Co-production with the public and communities as end users of research, 15 November 2018 – summary of discussions

'If you're not involving people in your research, how do you prove that it is relevant to them?'

Key issues/findings

- Equalising project ownership and/or basing on degree to which directly affected by outcomes
- Recognising value and particular contribution of different forms of expertise (e.g. academic and by experience)
- Levelling power relations so everyone has equal confidence to speak/contribute
- There is lots of scope for learning from how different disciplines approach co-production

Benefits

- Increases the transparency and accountability of the work being undertaken
- Enables the researcher to become more aware of the precise needs of a particular population/of those who will be the end users/beneficiaries of the research and to strengthen a project by drawing on their local knowledge, expertise and skills to ensure that its usability and relevance is maximised
- Getting a more holistic and fully rounded perspective on a problem/challenge
- Can open up access to new (financial and other) resources
- Empowers members of the public/end users, makes them feel more valued and listened to (as those often who are ultimately funding the research)

General challenges

- Raising the profile of the University/your research with the right people how do they know you exist in the first place?
- Creating tripartite partnerships between researchers, the public and practitioners and/or policy makers
- Whole different set of challenges in working with children and particular skills needed
- Do funders and the media properly appreciate and understand the value of co-production?

Managing power difference

- Anxiety of public participants volunteering individually as to whether voice will be heard against that of members of formal/professional organisations
- Being aware of and counteracting any disproportionate influence of lobbyist groups
- Create an environment where all have confidence to speak and that will be heard

Overcoming barriers

- Linguistic and cultural barriers level your language so most likely to be understood by greatest number
- Engaging those groups that are hardest to reach but also who often experience the most pressing challenges and therefore whose input and perspectives need most to be heard. Part of the solution maybe to collaborate with gatekeeper organisations and individuals – charities, faith groups and community leaders.

Dealing with resistance

Managing resistance to an idea/approach and/or differences of opinion in how to proceed – find the fairest but also most pragmatic ways of dealing with this. At the start of the project

- agree a way forwards (maybe voting on a menu of choices) and a protocol for dealing with differences that may arise.
- If your research idea does not meet any resistance then it is possibly underpowered if the reaction is very hostile then try to understand the disruption that it poses to current practice/the status quo and ask yourself whether that disruption is truly valid and justified

Dealing with expectations

- Research findings may not validate the hunches or even deeply held beliefs of participants (e.g. there is often a mismatch between the evidence base and patient perceptions) how do you manage to still make them feel they have been heard?
- Academics who have to date spent more time in fundamental rather than applied or engaged research may overestimate the extent to which they have control over their project generating impact and the type of impact generated

Differences in priorities

- Differences in priorities of contributing organisations so important to look for common ground and win-win solutions example of OFSTED prioritising academic achievement but now that evidence that academic performance is positively correlated with mental health are now considering including mental health in school audits
- Do your homework try to understand where the other organisation might be coming from in terms of culture, values, reputation, mission, interests...

Ethical challenges

- Baseline can change i.e. project may develop in ways which are not necessarily fully reflected in the original ethics application
- Interventions (esp. in sensitive areas and with vulnerable groups) can have long term repercussions that it may not be possible to perceive or predict at the onset
- Getting meaningful informed consent from young people (how feel now may not be how feel in future – perceptions, circumstances and interests can change beyond life-course of project/ participation in project)

Financial considerations/challenges

- There are finely balanced pros and cons for remunerating public/patient participants. Providing payment can signal the importance that you attach to the public's contribution and encourage greater commitment. On the other hand it can be seen as patronising and as if the public is working for rather than with the academic and/or professional project members
- Even a small reward/offer of remuneration can yield a large boost in engagement. Important to think carefully about what sort of reward would be valued by the particular age/demographic group.
- Need some sort of formalised mechanism (e.g. pre-financing arrangements) to better support working with organisation with very small budgets as for instance delays in payment (often caused by levels of bureaucracy in large institutions like universities) can cause serious cash flow problems

Contractual considerations

- It is important that all parties on a project clearly spell out their understanding of and agree expectations and contractual responsibilities at the start. Also advisable to agree a protocol if things start to unravel and choose an impartial arbiter to oversee this.

- Need to be aware that even if something is not formally worded as a contract may still be taken as such and have that legal status

Other considerations that were raised

Global Challenges Research Fund

- The Importance attached to embedding co-production and impact into GCRF projects is influencing academic literature and practice more widely
- Perceived and actual power relations danger of continuing to act in a 'colonial' way, claiming superior knowledge/expertise. However even if have safeguards against this, a certain wariness of being seen to influence practice and policy full stop given colonial past.
- Ideally LMICs would be the project leads

Arts-based methodologies

- Creativity encourages openness to exploring beyond usual boundaries and to seeing challenges from different perspectives
- The arts can through constituent devices of story-telling and metaphor be used to nurture engagement with sensitive issues that people might otherwise be reluctant to directly discuss
- Need to be wary however that the use of art does not become purely instrumental and that continues to have (aesthetic) value in itself
- Funding for the arts is very competitive and often short-lived so the challenge is how to access support that continues beyond the immediate project time frame so that skills and knowledge are not lost

Evaluation

- Important to evaluate from a baseline i.e. to have a pre- as well as a post-activity evaluation
- How to optimise evaluation so both useful and not a chore (for public/patients members of project): think imaginatively, be creative and 'game-ify' if possible (a link to some useful resources is at the end of this report)

Moving forwards

The feedback expressed a strong appetite for developing a programme of capacity-building, training and practice-sharing activity going forwards. Amongst the suggested areas of focus were:

- Exploring ethical considerations around recruiting and engaging with project partners and especially vulnerable individuals
- Working with patients, communities and policy makers to develop and implement new models of health and community care
- Engaging the currently unengaged and hard-to-reach
- Applying and combining different engagement models and practices across different contexts, cultures, sectors and subject areas
- Effective use of creative methods e.g. storytelling, digital techniques to engage public participation through the life-course of the project and to facilitate evaluation and follow-up
- Training in how to communicate with different audiences
- Exploring the strengths and weaknesses of specific methodologies

There were also a significant number of requests for more one-to-one support with identifying funding opportunities and writing proposals.

Finally a number of people suggested that some kind of official or semi-official representative body be set up to steer and oversee the entire domain of co-production and design at the University. One part of the responsibilities of this could be to develop stronger relationship with funders and inform their thinking on this subject.

Some useful resources mentioned

- Science Shops
- University of Durham Participatory Action Research Toolkit
- Partnership Working in the Arts and Humanities: A Guide to Best Practice
- AHRC Connected Communities: Directory of Resources
- Barbara Evans et al 'WASH coalition building guidelines' handbook on building tripartite relationships (between academics, policy makers, communities)
- Barbara Evans et al 'The Partnership Paperchase: Structuring Partnership Agreements in Water and Sanitation in Low-Income Countries'
- University of York guide/ list of resources on evaluation
- Ethics in Participatory Research for Health and Social Wellbeing
- A Research Handbook for Patient and Public Involvement Researchers
- Co-producing Research: a Community Development Approach