

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



1. Project overview, methods and about this toolkit

Many people with chronic conditions and disabilities combined with minoritised ethnic identities faced considerable obstacles before the pandemic in accessing or utilising networks of support, health and social care (Di Gessa et al., 2022; Germain and Yong, 2020; Rivas et al., 2022). As such, they belonged to what is often called a particularly underserved group. During the pandemic, some issues increased disproportionately and widened the inequalities gap between disabled people from minoritised ethnic groups and those without disabilities from the native white British population (Germain and Yong, 2020).

The NIHR-funded CICADA study (NIHR132914) took an intersectional approach to understand the pandemic experiences of disabled people from minoritised ethnic groups 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 (Metcalf and Urwick, 1942), disabled people from minoritised ethnic groups so they had an active and transformative voice in our processes, data and outputs. The study had an asset- and strengths-based focus, 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.

1.1 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, and native white British comparators. The specific minoritised ethnic groups chosen were intended to reflect recent migration waves and those at most risk from COVID-19 interviewed. Some 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 health 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 co-create workshops, with 104 attending to explore changes five months after interviews and 35 of these also taking part approximately 10 months after the interviews. Co-creation in the way we use it here refers to: *“the collaborative generation of knowledge by academics working alongside stakeholders from other sectors”* (Robert et al., 2022, p.15). Following these, mixed stakeholder co-design workshops were attended by health professionals, community leaders, charity leads and members of the public (a total of 16 people) to co-design rapid-impact solutions to issues. We asked four key informants: a policymaker, GP, and community leaders for recommendations on how to put these into immediate practice.

1.2 About this toolkit

This toolkit documents our ways of working on CICADA to enable a discussion of best practices and provide researchers with a framework for collecting data 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., 2022).

Step One: The research team discussed the lessons learned when working with minoritised ethnic groups 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. Brief examples are presented to substantiate some suggestions.

Step Three: The advisory board members (including members of the Patient Advisory Group) were asked to give feedback on the toolkit, and to evaluate whether the information represented their own experiences as patients or other stakeholders in the research topics.

What it covers?

The toolkit discusses both theoretical and practical aspects of inclusive research (Figure 2 below) and cultural considerations. We conceptualise the term culture in an inclusive way to encompass the values, beliefs, customs, and social behaviour of all groups, including people who are linked by disability, not just those distinguished by ethnicity or place of origin. When we use culture, we mean:

“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).

Everyone has or belongs to a culture or cultures, and culture informs people’s different ways of living and experiences of daily life. The constitutive elements of culture are dynamic and evolve with time due to changes in external historical, economic, ecological, and political contexts. This means there are often differences and sometimes also tensions between generations, socioeconomic groups, genders and so forth that exist within and cut across commonly used categories of people such as ethnic or disability groups. Many of these equate with what are referred to as social determinants of health and relate to what is ‘done to’ particular groups of people by discriminatory external structural and environmental factors. This is the basis of intersectionality theory (see Box 1) which underpins this toolkit. As Chiarenza (2012) says, rather than focusing on traditional cultural groups:

“inequalities in health and in access to health care can be best understood in terms of the position of members of [those] different groups within social structures or hierarchies of rights” (Chiarenza, 2012, p.68).



Figure 3: What the toolkit covers.

Box 1: Intersectionality theory

Intersectionality theory, which has roots in black feminism, emphasises the importance of considering inequities based on discrimination by race, gender, class, and sexuality working in combination. Intersections between the different discrimination axes – which are not simply additive, and which have different impacts in different contexts - more accurately represent the complexities of social experiences than classifications of people according to one or two of these axes. The 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.

Failure to consider intersectionalities 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); this results in epistemic injustice (the inequitable exclusion of some sources of knowledge). McCall (2005) suggests three ways of challenging the unidimensional categories used in research:

- ‘anti-categorical’: In CICADA we grouped participants by ethnicity and disability categories and then critiques these as problematic. We underwent this critical process with our PAG and community co-researchers when considering our community of focus, during recruitment and analysis.
- ‘inter-categorical’ – As an example of this, in CICADA we fixed disability in analyses and considered different experiences depending on ethnicity. We then fixed ethnicity and considered different experiences depending on disability. This is why we included white and non-disabled comparators.

In CICADA by using all three approaches at different times, we did not consider culture as either fixed or uni-dimensional, which is critical to enabling true cultural integrity, the approach we advocate in this toolkit. Our approach was enabled by our purposive quota sampling and large dataset. 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.

Intersecting factors may have different effects at different times and in different environments or ‘ecosystems’. While we do not delve into the related systems theory here, the interested reader may wish to inspect socio-ecological frameworks (Marsiglia and Booth, 2015; Domenech Rodríguez and Bernal, 2012), such as those outlined by Bronfenbrenner (1979, 1986) CICADA drew on this in considering which stakeholders to include as participants in the study, aiming for representatives from all levels in our co-design and co-creation work.

The next sections of the toolkit consider these concepts in terms of different understandings of cultural sensitivity and how these are used in the study.

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



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

2.1 Cultural competency

Cultural competency has been promulgated within health and social care and associated research for decades, both as something to practice and as something to incorporate into research outputs. More recently it has assumed a place within more participatory research and patient and public involvement work. Its roots can be traced back to the human and civil rights movements of the 1960s and 1970s (Chiarenza, 2012). According to Cross et al. (1989), it is:

“a set of congruent behaviours, attitudes, and policies that come together in a system or agency or among professionals and enables the system, agency, or professionals to work effectively in cross-cultural situations” (Cross et al., 1989, p.13).

This Western world concept tends to translate in practice into approaches that increase awareness of the so-called typical characteristics of minority cultures so that research and service delivery can target them specifically. Its claim is that by responding to minority culture characteristics and needs, cultural competency should:

- Improve cross-cultural communication,
- Reduce disparities in research and care access and quality,
- Prevent cultural discrimination by professionals in health and social care and researchers.

Some people differentiate between cultural competency as an organisational framework, and the development of cultural awareness, sensitivity or knowledge as the specific process within this. Procedurally, researchers and practitioners, such as those in health and social care, learn about the norms, customs and beliefs of other groups (Shepherd et al., 2019). This is intended to sensitise them to the particular needs and what are often termed “vulnerabilities” (but see our section on problematic terms later in this toolkit) of these other groups (Agaronnik et al., 2019; Hopf et al., 2021; Yeager and Bauer-Wu, 2013). The logical conclusion of cultural awareness within a cultural competency framework is that the greater the researcher or practitioner’s knowledge of these norms and customs, the greater their cultural competency and the better their research and practice in health and social care for or with other cultural groups. As such they are seen as experts in the research and care of these groups.

This is flawed logic. First, cultural competency can be seen as discriminatory, as it ‘others’ the different cultural groups (Yeager and Bauer-Wu, 2013). Second, by doing so, the focus is on the ‘other’ as problematic, not on the mainstream (usually White British or American) group as unfairly advantaged. This tends to preclude the need for self-awareness or reflection of their own culture by the practitioner or researcher (Agaronnik et al., 2019; Yeager and Bauer-Wu, 2013). In the experience of the CICADA team, some increased self-awareness does

develop organically in those trained in cultural competency, but it is not a requisite. Rather, as Yeager and Bauer-Wu (2013) posit:

“Cultural competency is focused on the provider being confident and comfortable when interacting with the ‘other’” (Yeager and Bauer-Wu, 2013, p.252).

Third, without reflection, existing staff biases may preclude their putting into practice what they have learned. This is not necessarily because they wish to discriminate but rather because they will be drawing on ingrained tacit knowledge – the knowledge they have developed through practice – rather than the factual knowledge provided in cultural competency training (Yeager and Bauer-Wu, 2013). Ironically some of the CICADA team found, when undertaking a previous diabetes study, that the development of tacit knowledge of culture in a diverse area of London failed to give healthcare practitioners confidence in their cultural competencies even though in interviews they showed cultural sensitivity (Goff et al., 2020). This reflects the idea that the knowledge change at the end of cultural competency training is effectively the endpoint of learning (Prasad et al., 2016).

Fourth, since culture is not fixed, but changes with external influences, the cultural competency model may be seen as naïve – knowledge that is developed through training may become quickly outdated.

The fifth problem is related to the fourth and concerns the issue of essentialising and homogenising stereotyping. This is the point made by Chiarenza (2012) above. Wootton’s (2021) study, in which 60 Polish migrants to the UK were interviewed, provides an example of the issues, that would be hard to predict. Some of Wootton’s migrants had come fairly recently for largely economic reasons and others had come following World War II as asylum seekers. She found the two groups differed culturally in many important ways that cultural competency training would not consider, but that the CICADA lead, who is half-East European, has lived experience of, as an ‘insider’. In particular, those coming as a result of the war nostalgically replicated the social structures ‘back home’, acquiring land and property for

community activities. More recent migrants, in contrast, initially eschewed traditions of home, which reminded them of

hardship, but then resumed them to recover their

identities (Wootton, 2021). This study shows that

acculturation, or adaption to a new culture, which is

excluded from homogenising approaches, is not a

linear, unidirectional process. Nor is it necessarily

positive (e.g., Gil et al., 2000). Acculturation may

be considered as the relative inclination towards

the new host culture versus the culture of the

place of origin (Oetting & Beauvais, 1990–

1991). The greater this is, the more assimilated

a person is. Notably, people may exhibit

different levels of acculturation within different

settings, for example using code-switching and

drawing selectively from a bicultural/bilingual

identity. We encountered this in our CICADA

interviews, which necessitated a researcher

who could respond flexibly to this.



Sixth, culture in cultural competency training is typically focuses on race and ethnicity (Kumaş-Tan et al., 2007), when, as we have argued above, there are many other cultures such as those built around gender, socioeconomic status, disability, health condition, geographic location, country of origin, or sexual preference.

Seventh, cultural competency programmes are often designed by White middle-class staff and may perpetuate their standpoints of other groups' cultural values, beliefs and norms. In the same way, researchers, even when meaning to do well, cannot escape their own biases. Madison (1992) argues that:

“the cultural biases inherent in how middle-class white researchers interpret the experiences of low-income minorities may lead to erroneous assumptions and faulty propositions concerning causal relationships, to invalid social theory, and consequently to invalid program theory” (Madison, 1992, p. 38).

Similarly, and our eighth point, the often implicit norm within health and social care is Whiteness, an issue we discuss below in relation to cultural adaptations and tailoring (Yeager and Bauer-Wu, 2013). Ebony Caldwell, a disabled psychiatrist, also highlights ableist attitudes. She describes the significance of centring the experiences and perspectives of disabled people in mental health care, including the consideration of intersecting identities (Caldwell, 2021). Ethnocentric, disablist and ableist practices act as blind spots that mean some minoritised ethnic groups and conditions or impairments (such as intellectual impairment, 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).

Ninth, knowledge in cultural competency training is often developed at the surface level. Resnicow and colleagues (2000) outlined how aspects of deep structure differ from those of surface structure. The former include language, music, foods, clothing, and the latter involve more deeply ingrained social, historical, environmental, and psychological factors.

Some of these nine issues relate to the practice of cultural competency rather than being inherent to the approach. One way to mitigate these is for a research study or practitioner team to always include, as a minimum, a lead from each cultural group at the centre of a study or local practice, no matter what the perceived knowledge and experience of any White lead. However, this does not solve the core problems of cultural competency. Another approach that has been suggested is to use participatory research to develop cultural adaptations using a cultural competency lens.

“Culturally adapted” interventions often tweak both content and delivery of the intervention. Soto and colleagues (2018) found that to be more effective than non-adapted interventions, a culturally adapted one had to explicitly adopt a patient-centred approach. This was more critical than using specific treatment modalities, matching the professional and patient by ethnicity, or the severity of the condition being treated. “Culturally informed” interventions may involve adding content to an existing intervention that is relevant to the target cultural group rather than tweaking the whole, for example specific modules of an education intervention (Falicov, 2009). ‘Cultural attunement’ (Falicov, 2009) involves adding to interventions to boost engagement and retention of particular groups and is focused on

delivery rather than content. Surface structure adaptations are more likely with cultural attunement than cultural adaptations and culturally informed interventions, as they are relatively easy to change.

While we strongly advocate for participatory research, which was at the heart of all CICADA activities, cultural adaptations are not without issues, as discussed in Box 2.

Box 2 Cultural adaptations and some recommendations

With the emergence of cultural competency as a concept, researchers and practitioners in the Western world began to appreciate that healthcare had largely been developed to suit the mainstream population and was very 'White-centric'. This led to an increase in cultural adaptations of existing evidence-based treatments. These are described as:

“the systematic modification of an intervention or protocol to ensure that language, culture, and context are compatible with the cultural patterns, meanings, and values of the intended recipients or participants” (Bernal et al., 2009, p.361).

Cultural adaptations are considered pragmatic – slightly modifying an intervention so that minoritised groups can better engage with it is more cost-effective and quicker to do than designing a new intervention from scratch (see Rosselló and Bernal, 1999, for an early example). This is therefore attractive to funders and relatively easy to take up into practice since it is based on an existing model in use. Meta-analyses have shown cultural adaptations to be effective (e.g., Soto et al., 2018), even though it is essential to understand whether adaptations are surface level or deep and developed through collaboration with the relevant groups to properly evaluate the relationships between effectiveness and adaptations (Wadi et al., 2022).

The CICADA team advocates for reflexivity when cultural adaptations are undertaken so that they do not reinforce the issues of the cultural competency on which they are typically based. Cultural adaptations, while effective, tend not to be transferable to multiple populations, assume homogeneity within the relevant community and may the white-centric approaches on which they are based may be entirely inappropriate (see for example Dodgen and Spence-Almaguer, 2017). As Falicov (2009) observed, cultural adaptations assume that:

“...the core components of a mainstream form of treatment should be replicated faithfully while adding-on certain ethnic features. This assumption must be based on the idea that the core components are culture-free and even more problematically, that the theory of change involved is universally powerful.” (Falicov, 2009, p. 295).

Note that these adaptations are content-oriented, and the focus of cultural competency on content over process is a topic we come back to in the next section. Another key point is that, as we have already argued in this toolkit, it is not only ethnic groups that have culture, and conflation of the two is a common failing of culturally adapted interventions, just as it is seen within narratives of cultural competency.

Moreover, the CICADA team argue that pragmatism in development is not the same as pragmatism in delivery. If a cultural adaptation were to be developed for each ethnic group

This is important: every person is at one and the same time as everyone else, like certain other n.d.), and with further inter-mixing of these) there would be a plethora of adaptations that could never all be used in practice in different regions, so some less common ethnic groups would have no adaptations, putting them at an even worse disadvantage than before, especially if providers were to try to fit them into the adaptations made for the most common groups. It is more efficient ultimately to look for commonalities across groups that are based on deeper level structures. This can be undertaken for example by a process called population segmentation (Balcazar et al., 1995), which was suggested as a variation of the market segmentation used by commercial businesses. This was the approach used in CICADA and is aligned with an intersectional approach.

2.2 Cultural humility

In 1988, Tervalon and Murray-Garcia proposed the idea of cultural humility, which had developed as a concept due to the growing racial, ethnic, and cultural diversity in the United States. Cultural humility was explained as:

“...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” (Tervalon and Murray-García, 1998, p. 123).

This begins with an examination and critique of one’s personal cultural identities, attitudes, assumptions, biases, and values (Kumagai and Lybson, 2009; Tervalon and Murray-Garcia, 1998), as well as how these affect our understandings of others. This self-reflection should lead to a more balanced understanding of the value of one’s knowledge, beliefs, experiences and skills in comparison to others (Hook, Davis, Owen, Worthington, & Utsey, 2013) - the humility. Carol Dweck (2006) has opined that humility entails both admitting our shortcomings, and actively seeking to overcome them by being open to and learning from others as a “growth mindset” (Dweck, 2006). This recognises that we are all experts in our own lives (Kennedy, 2003) and that we all have a culture or cultures with areas of connection. This is important: every person is at one and the same time as everyone else, like certain other people, and like no-one else (Kluckhohn & Murray 1953, p.35).

Similarly to Dweck, Yeager and Bauer-Wu suggest that humility requires courage to face up to one’s privileged status compared with discriminated-against others and also the flexibility to acknowledge the strengths of others and to move away from viewing difference as problematic. The reflexivity should continue lifelong; Tervalon and Murray-Garcia (1998) consider 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” (Tervalon and Murray-Garcia, 1998, p. 118). This practice recognises the fluidity of and influences on culture that we described at the start of this toolkit.

Attributes	Cultural Competency	Cultural Humility
View of culture	<ul style="list-style-type: none"> - Group traits, - Group label associates group with a list of traditional traits and practices, - De-contextualised 	<ul style="list-style-type: none"> - 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	Competency/expertise	Flexibility/humility

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

The terms cultural competency and humility have occasionally been used interchangeably despite important differences, which Yeager and Bauer-Wu (2013) outlined in a helpful table 1 above. Rivera and Grauf-Grounds (2020) usefully differentiated cultural humility from cultural competency by describing the former as process-oriented for better practice and the latter as content-oriented with the aim of increasing knowledge, confidence and self-efficacy in interacting with and supporting a variety of other people. Cultural humility leads to competencies in the sense that competency is generally understood, as the ability to do things well, rather than in the restricted use of ‘cultural competency’ as knowledge about the ‘other’ that we described above. Yeager and Bauer-Wu explain that:

“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...” (Yeager and Bauer-Wu, 2013, p.3)
For more see Box 3 below.

Lekas et al (2017) highlighted that competency suggests an ego-centric mastery, while humility encourages a person-centred approach. (See also Box 3 for a distinction based on epistemic justice). Campinha-Bacote proposed the combination of both, with ‘cultural competemility’, which she described as:

“the synergistic process between cultural humility and cultural competency in which cultural humility permeates each of the five components of cultural competency: cultural awareness, cultural knowledge, cultural skill, cultural desire, and cultural encounters” (Campinha-Bacote, 2019 p.2)

Box 3: Epistemic justice and cultural humility

The distinction between cultural competency and cultural humility may also be understood in terms of epistemic justice. According to Fricker (2007), there are two categories of epistemic injustice: 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 competency assumes the ‘other’ needs to be understood only so that they can be persuaded to adopt the ways recommended by the 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, p.82). He called this ‘subjugated knowledge’ (Foucault, 1980, p 82). Cultural competency may sustain this 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 valuing of 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.

According to Yancu and Farmer (2017), cultural competemility combines process and content.

Despite some advantages over cultural competency, cultural humility (and cultural competemility) is inherently problematic because it implies privilege despite reflecting on this, and 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.



Section 3: Establishing cultural integrity in the CICADA research

3. Establishing cultural integrity in the CICADA research

Cultural integrity equates with:

“researchers establishing a level of cultural trust by respecting or behaving in a manner consistent with participants’ cultural values” (Pelzang and Hutchinson, 2018, p.2).

This calls for in-depth knowledge and comprehension of the sociocultural and political dynamics of the research setting and therefore collaborative ways of working with people within this setting and who are members of the groups to be researched (Pelzang and Hutchinson, 2018). The next sections show how the cultural integrity of the CICADA study was maintained according to Im et al’s (2004) core principles of cultural integrity: cultural relevance, contextuality, appropriateness, mutual respect, and flexibility.

3.1 Cultural relevance to the study’s design

At the stage of conceptualising a study, its cultural relevance needs to be evaluated, that is:

“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 is made clear by its aims, which build on previous knowledge of inequities. These aims are to explore how UK care was experienced during the pandemic by disabled people and people from minoritised ethnic groups, to improve understanding of what has happened and why and thereby to contribute and inform evidence-based formal and informal strategies, guidelines, recommendations and interventions for health and social care policy and practice, to mitigate inequities and improve the identified experiences and health and wellbeing outcomes.

The idea for the study, its intersectional approach, and the basic protocol, arose from the lived experience of the study lead with both disability- and asylum seeker-linked cultures, and was developed through scoping of the relevant literature. This shaped the broad choice of participant groups. The survey and interview questions included consideration of cultural values, and influential formal and informal networks (appreciating these might be positive or negative). Cultural relevance was assured because it matched the aims of the study, with our approach and processes foregrounding citizenship status as well as disability and ethnicity, and carefully modified through 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.

Madison (1992) considers such collaborative study design and planning to be critical and enhanced by collaborative problem definition. All too often research is undertaken about other cultures using research questions that promote the deficit model, using such terms as ‘underprivileged’, ‘at-risk’ and ‘chronically homeless’. We found that even amongst the team, in whom collaborative ideas were ingrained, sometimes we lapsed into this terminology in our writing of outputs because of their ubiquitous use in policy and even in funding streams.

The team recognised that race and ethnicity are intricate and multifaceted concepts affected 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. After careful consideration and consultation, the team decided to use the phrase “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 and inclusive approach 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 4 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 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, for instance those that focus on identity consideration such as Suleman et al. (2021). Disability is not a necessary consequence of any chronic illness and not everyone who is disabled has poor health. 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 4.

Box 4: 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 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 (Council on Foreign Relations, May 2023). 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 due to 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 under Soviet control in the 20th century (Pew Research, 2018) and any other countries excepting Germany that are generally considered Central European. Thus, we included the following countries 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).

We were able to acquire contextuality in our research by collaborating with community co-researchers who were familiar with the research context (see Box 5).

Minoritised ethnic groups in the Global North countries and disabled groups around the world are at higher risk of health disparities and are frequently not engaged in research. The recruitment of ethnic minorities into research is hampered by several factors, including stigma or prejudice, a lack of trust, disparities in explanatory belief frameworks, practical concerns, and a shortage of researchers who are aware of cultural differences (Farooqi et al., 2022; Moore et al., 2022). Similar issues apply for disabled people. These all link back to epistemic injustice.

Box 5 Example of barrier in recruitment related to our undocumented participants

We approached undocumented migrants personally and outlined the goals and methods of the study in ways they could understand, with a simple document that was also described to them verbally. Many undocumented migrants were unsure about participating. Some agreed, and then pulled out at the last moment. This can be attributed to their fear of losing anonymity. The first author’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 CICADA, we

did not simply ask the community leaders or third sector groups 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.

The importance of the lay researchers cannot be emphasised enough here. It is essential for researchers to build trust within the community they wish to work with. A common approach is for university researchers to immerse themselves within the community for a protracted period, attending community groups and talking to people in places of worship and other public spaces. One of our team spent several months doing this for the HEAL-D project we have mentioned elsewhere, for example. She did so very effectively but the CICADA project was too short for this to be possible – instead our lay researchers acted as our bridge to the participants we wished to recruit. Given the other points we have raised in this toolkit, for true cultural relevance this may be considered a gold standard option.

A few participants were hesitant to sign the consent form. However, lay researchers acted as cultural consultants. They emphasised to participants that they could use initials and recorded verbal consent in which voices were disguised, and they supported us in improving materials so that participants would fully see the significance of having consent forms and what they involved. Not surprisingly given that some participants were undocumented or asylum-seeking people, certain terms (such as “anonymity”, “data protection”) appeared alarming. During training, the lay researchers fed back to the research team that the language 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 to take part and were not explained by research staff in simpler terms. Telephone completion of surveys is one way to overcome this issue.

A few people from the minoritised ethnic groups were worried about others in the community finding out about their disability or chronic condition if they took part in the study. This was highlighted by a co-researcher, emphasising the significance of showing cultural integrity: She explained: *“I am working with young women who are recently migrated to the UK. I found a South Asian woman 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 better understanding of participants. This was undertaken sensitively, and we did not ask for information that was not relevant to the study. Each participant was asked about religious holidays so we could respect these, and recruitment times were fitted around Eid as a result. Also because of this, we learned that some participants only observed key days for religious holidays, so that



recruitment did not have to stop completely at these times. All these conversations helped us 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 conveys concepts that may not be equivalent in direct translation which then loses some of the meaning. For example, 'gemütlich' in German is often translated as meaning comfortable, but has a deeper, more spiritual meaning of congeniality when Germans use it, reflecting its etymological roots. Language is living and changing, and both shapes and incorporates values and beliefs. Its accumulated cultural, social and political meanings may be 'lost in translation' (Temple & Edwards, 2002). Concepts do not traverse cultural barriers without difficulty and direct seemingly objective translation can compromise study reporting, being typically less accurate than translation that takes this into account (see Box 6 below).

Similarities and differences between cultures may not map clearly, particularly when multiple languages are spoken (Chen and Boore, 2010). This problem can be mitigated when translators are fluent in the target language as well as the source language and have good knowledge of relevant cultures. Chen and Bore (2010) suggest the researcher should also have this expertise, but we would argue that this depends. In our case, this was a reason to use lay co-researchers but some of our core research team undertook high quality work without meeting this requirement. There is much debate about this issue, which we do not enter into here, but suffice to say that although it may often be helpful, it is not always possible, especially when many cultures are being explored as in CICADA. Our lay co-researchers were carefully chosen to augment our core team in this way and provide a way to reach more groups.

Box 6: 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. We used self-interviews to familiarise lay researchers with the data collection process and encourage them to raise any questions with the project lead. Lay researchers mentioned that they would like to speak in the participant's mother tongue where possible to overcome the difficulties of using another interpreter and to capture experiences more accurately. A researcher must be culturally self-conscious to properly conduct their research.

Simply checking the language box is not enough; they must also be aware of their own culture and how it may affect the interaction. 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.

Mutual Respect

Mutual respect involves researchers and participants respecting each other's cultures, views, beliefs, and values, but more than that, it involves mutual appreciation of their equal value; as such researchers need to fully recognise the power differentials involved and work to overcome these (Im et al., 2004). For mutual respect to align with epistemic justice in this way, 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. In some cultures, it may involve physical manifestations such as bowing when saying thank you which is important in some Asian cultures. Ideas of respect may differ at the individual level too. Given our intersectionality lens, 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., 2017), and listening to them.

Through this, other markers of respect become shared. The ultimate objective of mutual respect 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 maintaining confidentiality and anonymity for everyone, but especially for undocumented migrants. To protect their anonymity, they employed pseudonyms on the consent form, voice-over to mask their voice or face identity, 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. As further reassurance, 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. Everyone also felt valued and that their voices were all heard. This was fostered particularly in our co-design workshops (see the net section for details), where the process of making individual models of useful coping strategies that did not depend on verbal language and then taking turns to show them to the rest of the workshop participants gave everyone the feeling of being listened to.

Flexibility in interviews

A lack of trust in researchers because of bad experiences is another reason why people from minoritised ethnic groups might not engage with research. Several lay researchers highlighted the impact of prejudice, stigma, 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 or chronic health condition experience helped them to build rapport with interviewees, thereby leading to richer data. Using collaborative terms during data collection such as ‘us’ and ‘we’, or mentioning mutual health conditions, also helped in this regard. Another approach based on mutual respect is the strengths-based approach that underpinned the CICADA study. This is explained in more detail in Box 7.

Box 7: Strengths/asset-based approaches

CICADA used a strengths/asset-based approach, with a holistic emphasis on both personal strengths that people have at their disposal and 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 are viewed as ableist and white-centric, in assuming the person is as they are because they have not tried or engaged sufficiently well. This shows a lack of respect. A strengths-based model suggests structural barriers prevent this.

Our specific approach 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 requirements, where additional resources could enhance or grow existing assets and strengths. We were careful to avoid reducing the necessity for government action and health and social care services as a result or to suggest improvements should be a community obligation. A strengths-based approach attempts to empower communities and individuals in meaningful and long-lasting ways rather than trying to shift attention away from the structural causes of disparities (Foley & Schubert, 2013).

In the survey, flexibility was also built in after piloting, on the advice of our patient advisory group members. 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 8), and choice of options.

Box 8: An example of piloting comments that led to changes in survey questions

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.

3.2 Culturally nuanced participatory methods in workshops

As Vaughn and Jacquez (2020, p.7) point out, the use of participatory research is an effective way of achieving “*knowledge production and real-world action conducted in a democratic, collaborative manner.*”

Participatory research has many other benefits that we do not explore here, but we wish to emphasise its relevance to cultural integrity. When done well, fostering true collaboration, it facilitates awareness of and respect for diverse cultural values, traditions and beliefs, and enables epistemic justice. Additionally, it recognises everyone's right to participate in research and decision-making that has an impact on them directly.

The CICADA team developed a blueprint for culturally sensitive participatory research. Co-create workshops with 104 interviewees in May and September 2022 explored changing experiences and facilitated knowledge exchange between researchers and interviewees. In-person and online, these employed participatory tools such as patient journey mapping and structured brainstorming (a 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 having equally valued expertise, 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 knowledge production and knowledge exchange in an equitable fashion. Like interviews, the use of elements of cultural integrity (such as language, flexibility and mutual respect) in workshops fostered cross-cultural understanding and active engagement.



Figure 4 Co-create workshop at Bromley by Bow in London

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). Groups 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 interventions such as local art classes to improve mental health through to larger ones such as the provision of free school uniform). 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 participant was given four sticky dots, and they were able to vote for the themes and the ideas they believed should be prioritised. 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.

In addition to co-create workshops, two co-design workshops were organised in 2022 with research participants, policymakers, health professionals, NGOs, and patient advisory group members. The co-design workshops were conceptualised and led by a designer researcher who was also a specialist lecturer in Patient and 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.

Overall, in both types of workshops, the activities gave participants a voice and agency 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.

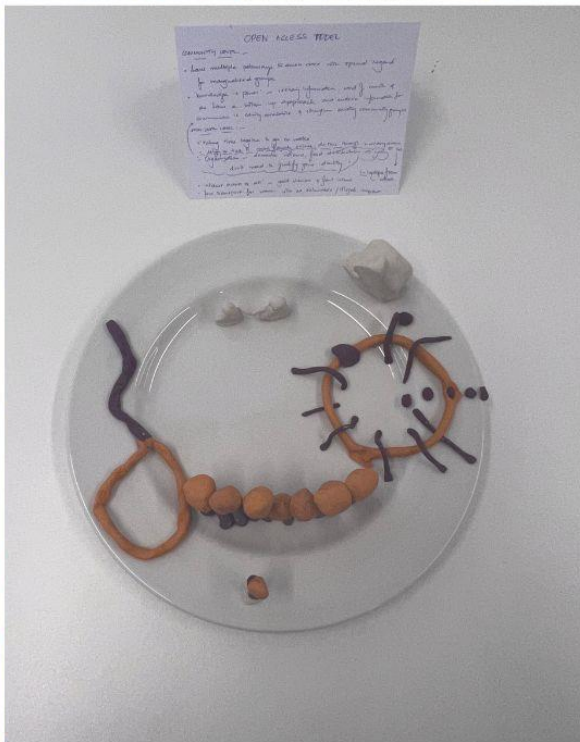


Figure 5 Co-design workshop at UCL in London

3.3 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 knowledge exchange, 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). The Q&A enabled effective knowledge exchange between the audience and the research team.

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.”

3.4 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 inequities, discrimination and de-centring 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 research processes to avoid exacerbating perceptions of discrimination and distrust if we are to ensure minoritised groups are more successfully represented in research.

Appendices



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 group members. This could be done for example through the development of a jargon-proof booklet written collaboratively by researchers, community members and administrative staff from human resource or finance departments.
2. Principal investigators should consider giving project managers or research team members with lived experience dedicated time to work with lay researchers and patient advisory group members 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 directly, in-person or online depending on what is more appropriate.
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, to value their participation. This may require the development of workarounds within university systems such as the use of petty cash.

Best practices for collaborating with lay researchers

1. Comprehensive training should be provided on ethical considerations and practices in research, including appropriate ways to obtain informed consent and manage potential risks to participants. 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.

2. 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.
3. Buddying a lay researcher in their first interview should help to ensure the integrity of the research process.
4. 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 researchers 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 externally in the way needed.

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.

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. Think about the formats, media and platforms:
 - For all communications e.g., newsletters, correspondence, offer a choice.
 - If using participatory methods, give a choice e.g. collage, paint, plasticine, photographs etc, and consider the mosaic approach (Clark and Moss, 2011), and not just for children as in the original paper.
 - With surveys. The AASPIRE study found that exclusively text-based, online surveys underrepresented those with low educational attainment who responded better to in-person options or read-aloud computerised features (Nicolaidis et al., 2019).
 - 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. We offered other formats, but they were not taken up.
2. Planning and reminding:
 - As much warning as possible of changes to plans.
 - Sending materials to examine in advance.
 - Individualised reminders.
3. Meeting support:
 - Individual support before and during meetings if needed (for example to use Zoom). Also develop 1 page visual 'how to' or 'where to' guides.
 - Structured meetings with clear agendas and transitions.
 - Interpretation, hearing loops or sign language if needed.
4. Comfort:
 - Reasonable adjustments such as room layout, seat type. Sensory adjustments as needed (e.g. lighting, heat, sound).
 - Ice-breaking exercises.
 - Checking back at the end of meetings what went well and what needed to change.
5. Simple documents:

- Simple and concrete consent forms, with images, and text-to-speech, and with digital signing or verbal consent (recorded, but not on the same audio as any interview).
- Piloting and adapting survey questions as a participatory process. For example in the AASPIRE study, graphics were added to Likert-type scales, to help comprehension (Nicolaidis et al., 2019).

6. Qualitative interviews

- Open ended questions are usually preferred. But neurodivergent people may be challenged by open-ended questions (which need to be made more concrete) or the processing of questions in real time.
- Offer remote or face to face, synchronous and asynchronous modes of participation and both oral and written responses.
- Ask for examples of specific experiences. Use probes that anchor events (e.g., 'when Boris Johnson had to resign'; 'when it was your birthday').

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

Language is organic, 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 ‘**seldom heard**’ when talking about services. These terms should not be used to refer directly to an individual.
4. 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 or other characteristics. This term should not be used to refer directly to an individual though they can be described as coming from a **disadvantaged background**.
5. Avoid saying ‘this **broad ethnic group**’ and use the format ‘this **ethnic group as a whole**’.
6. Use the term ‘people with a **mixed ethnic background**’ or ‘people from the **mixed ethnic group**’ and not ‘**mixed race people**’.

Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation are all **protected characteristics** under the Equality Act 2010. Ethnicity is not so ethnicity and race should not be used interchangeably. **Ethnicity is different to race.**

7. **Capitalise ethnic groups** derived from a place name (e.g., ‘West Indian’, ‘Chinese’, ‘Asian’).
8. Never use ethnicities as **nouns**, instead refer to, for instance, ‘**black people**’, ‘Chinese women’.
9. There is a difference between, for example, ‘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 or a nationality, write for example ‘people from the Indian ethnic group’, not ‘Indian people/.

10. 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.
11. ‘Intellectual disabilities’ is preferred to ‘**Specific learning disabilities**’ but both are better referred to as **intellectual impairments**. In some cases. ‘**specific learning difficulties**’ may be used to refer to conditions such as autism, dyslexia and dyspraxia, so that they are categorised as a disability for statistical purposes in policy and practice. We therefore used this in CICADA, though many neurodivergent people disagree with this.
12. 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’s state of health. Avoid ‘**the mentally ill**’, ‘**victim**’ or ‘**sufferer**’. Time to Change has good practice guidance on this at <https://www.time-to-change.org.uk/media-centre/responsible-reporting>.
13. 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 with contact details for a charity such as The Samaritans. This charity has guidelines on good practice for reporting on suicide at <https://www.samaritans.org/about-samaritans/media-guidelines/media-guidelines-reporting-suicide/>
14. An individual cannot be ‘**diverse**’. Similarly, a person cannot be **neurodiverse**. Diversity means 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.
15. Religions and religious denominations are usually treated 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 way 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.

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, except for 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, and should generally also be avoided. Countries in each were said to be similar in political, geopolitical and economic factors but in fact by 2030, three of the four largest economies are predicted to be from the Global South – China, India, the United States and Indonesia. This has been accompanied by shifts in economic and political power. Moreover, countries in the Global South were mostly colonised by countries from the Global North. The terms '**developing countries**', '**less developed**', '**underdeveloped**', '**developed world**' and '**Third World**' should be avoided as these terms position the richer countries as the ideal that is measured against.

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Suggestions on further readings on intersectionality theory

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