Internet-delivered self-help Acceptance and Commitment Therapy for family carers of people with dementia (iACT4CARERS): A mixed-methods process evaluation of reach and recruitment

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This is an Accepted Manuscript of an article published by Taylor & Francis in Aging & Mental Health

Abstract

Objectives: A mixed-methods process evaluation was conducted alongside a randomised controlled trial of iACT4CARERS, an eight-session, online, self-help Acceptance and Commitment Therapy intervention with minimal therapist support for family carers of people with dementia. The study examined the reach of the intervention and factors influencing recruitment to inform equitable implementation.

Methods: Demographic data from 565 screened carers and interviews with 30 referrers across UK health services were analysed.

Results: The screened sample was predominantly aged 50-79 years (82.5%), female (77%), and White (91.7%). Five themes were identified: referrers' coordinated referrals, mutual motivation, and community outreach supported engagement; referrers' trust-building, tailored communication, and timely approaches facilitated participation; carers' time constraints and referrers' assumptions about older carers' digital skills influenced recruitment; proactive outreach was important for engaging ethnic minority carers; and cultural perceptions of mental health created barriers to participation.

Conclusions: The sample was broadly comparable with previous estimates of the UK dementia carer population. For the equitable implementation of interventions such as iACT4CARERS, coordinated recruitment across health, social care, and voluntary organisations, alongside centralised intervention delivery, may be critical. Outreach can be further strengthened by enhancing referrers' communication and empowerment skills, including challenging assumptions about older carers' digital abilities.

Keywords**:** Dementia, Caregivers, Anxiety, Depression, Diversity, Process Evaluation

Introduction

Unpaid family carers provide the majority of dementia care worldwide, with informal care accounting for approximately half of the global cost of dementia (Wimo et al., 2023). Family carers of people living with dementia are at markedly increased risk of mental health difficulties, with approximately 32% experiencing clinically significant symptoms of anxiety and depression (Collins & Kishita, 2020; Kaddour & Kishita, 2020). Despite this high prevalence, access to psychological support is frequently limited by caregiving demands and constrained health and social care capacity, resulting in substantial unmet need.

Internet-delivered self-help psychological interventions offer a potential accessible, scalable, and cost-effective way to overcome such barriers. One example is the iACT4CARERS intervention: an internet-delivered self-help Acceptance and Commitment Therapy (ACT) for family carers of people living with dementia, which can be completed at home at the carer's own pace with minimal remote support from therapists. ACT aims to increase family carers' psychological flexibility, a central underlying process in ACT (Hayes et al., 2013), by fostering the ability to step back from restrictive thoughts and allow painful emotions; to focus on and connect with the present moment while developing a broader sense of self that can observe thoughts and emotions without becoming overwhelmed by them; and to clarify personal values and build patterns of values-based behaviour. The iACT4CARERS trial evaluated its clinical and cost-effectiveness in a fully powered randomised controlled trial (RCT) within UK healthcare services (Kishita et al., 2024) and demonstrated significant reductions in anxiety and depressive symptoms compared with usual care alone (Kishita et al., 2026).

Beyond establishing effectiveness, process evaluation is critical for assessing the mechanisms of impact, the fidelity and quality of implementation, and contextual factors associated with variations in outcomes, providing insight into the intervention's real-world applicability (Skivington et al., 2021). One of the key elements in process evaluations is the "reach," defined by UK Medical Research Council (MRC)

guidance as the extent to which the intended population comes into contact with the intervention, and how (Moore et al., 2015). Evaluation of reach requires quantitative and qualitative assessment of recruitment and enrolment processes, contextual influences on outreach and engagement, and the representativeness of participants, including groups commonly underrepresented in research, such as carers from ethnic minority backgrounds (Young et al., 2020), to inform equitable and effective implementation in real-world settings.

Evidence on the reach of psychosocial interventions for family carers of people living with dementia is limited. A recent systematic review of process evaluations of psychosocial interventions for people affected by dementia identified 24 studies (Wyman et al., 2022). Of these, five did not report any data relating to 'reach'. Thirteen studies reported only the total number of participants recruited, with some also providing basic demographic characteristics or brief descriptions of recruitment processes. The remaining six studies presented limited information on barriers to recruitment, typically drawing on case files or records of reasons for non-participation, and only one study supplemented this with a focus group involving 10 referrers. No studies provided in-depth qualitative examination of recruitment processes or contextual barriers and facilitators, and there was little consideration of sociodemographic biases in samples, including reach among carers from ethnic minority backgrounds.

To address these gaps, we conducted a process evaluation to examine reach in greater depth, using mixed methods that include thorough qualitative investigation, to understand how and why recruitment strategies succeed or fail, identify modifiable barriers to outreach and engagement, and inform the successful equitable implementation of interventions for family carers of people living with dementia. Although reach can be quantified using recruitment and referral metrics, these measures provide limited insight into the contextual factors shaping reach. Qualitative exploration of referrers' experiences can help explain how recruitment and outreach operate in practice and identify modifiable barriers and facilitators to future implementation and scalability. Nationwide recruitment in the

iACT4CARERS trial was highly successful, with the trial reaching its recruitment target six months ahead of schedule. Consequently, insights into recruitment processes and contextual factors relating to these processes within this trial are likely to be particularly valuable. This paper presents a process evaluation of the reach of the iACT4CARERS intervention, combining quantitative screening data with in-depth qualitative insights from healthcare referrers.

Methods

Study design

A mixed methods process evaluation was embedded within the iACT4CARERS trial, integrating quantitative and qualitative data to provide a more comprehensive understanding of the implementation processes. The iACT4CARERS trial was a multi-site, single-blind, parallel-group, two-arm RCT evaluating the clinical and cost-effectiveness of iACT4CARERS plus treatment as usual (TAU) versus TAU alone in family carers of people with dementia experiencing anxiety symptoms. Family carers were randomised in a 1:1 ratio to either the intervention or the control group. The trial was pre-registered (ISRCTN45995725) and ethical approval was granted by the NHS London-Queen Square Research Ethics Committee (REC reference: 23/LO/0188). The qualitative component of this study is reported in accordance with the Standards for Reporting Qualitative Research (SRQR) guidelines (O'Brien et al., 2014) (see Supplementary File).

A full description of the iACT4CARERS programme is provided in the published open-access study protocol (Kishita et al., 2024), therefore, only the recruitment procedures relevant to this process evaluation are described below. Briefly, family carers in the intervention group completed an eight-session online self-help programme over 12 weeks, targeting psychological flexibility. Family carers received weekly written feedback from a non-expert therapist (e.g., assistant psychologists and occupational therapy associates), with the option of up to two 30-minute phone or video sessions. The

programme was available only in English, with optional interpreter support available where required. Family carers required an internet-enabled device, with mobile data costs reimbursed where necessary. Written materials supported video and audio content for those with hearing difficulties, but visual impairments were not accommodated. Technical support was available to family carers throughout the trial.

Recruitment procedure

There were three recruitment routes. The first was through National Health Service (NHS) secondary care (condition-specific specialist) services across England. Twenty NHS sites across England participated in the trial, providing staff as trial therapists and referrers responsible for identifying and inviting potential family carers to participate. Referrers at these NHS trial sites employed multiple recruitment strategies, including contacting carers from databases of service users who had previously consented to research, approaching carers through clinical services such as memory clinics, and collaborating with local community organisations, such as voluntary-sector carer support groups. Once potential carers were identified, referrers obtained verbal consent for the study team to make contact, provide further details and invite interested carers to a screening session. The second route was self-referral via community advertising. This included adverts in local newspapers, the national recruitment website (Join Dementia Research), relevant charities, and community services such as Dementia UK. Carers could self-refer by telephone, email, or via the study website. The third route was through Participant Identification Centres (PICs), primarily NHS primary care sites (general practices). Patient records at 10 PICs were used to identify potentially eligible carers, who were then contacted by letter or email and invited to directly contact the study team to register their interest.

NHS site training and recruitment materials

All NHS site staff involved in recruiting family carers attended an initial one-hour meeting covering eligibility criteria, referral procedures, and recruitment resources available to facilitate

recruitment. These resources included a flyer, eligibility checklist, and a brief video explaining the study procedure, co-produced with individuals with lived experience. The video was available in English, Punjabi, and Urdu, reflecting that Asian patients—the UK's second largest dementia-affected group after White British—most commonly speak these languages (see the Punjabi version https://bit.ly/3pN1lQI and the Urdu version https://bit.ly/3XMmB5P). NHS site staff also participated in bi-monthly group meetings, facilitated by the study team, to review recruitment progress and share effective recruitment strategies. In addition, sites falling behind monthly recruitment targets were offered individual meetings to discuss challenges and identify solutions during the trial.

Data collection

Recruitment sources were documented for all carers referred to the study team, and reasons for non-attendance at screening were recorded when reported. Quantitative data on participant demographics, including age, gender, relationship to the care recipient, ethnicity, and geographical location, were collected during the initial screening sessions, following consent, to assess sample diversity and reach.

Individual semi-structured interviews were conducted with 30 referrers (staff at NHS sites involved in identifying and referring carers) to explore factors influencing outreach and recruitment. Purposeful sampling ensured representation across sites varying geographically and in recruitment success, with efforts made to invite at least one referrer from each participating NHS site. Each site was asked to nominate referrers actively involved in recruitment, including one from the clinical team and one from the research team, wherever possible to capture perspectives from individuals with different roles and recruitment experiences. The sample size was informed by the concept of Information Power (Malterud et al., 2015).

Interviews were conducted between August 2024 and March 2025. After receiving study information and providing written consent, referrers participated in semi-structured video interviews.

The interviewer used a topic guide with open-ended questions and prompts to ensure all areas of interest were covered (see supplementary file). The topics included the referrers' roles, previous experience in approaching carers, recruitment processes, perceptions of recruitment materials, and barriers and facilitators to outreach, including for carers from ethnic minority backgrounds. The interview guide remained consistent throughout data collection. Interviews were conducted by DH, a PhD-qualified researcher experienced in interviewing and familiar with trial procedures, with no prior contact with referrers. Interviews lasted approximately one hour, were audio recorded, transcribed verbatim, anonymised, and checked for accuracy. Any identifiable information was removed prior to analysis.

Analysis

The analyses and interpretation reported in this paper focused on implementation processes and contextual factors relating to "reach" guided by the MRC framework for process evaluations of complex interventions (Moore et al., 2015). Descriptive statistics summarised the demographics of carers who attended screening to assess sample diversity and reach. The number of carers referred, including those from ethnic minority groups, was collated for each site. Site-level recruitment contributions informed interpretation of the qualitative data, including contextual and referrer-related factors associated with greater recruitment. Quantitative analyses were conducted using SPSS version 29.0.2.0.

For the qualitative interview data, three researchers (DH, NK, AC) initially familiarised themselves with the data. The initial coding was conducted inductively. The researchers then met to discuss the coding and developed a codebook informed by the MRC framework, which provided a sensitising framework for considering factors relevant to recruitment and outreach (e.g., referrer-related factors and recruitment processes facilitating or hindering outreach). The analysis was primarily inductive, with codes and themes developed from the data. This approach allowed additional themes identified during familiarisation (such as organisational factors that facilitated or hindered outreach) to

be generated from the data rather than being constrained by the framework. A subset of four transcripts was independently coded by each of the three researchers using the initial framework, and similarities and discrepancies were discussed to refine the framework. DH and AC subsequently repeated this process of refinement by coding an additional six transcripts and resolving discrepancies. DH then applied the coding framework to the full dataset using NVivo 14.

Following coding, data for all codes were extracted, and main themes and subthemes were identified through discussion between DH, AC, and NK. To enhance the credibility, accuracy, and trustworthiness of findings (Birt et al., 2016), these themes and sub-themes were sense-checked by three referrers who participated in the interviews, ensuring that their perspectives were accurately represented in the analysis. Five referrers were invited, with three participating. Referrers were purposively selected to represent different geographic areas and levels of recruitment success, including recruitment of carers from ethnic minority backgrounds. They reviewed the themes and sub-themes, including explanations and illustrative quotations, and provided feedback on whether these reflected their experiences. The analysis was subsequently refined, primarily through rephrasing of themes and sub-themes to address feedback and avoid unintended interpretations. Final consensus among DH, AC, and NK established the definitions and visual mapping of overarching themes and sub-themes.

All three authors involved in data analyses (DH, NK, AC) had backgrounds in psychology and mental health research. NK was the lead investigator of the iACT4CARERS trial and led the intervention development. DH and AC were research staff on the trial, responsible for processing referrals and conducting screening assessments, and therefore had knowledge of overall and site-level recruitment prior to data collection and analysis. DH led this study and conducted all qualitative interviews. The prior knowledge may have influenced DH's data collection, despite having no prior relationship with individual referrers. For example, it may have subconsciously prompted greater exploration of successful recruitment strategies among referrers from higher-recruiting sites, and greater exploration of barriers

among those from lower-recruiting sites. To mitigate this potential bias, the interview guide prioritised open questions before using follow-up prompts exploring both barriers and facilitators. For analysis, transcripts were anonymised and site-identifying information removed to reduce the potential influence of knowledge about individual sites. The analysis was primarily led by DH and AC, with NK remaining in an advisory role to minimise potential researcher bias while providing contextual clarification of the study procedures. An inductive approach and sense-checking supported reflexivity and ensured that both barriers and facilitators were considered.

Results

Quantitative findings: Reach

A total of 920 family carers were referred to the study, of whom 353 did not attend screening (see Supplementary Tables 1 and 2 for recruitment sources and reasons for non-attendance, and Supplementary Figure 1 and Table 3 for overall participant flow by recruitment source). Of the 567 family carers who attended screening, 496 were eligible and randomised over a 14.5-month period (November 2023-January 2025). Although recruitment was planned over 20 months, the target sample size was reached ahead of schedule.

Two recruitment sources contributed most to the overall sample. Of 628 carers identified and referred by NHS trial sites, 331 attended screening (52.7% uptake). Of 219 community self-referrals responding to study advertisements, 203 attended screening (92.7% uptake). Across 10 PIC sites, 73 eligible carers were identified and invited to self-refer, of whom 33 attended screening (45.2% uptake). At PIC sites, patient records often did not clearly identify carers or indicate whether the care recipient had dementia, which limited opportunities for targeted recruitment.

Of the 567 carers who attended screening, two withdrew during the early stages and were therefore excluded from analyses. Recruitment across regions was broadly proportional to the

distribution of NHS trial sites, with the exception of the East of England, where higher recruitment reflected the presence of the main trial site (Table 1).

Of the 565 carers with available screening data, 47 (8.3%) were from ethnic minority backgrounds, including 20 recruited in London. Asian carers (n = 22) were primarily recruited through NHS services (n = 11; 50%) and self-referral (n = 10; 45%), whereas Black carers (n = 13) were mainly recruited through NHS services (n = 10; 77%). Carers from mixed and other ethnic groups were recruited equally through NHS services and self-referral. Most carers were aged 50-79 years (82.5%), with limited representation of those aged <40 and >79 years (Table 2). The majority were female (77.0%) and reported higher levels of education, with only 1.1% reporting primary education as their highest qualification. The sample comprised approximately equal representation of spousal and adult-child carers. Most had been providing care for at least one year, while only 9.4% had been caring less than one year.

[Insert Table 1 and Table 2 here]

Qualitative findings: Outreach processes and context

Of 40 invited referrers, 30 participated, representing 18 out of 20 NHS sites. Most referrers were from NHS trial sites based in the South West (*n* = 8, 26.7%) and South East (*n* = 7, 23.3%) regions of England, followed by London (*n* = 5, 16.7%), East of England (*n* = 4, 13.3%), East Midlands (*n* = 2, 6.7%), North-West (*n* = 2, 6.7%), and Yorkshire and the Humber (*n* = 2, 6.7%). Fourteen referrers held roles within departments supporting research activities (e.g., research nurses) and 16 were clinicians, mainly from Memory Assessment Services and Older People's Mental Health teams.

Qualitative data obtained from interviews with referrers yielded five overarching themes: (1) organisational and community networks supporting carer engagement, (2) referrers' practices that promote carer recruitment, (3) perceived barriers for carers identified by referrers, (4) targeted strategies for reaching underrepresented carers, and (5) cultural considerations in engaging carers from

ethnic minority groups. Several subthemes were identified within each overarching theme (see Table 3 for an overview and illustrative quote for each subtheme); these themes and subthemes are described in detail in the following section.

[Insert Table 3 here]

1. Organisational and community networks supporting carer engagement

1.1. Collaboration as an enabler in clinician-led recruitment

The NHS-based recruitment routes which made the largest numerical contribution involved clinical staff working in Memory Assessment Services and Older Peoples' Community Mental Health Teams in secondary care services. Successful recruitment was often underpinned by a collaborative team culture, where clinicians shared a collective understanding of the study's value in supporting family carers. In such settings, mutual motivation and coordinated referral practices appeared to facilitate sustained engagement and greater recruitment levels.

Referrers based in NHS research departments also described how a culture of receptiveness and shared commitment among clinical teams enhanced recruitment efforts ("*one of our memory clinics, the whole team is very supportive (…) so we got a lot of referrals from them",* R-19). In contrast, limited engagement or resistance within clinical teams posed notable challenges ("*they automatically think, if you're going to talk about a research opportunity, I think they think 'Oh, that's going to be more work for me'"*, R-1). Where clinicians were less engaged, barriers often stemmed from workload pressures and time constraints, which restricted their ability to take on additional research-related activities.

1.2. Community outreach as vital route for reaching unaffiliated carers

Clinicians often reported that many carers were not in regular contact with healthcare services, making recruitment challenging. Referrers working in Memory Assessment Services (which specialise in providing support for dementia diagnoses) noted that their contact with carers was typically brief, providing only a short window for potential recruitment. As a result, clinicians were less likely to engage

carers at a time when they might be most receptive to interventions aimed at supporting their mental health.

To reach carers outside healthcare settings, referrers described the need for proactive community engagement alongside clinicians' referrals. Strategies included attending local authority or charity-led events for carers. The approach which yielded the biggest numerical contribution involved attending community-run carer groups in person; as one referrer (R-1) noted, "*Where I got the most traction was actually going directly to carers' groups*," while another (R-30) observed, "*The carers' groups in particular, lots of people wanted to take part*." This approach was particularly effective when referrers participated in full sessions, enhancing approachability and fostering direct connections.

2. Referrers' practices that promote carer recruitment

2.1. Providing clear, accessible, and multiformat recruitment materials

Referrers generally reported that the recruitment materials available to promote the study were clear, concise and informative, which facilitated successful recruitment. The video, in particular, was frequently cited as a more helpful resource for explaining the study and intervention to carers compared with static materials, such as the study flyer. As one referrer (R-17) noted, "*I really liked the video (…) that explained what the study did, and in a much clearer way than what I probably would have done*". The video was especially valuable in situations where in-depth, direct conversations were not possible during the initial introduction to the study; as one referrer (R14) stated, "*having resources that even if they can't have that full conversation (…) having things that people can take away and digest in their own time*". The video was also useful when referrers lacked sufficient knowledge and experience of ACT to provide a full explanation of the intervention.

2.2. Building trust and tailoring communication to facilitate carer engagement

Referrers highlighted that engaging carers and encouraging participation was more successful when they already had an established professional relationship with them. For carers they had not met

previously, referrers emphasised that building trust and rapport was a crucial first step before introducing the study, as this helped carers feel comfortable and more receptive to participation. For example, referrers described the importance of "*giving them time to have a chat*" (R-9) and delaying discussion of the study until a connection had been established. Referrers further noted that skills developed through clinical experience, such as "*active listening"* (R-15) and adapting communication styles to the needs of individual carers, were key to fostering engagement and ensuring carers felt understood and supported.

2.3. Recognising the importance of timing in carer support

Referrers had differing views on when in a carer's journey the intervention was most appropriate. Some believed it was more beneficial for carers who had been in their caring role for a long time, noting that for new carers, "*it's either a bit overwhelming, (…) or some of them weren't anxious or things weren't bad enough yet in their minds to feel that it was useful for them yet*" (R-13). Others considered it more suitable for carers new to the role, as those with longer experience were "*almost settled with their life (…) having gone through that level of stress, so it was difficult to convince them, like, 'It is useful for you.'"* (R-15). Referrers who tended to recruit greater numbers of carers avoided a fixed 'optimal' timing. Instead, they emphasised an individualised approach, offering the intervention at multiple time points across different individuals rather than assuming it would be more beneficial at a specific stage —an approach they identified as key to their success.

2.4. Recognising carers' need for reflection before engagement

Most referrers noted that carers often needed time to consider participation, highlighting the importance of allowing space for reflection. However, referrers who tended to recruit greater numbers of carers were more likely to follow up proactively, for example, by making a telephone call after initially introducing the study. In contrast, referrers who tended to recruit lower numbers of carers typically introduced the study and then waited for carers to respond on their own. While follow-up was seen as

crucial, referrers emphasised the importance of taking a gentle, balanced approach—allowing carers time to consider participation while still offering encouragement. This was particularly important when care recipients had recently received a diagnosis, as carers could be in emotional shock and not yet ready to engage fully with support options, despite potentially benefiting from psychological support.

3. Perceived barriers for carers identified by referrers

3.1. Time constraints and strategies to support participation

Referrers identified carers' lack of time as one of the most common barriers to participation. For example, one referrer (R-8) noted that carers "*were really opposed to it already because of 'I've got enough to do, I don't have time for that'*". This was particularly pronounced for carers balancing full-time work alongside their caring responsibilities.

In attempting to overcome carers' time constraints, referrers proactively emphasised the flexibility of the intervention when introducing it to carers. Referrers highlighted that the online delivery of the intervention meant that carers "*don't have to really go out, or take time out during working hours*" and *"go through the therapy sessions in the middle of the night if you find time, or at any time*" (R-15). The ability to pause and resume sessions was also important; as R-4 noted, being able to "*come back and forth to it*" was "*one of those things that would often change peoples' minds*". Flexibility was described as "*a massive factor in getting people on board*" (R-9).

3.2. Technology-related concerns among carers and referrers' assumptions

Referrers who struggled to recruit carers often reported that older carers were discouraged by the online delivery of the intervention. This was attributed both to limited access to the necessary technology, such as not having an email address, computer, or internet connection, and to low confidence in using it. As one referrer explained, "*for older carers (…) a lot of them use online. But they're not terribly confident with online*" (R-17). In addition to these practical challenges, several

referrers observed that clinicians' assumptions about older carers' technological limitations could themselves hinder recruitment.

Some noted that these assumptions were not always accurate. As R-28 reflected, "*if [carers] weren't tech savvy, they may get frustrated*", but later added, "*The people I spoke to weren't (…) I think that is something we kind of assumed they would be, but actually (…) things have moved on, haven't they? So the older generation are pretty good these days."* Referrers who were more successful in recruiting carers tended to address these concerns proactively, reassuring carers that the study team could provide help with any technical difficulties. Many also suggested that offering such technical support would be essential for wider, real-world implementation of the intervention.

3.3. Limited awareness of support needs and openness to psychological help

Referrers highlighted that another key barrier to recruitment was carers' tendency to prioritise the needs of the person they cared for over their own, often not recognising or acknowledging their own need for support. As one referrer explained, "*a lot of the carers that I speak to, quite often themselves, they're not the main focus. It's the person that they're caring for.*" (R-27). Some carers also underestimated the impact of their own difficulties, which limited their willingness to engage with support services.

Referrers also noted reluctance was evident in relation to psychological interventions, particularly when they were described as "therapy", with carers hesitant to view themselves as having mental health needs. Referrers perceived this response to be more common among older male carers, as R-1 reflected, "*I think that, especially for some men, older men, there's still a lot of stigma involved in that whole, 'I don't want to talk to a psychologist' (…) 'I don't need that.'*"

4. Targeted strategies for reaching underrepresented carers

4.1. Proactively identifying minority carers through NHS-based records

Some referrers were able to identify carers from ethnic minority backgrounds who were actively involved with their service and prioritise outreach to these carers to facilitate ethnically diverse recruitment. This was most effective when referrers collaborated with other colleagues and could identify carers from multiple caseloads; for instance, R-7 reported asking colleagues "*do you have anyone on your caseload from this background and do you think they might be interested?*", and considered that this strategy resulted in multiple referrals of carers from ethnic minority backgrounds. Some referrers were also able to prioritise outreach to carers from ethnic minority backgrounds who had registered on "consent-to-contact" lists for research.

Identifying minority carers via NHS-based records was a strategy predominantly used by referrers based in more ethnically diverse areas (who ultimately recruited higher numbers of minority carers); these strategies were not reported by referrers based in areas with lower cultural diversity who often mentioned that they did not have high numbers of carers from ethnic minority backgrounds actively engaged with their service.

4.2. Community outreach drives engagement in non-diverse areas

In regions with lower ethnic diversity, referrers highlighted the importance of adopting broad, community-focused recruitment strategies to reach carers from underrepresented groups. While the number of carers recruited from ethnic minority backgrounds was lower than in more diverse areas, these approaches enabled the inclusion of some participants who might otherwise have been missed. Referrers emphasised that having established connections with ethnic minority community groups was critical for effective outreach, though establishing these connections is an ongoing and time consuming process; R-6 highlighted that "*it takes considerable time to build trust in the communities (...) it's actually knowing what groups are out there (…) and you can't go into a group cold and say, 'Hello. I've never met you before. By the way, are you interested in iACT4CARERS'" You can't do that."* To address these challenges, collaboration with community organisations outside the NHS, such as local charities already

connected with ethnic minority communities, was seen as particularly important for maximising recruitment opportunities.

5. Cultural considerations in engaging carers from ethnic minority groups

5.1. Local diversity is important, but targeted outreach is still required

There was considerable variability in the ethnic diversity of areas covered by participating NHS trusts. Referrers in high diversity areas, such as London, commented that local diversity was a significant facilitator in reaching minority carers, while those in more rural areas often attributed difficulties to limited population diversity. Referrers working in Memory Assessment Services in less diverse areas also noted that under-representation of ethnic minority patients within their service compounded this challenge. However, higher local diversity did not always translate into higher recruitment. For example, one referrer (R-26) based in a highly diverse area, recruited few ethnic minority carers, noting that they "*didn't do anything specific at our trust, but our trust is very diverse*". This suggests that while local diversity can facilitate outreach, it may be insufficient on its own and should be combined with targeted approaches to maximise engagement and recruitment of carers from ethnic minority backgrounds.

5.2. Cultural perceptions of mental health and help-seeking as barriers to engagement

Referrers identified cultural differences in attitudes toward mental health and help-seeking as key barriers to engaging carers from ethnic minority backgrounds. One referrer described how raising the topic of mental health could lead to immediate resistance from key community members, making outreach challenging. R-11 described working with Senegambian and Afro Caribbean groups and encountering "*stigma related to the cultural differences. Straight away one of the first things was like, 'It's mental health isn't it', and I was like 'Yeah'. He was like, 'Yeah they're not going to like that.'"* Cultural perceptions of caregiving also influenced engagement, particularly in communities where caring is viewed as a family responsibility, and seeking support outside the family is discouraged.

Discussion

This study aimed to evaluate the reach of the iACT4CARERS intervention by examining the contribution of various recruitment strategies and identifying contextual barriers and facilitators influencing outreach and enrolment. The sample was broadly comparable with previous estimates of the UK dementia carer population in terms of age and gender. Specifically, 76% of UK dementia carers are aged 55-84 years (Centre for Economics and Business Research, 2019), while 60-70% are female (Alzheimer's Society, 2015). Although data on the ethnic composition of UK dementia carers are unavailable, 92% of people aged over 65 years are White British, and approximately 3% of people with recorded dementia are from non-White ethnic groups in the UK (Pham et al., 2018).

Secondary care services were the recruitment route which made the largest numerical contribution, supported by a collaborative culture and sustained clinician engagement, which outperformed NHS primary care services. However, referrers noted that secondary care clinicians often had limited contact with carers who do not regularly use healthcare services post-diagnosis, as well as underrepresented groups, including carers from ethnic minority backgrounds. This pattern is consistent with evidence from a recent systematic review identifying barriers to service access experienced by these groups, including geographical constraints and limited awareness (Giebel, Hanna, et al., 2024).

Successful recruitment in the iACT4CARERS trial may reflect strategies addressing such known barriers. The trial was fully remote and complemented by active outreach from NHS referrers, who often acted as navigators in collaboration with community-run carer support groups to increase awareness and engage carers beyond routine clinical pathways. Importantly, the iACT4CARERS trial also enabled direct recruitment of community participants through self-referral, alongside standard clinician referral routes, with intervention delivery coordinated centrally. This model was associated with successful reach and recruitment, suggesting that a centralised model of intervention delivery may have potential to support family carers within a national healthcare system. More specifically, centrally coordinated outreach

across health, social care, and voluntary and community sector organisations, combined with remotely delivered interventions coordinated through healthcare services, may provide a more integrated and accessible approach to identifying and supporting family carers.

Further strengthening outreach may require improvements in primary care information systems to facilitate the identification of family carers, including relevant subgroups supporting people with different health conditions or care needs. More systematic identification of carers within these systems could enable timely and targeted dissemination of information about available support, potentially improving access to appropriate interventions and reducing reliance on carers identifying and navigating support independently.

Previous studies examining barriers to carers' engagement in psychosocial interventions have predominantly focused on barriers reported directly by carers themselves (Qiu et al., 2019). In contrast, this study explored barriers from the perspective of staff in healthcare services who were involved in outreach and referral. Notably, the barriers identified by referrers closely reflected those previously reported by carers, including limited free time and difficulty recognising and prioritising their own emotional needs (Giebel, Prato, et al., 2024). These findings were also consistent with the process evaluation conducted as part of the iACT4CARERS trial with family carers of people living with dementia (Couchman et al., 2026).

An additional noteworthy finding from this process evaluation was that referrers' assumptions, particularly regarding older carers' willingness or ability to engage with an online intervention, may have inadvertently constrained reach. Evidence from a recent review demonstrates that older people's attitudes toward technology are shaped by complex interactions between personal characteristics, technology-related factors, and the broader social context of technology adoption (Zhang, 2023). Furthermore, experimental evidence suggests that negative attitudes toward ageing among healthcare professionals may influence older adults' uptake of digital technologies (Mannheim et al., 2021). Future

research should therefore consider training referrers not only to optimise outreach strategies, but also to critically reflect on and challenge assumptions about ageing that may unintentionally limit equitable access.

To our knowledge, this is the first process evaluation providing in-depth qualitative insights into the outreach and recruitment of an online psychological intervention for family carers of people with dementia. While some barriers identified by referrers, such as carers' limited free time due to caregiving responsibilities, may be difficult to directly address, our findings highlight the potential for referrers' interpersonal and clinical skills to enhance outreach even in constrained contexts. Strategies such as building trust and rapport, tailored communication, and careful consideration of the timing of contacting carers were perceived as particularly important for promoting engagement. Future research should examine procedural strategies for tailoring communication and evaluate targeted training for less-experienced referrers to enhance outreach and support carers' recognition of their mental health needs.

Limitations

One key limitation is that we were unable to assess the extent of recruitment reach in relation to the wider UK population of family carers of people living with dementia, as comprehensive population-level data are unavailable. Our findings should therefore be interpreted in relation to the characteristics and representativeness of the recruited sample, rather than as an estimate of population-level recruitment reach.

We were also unable to determine the number of individuals exposed to recruitment materials due to the use of multiple recruitment strategies, including community-based advertising. Demographic data were not available for individuals referred to the study team who subsequently declined consent and screening (n = 353), including 121 who did not respond following referral, for whom reasons for non-participation were unknown. Consequently, we could not compare those who attended screening with

those who did not, limiting our understanding of recruitment reach and potential barriers to engagement before contact with the study team.

The qualitative data captured recruitment experiences within NHS trial sites but did not include referrers from PIC sites. The findings therefore provide limited insight into recruitment challenges within primary care settings, which future studies could explore. Finally, while the quantitative data indicated that Asian carers may be more likely to self-refer than Black carers, the small numbers within individual ethnic minority groups limited exploration of differences across these heterogeneous groups, particularly in the qualitative data. Future research could examine the barriers and facilitators to reaching and recruiting dementia family carers from specific ethnic groups into clinical trials.

Conclusions

This process evaluation suggests that the iACT4CARERS intervention may achieve good reach in secondary care services when supported by collaborative teams, additional staff training, and regular meetings to facilitate engagement. However, these resources may not be routinely available in secondary care, and whether comparable reach can be achieved under routine implementation remains to be established. Furthermore, for the equitable implementation of interventions such as iACT4CARERS, coordinated recruitment across health, social care, and voluntary organisations, alongside centralised intervention delivery, may be critical. While some barriers to carer engagement may be difficult to overcome, referrers can help mitigate their impact through effective communication, and in some circumstances, by reflecting on and challenging their own assumptions about which carers may benefit from the intervention. These findings have important implications for the design and implementation of psychosocial interventions for dementia family carers: coordinated centralised intervention delivery, alongside training for referrers to tailor communication, build rapport, and critically appraise their own assumptions, could enhance engagement and equity.

Funding

This study was funded by the National Institute for Health and Care Research (NIHR) Health Technology Assessment Programme (NIHR150071). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. The funder had no role in the study design, data collection, analysis, interpretation, or report writing.

Acknowledgements

We would like to express our sincere gratitude to the participants and therapists who took part in the trial, as well as to all NHS trusts, GP practices, charities, and the NIHR East of England Research Delivery Network for their support in recruitment and study delivery. We also sincerely thank members of our Public Advisory Group, led by Ruby Ali, the Trial Steering Committee (David Gillanders [Chair], Geoff Angel, Peter Davis, Anju Devianee Keetharuth, Christopher Graham, Daniel Stahl), and the Data Monitoring and Ethics Committee (Sam Norton [Chair], Matthew Bursnall, Rosa Romero Moreno) for their guidance and oversight. For the purpose of Open Access, the author has applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising. RLG was supported by the NIHR University College London Hospitals Biomedical Research Centre at University College London Hospitals NHS Foundation Trust and University College London.

Declaration of Interest Statement

The authors report there are no competing interests to declare.

Data Availability Statement

De-identified participant data will be available on reasonable request following publication of the trial results. Requests should be submitted to the corresponding author and include the required data fields and intended use, supported by a protocol or research plan where possible. Requests will be

reviewed on a case-by-case basis, and a data-sharing agreement with the study sponsor will be required before data release.

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Table 1

The Number of Participants Screened, Broken Down by Ethnicity and the Region in Which They Lived

Region of England	Number of NHS Trial Sites in Region	Carers screened					Total carers screened (% of total)
		White	Asian	Black	Mixed	Other	
North-East	0	18	0	0	0	0	18 (3.2%)
North-West	1	27	1	1	0	0	29 (5.1%)
Yorkshire and the Humber	2	49	0	0	0	0	49 (8.7%)
East Midlands	2	63	3	0	1	1	68 (12.0%)
West Midlands	0	7	0	0	1	0	8 (1.4%)
East of England	3	108	6	0	0	0	114 (20.2%)
London	3	40	7	9	2	2	60 (10.6%)
South-East	5	125	3	3	4	1	136 (24.1%)
South-West	4	81	2	0	0	0	83 (14.7%)
Total carers screened (% of total)		518 (91.7%)	22 (3.9%)	13 (2.3%)	8 (1.4%)	4 (0.7%)	565

Table 2

Demographic details of participants who completed the screening session (N = 565)

Variable		*N*	%
Age	20-29	4	0.7
	30-39	6	1.1
	40-49	54	9.6
	50-59	161	28.5
	60-69	148	26.2
	70-79	157	27.8
	80+	35	6.2
Gender	Female	435	77.0
	Male	130	23.0
Education	Primary school	6	1.1
	Secondary school (O Level/GCSE/A Level)	163	28.8
	Vocational diploma	118	20.9
	Bachelor's degree	168	29.7
	Postgraduate degree	110	19.5
Relationship to care recipient	Spousal carers	291	51.5
	Adult child carers	255	45.2
	Other	19	3.3
Working status	Part-time	107	18.9
	Full-time	100	17.7
	Not currently working	50	8.8
	Retired	308	54.5
Length of caregiving in years	0-1 year	53	9.4
	1-4 years	319	56.5
	4-7 years	130	23.0
	7-10 years	50	8.8
	10+ years	13	2.3
Living circumstances of care recipient	In own home alone	143	25.3
	Living with carer in same house	311	55.0
	Living with other family member(s)	62	11.0
	In a care home / hospital	49	8.7
Care recipient diagnosis	Alzheimer's Disease	266	47.1
	Vascular Dementia	72	12.7
	Dementia with Lewy Bodies	24	4.2
	Frontotemporal Dementia	21	3.7
	Mixed Dementia	133	23.5
	Other type of dementia	20	3.5
	Dementia type unknown	29	5.1

Table 3

Overarching themes and subthemes

Main Theme	Subtheme	Illustrative Quotes
1. Organisational and community networks supporting carer engagement	1.1. Collaboration as an enabler in clinician-led recruitment	*"I went through caseloads with each team member, so I would try and sit down with them once a week (…). They would help me identify who was on their caseload, because obviously I only see a few people per week (…)."* R-3
	1.2. Community outreach as vital route for reaching unaffiliated carers	*"We [Memory Assessment Services] are only seeing people at the very beginning of their dementia journey or if there is a clinical need. So yeah, there's probably quite a big group of people that potentially miss out because we've not seen them." R-2*
2. Referrers' practices that promote carer recruitment	2.1. Providing clear, accessible, and multiformat recruitment materials	"*So trying to explain loosely what the acceptance and commitment therapy is (…) we'd use the video from the website, and sometimes for some of the groups in places it was easier to play the video and then just talk off the back of that.*" R-14
	2.2. Building trust and tailoring communication to facilitate carer engagement	"*It's not like straight away, going in, telling them about the study. So, making that rapport with them, how they're doing, what – how their life is going (…) I mean, understanding them, and then approaching them with the study*" R-15
	2.3. Recognising the importance of timing in carer support	"*I suppose we'd have to be careful not to say – link it to disease progression (…) How people cope and how people psychologically deal with things is not always in line with the severity of the condition at that point*." R-14
	2.4. Recognising carers need for reflection before engagement	"*I think one thing that did help was actually saying to people that, 'Look, actually by giving me your details today, it's not that you're locked into the study. It's just that you're putting your name down, essentially, to find out more information (…)' I think that really helped, actually, because it didn't put the pressure on them to say yes or no right then and there.*" R-20
3. Perceived barriers for carers identified by referrers	3.1. Time constraints and strategies to support participation	"*There will be daughters or sons saying that 'I'm already working two jobs, having to care for my loved one, and it's a lot just to think about research'*" R-19

	3.2. Technology-related concerns among carers and referrers' assumptions	"*A lot of the teams that we spoke to would raise a couple of concerns, like the fact that it was delivered via a tablet or a smartphone (…) they would say, 'A lot of the carers that we work with, they don't have a tablet, they don't have a smartphone. If they do, they don't know how to use it*.'" R-24
	3.3. Limited awareness of support needs and openness to psychological help	*"They don't want to appear that they are struggling (…) I was speaking to one person who didn't quite realise how stressed and how anxious they were until we delved into it a bit."* R-29.
4. Targeted strategies for reaching underrepresented carers	4.1. Proactively identifying minority carers through NHS-based records	"*Most of the people that we could screen came from the consent for contact list (…) that's the best way we decided we could target this group*". R-19
	4.2. Community outreach drives engagement in non-diverse areas	"*Through The Alzheimer's Society base, they have community workers, and they try and link with a different group each in the community. The one I spoke to links with the Hindi community, and I went along with her (...) a few then came forward (...).*" R-6
5. Cultural considerations in engaging carers from ethnic minority groups	5.1. Local diversity is important, but targeted outreach is still required	"*Our problem is getting [people from ethnic minority backgrounds] through the doors to the service in the first place. So, our demographic area is predominantly White anyway, but we are reliant on the GPs referring patients to us. And we still see a skew of the patients we see in the memory service do not accurately reflect the population*." R-3
	5.2. Cultural perceptions of mental health and help-seeking as barriers to engagement	"*So there were a few [carers] that I targeted specifically that were from ethnic minorities, but not with a positive response. (…) the family are very much 'we're going to look after her, we'll do whatever it takes'. (…) Very, very close family, and very almost reluctant to accept help even if they're struggling (…).*" R-2