PEP TOGETHER SESSION: THURSDAY 7TH MAY, 2020

NCCPE Updates

- Registration for the NCCPE’s PEP Network is now free of charge until March 2021, with the status of current members extended at no cost for the next membership year. To find out more, click here.

- The NCCPE will also be hosting an online PEP Network event on the 27th of May, with some opportunities to discuss practice and the challenges that professionals currently face. Registration is now open: https://www.publicengagement.ac.uk/may-2020-pep-network-meeting-booking-form

- Future PEPTogether sessions will be held on a fortnightly basis, with each session extended to 75 minutes in length. This change is designed to allow space for longer conversations and the discussion of more complex issues; however, we welcome any feedback from delegates regarding this decision.

- Our next PEPTogether will revolve around the sharing of stories from our delegates. If you have a story that you would like to be included - be it a challenge you are facing, an exciting opportunity that has arisen in your work, or an interesting example of practice – please email Maddy Foard (Maddy.Foard@uwe.ac.uk)

- The NCCPE is hosting a blog post by Bentley Crudgington (University of Manchester) on our website, the topic of which is ‘Inelegant Engagement’. Inspired in part by their eponymous workshop at Engage Conference 2019, Bentley’s blog post recontextualises their argument in the current COVID-19 era, and includes a report compiled of findings from the original session in December: https://www.publicengagement.ac.uk/whats-new/blog/are-we-capable-becoming-inelegant

- For PEPs who wish to share any news, updates or stories during future sessions, please contact Maddy Foard (Maddy.Foard@uwe.ac.uk)
Poll: How confident are you in approaching ethics of engagement in the current climate?

Poll Results

<table>
<thead>
<tr>
<th>No Response</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - not at all</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5 - very</td>
<td>2</td>
</tr>
</tbody>
</table>

The Ethics of Engagement – Sophie Duncan

Ethics can be defined as ‘doing no harm’, and ‘working for a common good’. In the realm of public engagement, it’s crucial that our practice does not harm those we work with, or potentially open them up to harm from others.

Sarah Banks (Durham University) has created the following definitions for the two ethical areas that meet during a Public Engagement project. These are:

- The ‘Top Down’
  - The requirements for an institutional ethical review, which focus on consent, privacy etc. These are often felt to be intrusive or premature when applied directly to Public Engagement; it may focus less on the ethical nuances of Engagement that need to be considered.
  - The norms, values & motivations of academics & professional practitioners –
    - A commitment to build capacity, empowerment
    - The need for credibility, validity, reliability; ‘objectivity’
    - Doing ethnographic research on, and writing articles about, the research process and the role of community partners
- The ‘Bottom up’
- The norms, values & motivations of community partners & service users –
  - Existing ethical frameworks that may not correspond with an academic context.
  - Friendship
  - A desire for change
  - Different measures of success
  - Less or more concern about validity, reliability (e.g. insisting on using survey; interview friends)

In some respects, Public Engagement results in a collision of these two worlds, whereby a space is needed in which separate motivations and ethical frameworks can be navigated/bridged. This must be underpinned by a respect for the ethical processes of other organisations/partners; a space in which multiple parties can come to a shared understanding of the ethics of the context that they are working in.

The principles Sarah outlines are:

- Mutual respect: remembering that ‘respect’ may look different from each side of the engagement.
- Equality and inclusion.
- Democratic participation.
- Active learning: the principle that everyone is a learner in the process, and that knowledge should be shared.
- Making a difference: ensuring that participatory research has an impact, and is not just research for research’s sake.
- Collective action: both sides taking responsibility when it comes to acting on the findings of research.
- Personal integrity.

Of course, engagement does not simply include participatory research ‘processes’, but a wide range of aspects - from inspiring participants to consulting and producing knowledge together, with a vast range of potential groups and individuals. It is important to be aware of the specific ethical considerations and processes which are particular to the type of engagement you are doing.

Further resources on ethical engagement (including those written by Sarah Banks) include:

- Community-based participatory research: A guide to ethical principle and practice – click here
- Ethics in community-based participatory research: Case studies, case examples and commentaries - click here
- The NCCPE website

This session’s speakers were:

- **Helen Craig**, Public Engagement Manager for Life and Medical Sciences at University College London
- **Mhairi Stewart**: Head of Public Engagement at University of St. Andrews.
- **Shane McCracken**: Executive Producer of the ‘I’m a Scientist’ programme

**Helen Craig- UCL**

During her talk, Helen posed the question: is it right for universities to assume they are the sole arbiters of good ethical practice, and to make decisions on what is/isn’t ethical?

- At Engage Conference 2019, Helen co-hosted a workshop discussing Public Engagement and Research Ethics, during which two questions were explored:
  - Are you confident that you know when your research project will need ethics approval? (Around 60% of respondents said that they weren’t)
  - Are University ethics themselves fit for purpose when it comes to co-produced research and Public Engagement? (71% believed that they were not)
- How do different groups feel about university ethics procedures?
- Helen mentions that, for the public groups and researchers she has worked with, they see a distinction between two areas; ‘ethical behaviour in Public Engagement’ and the ‘research ethics in PE’ – i.e. the ‘big’ vs ‘small’ ethics
- For some, following the procedures of their institution can leave them with the sense that they’re not acting with integrity. Some ethics procedures take a long time to follow, during which time institutions may be stringing their partners along, or putting arbitrary hurdles in the way (for example multi-page agreements/consent forms which require extended reading time, or aren’t appropriate for one’s audience).
- And participants in co-production specifically ask; why should publics have to give the power to determine the ethics of a project over to universities, when the results of this research should be shared?
- On the other hand, Universities and ethics committees do want to engage with PE concerns and are often happy in principle to adjust to be more appropriate, but there are issues around lack of time and understanding.
- For PEPs, the concerns are often more ground-level, relating to data handling and health and safety.
- One question that has arisen recently is the question of whether it is ok to engage with the individual people you are researching, and what clearance is needed for that? This also raises questions regarding power and the possibility of research without PE continuing.
- Helen shared some practical tips, namely:
  o Discuss any potential ethical problems with the people involved in the project, as early as possible.
  o Discuss these issues with the research ethics staff at your institution, and agree to create a written guide or form.

Mhairi Stewart – University of St. Andrews

Mhairi’s talk revolved around the potential ethical risks involved with Public Engagement, and included some suggestions around avoiding the ethical pitfalls that can occur over the course of a project.

- Mhairi begins with evaluation, and its definitions in the PE context:
  o Simply put, evaluation is the process of determining how well a project is going, and to demonstrate a change coming from action.
  o In this respect, evaluation is a form of research by another name. While the evaluative process requires collecting information, there are rarely any ethical procedures enforced.
- Even a ‘service evaluation’ must have a fall-back framework. Did attendees consent to their data being kept, and for how long can an institution retain that data?
- Misuse of information or breaches of data can result in disastrous consequences; both for the individual who has suffered and for the institution i.e. court cases, or enormous GDPR fines.
- How do you engage ethically, and evidence it?
- Ethical framework must protect all stakeholders - including researchers.
- Are the data-agreements you make built on a solid foundation? Are you certain, for example, that email addresses aren’t being retained for follow-up (without the individual’s permission)?
- There are different ways of collecting/ retaining data that must be subject to the same scrutiny; for example, online questionnaires whereby it’s possible to identify the individual responding, or databases of festival contacts.
- There are clearer regulations in place for handling post-code or email data.
- The use of photography also requires care to navigate; some institutions have had to remove photos that were taken without the consent of the individual, or the parent/guardian in the instances involving children.
- Often PE will involve vulnerable people.
- When working with very sensitive or difficult subjects, have we considered the human element of these interactions, and the effect it may have on others?
- Regarding the mitigation of risks, the best safety net is awareness: both of the potential issues, and of the places where you can receive advice on these.
- Continue openly examining ethics throughout the project; discuss these issues with an ethics committee, and ask for advice on a case-by-case basis. Talk to an information compliance officer at your institution. Ask your researchers and stakeholders for guidance and documentation.
Mhairi proposes a ‘traffic light’ system; a series of ‘Yes / No / Maybe’ questions that help all stakeholders reflect on the potential ethical implications, and asks delegates in the session to suggest possible questions that can be used in this way.

Shane McCracken – I’m a Scientist

Shane’s discussion focused on the ethics of data collection and sharing, with reference to GDPR rules and regulations.

- The definitions of ethics as ‘doing no harm, and acting in the common good’ are both crucial to the way in which I’m a Scientist operates.
- Regarding online engagement, there is an overlap between the ethics employed in the digital sphere, and outside of it. While online engagement can overcome the physical distance between the engager and audience, there are other distances that remain – for example, in understanding the context or the nuances of the conversation between professionals and participants (particularly in a text-based arena of engagement).
- Shane raises two key areas that must be considered when engaging online: safeguarding, and privacy.
- Regarding safeguarding; for many, the starting point is a DBS check (crucial when children are involved). However, this is only a single element of safeguarding, and there are many others to take into consideration.
- For Shane’s organisation, a key element of safeguarding is the attempt to identify whether participants in their conversations are currently at risk. These can emerge particularly in zones focusing on medical research of mental health; Shane provides examples of research projects investigating pain, or projects examining the relationship between employment and health.
- Sometimes, questions or responses from participants can signify a greater issue in their personal lives. At I’m a Scientist, moderators are trained to identify potential safeguarding issues, and to report possible issues to someone in greater authority/ with more experience as a safeguarding lead. These concerns may be passed on to Shane himself, with a discussion on whether any possible action is needed.
- If there is a chance that child is not in a safe position, I’m a Scientist will inform the child’s teacher or school, who will have more direct safeguarding procedures for said child in place.
- Training, therefore, is key, as well as easy and clear processes for staff to report their concerns.
- Regarding privacy; if institutions refer and adhere to the GDPR guidelines in place, there shouldn’t be an issue. Only keep information for as long as it is needed/ you are permitted to by law.
- Be very clear about what you are collecting; clarity for schools and students is key.
- If you are controlling the platform where the data collection takes place, then there is a greater sense of security; using another environment (i.e. one that requires cookies, or a social media site with privacy issues) is less advised.

Questions and responses from delegates
Q: ‘How might we be involved in building the capacity of ethics committees to understand our kind of work? I’m thinking primarily about participatory/cocreative engagement/research.’

- Helen: ‘We might not have answer yet, but the only way is through communicating. It’s important that all those involved understand what PE is and how it operates; running people through what it means and making sure it can’t be worked around or ignored. This may involve meeting in person and co-creating a specific guidance. It also might require the devolving the research ethics of public engagement, taking it from the central research ethics team to a team much more experienced in PE.’
- Mhairi suggests bringing participants case studies of prior examples, and gives an example of creating pro-forma for common activity.
- Shane: ‘Try to involve an ethics committee in your engagement activities. You can also get them involved in I’m a Scientist; that involvement is also a great way of showing participants how research extends beyond the lab!’

Q: ‘How do you carry out ethics training/awareness at universities?’

- Shane: ‘While there are plenty of training course available, some of the best learning can be achieved simply by ‘doing’. Having training courses running alongside your main work is an effective, twofold approach. Much of training involves thinking about the wider population beyond researchers- how might they be different, and what might they need?’
- Sophie gives an example from her time at the BBC; a compulsory ethics training course which included all staff, regardless of their role in the organisation. Participants were shown ten different examples of practice (for example, media decisions), and worked in groups to determine if each example was ethical or not. This was a valuable exercise in discovering the different ethical perspectives of BBC staff, from all rungs of the organisation.
- At Mhairi’s institution, ethics are embedded in training and guidelines are sent to staff. However, she would like to see an online training element or quiz which is widely embedded in institutional induction material (in the way that the training for GDPR is mandatory for all levels of staff).
- Helen: ‘At UCL, the set training tries to include ethics, but it’s only specific to those particular researchers engaging with it; in truth, this needs to become part of the overall research practice.’

Q: ‘I have had challenges in ensuring consent from medical researchers themselves, especially when they don’t really understand non ‘positivist’ research approaches. Is this something that others have grappled with?’

- Helen: ‘This is a classic problem. There are certain, research focused staff who are very meticulous when it comes to ethics, but who often create overly long forms for simple procedures. There are also issues of staff who don’t see the human side of their interaction as important, focusing instead on the cold, hard data, without taking certain ‘human’ ethics into consideration. Some of the best examples of balance can be found in the Social Sciences.’
- Shane gives an example of a project in which a first-time researcher was overwhelmed by the ethics process, due to the length of time and work required. Ethics processes are
necessary, but they need to be appropriate and less intimidating for new researchers and partners.

- Sophie notes that those working in interdisciplinary engagement teams often develop a mutual respect of their colleagues’ backgrounds, and a sensitivity to different perspectives which could be practiced within the research community before the publics are involved.

Further comments from delegates:

- ‘I’m currently working on a safeguarding policy for my organisation (a small research institute, not a university). We are exploring the best way to disseminate this policy so that everyone is aware of it, and finding ways to assess whether the document has been read and understood. This is important; during campus visits, any member of staff could potentially come into contact with a child or adult at risk.

- ‘I did this online training ahead of writing policies and found it really useful: (https://www.childprotectioncompany.com/CPC/). We are embedding it in our training programme, and sending guidelines to people involved with centrally organised activities. I would like to have an online training provision embedded in our induction material that all staff had to undertake within a period of time; my institution did this for GDPR and got a good uptake.

- ‘There is some evidence that compulsory training doesn’t lead to behaviour change, at least in the context of equality, diversity and inclusion. I mention this linked to the training in ethics rather than child protection, as I think the latter is a different case.’
  o ‘Might this indicate that training needs to be more relevant to the researcher i.e. how it will benefit them and their work?’

- ‘This is the online learning platform that many Health and Social Care staff are familiar with, which provides safeguarding, ethics and data training: https://www.e-lfh.org.uk/’

Group discussions: Ethical Challenges

During this session, participants were moved to smaller groups, and asked to answer the following three questions:

- What ethical challenges have you come up against, and how did you address them?
- What challenges have you face arising from our current context?
- Do you have examples of great practice in ethical engagement?

Group 1

- Regarding the ethics of online engagement, it’s important to think about the platform used– especially if it’s not your own. For example, platforms such as Twitter are not based around the same ethical principles you want to implement in your work.

- It’s also important to encourage researchers, when signing up for Twitter, to approach it with a good deal of caution. The decision to use such a platform needs to be informed – for example, awareness of how the twitter algorithm encourages ‘pile-ons’ and immediate responses, or of how the site often fails to enforce its own community standards.

- What motives do private companies (such as Twitter or Facebook) have? How might they be using data in ways that are potentially harmful?
- One delegate commented that while they take care to ensure their work is GDPR compatible, this is rarely checked by the institution unless the researcher asks for help from the relevant office. This results in the PE team being solely responsible for evaluation, ethics, etc.
- The ‘I’m a Scientist’ platform was built partially as a way to avoid compromising data, and to have control over the information collected.
- Online engagement can be excluding if not designed or formatted in ways that are accessible. Accessibility itself is an ethical consideration, but can be also be equated with ‘usefulness’; after all, increased accessibility helps everyone who engages with your content!
- Can we use other more accessible ways of engagement? In previous sessions, letter writing and phone calls were suggested: these can also provide greater control over one’s data.

Group 2

- How can you make online as safe a space as face-to-face working? It is incredibly hard to offer the same kind of confidentiality and personal support in an online space
- ‘We need to really re-think the methods in which we work with our vulnerable research participants – and to simply make sure we are ‘there’ for people.’
- One participant in the group increased the amount of time they were available if people wanted to chat.
- ‘We need to let go of research, and just think about being there and giving back. The pastoral support side is so important.’
- ‘I have set up Zoom drop in sessions - just to allow space for people to bring things up outside more formal meetings.’
- ‘We have found there is support available in our institutions. One of our group works for both HE and the health service, so really clear routes are needed to signpost people to support services - this really helps!’
- ‘I am deliberately avoiding having more challenging conversations at the moment because of the risk of causing harm.
- ‘I am really anxious that, for many people in lock down, support is needed more than ever - and I am really anxious that I am not able to meet that need due to the loss of face-to-face engagement.’

Group 3

- How do you manage the power balance when the universities hold the funding and ethics approval processes, rather than the communities?
- ‘We need to lobby for processes to be made central, making the onus on the institution rather than the individual (this applies to safeguarding policies, as well as ethics processes). Having local policies is a risk.’
- ‘Can we pool templates across the sector? An example or a case study could be used as a starting point’
- Where else in your organisation might there be examples? Perhaps widening participation could provide these?
- As with GDPR, it will only become a priority when training is made mandatory, and the risks of bad practice stressed to trainees.

Group 4

- Some of these conversations have arisen during the UKRI funded EPPE program, particularly the balance between giving community partners ownership and a say in the proceedings r.e. generating data, while ensuring that the onus of the responsibility and risks falls on the institutions and their procedures.
- Might it be ok that we don’t always know how to balance these things?
- Communication is important in finding where the line can be drawn; ensure there are key people available in this context. Referring to PPI experts (etc.) for advice can be very useful.

Group 5

- When engaging vulnerable groups online, it’s important to be sensitive to the context in which the conversations are now happening. One example is in research around mental health, which requires a series of online discussions,
- Previously, young people could provide details of their experience at a room on the university campus. However, during the crisis, one of the only spaces now available for these conversations is the online sphere, which for a young person, might physically mean their home or bedroom.
- The lack of physical interaction therefore raises difficulties; how can you provide spaces like breakout rooms, or ensure that there’s a physical transitional point between the (potentially distressing) conversation and the ‘return to normality’, as it were?
- How can you be certain that these conversations are secure, and that the participant is safe?
- Some suggestions have involved more casual check-ups and chats, or the use of games to provide a more relaxed setting (i.e. Pictionary)
- Sophie suggest a blog or slack channel to collate practice and discussion around approaching these particular issues.

Final comments:

- ‘Moving online also means moving into the domestic space. The ethics of that is very different.’
- ‘It’s important to remember that people might not feel equal and taken care of, simply just because you tell them they are.’
- Shane: ‘We have to acknowledge that the context is different online; while there are a variety of approaches, there are many ethical aspects to consider carefully. We can’t simply continue as before, replicating our old practice.’
- Helen: ‘Continued communication has been a reoccurring theme in this session. It’s important to keep talking about ethics openly as research progresses.’
- Mhairi: ‘So many of us are dealing with different facets of this topic: let’s collaborate and create these ethical frameworks together!’
Resources shared by delegates:

Inelegant Engagement blog post
https://www.publicengagement.ac.uk/whats-new/blog/are-we-capable-becoming-inelegant

Government GDPR documentation:

EU GDPR info: https://gdpr.eu/what-is-gdpr/

Online training on policies: https://www.childprotectioncompany.com/CPC/

eLearning for Healthcare training resource: https://www.e-lfh.org.uk/

Commentary piece on current ethics: thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30150-4/fulltext