"With Care and Curiosity: A WHO Resource on Arts Practice and the Ethics of Care Jameel Arts & Health Lab and the World Health Organization

Summary of UK Community Consultations

Convenor: Dr Julia Puebla Fortier, Arts & Health South West Hosted by The National Centre for Creative Health

"Arts Practice and the Ethics of Care," is a Jameel Arts & Health Lab project commissioned by the World Health Organization Arts & Health initiative to 1) identify ethical considerations adopted by arts practitioners when engaging in projects where care is a central concern and 2) to identify considerations for caring for arts practitioners when engaging in contexts of care. The final product will be a resource document, website, and social media platforms that aim to share these considerations with communities of arts practitioners worldwide. Public consultations convened by the co-authors from the seven WHO global regions are an essential element of the resource.

UK Consultation

There were two 2-hour online consultations (23 and 29 June 2023) that were advertised via newsletters and social media by host organisation *The National Centre for Creative Health* (UK) and partner organisations *Arts & Health South West, The Culture, Health and Wellbeing Alliance, and London Arts and Health Forum.* The meetings each had 20-25 consultation participants (CP) and were led by project co-author Dr Fortier. For further inquiries, please contact her at jpueblafortier@gmail.com.

Questions asked in the consultations

The following recommended questions were posed to the consultation participants (CP):

1. What constitutes 'care' as part of your work? (CP engaged in small group conversations (4 participants) and recorded highlights on a Jamboard.

2. What care do you need to sustain you in your work? (Small group discussions and Jamboard)

3. What ethical considerations do you keep in mind when working with people and in places where care is needed? (CP engaged in a full group discussion on this question, also recording key points on the Jamboard)

4. *Tell us a story about a project you were involved in where care was needed or where you, as an arts practitioner, needed care.* (This was also a full group discussion but generally short as it was at the end of the consultation. Fewer points recorded on the Jamboard)

Summary of key themes

The comments below are summarised from the two consultations. Given the number of CP (20-25 for each consultation), there was a heavy reliance on the Jamboard to record key points. This has resulted in a more brainstorming and breadth approach to answering the questions that has been organized below according to key themes. Quotations from the group discussion recording and transcripts that address the nuances of key points are added where appropriate.

Q1: What is care in your work?

CP approached this question from many different perspectives, including the care they deliver to their participants/service users as well as what care means for them as practitioners. These latter points are addressed in the responses to Q2.

With respect to *how they define care as they deliver it*, words and phrases used included:

- Compassion
- Consideration
- Relationships
- Looking after people
- Trust building
- Nurturing emotional wellbeing
- Facilitating social engagement
- Creative activity itself as care
- Being human
- Empathy
- Seeing and being seen
- Authenticity
- Genuine interest
- Presence and being in the moment
- Affirmative body language and non-verbal communication
- Love
- Using high quality materials
- Using a coaching/positive psych approach
- Making tea, having a tea break, space for informal chat, and physical comfort
- Flexibility, gentleness, transparency, empowering, embedded, coproduced research

One dance practitioner describe care as presence:

From the dance side, another word and theme that's coming up for me is about presence. And being really in the moment and present with someone to really see them and show that you see them potentially through body language or through affirming what you see or how you witnessed them and how you experience them through your verbal language. And there's lots in terms of nonverbal communication, I think that you can show that you care.

Another practitioner described the importance of small moments and attention in the context of larger constraints:

It was attention to detail, isn't it? It was the small things. Yes, of course, there's sort of wider ranging issues around organisations and process. But it was very much about the intuitive awareness and intentionality of moments between the artist and the creative practitioner and the person in front of them. And that, I guess, will be the whole sort of challenges because organisations that work in that sort of way with creative health, so much of is person-centred. And how does one balance out the time and intentionality that's required for being person-centred in terms of care with the other side of things, which is the limitations of resource and organisational culture and process etc. and cultural context of course. But there's something very beautiful about humanity that comes across, and the genuine care, whatever that means, and the word 'love' was actually used. And I think that's not too far of a stretch, because I think there is something about loving there, whatever that means, and how do we define love? But it feels very important.

CP also identified *constraints to delivering care* as they would like to do it. These include:

- Needing to sacrifice compassion to fit boundaries, schedules, limited time
- Being human in professional/medical contexts
- Concern that institutions cannot always be trusted to care
- Working in challenging settings and/or with complex needs

There were many concerns raised about managing the emotional content of the work, including managing professional boundaries (e.g. artist/art therapist), recognition of transference in sessions, managing group dynamics, not being triggered by the work, and experiencing burnout.

One CP relayed a conversation her small group had about boundaries in the context of care:

I think boundaries came up as a big main overall theme, either setting boundaries for yourself and ensuring that you are able to care and, you know, making sure you're well and healed before you offer the care. And then also working in collaboration with other people so that you offer the best form of care. Because sometimes working with people who are vulnerable might, you know, might be you might need to approach it from a multifaceted angle, rather than just take everything on yourself. And going one step further, if you're moving into the health realm, then you perhaps might need some supervision. So from a qualified professional or therapist. Issues around boundaries and supervision arise again below.

Q2: What care do you need to sustain you in your work?

This question was addressed in great detail by the participants, and key points are organized in categories below. First, one CP identified care for herself in a way that captures many of the themes expressed:

It's really important for me to feel validated as well as validating others. So much of the energy exchange is sort of outward and offering support to other people. So thinking about how we, where we get our water from, if you will. And making time for that is another thing that I find really difficult, but it's very important. So having time and making that something quite, quite a practice of itself, making time. And also building in that time for reflection with the right people. So I might have some training, and find that I don't feel that that was actually relevant to me. So picking the right things to sort of support yourself, as well within your practice. Nutrition, physical stuff, very important to me as well. And I often forget to look after those sides of things. And just picking up also on those networks of practice it, I find it really helpful to step outside of, I mean, I'm a musician, but I find it really, really important to listen to people working in lots of different areas.

Having access to practitioner support

- Debriefing after sessions, with colleagues or managers
- Reflective practice with colleagues
- Peer support and a network
- Mentoring
- Supervision that celebrates as well as examines
- Training to manage the emotional landscape of the work
- Clear definition of roles and boundaries, especially regarding boundaries with arts therapies
- An overseeing body for arts practitioners
- Robust national cultural policy

While lengthy, the following quote describes an approach taken by one organization that has made practitioner support and care a key part of their operational approach, fundraising, and governance:

We have an emerging framework of training and support, which has been developed, not only since Blue Cabin came to be, but I think it's from decades of learning the individuals of bringing to the space that we're in.[...] It's a framework of training, support, supervision, reflection, check ins, check outs, cups of tea, self-care sessions, and to name but a few, whilst also knowing that for some people, there will be a route that we haven't found, too, ensuring they're practising safely that we can always we can always do more. I think key to that is also working at a governance level. So I do work with the trustees [...] so that they understand why I will need to budget X number of pounds per year as core. We treat it as core now, that's a core cost that we need to fundraise for every year to make sure that that framework of support is embedded. And it's not just ad hoc and add on. So for example, I'm more than happy to share for 12 artists and team members to have embedded supervision, self-care. And for us to have a budget for therapy for us to have a return therapist on retainer for reactive support. For the team to be able to come together really, really frequently you're looking at up to kind of 20,000 pounds, and we are a tiny team. We are a small team of people. [...] For the work we do with care experience, people in the emotional labour of the work, we have to safeguard our team and therefore it's all sort of do with governance awareness. It's really important that they know that that is about us practising safely but that does come with a budget heading and a budget line that we build into our budgets now. So you need to have that understanding at that governance level as a charity that that's not going to be challenged in a way that stops that safe practice.

Several CP spoke about the importance of having practitioner support built into funding bids and programme budgets.

When we put in funding applications, for example, we always put in an element of support for freelance practitioners as part of that, and we make that clear that that's, that's what our practice is based on. And actually, we've had a reasonable amount of good support around that. But I think I'm thinking about the Arts Council, for example, I don't think they're at yet at a stage where they automatically build that in to funding applications. So actually, I've asked them to think about doing that.

Attending to Self-care

- Having time for self-care
- Creating a balance of face-to-face encounters, admin, and discovery time
- Time and energy to engage in a personal creative practice, taking part in supportive creative wellbeing activities
- Taking breaks during the year
- Support for practitioner physical and mental health needs, including accessible environments
- Watching out for burnout
- Keeping up on current practices, CPD as good for practitioner mental health
- Keeping perspective about the scale and realistic impact of the work

One organizational leader spoke of the importance of creating an awareness and practice of attending to both the internal and external aspects of the work:

You know, like, like doing something useful for the environment, like planting or seeding, or rewilding or picking up litter, you know, like, we are, we are nature and,

you know, we influence the environment, the environment influences us. So, for me, there's a kind of, not only a self-care, but a self-collective care in this balance thing of relationships, psychologically. So, you know, I like that term "ecological health", not only the medical treatment notion, but looking relationally micro-macro.

Conditions for financial wholeness:

- Appropriate pay for skills
- Pay for travel and material costs
- Pay for planning and design
- Pay for self-care time
- Funding for training
- Attention to the needs and concerns of freelancers (support, precarity, unpaid time, need for organizational support)
- "Trust-enabled" funding (e.g., less red tape in applications, fewer demands for evidence)

Several CPs highlighted their frustrations with the lack of recognition of their skills and value when working with partner institutions. One said:

And even with very forward-thinking and, you know, progressive clinicians and NHS partners, there is still regularly an assumption that artists will work without pay, or that they can be underpaid, or we have to stop apologising for being professionals in this field and be very consistent and make sure that our early career colleagues are supported to make sure that they know how to ensure that they are paid for their work. Know that the NHS won't send staff to work for free all they often ask them to do unpaid overtime. But that's a different matter, I think I mean, the basic right of subsistence is essential for wellbeing. I mean, it's, you know, it's a bit of an obvious point. But it it's amazing how often it's glossed over.

The role of preparation and administration in practitioner wellbeing

- Time and space to prepare, innovate
- Recognition of time needed for collaborative processes
- Flexibility of work schedules and conditions
- Getting help with admin and finances

Q3: What ethical considerations do you keep in mind when working with people and in places where care is needed?

Many of the responses given by the CP to this question focused what they considered the elements of safe practice. These include:

- Prioritising safety, being in a safe environment, and engaging in risk management
- Ensuring informed and understood consent

- Ensuring the confidentiality of personal material shared in workshops
- Clearly explaining to participants the activities and the limits of the practitioner's responsibility
- Referring participants to appropriate professionals and services when needs arise
- Not overstepping professional boundaries
- Adequate staffing, including working with co-facilitators and participant support staff (never working alone, according to two respondents)
- Undertaking safeguarding* training and following appropriate procedures
- Using trauma-informed approaches and policies
- Feeling secure to discuss difficult situations with managers or funders without fear
- Stepping away from toxic, unsupported environments
- Not experimenting on or putting people at risk (as in pilot programmes)
- Developing sustainable projects and having appropriate exit strategies so people are not abandoned

* In the UK, safeguarding is defined by the Care Quality Commission as 'protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect.'

One CP related ethics to the broader notion of clearly communicated and agreed to intentions related to workshops:

I think you always have to start with why are we doing this? The question "why?" always helps me define the ethics of a session, you know, why are we doing it? Are we doing it to have fun for an hour? Are we doing it to forget? Are we doing it to discuss or bring up, raise issues? Or are we doing it to understand better? Or are we making a piece of art here? You know, so what is the informed consent for people sharing stories? So I always I just think, I actively do that, even with small groups. And obviously, sometimes when you're doing research things for a university, again, the whys very clear. But actually reminding yourself of that, why am I, why are we doing this? Who's it for? Have you properly listened to whether those people actually want it as well? What the need is, I think, really helps underlying, forming ethical considerations for the work you're doing and, you know, containing what the care needs to be.

Several people mentioned having appropriate training as essential to care for both participants and practitioners, and that there is a relationship between appropriate training and safe, ethical practice. One CP said:

As a creative producer, I actually find it really difficult now, both with health projects and non-health projects, whether it be schools or communities, to ensure that the arts practitioners that I'm commissioning to work on those projects, should have that embedded ethics of care within their practice, or, and if they've had any training around it, because there isn't the training that used to be unless you go and do a post-grad in art therapy, for example, there doesn't seem to be any middle ground.

And so what do we do with that, within our profession, when we are commissioning? Because there's lots of funding around social prescription projects. And Arts and

Health seems to have exploded in the past couple of years, with everybody having that as their main focus. So how can we ensure that the practitioners we're working with are suitably aware of and trained to deliver ethically and mindfully and considerately?

Additional issues

The intricacies of developing a trustworthy collaboration

Collaboration was addressed by the CP in terms of working with partner or commissioning organisations rather than community collaboration. CP spoke of the need to have conversations at the outset with partners, funders, and practitioners — all who are involved in a project — about values, ethical approaches, and desired outcomes.

One CP talked about taking a collaborative approach to safeguarding when small arts organisations may not have robust policies but can co-design strategies with the larger counterparts:

Particularly you're working with smaller organisations, you don't have a big structure around you. And those, I found very useful bits of conversations to have with partners to see their safeguarding from their perspective and or add, not being afraid to add emotional safeguarding to the practical safeguarding, and in a way you have it all in one document. And that's quite a simple structural thing that you can bring when you don't want massive, complicated stuff. But you can check in with yourself and check in with your partners and therefore use the similar methods. I don't know if that's useful, but I think it's for smaller activities, I found that really helpful. Yeah, and they know their clients best. And even if you're working in slightly independently or in active partnership, can be really helpful.

Another CP addressed the conflicts that can arise when partners have organizational imperatives that might conflict with what is perceived to be of benefit by artist practitioners or community participants. They described a partnership with an academic institution that wanted to take a randomised controlled trial approach to delivering a programme. The exclusion that resulted from this seriously damaged relationships with local community partners.

Being clear about boundaries and realistic expectations from each partner was seen by one CP as essential but often difficult for creative health practitioners to navigate:

I think the concept of 'no' is really important in creative health. And in fact, in the cultural sector, when you're working within this area, and the ability and confidence and capacity that is actually required in order to be able to say no, particularly when you have different cultures coming together, whether it's academics, or whether it's a

an arts organisation that's talking to a health organisation that, you know, to be fair, has some sense of entitlement attached to it, possibly more so than the arts

organisation itself. So the power dynamics that are assumed when you're trying to work cross-sectorally, are huge. So being able to really have confidence in your own ability to say no, and what is right for you as an organisation to where to work is really important in terms of care. And I think that really, that kind of boundarysetting and competence has to be at the centre of any sort of notion and definition of care.

Another CP elaborated on the need for articulating clear boundaries and responsibilities with both partners and participants when taking on new work:

[...] when you've been expected to be counsellor, educator, social worker, tutor, in loco parentis, all of that, to bring that now into the new spaces that I'm holding makes me really look at the clear boundaries of who's responsible, what I'm responsible for, and the levels of self-responsibility of the participants that I'm working with. And making that expectation really clear.

CPs also addressed collaboration from the perspective of participating in nurturing peer support networks.

I'm a consultant in arts, heritage, health, wellbeing. And I think from my perspective, it's about being part of a network or network on lots of networks that interrelate and kind of attending things like this, actually, these sorts of webinars to kind of keep on being aware of current strategies, policies, movements, etc, like that. So for me, it's kind of really connecting with colleagues, part of alliances, and looking at possibilities that provides a sense of forward thinking, and, and, you know, opportunities, etc, like that. So for me that I think that was my immediate thought is feeling like I'm part of, of a movement or, you know, lots of different initiatives and networks of people with common, you know, experiences or on or things to learn from, etc.

Another said that more opportunities for peer support and conversation would be highly beneficial:

It's incredible how this technology enables you to speak to people all over the world, all over the UK, about complex things in 12 minutes or 15 minutes. And I think that the feeling is that there needs to be more, more of these opportunities to speak to one another, learn from each other. How do we do that? I'm already thinking that so many other people from my workplace would have benefited so much from just connecting in and hearing the voices of this community of through this consultation. And so yes, more, please.

Understanding the social and political needs of the participants and how they are prioritized

As it appeared that most CP came from an arts and health background rather than community participatory arts, this issue was not addressed in as much detail. Considerations raised included:

- Attention to memory, histories, environment, and place
- Being inclusive, ensuring access and eligibility
- Use position and power to advocate for others
- Consideration of and respect for different perspectives
- Consideration for language differences
- Taking a proactive approach to cultural competence, anti-racism
- Aiming for equity, justice, tolerance, integrity, and mutual benefit in delivery

Caring for those who are most vulnerable and invisibilized

Many CP spoke of the need for adequate knowledge and training about the needs of and attention to safety and risk management for participants who may have complex health or social needs, with specific references to dementia, neurodiversity, physical disabilities, and those with mental health concerns. Many discussed specialised training and delivery approaches they take according to the conditions of participants. A person or patient-centred approach was mentioned several times, and a few CP discussed the delicate balancing act of promoting participant autonomy in the context of support needs, especially in the presence of participant carers (family or professional). One CP proposed health outcomes as a marker of quality of delivery.

One CP spoke of the need for accommodations for practitioners with accessibility needs:

Well, I'm disabled. So there's institutional structures that prevent me from getting the care that I need to carry out my role effectively, in terms of people's attitudes toward employing disabled people. I've had an unsuccessful interviews for, well, last week, in which I asked about reasonable adjustments. They said, 'We will only provide them if we have to.' So there's, you know, attitudinal barriers. So hearing loops are luxuries. [...] And even that is a bit of a kerfuffle because they're like, Well, where do we get it from, you know, it's attitudinal and it's resource issue. But primarily for as a disabled person, I just find it to lack of awareness, and a lack of desire to, to be more inclusive.

What considerations were named (or would you name after your conversation) as being important for artists to keep in mind when working with communities?

While artists in the UK often work with and in communities, in these consultations they tended to focus their responses more on care in relationship to their interactions with individual participants. This is typical of the discourse around care in the context of arts and health. Issues related to community engagement would more likely come up in the context

of participatory arts or community arts and those who identify as working more in that context.

Resources recommended in the consultations:

Community-based Participatory Research: Ethical Challenges <u>https://www.dur.ac.uk/resources/beacon/CCDiscussionPapertemplateCBPRBanksetal7Nov2</u> 011.pdf

Community-based participatory research: A guide to ethical principles and practice<u>https://www.publicengagement.ac.uk/sites/default/files/publication/cbpr_ethics_g</u>uide_web_november_2012.pdf

Sarah Banks, Everyday Ethics in Professional Life: Social Work as Ethics Work. <u>https://www.tandfonline.com/doi/full/10.1080/17496535.2015.1126623</u>

Stitching Together Good Practice Guidelines <u>https://stitchingtogether.net/good-practice-guidelines/</u>

Learning Framework for Artist Pedagogues <u>https://sppa-uk.org/wp-</u> content/uploads/2017/09/Learning-Framework-for-Artist-Pedagogues.pdf

Newcastle CBT Supervision model

https://eprints.ncl.ac.uk/file_store/production/163097/2D19347D-6093-415E-8582-C1A629FB98B5.pdf

Oliver McGowan Mandatory Training on Learning Disability and Autism <u>https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism</u>