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# The *Chinese-Think Brain Health* community intervention for dementia prevention in the UK: from theoretical cultural adaptation to evaluation

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(accepted 13 May 2025)

## Abstract

People from different ethnic minorities in the UK are experiencing a steeper increase in dementia diagnosis compared to their white counterparts but are more likely to have a higher risk of dementia, to be diagnosed at a younger age and to die earlier from the condition. These disparities suggest the need for urgent interventions to prevent and reduce dementia risk. Despite the significant presence of Chinese people in the UK, there has been little dementia research involving them, so this study is the first in the UK to focus on Chinese communities living in five major cities. Using a cultural adaptation theoretical framework, we adapted Alzheimer's Research UK's virtual dementia prevention campaign *Think Brain Health* to meet the needs of Chinese people. We used a mixed methods approach to evaluate knowledge of dementia and brain health activities, and intention regarding help-seeking. We performed descriptive, chi-square and thematic analysis; 54 Chinese people completed the intervention, with 85 per cent aged over 60 years. Over half (56%) could not speak, read or write in English. Our results showed significant improvements in knowledge of dementia and brain health, and an improved intention to seek help and information. All participants reported a positive experience of the culturally tailored intervention and valued working with dementia researchers who were able to deliver the intervention in Chinese languages. Future work involving Chinese communities in the UK will need to identify an appropriate but non-stigmatizing Chinese term for dementia.

**Keywords:** brain health; Chinese communities; cultural adaptation and tailoring theory; dementia prevention; mixed methods; UKA

## Introduction

One in two of us will be directly affected by dementia in our lifetime, either as a carer for someone with dementia or living with the condition ourselves (Beasley et al. 2023). With a projected cost of £47 billion in 2050, dementia will be the most expensive health condition in the UK (Cantarero-Prieto et al. 2020) and most of this cost will fall directly on people living with dementia and their families (Wittenberg et al. 2019).

Substantial evidence shows that dementia can either be prevented or its onset delayed by reducing lifestyle-related risks (Livingstone et al., 2020). Importantly, keeping active physically, cognitively and socially in mid-life and later life has been associated with improved cognitive function in older people and those at risk of developing dementia (Jia et al. 2019; Kheirouri and Alizadeh 2022; Kivipelto et al. 2020; Ngandu et al. 2015; Stillman et al. 2020; Xu et al. 2023). As an effective pharmacological treatment for any cause of dementia has still to emerge and as we are facing the prospect of growing economic costs of dementia, governments across many countries in Asia, Europe and the Americas have consequently focused on the prevention of dementia, including encouraging their populations to modify their lifestyles, for instance by increasing levels of physical activity as ways of reducing dementia risk (Hampel et al. 2022).

## The Chinese population in the UK

The Chinese ethnic group in the UK comprises 445,590 individuals or 0.7 per cent of the UK population (ONS 2021). This number excludes an additional 201,877 Hong Kong Chinese migrants who have settled in the country since January 2021 on the British Nationals (Overseas) Visa scheme (Hong Kong Watch 2024). Over half of the Chinese population in the UK was born in Eastern Asia, with the majority coming from Hong Kong, and at least 15 per cent originating from Southeast Asian countries including Vietnam, Malaysia and Singapore. A quarter of the Chinese population is over 50 years old, with around 13 per cent aged over 60 (ONS (Office for National Statistics) 2021). They are dispersed widely across the country, with the largest communities residing in London, followed by significant populations in Manchester, Birmingham, Glasgow, Edinburgh and other cities.

The Chinese language is rich and diverse and encompasses many different dialects or spoken languages, each with its own unique phonetic, lexical and grammatical characteristics. Three Chinese languages (Cantonese, Mandarin and Hakka) are spoken, and two written forms of Chinese (Traditional and Simplified Chinese) are used in the UK. Typically, Chinese people from Hong Kong speak Cantonese and Hakka and write in Traditional Chinese. Migrants from China speak Mandarin and write in Simplified Chinese; those from Taiwan speak in Mandarin and write in Traditional Chinese; and Chinese people from Malaysia and Singapore can speak different Chinese languages and write in both Chinese languages. This linguistic diversity poses barriers to communication within the Chinese communities.

Communication in English is a problem for many older Chinese people. Often working long hours, many Chinese people have limited opportunities to develop their English language skills and have little experience of communicating with others outside

their communities (Yu 2000). Many older people rely on interpreters to access health-care and support services, which can create challenges, including unavailability and poor quality of the translation (Liu et al. 2017). As a result, many Chinese people have turned to local, Chinese-led organizations for support (Baghirathan et al. 2020). Issues such as trust and confidence in health professionals, and patients feeling that they have been disrespected and excluded from decision-making in the care process have all been reported (Chau and Yu 2002 & 2004; Healthcare Commission 2008). Compared to other ethnic minority groups in the UK, Chinese people make less use of the health and social care services (Rudat 1994) from which they are more likely to be excluded owing to language barriers (Yu 2000).

## Literature review

### *Dementia in the Chinese population in the UK*

Assuming that the incidence of dementia among Chinese people in the UK matches that of the general population, that is one in 11 individuals aged over 65, an estimated 3,790 Chinese people, is currently living with dementia. Despite this significant number, there is little understanding about the experiences of dementia in this population group. We found only one published small dementia study in the UK, which reported poor awareness and knowledge of dementia within the community and misconceptions about dementia (Baghirathan et al. 2020).

Cultural beliefs and practices, values and attitudes play a significant role in shaping perceptions and experiences of dementia and services within different communities (Bedford 2004; Bedford and Hwang 2003). Within the Chinese communities, dementia tends to be viewed through a cultural lens that emphasizes filial piety, respect for elders and the importance of family cohesion. A tradition of filial responsibility is ingrained in Chinese culture with the younger generation feeling a strong sense that it is their duty to care for their older parents at home – a belief that can lead to reluctance in seeking help. However, there is some evidence of a decline in filial responsibility for Chinese families in the UK possibly resulting in families being unable to fulfil their caring responsibility owing to their long working hours, moving away for work and competing childcare responsibilities (Chiu and Yu 2001). Other factors that may lead to elderly parents living separately from their children include guilt at burdening their children, parents' choice to live independently and a growing gap between the first and second generations (Chau 2008). This evidence suggests a possible increase in demand for dementia social care from elderly Chinese people in the future.

A misconception of dementia as part of normal ageing alongside a strong sense of stigma towards dementia have been linked to cultural beliefs about mental health in Chinese communities and have been thought to lead to a reluctance to acknowledge or seek help for cognitive decline (Baghirathan et al. 2020). The use of holistic health approaches such as traditional Chinese medicine could delay medical help-seeking and poses issues of symptom communication with health-care professionals (Chau 2008; Liu et al. 2017; Yu 2000). Language barriers – including among new Hong Kong migrants – also present a significant obstacle to accessing dementia care and support services for Chinese individuals (Baghirathan et al. 2020; Holland 2021).

**Table 1.** Chinese terms for dementia in use in the UK (in both Chinese characters and the Pinyin system for Chinese pronunciation)

Cantonese	Traditional Chinese characters	Mandarin	Simplified Chinese characters	Meaning
<i>Chi Ngoi Zing</i> (medical term)	痴呆症	<i>Chi Dai Zheng</i> (medical term)	痴呆症	Crazy, mad, idiotic, mentally retarded, clumsy, intellectual disability
<i>Sat Zi Zing</i>	失智症	<i>Shi Zhi Zheng</i>	失智症	A dysfunction of intelligence or loss of wisdom
<i>Nou Teoi Faa Zing</i>	腦退化症	<i>Nao Tui Hua Zheng</i>	脑退化症	Degeneration of the brain
<i>Teoi Zi Zing</i>	退智症	<i>Tui Zhi Zheng</i>	退智症	A gradual decrease in mental capacity
<i>Jan Zi Zoeng Ngoi Zing</i>	認知障礙症	<i>Ren Zhi Zhang Ai Zheng</i>	认知障碍症	A cognitive disorder

Crucially, at least five terms (written in the Pinyin system of Chinese pronunciation used in this article) are being used in different UK Chinese communities to describe dementia – all of which influence how dementia is perceived and in turn whether help is sought both before and after a diagnosis. *Chi Ngoi Zing* (in Cantonese) or *Chi Dai Zheng* (in Mandarin) is the medical term for dementia used by the World Health Organization; it is widely used in China, Singapore and Malaysia and translates into English as stupid, crazy, idiotic or mad. This term is perceived by many Chinese people as pejorative and derogatory (Baghirathan et al. 2020; Chiu et al. 2014). Partly because of this term, a diagnosis of dementia within Chinese communities is likely to carry high social stigma; consequently, people living with dementia and their families are more likely to keep knowledge of the diagnosis within the family, and conceal or downplay symptoms of the mental health issue in their community (Baghirathan et al. 2020). This behaviour could be explained by *face-saving*, another key cultural feature of Chinese people, where maintaining ‘face’ is important to keep social reputation, image, dignity and honour (Bedford 2004; Kong et al. 2020). When dementia is described as crazy, mad and stupid in the communities, losing face for a Chinese person with dementia would mean loss of respect and social standing, and feeling shame and stigmatized. Four other terms – *Sat Zi Zing*, *Nou Teoi Faa Zing*, *Teoi Zi Zing* and *Jan Zi Zoeng Ngoi Zing* (in Cantonese) – are currently in use within different Chinese communities and are sometimes prefixed by ‘*lo yan*’ (old people). However, none of these alternative terms accurately conveys an understanding of dementia and its symptoms and may thus contribute to a failure to recognize the initial symptoms of dementia as being different from normal ageing (see Table 1).

Partly owing to cultural values and language barriers, including the different dementia terms, Chinese people living with dementia and their families may encounter challenges in accessing a timely diagnosis, information or support. Addressing these issues requires culturally sensitive approaches that recognize and respect the cultural norms, values and language preferences of Chinese communities.

**Table 2.** Think Brain Health campaign: contents of Brain Health Basics

Brain Health Basics	Themes	Core information
<b>Three Simple Rules (Brain Health)</b>	Love your heart	<ol style="list-style-type: none"> <li>1. Keeping blood pressure in check</li> <li>2. Eating a balanced diet</li> <li>3. Physical activity</li> <li>4. Quitting smoking</li> <li>5. Drinking responsibly</li> </ol>
	Stay sharp	Evidence and examples to keep the brain active to improve cognitive functions.
	Keep connected	Evidence about social engagement and participation to avoid social isolation and loneliness.
<b>Four things you need to know about dementia (correcting misconceptions)</b>	<ol style="list-style-type: none"> <li>1. Dementia is more than memory loss</li> <li>2. Not everyone will get dementia as they age</li> <li>3. Dementia is not a normal part of ageing</li> <li>4. Dementia is rarely passed down in families</li> </ol>	
<b>Research is making real progress on dementia</b>	Information on the latest studies	

### **The Think Brain Health campaign**

To promote dementia prevention, the UK's largest charity Alzheimer's Research UK launched the first virtual Think Brain Health (TBH) campaign in January 2021 (Alzheimer's Research UK 2021). This campaign aimed to change the public's attitudes about dementia prevention, with core brain health information being delivered as *Three Simple Rules* (Love your heart, Stay sharp and Keep connected). Information on five lifestyle behaviours for prevention of dementia made up the *Love your heart* rule (Table 2). The importance of keeping our brain active to improve cognitive functions was discussed as part of the *Stay sharp* rule, while the *Keep connected* rule related to increased social engagement and participation as a way of avoiding social isolation and loneliness. On dementia, the campaign focused on four misconceptions about dementia and research progress. Additionally, the website included a quiz (The Brain Health Quiz) made up of eight questions aimed at raising awareness about the brain and its function. To encourage the public to explore their lifestyle-related risk and healthy brain behaviours, Alzheimer's Research UK has since continued the campaign with the *Brain Health Check-In tool* launched in February 2023.

The TBH campaign had a wide reach with 1.2 million visitors by January 2024. Social characteristics of the visitors revealed that more younger people (under 60 years of age) accessed the website than older people, and fewer than 5 per cent of the 158,343 visitors who provided ethnicity data were people from ethnic minority backgrounds. These characteristics are typical of people in the UK who are digitally excluded, with more frequent users of the internet being more likely to be under 65, to be from White British backgrounds and to be male (House of Lords 2023; ONS 2019). This suggests that, to be inclusive, the TBH campaign, as with other public health interventions, needs to use other methods to promote dementia prevention across the UK's multicultural society.

Using the term 'brain health' in the ethnic minority populations, the TBH campaign has the potential to reduce social stigma about dementia, and to shift perception and attitudes towards dementia by emphasizing that it can be delayed or prevented with lifestyle modifications. Additionally, for the Chinese communities, the term 'brain health' can help to avoid potentially contentious discussions about the most appropriate dementia term(s) and enable a more open discussion around the condition.

The *Chinese-Think Brain Health* (*Chinese-TBH*) project was funded by Alzheimer's Research UK in January 2022, to promote dementia prevention in Chinese communities across the UK through a culturally tailored campaign. The project comprised three phases: Phase One involved a face-to-face, culturally adapted/tailored *Chinese-TBH* community intervention in the five UK cities with the largest Chinese populations – London, Manchester, Birmingham, Liverpool and Bristol. Phase Two consisted of a national online survey using a Dementia Attitude Monitor and the Think Brain Health Quiz questionnaire in both Simplified and Traditional Chinese languages. Phase Three included a webinar on brain health aimed at building the capacity of Chinese organizations that support the older adult population.

This article discusses the work performed in Phase One – specifically the development, implementation and evaluation of the *Chinese-TBH* community intervention. A cultural adaptation framework was adopted as its theoretical foundation, which placed an emphasis on adaptation and tailoring health interventions at both the surface and the deep structures of socio-cultural influences to align with the cultural context of a specific population (Resnicow et al 1999).

## Theoretical framework

To promote and improve health and wellbeing within a population, service providers have increasingly turned to digital technologies. However, when digital health interventions are designed for majority populations, they often require adaptation or tailoring to improve their effectiveness and acceptability for specific target audiences. By making these adjustments, digital health interventions have been shown to be both acceptable and effective across a wide range of populations, including carers of people with dementia (e.g., Messina et al. 2024) and older people with low digital literacy (e.g., Carrasco-Dajer et al. 2024). Digital interventions have also been adapted for people with culturally diverse backgrounds (Barrera et al. 2017; Ellis et al. 2022; Escoffery et al. 2018; Nierkens et al. 2013). However, not all have been partially or fully adapted using cultural adaptation theory, which has often contributed to impacts that were less than expected (Balci et al. 2022; Brijnath et al. 2021; Chu and Leino 2017; Day et al. 2023; Napoles et al. 2010).

The cultural adaptation of an intervention is a crucial process to enhance its effectiveness and relevance for a specific target audience. This process involves making systematic modifications to the intervention to align it with the cultural needs, values and preferences of the intended audience. Theories of cultural adaptation emphasize that these modifications should occur on two levels: surface structure and deep structure (Lim 2024). **Surface structure adaptation** involves the more apparent and visible aspects of the audience, such as translating materials into the audience's language, using culturally relevant images and metaphors, adapting the format of delivery

to align with cultural norms and incorporating examples or references that resonate with the audience's daily life experiences (Resnicow et al 1999; Bernal et al. 1995). **Deep structure tailoring** goes beyond the visible features and addresses the underlying cultural, social and historical factors that influence the attitudes and behaviours of the target population. Deep structure modifications are more profound, involving an understanding of the cultural beliefs, values and practices that affect how individuals perceive and engage with the intervention as well as the social determinants affecting health and wellbeing. These changes might involve integrating culturally specific health beliefs, acknowledging historical contexts that shape trust or mistrust in certain practices and considering social dynamics such as the complexity of the Chinese dementia terms. Epidemiological evidence should also be included in adaptation to enhance awareness and/or the perceived relevance of the health issue (Krueter et al 2004). Adaptation at both surface and deep structure levels aims to develop interventions that meet the needs of the intended audience with the goal of ultimately creating attitudinal and behavioural change, and, in the longer term, sustainability (Resnicow et al 1999). Consequently, any adaptation of an effective risk reduction strategy aimed at people from ethnic minority backgrounds would need to have both surface and deep structure elements.

## Methods

Ethical approval for the project (1222JLUOWHEA) was obtained from the Research Ethics Board, Faculty of Education, Health and Wellbeing, University of Wolverhampton in February 2022.

### Developing the *Chinese*-TBH community intervention

For the materials of the *Chinese*-TBH intervention, we maintained the core elements of the TBH campaign (i.e., core brain health and dementia information) and tailored them at both deep and surface structure levels.

#### *Deep structure adaptation*

To facilitate the long-term goal of the *Chinese*-TBH project of changing attitudes towards dementia and to improve help-seeking behaviour and early diagnosis, we included a discussion about the range of Chinese terms for dementia and how these impacted help-seeking and utilization of local care and support services in the project. We made this discussion the first topic in our intervention to allay distress about the medical term (*Chi Ngoi Zing* in Cantonese, *Chi Dai Zheng* in Mandarin) and to explore the impacts of the different terms on help-seeking and timely diagnosis. On dementia, we included information to explain the difference between normal ageing and dementia, the four common types of dementia and signs. As 'Think Brain Health' was a new and unfamiliar phrase, and during the recruitment phase some people misunderstood it as brain injury or trauma, we added a section to introduce the term 'brain health' and explain its relevance to dementia (the relationship between dementia and our brain and how looking after your brain will reduce the risk of dementia). The additional components resulting from this adaptation were then organized in logical order with the core components of TBH to produce the final *Chinese*-TBH community intervention.



### Surface structure adaptation

To enhance recruitment, we collaborated with five Chinese local organizations: the Birmingham Chinese Community Centre, the Manchester Chinese Health Information Centre, the Chinese Wellbeing Trust in London, the Chinese Community Wellbeing Society in Bristol and Chinese Wellbeing in Liverpool. We worked closely with the Chinese community organizations to plan the delivery of the intervention, including preferred Chinese terms for dementia, the appropriate spoken and written Chinese languages, and images and examples of brain health activities to use in each community. As a result, we prepared two versions of contents: one in Simplified Chinese and the other in Traditional Chinese. These were translated by the Chinese community organizations and were agreed by members in the five cities. Initially, we used the medical dementia term (*Chi Dai Zheng/Chi Ngoi Zing*) in our materials, but later as a further version we used *Nao Tui Hua Zheng / Nao Teoi Faa Zing* following a request from the Liverpool and London community organizations who felt that the medical term would be stigmatizing. Altogether, four different versions of educational materials were developed to meet the language needs across the five different communities and to use the preferred Chinese term for dementia. We used PowerPoint and delivered the intervention in multiple languages, namely Cantonese, Mandarin and Hakka. We also scheduled the activities (hours, location) and delivered them in the preferred format (on site, virtual or hybrid). We provided a participation fee as a recognition of participants' time commitment to the project, as well as lunch and refreshments.

### Recruitment

All of the five Chinese community organizations have a strong history of working to improve the health and wellbeing of older Chinese people in their communities. Through these organizations, we aimed to recruit 10 to 12 participants in each site who were Chinese, aged over 55 years and had the capacity to consent to participation. A poster advertising the study was shared on social media by each of the five Chinese Community organizations and recruitment was conducted either in person at the community centres or via telephone. The staff at the community centres and/or the researchers went through the Participant Information Sheet with each potential participant and accommodated the participants' preferences for virtual rather than on-site workshops. Informed consent was collected via email, through the post or verbally, over the telephone, according to how the sessions were delivered.

### Implementation of the Chinese-TBH community intervention

Implementation of the *Chinese*-TBH intervention took place across a series of three workshops: we delivered the adapted *Chinese*-TBH campaign materials in the first workshop; the second workshop focused on the co-design of a poster and leaflet to enhance learning about brain health and dementia; and in the final workshop we reviewed our learning from workshops 1 and 2 to consolidate knowledge.

In total, we conducted 15 workshops – three in each of the five cities – between mid-March and May 2022. We used a variety of delivery formats to meet participants'



preferences: on-site (Manchester and Birmingham); blended with both on-site and virtual at the same time (London and Bristol; and virtual (Liverpool)). Workshops in each city took place with a gap of between one and three weeks, except in Manchester where the three workshops were completed across two consecutive days. Each workshop lasted between two and three hours with lunch and refreshments provided. To finalize the posters and leaflets, draft designs were circulated, discussed and agreed among the participants in each city. In two cities (Manchester and Birmingham), an additional session was held to finalize the poster and leaflets.

### *A mixed-methods study design*

We evaluated the *Chinese*-TBH community intervention using a before-and-after study design and focus group discussion. Participants were asked to complete a questionnaire to assess their knowledge of brain health and dementia, and the strength of their intention to seek medical help before and after the intervention. Participants rated themselves in terms of their knowledge about dementia and the signs of dementia; misconceptions about dementia; knowledge of brain health and the *Three Simple Rules* (see Table 5 for the seven brain health activities) that can help to prevent dementia. At the end of the intervention, we conducted a focus group discussion in each city to evaluate participants' experiences and suggestions for future work and improvement.

### *Data analysis*

Data obtained from the before-and-after questionnaire were analysed using SPSS (version 10) software. Descriptive and chi-square analyses were performed to compare knowledge about dementia and brain health, intention to seek help and information before and after the intervention. Where we made multiple comparisons, we used a reduced level of significance to reduce the risk of Type 1 errors. The effectiveness of the before-and-after intervention is demonstrated using effect size measured by Cramer's  $V$  and  $\phi$  ( $\Phi$ ). An effect size is considered small if  $\Phi \leq 0.10$ , medium if  $\Phi = 0.30$  and large if  $\Phi \geq 0.50$ .

The focus group discussions were primarily conducted in Cantonese, with occasional use of Mandarin in Birmingham and Bristol, and audio recorded. The staff of the community organizations coordinating the workshops translated the recorded discussions into English; these were subsequently reviewed by the researchers (JL and MC) for accuracy.

Thematic analysis was used to analyse the data (Braun and Clarke 2006). The data were analysed by the researchers (JL and MC) and the findings were shared and confirmed by the community organizations.

## **Results**

### *Participants*

In total, 59 people participated in the intervention across the five cities with 54 completing the intervention (five participants did not attend the third workshop owing to illness and other commitments and they were excluded from the data analysis).

**Table 3.** Socio-demographic characteristics of participants and their English proficiency by city

City (N = 54)	Age	Gender	Country of origin	English language proficiency
<b>London (n = 10)</b>	50–59 = 3	Female = 8	Hong Kong = 8	Speak, write and read = 6
	60–69 = 1	Male = 2	Singapore = 1	Speak only = 0
	70–79 = 6		Malaysia = 1	Cannot speak, write or read = 4
	80–89 = 1			
<b>Birmingham (n = 10)</b>	50–59 = 3	Female = 9	Hong Kong = 7	Speak, write and read = 0
	60–69 = 2	Male = 1	China = 1	Speak only = 0
	70–79 = 4		Vietnam = 2	Cannot speak, write or read = 10
	80–89 = 1			
<b>Manchester (n = 15)</b>	50–59 = 0	Female = 11	Hong Kong = 14	Speak, write and read = 7
	60–69 = 9	Male = 4	Taiwan = 1	Speak only = 2
	70–79 = 5			Cannot speak, write or read = 6
	80–89 = 1			
<b>Liverpool (n = 12)</b>	50–59 = 1	Female = 11	Hong Kong = 12	Speak, write, and read = 2
	60–69 = 2	Male = 1		Speak only = 3
	70–79 = 8			Cannot speak, write or read = 7
	80–89 = 1			
<b>Bristol (n = 7)</b>	50–59 = 1	Female = 6	Hong Kong = 6	Speak, write and read = 5
	60–69 = 2	Male = 1	China = 1	Speak only = 0
	70–79 = 3			Cannot speak, write or read = 2
	80–89 = 1			

More than half of the 54 participants were aged over 70 years, with the majority being female; there were just seven male participants (Table 3). Most participants originated from Hong Kong, with a few from China, Vietnam, Malaysia, Taiwan and Singapore; all were immigrants. On English language proficiency, fewer than a third (16 people, 30%) could speak, write and read English, while 30 (56%) could not speak, write or read in English. Seven people (13%) said that they could speak but not write or read in English.

Cantonese was the main spoken language in all the cities, with Hakka and Mandarin being spoken by some participants in Bristol and Birmingham. Traditional Chinese was the written language used in the posters and leaflets in London, Manchester, Bristol and Liverpool. In Birmingham, an additional poster was produced in Simplified Chinese language, aiming at the increasing number of migrants from China settling in the city. Altogether six different versions of posters and six different leaflets were produced in the five cities with a total of 30 posters and 900 leaflets being printed for distribution.

## Quantitative findings

### *Knowledge of dementia and signs of dementia*

We asked the participants about their knowledge of dementia as a condition (see Table 4). We compared levels of self-reported knowledge before and after the intervention using a  $3 \times 2$  contingency table and chi-squared test, omitting respondents who felt that they needed more information. The results indicated a significant difference in self-reported knowledge levels ( $\chi^2 (2, N = 88) = 35.54, p < 0.001$ ). Using Cramer's  $V$  (which is appropriate for contingency tables in excess of  $2 \times 2$ ) gave a large effect size of 0.45. We explored these results further by using  $z$  values to calculate the chi-square score for each cell. This cell-by-cell analysis indicated that there was a significant increase in the numbers of participants responding that they knew a lot about dementia after the intervention compared to before ( $\chi^2 = 18.49, p = 0.00001$ ).

We also compared knowledge of dementia signs using the same procedure. Analysis indicated no significant difference in knowledge of the signs of dementia ( $\chi^2 (2, N = 74) = 4.31, p > 0.1$ ). However, analysis was impacted by the fact that over half of the participants reported after the intervention that they still wanted to know more about the signs of dementia (compared to just one person who wanted to know more about the signs of dementia before the intervention).

### *Misconceptions about dementia*

Misconceptions about dementia were assessed using 'Four things to know about dementia' statements. Using a series of  $2 \times 2$  contingency tables and chi-squared analyses, we found significant reductions in the level of misconceptions about dementia after intervention: 'Memory loss is the only sign of dementia' ( $\chi^2 (1, N = 108) = 23.08, p < 0.000001, \Phi = 0.46$ ), 'Dementia is part of normal ageing' ( $\chi^2 (1, N = 108) = 18.56, p < 0.0001, \Phi = 0.41$ ), 'Everyone will get dementia as they aged' ( $\chi^2 (1, N = 108) = 8.8, p < 0.001, \Phi = 0.29$ ) and 'Dementia is a genetic condition' ( $\chi^2 (1, N = 108) = 9.69, p < 0.001, \Phi = 0.30$ ). The results, all of which had small or medium effect sizes, indicated that fewer people agreed with these misleading statements after intervention compared to before.

### *Dementia research is making progress*

We also found a significant increase in the number of participants agreeing with the statement that 'Research has made progress' ( $\chi^2 (1, N = 108) = 7.28, p < 0.0001, \Phi = 0.26$ ) after the intervention.

**Table 4.** Knowledge about dementia and brain health and help-seeking

Misconceptions, knowledge about dementia and dementia research, and help-seeking	Pre-intervention agreement (N = 54)	Post-intervention agreement (N = 54)	Effect size
<b>Misconceptions about dementia:</b>			
I know a lot about dementia	2	20	0.734 (p < 0.01)
I know something about dementia	38	13	
I don't know anything about dementia	14	1	
I want more information about dementia	0	20	
<b>Knowledge about the signs of dementia:</b>			
I know all the signs of dementia	3	0	0.64 (p < 0.01)
I know some of the signs of dementia	39	21	
I do not know the signs of dementia	10	1	
I want to know more about the signs of dementia	1	31	
I do not want to know	1	1	
<b>Four things to know about dementia:</b>			
1. Memory loss is the only sign of dementia	28	5	
2. Everyone will get dementia as they age	19	6	
3. Dementia is part of normal ageing	33	11	
4. Dementia is a genetic condition (it can be passed down within the family)	31	15	
<b>Research has made progress about dementia:</b>			
Research has made progress about dementia	20	41	
<b>Help-seeking after symptoms are identified:</b>			
I will make an appointment to see the doctor/GP	32	47	
I want to be diagnosed as soon as possible	24	37	
I will tell my family members about it	23	39	
I will talk to my Chinese health organization about it	25	35	
I will find more information about it	24	28	
I do not know where to find more information about it	10	10	
I still want more information about dementia and brain health, even though I have participated in this project	1	41	

### *Intention to seek help and information*

Participants were asked about their intention to seek help and information if they were to identify signs of dementia (see Table 4). The chi-squared analysis found a significant

increase in help seeking with GP, family and local community organizations: 'I want to be diagnosed as soon as possible' ( $\chi^2 (1, N = 108) = 6.37, p < 0.01, \Phi = 0.24$ ), 'I will make an appointment to see the GP' ( $\chi^2 (1, N = 108) = 10.61, p = 0.001, \Phi = 0.31$ ), 'I will tell my family about it' ( $\chi^2 (1, N = 108) = 9.69, p < 0.0001, \Phi = 0.30$ ) and 'I will talk to my Chinese community organization about it' ( $\chi^2 (1, N = 108) = 3.75, p < 0.1, \Phi = 0.18$ ). Our results with small or medium effect sizes demonstrated increases in numbers of participants who reported that they agree with these statements.

There was no difference in participants' willingness to seek out more information after they had recognized dementia. Levels of agreement with the statement 'I will find more information about it' were unchanged ( $\chi^2 (1, N = 108) = 0.59, p > 0.1$ ).

### Knowledge about brain health and the Three Simple Rules on dementia prevention

We evaluated knowledge of brain health firstly by asking participants if they had heard of the term 'brain health' and then assessing their knowledge of the seven brain health activities encapsulated in the *Three Simple Rules*. Using the chi-squared test, we found a significant increase in knowledge in all areas, except for two activities, 'Love your heart 3 – Be physically active' and 'Stay sharp – Keep your brain active'. We managed to significantly increase awareness of the term 'brain health', but the effectiveness of our intervention is mostly moderate in relation to knowledge of brain health activities (see Table 5).

There was also a significant increase in the number of people after the intervention who agreed with the statement that 'Keeping a healthy brain can help to prevent dementia' ( $\chi^2 (1, N = 108) = 30.02, p < 0.0001, \Phi = 0.53$ ) as well as those who could identify all seven brain health activities ( $\chi^2 (1, N = 108) = 16.38, p < 0.0001, \Phi = 0.39$ ) after the intervention.

Our analysis also showed a significant increase in people who said they still wanted more information about dementia and brain health even though they had participated in the intervention ( $\chi^2 (1, N = 108) = 62.34, p < 0.00001, \Phi = 0.58$ ). Specifically on brain health, over three-quarters of the 54 participants said they still wanted more information after the intervention.

### Qualitative findings

The key qualitative findings centre on how language, culture, stigma and community engagement shape perceptions and understanding of dementia in the UK Chinese communities. Five key themes are presented next:

#### Theme 1: multiple dementia terms in Chinese and stigma

Within this theme, participants discussed the stigma of the medical term, their preference for alternative terminology and, at the same time, a realization that the multiple terminologies used in the communities have caused confusion and diluted the seriousness of dementia. Across all sites, participants expressed strong discomfort with the term 'Chi Ngoi Zing' (痴呆症), commonly used in Chinese medical discourse to denote dementia. Translated literally as 'crazy/mad disease, foolish/stupid sickness', the term was universally viewed as derogatory and stigmatizing, where mental and

**Table 5.** Knowledge of brain health and the *Three Simple Rules* before and after the intervention

Brain health knowledge	Pre-intervention (N = 54)	Post-intervention (N = 54)	$\chi^2$ results
<b>Have you heard of the term ‘brain health’?</b>	13	50	$\chi^2$ (1, N = 108) = 52.15 adjusted $p < 0.0001$ , $\Phi = 0.69$
<b><i>Three Simple Rules</i> for brain health:</b>	<b>Pre-intervention (N = 54)</b>	<b>Post-intervention (N = 54)</b>	
• <i>Love your heart 1</i> – Keep your blood pressure in check	29	47	$\chi^2$ (1, N = 108) = 14.39 adjusted $p < 0.0001$ , $\Phi = 0.37$
• <i>Love your heart 2</i> – Quitting smoking	22	43	$\chi^2$ (1, N = 108) = 17.04 adjusted $p < 0.001$ , $\Phi = 0.40$
• <i>Love your heart 3</i> – Be physically active	41	48	$\chi^2$ (1, N = 108) = 3.13 adjusted $p < 0.1$ , $\Phi = 0.17$
• <i>Love your heart 4</i> – Eating a balanced diet	32	46	$\chi^2$ (1, N = 108) = 9.05 adjusted $p < 0.01$ , $\Phi = 0.29$
• <i>Love your heart 5</i> – Drink responsibly	26	45	$\chi^2$ (1, N = 108) = 14.84 adjusted $p < 0.0001$ , $\Phi = 0.37$
• <i>Stay sharp</i> – Keep your brain active	43	49	$\chi^2$ (1, N = 108) = 2.64 adjusted $p = 0.1$ , $\Phi = 0.16$
• <i>Keep connected</i> – Be socially active	39	51	$\chi^2$ (1, N = 108) = 9.6 adjusted $p = 0.01$ , $\Phi = 0.30$
<b>Number of participants who correctly identified all seven activities in the <i>Three Simple Rules</i></b>	18	39	$\chi^2$ (1, N = 108) = 16.38 adjusted $p < 0.0001$ , $\Phi = 0.39$
<b>Do you know that keeping your brain healthy can help to prevent dementia?</b>	25	51	$\chi^2$ (1, N = 108) = 30.02 adjusted $p < 0.0001$ , $\Phi = 0.53$

cognitive health issues are highly stigmatized, often associated with family shame and loss of face in the Chinese culture. Use of the term ‘*Chi Ngoi Zing*’ (痴呆症) therefore evoked connotations of madness, stupidity and shame, and was reported to discourage help-seeking as families may hide symptoms or engaging with dementia materials.

*No one likes to be called ‘Chi Ngoi’ – crazy, mad, stupid – or have others call their family like that. It is derogatory. (Manchester)*  
*If an old person is always unhappy, in a daze and have mental illness, do not call them ‘Chi Ngoi’ because this will upset them. It is better to call them ‘Nou Teoi Faa Zing’.* (Liverpool)

Using the term ‘*Chi Ngoi Zing*’ in awareness-raising materials (like leaflets or posters) turns people away, particularly older adults who may feel insulted or judged. Participants across the cities highlighted that this would discourage community engagement and undermine awareness campaigns.

In contrast, terms such as ‘*Nou Teoi Faa Zing*’ (‘*Nou*’ means brain, ‘*Teoi Faa*’ means degenerating/decline) and ‘*Teoi Zi Zing*’ (‘*Teoi*’ means degenerating/decline, ‘*Zi*’ means wisdom) were perceived as more neutral and respectful. These alternatives were considered to be less emotionally charged, helping reduce stigma and encourage engagement; thus, they would be more acceptable for public health messaging and discussion.

*If our poster or leaflet are titled with ‘Chi Ngoi Zing’, people will subconsciously avoid it. (London)*

*[I]f I were elderly and could read Chinese, when I saw a story with ‘Chi Ngoi Zing’, I would never read it. (Manchester)*

*If we use ‘Nou Teoi Faa Zing’, people will come and ask more if they find their brain, memory is not as good. I think ‘Nou Teoi Faa Zing’ is better as it is more widely acceptable. (Liverpool)*

Many participants noted that the use of multiple terms for dementia within the Chinese communities has led to confusion and misunderstandings about what the condition is. Some referred to it as Alzheimer’s disease, while others used various alternative terms (see Table 1 for the terms and meanings). Many participants raised concerns about the proliferation of the different Chinese dementia terms, which has led to confusion and reduced the perceived seriousness of the condition. They expressed a preference for a unified, community-endorsed term that could be consistently used in public health efforts.

*Many people have no idea what the disease is because we have so many Chinese terms being used in our community. (Manchester)*

*It’s better to have a unified name because it used to be called Alzheimer’s disease, but now there are so many other names for dementia, which is very confusing. (Bristol)*

### **Theme 2: public messaging – the power of ‘brain health’ (*nou gin hong*)**

Participants overwhelmingly endorsed ‘*Nou Gin Hong*’ (腦健康, ‘brain health’) as an effective alternative for public messaging. Framed positively, this term was considered engaging, non-stigmatizing and more likely to encourage individuals to explore health information. Critically, *Nou Gin Hong* (‘brain health’) shifts the focus from a biological issue (dementia as personal failure and stigma) to prevention and wellness, aligning with traditional Chinese medicine concepts of holistic health that prioritizes preventive health (Tai Chi, diet, herbal medicine).

*We think ‘Nou Gin Hong’ is better. People are more attracted to look at the poster and leaflet if it’s titled ‘brain health’. (London)*

As a result, many of the posters designed by our participants used this term as a headline, replacing direct references to dementia. These included slogans such as ‘Use your brain every day to stay healthy’ (London), ‘Think brain health – to reduce the risk of



dementia' (Manchester), 'Keep your brain healthy, Keep dementia away' (Birmingham) and 'Tips to keep your brain healthy' (Bristol).

### *Theme 3: help-seeking and barriers in health-care access*

While many participants expressed willingness to seek help for cognitive decline, many noted barriers related to language and communication such as difficulty communicating symptoms to English-speaking doctors, distrust owing to past negative experiences and limited understanding of medical jargon. Limited English proficiency and reliance on interpreters affected their ability to describe their symptoms and understand the diagnoses. Some preferred to consult Chinese-speaking GPs or seek informal advice from community centres.

*Sometimes it is difficult for me to express myself with a doctor. I prefer to use an interpreter from the community centre. (Bristol)*

*[M]any of us are registered with a Chinese doctor (GP). They can speak Cantonese and understand us when we tell them our problems. (Birmingham)*

*It's very convenient, we go to the Chinese community centre for advice. I don't go to the doctor because of language problems. (Bristol)*

### *Theme 4: delivery in the mother tongue for cultural relevance and trust*

Delivery of educational workshops in Cantonese by Chinese researchers was cited as crucial to participant engagement. Participants emphasized how being educated in their mother tongue (mainly Cantonese) by Chinese researchers who share their cultural background was transformative. This delivery approach had created a culturally safe space, fostered open discussion and increased understanding of the topic.

*Having someone from Chinese culture develop and lead the sessions made the discussions more engaging. We feel free to express our views. (Bristol)*

*The delivery in Cantonese meant that we have a better understanding of the subject matters and meaningful discussions in the groups. (Birmingham)*

*The contents delivery in our language gives a more intimate feel of the subject matter and not monotonous/boring, unlike those delivered in English language. (Manchester)*

### *Theme 5: empowerment through co-design and culturally tailored content*

The Chinese-TBH intervention was widely praised by the participants across the cities. It increased knowledge, empowered participants to educate others and encouraged lifestyle changes. Participants valued their involvement in co-designing posters and leaflets, noting that the activities reinforced their learning and gave them a sense of ownership. Many expressed prides in being able to disseminate information to their families and peers.

*The poster and leaflet design session helps me to better understand dementia. It is also a gathering of 'brain stimulation' for everyone. (Manchester)*

*We felt a sense of pride in the co-design session, producing posters and leaflets to share with family and friends. (Liverpool)*

*I can provide and share with my relatives and friends and those around me with relevant knowledge. After all, the Chinese who participated in the workshop activities are just a few. (Bristol)*

Participants also requested more frequent, shorter sessions and discreet Q&A formats to facilitate deeper understanding, and more information on dementia prevention such as diet and physical activities. Several emphasized the need for outreach to younger generations, who were perceived as uninformed or uninterested.

*We need more info on diet and types of activities to keep our brain healthy. What types of exercise is suitable, how much to do, what is good diet? (Birmingham)*

*Some participants would like more face-to-face Q&A sessions with individual enquiries about dementia because it is stigmatizing to talk about it openly. (Manchester)*

*Young people don't know, not interested. I told my son what I learnt; he just nodded his head. Young people also need to know. (Birmingham)*

## Discussion

Overall, our culturally adapted and tailored *Chinese*-TBH intervention resulted in improvement in both knowledge of dementia and brain health, and intention to seek help and information. We found significant increases in knowledge of dementia as a condition, dementia signs and brain health as a term to describe action to reduce the risk of dementia, and the seven brain health activities that can help to prevent dementia, following intervention in five major cities in the UK. These results are supported by our qualitative findings where participants talked about the value of the intervention in raising their awareness and knowledge of dementia and activities that could help to prevent dementia, and their 'sense of pride' in being part of the intervention to help their communities.

Crucially, the intention to seek help for signs of dementia has increased substantially after the intervention. The numbers of participants who reported that they agreed with 'I want to be diagnosed as soon as possible', 'I will make an appointment to see the GP', 'I will tell my family about it' and 'I will talk to my Chinese community organization about it' have significantly increased. A 40 per cent increase was observed for those who would talk to their community centre and this is possibly to sort support for interpretation services because of the language barrier and previous negative experiences with GP consultations and the NHS interpreting service. We have raised curiosity about dementia and dementia prevention in our project, with a significant increase of participants who said that they wanted more information about dementia and brain health. On brain health activities, over three-quarters wanted more information, specifically relating to the types of diet and physical activities that are suitable for elderly people. They also said they wanted more sessions, preferably in shorter and bite-sized format, and face-to-face and private Q&A sessions for individual enquiries.

Previous dementia interventions targeting people from ethnic minorities that either did not apply cultural adaptation theories or did so only partially were found to be less impactful than expected (Lim 2024). In our project, we systematically adapted and tailored the Think Brain Health (TBH) campaign at deep structure levels to address the

social and cultural factors that influence poor awareness of dementia and dementia prevention as well as hindering help-seeking and timely diagnosis for dementia in the UK Chinese communities. After our intervention, knowledge of dementia and dementia signs, including misconceptions about dementia as measured with four statements, had reduced significantly. We were able to deliver these positive results because we implemented the intervention using the preferred dementia term for each city and provided a space in which to openly discuss the medical term and other dementia terms at the start of the intervention.

Our qualitative study highlights the crucial intersection of language, culture, stigma and health education in dementia care within Chinese communities in the UK. The findings point to the need for respectful terminology, culturally competent interventions and tailored health messaging to promote early diagnosis, reduce stigma and empower communities. On dementia terminology, the findings showed that most of the participants agreed that the medical term was disrespectful, derogatory and stigmatizing, and that Chinese people would avoid any dementia-related activities if they saw the Chinese medical term being used. Some participants preferred '*Nou Teoi Faa Zing*' (brain degeneration) as a replacement for the medical term '*Chi Ngoi Zing*'. On another hand, a group of participants questioned the accuracy of the preferred term, stating that it doesn't represent all the signs and causes of dementia; they felt that the medical term is better at representing the clinical features of the condition and that to avoid it is to avoid the central issue of poor dementia awareness. Others wanted a single, unifying term that can consistently describe the condition.

Our qualitative findings also highlighted an emerging tension within Chinese communities regarding the varied terms used for dementia. This complex issue warrants careful consideration by care and service providers to ensure culturally sensitive communication and build consensus before implementing any health interventions. We have demonstrated in our intervention that tackling the issue of dementia terminology is a top priority: having the right terminology for the target community is pertinent to successful recruitment and implementation, and, ultimately, the effectiveness of the intervention. We need further research with the UK Chinese people to find and agree on a unifying term that can accurately describe dementia as a condition. This may be a new term and not one taken from a specific country, so as to reflect the vast diversity in this population group. Adopting more neutral terminologies could reduce resistance and encourage engagement; for instance, reframing dementia awareness through the lens of 'brain health' ('*Nou Gin Hong*') aligns with health promotion strategies that emphasize agency and preventive action, avoiding stigmatizing and negative messaging.

At the surface level, we tailored the virtual TBH campaign for a face-to-face intervention (on-site and online) and implemented strategies to successfully reach, engage and retain participants. Previous research with ethnic minority people employed a common strategy to engage and recruit participants through the local community and religious organizations (Dabiri et al. 2024). The success of our project in recruiting a large number of Chinese participants, 85 per cent of whom were aged over 60 years, is attributed to our collaboration with five local Chinese community organizations. We also achieved a high retention rate with 91.5 per cent of participants successfully completing our intervention. Here we felt that this was owing to our strategy of seeking a commitment at the recruitment stage and at the start of the first workshop. In the first

workshop, we also highlighted the epidemiological fact of low research participation among ethnic groups in dementia studies and emphasized the benefits of participation in the brain health workshops.

Often, studies involving ethnic minority communities use bilingual facilitators from the same ethnic group to implement/deliver the intervention (James et al. 2021; Napoles et al. 2010). However, a successful intervention depends not only on it being delivered in the audience's languages but also on the ability of the facilitators to answer questions and provide relevant information to their audience. In our project, Lim and Champ, who are of Chinese ethnicity and speak Chinese languages, delivered the intervention. They are also researchers with expertise in the subject matter as well as educators, who were able to meet the information needs of the participants. Thus, being able to speak the language and having the right experience in the field are important characteristics for successful intervention delivery in ethnic minority communities. Essentially, our study reinforces the effectiveness of culturally tailored interventions delivered in participants' mother tongue. Such approaches build trust, foster open dialogue and empower individuals to become health ambassadors within their own communities. The participatory nature of the intervention, including co-designed workshops, strengthened engagement and created a multiplier effect as participants shared knowledge with their networks.

Another crucial surface adaptation strategy is the intervention delivery as a series of three workshops; the first being an educational workshop, the second a co-design workshop to enhance learning and the third aimed at recapture and reinforcing learning from previous workshops. Applying the pedagogical principle of repetition in learning (Bruner 2001; Tomlin 1994) in our delivery, we produced positive results in our intervention. We used an interactive and participant-centred approach in our delivery; participants could stop us at any time to ask questions. We repeated the information about dementia and brain health using examples in the first workshop. For the co-design workshop, we reminded participants of what we had learnt about dementia and brain health in the first workshop. In the final workshop, we recaptured our learning using a series of questions such as 'Can you remember what we have learnt previously? Is memory loss the only sign of dementia? What are the four misconceptions about dementia? What are the signs of dementia? What is brain health and what do you need to do to keep your brain healthy?'. Our participants talked about their positive experience of participation in the intervention and the value of the intervention for them and their communities. Specifically, they talked about the co-designed workshop, saying not only that the activity had reinforced their understanding of dementia and brain health but also that they had enjoyed the interaction while working on the posters and leaflets and felt a sense of pride that their posters and leaflets would be used in the communities to raise awareness about dementia and brain health. Applying the pedagogic principle of repetition learning to intervention design meant that we successfully generated positive outcomes in our study.

### ***Strengths and limitations***

Our project has several notable strengths. It was the first in the UK to bring together five Chinese communities across the country to raise awareness about dementia, involving the largest number of older Chinese people in the country; and the first project to

adapt Alzheimer's Research UK's Think Brain Health campaign to an ethnic minority population. We applied fully the cultural adaptation theories to design and implement the *Chinese*-TBH intervention, and used the pedagogic principle of repetition learning in our intervention design.

Applying cultural adaptation theory necessitates a deep and comprehensive understanding of the target community – their needs and challenges; health beliefs and practices; social structures and dynamics; historical and societal context; cultural beliefs and practices; socio-economic circumstances; and preferred modes of engagement and access. It also requires the ability to identify which of the deep and surface structure elements are relevant to driving the necessary change in the target community. Achieving this level of understanding and ability often requires being part of the community, speaking the language or living within it. Without meeting this requirement, true cultural adaptation may not be realized. However, as researchers sharing the same cultural background with deep understanding and knowledge of the dementia issues faced by the Chinese community, we were able to overcome this barrier effectively to create trust, and produced a transformative intervention.

Our project has some limitations. Although the community organizations were successful in recruiting the number required for our project, these participants were mostly people who were users of the community centres. We were not able to reach other Chinese people in the five cities who were not users or members of the community organizations. Moreover, recent migrants from Hong Kong have identified themselves as a distinct subgroup within the broader Chinese community in the UK.

### *Implications for research and intervention*

There is still much work to be done in the Chinese population given its diverse characteristics, and poor knowledge of dementia and brain health. Our findings showed a lack of consensus and tension around the dementia terms which possibly explained poor awareness, poor help-seeking and advanced diagnosis for the condition in the communities. Research is urgently needed to address the issue of dementia terminologies and to build consensus for a single term which describes the condition accurately across the different Chinese communities in the UK. More culturally tailored work is needed to tackle language barriers, cultural stigmas and misconceptions surrounding dementia and to increase knowledge about brain health for dementia prevention in the Chinese communities, including among the younger Chinese people.

### **Conclusion**

The *Chinese*-Think Brain Health intervention demonstrated the success and effectiveness of a project that has been systematically adapted and tailored to meet the needs of the target communities by dementia researchers from the same cultural backgrounds who have deep understanding of the problems and health needs of the Chinese communities. The full application of cultural adaptation theories and the pedagogic principle of repetition addressed the health needs as well as the digital barriers faced by

older Chinese people. Our approach is suitable and appropriate for people with other culturally diverse backgrounds.

**Acknowledgements.** This article has been developed as part of the *Chinese-Think Brain Health* project. We wish to thank the Birmingham Chinese Community Centre, the Manchester Chinese Health Information Centre, the Chinese Wellbeing Trust London, the Chinese Community Wellbeing Society Bristol and Chinese Wellbeing Liverpool, as well as the community members and research participants involved in the research and design development process, for their time and contributions to making it happen.

**Author contributions.** Jennifer NW Lim was the project lead, participated in the adaptation and tailoring of the project materials for the community intervention, led the implementation and evaluation in the five cities, led the data analysis and drafted the article. Mei Champ was a member of the project team, participated in the design of the project, participated in the delivery, evaluation and data analysis, and contributed to the writing and review of the draft. Richard Cheston was a member of the project team, participated in the design of the project and contributed to the writing and review of the draft.

**Funding source.** The *Chinese-Think Brain Health* project received funding from Alzheimer's Research UK under the Inspire Fund Gold Grant Award agreement ARUK-IF2021-003. This document reflects only the author's view. The funding body had no influence on the study design, the data collection and analysis, the writing of the article or the decision to submit the article for publication.

**Competing interests.** The authors have no conflicts of interest.

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