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#### SHORT REPORT

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# Understanding engagement in diet and dementia prevention research among British South Asians: a short report of findings from a patient and public involvement group

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#### Abstract

Background: Dementia is a global public health challenge. Evidence suggests that individuals from South Asian communities are an at-risk group for dementia, partly as a result of early and cumulative exposure to known dementia risk factors, such as obesity and type 2 diabetes. There needs to be more culturally appropriate community engagement to increase awareness of dementia and identify better strategies to encourage participation in dementiarelated research.

Methods: We aimed to better understand the barriers and facilitators towards engaging with, and participating in, diet and dementia related research among British South Asians. This was achieved using a public and patient involvement (PPI) approach. A community-based, engagement event involving information sharing from experts and roundtable discussions with South Asian communities (n = 26 contributors) was held in June 2023 in Newcastle-upon-Tyne, UK. Collaboration from preidentified PPI representatives (n = 3) informed the content and structure of PPI activities, as well as recruitment. Data were synthesised using template analysis, a form of codebook thematic analysis. This involved deductively analysing data using relevant a priori themes, which were expanded upon, or modified, via inductive analysis.

**Results:** The findings highlighted the importance of trust, representation and appreciation of cultural barriers as facilitators to engagement in diet and dementia risk reduction research. Consideration of language barriers, time constraints, social influences and how to embed community outreach activities were reported as driving factors to maximise participation.

Conclusions: This PPI work will inform the design and co-creation of a culturally adapted dietary intervention for brain health in accordance with the Medical Research Council and National Institute for Health and Care Research guidance for developing complex interventions.

#### **KEYWORDS**

dementia, diet, public and patient involvement, research engagement, risk reduction

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#### Key points

- Patient and public involvement activities among British South Asians in the North East of England highlighted the importance of trust, representation and appreciation of cultural barriers as facilitators to engagement in diet and dementia risk reduction research.
- Language barriers, time constraints and community outreach were driving factors to maximise participation.

## INTRODUCTION

Dementia is a progressive condition, with a deterioration in cognitive decline, severe enough to interfere with daily activities of living.<sup>1</sup> It is a global public health challenge, affecting 55 million people worldwide.<sup>2</sup> It is estimated that dementia (all cause dementia) rates are 22% higher among Black ethnicities compared to White ethnicities in the UK, whereas individuals from Black and South Asian communities who are living with dementia usually die younger and sooner after diagnosis.<sup>3</sup> Because there is currently no cure for dementia and pharmacological treatment is limited in both availability and efficacy, research attention has been centred on modifiable risk factors.<sup>4,5</sup>

The UK has a diverse and ever-changing population. In 2019, 84.8% of the population of England and Wales identified their ethnicity as White, decreasing by 1.2 percentage points subsequent to the 2011 Census. People from Asian ethnic groups made up the second largest percentage of the population (9.3%), followed by Black (4.0%), mixed (2.9%) and other (2.1%) ethnic groups.<sup>6</sup> Estimations suggest more than 25,000 older people from ethnic marginalised communities live with dementia in the UK, partly as a result of early and cumulative exposure to dementia risk factors across the life course." This is evidenced by previous studies from Mukadam et al.,<sup>8,9</sup> who found the impact of modifiable risk factors such as hypertension, obesity and diabetes on dementia risk was increased among South Asian people compared to White people. There are also particular difficulties in diagnosing and treating dementia among UK ethnically marginalised groups, especially within the South Asian population, as a result of lower levels of literacy, language barriers, and a lack of appropriately translated and culturally adapted tools for this ethnic group.<sup>10</sup> Consequently, individuals from South Asian communities often receive a diagnosis of dementia when the condition is within its advanced stages, resulting in poorer outcomes overall. Together with the higher prevalence of vascular, lifestyle and environmental risk factors for dementia, there is a need to better understand the barriers and facilitators of undertaking dementia risk reduction research among these communities.

Diet is one lifestyle factor which may be related to dementia prevention.<sup>5</sup> A healthy diet has been significantly associated with reduced cognitive decline and

dementia risk.<sup>11</sup> Research on certain nutrients, such as B vitamins and fatty acids,<sup>12</sup> and dietary patterns such as the Mediterranean Diet has shown promise with respect to potential preventative strategies for dementia.<sup>13</sup> These healthy dietary patterns, rich in antioxidants and flavonoids, may modulate the oxidative stress and inflammatory pathways implicated in accelerated cognitive decline.<sup>14</sup> Processes such as neurogenesis and neural connectivity involved in the functioning of the brain are also influenced by dietary components.<sup>15</sup>

The development of dietary and lifestyle interventions requires careful planning to ensure they are relevant, person-centred, culturally appropriate and can be translated into practice.<sup>16</sup> The Medical Research Council (MRC) and National Institute for Health and Care Research (NIHR) have published guidance for the development of interventions, which should be multiphase, iterative, theoretically underpinned and informed by relevant stakeholders.<sup>17</sup> Stakeholders are those who will either deliver, use or benefit from the intervention and the first phase of the invention development process should integrate public and patient involvement (PPI). PPI is important to ensure the needs, values and beliefs of the target population are drawn upon and are embedded within the research design. In addition, interventions guided by PPI are usually more effective in practice.<sup>18</sup> Ethnically marginalised communities continue to be underrepresented in health research, despite comprising a large proportion of the UK population.<sup>19</sup> In relation to dementia, evidence suggests a limited understanding of the causes of dementia among South Asian communities<sup>10</sup> and, consequently, there are calls for more culturally appropriate community engagement to increase awareness.<sup>20</sup> It is crucial to improve representation and enhance recruitment of individuals from South Asian backgrounds in dementia risk reduction research.<sup>21</sup> To address this, the barriers and facilitators to engagement in such research from the participants' perspective must be considered, for which, research evidence is lacking.

Although the adoption of a Mediterranean Diet in countries such as the UK<sup>11</sup> and Australia<sup>22</sup> has shown high levels of acceptability through intervention studies, it is still unknown which, if any, culturally adapted, or country-specific dietary patterns can positively impact brain health. The dietary practices of British South Asians are of great interest because of the possible role of acculturation, such that dietary habits may have been influenced by the host country post-migration,<sup>23</sup> as well as the influence of cultural traditions, faith practices and taste preferences, which may vary from generation to generation.<sup>24</sup> Accordingly, combined with a lack of understanding surrounding the optimal strategies to engage British South Asians within dementia risk reduction research, this has led to a paucity of data within the field of diet and dementia among British South Asians. We aimed to gather information to better understand the barriers and facilitators towards engaging with, and participating in, diet and dementia related research among British South Asians. This aim was achieved by employing a PPI approach, through a community-based, engagement event involving roundtable discussions. It is intended that the information gathered from this PPI phase will inform the next phase (s) of this research and future grant applications to codesign a culturally adapted dietary intervention for dementia risk reduction among British South Asians. This approach conforms with the guidance for developing complex interventions as recommended by MRC and NIHR.<sup>17</sup>

## METHODS

In accordance with Guidance for Reporting Involvement of Patients and the Public (GRIPP2),<sup>25</sup> three South Asian community-based PPI Representatives (PPI-Rs) were identified through relevant charitable networks. The community PPI event was co-developed with PPI-Rs. Briefly, this involved meetings where the priorities for encouraging engagement in diet and dementia related research for South Asian communities were discussed. The unique knowledge and lived experiences from the PPI-Rs who are immersed within South Asian communities in NE England, informed the aims, content and structure of the PPI event. The PPI-Rs provided important guidance on event location, recruitment strategies to engage the community, event structure and data collection methods. PPI-Rs recommended embedding education around diet and dementia research as part of the event as this could be an opportunity to "learn and share" to encourage better engagement and uptake by attendees and viewed as an opportunity to "give something back to the communities". PPI-Rs also recommended group discussions as the preferred mode of data collection to generate ideas and facilitate a supportive and cohesive environment for contributors. Because this was a PPI investigation, it was exempt from ethical approval.<sup>26</sup> Key contacts of PPI-Rs were invited to attend the engagement event, or attendees booked a place in response to an advertisement placed in newsletters of relevant charitable organisations. During the event, attendees provided verbal consent for anonymised verbatim quotes to be used in publications or future grant applications.

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The engagement event was held within a community location in the West of Newcastle Upon Tyne; a prominent hub for the South Asian community. The event was held in two parts; first, an information session, facilitated by research staff, provided a lay introduction to diet and dementia prevention research. A registered dietitian who supports dietary behaviour change among South Asian communities delivered an interactive information session focused on the South Asian Eat Well Guide. The second part involved roundtable discussions, adopting a focus group style methodology. Each roundtable discussion began with an opening discussion on diet and dementia related research and priorities for South Asian communities. This was followed by a focused discussion exploring two broad topics: (1) barriers and (2) facilitators to engagement in diet and dementia related research. Each roundtable had one facilitator who asked prompting questions surrounding each topic, and one note taker (research staff/ students). Conversations were captured by hand-written notes, documenting the discussions chronologically. Checks were made with contributors during, and at the end of the roundtable discussions, to validate understanding. After the event, additional field notes were made by the research team, to capture further reflections, feelings and evaluations of the discussions. A copy of our facilitation guide can be found in the Supplementary Material (S1).

The data synthesis followed a template analysis approach.<sup>27</sup> The term "template analysis" refers to a particular way of thematically analysing qualitative data, by deductively analysing textual data using a-priori themes; preidentified themes strongly expected to be relevant to the analysis. These themes can be expanded on via inductive coding as appropriate. This analytical approach was considered to meet the aims of this PPI event, in that it allowed the researchers to focus on relevant, predefined areas as a-priori themes at the same time as retaining openness for additional emerging themes to be included. Here, the research team developed a template consisting of *a priori* themes likely to occur in the data. For this study, these preidentified a-priori themes were: accessibility; trust; time; family life; language; cost; religious beliefs; stigma; dietary restrictions; community engagement; advertisement and incentives. These themes were generated based on previous experience of the research team in this field, as well as from a broad literature review<sup>10,19,21,28-31</sup> during the planning phase. Following data collection, handwritten notes from roundtable discussions were converted to electronic format using Word (Microsoft Corp.), saved electronically, and accessed only by members of the research team. The template was then used to analyse the text through multiple reading and considerations of the qualitative data. Themes were consequently further developed, refined or discarded, if they did not prove to be helpful in capturing key meanings in the data.

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Applicable relevant quotations were selected from notes, as evidence to support interpretation. Findings were discussed with PPI-Rs through inperson and online meetings with researchers to further support interpretation and understanding of the data. No personal identifiable information was recorded during data collection; therefore all data were anonymous.

#### RESULTS

In total, 26 individuals attended the event (n = 24 female; n = 2 male) who were residents in Newcastle, Gateshead and South Tyneside Council areas. There were five roundtable group discussions, and the key themes generated from the template analysis have been summarised in this section.

# Barriers and facilitators to participation in diet and dementia research

Contributors described many reasons why they may be more, or less likely, to participate in a diet and dementia related research study. Although our developed template for data analysis was extensive and indepth, here we discuss the key themes which were most prominent among discussions. Data captured the following *a priori* themes: (a) time, (b) language, (c) cost, (d) community engagement, (e) advertisement and (f) trust. Three additional themes were defined based on the data generated: (a) knowledge, (b) dietary compliance and (c) social influences. We highlight the key barriers and facilitators here, with a summary of themes and representative quotes in Table 1.

#### Knowledge

The majority of public contributors were not aware of the risk factors for dementia prevention and the link between dementia and diet before this event. There were discussions around dementia being regarded as a sensitive and taboo topic among South Asian communities. Stigma is often attached to a dementia diagnosis and therefore some individuals may be reluctant to talk openly about it, for example one participant stated,

"dementia has not always been talked about in our society"

However, some contributors mentioned they would share information around the topic of dementia with their family members, highlighting the benefits of social support for behaviour change. Most groups raised concerns around rising numbers of people living with dementia within their communities and appeared to view the condition negatively, with connotations of worry. For example, two individuals stated

"dementia is one of my biggest fears"

"when you look at people suffering with dementia, you don't want this to happen to you"

#### Dietary compliance

During the opening discussions around priorities for diet and dementia related research, many viewed this research area as a priority, and discussions organically developed to further highlight the challenges of complying with a healthy diet. Although "dietary compliance" was not a preidentified a priori theme associated with engagement in research in this study, the research team agreed it was important to highlight this as an additional theme as it offers important considerations when designing diet and dementia prevention research. The challenges highlighted surrounding compliance with a dietary intervention included greater accessibility of convenience foods, working patterns, and influence of cultural and beliefbased traditions (e.g., fasting practices and celebrations). Contributors identified knowledge gaps in several areas, including portion sizes, examples of 5-A-Day, modified South Asian Eat Well Guide, and understanding of links with dementia that may impact adherence to healthy eating. Some individuals suggested that there may be inter-generational differences and consequent diversification of eating behaviours. It was acknowledged that older generations may be more likely to adhere to traditional recipes and foods, whereas younger generations may prefer fast food options primarily because of its convenience. For example, some individuals stated:

"the next generation is changing how they eat"

"older generation still cook, younger generation eat separately"

"the new generation reject the traditional food style"

"adaptation to the South Asian Eat Well guide is not commonly known"

#### Time

Time was generally discussed by all groups as a barrier due to shift work (particularly for men who work in catering businesses), family duties/caring responsibilities and religious commitments. Ensuring that research appointments do not

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Themes	Notable quotes			
Time	"Women don't have time to look after themselves" "We prefer to have meetings during the hours of 10–3 pm to fit around our other commitments" "Because of working late I need my time to sleep. Too busy to do anything else – routine"			
Language	"People are more interested and able to learn when it's in their own language" "Our elders tend to speak in their mother tongue, but generally always have English speakers with them" "People want to get help, it's just language that stops them" "Qualified interpreter is important"			
Cost	"How can you have fish 2 × per week if you have a big family, it costs a lot"			
Knowledge	<ul> <li>"Dementia has not always been talked about on our society"</li> <li>"Diet with dementia is something new for me"</li> <li>"Adaptation to eat well guide is not commonly known"</li> <li>"Need education between normal forgetfulness versus dementia"</li> <li>"I can always put the leaflets on the coffee table for my in-laws to read"</li> <li>"GP give tablets – not dietary advice"</li> <li>"Need genuine sources of information"</li> <li>"Dementia is one of my biggest fear"</li> <li>"People do not talk about dementia because they do not want to admit"</li> <li>"When you look at people suffering with dementia, you don't want this to happen to you"</li> <li>"Stress is much higher these days, cost of living The more stressed you are, the more you want bad food"</li> </ul>			
Community engagement	"Organisations don't reach out" "Work needs to go into more community outreach projects" "We promote other events and it is hard to get other involved" "Use trusted groups for example mosques" "Make use of buildings within our communities, we have various mosques, temples and schools available" "Approach local businesses and shops to help spread the word" "Word of mouth is often the best route" "If a charity is involved, it helps involvement" "Not talking at us, more interactions" "Quizzes and competition can excite people and bringing cultures together"			
Advertisement	"Visual, interactive, engaging" "Word of mouth is often the best route" "Approach local businesses and shops to help spread the word"			
Trust	"Community leaders – founder is respected, people will follow them and spread the word" "Get more involved with our community leaders. They are key to getting people involved in research projects"			
Social influences	<ul> <li>"They are set in their ways, especially older women"</li> <li>"Men would also be interested in healthy eating advice if demonstrated by healthcare professionals"</li> <li>"Consider having separate male and female engagement groups""Women are sick of being at home and want to get out"</li> <li>"Next generation is changing on how they eat – becoming worse"</li> <li>"A lot of the older generation find it easier to discuss things separately"</li> <li>"New generation reject traditional food style"</li> <li>"Younger generation don't think about brain health"</li> <li>"Friend circle is very important helps diet change!"</li> <li>"Having vegetable and lentil means that you are poor; meat means you are rich"</li> <li>"Some people may look down on people who eat vegetables and lentils, as this indicates that they are poor. People think that having meat means that you are rich"</li> </ul>			
Dietary compliance	"The next generation is changing how they eat" "The new generation reject the traditional food style" "Fast food options have become widely available" "Older generation still cook, younger generation eat separately"			

clash with time for prayer or religious festivals was highlighted as a priority, as this can be a barrier to involvement in research. In addition, contributors stated that the location of the research study must be local and easily accessible with either good public transport links, or within walking distance. It was highlighted that engagement in research may be improved if the researchers were able to immerse research activities within existing local South Asian community facilities, such as charitable groups, faith organisations or recreational centres.

## Language and trust

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Public contributors identified language as an important consideration, as educational resources in languages other than the mother tongue can be difficult to understand, particularly for first-generation migrants. There were suggestions to overcome this by having a wider-family, intergenerational approach, which would allow for sharing of information and translation into native languages. Interest in dementia education may be greater if it is presented in multiple languages because, if resources are expressed in a different language, this may impact engagement, interest and uptake. For example:

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"people are more interested in, and are able to learn when it is in their own language"

"people want to get help, it's just language that stops them"

There were also indications about the importance of using qualified and approved interpreters as this can have an impact on the accuracy and quality of the translated materials. It was suggested that using accredited interpretation services for example that have a diploma in Public Service Interpreting, could act as a facilitator by upholding confidentiality and professional boundaries, therefore improving trust. They also suggested that having a researcher who can speak their own language could help build a better rapport between the researcher and the participant.

#### Community engagement

Delivery of education plays a key role when it comes to communicating information within diet and dementia related research. It was felt that community leaders, together with health and nutrition professionals, could provide a crucial role in this education by relaying important messages about the benefits of diet. These community leaders could act as "ambassadors" for members of the public to encourage engagement in a research study. Individuals also mentioned that sometimes organisations "do not reach out" to the community to educate people about the importance of healthy eating. For instance, some contributors reported:

> "men would also be interested in healthy eating advice if demonstrated by healthcare professionals"

"GPs give tablets - not dietary advice"

Contributors stated that organising a mixture of faceto-face activities and online meetings can increase one's involvement in a research study. Some attendees also suggested that they are more attracted to interactive activities such as cooking and educational sessions to help build understanding and skills. For example:

> "quizzes and competition can excite people and bringing cultures together"

Utilising activities linked with charity events, picnics, outdoor exercise, and after-school clubs can be an opportunity to engage and recruit diverse samples. For example, one person stated:

"if a charity is involved, it helps involvement"

### Social influences

Social influences may have an impact on both the likelihood of dietary change, and research engagement. Specifically, gender segregation was recognised as a key factor; some female contributors suggested they would avoid any close contact with men, for cultural reasons. This was deemed especially relevant for older participants. Therefore, having male research staff could act as a barrier for uptake by women. This may also be the case for some male contributors and female researchers. Some contributors discussed that men and women play different roles in the society suggesting that most of the men are occupied with their work and are not as socially active in the community. By contrast, the majority of the women may be housewives, and are more interactive within the community setting. For example, one woman said,

> "your friend circle is very important ... this helps to facilitate a diet change"

> "consider having separate male and female engagement groups. A lot of the older generation find it easier to discuss things separately"

Also, some contributors were apprehensive to participate in dementia research and have conversations around dementia, owing to the associated stigma; there were feelings that others may look down on them and their families. Hence, peer pressure could act as a social barrier. For example:

> "people do not talk about dementia because they do not want to admit"

> "some people may look down on people who eat vegetables and lentils, as this indicates that they are poor. People think that having meat means that you are rich"

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#### Advertisement

All groups agreed that lack of culturally appropriate advertising information regarding the research study can impact recruitment. Examples of poor advertisements include lack of community outreach activities, poor visual communication, language barriers and if researchers are not present to "advertise" and explain their research. Hence, this would possibly result in limited trust in researchers, poor rapport and diminished interest in research engagement. For example, one person said:

> "more work needs to go into more community outreach projects"

Contributors stated that they are more likely to be attracted to advertisements that are interactive and engaging. Some individuals also suggested a specific preference for advertisement in the form of leaflets, videos, and infographics on social media and/or messaging platforms. For example, using messaging apps like WhatsApp to widely disseminate information to individuals within the local area. A few of the contributors expressed concern about data sharing of personal information, and it was suggested that increasing awareness that a confidentiality agreement is in place could help build trust.

## DISCUSSION

Employing a PPI approach, roundtable discussions were used to explore the barriers and facilitators of engagement in diet and dementia related research among British South Asians. It was clear that the majority of public contributors were unaware of the possible link between diet and dementia. This is consistent with survey research among a nationally representative sample of 2259 UK adults, where only 33% reported it was possible to reduce risk of dementia, compared to 79% who suggested it was possible to reduce risk of diabetes and 75% for heart disease.<sup>32</sup> With the Lancet Commission<sup>4</sup> highlighting that up to 40% of dementia cases are potentially preventable, raising public awareness and understanding of the modifiable risk factors associated with dementia is of importance.

In this PPI study, discussions highlighted that recruitment, engagement and retention within dementia prevention research are mainly influenced by time, trust, social factors (e.g., cultural and gender norms) and first-language. This is similar to findings in the wider research literature.<sup>28,33,34</sup> It is reported that a substantial number of South Asians who have lived in the UK for more than 10 years cannot speak fluent English, with estimations that this applies to 30% of Bangladeshi, 23% of Pakistani and 14% of Indians.<sup>35</sup> As a result, some South Asian individuals may not be able to understand the objectives

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of a research study presented in English; thus, this challenges researchers to present understandable information to individuals for recruitment; for example, the use of infographics and figures to supplement written text.<sup>36</sup> Studies recommend that researchers choose suitable bilingual interviewers to assist in information gathering.<sup>37</sup> This would then help to allow individuals to speak comfortably in their first language. However, bilingual interviewers must be trained and supervised to ensure research quality.<sup>37</sup> Previous research found a 15% increase in research participation among young African Americans when the interviewer was also African American.<sup>38</sup> Furthermore, a systematic review suggested that cultural congruence can be an important facilitator.<sup>39</sup> This is because individuals may feel more comfortable within a setting they are familiar with and can potentially enable participation. Researchers therefore need to consider these cultural dynamics and adapt approaches accordingly. When designing research in diet and dementia prevention, embedding the use of translated educational materials and gualified interpreters may improve engagement and allow for a more diverse sample, inclusive of varying generations. In addition, having PPI involvement from South Asian communities at each step of the research process, can ensure that information provided to participants is accessible, relevant and understood.40

The gender distribution of contributors in this PPI study was skewed toward females (80% female versus 20% male). Many women tend to feel more comfortable in female-only facilities and may be uncomfortable with close physical contact with men due to cultural reasons.<sup>30</sup> For instance, exercise facilities and gyms that do not facilitate a physical separation between genders can deter South Asian women from engaging.<sup>41</sup> Therefore, in research, there may be a requirement to organise gender specific events. Furthermore, men are usually known as the head of the family, and the decision maker. Women might be more responsible for the food preparation within the household. It is reported that men tend to have higher power over dietary decisions, and women may require the male's permission to make dietary changes.<sup>30</sup> Researchers need to better understand these gender specific roles and influences to ensure the intervention is culturally appropriate and can be targeted to be inclusive of these needs and values. Investing sufficient time to fully understand these intricacies will be pertinent to the success of research among these communities.

It was evident within this PPI work that community outreach and involvement is a driving factor to promote engagement in diet and dementia research both currently and in the future. Building relationships with relevant stakeholders (e.g., charitable, or statutory organisations or voluntary groups who support South Asian communities) means that they can act as 'gatekeepers' to recruitment and support with advertisement of research IHND

studies, as well as providing a preferable setting for hosting research related activities. This then builds a level of trust between the potential participants and researchers. This is supported by participatory research among Black–British adults focused on diabetes education, where individuals felt it was best to avoid medical type settings for engagement in health-related research, rather, opting for community, faith-based settings to overcome issues of distrust and to allow convenience.<sup>42</sup> Furthermore, a narrative review of barriers and facilitators to lifestyle changes among minority ethnic populations highlights places of worship as 'safe' environments when conducting health promoting activities.<sup>31</sup>

It has been long established that codesign and citizenled action leads to greater individual and community empowerment.<sup>43</sup> Capacity building approaches, such as community ambassador programmes, allow lay people to act as change agents in their community, who offer community leadership and support.<sup>44</sup> The community ambassador approach offers several advantages, including building trust and credibility within minoritised ethnic communities, tailoring health messages to specific cultural contexts, fostering sustainable interventions through community engagement and addressing systemic barriers to health equity.<sup>45</sup> Using this kind of community model may be a suitable method for promoting diet and dementia risk reduction education. This approach has been recommended by research commissioned by the Scottish Government to understand diet, weight and type 2 diabetes among ethnic minority communities. This scoping review highlights the importance of community engagement when working with ethnic groups, facilitating trusted links between researchers and faith/community groups, with opportunities for peer-led interventions to offer support, improve awareness and encourage other members of the community to be involved.<sup>46</sup>

This PPI work has provided important learnings that will be taken forward to inform the design of the next phase of this research. This will involve the cocreation of a culturally adapted dietary intervention for brain health, incorporating a community ambassador model, in accordance with the MRC and NIHR guidance for developing complex interventions.<sup>17</sup> This will be a multiphased approach to intervention design, incorporating PPI and the involvement of relevant stakeholder's (e.g., charitable groups) to inform the content, delivery methods and setting for a dietary intervention, which will be underpinned by relevant behavioural theory.

## CONCLUSIONS

The recruitment of South Asian communities into research studies continues to be a challenge for researchers. The provision of culturally appropriate and adapted resources is vital to improve engagement and retention. This is of importance not only for the interventional/ educational resources provided within a study, but also with respect to recruitment strategies, the research team, provision of participant information and the dissemination of findings.

### AUTHOR CONTRIBUTIONS

Andrea M. Fairley and Rebecca F. Townsend conceptualised and designed the study. All authors provided feedback on the study methods. Yi J. Sim, Andrea M. Fairley and Rebecca F. Townsend facilitated the PPI event, roundtable discussions and collected data. Yi J. Sim led the analysis and synthesis of the data, with support from Andrea M. Fairley and Rebecca F. Townsend. Yi J. Sim compiled a first draft, which was subsequently shaped by Andrea M. Fairley and Rebecca F. Townsend. All authors provided feedback on the final version of the manuscript submitted for publication.

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#### CONFLICT OF INTEREST STATEMENT

The authors declare that there are no conflicts of interest.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available because of privacy or ethical restrictions.

### TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with Guidance for Reporting Involvement of Patients and the Public (GRIPP2). The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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## PEER REVIEW

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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