

PPI- What matters to me.....

NIHR INVOLVE definition

Research being carried out “ with “ or “by “ members of the public rather than “ to “, “ about “ or “ for “ them

Crucially not Engagement with researchers or participating in research

Have broad PPI experience, lay grant review, member of funding committee's, member of patient and public groups, co applicant on research grants, help educate researchers about Involvement and Insight

Why Patient and Public Involvement?

Research gives me hope, no one will want a researcher to succeed more than a patient living with a disease

Collaboration and multi disciplinary working improves everything

Research can't succeed without patients, blood and tissue samples, imaging etc, publicly funded. Ethical and moral considerations

To ensure that research meets the actual needs of patients rather than perceived needs. Survival V Quality of life

Being a Critical Friend

“ Someone who shares your common goals but not blindly and not without question “ G Laidlaw 2018

Be constructive, explain your reasoning

Grants go through robust review process, best to get issues sorted before submission

OK to use personal experience to illustrate your point but try to consider wider picture too

It's permissible to be critical, offer alternative point of view, point out flaws or weaknesses

So What



If this research wasn't funded how would I feel about that?



Is this topic important to me and other patients? Is there something more important?



What would be my priority for research?



Would this make a difference to my quality of life?



What symptom/s do I have that are ignored or that there isn't an answer for?

PROMS: Patient Reported Outcome Measures

- Have the research team chosen the right measures?
- Are they important to me as a patient?
- Are the outcome measurement tools the right ones?
- Were the outcome measurement tools developed with patient involvement?
- Do they accurately measure my experience?
- Do test results such as troponin, echo's, MRI scans correspond to my symptoms?
- How many questionnaires are too many/ measurement overly burdensome?

Exclusions



Many more people living with multi morbidity but research doesn't always reflect that

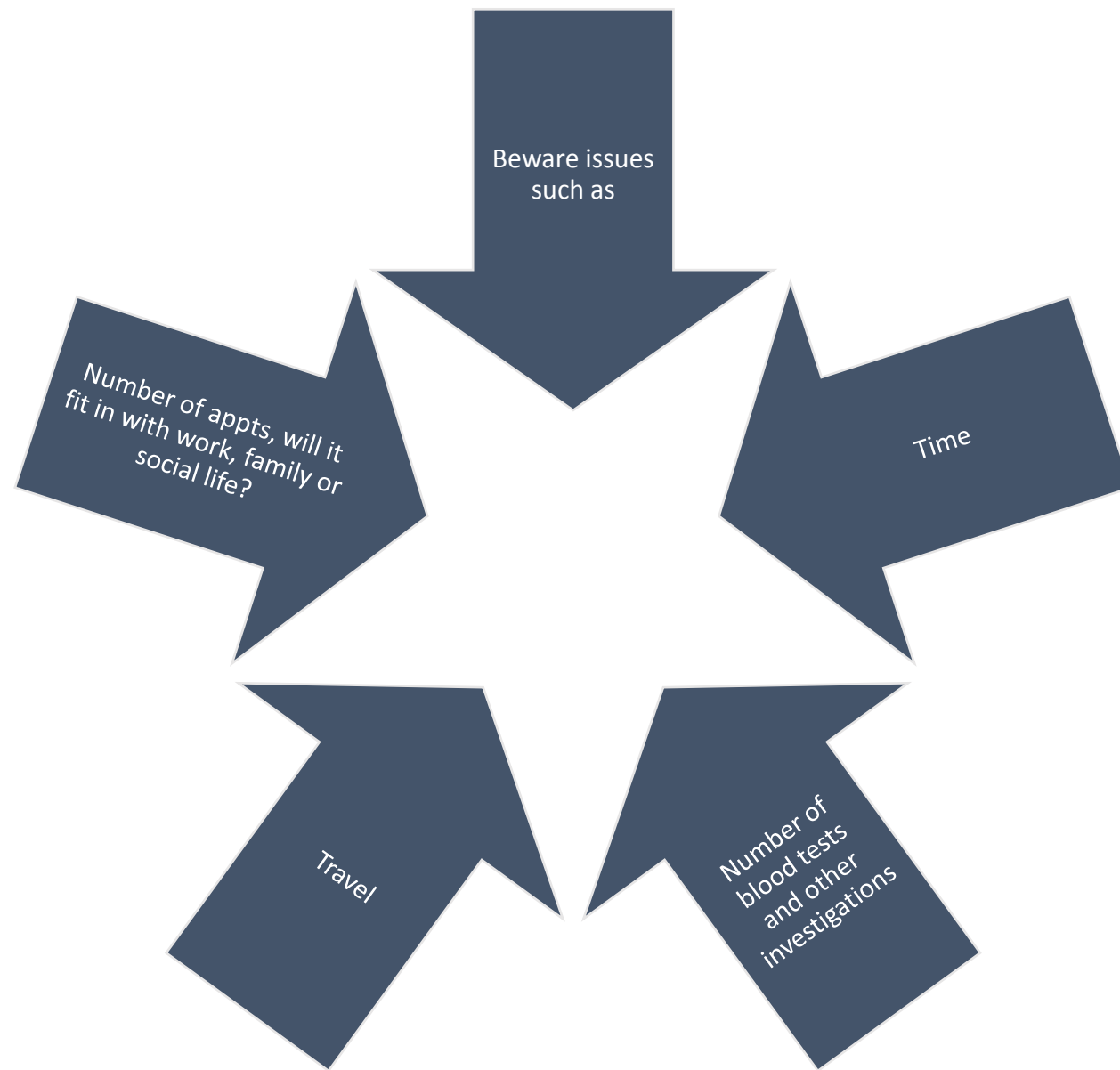


If exclusions are too broad then what relevance will the research have especially if it informs treatment guidelines

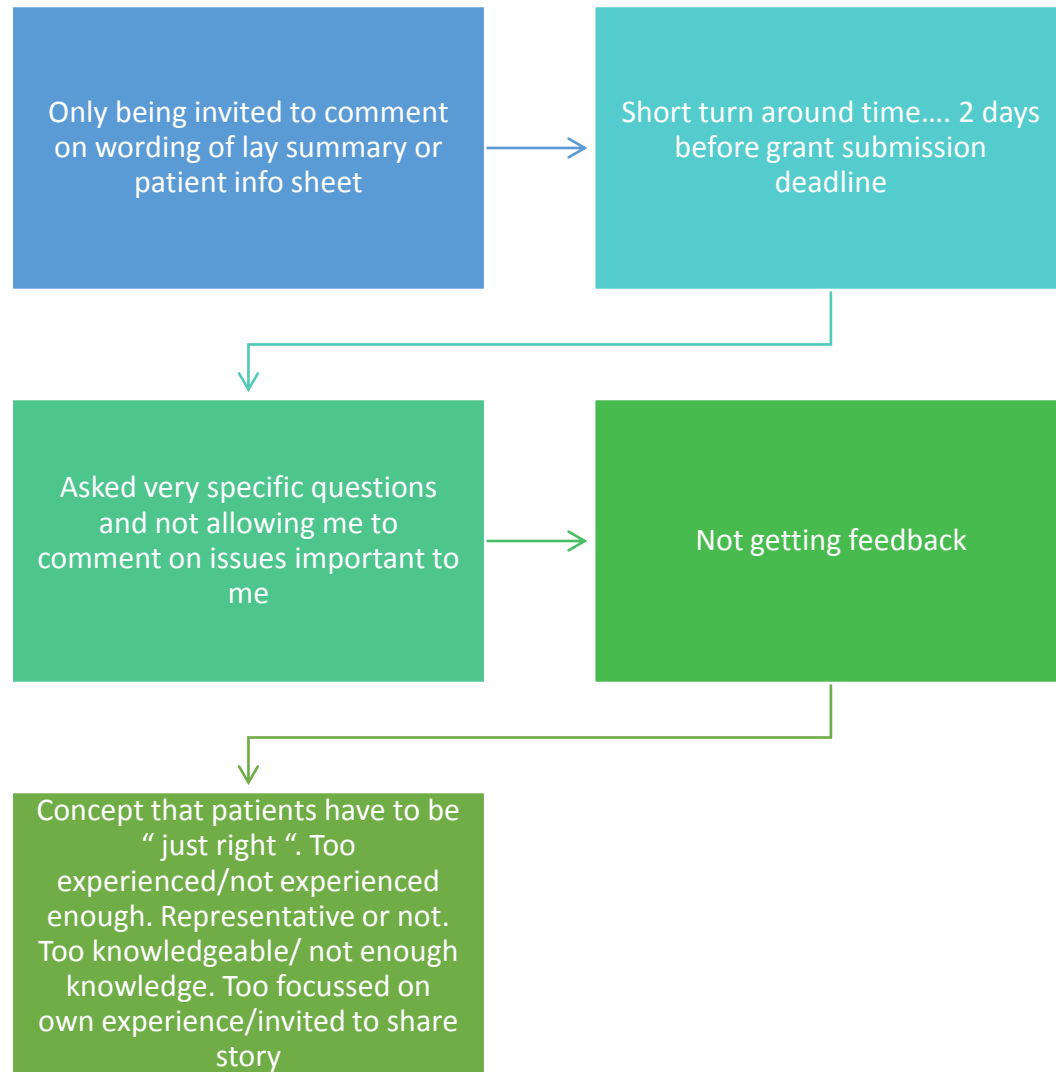


How do we make research “ real world
“ ?

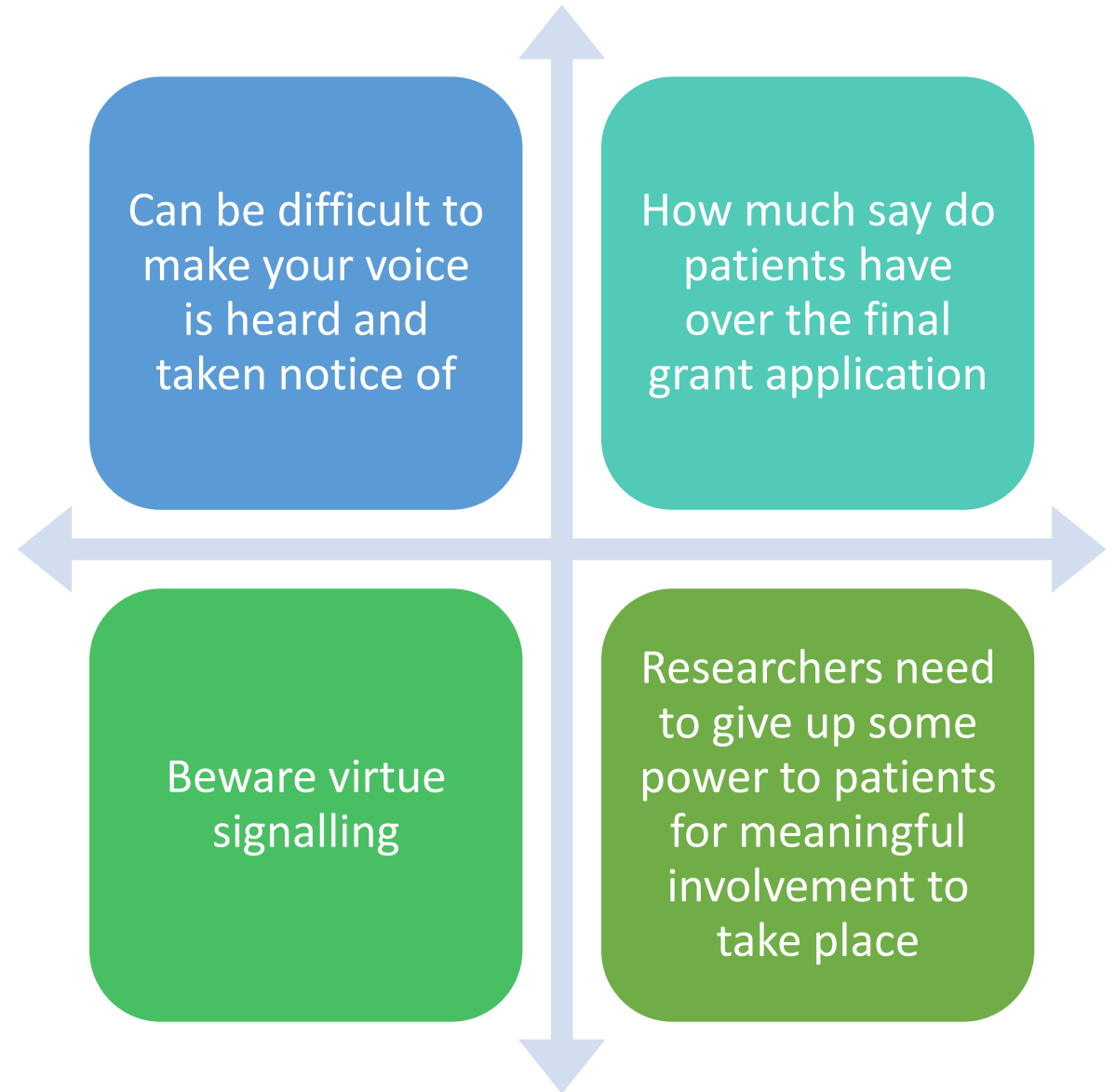
Burden of participation



Personal soap box.....



It's all about Power



Personal Positives



GIVES ME A FEELING OF SELF
WORTH, THAT I STILL HAVE
SOMETHING TO OFFER



TRAVEL ALL OVER THE UK, ?
PARIS THIS YEAR



HAVE DEVELOPED LOTS OF
NEW SKILLS



MET LOTS OF PEOPLE, SOME
HAVE BECOME VERY GOOD
FRIENDS

In an ideal world.....



Patients would be involved from identifying research question to dissemination and all points in between



We wouldn't be expected to be representative of ALL patients



Every grant would have a lay co applicant



Our contribution would be recognised by appropriate financial or other reward



PPI would be mandated for all grant applications and funding refused if not compliant

Take homes

Think of PPI as
conversations

Its about everyone
using their skills
and experiences to
improve research

Don't view PPI as
THEM and US,
ultimately we all
have the same aim