X-Net PPI Workshop

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Welcome

Your facilitator

Sarah McLusky is a freelance consultant, facilitator and trainer. She has been working alongside researchers helping them with communications and engagement for over 10 years. You can find out more about Sarah at https://sarahmclusky.com/

About X-Net

X-Net is a research network funded by the Medical Research Council and hosted by the University of Edinburgh. X-Net is trying to understand how to make it easier for researchers in computational and mathematical sciences, and biomedical research to work more closely together. This will help researchers tackle complex health challenges like COVID. Find out more at https://x-net.bio/

How we work together

We agree to...

only share what's written on Padlet   — SARAH MCLUSKY

democratically   — SARAH MCLUSKY

listen to each other   — SARAH MCLUSKY

respect different views   — SARAH MCLUSKY

take turns to speak   — SARAH MCLUSKY

leave ego at the door   — SARAH MCLUSKY

be kind   — SARAH MCLUSKY

Structural and cultural barriers

People don't necessarily know exactly how research links with frontline medicine

Research can be seen as 'backroom brains' who don't have relevance to what frontline healthcare professionals do and are out of touch with 'the real world'

Would help to provide some kind of education on different types of research and how they relate to each other and to what practitioners do   — ANONYMOUS

Lack of 'science capital'

Learned this volunteering for the Science Museum - many people say they like science but feel it's 'not for them' and they can't participate/seen as something not necessarily relevant to them.

OU very good as they teach you that science is everywhere - cooking, baking, reading maps etc
— ANONYMOUS

3rd Sector and Patient Organisations are a great source of information for patients/self management programmes etc but they need funding to cover their costs.

Misinterpretation of GDPR legislation. Important information not being shared.

Who controls and whose Budget!

changes

where there are massive changes - an example was when NPSA disbanded - I was working with them as a Patient Safety Champion

Science isn't always black or white and scientific bias can be difficult to understand for members of the public. Perhaps Researchers need school visits etc to raise awareness and break down barriers. Too many people believe what they read on the internet as being gospel, and challenging experts with years of experience in their fields.

Yes! Also currently there is often lack of understanding of how research is done, how it's structured and the pros/cons of that.   — ANONYMOUS

Health is a taboo subject for some cultures, especially mental health and women's health issues. Need to find ways of breaking down barriers and taboos. Can stop families seeking medical help for fear of bringing shame on their families.

Accounts/access

sometimes can't access things if don't have eg NHS email

This means not all PPI members are able to fully participate in meetings or get access to training information on staff net etc.   — ANONYMOUS

Need mutual trust - NHS very risk adverse.   — ANONYMOUS

Examples of barriers

Different ways of working
Different 'languages'
Different priorities
Time
Organisational rules/regulations/structures

Agreeing a common language so people understand   — ANONYMOUS

adjust your vocabulary to suit your audience e.g. researchers vs end-consumers   — ANONYMOUS

Jargon - need to have common terms. Eg brand name vs generic   — ANONYMOUS

enable informal information sharing e.g. over breaks/out of the normal meeting sphere   — ANONYMOUS

Time - finding it! Automatic meeting finder to find when peopl are available. Also Teams. Use technology. Time zones   — ANONYMOUS

signpost capacity building reference sites which bring participants to same level   — ANONYMOUS

People taking up a lot of the time/taking over! Need to have a moderator/coordinator   — ANONYMOUS

Like in a forum - need someone to stop things getting out of hand   — ANONYMOUS

ensure there is 2 way communication and a collaborative approach is maintained   — ANONYMOUS

need joint agreed goals for all members of team matched in their individual goal plans for appraisal   — ANONYMOUS

Need an appraisal system to be sure everyone has same goals   — ANONYMOUS

Soneone to keep goals on track and check in to see if they are the same   — ANONYMOUS

Minutes/agreement of what is decided   — ANONYMOUS

allocate strong chairs to ensure balance and input from all is maintained. Avoid single interest group driving the agenda/outcome   — ANONYMOUS

Different IT systems in NHS - would be much easier if everyone were linked. Eg GP not linked to hospital, A&E not linked to other departments. Nothign is linked   — ANONYMOUS

sharing repository for documents to give all people opportunity to review and feedback - ensure language is suitable for different audiences   — ANONYMOUS

Different procedures between depts too eg in NHS   — ANONYMOUS

Perhaps need "Code of Conduct at Meetings"- some Community Councils adopt this practice.   — ANONYMOUS

ways of talking to ea other, communicating and understanding remit

In addition, there is a legal requirement for workplaces to avoid discrimination and promote inclusion. The Equality Act 2010 makes it unlawful to discriminate against people on the basis of nine protected characteristics. These are:Age.Disability.Gender reassignment.Marriage or civil partnership.Pregnancy and maternity.Race.Religion or belief.Sex.Sexual orientation.

feedback

we often don't hear about outcomes

health and social care working together and integration between 2 of them

cultural

time - industry working is often quicker

different units working together within an org

Finding ways to embrace everyone's communication styles can make everyone feel like they're being heard.

diversity and inclusion and how orgs reach out to people who are seldom heard

Judging or making assumptions without making an effort to understand the person or people

Hubris

structural

different unis and orgs have different policies and procedures

Not everyone can or wants to communicate in the same way. Be open to this and don't judge.

Interpersonal barriers

Need mutual understanding. All want same thing however in reality procedures not always followed because staff shortages or equipment failure. Eg. Healthcare staff not able to wash hands properly due to water being too hot and scalding hands. Basic hygiene. Procedures also not followed due to lack of of time/staff shortages etc. Never any spare capacity built into NHS, always fire fighting. Staff need to to carry out research.

interpersonal

lack of reciprocity - ppi members putting in more (compared with what they get out - particularly if there is no remuneration)

Facilitation - have a role for that

Everyone not pulling their own weight. Misusing the position they are in.

Hierarchy - in medical and academic worlds.

Misuse of power

Interpersonal barriers

PP being unnecessary evil.

Some researchers can have difficulty working with members of the public. Lack interpersonal skills. — ANONYMOUS

Lack of patience and don't like too many questions as they take it personally. — ANONYMOUS

Use simple language. — ANONYMOUS

Transparency is important. — ANONYMOUS

mixing personal preferences with professionalism or lack of.

Being seen as a necessary evil.

Researchers now need to work with patients/public to access funding. — ANONYMOUS

Lack of appreciation for 'soft skills' like collaboration and communication

Probably research to show that this improves outcomes — ANONYMOUS

PPIs are good for this because you get the patient/public point of view. Reviewing patient information leaflets - important to be sure that the point of view of the end user is communicated — ANONYMOUS

Examples of interpersonal barriers

Trust (or lack of)
Power dynamics
Control/leadership
Difficulties agreeing shared goals

Have professional and lay person co-chair to avoid single agendas and ensure all contribute — ANONYMOUS

be clear about roles and tasks and training of people in team — ANONYMOUS

sometimes some disciplines feel superior but need to appreciate others are equal — ANONYMOUS

trust building activities. understanding of working to a common goal - get to better understand people from their engagement activity. Try and get continuity of people — ANONYMOUS

Respect for everyone - including people in other roles from you (eg communicators/nurses/AHPs)

More dominant/confident ones may actually be insecure - don't take the time to listen. — ANONYMOUS

MOre insecure - more likely to bully/dominate. Need to learne collaborative — ANONYMOUS

different personalities require different methods of communication e.g. website comments/email comments as well as vocalise in a meeting - pre and post the meeting — ANONYMOUS

As a medical writer -sometimes role is not respected by researchers — ANONYMOUS

interpersonal

critical friend not critical enemy

interpersonal

leave ego at door

interpersonal

autocratic boss

interpersonal

not getting on with team

Personal barriers

Training important to improve quality of feedback which improves quality of feedback. No good asking people what training they require if they don't know what is available.

State Benefits

Some people may lose their state benefits or incur tax by receiving any form of payment by participating in research. However, payment helps support the inclusion of hard to reach groups who may influence particular research. Out of pocket expenses can be very complicated especially when there are hidden costs involved ie broadband etc. Also debateable if, in reality, vouchers can be classed as unearned income.

personal

where you feel you are not giving an intellectual response eg my experience with NICE - where my input was purely experiential

Someone who is hard of hearing may not be aware of existing technology that could help their participation in Research.

Hidden/out of pocket expenditure can be a barrier for some as they may not be able to afford/replace or have access to up-to-date IT equipment/smart phones/broadband etc. Broadband network package fees recently increased across the board.   Social tariffs available by some network providers.

Lack of incentives to participate for some. Time is precious.

> *Yes - and if you are benefitting from someone's expertise should they not have that acknowledged, including patients? Especially as it can be more challenging as a patient (health/uncertainty etc)*   — **ANONYMOUS**

Keeping pace with technology changes can be challenging once someone retires from the workplace. Older people have lot of experience (wisdom) and should not be excluded from participating in research.

Patients unable to participate in research in other parts of UK or the world due to travel or accommodation costs. However, since Covid everyone making use of Zoom which gives access to researchers all over the world.

Asking people where they live may not be inclusive as some people may be homeless

> *Poverty is about how you feel in relationship to other members of societies and other variables. Richard Wilkinson epidemiologist in the UK who shows that it's not so much being poor, it's not so much feeling poor, it's feeling poor surrounded by plenty. It's inequality*   — **CLARAMDB2727**

> *What about those living on the streets.*   — **ANONYMOUS**

Socio-economic barriers

Needing help and being afraid to ask for it (stigma)

'Impostor syndrome' - patients can feel like they don't have anything worth sharing

'you shouldn't feel this way' - lived experience can be dismissed

> *A facilitator is helpful to give confidence*   — **ANONYMOUS**

> *I have much more confidence in 'work persona' than as a patient due to encounters with the medical system. Can help to be reminded that my input as a patient is valuable.*   — **ANONYMOUS**

Ageism

> *With age comes experience and wisdom!*   — **ANONYMOUS**

Not able to read or write in English, and not be provided with the resources for an interpreter or translator.

> *What about Adult Literacy in UK where reading age is 9 years. People who can't read can't read posters so don't get opportunity to be included in research projects. Their views are also important.*   — **ANONYMOUS**

> *Those with sight loss also need to be included.*   — **ANONYMOUS**

Facilitator - builds trust, ensures people are willing to participate

Inclusivity for those with disabilities (no room for ableism).

Work life balance: parenthood, carers, multiple jobs

Lack of awareness about opportunities

Job security - who employs people?

People having to reapply every year

> *Standard in research - no permanent contracts, if you annoy a PI you can lose your job, have to prove your worth. Too cutthroat. Can have to spend time reapplying* — ANONYMOUS

> *People leave research* — ANONYMOUS

Lack of awareness about differences

Lack of training

> *Need training to increase confidence* — ANONYMOUS

Feedback

Giving participants feedback on their contributions

Confidence - need for training

> *freedom to express opinions without fear of retribution* — ANONYMOUS

personal

digital exclusion - may not have up to date equip

> *Lack of Broadband connectivity, baseline IT equipment/skills* — ANONYMOUS

personal

not understanding QR code for example

> *lack of ownership - feedback given to project/groups but no awareness or communication of end-product/outcome* — ANONYMOUS

> *Not everyone uses/has a smartphone.* — ANONYMOUS

personal

lack of I.T. skills

> *Can make people nervous using eg video call if they haven't before* — ANONYMOUS

> *At work I had to get used to it - practice makes perfect* — ANONYMOUS

> *Difficulty keeping up with pace of changes in IT world once leave workforce.* — ANONYMOUS

barrier - personal

lack of specialist knowledge eg surgery

> *set training for participants. Help people come to a common view of what is required and also validate their input* — ANONYMOUS

> *set early expectations of participants - have specialist sessions with technical experts and then engage differently with lay people* — ANONYMOUS

> *speak in the common language of the participants e.g. if lay people in the room then use lay language* — ANONYMOUS

What is at stake

Worth remembering -"Science today is changing rapidly and becoming more complex, so no single researcher or single site can bring all the expertise to develop and validate medical

innovations or to ensure their safety. Thus, efficient sharing of information between institutions has become even more important than in previous eras, when there were fewer new therapies introduced."

Patients have valuable personal/community connections which could save time and effort in collecting research material/information.

Researchers need to work together - to be able to spark off each other and see something from another's perspective. Collaboration - shared resources.

Patients not always advised of outcome of research projects. Was research funding successful? Did research go ahead? Was patient input valuable? If patients don't feel valued they could lose interest and not participate in future research projects.

Reduction in 'keep inventing the wheel'. Research that is relevant to patient.

If researchers are not working together it creates reputational damage and creates mistrust and less inclination to engage in future

It is important because whilst I may not benefit, it cuts barriers and longevity of research thus next generation benefits

Duplication is a waste of time and money.

Prevents duplication of resources and work so less waste/better use of taxpayers money/faster progress

Why is it important to you that researchers work together more effectively?

to deliver positive outcomes for patients — **ANONYMOUS**

Most fair, inclusive and effective use of limited resource to improve care/interventions — **ANONYMOUS**

for researchers to enjoy work and others want to be researchers and for it to be the most productive — **ANONYMOUS**

To be fairer to all different disciplines of research and individual working styles and backgrounds of researchers — **ANONYMOUS**

Better quality research, more relevant research, actually reflecting what is needed. Improving study design. Making it more generalisable to real patients. Advancing science and understanding — **ANONYMOUS**

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