

RESEARCH: EDUCATIONAL AND
PSYCHOLOGICAL ASPECTS

Development of Healthy Eating and Active Lifestyles for Diabetes, a culturally tailored diabetes self-management education and support programme for Black-British adults: A participatory research approach

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Abstract

Aims: To develop an evidence-based, culturally tailored, diabetes self-management education and support programme for Black-British adults, called Healthy Eating and Active Lifestyles for Diabetes (HEAL-D), using participatory methods to engage key stakeholders in the intervention design process.

Methods: Black-British adults living with type 2 diabetes, healthcare professionals and community leaders were engaged in an intervention development study. The intervention structure, format, content and delivery were developed through three phases of participatory research: Phase 1, formative research, involved focus groups and interviews; interactive co-development workshops were conducted in Phase 2; and Phase 3 focused on materials development.

Results: In Phase 1, focus groups and interviews identified the importance of nurturing collectivism, a reliance on informal sources of information/advice, barriers to attending appointments associated with competing priorities of work, travel and carer commitments, and a preference for directness and simple, clear advice/messages. A priority for healthcare professionals was the intervention embedding within current primary care structures and aligning with incentivised targets/metrics. Phase 2 (workshops) highlighted key requirements: avoidance of medical settings, appropriately trained and culturally knowledgeable educators, flexible appointments, preference for verbal and visual information and avoidance of technical/medical terminology. In Phase 3 (materials development), culturally sensitive videos, short films and information booklets were developed to convey educational messages, and food photography was used to provide culturally relevant dietary advice.

Conclusions: Participatory methods provide a means to understand the needs of specific communities. This approach enables the development of healthcare interventions that are sensitive to the needs of service users and providers.

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KEYWORDS

African, Black-British, caribbean, culture, education, ethnicity, health services, self-management, type 2 diabetes

1 | INTRODUCTION

Tackling ethnic inequalities in type 2 diabetes is a global healthcare priority.¹ In populations of Black African ethnicity, rates of type 2 diabetes are around 3 times higher than in populations of White European ethnicity,² and it develops, on average, 10 years earlier.³ Furthermore, poorer glycaemic control is evident at the time of diagnosis, and greater medical management is required to achieve good control.⁴⁵

Poor access to diabetes healthcare is a significant issue for minority ethnic groups.⁶ Specifically, Black communities report that healthcare professionals lack cultural understanding⁷ and their advice lacks cultural relevance⁸ or is poorly adapted to their culture and needs.⁹ Socio-economic barriers to healthcare engagement are also often cited.¹⁰ In the United Kingdom, healthcare is free at the point of delivery. Despite this, UK minority ethnic groups report finding it relatively difficult to access first-line primary care services for diabetes management.¹¹ Furthermore, they are more likely to report that they have not had the opportunity to attend a diabetes education course, as recommended in national management guidelines,¹² compared with White populations. These issues may contribute to the poorer diabetes outcomes and increased morbidity experienced by Black patients.

Culturally tailored healthcare is proposed as a primary means by which to tackle ethnic inequalities in health^{13,14} and is identified as a priority by patients.¹⁵ Culturally tailored education has resulted in greater improvements in diabetes control and knowledge than usual care, and the benefits are maintained long-term.¹⁶ Cultural tailoring of healthcare can take many different forms, for example, tailoring of materials to specific languages or cultural foods.¹⁷ To date, culturally tailored interventions for Black communities have largely been based in America and may not translate to other countries.¹⁶ In the United Kingdom, for example, the healthcare structures are different and so may be the cultural needs of the communities.¹⁴

Participatory methods are an effective means by which to develop healthcare interventions for ethnic minority communities.¹⁸ Through establishing partnerships and fostering engagement of those who are affected by the intervention, participatory methods enable a sustained and open dialogue between stakeholders and researchers to produce a more complete understanding of their needs, ensuring its acceptability and sensitivity to the needs of both service users and providers, whilst also enabling incorporation of culture in the intervention.^{18,19} These methods focus on sharing power, whereby all stakeholders are considered equal, and have been used in the

Novelty Statement

- Culturally tailored diabetes self-management education offers greater benefits than standard care for people from minority ethnic backgrounds. To date, culturally tailored interventions for Black communities have largely been based in the United States.
- Black-British adults living with type 2 diabetes, healthcare professionals and community leaders participated in co-developing a culturally tailored diabetes self-management education and support programme to ensure its acceptability and sensitivity for both service users and providers.
- Participatory methods provide a means to understand the needs of specific communities. This approach enables the development of healthcare interventions that are sensitive to the needs of service users and providers.

effective development of culturally tailored health promotion interventions for African-American communities.^{19,20,21}

We aimed to undertake an intervention development study, using participatory methods to engage key stakeholders in the design and development of a culturally tailored, diabetes self-management education and support (DSMES) programme for Black-British adults, called Healthy Eating and Active Lifestyles for Diabetes (HEAL-D).

Our objectives were the following:

- To use participatory methods to understand what is needed, in terms of structure, format, delivery and content, to ensure cultural sensitivity of a DSMES programme for Black-British communities.
- To develop HEAL-D as a DSMES programme that is sensitive to the needs of service users and providers and is implementable within the healthcare system.
- To refine the programme theory for the HEAL-D intervention.

2 | PARTICIPANTS AND METHODS

An intervention development study was conducted using participatory methods to engage key stakeholders in the design and development of HEAL-D as a culturally tailored DSMES programme for Black-British communities.

The research was approved by King's College London University Ethics Committee (LRS-15/16-3240) and UK Health Research Authority (IRAS 194991). All participants provided informed, written consent prior to participation.

2.1 | Intervention development

To ensure its clinical utility and potential for embedment within current healthcare services, it was established that the intervention curriculum should align with existing UK diet and lifestyle management recommendations and guidelines¹²²²:

- Achieve 5%–10% weight loss or weight maintenance in those of healthy weight.
- Undertake 150 min/week of moderate-to-vigorous intensity aerobic physical activity plus 2 sessions/week of strength training.
- Balance carbohydrate intakes through portion control and promotion of low glycaemic index and wholegrain sources.
- Limit saturated fat intake (<10% of energy intake), replace with mono-unsaturated fats.
- Limit salt intake (<6 g/day).
- Consume oily fish at least twice per week.

The structure, format and delivery of the curriculum, and accompanying resources, were developed in three distinct phases of participatory research (Figure 1). A stakeholder advisory group (SAG) consisting of stakeholder representatives was set up to inform and guide all stages of the intervention development, particularly to seek the opinion of key stakeholders relating to interpretation of the qualitative data.

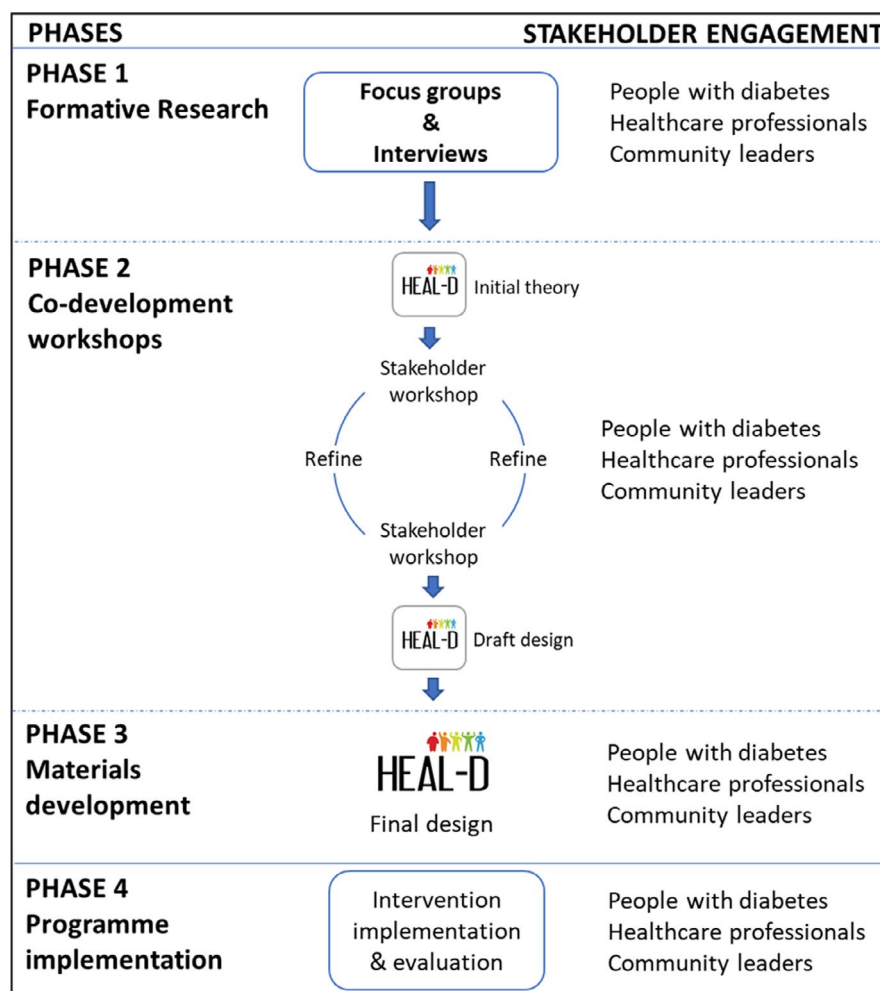
2.2 | Participants

Three stakeholder groups were engaged in the research.

2.2.1 | People living with type 2 diabetes

Men and women (aged 18–75 years) were recruited of self-defined Black-British, Black African or Black Caribbean ethnicity, residing in London, and with type 2 diabetes (documented diagnosis by healthcare provider). As HEAL-D was intended in its first incarnation only for delivery in English, non-English-speaking individuals, as well as people with

FIGURE 1 Stakeholder participation in the design and development of the healthy eating & active lifestyles for diabetes self-management education and support programme



other chronic conditions affecting their diet and lifestyle needs, e.g., chronic kidney disease, were excluded.

Recruitment was via letters of invitation sent to people who had participated in previous diabetes research and to eligible participants identified through general practice database searches within the London boroughs of Lambeth and Southwark. Self-referral was also facilitated through advertisements in the local press and networking with churches, mosques and community groups with predominantly Black-British communities/congregations in the London boroughs of Lambeth and Southwark.

Eligibility was confirmed via a short telephone screening questionnaire.

2.2.2 | Healthcare practitioners

Healthcare practitioners (e.g. general practitioners, general practice nurses, diabetes specialist nurses and dietitians, and commissioners) who provide primary and intermediate care services to Black-British communities in the London boroughs of Lambeth, Southwark, Brent (boroughs recognised for significant representation of Black communities), were invited to participate in the study by email and telephone.

2.2.3 | Community leaders

Community leader participants were identified from the research team's networks and active partnerships, for example, through the Diabetes UK Community Champions network, which is a volunteer health advocacy initiative, and several London churches and mosques. Subsequently, the reach of our recruitment was expanded through 'snow-balling', whereby participants introduced us to other individuals within their networks. The emphasis was on faith leaders, activists and volunteer health advocates, serving or working with Black-British communities/congregations from across London.

2.3 | Procedures

2.3.1 | Phase 1: Formative research

Focus groups and interviews were conducted, aiming to explore the relevance, acceptability and feasibility of cultural tailoring methods that have been used in health promotion interventions targeted at Black communities from the literature, whilst also identifying other issues and priorities that might be relevant to the design and context of HEAL-D.

The focus groups were conducted with people living with type 2 diabetes. They were held in local accessible community venues, e.g., church halls, as well as on university premises. Participants were purposively sampled to get a spread of

socio-economic position, generational status and ancestral origins, and separate focus groups were conducted with men and women and patients of direct African *versus* Caribbean ancestry. The focus groups aimed to explore key themes identified in the literature relating to barriers to healthcare engagement, as well as exploring perceptions of diabetes and barriers/motivations to diet and lifestyle behaviour change. A topic guide was used, and prompts such as food models, video clips and body weight images were used to steer discussions and ensure coverage of key themes whilst encouraging free discussion of opinions/perspectives (Data S1). Focus groups were selected to enable us to understand normative needs, as suited to the development of a community intervention.

Semi-structured interviews, conducted with healthcare practitioners, explored issues relating to healthcare needs and engagement. Topics for discussion included experiences of delivering healthcare to Black-British patients and barriers and facilitators to working in partnership with community groups to deliver care for Black-British communities (Data S1). Interview methods were chosen to enable us to gather a full range of experiences and therefore optimise implementation.

Semi-structured interviews with community leaders focused on issues relating to the role of community networks in promoting health and healthcare engagement in Black-British communities and to sustaining health amongst community members (Data S1).

The focus groups and interviews were digitally recorded and transcribed verbatim. The data were analysed using the framework approach in NVivo (QSR International). We also used the Behaviour Change Wheel and COM-B framework (reported elsewhere²³) to identify behaviour change techniques that would be relevant to enhance self-efficacy and behaviour change and could be implemented within the delivery of the curriculum. Whilst our initial framework matrix was deductively developed to identify the relevance of existing themes from the literature, we were sensitive to emergent themes in our data (e.g., contextual themes relating to the health system), which helped inform our programme theory, as well as understanding issues of implementation, e.g., favoured settings and timings.

Following initial analysis of the qualitative data, a feedback meeting was held with the SAG. Anonymised interview extracts were presented to illustrate the key themes and issues that were identified. Open discussion/debate was encouraged to enable the research team to understand alternative interpretations.

2.3.2 | Phase 2: Co-development workshops

Following evaluation of the focus groups and interviews, the same stakeholders (patients, healthcare practitioners and community leaders) were invited to participate in 2 half-day (3.5 hr) workshops, held in community locations.

The workshops sought to gain stakeholder involvement in developing the details of the intervention, including the setting, the media channels, structure and delivery, as well as steering the research team to understand patients' literacy and numeracy needs and health literacy. The workshops were structured to begin with a lunch (African and Caribbean cuisine, sourced from specialist caterers) to foster interaction among the participants, followed by small group discussions/tasks in which four to five mixed stakeholders, each with a facilitator from the research team, were provided with tasks.

In the first workshop, scenarios were used to understand important themes that arose from both the formative research and the existing evidence base, namely, setting/location, educator credentials, session timing and literacy/numeracy needs. After discussing the scenarios in their small groups, a volunteering group spokesperson (not the facilitator) presented their feedback to the rest of the participants. A broader discussion was co-facilitated by the spokesperson and a member of the research team to brainstorm key issues, pros and cons relating to alternative scenarios presented to them, for example, regarding the intervention setting, noting feedback on flip charts. The attendees were also asked to review existing educational/support materials, e.g., leaflets, and provide feedback on, for example, language/phrasing, content, pitch and understanding. The research team then facilitated cross-discussion between groups.

The second workshop focused mainly on engaging with people living with type 2 diabetes and aimed to seek input into the development of the HEAL-D education and support materials. Following a lunch, participants were engaged in a series of activities. Participants were shown a selection of educational videos, ranging in detail and complexity, that aimed to explain about diabetes and its management. For each one feedback was sought as to what aspects were clear and understandable. In other activities, participants were given samples of the draft resources that had been developed, for example, educational booklets, and were asked to provide verbal or written feedback on which information was easy to read *versus* too complex, whether the pictures/images were helpful/motivating, and what messages of advice they perceived were being conveyed. Following small group discussions, the researchers facilitated feedback and a group discussion to clarify/confirm the researchers' understanding.

2.3.3 | Phase 3: Materials development

During Phase 3 the research team met weekly to discuss the iterative intervention development. The curriculum and appropriate activities/materials, based on relevant behaviour change techniques that were identified through the COM-B framework, were mapped to each behavioural goal. At

regular intervals, stakeholder feedback was sought through the SAG, and refinements were made.

3 | RESULTS

3.1 | Phase 1 (formative research)

Eight focus groups were conducted, involving 41 people living with type 2 diabetes (14 men, 27 women; 18 Caribbean, 23 African ethnicity; three groups with African women, two each with Caribbean women and Caribbean men and one with African men). The mean age of participants was 62 ± 11.7 years, ranging from 30 to 84 years. The majority of participants (88%) were first generation migrants; the most common countries of birth were Nigeria ($n = 17$) and Jamaica ($n = 13$). Semi-structured interviews were conducted with 11 healthcare practitioners, including two primary care physicians, three primary care nurses, four diabetes specialist nurses and two diabetes specialist dietitians. Nine community leaders, including five faith leaders (three Christian and two Muslim) and four volunteer health advocates, participated in semi-structured interviews.

The main findings that arose from the different stakeholder groups, including the emergence of themes and priorities, and the learning we took for our intervention development are shown in Table 1, along with illustrative extracts from the qualitative data that led to them. In relation to existing recommendations in the literature, nurturing collectivism was strongly supported. Powerful social connectedness was evident amongst our focus groups participants; we observed participants being motivated by story sharing and the accounts of others, and participants frequently shared contact details to remain connected outside of the research. Other recommendations that were supported were the relevance of social networks and provision of social support, although these emerged as mainly relevant to women. The findings relating to use of community gathering places, culturally concordant educators and lay educators were less clear. In some cases, there was rejection of these; for example, people living with diabetes were equivocal as to the importance of having culturally concordant healthcare professionals/educators, whilst healthcare practitioners recognised clear benefits. Another frequently cited issue, for which we got mixed opinions, was distrust of conventional medicine and healthcare settings. Whilst there was a strong desire to avoid taking medications and a preference for natural therapies, our patients did express trust in the healthcare system, and healthcare professionals were seen as credible individuals. Whilst our patients did not discuss a rejection of medical settings, our community leaders supported the assertion that community gathering places are a means by which communities can be accessed.

TABLE 1 Findings from the formative research: relevance of themes from the literature and emergent themes to the stakeholder groups, with indicative quotes, alongside learnings for HEAL-D development

People living with T2D	Community leaders	Healthcare professionals	Learning for intervention development
Theme: <i>Draw on social networks and deliver care in a social context</i>			
Relevance of theme: MODERATE (notably, mainly relevant to women) <i>'I think one of the best parts of it, apart from the information, was the support you get from people in the group. And that camaraderie' (FG4: Caribbean females)</i>	Relevance of theme: STRONG (supported by faith and non-faith leaders) <i>'when service is finished and we meet down here, start socialising and have a little refreshment, you know' (CL3: Faith leader)</i>	Relevance of theme: MODERATE <i>'people come to clinic and say, 'Oh, my friend told me to do that, so I did it.' So people listen more to the people - their friends or people from their community.'</i> (HP10, DSD)	Social networks are important in African and Caribbean cultures and offer opportunity for engaging communities with health promotion and for information sharing, particularly for women.
Theme: <i>Promote community engagement</i>			
Relevance of theme: WEAK	Relevance of theme: STRONG (supported by faith and non-faith leaders) <i>'It's good, because when they see you as a leader among them they like to listen to you.'</i> (CL3: Faith leader)	Relevance of theme: MODERATE <i>'It's about finding out who in your local community are the key players who can make connections within that community. It may well be that that sort of model would be the route into people who have diabetes who aren't coming to structured education at the moment' (HP5, GP)</i>	Community institutions such as churches and mosques can facilitate engagement with a health agenda but this is not raised as a priority by people living with diabetes.
Theme: <i>Nurture collectivism or cultural cohesion</i>			
Relevance of theme: STRONG <i>'Remember we're a proud people... although we claim to be British, we're black' (FG1: Caribbean females)</i>	Relevance of theme: STRONG <i>'It's part of living in a foreign country. It's part of what we identify ourselves by' (CL4: Faith leader)</i>	Relevance of theme: MODERATE <i>'So two Afro-Caribbean men have got something in common, they both relax, so they normally would start talking. So that's really, really nice when that happens, when they're really chatty and they're talking to each other; that's great.'</i> (HP9, DSN)	Collectivism and cultural cohesion are evident and provide an opportunity to engage communities.
Theme: <i>Use community gathering places</i>			
Relevance of theme: WEAK	Relevance of theme: STRONG <i>'It's a mosque and also it's an organisation combined together. The basic thing is that it serves as a... centre and also school, like a big school.'</i> (CL7: Faith leader)	Relevance of theme: WEAK	Faith-based settings are engaged with the health agenda, and are trusted by their congregations, which may offer a means by which to access communities but this is not raised as a priority by people living with diabetes or healthcare professionals.

(Continues)

TABLE 1 (Continued)

People living with T2D	Community leaders	Healthcare professionals	Learning for intervention development
Theme: <i>Provide a social support structure</i>			
<p>Relevance of theme: MODERATE (notably mainly relevant to females)</p> <p><i>'I think it's the camaraderie of a group as well. You get to know people. Support. Positive support from other people.'</i> (FG1: Caribbean females)</p>	<p>Relevance of theme: STRONG (supported by faith and non-faith leaders)</p> <p><i>'Yes, and they make friends with a lot of people as well, apart from their family'</i> (CL2: non-faith leader)</p>	<p>Relevance of theme: WEAK</p>	<p>Provision of a social support network encourages engagement, particularly for participation in physical activity. The importance of social networks for motivating behaviour change is particularly evident for women. The importance of social support is recognised by healthcare professionals but not specifically relating to African and Caribbean cultural groups.</p>
Theme: <i>Employ culturally concordant healthcare professionals</i>			
<p>Relevance of theme: MODERATE ACCEPTANCE & REJECTION</p> <p><i>'because she's black she takes out this [culturally tailored leaflet] because she knows it's what we cleave. So I thought it was good and it was more encouraging.'</i> (FG4: Caribbean females)</p> <p><i>'it wasn't because she was black that I trusted her; it's because she had the correct documentation. It was her documentation and she was very convincing.'</i> (FG1: Caribbean females)</p>	<p>Relevance of theme: MODERATE ACCEPTANCE & REJECTION</p> <p><i>'Some of them will want someone that is also of their ethnicity.'</i> (CL8: non-faith leader)</p> <p><i>'Probably from someone like you, it would mean a lot to them. Someone actually outside my ethnicity is trying to, does care about and to them you look at, oh, this government actually cares about us.'</i> (CL9: non-faith leader)</p>	<p>Relevance of theme: STRONG</p> <p><i>'and I can say that because I am from there.'</i> (HP8, DSN)</p> <p><i>'it's been a real learning when I've sat in with practice nurses that are from the Caribbean and when they're talking about food then they, because it's their culture, they would pick up on things that I wouldn't have necessarily thought about.'</i> (HP11, DSN)</p>	<p>Culturally concordant healthcare professionals feel more confident in supporting people living with diabetes. However, people living with diabetes and community leaders do not feel this is essential and that cultural understanding and credible documentation are important considerations.</p>
Theme: <i>Employ lay members as educators</i>			
<p>Relevance of theme: WEAK</p>	<p>Relevance of theme: MODERATE</p> <p><i>'so he said, 'Why don't I come and lead on it?' He did and when he led on it everybody understood what he was talking about because he was one of them, he spoke - grass roots. He told them how it is, he told them what they should do, and they just liked it.'</i> (CL8: non-faith leader)</p>	<p>Relevance of theme: MODERATE</p> <p><i>'I've been involved in training for lay educators. It's quite time consuming. We invested a lot of time with one educator who was very keen, very motivated, but then she got another job and then she left. So, I think it's good to have that skill mix, but it then poses problems in training and keeping people updated.'</i> (HP11, DSN)</p>	<p>Lay members of the community may be well placed to foster trust and engagement with a health agenda. However, there are challenges with training needs and retention.</p>

(Continues)

TABLE 1 (Continued)

People living with T2D	Community leaders	Healthcare professionals	Learning for intervention development
Theme: <i>Distrust/rejection of conventional healthcare</i>			
<p>Relevance of theme: STRONG ACCEPTANCE & REJECTION</p> <p>'Every medicine I was prescribed at the time, I'd just dump it. I'd say, 'Go away'' (FG3: African females)</p> <p>'I knew the NHS would bring a programme that, they will not bring somebody that's not an expert in diabetes.' (FG2: African males)</p>	<p>Relevance of theme: MODERATE ACCEPTANCE & REJECTION</p> <p>'we are not anti-doctors, you know.' (CL3: faith leader)</p> <p>'It's cheaper for them, they are used to it and they don't want to get involved with all this, what they call western medication. They don't trust it. What I advised them to do is use whatever you want to use but take your medication as prescribed, unless your doctor, your GP, knows that you are also taking these other herbs.' (CL2: non-faith leader)</p>	<p>Relevance of theme: STRONG</p> <p>'I think sometimes certainly from the African perspective they tend to want to use more natural herbs, lots of herbs that can be bought in local markets, leaves that are boiled or herbal remedies, natural spices that they believe would be better than the traditional Western medicines.' (HP11, DSN)</p>	<p>A strong rejection of medications and a desire for, and trust in, non-pharmacological therapies is recognised by all stakeholders. However, healthcare practitioners and the healthcare system are trusted by community stakeholders, although healthcare professionals question whether there is trust.</p>
New emergent themes			
Theme: <i>Communication style and preferences</i>			
	<p>'because all their communication is verbal, rather than written. I'm not saying they don't read or they don't write, but spoken word has always been there down from generation' (CL1: non-faith leader)</p>	<p>'what I love about the English culture is that people are really polite. I love that, but I think with the Caribbean people it's a bit more, they are polite, but it's different. I think they like people being a little bit more direct.' (HP9, DSN)</p>	<p>A preference for verbal communication and information sharing, and visual messages. Direct communication style is preferred.</p>
Theme: <i>Informal sources of information and advice</i>			
<p>'No, a friend of mine, she told me to use cinnamon tea.' (FG4: Caribbean females)</p>	<p>'I am the first port of call to my friends outside, so any information or anything they need or want, I get the call' (CL1: non-faith leader)</p>	<p>'people come to clinic and say, 'Oh, my friend told me to do that, so I did it.' So people listen more to the people - their friends or people from their community.' (HP10, DSD)</p>	<p>Health-focused information and advice is often sought from informal sources.</p>

(Continues)

TABLE 1 (Continued)

People living with T2D	Community leaders	Healthcare professionals	Learning for intervention development
Theme: <i>Privacy and isolation</i>			
<p><i>'It's not part of our culture... my dad doesn't know that I have diabetes, my mum doesn't know, none of them know that I'm diabetic. Not even one.'</i> (FG2: African males)</p> <p><i>'We don't talk about health issues.'</i></p> <p><i>'it's a personal health condition. Why should we have to tell people?'</i> (FG1: Caribbean females)</p>	<p><i>'But there's a stigma and there is, I would say it is a taboo subject. People don't discuss it'</i> (CL3: faith leader)</p> <p><i>'people don't come out and just say.'</i> (CL5: faith leader)</p>	<p><i>'I think there's a lot of stigma attached with it where people don't talk about it. One person described it as being worse than a diagnosis of cancer and having to accept the diagnosis.'</i> (HP11, DSN)</p>	<p>Specific to African communities, a high level of privacy about personal health and reluctance to disclose disease status may pose issues with engaging people in a group-based programme. Alternatively, group-based programmes may offer support that is not provided through other networks.</p>
Theme: <i>Credibility of advice</i>			
<p><i>'A friend of mine who has actually got into it gave me two packs and it detoxes you.'</i> (FG8: Caribbean males)</p>	<p><i>'we've got all the herbal remedies from - I believe in some of them. I grew up with them, so for those I grew up with and I know, and I've seen work, fine.'</i> (CL2: non-faith leader)</p> <p><i>'There's a lot of herbal bush. We encourage them.'</i> (CL5: faith leader)</p>		<p>Natural remedies, e.g., bush teas and herbal medicines are commonly used, trusted and advocated.</p> <p>Utilising lay educators and community figureheads, such as church leaders, in the delivery of a healthcare programme may pose challenges due to the credibility of advice being advocated.</p> <p>Community organisations may be advocating against conventional medicine.</p>
Theme: <i>Barriers to attending healthcare appointments</i>			
<p><i>I have to work from seven in the morning until about seven in the night consistently.</i> (FG8: Caribbean males)</p> <p><i>'I can't say a specific time. The type of job I do I can't precisely say this day or this time.'</i> (FG2: African males)</p>		<p><i>'It was very difficult to get people to attend, just because everybody's so busy'</i> (HP2, PN)</p> <p><i>'a lot of them are looking after their grandchildren.'</i> (HP11, DSN)</p>	<p>Busy working lives are a barrier to attending healthcare appointments. Regular travel 'back home', often for prolonged periods, pose a barrier to attending healthcare appointments or programmes.</p>
Theme: <i>Embedding within current health services and frameworks</i>			
		<p><i>'I mostly get upset because I can't hit my QOF, I can't get my money in my practice. so we're delivering bad care by being target driven.'</i> (HP5, GP)</p> <p><i>'We've had a self-management KPI included in the diabetes KPIs as well, so all practices have been incentivised'</i> (HP4, PN)</p>	<p>Programme must embed within NHS systems and align with current incentives and metrics.</p>

Note: Relevance was rated as STRONG when the majority of the participants within a stakeholder group provided support for the theme, MODERATE when there was support from around half the stakeholder groups and WEAK when there was no support or support from less than a quarter of the stakeholder group.

TABLE 2 The HEAL-D programme: session learning outcomes, content, materials and behaviour change techniques

Learning objectives	Content and materials	Behaviour change techniques
1. Diabetes – It's in your hands! An introduction to T2D self-management		
Understand what T2D is and how it develops.	<i>Diabetes – It's in your hands</i> slide set	<i>Action planning</i>
Understand the role of insulin, glucose and blood glucose in health and T2D.	<i>Getting Started</i> information booklet	<i>Goal setting (Behaviour/Outcome)</i>
Be introduced to key ways in which diet and lifestyle influence T2D.	<i>Diabetes Explained</i> information booklet	<i>Self-monitor (Behaviour/Outcomes)</i>
Understand the principles of a healthy, balanced diet.	<i>Balanced Diet</i> information booklet	<i>Social support (Unspecified)</i>
Understand how to set personal goals.	<i>Diabetes Explained</i> animation film	<i>Social comparison</i>
	<i>Diabetes True/False</i> interactive group activity	<i>Info. about health consequences</i>
	<i>Our Objectives</i> interactive group activity	<i>Problem solving</i>
	<i>Tree of Life</i> interactive group activity	
	<i>Measuring Your Progress</i> form	
	<i>Setting Goals</i> homework card	
	Tape measures	
2. Get Moving!		
Understand the importance of physical activity in T2D management.	<i>Setting Goals</i> homework feedback	<i>Action Planning</i>
Know the physical activity recommendations for T2D management.	<i>Get Moving!</i> slide set	<i>Goal setting (Behaviour/Outcome)</i>
Understand the difference between strength training and aerobic exercise and why they are important in T2D.	<i>Get Moving!</i> information booklet	<i>Self-monitor (Behaviour/Outcomes)</i>
Review HEAL-D activity targets and set personal physical activity goals.	<i>Overcoming Barriers</i> interactive group discussion	<i>Social support (Unspecified)</i>
Explore personal barriers to engagement in physical activity.	<i>Get Moving!</i> patient stories film	<i>Social comparison</i>
Know what physical activity provision is available locally.	<i>Activity Rope</i> interactive group activity	<i>Info. about health consequences</i>
Learn about the HEAL-D physical activity resources.	<i>Step It Out</i> homework card	<i>Problem solving</i>
Explore problem-solving and action planning techniques.	Pedometer	<i>Instruction on performance of behaviour</i>
Participate in a group-based physical activity session.	HEAL-D home exercise videos & exercise band	<i>Info. about antecedents</i>
	Group exercise session – Park & Stride walking group	<i>Demonstration of behaviour</i>
		<i>Graded tasks</i>
		<i>Credible sources</i>
3. Taking Control!		
Know different types of carbohydrate and food sources of these.	<i>Step It Out</i> homework feedback	<i>Action Planning</i>
Understand how carbohydrate foods affect blood glucose.	<i>Taking Control!</i> slide set	<i>Goal setting (Behaviour/Outcome)</i>
Know carbohydrate content of commonly consumed foods.	<i>Taking Control!</i> information booklet	<i>Self-monitor (Behaviour/Outcomes)</i>
Know appropriate portion sizes of carbohydrate foods.	<i>Identifying Carbohydrates</i> group discussion	<i>Social support (Unspecified)</i>
Review the role of insulin in blood glucose control.	<i>Taking Control!</i> patient stories film	<i>Social comparison</i>
Participate in a group-based physical activity session.	<i>Sugar Cube Game</i> interactive group activity	<i>Info. about health consequences</i>
	<i>Overcoming Barriers</i> interactive group discussion	<i>Problem solving</i>
	Carbohydrate portion guide handout	<i>Instruction on performance of Behaviour</i>
	<i>Take Control</i> homework card	<i>Demonstration of behaviour</i>
	Group exercise session –strength training or walking group	<i>Credible sources</i>

(Continues)

TABLE 2 (Continued)

Learning objectives	Content and materials	Behaviour change techniques
4. Shape Up! Understand how weight and shape influence T2D. Understand that reducing waist circumference is beneficial for T2D management. Learn about and experience mindful eating. Participate in a group-based physical activity session.	<i>Take Control</i> homework feedback <i>Shape Up!</i> slide set <i>Shape Up!</i> information booklet <i>Middle Measurements</i> interactive group activity <i>Mindful Eating</i> homework card Group exercise session – Circuit training or walking group	<i>Action Planning</i> <i>Goal setting (Behaviour/Outcome)</i> <i>Self-monitor (Behaviour/Outcomes)</i> <i>Social support (Unspecified)</i> <i>Social comparison</i> <i>Info. about health consequences</i> <i>Problem solving</i> <i>Instruction on how to perform Behaviour</i> <i>Info. about antecedents</i> <i>Demonstration of behaviour</i> <i>Credible sources</i>
5. Drop the Pressure! Understand how salt and saturated fat affect cardiovascular health. Understand what foods monounsaturated fats and n–3 polyunsaturated fats are found in. Understand the importance of vegetables for heart health. Know the salt content of common foods and hidden sources of salt in the diet. Understand the importance of physical activity and weight management for heart health. Participate in a group-based physical activity session.	<i>Mindful Eating</i> homework feedback <i>Drop the Pressure!</i> slide set <i>Drop the Pressure!</i> information booklet <i>Finding Salt</i> interactive group activity <i>Try a New Activity</i> homework card Group exercise session – Dance aerobics or walking group	<i>Action Planning</i> <i>Goal setting (Behaviour/Outcome)</i> <i>Self-monitor (Behaviour/Outcomes)</i> <i>Social support (Unspecified)</i> <i>Social comparison</i> <i>Info. about health consequences</i> <i>Problem solving</i> <i>Instruction on how to perform behaviour</i> <i>Demonstration of behaviour</i>
6. Putting it into Practice: cook & taste Learn techniques for cooking with less salt and oil. Learn techniques for adding extra vegetables into the diet. Learn techniques for reducing saturated fat in the diet. Learn techniques for reducing carbohydrate portion sizes. Take part in a cook and taste session. Taste foods/dishes prepared with reduced salt and fat. Taste foods/dishes prepared with increased vegetables.	<i>Try a New Activity</i> homework feedback <i>Putting it into Practice</i> information booklet Cooking stations for increasing vegetables, low fat/healthy fat, reducing salt, reducing carbohydrate, increasing fibre. Preparing low salt seasonings station. <i>Diabetes Friendly Cooking</i> homework card	<i>Instruction on performance of behaviour</i> <i>Demonstration of behaviour</i> <i>Credible sources</i>
7. Plans for Life Reflect on successes of HEAL-D programme. Identify situations which may cause lapses. Identify tools to manage challenging self-management situations. Participate in a group-based physical activity session.	<i>Diabetes Friendly Cooking</i> homework feedback <i>Plans for Life</i> slide set <i>What We've Learnt</i> interactive group quiz <i>Managing Lapses</i> interactive group discussion <i>Celebrating Successes</i> interactive group discussion HEAL-D certificates of participation Group exercise session – Zumba™ or walking group	<i>Problem solving</i> <i>Self-monitoring of (Behaviour/outcomes)</i> <i>Social comparison</i> <i>Social support</i>

Emergent themes included a strong reliance on informal sources of information/advice (e.g., family and friends), issues around privacy and stigma, barriers to attending

appointments associated with the competing priorities of work, travel and carer commitments, and a preference for directness and simple, clear advice/messages. Specific to

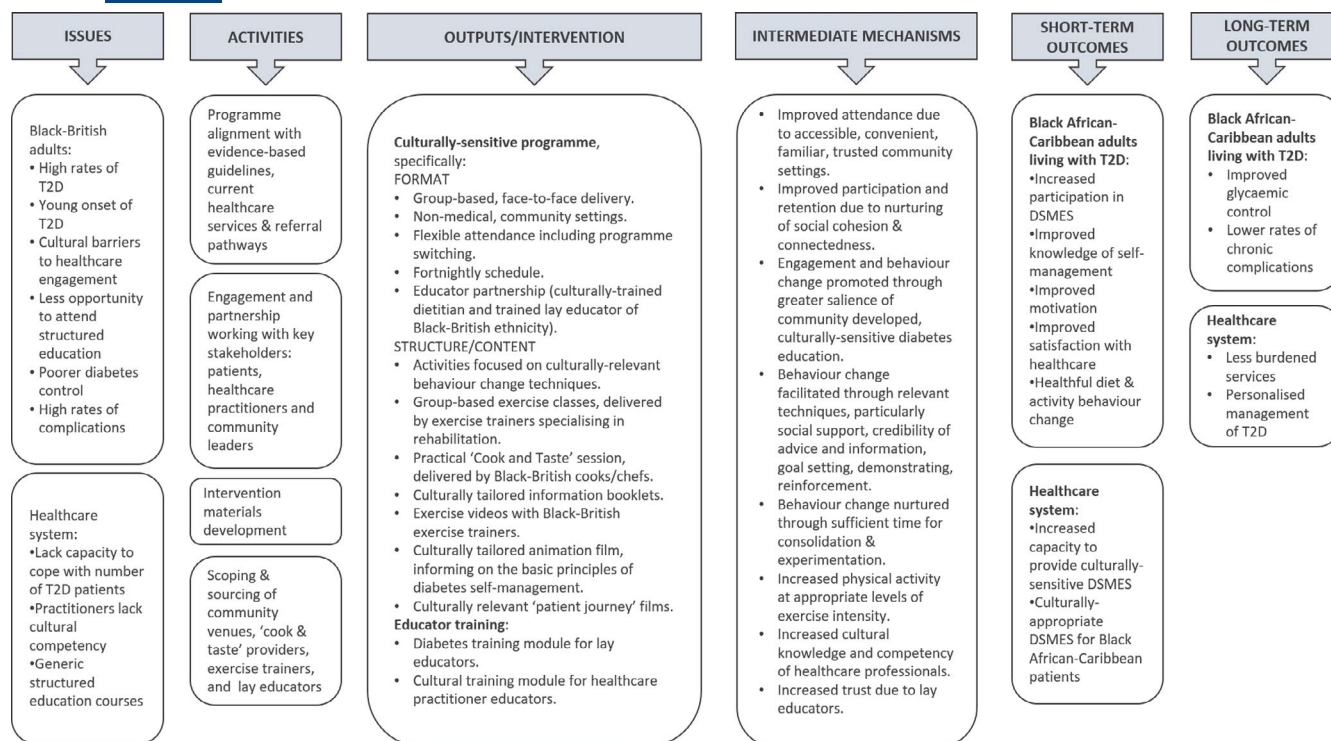


FIGURE 2 HEAL-D logic model

healthcare professionals and commissioners, the importance of an intervention embedding within current primary care structures and aligning with incentivised targets/metrics was clear.

3.2 | Phase 2 (co-development workshops)

Two workshops were conducted, approximately four weeks apart. In the first, 27 stakeholders (three healthcare professionals, four community leaders and 20 patients) attended.

The scenario discussions led to the following conclusions:

- **Intervention setting:** avoidance of medical settings was agreed by all stakeholders.
- **Educator credentials:** patients and community leaders were unanimous that the programme educators needed to be appropriately trained/qualified in diabetes management, although they didn't have strong opinions on different practitioner types (e.g., nurses and dietitians). The need for educators to share the same cultural/racial background was rejected but the importance of having cultural knowledge, particularly relating to dietary practices, was recognised.
- **Timing of sessions:** stakeholders stressed the difficulty of attending appointments alongside work and carer commitments and the need for the programme to be delivered at times when they were free to attend.
- **Literacy/numeracy needs and communication preferences:** basic levels of numeracy, literacy and health literacy were

evident and a need to avoid medical terminology. Findings from Phase 1 relating to preferences for verbal messages/advice rather than written documents was explored, with some patients keen to have detailed written information and others finding this off-putting.

After the scenarios, the groups provided feedback on samples of existing educational leaflets. The main learnings were that participants were seeking very clear and prescriptive advice on how much carbohydrate they should be consuming and that guidance on portions should avoid using weight measures but instead focus on household measures, such as a mackerel tin or handfuls, which are more relatable. Other important learnings were the need for leaflets to feature relevant cultural foods and to avoid medical terminology.

The second workshop was attended by 11 participants (eight people living with T2D and three community leaders), all of whom had attended the first workshop. Draft HEAL-D educational materials, including information booklets and educational slides, were discussed by the participants. The main learnings were technical terms (e.g., hyperglycaemia) were off-putting, and simple phrasing was preferred; the use of visual images to illustrate information (e.g., hands to illustrate portion sizes) were favoured as more accessible. The participants liked the colourful nature of the leaflets and the logo and professional quality of the graphics gave participants confidence and trust in the materials.

In response to findings from Phase 1 and the first workshop, in which a preference for visual and verbal information was expressed, the research team considered whether film/video media might be an effective means to convey important programme information. This was explored in the second workshop, whereby participants were asked to view existing educational diabetes-focused films and provide feedback on their length, language and content, to inform the making of a bespoke HEAL-D educational film. Participants were positive about the use of films and recommended that they should contain information specific to Black-British groups (e.g., prevalence rates and foods that affect blood glucose) and the use of animation and visual images increased their understanding.

3.3 | Phase 3 (materials development)

The programme resources were developed with continual SAG feedback to ensure relevance and acceptability for participants. For each session, activities and materials were developed to draw on relevant behaviour change techniques, as identified through the COM-B mapping of the patient focus group data.²³ The HEAL-D sessions, learning outcomes, content, materials and behaviour change techniques are detailed in Table 2.

Key aspects of the programme design and the rationale for their use were the following:

- Group-based delivery, fostering collectivism and social connectedness, inviting inclusion of a 'significant other' to draw on social support structures, whilst aligning with current healthcare services to increase potential for implementation.
- Curriculum aligning with evidence-based diet/lifestyle guidelines, nurturing patients' desire to manage diabetes through 'natural' means, whilst aligning with current healthcare services to increase potential for implementation.
- Delivery in non-medical, community settings to overcome issues of distrust and increase convenience.
- Delivery by a diabetes specialist dietitian in partnership with a trained Black-British lay educator, ensuring credibility of advice and information, whilst conveying cultural understanding.
- Flexible attendance including programme switching to enable participants to attend missed sessions and sessions at convenient times and venues.
- Curriculum delivered in seven sessions, on a fortnightly basis, to allow sufficient time for participants to implement and experiment with the behaviour change of focus.
- Group-based physical activity classes, delivered by trained exercise instructors, to foster social cohesion whilst demonstrating a range of activities that are culturally acceptable (e.g., walking and dance) and at appropriate levels of exercise intensity.
- A practical 'cook and taste' session, delivered by Black-British cooks/chefs, to overcome barriers to changing cooking practices.
- Short films, drawing on story sharing and role modelling, to motivate behaviour change relating to limiting carbohydrate portions and increasing physical activity levels.
- Culturally tailored information booklets, using photography of cultural foods to illustrate appropriate portion sizes, to reinforce educational messages and behavioural goals.
- A culturally tailored animation film, 'diabetes explained', to inform patients of the basic principles of diabetes self-management. This video was publicly available on the programme website to allow patients to re-watch.
- Provision of exercise videos led by Black-British exercise trainers to encourage participation in physical activity.
- Curriculum delivery using specific behaviour change techniques that were chosen through detailed analysis of our focus group data using the COM-B framework.²³

The components and activities of the HEAL-D programme, mapped to the proposed outcomes, are depicted in a logic model (Figure 2).

4 | DISCUSSION

For interventions to be effective, implementable and sustainable, they must be responsive to the needs of both service users and service providers. Participatory methods are an effective means by which to identify and understand the needs of key stakeholders, thus aiding the development of sustainable healthcare interventions.¹⁸ We used participatory methods in the development of HEAL-D, a DSMES programme, specifically tailored to the needs of Black-British adults, to identify key adaptations that were needed in terms of structure and format to ensure cultural relevance and acceptability, whilst aligning the intervention with existing healthcare structures to ensure its implementation potential. Our three phases of participatory work enabled us to develop a detailed understanding of the priorities of our stakeholders. The first phase, our formative research phase, identified key issues among our different stakeholder groups. Service users led us to understand the importance of nurturing collectivism and identified a reliance on informal sources of information/advice, barriers to attending appointments associated with competing priorities of work, travel and carer commitments, and a preference for directness and simple, clear advice/messages. Our service providers prioritised the need for the intervention to embed within current primary care structures and align with incentivised targets/metrics. Our Phase 2 workshops, which brought our stakeholders together, identified

key considerations for the intervention structure, format and delivery, particularly avoidance of medical settings, the need for appropriately trained and culturally knowledgeable educators, flexible appointments, preference for verbal and visual information and avoidance of technical/medical terminology. The final phase focused on stakeholder input into the development of the intervention materials to ensure their cultural relevance and sensitivity.

Tackling ethnic inequalities in type 2 diabetes is a healthcare priority in the United Kingdom.¹¹ Ethnic minority groups often find it harder to access healthcare; for example, healthcare professionals may lack cultural knowledge or understanding, and patient resources usually align to the cultural practices of the majority population.²⁴ Culturally tailored interventions are proposed as a means by which to improve engagement amongst minority ethnic groups.¹⁴ There have been many different methodologies used in the development of culturally tailored healthcare interventions across a range of health conditions. Barrera and Castro developed a framework for culturally adapting healthcare interventions from a consensus of existing methodologies, outlining five stages in the process: information gathering; preliminary design; preliminary testing; refinement; and final trial.²⁵ The work we report here for the development of HEAL-D aligns with Stages 1 and 2 of this framework in which we have conducted extensive formative research to inform the design of our intervention. The next stages of our work are to deliver HEAL-D in a pilot trial (Phase 4, see Figure 1), with community evaluation to identify refinements that are required prior to testing efficacy in a definitive trial (to be reported separately).

To date, culturally tailored DSMES interventions for Black communities have mainly been developed and evaluated in America.¹⁶ Whilst some aspects of the format and structure of HEAL-D are comparable to the American interventions, for example, the use of non-medical settings, there are many aspects of HEAL-D that are distinct. This is largely due to the focus we took in ensuring HEAL-D was sensitive to the needs of the healthcare system, maximising its potential to embed in primary care beyond the research period. Our involvement of healthcare practitioners in our intervention development enabled us to understand the priorities and needs of the healthcare system, whilst identifying scope for change. Key aspects of health system alignment were the need for the programme to meet criteria for performance metrics/incentivised services (i.e., evidence-based curriculum, delivered by healthcare professionals) and for it to embed within the referral pathway for structured education. In some cases, our formative research identified opposing needs/priorities between patients and practitioners, for example, delivery by cultural concordant practitioners; in these cases, our interactive workshops enabled us to work with our different stakeholders to explore

these issues and understand how to structure the intervention to meet all needs.

Often intervention tailoring for minority ethnic groups is targeted at observable, superficial traits such as language, where educational materials are translated into the first language of the target population. To date, in the United Kingdom, culturally tailored diabetes structured education programmes have mainly used these types of adaptations, targeted at South Asian communities, which form the largest minority ethnic group in the UK population.^{16,26} In the Resnicow et al. model of cultural sensitivity, which was developed to inform public health intervention development, traits such as language are considered 'surface' structures of culture, and tailoring at this level is proposed to increase the receptivity or acceptance of messages. However, the model proposes that tailoring to 'deep' cultural structures, such as health beliefs, is more likely to result in an intervention that conveys salience.²⁷ Our participatory methods enabled us to gain an in-depth understanding of our target communities and the factors that influence their health behaviours and to target these 'deeper' structures of culture in our tailoring. Whilst there is significant diversity in participatory research methods, they all centre around a 'bottom-up' approach, in which research is carried out *with* the people or communities who will benefit rather than *on* them. The key aspect of participatory research is partnership working and the location of power, which is shared equally between the research team and the community participants as opposed to conventional research methods that involve limited interaction and decision making with people outside of the research team. Participatory research originated in the social sciences and has been criticised by conventional health researchers because it is less well defined and harder to measure and reproduce than mainstream health research methods.²⁸ In intervention development, it is the perspectives of the target community, rather than the research team, that define the intervention details. Whilst we strove to remain true to the ethos of participatory research in this intervention development study, at times, we were limited in our ability to do this by competing needs; for example, the requirement for our intervention to deliver an evidence-based curriculum meant that our stakeholders could not make decisions on this aspect.

The strengths and limitations of our work warrant consideration. We have used participatory methods to conduct comprehensive intervention development research. Engaging key stakeholders in this process has enabled us to identify and prioritise key components of our intervention structure and format, ultimately seeking to ensure that our intervention is sensitive to the needs of both service users and providers. The key components of our programme that will effect change are presented in our logic model. Ultimately though we must be cautious in drawing conclusions about the appropriateness of our intervention until it has been implemented and evaluated.

It is important that our future evaluation work tests each part of our programme theory to understand whether it operationalises as proposed; such an approach will require further engagement of key stakeholders. We acknowledge that our intervention was developed with a focus on the UK healthcare context and our findings may not translate to broader contexts. Whilst we believe many of our formative findings are relevant to Black communities in other regions, there are aspects of our intervention that are specific to UK healthcare provision. Our methods, which provide an in-depth insight into intervention barriers and facilitators, have demonstrated the importance of understanding the context in which an intervention is trying to effect change.

Participatory methods, engaging key stakeholders in the intervention design process, enable the development of healthcare interventions that are sensitive to the needs of service users and providers and enable intervention designers to understand the needs of their target communities. Engaging communities who might otherwise have poor access to healthcare in intervention development offers an opportunity to tackle health inequalities through the development of culturally sensitive healthcare interventions.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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