

## A peer led approach to evaluating the 'soft and fluffy' University of Huddersfield<sup>1</sup>, People's Voice Media<sup>2</sup> and Creative Minds<sup>3</sup>

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*Thanks as well to everyone who took part in the Conversation for Change Event it was great to hear such lively discussions and passion in the room and we look forward to future collaborations.*

*We would also like to acknowledge the support from our community partners who encouraged people to take part in this work including Artworks, Creative Recovery, Live Arts Café, Qudos, Spectrum People, co-Active, Photo Voice group, Wakefield Arts Café, Dwell Time, Words in Mind, Kirklees Recovery College and all the Trust staff and partners from the Good Mood Football League.*

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This Report is dedicated to the memory of Alan Fieldsend one of our community reporters who sadly died during the course of the project.

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*The University of Huddersfield is a thriving post-1992 institution of international renown, with a strong foundation in innovative approaches to research and evaluation. This evaluation involved a collaboration between the Centre for Applied Childhood, Youth and Family Research, and the Centre for Applied Research in the School of Human and Health Sciences. We are committed to applied research and evaluation that makes a difference in services and wider society. We have extensive experience of conducting evaluations and particular expertise in using participatory, creative/visual and systemic action inquiry approaches.*

*People’s Voice Media is a charity founded in 1995 and is committed to supporting people to improve their lives and bring about positive social change from the ground up.*

*Creative Minds is a successful, award-winning Charity developed and hosted by South West Yorkshire Partnership NHS Foundation Trust and developed in response to calls from service users and their carers for creative approaches to understand and support their mental health and wellbeing.*

## Introduction

Service users of Creative Minds tell us that creative activities are good for wellbeing. They not only promote faster recovery rates, but can be life transforming. Although we know this, from our experience the benefits of creative approaches are really hard to capture. Service users want to spend time doing activities, not filling in evaluation forms or completing on-line surveys. Those that do complete evaluation forms, only give us a limited picture of the experiences of those who are willing to engage, leaving a gap in capturing wider service user experience and lack of evidence around impact of activities.

We have spoken to those who access our creative activities about what would work for them, and want to create new ways of capturing their experiences as evidence alongside other evaluation methods. This will turn what can be a challenge to our projects into something that could be a real asset to communities and fun for service users.

This matters because, if we can fully understand the impact of creative activities and “soft and fluffy” approaches this will enable us to inform future service improvement decisions in response to service user experiences

## Our aim:

With funding from the Health Foundation - Q community award, our aim was to develop a new means of evaluating “soft and fluffy” creative activities delivered by Creative Minds.

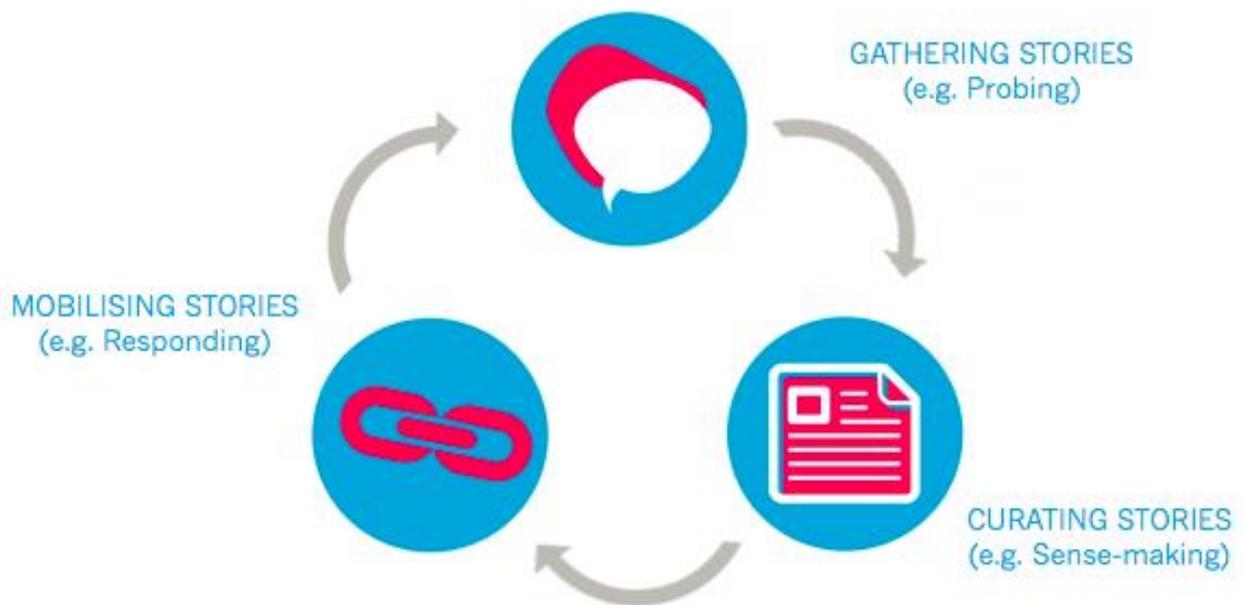
We trained a peer-led network of Community Reporters to collect stories from participants of our creative activities, to evaluate creative activities and provide new insights into what are often described as “soft and fluffy” approaches to mental health recovery and wellbeing and use these to inform conversations for change.

## Our approach:

Our approach was to support people to tell and share stories of their experience of using creative approaches to recovery and/or wellbeing through Community Reporting.

Community Reporting is a storytelling movement that was started in 2007 by People’s Voice Media, and it uses digital tools such as portable and pocket technologies (tablets, smart phones) to support people to tell their own stories in their own ways. Central to the approach is the belief that people telling authentic stories about their own lived experience offers a valuable understanding of their lives. Community Reporting has three distinct components – story gathering, story curation and story mobilisation, as depicted in the diagram below.

## Community Reporting



Users of various community services across South and West Yorkshire were invited to train to become Community reporters and gather stories about using creative approaches to recovery and/or wellbeing.

Those who expressed an interest undertook the Institute of Community Reporting (ICR) approved training programme (see below for further details of the training). Following the training they gathered and curated stories and attended a conversation for change event held at the University of Huddersfield, November 2019. The conversation for change event used the Community Reporter stories to prompt a conversation around the topic of creative approaches to recovery and/or wellbeing. Our aim was to stimulate debate at the following levels:

- Individual (ideologies and behaviours): e.g. person could change their perception of a topic, a professional could change their practice etc.
- Organisational (delivery and spaces): e.g. an organisation may change the ways it does things, a service or space could be re-designed, re-purposed or co-created from scratch etc.
- Systemic (society and culture): e.g. a policy could change or be written, practice could change across a whole sector, social norms may change.

## Community Reporter Training:

### *Story Gathering*

Participants were trained in story gathering techniques and provided with the knowledge and skills to become responsible story tellers and gatherers.

### *Responsible Storytelling*

In order to ensure consistency within the practice of Community Reporting, techniques and discussions around responsible storytelling were embedded into the training. The training explored the ethics and values of Community Reporting, the type of content that people's stories should and shouldn't include, an exploration of permissions and consent, and how people can keep both themselves and others safe in online and offline environments. A Community Reporting Best Practice Guide was co-produced which outlined a 'code of conduct' for this group of Community Reporters.

### *Supportive Learning Environments*

The learning environment for the Community Reporting training was tailored to the needs of the participants so that people felt confident enough to try the approach and feel empowered to share their ideas and opinions. The training adopted an asset-based approach, with an emphasis on there being no experts, only people with a range of capacities. Rather than starting with the areas that people need to develop (i.e. digital skills), training started with what people already knew and training focused on building those skills. People were encouraged to share their knowledge, skills and experience with others and offer peer-to-peer learning and support. The trainers were also part of the storytelling, they shared their own stories to ensure conversations that take place are more peer-to-peer than trainer-to-trainee. Opportunities for everyone to have their say were provided. Listening to others and ensuring that people feel that their lived experience is a valid and valued story to share was strongly encouraged. Through constructing these supportive learning environments, storytelling spaces in which people feel secure enough to share their authentic stories, within a group setting and online, were created.

### *Story Curation*

After a period of time, when most participants had gathered stories, the training then focused on story curation. Story curation is about the gathering, organising and analysis process that is undertaken to present the key findings from a collection of individual stories. The participants were trained in the following process of analysis.

#### *The analysis process*

There were three stages in the analysis process through which the set of findings emerged. The first stage was the 'topic' level. This stage was concerned with identifying the subject matter(s) in the story. This is based on a basic textual analysis process in which the metadata, such as the categories and tags attached to a story, are used to identify what it is about (i.e. attending an art group).

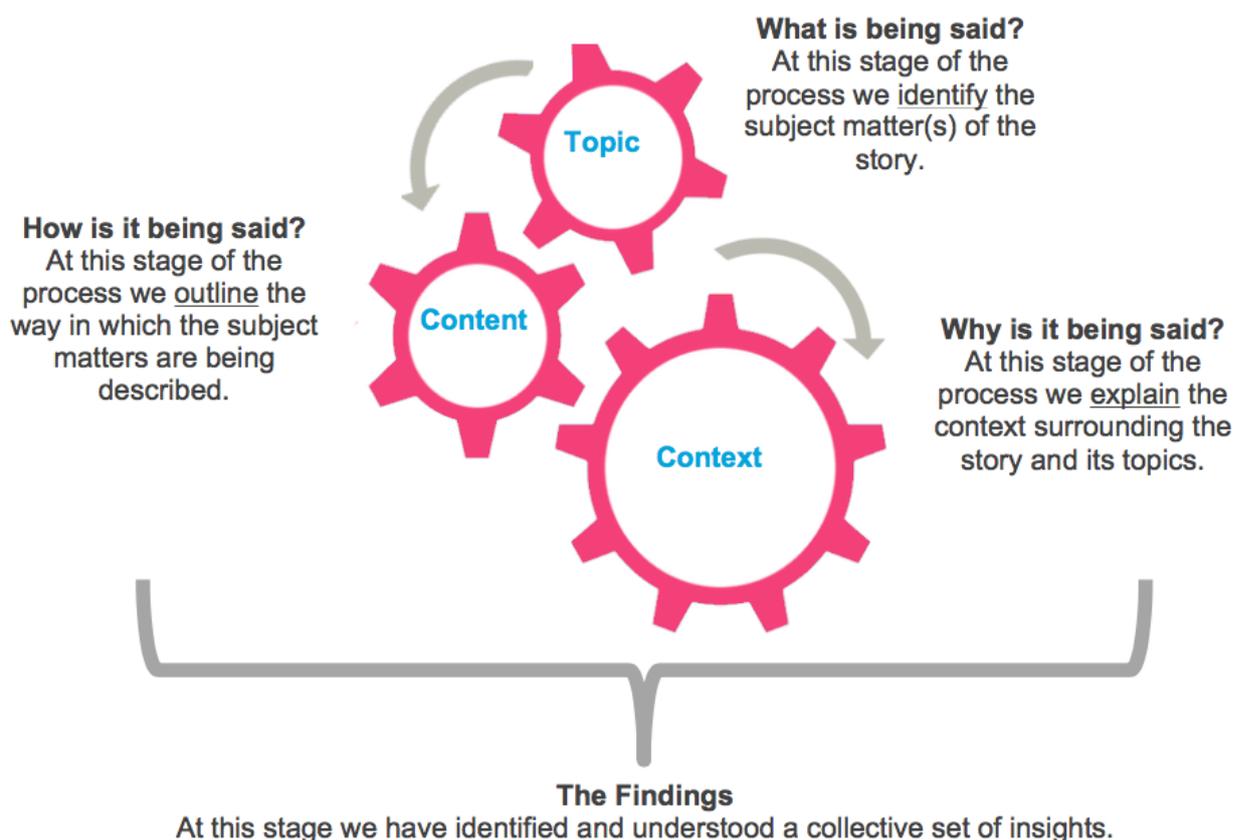
The second stage was the 'content' level. This stage outlined the way in which the subject matters were being described. This phase used a more interpretative approach to situate the subject matters within the perspective they were told through looking at them in more detail (i.e. attending an art group was essential to my recovery).

The third stage of the process was the 'context' level. This stage was focused on explaining the wider context in which story was being told (this person talks about a

long history of mental health and dissatisfaction with traditional approaches to recovery).

As depicted in the diagram below, the analysis process results in the identification and understanding of a key set of themes from a collection of stories that can be synthesised into a collective set of insights. These insights are not a set of judgements or a critical evaluation of the stories, but rather an objective presentation of the findings that emerged from the stories during the analysis process. From these insights, we produced thematic overview films, a presentation, a report and a magazine article, to mobilise the knowledge from within the stories and connect them to decision makers at various levels.

### The Institute of Community Reporting Analysis Process



### Findings from the stories:

22 participants were trained in Community Reporting and 99 stories were gathered on the topic of creative approaches to wellbeing, from people with experience of using a range of creative activities. By creative activities we refer to community-based activities involving arts but also sport, physical and nature-based activities in which people have an opportunity to engage freely, flexibly and creatively according to individual needs and preferences. For example, the Good Mood League, a football club, Live Arts Café, Artworks, Art for Wellbeing and Co-Active. All of the stories gathered can be accessed here: <https://communityreporter.net/creativitywellbeing> and for a compilation of the stories see here: <https://communityreporter.net/story/soft-and-fluffy-friday-7-february-2020-137pm>

### Creativity is....

*“An opportunity to express yourself in a different way and to be with other people – kind of just letting go of the everyday experience of life and thinking too much and doing too much”*

**Creative activities offer something different:** some people described participating in a creative activity as an alternative or supplement to other therapy /support. They compared traditional services with the creative activities and identified differences in the sorts of spaces, the people, levels of encouragement & compassion, relationships with staff and the sense of choice they experienced. They described the creative activities as “helping their mental health in a way that isn’t about mental health”. It was “something more varied”, personalised, accessible and flexible. They could choose to engage when they wanted, with whatever ‘activity’ they wanted, in their own way.

The following subthemes capture the key elements that helped people experience a change/shift in their wellbeing:

**Shifts my focus and “distracts me”:** participants reported changes in the way they think and feel (cognitive and affective changes) during creative activities. They described how participation in activities served to remove negative thoughts “helps me forget the bad days”; “opportunity to forget about / escape the illness”.

*“I started seeing things differently..., my whole life changed, my purpose in life changed, I started acting differently, it [creativity] gave me a different perspective and that’s what I needed”*

Participating in creative activities also helped people to feel happier and more relaxed. Dancing and writing were described as an *aid to mindfulness*. For example, “it’s about being in the moment with people “; “I can connect at a deeper level, when I’m writing I really lose myself”.

The experience of medication and participating in creative activities were also compared:

*“Much more than any medication can, it [creativity] really does help to feel alive not just be alive”*



Although necessary to “survival”, medication was described as something *“that dulls things”, something that “doesn’t really help me to feel any better it just helps me to survive”*

**Facilitates expression & exploration:** creative activities help and allow a person to express them self in different ways; one person described how writing enabled them to verbalise. People described feeling “truly understood” and “listened to” through participation in the different activities/ groups. This facilitation of expression and exploration was described by one person as “a cure to a lot of my anxiety and depression”. She described a sense of freedom and an ability to be anyone/thing on canvas, and this freedom of expression and exploration enables her to “work through the issues” associated with her anxiety and depression. People also described how creative recovery supplemented their ‘formal’ mental health care and helped them target specific difficulties. For example, one person described how she had difficulty identifying some of her emotions. Art has enabled the visual expression of difficult emotions and helped her community psychiatric nurse (CPN) provide targeted support.



**Acceptance & inclusion:** Creative activities / groups are free from stigma. Instead “you feel accepted and included”, regardless of your ability and diagnosis. The group and / or activity helped people to feel normal. Interaction with people who have similar experiences was described as key; it provides an opportunity to support and meet people with similar problems. The groups / activities create a sense of community “a family” which helped people feel safe and included; “part of something”, “you feel wanted”. One person described how the Good Mood League (football) helped people feel part of the ‘normal’ world, as opposed to a client. Another person described the worst part of the creative activity “was having to go home”.

*“they are more family than family”*

**Freedom & flexibility:** There’s no one way to be creative – you can engage when you want, with whatever ‘activity’ you want, in your own way – it needs to be personal. People reported how creative activities had supported them at different times in their life. Some had re-connected with creative activities. People reported how engaging in creative activities enabled a sense of freedom to be themselves and find themselves, and to feel a sense of freedom from judgement and stigma associated with mental health diagnoses.

**Creating the right environment:** The physical (atmosphere) and mental space were critical features. People described how the physical space “has to feel right”. They described the spaces they visited as “safe”, “inclusive” and “relaxed”, “with people and staff who were caring and understanding – the art was a bonus”. Somewhere they felt free to be themselves. The activities were also described as something which provided (mental) space “to think and get away from things”, “to reflect on your life”.

**Structure and routine:** the structure and stability of the different activities / groups were very important.

The consistency of the group and the people gave a sense of stability in that it reduced the need to see lots of different people (reduced referrals to different health professionals). The activities provided something to look forward to and helped them concentrate and feel motivated (in and out of the group). For some people, attending a group was the only thing that helped them leave the house. Leaving the house to attend the different activities lowered their risk of relapse. One participant described how the structured sessions specifically helped her symptoms of bi-polar disorder. She described how the structured sessions provided somewhere meaningful to go when she was feeling low but also how they helped provide a sense of balance and

stability when she felt manic and chaotic. The stability and structure of sessions served to “balance your highs”.

The structure of the sessions i.e. doing something also reduced difficulties associated with socialising. Many of the people interviewed expressed a difficulty socialising with others which often led to extreme social isolation. Attending a group with structure (a planned activity) where the activity was in the foreground served to facilitate socialising, increase peoples’ social skills and their confidence to socialise outside of the group / in new, larger groups.



Staff facilitating creative sessions echoed the benefits of the structure and routine that the activities offer. They further added the idea of a ‘chain reaction’ of benefits including how the activities facilitate and enrich their interactions with the people they support. For example, see excerpt below from a support worker discussing the Good Mood League:

“the more active they are the more groups they engage in, their routine becomes better, they have more structure and I can have more conversations with them. I can engage with them more, rather than if I’m going to see them just at home doing nothing, just a home visit asking them 3 or 4 questions and not trying to do anything productive. Taking someone out for the day or for the afternoon, that might be more appealing to someone, rather than just staying at home for the day.’

**Creativity as innate & essential:** “the essence of life” - helps a person to feel alive and is essential to wellbeing and recovery. Creativity was described as “holistic” - helps a person’s physical and mental wellbeing. For example, several people attending the football groups reported increased confidence and physical fitness. The groups also helped them socialise and make friends. The reported benefits were multiple, meaningful and all encompassing. Hence, mental health support without access to creativity to express and explore issues was described as potentially “damaging to a persons’ wellbeing”. One participant described how it’s imperative

that access to creative activities like football remain – he described the football groups as something that he needed in his life. Attending the group was likened to going to work every day – it was “a job, not a hobby”. Similarly, another person also described creativity as:

*“more than a hobby, it’s a lifestyle for me. It’s my whole life, I don’t know what I would do without creativity in my life”*



Creativity was described as a “god send” for some people. People expressed concern about cuts to these ‘essential’ services. They expressed frustration at the irony of financial cuts to the very services that ‘work in recovery – it’s a fact’ and have the potential to take the strain of ‘mainstream services’ by offering “life changing”, “lifesaving”, “vital” cost effective support.

*“creativity means life. If I didn’t have creativity in my life I would not be here today. I did an art class that saved my life and it continues to keep improving my life and keeps me well and maintains my status quo in this emotional roller-coaster of life”*

There was a very strong opinion that these services should be expanded, not reduced. One member of staff described it in the following way:

*“a no brainer for funders in terms of the return on the investment that you get, while they play football all their mental health and social issues are forgotten and that transcends into the rest of the day, probably rest of the week to the next session that they play football, keeps people well, keep them out of hospital. A lot of the people now are not taking meds they are doing physical activity, looking after their physical health, they’re exercising, stopping smoking”.*

Funding for this sort of activity was also described as 'invaluable' by one of the group members:

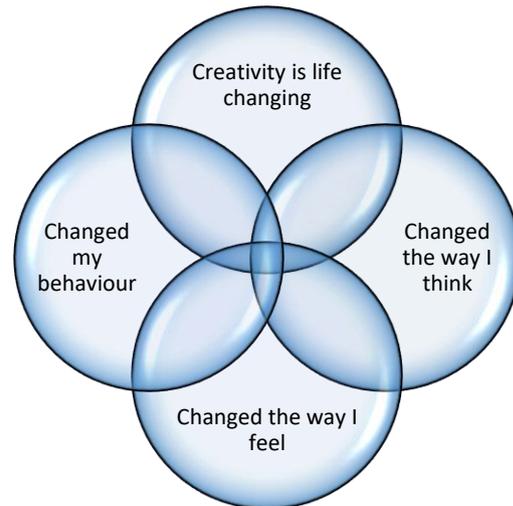
*I really do think it can be the difference - it makes a massive difference - between someone being really unwell with whatever their mental health issue is being isolated, lonely, depressed, whatever - it can be the difference between that and the feeling that they're living a fulfilling active life and building up a lot of social networks and friendships. So, I think the funding for these sorts of leagues is absolutely invaluable, it can make a massive difference to people's lives basically.'*

**Achievement and Progression:** people talked about how creative activities helped them to change and (positively) progress in various aspects of their life; how they think, feel and what they do (their behaviour). This 'change' helped them feel a strong sense of achievement and confidence. Creative activities were described as "life changing" and "essential to recovery". In terms of cognitive progression (the way we think) one person reported how taking part in activities "helps you envisage a future". Creative activities were described as something which helps you find passion and enjoyment in life, "improves life" and "gives a sense of purpose". People described "a changed outlook" from participation in creative activities.

People also talked about tangible achievements such as gaining paid employment, voluntary positions, learning a new skill(s), showcasing their talent" and taking on new challenges, as a result of their participation in creative activities.

People described a chain reaction of inadvertent achievements and benefits of participating in creative activities, such as overcoming anxiety, socialising, (re)learning to communicate with others, forming and maintaining new friendships, losing weight and feeling healthier (lowering blood pressure), being more productive, feeling a sense of connection, belonging, self-worth and recognition were also described. All of which helped them to self-manage their mental and physical health.

*“should prescribe creative recovery to everyone suffering with their mental illness – it changes people lives”*



### **Accessing and accessible creative**

**activities:** formal referrals from health professionals and informal referrals from friends were described throughout the stories. Creative activities were described as more accessible in relation to mental health services. People described how difficult it is to access mental health support; access to ‘medical help’ was described as “being way down the line”. Whereas access to creative activities (recovery) was easy, with far reaching benefits. Staff on the other hand talked about how mainstream services need to make accessing these types of services even easier for people they support.

*“accessing services is hard for some communities because of the barriers we place and the onus we place on people coming to find us. It should be the other way round - we should be actively engaging with and involving people and making it easier for them, rather than putting barriers in place saying actually you have to go and see this professional before you can come and see us - we have to do the pre-emptive stuff and early intervention work to try and include these communities because they're there, they're not hard to reach at all, they're not hard to find.” (staff, Good Mood League)*



*“don’t give me a tablet for my depression give me a football”*

### Conversation for Change: Reflecting on community reporter’s stories

Over 30 people, including mental health staff from the NHS and third sector organisations, volunteers, commissioners and service users and carers, attended a conversation for change event held at the University of Huddersfield, November 2019. The conversation for change event used the Community Reporter stories to prompt a conversation around the topic of creative approaches to recovery and/or wellbeing. The stories were presented audio-visually (short video clips), in poster format with a QR link to enable people to read and listen to the stories and textually (participant quotes) with photographs as part of an oral presentation.

Attendees were invited to share their thoughts and responses to the stories, and consider how the stories challenge current thinking and mental health practice. The aim was to stimulate thought and encourage debate at an individual, organisational and systemic level.

Thoughts and responses to the stories were unanimous – for example, statements such as inspiring, hopeful, emotional, creativity is not just one thing, not just numbers, linked to physical health, connection, confidence, and positive risk taking were noted.

*“Benefits of creativity are massive”*

In terms of challenges some key issues were raised:

**Translating the evidence** – there was a lot of debate and frustration around the ‘evidence’ and translating the service user experience of creativity into a language used by commissioners. Despite an abundance of personal in-depth stories from service users featuring detailed evidence of how creativity has helped them recover and maintain their mental health, these stories are not ‘measurable’ and cannot be translated and/or recognised in clinical and cost-effective terms (i.e. they do not show a reduction in service use) and consequently remain largely unfunded. Further work to bridge the translation gap between commissioners and service users/providers to encourage the relevant people/services to listen to and value this type of service user led, chosen and generated evidence, is urgently required.

**Defining creativity** – there was some debate around the term creativity and misconceptions surrounding it, from a staff and service user perspective. Discussions focused on the concern that there was a very narrow understanding of what creativity is (e.g. limited to drawing, singing, writing etc.), what it can offer and the implications of such. In particular, the challenges of trying to engage existing, new and /or younger service users to engage in creativity was potentially problematic as people struggle to imagine engaging in and benefiting from something they may never have experienced and don’t feel they have the requisite skills to do. All too often people will say “I’m not very creative” and consequently creative opportunities are not offered or pursued. Further work to dispel the myths surrounding what creativity is, and highlight its diversity and inclusivity, is required.

**Education and training** – linked to both of the points above was a debate around including creativity – what it is and the evidence surrounding the benefits of engaging in creativity, into the curricula for mental health professional training (psychiatry, nursing, occupational therapy). The difficulties with such included ‘set’ professional competencies. Offering creativity as a supplement and/or alternative treatment however would not conflict with general professional value competencies such as “practising in a holistic, non-judgmental, caring and sensitive manner that avoids assumptions, supports social inclusion; recognises and respects individual choice”.

Throughout these discussions there was a definite sense of ‘locked in syndrome’ – we are operating in a system that seems unresponsive and unable to change, despite overwhelming evidence from people with lived experience regarding what works and what should therefore be funded. Notably, through discussion and attendance, a large majority of this work is heavily reliant on the good will of volunteers, most of whom have first-hand experience of the mental health benefits of creativity. Related to this, there was ambiguity regarding whose role it is to offer and provide creativity. The social prescribing model in primary care was discussed and respected, however the challenges of applying the same model in mental health care was a source of frustration due to the limited, funded services available to sign-post to. There was a plea for parity of esteem between physical and mental health and investment in ‘creative’ projects which will save money on medicines and hospital

provision, including crisis provision due to the sustained support networks provided through creative projects.

Despite frustrations peers encouraged each other to galvanise change in their own place of practice and “start small”. Examples included finding out about local opportunities and sharing with people they support, and sharing knowledge of local opportunities amongst colleagues.

## Conclusions & Recommendations:

*“We know creativity works in recovery – it’s a fact”*

These findings strongly echo those recently reported in the Health Evidence Network (HEN) synthesis report on arts and health (Fancourt & Finn, 2019). This report found evidence from a wide variety of disciplinary approaches and methodologies to support the positive impact of creativity in supporting prevention, treatment and management of mental illness. The findings in this report and the scoping review showed how arts-based activities can build self-esteem, self-acceptance, confidence and self-worth which all help to protect against mental illness, and how creativity can provide supplementary support to traditional pharmacological approaches for people with mental illness.

We acknowledge, like Fancourt and Finn, that there is a need for more economic evaluations of creative interventions within mental health in order to gain funding, and that future evaluations should allow for a more balanced appraisal of where creative interventions provide mental health support, to a greater or lesser extent.

To conclude, despite national drivers that promote a general move away from an expert controlled health system to one that is much more in the hands of the individual and community, frustration and concern as to how and whether this is translated into practice remain strong.

We believe that empowerment of individuals through participatory and service user-led approaches such as Community Reporting and co-production with policy and practice professionals are key to taking this agenda forward if we can find ways to translate the robust evidence and invest in creativity, dispel myths surrounding creativity, and develop the training of our professional workforce to recognise the potential of creativity for our health and wellbeing.



**Reference:**

Fancourt, D, Finn S (2019) What is the evidence on the role of the arts in improving health and well-being? A scoping review. <http://www.euro.who.int/en/data-and-evidence/cultural-contexts-of-health-and-well-being/publications/what-is-the-evidence-on-the-role-of-the-arts-in-improving-health-and-well-being-a-scoping-review-2019>