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Protocol for the next generation brain health survey on attitudes, understanding, and exposure to brain health risk factors in young adults globally

Laura Booi[1,2] · Sarah Gregory[3] · Katie Bridgeman[3] · Katie Willingham[4] · Michaela Davies[5] · Nana Agyapong[6,7] · Auswell Amfo-Antiri[6,8] · Maritza Pintado-Caipa[2] · Natalie Jenkins[9] · Harris A. Eyre[10,11] · Li Su[12,13] · Brian Lawlor[2] · Graciela Muniz-Terrera[3,14] · Francesca R. Farina[2,15]

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Abstract

Background Evidence suggests that risk factors for Alzheimer's disease and related dementias (ADRD) are at least partially modifiable, and that lifestyle risk accumulates as we age. However, the prevalence and impact of lifestyle-related risk factors in young adulthood (i.e., 18–39 years) remain poorly understood, with some risk factors that are developed in early adulthood being difficult to remove and reverse at midlife. The Next Generation (NextGen) Brain Health Survey is the first of its kind to be designed specifically for young adults, with the aim of exploring attitudes, understanding and exposure to ADRD risk and protective factors in this life stage.

Methods The NextGen survey is an international, cross-sectional survey of young adults aged 18–39 years. The survey was developed in three phases with ongoing input from public advisors (i.e., young adults from Europe, North America, and Africa). First, we adapted items from existing literature for the target population. Second, we conducted focus groups with young adults to review the items and explore new themes. Third, we piloted the survey in an international network, including brain health researchers, clinicians, and advocacy groups. Feedback was integrated to create the finalized survey.

Discussion The NextGen survey is conducted online and made available to individuals aged 18–39 years internationally. Results will contribute new knowledge about young adults and ADRD risk exposure before mid-life, including much-needed evidence in populations that are traditionally under-represented in research. Findings will help identify mediators

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✉ Laura Booi, L.booi@leedsbeckett.ac.uk; Sarah Gregory, Sarah.Gregory@ed.ac.uk; Katie Bridgeman, katie.bridgeman@ed.ac.uk; Katie Willingham, Kwilling00@gmail.com; Michaela Davies, michaeladavies604@gmail.com; Nana Agyapong, nana.agyapong@ucc.edu.gh; Auswell Amfo-Antiri, auswellnyar@gmail.com; Maritza Pintado-Caipa, maritza.pintadocaipa@gbhi.org; Natalie Jenkins, Natalie.Jenkins@ed.ac.uk; Harris A. Eyre, harris.eyre@gmail.com; Li Su, l.su@sheffield.ac.uk; Brian Lawlor, brian.lawlor@gbhi.org; Graciela Muniz-Terrera, muniz@ohio.edu; Francesca R. Farina, francesca.farina@northwestern.edu | [1]Centre for Dementia Research, School of Health, Leeds Beckett University, Leeds, UK. [2]Global Brain Health Institute, Trinity College, Dublin, Ireland. [3]Edinburgh Dementia Prevention, Centre for Clinical Brain Sciences, Edinburgh, UK. [4]Participant Panel Contributor, Newcastle Upon Tyne, UK. [5]Participant Panel Contributor, Vancouver, Canada. [6]Participant Panel Facilitator, Cape Coast, Ghana. [7]Department of Clinical Nutrition and Dietetics, College of Health and Allied Sciences, University of Cape Coast, Cape Coast, Ghana. [8]Department of Integrated Home Economics Education, University of Education, Winneba, Ghana. [9]School of Psychology and Neuroscience, University of Glasgow, Glasgow, UK. [10]Brain Capital Alliance, San Francisco, CA, USA. [11]Meadows Mental Health Policy Institute, Dallas, TX, USA. [12]Department of Psychology, University of Cambridge, Cambridge, UK. [13]Department of Neuroscience, University of Sheffield, Sheffield, UK. [14]Ohio University Heritage College of Osteopathic Medicine, Athens, USA. [15]Pritzker School of Medicine, University of Chicago, Chicago, IL, USA.

and modifiers of associations between knowledge, attitudes, and risk exposure, and provide the basis for comparison with middle-aged and older populations.

Keywords Young adults · Brain health · Risk factors · Alzheimer's disease and related dementias

1 Background

Population aging in the coming decades demands concerted efforts to decrease the prevalence and societal burden of Alzheimer's disease and related dementias (ADRD). Around 45% of ADRDs are associated with potentially modifiable lifestyle-related risk factors [1]. While it is widely accepted that lifestyle-related risk accumulates as we age, most ADRD research continues to focus on mid- and later life (i.e., 40 + years; [2, 3]), and to a lesser extent childhood [4–6]. Consequently, the prevalence and impact of lifestyle-related risk factors in young adulthood (i.e., 18–39 years) are poorly understood. Earlier in life, lifestyle may be driven by family choices where individuals have limited agency, however the age of young adulthood is where individuals begin to become independent (in many contexts) and therefore make choices about their lifestyle. At the same time, youth brain health has become a global priority with growing recognition of issues such as stress, mental health and meshed concerns regarding lowered educational attainment, workforce preparedness and labor participation [7–9].

The promotion of brain health is a global priority [10]. This rapidly expanding field recognizes brain health as more than the absence of disease, and emphasizes the need to enhance protective factors across the life course [8, 10]. A handful of studies have investigated knowledge and attitudes towards brain health in individuals as young as 18 [11–17]. However, no brain health studies have been designed or implemented to specifically target young adults, with their unique interests and needs in mind. Therefore, we have only a surface level understanding of young adults' attitudes towards brain health, their risk exposure, and how this relates to existing knowledge in older age groups. Moreover, because previous studies were not tailored to young adults, many other potentially important lifestyle factors remain unexplored, including substance use, screen time and environmental support, among others.

Recent literature emphasizes that lifestyle modification alone constitutes a superficial intervention for equitable dementia prevention [18]. Achieving dementia reduction at a population level requires a public health approach rather than an individual-centered focus [19]. To prevent further widening of existing inequities in dementia risk and access to care, this survey's development integrates both primary prevention and public health perspectives. By adopting both population- and individual-level frameworks, we aim to understand young adult brain health as reported by young adults. Young adults may have a skewed perception regarding the impact of lifestyle adjustments—such as exercise routines or supplements—on reducing their risk of ADRD, often influenced by the promotion of non-validated practices by for-profit companies [20]. This current survey will contribute important data to what is known about risk factor prevalence for ADRDs in young adults, and their beliefs about brain health. The ultimate goal of any interventional work targeting this age group should be to align individual risk factors with structural determinants, thereby promoting a more equitable society and reducing dementia incidence.

Multiple ADRD risk factors have their onset in young adulthood; for example, three-quarters of mental health conditions develop before the age of 25 [21] and the prevalence of heavy alcohol use peaks at age 20–24 years [22]. Young adults could therefore benefit greatly from early intervention, potentially reducing their risk of ADRD and other chronic conditions in later life. Despite this, almost no educational or public health messaging is targeted to this group, and we know very little about how and where they access information about brain health. In addition, brain health is only now being integrated with mental health [23]. The importance of young adult brain capital, corresponding to brain health and the economy, is just starting to be discussed [7]. Early evidence highlights the importance of making these links, with one study showing associations between depression, premature cardiovascular disease and suboptimal cardiovascular health in young adults [9]. Increased vulnerability to conditions such as these in early adulthood has potential to impact clinical morbidity in mid- and later life, with inevitable mediating and modifying effects on brain health.

Another major limitation of brain health research in younger groups is lack of diversity. Evidence is limited to specific regions (e.g., Europe, United States and Australia) and demographic groups (e.g., White women). By comparison, there is under-representation from the Global South, as well as from racial and ethnic minority groups, young male respondents, individuals from lower socio-economic backgrounds, those with disabilities and neurodiverse groups. Increasing diversity in research is both a national and international priority [24-26].

Enhancing knowledge around brain health in these groups is crucial to ensuring equitable prevention efforts which are appropriate and effective for everyone. To this end, multiple resources have been developed with the goal of promoting equality, diversity, and inclusion in research [27–29]. These resources are ripe for implementation in brain health research to ensure more equitable representation from study inception to dissemination.

Beyond research, the market is already capitalizing on growing public awareness of ADRD and its risk factors. Direct-to-consumer products like 23andMe are increasing access to genetic testing, making it easier for individuals of any age to obtain information about their risk through APOE4 screening [30]. Without sign-posting and support, broad access to risk information has potential to cause distress, lead to misinformation, and feed into fear and stigma surrounding ADRD [31]. Ensuring young people are supported to understand information about ADRD risk factors, and how this relates to their own brain health and health behaviors, is crucial to mitigating fear and stigma—both for individuals living with a diagnosis of dementia now and for future generations.

1.1 Aim

Evidence suggests that lifestyle risk factors for ADRDs are at least partially modifiable. However, there is a stark knowledge gap around how young adults conceptualize their brain health and risk for ADRD. To address this gap, we are undertaking an international cross-sectional survey in young adults aged 18–39 years to investigate their attitudes and understanding of ADRD and brain health, exposure to lifestyle-related risk and protective factors, and motivations towards healthy lifestyle behaviors. Results will contribute new knowledge about young adult brain health and ADRD risk exposure before mid-life, including much needed evidence in under-represented populations. In addition, our findings will help to identify mediators and modifiers of associations between knowledge, attitudes, and risk exposure, as well as providing the basis for comparison with evidence in middle-aged and older populations.

2 Methods

2.1 Design

The NextGen brain health survey is a cross-sectional survey of young adults aged 18–39 years. The survey protocol was developed by the authors in collaboration with public advisors (patient and public involvement representatives, or PPI) who are young adults with a family history of ADRD or a general interest in brain health. All data collected will be completely anonymous with no identifying information collected from respondents. Participants are not required to enter their name, initials or any other identifying information to complete the survey. In addition, their IP address is not collected. The survey consists of 35 questions, separated into three sections: demographic information, dementia awareness, risk exposure, and intimate partner violence. Further information about the survey may be found in the completed Checklist for Reporting Of Survey Studies (CROSS; Appendix 1).

2.2 Population

The survey will be conducted online using Qualtrics Online Survey Tool, and made available to individuals aged 18–39 years in any country. As previous research has primarily focused on Europe, North America, and Australia, [11–16] we aim to achieve broad geographical representation, including South America, Africa, and Asia. We will also prioritize recruitment of diverse populations, including racial and ethnic minority groups, individuals with a lower socioeconomic status, those with disabilities and those who are neurodiverse[24-26]. We have actively worked to make sure the survey is accessible and user-friendly across a range of neurodiversity, and we monitor response rates of disability and neurodiversity to understand if there is adequate representation in our response rates. Additionally, we collaborated with NGOs that actively engage these populations to enhance targeted dissemination efforts. Qualtrics prevents the same device from completing the survey multiple times. The survey will initially be made available in English, Spanish, Mandarin Chinese, Hindi, Japanese, French and Amharic with the potential for further translation. Each translation is piloted with a young adult PPI member or collaborator who is a native speaker of the translated language. Inclusion criteria are: being aged 18–39 years, sufficient language proficiency to engage with the study, and completion of informed consent. Participants will be recruited using a snowball sampling approach through the NextGen Brain Health Study and collaborator networks, including the Global Brain Health Institute (GBHI; www.gbhi.org). GBHI represents a diverse

community of over 266 professionals working in brain health from more than 62 countries, as well as expert collaborators, including various brain health and ADRD organizations. To ensure that we have representation in key areas, we have established stakeholders in Latin America, Asia and Africa. In each of these regions we have an NGO connection, a Voluntary Community Sector Enterprise (VCSE) connection, as well as lived experience experts of young adults in these regions. Alongside this, we have established quotas which are informed by both our PPI and stakeholder engagement, as well as the literature. Authors will also be following the UK Standards for Public Involvement [27] for all aspects of the PPI work. The snowballing procedure will end for recruitment in a region or defined population once these quotas are reached. The research team will be monitoring the quotas, we have established a three-pronged plan for ensuring under-served populations are enrolled:

1. VCSE collaborations and network focused outreach (based on continents and a three-month focus period for engagement).
2. Social media videos.
3. PPI involvement.

The study was approved by the research ethics committee at the University of Edinburgh (ID: 23-EMREC-017). All methods carried out are in accordance with relevant guidance and regulations.

2.3 Measures

The NextGen survey comprises demographics, brain health and ADRD knowledge, risk awareness, exposure to risk factors, and attitudes and motivation towards healthy lifestyle behaviors (Appendix 2: Brain Health Survey Content). Demographic variables include age, sex, gender, race, ethnicity, sexuality, education, employment status, country of residence, languages spoken, relationship status and living situation. The remaining sections include a series of Likert-type and multiple response question. Questions focus on the following four areas:

(i) knowledge (e.g., "How much would you say you know about dementia?");
(ii) personal experience (e.g., "Do you have a family history of dementia? e.g. a parent, grandparent, sibling, or extended family member diagnosed with the condition");
(iii) risk awareness and exposure (e.g., "Here is a list of factors that can influence a person's risk of getting dementia. Please indicate how important you think each factor is."), and;
(iv) risk reduction (e.g., "At what life stage do you think people should start to take action to improve their brain health?").

We recruited a panel of young adults based in Europe and North America (n = 6), and Africa (n = 6), as public advisors to provide feedback on the survey design and content. The survey was developed in three phases, with ongoing input from public advisors throughout. First, we developed an initial set of items using existing literature on brain health and ADRD surveys [12–16], adapted for the target population. We then conducted focus groups with young adults based in Europe and North America (n = 39) to explore their awareness and understanding of brain health. Focus groups were conducted over Zoom and lasted 1 h with 6–8 participants per session (Appendix 3: Focus Group Discussion Guide; Table 1: Focus Group Participant Demographics). Importantly, these focus groups included representation from under-represented groups in brain health surveys, with a majority of participants identifying as Black or African American, a small majority of male participants and some with less than university-level education. Common themes from the analysis were used to revise existing items and create new items. Third, we piloted the survey within our networks, including with public advisors, brain health researchers, clinicians, ADRD patient advocacy groups, and research participants. Feedback from these groups was integrated into a final version of the survey.

To enhance reach, we used professional language translation services to translate the survey into Spanish, Mandarin Chinese, French and Hindi. Feedback was integrated into a final version of the survey. In addition to language translation, we tailored some items to be more regionally or culturally appropriate (Appendix 4: Tailored Questions). We also made some questions optional, for example, sexuality.

Table 1 Demographics of focus group participants (N = 39)

Gender, *N* (%)	
Female	18 (46.2)
Male	19 (48.7)
Non-binary	2 (5.1)
Age, mean (SD; range)	26.3 (3.7; 22–39)
Race, *N* (%)	
Black or African American	29 (74.4)
White	6 (15.4)
Asian	3 (7.7)
Mixed	1 (2.6)
Ethnicity, *N* (%)	
Hispanic or Latinx	7 (18.0)
Non-Hispanic or Latinx	27 (69.2)
Prefer not to say	5 (12.8)
Region, *N* (%)	
Europe	22 (56.4)
North America	17 (43.6)
Education, *N* (%)	
Secondary school/high school	3 (7.7)
Undergraduate degree	16 (41.0)
Postgraduate or advanced degree	20 (51.3)
Employment status, *N* (%)	
Employed (full time or part time)	33 (84.6)
Student	3 (7.7)
Unemployed	3 (7.7)

Europe includes Ireland, England and Scotland; North America includes Canada and the United States of America

2.4 Statistical analysis

Data cleaning and analyses will be conducted in R v4.2.1. Descriptive analyses will be conducted, including distributions of demographic variables and descriptions of all other responses. Answering patterns by groups defined according to demographics will be explored using clustering techniques such as factor analysis and latent variable modeling. Data will be combined to explore a priori research questions; for example, how does motivation towards healthy lifestyle behaviors differ across regions? We will also employ exploratory analysis strategies to assess for unanticipated trends. We will investigate potential mechanisms of missing data (i.e., MAR or MNAR) using standardized methods. How missing data is handled will depend on the outcome of this [32] but it may include multiple imputation. We will try to retain as much data as possible.

We will recruit a minimum sample of 5,000 young adults, consistent with previous brain health surveys (see power calculation below). We aim to recruit equal numbers of participants across geographical regions, sex and gender. We also aim to recruit 20% LGBTQIA + participants, 15% neurodiverse participants and 15% participants with disabilities, in line with global prevalence estimates. We anticipate that these numbers will be adequate to examine our main research question, which is "What is young adults' level of knowledge and awareness about dementia and their own brain health?" Providing power analyses for all possible research questions is not feasible, however, we can provide some level of statistical power. In a multiple linear regression analysis with eight predictors, R square equal to 0.10, significance level of 0.05, and a sample size of only 500, the statistical power is > 0.90 (G*Power v3.1.9.7).

3 Discussion

Understanding the factors that can reduce ADRD risk and promote brain health in young adulthood has significant potential to inform lifestyle intervention and prevention strategies. Currently, risk reduction for ADRD in young adults continues to be neglected in brain health research. The NextGen brain health survey seeks to address this problem by characterizing awareness and attitudes towards brain health, ADRD risk and protective factors, and motivations towards healthy lifestyle change in young adults.

To our knowledge, this is the first study to specifically focus on how young adults as a unique segment of our society think about brain health and ADRD. Results will provide the most comprehensive evidence in young adults to date. Specifically, our findings will provide new knowledge of awareness, attitudes and understanding of brain health, exposure to ADRD risk and protective factors, and motivation and autonomy around healthy lifestyle change. These insights will help to inform future interventions aimed at reducing risk and preventing ADRDs. In this way, our study will provide a unique contribution to the field, distinct from other areas of focus with younger populations (e.g., developmental neuroscience that seeks to resolve problems that occur early in life). Instead, our research aims to prevent ADRD from occurring in late-life.

A strength of our study is inclusion of diverse populations, with broad representation across sex, gender, race, ethnicity, education, socio-economic status, and geographical region. We will have a period of recruitment of two years and will prioritizing recruitment of traditionally under-represented groups. This will allow us to explore brain health from an intersectional lens and identify important avenues for future research [33]. Another unique strength of our survey is the commitment to co-development with young adult public advisors. The foundation of the survey is based in the UK Standards for Public Involvement [27] and the NIHR Include Guidelines [34] to ensure the voices and perspectives of members from diverse regions are included from initial study design to dissemination. We worked closely with VCSEs that support under-represented communities to recruit public advisors. In doing so, we were able to tailor our survey to the specific interests and needs of diverse young adult groups. More broadly, the inclusion of public advisors contributes to ongoing efforts towards public involvement in ADRD research.

Depending on the data collected, it may be possible to examine differences within some regions (e.g., comparing countries in Latin America); however, further research will be needed within specific local contexts. Being that our data will be self-reported, future studies that incorporate objective measures (e.g., of cognition and lifestyle exposure) will be needed in young adult populations [8]. To this end, results from our survey will directly inform a prospective cohort study in young adults aged 18–39 years, parallel to the mid-life PREVENT Dementia study. Novel clinical models for young adults, juxtaposed to what has already been developed for older adults [35] is also a potential outcome for this study.

Only a decade ago research into ADRD among healthy middle-aged adults was in its infancy. Today, evidence from these studies is informing new approaches to ADRD prevention with mid-life being recognized as a critical window for lifestyle intervention [36, 37]. Now, the NextGen brain health study seeks to push the needle even further, bringing young adulthood sharply into focus as the next step towards preventing ADRD and optimizing brain health across the life course.

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Author contributions LB and FRF designed the study, with SG and KB as major contributors. LB, FRF, SG and KB were all major contributors in writing the manuscript. All other authors, KW, MD, NA, AA, MP, NJ, HE, LS, BL, GT, provided feedback on study design and contributed to writing the manuscript. All authors read and approved the final manuscript.

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Data availability No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate The study was approved by the research ethics committee at the University of Edinburgh (ID: 23-EMREC-017). All participants will provide informed consent.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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