Navigating Ambiguity and Boundaries:

The experiences of arts, health and wellbeing facilitators working with individuals with challenging conditions or situations

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Declaration of work

I, Julia Puebla Fortier, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed,

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1 November 2023

Abstract

Creative engagement offers many possibilities to support people living with health, psychological, and social challenges. For the artists who facilitate these arts, health and wellbeing (AWH) programmes, the work can be inspiring and rewarding. But it can also be emotionally demanding and challenge the boundaries of creative expression, caring, and their own capacities.

This thesis examines how AHW facilitators manage the potential benefits and challenges of working with individuals living with challenging conditions or situations. Based on participatory qualitative research conducted in England through an online discussion group, focus groups, in-depth interviews, and research partner collaboration in 2020-21, it draws on the stories and reflections of 43 facilitators working across art forms and with participants with a wide range of conditions, ranging from chronic illnesses and disabilities to dementia and terminal diagnoses. The study was guided by theories of emotional labour, role ambiguity, and boundary spanning.

The study found that facilitators vary in their approaches and capacity to manage the benefits and challenges of working with people living with challenging conditions or situations. Facilitators juggle tasks and responsibilities that integrate knowledge and skills from across multiple disciplines. They are dedicated and conscientious, describing a high level of responsibility in their work and concern for their participants' welfare and outcomes. However, the demanding nature of the work and the physical and interdisciplinary context in which they perform it can be taxing and sometimes risky. Practitioners speak frequently of the emotional aspects of what they do and the challenges that arise related to managing medical and psychological crises, behavioural issues, and disclosures of abuse and trauma.

AHW practice is inherently a boundary-crossing activity that is generative and rewarding. Working with individuals living with challenging health and social conditions adds complexity as facilitators adapt creative activities and respond to manifestations of those conditions. Ambiguity and uncertainty about their role, responsibilities, and practice choices often arise when crossing these disciplinary boundaries to meet complex needs. The emotional work they engage in is multidimensional and intersects with both the positive and challenging aspects of their work.

The thesis concludes with practice, policy, and research recommendations, including those related to managing ambiguity and boundaries, supporting emotion work, promoting professional development, and strengthening support and working conditions.

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Dedication

I dedicate this work to my parents, MariAna and Edward Fortier, who have been my inspiration for all things creative and intellectual. Throughout their lives they modelled hard work, compassion, and a commitment to service and social justice. I know you would have loved to have seen this day!

Practical wisdom and judgment, rather than seen as “things” hidden inside the mind, are best talked of as emerging developmentally within an unceasing flow of activities in which practitioners are immersed. When practitioners (namely, individuals immersed in a practice, experiencing their tasks through the emotions, standards of excellence, and moral values the practice engenders) face a bewildering situation in which they do not know how to proceed, the judgment they exercise emerges out of seeking to establish a new orientation to their puzzling surroundings. They do so through actively trying to be in touch with their felt emotions and moral sensibilities, while attempting to articulate linguistically the feelings experienced, in order to get a clearer view of relevant aspects of the situation at hand. Coming to a judgment involves moving around within a landscape of possibilities, and in so doing, being spontaneously responsive to the consequences of each move.

John Shotter and Haridimos Tsoukas
‘Performing Phronesis: On the Way to Engaged Judgment’ (1)

You find your own way, don't you? I mean, as soon as you feel a need to do it, you will, you will find what you need, I think, and that's why it's a difficult thing to, to say, isn't it? The training is, there are bits and pieces in the training, but then it has to be you. It's got to be your passionate feeling that takes you through it, I think.

Helene (F3-V-46)
Arts, health and wellbeing facilitator

Acronyms and abbreviations

ACE	Arts Council England
AHSW	Arts & Health South West
AHW	Arts, health and wellbeing
APPG	All-Party Parliamentary Group
CCS	Challenging (health, mental health or social) conditions or situations
CHWA	Culture, Health and Wellbeing Alliance
GP	General practitioner
ICS	Integrated Care System (in the NHS)
LSHTM	London School of Hygiene and Tropical Medicine
NCCH	National Centre for Creative Health
NHS	National Health Service
ODG	Online discussion group
OPA	Organisational Policy Analysis (research project for the DrPH degree)
UK	United Kingdom
US	United States of America
VCSE	Voluntary, Community and Social Enterprise

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Chapter 1. Introduction and Background

1.1 Introduction

Engaging in creative arts activities promotes a variety of positive health and wellbeing impacts and has generated interest from many countries and international organisations to support national and global health agendas. (2–8) These beneficial activities are increasingly recognized and being incorporated into national health and social care initiatives in the United Kingdom (UK). (9–12)

Research on arts, health and wellbeing (AHW) has increased significantly in recent years, looking at a wide variety of conditions, interventions, study designs, and measured outcomes. Evidence reviews show promising trends with respect to the impact of AHW interventions on health outcomes, but also reveal research challenges related to consistent definitions, intervention descriptions, and methodologies. (2,13–18) Many well-designed studies show benefits in specific circumstances such as the use of art therapy with children in hospital settings, (19) music with dementia patients, (20) and dance for Parkinson’s patients. (21) A recent scoping review of arts for wellbeing in the United States (US) found positive associations between arts engagement and wellbeing among mostly descriptive studies, with benefits related to self-esteem and identity formation, cognition, physical balance, and physical conditioning. (22) With respect to mental health, recent investigations and evidence reviews point to positive impacts on physiological, psychological, wellbeing, and social measures. (2,14,23–25) During the COVID-19 pandemic, personal creative activity was widely recognized and promoted as a way to support mental health during lockdowns when access to other social activities was restricted. (26–29) Davies and Clift have recently proposed a glossary of terms and concepts to support the development of and communication about research, policy and practice about arts and health. (30)

For the most part, research and evaluations on AHW programmes focus on the experiences of and outcomes for participants. Less is known about the practices and experiences of AHW facilitators who deliver the programmes. Concerns have been raised about the capacity of artists who are not arts therapists to manage vulnerable participants who may have complex needs that challenge these practitioners’ skills, experience, and available support. (25,31–34) Also implicated is the emotional impact on practitioners of working with participants who experience challenging physical, mental health, or social conditions. (35,36) These concerns arise in the context of historically ambiguous and contested notions of what constitutes AHW practice, including role definition, skills, training, and the kinds of relationships these practitioners have with other health and social care practitioners and organisational structures. (37–39)

This thesis examines how arts, health and wellbeing facilitators manage the potential benefits and challenges of working with individuals living with challenging health, mental health, and social conditions or situations (CCS). Using participatory qualitative research methods conducted in England in 2020 and 2021, it draws on the stories and reflections of 43 arts, health and wellbeing facilitators working across art forms and with a wide range of conditions, ranging from chronic illnesses and disabilities to dementia and terminal diagnoses. The study was guided by theories of emotional labour, role ambiguity, and boundary spanning.

I became interested in this topic while completing the Organizational and Policy Analysis project (OPA), which is the first part of the Doctor of Public Health programme at the London School of Hygiene and Tropical Medicine. (31) Working collaboratively with Arts & Health South West in 2018-19, I developed a participatory action research project on cross-sectoral collaboration for arts and health in South West England. My interviews and discussions with AHW facilitators and other stakeholders during this OPA project raised questions about the skill level and organisational capacity of artists to engage in health-oriented projects. Some facilitators spoke about the impact of increasing levels of participant needs and related demands on them, especially in the context of austerity cutbacks to government services and an increasing number of social prescribing referrals. I decided to use the thesis to explore the perspectives of AHW facilitators on working with participants with challenging health conditions or social circumstances. My goal was to better understand the facilitators’ experiences and to interpret my research findings in the context of knowledge and experiences from other disciplines that might point to potential actions for the field.

1.2 Background

This section reviews the historical and policy context for AHW activities in the UK. It addresses key concepts related to AHW practice, including the distinctions between different types of practitioners and issues that arise with respect to training, skill, and the types of conditions encountered. It introduces the sensitizing concepts used to approach data collection and analysis and concludes with the rationale for new research. As the extant literature on AHW facilitator experiences was limited at the time of the research proposal review (2020), examiners advised against a systematic or scoping review. A focused review of the literature and subsequently published relevant publications have been included in the background sections below and will be engaged in more detail in the discussion chapter.

1.2.1. Arts, health and wellbeing activities in the United Kingdom

Using artistic activities and interventions to support health, mental health, and social care outcomes is a long-established practice in the UK, as documented by the Royal Society for Public Health in 2013. (40) In 2017, the UK All-Party Parliamentary Group (APPG) on Arts, Health and Wellbeing issued a report on the growing evidence and practice base in the UK based on a literature review and testimony from over 300 stakeholders across multiple sectors and levels of government. (8) The field of AHW, (also referred to as arts in health, arts for health, and creative health), encompasses an almost infinite variety of activities delivered by artists and others from different disciplines and professions. The APPG report describes five categories of activity where arts and health intersect, as described in Figure 1:

Figure 1. Arts, health, and wellbeing activities

Arts-based therapies: drama, music and visual arts, dance/movement
Arts on prescription: health provider referrals for creative activities
Participatory arts programmes: arts activities intended to improve and maintain health and wellbeing in health, social care, and community settings
Arts in health and care environments: arts in hospitals and social care settings
Medical training and medical humanities: the inclusion of arts and medical humanities in the training and support of health and care professionals

Participants find their way to AHW activities through different pathways. (8) They may see a free-standing programme advertised in the community and choose to attend; they may pay a participation fee, or the programme may be funded by grants or other sources. Support groups for specific conditions, such as dementia or bereavement, may organise AHW programmes for their members and the broader community. Health, mental health, social care, and community organisations may offer AHW activities as part of their patient/client support programmes. Specialised arts and health organisations may secure funding from a variety of sources or delivery partners and employ artists to deliver them. As cultural funders like Arts Council England increasingly require social outcomes from grantees, (41) more cultural institutions like museums and performance organisations offer creative wellbeing activities for general audiences or targeted at specific needs. Increasingly common are patient referrals to social prescribing programmes that may include arts options. These will be described in more detail below.

Following the APPG report, two national organisations were created to promote AHW in national agendas and to support AHW practitioners: the Culture, Health and Wellbeing Alliance (CHWA) and the National Center for Creative Health (NCCH). These organisations advocate for and sponsor pilot programmes and research to demonstrate the value of creative activity for health and wellbeing, including in the context of social prescribing initiatives. Through successive articulations in national plans, ACE has made creative health a key focus of its funding, (42) and other large funding bodies such as the Heritage Fund have stipulated wellbeing objectives for all grantees. (43,44)

1.2.2 Arts, health and wellbeing programming in social prescribing

Many recent discussions in policy fora and academic literature address the potential beneficial impact of including AHW programmes into larger agendas across sectors and levels of government. These agendas may include reducing costs through prevention, improving treatment adherence, and reducing inappropriate health care utilization; providing complementary psychosocial support services for people experiencing mental health conditions; supporting patient-centered, integrated services in social care; and promoting community resilience, social cohesion, and sustainability in local services. (45) Notably, the role of arts in supporting health and wellbeing was highlighted in the announcement of new social prescribing schemes in 2018. (10) The creative arts field has a long history of participating in social prescribing projects, including those developed in partnership with the National Health Service (NHS) and other statutory services, as well as those emerging organically from the community. (8,12,46–48) NHS documents, both national and local, identify a variety of conditions or situations considered appropriate for social prescriptions. (49,50) General practitioners (GPs) may refer into community activities people who:

- have one or more long-term conditions,
- need support with their mental health,
- are lonely or isolated, or who
- have complex social needs which affect their wellbeing (49), p7.

Over the years, many referral and delivery models of social prescribing have been trialled. (48) Health centers or community organisations may have programmes to which they refer their patients or clients. GPs can refer patients, often via a coordinating link worker, to already-established community programmes. Some programmes (like arts on referral or arts on prescription) may be tailor-made as part of a clinical referral programme. (48)

While a variety of benefits have been documented, a definitive evidence base has yet to emerge on social prescribing more broadly. (51–55) Some promising benefits for participating in social prescribing activities include building social connections, improving condition self-management, and developing new skills. (56–59) The 'social cure' has been suggested as a mechanism whereby social connections made through participation in community activities can lead to psychosocial benefits. (60) There are also implementation challenges in social prescribing that could affect referrals made to AHW programmes. In one study, participants who received a social prescription reported the powerful impact of the link worker in making connections and building confidence, but others said they did not feel understood or supported in the activities they had been referred to. (61) Inadequate psychological support in community activities may trigger or exacerbate the underlying causes for someone's psychosocial dysfunction. (62) An evaluation of a Shropshire social prescribing programme recommended additional training for social prescribing advisors on mental health and substance abuse conditions, which could also apply to those organisations receiving the referrals. (63) At the community level, success in one social prescribing programme was ascribed to strong third sector infrastructure and good relationships with the health sector, (64) suggesting the potential danger of overburdening smaller organisations if patients are referred to community programmes that are not joined up (65) or negatively affected by reduced local financial support. (56)(66) Patients with higher levels of need might also be referred for community services to alleviate pressure on overburdened GP offices and to provide intermediate support for long wait times for mental health or other services, calling into question whether they will be adequately supported. (66–69)

1.2.3 Arts, health, and wellbeing facilitators professional and practice issues

The APPG report on AHW identified five approaches to delivering AHW activities in the UK (Figure 1), delivered by different kinds of practitioners. Arts therapies in the UK are provided by clinically trained individuals and some modalities are accredited by the Health and Care Professions Council. Three other approaches of delivering AHW activities – arts on prescription, participatory arts, and arts in health and care environments – may also be delivered by individuals variously referred to as artists, creative health practitioners, arts and health practitioners, or facilitators (I will refer to them as AHW facilitators, to foreground their role in guiding and supporting others to participate in an activity). To distinguish them from arts therapists, AHW facilitators typically do not have formal clinical training in counselling or psychotherapy, although they may have formal or informal art training, and some may have training in group facilitation or psychosocial support. (70–72) In some cases health, social care, and allied health professionals with an interest in art may deliver AHW activities. In an early view on the differences with arts therapists, Broderick suggests that arts and health practitioners do not bear a clinical duty of care, the artist–participant relationship begins without prior knowledge, and the artist has no access to confidential medical information. (73) Van Lith and Spooner's more recent survey of arts therapists and arts and health practitioners attempts to differentiate the goals, mechanisms and outcomes of each practice. (70) The distinction between arts therapists and AHW facilitators is relevant to the types and severity of conditions they work with, the intervention intentions, and the kinds of interactions therapists/facilitators have with clients/participants. This thesis looks at the experiences of non-therapist AHW facilitators.

Most of the literature on AHW practice (as opposed to arts therapies) focuses on participant experiences and outcomes. Much less has been written about the practices and experiences of AHW facilitators as they deliver their programmes. Some studies have examined AHW practice to propose descriptions or principles of practice, but only a few address facilitators' perceptions of their practices. Raw's ethnographic examination of experienced community arts practitioners in two countries formed the basis for her 'practice assemblage' framework that emphasizes the interrelatedness of six elements of arts and health programmes: intuition, commitment, ethics, affirmative relationships, spatial, and creativity. (74) Tan interrogates his own AHW facilitation practice to propose a metaparadigm – the governing concepts – of a caring arts-health practice that considers the participant, wellbeing outcomes, the environment, and the quality of the activities. (75) Surveys of facilitators have been used to identify important elements of AHW practice and issues that arise when facilitators interact with participants. Looking at the similarities and differences between arts therapists and AHW facilitators, van Lith and Spooner warn about possible patient safety risks if artists have to handle situations outside their scope and expertise. (70) AHW facilitators working with life-limiting illnesses in Lee's survey describe benefits and vulnerabilities for both their participants and themselves, including those related to creativity, personal growth, and emotional impacts. (76) Smaller studies and programme evaluations have discussed facilitator intentions and skills in different settings. (77–80) In recent years, AHW stakeholders have proposed principles and frameworks for the content of arts and health programmes. (81,82) Good practice principles have been proposed for different types of activities, such as creative writing (83) and textile work (84); and contexts like nursing homes (75) and health care settings (85), for example. Key practice considerations common across these documents include the suitability of activities for participants, clarity of roles and responsibilities for facilitators, and attention to risk management, confidentiality, and ethical behavior. However, these documents tend to frame their recommendations as suggestive rather than prescriptive. Only the US has a code of ethics and standards of practice that have been developed and formally adopted by a national arts and health organisation. (86)

With respect to training for AHW facilitators, a 2003 stakeholder symposium in the US on arts in healthcare raised the need to identify practitioner competencies and related training. This has led to the development of a core curriculum, promoted as a pathway to eventual certification by their national arts and health organisation. (87,88) Moss et al addressed the training needs of arts and health facilitators in 2009 by developing and piloting a model curriculum in Ireland. (33) While there are non-therapy arts and health academic courses in several countries (e.g. the BA and/or MSc programmes at the University of South Wales, University of Derby, and University College London in the United Kingdom), no country currently has formal training requirements to practice as an AHW facilitator. The tension between creative freedom for individual facilitators and the need for professionalization has been raised by many over the years, with some variations by country. (38,39,70,73) 89,90) In 2009, Dileo and Bradt grappled with the distinction between establishing a discipline and creating a profession for arts and health and proposed a pathway for how professionalization might occur in the US. (89) On the other hand, in 2020 Yoeli critiqued the capture of arts and health in the UK by neoliberal paradigms of social good and health outcomes. She suggested that this trend subverts the aim of art for art's sake (while recognizing that some professionalization for practitioners may be necessary). (37) In the UK, early drafts of The Culture, Health and Wellbeing Alliance (CHWA)'s quality framework for arts and health had clear statements by the developers that it was not intended for defining or accrediting practice. (91)

Some of the literature cited above raises issues that may arise for facilitators working with participants with physical and psychosocial vulnerabilities, with respect to both the potential for beneficial outcomes and the risks posed by potentially challenging experiences. (33,70,72,74,75,78,83,85,92,93) Van Lith et al. describe the mechanisms and skills that artists use to support mental health recovery, focusing on the meaning creation and transformation potential of art created in relationship with others. (78) Lee's recent survey of artists working in palliative care highlights the imperative of emotional safety for both patient and practitioner in the context of art-making that can evoke strong emotions. (76) A trauma-informed hip-hop dance programme for young people exposed to abuse or violence stresses that facilitators should have training and a sound knowledge of the biological, psychological, and social effects of trauma, and describes their emotional safety protocols. (94) Raw's research acknowledges the possibility of emotional vulnerability for both participants and facilitators, but most of the experiences she described in her study were positive. (74) The need for formal training and/or professional practice standards is often framed in the language of preparing AHW facilitators to adequately respond to vulnerable individuals and their complex needs. In a frequently cited article, Moss and O'Neil justify their proposed training programme as necessary to prepare arts facilitators for work with vulnerable people. They note that without such preparation, "it is possible that the quality of intervention by artists could vary, and at times this might pose a risk to patients through breach of confidentiality or unawareness of emotional supports needed for patients engaging in arts activities." (33) However, there are no training requirements for AWH facilitators in the UK.

The issue of ethical practice and 'doing no harm' is addressed by Jensen (72). She notes that, while not technically therapy, participatory arts may be therapeutic, evoking strong responses for participants and unintended outcomes for both participants and facilitators. She observes that facilitators' ethical behavior is often guided by personal beliefs, but specific attention is needed with respect to the participants' ability to participate and the practitioners' skill to work safely with them. She uses principles derived from arts therapies to propose a framework of ethical practice for artists working in health. White et al refers to the governance of participatory arts in health as the joint responsibility of all partners involved in designing and delivering the activity and not the sole burden of the artist. (85) This stance is echoed by Naismith in her investigations of the support needs of AHW facilitators. (95,96) She advocates for affective (emotional) support that is complemented by resources and organisational structures to make AHW practice sustainable for facilitators. Both White and Naismith acknowledge that working in health settings implies compliance with its rules, protection from risk, and context-specific training.

The issue of joint responsibility for the support and safeguarding of vulnerable individuals was also raised by my OPA research conducted in South West England in 2018-19. Responding to public health agendas on complex health needs, mental health, and loneliness, AHW practitioners identified the potential risks of collaborating with community partners where staff have a low level of skill or where resources do not cover programme needs. They expressed concern that "care support for vulnerable individuals is either not available or has slowly been cut back, leaving arts practitioners who are not trained as social workers or mental health professionals to manage the complexity and risk that may arise in AHW sessions." (97) This was also raised as a risk in the referral of such individuals via social prescribing schemes to community arts programs that are typically small operations with unstable funding that contract with freelance community artists.

1.2.4 Boundary spanning and emotional labour as sensitizing concepts

In reading the literature and thinking about the experiences of AHW facilitators working with individuals with complex needs, I considered several concepts and theories that could guide my study, such as burden of care and emotional labour. However, I did not want to predetermine how I would listen to the facilitators' stories or weigh issues that might have significance. While I did not take a strictly grounded theory approach in this thesis, I aimed to let participant voices lead in the unfolding of the topic (the study methodology is discussed in detail in Chapter 2). Sensitizing concepts are background ideas and interpretive devices that can guide a researcher in their exploration of a topic and subsequent analysis of data. (98,99) Using this approach allowed me to hold concepts loosely in mind without having them be the roadmap for the inquiry. Below, I discuss the sensitizing concepts I identified at the beginning of the project. I will return to how I used them in the methods and discussion chapters (chapters 2 and 7).

Boundary spanners are individuals who facilitate collaboration across disciplinary or institutional boundaries. (100,101) They must manage the complexity and tension that arises from interacting with different knowledges, relationships, roles, and interests. This characterization of AHW facilitators was supported by my OPA research, which identified seven factors that affect how arts, health, and local government actors navigate sectoral boundaries while trying to align common goals. In their collaborative work, they must negotiate value and legitimacy, relationships, power, policy and system complexity, capacity, resources, and alignment imperatives to pursue AHW agendas. (97) Akkerman describes boundary encounters that arise in education work as ambiguous but potentially transformative opportunities where new practices and disciplines can emerge. (102) Much of the literature on boundary spanning comes from business and public administration and focuses on individuals mediating relationships on behalf of and across organisations, e.g., Williams (101) and Long. (103) In 2019, Daykin proposed looking at AHW practitioners as "boundary workers" who experience ambiguity in their roles, which can be rewarding but also emotionally taxing. She suggests that such boundary spanners "clearly need to demonstrate a wide range of skills, aptitudes and leadership qualities as well as the ability to navigate surrounding discourses and practices and maintain their own legitimacy.” (104)

Daykin also refers to Needham et al’s exploration of the linked theoretical concepts of boundary spanning and emotional labour. (104) In their theoretical exploration Needham et al propose that in public-facing jobs, managing relationships across boundaries can be emotionally taxing, with respect to meeting the needs of clients as well as navigating organisational and paradigmatic differences. (105) They draw on Hochshild’s concept of emotional labour, where employees must align their emotions according to the expectations of the job. (106) This often involves both surface acting (where the displayed emotion is different than the felt one), and deep acting (where an employee attempts to align their emotional response to the demands of the situation). (106,107) Hochschild’s work was part of an emerging exploration of the social foundations of emotion. (108) While early research on emotional labour focused on service encounters, emotional labour has also been shown to be a part of professional roles such as teaching, health care delivery, and the law. (108–110) Discomfort, stress, and burnout can arise when the dissonance between felt and displayed emotions is too great, or the interpersonal demands of the work are unrelenting. (111) Personal employee characteristics, job autonomy, and the underlying purpose and expectations for the work may mediate the negative aspects of emotional labour. (112,113) Hochschild’s research highlights the gender aspects of emotional labour, noting how gender can shape social interactions and that women predominate in jobs requiring emotional labour. (106) According to the membership data of the national AHW organisation in the UK, AHW practitioners are also largely women. (114)

Some studies of socially engaged arts practice address the emotional aspects of the work, but most focus little on how facilitators manage it in practice. Preston explores how the emotional labour of applied theatre artists facilitating participatory arts in urban community settings is intensified by the challenging situations of the participants, high funder expectations, and precarious work arrangements. (36) Sextou’s survey of applied theatre and puppetry practitioners in health care identifies emotional and interpersonal skills and tools needed for working in this context, including emotional and social awareness, empathy, self-awareness, and a person-centred approach. (115) Perkins et al observe that musicians working with mothers who experienced post-partum depression were challenged by hearing the personal circumstances of participants but did not describe strategies they might use to cope with this or that it had a significant impact. (116) Swindells et al briefly describe facilitators taking a boundaried approach to the personal challenges of participants without describing the personal or interpersonal techniques they use for doing so. (117) Broome (2019) reports on artists' perceptions of facilitating care home residents with dementia but makes no reference to the challenges or impact this work might have had on them. (118) Recent studies by Lee (76) and O'Connor (77) raise some of the emotional stressors faced by AHW facilitators working in hospital and community-based settings. These include managing patients/participants' distress, holding on to their difficult stories, and experiencing burnout. Reports commissioned by the Baring Foundation discuss how the lived experience of mental health concerns is common among AHW facilitators working with those conditions and affects how they deliver and experience AHW activities in a mental health context. (11,71)

Arts, health and wellbeing activities have long been understood to be inherently interdisciplinary and cross-sectoral, as they involve elements of creative practice and the intent to effect positive health and wellbeing outcomes. When working with vulnerable participants, non-clinically trained AHW facilitators may face unpredictable emotional content. They must navigate the professional and interpersonal boundaries between creative activities with a possible therapeutic impact (arts and health) and those with a distinct therapeutic intention (arts therapies). Until recently, the AHW literature has had a limited theoretical engagement with respect to understanding the experiences and roles of AHW practitioners working with individuals with complex health or mental health conditions or those living with challenging circumstances. Considering the emotional labour of AHW facilitators through the lens of boundary spanning may illuminate how these facilitators manage their professional identity, aspirations and emotional needs while attending to the needs and expectations of their participants.

1.2.5 Rationale for this research project

As AHW activities are increasingly incorporated into health and social care agendas in the UK, they are often accompanied by higher expectations from funders and greater implied responsibilities towards participants living with challenging conditions or social circumstances (CCS). It is important to better understand how facilitators engaged in working with CCS manage the benefits and challenges of their work, and what factors support or hinder their ability to do so. A growing body of literature acknowledges the challenges, risks, and safety issues that may arise, but in many cases these are generalized accounts, small sample studies, or focus on specific artistic practices or conditions. While there have been attempts to define the parameters of practice and training that could better prepare facilitators for this work, these have not been taken up by the field in a systematic way. This study looks at AHW facilitators representing different art forms, practice settings, and levels of training and experience who work with a range of participant conditions or situations. This broad approach can help identify common issues that occur in a variety of contexts. The relationship between boundary spanning and emotional labour proposed by Needham et al and Daykin has not been used previously in other empirical studies and may shed light on how AHW facilitators navigate the complexity of working with individuals living with CCS.

1.3 Research question and sub-questions

The overall research question for this thesis is:

> How do arts, health and wellbeing facilitators manage the potential benefits and challenges of working with individuals living with challenging conditions or situations?

Specific sub-questions are:

1. What successes and challenges do facilitators experience when working with individuals with challenging conditions or situations?

2. How do facilitators attend to and manage their own responses to distress or challenges presented by participants?

3. What are facilitators' perceptions of their personal capacity (skills, training, experience, attitudes) to respond to participant needs and expectations?

In the following chapters I will describe my methodological approach and the methods used to investigate these questions (Chapter 2). This will be followed by four results chapters:

> Chapter 3. Painting the landscape: The work and context of facilitating arts, health and wellbeing for individuals with challenging conditions or situations
>
> Chapter 4. Juggling in the spotlight: What AHW facilitators do in their work with challenging conditions and situations and how they experience it

Chapter 5. On the stage and behind the scenes: Managing the challenges of facilitation and the role of support

Chapter 6. Creating a mosaic: Boundaries and ambiguity in facilitator role identity and preparation

The results chapters are followed by the discussion chapter, which presents a summary of the results in light of the research questions; an examination of four key themes using literature from arts, health and wellbeing and other disciplines and professions; and a reconsideration of the applicability of Needham et al and Daykin as useful interpretive concepts. The strengths and limitations of the study and reflections on the research process are then presented. Chapter 8 offers policy and practice recommendations and concluding thoughts.

Chapter 2. Methods

This research project used a participatory qualitative research approach to understand AHW facilitators' experiences, practices, and responses to working with individuals living with challenging conditions or situations. In this chapter I will state my rationale for taking a qualitative and participatory research approach; discuss the recruitment, data collection, and analysis methods I used; review the ethical considerations related to the project; and describe my positionality.

2.1 Ontology and epistemology

I approached this research project from an idealist ontological position, which posits that humans construct reality through thoughts and ideas that are subject to many forms of interpretation. (119) In this study, I was interested in the narratives of my research participants' experiences; their perceptions of their responses to phenomena arising in their work and their interactions with others; their thoughts, emotions, and attitudes; and their views on the impact of external social realities that affect their life and practices. (120,121) Further, I hold an interpretivist perspective that knowledge arises from our experiences, is subjective, and is affected by our values and context. (119,122) Finally, I acknowledge a constructivist approach to knowledge and knowledge creation, whereby individuals (including the researcher) interact with the world and each other to develop findings as the investigation proceeds (Guba and Lincoln 1994, in Hiller). (121) Following from this constructivist position and from Braun and Clarke's assertion that researchers should take ownership of their active role in co-constructing knowledge products in research design, execution, and analysis, I deliberately use the first-person voice to make clear in this section my actions and role in generating research knowledge. (123)

Recognising that qualitative research can encompass different epistemological approaches, in addition to claiming an interpretivist position I try to incorporate both phenomenological as well as critical thinking. I constructed research questions that gave primacy to my research participants' personal stories and lived experience, exploring with them what meaning these have for them. (124) I attempt to be critical by contextualising and analysing these experiences in the social and economic reality they practice in, including how this reality impacts them personally and professionally, how their approach to practice fits into larger concerns about patient care and safety, and to what extend the structures of the AHW field do or do not support them. By taking a participatory approach (discussed in more detail below), my intention was for this research to be conducted with research participants and informed by their lived experiences to ensure that it was centred around their needs and concerns, and that the findings would be relevant and useful for them. I hoped that by engaging research participants in reflective conversations and reviewing a collective analysis it could empower them to be more agentic in their work and, that by involving AHW stakeholders as research partners, they could take action to address the issues raised. (125)

2.2 Qualitative research

This study used a qualitative research methodology. Qualitative research allows for the exploration of phenomena through methodologies that “celebrate richness, depth, nuance, context, multi-dimensionality, and complexity.” (120) p 1. These values mirror the extant descriptions of arts, health, and wellbeing practice, making this approach suitable to explore the varied experiences and perceptions of those who engage in it. Expanding on this point, Mason proposes that the characteristics of qualitative research include taking a broadly interpretivist position; using data generation methods that are flexible and sensitive to context; and attending to complexity, detail, and context in a holistic approach to data analysis (120) p 3-4. As seen in the introduction, the context related to this topic is in flux, in terms of practices to be examined and the possibilities for data collection. This requires a flexible and multi-pronged approach. Complexity must be considered relative to the people and entities AHW facilitators interact with, the norms and expectations they must consider and navigate, and how they make sense of unfamiliar situations and give meaning to new experiences. Quality in the research process can be supported by using guidelines and frameworks, which I used to structure and benchmark the research journey as it unfolded. (126)

2.3 Participatory research approach

Participatory research directly engages as co-researchers individuals or communities who are the focus of the intended research topic. Drawing on their lived experiences and expertise, these individuals collaborate with researchers in a shared learning process to define and support the knowledge production and translation process, enhancing the researcher’s and their own understanding of the topic, potentially to take action at the level they choose. (127) There are many participatory research approaches (128) but they have some common elements, including originating the research problem in the community, aiming for participant control in the research process and equality with researchers, and a formulating a real-word application of findings for change. (129) As described in section 1.1, this project arose directly from issues raised by AHW facilitators and stakeholders in the OPA project, which were also being discussed more widely in the field. The research process and structures, described below, were designed to give a collaborative voice to facilitators in design and execution. The intention was to generate data and recommendations to aid stakeholders in addressing needed changes identified or validated by the research.

Defining engagement is unique for each research process and must be negotiated with research partners and participants according to their desires and capacities. I felt a participatory research approach involving AHW facilitators and their supporting organisations could stimulate their exploration and reflection about their work while also supporting my understanding and execution of this project. (127,130) In addition to helping me design the project, advise on its execution, and discuss the results, I saw two specific benefits from involving AHW facilitators: for individual facilitators, it could support a deeper understanding of their own experience and that of their counterparts (131); and for organisations, engagement in the production of evidence could lead to the further development of the field and professional advocacy with stakeholders in real-time. (132) Jagosh et al describe how a partnership synergy of skills, perspectives, and resources can enhance the development and implementation of research design, improve participant recruitment, and generate capacities of partners that extend beyond the project itself. (133)

However, a participatory approach can also create heavy time and process demands on all parties and stretch usual academic conventions related to the formulation of research aims and approaches. (134) Bergold reviews the pros and cons of defining a continuum of participation in research, stating that the essential criterion is participant decision-making authority. (131) Given the limited time and resources available for the DrPH thesis, I designed an approach that incorporated key principles and realistic elements of participatory research while acknowledging that actual participation in decision-making resided primarily with me and the facilitator research partners rather than the research participants in the interviews and discussions. The success and limitations in implementing this approach will be discussed in sections 7.7 and 7.8.

During the project conception phase, key issues related to this topic were discussed with several AHW facilitators and organisations that represent them regionally and nationally. Along with a review of the literature, those conversations shaped my thinking and influenced the initial drafts of the research proposal. With Arts & Health South West (my research partner for the OPA project) in particular, I had many discussions about the potential value of the research, approaches to conducting it, and who could be involved as research partners and participants. As the proposal was developed, I brought together representatives of eight regional and national organisations to collaborate on the project as research partners: Arts & Health South West, London Arts in Health Forum; Leeds Arts Health and Wellbeing Network; The Culture, Health, and Wellbeing Alliance; Arts & Health Hub; Flourishing Lives; creativeShift, and Creativity Works (see Annex M1 for individual names). All the individual partners had personal experience as an AHW facilitator and/or manager of projects involving facilitators.

These research partners were convened as a group to envision their collective role in May 2020, contributing to a research partner engagement guide (Annex M2) and signing a participation agreement (Annex M3). During the project, I met with them eight times for hour-long meetings using Zoom, along with email communications and occasional individual conversations. The group helped refine the research tools and advised on and assisted with the recruitment of research participants. They reviewed the results chapters, the discussion chapter, and recommendations, offering feedback and insights. They have individually and as organisations used this study's findings in their own work and are helping shape knowledge translation strategies to raise awareness among stakeholders and make findings accessible for formal and informal policy development. Specific examples of their contributions to the research design and execution include deciding on the appropriate language to use regarding participants that might be vulnerable or present challenging scenarios, resulting in changes to recruitment and interview language; proposing creative elements in the discussions and interviews to put facilitators at ease; participating in mock interview and focus group discussions to refine the topic guides and discussion management. During our meetings and in comments on drafts, they helped me interpret issues raised during interviews, such as how facilitators saw their role in supporting social engagement and the possible factors behind facilitators' reluctance to address training. Their ongoing input and support validated the research approach and emerging findings and reaffirmed the relevance of the project.

I also created mechanisms for the AHW facilitators who were research participants in the study to participate actively in the project. They were sent updates and summaries of the analysis as the study went forward, encouraging them to engage with me on interesting points or concerns privately or through the project blog (see section 2.4 below) They were invited to review and comment on the results chapters and the discussion chapter (January-August 2022) through written feedback or by participating in webinars (March 2022) where I presented a summary of the results and they could engage with each other on key themes. I also invited them to respond to a call for proposals to collaborate in a creative public engagement event on the research and commissioned one artist facilitator who was a research participant to co-design and deliver this work through an LSHTM public engagement grant. (135)

2.4 Research setting, sampling, and recruitment

The field of AHW facilitation is diverse with respect to experience and types of practice so the aim was to recruit a sample of facilitators that would reflect that diversity to the extent possible. A maximum variation sampling approach was used to capture the variations among individuals based on specified characteristics, to increase the likelihood that the findings would reflect different experiences, circumstances, and perspectives. (136) The characteristics chosen to identify this diversity included geographic location, art forms used by the facilitators, the health and wellbeing intention of their work, years of experience in arts and health, work setting, training, and access to support. These criteria were included as questions on the recruitment form (Annex M4). Initially, Greater London and South West England were selected as distinct regions for recruitment that could reveal different types of practice settings and access to practice resources. On recommendation from the research partners, Yorkshire and the Humber was added as a recruitment target to add geographical diversity, and a research partner from this area joined the group.

For recruitment, I worked with the research partners and other AHW sector support organisations to disseminate recruitment announcements through their newsletters, social media platforms, and personal contacts to combine criteria, snowball, and opportunistic approaches (136). I also set up a WordPress blog (https://artsandwellbeingpractice.wordpress.com/) and Twitter account (@CreateFacilit8) to support the recruitment effort. Research partners suggested that Twitter is a platform where many AHW practitioners and stakeholders are active in ongoing discussions on the field and would be a good site for recruitment. Individuals interested in participating were directed to the blog for more information and a link to the online recruitment form (Annex M4). Recruitment took place between 10 September and 25 October 2020. Through the blog traffic statistics, I was able to track how potential research participants were directed to the site and how many of those clicked on the recruitment form after reading the announcement. Twitter was the most frequent referral point. The blog and the Twitter account were used throughout the project to provide updates and to make announcements of presentations, workshops, and other public engagement activities. (Annex M5)

A total of 56 facilitators initially completed the online recruitment form and 43 participated in the research activities (reasons for non-participation are discussed in the subsections on individual methods below). Using a predefined allocation protocol (Annex M6), I assigned respondents to one of three data collection methods (described in more detail below), attempting to achieve an equal diversity in each data collection method of geographic location, years of practice, and art forms. Upon enrolment in the study, facilitators were assigned a code that reflected the research method they participated in and their region, art form, years of practice, and training.

Facilitators were asked on the enrolment form to choose a pseudonym for use in the project (although fewer than a quarter chose something different from their first names). Because some facilitators could be recognizable from the combination of their names, personal stories, and practice characteristics, new pseudonyms were assigned to all the research participants. From this point forward, I will refer to the research participants as ‘facilitators’ to distinguish them from the participants in their programmes.

2.5 Data collection methods

Four data collection methods were used in this project, starting with methods intended to capture broad views on the topics and funnelling down to more in-depth approaches to uncover rich personal experiences, new issues, and additional nuance to the themes raised in early methods. These methods, elaborated in the subsections below, included the participant recruitment form, an online discussion group, a focus group, and semi-structured interviews. Each method collected data in a slightly different way, which allowed individuals to choose a mode of interaction they preferred (individual or in groups, written or spoken). This also allowed for the comparison of topics raised and sentiments expressed in group discussions and one-on-one interviews. I was also able to compare written responses in the online discussion group with more spontaneous responses in the focus group and interviews. Table 1 shows each method, the number of facilitators who participated, and the format and period of data collection.

Table 1. Data collection methods

Method	# of facilitators	Time period of data collection	Format
Participant recruitment form	56	Sept–Oct 2020	Online survey form
Online discussion group	19	Nov 2020–Jan 2021	Online written forum, 1 theme per week
Focus group	6	Nov 2020, Jan 2021	Zoom, 2 hours each
Interviews	18	Nov 2020–Mar 2021	Zoom, 1-2 hours each

Remote methods were used for the data collection. I originally intended to use participant observation methods to watch facilitators in their work settings, complemented with in-depth interviews. However, due to contact restrictions related to the COVID-19 pandemic that came into force right before the research proposal review, and which were still in effect during the data collection period (September 2020–April 2021), participant observation methods were not used. The remote methods used included a website-based online discussion group and Zoom meetings for the focus group and interviews. At the start of the research project, there was a growing body of literature addressing the potential and limitations of different remote research methods, using examples from empirical research and addressing practical and ethical considerations. (137–140) For example, Marhefka provides a thorough guide to using video-conferencing to compensate for social distancing during COVID-19. (141) The literature on these methods has increased over the last two years (e.g. Engward, (142) Maldonado-Castellanos, (143) Khan (144))

The topic guides (Annex M7) for the online discussion group, focus group, and interviews were the same in content, with slight variations to account for posing written questions in the online discussion group versus the phrasing and timing of questions in real-time focus groups and interviews. The guides were informed by initial partner discussions (and their engagement in a mock focus group and interview), the empirical literature, and the research questions, and iteratively refined according to the data collected from early methods (online discussion group and the initial focus group). I sought research partner advice about the rephrasing of some questions; for example, how to ask about facilitator training experiences. In keeping with my intentions around the sensitizing concepts of boundary spanning and emotional labour, I did not ask about them directly but developed follow-up questions to use if facilitators raised these. Especially concerning concepts of emotional labour and managing interpersonal boundaries, the facilitators addressed these in detail without prompts.

One of the original objectives of the thesis was to examine how AHW practices and experiences changed due to the COVID-19 pandemic. Questions relevant to the practice changes were included in the topic guides, and these questions were addressed by the online discussion group participants in Weeks 6 and 7, and in a second round of conversations with the focus group and interview participants (January-April 2021). However, due to the richness of the material from the pre-COVID-19 practice discussions, space constraints in the thesis, and time limitations, I have not analysed the COVID-19 period data for this thesis. These will be examined separately and reported on in the future.

2.5.1 Online participant recruitment form

As noted above, potential research participants were invited to complete an online recruitment form (Annex M4) that collected sampling criteria information to allocate them to the main research methods. The secure survey platform Online Survey (https://www.onlinesurveys.ac.uk/) was used to collect this information. A total of 54 people completed this form during the initial recruitment period. One additional facilitator was recruited to the study from my networks and another joined the study on the recommendation of one of the interviewed facilitators. In addition to using the data for allocation purposes, the recruitment data were analysed alongside data from other methods to get a more complete view of facilitators' backgrounds. Data were collected on geographic location, art forms used by the facilitators, the health and well-being intentions of their work, years of experience in arts and health, work setting, training, and access to support. A snapshot of these responses is in Annex M8.

2.5.2 Online discussion group

I began data collection on the key research questions with the closed online discussion group (ODG) in November 2020. This method was conducted first to allow the largest group of facilitators to raise a broad range of issues over a defined period. As the discussion group moderator, I gave weekly discussion prompts to the group over seven weeks on key research themes, with facilitators posting their written responses on the forum for others to see. I regularly encouraged the facilitators to interact with each other as they might do in other peer group discussions or communities. Such groups with health professionals (138) and with health consumers (139) demonstrate the potential for efficient collection of rich data in an iterative fashion that allows for evolving interactions and ongoing validation between researchers and participants.

I considered several popular platforms for online discussion groups, such as Facebook and Slack, for their familiarity to many users and ease of use. However, concerns from LSHTM about data protection resulted in LSHTM's IT department developing a custom platform using the phpBB.com software on its secure servers. This was a new endeavour for the IT department and was collaboratively designed and tested over four months by me, the research partners, and the IT department managers and technicians.

From the original recruitment group, 23 facilitators were enrolled in the online discussion group (10 others chose not to participate for various reasons after being invited). Four did not participate after enrolling, including two with neuro-cognitive difficulties who found the platform difficult to work with (they also chose not to accept offers to switch to interviews). Weekly discussion “transcripts” were downloaded as Word documents for analysis.

2.5.3 Focus group

I convened one focus group for this thesis. Six facilitators were allocated to this focus group, which met twice to explore the research themes. In the field of AHW, some facilitators participate in peer discussions to share positive and challenging facilitation experiences and explore different viewpoints to inform their practices. Focus groups offer a similar opportunity to explore the key research themes through practice-focused discussions that take advantage of debate, iteration of ideas, and group dynamics (145). The first focus group meeting was held online using the Zoom platform in November 2020 after the initial inquiry period of the online discussion group (allowing for some slight adjustments to the topic guide based on those discussions). This 2-hour focus group discussion focused on their practice experiences pre-COVID-19. Given the potential impact of eight months of changed personal and professional practice for them, I used a guided imagery exercise at the beginning to assist with the recall of their pre-COVID-19 experiences, asking them to visualise the setting and feeling of their workshops. During the first hour, facilitators gave answers in turn to the questions posed. This progressed to a more interactive discussion as participants grew more comfortable with each other and the format and responded to each other’s stories and comments. The focus group was recorded on Zoom, and the audio files uploaded to Ottter.ai for verbatim transcription. I corrected and anonymized the transcripts and downloaded them as Word files for further analysis. While the original intention (pre-COVID-19) was to have face-to-face meetings, the online format allowed for more flexible accommodation of people’s schedules and easier access for participants from different parts of England.

2.5.4 Semi-structured interviews

I conducted in-depth semi-structured interviews with 18 facilitators. These were held on the Zoom platform from November 2020 to March 2021 (participants were offered telephone interviews as an alternative but none chose this). The interviews covered their practice experience before the COVID-19 restrictions and the same guided imagery prompt was used. The interviews, which lasted from one to two hours, allowed for an in-depth exploration of the key research themes, eliciting detailed recall of experiences and reflections on personal and work-related decision-making. Interview recording and transcription followed the same process as for the focus groups.

After the first interview, I invited the facilitators to keep diaries of their facilitation experiences over one month, reflecting on one or two of the key study themes raised in the interviews (experiences, responses, preparation, emotional impact). Reflective practice diaries are a recommended tool that some facilitators use and could allow for the documentation of work experiences in an immediate and reflective way that could then be discussed (if the interviewee chose) in the second interview. Given the potential logistical and ethical concerns about mailing and protecting physical diaries, I did not collect or directly review these diaries, and only a few facilitators mentioned using them in the second interview (it is likely that this technique was not widely used as the period between interviews fell largely in the December holidays).

2.6 Data analysis

I analysed the data I collected using a combination deductive-inductive approach. I was guided by Tsoukas' notion of "conjunctive theorising," avoiding the temptation to simplify and abstract and instead trying to reveal complexity by bringing together different perspectives from many sources throughout the data collection and analysis process. (146,147) These sources include, for example, contemporaneous literature; real-world, contextualised experiences told from individual voices (interviews and discussion groups); perspectives developed in dialogue with others (research partner meetings, participant observations, and public workshops I led); and views offered by stakeholders engaged at multiple levels of action, from facilitation to national policymaking (informal discussions and consultations).

This conjunctive theorising began during the research proposal development phase, and I kept a research journal to record and comment on the variety of inputs. I wrote analytical memos and reflections on the research processes and emerging findings at key stages of the project. I also dictated reflective voice memos after each interview and focus group, which were transcribed and considered alongside other notes and reflections. As part of the inductive approach, I began formal coding with the transcript of the first focus group, using a line-by-line method in an Excel document to identify issues that might form the basis for future codes and that could be further explored during interviews. During the same period, I informally coded and wrote memos on transcripts from the online discussion group with a similar purpose. I continued with this iterative and comparative process of identifying related or unexpected themes arising from an inductive analysis of the data in successive rounds of more detailed coding and memo-writing. (148)(65)

After compiling the data from the interviews, focus group, and online discussion group into one document, I used the research questions and concepts of boundary spanning and emotional labour to deductively develop a framework for an initial “large-sort” coding exercise. I chose 22 broad codes and coded all transcripts in this first round using Quirkos qualitative analysis software (www.quirkos.com). This allowed me to consider the data in more manageable chunks that could be further analysed through more fine-tuned coding. I then conducted a second coding exercise using Quirkos with the code that contained the largest number of quotes—facilitator experiences and impacts—creating 34 sub-codes that were organised into a coding tree of four main themes (Annex M10). For other codes with smaller amounts of data, I sub-coded these by hand, which allowed for a more nuanced consideration than working with Quirkos.

Informed by Neale’s method of iterative categorization, (149,150) I summarized the key messages for each subcode, grouping messages into themes, and proceeded to write the results related to each theme. During this process, I referred to memos written at earlier stages of the process and reviewed whole transcripts to ensure an understanding of the context of individual statements. Visual mapping of concepts was used to better understand the relationship between related elements.

During the process of writing the results, I recognized that there were longer excerpts of discussion group and interview data that told stories addressing multiple themes in a single narrative. Several of these were captured to use as vignettes (shown as “stories” in boxes in the results chapters). I intended to transcend the atomization of fine category thematic coding by including more of the individual voices and contexts related to the interconnected points being made by facilitators. (151)

During the process of analysing key themes, I noted that certain statements made by facilitators were evocative of underlying emotions and beliefs about their work. Seeing these as revealing “hot spots”, I used a poetic inquiry method informed by Glesne (152) to juxtapose and highlight the voices of different facilitators on key research themes. (153,154) This involved highlighting selected transcript statements that strongly expressed a facilitator’s view, copying them into a separate document, and rearranging the phrases to construct a poetic analysis that succinctly represented the consonance or tension between different views. This “re/presentation” of facilitator views invites the reader to construct their own interpretations alongside the research participant and researcher. (155) The examination of data through this poetic lens also aided my analysis, as I was able to identify and juxtapose varying perspectives, highlighting differences and tensions. Due to space constraints, only one of these poetic analyses is in the main text of the thesis; an early experiment is in Annex M11.

As described in the participatory approach above, I shared data summaries, draft results chapters, and discussion chapters with the research partners and facilitators for comment as part of the data validation and analysis process. Portions of the results have also been shared in public presentations where feedback was received. These processes allowed for further validation of the results and analysis. Feedback received included other facilitators' similar experiences, and suggestions on how to clarify discussion points and make recommendations more relevant to particular audiences.

2.7 Ethical approval and key considerations

Ethical approval for this study was granted by the LSHTM Observational/Interventions Research Ethics Committee (#22523) on 8 September 2020 (Annex M12). Amendments were subsequently approved for the collection of feedback on the online discussion group experience, and for the inclusion an additional method (webinar presentation) for presenting results to research participants and soliciting their feedback. The method was included to respond to requests from the research participants.

With respect to online methods of research, my ethical approach was informed by the literature on these methods; in particular, ethical guidelines developed by the UK Government Social Research unit, (156) the British Psychological Association, (157) and the Association of Internet Researchers. (158) A wide range of issues can arise using online methods, including the privacy and security of online discussion groups, informed consent, and reporting and disseminating research results. (159) Specific data management protocols for the online discussion groups and online focus groups were detailed in the Data Management Plan required as part of the school's ethical approval process.

To support good ethical practice, a working agreement for the research partner team was developed. This covered elements of good research practice related to their participation in the research process and was informed by the Critical Participatory Action Research Group Protocols: Ethical Agreements for Participation in Public Spheres. (160) The template document can be found in Annex M3. Research partners either signed this agreement or consented to it verbally. To my knowledge, partners adhered to this agreement during the research process.

As part of completing the recruitment form, facilitators had to sign a consent form before proceeding with the part of the form that requested personal data from them. Before participating in the data collection method they were assigned to, they had to read the participant information sheet and complete an online consent form (Annex M13). Before the data collection methods began, I reviewed the key elements of these forms with them and asked if they had any questions. Facilitators were assigned a participant identifier code and pseudonym as soon as the information was downloaded, and the code sheet was kept separately in a password-protected electronic file. While they used their pseudonyms if they interacted with other research participants in online discussion groups or focus groups, they were advised that their anonymity might not be assured in focus group interactions where a visual element existed (e.g. Zoom meetings). No information that could be considered identifying was used in preliminary reports or will be in future publications.

The primary risk anticipated for the research participants was the distress that might arise while they were discussing issues that were emotionally challenging in their work. I have 140 hours of combined training and practice experience in telephone crisis counselling that informed my facilitation and interactions with them, and I also wrote a distress protocol (Annex M14) to guide my response to conversations that were distressing for participants. (161) They were informed at the beginning of each data collection event that they could pause or stop at any point. On two occasions, participants did relay significantly distressing experiences. We paused and discussed their desire to continue, and both were happy to do so. I followed up by email to ensure they were feeling alright afterward and offered information about support resources they could access. What I did not anticipate was that I would have a strong emotional reaction during one interview when the participant discussed distressing events that were similar to my own experiences. While I was able to maintain my composure during the interview, I felt the need to seek additional support from my supervisor and a mental health professional after the fact, and to do additional reading on how to manage such events in the future. (162–164) Some of this literature highlighted the emotion work faced by researchers investigating sensitive topics. (165) The impact of this event on my thinking about the facilitators' experiences is discussed further in the reflexivity section in Chapter 8.

This project has been self-funded. There were no direct research costs as the software tools/apps were available free of charge or through institutional subscriptions. I received an LSHTM COVID-19 Funded Extension scholarship for April-August 2022 and was awarded an LSHTM Public Engagement Small Grant Scheme award related to the research (June 2022). I received a consulting contract from Arts & Health South West (one of the research partners) to lead agenda-setting discussions and training workshops related to professional development for AHW practitioners (August 2021-present). I was also paid a fee by Arts Council England for a brief consultation in 2022 on the results of this research related to the training of AHW facilitators. Both activities drew on knowledge I developed while conducting this research.

2.8 Positionality

In the introduction, I described how my prior research on arts and health in South West England raised issues that I wanted to explore further in the thesis. Here, I focus on four issues in relation to my positionality on this topic: my prior engagement with arts, health and wellbeing; my experience related to therapy and counselling; my perspectives on participatory approaches to policy and research; and my public health background. These experiences have informed my approach to the research questions, methodology, and analysis. I have several long-standing creative practices that I engage with on my own and with groups, occasionally in facilitation roles. Prior to and during the doctoral programme, I participated in AHW activities led by arts facilitators and arts therapists. This has given me the opportunity to observe and discuss the activities with both types of practitioners and to explore the mechanisms of each type of practice. I have engaged in personal therapy, trained for and delivered telephone crisis counselling, and taken courses on trauma-informed expressive arts therapies. Through this, I have developed insight on managing health and mental health challenges for myself and in the context of supporting others. These experiences have also increased my understanding of the different levels of knowledge, skills, and training different types of mental health workers have. I have conducted qualitative research in multiple settings and for different purposes (ethnographic research and research oriented to supporting policy and practice) and believe strongly in an approach where knowledge co-creation arises from empathetic and curiosity-driven dialogues between researchers, participants, and others. The US and international health policy and advocacy work I engaged in before entering the doctoral programme informs my view that participatory processes are useful and meaningful for all parties and mostly likely to result in a product that represents a diversity of stakeholder views. This same policy work informs my public health orientation to health and social issues – I am committed to efficacy, safety, and support for practitioners and the public.

Overview of the results chapters

The results of this study will be presented in four chapters.

Chapter 3. Painting the landscape: The work and context of facilitating arts, health and wellbeing for individuals with challenging conditions or situations

This chapter presents the varied activities and intentions of arts, health and wellbeing (AHW) facilitators. It describes the challenging conditions or situations (CCS) of the participants they work with and explores the work context for AHW facilitators.

Chapter 4. Juggling in the spotlight: What AHW facilitators do in their work with challenging conditions and situations and how they experience it

This chapter looks at the intentions and actions of AHW facilitators, including how they: 1) facilitate creativity for health and wellbeing, 2) encourage social engagement, and 3) make space for creative expression and emotions. It examines the rewards, validation, and motivation of working the participants with CCS, and what kinds of challenging experiences arise while working with individuals with complex needs.

Chapter 5. On the stage and behind the scenes: Managing the challenges of facilitation and the role of support

This chapter addresses how facilitators manage interpersonal dynamics during sessions and how they process their experiences after sessions. It also explores their views about practical and affective support for their participants and for themselves.

Chapter 6. Creating a mosaic: Boundaries and ambiguity in facilitator role identity and preparation

This chapter considers how facilitators navigate the freedom and ambiguity of a multidisciplinary practice. It describes the skills and attributes of AHW facilitators and the role of training in the preparation of facilitators working with people with CCS. It also looks at the role of experience as a pathway for developing their practices. It ends with the presentation of different views on the need for practice frameworks and qualifications.

The results will be presented thematically, incorporating data from all data collection methods and supported by illustrative quotes, participant stories, and one poetic analysis. A summary and crosswalk table matching results, discussion themes, and recommendations is at the end of each results chapter. In the results and discussion chapters, “facilitators” refers to the research participants in the study and “participants” refers to the individuals who take part in the facilitators’ programmes. “Funders” represents grant funders, commissioners, and employers who pay facilitators for their AHW work.

Facilitators are referred to by pseudonyms and each quotation is followed by a unique identifying code indicating the data collection method they participated in, the art form they use, and their years of experience as an AHW facilitator.

The key to the identifying codes is as follows:

> **Data collection method**: F - focus group; I - interview; O - online discussion group
>
> **Identifying number**: 1, 2, 3, etc.
>
> **Art form used**: V - visual arts; Mx - mixed art forms; Mu - music; W - creative writing; D - dance; Mg - museum/gallery-based practice; P - poetry or spoken work; T - theatre; O - other
>
> **Years of practice**: 03 - 0-3 years; 46 - 4-6 years; 6 - 6+ years

Sample: F1-D-03 = Focus group, participant 1, dance, 0-3 years of practice

In the quotations, text that is italicised represents emphasis by the speaker; text in brackets represents anonymisation or clarification made by me; text in parenthesis represents my speech during the interview.

Chapter 3. Painting the landscape: The work and context of facilitating arts, health and wellbeing for individuals with challenging conditions or situations

Chapter overview

This chapter introduces arts, health and wellbeing (AHW) facilitators and their work with people living with challenging conditions or situations (CCS). In this chapter, I will describe three key themes: 1) the varied activities facilitators undertake and the intentions they have for their work; 2) the challenging conditions and situations of the participants they work with; and 3) the work context in which facilitators practice and their views of the physical and financial aspects of their working arrangements. By examining this backdrop for their facilitation work, we can begin to see the background issues of emotion work and boundary crossing that will become more evident in subsequent chapters.

Prior to addressing these three themes, it is useful to understand the unique and individualised practices and contexts of arts, health and wellbeing (AHW) facilitators who work with individuals with CCS. This vignette of Olivia, a circus artist, touches on themes that will be explored further in this chapter. (I4-O-46)

Olivia has worked on a variety of social circus projects as a performer, producer, and teacher. More recently she has worked with an arts organisation that offers health and wellbeing-oriented classes in visual arts, performance, drama, and circus for participants from all backgrounds, from toddlers to older adults. In partnership with a local NHS trust, this organisation has worked with people who have a variety of complex health conditions, such as epilepsy and type 1 diabetes, as well as neurological and physical diversities. Pre-COVID, their work took place in a variety of community settings.

According to Olivia, a typical session, which could be tailored to one health condition or accommodate a variety of participants, might start like this:

> We set up the equipment, and we very much kind of create a schedule for that session. So they know what's going to happen when so they know what their expectations are of them in that particular session. So we'll have a whiteboard, old school flip chart, that we can draw on so that we can do it in, in visual, so that they know, so it will be pictures, as well as words. So, they know that at 7:00, we're going to be sitting down talking; at 7:30, we're going to be getting their, their trapezes out, for example. And just so that, for a lot of them, especially for those with autism, they really need to know what's happening when, so that they can have that in their minds, when you just throw something in there, it can send some of them into a spin, because they don't know what, what was happening next. So that would be the start of a session. (I4-O-46)

Depending on the specific needs of the participants, adaptation of the activities and equipment is often necessary:

> Actually, […] the visually impaired were brilliant at tightwire. But just because you know that that input comes from elsewhere, it comes from feel rather than being able to see, oh, my goodness, if I fall off this, it's gonna hurt. It's just purely done on what they can feel, and corrections […] So yeah, we, we just kind of look at what's possible for individual participants and try and think of ways of using the equipment in a different way. The goal is to help build resilience and to work on their coordination and their physical skills as well. Obviously, we make a lot of adaptations in the way that we teach. (I4-O-46)

This description shows the many ways Olivia invests considerable preparation to make both small and significant accommodations for different physical and neurological conditions, anticipating potential challenges and being surprised by participants' abilities to adapt. She also points to specific physical and psychosocial goals for the programme.

3.1 The varied activities and intentions of arts, health and wellbeing facilitators

Reflective of the broad diversity of arts, health and wellbeing as a field, each facilitator in this study designs and delivers their work according to their own interests and expertise, or co-designs programmes with those who commission the work. Of the 43 facilitators in the study, 15 use visual arts, seven use mixed art forms, six use music, six work with written or spoken word, four use dance, four have a museum/gallery-based practice, and one each uses theatre/drama, aerial circus arts, animation, or photography.

Many facilitators appreciate the freedom and creativity inherent in delivering programmes that use multiple art forms in different settings and with different health and wellbeing intentions. The interdisciplinary combinations of activities they offer reflect this. Some of these include:

- Art and art history in museums for people with disabilities or dementia
- Singing for health choirs for people with chronic obstructive pulmonary disease (COPD)
- Theatre-based programmes for those in recovery
- Spoken word life-story activities for adults with learning disabilities and mental health challenges
- Classical Indian dance for wellbeing and confidence building
- Arts-based public engagement for physical and mental health in collaboration with researchers and clinicians

Tessa, who worked for many years in community arts education before turning to arts and health activities, said her arts for wellbeing courses are structured so that every week participants have an opportunity to try a different activity:

> …like a little taster of different things, different processes, different materials, different ways of working. So even that, that makes the body move differently. You know, and in those classes, and the first set of art for wellbeing courses we did were based in a local community hospital, and the people taking part were referred through the services within the hospital, like the physios and the, you know, the occupational therapists and people like that. And so back to the ordinary pottery classes, the stuff that was just in the [adult education] centre, so we get people with, you know, mental and emotional and psychological issues, people who are bereaved. (I5-V-6)

Jayne described how she adapts creative activities in a neurological hospital where she might work with patients for a few weeks or over the course of several months:

> So there I could, I could tailor projects to their, what they would like to do, and also to their specific needs, you know, if they needed to use a hand more, to use both hands, or […] the therapists would kind of like, give me guidance as to what would help them. And so, you know, the neurological hospital got me learning how to rag weave carpets, and you know, all sorts of strange things that I would never know. But if that's what people want to do… (I17-Mx-6)

Facilitators described a variety of motivations and goals for their work. During the recruitment phase of this study, they were asked to give a short free-text description of the health, mental health, or wellbeing intention of their work. More than half expressed a desire to promote and support wellbeing or mental health. Another quarter described their social engagement intentions, and the rest detailed their aim to teach an appreciation of creativity or creative skill development. A table of the concepts and phrases taken from their answers can be found in Annex R1. These indicate overlapping health, psychological, social, and personal development goals through the vehicle of creative activity, indicating the interdisciplinary nature of their work. This will also be reflected in the more detailed descriptions of their experiences in subsequent results chapters.

3.2 Delivering arts, health and wellbeing activities to participants who live with challenging conditions or situations

Facilitators were asked to describe the kinds of conditions they encountered working with participants with CCS. Sometimes facilitators know of participants' situations in advance, and other times they or their organisations choose not to know or are not told by referring organisations. Participants with CCS find their way to AHW activities via different pathways, including self-referral, as part of patient support groups, or by referral from health or community services. Few facilitators in this study 'specialise' in one condition or situation. Most work with groups that have a mix of conditions or cater to multiple groups that are specialised to different conditions (e.g., someone leads a singing for mental health group as well as a singing in care homes group). This range potentially requires different skills, knowledge, and approaches according to the participants' needs and the desired outcomes. Drawing on facilitators' mentions of different conditions during data collection, Table 2 below gives a sense of the frequency of different conditions, organised by general categories (rather than using a strict clinical typology).

The predominant category of conditions mentioned by facilitators was participants living with mental health conditions. This was followed by a wide variety of other health conditions across the life span, including childhood cancer and dementia. The third most frequently mentioned category was physical disabilities and neurodiversity (including learning difficulties and autism). There were also categories of social states or situations (such as bereavement and social isolation); and described categories of people (such as care home residents). The "other" category includes physical or emotional crises or situations that a facilitator must deal with immediately (such as epileptic seizures and psychotic episodes). Table 2 below shows the number of times different types of conditions and situations that were mentioned by facilitators (using terms given by them), with terms in bold signifying those mentioned five or more times. This typology of CCS may include overlapping counts and indistinct boundaries, as some facilitators don't take a diagnosis or condition-based view of their clients. The intention of the table is to highlight the range and complexity of conditions and situations encountered by facilitators.

Table 2. Challenging conditions or situations encountered by AHW facilitators

Mental health conditions (n=59)	**Health conditions (n=37)**
Mental health (general description) ***Anxiety*** ***Depression*** ***Inpatient mental health/forensic*** Bipolar Personality disorders Suicidality/Suicide support Psychosis Self-harm Trauma Schizophrenia	***Dementia*** ***Work in hospital setting (children's unit, cancer, neurology, rehab, teens, complex health)*** Chronic conditions Parkinson's Disease Chronic pain Cancer Traumatic brain injury Chronic Obstructive Pulmonary Disease Multiple Sclerosis Epilepsy Eating disorders Type 1 Diabetes (youth) Motor Neurone Disease ME/chronic fatigue Terminal illness

Physical disabilities and neurodiversity (n=32)	**Social states, conditions or situations (n=20)**
Physical disability/mobility issues ***Learning difficulties*** ***Autism*** Visually impaired Down syndrome Neurodiverse Profound and Multiple Learning Disability Williams syndrome Asperger's syndrome	***Bereavement/grief*** ***Social isolation/loneliness*** Schools: regular schools, special needs, exclusion People in prison Homelessness ESL/migrants Domestic violence Human trafficking
Described categories of people (n=18)	**Other (n=22)**
Care home residents Disadvantaged young people with challenging behaviour Health care professionals/community workers (wellbeing/stress/burnout) Difficult personalities, challenging behaviours Individuals from deprived communities Dementia carers Difficult issues (non-defined)	***Physical or emotional situations/crises in sessions*** • Epileptic seizures, asthma attacks, physical injury • Physical fights, threats of violence • Panic attacks, psychotic episodes, suicidality, self-harm, danger to self/can't be left alone ***Multiple diagnoses, e.g. physical and mental health conditions*** Addiction recovery Physically or emotionally vulnerable

3.3 The work context for AHW facilitators

3.3.1 Delivery settings and conditions of work

Before the COVID-19 pandemic, most facilitators in this study practiced in community-based (non-clinical) settings. Nearly half worked in health, mental health, or social care settings, and ten worked online. Other settings mentioned included schools, prisons, the outdoors, and their own studios. Many worked in multiple types of settings. For programmes not affiliated with organisations, facilitators used community spaces such as libraries and church halls, art spaces, gardens, or forests. Some facilitators partnered with organisations like museums or care homes to deliver programmes onsite where they could take advantage of organisational and infrastructure assets like art and heritage collections or support services for staff and participants. Sylvia, who combines photography with mindfulness techniques said that she did some courses at a museum in a local park:

> That's where we were based, the venue, which is a beautiful building. And then there's a beautiful garden, and then there's a massive arboretum with the lake and everything, it's really beautiful, it's a perfect spot, we're really, really lucky. (I7-O-03)

However, sometimes the work environment can pose its own challenges for facilitators. Since they are primarily not working in dedicated art studios, facilitators often do not have access to the supplies and physical set-up that would be optimal for creative activity. When working in hospitals or community spaces, many freelance artists do not have a dedicated space to store art supplies or conduct their sessions. Jayne described having to travel a long distance to her work site several times a week with her ‘art studio in a backpack’. (I17-Mx-6) Safety risks can arise when working in a setting that is remote or doesn’t have other people nearby. Having practiced in such circumstances, a few facilitators described the importance of having a person or an organisation to call on in difficult situations or to support participants who might need to step outside of the session in a moment of distress.

Many facilitators are also working in physical and organisational spaces that have their own rules, imperatives, and idiosyncrasies that can be challenging to navigate. Trisha, who worked in locked mental health wards, described a chaotic, difficult environment. She did not have enough authority or support to manage patients who were disruptive or to negotiate activities that might have been appropriate but were not considered acceptable by some staff. For example, she ran a regular creative activity session in a common area where people could come in and out at will:

> I'm not in control. I can't shut the door because it's an open door [session]. So I can't say ‘actually, could you come back in half an hour and, and, I'll do something with you then’. So I was reliant on the staff. And the staff member that they asked me to work with, who was an OT assistant, I think was probably struggling a little bit. And it felt kind of, I think she felt quite disempowered by the whole situation. And so it didn't, it, a lot of the time it didn't work. That's what I felt. If I felt somebody got something out of it, I felt like it was a real achievement. But a lot of the time, it felt a little bit like man, management, I suppose just… Yeah, it but, as I say each week was kind of different. (I12-V-6)

In this setting, she felt like she wasn’t a member of their staff and not empowered to raise these issues with management. She contrasted this with a programme that successfully ran in another unit where patients were invited to come in small groups and at specific times, which minimised disruptions. She said this contributed to a calmer atmosphere and the ability to carry out more structured activities.

Other facilitators described similar situations when working with people with personal or social vulnerabilities in settings like community afterschool programmes or schools for excluded learners. Teresa described some students as disruptive or violent, with staff having little authority to reprimand them and teachers sometimes needing to lock themselves in rooms to protect themselves from students. Whilst she was empathetic to the social situations the students came from, she observed:

> It was *really difficult*. And I had to get a new group… so I had six groups from nine in the morning to about two, with literally a 10-minute lunch break, where you'd lock yourself in the room, because they'd be standing outside, booting the door. (I3-Mg-03)

A few facilitators observed that their AHW activities sometimes seemed to be filling gaps in a statutory system that has been reduced by many years of austerity measures. Noting the progressive cuts in services in the local authority and in the third sector, Lisa expressed doubts about artists' roles and responsibilities when working with participants who used to fall under the purview of other programmes that no longer existed to support them:

> It's very questionable that artists are facilitating those kinds of sessions, when actually, you need a bit more structure around that kind of delivery. And, yeah, and I think it does put artists in vulnerable positions. (I10-Mx-6)

3.3.2 Precarious work

While the settings of their work vary considerably, the facilitators in this study reported common financial concerns: very few said they had long-term contracts with a single organisation for their AHW work. Most are freelancers on single project contracts or grants or juggle a series of short-term contracts from different funding sources where priorities may vary from year to year. Some work in AHW programmes where some artists are paid and others are volunteers. Even projects sponsored through NHS arts on prescription programmes, collaboratively developed and contracted for with a stable group of artists or an arts and health organisation, are funded as short-cycle programmes with a constant sense of uncertainty regarding continuation. There are some AHW organisations that secure funding for projects and use their roster of artists to deliver them. These organisations may also provide in-house training, administrative and affective support, and delivery space for their freelancers. Another delivery model described was a social enterprise approach whereby a single artist started out delivering programmes on her own, and then gradually added freelancers to expand capacity. She uses a combination of corporate clients and some grant funding to subsidize work that she delivers for free to those who cannot pay.

Most facilitators had a salient understanding of the value their work to both participants and to the wider system of health and social care. Many described the fortune of very supportive working arrangements with employers, delivery partners, or funders. Yet facilitators' perceptions of value are often juxtaposed with the demands and precarity of the work. Jayne said she recognized that not many people would want to do what she does "because it's hard." Laughing, she added, “and it’s not very well paid.” She then went onto acknowledge that she does find the work incredibly rewarding and loves the health care setting where she is employed. She said that she has worked on month-to-month contracts for over ten years at the same organisation at a rate of pay that has changed little over this period. From her point of view, it’s regular work:

> So, you know, I think, people who works in the arts, so, we're used to it being precarious, in a way aren't we? But, and so I'm very fortunate that it's, so that [regular work] has been a big help to me. So as long as I have enough to pay my rent, and feed myself, then, then I'm okay. (I17-Mx-6)

She also mentioned that she had to move from her long-term home several years ago because she could no longer afford the rent increases. She noted that while her work with the organisation has been supported over the years, she has come to understand the instability of the funding that stems from constantly shifting institutional priorities.

Another facilitator commented on funders’ apparent lack of understanding regarding the value of the care and responsibility of their work when they are questioned about their fees:

> And I guess a lot of [facilitators] that I work with are the same, we, we really *care* about what we do, and we really connect with the people that we're working with. And so you do sort of take on a lot of their, a lot of their stuff. And you have those worries, because you have not only, you know, wanting them to have a good experience, but you know, you have the responsibility from the parents, and you have the responsibility from the funders and the organisations that you're working with. And it's something that you don't notice while you're actually in the room, and you're doing stuff, but it's in the background, obviously, along with the planning and all that kind of stuff as well. And that's why, you know, when people ask you how much you charge for your work, and you say, it's this, and then, 'oo, oh gosh', but then it's like, well, you don't know how much work goes into it beforehand. And afterwards. (I4-O-46)

Several facilitators expressed frustration with having to continuously evaluate and justify the impact of their programmes in the context of unstable funding and short-term projects that might not be long enough for meaningful impact. Olivia described how that uncertainty can interfere with the participant’s expectation of continuation and affects a facilitator’s decisions about the content of programmes and the depth of their relationships with their participants. (I4-O-46) Sometimes a facilitator’s view on what makes an effective programme does not always match the funder’s constraints:

> Whether it's, you know, maintaining mental wellbeing, you don't go to a 10-week program and go, ‘I feel better now.’ […] In order for people to deliver this effectively to get maximum impact for participants, it's in, you *need* this whole package. And that needs to be accepted by, by funders and commissioners and respected within the health service, because I *know* that I am reducing the amount of time and support that people need within mental health services, and I *know* that I'm improving people's lung function. I know that, you know, I'm providing key support for families and people living with dementia. (I-14-M-6)

Several facilitators expressed anger at how little money was available for them to fully cost the delivery of their activities. Many detailed the time they must work 'off the books,' putting in many hours not covered by the fees they are paid. This can include planning, buying art supplies, responding to participant inquiries, engaging in evaluation activities, seeking project funding, or simply thinking about their participants' needs and how to adapt activities for each individual. Lisa observed:

> Most people are sort of begrudging about the idea that they might have to pay you for prep time. You know, or even packing up afterwards. You know, just the physicality of getting in and out of spaces with materials and things, let alone the fact that you're gonna think about what you're going to do, and maybe, you know, maybe make prototypes, maybe kind of think about differentiation, you know, so you're offering a range of potential activities within one framework. (I10-Mx-6)

She added:

> That's why I'm kind of at the stage now of, of, of maybe, you know, either disappearing into another direction or pursuing the art therapy, because it *is really arduous*. There's *so* much extra work in it. And if you think a lot of the other artists that I work with, or that I book in, when we're just working creatively, they just get to come in and they get a really high day rate, and they do the job. And it's done. Whereas with this kind of social engagement work it's *really* difficult. And I don't think it's, you can never factor in the amount of hours it actually takes. And I just find this again and again, with every project. (I10-Mx-6)

A few facilitators said it felt difficult to stand up to sub-optimal work conditions or unreasonable expectations from funders, not wanting to jeopardize future work. Sophia said:

> Challenging situations can cause a lot of anxiety, and concern because, although I have a great relationship with the organisations I work with (and I know they work hard to provide safeguarding for me), the bottom line is I'm a freelancer, and may not be hired again. (O12-O-6)

While facilitators in this study work with a wide range of participants, not all of whom live with CCS, two spoke of their discomfort with how they feel compelled to position their work in order to secure funding or fulfil donor expectations. Faith observed:

> Like I *know* that in order to draw in extra funding or to kind of, you know, I have to talk about my service users as if they're *needy* in some way. You know, like, we work with people with long term conditions and actually, that can feel really uncomfortable because my whole other ethos is about ...the people that I work with are as equally deserving and as equally capable and as equally everything as everybody else. And *yet* in order to get the press release, in order to get that next bit of funding, not, I have, then, to go back to describing them as vulnerable and isolated and, you know, *needy,* and that that can feel really difficult as well. (I14-M-6)

The dilemma in the intersection between their scope of the practice and notions of 'desirable' value can also be seen in funders' expectations for social outcomes. Lisa commented on the mismatch between what she does on an individual participant level with what funders expect when writing a bid:

> Sometimes it feels like you're asked to make some massive claim that's not really based in any kind of evidence was or any realm of possibility whatsoever. And is like, some kind of like, you know, becomes like some kind of abstract concept of societal change. That's like, you can't, you're actually asked to do that, within the framework of funding and all your outcomes, aims and objectives. You're saying, how are you going to see societal change and greater impact and things like that, which is a huge claim and is actually really impossible to evidence and should you be making those claims either and should, should you be encouraged to do so? (I10-Mx-6)

She linked her discomfort with this broad scope of responsibility to her rate of compensation: “Because, you know, we don’t get paid enough to do that,” she said, laughing. But her concern also hints at the ambiguous scope of AHW for funders, facilitators, and participants alike, situated as it is between community arts and art therapy. Intentions and desired outcomes can be stretched towards ambiguous societal goals but not always feel comfortable for the facilitator, who sees their main responsibility to the individual.

Summary of Chapter 3

This chapter provides an introductory context for understanding the work of AHW facilitators, details the challenging conditions or situations of the participants they work with, and examines their work context and conditions.

AHW facilitators describe highly individualised practices with intentions that particularly focus on supporting mental health, wellbeing, and social engagement. This individuality offers the potential for creative innovation but also ambiguity in defining the parameters of their practices, which is discussed further at the beginning of chapter 6 and in Discussion section 7.3. Juxtaposed with the broad range of complex conditions and situations they encounter in their work, this presages the need for facilitators to understand how their creative activities may intersect with the physical and psychosocial manifestations of those conditions and how they can effectively adapt to those needs. The complexity and severity of many of the described conditions also suggests the kinds of knowledge, skills, and practical preparation that may be necessary to respond effectively. These issues will be taken up in more detail in subsequent chapters that address their key facilitation tasks (chapter 4), how they prepare for and manage challenging situations (chapter 5), and what skills and training they draw upon (chapter 6).

AHW facilitators work in many different types of settings but describe some common issues with respect to the impact of both place and overall working conditions. Some settings are rich with respect to material, personal support, and organisational resources, which facilitators say offer supportive working environments that inspire their loyalty and a sense of security. Other settings are described as difficult and even risky, and facilitators experience uncertainty and stress over deficiencies in the physical set-up, poor structural support, and lack of authority. Observing psychosocial conditions that may arise from or be exacerbated by gaps in social and mental health care, some facilitators feel overly burdened by the complexity of participant needs and lack of support for participants and for themselves. The multiple dimensions of participant needs and different types of support are addressed in chapter 5. These stressors are exacerbated by an almost universal perception of employment precarity and underappreciation by those who fund or commission AHW work with respect to both facilitator value and overall responsibilities. Facilitators describe the bind of loving the work while accepting poor working conditions because they want to make a positive contribution but their fear a negative response to bargaining for better arrangements. Another source of frustration is the tension between high expectations from funders, poor recognition of the complexity and skill required for their work, and what they are actually paid. They perceive these factors as both personal stressors and impediments to delivering well-resourced programmes that might have better outcomes for participants. The effect of high expectations on facilitators and their sense of responsibility to participants is detailed in chapter 5, and the relationship between adequately supported programmes and the current structure of social prescribing is explored in Discussion section 7.5.

Chapter 3 Crosswalk Table

Section	Key points	Discussion	Recommendations
3.1	Highly individualised AHW offerings with intentions that address mental health, wellbeing, and social engagement	7.3.1 Promise/challenge of bricolage work	3 guidance 4 professional development
3.2	Facilitators work with participants with a broad range of conditions, with mental health conditions prominent		1 participant safety
3.3.1	Some delivery settings are resource-rich and others are difficult. Some facilitators feel they are filling gaps in a broken statutory system	7.5.2 Tolerate poor conditions to keep work	2 facilitator wellbeing
3.3.2	Facilitators experience precarious contracting and uncertainty. They enjoy their work but feel caught between high expectations and poor reward/recognition of effort involved	7.5.5 Poorly resourced programmes, implications for SP	1 participant safety 2 facilitator wellbeing

Chapter 4. Juggling in the spotlight: What AHW facilitators do in their work with challenging conditions and situations and how they experience it

Chapter Overview

This chapter explores in more detail the tasks and experiences of facilitators working with people with CCS. These facilitators juggle many different elements of intention and action, facilitating creative activity for health and wellbeing, supporting social engagement, and making space for creative expression and emotions. Sometimes they do these things simultaneously, and other times they give attention to one over another, switching back and forth. When it goes well, these elements move effortlessly in time and space and bring joy to the facilitator and their participants. But the reality of working with physical and psychosocial complexity can also strain the dexterity and composure of the facilitator.

In this chapter, facilitators describe the challenges and risks that arise when working with people with CCS. The actions, perspectives, and felt experiences of facilitators described in this chapter highlight the many dimensions of emotional work they do in their engagements with people with CCS. This work has many positive and validating aspects for facilitators, which they often describe as inspiring and motivating. It can also be very demanding, both in the moment and in its carry-over effects on their physical and emotional lives.

4.1 Facilitating creativity for health and wellbeing

AHW facilitators lead artistic activities that involve developing the skills and aesthetic sensibility of their participants, but mastery is not the primary objective. They believe that the act of engaging with and being immersed in creative activity is an affirming health and wellbeing promoting activity. Some of the intentions facilitators describe include supporting participants to explore their creativity and hidden talents, try new things, do creative things on their own, and take ownership of the form and the process. Facilitators also describe a personal development and support intention for participants. They structure a creative process they hope will lead to a sense of achievement and self-confidence in the people they work with by supporting the achievement of artistic goals and offering positive feedback and encouragement.

Facilitators gave examples of their participants developing new perspectives on the world around them and on their own problems. Kate said her flexible approach to guiding creative activities with people who have mental health concerns can lead to changed attitudes and self-conceptions that go beyond the artistic process. (I18-V-6) She teaches participants some art skills but allows them to take control of their own creative decision-making. She described one participant who said at the course outset, “Things have got to be precise. And I need to know exactly what I'm doing.” Kate replied “Well, you know, see how it goes for you. Because we will play, we will explore, and there's no right or wrong answer.” Several sessions later the participant said “I caught myself this week, outside of the artmaking, but kind of going, ‘Ooh! I don't have to know how to do that.’” Kate said she realised the participant had transferred the lessons from the session into a personal awareness in other parts of her life. She added:

> When we look, when we analyze it, we are actually doing quite a lot. But it is just messing around with art materials. And I think the fact that… that messing around with art materials can give people that much, um, god I, I don't know what's the word… agency, is that the word? (I18-V-6)

Facilitating creative activities with individuals with CCS often requires adjustments to the usual approaches to teaching an art form. Many facilitators explained their adaptations for people with physical, neurological, or communication limitations. Some facilitators described this as a challenge, and others saw it as invigorating or as something to be positively overcome to enable participation. Tessa, who has participants work with a variety of art-making materials, described the emotion she felt in being able to adapt the creative activities and communication to support a participant with motor neurone disease. (I5-V-6) Olivia talked about developing circus activities for a wide range of abilities in a course designed to promote physical activity and self-management for teens with type 1 diabetes. She observed it is sometimes difficult to know how to balance their desire to stretch themselves while managing safety concerns. (I4-O-46)

Artists who have learned specialised cross-disciplinary techniques to work creatively with particular conditions describe how participating in an enjoyable art activity can have multiple health impacts on the experience of physical illness, isolation, or mental health. Faith described this dynamic in her singing for breath group for chronic obstructive pulmonary disease (COPD):

> When you look into the, the kind of trajectory of COPD, most what, what happens is people get, because they're breathless, they find things harder. And so they stop doing things as much. But unfortunately, that makes the condition worse. And it's like a kind of decreasing spiral. And the research shows that when you encourage people to do something that's kind of manageable and has both that sense of exercise and doing something for their respiratory condition, but also has that social element, that you got some way to kind of changing that spiral in the other direction. And that's *exactly* what we found so, but because of that increasing isolation that a lot of them experience, mental health becomes an issue as well. So not only are they then struggling with a physical condition, but they're also really, really struggling with those increased feelings of isolation, separation from friends and family. And, you know, I've got a few, I've got a couple of people who come to that group who *literally,* coming to my group is the *only* time they leave the house. (I14-M-6)

This observation demonstrates the range of knowledge and skills related to health conditions and the emotional sensibility that this facilitator uses to adapt creative activities for both artistic and health or wellbeing intentions. This description was unusual amongst the facilitators in the study and suggests an approach that is deliberate and outcome-focused rather than seeing creative activity as simply a distraction or escape from participants' situations (for example, Sophia's story in 4.4). It may be that this orientation towards delivery is inherent in the specialised singing-for-health training Faith received.

4.2 Encouraging social engagement

Most facilitators recognized the value of social engagement that can arise in a creative group, and several see facilitating this as an explicit part of their goals. Facilitators described this engagement as a positive aspect of the emotion work they do and say it is a key source of satisfaction for their participants and for themselves. As described by Faith above, social engagement can positively impact mental health and wellbeing. Facilitators make connections with individual participants over the art-making in person and sometimes by following each other on social media. As participants come to a venue over a period of time, such as when families participate in art engagements in a cancer ward, there is a regularity and sense of looking forward to the encounters where powerful relationships between the facilitator and participants can develop in the context of difficult circumstances.

Facilitators also talked about developing connections between members of the group where, in addition to art-making, participants share their personal stories with each other, form group bonds, and support each other by giving encouragement or showing empathy to individuals in distress. Sometimes the art-making prompt is the gateway to the engagement. Jayne said:

> I got people talking about holidays and sharing experiences, and, and everybody just came alive. It was, it was just an *absolute* privilege, and then I'd get people doing a bit of drawing... But, you know, mostly, it was really about storytelling. (I17-Mx-6)

When participants have communication difficulties, facilitating social engagement is a challenge that can be especially rewarding to overcome. Jayne said:

> I can remember a woman, even in a deep, deep stroke with no communication at all, but bringing in objects, and it was a, it was a stone that had been cut so you could see inside and she was just lost in it. And then we kind of had a conversation retracing our fingers around it together, you know this, there's just *always something*. If somebody, if you've got that engagement, then you can develop it in some kind of way. (I17-Mx-6)

Describing a participant who could not speak and struggled with dexterity and fine motor skills, Tessa recognized that being able to help her connect with others personally validated the frequently complex adaptations she had to make for this individual to participate:

> Part of why people come to sessions is to do with connecting with others, and that was partly it for her, which is actually quite difficult for her because of her verbal communication or lack, lack of verbal communication. And talking through an iPad means that she has to take a long time to put what she's trying to say into the iPad and then to say it but despite all that, I feel like she's gaining... She's gaining things from the group from coming to the group, which is *fantastic* for me, it's like, but I do feel quite emotional about, and kind of, very kind of vehement about wanting to be there for her, really, to make sure it works for her. (I5-V-6)

Some AHW organisations take a different view of social interactions in their groups, and they often have their own approach and protocols for their artists. Guided by her organisation's philosophy and her facilitation experience, Kate tries to steer participants in a mental health recovery art-making group away from discussions of their personal difficulties:

> I'm really comfortable with this now. But there's always the issue of people wanting to talk, wanting to talk about their issues. And so people wanting to use it as a space to share experiences, but I'm really, as facilitators are in this field, I'm really clear to people, it's not a talking therapy group. And the, the focus is the art-making. And that's the therapeutic thing that we're doing…
>
> I'm not, you know, you don't want to be going, 'stop talking or don't talk about that,' you know, you've got to find ways of doing it that are gentler and more positive. I guess that's what I try and do so and that's why the arts are lovely, because you're constantly bringing people back to the art and, sometimes, well, most of the time. (I18-V-6)

While Kate refers to "facilitators […] in this field", the prior examples and those in the next section show the variety of philosophies and approaches to dealing with the sharing of personal experiences

4.3 Attending to and making space for participants' creative expression and emotions

Engaging in creative activity often stimulates emotional expression through an artistic medium. As the facilitators described in different ways above, the social engagement around these emotional promptings can be something to be encouraged or be steered away from. Facilitators described the intricate and subtle ways they monitor the emotional and physical states of their participants, accommodating and making space for their participants' feelings, needs, and circumstances. This work demands emotional intelligence to perceive and respond to others and invokes a strong sense of caring and responsibility from many facilitators.

Christine highlighted the energy required by her constant engagement and focus during sessions to monitor participants' states, and the need to react or adapt to situations that emerge:

> Yeah, I mean, it's, you have to absolutely concentrate for the whole session. You know, you just can't, you can't switch off at all. It's an absolute focus. And generally, you find the two hours have just gone because you, you're just totally there in the situation, thinking about it all the time, listening to what everybody's saying, and thinking what the implications of those comments are. (I2-P-6)

The phrase "holding space" was mentioned by many facilitators as an important aspect of their work and a responsibility that can have both positive and negative aspects for them personally. Facilitators described this concept in different ways, including creating a comfortable environment, offering empathy and sympathy, holding the group, creating conditions of physical and emotional safety, and making sure participants feel heard and supported.

While the facilitators see this as a positive aspect of their work, it can also create a bind for them as they feel the need to listen to and 'hold' the different stories and experiences that come into the creative space. This can be hard work -- caring for the participants, being concerned about their experiences, feeling responsible for their wellness, and needing to be aware and responsive at all times. Mary said that in her spoken word programmes, sharing personal material is part of the activity and many things come out. (F6-P-6) She did not really see it as challenging, more that is part of the intention. For others, sometimes it can be quite distressing and have consequences for the facilitator's emotional wellbeing. Tessa said she felt that, in doing this work, she had to be "open, in order to create that safe space, I guess, for people coming in." But she became emotional when she described thinking about participants who were struggling in their lives and had stopped attending sessions:

> And then they contacted me to say, 'I'm really struggling. I really want to do it. I can't do it. You know, I haven't been able to do it yet. But I would really like to…' And how I can support them to actually make that happen? You're holding that all the time… [crying]. I think that's the stuff, you're holding on to everyone. (I5-V-6)

These reflections point to the many types of emotion work facilitators engage in when making space for their participant's stories and needs, from the performance of creating positive experiences to the emotional investment facilitators make in their work and the impact it has on their participants. How facilitators manage, experience, and self-regulate around these emotional dynamics is discussed more deeply in chapter 5.

4.4 Rewards, validation, and motivation when working with participants

Most AHW facilitators said their creative health work is very fulfilling. The challenges and complexity of working with participants who have CCS make the rewards of success even richer. Facilitators describe what they do – facilitating creativity, supporting social engagement, and making space for emotions and expression – as positive and beneficial for their participants and for themselves. This benefit, and the validation they receive from participants, is what motivates them to continue with the work, despite the challenges that may arise.

Facilitators described some of the positive effects of creative health sessions on their participants. They witnessed them achieving things that might not have seemed possible or forgetting for a time what their problems are. Some facilitators described tracking the progression of their participants, taking in the positive results from evaluations or formal measurement, or having participants' art achievements win awards or be recognized by others. This validation was described by many facilitators as a key source of energy and motivation for doing this work. Participants often expressed the value of the sessions directly to the facilitator. Gillian said:

> People say lots of really positive things to me about it, they say, you know, they say thank you a lot. They, they say, how much it's meant to them. And that it's really been something that has been sort of profound and positive for them and been like, a highlight in their week, you know, and has helped them especially if they are going through a tough time, perhaps if they're recuperating from something. (I13-V-6)

Some facilitators describe the benefits of doing this work in very personal terms. It is important to them that the work has a positive impact. They describe it as 'utterly inspiring', 'rewarding', and 'exciting', with the challenges keeping them on their toes and 'keeping it alive'. Some said that the challenges were actually part of the appeal of the work, using phrases like 'excited by it' (Catherine, O8-Mx-6) and 'if it weren't challenging, we wouldn't be doing it' (Ella, F5-T-6).

Most facilitators said the social aspect of their work was valuable to them personally, and several described the work as important to their own wellbeing. Catherine, who had previously worked as a counsellor, said:

> I didn't know for myself, in terms of my own mental health, being part of an arts team is amazingly helpful. You know, normally at this time of year, I'd be, I'd be sad. And I would, I used to have a problem between about [autumn and spring], where I had this sad period. Since I've been working with expressive arts. I haven't felt that at all. That's helped me. But, you're not supposed to say that are you, as a counsellor, not supposed to say it's helping *me*. (I9-Mx-6)

The intersection of a facilitator’s lived experience and the positive and negative effects of working with CCS is explored further in section 5.2.3.

Freya and Jayne used the word “addictive” to describe the feelings that often arise for them in sessions:

> There’s like a feeling you get, like, when people have a good time, and you’ve been a part of that, and you’ve helped facilitate that. And there’s just like a vibe and like that feeling is, is really good. And it like yeah, it feels really, it’s quite addictive, I think. I feel like, once I was working with groups and like delivering sessions, like when you first do a really good session, you get like such a buzz. And then you are always chasing that like positive session buzz. And for me, it only comes from like, their experience. (Freya, I15-V-03)
>
> Mostly, it’s, it’s about, you know, doing something nice. And, and, and that’s very addictive, isn’t it? Yeah, I guess, you know, for them and for me, (right) perhaps. (Jayne, I17-Mx-6)

Other facilitators use words like ‘privileged,’ ‘lucky,’ and ‘blessed’ to describe their feelings about doing arts and health work. Christine said:

> But *most* of the time, what we do is incredibly rewarding, because you see people developing confidence and self-esteem and having fun and forgetting about what, what it is that’s their problem. And I always say I am the *luckiest person* there is because every week, I make a difference to somebody’s life. Every week. And it’s just a fantastic thing to be able to do. (I2-P-6)

Sophia’s story

Sophia is an animation artist and facilitator. In this vignette drawn from the online discussion group, she parsed her role identity from messages she’s heard from the AHW field as well as from the views of her colleagues, all in the context of the many settings she practices in. She finds it personally rewarding to facilitate opportunities for participants to overcome obstacles and to support their personal development.

> Pre-Covid the facilitation part of my practice was in a variety of settings; schools, PRUs [Pupil Referral Units], community groups, care homes, day centres, wards. Not exclusively but often arts in health, so; mental health service users, eating disorders ward, adults with learning difficulties, adults with PMLD {Profound and Multiple Learning Disability], people living with dementia, older people at risk of loneliness, family support projects.... Always as a creative facilitator, never a therapist, although a colleague once termed our work as ‘distraction’ therapy. A health worker commented ‘You get to help people have fun’. (I love that idea!)
>
> Possibly the main challenge is managing other people’s limited expectations of what the participants can achieve, e.g. the support staff who pulls the wheel chair back so they can complete the activity on behalf of the participant because ‘they can’t do that’... or tells me a participant can’t join in a storytelling activity because ‘they can’t speak’. Group dynamics are often challenging too, but I have learned from colleagues ways of gently diffusing and managing these situations.

> The positives are endless! The smiles!!! The sense of pride, achievement, self-esteem, growing confidence, and even just forgetting their worries for an hour.
>
> Transformative moments for me are when the group forms and supports an individual to achieve. The support staff who work with me and find innovative, practical solutions to enable a participant to join in. The moment when, after several sessions of persistence and gentle inclusion by my colleague, the participant contradicted his carer, and *did* speak. (O12-O-6)

4.5 Challenging experiences in facilitating work with individuals with complex needs

The nature of the complex medical, psychological, and social needs and situations that facilitators encounter with participants means that there will inevitably be challenges that arise in their creative facilitation work. While most facilitators in this study described demanding situations in their work, there are some who noted the infrequency or lack of impact of these experiences, or even that they were stimulated by this aspect of their work. “Nine times out of ten everything goes OK”, said Terry. (F2-V-46) Christine said:

> I do want to stress that these challenges are the exceptions, you know, that you do get the difficult cases. And they do stick in your mind, because, and I don’t want to call them cases, they’re people. But *most* of the time, what we do is incredibly rewarding. (I2-P-6)

Nevertheless, comments by facilitators related to challenging experiences outnumbered positive descriptions by almost two to one, and there were many uses of the words ‘difficult’, ‘exhausting’, and ‘hard’ to describe their work.

Many facilitators have worked with groups that are condition-specific, such as people living with dementia, cancer, or neurological conditions. Adapting to these conditions is a regular part of the work. Sometimes the conditions or situations themselves present challenges, other times the behavioural aspects of psychological conditions or social situations manifest during sessions. Most facilitators in this study have encountered one of these situations, and some have experienced several or find that many of their groups are characterised overall by a challenging dynamic. Several say that while these situations might be infrequent, they nonetheless have an impact on all who are in the room.

Facilitators described a wide range of psychological and behavioural challenges presented by some participants, such as those who display anger, have conflicts with each other, exhibit paranoid behaviour, threaten violence, or engage in self-harm. For example, Trisha described a disagreement between two patients in a locked mental health ward about whether music would be played during the art activity. One of the patients became agitated and threatened to grab a piece of pottery and use it to hit someone. Trisha said:

> So then the OT assistant was saying, well, that's not going to happen, you know, you're not allowed to take anything out this room. But, but then [the patient] grabbed this massive pot, and she ran out of the room off to the ward. And, and there's a lot of kerfuffle in the corridor going on. And she didn't come back. The other guy who I was working with just found this just too difficult. He went off. And he came back after about half an hour and it was kind of towards the end of the session. (I12-V-6)

While there were staff to manage the distressed patient, Trisha recalled that she was quite frustrated by the situation and felt bad that the other participant was upset. She remarked on the unpredictability of the environment and how this must continually be accounted for when planning activities in this setting. (I12-V-6) It also points the need for assistance in managing participants who may be having a problem while others in the group are attended to, which is explored in-depth in section 5.3 on support.

With respect to behaviours that don't necessarily arise from a physical or psychological condition (e.g. participants not listening, making racist or sexist comments, interrupting, or dominating a session), some facilitators said they often feel uncomfortable or challenged with respect to setting boundaries around these behaviours. They describe having to maintain a cool and respectful demeanour, setting limits in a way that doesn't undermine the participant or the confidence-building intention of the sessions. Sometimes this is successful, and sometimes the participant doesn't return.

Gillian said it was hard to work with participants' self-judging and negative attitudes about their own conditions or the art-making when they refused to engage in an activity or destroyed their own work:

> That I find difficult. It's like if, if, because often, if there's that kind of like refusal [to participate], or defence kind of thing, you don't necessarily know why or what's going on there. Quite often, I think, if that's going on, usually, there's something that's quite triggered in a person. And it's not necessarily fair, especially in a sort of, almost like a public context, like, within, within a group space like that, to push someone to go where they're not willing to go. (I13-V-6)

Gillian is pointing to the evocative aspect of creative activity where the facilitator is not just teaching art but needs to be aware of and manage emotional volatility that may arise in a group setting with vulnerable participants. Understanding this dynamic and having strategies to respond may protect the facilitator from seeing such events as personal failures, which is discussed more in section 5.2.2.

Disclosures of abuse can trigger the need for facilitators to stop and engage in safeguarding procedures alongside managing the upset this may cause for themselves and others in the group who witness it. Freya described her first experiences working with adults who had complex needs and trauma. She felt unprepared for what they would tell her about their lives, holding that knowledge in herself while maintaining a calm and receptive stance. (15-V-03) For a facilitator, this simultaneously requires personal emotional regulation and juggling between protecting individual participants, the group, and themselves. Marie described the discomfort she felt when a participant made a personal disclosure about domestic violence in a group. She recognised the value of creatively prompted self-expression but wants to feel better prepared so that she can respond effectively:

> This was definitely challenging for me as I wasn't expecting the disclosure but at the same time wanted to support the person and the group in the best way possible. I am not trained to support people who have experienced domestic violence so questioned my ability to respond effectively. […] As a facilitator of creative activities, I do have mixed feelings about this, I am happy that I facilitate freeing environments, that's what creativity is all about, but I don't feel completely equipped to support those who have or are experiencing personal challenges. (O2-Mx-6)

This example shows that a facilitator needs to be aware of and feel comfortable with safeguarding procedures (which in fact may require immediate action that could take a solo practitioner away from the group). For their participants' safety and their own confidence and wellbeing, it is important to know how to provide basic support in these triggering circumstances. Having these skills, access to co-facilitation, and adequate participant support follows from both responsibilities.

A few facilitators described experiences of suicidality amongst their participants. One described a participant from a social prescribing programme who had come out to her co-facilitator and said they were considering taking their own life. The co-facilitator had only her colleague to share the story with, something that they both found difficult to carry. Another facilitator had several participants text her outside of sessions that they were thinking of committing suicide. She was able to contact each individual's referrer to get them to respond, but this option may not be available to solo practitioners or for participants who self-refer to creative programmes. These suicidality examples, and Teresa's story below, show the importance of having an organisational structure that cares for the participant as well as the facilitator, who must bear the impact of such traumatic situations. It also points to the need for mental health first aid or similar training to equip facilitators with management and emotional safety strategies to protect vulnerable participants and themselves.

Teresa’s story

Teresa’s account below describes her experience of suicidality after an art-making session in a prison setting.

> **Teresa**
> [O]n my, probably my first, maybe my second week, one of the guys who was *amazing*, came and sat next to me, and we talked about art, did the whole thing and he was really good, I think it was the first day. And then he killed himself that evening. (Oh!) And he was so talented. And you know, he was about 50ish, I think, and very generous to everybody else, you know, lovely guy.
>
> And then, so that was difficult for *me*. But also, when the guys came into the room next day, and obviously everyone knows, but they don't say anything. So that was hard, because they were protecting their... vulnerability. And they said to me, you know, we're well, in, not in private. But when no one else was in earshot. A couple of them said, you know, I'd say, 'you're alright?' And they just kind of shut me down. Because if anyone hears them being emotionally vulnerable, or whatever, their, you know, *that*'s a weakness. So nobody said anything.
>
> So I was like this, I felt really… (pause) you know, upset for him. And these guys who knew him, but no one was saying anything. Nobody said anything. Nobody ever said anything, you know, one guy came in, who'd heard everything and was really upset and angry, because he'd, he'd heard, he'd been outside the room, you know, because this guy took his own life in a quite, awful way. And he could hear it. And he could hear the other side, that the officer is not responding as he fell. But, you know, so he was really angry and upset. And there was also, that was the only thing. But that's quite difficult.
>
> **Julia**
> How did you how did you manage that, that experience, for yourself?
>
> **Teresa**
> Um, well, like, I did talk to my manager, because I was quite new, I think at that point. And I remember say, I did say to her, and she said to me, she said, she was very nice. And she said, there, you know, we have a phone line you can ring, and stuff. She said, you can do that. But she also said something, which was quite useful. And she said, You know, I said, 'I don't know why he would do that.' Why that happened. And she said, it was a trigger, you know, she said, you can never, it's not necessarily anything to do with anybody. It's just that trigger point, which that person is waiting, you know, you don't know when it's gonna happen. And was I like… it was fine, you know, everything was good, looking forward to the next day, I've got all these books ready for him and we've talked about the project he's going to do it. So yeah, that's kind of it, really. (I3-Mg-03)

This story demonstrates Teresa’s exposure to the trauma of the situation, its repercussions on others, and as she revealed later in the interview, the intersection with her own lived experience. It did not appear from her retelling of the incident that there was adequate emotional support for her or the other participants. The story also illustrates the challenge of navigating the particular emotional display rules of this institution and the tragic contrast of her own hopes for the participant with his seemingly inexplicable action.

Summary of Chapter 4

Facilitators have described different ways that creative activity leads to wellbeing effects.
The relationship between creative activity as a catalyst for social engagement and emotional expression arises as a positive benefit for some facilitators but may require containment in the view of others. These views have implications for how facilitators design workshops and how participants experience them. From the participant perspective, social engagement related to their conditions or experiences might be desirable, and they may also want to express and receive support for emotional reactions that are released by their creative explorations. On the other hand, facilitators feel different levels of comfort with these interpersonal dynamics that may relate to their training, practice philosophy, and how they manage boundaries. These issues will emerge in more detail in the results chapters 5 and 6 and be discussed in the larger context of emotion work and professional development in discussion sections 7.2 and 7.4.

The varied challenges of working with participants with CCS described in this chapter begin to point to the range of non-artistic knowledge and skills facilitators use in this work as they need to respond to medical, emotional, and behavioural needs or emergent situations. This is explored further in results chapter 6 and discussion section 7.4. While critical incidents may be uncommon in the context of a practitioner’s overall experience, the unpredictable nature of personal crises suggests that facilitators need to prepare for potential challenges through training and by having adequate support. The examples in this chapter also highlight the responsibility that programme commissioners and social prescribing referrers have for fully understanding AHW facilitators’ skill and support capacities alongside participants’ vulnerabilities and exercising accountability for the safety of both. This is further addressed in discussion sections 7.4 and 7.5.

The examples above also highlight the interpersonal and intrapersonal emotion work facilitators engage in to manage their participants’ experiences and their own reactions. This emotion work can draw on positive facilitator attributes and have positive benefits for both, but it can also have negative impacts on facilitator wellbeing and highlight deficits in emotional management skills and support. How facilitators manage these challenges in the moment and after their sessions is explored further in Chapter 5 and in discussion section 7.2.

Chapter 4 Crosswalk Table

Section	Key points	Discussion	Recommendations
4.1	Teaching creativity is central Creativity helps mindset changes Condition-related adaptations are necessary – not always easy Creative enjoyment can lead to multiple wellbeing outcomes	7.2.2 positive emotion work 7.4.4 better understanding mechanisms of creativity on health, need for more research into training/practice	4 professional development 5 research
4.2	Social engagement a key positive outcome for participants and facilitators. Some facilitators want to focus on the art and limit discussion of personal difficulties	7.2.2 positive emotion work	4 professional development
4.3	Attending to participant emotions requires facilitator empathy and skills – it is often emotional support work. Sometimes this is intended and expected, sometimes it is overwhelming.	7.2 emotion work 7.4.2 breadth of skills 7.2.5 empathy and boundaries	2 facilitator wellbeing 3 guidance 4 professional development
4.4	Facilitators find the work personally rewarding and validated by feedback and participant experiences	7.2.2 positive emotion work	
4.5	Facilitators face challenging situations in their work, including manifestations of conditions, behavioural issues, negative attitudes, safeguarding disclosures, and suicidality.	7.2.1 dimensions of emotion work 7.2.3 demands of caring 7.2.6 making emotion work visible 7.4 training 7.5 support and implications for social prescribing	1 participant safety 2 facilitator wellbeing 3 guidance 4 professional development 5 research

Chapter 5. On the stage and behind the scenes: Managing the challenges of facilitation and the role of support

Chapter overview

This chapter looks at how facilitators manage what arises in their sessions, between themselves and their participants; how they manage and process their own experiences when the sessions are over; and to what extent they can call on external support to help in their work. As part of managing the emotional dimensions of their work, facilitators must make decisions about the interpersonal boundaries they use with participants and the intrapersonal boundaries they use within themselves.

5.1 How facilitators manage in sessions, with and between participants

As described by the facilitators in this study, managing interactions with participants in AHW sessions involves many different tasks. These include detailed preparation before sessions, managing emotional expression in the group, managing expectations, balancing the needs of individuals and the group, and managing themselves in relation to others.

5.1.1 Preparation

Several facilitators said that preparing for what might occur in advance of sessions was a critical part of working with people with CCS. For some this starts with programme design, to ensure that activities are adapted and appropriate and that support is in place for participants and/or the facilitators. Charles said his arts-in-hospital research programme gave careful consideration to care, ethics, and responsibility in designing how participants and artists interacted, providing support to all at each step of the process. (I1-Mu-46) Other facilitators discussed the value of participant risk assessments and knowledge of participant needs in advance to ensure the programme runs smoothly. Mary said:

> But yeah, just before you even start a project is, is find out, you know, find out who's there to support you, find out make sure, you know, you know that there's any extreme problems. I mean, I think personally, I think it's important to know if there's anything you need to know about in advance and can be prepared for that, just pre-planning, so that when you go into that space, you feel more secure, and therefore the group feels more secure. (F6-P-6)

In the focus group, Terry linked this kind of advance knowledge with how she manages responsibility for her participants, saying:

> We have risk assessments for everybody, and they're updated, and I'm informed of all of these before I work. So, I think again, it's, it is like what [Mary] was saying, like making sure that you know

> what, exactly what you need before you will walk into the situation. The impact on me therefore, is minimized, because I take that responsibility away from myself almost, if that makes sense. (F2-V-46)

But how much advance knowledge facilitators want to have about their participants varies. Some want to anticipate and manage risk and others don't want to prejudice their interactions with the participant, preferring to see them as a person doing art rather than a person with a condition or a 'problem' to be managed. Freya said she feels better not knowing, because then she might be taking that knowledge into herself from the beginning, affecting how she interacts with a participant. She believes she could probably spontaneously manage anything difficult that came up. But she also knows the importance of critical information to guide what she does, and is conflicted:

> But then knowing is important, because, if I'm running a session, and I go towards a topic, it could be completely inappropriate for a participant if I didn't know, because… we used to do like a stress management workshop. And we used to just, and we used to have like scenarios, we used to talk through with the young people, about like, pretend children that were going through stuff, and we needed to know what they were going through. So, we could pull anything and change anything, just in case it was triggering for them. So, I think it's important to know, but sometimes not knowing was okay. Like it felt a bit better. (15-V-03)

Kate's organisation tends not to share the details of participants' conditions with facilitators. She said she relies on a different kind of preparation, combined with experience and intuition, to manage unexpected crises. She said that in such moments during a session she is thinking:

> [W]hat's going in my head is, how am I going to deal with this? In a quick, what's the, what's the quickest, when you're making very quick, quick decisions, really quick decisions, and acting on them without I guess, because in my head, I've got these systems in place. So it's kind of drawing on those resources, of knowing what they are, and just acting just, just then doing them rather than… I think it's preparation, I think I've prepared for things that might happen. So just by knowing the venue I'm in, the partner I've got there. I know that if there's a situation, this is what I do. (I18-V-6)

Another strategy used by facilitators to manage what might arise in working with participants with CCS is being clear about their role and responsibilities and delegating or referring out participants they feel should be cared for by others. These statements might be conveyed verbally when talking to a potential participant before a class begins. They might be written into participation contracts and include further details about the facilitator's role, qualifications, and referral or signposting practices. Several facilitators said these contracts have both a management and a preventative value. Maddy said she didn't feel a burden of care as she was clear about the contract and signposted to excellent services, adding "I feel the contract and clear definition of the session is effective in managing risk." (O11-Mx-46) Others said they had discussions in advance with the organisations that funded their projects, making clear what they offered and what they did not take responsibility for.

Other role delineation/management strategies used by facilitators include having support for participants in sessions and having advance arrangements for referral to other services. These will be discussed in detail later in this chapter.

5.1.2 Managing emotional expression in the group

Facilitators described many different approaches to managing the emotional expression of participants in sessions. Some said they deliberately allowed space for personal stories and emotions to come out (as described in section 4.3 on holding space). Others spoke in terms of limits and boundaries, and many described the challenge of finding a balance between free expression and restraint.

Gillian often explains to her participants that creative activity can invoke emotional material and she invites them to talk about it. She linked this invitation to the satisfaction that participants express about her facilitation:

> A lot of the time, with creative stuff, there's this voice in people. And so that, and I will raise that a bit like, at the beginning of the session, if anything comes up, you know, quite often I will say, you know, if, if stuff comes up, and you want to share it, or you want to talk about something, you know, this is a safe supportive space, you're welcome to do that, you know, or you don't have to. And if you want to ask afterwards, privately, about something, you know, it's like... this, you know, doing any kind of creative work can kind of stir up the silt. And I suppose what I'm saying is, let's, let's be okay with that, you know, that's what I try and say to people, and, and I think that's what they respond to, and in their comments, they say things that, they say, you know, '[Gillian] is really, you know, enthusiastic and supportive' and, you know, 'encourages us in personal ways', you know, like, sort of 'responds to us as individuals', kind of thing, and has made me feel kind of more, more confident, and more willing to keep going with my own creative work, you know. (I13-V-6)

Sylvia designs her sessions so that participants break into small groups to discuss their art-making and what it brings up for them so that, with each session, participants feel more comfortable and perhaps explore more personal material. She directs that they should only go as far as they feel they can go and signposts them to outside support if they need it. (I7-O-03)

Mary said that participants often share personal material in her spoken word programmes. (F6-P-6) She didn't really see it as challenging, more that it was part of the intention of the programme and natural, given the art form. Brynn sees that expressing difficult emotions can be generative for participants, but also requires a delicate balancing act to maintain boundaries:

> Of course, upsetting feelings need to be given space to breathe and can be extremely cathartic, and can also produce very creative work that others relate to, so it is how you encourage a supportive environment that allows these feelings to be valued and not to be damaging. However, there are clear boundaries where if there are emotions that come up that you feel as a practitioner need more professional support, you can forward the person to these extra places and also this allows you as a practitioner to know your own boundaries. (O19-P-6)

Some facilitators described situations where they felt it was necessary to guide or boundary their participants' emotional expressions. They did this through gentle redirection or by limiting discussion about particular topics. Kate and Christine described different ways of doing this in their respective creative forms of visual art and writing. Kate said:

> I'm sort of realizing that things are going a little bit too intense in the conversation or chatting or not appropriate for the type of group and I can just bring it back to the art really subtly and gently, usually, without having to be too hard-handed about it. Occasionally I have to be more direct with somebody. And, and, you know, 'this is not the space where we're doing that, this is your time out from all that.' And, but I would usually do that after a session, you know, give somebody a call or, or hang around a little bit after the session or something like that. (I18-V-6)

Christine described teaching participants how to write about emotions from a depersonalised perspective to start with, giving them space to express their emotions in a manageable way.

> If you're looking at it from a writing point of view, then what they write, without any structure, is self-indulgent. I think that they are far more likely to be helped if they can manage what they're feeling and, and look at what they're feeling. And think about what they're feeling. So, it's a way of doing that. (I2-P-6)

Sometimes facilitators struggle to absorb participant emotions and experiences that can feel overwhelming for them. Freya described her difficulty working for the first time with adults with very complex needs and trauma in a community-based programme:

> I found it really hard to understand like how much they would share with a stranger. And obviously, like, it will be the first time I met them, and they'd be telling me, like, really horrible things about their lives and really difficult things. And it took me, Yeah, I couldn't really get my head around that because I would… never… do that. […] But it was, it was strange to have to hold that, I think, and figure out a way to do that. And it was hard, like in my full-time job. Like I found it very difficult to work with people like that. (15-V-03)

Facilitators working one-to-one with participants often describe such arrangements as emotionally intense and demanding. It can be challenging because the regular closeness creates an atmosphere of personal sharing alongside the artmaking. Helene said she sometimes hears about situations of potential danger faced by a client who engages in risky behaviour following a traumatic brain injury. Recognizing a pull towards a 'mothering' role, she poignantly describes the emotional bind she finds herself in, between offering support and getting too involved:

> So, I'm one of her prime people she speaks to, and it is quite hard, I think, not to feel emotional and get cross about things and you have to really, I just have to really, be really careful. Luckily, we have a really good, she has a great collection... she has two or three carers who are fantastic and we talk a lot very openly about the situation and the girl herself is fantastically open. But, but it's, it's funny how you do you start really caring and start wanting to go 'Now listen, you've got to sit down and you mustn't do this. And this is what...' you know I'm feeling, just thinking oh my god, I'm kind of suddenly turning into a sort of mother a bit.
>
> But I do… you do have to pull back a bit because also you you've got to give them the right help, not just the help that you think you would need in any given situation and, and that's the difference, isn't it is, from being a therapist to being an artist, you know, that's the, you're kind of there and you are a support, but you've got to, you've got to support, you're not, you know, you're not being called upon to sort out their psychological problems, per se, it's the, it's your, your, in the experience of their life around a bit a bit of bit. It's quite hard, sometimes I think it's really quite hard. (Yeah). And not to really, really, really be fond of some of them, really fond. And, and that's quite hard, because that's a huge emotional thing. (F3-V-46)

In several of her comments, Helene describes how she struggles to manage her client's emotional expression and the limits of her emotional engagement as a facilitator. She fears she might be straying from the territory of therapeutic art into that of talk therapy or motherly support. The ambiguity of these disciplinary boundaries may contribute to thin interpersonal boundaries with her client, which adds to her ongoing emotional distress. (F3-V-46)

5.1.3 Managing participant and personal expectations related to outcomes

One of the challenges most frequently mentioned by facilitators was managing expectations, both the expectations participants have for themselves and the expectations that facilitators have for their work.

Participants sometimes have expectations for themselves that facilitators feel they must respond to or may feel concerned about. These can include wanting to have a wonderful piece of art at the end of a session or feeling frustrated because they can't do the activity fast enough or to the standard they have in mind due to artistic or physical limitations. Ethan described participants who are reluctant to engage because of preconceived notions of what is good or bad artistically. (O10-Mu-6) Olivia described trying to manage the unrealistic expectations of participants and then feeling personally responsible because something did not work out. (I4-O-46) As mentioned before in Sophia's story (section 4.4), sometimes it is difficult to manage a carer's expectation of what a participant can and can't do. (O12-O-6)

The weight of these expectations can be a part of the facilitators' experience and affect the expectations they have for themselves to have a positive impact for all their participants. Many said they feel that participants should come away with an experience that results in a tangible achievement or improved health outcome. They are frequently aware that they are expected by others to ‘make a difference’, and one said she was aware that she burdens herself with doing a good job (O3-M-46). Many use the word ‘responsibility’ to describe how they experience the expectations they have of themselves or that they perceive others have of them. Olivia said that the feeling of responsibility was in the background all the time, to make a difference, be aware of participants’ conditions, and make sure they don’t do anything harmful: “So although it’s there, it’s in the background. And I think that’s why it can be more exhausting because it’s just kind of there.” (I4-O-46)

Related to this is their desire that arts for health should work for everyone, and some find it difficult to accept that it might not. Some facilitators described their distress at feeling helpless when they cannot positively affect a participant’s situation or keep them in the group. Lisa observed that when you’re working with someone who has mental health issues, it’s incredibly sad to observe the signs of their illness returning and know that when they crash you can’t help them. (I10-Mx-6) Ella told of a project she was doing with occupational therapists in a hospital setting, where hope, concern, and hardness intermingle:

> At that time, I did have discussions about ‘oh, my God, I can see so and so and they’re falling down, and what can we do? And how can we intervene, and they’re going to end up back in hospital.’ And I learned then that actually, there’s, not only is there nothing I can do, there’s nothing the OTs could do either, that person just had to get ill, to be hospitalized, to go around again. And so I, I bring that kind of hardness to my understanding of where my boundaries and expectations are when I’m working in a group. (F5-T-6)

Other facilitators echoed this kind of hard-won equanimity about expectations and outcomes. Several said they create personal boundaries to protect their own mental health. Marie said that the demands of the work were significant enough that on occasions she considered leaving the field, but she is learning to manage her expectations. (O2-Mx-6)

Sometimes there may be a mismatch between explicit and unspoken expectations from funders, participants, and facilitators and the limits of AHW activities. Understanding these dynamics and making intentions and potential impact more explicit from the outset could help facilitators manage expectations and instil more confidence about the extent of their responsibility to achieve certain outcomes.

5.1.4 Balancing the needs of individuals and the larger group

Many facilitators described the challenge of attending to the needs of individuals while maintaining the engagement of the group and tending to the process of the session. This balancing is often related to the extra attention needed by one person in crisis, such as a seizure or psychotic episode, which can lead other participants to become 'wobbly and sensitive' as a consequence and simultaneously needing attention (F6-P-6). Ethan said

> I have had to deal with many behavioural challenges where say, an individual is having a struggle participating within a group. In these cases, it is a challenge not to get too drawn into the needs of one individual to the detriment of the whole workshop. (O10-Mu-6)

When facilitators are working with co-facilitators or participant support, they can share the responsibility for attending to individual needs while continuing group work. But even with support, it can be difficult to strike a balance between individual and group needs when more complex issues are involved. Two facilitators used the word 'tricky' to describe their feelings about having to exclude participants with challenging behaviours, often recognizing that the participant benefitted from the activities but their presence was disruptive to the group. Tessa described a participant who she felt had been wrongly referred to her programme by a social prescriber who did not know the participant's history. The participant began to exhibit paranoid behaviour during classes and had to be excluded:

> So it was, you know, her situation was *so tricky*, really, that I felt like, oh, my God, if I was in her shoes, what would I be feeling, I'd, I'd be feeling let down, I'd be feeling really let down by the service, the services that had been offered to me. And that, I was really kind of empathizing with that. But also understanding that we couldn't have someone in the class like that, because that wasn't appropriate for *her* if it was making her feel like, worse, but also for other people who were trying to, you know, who were just sitting chatting to her, and then she'd ring me and say, that person knows this about me. (I5-V-6)

Kate described a similar case of a participant who had been referred from a social prescribing scheme and was disrupting the group due to an unidentified or undisclosed mental health condition. (I18-V-6) Through the social prescribing service, the participant was asked not to come back but then returned to the group and was confrontational to her about the exclusion.

5.1.5 Facilitators managing themselves in relation to others during sessions

As facilitators work to manage the physical and emotional needs of their participants, they must also regulate their own feelings and responses during sessions. As in many other work environments, they must smile and appear in control when complicated situations arise or they are not feeling well themselves. But there is also the more delicate balancing of empathy and detachment within themselves when they are drawn strongly to participants' needs or circumstances.

Freya described working with participants who relayed difficult personal stories that she found quite triggering. She has to balance her desire to express her feelings of empathy and connection to those stories with the need to maintain the boundaries that she believes are appropriate as a facilitator:

> And I think that was hard to manage because your meant to like, run your session, and then you have to hold back that emotional reaction and you can't say, 'Oh, me too', because you're the facilitator. Whereas another, if you're in that group, you could share that. But it's not my role to share. And I think I always found that difficult, more with adults, more difficult that boundary between like, how much of yourself do you bring to a session and how much do you hold back and can like, protect, for their, for their sake, and for yours. Yeah, it's something I'm still figuring out. Definitely. I think it's like, you put it on hold, and then after a session, I think that's when you feel, and then you like try to digest and process. (15-V-03)

Freya described how she tries to show empathy and compassion for the participant, but within limits according to what she offers: "You're there to run the session. It's not like a therapy session for them." She processes the events after the session by self-evaluating her response and discussing it with a colleague or family member. (I5-V-03)

Christine described a similar struggle and framed her emotional self-control towards participants' distress in terms of her responsibility as a facilitator:

> Because if I started showing too much emotion, then it will be hard for them not to, and they've got their own stuff to deal with, you know. So I think it's because you're, you're aware of the fact that you're, you have a duty of care to everybody in the group, not just the person. (I2-P-6)

Two facilitators used a bird metaphor to characterise how they project an image of calm while working hard under the surface to assess how to respond. Charles said:

> It's almost like a duck, you know, where you kind of just keep it floating along, but underneath, I'm kind of trying to work out which direction it's gonna go next smoothly. And not, but you know, not jeopardize anyone's participation or, or kind of alienate anyone that's involved. (I1-Mu-46)

Invoking a very similar image, Kate said her response to a participant crisis was like being a swan. She added:

> So you're like, on the surface, you're like, 'Okay, everybody I'm just gonna talk to so and so, I'll check she's okay.' Underneath, you're 'right, what we're gonna do?' But, you know, I texted the, my social prescribing partner, subtly and gone, 'I need some help here.' And she came down. And so we managed it in what I hope was a didn't appear a frantic kind of dramatic way. See, yeah, that, but that, but they're difficult. (I18-V-6)

Later in the interview Kate added that she manages her emotions internally so she can reassure the group when a crisis arises. She feels this works best when she is prepared in advance for these possibilities:

> I'm very much aware of the impact of that on the other people in the group. And it's actually quite distressing for them to be aware of that, to witness, or to… and, and I want to seem like I'm making it okay. And that I'm, that I'm not distressed, that I'm not panicking. […] I think the more I know that that's true that it can be sorted out, and I have got systems in place, then it's okay. And I think what I've come to do, or I've learned to do, the more I've been doing it, is, as long as I feel like I've done the best I can do in that situation. And… I'm okay, I can let go. (I18-V-6)

Some facilitators talked about acting or having a persona that allows them to separate their personal feelings and reactions from the person who has to perform a role. Ethan wrote about the delicate balance he tries to maintain, knowing that his vulnerability and humanity allows him to do the work, but that he must also maintain "a safe professional edifice/framework/persona to whatever degree I can." (O10-Mu-6).

Others take what they described as an anti-persona, more humanistic approach to managing interactions with participants. In response to a discussion on persona and detachment in the focus group, Terry said:

> I probably deal with it in a different way. Because I don't, I do the opposite of taking on this persona. And I, I'm much more kind of reflective, and try to keep myself on a gentle level, if that makes sense. So that is like we were talking about, it is a human interaction." (F2-V-46)

Nina, who works with participants living with dementia, describes an approach that she feels brings her closer to her participants when they're experiencing distress:

> I was gonna say, like, what, like, impact on me is like, what I think is I should have like, like, be, like, have empathy and like, try and put myself in their shoes. And just yeah, being sensitive to people's feelings. And and then I often find that when I do that, or like, take a pause and like, not try and fill some kind of silence then. And like things do change. And their attitude maybe would change. And then you might have, like, after that kind of tricky experience, that situation. You become closer as well. Yeah. (F4-V-13)

Another issue frequently mentioned by facilitators was the need to balance their empathy for participant circumstances with a distance that is self-protective. Mary adopted a stance of detachment to define the limits of her responsibility and to protect herself emotionally:

> I've also kind of learned through all of this work that you can't take responsibility for somebody else's feelings and how they necessarily react, you know, you have to have some distance. And I say that as somebody who's had one of my participants I have been working with a couple years messaging me tonight: 'I'm going really depressed and really bad.' And I, you know, I do I do have that personal connection with them as well. But I try not to let it really get, you know, really deeply

> affect me, because I don't see it as the kind of problem, you never know how things are going to turn out. You never know why things are like they are. You can't take on everybody else's stuff, you won't be able to do this work, you'll go mad. (F6-P-6)

Ethan linked his management of caring and detachment with the difficulty and precarity of the work:

> It's tricky being caring without getting involved, while being involved just enough to provide a caring human presence, all the while maintaining a professional detachment. I must be able to do it because I get asked back to do more, but it's a complex balancing act and the work and pay is uncertain, so I don't feel too much personal responsibility or burden in terms of the needs of the people I'm working with. I think I have just about enough peace of mind for me do work that is useful for wellbeing, just enough. (O10-Mu-6)

Bringing together previous comments about holding space, the intensity of working one-to-one, and managing the emotional expression of participants, these facilitators are balancing their desire to create an experience for participants that conveys caring while using interpersonal boundaries to limit their responsibility and protect themselves emotionally. Some facilitators have been successful in this but others, especially those with a more open-ended approach, still struggle.

5.2 Managing within: Facilitators processing their experiences after sessions

As alluded to before, facilitators continue to manage their experiences after sessions are over. This is when the events of the sessions begin to settle and are reflected on. Sometimes the emotional impact is intense and affects how they view their abilities as facilitators. Other times they use strategies for engaging positively in a process of reflection, learning, and self-care. They note the value of training and support, which will be discussed in later sections.

5.2.1 Absorbing the impact

Many facilitators described experiences of positive openness and connections between themselves and their participants, from which they took great satisfaction and validation. But the intensity of both the positive and challenging experiences can feel encroaching and take its toll. Sylvia said:

> At times, for me personally, at times, it's been *utterly* inspiring. You know, and I've learnt so much from, from my clients, you know, it feels like a two-way thing. And other times, I've been exhausted, you know, because I give out so much, you know, with my energy, my, my, obviously, my time, but the, the energy, the thought, the holding a group, and, you know, every single group is different. (I7-O-03)

Olivia said that sometimes even the positive experiences can become overwhelming:

> Because it is easy to you know, to take it all as a personal mission. Sometimes. That you're responsible for these for these people that you're working with and, and whilst you know that you get the highs of all the positive experiences that happens, that does that even that leaves you open to vulnerability yourself. […] you notice, that that is happening to you, that you are taking on board everything from, you're like a sponge, almost, you soak up other people's conditions and what they're dealing with. And you're trying to figure out how to how to bring a positive experience to these people and how to how to make it accessible to them. And you don't notice that you're kind of, you're soaking it up, and suddenly you're really heavy with it, with all of this, and how do you then get rid of that for yourself and find time for yourself as well. (I4-O-46)

These two quotes evocatively demonstrate the intense and demanding nature of the emotion work facilitators engage in. As noted in section 5.1.5, some facilitators are explicit about using boundaries as a strategy to detach from events and protect themselves, while others find this more difficult or even undesirable, despite the emotional weight.

Feeling adversely affected after sessions was mentioned by several facilitators with respect to early career experiences or concerns about complex cases, which points to the need for adequate preparation and skills for working with CCS and having access to support structures. Bridget said:

> When I initially started this work, I found challenging situations very stressful and would often take these thoughts home with me. Through peer support and learning that it's helpful to switch off from work when leaving I have found it much more manageable. In the first year of working for a children's charity using the arts as therapy, I would often not sleep well due to concerns around complex cases. I think I have more support now from my line manager so this doesn't happen anymore. (O22-L-V)

Wendy also reported sleepless nights and feeling overwhelmed by distressing events and affirmed that these impacts can be moderated by having someone to talk to. (O6-Mg-03) However, many facilitators work as solo freelancers without an organisational structure and the need for support may go unacknowledged by funders. This is discussed further in section 5.3.4.

5.2.2 Navigating confidence

The issue of confidence was raised by a large number of facilitators and there are a number of issues that can impact a facilitator's confidence, both negatively and positively. Several facilitators noted that challenging early career experiences or the first instance of encountering a challenging situation made them feel scared or unsure of how to respond. This can include witnessing self-harm, hearing disturbing disclosures, or first experiences working in settings like prisons or with participants who live in challenging circumstances. These feelings of uncertainty can be disturbing if facilitators are caught off guard or don't have support structures to help them manage the experience. Some facilitators also recognize that a lack of training in managing particular conditions or circumstances might cause them to question their ability to respond appropriately.

An unsupportive working environment can also undermine a facilitator's working confidence. Trisha said she felt bad that chaotic circumstances in a mental health ward disrupted a participant's experience and she worried that she overcompensated in her response. (I12-V-6) Self-doubt can arise when there are repeated 'failures' to overcome these circumstances and the usual approaches don't work.

Self-reflection after sessions is considered by many in the field to be an important part of good practice, and this is discussed further in section 5.2.4. But for some facilitators, this introspection can bleed into second-guessing actions taken or self-criticism for perceived failures. They described feeling anxious after the fact about how well they supported someone in a session or recalled the lasting impact of missteps more powerfully than successes. Marie said:

> Sometimes I can move on quickly, but sometimes I can overanalyse my effectiveness and this can become exhausting. I have a safeguarding responsibility, to be vigilant and what if I don't spot someone who needs support? I am constantly asking myself if I could have done better? This definitely relates to the duty of care and health and safety awareness required during my delivery of creative activities. (O2-Mx-6)

Recalling a few difficult circumstances, Christine used the word 'inadequacy' several times to describe what she perceived as shortcomings in her responses. Yet some the situations she described were quite high stakes, like suicidality, or had graphically disturbing elements. Of one participant in a prison group activity, she said:

> I'd asked them to write about their ideal room. And most of them had, you know, lovely, airy, sunlit places by the sea or nice cozy places with a, with a fire and comfy armchairs. And his was a basement with hooks on the wall, from which there were bits of human flesh hanging. And again, that… it's, it's, it's this feeling of inadequacy, that is, you know, it makes it very difficult. That's, those are the situations when you' just don't *feel adequate.* (I2-P-6)

Gillian recounted moving between self-criticism and confidence in her work, especially when encountering participants with whom she didn't make a connection or who refused to engage in the activity:

> …so if, if I noticed that going on, that'll kind of, you know, I'll feel a bit awkward. And I might even go away and feel like, I'm a crap teacher, because, actually, you know, I didn't manage to do it for this person. […] Yeah. So, but the other side of that as well is that I want to be, I actually do, I really love my job. And I, you know, and I, and I think I'm good at it. And that's, that's a very sustaining part of my life now. And I want to be better at it, I feel aware of all of my sort of gaps and lack of kind of robust practice in my own sort of work. (I13-V-6)

She went on to say that she was thinking of pursuing training in art therapy or a similar degree so she could be confident in her own practice and feel like she's doing the right thing.

The value of training as a component of confidence building was echoed by other facilitators. Bridget noted that training in safeguarding and risk management helped her establish safety measures in her session that gave her confidence in her work. (O22-V-46) Marie said that training is key, but it was experience that led to confidence. (O2-Mx-6) She felt anxious and ill-equipped earlier in her career, and now is confident and feels that her best is good enough. The relationship between feelings of self-assurance and experience was mentioned by many facilitators. Talking about how to manage participants' reactions and one's own reactions to them, Namita said:

> …it takes many, many years of, you know, understanding and having different reactions and dealing with those reactions. And those situations, that makes you a lot more stronger in your approach and a lot more, I guess, I guess a lot more detached, but at the same time confident with what you are, with what you are, you know, sort of delivering. (F1-D-03)

Lara said that being supported by a manager to make good decisions makes a difference and keeping herself 'research informed' helps her to feel competent (O4-W-6). Sylvia linked her personal history of mental health issues and low self-esteem to the value of working with a university to expand and evaluate her programmes in building her confidence. (I7-O-03)

Support will be discussed in section 5.3 and both training and experience will be explored in more detail in Chapter 6.

5.2.3 The impact of lived experience on facilitation work

Some facilitators said that their lived experience of certain conditions or temporary states informed their practice and approach with participants but could also feel personally challenging. Such lived experience was mentioned by six facilitators, and two others said they were aware of a colleague with this experience. Among the conditions mentioned were illness, anxiety, depression, low self-esteem, personal bereavements, and family members with mental health issues or disabilities. A few facilitators said they recognized their own experience in the process of training for this work. Sylvia said she realised her own PTSD for the first time when taking a Mental Health First Aid course (I7-O-03), and others said that they did AHW work because similar creative experiences helped them with their own situations and they were inspired to share the benefits. Having had these experiences sensitizes them to issues that could be challenging for their participants, enabling them to respond early because they can recognize the signs of distress. As described by Gillian, it can help them empathize with and make emotional connections with participants in crisis:

> I lost [two close family members], so I've had to very close bereavements myself and I'm not afraid of being with people who are bereaved, which a lot of people are, I think, you know, so she [a participant] was very open with me emotionally, you know, and I remember one day sort of, you know, having a hug with her in the store, cupboard, and things, you know, like sort of being, getting very personal kind of thing.

Teresa said that living with a family member who suffered from mental illness for many years helped her develop strategies and a kind of resoluteness for coping with the difficult situations presented by her participants. She added:

> I think what [family member] has given me has helped me be a better person to be able to do those things, for people that I think are in really difficult situations, even, you know, when you find out people in prison, what their lives have been like, not all of them, but some of them have had the similar sort of upbringing, that in excluded centres they've had. So it's, it's made me, I hope, a compassionate person, I think. Yeah, without being all sort of fluffy. (I3-Mg-03)

Some facilitators described a circular process of drawing on their own experience to create an AHW programme, and then using the tools they are teaching to support themselves. Catherine said that just being engaged in arts, health and wellbeing work was beneficial for her mental health. (I9-Mx-6) Terry said that her own experience of managing her mental health helped her learn when to step back from the work when it was getting to be too much. (F2-V-46) A few facilitators said they used their own mental health supporters to process participant-related issues in the sessions they run. How some facilitators see their lived experience as a qualification for doing AHW work is explored in more detail in section 6.4.2.

Sometimes these participant issues can be triggering or retraumatising for them. Catherine was aware of a colleague who had suicidality in her own family and was triggered by a suicide attempt she witnessed. (I9-Mx-6). Recognizing that there are two sides to the impact of lived experience, Gillian added to her story about bereavement above and said she could also find it challenging when participants shared experiences that echoed her personal life. With respect to her family member with complex mental health issues, she said:

> And so if I was working with an adult who was displaying quite complex mental health issues, particularly a woman, that would, I would find that quite triggering for me. And I think that was hard to manage because your meant to like, run your session, and then you have to hold back that emotional reaction an' you can't say, 'Oh, me too', because you're the facilitator. (I13-V-6)

5.2.4 Strategies for positively managing their experiences

Facilitators described how they cope positively through self-awareness and self-care practices. Similar to the transformation of lived experience into facilitation strategies, many said they process their difficult session experiences into lessons and tools for future work. Fiona said that when she is challenged by a group she will use her reflective diary to help her make sense of what's going on. (F5-W-T-6). Kate said that even if a session goes well, she likes to pick apart what was good and what could be better next time, trying to find solutions to emotional issues that arise:

> And I, I think what I do is, I try and do some, if there's something practical I can do about that. So the emotion is, is the emotion because that person needs support with something or is struggling with, you know, that bit of art making, or whatever it is. So I think I try and do, I try and work out something practical, and to, to deal with whatever that emotional stuff was. (I18-V-6)

Christine talked about developing greater self-awareness and crafting response strategies from prior experiences as a preventive self-care strategy:

> It was very useful to me that time when I was working in the hospital, and I realized what it was doing to me. And I learned to know what the signs were, and how to manage it. And that was a really, really useful experience. Because once you once you've worked out what's going on and how to deal with it, then you can, you can use, you can use that in other situations as well. […] So basically, you know, if you if, if you didn't look after yourself, you won't be able to do the work. (I2-P-6)

The theme of experience-based learning and practice development is explored in more detail in section 6.4 and discussed as a possible strategy to inform training in section 7.4.3.

Other facilitators described how they try to "practice what they preach", which may include practicing mindfulness, taking breaks from work, or using their artistic practice as a form of self-care. While she acknowledged the difficulty of her work, Jayne said she never felt terribly bothered by challenging situations with participants, which she attributed to her personal circumstances and art practice:

> I'm very fortunate, you know, I am a woman of you know, who's been around the block a few times, and I do have a very supportive home. So if ever I need to talk at home, I have that. I also have my own art practice. So you know, that is, it's quite a private and stubborn kind of art practice these days, but probably that's, you know, an important thing for me. (I17-Mx-6)

Several facilitators mentioned talking to family members when they got home, and many expressed a desire for more formal debriefing and support options, which is addressed in the next section.

Addressing themes raised in previous sections, Norah said she coped with the challenging material of her work by having realistic self-expectations and appropriate boundaries:

> I have managed my response by being, doing what I can but not expecting more from myself than is possible. I see myself as someone who is very available and generous and empathetic, yet very able to create boundaries to protect my own mental health. (O21-D-6)

5.3 Support for participants and facilitators

> When I moved into this work, I also didn't know the support I'd need! I have worked in engagement for a long time but wasn't fully prepared for the different requirements of wellbeing work. (O6-Mg-03)

When talking about their work with individuals with CCS, all facilitators addressed the issue of support. From their statements, support can be characterised as people and structures outside the facilitator's personal resources to help with needs that arise during and after their sessions. While the topic was raised in some way by everyone, some facilitators who previously did community arts or cultural engagement work said they did not fully appreciate the importance of support until actually doing creative work in a health and wellbeing context.

This section will look at support needed by participants and facilitators in AHW sessions, support that facilitators need outside of sessions, manager's perspectives, and particular issues that arise around providing support, including what happens when support isn't there or doesn't address needs.

By way of context, the staffing arrangements that facilitators in this study reported at intake reveals the extent to which they were working on their own or with others. This data shows that the vast majority of facilitators worked alone some of the time, and nearly a quarter said they only worked this way. This means they bear the primary weight of responsibility for what happens in their sessions, although some have referral arrangements or organisations that provide assistance to varying degrees. More than half of the solo facilitators worked with non-clinical co-facilitators at other times, and a quarter worked with clinically trained co-facilitators. Working with participants' accompanying support people was mentioned by more than half the facilitators. The sections below examine the implications of working solo and working with partners or organisations that may or may not provide support.

5.3.1 Support during sessions for participants and facilitators

5.3.1.1 Support for participants

As seen in previous descriptions of facilitators' experiences, participants with CCS often need dedicated support workers to monitor and assist with their physical or emotional needs during creative sessions. Such direct support may be provided by family, friends, volunteers, or staff from partner organisations. Individuals with physical limitations may need assistance with the hands-on aspect of creative work; groups that have several people with complex mental health needs may need someone else to help with distress that arises during the session; and older participants, especially those with dementia, may need support with the physical, cognitive, or emotional aspects of participating in a creative group. Some participants may need constant accompanying. Others, even the seemingly 'well', might be fine until a moment of crisis that needs immediate attention. As facilitators have said previously, it is very difficult to be solely responsible for delivering the creative activity, managing social interactions, and attending to multiple individual needs that might require special skills or knowledge. Lisa acknowledged the impact of good support on differentiating the burden of care responsibility and what creative activities she can undertake:

> And in special schools, actually some of those experiences have been great, because they are, you have all those care workers, or care providers, and you really are sitting on seriously caring framework where everything's kind of sorted. There's, there's no question. So then it's, then it just changes the art because you're working out, um, you know, what, you know, what's best. (I10-Mx-6)

This comment suggests that partner organisations, social prescribing referrers, and AHW programme funders have an important role to play in ensuring participant and facilitator safety by arranging for support based on prior participant need and risks assessments.

5.3.1.2 Support from co-facilitators

Several facilitators also spoke of the need to have artistic co-facilitators to develop projects, balance facilitating styles and skills, share responsibility in sessions, support each other when energy is flagging, or substitute when one is ill. Helene, who spoke previously of the emotional demands of doing one-to-one work with individuals who have challenging conditions, said that working with another artist in sessions was “a huge help, huge. I can’t, you know, the difference between working independently is just enormous.” (F3-V-46).

While most of the facilitators in this study reported working alone at times, others said they would not work without another facilitator. They described situations when they did not have anyone to help with a participant crisis or could not simultaneously attend to the group and a participant who left the room. Kate recalled a psychological event with one participant that resulted in a physical injury. It left her quite shaken, and she no longer works in venues where she is on her own “because I think when things like that happen, and you're on your own…yeah, it's just not great. I don't think it's good practice.” (I18-V-6)

5.3.1.3 An organisational structure as support

Most facilitators who work with or in organisations appreciate the variety of formal and informal supports that are available to them and said this makes them feel more secure in their work. This can include working in organisations where they have access to staff, infrastructure, and supportive policies; or having referral arrangements that take responsibility for connecting participants with other providers. These structures can offer support both for participants and facilitators.

Hospitals, care homes, prisons, and specialised schools are environments with structures that can provide support to an AHW facilitator (although what is actually made available to them may vary by setting). Several facilitators said they appreciated having access to support programmes, staff, and feedback or oversight of their work. Jayne described working at a hospital where these elements were in place:

> And so although I was working alone, I always had the staff around me, you know, be it the play specialists -- I learnt so much from the play specialists on the children's wards. So I was never on my own. If there was an issue, they were always there to support the patients involved, and myself, if need be. (I17-Mx-6)

She said that staff would explain what the patient’s needs were, and check in with her afterwards, and that this nurturing structure of people was one of the reasons she has continued working with the hospital for a long time. Another hospital-based artist said that the advice centre run by a charity there was a long-standing source of on-site emotional support for her: “You know, because sometimes you work with somebody and it's just, you know, you might not cry with them, but afterwards, you just *need* a hug.” (Christine, I2-P-6)

Facilitators said that having managerial support and referral structures meant they didn’t feel so burdened with the responsibility for group or individual situations. When that support is in place, they said they worried less, and the work felt easier. If a difficult situation arose, like deciding whether someone should be excluded from the group, the decision-making could be shared with managers or referrers. One facilitator said that being able to talk to someone else meant she didn't feel alone with the responsibility, and it allowed her to be a little more emotionally detached.

5.3.1.4 Delegating responsibility and differentiating roles

Being able to discuss and delegate responsibilities for participants to support workers, managers, and referral agencies helps ensure that appropriate support is available for the participants and helps facilitators maintain the boundaries of their distinct role. Sophia said:

> I, and the organisations I work for, insist on the presence of someone from the partner organisation to support the group I’m working with, especially in terms of their specific health needs. I don’t have their specialist training so I wouldn’t attempt to do their job. It would, quite simply, put people at risk if I were to do so. (O12-O-6)

Partner organisations can assess the needs of participants before courses start and provide appropriate support workers in sessions. Maintaining close connections with social prescribing referrers can also allow the artist to pass back responsibility for participant needs. Purpose-designed programmes, especially those within health structures, often address artist training, support, and differentiation of responsibilities from the outset. One example is the arts on prescription programme co-produced with the NHS that Olivia works with, where there is a robust structure of training for artists but also clinical backup and oversight. The benefits of role definition and clear delegation will be discussed further in section 6.1.

5.3.2 Support for facilitators outside sessions

Facilitators spoke in detail about the need for and types of support they seek for themselves outside sessions. While many facilitators said they received little or no formal support, all facilitators had a clear idea of what they thought would be beneficial. This includes debriefing after sessions, practice improvement and learning discussions, interactions with peers, and supervision or opportunities for emotional processing. Facilitators use this support to understand their role and manage their practice, and to process the emotional work that goes on during and after their sessions.

5.3.2.1 Getting advice and support from managers and direct colleagues

An important element of support for many facilitators is the opportunity to get practical advice and mentoring to develop their practice. They appreciate having someone to talk through what their practice means, how it can be improved, client-related issues, and theoretical issues. They might want to do this with a direct manager, but some said they'd also like to discuss these issues freely with their funders, beyond the standard programme report and evaluation forms.

Some facilitators appreciated (or longed for) casual or formal debriefings with managers or other artists after sessions. Charles, who works on a research-based hospital programme said:

> I might feel disappointed in the, in the way a discussion's gone and wish I'd done it a better way. I think, I think that this, the way that I kind of try and make that better is to debrief, so I will talk to, you know, I have a good relationship with the Youth Support Coordinator. So, I'll debrief with them. If I have anything that feels to me like a concern or that I feel uneasy about... I make sure that… it's out there, so I would get it to them. And then talk it through with them. (I1-Mu-46)

For those who had this opportunity in their face-to-face work, the value of hallway or coffee conversations was acutely felt when they were no longer possible during COVID-19. Several facilitators said that instead they had these conversations with a partner or another family member.

A few AHW facilitators in this study were also programme managers. Their views from the managerial position reinforce what other facilitators have said but also show their unique position of both responsibility and needs. They try to offer opportunities for reflection, supervision, off-loading, and practice development to the artists who work with them. Sometimes they provide this by making themselves available to listen, and sometimes this was offered by other staff or through structured opportunities for emotional support.

Charles recognized that some artists in his programme may not take advantage of the support offered and think they can look after themselves. He recognized that he needs to pay careful attention to what might be going on under the surface for these artists, several of whom work with young cancer patients:

> [Y]ou have to be very careful to listen for real issues. And we've had a couple where, you know, someone might go home, and then say that they went home and cried, and then you think, okay, now we've had a real issue. And it's, you know, it's not their fault, and it but it needs to be explored a little bit. So that's what we tried to do just listen carefully for, and not just kind of, let them get on with it and hope for the best, I think. (I1-Mu-46)

Some manager-facilitators said that in being responsible for providing support to employee facilitators, they feel they must also ‘shoulder the burden’ of their concerns. They face the multiple demands of wanting support for what they hear as a manager and what they experience when they deliver services themselves, often alongside looking for funding and the other demands of running a project or organisation.

5.3.2.2 Formal and informal peer support

Many facilitators said that talking to peers was an essential part of supporting their own wellbeing and practice development. Facilitators connect with their peers in a variety of ways, such as when working in teams or for the same organisation. Throughout the COVID-19 pandemic, more facilitators discovered and participated in virtual groups on a variety of platforms: online meetings and webinars, WhatsApp groups, and social media conversations. Some are labelled as AHW peer support groups or conversations, and others are communities of practice related to specific forms of practice such as hospital-based work or singing for health. Facilitators described the value of these peer interactions, including being able to discuss day-to-day challenges related to delivering workshops, getting advice and problem-solving for particular situations, general support, sharing practice models, and having a regular connection with people doing the same work. Olivia described the general value of peer activities and specifically what her team put in place to meet several support needs:

> You know, having a bit more of a supportive, a bit more of a community of practitioners, maybe where we can check in with each other. And maybe’ I mean, it's really difficult to get, especially as an older artist, there's opportunities for self-development as well. But also self-care, and to go… you know what? We've been working on this project. But here at the end of it, we've organised a weekend away for people to go and develop their own skills, but also to share their experiences and kind of, you know, recharge, rejuvenate, ourselves as well. (I4-O-46)

Namita observed that in the past, artists often worked solo to protect their work and ideas, but the pandemic has brought opportunities to work with other artists from different disciplines and this has been inspiring and sustaining. (F1-D-03)

However, several facilitators, especially those working solo, said they wished that there were opportunities for them to connect with their peers. Bridget wrote:

> I would like more peer support with both my jobs. I often don't see the other creative practitioners but when we do meet, it's very helpful to share any difficulties we are facing -- often through mixed experiences we can support each other and offer solutions. I would like this to be more regular. (O22-V-46)

5.3.2.3 Supervision to support the emotional effects of the work

Some facilitators talked about getting supervision through projects or hosting organisations to help manage the impact of working with people with CCS. The desire for this support reinforces the previously mentioned emotional demands of AHW work, whatever level of skill, training, or experience a facilitator has. Facilitators want to discuss how to manage the challenges presented by their participants, how to deal with personal impact, and how to cope with burnout.

From their descriptions, supervision can mean different things: sometimes emotional or psychological support by a qualified mental health professional, sometimes more broad-ranging support related to participant/practice issues that arise during sessions. Facilitators said they would like to have this available on an as-needed basis, or on a regular schedule with a line manager or other designated support person. Freya described having access to a staff support worker every two weeks when employed by an organisation:

> And we were meant to talk about work things that were triggering. And then often, that was quite hard, because it would be linking to personal things. But I found that like a really, really good resource. But yeah, I think it was just relying on... yeah, being able to share it with someone, like another professional on your level, not a client, or a participant. I think that always felt to be the best way to like process for me. (15-V-03)

Some facilitators received group supervision through their organisations, with varying views as to the value of it, with some saying they did not like the way it was delivered, or they preferred to have one-to-one sessions. Other facilitators mentioned self-paying for private supervision, either strictly related to practice issues or combined with ongoing therapy for personal matters. Terry described sometimes using her therapy sessions to work through anything she finds challenging in her AHW practice, which again points at the vulnerabilities at the intersection of a facilitator’s lived experience and that of their participants. (F2-V-46) Sylvia’s description of what she discusses in supervision describes the range of issues that other facilitators said they wanted support with, including practice improvement, issues with clients, validating their approach, and self-care. She ends with the recognition that she is feeling burned out by her work and needs to take a break:

> It's someone I can go to who I can talk about my practice […] how I'm developing it and what it means and how it can maybe be improved and the kind of good practice stuff around it, the delivery and then any theoretical stuff […] And, this is more important, someone I can talk to about people in the sessions, like my clients. And, you know, stuff that like, ‘they're, they're being affected and in certain ways... And how do I deal with that? Did I do that right? Or can I learn from that?’ Yeah, and like learning, you know, how can I learn and improve what I'm offering, how I'm doing it, what I'm doing and how I'm doing that? And also, how can I support myself and look after myself better if I am being affected? Or especially if I'm getting exhausted and burnt out? Which, at the moment, I'm exhausted and close to burnout, which is why I need to stop in December. (Yeah.) I'm working far too hard. (I7-O-03)

5.3.3 Challenges in obtaining support

Facilitators identified several challenges related to getting support for themselves or their participants. These include support not being provided or not meeting needs, the difficulty of being a solo facilitator, and what support facilitators think they need and how they feel about asking for it.

5.3.3.1 Support is often not provided or is inadequate

Many facilitators in this study said that support was not provided for participants in sessions or for them as facilitators. Those working with organisations were more likely to describe having colleagues that understood the need for this and built that into their programme models. But this is not always the case. Wendy, who works with and manages other artists in a museum setting, said that there is increased funding for museums to deliver wellbeing work. But she felt that many museums did not understand the impact of doing wellbeing work on facilitators and what they might need. She said she was aware that in a clinical setting, she would receive supervision, observations, and training. But as some facilitators mentioned, such support can vary even in those settings. One facilitator working with an NHS arts on prescription programme said that the members of her team supported each other in their work. But she felt this concern was not always demonstrated by their managers:

> It often doesn't feel like that's reciprocated, that they are checking in with us, going 'are you guys okay? Actually, is this too much for you? Have we given you too much? And, do you need to just sit down and have a chat and a cup of tea and a bit of cake or whatever.' You know, *that's* not being recognized. (O6-Mg-03)

Facilitators said that sometimes support for participants in sessions does not always work. A support worker may leave suddenly due to a family emergency, distressing both participant and facilitator. The support worker may not be attentive, leave participants unattended, or not work cooperatively with the facilitator. Referral pathways may not always address the participant's needs, which then come back to the facilitator to respond to, as with one of Kate's participants in section 5.1.4. Nevertheless, having those structures in place can be better than practicing alone. Mary said:

> That's the kind of challenge often, no matter what things you put in place, everything can go out the window, because these are kind of volatile settings with them, as human beings, trying to deal with human beings. So, but it is really important, as an artist, to not be put in a situation on your own, I really believe that. (F6-P-6)

With respect to support for facilitators themselves, some said they didn’t connect with a supervisor’s approach or did not feel it was of good quality. As mentioned by Charles above, sometimes facilitators do not take advantage of well-conceived support structures because they don’t recognize their own needs or may not feel comfortable disclosing an emotional impact. (I1-Mu-46) Teresa, who spoke earlier of the conversation she had with her line manager after the prison suicide, said she had mixed feelings about the referral to telephone support:

> I remember I was, over that week, I was sort of looking at the helpline thing. I thought, I can't ring that, I don't know these people, I don't want to phone an anonymous person up and talk to them. I couldn't do it. Because... my [family member] died […] this year. So, you know, I've been through all of the mental health issues for years, and I've, you know, it's been particularly bad. So I've got lots of *experience* in kind of... strategies and trying to kind of… figure that out. And my work colleague, who I worked with in my other job for 25 years or so, they were better [to talk to], because they knew me. (I3-Mg-03)

The dilemma of assessing who is a safe and comfortable person to speak with in a crisis has also implications for the acceptability for participants of standard referral or signposting practice used by many facilitators when their participants have difficulties. It could explain why some facilitators feel compelled to provide emotional support to their participants, even when it stretches their capacities.

5.3.3.2 Solo facilitator and early career support needs

Many solo facilitators described not having access to any support options, either for themselves or their participants. Some facilitators say this lack of support options potentially reinforces the isolation and overwhelming sense of responsibility experienced when working on their own. Tessa said:

> I think for me, it's that when you're isolated, when you're working in isolation, it's hard to actually get a hold of the quality of work that you're doing, you're not really getting feedback, apart from the, you know, the affirmations from participants, but it's not actual feedback as such. And so, you know, it's hard to *know* how good a job you're doing in a way and, and to really feel… I do feel valued, by the organisations I work for. But when you're working with other people physically, and you're having appraisals, and that kind of thing, in that kind of system of you know, when people work like that, that's, you kind of get more of an idea of your strengths and weaknesses and what, all of that sort of stuff. But working in isolation, it's hard for, hard to kind of get a feeling of that, for me anyway. And so I'm, I'm really trying to build more connections and, and with my colleagues, through, through the last few months, I've tried to get my colleagues and I together more, just to talk about how it how it is for us and to, get, support each other more and that kind of thing. So, and that's made a massive difference, I think, too. (I5-V-6)

The absence of support and its impact is also highlighted by early career facilitators. Marie compared her experience with the supervision that is available to counsellors and said she had to rely instead on her family:

> I didn’t have enough support when I was a beginning facilitator. I found my own strategies for coping. I think it would be very helpful to have some options to access support when required. A trained counsellor has opportunities for reflection on the challenges faced with their clients, a chance to discuss challenges with their supervisor. I would say I survived in the early days without any collegial or organisational support and relied heavily on the support of family. (O2-Mx-6)

Invoking the isolation of practicing alone and ‘surviving’ early career experiences, she and Tessa highlight the emotional impact this work has on facilitators, and how they must often learn how to do it without guidance or reassurance from those with experience. (I5-V-6). Issues relayed in previous sections with respect to complex participant needs and unexpected crises emphasise how having adequate support is also a safety issue for solo practitioners.

5.3.3.3 The desire for more support and issues with asking

With respect to what they would ideally like to have as support options, facilitators said they want more opportunities to work with colleagues or in teams to develop activities; more overall support for their activities within organisations, including more appropriate physical space and material resources; more personal supervision, feedback and appraisals from colleagues, managers, community referrers and funders; and more consolidated ‘one-stop shop’ offerings of training and support options.

Many facilitators feel able to ask for what they need, and several said they increasingly build these requests into their bids for work. But this doesn’t feel easy or safe for everyone. Ethan, relaying an incident with a participant in which he didn’t feel supported by his contract manager, said:

> I only mention this to give some indication of a possible lack of genuine support available to a self-employed practitioner from a gatekeeper organisation in a community arts setting. If you want to work, you have to present as resilient, competent, professional, happy, just fine and always positive - you won't get work otherwise. (O10-Mu-6)

This assessment invokes the pressure to display positive emotional labour and self-sufficiency in order to get or keep jobs, to the detriment of asking for what might be necessary for the wellbeing of both participants and facilitators.

Two other facilitators observed that funding available for projects is often quite small, and bids that have more than one facilitator are sometimes not accepted. Ella made a link between the funding pressure to work solo, the impact on her, and the lack of recognition by funders that staffing is linked to quality and facilitator wellbeing:

> One of the sort of gaps that we face as artists is, is that we are always constantly questioned about the impact of our work. And because of that, there is this, there's this almost sort of an attitude

> that do really need that sort of money? I mean, we all agree that we need two facilitators, and yet somehow, it's always a challenge to get cost covered for two facilitators. And that just means that okay, I need to sort of go by myself, go solo, but then also had that much more pressure mentally, physically, emotionally, to drive that whole program or project or by myself.
>
> But I need that funding, because that's how I will sort of go on. So it's, it's that gap that we need to fill where artists and, and the entire sector is looked at more, with more sort of serious eye. And it's not just like, 'Oh, well, it's, it's good to have, but do we really need it?', you know, and I guess that perspective change will, will help fill in those gaps of, you know, having appropriate and good enough funding options for all of us to tap into where we can demand or where we can request for two facilitators, three facilitators, and then obviously, improve the quality of work, improve the output of work and improve our own mental health in in the interim. (F5-T-6)

These concerns echo the issues raised in section 3.3.2 about the pressures of precarious contracting and the lack of recognition by some funders of the complexity and demand of AHW work.

Summary of Chapter 5

This chapter examined the different ways facilitators manage interpersonal dynamics during sessions and how they manage their emotions during and after. It also reviewed facilitators' views about practical and affective support for their participants and for themselves, and what happens when support is inadequate or unavailable.

Overall, the examples in this chapter reinforce the highly relational nature of the work AHW facilitators undertake with individuals with CCS, first raised in chapter 4. Whether encouraging or boundarying emotional expression, facilitators are engaged in perceiving, managing, and supporting participant emotions, which constitutes many aspects of emotion work. Even when participants have dedicated support or programmes are delivered in an organisational context, the impact of carrying participant stories and challenging experiences can have a personal impact on facilitators. Because of the interpersonal bonds that can arise between facilitators and participants it may be unclear when these interactions move towards a more consequential emotional support role that may feel therapeutic or invoke a personal responsibility by the facilitator to the participant's wellbeing. This suggests that facilitators can benefit from skills and guidance around how to manage these issues, regardless of whether they practice alone or with participant support. While there are unlikely to be strict guidelines that would cover every situation, knowing how to set realistic programme intentions and boundaries through training, peer discussions, and supervision can help facilitators manage their sense of personal responsibility for uncertain participant outcomes. It can also help them manage expectations with participants and funders. This is also linked to how they manage caring and the potential ambiguity of role definitions and programme scope, which will be discussed in sections 7.2 and 7.3.

The fact that many facilitators often work solo may contribute to the exhausting sense of responsibility and burden that many facilitators described. Some facilitators are clear that solo work is not a safe practice for either participants or facilitators, but this arrangement appears common and several facilitators report that funders are resistant to paying for support or co-facilitators.

This chapter also highlights the need for referrers and programme partners to take more responsibility for assessing participant needs and risks. The examples here point out the challenge of including individuals (often referred from social prescribers) whose conditions are disruptive to the larger whole or pose safety issues. Such individuals can challenge the skill and capacity of facilitators, especially when participant support is not provided. This highlights a broader concern that social prescribers may be referring people with very complex needs to community activities that do not have capacity to support them.

Similarly, the desire not to know details of participant conditions in advance held by some facilitators, coupled with some of the challenging situations described and the variability of support, point to risks that can arise for both participants and facilitators. This contrasts with the meticulous preparation described by other facilitators and the availability of organisational support, which gives them a sense of confidence when difficult situations arise. While some facilitators describe their work as ‘just doing art’, the intuitive and spontaneous responses employed when challenging issues arise may work for more experience practitioners but could be risky in a less experienced practitioner, especially one practicing alone. This will arise again in section 6.3.1 where some facilitators describe being caught off guard or stressed by unexpected situations in first-time arts and health experiences without prior training.

Chapter 5 Crosswalk table

Section	Key points	Discussion	Recommendations
5.1.1	Some facilitators specifically prepare for participant conditions and others prefer not to know and take an intuitive approach to management	7.4.3 experience and training 7.5.1 safety and role delineation	1 participant safety

5.1.2	Some facilitators encourage emotional exploration in their sessions while others boundary this expression. Some feel overwhelmed by participants' stories or experiences.	7.2 emotion work of facilitators	2 facilitator wellbeing 4 professional development 5 research
5.1.3	Facilitators struggle to manage personal and participant expectations and their sense of responsibility related to the experience and impact of their programmes	7.2.3 caring and role 7.2.4 confidence and impact 7.3.2 role ambiguity	3 guidance
5.1.4	It can be difficult to balance the needs of individuals in crisis with the needs of the larger group	7.5 support and social prescribing	1 participant safety 2 facilitator wellbeing 3 guidance
5.1.5	Facilitators must maintain emotional control and perform positive emotional labour even as they balance empathy and interpersonal boundaries	7.2.3 caring and role 7.2.5 empathy and boundaries 7.3.2 role ambiguity	2 facilitator wellbeing 3 guidance 4 professional development 5 research
5.2.1	The intense emotion work of AHW facilitation is demanding and sometimes overwhelming	7.2.3 caring and role 7.2.4 confidence and impact 7.2.6 making it visible 7.5 support and work conditions	2 facilitator wellbeing 3 guidance 4 professional development 5 research
5.2.2	Facilitator confidence can be affected by challenging situations, unsupportive work environments, second-guessing, and overall experience, training and support	7.2.4 confidence and impact 7.4.1 training and confidence 7.5 support and work conditions	1 participant safety 2 facilitator wellbeing 3 guidance 4 professional development 5 research
5.2.3	Lived experience of conditions can inform facilitator practice but also feel personally challenging	7.2.2 positive emotion work 7.2.5 boundaries 7.4.3 experience informs training	4 professional development
5.2.4	Facilitators use personal positive coping strategies to manage challenges	7.4.3 experience and training 7.5.3 support and reflective practice	2 facilitator wellbeing 4 professional development
5.3.	Most facilitators work solo some or all of the time	7.5.1 safety and role delineation	1 participant safety 2 facilitator wellbeing 3 guidance
5.3.1.1	Some participants with CCS need personal support in sessions for assistance and safety	7.5.1 safety and role delineation	1 participant safety 2 facilitator wellbeing
5.3.1.2	Co-facilitators can share responsibility for running the session as well as managing unexpected crises	7.5.1 safety and role delineation	1 participant safety 2 facilitator wellbeing 3 guidance

5.3.1.3	Working within an organisational structure offers support and safety arrangements for facilitators and participants	7.5.1 safety and role delineation 7.5.2 responsibilities for support	1 participant safety 2 facilitator wellbeing 3 guidance
5.3.1.4	Shared responsibility for participants allows facilitators to maintain their distinctive role and capacities.	7.3.2 role ambiguity 7.5.1 safety and role delineation 7.5.5 responsibility and SP	1 participant safety 2 facilitator wellbeing 3 guidance
5.3.2.1 and .2	Facilitators want advice and support from colleagues, managers, and peers	7.5 support and work conditions	2 facilitator wellbeing
5.3.2.3	Facilitators need professional support and supervision to cope with the emotional demands of the work.	7.5 support and work conditions	2 facilitator wellbeing 3 guidance
5.3.3.1	In actual practice, support is often not provided to facilitators or their participants, or may not meet needs	7.5 support and work conditions	2 facilitator wellbeing
5.3.3.2	Not having access to support for solo and early career facilitators reinforces their isolation, burden of responsibility, and can be a safety issue	7.5 support and work conditions	1 participant safety 2 facilitator wellbeing
5.3.3.3	Facilitators know their support needs but some fear asking for, or budgets preclude, additional staff	7.5 work conditions	2 facilitator wellbeing

Chapter 6. Creating a mosaic: Boundaries and ambiguity in facilitator identity and preparation

Chapter Overview

A mosaic is a bricolage of different materials that vary in size and colour. The artist has the freedom to use what they have at hand to create their work, without rules or templates. This creative freedom offers the possibility to realise a very personal expressive piece, but the ambiguity about how to proceed or the eventual outcome can create uncertainty. The field of arts, health and wellbeing is characterised by a freedom similar to creating a mosaic. Each facilitator's professional practice is unique, and each engagement is shaped by the varying circumstances of participants, events, and context.

This chapter examines how AHW facilitators define their role and practice in the context of boundary crossing and ambiguity. It will explore how they define the skills, attributes and knowledge needed to work with participants living with CCS, and the role of training and experiential learning in their preparation and practice development. I will also look at facilitators' views on practice frameworks and formal qualifications. Along the way I will identify examples of boundary crossing, navigating ambiguity, and how facilitators position themselves and prepare for emotion work.

6.1 Freedom and confusion: Navigating ambiguity in the AHW facilitator role and practice

As seen in the two previous chapters, crossing disciplinary boundaries is demonstrated by AHW facilitators in the way they structure their creative programmes to include health, wellbeing, and social elements; in the variety of intentions they hold for their work; and in the ways they interact with their participants and delivery partners/employers. The absence of accepted professional structures for AHW work means that facilitators have the freedom to define what they do and how they do it according to their own interests and skills, while also considering the desired programme objectives of their funders.

In this study, some AHW facilitators attempt to define their roles and interactions with participants from a predetermined practice philosophy, although sometimes this can be challenged by behaviours or circumstances that arise when working with people with CCS. Others make intuitive, spontaneous decisions or vary their responses from one setting or population to another. Some facilitators work in settings that have their own structures (schools, prisons, NHS programmes, mental health facilities), each specifying different rules and freedoms in delivering AHW programmes and interacting with participants. Commissioners of freelance facilitators may define how the activities are described and delivered. One facilitator said a local authority insisted that an arts and health programme could not be described as therapy or support, but education was acceptable. Other organisations specify clearly what kinds of interactions and discussions are allowed.

This variable freedom to self-define AHW programmes may also result in ambiguity about the boundaries of the facilitator's identity, role, and responsibilities. This was demonstrated by two individuals responding to this study's recruitment call who, in the context of interviews, appeared not to have worked directly with individuals using an articulated health or wellbeing intent. One was an artist who promoted her art on social media alongside general mental health support messages. Neither had considered the kinds of activities, responsibilities, or competencies that might be necessary to deliver on specific health or wellbeing outcomes. The lack of role definitions and entry requirements for the field in the UK means that anyone can call themselves an AHW practitioner.

Reflecting this definitional ambiguity (and perhaps as a result of it), the words used to describe health, mental health and wellbeing objectives in this work are also subject to individual interpretation. From the facilitators' stated intentions (Chapter 3 and Annex R1), *wellbeing* appears to be a catch-all term that includes facilitating creativity, promoting social interactions, building confidence, teaching mindfulness, and having fun, among others. *Health* can mean delivering creative activities in a health delivery context, sometimes with defined health outcomes, or it can mean supporting individuals outside that context as they cope with individual medical conditions or their overall health. As discussed in the previous chapter on managing, some creative facilitators deliberately collaborate with partner organisations or use participant carers or support staff to demarcate their role, manage the complexities of participants, and limit their responsibility. Sylvia said:

> […] and like what like we've been talking about with epileptic fits, and seizures and things like that, they have happened, normally in within the trusts that I work with. But there's a team of people around me, so I don't have to necessarily, I have to get the right people involved. But I don't necessarily have to be trained in-depth to deal with those situations, if that makes sense.
> (I7-O-03)

Other facilitators working with people with CCS have felt a responsibility to acquire specialised knowledge and skills to work with particular health conditions. The reasons for this will be explored more in the section on skills and training below.

It is in “supporting mental health” where ambiguity about terms such as “therapeutic” and “therapy” arises most frequently and where some facilitators in this study make definitional and boundary demarcation statements about their professional identities and practice philosophies. While many frequently encounter the emotions and difficult experiences of their participants, some facilitators try to distinguish what they do from how they individually conceptualise “therapy”. Freya said:

> I would […] never try and like touch on things directly. Like I'm not a therapist, I would never want to open things up. But sometimes things would go there. And people will sometimes share things and become quite emotional. (15-V-03)

Christine reiterates her organisation’s philosophy to draw disciplinary boundaries in her work:

> We are not here to provide therapy. In [organisation], we provide art, the arts and creative activity, and that in itself is therapeutic. (I2-P-6)

Ambiguity about role definitions and related expectations also arises in interactions with their participants and colleagues. Trisha, who facilitates recreational arts activities in a mental health facility where there are also arts therapists, said:

> I know a lot of the time when people have come to the sessions, and sometimes they'll be on their phone, and they'll say, ‘Oh, I'm in art therapy at the moment, I'll phone you back.’ So for them, there isn't, they don't see a distinction. But I think that there definitely is, and obviously, there is a crossover. (I12-V-6)

Charles said this role confusion comes up with colleagues in the hospital where he works, and he has developed a strategy to deal with this:

> I have to have this kind of elevator pitch where I kind of say, you know, art therapist is a therapist, one to one, talking about experiences, not necessarily focusing on the art work, and I'm saying that, I'm, I'm talking about recognizing everyone that comes into the hospital is a creative individual in their own right, with creative needs. (I1-Mu-46)

Kate, whose organisation declares that art by itself is therapeutic, explains her position on the distinction between therapeutic arts and art therapy:

> So, I think what we do is arts for therapeutic purposes. So I think the therapeutic is there. But we're not art therapists in that we're not using art as the tool to explore issues. And the art isn't a tool in that way. So the art is, because it's therapeutic to make art and to be in that space, in the way that we hold the space, in the way that we, you know, allow people to be creative and to play and to make mistakes and to explore and to make discoveries, and are all therapeutic. (I18-V-6)

However, as seen from the earlier descriptions of practice such as in section 5.1, other facilitators deal extensively with the emotional states of their participants. They provide emotional support when the creative process prompts emotional responses, and encourage emotional expression and discussion through their empathetic 'holding space'. The following poetic analysis, each line excerpted from a different facilitator's statement, points to the ambiguity they experience between their declared role definitions and what they may be called upon to do in practice:

Poetic analysis: Not a therapist

A role definition statement, almost a mantra, was "I'm an artist, not a therapist." The notion that AWH facilitators frame their role against what a therapist does suggests they recognize that 'sometimes things would go there' and they need to set limits on what support they can offer. This poetic analysis, each line excerpted from a different facilitator's statement, points to the ambiguity they experience between their declared role definitions and what they may be called upon to do in practice:

Not a therapist… not sure where the line is

Always a creative facilitator, never a therapist
They would never expect me to ask… I've never said that's my role
Not called on to sort out their psychological problems
They come… and they leave their issues
I'm a human being, meeting a human being in a space
Supporting people in their arts practice
That, in itself, is therapeutic
I'm an artist making art and it's therapeutic
If what I'm doing doesn't tick the wellbeing box, then I'm not doing it right
I'm there to facilitate a process
To encourage conversation, to encourage feedback…. in small groups… quite a deep level
I would never want to open things up. But sometimes things would go there.
Not quite sure where the line is, I suppose
This grey space between… may need to be further defined.

These statements reveal different reactions to the boundary-crossing nature of the emotional material offered up by participants and how each facilitator orients their role and responsibility towards an appropriate response. Some express uncertainty about where the lines are between doing therapy, encouraging the exploration of personal stories, and simply responding as an empathetic human.

It is also important to consider other manifestations of disciplinary boundary-crossing that AHW facilitators engage in. Those who work within other health, mental health, or social organisations are aware of the different intentions, values, social norms, and hierarchies that they must navigate. In some cases, this might feel uncomfortably like being an outsider (Trisha's experience in a mental health facility). In other cases, such as Olivia developing programmes with NHS partners, the strengths and differences between disciplines are acknowledged and differentiated responsibilities are planned for. With a few exceptions, AHW facilitators crossing disciplinary boundaries with other staff or institutions did not address this aspect of their work in as much detail as other aspects, and they did not often raise it as one of their key challenges.

6.2 The skills and attributes of creative facilitators

The lack of firm definitions for the role and practice of AHW facilitators is also reflected in the views they gave on the skills and attributes needed to work with CCS. This section reports the answers they gave directly to interview/discussion prompts about skills, adding in additional skills gleaned from the descriptions of their work in other parts of their interviews. Facilitators often added attributes (personal characteristics and personality traits) to their answers about skills (abilities learned through work or training), sometimes questioning what important qualities for this work might be inherent to the person versus what can be taught or learned. How their skills were acquired will be discussed in the section on training.

One might assume that having artistic skills would be the first to be mentioned by facilitators, but this was not usually the case. This could be because most facilitators had formal arts training and thought of that as a given for creative health work. Several facilitators said a high level of artistic skill in their chosen field was needed by a facilitator, but a few said that a basic level of art skill was enough. Others said it was important to be willing and able to modify creative activities and support a participant’s engagement regardless of their ability or barriers related to their condition. Olivia described working with a blind aerialist to adapt circus activities for the visually impaired in an NHS arts on prescription group:

> So we very much spent time kind of really breaking down, it's just about breaking down what you do and talking through it and making it really simple… And, and it's when you realise how much, especially when you, when you've got a skill that you're an expert that you've done for years and years, here's how you do, just do something without thinking about it and go, how do I explain that to somebody who can't see what I'm doing? (I4-O-46)

Trisha, who works in a mental health setting, said that her prior experience as an occupational therapist guides her to take a similar approach of breaking down a complex art project into discrete steps to make it easier for her participants to understand and follow. (I12-V-6) These skills were described by others as being able to scaffold a session, differentiate tasks according to participant interests and skills, and in general having a skill set similar to being a teacher. A related attribute mentioned by several facilitators was having the patience to work with individual ability levels, attitudes, and emotional states.

More frequently mentioned by facilitators were interpersonal attributes and skills, which might be described as being comfortable with social engagement and having the skills to facilitate this engagement amongst others. Active listening was raised as both a skill and an attribute by several participants, as well as having the ability to read and respond to body language and the ‘feel’ of a room. Faith said:

> So for me, I go into a group setting, that's what I do, I read a room, I'm very aware of people's body language, you know, I, I could be talking to somebody and noticing that somebody over there is either tuning in or not tuning in, you know, I'm very picky upon very subtle things, like the fact that somebody might have made eye contact for the first time. (I-14-M-6)

Other interpersonal attributes mentioned included having a personable nature; being kind, warm and empathetic; being able to put people at ease; and having a sense of humour. These skills support the intention of facilitating positive social engagement that was described in section 4.2.

Facilitation skills and being able to manage group dynamics were raised as important skills by almost all facilitators. Melanie said that it was important to convey confidence as a facilitator but not be too commanding. (I16-Mg-03) Freya described having the ability to gently hold a group and unobtrusively lead:

> And the best [facilitators] are always the ones who really subtly manage a group and do things like getting everyone to, to encourage each other while the session's running. And like giving enough space for people to figure out rather than being like this kind of teacher and like, step by step hands on all the time. Like, they're the ones that like I get the most out of, and I see the other participants getting the most out of, um in a health way, as well as like, even in a skill way, but both, I think it gets both. (15-V-03)

Being able to manage disruptions or crises calmly and gracefully was mentioned frequently in the context of working with people who had mental health conditions or came from challenging family or social situations. Even smaller discomforts require skilful handling, like how you respond when a song you’re leading triggers something for a participant. Faith said:

> And again, it's about being able to manage that on the fly, because sometimes people need to release and express and so it's about them, being able to hold that uncomfortable space and making that okay, for the person that's experienced it, *and* everybody else. So, um, you know, being able to make it okay, that you're changing what you're doing for everybody because of one person, and not making that feel uncomfortable. So, and so I think it takes a lot of different levels of awareness and energy to go into that space. (I-14-M-6)

Facilitators discussed other attributes they felt were important to the performance of their role. Having a flexible attitude and being able to adapt quickly and improvise were mentioned frequently. Other attributes mentioned included having a can-do nature, being reflective about what happens in sessions and their own performance, and cultivating a sense of excellence but having humility. Faith said:

> There's no space for *ego*. I think that's, what I mean, you know, you go into that room and you're an equal with everyone and, and a lot of artists come to it because they, they carry a sense of ego, but you can't have that in this work. (I-14-M-6)

Section 4.3 detailed some of the approaches facilitators use to encourage and manage the emotional expression of their participants, and this is elaborated on in section 5.1 on how they manage this in sessions. Nevertheless, facilitators had different views on the need for explicit counselling or other psychology-related skills that often reflected their philosophy on how much to engage with emotional material. Several facilitators said they had acquired such skills for other professional roles or specifically for their arts and health work and used them in this context. Some felt strongly that they needed to acquire more skill in these areas. Others were clear that this was not their role, and they didn’t encourage participation discussions where they might need such skills. Catherine, who had trained as a counsellor and sometimes did supervision for AHW facilitators, expressed her ambivalence about this latter stance. She said she understood that some facilitators might be afraid of difficult situations, but their unwillingness to become more skilled in dealing with them could be unethical.

The range of interpersonal skills and attributes identified by the facilitators as important to their work underscores the amount of emotional intelligence, performance, and management work they do and the disciplinary boundaries they cross in delivering creative activities in a health and wellbeing context. This will be discussed in more detail in sections 7.2 and 7.3.

Several facilitators mentioned knowledge areas they considered important or helpful to know about, alongside knowing how to perform or respond. Learning about safeguarding scenarios and procedures was mentioned as essential by many of the facilitators. However, similar to the ambivalence they expressed related to psychological skills and knowledge, they varied in their views about how much they need to understand about the health issues their participants present, as described in section 5.1.1. Some facilitators said they rely on collaborating partners to bring this knowledge to projects. Wendy said:

> I have also sought out partnerships to support the work we deliver, where myself or my team may not have the specific skills to work with a specific audience. For example, we have worked alongside the Alzheimer's Society, disability groups, prison groups, faith groups etc. By working with those who are experts in a particular audience we have learnt from them, but also not had to be "everything." (O6-Mg-03)

Others said it was valuable to have a basic understanding of participants' conditions, how they might manifest and be responded to, and what impact medications might have. Only a few facilitators talked about reading research studies and evaluations from other programmes to inform their practice.

6.3 The role of training for facilitators working with people with complex or challenging conditions

Because there are no requirements to enter the field of arts, health and wellbeing and no prescribed educational pathway, an individual pursuing this work may or may not pursue training to support the acquisition of knowledge and skills. This ad hoc approach to developing competencies reinforces the general ambiguity of the field and suggests that facilitators as a group will have varying degrees of readiness for working with individuals with CCS.

This section looks at the kinds of training and ongoing education facilitators report undertaking and what value they assign to it, what they would like more of, and what barriers they see to pursuing training.

6.3.1 The types and amount of training

Facilitators in this study varied significantly in the amount and type of training they said prepared them to do arts and health work with people with CCS. At one end of the spectrum, some mentioned only taking a safeguarding course beyond their initial or continuing arts education, a course often required by employing organisations. At the other end, two facilitators with clinical backgrounds (a physician and a nurse) had undertaken additional coaching training and were both pursuing doctoral degrees related to arts and health. Many facilitators in the interviews struggled to remember what training courses they had taken at which point in their careers, but in the online discussion group some were more specific with their written answers. One facilitator with a focus on arts and mental health offered a list that suggests a learning strategy that is broad, deep, and eclectic. In addition to having a BA and MA in art, Bella has undertaken health and wellbeing courses and certificate programmes on ADHD, substance abuse, social prescribing, dementia and the arts, self-harm and suicidal thoughts, domestic violence, and mental health for specific populations including older people and children. (O8-Mx-6) Her answer was unusual in its specificity.

Overall, the facilitators each defined training in their own way, offering a wide range of learning topics and formats. As mentioned, most facilitators in the study have had formal arts training, although several come from other professions such as teaching, counselling, and occupational therapy. They described learning that contributed to their arts and health practice as coming from a variety of sources, including:

- certificate and degree courses
- conferences, one-off courses or workshops
- training delivered or required by their employer
- self-directed learning such as reading studies, reports, books, and blogs; watching YouTube videos; searching the internet; following Twitter
- participation in peer support groups and practice networks
- experiential learning, including observing, volunteering, and mentorships (these will be described in more detail in the section on experience below)

While there are an increasing number of college and university degree courses on arts and health, training is not a requirement for most arts and health practice and so there is no pattern to the types of courses facilitators in this study have taken. Almost all the facilitators raised safeguarding training, and many mentioned taking a mental health awareness or mental health first aid course. Many also took courses related to the conditions of the participants they work with. Some of these have a defined curriculum, such as singing for breathing or creative activity for dementia. Others have attended workshops or conferences that provide health information about specific conditions (e.g. learning differences or cancer care). Some facilitators working with the NHS have required training related to the conditions they might encounter, along with health coaching.

Also frequently mentioned was training related to interpersonal skills and workshop facilitation skills, although not necessarily specific to AHW work with people with CCS. These courses might include working with groups, coaching, managing boundaries, and diversity issues. Some took these courses throughout their ongoing arts and health work, but others had taken this type of training in relation to their previous careers.

While this study specifically excluded clinically trained arts therapists, several facilitators mention having taken an arts therapy foundation course or individual courses, had obtained degrees in psychology, or had undertaken some counselling training.

The training described above may happen at any point in a facilitator's career. However, many facilitators said their first-time arts and health work experiences occurred without any prior arts and health training. Several said they had been recruited on the basis of prior work in community or participatory arts, or they had accepted a commission with an arts and health focus without understanding the complexity of the setting or the population they were working with. As the quotes below suggest, this could have a negative impact on the facilitator, who may not know how to respond to challenging situations that arise, and also on participants, whose safety could be compromised by an artist without the skill to manage physical or mental health needs. Tessa said:

> I had a very quick induction and pretty much no training. No, someone came to me saying, from the organisation who was the kind of program coordinator at the time, and said, 'Oh [Tessa], I think you'd be really good at this work', having worked with me in the past. 'Would you like to become part of the team, we need another member.' And that's how I, you know, there was no interviewing process, there was no process that went on, in particular […] I just started working and kind of making it up as I went along. But from the, yeah, from the experience that I've had before with working with groups, of all sorts of different groups... Yeah. So I, it wasn't that I was coming to it completely cold. (Right). And they had seen me work in a situation specifically with young people. But, yeah, but I had, I don't remember having any kind of specific training or induction, whereas now there is a lot more, I think, for people who join the organisation. (I5-V-6)

Another facilitator said:

> I have a degree, I'm trained as an artist, I have a lot of experience in working in groups. And I've learned a lot from working in group facilitation structures over many years. But yeah, I haven't had any direct training in it. And that I mean, within spoken word, and within the poetry world I'm from, there is not much, especially going into schools and things, there's a real fake it 'til you make it thing that that happens when you're trying to learn how to do workshops. And yeah, some organisations are really trying to sort of sort that out. So many artists will contact you and say, 'Oh, my God, I've got this workshop, what do I do?' And you end up sort of finding your way into sort of more vulnerable groups. I mean, I ended up working with vulnerable groups by accident, completely by accident, just by someone seeing a gig I did and liking it, and then asking me to do it. You need to have all the checks and things, but yeah, you kind of sort of learn on the job. And I'm not saying that's the best thing. But that seems to be what's happened. But again, I'm not a mental health professional. I'm not a trained teacher. I do my role, which I do believe I'm very qualified to do. (F6-P-6)

In this instance, the facilitator recognizes the impromptu nature of being offered work that might exceed experience or competencies. She tries to balance her discomfort related to feeling unprepared for some experiences by reasserting her identity as an artist, boundarying her responsibility. Evidence from previous chapters also suggests risks that can arise when the needs of the participant group are not defined in advance, the facilitator is not experienced, and provisions for support are missing.

Another story demonstrates the potential risk in the lack of clear qualifications for new entrants to the field. Karina, a young dance professional who identified herself as an AHW facilitator for this study, talked about wanting to set up dance and wellbeing workshops for school-age children. She hadn't previously considered what scenarios might arise in wellbeing-oriented work or what additional training she might need, and this was explored a little in the context of the interview. She said:

> So I have a call on Monday with [organisation's name]. And they're an amazing organisation who are kind of helping people transition if they're not professional dancers anymore […] So I think that's a really good question. I could ask her like, Is there anything that you know of as a dance organisation that maybe I could take before January, or in January, to get ready for the new year? and see that kind of space that you're talking about? Is it to do with mental health? Or is it to do with how you deal with a situation? And that could literally be anything? And it does that go back to safeguarding and just what you would normally do in a school environment? And yeah, that's amazing. Yeah, brilliant. (O14-Mg-03)

She said she was grateful for the discussion in the interview about additional training she might need to learn more about potential vulnerabilities and risks she might encounter in a new kind of work.

Reflecting on the issues that had arisen in working with CCS over the years, several facilitators said they would like additional training on a variety of topics. Many said they would like to deepen their arts skills and others wanted to know more about health and mental health topics. A few wanted to pursue postgraduate courses related to arts and health, and three spoke eloquently about how art therapy training could help them better understand the needs of their participants, develop additional skills, and feel more confident that they were doing the right thing. Each of these facilitators had more than ten years of experience in community arts and/or delivering arts for health or wellbeing activities in clinical settings, suggesting perhaps that it is experience that has helped them appreciate the complexity of the work.

Facilitators said there were a number of barriers to education and training for AHW work. A frequently mentioned issue was a lack of knowledge about what training would be useful and how to find it. Many facilitators said they just didn't know how to find courses, although Lisa said that now there is a barrage of options online that are difficult to navigate because no organisation or framework provides guidance on what to take. (I10-Mx-6) Others said they had identified courses they would like to take but found them difficult to fit into a busy work schedule or that cost was a barrier.

6.3.2 Perceptions of the value of training

As each facilitator has a personalised approach to training, there were many views on what learning content and approaches were valuable and how this could help in their work with people with CCS. Facilitators also addressed the differences between training and experience as a way of acquiring skills and knowledge, and these experiential approaches will be discussed in more detail in section 6.4.

Many facilitators highlighted the sense of responsibility they felt for participant safety and managing risk. In this respect, safeguarding training was the most frequently mentioned as being essential to their work and something that inspires confidence in practice. Bridget said:

> I have had a lot of training over the years on safeguarding so feel confident that I approach this to the best of my ability. […] I have had a lot of training in risk management with the NHS so feel confident with this too. I think training and support gives me the confidence to know that we have safe measures in place for our clients' needs. (O22-V-46)

Many facilitators commented on the value of their education and training before moving into arts and health, which also speaks to the cross-disciplinary aspects of their practice and associated competencies. Coaching training and facilitation training were mentioned by several facilitators. Namita, a dance for mental health and wellbeing facilitator, highlighted her human resources and psychology education, saying:

> So I have, because I am a corporate trainer, besides being a creative practitioner, I think I sort of mix both the worlds whenever I choose to, you know, when, when I need to deal with specific situations, which are more psychologically based rather than creative practice based. (F1-D-03)

Just as there were varying perspectives on the roles and responsibilities of artists with respect to health issues, there were different views on training related to specific health conditions. A few said it was enough to have a little knowledge of health conditions, but not too much, emphasising putting the person before the disease and not having preconceptions about their health situation and its impact. But more facilitators reported having undertaken personal learning or courses on specific conditions and noted how this deepened their understanding of their participants' experiences. Some said that basic training on mental health or a specific condition was essential and expected by partner organisations, especially if facilitators were going to be working in the context of arts on prescription. One facilitator working in such a programme said they were told by their health partners:

> 'We don't expect you to be paramedics, or clinicians, but you need to be aware of what somebody might look like before they're about to have an epileptic seizure, or the different types of epilepsy that there are. And you need to be aware of how you know what diabetes is, and how it works, and all that kind of thing.' So again, so that we can just have that knowledge when we are practicing so that we can spot something before it might happen. (Olivia, I4-O-46)

Faith made a link between participant outcomes and the training she received around the nuances of Parkinson's disease and its impact on movement, mood, and cognitive functioning:

> So yeah, an understanding of that is *absolutely*… you know, not, not essential, because you could probably sing with any of those groups and still have some benefit without putting any of that in place. But if you wanted to do it *well*, and get *maximum* benefit, then there are definitely things that you need to know. (I-14-M-6)

Only a few facilitators mentioned training about managing interpersonal boundaries, but they did say it was helpful and even eye-opening for them, as they had not been aware of these concepts before or had not felt they had permission to enact boundaries. Freya said that her organisation's in-house boundary training was probably offered to staff because they were all burned out by their work. She said she found that incredibly useful because it made her rethink her practice and how she approached her interactions with participants:

> I think the thing that stuck with me most, was that, to really help someone you don't want to, you don't want them to be reliant on you. Because it creates a dependency, which is like really not helpful. Because really, you want people to be able to discover things for themselves, and then that they gain those skills to do it without you in their life, like in their whole life, not just in your session work. And yeah, I found that, because obviously, like I know about, I know not to like, give personal details or like cross the line or with whoever I'm working with. But yeah, I just found that really like, enlightening, for some reason. (15-V-03)

Kate said that her training gave her confidence to be more boundaried in her work, and she is now more careful about inquiring too much about participants' circumstances than she was in her early practice as she does not want to encourage too much discussion of personal issues. (I18-V-6) Not all arts and health organisations offer boundary training, and some facilitators take courses designed for other professions, like counselling or education.

Although most facilitators in the study had formal art training, there was some disagreement about how necessary this was to arts and health work. Some said they thought a solid arts training and being an excellent artist was fundamental, and others said that a little arts experience was enough, reflecting the wide range of activities that fall under the label of 'creativity.' Terry said that people can be talented artists without the training, and that the lack of a degree shouldn't be a barrier to doing this work. (F2-V-46) Several facilitators came to arts and health work from other professions and incorporated informal training or self-taught artistic skills into their practice. Sylvia, who had a solid background in facilitation and programme management prior to her arts and health work, said she had ‘a battle of confidence and a kind of imposter syndrome’ about how she taught herself the art skills she uses for her wellbeing workshops. But she now sees this as a strength, in being able to authentically communicate that anyone can benefit from arts engagement without a high level of skill. (I7-O-03)

Several facilitators commented on how the format of training made a difference as to whether it was useful or not. Experientially based approaches were considered by some to be more useful than lectures, such as learning from people who used real-life examples or taught through role-play. Some said that watching a good trainer and how they worked with a group was as useful as the content. Freya said:

> I find that really inspiring, about how to engage people who were reluctant or anxious… they just kind of like modelled these different tactics, which were like, very subtle, but really effective. And, yeah, I found that incredibly useful. Again, that training was very much like empowering me to notice that, and take from it, rather than like telling me, this is how you do this. (15-V-03)

There was a thread of ambivalence that ran through some of the interviews and discussions about the quality and utility of training experienced by some facilitators. The quality of the training on offer was sometimes criticised, either for having been badly delivered or not so relevant to arts and health delivery or the particular setting they were working in. Some people mentioned having learning styles that were not so compatible with lecture-style delivery or courses that required extensive reading and writing. The need for training and the timing of it was mentioned as an issue by a few more experienced professionals. They said that what was being taught in the course was something they had already learned through years of experience, and the training might be better suited to early career facilitators.

The uncertainty about how to best prepare for working with CCS was underscored in answers given to the interview question on what advice on training facilitators would give to a newcomer considering entering the field. (I began to ask this question after initial interviews where facilitators seemed reluctant to address what training they had undertaken). Many facilitators said they were not so familiar with what courses might be available for newcomers, or whether these would be the right place to start. Rather, the most frequent recommendation was to “try it out” through volunteering or shadowing, to get a better understanding of what the work entails by experiencing it.

Two responses to this question point again to the different philosophical and personal experiences of facilitators. Catherine, who originally trained as a counsellor, said that new entrants to the practice need to start with a good quality course, try it out, think about ethics, and “make yourself a safe person.’’ (I9-Mx-6) Freya, who came to arts and health through community youth work, thought that training was useful, but experience was the best preparation. She added:

> And the best way even for managing difficult behaviour, like if you deal with it wrong, and that participant has a crap session, and they're angry at you, and they walk out and they never come back. Like, you're only gonna learn how to deal with it differently by doing that, by getting it wrong sometimes. And talking it through with a colleague, like, I think, working in a supportive team and getting experience. (15-V-03)

A few questioned whether some skills or qualities needed by AHW facilitators could be taught, that perhaps they were inherent or came from lived experience or how you were raised. Christine said:

> So you need to be able to listen. But you, and I'm sure you can be trained to do that. But I do think that it's something that some people are born with, you know, my daughter, as well as I, we are the sorts of people if somebody's sitting next to us on the train, they'll tell us their life stories. So yeah, I'm sure you can be trained to do that. But some people just have it. Innately, I think. I think I, I think it comes down to, you know, your childhood. How you grew up. But other skills, managing group dynamics. I don't know if this can be taught, I'm sure you could teach it. But I think you would have to teach it in a, a group situation where people try out, you know, with a bit of roleplay, and so on. So that's something you probably could learn. Because you, you learn it by doing it. So I'm sure you could shorten that process. That's a really important one. (I2-P-6)

Some facilitators questioned whether training was the right way, or the only way to prepare for this work. Tessa said she had taken training on different topics through the organisation she works for. She said they made her think about things, but she wasn’t sure how much it really supported her practice. She added that it obviously does make a difference but it’s hard to draw a distinction between what you learn in training and what you learn by doing. (I5-V-6)

Many facilitators said that it was training plus experience, or experience more than training that truly prepared them for working with people with CCS. Ethan commented on how working in schools taught him how to manage interpersonal and group dynamics, and training is only part of the learning process:

> [E]ach time I'm asked into a different setting, be it a care home, a prison or a community centre with a focus on supporting those with mental health issues, I have never received specific training or counselling. Maybe I could have done with some, but my experience of other training has taught me more about the limits of what training can provide. It is always partial, it helps in giving you some tools about how to be, or maybe more importantly how not to be. (O10-Mu-6)

Marie acknowledged the partial role of training on her practice and suggests other factors come into play in how she approaches her work:

> I have attended training courses over the years which have explored a variety of approaches and guidelines on how to manage challenging situations. I have applied training guidelines when delivering activities in a wide range of learning environments. Confidence is key and I have gained confidence not through training but experience. Looking back, I was ill-equipped, very anxious and considered a different line of work. I have since appreciated my skills to support others and have the confidence to say my best is good enough. Motivation to continue in this line of work, with all the potential challenges involved has come from digging deep within myself, not attending training courses. (O2-Mx-6)

6.4 Experience as a pathway for developing practice

Most facilitators highlighted the importance of experience in learning how to be an AHW facilitator and developing their practice over time. They described experience gained from prior occupations, the knowledge and skills gained from working as an AHW facilitator, experiential learning such as volunteering and work-training arrangements, and how they incorporated lived experience of health concerns or life circumstances. They also address instinct as part of this larger tacit knowledge base that informs their practice.

6.4.1 Learning from practice experience

Facilitators gave the most assured answers related to AHW practice development on the value of learning by doing. They described several different approaches, including training in conjunction with experience, learning by working with colleagues, trial and error, reflective practice, and volunteering with or shadowing experienced facilitators.

Many facilitators gave responses that are exemplified by Ethan's succinct observation: 'There's training and then there's your first session, and that's when the real learning starts.' (O10-Mu-6) They described learning slowly on the job, project by project, often working on their own. They said they built up techniques and participant-related skills over time but were also doing the "inner work" of developing job-related resilience skills such as confidence and emotional detachment.

A frequently mentioned technique of "learning while doing" was using reflection as a tool to understand practice experiences in order to process them and use them as lessons for future work. Some facilitators keep practice journals, others described reflection as a less structured activity. Olivia said:

> And then you need to take that time outside of the work to, to reflect and kind of work out, ok, that really worked. Why did that work? Because sometimes you just do things spontaneously in a session, you go, Right. Well, that person can't do, is not doing this, or that's not working or they've said this, and you're reacting to a situation there and then. (I4-O-46)

She also said she deliberately engaged her young participants by asking questions about their conditions and letting them lead with their experience, and this educated her about what to do:

> …because that's, the that's the best way again to learn, because that's, that sinks, sinks in better than, than sitting in a in a classroom, learning facts and figures and having that, you, I mean, you do store all of that? And you have it in your toolbox. But it's actually, because it's also for them, they have to think about it as well. And it demonstrates to them that they know as well. They have, they've got knowledge of their own condition. So it empowers them to be able to share that knowledge. (I4-O-46)

Others said it was valuable and even essential to learn alongside peers, especially in the early days of practice. Ethan said:

> Most organisations I have worked for have a policy of working in pairs, certainly to begin with, and this obviously helps us to find our feet. It's also great for debriefing and for providing a degree of witnessing that is reassuring; if you're on your own it's almost impossible to know exactly what happened just then. (O10-Mu-6)

Faith said that talking to experienced facilitators and watching them do their work was an important part of learning how to be a facilitator. She added:

> … and *not doing it alone*. I do, I *do* think this is *not* something that people should just go into, on their own for the first time. I know that I did, but I had *years* of facilitation and youth work training. (I-14-M-6)

Volunteering, shadowing, and working with mentors were only mentioned by a few facilitators as their entry point into the profession, but several experienced facilitators said they used these approaches to train others. Christine described how she trains the assistant writers who work in her sessions:

> So I would start off by saying, you know, here's this session in the plan, and it's all detailed, and would you run it? […] Eventually, I had them running the whole session with me just there to step in if it was necessary. So yes, it is something, and they were learning about the group management and that sort of thing. I mean, it wasn't an emotional situation, but they were learning a lot about managing the groups and managing a session. Yes, you can […] have somebody working with you learning. And that definitely works. All the, all the assistants I have went on to run their own groups. (I2-P-6)

Two facilitators reported having benefited from a combined work and training experience. One had an arts and health apprenticeship that she combined with studying for a diploma. Another found a job that supplied training and mentoring over two years through a structured programme that employed artists to work in care homes.

6.4.2 Lived experience

In previous chapters, some facilitators discussed how having lived experience of health or social challenges motivated their desire to work in arts and health and influenced how they responded to working with people with CCS. How this experience prepared them for or informed their practice is explored in more detail here.

In answering the interview/discussion questions about training and experience, some facilitators invoked their lived experience as a kind of de facto qualification. Some facilitators answered the question by saying their own experiences (such as anxiety, mental health problems, dyslexia, domestic violence, or growing up in a particular kind of family) contributed to their ability to work in this context, giving them knowledge about the conditions or situations experienced by their participants as well as empathy. Namita said her experience of discrimination in the UK meant she could understand the difference and stigma that people with mental health conditions might feel:

> I think obviously, besides my sort of professional experience, I do feel like, personally, there's been a lot of, I wouldn't term it, I wouldn't term it "struggle." But I think, personally, there have been a lot of challenges that I've overcome myself as a person. And that gives you a sort of a perspective where you enter a space with no judgement, with no prejudice whatsoever. (F1-D-03)

Ethan highlighted the empathy developed from his own experiences as '*the key resource'* in supporting his work. (O10-Mu-6)

Facilitators who described supporting family or friends with health or mental health conditions were more detailed about how this informed their practice. Karina said that on a daily basis she manages the challenging behaviours of a family member with ADHD and possible autism spectrum disorder, a perspective that is immeasurably valuable in her work. (O14-Mg-03) Beth said that spending time with people who experience poor mental health and dementia has given her 'an insight that cannot be taught via zoom or conferences, but only by experience.' (O7-V-03)

Fiona was quite specific about how hanging out with people on drugs in her youth gave her both the emotional intelligence and management skills for this work:

> I would need to talk them down because I was the sensible person in the room. And, and those kind of experiences I've *totally* bought into spaces where people are on, appearing, to about to be wanting to start a fight. But actually, if I check in with my open body language, and I just keep my

> voice really calm, the situation's diffused. And I don't, I know that I've acquired those skills, but I've obviously acquired them through experience, my life experience as opposed to any particular training. And, but I can pass those skills on now because I know about them. (F5-T-6)

A few people said that being in therapy or participating in other art groups or peer support groups either helped them understand the experience of their participants or they used those activities as a source of techniques for running their own workshops.

Also contained in facilitators' comments about training and experience were observations that pointed to a more intangible element informing their work, something they often struggled to articulate. Some facilitators referred to being guided by instinct or the subconscious. Helene said:

> But you find your own way, don't you? I mean, as soon as you feel a need to do it, you will, you will find what *you* need, I think, and that's why it's a difficult thing to, to say, isn't it? Because I don't know, I think you, you either want to do it or you don't... That sounds utterly meaningless, doesn't it? But I don't think you can, in a funny way...The training is, there are bits and pieces in the training, but then it has to be you. It's got to be your passionate feeling that takes you through it, I think. Sounds so mingy… (F3-V-46)

Lisa's story

Lisa, a facilitator with more than 20 years of participatory arts and AHW experience, described how she often relies on instinct to guide her practice and responses. While she doesn't feel she has made consequential mistakes in her work, she desires a more structured, training-backed approach that offers a clearer rationale for actions taken with participants.

> And I want to be better at it, I feel aware of all of my sort of gaps and lack of kind of robust practice in my own sort of work. And like I want to, I'd actually really love to do lots more training in terms of, you know, training either in art therapy or, you know, I want to almost like be accredited like, so I feel more on solid ground with what I'm doing rather than it being like, just what I do as a person, it being like that I'm that I'm, you know, that, that I've got the toolkit, that I'm, that I'm a practitioner, with, you know, kind of excellence in what I do, and I… and most of the time, I feel like I'm winging it, really, I sort of get away with it.
>
> I know, from my own experience, or understanding, you know, that I'm not kind of making any major bloopers or kind of like, you know, doing or saying things that might be really detrimental for somebody. I'd like to I'd like to kind of have a slightly more sort of rigorous understanding of, you know, processes and methods of interaction I might use that that are kind of, you know, recognized as being useful. Yeah, so I can think, aha, yeah, this is what's happening here. Or, or perhaps it'd be useful to, you know, offer this type of thing or approach this person in this way, because of these things that are going on, rather than it just being like I say, almost like an innate response kind of thing. Yes, sometimes I just feel like I'm skating on thin ice, and I'd like something a bit more to hold on to. (I10-Mx-6)

6.5 Practice frameworks and qualifications

In the vignette above, Lisa describes her desire for a toolkit and an accreditation process to give her a conceptual structure and reference point for her work. (I10-Mx-6) As mentioned in the literature review, the AHW field in the UK does not have endorsed practice guidelines, codes of practice, or other professional frameworks. Facilitators in the study were not asked their views about practice frameworks or qualifications for working in arts, health and wellbeing, but this topic was raised by several. They use different terms for such guidance, without much detail as to what would be contained in them. Participants' accounts reveal a tension between loose practice boundaries that allow for unique approaches and the desire for more structure to guide their work.

Charles said that the mindset of freedom and the ability to flexibly define the bounds of the practice is what attracts him to the work. Having come from a clinical background, he compared AHW practice to the more hierarchical, right/wrong mindset of medicine, and said that there isn't one right way to deliver arts and health:

> You don't have to have one set of experiences to do the job. So you can always ask someone, and someone will always have a different solution, or a different angle of look at way of looking at something, which for me, is really refreshing (I1-Mu-46)

Several experienced facilitators said it would be useful to tap the wisdom of practitioners to identify the elements of good practice and develop this into a resource or a framework for the field, especially for those new to AHW and those who practice solo. Currently such a resource does not exist.

Referencing the challenges that arise when working with those with challenging health or mental health conditions, Lisa spoke of the need for a framework that would guide facilitators on how to respond and support when a participant is having a crisis. (I10-Mx-6) But she later observed that practice frameworks and plans can be pointless in community settings where the context is unstable and flexibility is required.

A few facilitators brought up the subject of qualifications and regulation of the field. Since there is not currently a qualification required to do this work, what facilitators meant by qualification varied or was not clear. Some said it was appealing to have a qualification, and others said that previous education or training gave them a qualification to do this work. Others said that they had never been asked for a qualification when seeking work or, as a manager, they wouldn’t necessarily see that as important.

The focus group wrestled with this topic, and in doing so also touched on other themes, including skills and training. With strong statements and reconsiderations from some of the more experienced facilitators in the group, this conversation is a microcosm of broader discussions in the field. A short recapitulation sheds light on some of the nuanced and often contradictory views that exist:

> Terry started the conversation by talking about funders’ concerns related to assessing quality through evaluations and pointed out that she has a qualification as a dance teacher, but that other artists working in this field don’t necessarily have similar qualifications:
>
> > So it's quite dangerous then for [participants], because there's no kind of quality assurance or anything like that. And so if you're paying people very little money, and you're not asking for any qualification, then that's very dangerous kind of waters. So, you know, quality, not quantity, I think is important, and some kind of regulation on that. (F2-V-46)
>
> The other facilitators shared their views about the combined importance of training, experience, and mentoring, although they may not have had access to these before their first experiences working with vulnerable participants. Terry expressed some of the ambivalence about role definition and its relationship to requisite skills that was emerging from the discussion:
>
> > When it comes to training, and it's just really a minefield, isn't it? Because I'm saying on the one hand, yes, we should be regulated. And then I'm saying, on the other hand, you shouldn't have to have any training. But again, I just think that what needs to happen is actually clearly defined what, rules? No. Clearly defined roles. So I keep coming back to it. But yeah, it's like, what role am I playing? What am I, what am I doing? And what am I expecting the outcome to be? And who am I working with? And then, then, yeah, that works accordingly, then to what skills you need, what training you need, what? (F2-V-46)
>
> Fiona pointed out that if you are looking at a field like psychotherapy or counselling, there is a difference in professional recognition between someone with a diploma and someone with a PhD, and she wondered if, without a similar qualification, AHW practitioners can’t command the same respect:

> … [W]e respect and give them roles in accordance with the knowledge and the training and a pay grade that matches that. And I think that when we, when we don't do that with the arts, we play into those same arguments where we devalue, um, the importance of our training. (F5-T-6)

She reflected on her prior comment that arts, health and wellbeing (and her sub-genre of theatre) is something of a “cowboy country” that has developed over many decades but still isn’t fully developed in terms of a canon or training requirements. This has impacts on how the quality of programmes and practitioners is assessed:

> We can't say what quality looks like because we haven't put the time in. And quality is assessed by impact of outcome, which is a health language, and it's not assessed by aesthetic and practice. And… I know a good practitioner, when I meet one, very quickly through just some small things, nuanced conversation. I know them even quicker if I'm in a room. And when we are running an exercise together, I instantly know because it's to do with eye contact, body language, interaction with participants, like yeah, this person is going to be so easy to work with. And it's how we translate that that kind of that known, that thing we just know, into a language into something that we can explain. (F5-T-6)

Her comments reveal the uneasy attempts by many facilitators to straddle the aesthetic/feeling-oriented arts world and the more metric-oriented value system of healthcare and other funders.

Terry observed that those funding arts, health and wellbeing activities often have no frame of reference for quality or qualifications, and that this approach would not be found in other professional contexts. (F2-V-46)

Mary responded to this by saying:

> I've just really been, I can honestly say nobody has asked me what my qualifications are ever, or at least not for many years. And that I get work based upon my outcomes of my projects, and the success that they've had. And a lot of them generate art that's quite successful. I get work by people seeing me perform seeing it, and then they come up to be amazing. And by being out there, as an artist, I get work to facilitate. But mainly just because I've got lots of positive successful case studies and films of work, I can show people look, this is what I've achieved. This is what the participants have achieved. Here's somebody talking about what they got from it. And that's this real sort of, yeah, sort of accessible, positive outcomes. And that tends to be how I get work. Nobody ever says, ‘What's your level of qualification?’ ever. (F6-P-6)

This stance is reflected by other facilitators with many years of experience, although it may not account for the need to assess competency and potential risk when employing early career facilitators.

Summary of Chapter 6

This chapter explored how facilitators navigate the freedom and ambiguity of a multidisciplinary practice and the implications this has for how they conceptualise their roles. Linked to examples from previous chapters, the lack of role definitions and practice guidance can leave some facilitators struggling to define the limits of their responsibility to participants and the extent of their emotional engagement. Several facilitators said they would like more guidance in the form of professional frameworks to support their practice and decision-making, however there are different views on the need for specific qualifications to do AHW work. Some see their prior training, work or lived experience, combined with an intuitive sense of what is good, as sufficient. Others recognise that qualifications and professional structures are required for other client-facing work and can help command better pay and respect from partners and funders. The relationship between these elements is discussed further in section 7.3 and 7.4.

The chapter also reported the skills and attributes of AHW facilitators and the varying views they have about the importance of training as preparation for working with people with CCS. Overall, experienced practitioners are able to define a broad range of skills they use in their work. They appreciate the complexity of their work, and many desire more training to strengthen their practice. However, newer facilitators may not be aware of the need for these skills at the beginning of their careers, possibly delaying their acquisition and refinement. Previous chapters detailed complicated circumstances that arose in the early years of some facilitator practices that made them feel unprepared and had a negative impact on their confidence. This can have implications for both the safety of participants and facilitators. It is problematic to 'wing it' or learn through experience 'even if you might get it wrong' when participants might be vulnerable to experimentation or unskilful approaches. Again, this links back to the need for delivery partners, referrers, and funders to be aware of the needs and vulnerabilities of participants with CCS and accurately match AHW programmes with staff that have the relevant knowledge and skills. Being able to refer to a framework of practice and essential competencies could help with this.

Chapter 6 Crosswalk table

Section	Key points	Discussion	Recommendations
6.1	AHW practice crosses disciplinary boundaries by combining processes and intentions that include health, wellbeing, and social elements.	7.3 ambiguity and boundaries in practice 7.2.3 caring and role concepts 7.2.5 empathy and boundaries	1 participant safety 2 facilitator wellbeing 3 guidance

	There is a freedom to self-define the practice, but this can result in ambiguity about the boundaries of facilitators' roles and responsibilities. This occurs most frequently in the desire to support mental health, where responding participants' emotional needs may be well-contained by some facilitators and overwhelm others.	7.2.6 making emotion work visible 7.3.2 role ambiguity 7.3.3 AHW and arts therapies	4 professional development
6.2	Skills needed to work with CCS include adapting creative activities, interpersonal and group management, and being able to handle emotional material and crises. Knowledge of safeguarding and some clinical information was also helpful.	7.2.1 dimensions of emotion work 7.2.6 making emotion work visible 7.4.2 acknowledging breadth of skills 7.4.4 research into practice	1 participant safety 2 facilitator wellbeing 3 guidance 4 professional development 5 research
6.3.1	There are no training requirements for AHW work, and facilitators vary significantly in the amount of training they undertake. Many have challenging first experiences with CCS without any prior AWH training or experience. Barriers to training include lack of guidance, cost, and time.	7.2.4 confidence and impact 7.2.6 emotion work visible 7.4.1 improvised training, confidence and safety 7.4.2 breadth of skills	1 participant safety 2 facilitator wellbeing 3 guidance 4 professional development
6.3.2	Valued training includes safeguarding, prior arts and professional education from different fields, interpersonal boundaries, condition-specific and mental health topics	7.2.4 confidence and impact 7.4.1 improvised training, confidence and safety 7.4.2 breadth of skills	1 participant safety 2 facilitator wellbeing 3 guidance 4 professional development 5 research
6.4.1	Learning from practice experience is common and includes practice self-reflection, peer observation and mentoring	7.4.3 experience informs training	4 professional development
6.4.2	Lived experienced of conditions seen by some as a de facto qualification for AHW work, supporting empathy, understanding of conditions and impact, and interpersonal skills	7.2.5 empathy and boundaries 7.4.3 experience informs training	4 professional development
6.5	Some facilitators desire a more conceptual and practical framework for their practice. Some like the current flexibility, and others would like more guidance, especially for crisis situations	7.3.4 professional guidelines	3 guidance 5 research

Chapter 7. Discussion

Introduction

This chapter first reviews the research questions for this thesis and how these are answered by the results. I then address several cross-cutting themes identified in the results, discussing these in the context of empirical and theoretical literature. I look specifically at how Needham's formulation of emotional labour and boundary spanning applies to the results. I discuss the strengths and limitations of the thesis from the perspective of practical, theoretical, and methodological considerations. I also reflect on my original positionality and some of the experiences and considerations that influenced my thinking and writing.

7.1 Research questions

This research study sought to answer the question of *how arts, health and wellbeing facilitators manage the potential benefits and challenges of working with individuals living with challenging conditions or situations*. Key findings related to each of the study's sub-questions are summarised briefly below.

Question 1: What successes and challenges do facilitators experience when working with individuals with challenging conditions or situations?

AHW facilitators vary in their approaches and capacity to manage the potential benefits and challenges of working with people living with CCS. They work with a wide variety of participant conditions, some of them quite serious or in challenging contexts. They describe the value of their main tasks: facilitating creativity, encouraging social engagement, and making space for expression and emotion. They are dedicated and conscientious, demonstrating a high level of responsibility in their work and concern for their participants' welfare. Overall, they hold a positive view of the value of their work and the impact it has on their participants. While the facilitators were not asked to address success in terms of participant evaluations or measured outcomes, they offered their perceptions of what was valuable and beneficial for participants and for themselves.

The facilitators also recognize how challenging it can be to work with people living with CCS and clearly articulate the personal impact this can have on their professional self-conception and overall wellbeing. The demanding nature of the work, and the physical and the interdisciplinary contexts in which they perform it, can be taxing. Facilitators spoke most frequently about the emotional aspects of their work and the challenges related to managing medical and psychological crises, behavioural issues, and disclosures of abuse and trauma. These challenges are heightened for some facilitators who feel uncertain about the boundaries of their role, their training and experience, or the level of support they receive.

Question 2: How do facilitators attend to and manage their own responses to distress or challenges presented by participants?

Facilitators use a variety of strategies to manage their participants' needs and their own during and after creative sessions. They have different rationales and approaches to boundarying their work, both interpersonally and intrapersonally. They desire to feel and show empathy in their interactions, but some have learned to be more detached with respect to personal investment in participant outcomes. Others feel a great deal of responsibility for their participants' welfare and sometimes blame themselves for situations that don't go well. Early career facilitators and those without preparation for challenging conditions or contexts struggle the most with self-confidence. Those with lived experience of health or social concerns sometimes feel vulnerable in this work but also try to transform their knowledge and skills into facilitation strategies.

Facilitators discussed the benefits of delegating responsibility and differentiating their unique role and capacities by having personal support for participants during sessions, working with co-facilitators, and/or having the backing of an organisational structure with safety and referral procedures they can rely on. Outside their sessions, facilitators value informal and formal peer support, managerial guidance, and emotional support from formal supervision or other psychosocial programmes. However, this support is often not available or may not fully address needs, and many facilitators are afraid to ask for it. In particular, early career and solo practitioners said they need support to manage working in relative isolation, develop their practice, and process their challenging experiences.

Question 3: What are facilitators' perceptions of their personal capacity (skills, training, and experience) to respond to participant needs and expectations?

Facilitators in this study described a range of personal attributes and skills they use in delivering AHW activities to individuals living with CCS, including being able to adapt art activities for the conditions of participants, using interpersonal and facilitation skills, navigating emotional issues, and managing disruptions and crises. Many of the experienced facilitators have undertaken a range of training on different topics for their AHW work, including courses that focus on specialised knowledge related to the conditions of people they work with. However, given the lack of formal training requirements or endorsed guidelines to work in this field in the UK, this preparation is often ad hoc and highly individualised. Several facilitators said they had no induction or training prior to their first experiences working with people living with CCS, and this sometimes had a negative effect. More said they would like additional training, especially related to knowing more about health and mental health topics. Barriers to pursuing this include time, money, and knowing what options are available.

On-the-job experience was held up by most facilitators as a key learning pathway, and some described how their work in other professions or their lived experience has helped them design and manage their programmes. Learning alongside other experienced facilitators was given high value, and some said that early career facilitators should never practice alone. While several facilitators described how instinct guides their practice and responses, others said they would value a more structured practice framework or accreditation process to guide their practice and signal competencies and quality.

Introduction to the thematic discussion

The following sections address key themes that arise across the results of this study:

1. The emotion work of AHW facilitators working with people with CCS
2. Ambiguity and boundaries in defining the practice of arts, health and wellbeing
3. The role of training and experience
4. The importance of support and fair working conditions.

I explore these themes alongside empirical and theoretical literature from several disciplines, including sociology, psychology, education, and management studies. Where possible, this includes literature on the work of AHW facilitators and others in participatory arts, including grey literature such as reports, policy documents, and evaluations. Given the limited literature on some themes in relation to AHW, I also draw on literature from other professions, including mental health, education, social work, and the health professions. While there are differences between AHW work and other professions, these studies provide insight by addressing issues similar to those found in this research and proposing solutions that can apply across fields. While the intention is not to delve too deeply into a sociological or psychological analysis of the reported experiences, examining some key issues may be useful for facilitators, partners, and funders with respect to understanding, preparing for, and supporting these aspects of their work.

7.2 The emotion work of arts, health and wellbeing facilitators

This section discusses the complex and multi-dimensional aspects of the emotion work of AHW facilitators and the impact of managing its positive and negative aspects. It explores the deep commitment facilitators have to their work and their participants, and how such commitment creates vulnerabilities that can be difficult to manage. It concludes with a discussion about the impact of ambiguous practice definitions and how some facilitators struggle to set appropriate interpersonal boundaries that could help manage this vulnerability.

7.2.1 Dimensions of AHW "emotion work"

There is a synergistic effect between the key activities of AHW programming that helps create the "emotion work" of facilitators. Creative activity can be a gateway to personal expression and emotions. This expression can spur further creativity and/or trigger powerful emotions. This takes place in a social context that involves interactions and relationships between facilitators and participants. Working with individuals with CCS complicates and intensifies this dynamic with respect to greater participant needs and demands on facilitators' energy, skills, and emotional resources.

This study shows that AHW facilitators engage in emotion work that has many dimensions and effects. Creative activities and participants' reactions to them often creates an emotional stimulus. (166) Facilitators use emotional intelligence -- 'the abilities to accurately perceive emotions, to access and generate emotions so as to assist thought, to understand emotions and emotional knowledge, and to reflectively regulate emotions so as to promote emotional and intellectual growth' -- to be aware of and respond to the experiences and emotions of participants and support social interactions. (167) p.10 They engage in emotional performance (Hochschild's emotional labour), which involves projecting a positive and competent affect and modulating their own personal emotions and reactions. (106) This performance also involves conveying knowledge and skills in a way that stimulates positive responses and engagement from participants. (106) Facilitators must often actively manage the emotional states of individual participants alongside the needs of the group, especially when difficult situations arise. (168) Finally, the emotional impact of these interactions means they must emotionally regulate during and after sessions, processing and managing emotions within the self. (169,170) These often simultaneously occurring activities require effort and skill and can be both energising and depleting.

The literature on emotional labour and related concepts on emotional management in work settings covers many professions, ranging from flight attendants to police officers. (108) Many studies describe the performative aspects of managing emotions as an ancillary part of work (e.g. dealing with customer emotions as a front-line worker). AHW facilitators also feel they must display positive emotions and redirect or reassess negative emotions while facilitating (Hochshild's surface and deep acting). (106) But it is the active management and absorbing of participant emotions more often tips them into emotional exhaustion. Of particular relevance to AHW work are professions where emotions are encountered in a more relational context as an expected part of worker/user interactions. This broader emotion work is found, for example, amongst teachers, (110,171) health care professionals, (109,172) and peer health and mental health workers. (173–175) James states that the emotional labourer's skills include being able to understand and interpret the needs of others, being able to provide a personal response, and being able to balance individual and group needs, skills which track AHW facilitators' descriptions of their work. (James, 1989, p 26, as quoted in Staden). (176)

7.2.2 Positive emotion work

Many facilitators discussed trying to balance the challenging and positive aspects of their work. While there were more facilitator comments on the challenging aspects (perhaps because facilitators are not frequently asked to address these issues and welcomed the chance to do so), they simultaneously stressed that they mostly found their work positive and valuable. They enjoyed seeing how the creativity and social engagement they facilitated led to positive feedback and outcomes from participants. Encouraging social engagement for participants is seen as a key benefit of group creative activities. (47,78,177–179) (180,181) These positive aspects can be a source of validation and motivation for them, as found in other AHW studies (74,76,182) and may counterbalance the emotional exhaustion and burnout that sometimes arise from the episodic and cumulative challenges. With respect to the protective effects of positive emotion work, the literature is somewhat mixed. Maslach finds that individuals with "high initial job involvement, professional commitment, idealism, and empathy for others are most susceptible to burnout, presumably because they invest more emotion in the enactment of their helping role." (Maslach, 1982, in Ashforth). (112) However Ashforth also suggests that positive identification with a role can make emotional labour enjoyable. (112) Later studies have found that workers with high emotional intelligence are better able to regulate their emotions, take a more problem-focused style of coping, and less likely to develop stress or depressive reactions. (170,183) While AHW facilitators described many aspects of emotional intelligence in their work, such as using past experiences to respond sensitively to participant reactions or boundarying their attachment to participant outcomes, it was not possible to correlate their coping strategies with the overall personal impact of their work. A study of cancer support group peer facilitators suggests that the high level of reward, including being part of members' journeys and seeing their progress in coping with illness, may mitigate the effects of emotional exhaustion. (184) This motivation is especially seen in AHW facilitators who described their lived experience as supporting their practice. Many studies of health and mental health peer support workers identify benefits and stressors related to emotion work that are similar to those described by AHW facilitators. (174,185–187) The variation in experiences and approaches they demonstrate suggest that a closer examination of facilitator skills, attitudes, and practice strategies, considered in light of emotional impacts, could shed light what supports safe and healthy work.

As the facilitators in this study described it, being empathetic and caring both does and does not feel like work: several say this impulse springs from their humanity. They did not describe doing AHW facilitation because someone said it was their job, but because it feels like a 'labour of love', as characterised by Graham (188) and Watson (174). In discussing the emotional labour of youth workers, de St. Croix observed that most feel that genuine, caring engagement is intrinsic to their work. (189) She cites Bolton's conception of philanthropic emotional work as a 'gift' to the clients and patients they interact with in contrast to other conceptual models she names where the impetus for emotional labour is prescriptive (required by organisations) or pecuniary (harnessed for profit). (189)

7.2.3 The demands of caring and managing role concepts

Whether in its positive or challenging manifestations, the emotion work of facilitating for participants with CCS is demanding. It can have a deeply affecting impact on facilitators, with several described instances of vicarious trauma. Alongside Lee's 2021 survey of artists working in palliative care, (76) this research shows how some facilitators are at risk of overinvolvement, compassion fatigue, burnout, and vicarious trauma. Huet's investigation of mental distress among art therapy trainees found several impacts that were similar to those in this study, including trainees feeling an increased understanding and empathy for clients, but sometimes over-identifying with them; feeling a sense of responsibility to them; lacking in confidence sometimes; and feeling a need for their own care and containment. (190)

A concern raised by this research is the fine line between facilitators' beliefs about the importance of the work, their caring, and their internalization of role obligations. Because some facilitators care deeply about their participants' experiences and sometimes become involved in the circumstances of their lives, they can be vulnerable to sympathetic distress and overidentification with role obligations, a risk also found among peer health workers. (112,186,187,191) This contrasts with a more detached model of provider-patient/client interaction found in other 'caring' professions like nursing, psychology, and social work, which have implicit and explicit rules about personal involvement. Despite the risks of entangled facilitator-participant relationships (192) raised by this research, historically some in the AHW field fear professionalisation because they don't want to introduce a more formal interpersonal distance into the practice (85,193) or constrain the creative and intuitive approach to AHW work (73,75,89,193) This is a concern that has been raised by other lay workers such as community health and peer mental health workers. (194–198) The notion of professionalisation (which could include training, qualifications, codes of ethics, and standards of practice) does not necessarily mean the elimination of the caring aspect of the work, as suggested by Freedberg's discussion of feminist approaches to empathy in social work. (199) The challenge is how to retain that while addressing the emotional safety of both facilitators and participants.

7.2.4 Confidence and managing impact

This study points to a complicated nexus of inexperience, internal and external expectations, and challenges to confidence, all of which complicate the impact of the internal emotion work facilitators do. Facilitators sometimes question their own competency when 'failures' such as participant upsets or leaving the activity arise from circumstances out of their control, echoing similar findings by Preston. (36) Ambiguity from all sides around intentions, activities, and realistic outcomes makes accurate self-assessment and confidence more difficult for facilitators. Early career AHW facilitators without training struggle more with difficult situations than those who cited training and experience as contributing to self-confidence in their ability to manage and respond appropriately. Looking again at the experience of nurses, those who report high levels of self-efficacy (believing in your ability to act in response to the demands of a situation) say they are better able to master the stressors of their work than those reporting lower levels. (200) Solo and early career practitioners in many professions struggle to manage the personal impact of emotion work and need support with this. (173,183) (190)

7.2.5 Empathy and boundaries

Setting appropriate interpersonal boundaries towards participants' personal circumstances is a complex task and different for each facilitator. The messages AHW facilitators receive from employing organisations, journal articles they read (73,117), and peer discussions (201) about 'not being a therapist', juxtaposed with high participant needs and their own caring instincts, may complicate their ability to boundary their emotional engagement with participants. Some spoke of 'taking home' the circumstances of those they work with. Others have discussion rules that might limit the natural instinct to explore the creative-emotional stimulus (something that participants may desire to do). Facilitators who understand (through training or organisational guidelines) and deliberately operationalize psychosocial boundary strategies say this helps them safeguard their participants' experience while managing the emotional intensity of their work and not becoming too attached to outcomes, similar to findings in other professions. (110,191) Grant and Kinman describe the notion of 'accurate' empathy, where effective emotional boundaries allow for the delivery of compassionate, person-centred care while avoiding over-involvement with service users or the development of cynical attitudes towards them. They have found that this approach can protect against empathic distress and generally enhance psychological wellbeing. (202)

7.2.6 Making emotion work visible

Regardless of the intention to not 'do therapy', this research shows that many AHW facilitators do use some therapeutic approaches -- acknowledging or encouraging creativity as potentially cathartic, providing emotional support, or working in groups to explore meaning or emotional reactions to art activities. And yet individually, and as a field, they may be at a disadvantage because these aspects of their work are underacknowledged and unsupported, and the full emotional dimensions of the work are not visible to partners and funders. (35,203) The lack of guidance around this topic can leave them unaware and unprepared, and facilitators would benefit from knowledge and skills that help them to support their participants and care for themselves. Staden also finds that nurses see the caring aspects of their roles as satisfying but not always visible or valued, an observation also made by Hochschild (106), p. 200). Citing James (1989), Staden observes that emotional labour often becomes visible only when something goes wrong or the labourer can't cope. (176) In reviewing studies on the emotional labour of health care providers, Riley agrees with the need to make such work more explicit and therefore more prominent in defining training and support needs. (204) AHW organisations and funders can respond to the challenging impacts of emotion work that is reported by facilitators, acknowledging both the positive and negative aspects of it and ensuring that facilitators are adequately prepared through emotional safety training, building on the positive strategies that some have learned through experience.

7.3 Ambiguity and boundaries in defining arts, health and wellbeing practice

This section addresses how the varied approaches AHW facilitators take in developing and managing their practices illustrate some of the longstanding debates about ambiguity and boundaries in the field. It discusses how bricolage and boundary crossing stimulate practice innovation but can present challenges in multidisciplinary contexts. Many facilitators struggle with ambiguity about their role and responsibilities and this intersects with the emotion work they do. It concludes with a review of prior attempts to provide guidance on these issues that could provide reassurance and credibility for practitioners and stakeholders.

7.3.1 The promise and challenge of “bricolage” work

AHW facilitators in this study take a “bricolage” approach of combining varied life experiences, personal philosophies, intentions, and context to develop very individualised professional practices. Building on Levi-Strauss’ proposition, the concept of bricolage has been applied in many disciplines and connotes an ability to creatively make use of what it is at hand, using seemingly unrelated knowledge or techniques. (205,206) Working as they do with health and care partners and the related physical and psychosocial needs of their participants, AHW facilitators must account for structures and responsibilities that are more demanding than creative activity alone. Akkerman and Bakker call out the ambiguity of working at the intersection of boundaries and the transformative potential that exists in this space. (102) They suggest that boundary crossing involves negotiating and combining elements from different contexts to create something hybrid – “a new cultural form”. Those who engage in this work need personal fortitude to engage with people across different practices but also to personally wrestle with and integrate these different strands of thought. Daykin notes the “lonely and ambiguous position” of AHW facilitators and suggests they need many skills to navigate these boundary crossing situations. (104)

The facilitators in this study have experiences of boundary spanning/crossing that can be challenging but also stimulating and generative – the “collisions and collaborations” that occur when the values of different disciplines meet in a programme. (207) Some who work in non-art contexts like hospitals, schools, and prisons may struggle with institutional rules, misunderstandings, and inadequate support for their work and this can cause distress. As discussed in the previous theme, negotiating disciplinary boundaries related to emotion work can be confusing and challenging regardless of context. Those working in established cross-disciplinary programmes like singing for health find these structures offer preparation pathways, guidance, and confidence. Co-designing arts and health programmes with other sectoral partners offers the opportunity to negotiate values and approaches and deliberately build on the strengths of different disciplines. (97) Solo practitioners spoke of similar internal boundary spanning benefits when they bring together different strands of their experience and interests. Rooted in a responsive and organic developmental process over decades, the complexity and hybridity of AHW as a field has been recognized by many and is seen as a strength for the diversity of approaches it embraces. (1)(8,71,74) The increasing programme and research funding for the field demonstrates that there are clearly new directions to explore (42,208)

7.3.2 The impact of role ambiguity

The other side of individual creativity in AHW delivery is uncertainty that arises from variable situations without clear guidelines for response. Role ambiguity often arises when workers need to cross boundaries and there is a lack of clarity about the scope of responsibilities and the behaviours needed to fulfil them. (209,210) This can be exacerbated by not having adequate information or feedback to perform the role, and uncertainty about the impact of actions on one's own goals and wellbeing. (211,212) Some AHW facilitators in this study have described many similar aspects of role ambiguity, including navigating disciplinary and interpersonal boundaries and wondering about the extent of their responsibility to individual participants and the overall outcomes of their programmes. This stands in contrast to others who communicate a clearer sense of their limits. The negative effects of role ambiguity on job satisfaction and performance have been reported in analyses of other professions. (213) Cashell recognized the impact of role ambiguity in creative arts therapists as a major source of uncertainty, frustration and anxiety. (214) Jensen found similar effects in museum practitioners delivering arts and health programmes to mental health users for the first time, and she suggests that attention to deliberate cross-disciplinary preparation and knowledge-sharing throughout projects can clarify role ambiguity and contribute to programme success. (215)

Role ambiguity complicates and is complicated by the emotion work of AHW facilitators, and this also has been seen in other professions. (200,216) If no one defines the role for them, facilitators say they feel pressure to take on whatever needs and expectations are presented to them by participants and funders. This is highlighted in the contrast between those who work solo without monitoring or supervision, some of whom describe greater emotional impacts from their work, and those who work with organisations (with referral pathways, practice guidelines, training or supervision) and convey more confidence about their role boundaries. Merrell notes that while a tacit understanding can exist between health clinic volunteers and other staff about the scope of their role, the absence of written guidelines contributes to ambiguity that can cause unease and distress, especially in the boundaries between lay and professional skills and knowledge. (217) Peer and allied health providers working across contexts where their role was emergent and often not fully defined are now moving towards more clearly defined practice and training frameworks as their fields mature. (218–220)

7.3.3 Addressing distinctions between AHW and arts therapies

This study shows that hard distinctions between 'just doing art' and being an instrument of health and social care are less clear-cut in many practices, especially as facilitators expand the range of CCS they work with and need additional knowledge and skill to do this. This fluid diversity potentially allows for a more expansive view of what is within the domain of AHW practice, but also what needs addressing to ensure the confidence and safety of AHW facilitators. The AHW literature shows that attempts to clarify the practice hinge on describing what AHW facilitators do or don't do in relationship to arts therapists as they try to maintain the ethos of artist as 'Outsider'. (37) (70,73,74)p. 164) Van Lith and Moss suggest that a friendly dialogue between the two fields may help draw role clarity and scope of practice definitions that could benefit both practitioners and funders. It could also provide helpful guidance on how AHW facilitators can better manage emotion work in a way that would be appropriate to their competencies. (33,70)

7.3.4 Addressing ambiguity through professional guidelines

Efforts have been made to articulate practice and professional development guidelines for creative facilitators in the UK whose practice may touch health and mental health issues. (32,39,84,85,221,222) While such efforts could address some of the practice and role ambiguity found in this study, none has been formally adopted by the AHW field and they were not raised as consulted guidance by facilitators in this study. The Scottish initiative (32) in particular called for a code of practice and professional development pathway that would both support practitioners and reassure funding bodies of quality of service. An evaluation of the Wales arts and health programme quality principles found it was valuable for professional development and addressing quality with partners and funders. (222) The need for guidance for commissioners interested in singing for health programmes was raised by Cave, who noted that without standardised accreditation it can be hard for potential employers to assess facilitator suitability for different kinds of work. (223) Further afield, stakeholders in Singapore called for increased professionalisation to support payment standards and recognition (224) and a national arts and health organisation in the United States has adopted code of ethics and standards. (86) In the UK, recent efforts to integrate AHW more fully in new NHS structures such as Integrated Care Systems (9) may require the AHW field to more clearly define what it offers, alongside practice frameworks that address competencies and ethics.

A frequent push-back by some in the field to the formalization of practice is that it would unnecessarily medicalise or instrumentalise the AHW field and potentially exclude some facilitators (37,74,85)p 386-7) Given the vulnerability of many individuals with CCS and the dilemmas described by facilitators in this study, directly addressing the key intentions, mechanisms, values, and safety principles of practice could provide clarity and confidence for facilitators, participants and funders. (81,82) An effort to develop a quality framework for AHW programmes (although not practice guidance) in England began in June 2022, and is currently being reviewed by facilitators and AHW stakeholders. (91)

The challenge for the field is how to articulate situations where more clear-cut guidelines apply and where a more values-based personal interpretation is acceptable. A proposal for principles of practice for arts in dementia speaks of subjectivity and interpretation rather than fixed specifics. (82) Some in the field propose a personal inquiry approach as the basis for a code of practice. (74,225) Given some of the examples presented here, this may not provide sufficient guidance for complex and ambiguous situations. It is potentially quite risky for early career facilitators who, in the current context, have no required preparation, guidelines, experience, or supervision to guide them. Recognizing these possibilities, Jensen made the case for an AHW code of ethics (72) which, to this point has only been taken up in the US. A recent critical review of arts on prescription programmes argues for comprehensive professional guidelines to support good practice. (34) Echoing concerns discussed in the AHW field, Gilliard et al, (194) Vanderwolle, (186) and others (220) (226) identify a tension in the field of peer mental health work where some prefer a values-based approach to preserve the essential qualities of peer support and others feel the role is best supported by a quasi-professional body that has some national authority. Gillard et al suggest further research on the impact of formal standards for peer mental health workers on both practice and client outcomes.

7.4 The role of training and experience

This section looks at how the role of training and the wide variety of practice experience represent the crux of many issues facing facilitators. These include concerns related to reinforcing the role definition and scope of practice; acquiring the knowledge and skills needed to work with people with health and psychosocial concerns; navigating the integrity of a creative practice; and attending to facilitator and participant safety. This theme examines discussions about AHW facilitator preparation, how these compare to views expressed by facilitators in this study, the value of training with respect to emotion work, and how to better incorporate experience-based learning and different forms of evidence on AHW practice.

7.4.1 Improvised training, confidence, and safety

The different ways facilitators responded to the questions about skills and training reflect the ambiguous state of the field on this topic and highlight careers that are often individually defined, improvisationally prepared for, and in many cases, yearning for structure to buttress their approach, skills, and confidence. The presentation of results on this topic in Chapter 6 has an element of structure and categorization to it that belies the way facilitators framed their responses as well as the content of them. In interviews, some hesitated in their responses or were reluctant to answer some of these questions. Others, especially those who had time to consider their answers before writing them in the online discussion group, were matter-of-fact and list-oriented in their responses.

Many facilitators in this study said that on-the-job experience plays a major role in how they develop the skills and instincts they use in their arts and health work. At the same time, some said they felt anxious and unprepared in the early part of their careers or in first experiences working with CCS, a finding also supported by Jensen's study of museum educators. (215) Even experienced facilitators with some training said they felt unequipped to deal with specific circumstances, like disclosures of abuse or manifestations of serious mental health problems. The lack of training requirements, role definitions, or a practice framework in the UK means that facilitators may or may not pursue training on topics that might help them develop relevant competencies and therefore will have varying degrees of readiness for working with individuals with CCS. As this study shows, this can potentially have a negative impact on the facilitator, who may not know how to respond to challenging situations that arise. In particular, for unskilled and/or unsupported artists, it could also compromise the benefits of the intervention or the safety of participants.

Over the years, many have made the case for structured training as a way for creative health practitioners to develop appropriate professional skills and be able to deliver safe, effective, and ethical programmes. (33,38,70,72,93,227) Moss and O'Neil led a literature and stakeholder informed proposal for a core curriculum for AHW practitioners more than 10 years ago. (33) There are many one-off workshops on arts and health topics and several further and higher education programmes in the UK, but the field has not coalesced around essential or entry level training requirements to be an arts and health practitioner, much less for working with individuals with CCS. This stands in contrast to the United States, where the National Organization of Arts in Health have recently developed a core curriculum that they intend as the basis for eventual certification. (87)

7.4.2 Acknowledging the breadth of skills needed

As mentioned earlier, some facilitators in this study (and others in the literature (74,117)) describe themselves as only or primarily artists in the context of AHW work. This research shows that they are clearly doing more. The range of coursework that many facilitators in this study have undertaken signifies that they recognize the variety of skills and knowledge they need in their work and are looking for ways to increase and strengthen them. Simultaneously, Karina's approach to beginning AHW work suggests that some artists are not aware of the range of issues could arise in practice, especially working with CCS, and that any artist could do it without additional training. Acknowledging the skills needed in an interdisciplinary practice (215) and developing an endorsed core curriculum that reflects the unique context of the UK could support a basic standard of preparation that would support early career facilitators and reassure those that fund or refer to AHW programmes. This confidence issue has been raised in the context of Lister's proposed social prescribing quality framework, which suggests activity providers (including artists) need to have the competencies aligned with the needs of the referred patients, noting some GPs may not use social prescribing because of their uncertainty about this issue. (228,229)

Recent studies and evaluations of arts and health/mental health programmes have recognized the importance of training in better understanding participant conditions, the rules and routines of settings, and skills related to safe and inclusive participatory practice. (118,179,181,230) A mixed model of training and mentorship for artists working in care homes led to an increase in confidence, better interpersonal skills, and a better understanding of how to accept the limitations of their programmes. (231) Artists in other health programmes have found boundary training useful (although, as in this study, they express varied opinions about how exactly boundaries should be managed with participants and how one should prepare for this). (80,232) In July 2022, Arts Council England included AHW facilitator skills development as one of the priorities in their Creative Health & Wellbeing plan. (42) They highlight an intention to work with the NHS to develop training resources to upskill the creative and cultural sector and their own staff, suggesting an interest in including health and mental health perspectives into these offerings.

With respect to the emotion work described in this study, many facilitators said they have benefited from or would like to receive more training on mental health and art therapy, which is echoed in the top results of a recent UK survey on previous and future training courses AHW facilitators saw as beneficial. (233) Recent guidelines developed for involving people with mental health issues in heritage projects recommend different levels of mental health training for all staff. (221) Some arts and health organisations have recently begun offering training on trauma-informed practice. (234) Research from other professions and para-professions where a high degree of emotion work is recognized emphasise the value and need for specific coursework to enhance understanding and skills. (110,172,185,192) For example, Staden asserts that the emotional components of caring that nurses do requires formal and systematic training that is grounded in psychology and sociology to manage feelings and acquire complex interpersonal skills. (176) Grant et al’s review identifies evidence-based strategies that could form an ‘emotional curriculum’ to foster emotional resilience in students training for the helping professions. (202)

7.4.3 How experience can inform training

While the content of some courses can be informed by the expertise of other professions, there is great knowledge and value that can be synthesized from the accumulated practice of experienced AHW practitioners. Some branches of arts and health practice related to particular conditions (e.g. dance for Parkinson’s disease or singing for health) have evolved to encompass particular sets of knowledge and skills that are increasingly being formalised as discrete programmes of preparation. However, the prominence given by facilitators in this study to experience-based professional development suggests that most rely on largely tacit knowledge accumulated over many years – Raw’s ‘virtual archive’ of practice. (74) Tacit knowledge has great value, and the literature suggests that the process of socialization, externalisation, combination, and internalization (SECI) can transform experiential knowledge into forms can be explicitly examined, compared across many experiences, refined to achieve greater efficacy, and be more easily passed on (Nonaka, in Abidi). (235) In this way, more clarity about the elements and mechanisms of AHW practice, developing practice frameworks, and supporting the acquisition of core competencies can reinforce each other.

The challenge is how to link experience-based expertise in AHW practice to a form of collective knowledge that can be examined and made useful to the larger field. It may be helpful to deliberately examine the concept of phronesis, or practical wisdom, explored by Flyvbjerg (236) and Shotter et al (1), and applied by Hemmestad to the teaching and practice of coaching. (237) In this framing, the usual tension between knowledge and craft is expanded to include practical wisdom that incorporates experience, ethical thinking, and context. As applied to coaching (the relational aspects of which are not dissimilar to AHW practice), a phronetic approach makes room for the complexity, flexibility, responsibility, and interpersonal/institutional power dynamics that can also arise in AHW practice. The process of developing this phronetic competence, advancing from initial knowledge through experience to intuitive and situation-dependent skill, parallels the learning process and ensuing confidence many experienced practitioners described in this study. In practical terms, this might involve a systematic examination of different practice examples and experiences to capture intentions and mechanisms of AHW programmes, as modelled in the recent mixed methods, realist approaches conducted by Cousins (82) with respect to arts and dementia practice.

This grounded knowledge could be used to develop a framework for entry-level and continuous learning supported by complementary learning modalities. This could include teaching theory and empirical evidence that can be applied in mentored practice-based experiences and structured reflection opportunities where the knowledge and experience of adult learners are directly acknowledged. (192) As mentioned before, these teaching approaches exist in some degree-based programmes, but practitioners in this study have said that learning opportunities need to be made more flexible and more affordable.

7.4.4 Translating research into practice

It may also be helpful to consider the value of translating research evidence on AHW programmes into a practical understanding of the relationship between mechanisms and outcomes in good practice. Despite the proliferation (and marshalling) of evidence reviews on AHW, orienting AHW practice towards medical or psychosocial outcomes runs counter to some views in the field about the rationale for, methods, and interpretation of evidence gathering and reporting. (89) This can include resistance to using outcome-oriented programme design and standardised experience or outcome measures. Only one participant in this study said that reading research studies was part of her ongoing professional development. (The high cost and inaccessibility of many AHW journal articles may also play a part). However, increasingly research studies and evaluation reports describe the details of delivery methods and theorise about the mechanisms of benefit (e.g. Holt 2022). (238) Using knowledge transfer frameworks that incorporate practice-based knowledge alongside research (239,240) could help develop approaches that give facilitators more confidence in what they are delivering and maximize benefits to participants.

7.5 Support, work conditions, and the broader context of AHW

This section explores how the findings of this study reinforce the recent attention given by AHW stakeholders to improving support and working conditions in the delivery of AHW programmes. The complexity of working with individuals with CCS demands varied support structures for participants and facilitators but this is often unavailable due to associated costs. Supported reflective practice, grounded in practice guidelines, can be a valuable form of self-support. Programme partners and funders should take more responsibility for work conditions that are safe, supportive, and appropriately value the care and skill being provided. And the high needs of some participants referred to AHW activities warrants more attention to skill, support and compensation, especially in the context of social prescribing.

7.5.1 Support to address safety and role delineation

This study shows how working with CCS frequently involves higher degrees of physical and psychosocial vulnerability for participants and more challenging situations that may arise for facilitators. Dedicated support for participants that is based on proactive risk-assessment is critical. Such support both ensures safety and allows the facilitator to maintain their artistic role and protect their wellbeing. Some of the stories and admonitions from more experienced facilitators in this study advise that facilitators should not work on their own without such support, a co-facilitator, and/or immediately accessible organisational staff that can respond in an emergency. This addresses a critical need to consider participant and facilitator safety, and overall programme risk management. Even if situations are not health-threatening, additional support allows facilitators to balance individual/group needs in a way that is less stressful for all. Partnership working can facilitate such arrangements.

7.5.2 Responsibilities for support

Naismith's detailed analysis of the needs and challenges to providing affective support for facilitators mirrors what those in this study find valuable and the issues they experience securing it. In other professions where emotion work may intersect with cross-disciplinary work and role ambiguity, supervision combined with continuing professional development activities and mentoring can provide oversight on critical incidents, clarify role responsibilities, offer emotional support, and help develop professional skills. (109,112,192,197,204,226,241) Peer support, supervision, and mentoring activities offered in a recent pilot programme demonstrated the value AHW facilitators found in participating. The evaluation documented a range of issues facilitators wanted to address in support activities, including practice advice, validation of common experiences, and help with boundary setting. However, scale-up of these programmes would require outside resources, as facilitators are often not in a position to pay. (242) Others have recognized the reality described in this study of restricted programme budgets that force facilitators to negotiate a zero-sum game with funders, where asking for support may mean less money in overall delivery fees. (232) (95,243) They also recognise the dilemma described in this study where facilitators often tolerate less than supportive conditions in order to secure or maintain contracts. CHWA proposes an ecosystem approach for support provision that delineates shared responsibilities among practitioners, funders, commissioners, infrastructure organisations, and researchers. (243)

7.5.3 Support and reflective practice

Reflective practice as a form of self-support and as a learning and ethical self-regulatory tool is mentioned by facilitators in this study and in the recommendations of others in arts and health. (95,243,244) This practice allows for the emotional processing of facilitation experiences and the analysis of situations that might inform adjustments to practice. Other professions recognise the value of reflective approaches for understanding and managing emotional labour. (172,245,246) Needham in particular recommends self-care plans and reflective practice for cross-disciplinary boundary spanners who engage in emotion work. (105) However, Naismith says that reflective practice does not remedy dysfunctional work conditions, nor can it replace affective support, especially for work impacts that are emotionally charged. (35,77) It may also be insufficient for ethical self-regulation. Self-reflection has the most value alongside practice supervision from experienced peers and grounded in a basic understanding of the practice boundaries, ethics, and professional guidelines. Williams states that individuals need such mental models for reflection to motivate corrective action in practice, suggesting that reflection serves both a supportive and practice boundary purpose. (247)

7.5.4 The ethics of well-supported work

As discussed in Chapter 3, some facilitators struggle with physical working conditions that are less than adequately resourced or unsafe. Many facilitators also cited the additional stress that arises from the precarity of short-term freelance contracts and compensation that does not cover hours worked. The impact of these working conditions has been recognized by many in the field and more broadly in the non-profit and cultural sectors. (36,71,96,232) Warran suggests that increasing financial inequality for freelance cultural workers is linked to adverse mental health impacts for them. (248) Belfiore, in her critical analysis of the 'Our Big Real Gypsy Lives' project funded by the Heritage Lottery Fund, describes participatory arts practitioners facing vague and unbounded outcome demands (also described in this study) that pose significant personal, psychological, and ethical challenges. (203) She contends that these practitioners are essentially exploited by a funding system that does not value their skills, their responsible approach to participant care, or the support they and their participants need during and after projects. She proposes a feminist scholarship 'ethics of care' approach that fully recognizes the responsibility of the funder to participant welfare and recognition and support for the emotional labour provided by artists working towards a social outcome.

7.5.5 Skill, responsibility, and social prescribing

This study shows that difficulties can arise when participants with complex needs are referred to AHW programmes where the setting, support options, or skills of the facilitator might not be appropriate. If we consider the main policy context for the potential expansion of AHW work, it most clearly arises in the NHS' initiatives around social prescribing. Reviewing the ethical issues related to the widespread adoption of these programmes, Brown et al caution that GPs "might 'off-load' to social prescribing services those patients who are regarded as "difficult" or who require more intensive support than social prescribing is designed to provide." (69) In recent studies, these concerns have been validated by link workers who are expected to assess and refer patients to community activities like AHW programmes. They describe problems that include a lack of important clinical information about the patients, severe health and mental health needs that the link workers struggle to manage and support, and a lack of training and support for themselves. (249,250) These concerns are echoed by the experience of some facilitators in this study who had to exclude referred participants whose mental health conditions made it difficult or risky for them to participate. This points to the linchpin role of link workers to assess whether the participant's needs are matched by the programme's competencies, whether there is personal support that goes beyond the activity provision, and who is responsible for providing this. Bungay et al's review of the literature on arts on prescription raises concerns also reported in this study, including who holds responsibility for the referred participants' health, the potential harms of short-term programmes, situations where the group dynamic may not work for some participants, and dilemma of variable practice approaches and inconsistent training. (34) Additionally, as this study confirms, the AHW field (and other sectors that participate in social prescribing) need to more directly confront a trending policy view that activities for individuals with high levels of physical or psychosocial needs can be delivered by poorly resourced and unsupported community volunteer programmes. (251,252) The findings of this study suggest that attention to provider skill level, organisational infrastructure, and clear delineations of responsibility are essential components of safe and high-quality provision for vulnerable individuals.

7.6 Revisiting Daykin and Needham

In Chapter 1, the sensitizing concept proposed for this thesis was the intersection of boundary spanning and emotional labour proposed by Needham et al (105) and explored for its relevance to AHW work by Daykin. (104) Needham et al suggest that individuals in public-facing roles who work across organisational or disciplinary boundaries engage in emotional labour as part of this work, including adhering to display rules and building trust across situations that may involve multiple rules, roles, expectations, and constituencies. Some jobs are explicitly designed as boundary spanning, and others gradually evolve to have boundary spanning aspects. There may be varying degrees of emotional labour required, and these variations may benefit from different strategies to manage consequent impacts. Daykin identifies AHW practitioners as boundary spanners with respect to the variety of settings they work in and the partnerships they navigate, noting that little attention has been paid to the emotional impacts of their work.

This study upholds the conception of AHW facilitators as people who work across disciplinary boundaries, using a wide variety of knowledge and skills to accomplish aims that span creativity, social engagement, emotional support, and health promotion. In a slightly different formulation from Needham, facilitators described a more integrative view of bringing together knowledge, skills, and approaches from different disciplines. They don't describe themselves as *crossing from* arts to health, but rather synthesizing to create something hybrid. Some aspects of working simultaneously within and across disciplines can be challenging. As Daykin observes and this study confirms, bringing arts into contexts that are distinctly in the domain of other disciplines can be challenging with respect to inadequate settings and material resources or encounters with staff and organisational structures that may not understand or fully support their work. Some facilitators describe a more positive experience when the work is co-designed and/or co-delivered, and when roles and boundaries are clear between cross-disciplinary collaborators. However, this study also shows that some AHW facilitators do not want to be boundary spanners, in that they want the creative activity to be the main intention, without deliberately engaging a health or psychosocial 'co-intervention'. Some, especially those working in non-art settings such as prisons, schools for the excluded or hospitals, are trying to provide a diversion from those settings for their participants or 'distraction therapy' from a participant's condition.

The notion of emotional labour that is caused by engaging in boundary spanning, as described by Needham, manifests somewhat differently in the findings of this study. In AHW practice, the emotion work itself is the major source of stress. For some facilitators, uncertainty about boundary crossing into therapy compounds this stress. The facilitators who seem most vulnerable are those that struggle with both disciplinary and interpersonal boundaries with respect to their role and their responsibilities to their participants. Others handle these boundaries with clarity, resolution, and equanimity. They determine the limits of their roles, communicate this clearly to participants and commissioners, and have systems in place to manage necessary referrals. This study also shows that the emotion work performed and experienced by AHW facilitators has dimensions beyond emotional labour tasks of observing display rules and building trust and includes managing emotional stimuli and actively using emotional intelligence.

Needham describes the differences between explicit and emergent boundary spanning, according to the state of development of different occupations. While AHW practice in the UK has a long history and is not emergent in that sense, it does appear that the emotional demands of the work have been less acknowledged in the past and this emerges strongly from this research and that of others. (36,76,96) Recognising that those in 'emerging' boundary spanning roles may not be aware of the emotional labour involved in these roles, Needham suggests that organisations can support self-care and reflective practice to build on the more fulfilling aspects of these jobs. This study shows that self-care and reflective practice are useful tools but can direct responsibility for managing the impacts of emotional labour on the labourer. (95) These tools are best considered in the context of adequate training and advance preparation for facilitators, and a degree of organisational awareness that addresses the appropriate setting and support needs for those engaged in AHW work.

7.7. Strengths and contributions of thesis: Practice and Theory

7.7.1 Practice

This study offers a novel and in-depth look at the practice, experience, and emotional landscape of AHW facilitators working with people living with a wide range of CCS. It is notable for a sample of facilitators that use a variety of arts modes; have different experience levels; and work in different geographic locations, organisational settings, and practice configurations. The candor and richness of their stories and their perspectives on AHW practice offer both detail and breadth to our current understanding of facilitator practice, motivations, and concerns. In particular, this study extends the empirical knowledge of emotional labour in AHW to look more deeply at the range of emotion work facilitators perform and how this intersects with the extant ambiguity of the field. It offers a detailed analysis of the practical implications of these influences for individual facilitators, those that fund or collaborate with them, and for the field of AHW as a whole.

7.7.2 Theory

This study explores how ambiguity in the field, role, and practice of AHW relates to the emotion work of facilitators working with individuals with CCS. As described above, this is somewhat different from the boundary spanning and emotional labour construct proposed by Needham. While this ambiguity stems in part from the reluctance by AHW facilitators and organisations to enact explicit boundaries in an interdisciplinary field, it also suggests that the synthesis of multi-disciplinarity by individual facilitators may result in a different (and more fruitful) mechanism than boundary crossing or boundary spanning. This bricolage approach allows space for the creative investigation of new forms and approaches if sufficient definition can be created with respect to boundary crossing that sometimes provokes anxiety in actual practice. It suggests further empirical and theoretical exploration of the positive and negative aspects of ambiguity/fluidity in work and their relationship to the emotional wellbeing of workers.

The study also offers an opportunity to consider a more expansive concept of the mechanisms, impacts, and supports related to the emotion work of facilitators than previous studies in AHW, bringing together multiple dimensions of emotion work often discussed separately in the theoretical and empirical literature from parallel professions. These dimensions of emotion work can be investigated more deeply with other AHW facilitators to better understand specific practice elements, and tested with other professions engaged in similar types of work.

7.8 Strengths and limitations of the thesis: Methods

The participatory approach of this study resulted in valuable involvement by research partners from project conception to the final review of the thesis. Our regular meetings were mutually beneficial in shaping our understanding of the experiences and needs of facilitators and, as detailed in section 2.3, they advised on data collection approaches and contributed data to the findings. Their engagement was strongest at the beginning of the project, but several partners read and validated the findings of individual chapters and helped shape the recommendations. A subset of the partners is using the research findings to support the development of projects to address core competencies and training on a national level. There was minimal engagement in the participatory elements of the project by facilitators who participated in the research interviews and discussion groups. Several facilitators said they were interested and happy to be informed about progress but were too busy to read drafts or attend the workshops designed for discussing the findings. Given the variety of options offered for ongoing engagement, it may be unrealistic to expect continued interest over a two-year project.

More broadly, the ongoing use of social media was key to recruiting a varied sample of facilitators and maintaining a good level of interest in the project that facilitated public engagement throughout the course of the research. (253) Taking the emerging research findings and their potential implications to multiple audiences throughout the project (Annex M5) created opportunities for awareness-raising, validation of findings, and participation in emerging debates on the topic. Overall, this experience demonstrates the value of an approach that is continuously and responsively involved in dialogue with research participants, other facilitators, field leaders, funders, and policymakers.

With respect to data collection methods, the depth and vulnerability conveyed in the interviews was complemented by similar information framed in different ways in the group discussion formats. Specifically, the focus group discussions featured lively interactions between the facilitators, adding an element of exploration and debate to key issues alongside the relaying of personal experiences. The written responses in the online discussion group offered considered and reflective contributions that contrasted with the spontaneity of the real-time discussions, and the participants offered more details related to topics such as training and support options.

The online discussion group was the riskiest data collection method, given the uncertainty about how participants would respond to the platform and to what extent they would engage with it. (253,254) Overall, participation in the ODG was as I expected from previous experience running online discussion groups, with higher levels of engagement early in the discussion period, dropping off towards the end (which coincided with the run-up to the December holidays and new COVID-19 lockdown restrictions). Full participation numbers are available in Annex M9. While the online discussion group was successful in many ways, including the quality of the responses given, the desired objective of interaction between participants that simulated a dialogue did not materialise as expected, with only a few people commenting on other's postings. I conducted a brief evaluation at the end of the ODG and a majority of respondents found the experience valuable in terms of reflecting on their own practice, reading about others' practices, and being able to learn and participate in this research study. Other critical issues raised included initial confusion about the functioning of the discussion group, concerns related to the user-friendliness and technical "clunkiness" of the platform, not having the time for or feeling reluctant to interact with other respondent's postings, and overall fatigue or dissatisfaction with interacting over digital platforms. I will write a full analysis of this method as a novel method for data collection with AHW separately to this thesis.

More generally, the original intention to conduct face-to-face interviews alongside participant observation of facilitators in delivery settings could have offered a different insight into their experiences. It would have contributed to a more embodied rapport in interviews and the opportunity to see what actions and decisions facilitators take in real time rather than rely solely on their retrospective interpretations. The need to collect data remotely during the pandemic may have affected the engagement and comfort level of facilitators with respect to participating in online options. Primarily using social media to recruit is likely to have biased the sample to those who use social media, excluding participants who do not. All of these considerations, however, may have also enabled participation by facilitators who may not have been able to participate through non-digital methods.

The timing of the research with respect to the pandemic may also have had an impact on the recall of practice experiences by facilitators. Data was collected November-March 2020, following seven months of significant changes to facilitators' practices due to the pandemic; this period was also just before and during the second lockdown. The impact of these events may have influenced recollections of their practice prior to the pandemic, although there is some evidence that recall of difficult or traumatic events can be more reliable than other memories. (255,256) It is possible the effects of the pandemic may have influenced emotions related to recalling challenging experiences from the past (and vice versa), as evidenced by some facilitators drawing comparisons with pandemic-related events and describing new insights on pre-pandemic experiences as a result of such events. This could be explored more in a future examination of the data I collected on the impact of COVID-19 and lockdowns on the facilitators' practices. This material could also point to issues that can be considered in a move to more hybrid delivery and inform training and safeguards that could help make this kind of engagement easier for facilitators and more valuable for participants.

7.9 Statement of reflexivity

Earlier in the thesis I reflected on four factors that shaped my approach to researching this topic. Over the course of this project, I came to appreciate the value and tension raised by my own multidisciplinary experience and approaches to this topic.

I deepened my knowledge of qualitative research methodologies, experimenting with new data collection methods and applying new analytical skills and theoretical knowledge to explore many possible interpretations. Inspired by hybrid practices of other researchers and my own creative health experiences, I studied and used creative methods such as poetic analysis to unlock new perspectives on data. Having a better understanding of these methods now, I might choose to use additional creative data collection methods for future investigations. One of the interesting features of doing remote data collection is how it complicates the experience and impact of building empathy with research participants. But we were all struggling with remoteness together, and by the time I connected with the facilitators, we'd had months of learning to connect quickly over Zoom. I do feel my telephone counselling experience helped with creating a good rapport in the focus groups and interviews and heightened my awareness of the emotion work the facilitators were doing.

It was enlightening in a visceral way to have an emotionally provocative interview experience that mirrored the stories that facilitators were telling about their own participants. I had to absorb stories that echoed difficult experiences from my own life while maintaining composure as an interviewer. From a personal and professional perspective, I could imagine "this is what it's like for them" when they hold their participants' stories. The experience heightened my empathy and strengthened my inclination to let the facilitators' words lead the way in the data analysis and reporting. But it also prompted my concern for them and their participants with respect to the distress and potential harm that could arise from these complex circumstances. (257) As I began to see/construct the implications of their challenging experiences, I sometimes puzzled about how to balance this empathetic stance with taking a critical public health view on AHW facilitation in the context of broader health and social care concerns. This especially arose while thinking about the capacity of facilitators to provide emotional support and what might be expected of them by participants, funders, and health/social partners.

Another dynamic that evolved during the process was the insider-outsider relationship to the topic and the field. At the beginning of the OPA, I started as an outsider, someone completely new to the practice and policy aspects of the field. Over the subsequent years of research and working closely with AHW organisations through consulting, training, and evaluation, I have become an outsider inside. As I reflect on the implications I have drawn from the research, and contrast them with prevailing AHW viewpoints on certain issues (e.g. 'just an artist'), I admit the discomfort of this ambiguous position. I must do my own balancing act between a public health stance (which is oriented towards structure, safety, and evidence) and the creative approach (which is more fluid, intuitive, and experience-oriented).

I was actively engaged in stakeholder discussions about my topic throughout the research process. As I began to publicly discuss some of my early findings, the practical implications of the research and potential next steps arose in conversations with research partners and other stakeholders. I was invited to lead an AHW workforce development initiative, which meant that I was actively involved in shaping an agenda on some of the key points I was wrestling with while analysing the data I had collected. Initially, I wanted to be agnostic about drawing conclusions from my data before I had completed the analysis. I came to see that my analytical thinking started with my initial readings of the literature and the first memos after interviews and evolved through to the end of the writing. It is inevitable that my broader engagements shaped my research thinking (and vice versa), and I often questioned whether it was necessary or possible to bracket one from the other.

The desire to 'conjunctively theorise' (146) can lead to an inclination to problematise. Seeing things as problems can lead to a desire to look for solutions. I struggled sometimes to remember that my primary role as a researcher is to report and reflect on experiences, not necessarily to 'solve the problem'. One example of this was puzzling about the exact elements of practice guidelines or a core training curriculum as a possible research product. While the experiences reported by my participants suggested some elements, I realised the real question was why the field hadn't taken up what had already been proposed, an enigma I am unable to answer from my data. My tendency to look for solutions is no doubt influenced by my policymaker background and, in particular, my involvement many years ago in an effort to enhance the credentials and recognition of medical interpreters in the US. Those lessons informed my practical recommendations. This kind of thinking is not outside the bounds in the DrPH programme, which has a more practice and policy orientation than a PhD. But it is often a delicate balance to interpret results knowing there are many possible applications that may be driven by different agendas. The feedback I received from facilitators, research partners, and other stakeholders support my interpretations – it is for the field to decide whether my recommendations should be pursued.

Chapter 8. Recommendations

The following practice, policy, and research recommendations are aimed at AHW stakeholders. These include:

- Leaders in the AHW field, such as the National Centre for Creative Health; The Cultural, Health and Wellbeing Alliance; and regional AHW sector support organisations
- Individual facilitators, especially those working with individuals with challenging conditions or situations (CCS)
- Funders, commissioners, and delivery partners of AHW programmes, such as Arts Council England, the Heritage Fund, regional or topical granting organisations, local authorities, NHS trusts and ICS entities, Voluntary Community and Social Enterprise (VCSE) organisations, and institutions from other sectors such as education, the prison system, social care, and culture
- University-based and independent researchers.

The recommendations address:

1. Participant safety and wellbeing
2. Facilitator wellbeing and work conditions
3. AHW practice guidance
4. Professional development programme
5. Research on AHW practice

8.1 Participant Safety and Wellbeing

Develop and implement protocols and structures to assure the safety and wellbeing of individuals with challenging conditions in AHW programmes

Rationale:

As participant wellbeing is the primary concern of AHW programmes, more consideration should be given to the appropriateness of referrals, differentiated responsibility, and structures to ensure participant needs are met and risks are minimized. Examples from this research demonstrate good practice in this regard as well as situations where participant safety was a concern. Addressing participant safety with appropriate protocols and structures can support facilitator wellbeing by clarifying roles, reducing risk and emotional complexity, and appropriately allocating responsibilities for participant welfare.

This recommendation is based on results data where participant safety was raised as a concern in sections 3.3 on work settings, 4.5 on challenging experiences with participants, 5.1 on managing in sessions, 5.3 on support, 6.2 on the skills of facilitators, and 6.3 on the role of training.

Implementation:

AHW stakeholder organisations should convene AHW facilitators and representatives of key referring sectors (e.g. health, mental health, social care, and the voluntary and community sector) to collaboratively develop and disseminate protocols for safe referral and participation in AHW programmes. This should include guidance on:

- Assessing and assuring ongoing communication on the physical and emotional needs and risks of all participants, and the provision of personal participant support as relevant
- Assessing the skills and experience of facilitators to manage basic safety and the impact of participant conditions, including training on safeguarding, first aid and mental health first aid
- Establishing support and referral pathways for emergent situations
- Clarifying the responsibilities of referring organisations or delivery partners related to appropriate referrals, providing participant support, and ensuring safe programme environments
- Clear contracting with participants about the facilitator role, programme details, participant expectations, and locus of responsibility for concerns.

Participant-referring organisations should use this guidance in the referral process and in ongoing relationships with AHW programmes. Other programme funders should use this guidance in developing specifications for programmes and contracts with providers, including appropriate consideration of staffing and cost implications. Social prescribers in particular should strongly consider the appropriateness of referring vulnerable participants to programmes that may not have the capacity to respond to this guidance.

Facilitators should discuss with potential referrers and funders how to implement this guidance in programmes and negotiate for relevant programme structures, support, and funding. They should acquire the relevant knowledge and skills to manage participant safety and wellbeing and communicate clearly with participants about programme functioning.

8.2 Facilitator wellbeing and work conditions

Develop and implement facilitator safe practice and working conditions guidance

Rationale:

Facilitators can experience uncertainty and stress in their work related to unbounded expectations and responsibilities, managing risk, lack of support for participants and themselves, and inadequate pay and working conditions. Guidance to address these issues can help funders, partners, and facilitators address these issues in programme design, funding, and implementation.

This recommendation is based substantially on results data in section 3.3 where facilitator wellbeing and work conditions were raised, along with additional concerns related to solo facilitation and the need for support in section 5.3, and the impact on facilitators of working with CCS and challenging situations in sections 4.3, 4.5, 5.1, and 5.2.

Implementation:

AHW stakeholder organisations should convene AHW facilitators and representatives of key referring and commissioning sectors to collaboratively develop and disseminate guidance/model contracts that address facilitator wellbeing, support and working conditions. This should include a process for facilitators and funders/programme partners to:

- Agree on the role, responsibilities, and expectations for AHW facilitators for each project
- Assess the project risks and remediation related to physical and emotional safety for facilitators
- Assess the support, experience, and training needs of facilitators according to the programme intention and participant profiles, especially related to CCS and emotional complexity
- Determine the safety of solo facilitation, critically for early career facilitators and/or when working with individuals with CCS

- Ensure safe working environments and access to organisational resources; referral systems; and provision of managerial support, affective support, and participant support/co-facilitators ensure the safety of participants and facilitators
- Compensation that reflects full project costing, experience of the facilitator, and provision of adequate support.

Facilitators and project funders and partners should collaboratively use this guidance to develop programme specifications, safeguards, support structures, and adequate compensation for each project.

8.3 AHW Practice Guidance

Develop and promote the adoption of practice guidance and core competencies related to the AHW role

Rationale:

AHW facilitators experience uncertainty about the scope of their role and practice, especially with respect to working with individuals with CCS. Practice guidance tools can support facilitator competency and confidence and clarify the scope of their work for referring and partnering organisations. They can also provide assurance to funders and delivery partners of relevant facilitator capacity for specific scopes of work.

This recommendation is based on results data presented related to role ambiguity, training, and the desire for practice guidance raised in chapter 6. The need for practice guidance is also implicated in data presented in sections 5.1 and 5.2 on the uncertainty raised by managing challenging situations, and in section 5.3 on the importance of having support.

Implementation:

National AHW leaders should convene a working group of practicing facilitators to review existing guidance tools and develop and endorse a uniform set of practice guidance for the field. Building on CHWA’s ongoing work to develop and pilot a Quality Framework for AHW practice, this guidance could encompass:

- a scope of practice, including definitions of roles and responsibilities
- a code of ethics
- identification of the skills, strategies, and the role of support for managing emotion work and addressing critical scenarios
- core competencies, including knowledge, skills, and attributes
- assessing the acceptability of a voluntary competency certification framework that spans essential knowledge and skills through to higher levels of competency that reflect more complex participant profiles, delivery settings, and intended outcomes.

This guidance could be developed in consultation with external stakeholder organisations representing AHW programme referrers and participants and adjacent professions such as the arts therapies.

Facilitators can use these guidelines to support the development and enhancement of their practice, design safe and effective programmes, and guide decision-making in critical scenarios.

Funders, partner organisations, and those that refer participants could use these tools to help shape programme design, accurately match facilitator competency to programme needs, and develop appropriate contracts.

8.4 Professional development programme

Develop a core professional development programme for AHW facilitators, in parallel with the core competencies described above.

Rationale:

A uniform programme of professional development can help facilitators develop the knowledge and skills needed to design safe and effective programmes, manage challenging situations, positively engage with emotion work, and develop a sense of self-efficacy and confidence.

Closely related to recommendation 3, this recommendation is based on results data presented on managing interdisciplinarity and role ambiguity in section 6.1; skills, training and experience in sections 6.2 - 6.4, and the desire by some for practice guidance and recognised qualifications in section 6.5. The value of training is also implicated in developing the skills required to deliver the positive aspects of AHW work detailed in chapter 4 and managing the challenging aspects of CCS and emotional complexity described in sections 4.5, 5.1, and 5.2.

Implementation:

National AWH leaders can develop and endorse a core professional development programme for AHW facilitators, in parallel with the practice guidance and competencies described above. Consultation with health and other stakeholders could help identify competencies that address working in different environments and with different conditions. This learning program could develop a curricular framework that includes:

- Essential knowledge and skill requirements for new entry and early career facilitators, especially those that address participant and facilitator safety
- Advanced levels of knowledge and skills that include recognition for experienced-based competencies and capacity to work with CCS
- Attention to emotional competency for facilitators, including understanding the mechanisms of emotion work, managing interpersonal boundaries, self-care, and support
- Examination and integration of relevant skills and knowledge from prior work and lived experience
- Pedagogical pathways that include didactic learning, supervised and mentored work experience opportunities, reflective practice, and peer-oriented learning and support groups.

Facilitators should undertake essential professional development coursework before beginning AHW practice, especially when working with individuals with CCS, and pursue life-long learning to update their ability to work with more complex programmes and participant groups.

Funders, partner organisations, and those that refer participants can assess facilitator skills, knowledge, and training to accurately match facilitator capacity to programme and participant needs.

8.5 Research on AHW practice

Rationale:

Additional research is needed to better understand AHW practice to support the ongoing development of good practice, professional guidelines, and training. The translation of current and future research on the mechanisms and effectiveness of AWH interventions make this accessible and usable for facilitators in practice and education.

This recommendation reflects the value of alternative research approaches to examine the AWH facilitator experience as discussed in methods sections 2.5 and discussion section 7.7.3. Additional practice-based research would further illuminate the emotion work described in chapter 5, and the impact of training in chapter 6. Knowledge transfer of research findings is discussed in section 7.4.4.

Implementation:

Researchers and facilitators can co-produce research using methods such as practice observation and participatory methodologies to explore the mechanisms used, skills needed, and real-time experiences and responses of facilitators as they do their work. Topics could include:

- the dimensions and implications of AHW emotion work, including the dynamics of emotional stimulus and management, social engagement and emotional support for participants, and facilitator emotional regulation.

- the impact of training and/or support on facilitator perceptions of self-efficacy with respect to managing CCS and emotion work in AHW practice.

Lead AHW organisations and research networks can also develop a knowledge transfer resources to translate AHW research findings, especially related to effective practices that lead to positive outcomes, into formats that are freely accessible to AHW practitioners and educators.

Chapter 9. Conclusion

The aim of this thesis was to explore how arts, health and wellbeing (AHW) facilitators manage potential benefits and challenges of working with individuals living with challenging health conditions or social situations (CCS). It examined facilitator experiences, how they manage their responses to distress or challenges, and how they prepare for doing this work. The study used a participatory qualitative methods design, involving both AHW research partners and 43 research participants throughout the process. Data was collected remotely, through an online discussion group, in-depth interviews, and a focus group.

This study adds substantial new insights into the practice experiences of AHW facilitators and the impact this work has on them. Facilitators are strongly motivated by their personal commitment to AHW work and the positive benefits they see for their participants. They must also manage and are affected by the physical and emotional needs that arise from their participants' ill health and social situations, stressors that are often exacerbated by challenging work conditions. The facilitators vary in the strategies they use to navigate the positive and challenging aspects of their work and point to a strong need for additional support for participants as well as for themselves. While many facilitators assert the primacy of their artist identity, they describe using a wide range of knowledge and skills across disciplines. Formal training for this work is ad hoc, varying from minimal to postgraduate training. Learning by experience was highly valued, but early career facilitators often struggled when first working with challenging conditions or situations.

AHW practice is inherently a boundary crossing activity that is generative and rewarding as facilitators create individualised practices drawing on multiple knowledges, skills, and experiences. Working with individuals with challenging health and social conditions adds complexity as facilitators adapt creative activities and respond to manifestations of those conditions. Ambiguity and uncertainty about their role, responsibilities, and practice choices often arise when crossing these disciplinary boundaries to meet complex needs. These ambiguities are intensified as facilitators try to balance their creative intentions with the many dimensions and demands of emotion work. Some facilitators manage this ambiguity through clear disciplinary and interpersonal boundaries, and others struggle to balance between empathy and feeling overwhelmed.

Working with funders, delivery partners, and other stakeholders, leaders in the AHW field can support better facilitator experiences and practices by recognizing and responding to the complexity, demands, and emotional impact of working with individuals with challenging conditions or situations. They can address the ambiguity of role and responsibilities by developing practice guidance for facilitators, identifying essential competencies for working with CCS, and creating a professional development pathway based on tacit and explicit practice knowledge, skills development related to working with CCS, and mentored experience-based learning. Commissioners, funders, and delivery partners can work towards more appropriate working conditions and adequate compensation, and social prescribing referral systems can collaborate with AHW providers to ensure that referrals match the complexity of patient conditions with appropriately skilled and resourced programmes.

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Annexes

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M1. List of research partners

Arts & Health South West: Alexandra Coulter
Arts & Health Hub: Daniel Regan
creativeShift: Julie Matthews
Creativity Works: Philippa Forsey
Culture, Health and Wellbeing Alliance: Victoria Hume and Hayley Youell
Flourishing Lives: David McDonagh
Leeds Arts Health and Wellbeing Network: Geraldine Montgomery
London Arts in Health Forum: Jenni Regan

M2. Research partner engagement guide

Creative facilitation: Navigating the benefits and challenges of
arts, health and wellbeing activities with vulnerable individuals,
including during the COVID-19 pandemic

Julia Puebla Fortier
Doctorate of Public Health thesis project
London School of Hygiene and Tropical Medicine

Research partner engagement guide
Ver. 4a – draft for discussion with potential partners
20 July 2020

This document describes the project's participatory approach and potential activities that research partners would be invited to engage in over the course of the research project (July 2020 – December 2021).

(Please see project summary document for research details)

Overview of a participatory research approach for this project

Participatory research directly engages as co-researchers individuals and communities who are the focus of the intended research topic. Drawing on their experiences and expertise, these individuals and communities work with researchers in a collaborative learning process to define and support the collection of data and communication of results to stakeholders. Defining engagement is unique for each research process, and must be negotiated with research partners and participants according to their desires and capacities.

Arts, health and wellbeing (AHW) practice has been much discussed by local practitioners and national stakeholders in recent years. Since the topic is already owned and actively engaged by the field a participatory approach fits with the overall ethos and direction of travel where facilitators are trying to understand and advance practices themselves.

Prompted by issues raised in my ongoing research engagement with Arts & Health South West, I have discussed key issues related to this topic with AHW facilitators and organisations that represent them regionally and nationally. Along with a review of the literature, these conversations have shaped my thinking, and influenced initial drafts of the proposal. With Arts & Health South West in particular, I have had many discussions about approaches to conducting this research and those who could be involved as partners and participants. Another regional organisation (London Arts in Health Forum) and a national organisation (Culture, Health and Wellbeing Alliance) have also agreed to be key research partners. I also propose involving four or five AHW facilitators who will collaborate on the project as research partners.

These research partners will be convened as a group to envision their role collectively. They are invited to help refine the research tools, review summaries of the data, contribute to the analysis, and shape the knowledge translation with respect to publications, public engagement, and future action.

Potential benefits to partner organisations:

- Learning and skills-building related to academic research processes
- Partnership affiliation with an academic research project
- Producing evidence related to key practice issues that could be used for developing the field and advocating for change
- Opportunities for reflection, discussion, and collaborative analysis
- Strengthened relationships with other partners
- Strengthened position to seek collaborative funding for related projects

Proposed partnership activities

There are a number of considerations related to how partners would be involved in the research project. Recognizing that each individual/organisation has different capacities and interests, I would propose a range of ways for these partners to engage in the project:

Activity	**Partner engagement** (brief description)	**Key dates, other**
Partnership management		
Partner engagement guide (this document)	Review and discuss draft document on roles and research participant engagement	May - June 2020
Key research documents		
Research proposal/ summary	Review and comment on full proposal/detailed summary, and public summaries	June – July 2020
Interview guides	Review and suggest revisions	July-August 2020
Data collection support		
Participant recruitment	Through organizational and professional networks, and specific recommendations, help recruit research participants	August-September 2020
Observation of professional practice discussions	Discuss and, as appropriate, facilitate access to stakeholder discussions on practice issues, including recordings, reports (ethics/data management agreed in advance)	Ongoing through project
Project engagement		
Project updates	Read, and as desired, give feedback on regular project updates	Ongoing through project. Need to determine frequency
Project discussions	Periodic all-partner discussions on project roll-out and key issues	Ongoing through project. Need to determine frequency

Data review	Access to summaries of data collected	Ongoing through project.
Data analysis	Comment on and discussion of data summaries and draft analyses	Approximately January – April 2021
Writing and reports	Review of drafts as desired, individual feedback and/or group discussions, co-writing of briefing documents	To be discussed – could be ongoing, or just in later stages.
Dissemination	Support in dissemination of reports to stakeholders, coproduced events, other	To be discussed – could be ongoing, or just in later stages.

M3. Working Agreement for Research Partners

Draft Working Agreement for Research Partners*

For discussion and adaptation by research partners

Lead researcher: Julia Puebla Fortier

Partners in the Creative Facilitation research study agree to participate in accordance with the following protocols:

A. Respect and open communication

1. Partners agree to communicate respectfully and openly with one another throughout the project.

B. Anonymity and confidentiality

1. The partners agree that all personal identifying information related to the research participants will be confidential to Ms Fortier. Research participants (and anyone they work with) will remain anonymous in all discussions (they will be identified by pseudonyms in writing and discussion).

2. The partners agree that all conversations and written discussions related to the research process will remain confidential to the group, unless otherwise agreed (see D below).

C. Access to and protection of information generated or collected

1. All partners will have access to notes, recordings, or transcripts that are generated or collected within the context of the partner meetings. These will not be shared beyond the partner group.

2. Partners will have access to data summaries and preliminary analyses generated by Ms. Fortier during the study period. Pending approval by the ethics committee, they may also have access to anonymised transcripts for the purposes of further research analysis after the initial study is completed. Unless already designated for public release by Ms. Fortier, none of this material should be shared outside the group without prior agreement with her.

D. Use of common material and review before release

1. Partners agree that if they wish to use or report common material generated within this project, they need to negotiate this use with Ms. Fortier and other partners. Owing to the academic research process, some material may be restricted until the finalization of Ms. Fortier’s research publications.
2. The authors of any reports about the research or the work of the partners will notify Ms. Fortier and the other partners about their intention prior to beginning and will give them access for review before publication.

E. Identifiability in reports and publications

1. Partners agree that:

a. it is appropriate to acknowledge the partners by name (e.g., as co-authors, in footnotes or in 'Acknowledgement' sections of published accounts of the research); but that

b. pseudonyms (e.g., for direct quotes) are to be used in the main text of accounts so that it is difficult for readers to attribute particular comments to particular people, unless those individuals consent to be named.

F. Rights to publication

The partners agree that Ms. Fortier retains the right to publication from the results of this study. Partners will be invited to review the fairness, accuracy and relevance of any accounts that pertain to them.

G. Reflecting on the research process

1. In order to ensure that the research process does not compromise the integrity of the group, or impact negatively on those involved, partners agree to periodically review (as a group) how the research is unfolding and impacting on the group and the individual partners.

F. Changes to partnership

1. Partners agree that, if new members join the group during the project, the new members will be required to agree to this partner agreement.

3. Each partner agrees to respect the rights of others to withdraw from the study at any time, or to decline participation in particular aspects of the study.

*   *   *

Certification of agreement

We, the undersigned, collectively, individually, and voluntarily give consent to our participation as research partners in the Creative Facilitation study.

In providing our group consent, we agree that:

1. We have each read an outline of the proposed study and partnership guide, discussed it, and understand the purpose, methods, potential risks and benefits of the research.

2. We agree that our participation will be of value to us as professionals reflecting on our own work, beneficial to scholarship in the discipline and profession of arts, health and wellbeing, and can contribute to the development of participatory research as a research approach.

3. We agree we will protect the anonymity of the research participants and the confidentiality of the partners' communications.

4. We understand that not everyone will be able to attend every meeting dedicated to the study and agree that work will continue in a partner's absence.

Signed,

XX

*Adapted from:

Resource 3: Critical Participatory Action Research Group Protocols: Ethical Agreements for Participation in Public Spheres

Kemmis S., McTaggart R., Nixon R. (2014) Resources for Critical Participatory Action Researchers. In: The Action Research Planner. Springer, Singapore
https://link.springer.com/chapter/10.1007%2F978-981-4560-67-2_7#Sec12

M4. Public engagement activities

Academic presentations, public education and stakeholder consultation activities related to research activities conducted as part of the DrPH.

Activities related to Thesis (Research Paper II)

Closing plenary presenter, Culture and Mental Health International Conference (Belgium), November 2022. “Stretching the boundaries of care: The emotional labour of creative health facilitators”

Poster presenter, National Organization for Arts and Health (US) conference, November 2022. “Managing the Emotion Work of Arts and Health Facilitation”

Collaborative Learning Workshop leader and presenter. Arts & Health South West, September 2022. “Facilitating Social Connection in Creative Health Delivery”

Collaborative Learning Workshop leader and presenter. Arts & Health South West, July 2022. "Navigating Emotions in Creative Health Delivery"

Steering Group Member, Creative Health Quality Framework. Culture, Health and Wellbeing Alliance, June 2022 – present.

Training workshop co-leader (2-days). South West (England) Regional Library Services, June 2022. “Using Creative Health to Support Wellbeing and Manage Stress”

Presenter, Creativity Health and Wellbeing Week, May 2022. “Developing a Collaborative Agenda for Professional Development in Creative Health”

Consultation on professional development for creative health practitioners. Arts Council England, January 2022.

Project lead, Creative Health Learning Alliance (consultation with regional stakeholders, organisation of public learning workshops). Arts & Health South West, August 2021 – present.

Consultant, professional development agenda for creative health practitioners participating in social prescribing in the west of England. Arts & Health South West and West of England Combined Authority, August – December 2021.

Workshop leader and presenter, Culture Health and Wellbeing International Conference, June 2021. “Learning and professional development for creative practitioners working in arts, health and wellbeing”

Workshop leader and presenter, Culture Health and Wellbeing International Conference, June 2021. “Feeling for the edges: How creative facilitators negotiate practice boundaries with themselves, participants, and commissioners”

Presenter, MARCH Network Conference: Ethical Dilemmas in Arts and Mental Health, March 2021. "Navigating disciplinary and emotional boundaries as a creative practitioner working in arts, health and wellbeing"

Co-supervisor, MSc Project Report by Daisy Danziger, towards a MSc in Global Mental Health, London School of Hygiene & Tropical Medicine. January – August 2021."Exploring the Role of Supervision for Non-Clinical Artists working in Healthcare Settings"

Presenter, Qualitative data collection in a COVID-19 era: methods, challenges and opportunities webinar, LSHTM, June, 2020. "Creativity and COVID: Using remote methods to explore the experiences and practices of facilitators delivery arts, health and wellbeing activities

Presenter, Re-Imagining the Future: A webinar discussion on the big questions for arts and health research and practice, May 2020. "Vision and Values: the distinctive role of the artist practitioner in this field."

Activities related Organization and Policy Paper (Research Paper I)

Workshop presenter, Nordic Arts and Health Conference, May 2022. "Cross-sectoral relationships in arts, health and wellbeing: An exploratory workshop on navigating your collaborations"

Presenter, International Congress on Music, Arts and Health (Barcelona), July 2021. "Cross sectoral collaboration in arts, health and wellbeing."

Presenter, Culture Health and Wellbeing International Conference, June 2021. "Navigating Power, Resources and Systems Complexity in Cross-Sectoral Collaboration for Arts, Health and Wellbeing"

Presenter, Beyond Measure: Research and evidence in culture and health webinar (University of Leeds), November 2020. "Cross-sectoral relationships in arts, health and wellbeing."

Lecturer, MSc Applied Gerontology course. NTU Singapore, April 2021. "What influences collaboration across sectors in arts, health and wellbeing."

M5. Online recruitment form consent and questions

Creative facilitation: Navigating the benefits and challenges
of delivering arts, health and wellbeing activities,
including during the COVID-19 pandemic
Ver. 3 -- 26 June 2020
Form hosted on Online Surveys

P. 1 Introduction and eligibility

Thanks for your interest in participating in the research study "Creative facilitation: Navigating the benefits and challenges of delivering arts, health and wellbeing activities, including during the COVID-19 pandemic." This form allows us to collect basic information about you in order to choose research participants and assign them to different research activities. It should take about 5 minutes to complete.

We have just a few eligibility criteria for this study:

- You have current or previous experience facilitating creative activities with an intended health and wellbeing outcome
- You are not a clinically trained arts therapist
- You work in one of the South West counties, the greater London area, or Yorkshire and The Humber
- You are over the age of 18

☐ I fit all eligibility criteria

Please note that more people may apply to be part of this research project than can be accepted. If you are not chosen, you will have the option of receiving updates and reports related to the project.

If you not yet read the project summary, please do so now (link to https://artsandwellbeingpractice.wordpress.com/2020/07/14/creative-facilitation-research-project-summary/
)

☐ I have read the project summary and understand the different activities I might selected to participate in.

P. 2 Consent to fill out this recruitment form:

Because we will be collecting information about you on this form, we need you to consent to filling it out. By ticking each box, you are saying that you understand and agree with each statement:

☐ The information collected on this form will be used to select participants for the research project in a way that represents a range of geographical location, experience, and type of arts, health and wellbeing practice.

- ☐ If I am selected, some of the data on this form may be used as part of the analysis process. It will not be linked to any information that could identify me in any activities or reports.

- ☐ The data on this form will only be seen by the lead researcher, and will be held in confidence in a password protected file on an encrypted computer.

- ☐ Filling out this form is voluntary and I am free to not complete the form, without giving a reason.

- ☐ If I am selected to participate in the project, I will have the opportunity to participate or refuse at that time, and will sign a participant consent form.

- ☐ If I do not participate in the project, my data from this form will be destroyed.

P.3 and following: Recruitment questions

First and last name

Pseudonym you would like to use during your participation

Email address where you can be contacted by the researcher

Age (confirm over 18)

Gender

County (drop down menu of relevant counties)

What research activity would you like to participate in? Please indicate by order of preference, 1 being the first preference. (Link to activity descriptions)

Online discussion group
Focus Group
In-depth interviews
None of these

Would you also (or alternatively) be interested in reviewing and commenting on summaries and analyses of the data collected?

Yes
No

Creative activity used in your arts, health and wellbeing facilitation (please pick your primary mode)

A. Museum
B. Gallery
C. Music
D. Dance/movement

E. Theatre/drama
F. Poetry or spoken word
G. Creative writing
H. Visual art
I. Mixed art forms
J. Other (please specify if possible)

Health, mental health or wellbeing focus of your work
(free response)

Years of facilitation experience

0-3
3-6
6+

Have you been facilitating arts, health and wellbeing activities since the imposition of COVID-19 social contact restrictions in March?

Yes
No
Plans to recommence in the next two months

Pre-COVID-19 facilitation practice settings (you may pick more than one)

Your own studio
Community based (non-clinical) setting
Health, mental health or social care setting
Online
Other:

Pre-COVID-19 activity support arrangements (please check all that apply)

I deliver activities as a solo facilitator
I work with co-facilitator(s) – non-clinical
I work with co-facilitator(s) – clinically trained
I work with participant support people (family, friends, volunteers, staff)
Other:

Training (please check all that apply)

Formal arts training (university, arts conservatory or academy)
Informal arts training
Facilitation or coaching short course
NHS/PHE health, mental health or wellbeing short course
Mentorship by an arts, health and wellbeing facilitator
Other:

If you are not selected for the study, please tick this box if you would like to receive updates and reports related to the project by email.

M6. Participant recruitment and allocation protocol

1. Recruitment process overview
2. Recruitment announcement
3. Activity assignment criteria

1. Recruitment process overview:

a. A brief announcement of the project and participant recruitment would be sent out through research partner and other AHW channels (newsletters, websites, social media). Taking a purposive/snowball sampling approach, partner organisations and other key contacts would also be consulted to identify specific interview or focus group candidates. These individuals would be referred to me. All interested individuals would be directed to step b.

b. Interested participants would be asked to complete a secure online recruitment form on a secure survey platform, such as REDCap. They will be instructed to review the summary on the project website. The recruitment form includes consent language to fill out the form.

c. Recruitment will remain open for one month for the online discussion group and longer for the focus group and interviews.

d. The researcher will download the responses to a spreadsheet, review each response, assign a participant code, and assign participants to the selected data collection method (according to criteria, below). Data management protocols will be followed.

e. Participants will be contacted about their selection and given additional information about the study, their assigned method, the info sheet and consent form. Their completion and submission of the participant consent form will complete the recruitment process.

2. Recruitment announcement:

Creative facilitation: Navigating the benefits and challenges
of arts, health and wellbeing activities with vulnerable individuals,
including during the COVID-19 pandemic

Are you an arts, health and wellbeing facilitator working in (locations)? We invite you to participate in a research study looking at how creative facilitators navigate potential benefits and challenges when working with vulnerable participants, including during the practice changes resulting from the COVID-19 outbreak. We are interested in facilitators' experiences of successes and challenges in this work, your perceptions of your personal capacity (such as skills, training, attitudes) to respond to those you work with, your own responses to their distress or challenges, and how COVID-19 has affected your practice.

This study is part of doctoral degree research at the London School of Hygiene and Tropical Medicine, and being conducted using a participatory approach with facilitators and partner organisations (list).

For more information about the project and how to participate, please visit this webpage (link to project summary and recruitment form link)

3. Activity allocation criteria:

Selection order: 1. interview participants, 2. focus group participants, 3. online discussion group. Consider their activity ranking preferences (rank 1 or 2 if possible). Select back-up participants in case some drop out.

For each activity, attempt to achieve a range of geographic diversity, years of experience, art form, and if possible, 1/4 participants who are not currently facilitating.

M7. Draft topic guides

1. Observation of professional practice discussions
2. Online discussion group
3. Focus groups
4. Interviews and diaries

1. Observation of professional practice discussions

Take field notes on key research themes, as they arise:

Theme 1: Facilitator experiences working with vulnerable individuals

- Descriptions of experiences
- Managing participant expectations
- Responding to challenging situations –
  - In session
  - Personally

Theme 2: Perceptions of capacity to respond to participant needs and expectations

- Training, skills, experiences that inform their capacity
- Relevance of that preparation in working
- What else they feel they need to respond appropriately (personal, organisational support)

Theme 3: Managing their own responses to challenging situations

- Professional practice implications (risk, safeguarding)
- Emotional response

Theme 4: COVID-19 changes

- Practice changes
- How these changes affect facilitators
- Additional stress from participants
- How they manage this stress (and their own)

Cross-cutting themes: navigating boundary issues and emotional labour

- Crossing disciplines and sectors
- Role ambiguity
- Coming up against boundaries
- Facilitator perceptions of and responses to these situations
  - Positive/opportunities
  - Negative/challenges

2. Online Discussion Group

Discussion prompts

Week 1: Introduction to the group

Day 1: Welcome message. Reminder of key group rules. Any questions about those or the functioning of the group. Tomorrow's icebreaker activity

Day 2: Please tell us a little about yourself (whatever you feel comfortable with): your arts facilitation practice, your practice environment (you don't need to name the facility, just the kind of setting that it is), your personal art practice if you have one, or anything else that would help us get to know you.

If you like, you can post some artwork you have created, or a bit of writing, or a photo of something that represents or inspires your facilitation practice. Please make sure not to post photos of the participants you work with.

Week 2: Theme 1 - Facilitator experiences working with vulnerable individuals

Tell us about your facilitator experiences of working with vulnerable individuals or groups, before the COVID-19 restrictions:

1. In your practice, what kinds of vulnerability did you see in the individuals or groups you worked with?

2. What kinds of experiences did you have that were positive or transformational?

3. What kinds of situations arose that were challenging?

Week 3: Theme 2 - Your capacity to respond to participant needs and expectations

1. What training, skills, or experiences have prepared you to do arts, health and wellbeing facilitation work?

2. What has been especially relevant in working with vulnerable individuals? How does it help you respond to their needs or expectations?

3. What other training or support helps when working with vulnerable individuals?

Week 4: Theme 3 - Managing your own responses to challenging situations

1. What is the impact on you, as a facilitator, of managing complex needs or challenging situations that may arise when working with vulnerable individuals?

2. How are these issues related (or not) to feelings of responsibility or burden of care?
    To safeguarding?
    To risk management?

3. What guidance, support, or self-care do you need to manage these issues?

Week 5: Pause for catch up

Week 6: Theme 4 - COVID-19 changes

1. Tell us how has your practice changed as a result of the COVID-19 restrictions on social contact? How have you managed these changes?

Week 7: Theme 4 – COVID-19 changes (con't)

Last week we talked about how your practice has changed as a result of the COVID-19 restrictions. This week's questions are related. If you have been working as a creative facilitator since the start of the pandemic:

1. Have you noticed a higher level of stress or need from the participants you work with? How do you help them manage these feelings?

2. How does witnessing or managing the distress of your participants affect you?

3. Is there anything that has helped or supported you in this process?

3. Focus groups

1st Focus Group meeting – pre-COVID-19 practice

Opening (10-15 minutes)

Welcome message. Overview of the session. Reminder of group rules. Any questions about those or the functioning of the group.

Introductions:
(they will be advised of this in advance, or they may be asked to complete it in advance and it will be shared before the focus group)

Please tell us a little about yourself (whatever you feel comfortable with): your arts facilitation practice, your practice environment (you don't need to name the facility, just the kind of setting that it is), your personal art practice if you have one, or anything else that would help us get to know you.

If you like, you can share some artwork you have created, or a bit of writing, or a photo of something that represents or inspires your facilitation practice. Please remember not to share photos of clients or identify them in any way. *(Note: in order to prevent inappropriate sharing, I could ask participants to send these images in advance, and I would screen share during the session while they comment)*

Opening exercise:

Since we're going to focus today on your practice pre-COVID-19, we'll just take a few minutes to settle ourselves in that space. On your own, think back to facilitation work you used to do before the pandemic social contact restrictions. Visualize the setting and the feeling you had when you walked into the room. How you set things up before a session, and what materials did you use? Imagine your workshop participants coming into the room. What activities did you do, and how did you interact with them?

Staying in this space of what your practice was like pre-COVID-19, we're going to talk about four themes related to working with vulnerable individuals and groups.

The questions will be shown on a slide or in the chat window for reference)

Theme 1 - Facilitator experiences working with vulnerable individuals (20 minutes)

Tell us about your facilitator experiences of working with vulnerable individuals or groups, before the COVID-19 restrictions:

1. In your practice, what kinds of vulnerability did you see in the individuals or groups you worked with?

2. What kinds of experiences did you have that were positive or transformational?

3. What kinds of situations arose that were challenging?

Theme 2 - Your capacity to respond to participant needs and expectations (20 minutes)

1. What training, skills, or experiences have prepared you to do arts, health and wellbeing facilitation work?

2. What has been especially relevant in working with vulnerable individuals? How does it help you respond to their needs or expectations?

3. What other training or support helps when working with vulnerable individuals?

(10-minute tea break)

Theme 3 - Managing your own responses to challenging situations (20 minutes)

1. What is the impact on you, as a facilitator, of managing complex needs or challenging situations that may arise when working with vulnerable individuals?

2. How are these issues related (or not) to feelings of responsibility or burden of care?
    To safeguarding?
    To risk management?

3. What guidance, support, or self-care do you need to manage these issues?

Wrap up (10 minutes)

Open discussion with the group – additional issues to raise, feedback on the discussion and the process. Overview of next focus group.

2nd Focus Group meeting: Facilitating with COVID-19 changes

Opening (10-15 minutes)

Welcome message. Overview of the session. Reminder of group rules. Any questions about those or the functioning of the group.

Re-introductions:
(they will be advised of this in advance, and may be shared in advance as above)

If you are comfortable, please briefly describe the space you currently use for your facilitation work (or share a picture or use your video camera). Or you can share your screen to show artwork you have created, or a bit of writing, or a photo of something that represents or inspires your facilitation practice since the COVID-19 restrictions.

Opening exercise:

Since we're going to focus today on your practice since the COVID-19 social contact restrictions, we'll just take a few minutes to settle ourselves in that space. On your own, think about the facilitation work you have been doing since the pandemic social contact restrictions. Visualize the setting where you work, and the settings of the people you work with, if you are familiar with them. How do you interact with them, and what activities do you do?

Practice changes (20 minutes)

We're going to talk now about your practice in the context of the COVID-19 restrictions on social contact, starting in March this year. At the beginning of the lockdown, what did you do to adjust your practice? What was that like for you as a facilitator. If you were able to continue with the people you worked with before, how did they respond to alternatives to face-to-face meetings?

Responding to distress (20 minutes)

If you continued to work with vulnerable individuals, did you notice additional distress from them during this time? Can you give one or two brief examples of how this manifests?

How have you managed to help them with this distress? What training or experience has been helpful? What barriers or lack of resources has limited your efforts?

How has the work of managing the stress of your participants affected you? What has helped you cope with this?

(optional short break)

Cross-cutting themes: navigating boundary issues and emotional labour (20 minutes)
We spoke last time about how this kind of facilitation often involves working across different disciplines, taking on different roles, working with people from sectors. This may happen in sessions with participants, when collaborating with partner staff and organizations, or in trying to meet different expectations or rules. (Summarize some key points raised in previous session).

Would you say this is still an issue in your COVID-19 practice? Is it more the case, or less, does it manifest in the same way, or differently?

[If yes,] What does this feel like for you as a facilitator? Are there positive aspects to navigating these different roles, disciplines or sectors? What are the difficulties? How do you respond? Does it have an emotional impact for you?

Overall impact of the pandemic (15 minutes)

How would you sum up the effects of the COVID-19 pandemic on your work with vulnerable individuals? Are there both positive and negative impacts? What do you see happening with your practice going forward? Have you developed new or innovative approaches that you might continue?

Wrap up (10-15 minutes)

Open discussion with the group – additional issues to raise, feedback on the discussion and the process. Ways to stay involved in the research process.

4. Interviews and diaries

The interviews (two interviews, 60-90 minutes, 3 months apart) followed the themes below.

In between the two interviews, interviewees were invited to keep a private practice diary. This was the prompt given to them:

> Practice-related issues (activities, format, challenges and successes in delivery)
> Responding to the emotional states of the people they work with
> Managing their own emotional state, as related to the facilitation work

In the second interview, those who kept diaries were asked if they would like to verbally share insights from the diaries. These diaries were not be seen or collected by the interviewer.

Interview 1:

Theme 1 – Facilitator experiences working with vulnerable individuals

Tell us about your facilitator experiences of working with vulnerable individuals or groups, before the COVID-19 restrictions.

In your practice, what kinds of vulnerability did you see in the individuals or groups you worked with? What kinds of experiences did you have that were positive or transformational? What kinds of situations arose that were challenging? What helped you respond to those situations?

Possible follow-up questions:
How did you feel when you managing these situations, during or after?

Theme 2 – Your capacity to respond to participant needs and expectations

What training, skills, or experiences have prepared you to do arts, health and wellbeing facilitation work? (Alternate question: What advice would you give about training for someone preparing to enter the field?)

What has been especially relevant in working with vulnerable individuals? How does it help you respond to their needs or expectations?

What other training or support would help you in working with vulnerable individuals?

Theme 3 – Managing your own responses to challenging situations

What is the impact on you, as a facilitator, of managing complex needs or challenging situations that may arise when working with vulnerable individuals?

How are issues related/or not to feelings of responsibility or burden of care?
How are they related/ or not to safeguarding?
How are they related/ or not to risk management?

What guidance, support, or self-care do you need to manage these issues?

Interview 2:

Theme 4 - COVID-19 changes

We'll start with some questions about how your practice has changed during the COVID-19 restrictions on social contact. [If you kept a practice diary since the last interview, you are welcome at any time to share thoughts from that diary. You don't have to you you'd rather not. At the end I will ask if there is anything else from the diary you want to share.]

Tell me how has your practice changed as a result of the COVID-19 restrictions on social contact? How have you managed these changes?

If you are still working with vulnerable individuals, have noticed additional distress from them during this time? How do you help them manage this distress? Is there anything that has helped or supported you in this process?

How does witnessing or managing the distress of your participants impact you?

How would you sum up the effects of the COVID-19 pandemic on your work with vulnerable individuals? Are there both positive and negative impacts? What do you see happening with your practice going forward? Have you developed new or innovative approaches that you might continue?

Sensitizing concepts: Listen for/follow-up if boundaries or emotional labour topics are raised by research participants

Boundary spanning:

What is it like to work with people from other sectors (and the organisations they represent) in developing and delivering this work, from design, contract negotiation to in-session working together with participants? What are these relationships like, how does it feel for you to manage them?

With partners, how do you communicate about and negotiate the kinds of activities you perform in your work? Do they have particular expectations of you and how does it feel to respond to those?

In delivering your work, are there 'norms' you feel you should follow? Do you have to move between different roles, and what is this like? Is it always clear what role you should be performing? How do you navigate what role you should be playing at any given time?

What's the emotional impact of moving across professional norms? Do things feel uneasy some times and it's not clear why? Does it cause uncertainty about what you are supposed to do, or why or how?

Emotional labour:

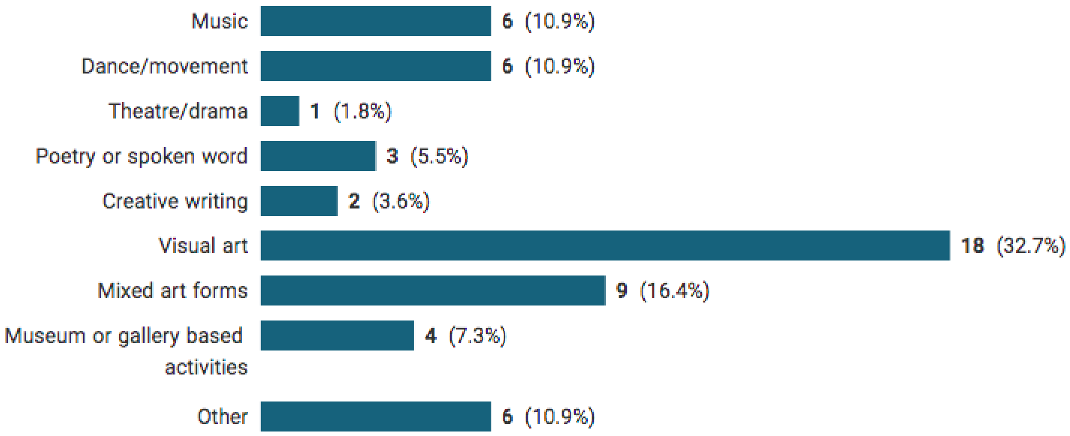
How do you monitor the emotional state of the group you are facilitating? What do you do to set a particular tone? How do you respond to changes in the emotional state of the group, or individuals in it?

How do you develop trust in the group – between you and them, and with each other? Is this more challenging with certain kinds of participants or in certain situations?
How do you develop trust between you and individuals in the group? How do the benefits of these trusting relationships manifest? How does this get challenged?

Are you conscious of doing this emotional or relationship management kind of work? How does it feel when you are doing it? Afterwards?

M8. Snapshot of responses to recruitment questions

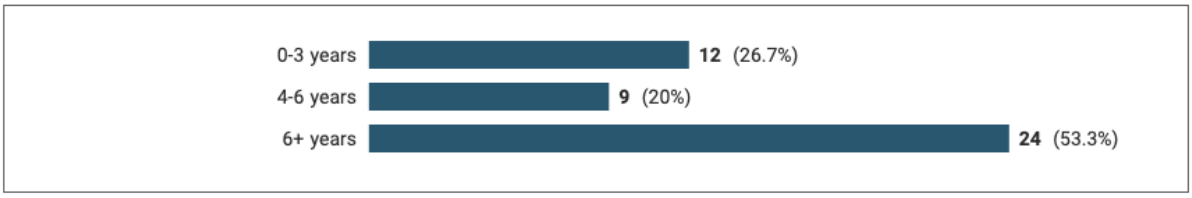
Art form:



Other:

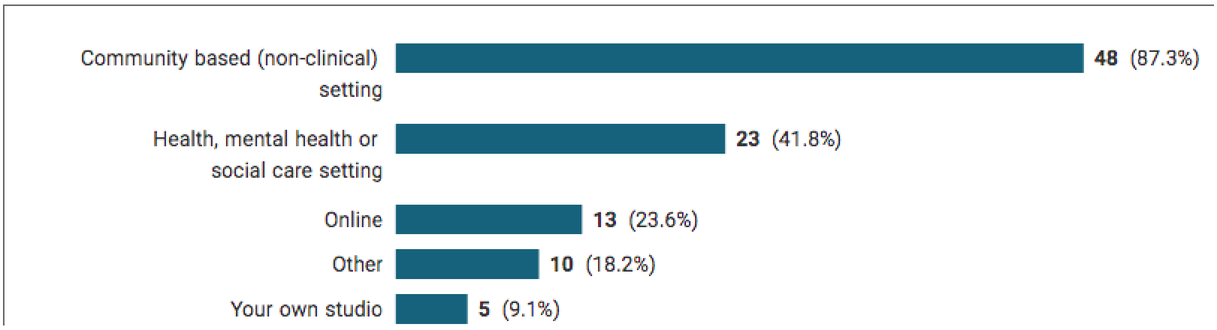
Aerial arts (circus), photography, journaling, animation and visual art, visual arts and traditional crafts

Years of arts, health and wellbeing facilitation experience



Practice Settings

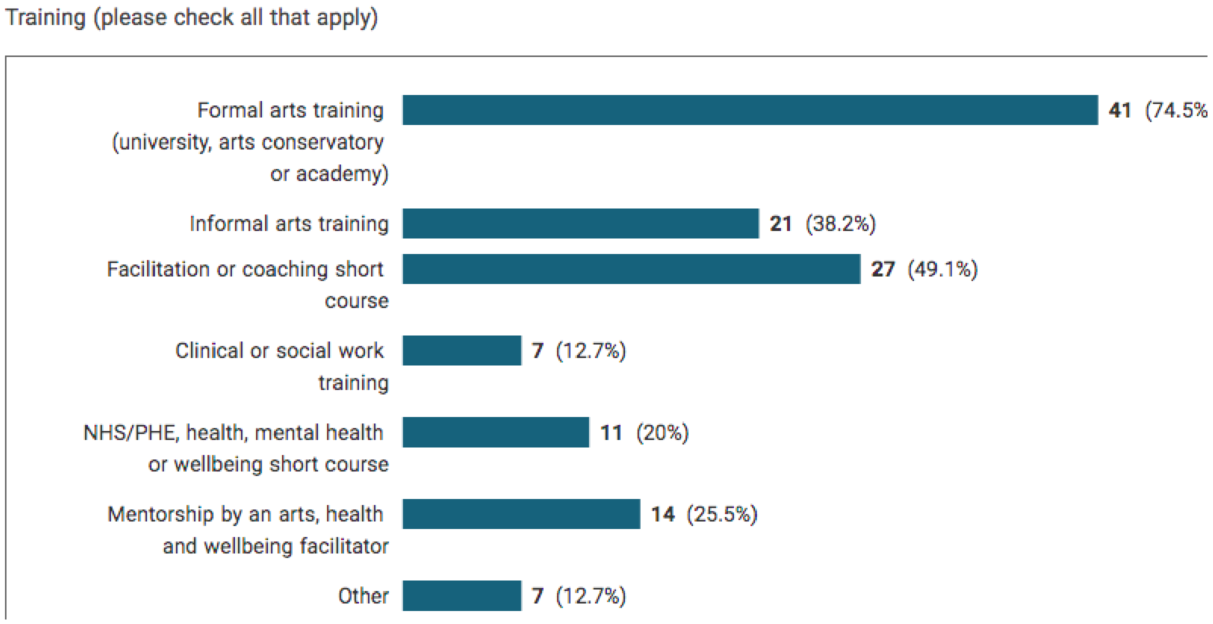
Pre-COVID-19 facilitation practice settings (you may pick more than one)



Other:

Schools, prisons, workplace, museum, nature/outdoors, dance studios

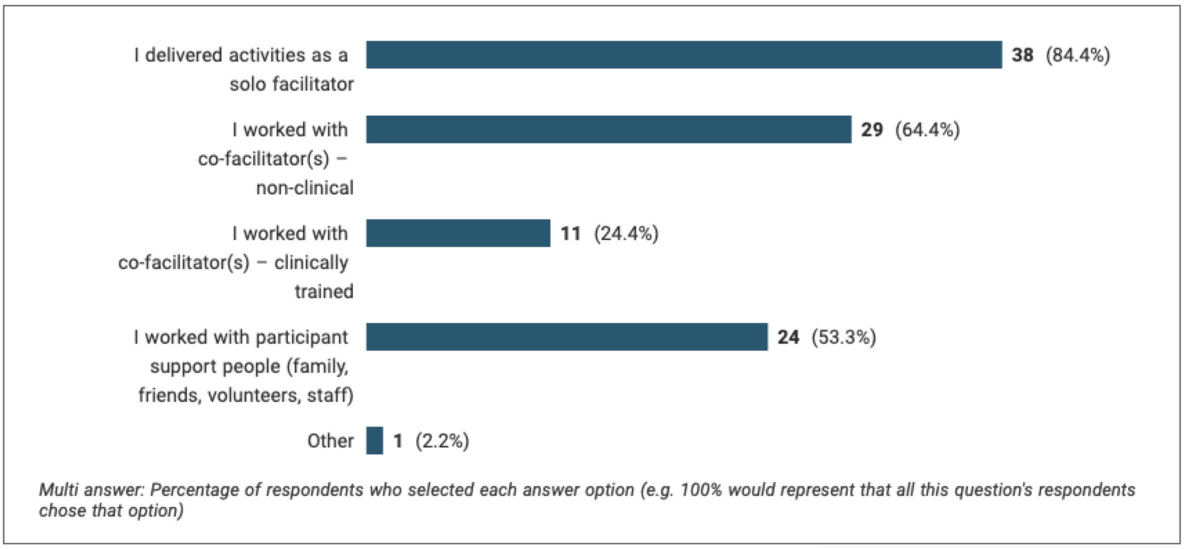
Training:



Other:

None, just experience. First aid, paediatric first aid, mental health first aid.
Apprenticeship course
Qualified coach, coach supervisor, medical educator, MSc Medical Humanities, now doing doctorate on this work. Various own art practices.
Online CPD, health and wellbeing webinars
Youth & Community DipHE, Singing for lunch health training, singing facilitation training, other health short courses including mental health and dementia awareness

Support arrangements:

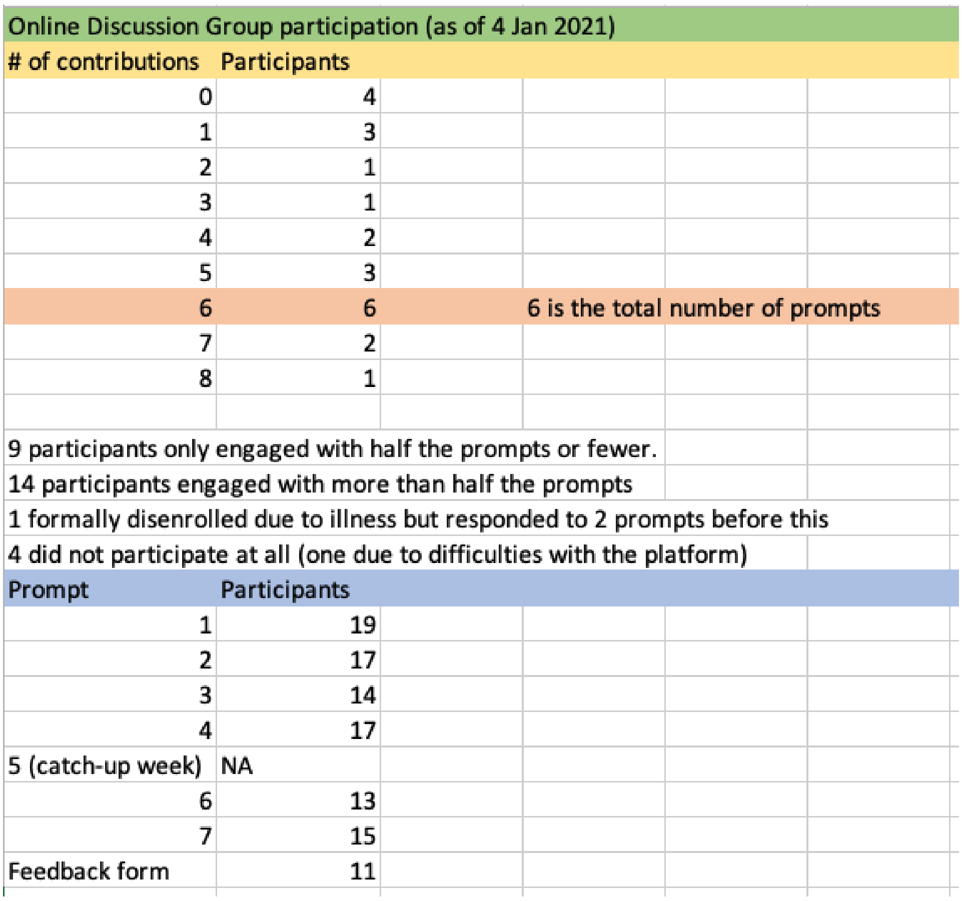


Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

Other:

Service users

M9. Online Discussion Group participation numbers



Online Discussion Group participation (as of 4 Jan 2021)

# of contributions	Participants	
0	4	
1	3	
2	1	
3	1	
4	2	
5	3	
6	6	6 is the total number of prompts
7	2	
8	1	

9 participants only engaged with half the prompts or fewer.

14 participants engaged with more than half the prompts

1 formally disenrolled due to illness but responded to 2 prompts before this

4 did not participate at all (one due to difficulties with the platform)

Prompt	Participants
1	19
2	17
3	14
4	17
5 (catch-up week)	NA
6	13
7	15
Feedback form	11

M10. Initial codes and Experience/Impact coding tree image

First stage code list (deductive, derived from topic guide):

Personal (stories – how they got to the work)

Work (description, philosophy and approach, intentions, perceptions of impact?) evaluations?

Participant conditions (challenging conditions, list, descriptions)

Positive experiences (participants)

Negative experiences (participants)

General experiences (general descriptions, ambiguous experiences)

Impact (on facilitator) >> management is a subset of impact, and support is part of that. Future sub-codes - divide into what they experience, how they feel about it, and what they do

Support (individual support people, org support, external support, eg supervision, peer support, partners)

Laughter (laughter during interviews)

Training

Skills (and qualities)

Experiences (as contributing to professional formation)

Advice to newbies

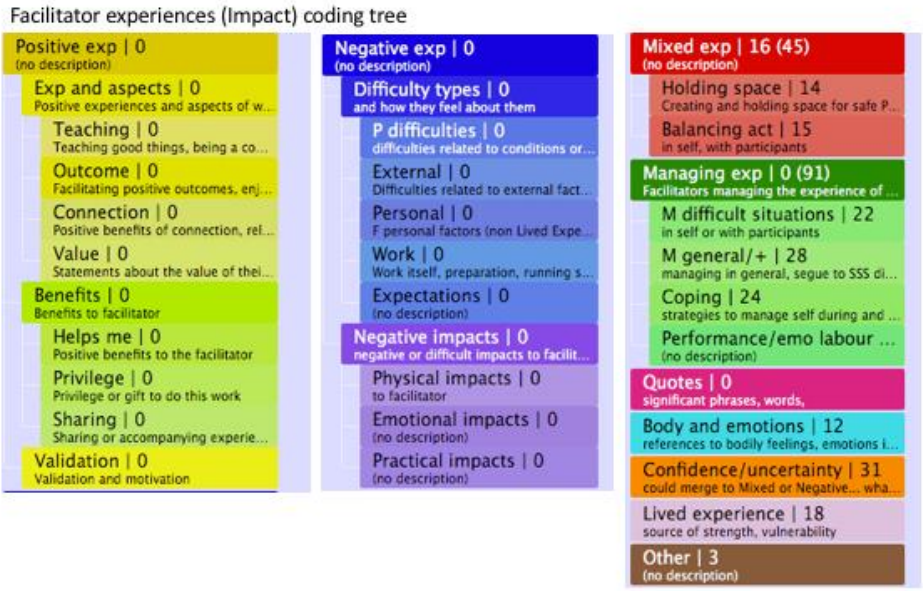
Boundaries (internal, interpersonal, disciplinary, continuum, physical space)

Responsibility (feelings of)

Safe/ethical practice

Coding tree of sub-codes for the main code Facilitator Experiences (originally called Impact)

Figure X. Facilitator experience initial coding tree



Facilitator experiences (Impact) coding tree

- Positive exp | 0
  (no description)
  - Exp and aspects | 0
    Positive experiences and aspects of w...
    - Teaching | 0
      Teaching good things, being a co...
    - Outcome | 0
      Facilitating positive outcomes, enj...
    - Connection | 0
      Positive benefits of connection, rel...
    - Value | 0
      Statements about the value of thei...
  - Benefits | 0
    Benefits to facilitator
    - Helps me | 0
      Positive benefits to the facilitator
    - Privilege | 0
      Privilege or gift to do this work
    - Sharing | 0
      Sharing or accompanying experie...
  - Validation | 0
    Validation and motivation

- Negative exp | 0
  (no description)
  - Difficulty types | 0
    and how they feel about them
    - P difficulties | 0
      difficulties related to conditions or...
    - External | 0
      Difficulties related to external fact...
    - Personal | 0
      F personal factors (non Lived Expe...
    - Work | 0
      Work itself, preparation, running s...
    - Expectations | 0
      (no description)
  - Negative impacts | 0
    negative or difficult impacts to facilit...
    - Physical impacts | 0
      to facilitator
    - Emotional impacts | 0
      (no description)
    - Practical impacts | 0
      (no description)

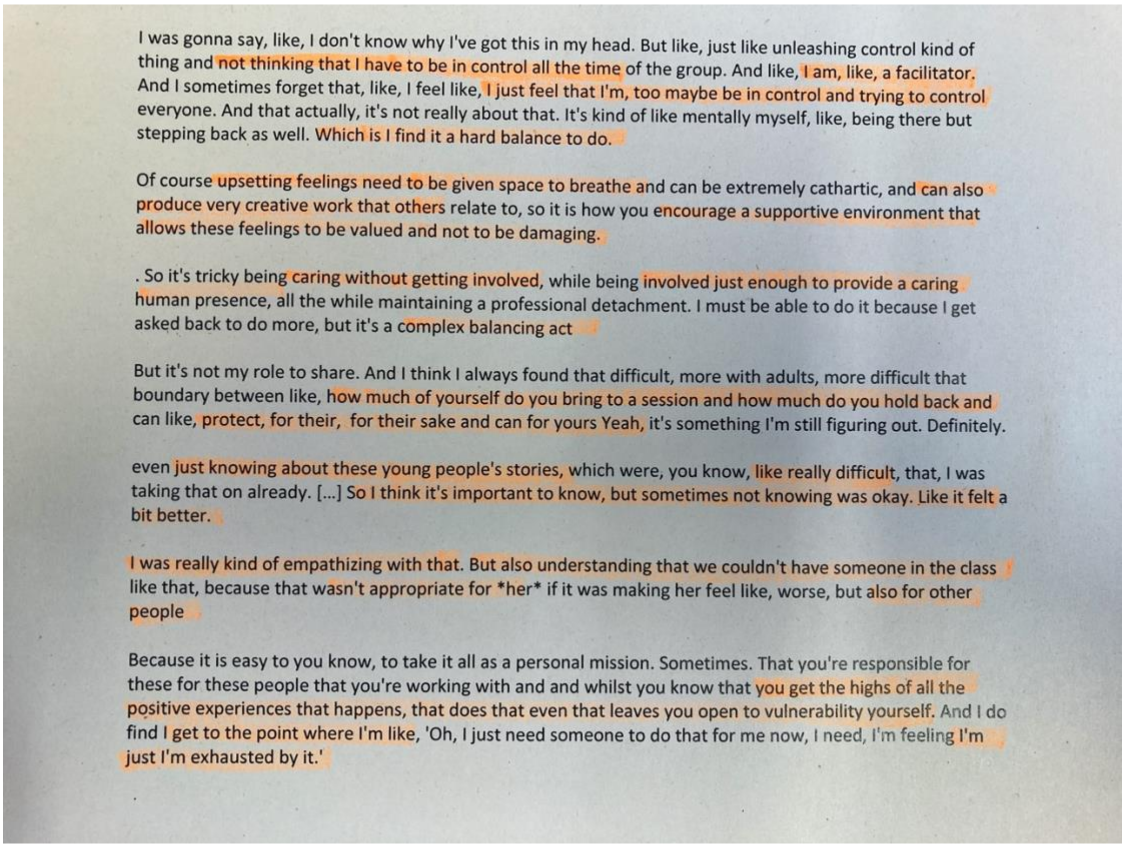
- Mixed exp | 16 (45)
  (no description)
  - Holding space | 14
    Creating and holding space for safe P...
  - Balancing act | 15
    in self, with participants
- Managing exp | 0 (91)
  Facilitators managing the experience of ...
  - M difficult situations | 22
    in self or with participants
  - M general/+ | 28
    managing in general, segue to SSS di...
  - Coping | 24
    strategies to manage self during and ...
  - Performance/emo labour ...
    (no description)
- Quotes | 0
  significant phrases, words,
- Body and emotions | 12
  references to bodily feelings, emotions i...
- Confidence/uncertainty | 31
  could merge to Mixed or Negative... wha...
- Lived experience | 18
  source of strength, vulnerability
- Other | 3
  (no description)

M11. Experimenting with poetic analysis

Juxtaposed opposites: How facilitators manage the mixed experiences of working the CCS

As I was coding my transcripts, I created a code called “Balancing act”. I was struck by how often facilitators described individual incidents or their facilitation work overall in terms of juxtaposed opposites. This suggests that they are aware of the need to constantly balance the rewarding and challenging aspects of this work, and hold internal contradictions related to their feelings and actions. The image and text below show how I highlighted phrases that exemplified this struggle, edited them to capture the salient portions, and rearranged them to create a free verse poem. This process allowed me to identify the impact of doing emotion work and managing ambiguity.

Figure X. “Balancing act” code, highlighted quotations



I was gonna say, like, I don't know why I've got this in my head. But like, just like unleashing control kind of thing and not thinking that I have to be in control all the time of the group. And like, I am, like, a facilitator. And I sometimes forget that, like, I feel like, I just feel that I'm, too maybe be in control and trying to control everyone. And that actually, it's not really about that. It's kind of like mentally myself, like, being there but stepping back as well. Which is I find it a hard balance to do.

Of course upsetting feelings need to be given space to breathe and can be extremely cathartic, and can also produce very creative work that others relate to, so it is how you encourage a supportive environment that allows these feelings to be valued and not to be damaging.

. So it's tricky being caring without getting involved, while being involved just enough to provide a caring human presence, all the while maintaining a professional detachment. I must be able to do it because I get asked back to do more, but it's a complex balancing act

But it's not my role to share. And I think I always found that difficult, more with adults, more difficult that boundary between like, how much of yourself do you bring to a session and how much do you hold back and can like, protect, for their, for their sake and can for yours Yeah, it's something I'm still figuring out. Definitely.

even just knowing about these young people's stories, which were, you know, like really difficult, that, I was taking that on already. [...] So I think it's important to know, but sometimes not knowing was okay. Like it felt a bit better.

I was really kind of empathizing with that. But also understanding that we couldn't have someone in the class like that, because that wasn't appropriate for *her* if it was making her feel like, worse, but also for other people

Because it is easy to you know, to take it all as a personal mission. Sometimes. That you're responsible for these for these people that you're working with and and whilst you know that you get the highs of all the positive experiences that happens, that does that even that leaves you open to vulnerability yourself. And I do find I get to the point where I'm like, 'Oh, I just need someone to do that for me now, I need, I'm feeling I'm just I'm exhausted by it.'

A complex balancing act

Not thinking that I have to be in control all the time… I am, like, a facilitator. I just feel that I’m too, maybe, in control… Being there but stepping back as well. Which is, I find it a hard balance to do.

> Knowing these young people’s stories (in advance)… really difficult. It’s important to know, but sometimes not knowing was okay. Like, it felt a bit better.

Upsetting feelings need to be given space to breathe… and can also produce very creative work… how do you… allow these feelings to be valued and not to be damaging?

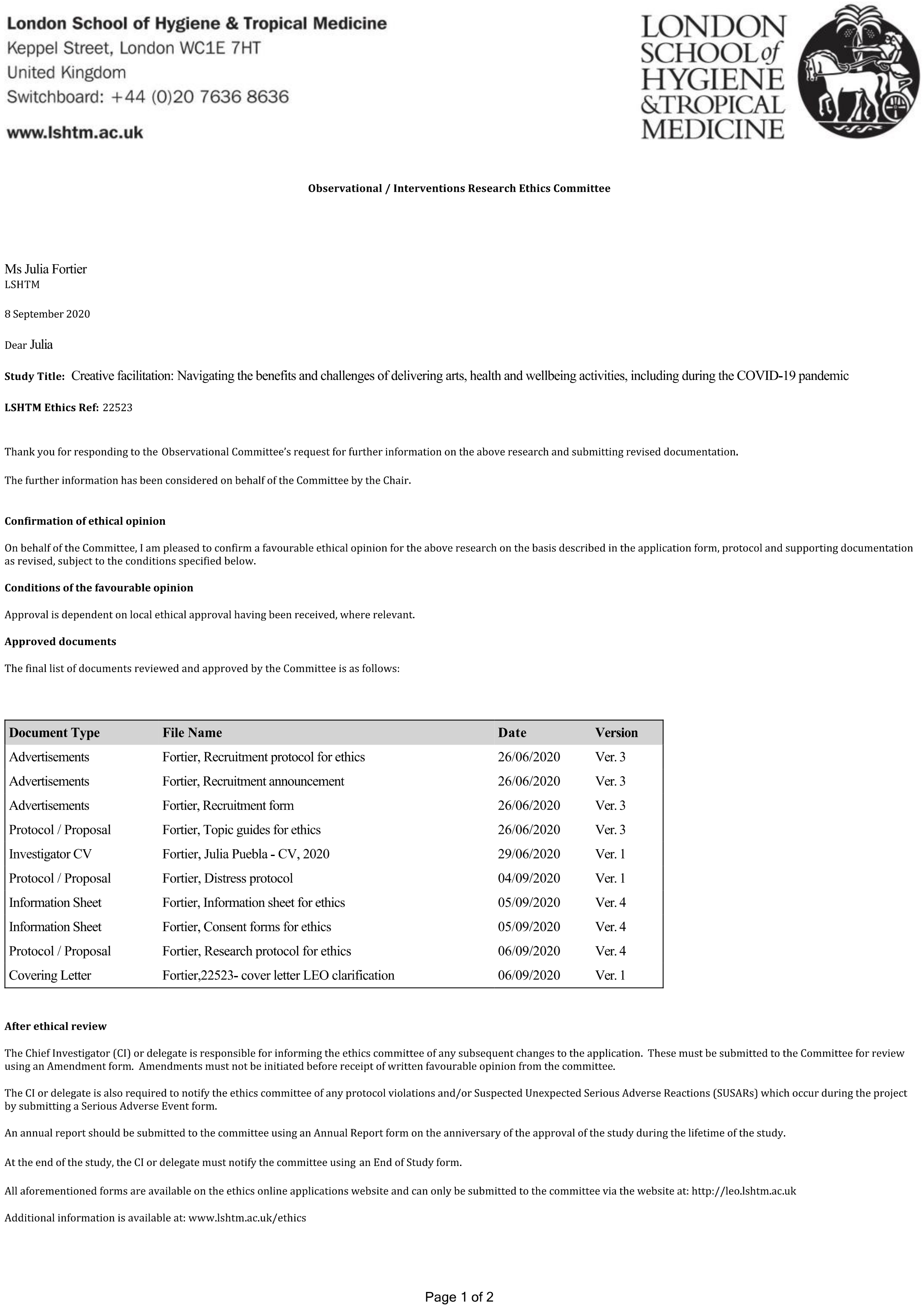
> I was really kind of empathizing with her.
> But… we couldn't have someone like that in the class… wasn't appropriate for her… or for other people.

How much of yourself do you bring to a session and
how much do you hold back… to protect, for their sake and for yours. I'm still figuring it out.

> You get the highs of all the positive experiences…even that leaves you open to vulnerability yourself…
> I get to the point where… I'm just exhausted by it.

So it's tricky being caring without being involved… involved just enough to provide a caring human presence… while maintaining a professional detachment. It's a complex balancing act.

M12. LSHTM Observational / Interventions Research Ethics



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Observational / Interventions Research Ethics Committee

Ms Julia Fortier
LSHTM

8 September 2020

Dear Julia

Study Title: Creative facilitation: Navigating the benefits and challenges of delivering arts, health and wellbeing activities, including during the COVID-19 pandemic

LSHTM Ethics Ref: 22523

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Advertisements	Fortier, Recruitment protocol for ethics	26/06/2020	Ver. 3
Advertisements	Fortier, Recruitment announcement	26/06/2020	Ver. 3
Advertisements	Fortier, Recruitment form	26/06/2020	Ver. 3
Protocol / Proposal	Fortier, Topic guides for ethics	26/06/2020	Ver. 3
Investigator CV	Fortier, Julia Puebla - CV, 2020	29/06/2020	Ver. 1
Protocol / Proposal	Fortier, Distress protocol	04/09/2020	Ver. 1
Information Sheet	Fortier, Information sheet for ethics	05/09/2020	Ver. 4
Information Sheet	Fortier, Consent forms for ethics	05/09/2020	Ver. 4
Protocol / Proposal	Fortier, Research protocol for ethics	06/09/2020	Ver. 4
Covering Letter	Fortier,22523- cover letter LEO clarification	06/09/2020	Ver. 1

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

M13. Information sheet and consent form

Participant Information Sheet

Ver. 2 -- 7 June 2020

Creative facilitation: Navigating the benefits and challenges of arts, health and wellbeing activities with vulnerable individuals, including during the COVID-19 pandemic

Julia Puebla Fortier, Lead Researcher
London School of Hygiene and Tropical Medicine

Introduction

You are invited to take part in a participatory research study on the experiences of creative facilitators working with vulnerable individuals. This information sheet explains why the research is being done and what it would involve. Please read it before you complete the study recruitment form (link). Please contact me at the details below if anything you read is not clear or you would like more information. Feel free to talk to others about the study if you wish. Joining the study is entirely up to you - take time to decide if you want to join.

Who is organising and funding this study?

This study is being conducted as part of my doctoral degree at the London School of Hygiene and Tropical Medicine. You can find out more information about me and the study at the project website (link). LSHTM is the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data. The study is self-funded. My research partners in this project are Arts & Health South West, the Culture, Health, and Wellbeing Alliance, [list others].

What is the purpose of the study?

This study looks at how creative facilitators navigate potential benefits and challenges when working with vulnerable participants, including during the practice changes resulting from the COVID-19 outbreak. We will ask facilitators about their experiences of successes and challenges in this work, their perceptions of their personal capacity (such as skills, training, attitudes) to respond to those they work with, their responses to their distress or challenges, and how COVID-19 has affected their practice.

By taking a participatory approach, I am working collaboratively with the research partners and the participants (such as you) to design, implement and report the research. The information collected is intended to help creative facilitators and the people they work with better understand their practices, experiences and concerns.

Why have I been asked to take part? Who else is taking part?

This call is going out to arts, health and wellbeing facilitators in South West England, London, and North East England. You have been selected based upon relevant experience and expertise on this topic. Other people with similar expertise from these areas have also been selected.

How will I participate?

(insert the relevant paragraph for each participant)

1. By participating in **interviews** with a researcher, who will ask questions about your practice, experiences, and perceptions of being an arts, health and wellbeing facilitator, before and during COVID-19. There will be two interviews, 60-90 minutes each, approximately 3 months apart, by telephone/video link or in person). The interview will be audio-recorded to support the researcher's note-taking and to ensure accuracy. You may also be invited to keep a private **practice diary**, which you could discuss with the researcher. *These diaries will not be seen or collected by the researcher.*

2. By participating in **focus groups** (two sessions, approximately 60-90 minutes each) with other 6-8 facilitators to discuss the questions described in #1. These online sessions (through a video conference platform) will be facilitated by a researcher, recorded, and the researcher will take notes.

3. By participating in a secure **online discussion group** organised by the researcher to talk with 20-40 arts and wellbeing facilitators about the questions described in #1. Over a period of 7 weeks, the researcher will offer discussion prompts, and participants will write their views and can interact with other participants. Your participation would take about 20 minutes per week, plus any additional time you choose to spend reading and commenting on the contributions of others. The contributions to this discussion group will be recorded by the researcher.

In addition, all participants will be invited to offer feedback on summaries or analyses of the data collected if they wish. You can choose to do this privately, or in a document where other participants share their feedback to the group and the researchers.

Attribution, privacy and consent

On the consent form (attached), you will ask to consent to the following:

I would like my oral or written contributions being attributed to me by a pseudonym. These pseudonyms will only be known to the researcher.

The key for these pseudonyms will only be seen by the researcher, and kept in a password-protected electronic file on an encrypted computer. If you participate in a focus group with video or face-to-face, it may not be possible to conceal your true identity from the other participants in that group. Group members will be instructed to maintain the confidentiality of group participants and their comments.

The information collected from all methods may be discussed among the research partners, although we will use pseudonyms in any discussions or write ups.

Do I have to take part?

No. It is up to you to decide whether or not to participate in the study. You can ask questions of the researcher before you decide.

What are the possible benefits?

We cannot promise the study will help you or your work directly, but you may benefit from the opportunity to share experiences and reflect on your facilitation practice with others. The results of this study may help arts, health and wellbeing organisations, partners and funders better understand and support the work of facilitators who work with vulnerable individuals. It may also be used to develop or improve programmes or policies that involve or affect facilitators.

What are the possible risks and disadvantages?

You may feel uncomfortable expressing your views to a researcher. You may feel distress if you or others discuss experiences and situations that may be emotionally challenging. This concern could be minimized by knowing that the researcher will try to create a supportive atmosphere for expressing your views and can refer you to additional support if you need it.

You may feel uncomfortable discussing your views in a group. We will try to minimize this risk by establishing ground rules aimed to create a respectful and supportive environment. We will also ask the group to respect privacy by not sharing the identity or contributions of group members outside the group.

What if I have more questions, or something goes wrong?

If at any time you have questions or a concern about any aspect of this study, you may speak to the researcher, (Julia.fortier@lshtm.ac.uk). If you remain unhappy and wish to complain to LSHTM formally, you can do this by contacting the primary supervisory, Bayard Roberts at bayard.roberts@lshtm.ac.uk, or Patricia Henley in Research Governance at rgio@lshtm.ac.uk or +44 (0) 20 7927 2626.

The London School of Hygiene and Tropical Medicine holds insurance policies that apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

Can I change my mind about taking part?

Yes. You can withdraw from the study at any time. If you choose to leave the study, you can allow past contributions to be considered, or you can withdraw your prior contributions within 2 weeks of the end of the activity you participated in.

What will happen to information collected about me?

All notes and recordings from the activities described above will be transcribed into an electronic file, which will be stored on a password-protected computer with a copy made to an encrypted USB stick. Handwritten notes will be destroyed after they are transcribed. Audio/video recordings will be destroyed after the researcher's completion of the Doctor of Public Health programme at LSHTM.

Any personal information (e.g., name, email address, etc) collected about you will be kept private. Only the researcher and authorities who check that the study is being carried out properly will be allowed to look at this information about you. Your personal information will be kept in a different safe place from the other study information. At the end of the project, the study data will be retained by the researcher and will be destroyed within 10 years of the end of the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information
- At https://www.lshtm.ac.uk/files/research-participant-privacy-notice.pdf
- by asking one of the research team
- by sending an email to DPO@lshtm.ac.uk

What will happen to the results of this study?

As a participatory research project, summary results of the research will be shared with research participants like you and partner organisations through regular updates on the project website, short briefing papers, and stakeholder dissemination events. The results will be written up in a thesis to be submitted to examiners convened by LSHTM. Data collected from the study will also be used in papers that may be published in an academic journal or in other reports or website documents made available to the public. No information that could be used to identify individual participants will appear in any publications.

Who has checked this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The London School of Hygiene and Tropical Medicine Research Ethics Committee (#22523). The Directors and select Trustees of the partner organisations have also reviewed the research proposal and approved the project and their participation in it.

Further information and contact details

Thank you for taking time to read this information sheet and consent form. Please contact me below if you have any questions. If you agree to take part in the study, please read and sign the study consent form and return it me. You can fill out the form online, or complete the printed copy and return it by post.

Many thanks for your consideration,

Julia Puebla Fortier
Doctor of Public Health Candidate
London School of Hygiene and Tropical Medicine
Julia.fortier@lshtm.ac.uk

Participant Consent Form

Ver. 2 – 7 June 2020

Title of Project: Creative facilitation -- Navigating the benefits and challenges of arts, health and wellbeing activities with vulnerable individuals, including during the COVID-19 pandemic

Name of Lead Researcher for project: Julia Fortier

Please tick each box:

- ☐ I confirm that I have read the Participant Information Sheet (ver x, date) for the above-named study. I have had the opportunity to consider the information, ask questions and have these questions answered satisfactorily.

- ☐ I agree to participate in the following activity: (will insert appropriate activity description – see Annex G below)

- ☐ I consent to the use of audio/video-taping of the activity above, which will be transcribed by the researcher and only seen by her.

- ☐ I would like my oral or written contributions attributed to me by a pseudonym. These pseudonyms will only be known to the researcher.

- ☐ I understand that any quotations derived from my contributions to the study may be included in public writings or presentations related to the study, and I will not be identifiable from this information.

- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I can withdraw my prior contributions within 2 weeks of the end of the activity I participated in.

- ☐ I agree to take part in the above-named study.

Printed name of participant Signature of participant
Date

(may be modified if completed via an online form)

G. Activity specific inserts for consent form

(As mentioned in the consent form above – each participant will receive a form customised to the activity they will participate in, with one of these inserts)

Interviews:

You have been selected to participate in interviews with one or two members of the research team. There will be two 60-90-minute interview sessions conducted by phone or online audio or video platform: one to discuss practice issues pre-COVID-19, and one to discuss practice changes during the pandemic. These interview will be recorded and transcribed by the researcher.

You may also be invited to keep a facilitator practice diary between the two sets of interviews, and will receive prompts to stimulate reflection. You can choose whether or not to discuss these reflections with the interviewer in the second interview. *The diary will not be seen or collected by the research team.*

Focus groups:

The creative facilitator focus group will be composed of 6-8 arts, health and wellbeing facilitators. It will be convened via an online video meeting platform [or face to face if possible], facilitated by the lead researcher, and supported by other members of the research team to provide technical and facilitation assistance. These interview will be recorded and transcribed by the researcher.

Participants will talk about the key research themes from the perspective of their own experience, and may discuss one or two facilitation scenarios. There will be two 60-90-minute meetings of this group – one to discuss practice issues pre-COVID-19, and one to discuss practice changes during the pandemic.

Group participants may be able to identify each other by name or visually. We ask group members to respect each other's privacy by not sharing information from the discussion that could result in others being able to identify group members or individuals they work with. There is a risk that some participants may not follow these rules.

Online discussion group:

The creative facilitator online discussion group will be a closed (private) discussion group composed of 20-40 arts, health and wellbeing facilitators. The discussion group will be facilitated by the lead researcher. Each week, over a period of 7 weeks, the facilitator will post a prompt and invite the group to respond. Group members can address the issue directly, and they can also interact with the responses of other group members. After the facilitated discussion period has ended, group members can discuss with the researcher whether they would like the group to continue, and on what terms.

Distress protocol

Creative facilitation: Navigating the benefits and challenges of delivering arts, health and wellbeing activities, including during the COVID-19 pandemic

Ver. 1 – 4 September 2020

Distress prevention and management protocol for research participant interactions

This protocol, guided by a model developed by Dempsey et al (2016), will guide the researcher's actions when encountering distress communicated by research participants in the data collection process. It is organised first by general considerations, with additional actions customized by research method.

Context and distress signals

Research participants will be asked to talk about challenges that arise in their facilitation work. They will be invited talk about challenging conditions, life situations or behavior presented by their workshop participants. They will also be asked to talk about their own personal and professional responses to these challenges.

Potential distress signals during interactions with the researcher may include: hesitations or long pauses in responding to questions, expressions of difficult emotions, requests to pause or stop the session, and feelings of distress after the interaction that they may communicate to the researcher.

General Considerations:

Participants will be informed at the beginning of the interaction that they are free to pause or end the interaction at any time, and the researcher is available to discuss issues of concern during or after the event.

If participants express emotions directly or indirectly, the researcher will listen and observe carefully and react with empathy. Participants will be invited to talk through these emotions or move on to other topics as they wish.

In online discussion and focus groups, all participants will be instructed to show courtesy, respect, and empathy to the contributions of others.

1. The interaction will be terminated if:
   - The participant decides to terminate their participation.
   - The participant decides to participate in an interview at another time or in a different format (this option does not apply to online or focus group discussions whereby the format cannot be changed or rescheduled for a single participant after it has begun)

2. The researcher will intervene if the participant is:
   - Experiencing anxiety or distress during the interaction. The participant should be asked if they would like to take a break and/or if they wish for the recording device to be switched off (see additional details below for focus groups).

- Continuing to show signs of upset. The participant will be asked if they would like the interaction to end and if they would like the researcher to call someone to spend time with them, such as a family member or friend.
- Unduly distressed. The researcher will remain with the participant until they are calm and composed. The participant may then decide to continue with the interaction or not.

3. The researcher will, with the participant's consent:
   - Refer to others if they request.
   - Gain permission to contact them later in the day or the following day to ensure they are no longer distressed. Alternatively, the researcher may ask if they would like a family member or someone from the local community to call them to offer support.
   - Contact details of useful numbers and support groups will be offered to the participant if they require them. These will be re-verified regularly and may include:
     - Samaritans, at 116 123 or by email: jo@samaritans.org for a reply within 24 hours
     - The Shout Crisis Text Line, by texting "SHOUT" to 85258

     Update, 10/19/20

If the study has raised any emotional issues which you feel you need to discuss with somebody, you can call Focusline 0800 0272127 or call the Samaritans, 24 hours a day, on 08457 909090 or there are a number of general support websites including http://www.sane.org.uk/resources; https://www.mind.org.uk/; https://www.rethink.org/; https://www.nhs.uk/conditions/stress-anxiety-depression/

4. The researcher will tell participants they are free to contact her by email or phone after the interaction event.

Method-specific considerations

Online discussion group: The researcher will communicate her support intentions and approach in initial group postings, provide regular reminders, and offer further details in a permanent post in the housekeeping section of the discussion forum. She will monitor the discussion group daily during discussion period (7 weeks) and be alert for any signs of distress expressed in participant postings. If appropriate, she may respond online or communicate privately to the participant(s) to offer message/email-based or telephone options to discuss 'offline' from the discussion group.

Online focus group discussions and interviews: The researcher will communicate her support intentions and approach at the beginning of the session; remind participants during the session that they can pause, turn off their video, or leave the session if they need to; and that I will be available to them after the session if needed. If in an online focus group, they will invited to communicate privately with me by chat during the session and/or communicate sensitive information to me privately after the session.

Dempsey, Laura, Dowling, Maura, Larkin, Philip, & Murphy, Kathy. (2016). Sensitive Interviewing in Qualitative Research. Research in Nursing & Health, 39(6), 480-490. doi: doi:10.1002/nur.21743

R1. Intentions of AHW facilitators in this study

Facilitators express a variety of motivations and desired outcomes for their work. In the intake for this study, they were asked to give a short free-text description of the health, mental health, or wellbeing intention of their work. The following table of the concepts or phrases were drawn from their answers (the number indicates the number of facilitators who mentioned them, and most gave multiple intentions).

Health, mental health or wellbeing intention of their work	***Number of mentions:**
Promoting/supporting wellbeing	15
Supporting mental health	13
Facilitating participation in and appreciation of creativity, developing creative skills	10
Promoting positive social interactions (interpersonal, community or political)	9
Helping build confidence and self-esteem	7
Offering stimulating activities for individuals with dementia, neurodiversity, learning difficulties	7
Supporting improved health/healthy lifestyles (variety of health conditions)	5
Offering a distraction from health/mental health conditions	4
Helping reduce loneliness/social isolation	4
Supporting self-expression/healthy expression	3
Enjoyment, fun	3
Teaching coping mechanisms	2
Mindfulness	2
Helping reduce stress and anxiety	2
Processing thoughts and feelings, fitness, supporting people with mental health problems to become AHW facilitators, staff wellbeing support, promoting diversity, relaxation, offering a therapeutic space, support and reflective practice for professionals, personal exploration and acceptance, self-care	1 each

*More than one answer may have been given