General Considerations for Research with Minoritised Ethnic Groups with Chronic Conditions and Disabilities: beyond cultural competency and humility

An output of the NIHR-funded CICADA study
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Section 1 Project overview, methods and about this toolkit

Many people with chronic conditions and disabilities, particularly those from minoritised ethnic groups, faced obstacles before the pandemic in accessing or utilising networks of support, health and social care (Rivas et al., 2022; Di Gessa et al., 2022; Germain and Yong, 2020). During the pandemic, some issues increased disproportionately and widened the inequalities gap between people with disabilities from minoritised ethnic groups and those without disabilities from the native white British population (Germain and Yong, 2020).

The NIHR-funded CICADA study took an intersectional approach to understand the pandemic experiences of this minoritised group as the basis for improving their situation. The longitudinal study aimed to capture the impact of changing pandemic contexts during its 18-months, starting from May 2021. We used participatory approaches that aimed to restore epistemic (knowledge) injustices (Fricker, 2007) that is, we worked with, not on (Follett, 1940), people with disabilities from minoritised ethnic groups so they had an active and transformative voice in our processes, data and outputs. The study used an asset- and strengths-based focus and participatory methods, to learn from and build upon what participants said worked well for them when coping with issues or managing their health, rather than to impose external solutions.

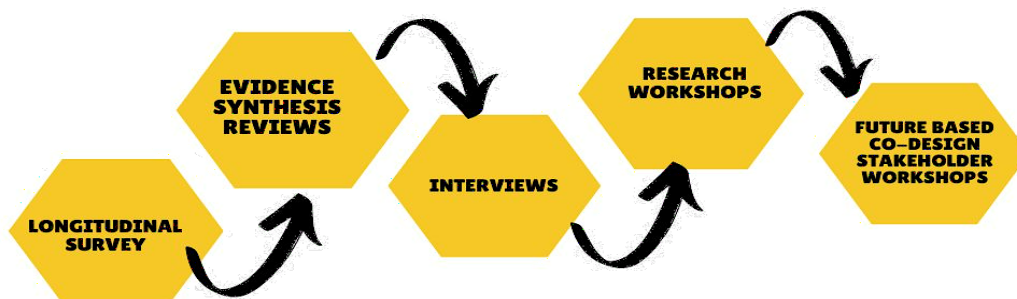*CICADA data informing this toolkit*

Figure 1: CICADA methods

CICADA involved a range of methods as Figure 1 shows. Existing evidence was considered, through a scoping literature review, and by exploring surveys undertaken to explore people's lives during the pandemic, in particular those linked to existing national cohort and panel datasets.

A new survey was also developed which was completed by people across the UK's four nations. This survey was sent to the same participants three times over 18 months (that is, in three waves), with 4,326 valid responses in wave 1, 3,498 in wave 2 and 3,100 in wave 3.

Approximately half the people who responded to this survey were of minoritised ethnicity and approximately half had a chronic condition or disability, due to the focused recruitment strategy.

The CICADA team conducted 271 interviews with people living in the UK (mostly England) self-identifying as Arab, Central/East European, African and South Asian, to reflect recent migration waves and those at most risk from COVID-19, with native white British comparators. Of these, 210 interviews were conducted in the autumn of 2021, mostly at six sites in England (London, Yorkshire, the Northwest, the Northeast, the Southeast and the Midlands). The remainder were conducted between May and September 2022 following top-up funding. Most participants had some form of chronic condition or impairment that led to their being disabled in their daily lives, though we also included comparators with no chronic condition or disability.

Over half (134) of the 2021 interviewees were invited to follow-on discussions in two series of workshops, with 104 attending to explore changes five months after interviews and 35 of these also taking part approximately 10 months after the interviews. Following these, mixed stakeholder co-create workshops were attended by health professionals, community leaders, charity leads and members of the public (a total of 16 people) to co-create rapid-impact solutions to issues. We asked four policymakers, GPs, and community leaders for recommendations on how to put these into immediate practice.

About this toolkit
This toolkit aims to document best practices and give researchers a framework for collecting information from minoritised ethnic groups in the UK who have chronic health conditions or disabilities. Some content may be relevant for minoritised ethnic groups or those with chronic conditions or disabilities separately.

Steps taken in its development
These steps were inspired by previous work in this area (such as Farooqi et al., 2018).

Step One: The research team discussed the lessons learned when working with minority ethnic communities with chronic conditions and drafted the toolkit.

Step Two: In terms of validation, the research team held iterative conversations to adjust the recommendations provided in each toolkit guideline. Where it was feasible, brief case examples are presented to substantiate the suggestions.

Step Three: The advisory board members (including members of the Patient Advisory Group) were presented with the toolkit and asked to provide feedback, considering whether the information included was reflective of their comments and experiences.
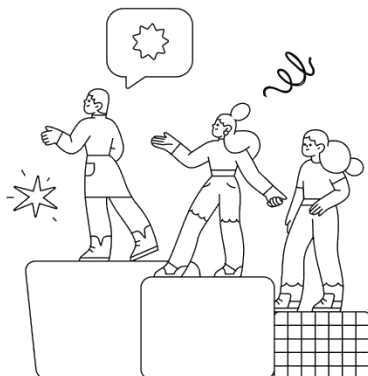
What it covers?
The toolkit considers both theoretical and practical aspects of inclusive research (Figure 3 below). This includes a discussion of culture as an inclusive term that encompasses the ideas, customs, and social behaviour of all peoples or groups, not just those distinguished by ethnicity or place of origin. Culture in the way we use the term refers to "the beliefs that people hold about reality, the norms that guide

their behaviour, the values that orient their moral commitments, or the symbols through which these beliefs, norms, and values are communicated" (Steensland, 2011, p.10).

Figure 3: What the toolkit covers.

Section 2 Cultural humility and competency and why we have moved away from these

Melanie Tervalon and Jann Murray-García introduced the concept of cultural humility to the fields of medicine and public health; they catalysed interesting and ongoing discussions on whether cultural humility is, in fact, more critical than working to become "competent" in the cultures of those with whom we work and interact (Tervalon and Murray-García, 1998). They outlined cultural humility as:

> *"a lifelong commitment to self-evaluation and critique, to redressing power imbalances [..] and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations" (p. 123).*

Cultural humility, initially proposed as a tool to help physicians work with the increasing cultural, racial, and ethnic diversity of the United States, is beneficial for all researchers. Understanding another person's culture is merely the first step in a lifelong reflexive process that begins with an examination of one's own attitudes and cultural identities (Tervalon and Murray-Garcia, 1998). It provides a critical awareness that is more than just self-awareness but requires one to step back to understand one's own assumptions, biases, and values (Kumagai and Lypson, 2009). Tervalon and Murray-Garcia (1998) also state that cultural humility is:

> *"[...]best defined not as a discrete end point but as a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues, and with themselves" (p. 118).*

This practice recognises the dynamic nature of culture since cultural influences change over time and differ depending on location and context. The purpose of the process is to be aware of our own morals and attitudes to increase our understanding of others (Yeager and Bauer-Wu, 2013).

Cultural humility- what it is not ('cultural competency')
Cultural competency and humility have occasionally been used interchangeably. Cultural competency places a strong emphasis on examining and evaluating the belief system of the patient or research participant (Yeager and Bauer-Wu, 2013; Agaronnik et al., 2019). Many organisations have made cultural competency training a requisite for clinicians to sensitise them to the particular needs and what are often termed "vulnerabilities" of diverse populations

(Yeager and Bauer-Wu, 2013; Agaronnik et al., 2019). The training programmes of cultural competency often centre on caring for racial and ethnic minorities and on behaviours and practices among these groups, with the purpose to break down cultural barriers to quality health care. Cultural incompetence is thought to be due to a lack of knowledge about the 'other' and perhaps related to the 'provider's' discriminatory attitudes toward the 'other' (Yeager and Bauer-Wu, 2013).
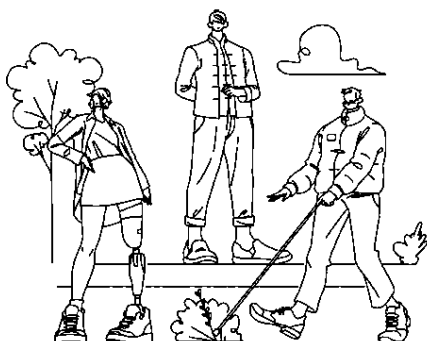
Consequently, cultural competency does not sufficiently incorporate self-awareness since the objective is to learn about the other person's culture as an outsider rather than to reflect on the provider's background (Yeager and Bauer-Wu, 2013; Agaronnik et al., 2019). Cultural competency is focused on the provider being confident and comfortable when interacting with the 'other'. To summarise, the objective of cultural competence is to produce confident healthcare providers with specialised knowledge and skills that can then competently serve specific communities, most usually ethnic or racial minority groups with care needs. Other terms such as cultural awareness, cultural knowledge, and cultural sensitivity are often supported by these same assumptions of cultural competency (see Table 1 below) (Yeager and Bauer-Wu, 2013).

A national survey of more than 3,000 doctors discovered that, despite the emphasis on cultural competency in healthcare, one in five of respondents felt unprepared to deal with socio-cultural issues, such as patients with religious beliefs that influence treatment decisions, patients who distrust the healthcare system, new immigrants, and patients with health beliefs that are in conflict with conventional medicine (Weissman et al., 2005). Kumas-Tan et al (2007) studied the frequently used cultural competence procedures and recognised assumptions embedded in these measures: culture is usually treated as if equivalent to ethnicity and race, and little attention is given to other components of culture such as gender, class, disability, health condition, geographic location, country of origin, or sexual preference. Culture is thus influenced by the patient or client as non-normative. In many care procedures and processes, for example, whiteness is implicit and signified as the norm (Yeager and Bauer-Wu, 2013). Ebony Caldwell, a disabled psychiatrist, also highlights ableist attitudes. She describes the significance of centering the experiences as well as perspectives of people with disabilities in mental health care, including the need for culturally responsive care and support for individuals with intersecting identities (Holmes, 2021). Ethnocentric and ableist practices act as blind spots that mean that some minoritised ethnic groups and conditions or impairments (such as intellectual disability, blindness, deafness, and other communication issues) are simply missing from research and from policy and practice decisions (see for example Rivas, et al., 2021 for a detailed discussion of this).

Attributes	Cultural Competence	Cultural Humility
View of culture	- Group traits, - Group label associates group with a list of traditional traits and practices, - De-contextualised	- Unique to individuals, - Originates from multiple contributions from different sources, - Can be fluid and change based on context
Culture definition	Minorities of ethnic and racial groups	Different combinations of ethnicity, race, age, income, education, sexual orientation, class, abilities, faith and more
Traditions	Immigrants and minorities follow traditions	Everyone follows traditions
Context	Majority is the normal; other cultures are the different ones	Power differences exist and must be recognised and minimised
Results	Promotion of stereotyping	Promotion of respect
Focus	Differences based on group identity and group boundaries	Individual focus not only of the other but also of the self
Process	A defined course or curriculum to highlight differences	An ongoing life process Making bias explicit
Endpoint	Competence/expertise	Flexibility/humility

Table 1. Difference between cultural competence and cultural humility. Source: Yeager and Bauer-Wu, 2013

In comparison to cultural competence, as mentioned in the previous section, cultural humility is a process of reflection to gain a deeper understanding of cultural differences to improve the way various groups are treated and researched (Yeager and Bauer-Wu, 2013). This leads to competencies in the sense that competence is generally understood, as the ability to do things well, rather than in the restricted use of 'cultural competence' which is rather the ability to know about the 'other'. Cultural humility does not focus on cultural competency or confidence and recognises that the more you are exposed to cultures different from your own, the more you learn about yourself - that is where humility comes in (Yeager and Bauer-Wu, 2013). Humility requires courage and flexibility. The strengths and challenges of individuals and groups are explored as well as the advantages and privileges of a certain group membership and their influence on other groups. When used by the researcher, this process of reflection includes the unpeeling of the layers that make up a person and incorporates an examination of personal, professional, and research values that may guide the researcher's actions (FISA Foundation, 2021). (For more see Box 1 below).

Box 1: The distinction between cultural competence and cultural humility

The distinction between cultural competence and cultural humility may also be understood in terms of epistemic justice. Fricker describes two categories of epistemic injustice, namely testimonial and hermeneutical. With testimonial injustice, the provider of knowledge is deemed to lack credibility, because of prejudices and pre-judgments regarding their social identity (Beach et al., 2021 provide examples). Cultural humility pushes against this, aiming to reduce power differences, whereas cultural competence assumes the 'other' needs to be understood only so that they can be persuaded to adopt the ways recommended by more knowing (and more powerful) health or social care worker. Hermeneutical injustice occurs when people are decentred by society so that their voices are not represented in the production of knowledge and social meanings. Hermeneutics refers to the interpretation of knowledge; if people are not involved in its production, their experiences and the concepts related to these will not be represented or recognised within normal discourses. This prevents decentred people from interpreting or making sense of their own experiences within social contexts, and people at the centre from understanding them or considering them credible producers of knowledge. Foucault coined the term "power/knowledge" to emphasise the co-dependence of these concepts. He described the subjugation of, exclusion from or masking of particular forms of knowledge within dominant (more powerful) institutional activities and discourses because they are seen as naïve, inferior, or below the required level of scientific rigour (Foucault, 1980). Cultural competence may continue this subjugation of knowledge in its othering of the less powerful, and the attempt to bring their practices and beliefs in line with those of dominant discourses. Cultural humility promotes a respect for difference and the minimisation of power differentials. Fricker (2007) highlights the need to reflect on the situation in which epistemic injustice occurs, before tackling it, in line with cultural humility's emphasis on reflexivity.

Despite some advantages over cultural competence, cultural humility is inherently problematic because it implies privilege and reflects power dynamics that we do not wish to advocate for. This term was also objected to by our advisory board members as it can exacerbate power imbalance and inferiority. In taking their comments on board, some of the useful components of cultural humility were incorporated into the toolkit and inspired by competency and humility, this toolkit underlines the value of cultural integrity. The sections that follow illustrate how and why this worked.

Before we delve into the elements of cultural integrity, it is quite crucial to understand intersectionality theory (see Box 2 below), which should inform any undertaking of cultural integrity.

Box 2: Intersectionality theory

Intersectionality theory, which has roots in black feminist thought, says that inequities based on discrimination by race, gender, class, and sexuality should be considered in combination. This is because, as complex systems of oppression, they "mutually construct one another and work together to shape outcomes" (Cole, 2009, p. 179) rather than in isolation from each other. Intersections between the different discrimination axes more accurately represent the complexities of social experiences (Veenstra, 2011) than when people are classified according to one or two of these axes. More specifically, people's combined position within these multiple social categories of "identity, difference, and disadvantage" (Cole, 2009, p.171) will affect their experiences, and this effect will differ over time and place and in different institutional domains (Hankivsky & Cormier 2011). For example, being female in a workplace dominated by males will lead to different experiences to being female among predominantly female colleagues. Extending this point simplistically, being female and black will lead to different experiences again, which will be affected by whether colleagues are also black. This example shows how there is no pre-determined or hierarchical influence of different intersections and that intersections are not simply additive (Hankivsky et al., 2010). Intersectionality theory particularly foregrounds the experiences of being female and racially discriminated against though more recent developments include the foregrounding of other experiences instead such as being disabled.

An underlying ethos of CICADA was that policy and practice targeted at broad uni-dimensional categories of people will often fail because they do not consider people's multiple identities and within-group diversity (Hankivsky & Cormier 2011). Policy and practice responses that privilege only one or two sources of inequities and over-homogenised categorisations can reproduce power mechanisms between and also within groups (Hankivsky 2012). This leads to some voices being more silenced than others, and some groups of people being entirely absent from policy and practice (Rivas et al., 2021). In other words, it results in epistemic injustice. McCall (2005) suggests three ways of using categories in research, such as those used for different ethnicities, races, impairments, and genders:

• 'anti-categorical' – this shows how categories limit understanding through oversimplification. For example, placing someone in a particular gender category fails to recognise the many other significant identities they have in life, such as employee, young adult and so forth. The intersectional researcher uses multiple categories such as race, gender, age, to group participants and then critiques and rejects the separate use of different categories as problematic through evidence that considers how they intersect in multiple ways. This is theoretically focused and reminds us of the need to transcend categories and think more holistically.

• 'intra-categorical' – this involves exploring data within one intersection between categories (usually two or three, such as disability, ethnicity and citizenship state used in CICADA, but it can be more, such as black middle class heterosexual older women) to challenge homogeneity. This is more practice-focused than the anti-categorical and provides thick description for action. It is the traditional intersectional approach.

•'inter-categorical' – this compares groups or individuals with different identities or experiences (e.g., men in wheelchairs with East European men in wheelchairs). The comparisons will tend to draw out the similarities and differences across different axes of oppression.

In CICADA we used all three approaches at different times. In this way we did not consider culture as either fixed or uni-dimensional, which is critical to enabling true cultural integrity. We do not discuss intersectionality in greater detail here since we cannot do it justice in this short toolkit. However, researchers are advised to use intersectionality petals or power wheels, and a framework such as recommended in the bibliography, to aid an intersectional approach.

Section 3: Establishing cultural integrity in the CICADA research

In quantitative research, ensuring validity and reliability of findings is key. In the same way, in qualitative research, ensuring rigour and trustworthiness is essential to enabling the credible and meaningful application of findings. In both cases, cultural integrity is important. Cultural integrity cannot be achieved without adapting and applying research in a culturally meaningful way and with in-depth knowledge and understanding of the sociocultural and political dynamics of a particular research setting. This requires collaborative ways of working with people within the research setting and who are members of the groups to be researched. The following sections show how the cultural integrity of the CICADA study was maintained by giving due attention to the principles of: cultural relevance, contextuality, appropriateness, mutual respect, and flexibility.

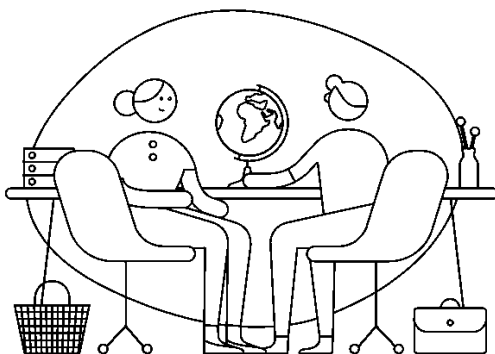### *Cultural relevance to the study's design*
Im et al (2004) contend that before commencing a study and beginning the data collection stage, the cultural relevance of the study being proposed should be evaluated. Cultural relevance refers to:

> *"whether the research question can serve a specific cultural group's issues and interests in improving their lives" (Im et al., 2004, p. 894).*

The cultural relevance of the CICADA study derives from its key aims to identify disabled minoritised ethnic groups' experiences of access to care in the UK, to improve understanding of the processes contributing to the patient issues and concerns identified, and to develop a basis upon which culturally relevant solutions can be found to help redress the concerns identified.

To ensure the cultural relevance of this study, two carefully considered strategies were used. First, the research proposal itself focussed on understanding the lived experience of different disabled minoritised ethnic groups. This knowledge also informed the decision to include questions that related specifically to cultural values and the influences (both positive and negative) these might have had on participants' knowledge, beliefs, values, and attitudes concerning healthcare support in the UK. Second, the participants' culture and context were placed at the centre of the inquiry. Accordingly, interview questions and the study's overall approach were carefully framed, with feedback from the lay researchers and advisory board members. During this stage, the research team engaged in a consultative process with a range of stakeholders, including researchers, patient-advisory group members, and community members, to determine appropriate terminology and language to use in the fieldwork.

The team recognised that race and ethnicity are complex and multifaceted concepts influenced by factors such as culture, time, language, and socio-economic status. Several commonly used

terms, such as 'ethnic minorities', 'ethnic minority groups', 'racialised groups', 'ethnic and religious groups', and 'minority ethnic group' were rejected (Selvarajah et al., 2020; Law Society of England and Wales, Feb 2023). After careful consideration and consultation, the team decided to use the term "minoritised ethnic groups" to draw attention to the de-centring and exclusion caused by structural discrimination. This term was also chosen to be more sensitive to the diversity within ethnic groups, in other words to recognise the intersection of ethnicity with other factors in minoritisation processes (Selvarajah et al., 2020; Law Society of England and Wales, Feb 2023). This enabled a culturally nuanced approach to be taken towards access and recruitment of participants. We also spent time deliberating on the terms used for the different minoritised ethnic groups included in the study, as shown in Box 2 below.

The team also considered how to reflect the conditions and impairments participants had. There were four considerations to be made. The first concerned the conditions and impairments to be included. The study's intersectional approach meant we wished to be as inclusive as possible. We therefore extended the definition of disability in Section 6(1) of the Equality Act 2010 (UK Government, 2010; our extension in bold text) to include people with a physical or mental impairment **or a health condition with no expected cure** that has or is likely to have a substantial and long-term (chronic) adverse effect on his or her ability to carry out normal day-to-day activities (such as getting dressed). Second, we included people with conditions and impairments that had not been formally diagnosed. This ensured cultural relevance since diagnostic processes often exclude people in 'grey zones' (Rivas et al., 2021) such as those with relapsing-remitting symptoms or with so called 'contested conditions' such as fibromyalgia, chronic fatigue syndrome and long Covid. A contested chronic condition is one with non-specific but distressing symptoms (such as pain, headache, nausea) and limited or controversial physical signs (such as lacking a definitive blood test), making it hard to diagnose (Dumit, 2006). Third, we called 'long term' anything lasting three months or more, to strike a balance between capturing new diagnoses or conditions and ensuring participants have had some experience of the pandemic in their ill health or disability state. The WHO defines a long-term condition as requiring ongoing management over years and the UK government specifies at least 12 months for disability (WHO, 2011). In making these decisions, we deliberated, for each decision we made, who might be left out of our study, and adjusted our approach accordingly to make it as inclusive as possible. At the same time we were reflective about who we had excluded, for example through most recruitment being via online approaches. These reflexive processes are in line with the restoration of epistemic justice across subjugated groups.

Furthermore, we combined chronic conditions with disabilities for an inclusive impact-led approach. This was of cultural relevance to our study because our focus was on the way activities of daily living were impacted during the pandemic. But this combination would be problematic in many studies (see for example Suleman et al., 2021), for example those that focus on identity considerations. Not everyone with a chronic illness is disabled by it and not everyone who is disabled is ill. The effect on personal and social identities of 'chronic illness' and 'disability' is often very different. So is the time in life at which the chronic illness or disability-related impairment occurs, for example someone born blind will have a different identity and probably also different coping strategies than someone who becomes blind in older age.

These decisions, resulting in a long list of included conditions and impairments meant we had to categorise then in ways that were manageable but had relevance in terms of structural barriers and within disability cultures, as shown in Box 3.

Box 3: Categories

Intersectionality considerations show that categories are inherently problematic as they over-homogenise the heterogenous. However, categories also serve a practical function in research, summarising participant groups in ways that funders can easily understand. Intersectional research therefore uses categories in order to unpack them. In CICADA, we categorised the disabling impacts of chronic conditions and impairments, rather than use the condition and impairment names themselves. For example, we considered mobility rather than a list of conditions that impact on this. This provoked discussion, for example an initial impact phrase 'needing dietary considerations' was considered to imply fasting and weight-loss diets rather than nutritional concerns and was discarded in favour of 'food-relevant'. We recommend considering conditions by impact rather than aetiology (cause) to understand the role of structural and environmental barriers, but we also note that category naming requires careful deliberation with public and advisory groups to choose the precise terms to use.

Similarly, we had to carefully consider how we defined some ethnic groupings in CICADA. Originally, we considered Arabs as an ethno-linguistic category, identifying as Arab people who spoke the Arabic language as their mother tongue and who were born in a country where Arabic is the common language. The recognised Arab World – The League of Arab States – was founded in 1945 with Arabic as the official language being the primary criterion, so this seemed a logical choice. The League consists of 22 countries: Algeria, Bahrain, the Comoros Islands, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Mauritania, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the United Arab Emirates, and Yemen. This differed from our other categories which were geographical, and we soon realised the benefits of subdividing it into two geographical subgroups – Middle Eastern Arabs and North African Arabs. These divisions are imperfect but recognise that Middle Eastern Arabs are more commonly considered 'white' in the UK and North African Arabs are more often a mixture of white Arabs and black Arabs. In our analyses we found they differed in several ways. Note that even this 'deconstruction' of Arab was imperfect, and researchers may wish to go further than we did. Our decision was practical and based on the amount of data collected.

As another categorisation decision made once our study had started, Eastern Europeans (with a focus on Polish people) were originally chosen for their recent migration histories and because of traditionally strong differences in attitudes in countries historically associated with Eastern versus Western Europe (Pew Research, 2018). These attitudes reflect their different political histories. However, our advisory panel considered it important to expand this category to include migrants from Central Europe. This is because they are often combined in policy, they are aligned with Eastern Europeans in their attitudes to many topics (Pew Research, 2018) and they are comparably discriminated against in the UK. However, when we tried to list the countries to be included in this expanded category, we found there was no single definition of Central European. Our final category encompassed countries in the geographic East that were part of the 20th century Soviet sphere of influence (Pew Research, 2018) and any other countries excepting Germany that are generally considered Central European. Thus, we included in this category: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Kosovo, Latvia, Lithuania, Montenegro, North Macedonia, Poland, Romania, Serbia, Slovakia, Slovenia, Abkhazia, Armenia, Artsakh, Azerbaijan, Belarus, Georgia, Moldova, Russia, South Ossetia, Transnistria, Ukraine.

We also considered Roma from Central and East European countries and we analysed them both as a part of this larger group and as the subgroup 'Roma'.

These examples show that even when categories are chosen to simplify research processes, and as the starting point for intersectional considerations, their use needs careful thought.

Contextuality: recruitment and ethics

Im et al emphasise that contextuality highlights the

> *"sensitivity to structural conditions that contribute to participants' responses and to the interpretations of situations informed by experiences, by validation of perceptions, and by a careful review of existing knowledge"* *(p. 894).*

Contextuality in our research was achieved by working with researchers who had the knowledge and understanding of the research setting to collect sensitive and accurate information.

Minoritised ethnic groups in the Global North countries are at higher risk of health disparities and are frequently not engaged in research. Published evidence suggests that multiple factors like stigma, lack of trust, differences in explanatory models, logistical issues and lack of culturally aware researchers act as barriers to ethnic minority recruitment into research (Farooqi et al., 2018). These all link back to epistemic injustice.

The CICADA researchers faced challenges in recruiting the participants due to power dynamics as participants may have their own expectations that can impact the study's progression. For instance, if someone wants to talk to an elderly adult of the Sikh faith, they should first contact them face-to-face. Contacting the older ones by e-mail in the first instance is disrespectful. The participants were recruited in a manner consistent with the cultural values they had. The cultural ethos of our participants was identified through pre-interview briefings and by holding meetings with gatekeepers and networks. See also Box 4 below.

Box 4: Another example of barriers in recruitment related to our undocumented participants

We approached them personally and provided them with a plain language statement explaining the objectives and methods of the study. Most undocumented migrants and asylum seekers were reluctant to participate, citing lack of time or lack of knowledge of the subject area as the main reasons. Others simply cancelled their scheduled interview at the very last moment. This can be attributed to their fear of losing anonymity. One of the researcher's strong networks with undocumented migrants enabled her to approach them in a respectful manner. Some were successfully recruited and shared photographs as well as doing interviews. Undocumented migrants placed their trust in her, and in the same way, the use of lay (community) co-researchers provided an extra distance that migrants felt gave them some protection.

The efficacy of research also depends on establishing connections with community leaders and groups that represent the population of interest (Karwalajtys et al., 2010). In this study, collaborative efforts with leaders helped in developing innovative and contextually appropriate strategies to access and recruit participants from diverse groups. For this study, the community leaders helped to increase the reach of the research and the research team benefitted from their cultural know-how. We did not simply ask the community leaders to recruit for us, instead we sought their guidance on how to do this ourselves and with our lay researchers. This difference is significant according to participants who commended us on our approach.

Another challenge faced by the researchers was that a few participants were reluctant to sign the consent form. However, lay researchers acted as cultural consultants to improve the relevance of outreach materials to ensure participants fully understood the intent of consent forms, as certain terms (such as "anonymity", "data protection") appeared alarming. During training, the lay researchers fed back to the research team that the language used in the information sheet and consent form could be viewed as overly complicated. Instead of sending the information sheet, the lay researchers used public engagement activities and community events to describe the research project though they also had to go through the forms in person with participants as required by ethics. This highlights that ethics review committees should adapt their processes so that they do not exclude under-represented groups (de Poli et al., in press). These challenges will likely mean that our quantitative data was less inclusive than our interview data because the information sheet and consent form were necessary reads in order to take part and were not explained by research staff in simpler terms. Telephone completion of surveys is one way to overcome this issue.

Overall, resistance among minoritised ethnic groups can be reduced with good publicity to raise the profile of the research, seeking guidance on language and cultural issues, and using community organisations to help overcome concerns and provide 'insider' information.

A few minoritised groups did not come forward to take part in the study due to the fear of others in the community finding out. This was highlighted by a researcher indicating the importance of demonstrating cultural integrity: She explained: *"I am working with young women who are recently migrated to the UK. I found a South Asian women with mental health conditions scared of being called 'mental'[pagal], so I think it is very crucial to think about the language we use."* In this instance, the researcher referred to the brain instead of mental health.

Once participants had been recruited, the research team used pre-interview meetings and screenings to build rapport and trust. They used a few questions to collect self-descriptions of ethnicity and health condition or impairment, with additional questions about reasonable adjustments related to disability and others linked to ethnicity to build a fuller picture of

participants, for example, own/parents' country of origin; religion/ faith; main/other spoken languages; main language spoken at home, and so on. Each participant was requested in advance to inform the team about holidays, celebrated or observed so that they could recognise these special days. All of these conversations also helped them get to know participants and build rapport.

Appropriateness: use of communication channels and approaches
Appropriateness in research refers to how well the study employs appropriate communication methods, conceptualisations, and translation procedures. It entails making certain that the research design, techniques, and communication tactics are appropriate for the participants' cultural and language contexts and other needs, and that any translations or adaptations are accurate, culturally sensitive, and respectful of disabilities and of local norms and values (Im et al., 2004, p. 89). Language, apart from being a tool or technical means for conveying concepts, is an essential part of conceptualisation, incorporating values and beliefs that carry accumulated and cultural, social, and political meanings that cannot be articulated through the process of translation (Temple & Edwards, 2002). Concepts do not move unproblematically across cultures and translation can be a source of threat to the accuracy of cross-cultural, cross-language qualitative research (see Box 5 below). It is also argued that epistemological difficulties in identifying similarities and differences can occur when different cultures and languages are used (Chen and Boore, 2010). Thus, as argued by Chen and Boore (2010), it is considered important for the researcher and translators to be fluent in both the source language and target language and to be knowledgeable about both cultures.
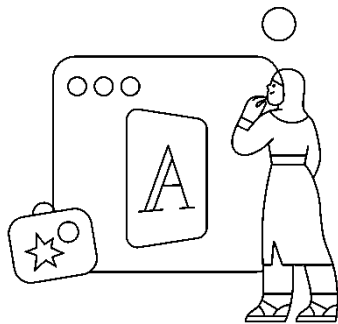
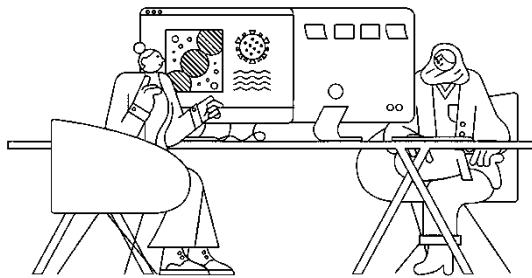> **Box 5: An example of cultural misunderstanding**
> They asked me, have you ever thought of killing yourself? I said, very clearly, I'm a Muslim, in my religion suicide is murder so for me it's not something I would ever contemplate. I said I would rather not be here. In my language, Urdu, we're a dramatic language, that doesn't mean I want to kill myself, it just means I don't want to be here. If it was somebody from my country they would know. But because of the metrics here, they had to take it very seriously. (P18, CICADA study, Arab/South Asian female)

In training sessions with lay researchers, the core research team used activities such as code-switching, role-plays and self-interviews to identify the language to use in topic guides for interviews. Lay researchers mentioned that they would like to speak in the participant's mother tongue where possible to overcome the challenges of having an additional interpreter and to capture experiences more accurately. However, ticking the language box isn't enough, a researcher needs to be culturally self-aware – not just of the communities' culture but their own too, and how that can impact the research. The team was also trained in using language appropriate for research about disabilities. In Appendix 2 we provide a list of currently preferred terms for different concepts, with the caveat that these are liable to change in a short space of time. This is because of the difficulty of encapsulating nuanced meaning accurately within one or two words, meaning that terms in use are deliberated on and rapidly problematised.

Some participants had communication difficulties that meant spoken and written language was not appropriate for them. One participant did an email interview because she could not speak easily. Our blind participants said they did not need Braille versions of documents because they had screen readers, but this may not always be the case for blind participants.

Mutual Respect

Mutual respect, which involves respecting the cultures of both researcher and participants alike, is achieved when researchers are cognizant of power differentials (i.e., between themselves and the research participants recruited to their studies); respect the views, beliefs, and values of research participants; and work to overcome traditional boundaries that separate researchers from participants (Im et al., 2004). For mutual respect to align with epistemic justice, it is necessary to appreciate that different people may have different understandings of respect. In Western healthcare, this is often treated as synonymous with giving others autonomy. However, in our work, respect involved treating others like an individual (being person-centred) and as an equal (or like you would wish to be treated), someone who matters (Beach et al., 2016; Beach et al., 2017), and listening to them. In keeping with this, as stated above, the ultimate objective was to retain mutual respect among participants, which guided the mindful recruitment approach and risk-mitigation strategies. Undocumented migrants found it challenging to participate in research and express their ideas. To address this issue, the team took initiatives to make participants feel safe and comfortable throughout the research process, such as providing flexible interview times and locations. Furthermore, the team were very conscious of respecting the privacy and anonymity of all participants, particularly undocumented migrants. To protect their anonymity, they employed acronyms on the consent form, voice-over to mask their voice or face identify, and had the researcher assist with payment voucher redemption as they did not want to use the vouchers or gift cards that are usually given in research. The lay researchers transcribed recorded interviews immediately and showed participants that they were deleting the audio recordings and that the central team would not have these. Where appropriate, researchers with disabilities disclosed their disability to participants to further develop mutual understanding and respect.

One of the reasons that minoritised groups might not come forward to take part in research is due to a lack of trust in researchers because of bad experiences. Several lay researchers highlighted the impact of prejudice, racism and discrimination and discussed how this impacted non-participation. The lay researchers, who were from the same ethnic groups as participants, felt that their ethnicity created a more conducive environment for building rapport with interviewees, thereby improving the quality of data collected. One researcher told us that rapport was created in part by adapting their language during the interviews to use terms like 'us' and 'we' to highlight their relevant lived experiences to their participants.

Another approach based on mutual respect is the strengths-based approach that underpinned the CICADA study. This is explained in more detail in Box 6.
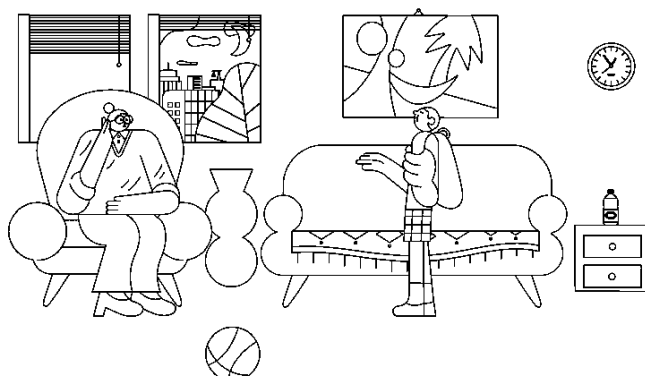
Box 6: Strengths/asset-based approaches

CICADA focuses on a strengths/asset-based approach, with a holistic emphasis on both personal strengths that people have at their disposal as well as social and community networks. We consider this more inclusive, with greater transformative potential, than more commonly used deficit-focused approaches to intervention development (Hombrados-Mendieta et al., 2019). Deficit models start from a position of ableism and white centrism, assuming failed interventions occur because the individual did not engage or try hard enough. This shows a lack of respect. A strengths-based model suggests structural barriers prevent this.

Our specific approach, sometimes termed Positive Deviance, looks for assets and strengths associated with positive outcomes in adversity. This moves away from the concept of 'resilience', which is often disliked by the groups our participants represented as it implies having to tolerate hardships (Sims-Schouten & Gilbert, 2022) rather than focusing on the cause of these. Our approach enabled us to consider areas of behaviour and community development needs, where further resources could develop or add to assets and strengths. We are mindful to ensure this does not reduce the need for state intervention (we have been careful not to deproblematise contexts or suggest improvements should be a community, rather than a policy, responsibility). A strengths-based approach does not try taking the focus away from the structural causes of inequalities (Foley & Schubert, 2013), but rather aims to empower communities and individuals in meaningful and sustainable ways. It is based on salutogenic theory (Antonovsky, 1996), which positions people as co-producers of health, rather than consumers of health services (Morgan & Ziglio, 2007).

Flexibility in interviews

Flexibility is described by Im et al. (2004, p. 894) as referring to whether "the researcher was flexible in the usage of languages and time for data collection." For this study, as described above, participants were invited to select the language in which they preferred their interviews to be conducted. Moreover, the interviews were conducted in a place that suited the participants and according to their own time and availability. Flexibility is also taken to mean whether the participants felt comfortable and were able to answer the question(s) put to them by the researcher. For this, all participants had the option of declining questions they felt unable to answer or uncomfortable about answering and the option to withdraw from the study. It was critical in this study to prioritise the well-being and agency of participants who had suffered trauma or marginalisation, such as undocumented migrants with disabilities. This increased the level of comfort and agency throughout the interview process. Significantly, no participants declined to answer any of the interview questions except around the visa status, and no one withdrew from the study. In addition, we offered flexibility in terms of changing the mode of the interview due to the participant's health conditions. For instance, a participant of South Asian heritage had speech issues. She initially preferred to have the interview over a phone call. The interview lasted for 11 minutes, and then the researcher had to make the decision to discontinue

the phone interview due to issues in understanding the participant. Instead, the researcher offered her an email option which was accepted and led to rich data. In another example, the researcher pre-briefed herself regarding the cultural background of an African male participant with dementia. Through email exchange and a pre-screening interview, the researcher became aware of their communication style. During the interview, the participant had difficulty remembering the questions and sounded frustrated. To ensure that the participant was able to fully engage in the interview, the researcher recognised the need for flexibility in the conversation. This flexibility allowed the participant to take breaks as needed and provide responses in a way that felt comfortable and accessible to them. The participant told the researcher that he enjoyed the conversation and felt respected, as currently his friends are frustrated by his health condition. The flexibility approach highlights the importance of considering the unique needs and cultural backgrounds of individuals from minoritised ethnic groups and who are disabled in research and other settings. By recognising and accommodating their needs, the researchers could promote greater agency and understanding for unheard voices.

In the survey, flexibility was also built in after piloting, on the advice of our public involvement team. We told participants in the introductory text that if they did not want to fill in the pages of questions, they could go to the end of the survey and just put some comments about their experiences in freetext boxes, that were accompanied by three simple prompts. Flexibility was also incorporated in the design or format and language of the questions (Box 7), and choice of options.

Box 7: An example of piloting comments that led to changes in survey questions

Q: Please specify the importance of up to five of your most significant worries over the past month by ticking one of the buttons for each item (where 1 is the least important and 5 the most important)
Reword for clarity.

Final 2 sliders re feeling lonely
Any reason why sliders are from very/more lonely to not at all/less lonely rather than other way around?
Better wording for option "I did not ask for support" yes/no
Clarity needed about meaning of answer – does it mean yes, I did not ask for support or no I did ask for support.

Section 3.3: Culturally nuanced participatory methods in workshops

The focus on Participatory Research (PR) methods is necessary to truly actualise the dual goals of PR: knowledge production and real-world action conducted in a democratic, collaborative manner. A deliberate choice of participatory research methods can help researchers more deeply engage stakeholders and communities at each step of the research process. Such engagement allows research to benefit from the collective wisdom of both researchers and communities which in turn creates more meaningful findings translated to action (Vaughn and Jacquez, 2020). Importantly to cultural integrity, it also enables recognition of diverse cultural values, traditions as well as customs, fostering a sense of belonging and intercultural understanding. It also fuels creativity as well as innovation. Researchers across many disciplines have a long history of working with non-academic stakeholders in PR, but the nuts-and-bolts narrative of *how* to do this work is frequently nominal (Vaughn and Jacquez, 2020). Recent research (Bröer et al., 2023) has been published on involving adolescents in Europe in the formulation of policy recommendations for weight and obesity prevention. The Confronting Obesity: Co-creating Policy with Youth (CO-CREATE) initiative, for example, has developed an approach for doing this (Bröer et al., 2023). As part of this strategy, the CO-CREATE team invited adolescents to share their ideas and refine them collectively in workshops utilising various tools and methodologies. This strategy, according to the researchers, fostered collaborative engagement and achieved a balance between offering activities and sharing knowledge, while also encouraging young people to think and act differently.

Similarly, the CICADA team developed a blueprint for culturally sensitive participatory research and co-create workshops. Research workshops with 104 interviewees in May and September 2022 explored changing experiences. In-person and online, these employed participatory tools such as patient journey mapping and structured brainstorming (collaborative problem-solving approach) (Lewrick et al., 2020). These tools were chosen because of the way they centralise the lived experience and the participants as the experts which can help overcome inherent power-imbalances and issues of accessibility. The defined structure afforded by these methods is also helpful to explore experiences and ideas in a gradual structured manner, developing consensus in an equitable fashion. Like interviews, the use of the elements of cultural integrity (such as language, flexibility and mutual respect) in workshops fostered cross-cultural understanding and active engagement Our patient journey map explored the healthcare experience in small groups with a community researcher as facilitator (groups chose primary or secondary care to focus on). They first discussed and recorded experiences throughout their 'journey' from booking to follow-up. They then collectively agreed how their thoughts and emotions shifted throughout this process, helping us to identify where the collectively agreed intervention points may be for improvement. In the final step the group went through the journey map collectively making suggestions to improve each step. In the structured brainstorming activity, we were looking at health and social care more widely. Each person in the group thought of three ideas they recommended for change (from very small such as local art classes to improve mental health through to larger such as supporting migrant women in abusive relationships to continue their visa applications separately from their partner). These were written on post-it notes by each person then added to a central flip chart. The group then went through the ideas and grouped them into themes collectively. Finally, each member was given four sticky dots and they were able to vote for the themes and the ideas they thought were the most important to address. The top results for each table were then presented back to the groups and discussed further. These tools were easily translated to an online format to increase accessibility of the workshops to those unable to join in person.
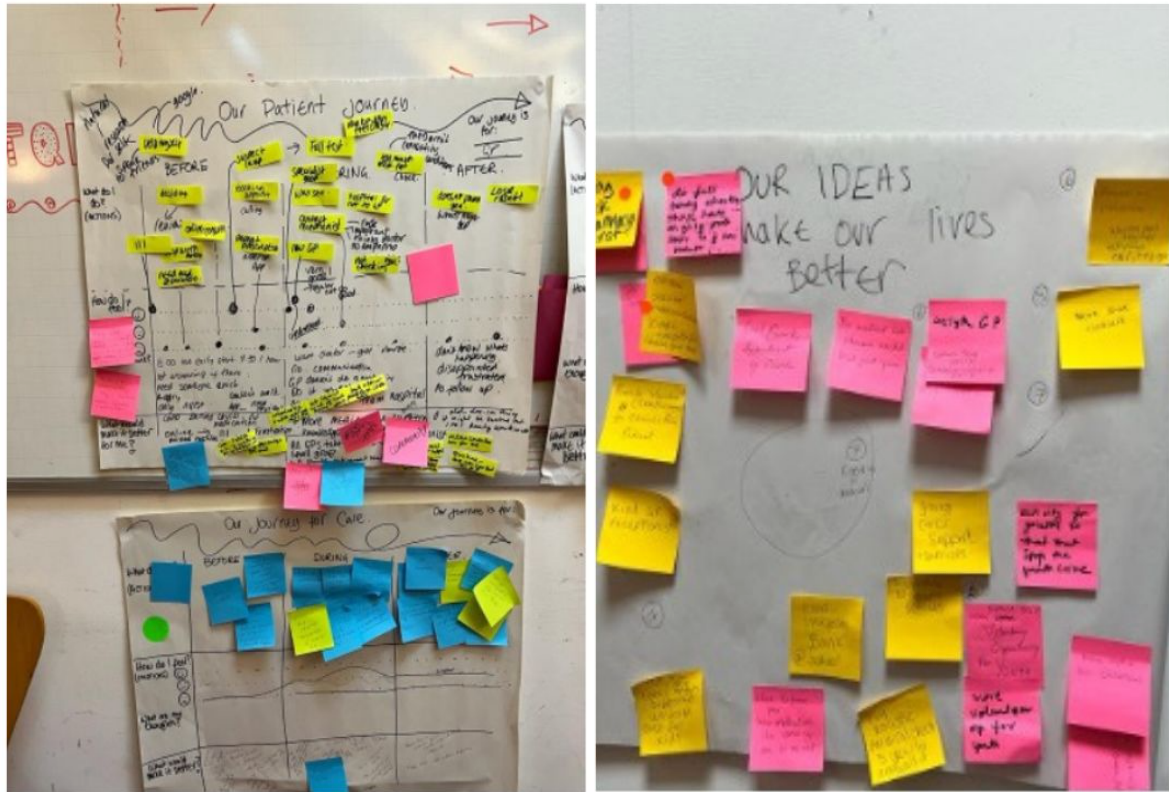
Figure 4 Research Workshop at Bromley By Bow in London

In addition to research workshops, two co-create workshops were also organised in 2022 with research participants, policymakers, health professionals, NGOs, and patient advisory group members. The co-create workshops were conceptualised and led by a designer researcher who was also a specialist lecturer in Patient Public Involvement. In the workshops we found mutual respect was greatly aided by the involvement of members of our public involvement group acting as facilitators. Their discussion of their own experiences with disability during the pandemic encouraged participants to contribute.

Figure 5 Co-Create Workshop at UCL in London

Overall, in both types of workshops, the activities gave participants a voice and agency in order to better place culture, particularly digital culture. We also incorporated the elements of mutual respect in workshops as described in the previous section. The research team also used presentations and online mind maps to help participants understand the aims and format of the workshop. During the workshops, participants freely expressed their voices and shared their personal experiences. Overall, participants in the study claimed that their cultures, views, experiences, and recommendations were listened to carefully by researchers and heard, and their participation in various research activities was valued by the team.

Section 3.4: Cultural integrity in theatre knowledge exchange event

Figure 6 Theatre Knowledge Exchange Event at UCL Bloomsbury Theatre in London

CICADA Stories, performed at the Bloomsbury Theatre in September 2022, was a successful innovative approach to broaden dissemination, with dramatisation based on our data, poetry,

dance, and Q & A. Five story composites were dramatised. The research team used cultural integrity by preserving the cultural values and language in writing theatre script using interview data verbatim to authentically dramatise participants' stories. The scriptwriter made sure the cultural values of the participants' stories were respected and valued. The research team shared the final scripts with the Patient Advisory Group Members and sought their feedback. The entire theatre team made sure the cultural values of the participants were respected and reflected in words, phrases, dress and props in the theatre dramatisation. After the performance, several members of the audience praised the use of dramatisation as thought-provoking and authentic. They also described how the performance deepened their knowledge and comprehension of how to utilise art to portray stories, as well as how it affected their perceptions of the stories that were told (see Box 8).

Box 8: Our audience members shared their views

"Thank you for bringing up the stigma surrounding diabetes in South Asians. The stigma can be reduced via awareness. Events like the ones you are running could do that and therefore should be supported."

"It [theatre] communicates in a diverse and exciting language."

Why cultural integrity? Our final remarks…
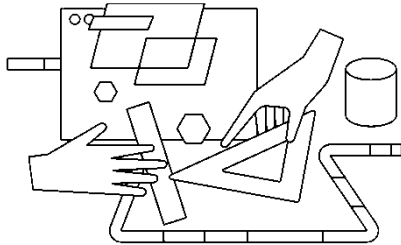
The key recommendation of this toolkit is that cultural integrity should be considered more carefully in the commissioning, design, undertaking and evaluation of research data and its collection. As extant research has shown, minoritised groups still face inequalities, discrimination and marginalisation in their healthcare and access to wider society, which have significantly impacted their mental and physical health. We need to be more attentive to the practices we utilise in data collection to avoid exacerbating perceptions of discrimination and distrust if we are to ensure minoritised groups are more successfully represented in research.

Appendix 1: Practical recommendations

In addition to the considerations so far discussed in this toolkit, we have some further practical recommendations to ensure cultural integrity, as follows.

Contracts

1. Researchers and universities should prioritise simplifying the language used in recruitment and payment contracts, particularly when working with lay researchers and patient advisory groups. This could be accomplished for example through the development of a jargon-proof booklet written collaboratively by researchers and administrative staff from human resource or finance departments.
2. Principal investigators should consider involving project managers or research team members with lived experience to work with lay researchers and patient advisory groups to ensure that payment methods and financial practices are clearly understood and that they are appropriate. This could help to address any misunderstandings or confusion that may arise due to differences in financial cultures between universities, research organisations and community members.
3. It is recommended that universities establish clear policies and accessible procedures for the Right To Work Checks, particularly for people on a British passport or with accessible needs. This should not for example involve burdensome in-person meetings when the pandemic has shown these can be conducted remotely.

Payment practices

1. Researchers should use transparent payment practices by providing clear information, including timelines of payment methods. This is particularly important for individuals who do not have regular sources of income. Researchers should make sure they speak to individuals in-person or online.
2. It is also crucial to acknowledge that individuals may have different circumstances or cultural expectations that can influence their ability or willingness to accept payment or reimbursement through conventional methods. Alternative payment methods thus should be considered such as cash, if necessary, in order to value their participation.

Best practices for collaborating with lay researchers

1. It is recommended to provide comprehensive training on ethical considerations and practices in research, including appropriate ways to obtain informed consent and manage potential risks to participants.
2. The ethical challenges need to be a focus, and this should be a dialogue, so that the research team can understand what is needed on the ground. This dialogic process needs to be accepted by research ethics committees as best practice.
3. It is important to provide clear guidance on the roles and responsibilities of lay researchers, including their obligations to ensure confidentiality and protect the rights

of study participants. This could include regular meetings with project managers or research team members to discuss any concerns or issues that arise during the study.

4. Buddying a lay researcher in their first interview should help to ensure the integrity of the research process.

5. Ensuring that data are handled securely and transferred safely is an important aspect of ethical research practice. However, the policy and guidelines for data transfer vary from institution to institution. We recommend a simple handout with a data-flow flowchart and transfer options listed would be helpful for all stakeholders involved in the research project to ensure that the data is handled and transferred securely. The handout should be designed in a clear and concise format, and the language used should be simple and easy to understand. It should be easily accessible to all stakeholders and shared with them at the earliest possible stage of the research project. This could involve providing training and support to ensure that all users are comfortable using the data flowchart and transfer options handout. It is also pertinent to ensure that the handout is regularly updated and reviewed to ensure that it is in line with the latest data protection regulations and guidelines. Lastly, we also recommended to check data transfer tools with the IT team at the start of the project as Teams is not allowed to share data or receive data.

Best practice for partnerships and participatory working

1. Be transparent about partnership goals and choose an appropriate approach to match those goals.
2. Clearly describe roles and expectations and select partners who can commit to them.
- Jointly create processes for effective communication and power-sharing.
- Individually assess accommodation needs, discuss as a group, and re-assess regularly.
- Discuss and address competing accommodations.
- Consider using a range of meeting formats to make sure all partners can engage (in-person, teleconference, video conference, text-based chat).
- Present concepts and information using accessible language and formats so partners can make truly informed decisions.
- Allow adequate time and space for partners to process information.
- In written communication including emails, provide a structured format to improve clarity (e.g. Purpose, Actions, Deadline, Compensation, Details).
- Provide materials in advance of meetings.
- Actively listen to community partners' views and demonstrate that you value their expertise.
- Follow through and implement the group's decisions, and regularly report back on progress.
- Celebrate success.
3. Use best practice for encouraging co-authorship of articles and material. The AASPIRE study has provided a model of good practice in community co-authorship which included the following:
    - Community partners given annotated versions of manuscripts to review, with comments explaining technical sections in lay language,
    - Group or individual meetings to discuss the appropriateness of written information,
    - Co-created materials.
4. In the PRESENT project (Rivas et al, 2019), community members developed a poster and infographic to aid their own understanding of the study.

Best practice for encouraging participation.

1. Multiple formats of all communications e.g., newsletters, correspondence.
2. If using participatory methods, multiple formats for engagement e.g. a choice of collage, paint, plasticine, photographs etc.
3. Ample warning of changes to plans.
4. Individualised alerts and reminders.
5. Opportunities to review materials in advance.
6. Pre-meetings, one-on-one support during meetings.
7. Structured meetings with clear agendas and transitions.
8. Sensory supports (e.g. natural lighting).
9. Interpretation.
10. Ice-breaking exercises.
11. Checking back at the end of meetings what went well and what needed to change.
12. Consent forms can be made simple and concrete, with images, and text-to-speech or ASL versions of online consent forms, and with digital signing or verbal consent (recorded, but not on the same audio as any interview).
13. The AASPIRE study found that exclusively text-based, online surveys underrepresented those with low educational attainment (Nicolaidis et al., 2013), who responded better to in-person options or adding read-aloud features for computer-based surveys (Nicolaidis et al., 2016; Nicolaidis, Raymaker, Ashkenazy, et al., 2015).
14. In CICADA we found that text-based online work excluded older people from some minoritised ethnic groups and we also suspected that some people who were particularly disabled by the CICADA survey format as a result of their impairments were also excluded, for example people who found it hard to type or got exhausted by the survey's length.
15. Piloting and adapting survey questions should be a participatory process. For example in the AASPIRE study, graphics were added to Likert-type scales, to help comprehension (Nicolaidis, Raymaker, Katz, et al., 2015).
16. Neurodivergent adults may be challenged by open-ended questions (which need to be made more concrete) or the processing of questions in real time.
17. For qualitative interviews, offer both synchronous and asynchronous modes of participation and allow both oral and written communication. Examples include email (asynchronous, written), telephone or in-person (synchronous oral), and instant messenger chat (synchronous, written).
18. As much as possible, use concrete questions, asking for stories about specific experiences rather than answers to questions about abstract concepts. Use probes to help anchor events and further elaborate on stories or concepts.

Appendix 2 Preferred terms and formats relating to disability, race and ethnicity at the time of writing this toolkit

Language is ever-evolving, and different terms used in research on under-represented groups will become current for a while, then become misused or issues in their implications will be realised and debated, and new terms will become current. This raises two points, first that to be sure of the best terminology to use, a research team should consult experts in the field at the conception of a study and at points throughout. Second, that the terms used with activist groups and academics may not always resonate with participants themselves when they are members of the public. We discovered in CICADA that some participants were confused by terms we used on the recommendation of our advisory group and wished to revert to terms that we sometimes found problematic, such as BAME. Other participants however were well versed in disability theory, or race arguments. In accordance with the principal of mutual respect, the solution to these dilemmas is to ask the participant what terms they understand, and to respect these.

At the time of writing, some terms could be marked out as potentially problematic, as listed below. See the main toolkit text for a discussion of 'ethnic minorities' and related terms:

1. Do not say 'vulnerable people' – people are not intrinsically vulnerable but made vulnerable by structural and environmental barriers and discrimination.
2. Do not say 'marginalised' – the preferred term is de-centred since it conveys the idea that the person or group can be re-centred.
3. Use 'underrepresented' rather than 'hard to reach' or even 'seldom heard' when talking about services. Use 'disadvantaged' with care; this can be due to a variety of changeable circumstances such as poverty or caring responsibilities, and should not be used to refer to disability, race or ethnicity. None of these terms should be used to refer directly to an individual though they can be described as coming from a disadvantaged background.
4. Avoid saying 'this broad ethnic group' and use the format 'this ethnic group as a whole'.
5. Use the term 'people with a mixed ethnic background' or 'people from the mixed ethnic group' and not 'mixed race people'.
6. Race is a protected characteristic under the Equality Act 2010. Ethnicity and race should not be used interchangeably.
7. Capitalise ethnic groups derived from a place name (e.g. 'West Indian', 'Chinese', 'Asian'). Never use ethnicities as nouns, instead refer to, for instance, 'black people', 'Chinese women'.
8. There is a distinction between, for instance, 'Indian people' (a nationality) and 'people of Indian heritage' (who may be British or any other nationality). Use 'heritage' and not 'ancestry' or 'extraction'. Where there might be confusion between ethnicity as an identity and a nationality, write for example 'people from the Indian ethnic group', not 'Indian people/.
9. Do not say 'the disabled', 'people with disabilities' or 'handicapped' – rather say disabled people or use person first terminology (e.g. person with diabetes rather than diabetic), showing people have had disability done to them, rather than it being their identity label. In the same spirit, disabled people have 'impairments', not 'disabilities'. There are many types of impairments, so when referring to a subgroup be specific. There are exceptions

to person first terminology such as autistic rather than person with autism, and blind/sight impaired or deaf.

10. 'Intellectual disabilities' is preferred to 'Specific learning disabilities' but both are better referred to as intellectual impairments. 'Specific learning difficulties' may be used to refer to conditions such as autism, dyslexia and dyspraxia, and as such, are categorised as a disability for statistical purposes in policy and practice, and therefore also in CICADA, though many neurodivergent people disagree with this.

11. People experience 'mental health conditions' or 'poor mental health' rather than 'mental health problems'. The term 'mental health issues' should be used for mental health as a concept, not for one person'a state of health. Avoid 'the mentally ill', 'victim' or 'sufferer'. Time to Change has good practice guidance on reporting mental health issues at https://www.time-to-change.org.uk/media-centre/responsible-reporting.

12. The phrase 'commit suicide' was used when suicide was treated as a crime, and the correct term now is 'taking one's life' or 'dying by suicide'. Do not refer to suicide attempts as 'successful' or 'unsuccessful'. Where suicide is discussed, it is good practice to include a statement including contact details for a charity such as The Samaritans, which has guidelines on good practice for reporting on suicide at https://www.samaritans.org/about-samaritans/media-guidelines/media-guidelines-reporting-suicide/

13. An individual cannot be 'diverse'. Similarly a person cannot be neurodiverse. Diversity means that the members of a group vary among themselves, so the population as a whole is neurodiverse. Saying a group is diverse has no meaning unless the axes of diversity are specified. Thus 'racially diverse' and 'diverse' groups are not synonymous though often treated as if they are. The label "neurodivergent" was developed by the autistic movement and describes individuals who think, behave, and learn differently to what is considered typical (neurotypical) in society. It thus simply describes a difference in processing the world around us.

14. It is often considered more appropriotiate to signify religions and religious denominations, as adjectives and nouns, using initial capitals, such as: 'Christian men', Christians, 'Hindu women', Hindus. Several Jewish participants in CICADA referred to being Jewish as a race, and therefore did not self-identify as belonging to the white British group. This means that using 'Jews' as a noun is inappropriate in the same away as this format should not be used for race or ethnic groups. Instead, a specific term, such as 'Jewish people' should be used, with clarity as to whether this refers to race or religion.

15. The Brandt Line was proposed by West German former Chancellor Willy Brandt in the 1980s to geographically split the world into relatively richer and poorer nations at a latitude of approximately 30° North. The original idea was that richer countries are mostly in the Northern Hemisphere, with the exception of Australia and New Zealand and poorer countries are mostly in tropical regions and in the Southern Hemisphere. However this division is not clear cut and the terms Global South and Global North are not always helpful, though often used. The terms 'developing countries', 'developed world' and 'Third World' should be avoided.

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Suggestions on further readings on intersectionality theory

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