there is PPIE involvement in all research and by all researchers.	782554-782545-82818177
Perhaps it is good to mention something about 'sharing participants feedback'. I.e. not only so people feel visible and that there input can be seen, but also to persuade others to get involved.	782554-782545-82986238
How will opportunities 'promoted widely'? Ref 'by all communities' makes me wonder about translation into potentially hundreds of different languages	782554-782545-83078313
Emphasise, that this is open to all, it is not an intellectual exercise.	782554-782545-83090244
no thank you	782554-782545-83145057
I broadly agree think tha tin the 1st bullet point it should be made clear it is the relevance of PPIE involvement that is at issue	782554-782545-83183076
it would be key to map the current PPIE group to identify the gaps and then use that to prioritise	782554-782545-83232555
Include audio versions of documents where possible	782554-782545-83249233
The first two bullet points are good aims but could be more precise/concrete. E.g. what does "more widely" mean in practice? How will you ensure that "PPIE activities and materials are understandable and	782554-782545-83248725

<p>you ensure that "the activities and materials are understandable and engaging to people from all communities"?</p> <p>Fourth bullet point - would it be possible to briefly summarise the findings from the website review here? I am curious to know what they are...</p> <p>Fifth bullet point - good idea but many PPIE contributors would not be suitable for this due to their professional background, high level of education etc. Perhaps this aim could be linked with the second aim to engage people from all communities?</p> <p>Sixth bullet point - I'm not sure what this means - needs clarification?</p>	
<p>what's missing is equality of opportunity ie you approach all your contacts. Rather than going to usual suspects</p>	782554-782545-83258506
<p>How would you promote it more widely? Currently it is only well visible if you are in hospital settings.</p>	782554-782545-83378116
<p>It is set out clearly</p>	782554-782545-83388050

**5** Do you agree with Priority 2?



**6** Please give your views on Priority 2. Is there anything that should be added or changed? If so, please give your reasons.

Showing all 43 responses	
Should this include something about connecting with/learning from the wider EDI community eg NIHR CED REPAG and others?	782554-782545-82327336
Consider conducting PPIE contributors surveys to measure their perception & experience of EDI, preferably with a robust tool that can be re-used to monitor changes over time.	782554-782545-82338041
Nothing here that would encourage people to take part ? Need to state why their involvement so important	782554-782545-82361493
But it should be number 3	782554-782545-82367947
I think it's fine.	782554-782545-82369234
It is very difficult to get a wide diversity of people taking part. I totally agree that having dialog with these groups to get them to better and fully understand the value of their contribution is vital. Also it is important to stress that by taking part it can greatly help researchers to understand health issues within their own communities.	782554-782545-82371153

Looks fine	782554-782545-82377433
Underserved communities might include the 'fit and well', who may be less motivated to become involved.	782554-782545-82377308
Some incentive encouragement for people to take part. The help for others and the self by taking part	782554-782545-82379833
Why not work with NHS-E and the NIHR and take on board what they have learned and are doing?	782554-782545-82381467
Ensure comprehension by non-native English speakers	782554-782545-82398120
See if the points could be written in clear and more concise English,	782554-782545-82403668
Access to training and information in BSL (British Sign Language) other languages	782554-782545-82408558
A worthy idea. First though, the public need to move to take ownership of their own health (improve self care involvement). This would lead on to greater research involvement.	782554-782545-82420539
It is important that all communities are reached and treated with equality.	782554-782545-82424143
Very important that it is inclusive and accessible to all and communities are involved with action plan. Also rarely heard communities.	782554-782545-82451773
see my comment above.	782554-782545-82476443
Excellent strategy	782554-782545-82489024
Provide updates on meetings and training events as and when they are planned	782554-782545-82490592
Consider how will you attract communities to become engaged, provide examples where PPI/E volunteers have made a difference in past projects.	782554-782545-82493884
There is a huge focus on supposed "under served" communities and has been for many a year now. Perhaps one should focus resource elsewhere? Perhaps they are OK being under-served and what we are chasing is not achievable	782554-782545-82521135
I am unclear as to exactly what "underserved communities" refers. It is likely to include engaging people from different ethnic backgrounds, people with disabilities and younger adults and all of these are important. However, as a white 59-year-old patient panel member and NIHR Research Champion, I still can not find the avenues to put the case for more meaningful research with PPIE opportunities in the field of TYPE 1 Diabetes at OCDEM (a renowned centre for the treatment of Diabetes) where I am a patient and desperately keen to be involved in and make progress with cure based and artificial pancreas based research.	782554-782545-82531888
Priority 2 mentions "people from all communities...from under-served communities" How will the committee ensure that individuals from ethnic background can access these information in their language, if English is not commonly spoken at home?	782554-782545-82539118
The focus should be on establishing a working PPIE structure that is then extended to underserved communities.	782554-782545-82594455

Needs a clear statement on recruitment strategy.	782554-782545-82596989
Agree fully with priority 2	782554-782545-82596838
Quite an inclusive aspiration	782554-782545-82694823
could we also add some mentoring to give people the time to become confident in critiquing researchers? Many members of the public would not feel they could comment on what a researcher has written.	782554-782545-82695673
Please expand on "Theme" Who will be carrying out the training and support mentioned	782554-782545-82704011
Nothing to add	782554-782545-82708179
As above, consider adding something about actively seeking out these participants?	782554-782545-82747913
This priority recognises that under- served communities could both make a big contribution and receive a benefit.	782554-782545-82756126
I presume there are rules for open items, like for example "Undertake" and "evaluate" as these don't mean anything to me as an action or a commitment.	782554-782545-82775113
Could there be something about flexibility of approach?	782554-782545-82818177
On this point* - is it worth including 'listen', 'understand', '...and develop an action plan...' *In collaboration with PPIE contributors and communities, develop an action plan to support, and increase the involvement of people from under-served communities.	782554-782545-82986238
This statement feels laudable but slightly unrealistic	782554-782545-83078313
If this is a public facing document, we need to start to implement/look at the language we use. Does everyone understand a "literature review"?	782554-782545-83090244
just say it is to serve the best interests of all	782554-782545-83145057
Underserved? Or underserved and underrepresented? I have done a lot of work with white elderly people during lockdown who may not be underserved but feel that their voices are not heard	782554-782545-83183076
What is the target? 50% parity with UK non-white UK demographics?	782554-782545-83232555
These aims look good to me. Hopefully some PPI contributors from underserved communities are having their say on this priority.	782554-782545-83248725
there are levels of underserved communities eg people living in deprived communities. But the homeless would be a different level - this needs to be considered	782554-782545-83258506
n/a	782554-782545-83378116

## 7 Do you agree with Priority 3?



**8** Please give your views on Priority 3. Is there anything that should be added or changed? If so, please give your reasons.

Showing all 40 responses	
I think it is worth considering whether the themes should have PPI champions attached to them (similar to the ARC in Oxford/TV) or offering PPI mentors for researchers to aid learning etc.	782554-782545-82327336
Consider having PPIE input in training events & evaluate impact.	782554-782545-82338041
But no mention of budget allocation to PPIE	782554-782545-82339598
Too many acronyms	782554-782545-82361493
But it should be number 1	782554-782545-82367947
I think it's fine.	782554-782545-82369234
Working together on an even playing field is so important. Often PPI volunteers feel very undervalued.	782554-782545-82371153
Jargon alert! ?what are themes? Give thought to including potential/ existing PPIE contributors to the training of researchers & creation of materials so their needs are embedded, and principles of PPIE are demonstrated	782554-782545-82371278
All projects and themes should have a stated context that is readily understandable by the public.	782554-782545-82377308
Some idea as to how you intend to actually do this .Lots of jargon what about active information of what will be involved	782554-782545-82379833
Seems OK	782554-782545-82398120
what is a Theme Lead, what is meant by embed, what is meant by Signpost staff? etc. Again the English could be much clearer and use less marketing language	782554-782545-82403668
No changes.	782554-782545-82420539
The research from this through the feedback should be analysed and up to date reports made available to everyone involved on the progress being made.	782554-782545-82424143
What are Themes? 'in collaboration with PPIE contributors' but not very clear how?	782554-782545-82451773
have some scenarios for theme leaders, researches and staff to deal with argumentative participants. have some practiced responses to diffuse	782554-782545-82476443

tense situations.	
All O.K.	782554-782545-82489024
to involve patients in the planning early stages of any training programme provide patient moderators to work with organisers of any project/s	782554-782545-82490592
Good points in this section, particularly the impact of PPIE where they have been involved.	782554-782545-82493884
Who are Themes, this is not defined?	782554-782545-82521135
I like the inclusion of "feeding back to contributors". As a member of the public who has participated in and contributed to research in other ways, contributor feedback tends to be a feature which is missing.	782554-782545-82531888
This makes sense.	782554-782545-82594455
Define 'themes' - or restate.	782554-782545-82596989
Agree with strategy 3	782554-782545-82596838
It's important to support the theme leads and research staff. Sometimes the researchers are just so busy with their projects, they cannot be expert in public involvement too.	782554-782545-82694823
I think this is very essential and all parties need to understand that it is a two way cooperation, not criticism.	782554-782545-82695673
This possibly answers my previous question in priority 2	782554-782545-82704011
Nothing to add	782554-782545-82708179
May like to add something about proactively making suggestions for methods of PPIE involvement?	782554-782545-82747913
It is important to foster active PPIE plans amongst researchers in the ways proposed.	782554-782545-82756126
It's not clear what "signpost staff" means for me	782554-782545-82775113
Again develop an expectation for PPIE with researchers. Make sure it is not just a tick box.	782554-782545-82818177
Is 'Theme' an understood term in this context? Might it be worth explaining that in materials.  On the last point - is it worth mentioning - 'signpost staff to opportunities to speak directly with PPIE contributors'? (Or this inferred in 'support and resources'.	782554-782545-82986238
I find the use of Themes a little confusing until I clicked on the link. An explanation of Themes first?	782554-782545-83090244
nothing to add	782554-782545-83145057
Can you clarify the reference to 'a consistnet approach is adopted'? And does learning from Oxford mean from Oxford University's experrience of embedding EDI?	782554-782545-83183076
need to list the training needed to improve diversity- implicit bias etc.	782554-782545-83232555
Pre-grant funding for PPI is always hard to come by and one of the major	782554-782545-83248725

Pre-grant funding for PPI is always hard to come by and one of the major barriers to researchers involving people effectively in research planning. Does the BRC have any budget to offer researchers for pre-grant PPI?

Also, I wonder if it is worth (somewhere in the strategy) referring specifically to PPIE in the early stages of research i.e. deciding on the research topic/question and designing the proposal? PPI is often neglected or tokenistic at these early stages, yet if communities (including underserved groups) are to really feel engaged and empowered, and really make a difference, they need to be involved right from the outset. This places emphasis on the need for researchers and the BRC to develop and maintain strong relationships with communities. At the moment there is no mention of relationship building in the strategy.

Perhaps this comes down to what is meant by "PPIE" in the strategy. At present the definitions of PPI and PPIE in the associated information sheet could include very tokenistic PPIE.

I appreciate that you've probably thought of these things already and there may be good reasons why you haven't included them in the strategy!

support includes training and Oxford have some of the best training in the UK for both researchers and ppi members. This should be expanded upon

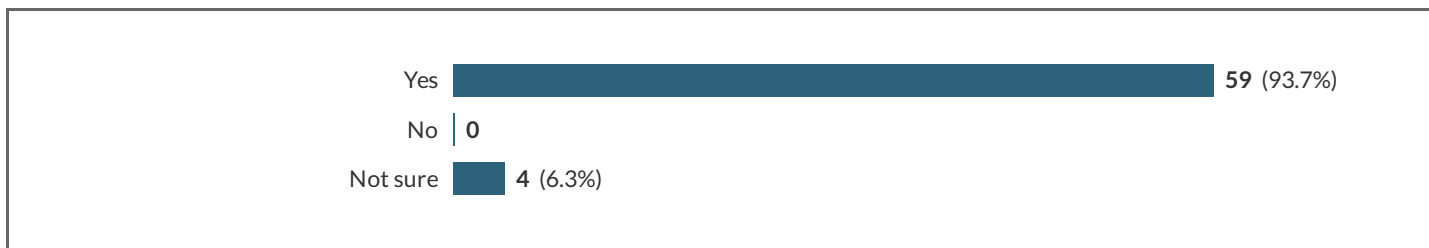
If you sign post it to the resources/best practices, I hope it will not be an additional help, not just push in that direction

782554-782545-83240729

782554-782545-83258506

782554-782545-83378116

**9** Do you agree with Priority 4?



**10** Please give your views on Priority 4. Is there anything that should be added or changed? If so, please give your reasons.

Showing all 32 responses	
This reads as very oxford centric - it would be useful to include examples of other organisations (national for example) that you might work with.	782554-782545-82327336
Consider sharing best practice.	782554-782545-82338041
Make any help given inclusive make sure PPI people kept informed	782554-782545-82361493
I think it's fine.	782554-782545-82369234
This is very important.	782554-782545-82371153
Is best practice shared around research organisations?	782554-782545-82377200

is best practice shared around research organisations?	782554-782545-82377508
Just not any detail of how this will be achieved	782554-782545-82379833
Too many acronyms - what is a BRC and OUH??????	782554-782545-82394154
Seems comprehensive	782554-782545-82398120
No changes	782554-782545-82420539
To network between all groups and organisations is vital to improve knowledge and create a consistent understanding of what is happening in all groups of people.	782554-782545-82424143
Collaborating widely is essential.	782554-782545-82451773
ensure some formal and informal meetings are organized to share knowledge involvement in research, service design and improvements.	782554-782545-82476443
Great ideas	782554-782545-82489024
to ensure patients are given every opportunity to get involved at the earliest opportunity in any programme	782554-782545-82490592
Important to ensure that PPI/E is not just a box ticking exercise, when it comes to grants/ funding projects.	782554-782545-82493884
No, perfectly sensible	782554-782545-82521135
In final BP, I think recognising the the potential for PPIE in "service design and improvement" is important. It should be extended to include "research design and identifying areas for research".	782554-782545-82531888
Makes sense - don't reinvent the wheel.	782554-782545-82594455
Agree with strategy 4	782554-782545-82596838
Partnership working is crucial these days and in the future.	782554-782545-82694823
I would also encourage a wider scope to include academic groups outside medicine, i.e Physics as these groups may contribute a different perspective.	782554-782545-82695673
Can't add anything further without having been more involved here	782554-782545-82704011
Nothing to add	782554-782545-82708179
There is a lot of good practice to be shared.	782554-782545-82756126
Could it be useful to mention communications here? I think publicising these connections and joint working would be very positive for all involved in PPIE.	782554-782545-82986238
implicit	782554-782545-83145057
how is this measurable.	782554-782545-83232555
Does this include Social Care?	782554-782545-83249233
I'm really glad to see this as there is currently too much silo working (at least where I am) and yet we could learn so much from other local organisations.	782554-782545-83248725
I just want to point out that some of our ARC's have a local focus so	782554-782545-83258506

just want to point out that some orgs eg PPIEs have a local focus so national working isn't really applicable	782554-782545-83378116
It looks like there are some restrictions with information exchange and using already existing resources. I hope you manage higher efficiency in the future.	782554-782545-83378116

**11** Do you think the strategy is engaging to patients and the public from all communities? Please identify any areas for improvement.

Showing all 54 responses	
It is very high level and think it really needs some concrete examples of what you might do eg P1 can you say where you might communicate opportunities, or how you will support researchers to make materials accessible? It might be more engaging if the text was broken up more eg visually more appealing.	782554-782545-82327336
Ensure PPI role is jointly developed and collaborated.	782554-782545-82338041
Too wordy	782554-782545-82339598
Need as stated an easy read version and reason why help needed and how this helps	782554-782545-82361493
There are some well known issues here which are almost impossible to resolve	782554-782545-82367947
Yes.	782554-782545-82369234
Hopefully it will be. Having info in different languages and aimed at certain groups within all communities is vital	782554-782545-82371153
As someone who is involved in PPIE there is nothing in the strategy to attract me or tell me why my contribution matters. I do not feel included in its execution as my perspective is not included in training, communication, publicity or literature. Patients should be at the heart of developing the strategy.	782554-782545-82371278
I'm afraid to say I don't. I appreciate this is a strategic level overview and I get your broad-brush ambition. But I fear it reads as a commitment to do all the right things without anything that convinces me that PPIE at the BRC will necessarily be very much different in 2027 compared with now, or indeed that there will be any accountability at BRC or individual project level to oversee/ensure delivery of the stated priorities. I'm very much not in favour of tick-box bureaucratic oversight, but, as it is said, by themselves 'fine words butter no parsnips'. To use priority 3 as an example, if I were to write it I'd say something like the following (I've taken the opportunity also to simplify the language - see next answer): Priority 3 "Everyone doing research will get guidance and support on how to make high quality PPIE a key part of their work. We will make sure every group of researchers ('theme') has a plan to achieve this. Each plan must include how researchers will get training, how to recruit more diverse PPIE contributors, and how to get the most benefits from doing PPIE. We will require every theme to monitor how its researchers use PPIE, and to report each year to the BRC's Strategic Partnership Board on PPIE achievements and challenges."	782554-782545-82372641

It does look good. The only part that I'm not sure has translated into this strategy is that patients input is VALUED. I think there needs to be a way of recognising patient input. On one of the projects I was previously involved with they suggested that they would make me a named author on the study. Sadly this didn't happen (And indeed I wasn't even informed when the study was published, despite having attended several meetings and contributed!) but was a good idea - to recognise the contribution that PPI members have made.	782554-782545-82377433
The question 'Why?' is not adequately answered by the strategy,	782554-782545-82377308
It's a bit bland, stating the things one might expect. How is the strategy to be implemented?	782554-782545-82378782
Language not universal there should be an easy read version if you wish to encourage people from all walks of life to take part	782554-782545-82379833
Again the bland use of 'engaging'. I fear that BAME communities might not find the 'fine words and intentions' either meaningful or relevant... sorry!	782554-782545-82381467
Ensure access for non-English speakers	782554-782545-82398120
Yes, plenty of focus on engaging patients/public	782554-782545-82402665
areas can only be identified after the strategy is implemented	782554-782545-82407956
Only if it is accessible by preferred language, I represent the DEAF community so it is important to have both BSL and Lipspeaker translation available - also visual access on website.	782554-782545-82408558
Yes	782554-782545-82409388
This sort of strategy is well-meaning and has many good points. However, it is important to remember that some people, particularly those from different cultures, may be suspicious of the reasons for attempts at public engagement. Care must be taken to ensure that, because of this, a clear explanation is given at the outset of any attempts at engagement	782554-782545-82411831
Its a useful strategy. People need more general awareness of the importance of their health.	782554-782545-82420539
Schools both private or state .	782554-782545-82424143
I think it reads more for healthcare professionals and isn't very relevant to the patient/public as it stands. I appreciate its difficult to write a complex document for both lay and professionals - perhaps there need to be another version.	782554-782545-82451773
I hope so.	782554-782545-82476443
Probably working as well as possible	782554-782545-82489024
working with local and national patient support groups	782554-782545-82490592
Perhaps improve the time scale from initial public interest to actually taking part. One of the committees I have been involved with (for over 10 years), have taken over two years to recruit PPI/E members on (2 vacancies), even though members of the public had volunteered early on. Although this may not reflect Oxford BRC practices.	782554-782545-82493884

Yes it is engaging.	782554-782545-82494707
Yes, but less focus on all - lets get the needs of the many outweighing the needs of the one	782554-782545-82521135
The strategy is largely accessible to a lay person but, up to Q.11, I hadn't realised it is aimed at the public!	782554-782545-82531888
Yes. I would like the information to be translated in multiple languages to accommodate the needs of patients and community members from ethnic minorities. Also, please write out abbreviations of groups to ensure that everyone understands the information presented.	782554-782545-82539118
The purpose needs to be understood before it engages.	782554-782545-82594455
If this statement is to be used for recruitment it must be much simpler and direct.	782554-782545-82596989
Suggest some researchers should come from diverse groups e.g black and minority communities	782554-782545-82596838
Include more people who need help	782554-782545-82642743
It's not really user friendly.	782554-782545-82643842
Yes, it's sufficient	782554-782545-82694823
I still think that it is hard to make people understand that this is not an intellectual exercise. There are people who won't come forward as they think they will have nothing to offer, so we need to find a way to break down this illusion.	782554-782545-82695673
As a member of the public I find it of great interest More simple language could be used if under- served communities mean areas of deprivation and non- English speaking people What does it mean?	782554-782545-82704011
Yes, but it maybe a little overwhelming as there is so much of it	782554-782545-82708179
Yes, it is very much essential.	782554-782545-82729904
I think the strategy is not engaging to patients and the public, but nor do I think that is the purpose of the strategy. I see the strategy as a mostly internal document to improve learning and action internally. What will be engaging to patients and the public is the outgrowth from the strategy.	782554-782545-82747913
The layout as presented in this survey is "word heavy". Shorter sentences and bullet points would make it more attractive.	782554-782545-82756126
Not sure the message is easy to get across	782554-782545-82775113
I think it is a top level strategy that may be difficult for people to engage with if they are not familiar with this sort of work and the organisations involved. Some examples and a bit more detail would help bring some quite generic terminology to life, and may also attract interest.	782554-782545-82986238
I still think that there is some language that is not easily understood in the statements, that we simplify/clarify.	782554-782545-83090244
The strategy will struggle to engage all communities unless it phrases its aims in more accessible language.	782554-782545-83145057
There is still a lot of jargon, and the language could be tightened up.	782554-782545-83183076

BTW what does the reference to 'images' in Priority 1 mean? And should 'communities' be defined more precisely?	
the PPIE steering group should reflect the communities they want to reach.	782554-782545-83232555
Perhaps make it clear that those with a disability are also included	782554-782545-83249233
Difficult for me to say as I'm a researcher and not from underserved community. I think tightening up priority one and making the aims as precise and practical as possible might help.	782554-782545-83248725
yes I think it's engaging - may be more for ppi members than the public at large	782554-782545-83258506
No, I think you are missing out, especially on ethnic minorities. It became possible for me to engage with projects as I was made work from home and I have now flexible hours. I think you would have to use this chance and try to reach people whose way of work was changed. Usually that would mean council workers, NHS workers and office-based company workers.	782554-782545-83378116
Yes	782554-782545-83388050

**12** Do you think patients and the public from all communities will find the strategy easy to understand? Please identify any areas for improvement.

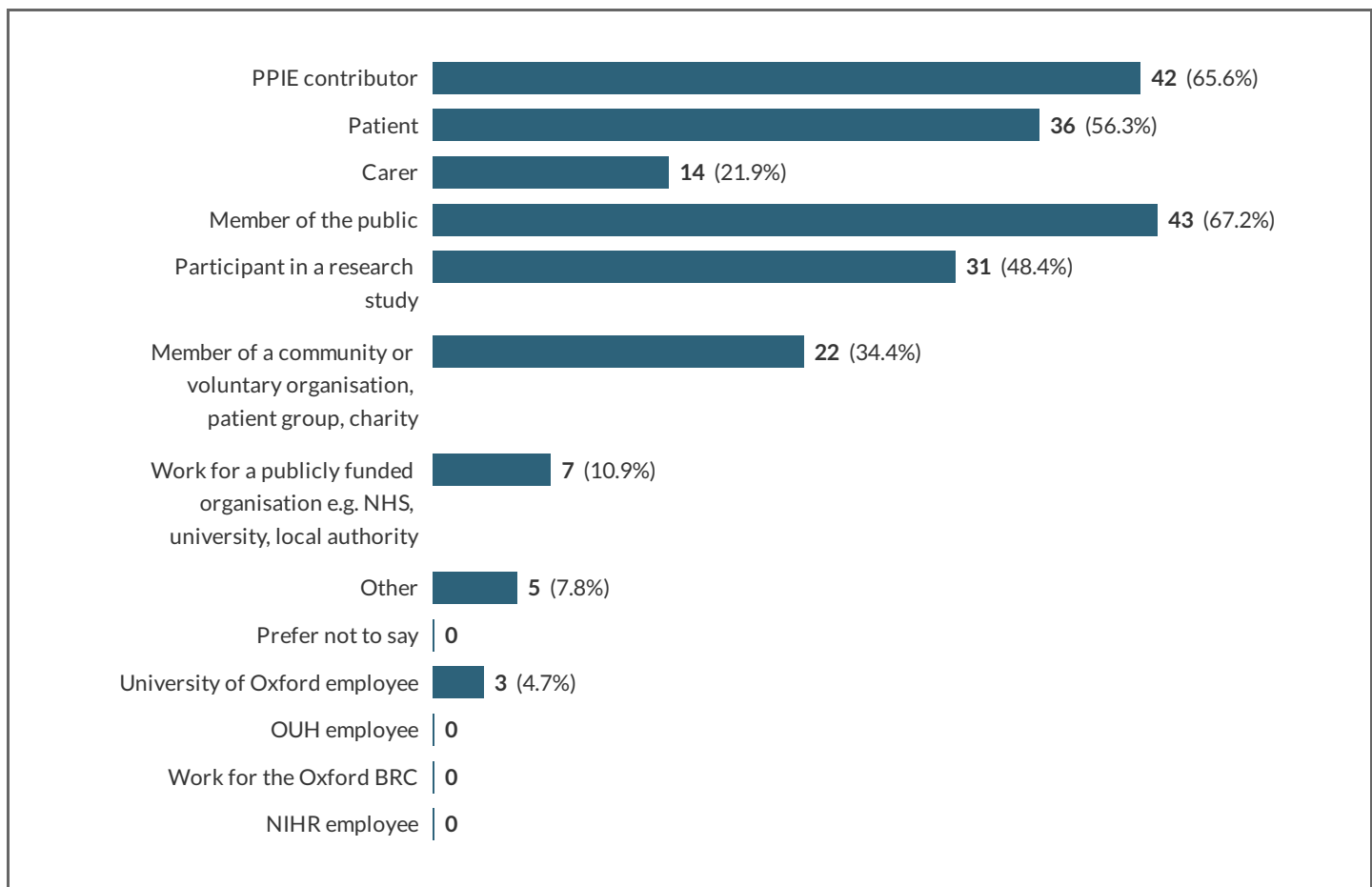
Showing all 55 responses	
I think it is very formal - some of the words/phrases are complex/jargon eg literature review, under served communities, theme and departmental PPIE groups. I think it would be hard for someone who doesn't know much about PPIE, academia etc to read this and have any idea what you were intending to do. There is a lot of text which might be difficult for some people to understand - an easy read version might be worth considering.	782554-782545-82327336
Consider a punchline to capture the essence of PPIE strategy.	782554-782545-82338041
No. Too wordy, unnecessarily complex	782554-782545-82339598
See previous remarks	782554-782545-82361493
The choice of language is generally far too wordy and the sentences too complex	782554-782545-82367947
Yes.	782554-782545-82369234
It depends, younger member of communities who have a good command of the English language will most likely to understand but many older groups where English is not their native language may have problems. This is particularly relevant to older women in these communities who due to their culture do not mix well with outsiders.	782554-782545-82371153
Some acronyms and jargon need explanation	782554-782545-82371278
I've put your theme 3 text through the Flesch Kincaid readability algorithm and it gets a score of 37.8, where plain English is said to be >60, fairly difficult to read 50-60, difficult to read 30-50, and very difficult <30. This is a fairly crude analytical tool. But attempting to read the text from the perspective of the sort of patient/public you are seeking to attract to PPIE	782554-782545-82372641

perspective of the sort of patient/public you are seeking to attract to PFIC, it isn't really talking their language and, as stated earlier, it also isn't telling them what are in practice the differences they will see as a result of your strategy. My possible revise of theme 3 scores 61.7	
Many of the bullet points are too detailed for time-short members of the public. Have a simple version - one sentence per priority.	782554-782545-82377308
Not particularly, it reads as though it's written by researchers for researchers.	782554-782545-82378782
Not really language very professional as stated not all will understand what help you need!	782554-782545-82379833
Difficult to answer! From a middle class, white male over 70 yrs its intelligible, but I cannot speak for people from socially deprived and non-white communities. You need to take the Strategy out into these communities and ask them! (And there is little value in asking healthcare and research professionals from BAME communities, because they are already inducted into the 'ways of health research' and can no #longer speak for "The Common Man"...	782554-782545-82381467
Provided it is presented in simple language, understood by non-native speakers	782554-782545-82398120
Generally yes.	782554-782545-82402665
If you make the language clearer and less acronyms!	782554-782545-82403668
I think the language used could be simplified slightly	782554-782545-82407707
it is hard to say, once implemented there may be further areas to work on	782554-782545-82407956
NO - it needs to be translated into their preferred communication methods eg Deaf Community would require either BSL video visual translation, or Subtilting or Lip Speaker video translation	782554-782545-82408558
Yes	782554-782545-82409388
As for Q. 11	782554-782545-82411831
Its down to changing public attitude. These are good proposals, but as they say."You can take a horse to water, but you can,t make it drink".	782554-782545-82420539
As long as all literature is available in multiple languages to cover all groups.	782554-782545-82424143
Do not make this a massive paper work exercise for everyone	782554-782545-82425031
Not particularly, especially if not involved in healthcare. It probably needs simplifying. Perhaps a further sheet is also required that explains what the patient/public involvement will actually be, or maybe just signposting to your great 'Get Involved' section on your website.	782554-782545-82451773
it may be difficult for some communities to understand. that is why it is important to ensure good training to those working with people who have complicated health situations.	782554-782545-82476443
You'll never get everybody to understand	782554-782545-82489024
getting patient experts who have been involved in services for a number of years will help newer patients wanting to get involved	782554-782545-82490592

The words are fine, but will this actually attract people to take part? Perhaps have an open day in the Community Areas you wish to attract involvement, this could gauge if the Strategy is achieving the goal.	782554-782545-82493884
Some of the lengthy papers need to be simplified or made into a precis style format. Some people are very busy and will not have time to peruse all the information.	782554-782545-82494707
I would like to think so	782554-782545-82521135
Plain English is used, document length is reasonable and the use of bullet points breaks up the text in a positive way. Referring back to my comments at an earlier stage about different learning and assimilation styles, perhaps the use of diagrammatic presentation in part may help to reach some for whom wordy documents may not have the same appeal.	782554-782545-82531888
Please see answer 11.	782554-782545-82539118
No. There is a danger the strategy will be self-selecting, i.e. people with a relatively high educational attainment together with an existing interest in health and science will apply.	782554-782545-82594455
See above re definition of Themes. Rewrite as if for reading age 8 - much like the strategy for red top newspapers. Involve a journalist from eg The Sun to help with the re-write.	782554-782545-82596989
Yes	782554-782545-82596838
Infographics	782554-782545-82643842
Very much so; unless you request the learning disabled to draft their type of simplified version with the help of an artist.	782554-782545-82694823
It has got a lot better in the last 5 years, but we still need to be on guard that we do not include jargon and acronyms, it is easy to fall into this as you get into medical research.	782554-782545-82695673
See above answer	782554-782545-82704011
Yes, but, as above there is so much of it.	782554-782545-82708179
Not always. More education will be required	782554-782545-82729904
Again, I think it is mostly internally orientated, or at a stretch orientated towards those patients/public members who are already involved in this sort of work. Most patients/members of the public need to be educated as to the value of PPIE work (which most have never heard of and those that have heard of it do not understand) before they can begin to assess whether the strategy is easy to understand.	782554-782545-82747913
as above.	782554-782545-82756126
From a public viewpoint it was difficult to understand until read a couple of times	782554-782545-82775113
No - I think without a workable example it might be quite difficult for some to follow the sort of path set out in the strategy. It is also not very strong on aims and impact. For example, as a participant - what impact can I have? How will my input change things? What have people done before? Why should I get involved?	782554-782545-82986238

As above, we need to avoid to much use of acronyms and uncommon phraseology.	782554-782545-83090244
I think it may be difficult for patients and public who are not familiar with PPIE to understand the strategy.	782554-782545-83108318
no; please simplify the terms used to define aims so that they are everyday language and not from an academic .taxonomy	782554-782545-83145057
No. I think it needs to be made much clearer that PPIE engagement is important to ensure the research is high quality, high priority to patients, and relevant to them, and to ensure the proposed interventions are acceptable to patients.	782554-782545-83183076
Maybe improve readability, also add audio read clips to key paragraphs ?	782554-782545-83249233
Again not really for me to say. I had no problems understanding it except where I have said otherwise.	782554-782545-83248725
No. I think you should have a different format for people with learning difficulties eg with pictures	782554-782545-83258506
I think that you used good English. It is very understandable.	782554-782545-83378116
As long as you use clear and simple English in all documentation	782554-782545-83388050

**13** Please select as many options from the list below as apply to you.



*Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)*

13.a If you selected Other, please give details.

Showing all 2 responses	
I also sit as a lay member on a HRA REC	<a href="#">782554-782545-82747913</a>
NHS Oxford Health Foundation Trust employee	<a href="#">782554-782545-83378116</a>