NIHR | Applied Research Collaboration West

People in Health West of England

Creating better patient and public involvement adverts – Q&A round up

Email best practice

Q: Developing templates - did you share these with researchers? How effective were these in changing practice?

A: This event was the first time we shared these templates. We hope that they will be useful to researchers, but we aren't intending to evaluate whether they are used. We will continue to promote the findings from this work in our day-to-day interactions with researchers who are looking for public contributors. We hope that others can too, now we've shared the findings.

Q: What makes a good/interesting subject line description of an opportunity?

A: As mentioned in the seminar, we'd recommend starting with the condition or health issue, as that's the hook that will draw people in if it's relevant to them.

Q: Do you now do emails for each individual opportunity now? Or do you condense them into 'digests' every couple of weeks with a few opportunities at a time?

A: Each opportunity gets its own advert and individual email. We found people were more likely to open an email with one subject of interest rather than a newsletter or 'digest'.

Q: Do you still use the newsletter as well, or do you only email out ads to people instead? If so, how do you target emails to people who might be interested?

A: People in Health West of England (PHWE) now exclusively sends individual opportunities. Our Mailchimp stats have shown this leads to more people opening our emails and clicking on any links in them. Targeting is difficult as we don't collect any personal details for the mailing list – just email addresses and names. We do, however, have the advantage of access to a whole lot of 'data' stored in people's brains as members of PHWE.

Q: I am wondering if the sender is an organization/generic vs a human name would change the response from the public in terms of opening email or participating?

A: We agreed during the seminar that humans rather than organisations are better for your email addresses. So try to use a real person rather than a generic organisational email address.

Other formats

Q: Online text ads v. physical posters - pros and cons please? Where do you recommend for placing posters?

A: Generally, it's easier to measure engagement with digital ads, whether via email, social media or websites. With analogue forms of ads, like posters and flyers, you never really know who's seen them. But really this decision should be about who you're trying to attract. If it's people using GP services, then a poster in GP surgeries could work. Similarly, posters and leaflets might be better for certain groups, like older people or people who are digitally excluded. But if it's people who have a specific condition, then you might be better off finding groups and accounts on social media. We know that posters placed in hospitals or GP surgeries for specific research projects attract very few people. Better for longer term, ongoing opportunities, but still less useful than emails.

Q: What hashtags do you use / organisations do you @ in the ads?

A: We will tailor this depending on the opportunity we're advertising. If it's about a certain condition, then you should be tagging patient advocacy groups, charities or other 'influencers' in that field. It's worth doing a bit of research on who to tag, even if it's just a quick search as you're writing a post. And it's the same with hashtags – have a bit of a search to find the tags people are using. You can also use tools like Hashtagify.me to find hashtags you could use.

Digital exclusion and including people who are often left out of patient and public involvement

Q: Do you have any tips on how to encourage people from diverse backgrounds to take part? I think a lot of organisations struggle to engage people from non-white backgrounds and men under 35 for example. We would love to ask people from these groups for their opinions but it's very difficult to get access to these communities. Do you have any particular advice for this?

A: If you want to do research with a particular community, it's important to build respect and trust with that community. So identifying some community partners, whether organisations, groups or individuals, to work with will help with that process. Being culturally sensitive is important here. Having a good partnership will help with that understanding.

Q: The digital literacy question excludes a lot of people - it's a problem - even assuming that people have access to a computer - we should address this at the recruitment stage?

Plus…

Q: For a better balance should there be a wider policy in regard to those individuals who are digitally excluded for whatever age or community or democratic economic level.

A: We've thought long and hard about this. Occasionally we have resorted to other methods if digital literacy means we are likely to miss all or most of the target audience (for example, homeless people). We accept that we can't reach everyone every time, but email gives us the largest single access point to most people.

Q: How do you manage people who don't have email access?

A: Again this depends on your study and who you're trying to attract. If the people you really want to target are likely to not have access to technology, then you do need to think carefully about how you'll reach them. Although 84 per cent of UK adults had a mobile phone in 2020, that's still 16 per cent without. And the number of adults accessing email the same year was 85 per cent. Digitally excluded people are more likely to experience other inequalities. You will always have to work harder to reach these people, and again trust could well be an issue. Some may not even use healthcare services, so routes via GPs or hospital waiting rooms may not be effective. However, there are many voluntary sector organisations who support people in difficult situations. Building partnerships with these organisations is a good first step.

Q: While advertising PPI online can reach lots of people, this can isolate digital-excluded people. As we've emerged from COVID restrictions, do you think that other ways to promote PPI opportunities might be viable (e.g. radio adverts, face-to-face recruitment AKA elevator pitches)?

A: Face-to-face is always the best way to recruit people, no matter who they are. Radio is a great channel for some groups, especially older people and there are community radio stations that target different groups. However, commercial advertising on radio (and other routes such as bus stops) can be costly. But if you can get on your local radio to chat to a presenter about your involvement opportunities, you should go for it.

Who to recruit – and how to do it

Q: Do you have much success contacting schools directly to try and get young people involved?

A: No. We've tried numerous times with little success. After school clubs are a better place to recruit but honestly, we have no difficulty recruiting young people by word of mouth. We had 38 separate Young People's Advisory Group (YPAG) meetings last year and could have filled the places two or three times over each time.

Q: Do you have recommendations about recruiting for patients who are terminally ill and may have a relatively poor prognosis e.g. stage 4 cancer?

A: Personally no. I haven't been involved in recruiting such a cohort.

Q: Experienced PPIers v. new people with experience of the research issue - pros and cons please?

A: Not really the subject of the webinar but you asked for it: Occasionally we have discussions about whether people are getting "professionalised" or "stale" but then we remind ourselves that we've been at it a while and nobody suggests we are stale (not within my earshot anyway). We'd recommend a mix of both depending on what you want from them.

Q: We've worked hard on our advert and have arrived at an ad that's simple and effective but the stumbling block for us is getting that advert in front of the right people! Have you any tips about how to build a mailing list for/ reaching older people who draw on social care?

A: My best and only useful tip is never stop recruiting. I get a taxi, I recruit the taxi driver. I get a haircut, I recruit the barber's daughter to my YPAG.

Q: How do your advertising approaches differ when you are recruiting children or young people?

A: We are lucky that we have developed a huge bank of young people in our YPAG over the years so never have rouble recruiting. Contact me (Mike.bell@bristol.ac.uk) if you want to discuss.

Q: With reference to mentioning payment/reimbursement in adverts. How do different organisations approach it. When would you bring up the complexities of it with contributors.

A: We recommend £25/hr in line with NIHR guidance. But as long as we make sure our contributors know what and how they are being paid, we go with whatever the researcher's budget allows – vouchers or bank transfer.

Using imagery

Q: I've been trying to make a poster, but it's been very difficult to find suitable pics, copyright free. Guidance please?

Plus…

Q: Nice visuals. Did you need to get a Shutterstock/stock image subscription to make these? Unfortunately, these subscriptions cost money and some Trusts may not have a budget for it.

A: There are lots of royalty and copyright free image websites out there, including Unsplash, Pixabay, Pexels and RawPixel (tick 'free' when searching their archive). These sites are quite American but you can find some UK imagery by including placenames in your search term. There are a number of free image banks focused on a particular group too. See this handy list of royalty free image banks.

Q: Would photos of the researchers/team on the advert help personalise the advert?

A: Always worth it (depending how scary they look).

How much detail to give people

Q: I'm looking for PPI in my PhD study, 3 phases. Too much to describe all 3 phases given what you've just said. Do you in this case keep it simple and just ask for help with a PhD study or advertise for phase 1 then ask them for future involvement when they've signed up?

A: Yes, that sounds like a sensible approach. As we've heard, people don't want to be bombarded with information – and asking people to commit to a long-term project could put some people off. So start with trying to get them involved in the first bit. Then work on them over time!

Q: Do you have guidance on the role of public contributors that you share when people respond to adverts? Or would you recommend you do this at the first meeting 'in person'?

A: As always, less is more. The more you give people to read early on, the more you will attract educated middle classes and possibly put off the non-readers.

And all the other questions!

Q: I think I know what 'Weight loss maintenance intervention' is - from Mike's poster - but I'm sure a lot of people don't. What leeway is there to rework an already defined name, title or description into plain(er) English?

A: You're right, it's still not very plain English. It's better to use plain language everywhere in materials intended for the public. And if that means not using a project's (often complicated and full of uppercase letters) official name, that's fine.

Q: Can you give us some tips on how to sustain the group of public in involvement of a programme which is for long term (let's say may be 3-4 years if we want them to keep involved?) and have many interconnections in between different groups?

A: Again, not the object of the webinar but building good relationships always helps, and keep people informed between meetings. We have a long-term Plain Language Panel and we meet twice a year for a food/drink get together.

Q: Was there anything in particular that the person in the group with dyslexia said was helpful/not helpful?

A: Keep it short and simple. We had a discussion about using different coloured backgrounds but decided if it was short and simple, that would be easier than trying to cover all colour preferences.

Q: Can you share about any experiences of creating ads or recruiting people for PPI with basic (non-clinical) research? Are there any specific tips and tricks for attracting people to research which isn't necessarily related to a particular medical condition?

A: Difficult other than making the ads as clear as possible that no specific experience is necessary.

Q: With regard to terms for Public Involvement. As an Applied Research Collaboration (ARC) I know the challenges of going out to communities to explain what it is. In a recent workshop run by the National Institute of Health Research (NIHR), our funders, they used 'Public Partnerships' (to encompass engagement, involvement and participation) but I would find some standard resources that every research project/centre can use, so we are all 'singing from the same hymn sheet' would be really helpful. I know that me and other Public Involvement Leads do this work, but I am guessing we all do this slightly differently, which must be so confusing.

A: Sounds like a title for another seminar. We asked our 'public contributors' what they want to be called but it doesn't help people who don't know what it means.