Experts by Experience
Co-created Knowledge and Authorship

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Whose opinions, voices and stories matter? Whose stories are carried forward, and who gets to shape them? How is lived experience recognised across different systems and structures? Who is an expert by experience, and how might they wish to position themselves in a creative research project? Can we move beyond default assumptions and established ways of working? How might we explore more open, non-hierarchical ways of knowing, while making space for each other's experiences and stories?

This pilot project is inspired by the National Centre for Academic and Cultural Exchange's (NCACE) recent publication Artists and Creative Practitioners working with Higher Education, and focuses on safety, authorship and the balance of power when working with communities. This work explores how the knowledge of people with lived experience is recognised, and how they can shape and share authorship of creative research. Bringing together case studies, reflections and conversations from different contexts, it seeks to create space for exchange across disciplines, communities and countries.

Our aim is to create and sustain an open space for conversation, exploration, reflection and critical dialogue. Rather than proposing a prescriptive framework, we invite contributors and readers to explore these questions together. The piece begins with a conversation between us about psychological safety, power and authorship in arts and community research. This conversation leads to three questions, to which contributing artist-researchers respond through case studies and reflections. The publication will be followed by a documented, international online roundtable.

In this conversation, we use the term "expert by experience" to recognise the knowledge, insight and expertise developed through lived experience. We acknowledge that **terminology** is not neutral: some may prefer "lived experience", "participant", "collaborator", "co-designer", "co-author", or other descriptions that more accurately reflect the specific nature and context of a project. We use "expert by experience" here as an umbrella term to honour the contribution, knowledge and agency of the individuals and communities central to these practices. We also recognise that language, roles, and relationships remain situated and evolving.

Conversation starter

Art-and-research projects are increasingly central to contemporary community practice, as diverse artistic approaches contribute to multiple strands of social research. However, this hybrid methodology introduces distinct challenges. Several institutions, organisations and associations follow their own, often similar, ethical guidance and policies. The emerging pace of engagement with communities who may be socially, financially or any other way vulnerable, and the growing palette of creative and artistic approaches might require something more transformative than a toolbox, an ethical form, or a set of rules.

This conversation starter is the first piece written by the two initiators, Kim Wide and Rita Sebestyén, who work with communities in artistic, creative, and socially responsive projects. The aim is to assess how our experience, different angles and positioning can lead to a set of questions about psychological safety, power balance, and authorship when researchers combine social, creative, and artistic methods working with communities. This piece sets the tone and mode of this exercise, which will be followed by a longer piece where three experts by experience and researchers will engage with the proposal, and finally, there will be an informal online roundtable with the contributors, held as an open, free, and internationally shared facilitated conversation for all those interested. All formal contributors, including initiators, position themselves for transparency and clarity of point of view.

Kim: Traditional research tends to use high language, come with a pre-determined research question that has been built without understanding the relational contexts or needs and is performed to communities and not with and by them.

Rita: The words we are using might be one important point to agree on in this project. The vernacular we use in theoretical, academic papers are not accessible for all who take part in these projects, which does not say anything about the quality of the academic research nor the capability of all collaborators. However, it shows how vital it is to use words that can circulate across several disciplines and all participants and co-creators of these projects.

Kim: Also, some might have a negative flair. I like the term expert by experience; it gives the dignity and position that needs to be conferred. Good to see something more agile, more powerful that gives agency. In our work, we ask communities to set their ambition, their ideas of how best to approach their needs together and use their contexts and networks to make something that works for their local setting.

Rita: Yes, that is much closer to co-creation and co-design, and then we also need to talk more about the roles in different projects. In my case, as I do artistic projects, it is natural that when a new work emerges through collaboration, questions of authorship, ownership, visibility, and intellectual property are inevitably addressed. Community participants become not only contributors, but co-authors and co-researchers, with a recognised role and identity within the projects.

Kim: This has been an issue for us in terms of how we experience the research framework and approach. Institution-based social research often positions participants as providers of testimony, experience, or data. Researchers come and observe, document and evaluate. Write, publish, and then leave. It is often anthropological - documenting people as subjects. I know that researchers in the field of community development and Socially Engaged Practices want to deeply share value, but the system of research (while changing) still needs to move more away from colonial and extractive frameworks.

Rita: At the same time, there needs to be a balance, probably constantly changing and depending on the characteristics of each project, of how researchers and artists collaborate with community members. Each expertise is crucial and might be the case that each project needs a different setting, and we should rather develop a dynamic network and system around it, rather than the prescriptive ethics and tools used so far, which were inevitably formulated from the angle of the institutions.

Kim: Yes. In our case, for example, the process revolves around not only co-creation of the projects and programmes that engage areas in determining their futures. We also want to establish a model of cultural democracy that is focussed on skills development, increased collaboration. This leads to the development of advocacy and new partnerships and relationships with local authorities, policy makers, businesses and larger organisations and institutions.

Rita: It is inevitable that the role of the experts by experience is shaped by and through their own perception, too. I like that your work is about actively reframing partnerships by newly developed advocacy. It was almost a very welcome side-effect of my practice that communities once experienced dignity and being listened to, they strengthened their boundaries and became much more mindful of their role, contribution and what they expected as an outcome.

Kim: Finally, even if ethically and generously approached, institutional research projects often mean that the information may take years to be validated or made publicly available to everyone. Paywalls for many journals mean that it is not easily shared. Communities have to wait a long time to use it for their local needs. Any funding applications, policy changes are postponed.

Rita: This is another accessibility issue then: how to assure that the outcome is accessible for all? And how can we make sure that the community that took part in the research will ripe the benefits of the conclusion, without the significant delays we usually have now. Also, connected to this, I am a supporter of the co-operative inquiry method which often includes all collaborators in the articles as authors.

In summary, we started our conversation from a narrowed down question of co-authorship and collaborative IP, and we arrived at three main questions that we will pass on to three contributors of the second written piece to reflect on them and bring up case studies from their own practice and experience. From the nature of this inquiry, we are focusing on those researchers who are also experts by experience and reflect on this topic from both angles.

Our questions:

1. Describe the dynamics, roles and relationships in an art-and-research project that you felt was genuinely honoured experts by experience. What made this approach meaningful, and how did it work in practice?
2. What are the most effective ways to share and translate the outcomes of arts-based community

research into practice? More specifically, how can we ensure that communities benefit from the knowledge created, that different forms of contribution and co-authorship are meaningfully recognised and honoured, and that questions of ownership, access and resources considered?

3. How do the wider ecosystems around art-and-research projects shape the conditions for safe, equitable, and sustainable collaborations? We mean here the ever-changing roles and relationships between artists, creative practitioners, facilitators, researchers, communities, experts by experience, higher education, governmental and other institutions, charities, not-for-profit organisations, funders and other partners involved in these practices.

Contributors were invited to respond to one of these questions, this way allowing them to choose the angle and focus relevant to their own practice and experience. They also had the opportunity to reflect on the language used to describe these roles and relationships, and to introduce any expressions or concepts they feel best capture the complexity of these practices.

Positioning bios:

Dr Rita Sebestyén is an artist-researcher working with communities experiencing liminal life transitions. Drawing on a background in performing arts, social research, and philosophy, she developed Embodied Artistic Research (EAR).

Embodied Artistic Research comprises three interconnected pillars: sideways storytelling, rituals and ceremonies, and community creation. Through storytelling, performative techniques, workshops, and conceptual art events, EAR creates incubators for social healing, grounded in an aesthetics of non-alignment, where untold stories are articulated, expressed, and witnessed.

Boundaries, dignity, and high-quality artistic expression are non-negotiable foundations of the method. Co-creators are involved from the design of the process through to the creation of collective artworks. They shape what they are ready to share, co-design rituals, practise deep listening, and experience what it means to be genuinely heard.

Kim Wide MBE is Co-CEO and Artistic Director at Take A Part, a socially engaged arts organisation with over two decades of experience in cultural democracy, placemaking and community-led creative practice.

Take A Part is a socially engaged arts organisation. We use art and the fundamentals of Asset Based Community Development as a way to develop conversations about their future ambitions and ideas. We know that creativity brings diverse groups of people together - often from backgrounds that do not necessarily engage in formal community meetings or consultation methodologies.

Our job is to use creativity to map ideas of an area and invite people together to set the local agendas. From this, we form local governance and project management groups called Arts Action Groups. These groups pick themes that are important to their community (health, wellbeing, education, environment, job creation, food inequalities etc) and together, we work to improve them.

Different but Complementary: Reflections on Co-Designing a Knowledge Exchange Project

by Dr Funmi Adewole Elliott

An anonymised Case Study

Reflections on question 1: **Describe the dynamics, roles and relationships in an art-and-research project that you felt was genuinely honoured experts by experience. What made this approach meaningful, and how did it work in practice?**

I recall a project that I co-designed and co-delivered with an artists' collective less than five years ago.. I have chosen to reflect on this piece of work because the collective said in their feedback that they found it beneficial. Additionally, I feel reflections on this project could also be used to consider issues around psychological safety, power balance, and authorship that arise when researchers combine social, creative, and artistic methods in work with communities. It was a knowledge exchange project, funded internally by the university where I was employed at the time. The collective comprised several mid-career artists of African Diasporic heritage, founded by one member who had the support of a regional theatre company. All members of the collective were well-known artists with strong track records in the performing arts, and their work sits well within the Creative Health sector. Below, I describe our work and consider why the collective found it beneficial, and discuss what running it taught me about these issues.

Project background

I had attended one of the collective's Creative Health programmes, intended for Black mid-career artists, and found it beneficial: At the event, I shared my practice, received feedback from members of the collective, and enjoyed the sociability of the event. When the funding programme was announced, I thought a knowledge exchange project would be mutually beneficial. Following preliminary conversations with the collective, I proposed a series of public-facing workshops and panel discussions in which the collective would participate alongside other practitioners.

Our goals were complementary: they wanted space to develop their practices and to explore further work opportunities, while I was interested in understanding Creative Health and the infrastructure it requires. Having agreed on the idea, I drafted proposals for the panel discussions while members of the collective designed their own workshops. We reviewed each other's materials and agreed on the project, timelines, and budget. The artists were paid for their time. The project consisted of workshops led by two of the members, based on their own practice, with all members taking part in the panel discussion. One member of the collective took on a dramaturgical role offering an extended critical response to the analytical perspective on creative health that I was developing through facilitating these conversations and discussing the work.

Throughout, the collective designed their own workshops and spoke on their own terms during the panel discussions. They also stipulated how they wished to be described and had final approval over publicity materials. I felt this created genuinely equitable and complementary roles, rather than a relationship in which I extracted their expertise for my own analytical purposes.

The dramaturgical role was not simply reflective but generative: this member's responses deepened my analysis and helped me understand the specific challenges mid-career artists face. Mid-career artists often have huge family responsibility whilst not having support from the cultural industries that often focus on early-career artists, leaving them with little time and space to develop and refresh their practice.

The exchange was reciprocal: through the project, the collective gained space to develop their artistic practices, and I learned more about the creative health sector and its intersection with the creative industries. By building a picture of the ecosystem around the collective's work, I gained a better understanding of the infrastructure available to artists working in creative health, as well as the organisations emerging to address gaps within it. I came to realise that the collective itself was filling one such gap in the arts ecology. At the end of the project, the collective's feedback was not that they had developed new skills, but that they had been given time and support to think, discuss, network, and look at their practice with fresh eyes. They were also able to raise their profiles within the sector and spoke about the importance of producer-type roles within it.

Why the co-designed approach worked

I have heard from several colleagues that co-design does not always work, and I have heard artists say they dislike co-designed projects because they do not find them genuinely collaborative. In this case, however, it did work, and I attribute this to several reasons.

Firstly, we were able to find a genuine intersection between our different goals. Together, we co-designed a project in which the collective's goal — to have space and time to develop their artistic practice — was met, alongside my own goal as a researcher: to deepen my understanding of the intersection between the cultural industries and creative health, with a view to understanding how infrastructural support for artists working in health and well-being might be improved. My ability to find this intersection was due in part to my own background as an artist, which enabled me to ask the collective the right questions alongside an awareness of the academic requirements placed on me. This suggests that the funded organisation or academic has to be able to understand the different positionalities they and the communities occupy to craft mutually beneficial goals.

Secondly, the funding allowed me to pursue a curiosity-driven project. Had the project not been curiosity driven, I would have needed to take a far more rigid approach; instead, I was able to fine-tune my goals as I went along. My sense is that where an academic, or whichever partner has secured the funding, is required to report back to a funder against a fixed set of parameters, it becomes much harder to ensure that all partners' goals are genuinely met. Without that flexibility, academics are sometimes accused of being extractive, appearing interested only in meeting their own goals. In business terms I was working across two different sectors in this project – the academia and the arts sector. I was able to bend to the needs of the arts sector in this case. Indeed, as one of the collectives said I behaved like a producer.

Thirdly, although the project was mutually beneficial, the work involved could not feasibly — nor appropriately — be shared equally. I sometimes hear colleagues argue that there should be no hierarchy in such collaborations, but I wonder whether that is ever truly possible. What communities want the researcher or academic to bring to the partnership is something different but complementary to what they themselves bring. I was responsible for the administration and I had an assistant helping me with the research. It was still a very heavy workload. Though the artist

filled evaluation forms, I had to write reports and analyses. If I had tried to share work equally or avoid taking the lead at certain points in the project, it would have not been mutually beneficial.

In brief, this project has shown me that equitable power dynamics between collaborators from different positionalities require both parties to understand the institutional relationships each inhabits. Without this understanding, negotiation becomes difficult, and one party is likely to experience the other's practices as extractive, benefiting at their expense.

Experts by experience must be honoured in concrete ways, and I see three approaches that achieve this:

1. the funded organisation clearly declares its mission and mode of operation, and communities choose to work with it on that basis;
2. the organisation remains flexible and adapts to what communities need;
3. or researchers and organisations pay experts by experience as consultants on the project.

As universities change shape — becoming more entrepreneurial, opening businesses and community interest companies, and partnering with an increasing range of organisations — it is ever more important that all parties share a common understanding of one another's contexts, agendas, and priorities. Perhaps community leaders will need training in these aspects so that they are to be empowered to collaborate in this way.

Positioning bio:

Dr Funmi Adewole Elliott is a performer, researcher and dramaturge. She has a background in academia, arts sector development and performance. She has a M.A in Postcolonial Studies, a PhD in Dance Studies and a Professional Certificate in Education. She is the founder of Enact Arts CIC, which supports initiatives that facilitate creative practice within and beyond professional contexts. She was a senior lecturer at De Montfort University and taught there for eight years before returning to independent practice in 2025. A pioneer in developing the professional context for Dance of the African Diaspora in the UK, Funmi has a longstanding track record as an advocate of dance as a profession. She has led professional development initiatives in several places in Africa, Europe and North America. She is an Honorary Fellow at Coventry University's Centre for Dance Research. Her contribution to the field was recognised with a One Dance UK Lifetime Achievement Award in 2019.

From Voice to Authority: Rethinking How Communities Benefit from the Knowledge They Create

by Dr Javeria Khadija Shah SFHEA

Reflections on Question 2: **What are the most effective ways to share and translate the outcomes of arts-based community research into practice? More specifically, how can we ensure that communities benefit from the knowledge created, that different forms of contribution and co-authorship are meaningfully recognised and honoured, and that questions of ownership, access and resources considered?**

When thinking about how arts-based community research can be shared and translated into practice, I want to resist the idea of translation as something that happens primarily at the end of a project. By the time research has produced an "outcome" to translate, many of the decisions that determine who will benefit from it have already been made. Who framed the question? Who decided what counted as knowledge? Who interpreted what was shared? Who controlled the resources? Who decided what could be published, exhibited or circulated? And, importantly, who acquired value from the process? For me, the most effective approaches to translation begin much earlier. They build access, recognition, ownership and benefit into the research relationship itself.

These questions have followed me throughout my own research practice. My earlier longitudinal research in British Further Education, eventually published as Imposed Identities and British Further Education, developed partly from a concern that people most directly affected by educational policy were often strikingly absent from the research and policy conversations taking place around them. I developed a person-centred approach that treated subjective experience and personal truths as central to understanding educational structures. The research drew on narrative and ethnographic approaches within a broader case study framework, while recognising that lived experience is neither uniform nor reproducible.

I also entered that research from a position of lived Further Education experience myself. This influenced the research design, but rather than assuming my experience could explain the experiences of others, I incorporated multiple perspectives and made a conscious decision to present individual voices without editing or reinterpretation wherever possible. At the time, I described part of the purpose as an attempt to "humanise the data" by bringing voice and agency to people affected by policy. Looking back, I can see an evolution in my own thinking because I would now challenge some of that language. People do not need researchers to give them a voice. They already have one. The more difficult question is whether our institutions and research cultures are prepared to recognise those voices as knowledge, and whether the people speaking retain meaningful authority over what happens after they have spoken.

This is where I find the language of "expert by experience" both useful and uncomfortable. I understand its intention. It challenges the positioning of people as passive research subjects and explicitly recognises knowledge developed through lived experience. The conversation starter also acknowledges that terminology is not neutral and that people may instead understand themselves as participants, collaborators, co-designers or co-authors. That openness is important.

I am nevertheless interested in who has the authority to confer the status of "expert" in the first place. Dignity is not something bestowed by institutional recognition. It precedes the research relationship. An institution can confer a title, payment, authorship, access or professional recognition, but recognising knowledge is not the same as creating its value.

For me, this distinction matters because otherwise we risk changing terminology without sufficiently changing relationships. "Participant" becomes "expert by experience", just as "consultation" can become "co-creation", while the distribution of power remains remarkably familiar. If the institution still sets the question, holds the funding, controls interpretation, owns the outputs and determines when and where they appear, then we need to ask how much has actually changed.

My relationship with lived experience as a methodology has also become increasingly personal. In my later work, I have used autoethnography to bring personal narrative into dialogue with wider cultural, political and historical structures. This deliberately complicates the distinction between researcher and "expert by experience". I can occupy both positions. My autoethnographic work on self-decolonisation, for example, begins with something apparently simple: my name. After more than twenty-five years of using the anglicised "Jo", I fully reclaimed Javeria Khadija Shah. That experience became connected to My Name Is™, a research project concerned with names, identity, belonging and cultural narratives.

Names provide an interesting illustration of what I mean by epistemic authority: the authority to determine what knowledge means and what happens to it. An institution may record a name, categorise it, shorten it, mispronounce it or analyse somebody's experience of it, but the person whose name it is possesses knowledge that cannot simply be replaced by external expertise. The researcher may bring methodological, theoretical or disciplinary knowledge. The individual or community brings knowledge formed through living. Neither needs to erase the other. The challenge is creating a research relationship in which different forms of knowledge can coexist without institutional status automatically determining which one is treated as authoritative.

This brings me back to translation into practice. I am not convinced that translation should mean taking knowledge from a community, processing it through academic or artistic structures and then finding an accessible way to return the finished product. Communities should not have to wait until the end of a research process to receive something that originated, at least partly, with them. The conversation between Kim and Rita identifies precisely this problem. Institutional research can position people as providers of testimony, experience or data, while researchers observe, document, evaluate, publish and leave. It can also leave communities waiting years for findings to be validated or made publicly available, sometimes behind paywalls, while opportunities to use that knowledge for funding, policy or local change are delayed.

I think one response is to stop treating community benefit primarily as a question of dissemination and begin treating it as part of research design. This means asking at the outset what value should remain with the people involved. That value might include payment, skills, relationships, creative outputs, resources, professional recognition, policy influence, usable evidence or increased capacity to advocate for change. There cannot be a universal formula because communities themselves should have some authority in determining what benefit means. An accessible report that nobody asked for is not necessarily more reciprocal than an inaccessible journal article.

This also changes how I think about sharing. Different forms of knowledge need different routes into practice. A film, performance, exhibition, workshop, community resource, policy briefing or open-access publication can each do different work and reach different audiences. The important question is not simply which format is most "accessible", but who needs the knowledge, where it needs to travel and what people need to be able to do with it once it reaches them. Those decisions should be made with communities rather than for them. Sometimes the most useful outcome may not be a public-facing product at all. It might be evidence that can be used locally, a resource the community retains, access to decision-makers, or greater capacity to continue the work after a funded project ends.

The same applies to authorship. I support meaningful recognition of intellectual contribution, including co-authorship where that reflects how knowledge has actually been created. However, co-authorship should not become another symbolic marker of equitable practice. A name on an output does not necessarily mean somebody shared authority over its creation. Conversely, not everyone contributing lived experience will want public authorship. For some, anonymity, collective attribution, acknowledgement, payment, ownership of creative work or control over future use may matter more. Recognition therefore needs to be negotiated rather than prescribed.

Ownership and consent are similarly ongoing rather than administrative questions. A signed consent form does not settle what happens to somebody's words, images, stories or creative contributions for the lifetime of a project and beyond. People need clarity about where their contributions may travel, who can access them, whether they may be reused and what happens after funding ends. Genuine agency becomes particularly visible at the point of refusal. Can somebody say that part of their story is no longer available for public use? Can they challenge a researcher's interpretation? Can collaborators decide that something created collectively is not ready to be shared? If they cannot, then we need to be careful about how confidently we describe the relationship as co-created.

There is also a material dimension that can become obscured by the language of participation. Knowledge creates value. Research can generate publications, exhibitions, films, reports, funding, professional reputations, institutional impact narratives and future opportunities. If lived experience contributes to creating that value, we should be transparent about where both resources and benefits travel. Payment matters, but payment alone does not resolve an extractive relationship if other participants in the research ecosystem continue accumulating longer-term professional or institutional capital from what somebody has shared.

For me, there is therefore an ethical responsibility attached to receiving somebody's lived experience that extends beyond securing consent. Researchers still need to ask what happens to that knowledge once it has been shared, who benefits from its circulation, what may be altered through interpretation, and what remains with the person or community when the formal research relationship ends. These are not simply questions for an ethics form at the beginning of a project. They follow the knowledge throughout their life.

Arts-based and community research holds enormous potential here because it can create forms of knowledge that move beyond the journal article and the researcher as sole interpreter. Story, image, film, performance, conversation and collective making can allow knowledge to be created, encountered and circulated differently. Yet creative methodology does not make a project equitable

by itself. Arts-based research can reproduce the same hierarchies as conventional research if we do not attend to who ultimately holds authority within it.

Perhaps, then, the shift I am arguing for is from voice to authority. Hearing lived experience matters. Recognising it as expertise matters. Co-authorship can matter enormously. But the deeper question is whether people have meaningful authority within the processes through which their experiences become knowledge.

If communities are genuinely to benefit from arts-based research, benefit needs to be designed into the relationship rather than distributed at its end. This requires us to understand authorship, ownership, access, resources, interpretation and the right to refuse as interconnected questions of power. It also asks researchers and institutions to accept that expertise does not only reside within institutions, and that recognition is not the same as conferral. The knowledge was already there. Our responsibility is to create research relationships through which it can be recognised, developed, shared and acted upon without taking authority away from the people whose lives helped to produce it.

Positioning bio

Dr Javeria Khadija Shah SFHEA is an interdisciplinary researcher, educator and practitioner working across education, cultural sociology, identity, decolonial practice and social justice. Her work has long centred lived experience and the relationship between institutional power, representation and identity. She is the author of Imposed Identities and British Further Education, developed from longitudinal, person-centred research exploring the experiences and trajectories of young people classified as "low ability", and leads My Name Is™, a research project exploring names, identity, belonging and representation. Her more recent scholarship uses autoethnography to connect personal experience with wider structures of power, including her own journey of self-decolonisation and reclamation of her name.

Javeria approaches this conversation from the overlapping positions of researcher, practitioner and person with lived experience. As a British-born Panjabi Pakistani woman whose work has moved across Further and Higher Education, community practice and cultural research, she is particularly interested in who is recognised as a legitimate producer of knowledge, who retains authority over lived experience once it enters research, and how research relationships can move beyond participation towards meaningful agency, ownership and benefit.

Creating Spaces for Encounters at the Edges of Academia

by Dr Elena Boukouvala

Reflections on Question 3: **How do the wider ecosystems around art-and-research projects shape the conditions for safe, equitable, and sustainable collaborations? We mean here the ever-changing roles and relationships between artists, creative practitioners, facilitators, researchers, communities, experts by experience, higher education, governmental and other institutions, charities, not-for-profit organisations, funders and other partners involved in these practices.**

My experience with art-and-research projects stems from two different contexts. The first is within academia, relating to qualitative participatory research processes I undertook during my undergraduate, master's, PhD and Postdoc studies within a variety of disciplines: psychology, dramatherapy, sociology and human geography. The second is the initiation of an international grassroots conference called Play Perform Learn Grow. Founded in 2017 in collaboration with universities and grassroots organisations, the conference brings together academics, therapists, people with lived experiences, educators and others who use creative methods in their work for social change. These diverse contexts have informed different starting points and perspectives regarding how wider ecosystems work and shape the conditions for collaborations among different partners.

As a researcher, I had the opportunity to collaborate with diverse communities, exploring together experiences of borders and belonging as well as their grassroots creative initiatives and rights-based claims. These communities included people with learning disabilities and mental health issues and individuals with histories of forced displacement. My most recent piece of research lasted for 4 years, looking at how young people in Lesvos, Greece -refugees, asylum seekers and locals- negotiated borders, belonging and citizenship processes through creative and digital methods. It investigated caring practices and creative initiatives that emerged in the Moria refugee camp creating processes of collective dissemination where the artists gave artistic form to the findings of the research through music, photography and performance whilst amplifying their own projects. The artists who participated in the PhD research became collaborators for the postdoctoral project which focused on how artists represent their own experiences of migration through their creative initiatives and impact public affects and politics. Having shared about the context of the research projects, I will continue with my thoughts and experiences regarding how ecosystems work shaping the conditions for collaborations.

Both projects were funded. The funding was tied to a specific timeline and a budget that had been alongside the project, there was also some flexibility in terms of times and the allocation of resources. This flexibility was paramount in allowing the projects to be co-designed with the participants and to respond more organically to the conditions of the sociopolitical context and the needs of the communities involved. For instance, one of the deliverables of the postdoctoral project was to create a performance with the collaborating artists in Lesvos and invite the current Moria camp residents as audience and guest artists. It was a powerful event that resulted in new

collaborations and friendships across the communities, though it was organizationally demanding. The allocated funds had to be revised, as new demands arose- such as the provision of food which became a crucial aspect of the event because many of the participants were fasting due to Ramadan. Furthermore, the artists needed additional funds to travel and to transfer their instruments, and the performances incurred extra production costs. The budget's flexibility allowed for some of those expenses to be compensated and enabled the process to be created more organically among the collaborators. A part of the funds had also to be fundraised, formal processes of funding were combined with grassroots community organising processes.

Another important aspect was the timeline and the versatility of the research design. My PhD project started at a very critical time in 2021, just after the COVID measures in Greece began to lift. The initial projection for the fieldwork was 6 months but it ultimately lasted 2 years. Many unforeseen issues arose: due to COVID measures it became impossible for research participants to meet in person and the research had to move online; the divisive climate and racist attacks in Lesvos required additional risk assessment regarding participant recruitment and the volatility of people coming and going made paramount the work with structured independent creative sessions. The unravelling of the research parallel to the onward migration of research participants changed its content and process. Consequently, the focus of my PhD shifted to tracing the onward migration journeys of people- a departure from the original research, but one that was more responsive both to the sociopolitical context and the needs of the participants. At the same time, as we began building closer relationships with the participants, I started noticing the gaps and the dissonances among the academic research terms and the participants' own imaginaries. For instance, none of the research participants used the term citizenship during their interviews. For many of the young people I worked with this was a term that was used in asylum offices – one they felt alienated from. The research started adopting the ways young people chose to speak about their experiences, looking at not only what they said but how they chose to say it. Accordingly, the ethics of the research shifted: while anonymity and confidentiality were important, the artists needed for their work to be recognised as their own. Together, we had to forge new processes that would meet the demands of the university space while honouring their own ethics and needs.

Creativity and dedicated spaces for dialogue were crucial to developing these new approaches. We decided to create a performance where participants could interpret each other's experiences, thereby protecting anonymity while honouring their ownership of their work.

Another complexity of this project was my dual role as both the artist/ facilitator of the creative workshops and the researcher. This positionality brought specific insights regarding the complexity of the fieldwork that I could later bring analytically into the research. At the same time, it generated tensions, grey areas and dilemmas. The presence of supervision, training and a peer community provided a vital, supportive foundation to return to throughout the project as it developed. Processes of reflexivity- the opportunity to talk without fear of judgement while maintaining rigorous and ethical research practices were equally vital.

To sum up my work within academia, the elements that appeared most important for fostering collaborations among different actors and deepening the participatory aspects of the research were:

1. methodological diversity and flexibility,
2. versatility in research design,

3. clear budgets and timelines with the opportunity to revisit them and a strong support network with supervisors and peers.

As the founder of PPLG, I operated from a different positionality- that of a practitioner, activist, and artist. PPLG emerged after working in refugee camps for three years and as a response to suicide attempts of young people in the camps. It was co-created along young people who lived in the camps at the time with the intention to ask our international community to support refugee communities in Greece. The focus of the conference developed into building a new ecosystem bringing together people that would not have met otherwise, coming from different backgrounds, positionalities and statuses, disrupting linearities and hierarchies. In the process of the following years the conference happened three times, bringing together 800 people from 40 countries. The participants presented their work and interacted with each other in workshops often without knowing about the other's professional, national and legal backgrounds. The focus remained entirely on lived experiences and connecting through the arts. This foundation became highly fertile for fostering new collaborations. Numerous exchanges took place among academics, therapists, activists, educators and diverse communities, new projects were launched and others secured funding through the horizontal sharing of information and resources. In this context, the timelines, the design and the meeting spaces could be designed and transformed by us, the organizing team which also involved representatives from many international universities this time from a very different positionality, that of the collaborator that supports a grassroots initiative. The primary challenge laid in making the conference sustainable- creating independent resources so it would not rely on external funding. It also required an immense amount of volunteer work, organisation and versatility to transverse and bridge different languages within the organizing team and the participants. In this case, the diversity of actors was already present in the organizers and the participation of the conference reflected it. The arts, rituals, cultural practices served as anchors and meeting points for people with highly diverse backgrounds, agendas and needs.

In closing, I would like to bring the focus back to versatility, the opportunity to transverse languages and the value of creating spaces for exchange among people who might have otherwise never crossed paths. I believe these are also some of the critical factors for ecosystems to create safe, equitable and sustainable collaborations.

Positioning bio

Dr Elena Boukouvala is a Developmental Psychologist, Dramatherapist (MA), Counsellor of Young People (MA), performance activist and artist. Since 2004, she has been working as a therapist and consultant in schools, mental health hospitals, addiction centres, elderly homes, refugee camps and community settings in Greece, the UK, Serbia, Romania, Moldova, Germany, Hungary, Lebanon, Algeria and the USA. Since 2016, she has been co-creating artistic exhibitions and performance events in refugee camps and public spaces. She is the founder and director of the Play Perform Learn Grow (PPLG) conference. Her PhD and Postdoc research focused on lived experiences of migration journeys and the creation of new communities through art. She has taught participatory methods at various universities, including Canterbury, Goethe, Harvard, Aristotle and the Open University. She is a graduate of the International Class of the East Side Institute and its Social Therapy Training and Dramatherapy faculty. She is currently based in Athens.

Further reading

The publications gathered here offer different perspectives on lived experience, co-creation, authorship, artistic research, and care. Some explore the ways knowledge is shaped and shared; others consider the relationships, responsibilities, and forms of collaboration involved in working across different practices and communities. It is intended to be a starting point for further reading and reflection.

Angelotti, M., Lucchetti, M. and Wielander, J. (eds.) (2024). *Visible: Art as Policies for Care. Socially Engaged Art (2010–Ongoing)*. Rome: NERO Editions. 334 pp. ISBN 978-88-8056-281-8.

Banks, S., Hart, A., Pahl, K. and Ward, P. (eds.) (2019). Co-producing Research: A Community Development Approach. Bristol: Policy Press.

Chapter: Bell, D., Pool, S., Streets, K., Walton, N. and Pahl, K. (2019). 'How does arts practice inform a community development approach to the co-production of research?', pp. 95–114. https://doi.org/10.2307/j.ctv80cccs.11

Cologni, E. (2024). 'Percipience, Embodiment, Contamination(s). The Artist as Wound. Practicing a Feminist Care Aesthetics'. *International Journal of Education & the Arts*, 25, Special Issue 1.25. https://doi.org/10.26209/ijea25si1.25

Davies, S. R. and Avkıran, A. (2025). 'Expertise in/of co-Creation: The Care Work of Citizen Participation'. *Bulletin of Science, Technology & Society*, 45(1–2), pp. 3–13. https://doi.org/10.1177/02704676251353100

Dembele, L., Nathan, S., Carter, A. et al. (2024). 'Researching With Lived Experience: A Shared Critical Reflection Between Co-Researchers'. *International Journal of Qualitative Methods*, 23. https://doi.org/10.1177/16094069241257945

Higgins, M. and Lenette, C. (eds.) (2024). *Disrupting the Academy with Lived Experience-Led Knowledge*. Bristol: Bristol University Press.

Chapters: Higgins, M. and Lenette, C. (2024). 'Unpacking disruptive methodologies: What do we know about lived experience-led knowledge and scholarship?', pp. 1–18. https://doi.org/10.46692/9781447366362.003

Lenette, C. and Higgins, M. (2024). 'The potential of lived experience-led knowledge to dismantle the academy', pp. 152–162. https://doi.org/10.46692/9781447366362.011

The Care Collective (2026). *The Care Manifesto: The Politics of Interdependence*. London: Verso. 128 pp. Paperback edition, ISBN 978-1-83674-356-9. Originally published in 2020.

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