



Design considerations for including diverse ethnic groups in mental health trials

This document summarises findings from the INCLUDE Ethnicity Frameworks completed for the STRIDE project. The identified challenges have been organised into the five main Office for National Statistics ethnicity categories: White, Mixed/Multiple ethnic groups, Asian/Asian British, Black/African/Caribbean/Black British, and Other ethnic groups. The intention is to support trial teams working in cancer, cardiovascular diseases, diabetes, maternal and infant health, mental health, smoking cessation, COVID, surgery, and dental health. By consulting these summaries, teams can quickly see the key challenges they may need to consider when designing inclusive trials and enabling participation from people across diverse ethnic backgrounds. Where a challenge is relevant to more than one ethnic group, it appears under each applicable heading. The challenges span factors such as cultural beliefs, practical concerns, and aspects of trial design.

White

ANTLER (mental health)	
Trial registration document	
INCLUDE Framework	
Challenges	
Only reported in White participants	• The highest group that do not speak English as their first language in the UK are non-British white groups, with only 36% of them speaking English as their main language (UK Government, 2017).

IMPACT		
(mental health; psychosis)		
Trial registration document		
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PANDA (mental health; psychosis)	
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Prodigy (mental health)	
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WHELD (mental health; dementia)	
Trial registration document	
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Only reported in White participants	Amongst Eastern European communities, understanding of dementia can sometimes relate to experiences of persecution.

Mixed/Multiple ethnic groups

ANTLER (mental health) Trial registration document **INCLUDE Framework** Challenges • Minority populations, though less prone to acute MDD episodes than Caucasians, face a higher likelihood of enduring chronic, severely debilitating depression, significantly impacting their daily functioning (Bailey et al., 2019). • Non-white groups see mental illness as more dangerous and express a greater desire to segregate from those with mental illness. There are also variations in perceptions of mental illness danger among minority groups (Eylem et al., 2020). Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial. • In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness. • A clinician's gender matching that of the patient can influence participation. Some ethnic groups, like South Asian women, may feel more comfortable Reported expressing themselves with a clinician of the same gender. across Group sessions may restrict participation for specific ethnic groups without a several focus on fostering a supportive and understanding environment. To bridge ethnic potential divides based on ethnicity, age, and gender, it is crucial to establish backgrounds culturally sensitive groups where patients feel their cultural, ethnic, and spiritual beliefs are understood by the group leader. • In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022). • Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises. • Images and content in information can impact the participation of various

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IMPACT

(mental health; psychosis)

Trial registration document

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Challenges

- There is a higher incidence of SMI in ethnic minority and migrant groups.
 Black Caribbean, Black African and South Asian people are more likely to receive a schisophrenia diagnosis (Kirkbride et al., 2012). This may pose challenges in locating accurate medical notes if they were previously treated in another country.
- People with diabetes and SMI have fewer routine eye checks, poorer glycaemic and lipid control, and perhaps ultimately have a 50% poorer survival rate, than those with a diagnosis of diabetes alone. Diabetes is more common in south Asian and black ethnic groups (Public Health England, 2016; Frayne et al., 2005).
- Even though Black, Asian and minority ethnic groups are at higher risk of developing a mental health disorder, it is less likely that they will receive support for their condition (NHS, 2018).
- Black and Minority Ethnic patients can present with a combination of more serious mental health conditions. This can then be perceived with higher risks (e.g. risk of self-neglect, risk to others) and having less social support.
 Discriminatory systems cannot not be entirely ruled out as a contributing factor with issues such as perception of risk (Gajwani et al., 2016).
- In more ethnically diverse areas, ethnic minority groups with SMI have a lower risk of death when compared with white British groups. This was interpreted to mean that ethnic minority groups diagnosed with SMI have lower mortality rates if they reside in areas of own-group ethnic density (Das-Munshi et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups. There is also intersectionality between experiences of stigma, with structural and interpersonal discrimination and low socioeconomic status also affecting level of stigma perceived and experienced (Eylem et al., 2020).
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- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).
- Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).
- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.

- Group sessions may restrict participation for specific ethnic groups without a
 focus on fostering a supportive and understanding environment. To bridge
 potential divides based on ethnicity, age, and gender, it is crucial to establish
 culturally sensitive groups where patients feel their cultural, ethnic, and
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- Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises.
- Images and content in information can impact the participation of various groups. For instance, if using pictures of people, it's crucial to ensure representation that accurately reflects the diversity of ethnic groups involved.
- There may be shame associated with illicit drug use in some cultures more so than others, e.g., data implies that less Asian groups use illicit drugs, when compared with black and white groups. Questions regarding this could be offputting if the reasons for asking are not sensitively and suitably explained.

PANDA

(mental health; psychosis)

Trial registration document

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- While minority populations are less likely to suffer from acute episodes of MDD than Caucasians, they are more likely to suffer from prolonged, chronic, and severely debilitating depression with heavy consequences on their level of daily functioning (Bailey et al., 2019).
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Prodigy (mental health)

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- In more ethnically diverse areas, ethnic minority groups with SMI have a lower risk of death when compared with white British groups. This was interpreted to mean that ethnic minority groups diagnosed with SMI have lower mortality rates if they reside in areas of own-group ethnic density (Das-Munshi et al., 2019).
- Reported across several ethnic backgrounds
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups. There is also intersectionality between experiences of stigma, with structural and interpersonal discrimination and low socioeconomic status also affecting level of stigma perceived and experienced (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Most staff said that they avoided raising the topic of sex with those from cultural/religious backgrounds that are perceived to be more 'traditional' or conservative, such as Asian, Middle Eastern and/or Muslim and Jewish, and particularly females from those cultures. Staff were of the view that discussion of the topic might be considered 'taboo' or shameful in these cultures.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).

WHELD

(mental health; dementia)

Trial registration document

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- Cultural values may include beliefs that dementia-related changes are part of the normal aging process rather than an abnormal process, such that in some groups and communities, cognitive decline may not elicit concern until symptoms are well beyond the early or mild stages (Anderson et al., 2010).
- Individuals within some cultures may be more likely to view cognitive decline as disgraceful and something that should be kept within the family. A dementing illness may be difficult to accept when the ethnic elder may be the historian, mediator, and provider of emotional and financial support for many generations of family members living in the same home (Anderson et al., 2010).
- In communities with a belief in reincarnation, dementia can be seen as a punishment for behaviour in a past life (Alzheimer's Society, 2021).
- In some Muslim communities, mental health and neurological conditions including dementia are often attributed to 'Jinns' supernatural creatures that harm humans or drive them mad.
- Other communities may see dementia as a form of evil spirits, witchcraft, Black Magic, or God's will.
- A lack of shared social or ethnic identity between clinician and patient could limit participation of certain ethnic groups (Huerto, 2020).
- Same gender preference of clinician with the patient may also have an effect on participation. Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- Questionnaires might limit participation due to language barriers or literacy levels.

Asian/Asian British

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	(mental health)
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Only reported in Asian/Asian British participants	mental health diagnosis, and this can cause some people from this community to hide it – in attempt to uphold their reputation or social status. • Asian Americans have more stigma to mental health than the white American
	population. There is much variation within an ethnic group too, for example Chinese Americans are less likely to use mental health services due to the perceived shame that is associated with a diagnosis. Whereas Filipino Americans are less like to seek support due to mistrust of systems (Martinez et al., 2020; Yang et al., 2008).
	 Face-to-face 1:1 sessions could be a barrier for people who would struggle to pay for travel to and from the clinic. In London, poverty rates are highest for Bangladeshi and Pakistani households and lowest for white households.

- In 2011, 47% of Asian households comprised married couples, the highest percentage among ethnic groups. This suggests potential increased support for caring for dependents, although complexities arise regarding the distribution of responsibilities, with women often shouldering more (Gov.uk, 2019).
- The participant information sheets are long and require a good understanding
 of English, with no translator option provided. This is likely to impact the
 participation of Asian groups who do not speak English as their first language.
- Asian ethnic groups are more likely to rely on their wider family when making healthcare decisions (Mok et al., 2015).

IMPACT

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- It is a taboo subject in some Indian and South Asian households to have a mental health diagnosis, and this can cause some people from this community to hide it – in attempt to uphold their reputation or social status.
- Asian Americans have more stigma to mental health than the white American population. There is much variation within an ethnic group too, for example Chinese Americans are less likely to use mental health services due to the perceived shame that is associated with a diagnosis. Whereas Filipino Americans are less like to seek support due to mistrust of systems (Martinez et al., 2020; Yang et al., 2008).
- Face-to-face 1:1 sessions could be a barrier for people who would struggle to pay for travel to and from the clinic. In London, poverty rates are highest for Bangladeshi and Pakistani households and lowest for white households.
- In 2011, 47% of Asian households comprised married couples, the highest percentage among ethnic groups. This suggests potential increased support for caring for dependents, although complexities arise regarding the distribution of responsibilities, with women often shouldering more (Gov.uk, 2019).
- The participant information sheets are long and require a good understanding of English, with no translator option provided. This is likely to impact the participation of Asian groups who do not speak English as their first language.
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- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).

• It is a taboo subject in some Indian and South Asian households to have a mental health diagnosis, and this can cause some people from this community to hide it – in attempt to uphold their reputation or social status.

 Asian Americans have more stigma to mental health than the white American population. There is much variation within an ethnic group too, for example Chinese Americans are less likely to use mental health services due to the perceived shame that is associated with a diagnosis. Whereas Filipino Americans are less like to seek support due to mistrust of systems (Martinez et al., 2020; Yang et al., 2008).

Only reported in Asian/Asian British participants

- Face-to-face 1:1 sessions could be a barrier for people who would struggle to pay for travel to and from the clinic. In London, poverty rates are highest for Bangladeshi and Pakistani households and lowest for white households.
- In 2011, 47% of Asian households comprised married couples, the highest percentage among ethnic groups. This suggests potential increased support for caring for dependents, although complexities arise regarding the distribution of responsibilities, with women often shouldering more (Gov.uk, 2019).
- Asian ethnic groups are more likely to rely on their wider family when making healthcare decisions (Mok et al., 2015).
- Chinese people are the least likely to use NHS secondary mental health services (UK Government, 2022a).

WHELD

(mental health; dementia)

Trial registration document

INCLUDE Framework

Challenges

- Cultural values may include beliefs that dementia-related changes are part of the normal aging process rather than an abnormal process, such that in some groups and communities, cognitive decline may not elicit concern until symptoms are well beyond the early or mild stages (Anderson et al., 2010).
- Individuals within some cultures may be more likely to view cognitive decline as disgraceful and something that should be kept within the family. A dementing illness may be difficult to accept when the ethnic elder may be the historian, mediator, and provider of emotional and financial support for many generations of family members living in the same home (Anderson et al., 2010).
- In communities with a belief in reincarnation, dementia can be seen as a punishment for behaviour in a past life (Alzheimer's Society, 2021).
- In some Muslim communities, mental health and neurological conditions including dementia are often attributed to 'Jinns' supernatural creatures that harm humans or drive them mad.
- Other communities may see dementia as a form of evil spirits, witchcraft, Black Magic, or God's will.
- A lack of shared social or ethnic identity between clinician and patient could limit participation of certain ethnic groups (Huerto, 2020).
- Same gender preference of clinician with the patient may also have an effect on participation. Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- Questionnaires might limit participation due to language barriers or literacy levels.

Only reported in Asian/Asian British participants

Reported

across

several

backgrounds

ethnic

- South Asian people have a 17% lower incidence of dementia than the average (UCL, 2022).
- In many communities there is no word for dementia, or it is neither easily translatable or commonly used, particularly in some South Asian and Chinese communities. In many Indian languages, 'pagal' describes behaviours similar to dementia but refers to madness caused by evil spirits or past misdeeds. In Chinese communities, while there are various words to describe dementia symptoms, the Mandarin word 'chai-dai' means idiocy or dull-wittedness.
- Asian Americans have more stigma to mental health than the white American population. There is much variation within an ethnic group too, for example Chinese Americans are less likely to use mental health services due to the perceived shame that is associated with a diagnosis. Whereas Filipino Americans are less like to seek support due to mistrust of systems (Martinez et al., 2020; Yang et al., 2008).
- Asian ethnic groups are more likely to rely on their wider family when making healthcare decisions (Mok et al., 2015).

Black/African/Caribbean/Black British

ANTLER (mental health) Trial registration document **INCLUDE Framework** Challenges • Minority populations, though less prone to acute MDD episodes than Caucasians, face a higher likelihood of enduring chronic, severely debilitating depression, significantly impacting their daily functioning (Bailey et al., 2019). • Non-white groups see mental illness as more dangerous and express a greater desire to segregate from those with mental illness. There are also variations in perceptions of mental illness danger among minority groups (Eylem et al., 2020). Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial. • In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness. • A clinician's gender matching that of the patient can influence participation. Some ethnic groups, like South Asian women, may feel more comfortable expressing themselves with a clinician of the same gender. Reported Group sessions may restrict participation for specific ethnic groups without a focus on fostering a supportive and understanding environment. To bridge across potential divides based on ethnicity, age, and gender, it is crucial to establish several culturally sensitive groups where patients feel their cultural, ethnic, and ethnic spiritual beliefs are understood by the group leader. backgrounds • In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022). • Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises. • Images and content in information can impact the participation of various groups. For instance, if using pictures of people, it's crucial to ensure representation that accurately reflects the diversity of ethnic groups involved. • Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012). African American and Hispanic/Latina women with depression or depressive symptoms more likely to report somatic symptoms compared with White women (Lara-Cinisomo et al., 2020). Only • Black adults have the lowest mental health treatment rate of any ethnic group, reported in at 6% (compared to 13% in the White British group) (NHS, 2018). • Black ethnic groups may consider mental illness to equate being considered Black/ as "crazy" in their social circles. Black people may also be more like to use African/ physical descriptions when attempting to describe their mental health, such as Caribbean/ describing bodily aches when talking about depression (National Alliance on Black British Mental Illness, 2017). participants

- Black communities are more likely to manage adversities on their own and more inclined to rely on spirituality, as opposed to seeking medical attention (Moore-Thomas & Day-Vines, 2008).
- In 2011, 18.9% of black households were single parent households, the highest of all other ethnic groups for this category. With black ethnic groups being more at risk of being diagnosed with psychosis, this could affect their ability to participate in sessions that require more time away from home (Gov.uk, 2019).

IMPACT

(mental health; psychosis)

Trial registration document

INCLUDE Framework

Challenges

- There is a higher incidence of SMI in ethnic minority and migrant groups.
 Black Caribbean, Black African and South Asian people are more likely to receive a schisophrenia diagnosis (Kirkbride et al., 2012). This may pose challenges in locating accurate medical notes if they were previously treated in another country.
- People with diabetes and SMI have fewer routine eye checks, poorer glycaemic and lipid control, and perhaps ultimately have a 50% poorer survival rate, than those with a diagnosis of diabetes alone. Diabetes is more common in south Asian and black ethnic groups (Public Health England, 2016; Frayne et al., 2005).
- Even though Black, Asian and minority ethnic groups are at higher risk of developing a mental health disorder, it is less likely that they will receive support for their condition (NHS, 2018).
- Black and Minority Ethnic patients can present with a combination of more serious mental health conditions. This can then be perceived with higher risks (e.g. risk of self-neglect, risk to others) and having less social support. Discriminatory systems cannot not be entirely ruled out as a contributing factor with issues such as perception of risk (Gajwani et al., 2016).
- In more ethnically diverse areas, ethnic minority groups with SMI have a lower risk of death when compared with white British groups. This was interpreted to mean that ethnic minority groups diagnosed with SMI have lower mortality rates if they reside in areas of own-group ethnic density (Das-Munshi et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups. There is also intersectionality between experiences of stigma, with structural and interpersonal discrimination and low socioeconomic status also affecting level of stigma perceived and experienced (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).

- Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).
- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- Group sessions may restrict participation for specific ethnic groups without a
 focus on fostering a supportive and understanding environment. To bridge
 potential divides based on ethnicity, age, and gender, it is crucial to establish
 culturally sensitive groups where patients feel their cultural, ethnic, and
 spiritual beliefs are understood by the group leader.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).
- Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises.
- Images and content in information can impact the participation of various groups. For instance, if using pictures of people, it's crucial to ensure representation that accurately reflects the diversity of ethnic groups involved.
- There may be shame associated with illicit drug use in some cultures more so than others, e.g., data implies that less Asian groups use illicit drugs, when compared with black and white groups. Questions regarding this could be offputting if the reasons for asking are not sensitively and suitably explained.
- Symptoms related to psychosis are higher in black men than any other ethnic group 3.2% in black men, 1.3% in Asian men and 0.3% in white men.
- Black adults have the lowest mental health treatment rate of any ethnic group, at 6% (compared to 13% in the White British group) (NHS, 2018).
- There is a greater likelihood of Black and Minority Ethnic groups being diagnosed with schizophrenia in predominantly white geographical areas. Rates of psychosis and detention in psychiatric settings are significantly higher in the UK and in the Netherlands compared with rates for African Caribbean men resident in the Caribbean. These differences are likely to be related to aspects of African Caribbean psychosocial experiences in certain countries (Khan et al., 2017; Salize & Dressing, 2004).
- Black ethnic groups may consider mental illness to equate being considered as "crazy" in their social circles. Black people may also be more like to use physical descriptions when attempting to describe their mental health, such as describing bodily aches when talking about depression (National Alliance on Mental Illness, 2017).
- Black communities are more likely to manage adversities on their own and more inclined to rely on spirituality, as opposed to seeking medical attention (Moore-Thomas & Day-Vines, 2008).
- In 2011, 18.9% of black households were single parent households, the highest of all other ethnic groups for this category. With black ethnic groups being more at risk of being diagnosed with psychosis, this could affect their ability to participate in sessions that require more time away from home (Gov.uk, 2019).
- Black groups may be more wary of white clinicians and potentially be more trusting if a black clinician approached them to participate.

Only reported in Black/ African/ Caribbean/ Black British participants

PANDA

(mental health; psychosis)

Trial registration document

INCLUDE Framework

Challenges

- While minority populations are less likely to suffer from acute episodes of MDD than Caucasians, they are more likely to suffer from prolonged, chronic, and severely debilitating depression with heavy consequences on their level of daily functioning (Bailey et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).

• Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).

- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- Group sessions may restrict participation for specific ethnic groups without a
 focus on fostering a supportive and understanding environment. To bridge
 potential divides based on ethnicity, age, and gender, it is crucial to establish
 culturally sensitive groups where patients feel their cultural, ethnic, and
 spiritual beliefs are understood by the group leader.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- African American and Hispanic/Latina women with depression or depressive symptoms more likely to report somatic symptoms compared with White women (Lara-Cinisomo et al., 2020).
- Only
 reported in
 Black/
 African/
 Caribbean/
 Black British
 participants

Reported

backgrounds

across

several

ethnic

- There are differences in presenting symptoms between African Americans and non-Hispanic Caucasians, with negative affect and interpersonal problems being harbingers of depressive disorder in African Americans (Bailey et al., 2019).
- Black ethnic groups may consider mental illness to equate being considered as "crazy" in their social circles. Black people may also be more like to use physical descriptions when attempting to describe their mental health, such as

- describing bodily aches when talking about depression (National Alliance on Mental Illness, 2017).
- Black communities are more likely to manage adversities on their own and more inclined to rely on spirituality, as opposed to seeking medical attention (Moore-Thomas & Day-Vines, 2008).
- Black adults have the lowest mental health treatment rate of any ethnic group, at 6% (compared to 13% in the White British group) (NHS, 2018).
- In 2011, 18.9% of black households were single parent households, the highest of all other ethnic groups for this category. With black ethnic groups being more at risk of being diagnosed with psychosis, this could affect their ability to participate in sessions that require more time away from home (Gov.uk, 2019).
- Black groups may be more wary of white clinicians and potentially be more trusting if a black clinician approached them to participate.

Prodigy (mental health)

Trial registration document

INCLUDE Framework

Challenges

- While minority populations are less likely to suffer from acute episodes of MDD than Caucasians, they are more likely to suffer from prolonged, chronic, and severely debilitating depression with heavy consequences on their level of daily functioning (Bailey et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).
- Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).
- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).
- Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those,

like black groups, who often receive initial treatment through A&E or during crises.

- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- African American and Hispanic/Latina women with depression or depressive symptoms more likely to report somatic symptoms compared with White women (Lara-Cinisomo et al., 2020).
- Black adults have the lowest mental health treatment rate of any ethnic group, at 6% (compared to 13% in the White British group) (NHS, 2018).
- People in all ethnic minority groups but most notably Black Caribbean, Black African and Black British people with a diagnosis of severe mental illness experience higher rates of contact with the police and criminal justice system, more admission to psychiatric hospitals, less voluntary in-patient care and less primary care intervention (Bhui et al., 2018).
- There are differences in presenting symptoms between African Americans and non-Hispanic Caucasians, with negative affect and interpersonal problems being harbingers of depressive disorder in African Americans (Bailey et al., 2019).
- Black ethnic groups may consider mental illness to equate being considered as "crazy" in their social circles. Black people may also be more like to use physical descriptions when attempting to describe their mental health, such as describing bodily aches when talking about depression (National Alliance on Mental Illness, 2017).
- Black communities are more likely to manage adversities on their own and more inclined to rely on spirituality, as opposed to seeking medical attention (Moore-Thomas & Day-Vines, 2008).
- In 2011, 18.9% of black households were single parent households, the highest of all other ethnic groups for this category. With black ethnic groups being more at risk of being diagnosed with psychosis, this could affect their ability to participate in sessions that require more time away from home (Gov.uk, 2019).
- Black groups may be more wary of white clinicians and potentially be more trusting if a black clinician approached them to participate.

Only reported in Black/ African/ Caribbean/ Black British participants

REMEDY

(mental health; psychosis)

Trial registration document

INCLUDE Framework

Challenges

- There is a higher incidence of SMI in ethnic minority and migrant groups.
 Black Caribbean, black African and South Asian people are more likely to receive a schizophrenia diagnosis when compared with white people (Kirkbride et al., 2012).
- Black and Minority Ethnic patients can present with a combination of more serious mental health conditions. This can then be perceived with higher risks (e.g. risk of self-neglect, risk to others) and having less social support (Gaiwani et al., 2016).
- In more ethnically diverse areas, ethnic minority groups with SMI have a lower risk of death when compared with white British groups. This was interpreted to mean that ethnic minority groups diagnosed with SMI have lower mortality rates if they reside in areas of own-group ethnic density (Das-Munshi et al., 2019).
- Reported across several ethnic backgrounds
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups. There is also intersectionality between experiences of stigma, with structural and interpersonal discrimination and low socioeconomic status also affecting level of stigma perceived and experienced (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Most staff said that they avoided raising the topic of sex with those from cultural/religious backgrounds that are perceived to be more 'traditional' or conservative, such as Asian, Middle Eastern and/or Muslim and Jewish, and particularly females from those cultures. Staff were of the view that discussion of the topic might be considered 'taboo' or shameful in these cultures.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).

• Black adults have the lowest mental health treatment rate of any ethnic group, at 6% (compared to 13% in the White British group) (NHS, 2018).

- Black African and Caribbean men have a higher chance of being sectioned through criminal justice routes (Gajwani et al., 2016).
- There is a greater likelihood of Black and Minority Ethnic groups being diagnosed with schisophrenia in predominantly white geographical areas. Rates of psychosis and detention in psychiatric settings are significantly higher in the UK and in the Netherlands compared with rates for African Caribbean men resident in the Caribbean. These differences are likely to be related to aspects of African Caribbean psychosocial experiences in certain countries (Khan et al., 2017; Salize & Dressing, 2004).

Only
reported in
Black/
African/
Caribbean/
Black British
participants

- Black ethnic groups may consider mental illness to equate being considered as "crazy" in their social circles. Black people may also be more like to use physical descriptions when attempting to describe their mental health, such as describing bodily aches when talking about depression (National Alliance on Mental Illness, 2017).
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- In 2011, 18.9% of black households were single parent households, the highest of all other ethnic groups for this category. With black ethnic groups being more at risk of being diagnosed with psychosis, this could affect their ability to participate in sessions that require more time away from home (Gov.uk, 2019).

WHELD (mental health; dementia)

Trial registration document

INCLUDE Framework

Challenges

- Cultural values may include beliefs that dementia-related changes are part of the normal aging process rather than an abnormal process, such that in some groups and communities, cognitive decline may not elicit concern until symptoms are well beyond the early or mild stages (Anderson et al., 2010).
- Individuals within some cultures may be more likely to view cognitive decline as disgraceful and something that should be kept within the family. A dementing illness may be difficult to accept when the ethnic elder may be the historian, mediator, and provider of emotional and financial support for many generations of family members living in the same home (Anderson et al., 2010).
- In communities with a belief in reincarnation, dementia can be seen as a punishment for behaviour in a past life (Alzheimer's Society, 2021).
- In some Muslim communities, mental health and neurological conditions including dementia are often attributed to 'Jinns' supernatural creatures that harm humans or drive them mad.
- Other communities may see dementia as a form of evil spirits, witchcraft, Black Magic, or God's will.
- A lack of shared social or ethnic identity between clinician and patient could limit participation of certain ethnic groups (Huerto, 2020).
- Same gender preference of clinician with the patient may also have an effect on participation. Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- Questionnaires might limit participation due to language barriers or literacy levels.
- Hispanic and black adults are less likely to use nursing homes than white adults, and this difference is magnified when taking into account black and Hispanic adults poor health and fewer socioeconomic resources (Thomeer et al., 2015).

Only reported in Black/ African/ Caribbean/ Black British participants

Reported

across

several

backgrounds

ethnic

- Black people have a 22% higher incidence of dementia recorded than white people (UCL, 2022).
- It is possible that cognitive decline is more rapid among African-American elders with dementia (Hargrave et al., 1998).
- Black people with dementia (both U.S.-born African Americans and African Caribbean) were more likely to have psychotic symptoms (Anderson et al., 2010).
- Some African-Caribbean communities see dementia as a result of possession by evil spirits.
- Black communities are more likely to manage adversities on their own and more inclined to rely on spirituality, as opposed to seeking medical attention (Moore-Thomas & Day-Vines, 2008).

Other ethnic groups

ANTLER (mental health)

Trial registration document

INCLUDE Framework

Challenges

- Minority populations, though less prone to acute MDD episodes than Caucasians, face a higher likelihood of enduring chronic, severely debilitating depression, significantly impacting their daily functioning (Bailey et al., 2019).
- Non-white groups see mental illness as more dangerous and express a greater desire to segregate from those with mental illness. There are also variations in perceptions of mental illness danger among minority groups (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- A clinician's gender matching that of the patient can influence participation. Some ethnic groups, like South Asian women, may feel more comfortable expressing themselves with a clinician of the same gender.
- Group sessions may restrict participation for specific ethnic groups without a
 focus on fostering a supportive and understanding environment. To bridge
 potential divides based on ethnicity, age, and gender, it is crucial to establish
 culturally sensitive groups where patients feel their cultural, ethnic, and
 spiritual beliefs are understood by the group leader.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).
- Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises.
- Images and content in information can impact the participation of various groups. For instance, if using pictures of people, it's crucial to ensure representation that accurately reflects the diversity of ethnic groups involved.
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- African American and Hispanic/Latina women with depression or depressive symptoms more likely to report somatic symptoms compared with White women (Lara-Cinisomo et al., 2020).

IMPACT

(mental health; psychosis)

Trial registration document

INCLUDE Framework

Challenges

- There is a higher incidence of SMI in ethnic minority and migrant groups.
 Black Caribbean, Black African and South Asian people are more likely to receive a schisophrenia diagnosis (Kirkbride et al., 2012). This may pose challenges in locating accurate medical notes if they were previously treated in another country.
- People with diabetes and SMI have fewer routine eye checks, poorer glycaemic and lipid control, and perhaps ultimately have a 50% poorer survival rate, than those with a diagnosis of diabetes alone. Diabetes is more common in south Asian and black ethnic groups (Public Health England, 2016; Frayne et al., 2005).
- Even though Black, Asian and minority ethnic groups are at higher risk of developing a mental health disorder, it is less likely that they will receive support for their condition (NHS, 2018).
- Black and Minority Ethnic patients can present with a combination of more serious mental health conditions. This can then be perceived with higher risks (e.g. risk of self-neglect, risk to others) and having less social support.
 Discriminatory systems cannot not be entirely ruled out as a contributing factor with issues such as perception of risk (Gajwani et al., 2016).
- In more ethnically diverse areas, ethnic minority groups with SMI have a lower risk of death when compared with white British groups. This was interpreted to mean that ethnic minority groups diagnosed with SMI have lower mortality rates if they reside in areas of own-group ethnic density (Das-Munshi et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups. There is also intersectionality between experiences of stigma, with structural and interpersonal discrimination and low socioeconomic status also affecting level of stigma perceived and experienced (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).
- Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).
- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.

- Group sessions may restrict participation for specific ethnic groups without a
 focus on fostering a supportive and understanding environment. To bridge
 potential divides based on ethnicity, age, and gender, it is crucial to establish
 culturally sensitive groups where patients feel their cultural, ethnic, and
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- Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises.
- Images and content in information can impact the participation of various groups. For instance, if using pictures of people, it's crucial to ensure representation that accurately reflects the diversity of ethnic groups involved.
- There may be shame associated with illicit drug use in some cultures more so than others, e.g., data implies that less Asian groups use illicit drugs, when compared with black and white groups. Questions regarding this could be offputting if the reasons for asking are not sensitively and suitably explained.

PANDA

(mental health; psychosis)

Trial registration document

INCLUDE Framework

Challenges

- While minority populations are less likely to suffer from acute episodes of MDD than Caucasians, they are more likely to suffer from prolonged, chronic, and severely debilitating depression with heavy consequences on their level of daily functioning (Bailey et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).
- Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).
- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- Group sessions may restrict participation for specific ethnic groups without a
 focus on fostering a supportive and understanding environment. To bridge
 potential divides based on ethnicity, age, and gender, it is crucial to establish
 culturally sensitive groups where patients feel their cultural, ethnic, and
 spiritual beliefs are understood by the group leader.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- African American and Hispanic/Latina women with depression or depressive symptoms more likely to report somatic symptoms compared with White women (Lara-Cinisomo et al., 2020).

Prodigy (mental health)

Trial registration document

INCLUDE Framework

Challenges

- While minority populations are less likely to suffer from acute episodes of MDD than Caucasians, they are more likely to suffer from prolonged, chronic, and severely debilitating depression with heavy consequences on their level of daily functioning (Bailey et al., 2019).
- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Black and ethnic minority groups in the UK are more likely to disengage from mental health services and experience a poor outcome from treatment. This could be due to the disparity of social identities between clinicians and patient (Alegria et al., 2020).
- Shared decision making is also important to increase participation, as this can either encourage or discourage collaborative engagement between patient and clinician (Alegría et al., 2008).
- Where possible using the patient's first language can support problem solving and aid the clinician understand the problem through the patient's eyes.
 Limiting participation only to people proficient in English with no need for an interpreter will disproportionately affect ethnic minority groups.
- Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).
- Clinic posters may effectively reach groups likely to use mental health services, such as White groups. However, they may not be suitable for those, like black groups, who often receive initial treatment through A&E or during crises.
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- African American and Hispanic/Latina women with depression or depressive symptoms more likely to report somatic symptoms compared with White women (Lara-Cinisomo et al., 2020).

REMEDY

(mental health; psychosis)

Trial registration document

INCLUDE Framework

Challenges

- There is a higher incidence of SMI in ethnic minority and migrant groups.
 Black Caribbean, black African and South Asian people are more likely to receive a schizophrenia diagnosis when compared with white people (Kirkbride et al., 2012).
- Black and Minority Ethnic patients can present with a combination of more serious mental health conditions. This can then be perceived with higher risks (e.g. risk of self-neglect, risk to others) and having less social support (Gajwani et al., 2016).
- In more ethnically diverse areas, ethnic minority groups with SMI have a lower risk of death when compared with white British groups. This was interpreted to mean that ethnic minority groups diagnosed with SMI have lower mortality rates if they reside in areas of own-group ethnic density (Das-Munshi et al., 2019).

- Non-white groups perceive mental illness to be more dangerous and express more need to segregate from those who have mental illness. There is also further difference in perception of danger with mental illness between minority groups. There is also intersectionality between experiences of stigma, with structural and interpersonal discrimination and low socioeconomic status also affecting level of stigma perceived and experienced (Eylem et al., 2020).
- Clinician unawareness or bias regarding cultural issues, and the inability to speak the patient's native language, may impact both the diagnosis and the patient's ability to participate in the trial.
- In the UK, black and ethnic minority groups are more often diagnosed with psychotic disorders and tend to seek help in A&E during crises. This pattern might indicate that psychoses are more severe in these groups due to delayed help-seeking at less severe stages of illness.
- Most staff said that they avoided raising the topic of sex with those from cultural/religious backgrounds that are perceived to be more 'traditional' or conservative, such as Asian, Middle Eastern and/or Muslim and Jewish, and particularly females from those cultures. Staff were of the view that discussion of the topic might be considered 'taboo' or shameful in these cultures.
- In the UK, non-white groups report inferior NHS experiences, potentially linked to lower trust in institutions. This trust disparity might influence comfort preferences, with some groups feeling more at ease in places like local libraries rather than hospitals (Allington et al., 2022).

WHELD

(mental health; dementia)

Trial registration document

INCLUDE Framework

Challenges

- Cultural values may include beliefs that dementia-related changes are part of the normal aging process rather than an abnormal process, such that in some groups and communities, cognitive decline may not elicit concern until symptoms are well beyond the early or mild stages (Anderson et al., 2010).
- Individuals within some cultures may be more likely to view cognitive decline as disgraceful and something that should be kept within the family. A dementing illness may be difficult to accept when the ethnic elder may be the historian, mediator, and provider of emotional and financial support for many generations of family members living in the same home (Anderson et al., 2010).
- In communities with a belief in reincarnation, dementia can be seen as a punishment for behaviour in a past life (Alzheimer's Society, 2021).
- In some Muslim communities, mental health and neurological conditions including dementia are often attributed to 'Jinns' supernatural creatures that harm humans or drive them mad.
- Other communities may see dementia as a form of evil spirits, witchcraft, Black Magic, or God's will.
- A lack of shared social or ethnic identity between clinician and patient could limit participation of certain ethnic groups (Huerto, 2020).
- Same gender preference of clinician with the patient may also have an effect on participation. Certain ethnic groups may feel more at ease 'opening up' or expressing themselves with a clinician of the same gender, e.g., south Asian women
- Ethnic minority groups in the UK are more likely to have a collective point of view and lean on their social circles for support and care, as opposed to institutions (Willis, 2012).
- Questionnaires might limit participation due to language barriers or literacy levels.
- Hispanic and black adults are less likely to use nursing homes than white adults, and this difference is magnified when taking into account black and Hispanic adults poor health and fewer socioeconomic resources (Thomeer et al., 2015).

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