

Literature Review: Mind culturally appropriate measurement of service user outcomes and evaluation within community services

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Introduction

Mind's Young Black Men programme 2019-2022 has been working to co-produce a range of wellbeing programmes to engage young black males between the ages of 11 and 30. The approaches being piloted include: development collaboration with local minds who are trying to develop services for young black men; peer support and a mentoring training scheme.

Centre for Mental Health is funded by Mind to co-develop a culturally appropriate tool or approach with young men, which can be used to measure the outcomes of Mind's Young Black Men programme. We will conduct workshops and interviews with young men as part of this process.

We began by reviewing academic and 'grey' literature to explore existing research. This literature review explores the meaning of culturally appropriate or culturally competent approaches. It includes evidence on effective approaches used with young black males and other minority groups in evaluation and co-production work. We review the principles and strategies which facilitate culturally appropriate outcome measurement and evaluation approaches, so they can inform our project.

It should be noted that there are valuable insights and experiences in this area which have not been formally published. The literature review will be supplemented by expert interviews to further develop our understanding of successful coproduction approaches with black boys and men. This will help us understand how the process of developing the tool or approach can be best placed to reflect black men's needs and interests.

Methodology

The literature review investigates what culturally appropriate outcome measurements look like and how they ought to be developed. Specifically, it explores:

- 1. What works for culturally appropriate outcome measurement and capturing experiences of young black men within community / mental health / health / social care services?
- 2. What works for culturally appropriate outcome measurement and capturing experiences of minority groups within community / mental health / health / social care services?
- 3. What are the facilitators to developing culturally appropriate measurement tools?

There is limited published research focussing on culturally appropriate outcome measurement for young black men, therefore learnings from work with other minority groups were included.



An electronic search of the terms in Appendix 1 was conducted on Google Scholar and Google to complete this literature review. Most of the included sources were peer-reviewed articles, although other research literature and resources were included. The reference lists of some included papers were searched, specifically to find papers with an outcome measure or approach focussing on young black men. Approximately half of the included papers were written since 2010. As there is not a great deal of existing literature on this topic, research from before 2010 was also included.

The literature review focussed on work which has been done with young black men as far as was possible. There is a section on measures or approaches from the literature which were specifically developed with and for black males, which are useful to know about for our research project.

A note on culture

Before beginning this work, it is worth describing the broader racialised cultural context in which the project is taking place. "Culture" refers to group norms and practices. Framing issues in terms of culture can be constraining or deterministic, as grouping people together carries the risk of doing injustice to individuals' experiences and can perpetuate stereotypes.

People experience the concept of culture in complex ways, which may well include problematic ways, and we should bring this understanding when speaking with young black men. For example, one's sexuality may not be accepted by one's religion or cultural background, and so many people push back against or have difficulties with various aspects of their culture. Culture is a dynamic concept, and people can have a complex relationship with it which shifts over time.

Focussing on culture alone can downplay the vital importance of intersectionality in understanding people's lives and experiences. For example 'the marginalized race, sexuality, and class of a poor, gay, African American person presents a far more complex social location than any single aspect of his identity alone' (Abrams & Moio, 2009). People's identities are complex and must be looked at through an intersectional lens, including their gender, sexuality, ethnicity, religion and race.

Culture is also a loaded concept – it is often only allocated to black and ethnic minority people and can have an othering effect. In this light white people are simultaneously presented as the 'the norm', somehow outside of categories like culture and race, and as unique people who you cannot generalise about (D'Angelo, 2018). Of course white people have culture too – for example the privileged norms, practices and forms of behaviour described by the "white privilege". It is important to bear this in mind, that white people and white researchers have been their own culture, and can have assumptions relating to this which they too bring with them into discussions on race.

Keeping these ideas on culture in mind will help us to have realistic ambitions for the project. A balance will need to be struck between reflecting the nuances of culture and developing an approach which can be used across many different black boys and men with diverse intersectional experiences. Keeping the racialised cultural context in mind can help us disrupt established cultural ways of understanding black males' mental health— which may be unhelpful and not serve their needs.



What do we mean by culturally appropriate, or culturally competent?

In the research literature, cultural competency is a more common term than culturally appropriate. Cultural competency is best described as a *process* which a professional or researcher 'continuously strives to achieve' with an openness to learning about other people's experiences (Campinha-Bacote, 2002). Related to this, cultural imposition should be avoided at all costs. This is 'the tendency to impose one's own beliefs, values, practises and patterns of behaviour on another culture' (Leininger, 1978).

A comprehensive definition of cultural competence was provided by Cross et al. (1989) in the context of healthcare systems:

'A culturally competent system of care acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally unique needs.'

In the context of our work, 'adaptation of services to meet culturally unique needs' is not directly relevant as we are developing an outcomes measure or approach, not a service. However the remaining 4 elements of the definition would apply to our project as shown below:

Aspect of cultural competency

Acknowledge and incorporate the importance of culture and expand cultural knowledge

Impact on the project

Successful co-production requires a robust commitment to active listening to what is being said by young people and our peer researcher, including on the importance of culture.

White researchers need to passionately convey their belief in working 'arm-in-arm' with young men to expand their cultural knowledge. This is important because when white people create standardised tools, measures may be unintentionally shaped by:

- unconscious bias against black people
- poor cultural awareness and competency
- benefitting from and seeing the world through a 'white privilege' lens

Assessment of cross-cultural relations and being vigilant towards the dynamics that result from cultural differences

We are acutely aware of the likely dynamics, for young African Caribbean men, of having white researchers in the room. Our starting point and process is very much influenced by recent work on white fragility, including that 'white people should move from asking 'if I am racist...' to 'how have I been shaped by the forces of racism?' (DiAngelo, 2018).



Based on our previous community engagement and coproduction work, successful co-produced outcomes rely on building trusting relationships. This happens through:

- promoting transparency about our awareness of white privilege and race-based power dynamics
- creating a culture of non-defensive openness to being challenged
- white researchers being hyper vigilant about their potential to bring unconscious biases into analysis and into the room
- our peer researcher steering delivery and engagement
- our peer researcher challenging when researchers may be interpreting dynamics or findings through a 'white privilege' lens

What facilitates culturally appropriate outcome measurement and capturing experiences for minority groups?

Only people who are part of the culture being focussed on, will know what is culturally appropriate. Outcome measures try to measure concepts such as wellbeing and resilience, which are subjective and may have different meanings in different cultures. Therefore, they must be considered and defined by those living in a particular culture (Constantine & Sue, 2006; Lopez et al., 2002). For example, Oeur (2016) conducted a qualitative study which included ethnographic fieldwork, exploring young black men's experience of growing up in an era of surveillance. Oeur emphasised that research with these young men must honour that they are individuals who can speak critically about their social worlds (Best, 2007). The interviews in this study followed Young (2004)'s approach - to ask young men to describe how they situate themselves in different worlds (such as their school, family, peer groups, local area and larger society) and what these worlds are like from their own perspective. The study challenged the dominant vocabulary in research literature, namely that marginalised young black men aggressively seek "respect" or masculine status. Oeur suggested that young black men growing up in an era of surveillance are really seeking dignity - 'a sense of humanity distinct from status-seeking, and the right to the presumption of innocence' (Rios, 2011) and this finding emerged from analysis of young black men's views.

Cultural generalisations should be avoided, as it can lead to invoking stereotypes, and in this way it can be difficult to define what a culture represents on a wide level. This issue was covered in 'Breaking the Circles of Fear; - a review of the relationship between mental health services and African and Caribbean communities (Centre for Mental Health, 2002): 'The only way to correct such cultural misinterpretations is on a **case-by-case basis** through questioning and learning and above all, through the formation of a therapeutic relationship between the professional and the service user'. For our purposes, the measure will need to pay attention to cultural meanings in different regions and should occur through an open and respectful rapport between the researchers and research participants. This will need to be balanced with the ambition to create a universal measure across the local Mind services. Therefore, the flexibility of the measurement approach, and producing appropriate support and guidance to accompany it will also be important.



Furthermore, measures should **take into account the target population's cultural and linguistic characteristics**, including regional and dialectical differences (López et al., 2017). This advice is given in a guide by the National Research Centre on Hispanic Children and Families. Developers of a measure ought to consider how a cultural group may be different from the dominant culture, for example in communication patterns, family roles, gender roles, religious views and other culturally-based beliefs and practices. This is also an important principle of intersectionality – that historically oppressed people's experiences can only be considered from their own viewpoints. This should be done to challenge the common tendency to describe BAME people in terms of how they differ from white middle class norms (Weber & Parra-Medina, 2003).

Understanding cultural meanings reduces the likelihood of construct bias, which can undermine the validity of an outcome measure or approach. For example, if being close with one's family is very important in a particular culture, a quality of life measure would need to assess this, otherwise it could not accurately reflect this construct (Vreeman et al., 2013). Consulting with the target group is important for establishing content validity, the degree to which elements of assessment tools are relevant and represent the targeted construct (Betancourt et al., 2009; Hollifield et al., 2013). **Systematically reviewing each item** of a measure for cultural appropriateness will hopefully lead to strong agreement among the targeted group about: which questions/answers should be kept, need revision, or should be deleted (Weaver, 2016). This is important for reviewing items on existing measures and defining which are most important or relevant to the group it is designed for.

Vreeman et al. (2013) recommended **cognitive interviewing** as another way to test how culturally appropriate a measure is. This qualitative research technique is when representatives from the target audience of the measure go through the measure item by item with a trained facilitator. The facilitator asks probing questions to assess the respondent's understanding of the questions, and how they decide to respond to each item. This is particularly important when understanding how children and early adolescents respond to measures, in terms of their reading age, comprehension level and attention levels. Children and early adolescents tend to have a lower attention span than in later adolescence and adulthood, and it is important the measure is not too long, as lacking focus can prevent them being completed (Scottham et al., 2008). It is advisable to make the groups varied in terms of ethnicity and culture, and to include people from low socioeconomic status groups and those with less educational attainment. This is because they are most likely to be excluded from influence (Bravo, 2003).

Being vigilant to the dynamics that result from cultural differences

Another key aspect of cultural competency is 'vigilance towards the dynamics that result from cultural differences' (Cross et al., 1989). Here, the work of Robin DiAngelo is informative. In her seminal book 'White Fragility', DiAngelo (2018) discusses the ways in which white privilege is maintained, and how white people are socialised to expect racial comfort and have no ability to tolerate racial stress. This leads many white people to react in an angry, defensive and threatened way when racism, or even race issues are raised in conversation. This emotional reaction immediately closes the conversation down, and on a large scale keeps racism unacknowledged amongst white people and protects their white privilege. DiAngelo recommends that white people take part in interventions which are 'stamina-building', which means building 'the stamina to sustain conscious and explicit engagement with race'. Through this, white people would no longer have a defensive reaction to race issues, which would help the model of white privilege to be spoken about, challenged and overturned. In line with this,



working alongside peer researchers and young black men, and keeping an open stance to being challenged and learning from their own experience, will be a vital foundation to the creation of a culturally-appropriate measure.

In response to longstanding inequalities in the healthcare of people from BAME communities, a model for cultural competence was developed in the field of psychiatric nursing (Campinha-Bacote, 2002). The model includes 5 key questions which a nurse should ask themselves when interacting with their patients and these are listed below. Such principles could be held in mind for white researchers and white professionals who may work with black men to fill in outcome measures. It is an important reminder that the ability to be culturally competent is a mixture of self-reflection, knowledge, skills, interaction and the enthusiasm to embark on this process.

Cultural Competence: Have You "ASKED" the Right Questions?

Awareness Are you aware of your personal biases and prejudices towards cultures

different than your own?

Skill Do you have the skill to conduct a cultural assessment and perform a

culturally-based physical assessment?

Knowledge Do you have the knowledge of the patient's worldview, cultural-bound

illnesses, and the field of biocultural ecology?

Encounters How many face-to-face encounters have you had with patients from

diverse cultural backgrounds?

Desire What is your desire to "want to be" culturally competent?

Further useful principles to guide the creation of this measure can be taken from MAC-UK's INTEGRATE model. MAC-UK works with several different projects across London. It specialises in working with young people with lived experience to co-produce projects and solutions to inequality and exclusion. MAC-UK uses a psychologically informed approach called INTEGRATE, which sets out principles for how to work with and engage young people and communities. To summarise, 'to reach those who are most excluded, the MAC-UK approach is to go out to where they are and offer a flexible, responsive and holistic service.' Although the below principles relate to the running of a project with young people, they are useful to hold in mind in our collaboration to develop a culturally appropriate approach. The principles which are not relevant for our purposes have been excluded.

INTEGRATE Practice Level Principles, MAC-UK

Everything is an opportunity Every time we encounter a new problem, it tells us

something isn't working and is an opportunity to create

a better solution.

Asking for young people's

help

Ask young people for their help as they are experts in

their own lives and their needs.



Doing with young people and not for young people

For example, supporting a young person to solve a problem, to make a telephone call - not doing it for them

Being empathic, curious, non-judgmental and sharing dilemmas Open up conversations and demonstrate empathy. If you have a dilemma, sharing it with a young person can build their confidence to help others. It also creates trust and a balanced relationship between equals.

Not knowing

It's likely we don't know everything or have all the answers. It's also likely that we don't know exactly what is going on for a young person, we don't always know what they have or haven't done. Being aware of this should inform our way of being with young people

We are a team

Us, young people and staff are part of the team/organisation/service and so we make decisions based on what is good for our

team/organization/service

We deliver what we promise and don't promise what we can't deliver Work hard not to commit yourself to something you can't deliver and try your best to deliver what you say

you will

From the eyes of the young person

Ask how a young person might interpret what you've said, or why they might be behaving a certain way. Try to think from a young person's perspective and support them to think about other's perspectives

Source: mac-uk.eu.rit.org.uk/our-approach

Overview of validated measures which focus on black males' experiences

There are not many validated measures focussing on black men's experiences, with just 3 main examples referred to in the literature:

- 1. The Masculinity Inventory Scale (MIS) (Mincey et al., 2014), which is a culturally-specific assessment of masculinity in black undergraduate men
- 2. The African American Men's Gendered Racism Stress Inventory (Schwing et al., 2013), which is a measure of experiences of stress informed by an intersectional approach between race and gender
- 3. More recently, the Black Men's Experiences Scale (BMES) (Bowleg et al., 2016) was developed to explore negative experiences of discrimination. It also incorporated positive aspects of what it means to be a black man. Bowleg et al. recommended that it might be used to ensure beneficiaries of a programme are matched to culturally tailored support, to develop resilience and coping skills.



Focus groups or interviews can identify the range, depth and meaning of possible responses and allow for development of culturally informed assessment tools (Hollifield et al., 2002). For example, the BMES (Bowleg et al., 2016) was developed by conducting focus groups and individual interviews with a sample of black men, using neutral open-ended questions such as, 'How would you describe what it's like for you as a black man?'. The answers were then analysed and brief phrase codes developed (eg 'it's not easy' being a black man and 'feeling blessed' despite challenges). These were then converted into frequency related items, ('eg how often have you felt it is a constant struggle to be a black man?' with Likert response options. This shows how the voices of black males were grounded in the measure.

The development of the MIS (Mincey et al., 2014) followed a similar process, with data from focus groups and interviews with young black man being analysed, key themes identified, and then used to create items in an outcomes measure. Survey items came directly from the quotes given by young men in their responses, and were made as succinct as possible. The potential items were then reviewed by two black masculinity researchers, which highlights the importance of having a peer researcher in the project team.

It should be noted that adapting existing outcome measures or approaches for cultural equivalence can be more practical than developing it from scratch (Daher et al., 2014). In these cases, researchers should consider how any given outcome measure has been developed, tested or "normed" against the scores of individuals from a particular population, to determine whether it is appropriate for the research participants (López et al., 2017). Then, a participatory approach should be used to develop or change the measure, where representatives of the target group define meaningful issues (Betancourt et al., 2009; Hollifield et al., 2013).

Limitations of the evidence base

Most of the evidence base from this literature review consists of qualitative studies with small sample sizes. Therefore, there is a need for the measures to be tested more widely in different populations to test their external validity, or in other words, how far they are generalisable to young black males living in different countries and in different age groups. There is clearly a lack of validated measures which have been developed specifically for young black males, which is the rationale behind the current project.

Key messages from this literature review

The overall approach in culturally-appropriate research

- Only people who are part of the culture being focussed on, will know what is culturally appropriate
- It is important to be vigilant to the dynamics that result from cultural differences, influenced by recent work on white fragility. As DiAngelo (2018) put it, 'White people should move from asking 'if I am racist...' to asking 'how have I been shaped by the forces of racism?' and considering the implications of this
- Cultural misinterpretations should be corrected on a case-by-case basis through questioning and learning and above all, through the formation of a good rapport between researcher and participant



- Researchers should always honour individuals as able to speak critically about their social worlds

Principles to remember when developing a culturally-appropriate measure

- Understanding cultural meanings reduces the likelihood of construct bias
- Measures should take into account the target population's cultural and linguistic characteristics
- Systematically reviewing items of a measure/evaluation approach and cognitive interviewing (with representatives of the group the approach is aimed at) can help us assess cultural appropriateness
- Some approaches have included black male's voices (recorded in focus groups or interviews) to directly shape the items in a measure, to keep their voices at the centre of the research

Concluding points

This literature review has identified principles to help guide the creation of a culturally appropriate tool or approach, which can speak to and reflect the outcomes important to young black men. Key principles include acknowledging the importance of culture, expanding cultural knowledge, assessing cross-cultural relations and being vigilant to the dynamics arising from this. It is important to seek to understand black males' experiences at the intersection between race, gender, sexuality and culture, otherwise the fullness of their experience cannot be captured by the measure. Guidance to help white researchers be culturally competent has also been highlighted – this needs to be an ongoing process. It requires self-reflection, commitment, enthusiasm, and a willingness to challenge oneself, and to be challenged on areas where white researchers may have preconceptions and limited understanding. In terms of the three existing validated measures for black males identified in the literature, they have used qualitative data collection to bring the voices of black males into the final measure. This has then been shown to black men or black researchers to check that they are relevant constructs to measure, which is likely to be an effective approach for our purposes.

Practical recommendations for the project

- Successful co-production requires a robust commitment to active listening to what is being said by young people and our peer researcher, including on their experiences of culture, race and racism. This will be particularly crucial during the workshops which will help us develop the measure, and subsequent interactions with young men to feedback on the measure
- Transparent and open discussions with the young people and our peer researcher are important. Be vigilant to the dynamics that result from cultural differences rather than avoid them. Be empathic, curious, non-judgmental and share dilemmas, as per MAC-UK's Integrate model for successful co-production
- White researchers need to passionately convey their belief in working 'arm-in-arm' with young men (which may be particularly important when introducing themselves to participants). This will help build trust with participants, help them feel able to share



their views openly and freely, and enable white researchers to expand their cultural knowledge. All of this will help shape a measure which captures black males' views as authentically as possible

Take into account and reflect the participants' cultural and linguistic patterns, which
may include slang. The way young men have phrased and described the outcomes
which are important to them, has been respected by existing validated measures to
good effect.



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Appendix 1

Search terms used in literature review:

culturally appropriate measurement tools cultural assessment tool health care capturing experiences of young black men



capturing experiences of young black men mental health capturing experiences of young black men community capturing experiences of young black men social care capturing experiences of young black men health Evaluation tools young black men what makes an outcome tool culturally appropriate what makes an outcome tool culturally appropriate black people