

Community Participatory Action Research (CPAR)

Stage 1: 2023/24

Collaborative Report

Lead Authors: Dr Joy Bevan & Dr Katherine Broomfield

University of Gloucestershire

Co-authors: Fathima Nafila Mohamed Nazreen, Akbal (Bill) Singh, Habiba Hansdot, Anamika Dam, Ashieyah Kriel, Jubaida Rashid, Prob Singh, Vicky Asirvatham, Omonigho Gbejewoh, Rasiegha Ketharalingham, Esra Tuncel, Farida Mehmood, Funke Dehinbo, Viva O'Flynn

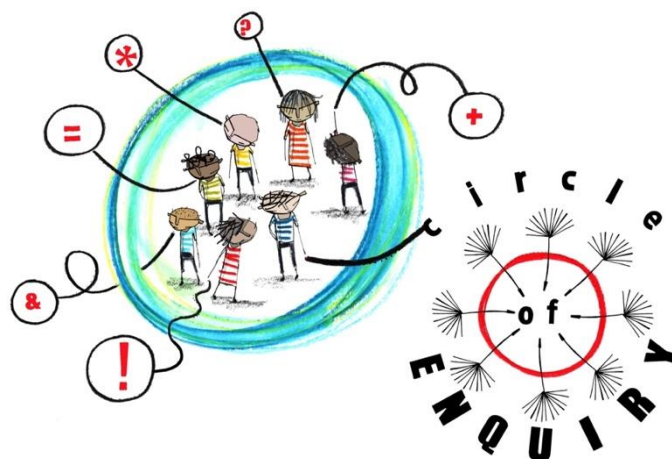


Table of Contents

Background	3
Project Outline	4
The academic research team	5
Calling the Community Researchers	6
Method	9
Project design.....	9
Ethics statement	10
Methodology.....	10
Training programme.....	11
Creative methods and engagement with project partners	12
Data collection	13
Data analysis	14
Data accounts: Community Research Responses.....	15
a. Individual defining of terms of mental health	15
b. Group perceptions of MHWB of diverse ethnic groups.....	15
Enquiry Findings	22
General recommendation	22
Four agreements for action and response.....	22
1. Greater/meaningful collaboration to embed the access and response requirements of local ethnic groups in public services.	22
2. Awareness and training around mental health and wellbeing.	23
3. Access to adapted programmes to support the mental health and well-being of young people from black and minority ethnic groups.	23
3. Sustainable research alliance.	24
Community Researcher Commentary on Project Stage One.....	24
Project Lead Reflections	26
Key messages	26
Recommendations.....	26
Concluding remarks	27
Appendices	30
Appendix 1: From Imogen Harvey-Lewis	30
Appendix 2: Community Researcher Report - generic recommendations.....	32
Appendix 3: Main developments in CPAR Stage One	34

Background

This report presents a process for engaging diverse ethnic communities that experience barriers to accessing mental health services. Developing an effective form of public engagement requires an approach that acknowledges and respond to the barriers of unequal powers that cause uncertainty, disengagement, and distrust. "Epistemic injustice" refers to how people from marginalized groups are frequently denied opportunities to create knowledge and derive meaning from their experiences. Okoroji et al., (2023; 01) suggest that in the mental health field, epistemic injustice is widespread in service-delivery systems and 'particularly impacts people from racialized communities'.

Our intention was to realise a new form of participation, which acknowledges the histories, capacity, and investment of the ethnic communities from Gloucestershire in the development of mental health services and their knowledge of and need for a legitimate response. This would mean responding to histories of fragmentation and disengagement and addressing systemic barriers to collaboration. The Integrated Care Board (ICB) acknowledged the need for deeper, meaningful partnerships with diverse ethnic communities in Gloucestershire to inform mental health service development across the system, and to confront the fractures which reinforce health inequalities across the UK. (NHS England, 2019, The Long-Term Plan; NHS Gloucestershire (2021) Black Lives Matter Report – Gloucestershire's Mental Health Services). NHS England has pledged its five-year funding allocations to local areas to achieve more accurate assessments of health inequalities and unmet need (NHS 2019).

We recognised that in establishing the research environment, the nature of existing agreements, and the receptivity to participate would all be crucial aspects of developing negotiations. The CPAR project commenced in September 2022 and stage one reached its conclusion in December 2023. The originality of the project design was to invite people representative of the minority communities to train as action researchers, working alongside an established research team to extend the enquiry: ***How can mental health services become more accessible to people from minority ethnic groups from the local community in Gloucestershire?***

The project sits within a community engagement climate which prioritises public health research (Denegri, 2019) and specifically, responses to black and minority ethnic groups' mental health inequalities (Harvey, 2021) through the nature of participation and co-production. In this form of participatory research, community interests become the primary factor to shape project developments. Participatory Action Research (PAR) conceptualises all stakeholders as participant-researchers to produce agreed solutions through an iterative cycle of observation, reflection, planning, and action (Baum et al., 2006). As project leads, we aimed to develop a project and partnership, rooted in co-production principles, that would facilitate the building of positive relationships and reciprocity across cultural groups. As trust developed, there would be the scope for establishing shared agreements, by engaging with diverse community groups across sociological and cultural variants, about the mental health needs of local people.

Fourteen community researchers have qualified in the programme and are now developing their identity as a sustainable research alliance (D.E.R.A. - Diverse Ethnic Research Alliance), and a bridge between local communities, mental health service commissioners, and the vocational training programmes and research initiatives of the School of Health at the University of Gloucestershire.

Project Outline

The intention set out by the Mental Health Commissioners of the Gloucestershire ICB was to invite community researchers, representative of diverse ethnic communities across Gloucestershire, to share knowledge of mental health needs to shape community service responses. The aims for the overall project were:

1. To build participative research capacity within the local health and care systems and promote community led research enquiries through the training of community researchers and mentors.
2. To deepen the understanding of local diverse ethnic communities' experience of mental health services through co-creation of knowledge and recommendations.
3. To strengthen partnerships through collaborative working with minority ethnic groups with community researchers holding active roles in community liaison and advocacy.

4. To develop new types of community engagement and forms of community outreach forums to advance knowledge of community mental health responses.
5. To evaluate the Participatory Action Research process with Community Researchers, with their accounts as data presented in a collaborative report.

The project was envisaged as having multiple stages of research and activity to address the overall aims. The first stage focussed on the central commissioner lead enquiry, but also, the aim to build the composure and cohesion of the group and their distinct identity as a community researcher alliance, representative of ethnic minorities.

The aims of stage 1 of the enquiry:

- To explore people's perceptions of mental health and well-being, and mental health service requirements, across diverse ethnic communities.
- To understand the value of a participatory research circle as a platform to explore concerns, interests, and exchange of perceptions.
- To recognise skills and methods in innovative forms of community engagement and collaborative service design.
- To identify how to establish agreements and build a social action plan for implementation.

The academic research team

Dr Joy Bevan was appointed as project lead for stage one of the Community Participatory Action Research (CPAR) project, to establish the research environment and negotiate the project design plan in consultation with the mental health commissioning service leads and representatives of minority ethnic communities, Gloucestershire. This leadership role included designing the specific form of participatory action research to be used, presenting this to community engagement forums, inviting and selecting the representatives to be trained as community researchers and mentors and constructing the training and mentorship programme.

Joy has a profile in social work and community development with diverse cultural communities. Her contribution has been the development of methods in specialised forms of participatory action research for use with community groups in contexts of mental health and resilience. This includes working with minority and excluded groups in community conflict and military siege (global), and in the UK, the use of community enquiry circles as a method of community research response to social fracturing and conflict resolution.

Dr Katherine Broomfield was invited to contribute to the project leadership, and delivery of the project workshops, to support in shaping the project sharing event, and to analyse the data and co-create the project outputs, such as reports and academic papers. Katherine is a speech and language therapist with significant experience in working for the NHS in post-acute adult rehabilitation services. She brought to the project experience of carrying out research with people who experience communication disability, and whose voices are seldom heard because conventional research methods are not suited to their needs. She uses creative methods to support the involvement of seldom heard voices in research to create opportunities for engagement that open-up dialogue to generate novel contributions.

Calling the Community Researchers

Four community engagement forums were taken to diverse communities across Gloucestershire to invite dialogue about the project intention, and to invite interest from people who wished to become community partners in research. Selection criteria included representation of ethnic minority groups in Gloucestershire and holding knowledge of mental health through personal experience, caring, or professional roles.

Fourteen people applied for and were invited to join the project. Their names and some background to their ethnic identities and experience of mental health are provided in Table 1. Not all Community Researchers were able to contribute additional details to the table in time for the preparation of this report.

Name	Ethnic identity	Additional features of identity	Knowledge or experience of mental health
Fathima Nafla Mohamed Nazreen	Asian – Sri Lankan	As a Sri Lankan Muslim originally from Sri Lanka, now calling the UK my home, my additional features of identity include representing the Sri Lankan Muslim, Hindu, and Buddhist communities. I possess a deep understanding of Sri Lankan Muslim culture, as well as familiarity with the Tamil-speaking Sri Lankan Hindu community and some knowledge of the Sri Lankan Buddhist community.	Having completed a diploma in basic psychology, I couldn't pursue a degree due to relocating to the UK. However, my strong interest in learning and supporting mental health has led me to actively participate in and complete several mental health training and awareness programs in recent years. This experience has provided me with valuable knowledge and insights into mental health issues, enabling me to effectively relate to and understand individuals' experiences.
Akbal (Bill) Singh	British-Asian (Indian)	I am of the Sikh faith and am very proud of my ethnic heritage and culture	I am first and foremost an Expert-by-Experience (EbE) and have my own journey of Mental Health with lived experience I have been a Mental Health Volunteer involved in many Workshops, Interviews, Sharing my Story seminars and chaired many EbE forums. I have also worked with several different mental health services in a variety of roles.
Habiba Hansdot	British Indian	I am Muslim...and Islam puts great emphasis on being a positive role model... which I try to be to the best of my abilities.	I have always been interested in mental health and since cov19 I have seen an increase in poor mental health across all different age groups.
Anamika Dam	German born British Indian	I am a British Indian single parent with Indian ancestry.	I have been a young carer for my bipolar mother and experienced three psychosis events. I want to make sure that mental health is not stigmatised.

Ashieyah Kriel	Mixed Race South African British	My Faith (being a Muslim) is my Identity, everything else feels transient.	I studied psychology at university. I've always had a keen interest in mental health. I appreciate the complexity of the human mind and how and what effects its character. I delved into Islamic psychology over the last couple of years so as to understand the Islamic perspective on psychology and how it could benefit our community and dispel the taboos around it.
Jubaida Rashid	British Bengali Muslim	I consider myself 80% British and 20% Bangladeshi with my language being the most important part of my heritage. The biggest part of my identity is my religion, Islam. It's more important than my identity as a British Bangladeshi.	In my role in children's services, I support young people and adults with mental health issues every day by providing information, guidance and signposting. I regularly take part in training to support families impacted by someone with poor mental health. I also have my own personal difficulties with mental health and have experience accessing various services first hand within the NHS.
Prob Singh	British Indian	I was born in England and I am a Sikh Punjabi Indian. I have lived in the UK all my life. I can speak Punjabi and Hindi language and understand spoken Urdu.	I work with various mental health services in the NHS community trust in Glos. bringing a 'Peer Support View' as an "Expert By Experience" with lived experience of mental health, and also as a Carer. I am able to give insight and suggestions from a lived experience perspective.
Vicky Asirvatham	Indian British		

Omonigho Gbejewoh	Unique (Nigerian)		
Rasiegha Ketharalingham	British – Tamil Sri Lankan		
Esra Tuncel	<i>Kurdish British*</i>		
Farida Mehmood	<i>Pakistani (British)*</i>		
Funke Dehinbo	<i>British Nigerian*</i>		
Viva O’Flynn	<i>Filipina*</i>		

*Table 1: Community researcher demographics, identities, and experience (identities with a * were completed by the researcher based on knowledge of the community researcher and not provided by the researcher themselves)*

The community research partners represent a broad range of ethnically diverse communities in Gloucestershire, with the intention always to extend the enquiry to under-represented groups at project stage two.

Method

Project design

We recognised in the design of the training workshops the emotionality of the enquiry and the consequences of the deep level of investment required by the community researchers. The method of the ‘circle of enquiry’ creates a more therapeutic level of exchange and response, moving through different stages of enquiry with attention to the composure and well-being of participants. Due to the developmental nature of the project and community researcher roles, the design included a monthly mentorship circle. This included features of holistic practice and meditative wisdom, guided by vocational practice principles of safeguarding and reflexivity to ensure all participants felt supported. The first outreach forum used this same approach, with the community researchers taking lead roles in the circle formation and engagement method.

The primary findings were formed into four agreements shared between the community researchers and project leads, and presented to community representatives, research leads and service representative at the CPAR Forum on 17 October 2023.

Ethics statement

This project was undertaken with ethical approval from the University of Gloucestershire Ethics committee, with explicit recognition in the ethics application of the depth of contribution the community researchers would provide and the nature of support they would require. (SREC.23.19.7 -Dr. Anne Daykin, Chair of Health and Social Care Research Ethics Committee, University of Gloucestershire).

Methodology

Participatory action research is a form of research enquiry that prioritises experiential knowledge and recognises the complexity and barriers within established social systems. The aim of this project was to collaborate with community partners in a radical and immersive form of engagement across diverse and marginalised groups to co-create outcomes that facilitate social change.

The concept of community enquiry through representation required certain requisites.

1. Recognition of the highly sensitised nature of the enquiry in terms of histories of heritage and oppression, displacement and racialized trauma, and the residual impact on people's sense of mental health and resilience.
2. Identifying the need for enquiry *and response*, as accounts would potentially generate expressions of pain and unresolved grief or uncertainty.
3. Understanding diversity within the accounts of personal experiences of culture-related psychological harm, the differences across distinct ethnic interpretations and the awareness of difference of experience across first, second, and third generation resettled communities.
4. Awareness that an enquiry into commissioning mental health services must recognise community approaches to mental health and well-being, cultural, and faith representations of 'wellness', alongside clinical mental health definitions.

‘Within and across’ became the project mantra for the development of a distinct form of exchange and co-creation of knowledge through interaction, within a ‘circle of inquiry’ which would mirror community inter-connectedness. Within this method, academic researchers and community partners worked collaboratively and with mutuality to create a trusting and safe environment for deep sharing. The circle method generates different ‘rhythms of enquiry’ through expression of self, to representation of community rhythms, to move across cultural identities and associations of mental health and resilience within an exchange platform.

Training programme

Community research partners were asked to commit to a series of three immersive training programmes. The content of these workshops was designed to both train research skills and foster mentorship between and across the community research partners. The participatory nature of the workshops operated as a mirror with allied health professional and social care practitioners facilitating the workshops by modelling research, listening, and engagement skills for participants/community researchers through both activity and reflective opportunities. Creative and immersive activities over the three days enabled community researchers to experience and embody their personal narratives to help them to surface and share their experiences with the group. Activities were designed to reflect the ‘rhythms’ of engagement – a) self, b) ethnic group, and c) wider community. An artist, Imogen Harvey-Lewis, who had experience of illustrating mental health experiences was invited to the workshops to respond to the contributions of the collective. Details about Imogen and her method of work are provided in Appendix 1. Her illustrations formed part of the data set. The artist also created 4 illustrations of the final four agreements that were negotiated during the workshops.

Workshop	Focus for enquiry	Knowledge exchange	Research skills	Mentorship
Day 1	Defining personal well-being and mental health across diverse ethnic communities	Respecting diversity; the individual in the collective	Locate self; holding an enquiry; multi-modal methods	Techniques in deep listening, exchange and response

			of communication	
Day 2	How can the vision and understandings of ethnic groups help to shape community mental health and well-being in Gloucestershire?	Creating a safe space in a communication research circle; holding a therapeutic rhythm; establishing trust and generating respect and empathy	Understanding how methods shape engagement; reflecting on applying different community engagement research methods in Gloucestershire	Inviting expressions with respect and empathy
Day 3	How can mental health services become more accessible to people from minority ethnic groups in Gloucestershire?	Agreeing on the focus of the report	Thematic analysis of collated data to identify 4 agreements	Co-ordinating the sharing forum

Table 2: Workshop details

Creative methods and engagement with project partners

The project design elevated the importance of multiple modes of communication across cultures, languages, modes of expression and different forms of neurodiversity. We employed creative practices and activities during the workshops to facilitate more depth of expression by modality.

In consistency with this investment in creativity, we invited Ramy Mousa and colleagues from Unit1 Films to generate an audio-visual representation of the project account which would then become a resource, alongside Imogen's work, for use in community engagement forums.

Data collection

The radical immersive nature of the circle enquiry called for the collection of a range of multi-modal data to reflect the dynamic and responsive actions of the workshops. We used creative data collection methods to support the multimodal expressions at play during the workshops and to iteratively generate a shared understanding, 'within and across' the group. Data consisted of journalling from the community researchers, reflective notes made by the academic project facilitators, photographs of activities, mind-maps and word-charts created during the workshops, and a series of images that were created by a professional illustrator in response to the workshops. Table 2 documents the data points and nature of data collected throughout the workshop programme.

Data point	Data activity	Data collected
1. Mapping researcher identities and sense of self	Objects in a box – community partners were asked to choose an object to represent the motivation, skills, or experience that they bring to the circle.	Illustrative responses Researcher reflective field notes
2. Mapping researcher identities and sense of ethnic identity	Community partners were asked to map their identity as researchers back to their community/journey/ sense of place	Post-it notes of reflections by the community partners
3. How can participatory action research be inclusive, responsive and transformative?	Group discussion	Researcher field notes Illustrator responses
4. Mapping wellbeing rhythms	Individual activity mapping personal experience to wider social-cultural views on mental health	Wheel of well-being
5. Understanding and acknowledging people's journeys around heritage	Group discussion	Researcher field notes
6. Understanding features of mental	Individual journalling	Written accounts

health within ethnic communities		
7. Sharing emblems of community rhythms	Sharing and receiving narratives of community mental health and well-being rhythms	Photographs of community emblems Researcher reflective notes about the sharing experience
8. Community research circles	Group discussions about the strengths and challenges of community circles to support MHWB in ethnically diverse communities	Group notes – Specialist knowledge and critical challenges
9. Mapping mental health needs across diverse ethnic communities in Gloucestershire	Small group work – creating definitions of MHWB	Group definitions Audio/video recordings of discussions Illustrator response
10. Primary enquiry: How can mental health services become more accessible to people from minority ethnic communities?	Group journalling	Reflective journals about group discussions; responses to semi-structured questionnaires

Table 3: Summary of the data collection points during the workshops

Data analysis

Data analysis was guided by the principles of thematic qualitative data analysis whereby researchers identify, analyse and report patterns (or themes) within data (Braun and Clarke, 2006). Researchers took a reflexive approach to analysis, working ‘within and across’ the emergent data over the course of the three-day workshops and during collective analytic discussions afterwards. The concept of reflexivity operates as a dynamic of enquiry, discovery and validation between the research participants in terms of the interaction of personal and collective subjectivity and analysis (Finlay, 2016). In essence, this manifested in active and interactive critical discussions amongst the research circle of the meanings and congruences that were emerging out of the workshops and data collection activities. The community researchers and the academic research team engaged in reflective journalling at the end of each day long workshop, and the patterns (themes) that emerged shaped the

discussions and activities of subsequent day. This iterative, or cyclical shaping of mutuality and shared understanding, analytic method resulted in the generation of thematic responses to the data and to four agreements for action and response.

This method emancipated responsibility for analysis from the academic researchers to the wider research 'circle'. The analysis was congruent with the aims of the wider methodology through 'elevating' the status of inclusive models of community engagement into a more radical form of 'discourse' based on diverse accounts and perceptions of mental health across ethnicity.

Data accounts: Community Research Responses

Due to the immersive nature of the circle method, an extensive amount of data was generated over the three-day workshops. Data analysis resulted in the establishment of a set of themed responses to the aims of the enquiry, presented in the following section.

1) Perceptions of mental health and wellbeing

a. Individual defining of terms of mental health

Many of the community researchers described good mental health and well-being as a state of happiness and contentment: "the ability to navigate life's challenges and remain resilient and content to continue". They also referred to having a "good state of psychological, emotional and social" components of well-being.

b. Group perceptions of MHWB of diverse ethnic groups

As a group, the researchers identified core components of mental health and well-being that transcended their individual expressions and were common across their diverse ethnic communities, as can be seen in Figure 1.

FEELING SECURE
 MENTAL STABILITY
 INTEGRATION
 BELONGING - EMBRACED
 NORMALISING difference
 Equality in Diversity
 STEREOTYPE
 Differences should be British
 Identity

Figure 1: Group summary of components of mental health across their communities

The group also identified common perceptions and misperceptions of the notion of mental health and well-being within their communities and how these could act as a barrier to people accessing necessary support from public services. Examples of these data, and the artist's responses to them can be seen in Figure 2.

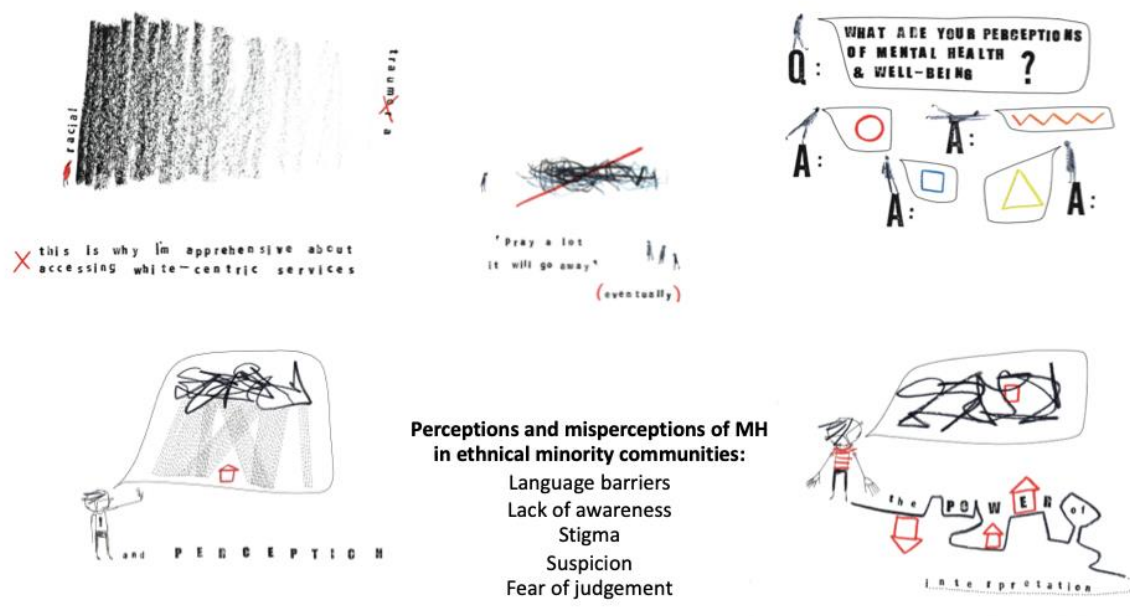
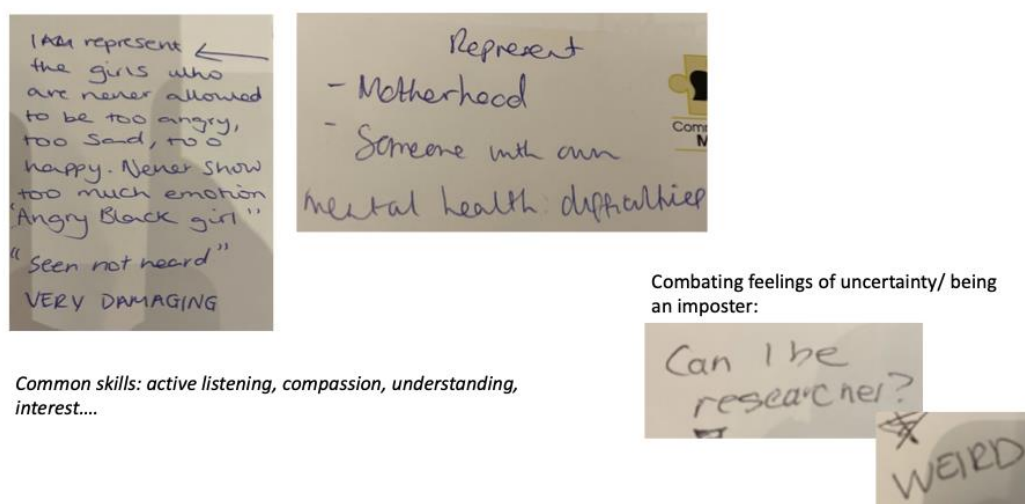


Figure 2 Data to represent some of the perceptions and misperceptions of mental health and well-being across diverse ethnic communities

2) PAR as a platform: Individual experiences

Accounts demonstrate how the composure both of individuals called to commit to the enquiry, and the group as it developed its sense of unity. One participant described “being fully present and listening actively... without any judgement”. The nature of the group nurtured the sense of worth within individuals as they engaged in a process of expression, exchange, and response true to the nature of group ‘mentorship’. The group reflected on, without being explicitly exposed to, the “therapeutic” intention of the circle of enquiry. This was also described as some as a “safe space” in which they could share experiences of “heritage” in a new way, built on trust and respect. Figures 3 and 4 represent some of the community researcher expressions that illuminate how the PAR platform fostered their experience and translated it into a sense of worth and strength. They commented that they hadn’t previously experienced this quality of space to share about heritage and the value of this in terms of coming to terms with their sense of heritage.

The journey to becoming a community researcher...



Common skills: active listening, compassion, understanding,
interest....

Figure 3: Notes made by the researchers during a workshop on day 1

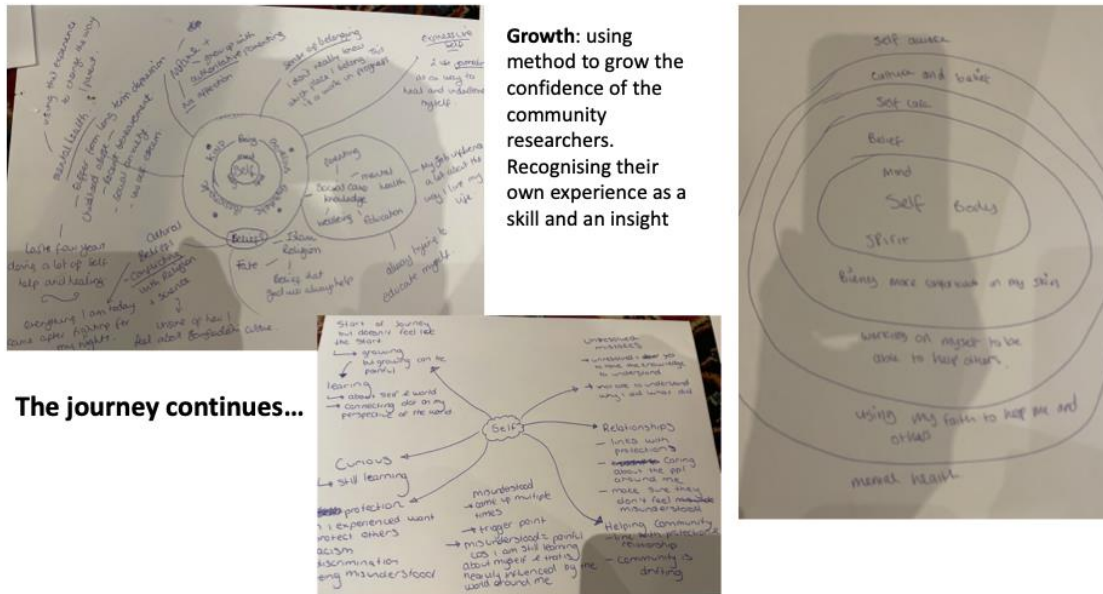


Figure 4: An activity during workshop 2 that demonstrates the growth in community researcher skill and confidence

This composure enabled expressions shared within the circle that reflected the heightened level of positive energy in the group; developing the enquiry from sense of shared worth made the disciplines of data enquiry and collection an inclusive iterative process. It also enabled more therapeutic forms of circle exchange and mentorship in forming a safe space for expressions of pain and uncertainty.

By the end of the three days of workshoping together, community researchers overwhelmingly documented feelings of being valued, respected, acknowledging the strength of the collective community, and the commonality of experience. This is beautifully summarised by one community researcher in their individual journaling at the end of day 3 (Figure 5).

I would go as far as saying that I have found it life-changing. I feel like I am a part of a community after feeling like I don't fit in anywhere for such a long time. I am more proud of my heritage than I was before I started and feel that this type of research can help minority ethnic groups heal and better the mental health particularly of the first generation born in UK who battle with identity issues.

Figure 5: Individual journaling by a community researcher, reflecting on PAR as a method

3) Understanding the nature of community contribution and community rhythms within the sustainability of mental health and well-being.

One of the most powerful activities over the course of the workshops, and where the academic team noticed a tangible shift in the mutuality and agreements that was growing across the groups, was during the sharing of community emblems at the start of day 2 (Figure 6).



Figure 6: A photograph of the community emblems shared by community researchers

Community researchers were able to recognise and share where they felt their communities held significant strengths and assets that could support mental health and wellbeing. Some of the assets that they went on to describe are presented in illustrations and annotations made by the researchers on the graphics alongside some key words that represent themes generated during group discussions.

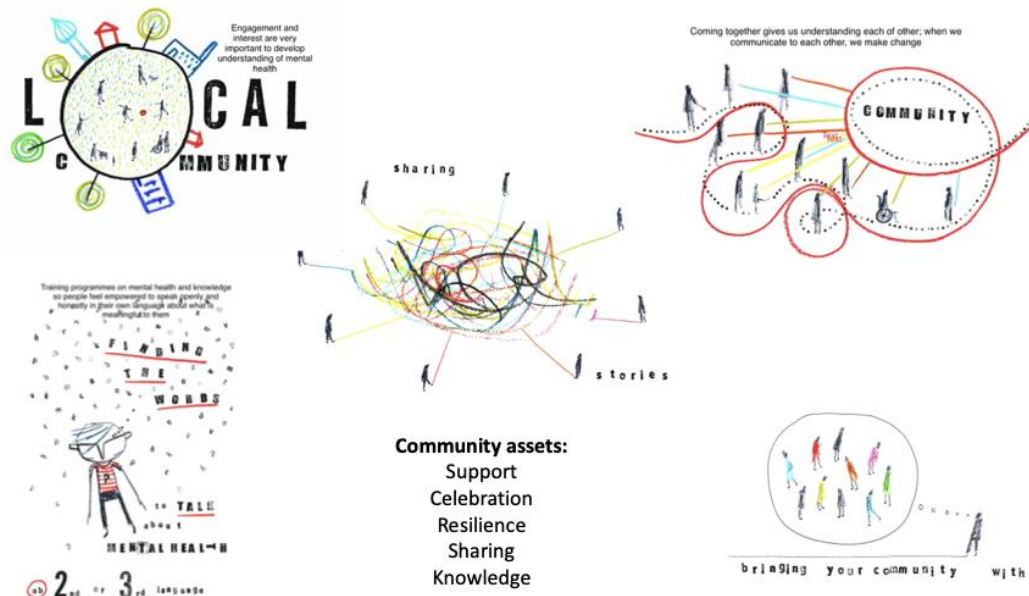


Figure 7: Community assets that can support mental health and wellbeing

4) Collaborative partnerships, agreements, and future plans

Visions of the project development increasingly shaped the dynamic of energy in the circle, requiring a high level of research pace and continuity in terms of responsiveness to change. True to the essence of PAR in moving from enquiry into social action, this had to be held in a way in which the three parts of the triangle of collaboration: ethnic community representation, mental health service commissioning, and academic research environment, could be held by the project leads.

Researchers concurred that to reduce stigma around mental health and fear within their communities about accessing public services, community assets need to be harnessed and enhanced. Researchers shared a collective voice about the need to raise awareness about the needs of the community, both within diverse ethnic populations about mental health and wellbeing but also in professional groups and services that provide support:

“acceptance of difference and acknowledging similarities between ethnic groups. Don't make assumptions”.

Figure 8 summarises the needs of diverse ethnic communities for specific, individualised support.

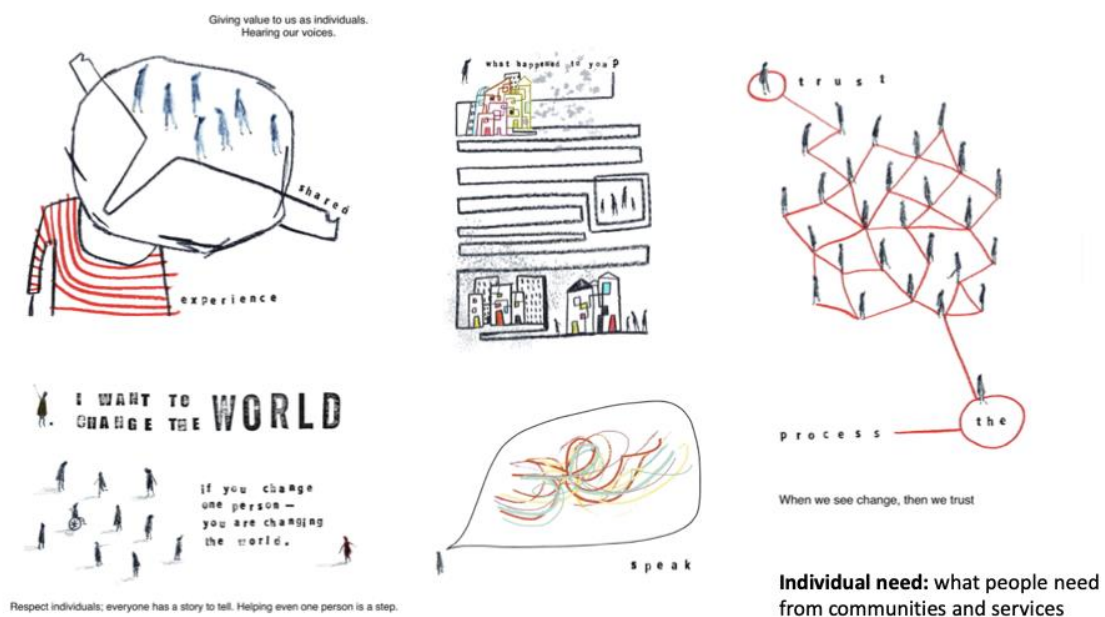


Figure 8: Summary of the needs of diverse ethnic communities from mental health support

The enquiry findings speak to more holistic approaches and deeper enquiries that can further shape services and inform future actions that will best support people from diverse communities to manage their mental health and wellbeing.

The findings, presented below, were identified in the final stage of the training programme, and presented back to community representatives, clinical mental health service commissioners, and researchers at the CPAR Forum in October 2023 then again at a community event in February 2024. The community researchers became the 'hosts' of researchers, community groups, and clinical commissioning leads who attended, inviting people into the circle with their accounts of the vision of the project, and the proposals for development.

Enquiry Findings

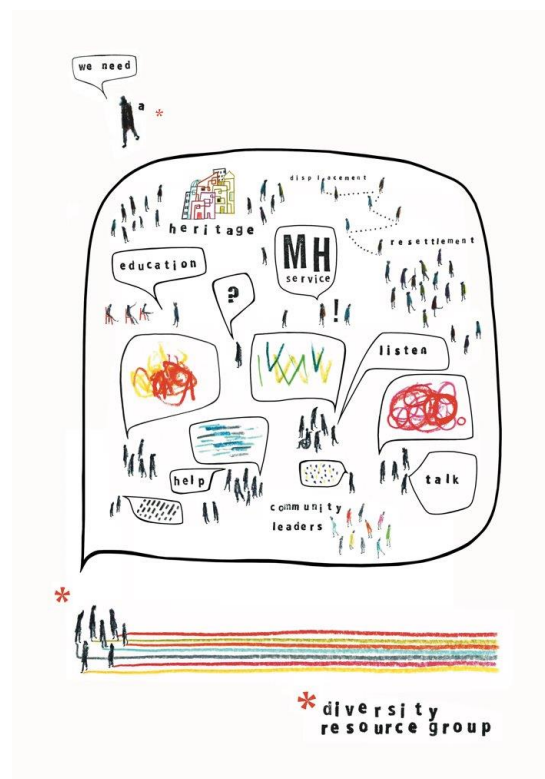
General recommendation

Mental health service providers need to acknowledge the complexity of minority and ethnically diverse communities' histories and social experiences to inform greater equity of access and response of these services. In particular, this includes recognising specific language differences, displacement, resettlement, and reorientation challenges, and how people carry and heal from aspects of racial trauma that may influence their mental health and well-being. Engaging with minority communities requires acknowledging stigmas and cultural and faith variants in defining mental health and distress, and equally, the strengths and knowledge of sustainability and healing within cultural practices.

Four agreements for action and response

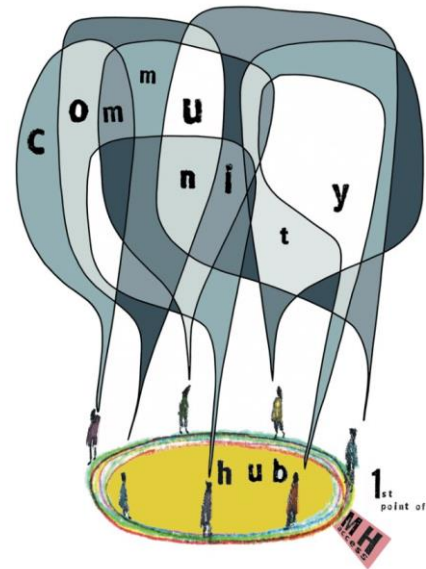
1. *Greater/meaningful collaboration to embed the access and response requirements of local ethnic groups in public services.*

To build on the skills and experience of the community researchers to establish a diversity resource group to inform service commissioning and community research forums. To engage with community rhythms that foster ongoing relationships between services and communities, acknowledging and working with specialist insights generated within and across ethnic groups about features of mental health they experience. To continue to identify and raise the profile of the specialized features of mental health local ethnic groups experience, for example, supporting others in journeys around heritage, displacement, resettlement and re-building.



2. *Awareness and training around mental health and wellbeing.*

Recognising the different cultural aspects of mental health and well-being, to develop a community hub in which selected community partners operate from to provide a first point of mental access. These partners, with specialized ethnically aware skills in mentorship and advocacy, can act as a point of liaison between individuals from ethnic communities and clinical mental health and community mental health services.



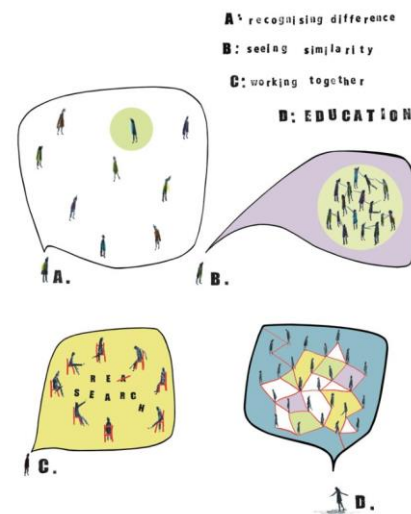
3. *Access to adapted programmes to support the mental health and well-being of young people from black and minority ethnic groups.*

This agreement recognises that young people from ethnic minority communities and more likely to experience cross-generation and cross-cultural tensions from being raised in home and community environments which have cultural and traditional roots that differ from the majority peer-population. There is a need for services to acknowledge these experiences and to promote inclusivity in their service provision that recognises and accounts for these specific experiences and needs.



3. Sustainable research alliance.

Establishing a sustainable development plan to extend the established community mental health action research alliance. To invite community researchers to have active roles in phase two of the research project, and to influence the foundations of a specialized education and research group to build ethnically diverse experiences into research developments, teaching and healthcare professional training at the University.



Community Researcher Commentary on Project Stage One

The following comments were written for the report by Community Researchers and represent their experience and evaluation of the project.

“This project is a new approach, inviting us to understand ways of representing self. We have to touch the points of stigma and uncertainty, and to take the opportunity given to express ourselves. Everybody needs an opportunity to express themselves in a community that represents them. It is about healing in a supportive environment.”

“Coming into the project felt very challenging, in terms of anxiety, uncertainty, and not feeling sure we were going to be able to ‘pull it off’. Concerns included how we would be received, be able to engage with others, to share freely and be able to make a valid contribution. This sort of ‘social anxiety’ has deep echoes in our experiences of heritage and identity, with associated memories of being isolated or stigmatized which can create poor mental health, a residual sense of depression and lack of self-worth.”

“The project felt like a safe space to talk about the things you have had happen in your life, the sense of ‘displacement’ you can carry when your parents and elders want you to protect the mother tongue and language, but you have to survive in British society. When you start

hearing about your mental health experience, being able to share in a safe space, this felt healing. The group has really made me appreciate life through listening to each other; it is truly 'education' in terms of gaining insight from experiences shared. When we think where we were when we started in the project, we have grown so much, and now it is finding the courage to take this step into the unknown."

"For young people, they can never find the space where they are accepted and find themselves searching for a sense of identity and belonging. Our human nature needs to belong. In the training programme, we used the rhythms of self, community, and others to better understand how we position ourselves. When you are of colour, you will always feel pre-judged, not accepted; I was so relieved to find other Moslem women here. In the circle, to be invited to bring something that represents our own identity and culture creates that sense of identity and gives you a voice. Being part of the group made me appreciate my identity and heritage more and the sense of inter-connection across the circle. If we could represent this we could have more harmony in the world."

"It was a new discovery to share my story in this way; before, I didn't think I had anything special to say, it was just life and what I had gone through. When I shared and I saw the way people responded to me, it become about me and I felt the compassion of others, the sense of connection. The immensity of displacement for people, trying to come to terms with it, takes you into a silent journey. For survival, you are reliant on the acceptance of others. The voice becomes strong in a circle in which you are received. It is important to give people that platform. You are then empowered to go into society with a sense of composure. Once you have been received recognition you know you are important. To use creative means to open up stories creates a sense of deeper identity and this opens up the possibilities for growth."

"To be able to identify and appreciate who you are is a powerful part of recovery in mental health; to know where you are heading. The sense of connection is hope – we understand what you are coming from – this is the time for you to heal."

“Thank you for the opportunity to be a part of the Forum and the mentorship circle for the Community Participatory Action Research (CPAR) Phase One project. Engaging with the Community Researchers (CR) was a truly rewarding experience, providing invaluable insights into their perspectives on advancing the enquiries.

The discussions, marked by a spirit of mutual respect and creativity, not only fostered a positive and constructive atmosphere but also emphasised the collective enthusiasm of all involved parties in driving the project to successful fruition.” (Sheila Banga, Commissioning Officer – Adult Mental Health, Autism and Advocacy, Integrated Adults Commissioning Hub, Gloucestershire County Council/NHS Gloucestershire)

Project Lead Reflections

Key messages

- Heritage and culture have to be acknowledged within mental health responses – this requires specialized skills and methods of community engagement.
- Professionals need to recognise precise features of mental health and trauma that minority ethnic communities might face, combined with aspects of ‘racialized trauma’ which will hinder people accessing standardized service platforms.
- Fear of breakdown: people who have had journeys of cultural displacement will have to have held ‘sense of self’ in adversity, so to now admit features of mental strain or trauma is deeply challenging.
- The fear of association with clinical mental health services, and the lack of connection to westernized approaches to diagnostic mental health as opposed to community rhythms of celebration and sustainability and ‘holistic health’.
- The importance of acknowledging cultural ways of supporting community well-being, and these representative roles within mental health partnerships.

Recommendations

- To further examine the nature of participatory action research in community collaboration and its development into sustainable collaborative partnerships.
- To embed lived experience roles within the development of ethnically diverse mental health services, with appropriate training and mentorship, and remuneration.

- To find ways of developing community lead services as specialised frontline ethnic community hubs.
- The development of more immersive forms of community research and creative methods of engagement to co-produce restorative and holistic approaches to mental health and the types of traumas that ethnic minority groups can face.
- To explore the capacity to develop specialised mental health response circles for minority ethnic groups with representative community researchers as mentors.

Concluding remarks

The essence of inter-connectedness within PAR has demonstrated its value through the accounts of this report. PAR methodology, applied creatively with multi-modal and active engagement approaches, served to elevate the status of community engagement and shift the focus of research from public inquiry to community engagement. Community research partners found the experience of being involved transformative; feeling ‘heard’ and ‘empowered’ to create change for their communities. ICB partners and funders recognized and valued the partnership working that we were able to demonstrate and have committed to funding subsequent steps of the enquiry to take it deeper into our communities. The interdisciplinary practitioner-researcher team has worked synergistically, building on their respective strengths and skills, to create and nurture this innovative and radical collaborative partnership for the benefit of the wider health and care community.

We suggest that community researchers can expand the concept of knowledge creation and transference by engaging in reciprocal research practices that value diverse ways of knowing and seeing. This form of partnership does require a deeper form of investment, however and an initial phase in which the terms and interests of minority communities are represented to legitimize their authority. The status of co-researchers provided people with legitimate authority to ground their lived experience in knowledge generation. This included broadening the conceptual debate of mental health to include perceptions of well-being, resilience, and sustainability within communities rather than the clinical or diagnostic categories that can dominate dialogue with health and care practitioners.

The design of the training and mentorship programme demonstrated the value of holding an immersive space for exchange, to validate peoples' experiences; the inclusion of mentorship skills alongside research skills promoted the premise that the emotionality of the enquiry required therapeutic skills of engagement and response. This was echoed by the community researchers feeling their communities needed space to be listened and received therapeutically in acknowledgment of the fears, raw experiences, and hardships that had impacted on their mental health resiliency.

References

- Baum, F., MacDougall, C. & Smith, D. 2006, "Participatory action research", *Journal of epidemiology and community health* (1979), vol. 60, no. 10, pp. 854-857. doi: 10.1136/jech.2004.028662
- Braun, V. & Clarke, V. (2006) 'Using thematic analysis in psychology' *Qualitative Research in Psychology* 3(2), pp. 77-101. Doi: 10.119/1478088706qp06309.
- Denegri, S. (2019) Downloadable definition of the impact of public involvement in research: <https://simondenegri.com/2019/07/03/downloadable-definition-of-the-impact-of-public-involvement-in-health-research-feat-patients-carers-and-the-public/> [accessed 03.04.2024]
- Finlay, L. (2016) 'Reflexivity: An essential component for all research?' *British Journal of Occupational Therapy* Volume 61, Issue 10 <https://doi.org/10.1177/030802269806101005>
- Harvey S (2021) Moving beyond 'the cheapest kind of understanding': enriching policy responses to BAME mental health inequality. PhD thesis, Bath Spa University. <http://researchspace.bathspa.ac.uk/14351/> Accessed on 06 Feb 2022
- NHS England (2019) The Long-Term Plan. Accessed on line 06 February 2022 <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- NHS Gloucestershire (2021) the Black Lives Matter Report – Gloucestershire's Mental Health Services.
- Okoraji, C. et al., Epistemic injustice and mental health research: A pragmatic approach to working with lived experience expertise in *Frontline Psychiatry*, 28 March 2023 Volume 14 - 2023 | <https://doi.org/10.3389/fpsy.2023.1114725>
- Russell J., Fudge N and Greenhalgh T (2020) The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? *Research Involvement and Engagement*. 6:63, 1-8.

Appendices

Appendix 1: From Imogen Harvey-Lewis

Summary of how I worked as an illustrator on the CPAR project in relation to the project themes and use of images.

My role as illustrator for this project was to mirror : to listen and interpret words and emotion into pictures. Complex situations shared, explored and unpacked within the talking circles, provided content for my nuanced illustrations.

The task was to capture shared emotive experiences, sometimes expansive and encompassing, sometimes specific and local, and translate them – real time - into accessible graphics which could be ‘read’ universally. Ensuring my personal presence within the project was quiet, alert, respectful and engaged, a natural empathy helped me to hear and respond with transitional kindness and purpose. A self-awareness of my presence within the room and among the community researchers was an essential element of my professional input.

All content was personal, valuable, and valued. Often the smallest soundbite sparked the most emotive illustration, captured in clear, concise (with words), minimal graphics. Representations of people were kept generic, both to protect the identity of the speaker, but also to ensure a readable lexicon of broad appropriation. The findings of this research project, and the input from our researchers, are intended to find targeted relevance to all interested parties nationwide.

Illustrations for this project naturally divided as a reflection of key themes prominent in the CPAR discussions. My artists’ role was to listen well and try to encapsulate the personal, whilst embodying the universal through pictures, shape, colour and text.

Short account of the conceptual framework captured through the illustrations around the generic enquiry.

These illustrations are drawn live. They are creative image captures of spoken word and shared experience direct and in proximity to the CPAR contributors. They are drawn with minimal edits and maximum honesty.

The conceptual framework captured through the images is equally simple.

The communicative power of emotive, abstract illustration, is that it speaks broadly and is not limited by localised specificity. A line or shape, the choice positioning of people, the minimum selection of text, contribute to an understanding. The act of interpretation of such work is in itself, an engagement: an invitation to connect to the subject, to work it out

(however subliminal that process might be) and to evoke thought, consideration or discussion. Our themes might be generic – Heritage and Identity; Family narratives; Mental Health and Trauma; Restoration of Self, - however the choice to use graphic illustration is specific and intentional. Whereas an approximate photograph might spark some connection, the plausibility is diluted and therefore less useful within a working research project.

Ensuring the images are honest, interesting, and engaging makes this work so positively challenging and inspirational.

Imogen Harvey-Lewis

www.imogenharveylewis.co.uk

Plimsole_girl on Instagram

Appendix 2: Community Researcher Report - generic recommendations

- We are a diverse community, everyone has diverse needs, we need services in community and primary mental health to be a positive response.
- Training healthcare practitioners in cultural sensitivity as first point of reference requires understanding the distinct nature of ethnically experienced features of mental health and trauma.
- Community mental health hubs are needed which can create safe spaces to receive and support people, and to go more deeply into defining mental health solutions.
- The communities need these sorts of partnership forums to be able to engage with practitioners skilled in participatory research approaches so that trust and understanding can be generated, and issues addressed. This sort of community connection takes time to listen and to understand the different inter-sections and how these are experienced by diverse groups of people.
- We need to prevent the hazard of access points which do not offer response.
- We need to combat stigma and patterning of service responses, prejudice and disengagement and to highlight and target the barriers.
- We need funding to be prioritised for mental health across diverse community needs, so that we can continuing addressing and responding to issues using these methods of approach.
- Current MH services are not working for minority groups. There is a need for training with key community partners to extend specialized forms of access based on knowledge of need.
- MH education and mentorship is needed in community hubs so that people can drop in and explore their experiences in a local context where they feel related to.
- The need for partnerships with local people so that they can be trained with ethnically specialized awareness to connect and network from this point of knowledge.
- To work with like-minded people and organisations who are trusted by local communities, eg, Immans and Priests.
- To have a say in service scrutiny, to identify where leaflets, notices, first points of access but also in-patient services create common patterns of concern for local ethnic groups in Gloucestershire.
- Generic assessment tools are often not appropriate for ethnic groups.
- There needs to be a sense of curiosity and awareness, so that service delivery is not just uniform and patterns white responses.
- The need to understand culture specific codes of living, rules for grief and loss, understandings of mental health and trauma, and general factors of ethnic community life.
- The need for people informed by cultural competency to influence types of grief and bereavement counselling.
- The need to feel valued and to understand our contribution; diversity adds to the richness of society.
- For those who lead and shape services to go into the conversations.

- A lot of people in ethnic communities are too frightened to access clinical services; there is a need for open forums.
- We need ethnically aware advocacy at critical points of MH service interventions, and also, a recognition that many of our cultures work in a family and community orientated way rather than individualistic. We stand together.

Appendix 3: Main developments in CPAR Stage One

Main developments in CPAR Stage One

Four community outreach meetings across Gloucestershire to invite collaboration in the establishment of, and take comments on, the research environment,

Initial community consultations to inform the project development plan.

Selection and training of 14 community researchers representative of Gloucestershire's minority ethnic communities.

University of Gloucester ethics approval and the development of three data enquiries to identify features of mental health service access needs.

Synthesis of the data into four agreements, shared with the CPAR Project and Commissioning Team.

Public engagement 'Forum' with representatives from community groups, mental health commissioning and University of Gloucestershire research leads to outline the development and aims of the group, and the four agreements for action themes in phase two.

Establishment of GDMHRA as an independent community research alliance, and establishment of the monthly mentorship circle to establish the identity of the community research group and mentorship as they develop specialised activities and roles.

Identification of specialized enquires for CPAR Phase Two and securement of funding for the enquiries.

Members of GDMHRA beginning to take roles within the School of Health, UoG, to support teaching and student selection of vocational programmes.

Report on the project at Plymouth University Conference.

