No Barriers Here©

No Barriers Here: for people excluded by identity, culture, ethnicity and race

Research Report

March 2023

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No Barriers Here: for people excluded by identity, culture, ethnicity and race

A research study exploring a different approach to advance care planning, using arts-based methods to deepen conversations, relationships and gain understanding of the experiences and preferences of people excluded by identity, culture, ethnicity and race.

This research was funded by NHS Charities Together

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**Consent was obtained for the use of all images and quotes within this report*

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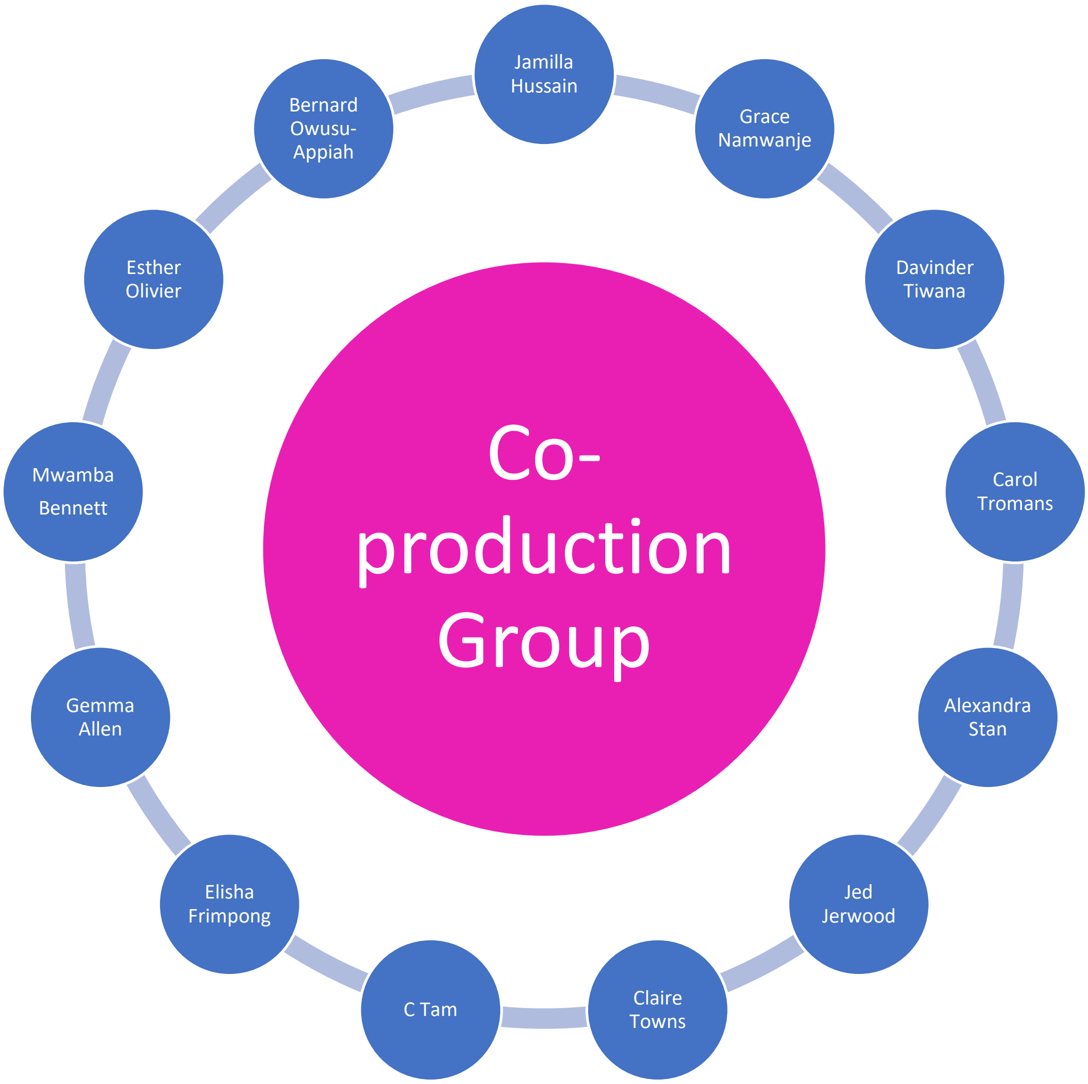

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Foreword

Palliative care should be provided through person centred services that pay attention to the specific needs and preferences of individuals. Access to equitable palliative care is harder for people and communities with perceived specific characteristics. Mary Stevens Hospice is committed to critically examining the societal barriers that exist in order to improve accessibility for all people.

Having the opportunity to explore the barriers experienced by people excluded by identity, culture, ethnicity and race, through the following research project, will enable the hospice to influence the changes that are needed at both a local and national level to facilitate change.

Claire Towns

CEO, Mary Stevens Hospice

Inequities in access and quality of care are persistent and pervasive for minoritised ethnic groups. Sadly, the end of life is no exception. The disparity between the lived experience and agency of those on the margins and those in positions of power to design, deliver and commission services is a reflection of the limited diversity within palliative care. But what now? How do we move forward?

No Barriers Here provides a vision, a movement…towards genuine inclusion, curiosity, equity and above all humanity. Being seen as a human worthy of love, kindness, respect is not universal for minoritised groups and something we are socialised to not expect from the dominant group. The No Barriers Here approach starts to disrupt that, using outside of the box – methods, thinking and intentions. It gets us to reconnect to the stuff that's universal, the stuff that we all intuitively know matters, the stuff that makes us all human and so helps heal the divide.

It's been great to be part of the co-production team, and I am deeply grateful to Gemma Allen and Jed Jerwood for showing us a way forward.

Dr Jamilla Hussain

On behalf of the co-production group

Introduction

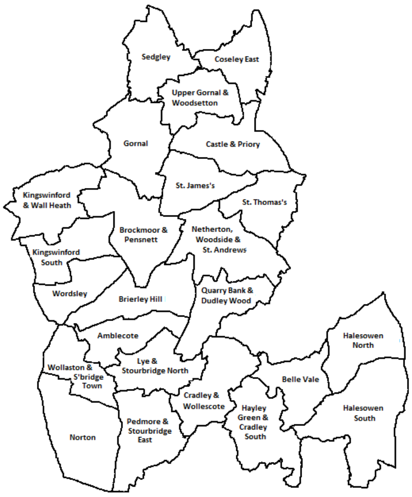
No Barriers Here: for people excluded by identity, culture, ethnicity and race was a two-year palliative care research and service improvement project focused on Advance Care Planning carried out between April 2021 and March 2023 in Dudley, UK.

Race inequity in Palliative Care Provision and Research

The NHS Race and Health Observatory (2022) highlighted the entrenched barriers in healthcare services which mean that services are not meeting the needs of people from minoritised ethnic groups. The COVID-19 pandemic has further highlighted health inequalities and racial injustice [1] which have long been known. People from minoritised ethnic groups still face barriers in almost every area of healthcare [2]. This is also true in palliative and end of life care [1,3–5]. Inequity exists not only in how services are set up and provided, but also in how research into improving palliative and end of life care with regard to race inequity is conducted [6].

Against this backdrop it is necessary for new approaches to be developed and explored which challenge existing practice in service delivery *and* in research activity. Approaches which challenge language and labels such as ‘BAME’, which listen to and address exclusion of minoritised ethnic groups and centre co-production. Equity-oriented research methods should create space for the stories and narratives of people excluded or marginalised in healthcare to be both told, heard and valued.

The locality



The population of Dudley and surrounding areas is diverse with just over 15% of people identified as from Black, Asian and other minority ethnic communities [7]. This represents nearly 49,000 people within the Borough, with greater numbers in the surrounding areas who may access services in the borough. Asian communities make up the largest ethnic minority group in the borough (8.4%), but with sizeable groups of Polish and Somali communities and the Black Country hosting 9.5% of all authorised traveller sites in the wider region. The 2021 Census figures from the Office for National Statistics show only 195 Roma people are currently living in Dudley. However, this is the first time that Roma was included in the Census and this number is likely to be undercounted. This is due to several issues including the often invisibility of Roma communities, the process of data collection and people being less likely to respond to official surveys.

Palliative Care in the Dudley Borough

Provision of generalist and specialist palliative care is available for people who have a life-limiting illness, people important to them and carers living in Dudley. Healthcare workers and organisations work in partnership to coordinate services and provide care, advice, and support for people with palliative care needs in their home, hospital, hospice and care homes. This includes physical, emotional, practical and spiritual support in addition to complex symptom management, coordination of care packages and support after death.

People can be referred to The Dudley Group NHS Foundation Trust, the community specialist palliative care team and The Mary Stevens Hospice by any healthcare professional.

The Mary Stevens Hospice

The Mary Stevens Hospice has provided palliative and end of life care to the people of Dudley since 1991.

The Mary Stevens Hospice provides a safe and compassionate environment for specialist care for adults aged 18 and over with incurable, life-limiting illness, including support for family and carers. The Mary Stevens Hospice cares for patients within a 10 bed In-Patient Unit and a Day Services Unit. A team of healthcare workers, including GP's, nurses, social workers, allied health care workers and volunteers deliver palliative and end of life care including symptom control, respite care, physiotherapy, holistic therapy, art therapy, spiritual support, carer support, bereavement support, a telephone advice line and community outreach.

Dudley Specialist Palliative Care Team

The Dudley Specialist Palliative Care Team work across the Dudley Borough in both acute and community settings including hospital, home, care homes and clinics. The team includes consultants, clinical nurse specialists and allied health care workers who offer specialist palliative care to inpatients in Russell's Hall Hospital and in the community.

An integrated palliative care strategy was developed in 2017 for all healthcare providers across Dudley and can be found here: Dudley EOL and Palliative Care Strategy

What do we mean by Advance Care Planning?

Advance care planning is the process of planning future care, including medical care, and includes thinking about and documenting personal wishes and preferences in areas such as preferred place of care, medication and life-sustaining interventions, nutrition, religious and spiritual beliefs and funeral planning. It can be carried out by anyone who has the capacity to do so, not just people who have life-limiting illnesses.

> *'Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.'*
>
> *International Consensus Definition of Advance Care Planning*[8]

Advance care planning should include a series of conversations, involving significant and important people to the person undertaking the planning and should be recorded and reviewed at regular intervals. Traditionally, advance care planning has been carried out through verbal conversations and recorded in written form on a proforma or template. We know this method is not accessible for everyone, and No Barriers Here was developed as a way of having deeper and more expansive discussions, particularly for people from minoritised groups or communities.

The origins of the No Barriers Here approach

No Barriers Here[9,10] was originally developed as a pilot project during the Covid-19 pandemic in response to the inequities experienced by people with learning disabilities in palliative and end of life care. People with learning disabilities are often not heard when expressing preferences for care, invited to consider their preferences or encouraged to have autonomy in care decisions and this is true when talking about death, dying, bereavement and planning for their own end of life care.

Covid-19 brought the disparities experienced by people with learning disabilities into sharp focus. An increased risk of dying compared to the general population, lack of accessible information and reports of blanket use of ‘do not resuscitate’ (DNACPR) forms caused increased distress for people with learning disabilities, their carers and family members. The need for different approaches to meaningful advance care planning was highlighted both in the media and amongst people with learning disabilities themselves who were also very aware of discriminatory treatment in healthcare at the height of the pandemic.

During the early months of the pandemic, The Mary Stevens Hospice worked with an advocacy organisation to establish emergency advance care planning easy read information, advice and support for people with learning disabilities. However, the hospice, partners and people with learning disabilities realised for people to discuss their future care needs with autonomy and for these wishes be heard and respected by healthcare workers, a more equitable advance care planning model was required .

No Barriers Here aimed to create space to explore experiences and wishes regarding people’s priorities, preferences and wishes for their own end of life care. It was co-produced between people with learning disabilities, supported by an advocacy organisation, Dudley Voices for Choice, The Mary Stevens Hospice and an art psychotherapist and used arts-based methods to create less-verbal opportunities for deeper more meaningful conversations about advance care planning themes.

What is the No Barriers Here approach?

No Barriers Here is an equity-oriented, arts-based, approach to advance care planning[11], aimed at people, groups and communities who may be marginalised in healthcare. It uses co-production to ensure that it is accessible, challenges inequity and is strongly influenced by the lived experience of people and communities.

It is delivered through a series of three workshops, delivered by facilitators trained in the use of arts-based methods and with experience in advance care planning. Each workshop is designed to explore a different aspect of the advance care planning process.

- Workshop 1 – Who am I? What is important to me?
- Workshop 2 – Who are the important people in my life who can help me make decisions about my care? Where would I like to be cared for? What are the most important things about my future care? What are my funeral plans?
- Workshop 3 – What would I like my legacy to be? What has been important in my life? How would I like to be remembered?

Each workshop uses different arts-based methods to enable verbal and less verbal exploration and expression of views, experiences and preferences.

The workshops serve two key purposes – firstly to offer those participating the opportunity to explore their own wishes and preferences in a less verbal, deeper way than traditional advance care planning approaches. Secondly, the learning and knowledge from the workshops is then used to develop education for healthcare workers to develop their confidence and competence in working with people they may perceive as different from themselves.

The Overarching Project

The overall aim of ‘No Barriers Here: for people excluded by identity, culture, ethnicity and race’ was to explore a different approach to advance care planning, using arts-based methods to deepen conversations, relationships and gain understanding of the experiences and preferences of people often excluded in healthcare by identity, culture, ethnicity and race.

The project was co-produced with people from local minoritised ethnic communities and created opportunities for local people, researchers, palliative care healthcare workers and other stakeholders to work together to explore, understand, listen and build relationships. The ethos of the project is ‘doing with’ not ‘doing to’ people and working alongside communities to improve experiences of care.

The overarching aims of the research study were as follows:

- to increase the number of people from minoritised ethnic groups engaged in advance care planning
- improve understanding amongst healthcare workers of the different needs of people excluded by identity, culture, ethnicity and race and the barriers experienced by people from minoritised ethnic groups, to accessing palliative and end of life care services
- increase knowledge and understanding of advance care planning, palliative and end of life care services and how and when services can be accessed amongst people from minoritised ethnic groups in the Borough
- build partnerships and relationships with a wider range of minoritised ethnic communities, individuals and groups, Mary Stevens Hospice and local community and hospital based palliative care teams

The project activity was organised into five phases in line with the No Barriers Here approach.

1) Establishment of a co-production group to develop, guide and provide challenge to the project
2) Delivery of a range of community engagement activities to build relationships
3) The delivery of a series of arts-based workshops with members of the local community who may experience marginalisation in palliative care because of their identity, culture, ethnicity and race
4) The development of an education programme for healthcare workers based on the themes from workshops
5) System change improvement programme developed from the themes identified in the workshops and education programme

Scope of the Report

This report focuses on the first three phases which support the research aspects of the overall project. The themes from the research study then informed the education and system change phases which will be reported later in the project.

No Barriers Here: for people excluded by identity, culture, ethnicity and race – Research Questions, Aims and Objectives

Research Questions

Three research questions underpinned the aims and objectives of the project:

1. Can the No Barriers Here approach help engagement with people excluded by identity, culture, ethnicity and race, in advance care planning conversations?
2. How does the use of arts-based methods improve understanding of the needs of, and barriers experienced by, people excluded by identity, culture, ethnicity and race, with regard to advance care planning and broader palliative care needs?
3. Does the No Barriers Here approach offer people excluded by identity, culture, ethnicity and race more accessible opportunities to explore and express preferences and wishes for their own end of life care?

Research Study Aims and Objectives

Aims:

- To understand the barriers experienced by people excluded by identity, culture, ethnicity and race to accessing palliative care and engaging in advance care planning
- To promote deeper understanding of palliative care services and the role of advance care planning amongst communities excluded by identity, culture, ethnicity and race
- To explore whether arts-based methods offer a more inclusive approach to advance care planning conversations

Objectives:

- To engage with participants of different ethnicities from within the locality and carry out arts-based advance care planning workshops in community venues using the No Barriers Here approach
- To use art-making to promote deeper conversations focused on advance care planning
- To use arts-based approaches to build relationships and improve engagement between palliative care services, hospice services and communities excluded by identity, culture, ethnicity and race in Dudley

- To use the knowledge and understanding gained from the workshops with healthcare workers to build knowledge and confidence in working with difference and promote inclusivity, particularly when providing palliative care and end of life care including advance care planning

How did we do it?

Methods and Methodology

This was an equity-focused, qualitative study using arts-based research methods and co-production principles.

Working in co-production

Co-production is an inherent pillar of the No Barriers Here approach. Working with the people and communities who are the intended beneficiaries of the project was integral to this research project. Setting up a co-production group of people from minoritised ethnic groups was the first task of the research team. Many members of the group were also from the locality, but the ability to meet online also allowed for the recruitment of people with specific expertise in working in race equity and palliative care. Co-production involves more than consultation and the co-production group advised, shaped and challenged the project throughout. The group were involved in the design of the study, supporting recruitment and data collection, participating in data analysis and will continue to be involved in the dissemination of the findings, including co-authoring journal papers and presenting conference papers.

Our film shares more of the co-production approach and a link to the film is included here: https://www.youtube.com/watch?v=G-ToRCT3UiU

Ethics and Governance of the Study

HRA approval was sought and the study defined as research, however, due to the nature of recruitment and delivery intentionally taking place outside NHS settings (as we aimed to recruit marginalised communities and people) NHS ethical approval was not required. The Dudley Group NHS Foundation Trust provided governance and approval for the study locally.

Methods

Three cohorts of participants were recruited into a series of three arts-based workshops exploring different advance care planning themes. Each workshop explored a different theme and offered participants opportunities to participate in structured art-making and discussion with the facilitators.

Week 1 – Introductions and getting to know each other	Who am I? What is important to me?	Pens, pencils and collage materials
Week 2 – Four key questions	Who are the important people in my life who can help me make decisions about my care? Where would I like to be cared for? What are the most important things about my future care? What are my funeral plans?	Fabric, materials, glues, collage materials, fabric paints, pens and oil pastels
Week 3 – My Legacy	What would I like my legacy to be? What has been important in my life? How would I like to be remembered?	Weaving

Each workshop was held in a community venue familiar to the participants and lasted for two hours. The workshops were held weekly at the same time and venue. Workshops were recorded for data analysis purposes and photographs taken of each artefact created. The workshops were facilitated by the Chief Investigator, who is an HCPC registered Art Psychotherapist and clinical academic researcher and co-facilitated by the Project Manager. Some workshops required additional facilitation and another member of the research team joined us for these sessions.

Each participant was given their own box of art materials and this box was used to contain the images and artefacts in between sessions. At the end of the workshops, the boxes and materials were given to the participant to take away as a means of remembering the project.

Use of Interpreters

Each cohort was offered an interpreter for the workshops. Cohort 1 did not require an interpreter, Cohort 2 had a qualified, external interpreter present as well as the community development worker who also assisted in the sessions. Cohort 3 declined a formal interpreter, but four support staff were present who supported informal interpretation of the sessions. The impact of these approaches will be discussed later in the report.

Why arts-based workshops?

The No Barriers Here approach uses arts-based workshops as a key principle to support more in-depth and meaningful discussions. Arts-based approaches allow for a less verbal approach which supports equity of access not only due to language barriers but also for others who find a solely verbal approach difficult to access due to past trauma, neurodiversity, physical or learning disability and other reasons particular to each person. Sometimes, speaking face to face with another person and using questionnaires and forms closes down conversations, whereas arts-based approaches open up conversations as well as slowing down the pace of the dialogue and allowing for deeper exploration and expressions of thoughts, feelings and experiences.

Who were our participants? How did we recruit them?

The aim of the study was to recruit participants from local minority ethnic communities. The community engagement phase allowed for the development of relationships with community development workers working with different groups and individuals across the borough. The co-production group also advised on recruitment approaches. In addition, leaflets and posters were translated into a range of languages spoken in the locality including Roma, Urdu and Punjabi and distributed to GP surgeries, pharmacies and other community venues.

Three cohorts of participants were recruited from three different communities in Dudley. As part of the co-production principles of the project, it was important for the groups to agree how to describe themselves rather than the researchers applying labels, which they did so as follows:

Cohort 1 – Black African and Black Caribbean Migrant People

Cohort 2 – Roma People

Cohort 3 – South Asian Older Women's Group

It would have been possible in a larger and longer study to recruit from other communities, and one of the limitations of any study concerning working with particular groups is ensuring representation. This study does not claim to represent all people or communities or indeed the views and experiences of all people within these communities. It aims to offer insight into approaches for working with different minoritised people and groups, particularly focusing on identity, culture, ethnicity and race.

It was important not to focus on easy or quick win recruitment, but rather to develop relationships, think about where best to hold workshops, who to engage with listen to and how to reach those who are most marginalised. The role of the community development workers, as people from particular communities themselves, but also working in the health and social care sector, was crucial to the recruitment process and will be discussed later in the report.

Inclusion and Exclusion Criteria:

Included:

- People from minoritised ethnic backgrounds living in, or accessing services in, Dudley borough
- Who have capacity to consent to participate (assessed by Lead Researcher who will obtain consent prior to participation)
- Aged over 18

Excluded:

- People from majority ethnic groups
- People who do not live in, or access services in, Dudley borough
- People under 18
- People who do not have capacity to consent to participate

Participant table

	Ethnicity	Gender	Age
Cohort 1 *(n= 16)*	Black British 5 Black Caribbean 6 Declined 5	Female 13 Male 3 Declined 4	11-18 1 19-29 2 30-39 3 40-49 2 50-65 2 65+1 Declined 5
Cohort 2 *(n=20)*	White other 14 Declined 6	Female 10 Male 4 Declined 6	19-29 4 30-39 2 40-49 6 50-65 2 Declined 6
Cohort 3 *(n=20)*	Asian Pakistani	Female 20 Male 0	30-39 4 50-65 12 65+ 4

Consent

Either written or recorded verbal consent was obtained from each participant prior to participating in workshops. The consent form was translated where appropriate and as advised by the community development worker to avoid making assumptions about which languages it should be translated into. In reality, some participants didn't have written skills in either their first language or English, so the interpreters talked them through the consent form and participant information sheet. Shorter participant information sheets were produced as advised by the co-production group, using visual imagery as well as written word (in a similar way to easy read was used in the pilot phase with people with learning disabilities). In addition, short recordings of the participant information sheet and consent form were also created for people unable to access written materials.

What constitutes ‘the data’?

Research data was collected in two forms. Firstly, the images and artefacts made in the workshops were photographed. Secondly, the workshops were filmed to support data analysis. In addition, participants feedback captured through discussions and interviews. Field notes were also kept during the workshops to aid reflexivity and form supplementary research data.

Note: Separate filming was undertaken by a professional film company at certain points in the project to create a film to aid with dissemination of the project – this footage was not used for data analysis purposes and separate consent was obtained.

How did we analyse the data?

An adapted reflexive thematic analysis [12] was used to analyse the data. Reflexive thematic analysis has six phases: familiarisation with the dataset, coding the data, generating initial themes, developing and reviewing themes, refining, defining and naming themes and writing up the analysis. As part of the dataset is visual, rather than transcribed words, it was important to use an approach which can be adapted for the analysis of imagery. Often, researchers analyse visual data by interviewing and transcribing the interview, therefore losing some of the visual content which perhaps is difficult to put into words. Methodologically, it was important not to rely on this approach for this study, but rather to adapt the analysis method to capture the less-verbalised meaning in the data.

Data analysis was carried out by the research team and members of the co-production group. The lead researcher and project manager carried out an initial analysis of the data. The co-production group met and undertook secondary analysis of the data and then contributed to the development and reviewing of themes. The research team then refined and defined the themes and wrote up the analysis for presentation back to participants and the co-production group.

Reflexivity position statements

Prior to beginning data analysis, the researchers and co-production group members considered their own positionality and relationship to the data. This is an important part of qualitative research and in particular to reflexive thematic analysis which acknowledges that we are not neutral beings but rather, we are in relationship to the data from or own identities and perspectives.

An example of a positionality reflection:

> *"I am an Asian, middle-aged woman. I was born in the UK to parents who had migrated here under a scheme for NHS professionals. I was from a middle-class family historically, but due to the poverty we lived in when I was a child in the UK, I feel my upbringing here was more working class. We didn't own our own home. My life now is more privileged due to my, and my husband's education and employment status. However, I feel continually reminded of my difference, particularly in the last 10-15 years. I am heterosexual, married and the mother of three children, so I have a degree of privilege in these regards, however my ethnicity and race are a part of my identity where I am aware of my own inequality. I bring lived experience of racism and of privilege to this project, I can relate to some people's experience of racism but in other ways, as an Asian woman born in the UK, I feel very different from many Asians who came to live here later in life"*

Our data analysis process

An adapted reflexive thematic analysis was used to analyse the data[12]. Reflexive Thematic Analysis has 6 phases:

Phase	What did we do?
Familiarisation	Reflexive positionality statements Watched filmed sessions Reviewed field notes Looked at images from each workshop Created large sketch notes for each session/cohort
Coding	Review of dataset and attach code labels to identify meanings and concepts Identifying surface level descriptive codes (semantic) and conceptual or implicit codes (latent) For visual images attach code labels to areas or parts of images and artefacts for written data attach code labels to quotes or words spoken Co-production group carry out coding on images from workshops
Generating initial themes	Codes clustered into potential themes Relate back to research questions
Developing and reviewing themes	Discussion with co-production group on potential themes Review dataset with potential themes identified
Refining, defining and naming	Themes finalised and organised into framework Theme descriptions developed
Writing up the analysis	Analysis written up Summarised and indicative themes presented in research report (Finalised themes to be disseminated in peer-reviewed papers in due course)

The data analysis process was deliberately collaborative and our own reflections on our positionality highlighted the need for other perspectives and analytic lenses in the data analysis process.

What did we find?

Key Findings

The findings reported here are divided into three thematic groups.

- Structural and Systemic – How systems and services are set up
- Personal Values – What is important to people?
- Methods and Approach – How we do things

**Findings are summarised and will be reported fully in peer reviewed papers at a later date.*

Structural and Systemic – How systems and services are set up

Misinformation and Myth

Participants across all three cohorts had limited knowledge of the palliative care system in the locality and much of the information that was held was inaccurate. Information about the palliative care system in the locality was not available for participants in a way which had been accessible or meaningful to them. Some concepts such as ‘hospice’ were not common in some participant’s countries of origin and hospice care was understood to be the same as hospital care. Hospital care was associated with a loss of control, handing care to ‘professionals’ and having to leave the family home. The concept of community palliative care or hospice at home was largely unknown across the three cohorts. Participants shared that a lack of translation of health information and letters was a barrier to accessing healthcare generally and only a small number of participants knew about palliative care. Participants commented that leaflets and information are not available in the right range of languages or rely on having access to the internet. This was a barrier for participants living in poverty or without written literacy skills in any language. For participants who were newer to the UK, there was confusion about the structure of the healthcare system generally, with very limited understanding of the palliative care system. Participants expectations of care were generally low. Those who worked in the care system had the best understanding of how to access services.

The importance of kinship caring

The expectation and desire to both care for, and be cared for by, family members was a strong theme across all three cohorts. Many participants had caring responsibilities themselves and some expressed concern not only about their own future care, but the care of relatives they would leave behind when they died.

For participants who had close friends who they wished to be involved in their advance care planning and care at the end of life, there was a need to express this to family members and healthcare workers as this is often outside both cultural and healthcare norms. It was unusual across the cohorts for non-family to be identified as important people but for those who did have close friends, it felt important to share this in their plans.

A desire to be cared for at home was expressed across all groups and this was associated with a desire to be looked after by family members. The concept of ‘hospice at home' or relatives being able to spend time in hospital or in hospice settings caring for relatives was not widely known. The Covid-19 pandemic had exacerbated this perception as participants lived experience had been that of the wider population – not being able to visit or care or have important practices honoured. For some participants this led to avoiding contact with health services. A lack of accessible information about services or access to healthcare workers who could explain how and when to access services exacerbated this avoidance.

The role of healthcare workers

Healthcare workers were viewed in different ways across the cohorts. For some participants accessing healthcare was felt to be a failure and very much seen as a last resort. Healthcare workers were viewed differently in the first cohort where participants were largely people who had lived in the UK for many years or were from second and third generation migrant families. This cohort had many participants who worked in social care settings. In the second and third cohorts, healthcare workers were viewed as somewhat distant and very much as a less favourable alternative to family caring. Most participants in the second cohort had experienced barriers to accessing healthcare and were actively seeking preventative or curative treatment for a wide range of unmet health needs, however, when it came to conversations about end of life care, a less medicalised model was seen as preferable by all participants. What appeared to sit beneath this belief was a fear that healthcare workers would not understand or listen to people's needs. Participants shared multiple examples of being discriminated against and not having their needs and opinions listened to. There was an awareness amongst the first cohort of the negative experiences many Black people have had in healthcare and in particular in research studies. The Covid-19 pandemic and rapid development of vaccinations had brought this fear to the foreground.

Variances in structural disadvantage

The structural disadvantages experienced by participants varied across the cohorts. The first cohort shared personal experiences of racism in healthcare settings as well as an awareness of the health inequalities experienced by Black people in the UK. This cohort was largely made up of people who were born in the UK or came here many years ago and some of the structural disadvantages experienced by more recently arrived communities were not experienced by this cohort. Many people worked in social care and this, as well as being in the UK for longer or born here had given the participants in this cohort a much greater awareness of the healthcare system and how to access it. Participants in this cohort were clear about their needs and wishes for their end of life care and this was reflected in the images and artefacts created.

In contrast, in the second cohort participants had more recently arrived in the UK and faced stigma and marginalisation within the local community that was profound and far reaching. Many people had unmet health needs and the participants presented far more in 'survival mode'. This made thinking about future care wishes a more abstract concept as the primary focus was on finding suitable accommodation, basic healthcare and access to education.

The third cohort were a group of older, female participants most of whom did not speak English or where they did it was limited and many of the group didn't have written literacy in either their first language or in English. The participants were very dependent on the facilitators in the group and largely reliant on their children socially and economically. This group expressed the most focus on the importance of the wider group community for their well-being but almost all the participants said they would want to be cared for by family members. The participants in this cohort experienced multiple structural disadvantage as older women, as people unable to communicate without family members – leading to high level of reliance on family members for access to healthcare appointments and access to social support.

An understanding of the differences in structural disadvantage experienced by different groups, communities and individuals is important for healthcare workers as it impacts on the ways in which people may access palliative and end of life care. The importance of advance care planning and the ability to express preferences for future care varied depending on the structural disadvantages experienced by participants.

The danger of homogenising people

One of the significant themes which developed from the workshop data was the tendency for services and healthcare workers to treat people from minoritised communities as a homogenous group. This surfaced in different workshops at different times but was experienced by all participants. Even the original funding bid talked about the needs of 'BAME communities' something which was challenged by the co-production group early on. The term 'BAME' was increasingly uncomfortable and it is unhelpful when trying to understand the needs of individual people. The co-production group preferred 'people excluded by identity, culture, ethnicity and race' or 'minoritised ethnic groups' but even at the time of writing this language is beginning to be challenged. In the reporting of this research, the authors have been careful not to report findings which describe the needs of all members of a particular community or group, but rather to report what mattered to people and individuals and then to report what structural and systemic and methodological themes developed from the data.

Participants shared experiences of being grouped with all people from a particular community or ethnic group as a way of 'othering' and it was important for people to be able to tell their individual stories and experiences and express preferences particular when they fell outside perceived cultural norms or traditions.

The experiences of participants highlighted where services and healthcare workers prioritise a sense of 'knowing' over curiosity and being able to sit with not knowing whilst retaining compassion. Participants shared experiences of having to reassure healthcare workers and other 'professionals' who became brittle or defensive when they didn't 'know'. There was a desire to be seen as an individual and for healthcare workers to be able to ask questions and explore preferences. Participants did not want or expect healthcare workers to know everything about them or their culture, religion or race. There was a view expressed that healthcare workers and services prioritised knowledge over curiosity.

Personal Values – What is important to people?

There were themes which developed throughout the data which relate to the values, wishes and personal priorities of participants. A deliberate decision has been taken in sharing the findings to not present about what was important to participants based on each separate cohort. This is to avoid homogenising groups of people by their race or ethnicity or perceiving people's racial and ethnic identity in stereotypical ways. Furthermore, by homogenising whole communities, we risk diluting rich cultural diversity and individuality. Therefore, the themes are presented in the next section as they arose across the workshops. When working in spaces concerning racial inequity and marginalisation, broad claims are made about specific groups of people which serve only to reinforce homogenisation, rather than understanding and respecting individuality and diversity not to break it down. One participant spoke about generalising communities, particularly in areas of high socio-economic deprivation, poor health outcomes and high crime rates.

> *"The media portrays us all as criminals. The actions of a small minority are used to justify how we are all treated. If people got to know us as people, this would happen less"*

Home

The majority of participants highlighted a complexity when discussing place of care and in particular the concept of 'home' versus hospital. For the participants in the study, the concept of home was more complex than considering care in an institutional setting or their place of residence.

For one participant, home was defined as wherever her children and grandchildren were. This participant shared the conflict of where she might want to be buried (country of birth) and the desire for that to be somewhere her children and grandchildren could visit (the UK). For another, the loss of a child who was buried in the UK presented a dilemma when considering where their preferred place of burial would be as a return to their country of birth felt like leaving the child behind.

> *"I lost a child, and they are buried in England. Home for me is Uganda but I couldn't leave my child to return home."*

Other participants shared the impact of the Covid-19 pandemic on their ability to travel back to their home countries for funerals or for end of life care and how difficult this had been. Some participants also shared the conflict they experience between their personal wishes and the expectations of their families and wider community.

Poverty and the need to remain in the UK for employment or due to family commitments like education of children also created conflict in participants ability to express their wishes. The cost of travelling home was highlighted as prohibitive for many participants.

"After Brexit and the pandemic our life has very much changed. We find it hard to go back to Romania to be treated for medical conditions."

"If someone is terminally ill and wants to go home to die, can you help with that?"

For some participants, where care at home was expressed as a preference, their unstable and inadequate housing contributed to the view that hospital would be a preferred place of care. Some participants, particularly those with the greatest structural disadvantages found it hard to think about preferred place of care because they were existing in day-to-day survival mode. This was particularly the case for those participants from newly arrived in the UK, those seeking asylum or with unclear immigration status.

"I came to England three weeks ago with my wife, son, daughter-in-law, who is having a baby and two grandchildren. We are living in one room, but we are together."

For others, the UK was felt to be home, however a fear of lack of respect for culture and religious practice and preferences was expressed by several participants. This contributed to a desire to remain out of institutional care settings such as hospital, hospice or care homes. This had led some participants to have to manage difficult deaths of family members at home with little support.

> *“The hospital doesn’t allow all the visitors or understand our prayer rituals. The chair on my plan shows a hospital chair for my appointments but that is the only time I want to be in hospital. Let me die at home. My family and friends from the Mosque will care for me but during the lockdowns this was difficult for many of us.”*

Family

The importance of family relationships was highlighted by all participants. Most participants were living with at least one other family member, however, there were a minority who were totally isolated from family and experienced additional needs and greater isolation. Some participants attended as couples or in family groups. Many participants had significant family members elsewhere in the world, not just in their country of birth or origin, but for older participants, the reality of having adult children who had chosen to settle in different parts of the world was expressed.

Many participants lived with adult children and grandchildren and were reliant on them for translation, support accessing healthcare and day to day support. Whilst also fulfilling domestic and caring responsibilities in the family home.

Family is a common theme in all No Barriers Here workshops, but what was distinct in this study was the importance of kinship caring included in the previous section. Participants demonstrated not only caring for relatives in the UK but also in the country of their birth, with responsibilities for not only family members but friends and neighbours. One participant explained the responsibility of living in a different country to their elderly parents who live in a remote African village.

> *"I collect bandages, medication like paracetamol and ibuprofen, vitamins and other equipment. I go home to see my parents and do health checks on them, other family members and neighbours. I take a thermometer and blood pressure monitor with me, food, blankets, and whatever people need. It takes a village to care... it's not like living here with the NHS, doctors and pharmacies."*

Participants expressed concerns about losing autonomy in their caring roles and this led to avoiding accessing services for some participants. For others, particularly those who had been bereaved, a lack of support outside the family and a lack of awareness of available services was also highlighted as an unmet need.

> *"Three years ago, I was losing my niece for pneumonia and my nephew for cancer. Since then, I couldn't face the pain of going to the cemetery in my Island to grieve...Two years of covid didn't allow me to travel home to hug my brother who lost two children in one year. I cannot thank enough No Barriers Here for the workshops that gave me the strength to face this place. To finally grieve my loved ones. For opening this healing path in such a beautiful way… allowing me to face the end of life."*

The third cohort were part of a group formed after the Covid-19 lockdowns to help overcome loss and loneliness. Membership of the group had impacted on the members sense of ‘family’ as broader than biological family. Several participants cited other group members as ‘important people’ who would be a source of support when they became unwell or were coming to the end of their lives.

The group discussed the importance of friends and highlighted that care decisions are often made by immediate biological family, not friends or the wider community. The importance of talking about different family and support structures was highlighted by participants. Two participants in the group were estranged from family members and explained that friends would ‘step in’ and take them to their own family home for end of life care, rather than admission to a care setting. Assumptions made by healthcare workers about family structures was also highlighted. These included a tendency to make assumptions about traditional, biological family structures when talking with people from minoritised ethnic groups.

Nature

Nature and participant’s relationship with the natural world was a prevalent theme across the whole dataset. Many participants connected a desire to return to their country of birth or origin with a connection to nature, particularly the sun and the sea. Again, this is common in many No Barriers Here workshops, but several participants highlighted that assumptions about them not wanting to access the outside, countryside or outdoor activities being common.

“People assume because I’m from the Caribbean I don’t like the cold weather. I love being outdoors and want to be allowed to go outside at the end of my life. Even if it is raining!”

The third cohort was formed of a group who have access to an allotment space which is used to grow food for the wider community. The group was formed of older, Asian women who had a high level of domestic and caring responsibilities. However, the allotment had offered a space for community, for shared projects, social contact, and had helped many members overcome recent bereavement and social isolation related to the Covid-19 pandemic.

Participants consistently created images with themes of nature when discussing their end of life care and care after death. Different customs relating to funerals also incorporated the outdoors and some participants highlighted how UK custom and practice in funerals was very different from what they hoped for. One participant expressed his wish for his funeral to be customary to the area he lived in Romania, with a van carrying his body stopping at several different outdoor points on the journey and explained to the authors how this varies to UK funeral practice.

Faith and Spirituality

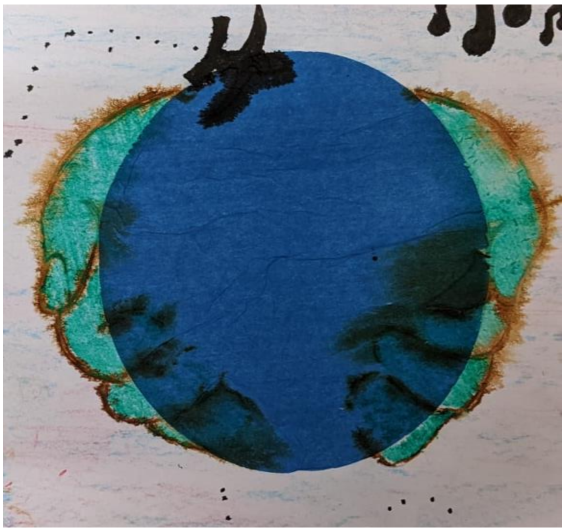
Faith and spiritual needs are common themes explored in advance care planning. In this study, what was significant was the tension between the understanding required by healthcare workers of different religions, religious customs, traditions and practices and the risk of this exacerbating homogenisation, stereotyping and making incorrect assumptions about people, communities and groups.

For those with a strong faith or religious identity, healthcare workers understanding the importance of spiritual practices was highlighted repeatedly. The fear that important practices would not be honoured was prevalent. This was particularly felt by people from less understood cultural backgrounds. Participants were very keen to share what was important to them in this regard and wanted to be asked and to be able to explain what was important.

> *"I would like to be at home, with my family praying and worshipping. Lots of noise!"*

One participant expressed not accessing healthcare services or advice from healthcare professionals due to *'Gods will'* explaining that whatever the illness or diagnosis that *'God will see me through'.* Nearly all participants across the three cohorts expressed their faith and spirituality, either through the drawing of religious icons and artefacts or symbolism in their artwork.

Many participants highlighted the tendency for healthcare workers (and other professionals) to have some knowledge but to then feel unsure about how to ask or talk about what they didn't know. This was experienced as avoidance or fear of getting it wrong by participants. Participants highlighted that the same skills are required to ask about healthcare issues as to have other types of conversations and welcomed an appropriate level of curiosity and exploration of their faith and religious practices and traditions.



> *"It's a kaleidoscope of joy and colour (end of life). It's not about a specific place but more of a feeling."*

Choice

Choice and autonomy was discussed by many participants in relation to when custom and practice dictated care at the end of life and after death and when personal autonomy and choice was possible or desirable.

Views about this varied across the three cohorts but discussions were common across all of the workshops. For some participants there was some comfort in knowing that family and the wider community, including religious leaders, would carry out end of life care practices, funeral and burial arrangements in line with tradition and/or religious customs. Other participants highlighted that this isn't always the case and for some people, a more individual or non-religious approach is preferred. Participants felt that as people from minoritised ethnic groups, they were more likely to have assumptions made about their religious beliefs or needs.

Some participants said this was the first time they had been able to express individual wishes or preferences, because they had their own assumptions that there was not space for personal choice. This was particularly prevalent in the third cohort with South Asian older women and that often decisions were often made by family members or based on their religion and culture. Most of this cohort were illiterate and had very limited English, therefore reliant on family members to translate information and ensure choice is appropriately communicated.

This theme closely linked with the earlier themes regarding kinship caring, family and home. Participants other main view about choice and making informed decisions was related to not having professional care imposed upon them and the widely held association with professional healthcare leading to a lack of control and choice. This is a significant theme and relates to the structural and systemic themes earlier presented and forms part of the recommendations later in this report.

> *"I wasn't allowed a yellow wedding dress, so the yellow symbolises the dress that I didn't have."*

Personhood

This theme links to the structural and systemic theme ‘The danger of homogenising people’ presented above. Many participants described feeling acutely aware of being treated as part of a group based on their identity, culture, ethnicity and race. This was often experienced as related directly to the colour of their skin. Participants from the Roma community highlighted the prejudice and fear about their community in the locality and whilst this was not related to skin colour it was related to ‘othering’ perpetuated by the local media in relation to crime, anti-social behaviour and living conditions.

“It is painful and unfair when one is judged by ethnicity, colour, region, sex etc. Is it not unfair to condemn and generalise an entire community as bad people because of one person or a group of people?”

Participants who did not speak English experienced avoidance by healthcare workers and felt accessing palliative and end of life care services would be difficult because of the lack of access to interpreters or understanding and knowledge of which languages were spoken.

“If they don’t send an interpreter to help us understand, it is very hard for us.”

“I need help and a person to speak on my behalf to be able to get to a specialist to be treated.”

“Because we are not British citizens they ask for statements and documents… I don’t understand what the [hospital] letters say so I don’t know what to do.”

Many participants, particularly in the first cohort, highlighted that people from outside the UK are assumed to be illegal migrants or asylum seekers. It was felt by some older participants, that as time went on, understanding of the periods of time where people from colonised countries, in the Caribbean and in South Asia especially, were actively encouraged to come to the UK to work. These participants shared that they felt this contributed to the racism and prejudice they experienced on a day-to-day basis.

“People think of migrants, and they think illegal!”

Participants felt that people from minoritised ethnic groups in the UK tended to be subject to far-reaching assumptions about their care needs in palliative and end of life care (as well as more widely in healthcare and in society). This was reflected in publicity materials only featuring white people, in leaflets and letters not being translated into appropriate languages, in information not being available in the spaces people frequented and in a lack of representation in the workforce.

Some participants commented on a perception that they were ‘hard to reach’ or ‘hard to engage’ and expressed confusion and frustration as to why this was perpetuated when clear barriers to accessing services or even knowing about what services exist were so present. Many participants made suggestions about how services could change to be more accommodating and welcoming and how information could be more widely available.

Participants expressed in different ways, how the perception of minoritised ethnic people and communities was driven by lack of knowledge about different people, religions and communities but also a lack of confidence in talking and working with people who might be different to themselves amongst healthcare workers. Most participants expressed that they did not expect healthcare workers to know about all people and how unrealistic this would be, but they hoped for an appropriate level of confidence and professional curiosity to find out.

Legacy

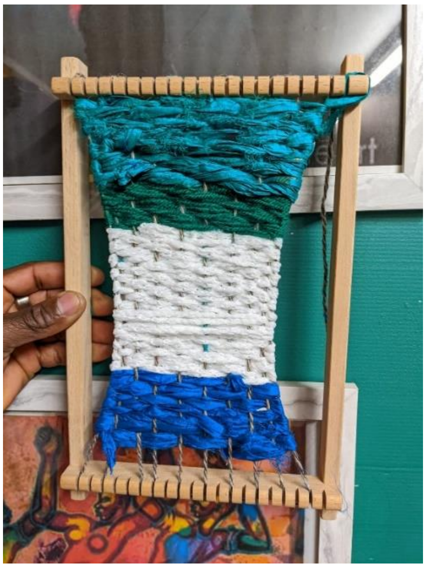
The final theme was that of the importance of legacy to the participants in these cohorts. All No Barriers Here workshops focus on legacy in Week 3 but this topic was particularly important to participants in this study who had experienced othering, displacement and racism. For participants who had come to the UK from another country, many had lost their previous status in the community, professional identity and identity as part of the majority. This experience of being viewed primarily through a lens of racial identity in the UK highlighted the importance of exploring, expressing and celebrating identity through thinking about how participants would like to be remembered.

“It’s not just what I want, it’s who I have been”.

For participants who worked in care or who had caring responsibilities it was important to be remembered for their work. For those who had been involved in projects in their country of birth, it was important that this was known and shared. Many participants wanted to be remembered in relation to their status in their families, as a good

Mum/Daughter/Husband/Wife/Father/Son. For others it was important to be remembered for status and role within the community or for business and professional achievements. Most legacies focused on morality or values-based wishes.

“Remember me as a kind and caring man”.



Methods and approach – How did we do things?

Methodological Insights

The study led to the development of key methodological insights which helpfully inform the advancement of approaches to delivering equity-oriented palliative and end of life care. Particularly, how to develop projects which offer different ways of engaging and building relationships with people and communities marginalised in palliative and end of life care and healthcare more widely. This study focused on people often excluded by identity, culture, ethnicity and race but the methodological insights could be used to inform approaches to working with other minoritised people, groups and communities.

Note: Full methodological findings will be reported in peer reviewed papers focusing of qualitative methods at a later date.

Collaboration

The collaborative elements of the approach were crucial in the recruitment of participants. The preparatory stages of the study included time to make links with community engagement workers in different communities, to involve some of those workers as co-production group members and to undertake awareness raising events across the local community.

The full community engagement project is reported separately. The role of the community engagement workers in the study was akin to what Russell[13] calls ‘the border hounds’. People who have one foot in the community and one foot in the ‘institution’. For the research team, our border hounds (and our co-production group) allowed us to recruit into this study. If two researchers/facilitators had tried to offer this project in a hospice setting without building relationships and working collaboratively we would not have recruited our 50 participants. The community engagement workers also helped overcome the fear of getting it wrong as outlined earlier in the report. This approach alleviated anxiety, built confidence and reduced fear – all of which contributed to open, curious, exploratory data collection and analysis.

> *"The first thing that struck me about No Barriers Here was the name - it unapologetically shines the light on the issue for those of us from minoritised groups. It is not us that are hard to reach, it is the barriers that need dismantling. It makes me feel safe."*

The other significant area of collaboration in the No Barriers Here approach and which characterised this study is the opportunity for individuals and 'professionals' to work together. By involving healthcare staff, support workers, community engagement workers and other people in positions of power or authority, albeit within the communities the project was focusing on – alongside individual community members (our participants) working together in the workshop stages; powerful insights and understandings into each other's positions and experiences were gained.

> *"It makes me feel I feel I know these people much better now, the images and the conversations we had shared so much more than I would have understood in a regular ACP meeting"*

Co-production

Co-production is a key principle underpinning the No Barriers Here approach. The idea that it is important to work alongside people and communities to develop services, to disrupt traditional commissioning hierarchies and to adopt different ways of working is prevalent in the public sector. In research culture, there is an increasing focus on disrupting traditional research hierarchies particularly when working in the equity sphere. Meaningful co-production is sometimes challenging and it can be easy to slip back to purely consultation levels of involvement. The development of the No Barriers Here approach was co-produced with a group of people with learning disabilities. The co-production group shaped the development of the model and it was essential to adopt a co-production approach for this study.

> *“This group is the most inclusive group that I’ve attended.”*

A group of people from a range of ethnic backgrounds, identities and cultures was invited to take part in the group to develop and direct the study. As two white people, the lead researcher and project manager recognised their own privilege and position as funded staff on the project. It is important to highlight the lack of funding available to pay for the co-production group member’s time. Some were able to attend as part of their professional role as well as from a personal perspective, but some gave their time for free which perpetuates inequity. It is key to recognise the discomfort experienced of the two authors leading a study on race equity and it was important to continually reflect and acknowledge our own unconscious bias throughout this work, both independently and with the co-production team.

The co-production group were involved in all aspects of the project. The following diagram highlights the significant impact points of the co-production group on the conduct of the study.

Similarly, to the role of the community engagement workers (some of whom were members of the co-production group), the impact of group is hard to adequately quantify. The way the study was conducted, shaped, reflected upon, delivered, analysed and conceptualised was oriented around the work of the co-production group as the co-researchers on the study.

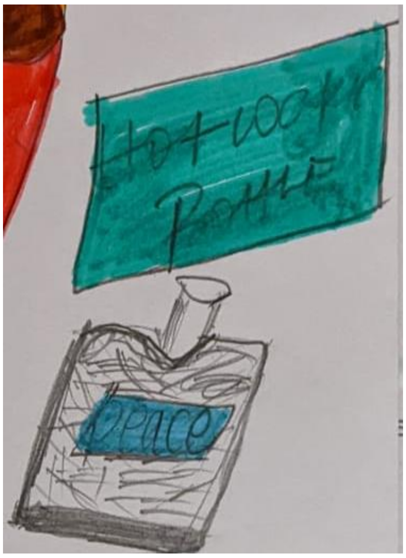
Arts-based methods and the use of less verbal approaches

The use of arts-based methods within the No Barriers Here approach evolved through the first co-production group of people with learning disabilities as a way of offering a less verbal approach to advance care planning. Arts-based approaches are common when working with minoritised people and communities as they offer a more equitable way of exploring and expressing feelings, thoughts and experiences. There are many reasons why people may find solely verbal methods inaccessible:- past trauma, power imbalances, neurodiversity, language barriers, physical disability and health conditions, mental ill health and many other reasons. Arts-based or creative methods have a universality which can be levelling. Throughout history, in all societies, humans have made marks and images, music, danced and communicated creatively.

> *"When I think of events and deaths that have happened its in song. Our history is poetry and music."*

Each workshop is designed to maximise participation. The activities have been chosen to slow down the process, allow space for exploration as well as expression and to avoid closed questions which can sometimes characterise advance care planning conversations. The activities allow participants to express a range of views and preferences from the more light-hearted but important views about how participants would like to be cared for to the deeper and more difficult aspects.

> *"If I have an incurable illness and I'm going to die please help me to fly home. If I can't die at home, then I would want my body repatriated. My casket must be open where possible and my rosary beads with me."*



“I can’t sleep without my hot water bottle, even in summer. If I was restless and unable to communicate, please make sure I have my hot water bottle!”

In this study, the parts of the approach which resonated with many participants was the gifting of a box of materials and the space to make individual images and artefacts. This allowed participants to focus on their own individual experiences and views and contributed to avoiding the homogenisation of groups of people discussed earlier in this report. Participants were able to compare and contrast their views and experiences through sharing the things they made with others in the group. This encouraged individual reflections as well as shared experiences to be highlighted.

The No Barriers Here approach allows for varying degrees of participation – there is no right or wrong way to respond to the themes of each workshop. For people who carry past trauma, arguably anyone from a minoritised group or community, the physiological impact of art-making can offer another benefit. Art-making slows down the conversation, allows time for self-reflection as well as sharing and offers a triangular rather than dyadic conversation, which can help to create a less intense environment. Participants responded well to the art-making aspects of the study, commenting that even though they may not believe themselves to be ‘creative’ or ‘arty’ this did not create a barrier for participants in the workshops.

Finally, the approach focuses as much on the process than the end product. It is the process which allows the deeper conversations and reflections to happen. Although participants were on the whole proud of what they had made, and keen to show each other, the value in the arts-based approach is in how the making process allows space to explore and express. The workshops are designed to offer simple art-making activities with a structured guide through the session to take the group through a process outlined in the diagram below.

Limitations and Challenges

There were some limitations and challenges within the research study which are important to acknowledge and to consider when designing future studies.

Funding for co-production participation

The grant for the study did not include sufficient funding to properly pay for co-production members time. Expenses were covered. It is important, especially when working in the sphere of inequity to properly recompense people for their time, especially when those people may be already economically disadvantaged.

Any research study has a funding envelope within which the study is designed and delivered. Future studies would benefit from recruiting further cohorts of participants and expanding the impact of the findings in wider education settings.

Future peer reviewed papers will explore the limitations and challenges further.

How can services respond?

What would improvement look like?

The following principles have been identified as key to the improvement of services:

- Funding de-centralised
- Meaningful co-working between statutory and community sector organisations
- Services are co-produced and co-designed with minoritised communities
- Co-production is properly funded
- There is a focus on early engagement with minoritised communities
- Information is available, accessible and timely - myths are addressed
- Care services support kinship caring and care at home
- Education focuses on developing skills in 'working with' rather than 'knowledge about' minoritised people
- Advance care planning approaches are provided in a range of ways including less verbal approaches

From the analysis of the data in the ‘No Barriers Here: for people excluded by identity, culture, ethnicity and race’ study, it is possible to make recommendations of how services and systems could be improved for people marginalised by identity, culture, ethnicity and race.

Recommendations and Implications for Practice

1. Local relationships and alliances between NHS and other palliative care providers and community organisations are developed and maintained with a view to developing a whole-system approach and co-produced services which meet local needs.

2. Equitable approaches to funding palliative care services are developed and new and creative funding routes for community organisations are made available with a view to improving access to palliative care for minoritised communities.

3. A Borough-wide communication strategy is developed, which aims to challenge myths and highlight how palliative care services can support and deliver personalised care, including care at home.

4. Purposeful steps are taken to review meeting structures at a strategic level, to ensure representation from community organisations and group leaders to include people who operate between communities and statutory bodies.

5. Information and communication strategies focus on developing strategies for the early identification and engagement of minoritised ethnic people and communities.

6. Local education programmes focus less on knowledge development, and moves towards developing the skills and attitudes required to work with people and communities who may be minoritised or experienced as ‘different’. Improved recognition and awareness are needed of inequity, intersectionality and discrimination people and communities experience.

7. Data collection and analysis is focused on ethnicity data, including ethnic categories, the collection and evaluation to improve access to palliative care services and highlight where disparities exist.

8. Clear and accessible information outlining what the palliative care system looks like and how and when it can be accessed is available in an appropriate range of languages, formats and locations.

9. A clear process for accessing interpreters and translating materials is available across the Borough. People know how and where they can access an interpreter to support attendance at healthcare appointments and to access care.

10. A willingness to step away from clinical services and healthcare professionals, to work directly with communities and community representatives to strengthen systems and support communities. This may include support for people to die at home, a leaflet for carers and a better understanding of the needs for people being cared for at home.

11. Healthcare professionals feel able to be curious and open to innovative approaches to advance care planning.

12. Strong leadership is required to ensure collaborative working and excellence in integrated palliative and end of life care for minoritised ethnic people and communities at strategic and policy level.

Summary

Key take away messages

Palliative and end of life care in the UK has historically focussed on the provision of care for white, middle-class people. People from minoritised ethnic groups and communities are often underrepresented and experience racism, discrimination and disparities accessing specialist and supportive care.

The findings and recommendations provided in this report are advised to be used at an individual, place-based and system-wide level. We all have a responsibility for our actions and learning, regardless of the role we hold within the healthcare system. Healthcare workers, providers and those responsible for commissioning services must place inequity in palliative and end of life care firmly on the local agenda and work collaboratively with communities to understand and remove structural and systematic barriers to palliative care, including advance care planning opportunities, that people from minoritised ethnic groups experience.

This report exists to share the stories and lived experience of people who are often outside of the margins of palliative care systems. It acknowledges the racism, discrimination, direct and undirect bias and underrepresentation people from minoritised ethnic communities experience when trying to access care or navigate inaccessible and complex systems. It is aimed to guide current practice, policy making, commissioning of services and the need of future research.

It is critical to explore and analyse the provision of services and care through a lens of inequity and inclusion, in co-production with people and communities and with an open culture of curiosity to different approaches and ways of working. Only then will we move forward towards genuine equitable and accessible palliative and end of life care.

> "Can race equity ever be achieved? Yes indeed, but it requires some real changes to make it happen; we can't continue with the same actions and initiatives; the evidence suggests they simply don't work."[14]

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