BMJ Open Resilience-promoting social networks among unpaid dementia caregivers: protocol for a mixed-methods, 2-year exploratory study

Allie Peckham,¹ M Aaron Guest ^(D), ¹ Keenan Pituch,² Jane Hook,² Marlene Umubyeyi Mporanyi,² Sage Sadow²

ABSTRACT

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AP and MAG contributed equally.

AP and MAG are joint first authors.

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¹Center for Innovation in Healthy and Resilient Aging, Arizona State University, Phoenix, Arizona, USA ²Arizona State University, Tempe, Arizona, USA

Correspondence to Dr M Aaron Guest: aaron.guest@asu.edu

Introduction Unpaid caregivers of people living with dementia often experience lower levels of perceived life satisfaction and higher rates of depression and anxiety compared with those caring for individuals without Alzheimer's disease or related dementias. While research on unpaid caregiver well-being and satisfaction has primarily focused on the characteristics of people living with dementia and their dyadic relationships, it has not adequately explored the role of social networks in supporting unpaid caregiver well-being. In this study, we aim to fill this gap by taking an egocentric social network approach to understand the multiple dimensions of social relations among unpaid caregivers of people living with Alzheimer's disease or related dementia.

Methods and analysis We will conduct a mixed-method, 2-year exploratory study that involves a structured surveybased telephone interview in year 1 and semistructured interviews in year 2 with caregivers of PLWD recruited through community and healthcare partners. Participants will participate in 1 60-min interview in year 1 (n=100) and a 45-60 min semistructured interview in year 2 (n=75). Eligibility for caregivers includes being an unpaid caregiver, aged 40 years or older, residing and providing care in Arizona or Nevada. The survey consists of questions about caregiver and care recipient demographics, caregiver background, caregiver stress, resilience, well-being and egocentric social network data. Network composition attributes, such as tie strength, the function of the relationship and reliance on network members, will also be assessed. In year 2, gualitative semistructured interviews will supplement these quantitative measures to understand network selection, perceived network changes over time and network strength.

Ethics and dissemination The Arizona State Institutional Review Board (00018191) approved this study. All participants will receive electronic informed consent documents to review and sign. During the initial interview, participants will be asked if they have any questions about the informed consent documents. We will confirm that participants have completed the required consent form before the start of any research activity. The findings of this study will be disseminated through peer-reviewed journal articles, academic and community presentations, and community-focused publications targeting caregivers.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- \Rightarrow The study will comprehensively understand caregivers' social networks and their impact on well-being by combining quantitative (structured survey) and qualitative (semistructured interviews) methods.
- \Rightarrow The study employs a novel egocentric social network data collection strategy rarely used in studies of caregivers, allowing us to delve into the personal social networks of caregivers, examining the strength, function and reliability of these networks in detail.
- \Rightarrow As this study is limited to caregivers of individuals residing in Arizona and Nevada, geographical restrictions might limit the generalisability of the findings to caregivers in other regions or states.

INTRODUCTION

Protected by copyright, including for uses related to text and data mi Caregivers of people living with Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) report lower levels ≥ of life satisfaction and higher rates of depression and anxiety compared with caregivers supporting individuals without an AD/ADRD diagnosis.¹² Unpaid caregivers—including **9** family, friends, chosen family and neighbours-play a critical role in supporting <u>s</u> the health, well-being and functional independence of individuals with AD/ADRD.³ However, these caregivers are more likely to experience physical and mental health decline, caregiver burden, missed workdays **D** and increased reliance on emergency-based & services.⁴⁻⁶ Health and social care systems **8** increasingly rely on caregivers who are not only expected to provide direct personal care but are also responsible for navigating fragmented and complex health and social care systems.⁷

While existing programmes and policies often centre on the person living with AD/ ADRD, with some indirect benefits to unpaid caregivers, understanding and addressing

caregivers' unique needs are essential for developing a holistic, person-centred dementia care model.⁸ This focus is particularly critical in an era of changing family structures-including blended families, childless families and families of choice-where caregiving networks often extend beyond traditional spousal or adult-child relationships. As we age, our social networks tend to shrink; however, diverse and loosely connected networks have been shown to provide crucial support during periods of uncertainty and change.^{9 10} Despite the extensive literature on the decline of social connectedness among older adults,^{11 12} research has yet to fully explore how network attributes and changes, particularly the value of weak ties during uncertain situations, contribute to caregiver resilience and well-being. Understanding these dynamics is essential, as weak ties may offer critical support, resources opportunities for problem-solving, ultimately and enhancing caregivers' capacity to adapt and thrive. This gap underscores the need for further investigation into social networks and their potential to inform innovative strategies that bolster caregiver resilience and improve caregiving outcomes (ie, well-being and burden).¹³

Caregiver resilience is shaped by access to resources within themselves and their social environment, including the characteristics, composition and quality of their social networks.^{14–16} Resilience is not a fixed trait but a dynamic process that provides protective mechanisms during stress and difficulty.^{14 17–19} Recent research has identified that increasing the caregivers' resilience levels can reduce the caregiver burden experienced.^{20 21} While research identifies that increased resilience improves caregiver burden, identifying network factors that contribute to caregiver resilience remains unknown, particularly for caregivers of persons living with dementia (PLWD).^{20–22}

This protocol paper outlines a research study to understand the key characteristics of networks that facilitate caregiver well-being. We do so by assessing the social network of the caregiver, also known as an egocentric social network approach. An egocentric social network refers to the personal network of connections surrounding an individual-the ego-encompassing their relationships, such as with family, friends, and so on. This approach places the individual at the centre of analysis. It examines their social ties' structure, strength and influence to understand how these relationships shape specific behaviours, decisions and overall well-being.² By adopting an egocentric social network approach, we aim to unravel the multifaceted dimensions of social relations among unpaid caregivers of PLWD. This approach shifts the focus from the dyadic caregiving relationship to the broader social context in which unpaid caregivers operate, providing insight into the roles and attributes of the individuals within unpaid caregivers' social networks.

Through a comprehensive, structured interview of 175 unpaid caregivers of PLWD in Arizona and Nevada, we will examine network size, engagement, relationship quality and demographic similarity to understand their impact on caregiver well-being. Our findings will offer

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valuable insights into the types and gualities of support networks that can promote resilience and well-being among unpaid caregivers of PLWD.

The research's significance extends to informing interventions that can promote network development for unpaid caregivers. This study serves as a preliminary step towards a more holistic, person-centred dementia care system that acknowledges the crucial role of caregivers in enhancing the quality of life for PLWD.

Study purpose

Protected The overarching purpose of this research is to gain a comprehensive understanding of the social network compositions of unpaid caregivers of individuals living **J** with ADRD and to evaluate the efficacy of these networks 8 in supporting caregiver well-being and resilience. Understanding which network attributes contribute to caregiver resilience and well-being will support the development of interventions promoting support networks for unpaid Inc caregivers of PLWD. guipr

Two specific research questions support this overarching aim.

- 1. How does the number of years providing care influence the attributes of caregivers' social networks and their perceived reliance on network members?
- 2. How do network type, strength and usage (ie, network composition) affect unpaid caregivers' resilience, wellbeing and burden?

These research questions are the guiding framework for our investigation into the social networks of unpaid ADRD caregivers.

METHODS AND ANALYSIS Study design

This research adopts an exploratory mixed method crosssectional design to investigate the social network compositions of unpaid caregivers for persons living with ADRD and to assess their influence on caregiver well-being and resilience. We selected this method as an exploratory mixed-method cross-sectional study, allowing us to investigate a phenomenon, in this case, social networks, to uncover new insights. This design is ideal for examining patterns or relationships in a population when the subject relatively new or poorly understood.
Participants, sample size and power
Participants will consist of 175 unpaid PLWD caregivers given

recruited through established community and healthcare partnerships in collaboration with the Arizona Alzheimer's Disease Research Center and the Nevada Exploratory Alzheimer's Disease Research Center.^{24 25} Inclusion criteria encompass unpaid caregivers aged 40 years or older, residing and providing care in Arizona or Nevada, who can read and speak English or Spanish, and who are available to complete a telephone survey. We selected individuals aged 40 years or older, as individuals in this demographic are likely to take on caregiving roles for

ageing parents or relatives. This age group often navigates the complex interplay of caregiving, career and family responsibilities, making them an ideal population for understanding the role of social networks in resilience.²⁶ Based on caregiver demographics, we expect to recruit 60% female and 40% male.

Exclusion criteria include any evidence of cognitive dysfunction that might interfere with study requirements, as set forth in our research protocol manual and as determined by trained members of the research team, or limited proficiency in English or Spanish. Given our target sample size of 175, we used PASS (2024) to determine the minimum detectable effect size for the regression analyses in aim 2.27 The effect size measure used is the increment to r^2 (ie, Δr^2) due to a given focal predictor/interaction, assuming that the other predictors in the model account for 20% of the variation in a given outcome. With power=0.80 and alpha=0.05, this sample size of 175 allows us to detect an Δr^2 of approximately 0.04. Thus, our sample size provides sufficient power to detect a relatively small effect associated with a given focal predictor. Cohen's effect size guidelines suggest that Δr^2 of 0.02 and 0.13 are small and moderate effects, respectively.

MEASUREMENTS AND OUTCOMES OF INTEREST Demographic questions

Participants will be asked for demographic information about themselves and their care recipients. This includes data on age, race, sex, sexual identity, ethnicity, religious affiliation and other pertinent factors. Understanding these demographics allows for a more comprehensive analysis of the caregiver population.

Survey measures

The following survey data will be collected during interviews from years 1 and 2. See table 1 for a list of measures.

Lawton Instrumental Activities of Daily Living²⁸: assesses the ability of care recipients to perform more complex daily activities, such as managing finances and transportation. It provides insights into the care recipient's overall functional capacity and needs. Katz Independence in Activities of Daily Living²⁹: assesses the ability of care recipients to perform essen-

Katz Independence in Activities of Daily Living²⁹: **Go** assesses the ability of care recipients to perform essential daily activities independently. It helps gauge the level of functional independence among care recipients and provides insights into their caregiving needs.

Zarit Caregiver Burden^{30 31}: is a widely recognised and validated tool for assessing caregiver burden. It measures the level of burden experienced by caregivers when caring for individuals with dementia. This instrument is used to quantify the challenges faced by caregivers in their roles.

Tarlow Positive Aspects Caregiving³²: is designed to **for** identify and measure the positive aspects of caregiving. It explores the rewarding and fulfilling elements of the caregiver role, offering a balanced perspective on caregiving experiences. Satisfaction with Life Scale³³: evaluates the general, all-encompassing level of satisfaction and contentment experienced by the participant. This measure does not

Satisfaction with Life Scale³³: evaluates the general, all-encompassing level of satisfaction and contentment experienced by the participant. This measure does not target any particular domain, allowing the respondent to perceive and rate the factors contributing to their satisfaction.

Table 1 Protocol measures			
Measurement tool	Cronbach's alpha	Number of items	Interpretation
Zarit Caregiver Burden ^{30 31}	0.92	12 items	Higher scores indicate a greater burden.
Tarlow Positive Aspects of Caregiving ³²	0.89	11 items	Higher scores indicate favourable caregiving appraisal
Lawton Instrumental Activities of Daily Living ²⁸	0.843	9 items	Higher scores indicate better IADL independence
Katz Independent Activities of Daily Living ²⁹	0.82	7 items	Higher scores better ADL independence
Satisfaction with Life Scale ³³	0.87	5 Items	Higher scores indicate greater satisfaction
UCLA Loneliness ³⁴	0.89–0.94	3 items	Lower scores indicative of less loneliness
Krause Social Support ³⁵	0.81–0.92	26 items	Higher scores indicate a greater level of support from others and greater support tasks performed by the elder.
Resilience Scale Friborg ³⁶	0.67–0.90 across 4 domains	33 items	Higher scores indicate higher resilience
Personal Well-being Index ³⁷	0.75–0.85	9 items	Higher scores indicative of higher personal well-being assessment
Satisfaction with Social Report Received ⁵⁸	0.90	3 items	Higher scores indicate higher satisfaction
ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living.			

and data mining, AI training, and similar technologies

UCLA Loneliness Scale:³⁴: measures the feelings of loneliness and social isolation experienced by caregivers. It helps assess the impact of caregiving on the caregivers' social well-being and emotional state.

Krause Social Support³⁵: assesses the social support networks available to caregivers. It measures the extent to which caregivers receive support from their social circles, including friends, family and community resources, which can be critical for their well-being.

Resilience Scale for Adults³⁶: assesses caregiver resilience. It explores the ability of caregivers to manage stress and adapt to the caregiving role effectively.

Personal well-being Index³⁷: evaluates caregivers' overall well-being and life satisfaction. It provides a holistic view of their well-being and allows for measuring the impact of caregiving on their quality of life.

Satisfaction with Social Network Scale³⁸: This is a threequestion Likert scale with questions capturing self-reports of overall social network satisfaction, daily assistance with activities and emotional support. This tool version was modified from the Barrera et al. (1981) Scale of Social Support.

Egocentric social network measures

We will collect egocentric social network data from caregivers.³⁹ In doing so, we will collect data on the social connections the caregiver interacts with as part of their daily life. We will employ a standard network generation process using a series of six name generators and questions that aim to populate the network with individuals.⁴⁰ The name generators for this study will focus on eliciting individuals in the participant's network who provide various forms of social support, social capital and information using a combination of exchange, contact and intimacy-based name generators.41 42 We will use a time recall of 1 year to increase respondents' ability to recall alters.⁴³ We will include measures of alter demographic similarity (the extent to which individuals view themselves as sharing demographic characteristics with their alters) and perceptual affinity (the similarity of interests among ego and alters, eg, similarity in likes, dislikes, hobbies and behaviours) to identify network composition.²³ We will assess tie strength (the strength of the relationship among individuals) and function of the relationship (use) using a modified serious items scale.²³

Furthermore, we will assess social support through the reliance on network members and the reciprocity in the relationship to classify the networks. Reciprocity will be measured by identifying the total number of network connections out of the possible total number of individuals. Finally, we will ask individuals to identify network members who know one another to determine relationships.²³

DATA COLLECTION AND ANALYSIS Recruitment

The study will use multifaceted recruitment strategies to reach a large and diverse sample of unpaid Arizona and Nevada-based dementia caregivers. Electronic and

print flyers advertising the study, including a OR code that links to an online eligibility screening survey, will be widely distributed. We will post Print flyers that will be posted in public community venues frequented by older adults and caregivers. Electronic flyers will be circulated via email, social media and other digital platforms. Printed postcards will be mailed directly to homes using the Every Door Direct Mail⁴⁴ through the United States Postal Service. We will also recruit directly from the Arizona Alzheimer's Prevention Registry⁴⁵ at Arizona's Banner Alzheimer's Institute²⁵ and the Nevada Exploratory Alzheimer's Disease Research Center's registry.^{24 46} This registry consists of a large pool of potential participants who have consented to be contacted about research opportunities relevant to brain health and cognitive 8 Additionally, we will supplement these recruitment functioning.

efforts by working directly with healthcare and senior centres through established community relationships. These methods have shown success in previous studies.47 Should we face challenges in data collection, we will expand to additional states. We will also work with existing partners to revise recruitment based on their uses related to text feedback and participant feedback on where they heard of the study. Data collection will occur from October 2024 to July 2025.

Screening process

Participants can enrol in the study through electronic marketing links or by contacting the research team via email or a dedicated 1-800 phone number. Participants will complete an initial online screener on the REDCap will complete an initial online screener on the REDCap of platform.⁴⁸ Following this screening, participants will immediately receive feedback on their eligibility and, if eligible, can complete the informed consent documentation and schedule research interviews through a linked ≥ calendar. This process is designed for efficiency and accessibility. It can be done on various devices (eg, cell uning, phone, tablet, computer) and takes approximately 5 min.

In our 2-year study, we will administer two distinct types of interviews with unpaid caregivers of people living with dementia (PLWD) (See figure 1). In year 1, we will complete a one-time (n=100) 45-60 min structured telephone interview with a research team member. We will rely on REDCap, a secure, web-based software platform hosted at Arizona State University, to support data capture for research studies to collect survey data. Network Canvas, an open-sourced network data collection tool, will be used for social network data collection.^{48 49}

Interviewers will follow the provided scripts and record the data using these tools. In year 2, we will conduct one structured and semistructured interview (n=75). The structured interview includes the above-mentioned components with an additional qualitative semistructured interview. The semistructured interviews will occur via video conference or audio-only telephone based on the participant's preference and last 55-65 min. Thus, in year 2, participation will include two interviews lasting at



Figure 1 Study structure.

most 2 hours and 5 min. These semistructured interviews will be deidentified and transcribed verbatim. Adding the semistructured interview in year 2 will allow a deeper exploration of participants' lived experiences and perceptions, including questions to understand the rationale for network selection and perceived network change over time. This will allow a more in-depth understanding of how individuals perceive their social networks to change throughout their caregiving experience.

In year 1, participants will engage in a 1-hour structured interview and egocentric social network data collection. In year 2, they will complete another structured interview and an egocentric social network interview, followed by a separate semistructured interview scheduled at their convenience. Participants will be informed of all research components before beginning the study and will have the option to take breaks during interviews or end their participation at any time. To prevent burnout among research team members, we will include 30-min breaks between interviews in the schedule and will engage in weekly team meetings to address any concerns research staff may have.

Analysis

Research question 1

Caregiver tenure will be measured by self-reported time as a caregiver. We will calculate tie strength and the frequency of relationship structures, such as the existence

and of reciprocity within the network, the number of ties and the number of potential network connections among alters. We will calculate the frequency of network attri-butes (eg, the number of family, friends, etc, that make up the network) and the role these individuals have within the network (eg, informational support, appraisal support, etc) Using general linear modelling, we will identify associations between these network attributes (eg, tie strength and caregiver tenure). We will also calculate perceptual affinity (similarity in beliefs, likes and dislikes) and demographic similarity (similarity among demographic factors such as age and gender) measures by scoring questions related to the two concepts using the approach laid out by Perry²³ and Guest.⁵⁰ Network homogeneity will be calculated using perceptual affinity and demographic similarity measures.²³ Tie strength will be assessed by combining the scores of the serious matters questions (ie, the number of individuals you could turn to for a serious event), reciprocal matters (ie, the number of people who would turn to you and vice versa) and social support questionnaires (ie, what support they provide).⁵¹ Finally, we will compare network attributes by categorisations using analysis of variance to identify network variance among attributes mentioned above and reliance on the networks for support. We will examine how sociodemographic similarity influences social network composition through linear regression. We anticipate that as

the length of caregiving time increases, network size and engagement of caregivers of PLWD will be smaller (both size and usage) and will consist primarily of individuals with high levels of sociodemographic similarity, which provide support in the care of the PWLD.

Research question 2

To address our second research question, focusing on the influence of network diversity on caregivers' psychosocial outcomes, we will conduct a multiple regression analysis separately for each outcome to assess the associations between network composition and the outcomes of resilience, well-being and burden, controlling for demographic variables and geographical location (rural/urban by zip code classifications). A multivariate Wald test (the maximum likelihood analogue of an Ftest) will be used to assess the overall statistical significance of the model, and each regression coefficient will be tested for significance with a z-test. We will also obtain a standardised regression coefficient estimate to measure effect size. We expect that caregivers of PLWD with more diverse sociodemographic characteristics will report higher levels of resilience and well-being and lower caregiver burden than those with more homogeneous networks.

To address research question 2, we will estimate separate regression models for caregiver resilience, well-being and burden outcomes to assess their associations with the focal predictors of network size, quality and length of time in a caregiver role. The model will also allow for potential interactions among the focal predictors and include covariates. The perceived quality of the network and length of time in caregiving roles will positively affect resilience.

Qualitative interviews will be analysed using a codebook approach for thematic analysis.^{52 53} This approach will allow us to identify critical perspectives on how and why individuals perceive network changes throughout their caregiving role. The analysis will follow an inductive approach, acknowledging the iterative and interpretive nature of data coding.^{53 54} Researchers will begin by identifying and labelling meaningful segments of data. We will then refine and expand these codes, creating a codebook that provides clear definitions for each code, examples of how to apply them and any details needed to distinguish between similar codes. Once developed, we will use the codebook to code the qualitative data; three multiple researchers will be engaged, which allows for different perspectives and refinement to be considered. We will then refine the themes and develop the narrative while analysing iteratively. Given the large research team that includes trainees, this approach seemed most appropriate and consistent for coding 75 semistructured interviews.

Once the qualitative data are coded and themes are identified, the findings from the qualitative analysis will be integrated with the quantitative results using a matrix approach. The matrix will serve as a tool for organising and systematically comparing qualitative and quantitative

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data, allowing us to explore how the different types of data complement and inform each other. The matrix will have several columns, each representing a key theme from the qualitative analysis (eg, network changes, perceived support and resilience). Rows in the matrix will represent different participants or caregiver groups, categorised by key variables such as network composition, resilience or caregiver burden. This will allow for a direct comparison between the qualitative findings (eg, caregivers' descriptions of their networks) and the quantitative data (eg, network size and network quality) across participants.⁵¹

Data handling and missing data treatment

by copyri Univariate and bivariate statistics, data plots and diagnostic statistics will be used to assess data quality. Missing data will be addressed using maximum likelihood estimation for outcome variables, and auxiliary variables will be included to account for missing data correlates. The including for uses study's exploratory nature will use an alpha of 0.05 and implement robust statistical methods to address normality violations.

Patient and public involvement

This research incorporates a community advisory committee that includes eight individuals with lived experience as a caregiver to someone living with dementia. These individuals were invited to participate early on in the process and have been instrumental in offering advice and guidance on data collection strategies (ie, semistructured interview questions), recruitment (ie, support groups or other relevant spaces to reach out to), developing list of resources (ie, what they have used and data mining, Al training, and simi found to be helpful that might help other caregivers) and will soon support analysis (coding both quantitative and qualitative data), interpretation and dissemination.

Ethics and dissemination

This research has obtained ethical approval from the Arizona State University IRB as Study # 00018191.

DISCUSSION

Overall, our study comprehensively explores the complex web of social networks among unpaid caregivers of PLWD. We aimed to address critical questions surrounding these networks' evolution and impact on caregiver resilience and well-being. Our findings have significant implications for developing interventions and support strategies **3** tailored to the diverse networks of unpaid caregivers. This research aims to expand social network data collection and analysis in dementia research beyond the caregivercare recipient dyad, recognising that individuals exist in broader networks. This research will inform the development of appropriate measures to assess diverse caregivers and interventions that strengthen network structures that improve caregiver well-being and relationships among caregivers, PLWD and formal care providers.

Furthermore, the research will provide a theoretical understanding of the usefulness of networks in older age. The dissemination of this work is paramount, as is the use of the findings to develop future interventions. Working with our Community-Based Advisory Board, we will review the findings and seek their interpretation of the results. We will present the findings at community events and scientific conferences. We also publish the final results in the peer-reviewed literature.

By understanding the mechanisms that influence the composition of unpaid caregiver networks, we can identify key areas where additional support is needed. This knowledge contributes to creating interventions that cater to the evolving needs of caregivers, ultimately reducing the burden they face.

While this study provides valuable insights, several limitations should be acknowledged to contextualise the findings and guide future research efforts. First, as this study is limited to caregivers of PLWD residing in Nevada and Arizona, the geographical restrictions may limit the generalisability of the findings to caregivers in other regions. Second, in this study, we are not measuring caregiving intensity. Therefore, we will not know the effect of caregiver intensity on forming social networks. We are, however, collecting data on caregiver stress and burden, which will allow us to analyse our findings based on network characteristics and self-report caregiver stress and burden.

Our innovative study represents a unique opportunity to advance the understanding of the intricate mechanisms behind caregiver networks and their influence on resilience and well-being. By translating our findings into practical interventions, we can contribute to the reduction of the adverse health outcomes commonly associated with caregiving, such as depression, burnout and stress. This work can bring about tangible improvements in the lives of caregivers and PLWD. It underscores the significance of understanding social networks in caregiving and emphasises the importance of tailored interventions to support unpaid caregivers at all stages of the caregiving role.

X Allie Peckham @PeckhamA

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Contributors MAG and AP designed and secured funding for the study outlined in this protocol. JH, KP, MUM and SG actively participated in the formulation of the protocol documents. Each author has thoroughly reviewed, offered comments and approved the final manuscript. MAG is the guarantor of the work.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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ORCID iD

M Aaron Guest http://orcid.org/0000-0001-7356-3734

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