

Photovoice as a promising public engagement approach: capturing and communicating ethnic minority people's lived experiences of severe mental illness and its treatment

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PROBLEM

Mental health related stigma, within widespread discrimination and exclusion,¹ inhibits many from seeking help.²⁻⁴ Moreover, conventional therapeutic methods relying on the spoken word only may not elucidate the full range and nuances of lived experiences.^{5,6} The use of photography alongside narratives (photovoice) can provide a powerful means for ethnic minority service users and their carers to communicate these experiences, with photographic displays to a broader audience contributing towards destigmatising mental illness.

METHOD

Photovoice can facilitate an authentic and meaningful method of co-creating/co-producing knowledge in healthcare.²⁻⁹ Our workshops were hosted at community centres in London and Manchester (England). The

project was explained verbally and through the distribution of information leaflets, while any queries were addressed. We then sought informed consent, distributed disposable cameras and notebooks with prepaid envelopes for their return, before asking participants to take photos (post-workshop) of their realities of severe mental illness or its treatment. Participants were reassured that there were no 'right' or 'wrong' approaches and no professional photographic training was provided to ensure that photos represented their views. Photos from returned cameras were then developed for subsequent workshops (approximately 2-3 weeks later), where participants selected three to five photos for individual reflection guided by photo-trigger questions. Any individuals' faces shown in images, including participants', were blurred unless they signed a separate consent form. Based on their narratives, photo captions



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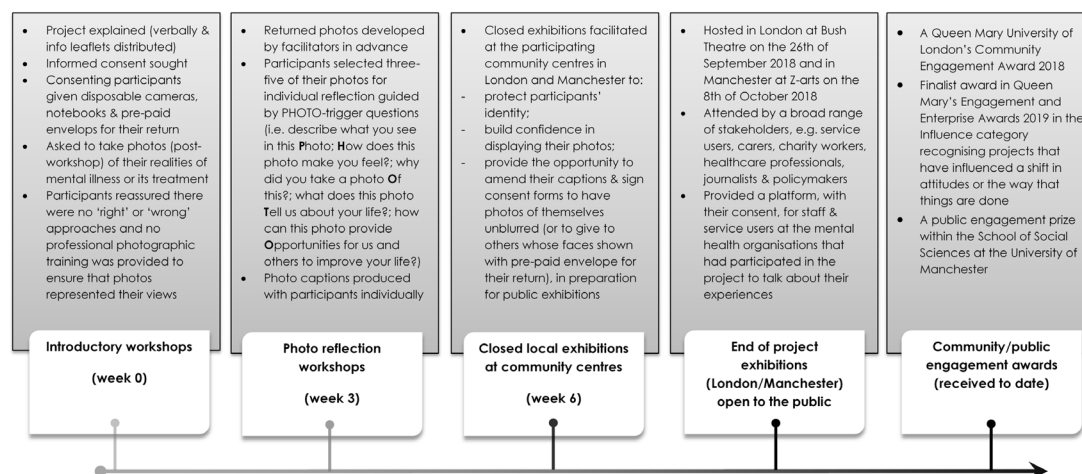


Figure 1 Overview of photovoice project with each respective partner in London and Manchester.

Table 1 Key characteristics of photovoice participants

Location, n (%)	
London	12 (57.14)
Manchester	9 (42.86)
Stakeholder identity, n (%)	
Service user (currently or former)	19 (90.48)
Carer	2 (9.52)
Age, mean±SD	
(n=18 responses)	47.06±12.90
Gender, n (%)	
Male	9 (42.86)
Female	11 (52.38)
Other	1 (4.76)
Ethnicity, n (%)	
Black African	4 (19.05)
Black British	2 (9.52)
Black Caribbean	5 (23.81)
South Asian	5 (23.81)
Other Asian	1 (4.76)
Arab	1 (4.76)
White and Asian	1 (4.76)
White Other	2 (9.52)
Reported diagnoses (eg, International Classification of Diseases), n (%)	
Schizophrenia	4 (23.53)
Bipolar disorder	4 (23.53)
Schizoaffective disorder	1 (5.88)
Personality disorder	2 (11.76)
Post-traumatic stress disorder	1 (5.88)
Severe depression	3 (17.65)
Obsessive-compulsive disorder	1 (5.88)
Substance misuse	1 (5.88)
Returned camera with photos, n (%)	
Yes	16 (76.19)
No	5 (23.81)

were produced with participants individually and closed exhibitions facilitated at the community centres to protect participants' identity and to give the option to amend their captions before the public exhibitions (figure 1).

RESULTS

Seven workshops were hosted over 6 months, with three subsequent exhibitions at community centres and two public exhibitions split between London and Manchester. Twenty-one people participated in the project (table 1). Post-it notes provided a simple, unstructured and anonymous feedback method after each workshop/exhibition, revealing how photography was seen as an accessible and

creative means to communicate priorities, while exhibition delegates overwhelmingly agreed that photos and captions were well displayed to communicate mental health narratives (see table 2). Public exhibition attendees represented a broad range of stakeholders, including service users, carers, charity representatives, healthcare professionals, journalists and policymakers.

DISCUSSION

Strengths

The number of photographs, photo-trigger questions and dissemination routes had to be limited to facilitate sufficient engagement and meet strict budget constraints. However, these restrictions also encouraged participants to concentrate on what mattered most to them (table 2). Thus, participants shaped the process by representing their lived experiences and main priorities, reflecting on these through photography, and pursuing wider impact by dissemination at exhibitions. This contrasts with evidence of the many projects claiming to 'co-create'/'co-produce' knowledge but that, in reality, employ service users as consultants merely to legitimate the researchers' findings.^{10–16}

Photovoice offered the opportunity to reflect on potential consequences and sources of illness or barriers to recovery, including intersecting forms of discrimination along racial, ethnic, class, gender, age and other lines (figure 2 and brochure: https://synergicollaborativecentre.co.uk/wp-content/uploads/2019/02/Synergi_Photovoice_Brochure_Updated-Nov-2018.pdf).

Service users also focused on their treatment with photos of recovery often positioned alongside those of suffering (figure 3). As a collective exercise, in which participants frequently valued the opportunity to share their personal images and narratives of mental illness, this illuminated how other participants had also confronted seemingly 'unalterable' illness states; yet, persevered through adversity.

Treatment options should be informed by people's capabilities; things of value that they can do as a consequence of possessing certain resources/skill sets (accumulated through lived experiences).^{17 18} Many participants considered how photography provided an empowering platform from which to communicate sensitive issues (table 2). This was consistent across a diverse sample of ethnic minority people and mental illness diagnoses (table 1). The exhibitions then enabled their visual testimonies of common humanity and creative potentials to further destigmatise the issue publicly.

Limitations

Some organisations struggled initially to participate due to limited resources, so were subsidised for helping to recruit people. There was also a request for further engagement that we unfortunately have been unable to pursue at the time of writing since funding for this particular project ran out (table 2). Another issue was

Table 2 Project feedback and statements

Rated feedback (on 5-point Likert Scale) from delegates at public exhibitions	
'Overall I found this event a useful experience'	Mean±SD=4.44±1.00 23 of 25 respondents (92%) either 'very strongly' or 'strongly' agreed to this statement
'The photos and captions were well displayed to communicate the narratives of lived experience of mental health and its treatment'	Mean±SD=4.48±1.12 23 of 25 respondents (92%) either 'very strongly' or 'strongly' agreed to this statement
Themes and supporting participant statements	
Creative and empowering method	<p>'We talk about these things all the time and are told to write these things down but to take photographs like these is better – it helps us to concentrate and focus on what matters.'</p> <p>'It's good that this project focus on understanding rather than assessments. There are not a lot of people that can describe these issues as those with lived experience. Similar to art therapy.'</p> <p>'I feel uncomfortable approaching people. Expressing my thoughts is something I would not normally be doing. I hope that people one day change their attitudes.'</p> <p>'The chance to discuss (and express) creativity in a confidential setting is very useful.'</p> <p>'I felt we are valued and important. Giving task also made me happy!'</p>
Facilitating recovery	<p>'The project gave me an insight into some of my problems and what I can do by myself to help myself.'</p> <p>'Mental illness is not the end of the world. You can recover from it. The photographs show my past life and present life. This is my real story. I have a life and I have to live for myself before I live for others. I hope that people will come and see my pictures and that they will gain confidence and that they will encourage them.'</p> <p>'The thing about taking pictures I think is very helpful ... Because when you look at the picture, the picture is always there for you ... and then you can share to people about it. I can ask you 'can you look at this picture?' ... I can show and ask 'do you see what I see now?' ... and then they say 'yes' and you know that at least you're not alone. In this society, still a lot of people have similar problems to you, so maybe you feel that you feel a bit better in that way.'</p>
Communication and impact	<p>'Great connection. Inspirational approach. Shaping a single narrative that reflects people of different cultures about mental health. Photography as a common language.'</p> <p>'With my pictures I would like to communicate to mental health authorities the importance of giving all people some sort of hope when they are facing problems, to offer them opportunities to express themselves in order to overcome obstacles and give some structure to their everyday lives.'</p> <p>'The highlight was to see the photos I took in the exhibition along with all the others.'</p> <p>'Images are intriguing but with the narratives they are powerful and insightful.'</p>
Requests for further engagement	<p>'Looking forward to see how this concept evolves. Would love for health professionals to see how the people they treat view their mental health journeys out of a clinical setting.'</p> <p>'The project should also be brought to and exhibitions hosted in other boroughs' (with particular reference to other London boroughs than those where the project took place).</p> <p>'There is a need for more and larger events.'</p>



Figure 2 'People don't mind hurting me, if they didn't mind then they would hold the umbrella up. It's something I find annoying that people are keeping them low deliberately ... In society there's a hierarchy of people that are cared for and those who are looked upon as more precious ... at the bottom of that chain would probably be Black youths ... I have seen a lot of Black guys stopped by the police in their cars or just walking. I've never seen people in the city, Bishops Gate, Liverpool Street or Canary Wharf being stopped by the police.'

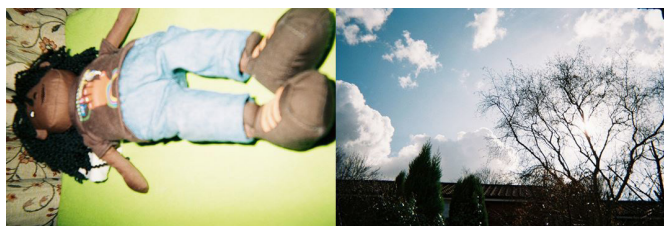


Figure 3 'These are contrasting images. The picture of the doll represents times when I feel low. The mood is dark and the doll is lying down to recuperate from a stressful day. The other picture is of the sun appearing through the cracks of the trees. It's when I feel better – a bright sunny day and uplifting atmosphere compared with the dark mood in the previous picture. The sunlight puts me in a good mood as it emerges through the trees, giving a sense of hope to get through more difficult times.'

potential self-selection favouring community centre attendees. However, hosting workshops locally to participants was vital for increasing accessibility.

Further evidence on the effectiveness of photovoice is limited.⁴ A randomised control trial³ demonstrated that a photovoice project significantly reduced internalised stigma after 3 months; however, longer follow-up periods are needed. Furthermore, the trial was conducted predominantly with the white majority population (in USA), so photovoice's effectiveness will also need to be tested with ethnic minority people with mental illness.

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Contributors KH was the principal investigator of the photovoice project. KH, JF, KB and JN were involved in the conception and design of the project. KH, JF and GMW organised and facilitated the London-based workshops and exhibitions, ND assisted with the public exhibition in London. JR, MH and JN organised and facilitated the Manchester-based workshops and exhibitions. KH and ND co-managed the budget. KH conducted the analyses of descriptive statistics and feedback and drafted the manuscript. The authors engaged in critical interpretation and commented on drafts of the manuscript in the context of public engagement and wider literature. All authors approved the final version.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Ethical approval was not sought as our project was not conducted for research purposes (this was a public engagement initiative engaging participants as partners to review mental health services and set priorities for the future). We followed relevant guidelines for best practices in working with vulnerable adults and the principal investigator obtained a Disclosure and Barring Service check. The project was also explained in detail to all participants in introductory workshops and any concerns addressed. Prior to taking part in the project, participants signed informed consent forms. The participants had the option to withdraw from the project at any time. All individual data has been anonymised and/or aggregated as summary statistics and we do not include any identifiable personal information about individuals (apart from names of the organisations and participants that wanted and consented, through conversation with the mental health organisation staff, to have their work acknowledged as collaborators).

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Data availability statement All data relevant to the study are included in the article.

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