



Understanding Distance Dementia Care in England: Mapping Policy, Practice, and Lived Experience

Kafadar AH^{1*}, James T¹, Comas-Herrera A², White C³, Knight F⁴, Leverton M⁴, Joddrell P⁵, Brar-Orgil J⁶, Clark A¹
¹University of Greenwich | ²London School of Economics | ³University of Hull | ⁴King's College London | ⁵Dementia UK | ⁶Independent Researcher

Key Message: Current health and social care systems remain poorly adapted to distance caring contexts, particularly problematic for dementia care where progressive cognitive decline necessitates greater coordination, information sharing, and communication facilitation between distance families and care professionals.

INTRODUCTION	METHODS	RESULTS		CONCLUSIONS
Increased social mobility, migration, and globalised workplaces mean more families are caring for their loved ones from a distance. Distance carers face unique challenges: higher travel costs, difficulty attending appointments, and frequent lack of formal carer recognition. Distance dementia carers face <i>additional</i> burdens due to; • progressive cognitive decline, • communication difficulties, and • safety concerns, requiring complex coordination across multiple stakeholders. Evidence on prevalence and experience of distance carers in the UK remains limited.	Situational Analysis of Distance Care in the UK Policy & Guidance Desk Review Review of national policies, legislation, and guidance documents relevant to distance caring in the UK Local Authority Website Audit Systematic audit of all 152 English local authority websites for distance carer information and support eligibility Scoping Review of UK Literature Systematic scoping review examining published UK evidence on distance caring, with dementia-specific focus Stakeholder Interviews (Ongoing) Semi-structured interviews exploring experiences, practices, and challenges in supporting distance care relationships Participants: staff/volunteers from health, social care, third sector and other organisations (e.g., Admiral Nurses, social care workers, local authority representatives) across England	Findings: Local Authorities 152 English local authorities audited across the situational analysis 11 Mentioned distance / location in carer support eligibility webpages 63 Confirmed distance carer support offered in follow-up contact (not on website) 3 Authorities Had specific guidance developed for distance carers • Substantial gap between policy and practice revealed across analysis: many authorities support distance carers but don't communicate this publicly • Several councils updated their website information following our inquiry, highlighting the impact of the research process itself • Distance carers face significant information access barriers before even reaching services	Findings: Scoping Review 9 Studies identified, including 3 focused specifically on dementia Key findings for distance dementia carers: • Distance dementia carers were excluded from diagnostic consultations and care planning, receiving only second-hand information • Progressive communication difficulties require care professionals to actively facilitate family contact • Cognitive decline affects technology use and remote monitoring capacity, a critical challenge for distance oversight • Behavioural changes necessitate rapid information sharing between distance families and care professionals Findings: Stakeholder Interviews N=3/12 completed to date (Carers UK, Age UK, Admiral Nurse). • No standard definition of "distance care" exists • Distance carers face unique stressors • Support is largely generic, not distance-specific • Technology show promise (sensors, trackers) • Systemic/structural gaps need addressing	Urgent need for systemic recognition of distance carers across health and social care policy Local authorities must improve visibility and accessibility of existing distance carer support Dementia-specific protocols needed for remote communication facilitation and information sharing FUNDING This project is funded by the National Institute for Health and Care Research (NIHR) under its Research Programme for Social Care (RPSC) Programme (Grant Reference Number NIHR207653). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. Contact: Dr. Aysegul Humeyra Kafadar ak7028m@gre.ac.uk ALZHEIMER'S ASSOCIATION AAIC>26