





# INSIGHT: Ethical Best Practice in Science Communication and Engagement

Advisory Workshop 1 and 2

Summary Report - September 2024

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#### 1. Introduction

INSIGHT aims to identify how researchers and practitioners communicating and engaging about science and health related topics consider the ethical dimensions of their communication. By conducting two advisory workshops and two focus groups (one in Bristol, one in Oxford) we will understand more about the role that ethics plays in communication and engagement with research. A series of interviews in UK academic institutions, and in museums, science centres, and other informal learning spaces, will contribute to the project gathering UK-based evidence on the ethical dimensions of science communication and public engagement with science and health topics. The project is being led by Dr Clare Wilkinson, Co-Director of the Science Communication Unit, UWE Bristol in collaboration with Professor Mike Parker, Director of the Wellcome Centre for Ethics and Humanities (WEH)/Ethox Centre, University of Oxford.

INSIGHT is exploring three questions over the duration of the project:

- 1) What are the key ethical considerations that need to be made in science communication and public engagement contexts, what frameworks exist and where are the gaps?
- 2) How do those communicating and engaging around science and health (researchers and practitioners) consider the role of ethics in their activities?
- 3) What support is in place for researchers and practitioners to assess and ascertain the ethical dimensions of their communication and engagement practices?

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This summary report provides an overview of the first Advisory Workshop conducted as a part of this project on Tuesday 30<sup>th</sup> May 2023, and the second Advisory Workshop conducted on the 8<sup>th</sup> May 2024. The Advisory Workshop involved a group conversation with invited participants who have experience or expertise related to the focus of the project. The first workshop intended to help us to understand the current ethical landscape of science communication, where ethical considerations are made and where gaps lie, and to understand how we can best share the findings of INSIGHT to have impacts. At the second workshop we provided a summary of our findings and dissemination plans.

We would like to thank our advisory group members for their participation in the workshops and their consent to feature their comments and contexts in this summary report.

### 2. Advisory Workshop Members

In alphabetical order:



Professor Ayelet Baram-<u>Tsabari</u>, Faculty of Education in Science and Technology, TECHNION, Israel Institute of Technology.



Professor Phaik Yeong Cheah, Bioethics and Engagement at the Mahidol Oxford Tropical Medicine Research Unit (MORU), University of Oxford.



<u>Dr Alessia Costa</u>, Post-Doctoral Researcher, Wellcome Connecting Science, UK.



<u>Dr Alun Davies</u>, Public Engagement, Centre for Tropical Medicine and Global Health, University of Oxford, UK.



Dr Barbara Groot, Senior Researcher, Leiden University Medical Centre, The Netherlands.



Dr Laura Lindenfeld, Alan Alda Center for Communicating Science, Stony Brook University, USA.



Dr Xuan Liu, PhD, Associate Professor, National Academy of Innovation Strategy, China.



Dr Ramya M. Rajagopalan, Assistant Professor, Sanford Institute for Empathy and Compassion, University of California, USA.

The agenda for the first meeting included introductions to the team and advisory workshop members, presentations on key aspects of the project, including its design, and opportunities to feedback on the project plans, including interview and focus group aide memoirs. In this summary we focus on the outcomes from two interactive activities 1) Ethical challenges mapping activity and 2) Frameworks activity.

### 3. Ethical Challenges Mapping Activity

For this activity we provided an initial framework to explain that our predominant interests around ethics in relation to science communication and engagement related to communication techniques relative to the ethical role of science in society (see Table 1). We also welcomed the sharing of other ways of thinking about ethics in the context of communication and engagement, as well as specific examples.

## Table 1: Adapted from <u>DAHLSTROM AND HO (2018)</u> Exploring the Ethics of Using Narratives to Communicate in Science Policy Contexts.

Ethical conduct of communication within scientific research (e.g. identification of funding sources, disclosure of conflicts of interests, use of informed consent and fair treatment, analysis, and reporting of research data).

Journalistic ethics of covering science (e.g. journalists should "seek truth and report it" by being objective, not misrepresenting factual information, not plagiarizing others' works, and avoiding conflicts of interests).

Ethical controversies surrounding science policy active ethical controversies (e.g. the examination of the autism-vaccine controversy, stem-cell research and biotechnology policy).

The use of communication techniques relative to the ethical role of science in society (e.g. the ethics of communicating science to a non-scientist audience) which has received less consideration.

We then asked, 'What are the key ethical challenges facing science and health communicators/engagers today?'

Advisory group members provided a number of responses to this question, including comments on inclusivity, values and beliefs as well as the ethical implications of specific scientific and technological developments on communication for example, artificial intelligence and social media platforms. Starting with the focus on inclusivity, discussion here included how science communicators and engagers 'reach out' and consider the motivations of those they seek to engage with, and those that are presently seen as un-engaged:

'There's a lot more awareness and reflection, I think at least in my field in genomics...there's a lot of drive to engaging disengaged communities because they are underrepresented in datasets. But the next question for me would be "What's in it for them?" Of course, there's the idea of making our science unbiased so that it applies more equitably to everyone...there are like valuable applications down the line [but] in the short term it is very much focused on, well kind of also improving the quality of our data sets. And so there is a little bit of attention there I think, in articulating the benefit, but without overpromising.' (Anonymised Advisory Group Member A)

The advisory member continued on the point of overpromising, that at present much communication happens in a segmented way focussing on specific high-end technology or scientific discoveries, without presenting the wider context and realities of the true implications for something like 'health'. As such this could cause 'over-hyping' of certain areas of research, creating ethical ramifications. Conveying the complexity of science, particularly during periods when the science 'appears to be changing all of the time', such as during COVID, meant communicators have a difficult challenge:

'Like part of that [the idea of presenting balance] would be the kind of equilibrium. But part is also kind of it's just the complexity of what we know and what we don't know and I without feeding into sort of possible mistrust' (Anonymised Advisory Group Member A).

Ayelet considered further the challenges of reaching underserved communities and groups and how to balance a respect for views, cultures and traditions whilst still presenting science with accuracy:

'For me key ethical challenge is that tension between and not shoving science into someone when he doesn't want it or she doesn't want it. So not interfering with the world views that people have but on the other hand it's very evident that some science is actually very important for decision making and for living healthy lives and making good decisions. And I think it's very tough ethical question of when is the active ignorant ignorance and gatekeeping due to ideological decisions... When should it be respected or worked with, having a dialogue with and when do we say, this is evidence based and data or evidence based knowledge that we have and we feel it's important that other people will know it, even if it's patronizing. If it means that we prioritize science knowledge over other types of knowledge, I feel this is completely unsolved and very serious ethical question' (Aylet).

Barbara from the perspective of citizen science highlighted that the ethical challenges of engagement extends beyond who we reach, and when involving citizens as co-researchers, 'what power do they have to share their insights in the reporting and how do we discuss power in who shares what and who gets paid for sharing what?' are also ethical issues.

Beyond what to communicate and who to reach, the quality of communication was also highlighted as a potential ethical issue. With more and more engagement and communication simply perceived to be a 'positive thing', Alun highlighted that the lack of review frameworks, including for ethical aspects of communication and engagement left many 'grey areas' where it is 'pretty much left up to the team to decide what they do in terms of engagement' without a sense of external oversight.

Next, broader questions around how science communication and engagement is supported, both from a funding and training and development perspective were raised. Alun highlighted that funding can sometimes depend on what is topical at the time:

'In the 90s, there was a real influx of money for HIV and consequently a lot of money for engagement and communication in that area. More recently, it's kind of COVID-19 and it feels like you know that that we're responding to the money in the sense that the group that has the most money and resources is able to communicate the most, the loudest. And I think that's a big ethical issue because you know, it's always at the expense of other really important things like primary care or malaria or other neglected issues' (Alun).

Whilst, Laura highlighted that there are ethical questions to be discussed over preparing scientists for communication and training 'who do you train, who do you not train?... Are you doing that in a corporate setting? only for universities?'.

Our next question led on easily from these points as we asked, who has responsibility for considering how these ethical challenges are navigated?

Funders and organisations had already been touched on but the first comment here from Laura highlighted that whilst there are ethical principles, for example for journalists, these are different than those that a science communicator might need. Laura described that the motivations might lead to different impacts and different ethical ramifications:

'[A science communicators'] goal might be to get people energized and excited, but from one context to another, you know, you may be producing content that's really responsible and relevant for certain community, but can have an unintended consequence in another, especially in social media where things can just be truncated and flipped very, very quickly' (Laura).

For those communicating and engaging it was also pointed out that they may not be the scientific, research or subject expert and care was needed as to where responsibilities then lie for points such as accuracy and information. An advisory member continued:

'I have a team of public engagement, community engagement and science communication practitioners and I myself get involved as well...but we're not the content experts...one day will be engaging, it'll be about malaria and the next day it'll be about tuberculosis. So, we are not these experts and we need the scientists to come and actually do the communication with our facilitation. I guess having a team is good, but scientists could be saying, OK, well you do it then you are the expert. So no, I'm not the content expert. And that message is really difficult to get through...So we, we do need everyone,

all scientists to be able to communicate to a certain extent and not leave it all to the comms people or engagement people' (Anonymised Advisory Group Member B).

Aylet commented that academics working in science communication, though also sometimes carrying out practice, were people she felt had some responsibility to think these issues through. Their work was not reliant on funding for engagement projects, and they could have the capacity and time to put in place guidance with practitioners but not as 'a top down thing'. Funding was then returned to. Laura highlighted that whilst in some countries funding for communication and engagement was underpinned, in others it was entirely reliant on external grants:

'In the US, a lot of it is anchored. When you get a grant like, you get a National Science Foundation grant. There's broader impacts and it just makes me wonder what responsibility to the funders of science have for ensuring that you don't just use some simple add on to your broader impacts, but that really you're drawing on quality work because it's really uneven and the people who review those grants, they may or may not have expertise in science, communication and engagement' (Laura).

Alun agreed and extended this beyond funders and end of award reporting to publishers, highlighting that rigorous reporting of communication and engagement should be expected but that at present this could be very rare. An advisory member built on this point adding that there are ethical issues in 'throwing away our experiences... not sharing with other people who will get it wrong or not get it right and making all the same mistakes' with their communication and engagement activities. Communicating failure, not just success in evaluation reporting was greeted warmly by the group. The same advisory member shared a specific request they had made to a funder to create a space for improved publishing of communication and engagement projects and outcomes.

The conversation then concluded with a point that different communication and engagement projects had different aims and goals, thus any ethical context has to reflect that complexity, that there are 'different layers of the system there are different senses of responsibility' (Laura).

### 4. Frameworks Activity

We prefaced the second activity with context from our funding application, namely that ethical issues including a desire to do no harm, ensure there is informed consent, voluntary participation, anonymity and confidentiality, as well as ways for participants to be informed of outcomes arguably apply to many communication and engagement settings, and yet currently, they often fall between the gaps of what is seen as 'research' and what is seen as 'dissemination'.

Those guidelines that do exist are also often associated to subtly different disciplinary areas (for example, social science and humanities, opinion and marketing research, evaluation associations, journalism bodies, or the museums sector) and their existence may not be obvious to those communicating and engaging around science and health issues.

We asked, which existing ethics resources/guidance/frameworks do you use in your work and/or would you recommend to others?

Laura started by sharing that the Graduate Certificate and Masters degree in science communication at her institution includes a required three credit ethics and law course, and building it into the programme integrated the ethical components. Beyond that there were also built in mechanisms when people were conducting research or engaging and applied research.

Barbara volunteered the idea of community-based ethics and engagement boards as an example used in some citizen science settings, which extends the role of citizen or public participation to the reviewing of grants and applications, an approach currently being used in India and being trialled in the Netherlands. Her work had been informed by guidance for participatory practice, for example Participatory Health Research: A Guide to Ethical Principles and Practice by the International Collaboration for Participatory Health Research, and its associated toolkits and cases. Milly shared that she had similarly used NIHR PPI (Patient and Public Involvement) resources for applicants to NIHR research programmes for guidance around aspects like paying participants. Alun explained that a project he has been involved in was for a large multi-country trial of COVID-19 vaccines, with engagement based on good participatory practice. This project used a relatively simple guideline but nonetheless there could be challenges:

'It [the guideline] highlights the importance of engagement at the beginning during and the end of the trial and highlights the importance of engaging communities for acceptability of trials and that kind of thing. One of the challenges with it is that as these large platform trials become multi country, then there's a need for kind of standardized scientific procedures across each

of the sites. Then it becomes harder for communities to have meaningful input into trial design through those community engagement mechanisms' (Alun).

Ayelet continued that she felt there were broadly two types of guidelines, frameworks that are focussed on 'science in general' and those that talk about specifically about science communication ethics such as 'how to communicate uncertainty or inequality and power and that kind of stuff'. For Aylet communication ethics raised important questions that were not always present in science-based ethics, for example questions about 'inequality and power' but also raising important questions around 'truth', Aylet's thinking had been informed by <a href="Douglas (2014)">Douglas (2014)</a> The Moral Terrain of Science, which had prompted her to consider:

'...Responsibility to truth to the scientific community and to society...It's a way of looking at the science communication as a well as a field of research in a way and then really our commitments, our prime commitments is to truthful knowledge, reliable knowledge to our colleagues and then to society. I would say that for a practitioner of science communication. Maybe it should be reversed. First of all, our commitment to society and then to our colleagues and maybe for me commitment to truth and then actually communicating reliable knowledge is actually very high. When we're talking with society, I as I said before, this not solved, and not everybody agrees with me on what, or how to prioritize and scientific knowledge versus other types of knowledge' (Ayelet).

These tensions and unresolved issues led to our next question and 'Are there gaps in these resources?' A range of gaps were identified amongst the group, including the lack of ethical guidance around social media, and more recently ChatGTP, as well as other tools which could generate 'fake content'. Laura's thoughts on this had been particularly prompted by attendance at a recent event as part of the Nobel Prize Summit, where such issues were discussed.

Next an important point was raised around gaps in terms of the process. An advisory me shared that whilst there were processes for ethical approval, these often focussed on the outset of projects or 'research', which encouraged accountability but for engagement projects an ethical committee decision may not have been required:

'Ethics is ongoing...without such processes [ethical review and best practice] it's very hard, I think, to see how these good principles, even if they are up there, can be enforced because not everybody, not all teams, will have either the resources, the knowledge, the time. Some may also be quite small teams, maybe within institutions who don't have sadly access to journals where these some of these frameworks are published. Not every team has an ethics person or a social scientist person. So, it just depends. It's not to say that social scientists have the, or ethicists have the answer, but at least maybe like

we come from a background through the experience of research ethics, where we kind of more familiar with the process and I don't know...One of the striking features for me when we merged as a team between social research and public engagement, we realize that we do the same things but as researchers, we wait for months just to have the green light and say, yes, you can go and my colleagues in public engagement can just go ahead. Not to say that they don't think about these questions, they do, but it's a very different process' (Anonymised Advisory Group Member A).

Xuan added to this, stating that whilst some communication processes, like science journalism had clear ethical guidance in place, others such as ethical processes in museums were less well considered with her work seeking to illuminate some of these issues. Xuan talked about two key aspects of this. The first involved values 'how we build up the value system during this kind of activity' the frameworks, the institutions and guidance, whilst the second aspect was focussed on 'how to shape people's behaviours in reacting to the science communication activities?', thus values was central to her thinking around these issues.

In conversation Mike, flagged that with work at WEH/Ethox with engagement practitioners from a range of settings in Africa and Southeast Asia there might be further opportunities for a component of the work to look at the context of engagement ethics in lower middle-income countries. Laura added that there was gap around the context of ethics in science communication training, including the ethical dimensions of charging for training.

### 5. Advisory Meeting 1 Summary

In summary, our advisory workshop participant comments highlighted a number of questions/points for further consideration within the context of the INSIGHT project. These included:

- Whilst we resisted providing definitions for communication and/or engagement in order to open up the conversation, it should be recognised that different contributors may be bringing different contexts and concepts to the conversation.
- A wide range of topics were covered in the workshop considering ethical issues at a practical, theoretical and philosophical level, and different dimensions of science/health communication and engagement (e.g. media, digital, co-production etc.). This suggests there will be several multi-faceted dimensions for consideration in the project.
- Longstanding ethical challenges in communication and engagement (such as hierarchies of knowledge, over-hyping, representing balance, power, focus on certain scientific/health topics and accuracy) remain important considerations. New and emerging areas for communication and

- engagement, like social media and use of Al are presenting new ethical challenges for consideration.
- There is a lack of consideration around the ethical dimensions of providing science/health communication and engagement training.
- The lack of sharing and/or rigour in assessing the quality/evaluation of science/health communication and engagement is an ethical issue.
- The intersection between the role of communicators/engagement practitioners and scientists/researchers can present ethical conundrums.
  There is the potential to learn more about the ethical challenges of science/health communication by exploring other disciplinary areas and working in more cross-disciplinary ways.
- The current focus on equality, diversity and inclusion in communication and engagement settings presents overlap with some of the ethical questions for science/health communication practitioners and academics. A number of these questions appear unresolved and/or under researched.
- There is a lack of consistency in ethics oversight in relation to communication and engagement and limited existing resources were directly referred to in the workshop. Several structural and organisational factors also influence the valuing of ethical considerations, for example the role of publishers, funding bodies, and institutions.
- Any resources or guidance that are developed in the context of science/health communication and engagement would need to be responsive to different aims and contexts, including cultural and social settings.

These summary points will inform our ongoing focus group and interview data collection and contribute to the analysis of that data. As a direct result of the Advisory Workshop, we also added an additional strand of interviews to the project and are seeking to conduct additional interviews with individuals who are responsible for UK-based science/health communication and engagement funding programmes.

### 6. Advisory Meeting 2 Summary

Our second advisory meeting was primarily focused on sharing data from our study, as well as an opportunity for the advisory group members to feedback on our further dissemination plans and ways we might take the project forwards.

The conversation at this meeting was focused on a number of key themes raised by the advisory group members, including:

- How we had analysed the data
- Whether there were different motivations for communication and engagement and how that was being influenced
- Differences between researcher and practitioners' insights

- Differences in perspectives on ethics depending on the discipline a researcher or practitioner was based in
- How different participants in communication and engagement activities were considered
- The different power dynamics at play in communication and engagement
- The experiences people drew on to navigate ethical challenges

We also discussed a number of specific elements of the data presented. The advisory group members were very complimentary regarding the outcomes of their project and gave informal agreement to remain involved in future projects that evolved from INSIGHT.