NIHR | National Institute for Health and Care Research

Journals Library

Check for updates

Programme Grants for Applied Research

Volume 13 • Issue 11 • November 2025

ISSN 2050-4330

Development of the best practice model to improve crisis management for older people with dementia: the AQUEDUCT mixed methods research programme including RCT

Martin Orrell, Donna Maria Coleston, Linda O'Raw, Emma Broome, David Challis, Tom Dening, Boliang Guo, Juanita Hoe, Brynmor Lloyd-Evans, Esme Moniz-Cook, Magdalena Opazo Breton, Fiona Poland, David Prothero, Marcus Redley, Miriam R Stanyon, Angela Worden and Jennifer A Yates

DOI 10.3310/KGRQ1188

NIHR | National Institute for Health and Care Research

Programme Grants for Applied Research

Check for updates

Extended Research Article

Development of the best practice model to improve crisis management for older people with dementia: the AQUEDUCT mixed methods research programme including RCT

Martin Orrell[1*] Donna Maria Coleston[1] Linda O'Raw[1] Emma Broome[2] David Challis[1] Tom Dening[1] Boliang Guo[1] Juanita Hoe[3] Brynmor Lloyd-Evans[4] Esme Moniz-Cook[5] Magdalena Opazo Breton[1] Fiona Poland[6] David Prothero,[1] Marcus Redley[6] Miriam R Stanyon[7] Angela Worden[1] and Jennifer A Yates[1]

[1]Institute of Mental Health, University of Nottingham, Nottingham, UK
[2]NIHR Nottingham Biomedical Research Centre, Hearing Sciences, University of Nottingham, Nottingham, UK
[3]The Geller Institute of Ageing and Memory, University of West London, London, UK
[4]Division of Psychiatry, University College London, London, UK
[5]Faculty of Health Sciences, University of Hull, Hull, UK
[6]School of Health Sciences, University of East Anglia, Norwich, UK
[7]Derbyshire Healthcare NHS Foundation Trust, Derbyshire, UK

[*]**Corresponding author** m.orrell@nottingham.ac.uk

Published November 2025
DOI: 10.3310/KGRQ1188

This report should be referenced as follows:

Orrell M, Coleston DM, O'Raw L, Broome E, Challis D, Dening T, *et al.* Development of the best practice model to improve crisis management for older people with dementia: the AQUEDUCT mixed methods research programme including RCT. *Programme Grants Appl Res* 2025;**13**(11). https://doi.org/10.3310/KGRQ1188

Programme Grants for Applied Research

ISSN 2050-4330 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

Programme Grants for Applied Research (PGfAR) was launched in 2013 and is indexed by Europe PMC, NCBI Bookshelf, DOAJ, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA) and Scopus® (Elsevier, Amsterdam, Netherlands).

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full PGfAR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/pgfar.

Criteria for inclusion in the *Programme Grants for Applied Research* journal

Manuscripts are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Programme Grants for Applied Research programme

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health and Care Research (NIHR), was established in 2006 to fund collaborative, multidisciplinary programmes of applied research to solve health and social care challenges. Findings are expected to provide evidence that lead to clear and identifiable patient benefits, in the relatively near future.

PGfAR is researcher led and does not specify topics for research; however, the research must be in an area of priority or need for the NHS and the social care sector of the Department of Health and Social Care, with particular emphasis on health and social care areas that cause significant burden, where other research funders may not be focused, or where insufficient funding is available.

The programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director. For more information about the PGfAR programme please visit the website: https://www.nihr.ac.uk/explore-nihr/funding-programmes/programme-grants-for-applied-research.htm

This article

The research reported in this issue of the journal was funded by PGfAR as award number RP-PG-0612-20004. The contractual start date was in September 2014. The draft manuscript began editorial review in January 2024 and was accepted for publication in April 2025. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

This article presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, PGfAR or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the PGfAR programme or the Department of Health and Social Care.

This article was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).

Abstract

Background: In many countries, supporting people with dementia to remain at home is a key priority. However, a crisis can lead to a breakdown of care at home. In England, various multidisciplinary teams have been set up to support people with dementia during a crisis, but little is known about the most effective way of organising these or their impact.

Objectives: The study aimed to:

1. Review evidence on best practice in teams managing crisis for people with dementia and develop an evidence-based Resource Kit to improve practice.
2. Conduct a process feasibility study for a randomised controlled trial of the Resource Kit and refine the research procedures and outcome measures based on feedback.
3. Test the Resource Kit with a representative sample of teams across England in a randomised controlled trial examining the impact upon psychiatric hospital admissions and other outcome measures.

Method/design: A systematic review of the impact of Teams Managing Crisis in Dementia on outcomes, including hospital admissions, and an online scoping survey of team managers were undertaken to understand current evidence and practice. Qualitative work, including interviews and focus groups, explored the experiences of team staff, people with dementia and their carers during a crisis. A tool of 50 standards to measure best practice in teams was developed and refined by consultations, a consensus workshop and field testing. A Resource Kit, which included the Best Practice Tool and activities to assist teams in meeting the 50 standards, was developed and field tested. A feasibility study refined the research procedures for a subsequent pragmatic randomised controlled trial of the online Resource Kit in teams in England compared to treatment as usual.

Setting: The study took place in National Health Service trusts providing mental health crisis services for older people with dementia across England.

Participants: Participants were staff members of Teams Managing Crisis in Dementia, and people with dementia and their carers referred to these teams.

Intervention: The trial intervention consisted of a Resource Kit containing the Best Practice Tool for teams to evaluate their practice and materials to develop aspects of their practice.

Main outcome measures: The trial used psychiatric hospital admissions for people with dementia from teams' catchment areas, according to postcode, as the primary outcome.

Results: The systematic review demonstrated some positive effect of crisis teams on hospital admissions, although there was a need for higher-quality evidence. The online survey of team managers reported considerable variation in ways teams worked. Both highlighted the need for a more standardised approach to managing crises for people with dementia in the community. Qualitative work with staff, people with dementia, carers and other stakeholders indicated that services operated to a variety of models and that there was no clear shared definition of a crisis in dementia care. A Resource Kit was developed containing a Best Practice Tool with 50 standards and materials to guide improvement in practice in specific domains.

The feasibility study for the randomised controlled trial of the Resource Kit indicated some sensitivity to change over time of the Best Practice Tool scores within teams, and different development choices by teams of domains in the Resource Kit. The primary outcome was identified as psychiatric hospital admissions with quality of life and well-being measures as secondary outcomes, reflecting limitations of data collection imposed by the Severe Acute Respiratory Syndrome Coronavirus 2 pandemic.

For the trial, the original target was 30 Teams Managing Crisis in Dementia, with power analysis set at 90%. However, due to the Severe Acute Respiratory Syndrome Coronavirus 2 pandemic, an approved amendment reduced the target to 24 Teams Managing Crisis in Dementia, adjusting the power analysis to 80%. However, only 23 teams were randomised, including 238 of their staff and 75 service users, including people with dementia and their carers. The Resource Kit

intervention was well received by teams but did neither reduce hospital admissions nor improve the well-being of people with dementia, their carers or team staff.

Limitations: The Best Practice Tool was not tested for psychometric properties due to small numbers of teams involved in field testing. There were limitations associated with the reduced choice of outcome measures for the trial due to the COVID pandemic.

Conclusions: Although the results showed no significant difference in admissions to psychiatric hospitals or the other chosen measures, the Resource Kit is valuable for team quality improvement, standardising procedures and offering a comparison tool. The study has also provided an example of how it was possible to undertake research with a hard-to-reach population, both during the challenge of a personal crisis and the COVID pandemic.

Future work: Future research could address quality improvement in teams using more process-based outcomes, comparable to initiatives such as the Memory Standards National Accreditation Programme in England.

Trial registration: This trial is registered as ISRCTN42855694.

Funding: This award was funded by the National Institute for Health and Care Research (NIHR) Programme Grants for Applied Research programme (NIHR award ref: RP-PG-0612-20004) and is published in full in *Programme Grants for Applied Research*; Vol. 13, No. 11. See the NIHR Funding and Awards website for further award information.

Contents

List of tables

List of figures

List of boxes

List of supplementary material

Report Supplementary Material 1 Statistical analysis plan

Report Supplementary Material 2 Work package 3 results

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/KGRQ1188).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

The supplementary materials (which include but are not limited to related publications, patient information leaflets and questionnaires) are provided to support and contextualise the publication. Every effort has been made to obtain the necessary permissions for reproduction, to credit original sources appropriately, and to respect copyright requirements. However, despite our diligence, we acknowledge the possibility of unintentional omissions or errors and we welcome notifications of any concerns regarding copyright or permissions.

List of abbreviations

AQUEDUCT	Achieving Quality and Effectiveness in Dementia Using Crisis Teams
BPT	Best Practice Tool
CI	Chief Investigator
CMHT	Community Mental Health Team
CMHTOP	Community Mental Health Team for Older People
COVID	Coronavirus 2, Coronavirus SARS-CoV-2
CSQ	Client Satisfaction Questionnaire
EBP	evidence-based practice
EQ-5D-5L	EuroQol-5 Dimensions, five-level version
GHQ-12	General Health Questionnaire (12-item version)
GP	general practitioner
HTP	Home Treatment Package
HTT	Home Treatment Team
ITT	intention to treat
MAS	memory assessment service
MDT	multidisciplinary team
MHA	Mental Health Act
MSNAP	Memory Services National Accreditation Programme
NCTU	University of Nottingham Clinical Trials Unit
PPI	patient and public involvement
PSSRU	Personal Social Services Research Unit
PwD	people with dementia
QoL	quality of life
R&D	research and development
RCT	randomised controlled trial
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SHIELD	Support at Home: Interventions to Enhance Life in Dementia
SU	service user
TAU	treatment as usual
TMCD	Teams Managing Crisis in Dementia
WP	work package

Plain language summary

Background

Dementia is the leading cause of disability and dependency among older people. Supporting people with dementia to live well and remain in their own homes is a priority. Unnecessary hospital admissions sometimes occur when care at home breaks down. Specialist crisis teams have been set up and may prevent this.

Methods and results

We worked with specialist mental health Teams Managing Crisis in Dementia and people with dementia and their carers. We developed a Best Practice Resource Kit to help these teams improve their practice. The Resource Kit allowed teams to measure their performance against standards and provided resources to improve practice. We obtained feedback on the Resource Kit and revised it. We undertook a clinical trial of the use of the Resource Kit by crisis teams. For a 6-month period, half of the teams used the Resource Kit and half provided usual care. We wanted to see if teams that used the Resource Kit had lower admissions to psychiatric hospitals of people with dementia from their catchment areas than teams providing usual care. We also measured differences between the two groups on quality of life, satisfaction with services and costs of care.

Twenty-three teams were randomly allocated into two groups. Eleven teams used the Resource Kit, and 12 teams provided usual care. Teams using the Resource Kit were positive about it. However, it did not reduce the relative number of psychiatric hospital admissions of people with dementia within area covered by the Team Managing Crisis in Dementia, according to postcode. We also found no difference in the other measures used, such as the well-being of people with dementia, their carers and staff providing crisis care. However, these results should be viewed with some caution due to the complexity of conducting the study during the pandemic, resulting also in reduced recruitment and limited data.

Conclusions

The trial was undertaken during the COVID pandemic, which may have reduced the effects of the intervention. Further, despite the Best Practice Resource Kit providing Teams Managing Crisis in Dementia with an opportunity to improve the quality of the service they provide, being part of the intervention arm did not impact the relative psychiatric admissions.

Scientific summary

Background

Dementia is a significant threat to global health and a leading cause of disability and dependency among older people. Policy has focused upon 'living well with dementia', support for care at home and avoiding unnecessary admission to inpatient care. However, fluctuations in the health and social circumstances of the person with dementia and their family carers may lead to crisis, breakdown in home care and admissions to hospital or long-term care.

A variety of services have developed, usually part of multidisciplinary mental health teams, to respond to crises in dementia care. However, there is little evidence or guidance as to what constitutes best practice and effective service design to deliver good outcomes. There is some evidence that specialist crisis services can reduce hospital admissions, but more rigorous evidence and a clearer specification of best practice is required. Effective investment in such services needs a more defined service model, ways in which they operate and their impact. This was the remit of the Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT) programme.

Objectives

The overall programme aims were to improve the quality and effectiveness of care for people with dementia (PwD) and their carers experiencing a crisis; to achieve a reduction in hospital admissions; better experiences for PwD and their carers and a reduction in costs of care. It was divided into three work packages (WPs).

Specific objectives

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia and development of the Best Practice Tool and Best Practice Resource Kit

- To determine best practice in Teams Managing Crisis in Dementia (TMCDs) by drawing on the perspectives and experiences of service users, carers, professionals and experts, and to synthesise this evidence.
- To formulate an evidence-based conceptual model and recommendations for achieving best practice in the organisation and operation of TMCDs to guide research and practice.
- To develop and validate a fidelity measure to assess to what extent TMCDs achieve best practice.
- To develop a Resource Kit for TMCDs to achieve high-quality and effective care.

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

- To conduct a process feasibility study of use of the Resource Kit in relation to practice, care outcomes and costs.
- To obtain feedback from participants about the acceptability and feasibility of the research procedures and measures employed.
- To refine the Resource Kit for use in a randomised controlled trial (RCT).

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

- To evaluate the Resource Kit in practice by conducting a RCT with a representative sample of TMCDs across England, examining the impact upon hospital admissions, costs, and PwD, carers and staff compared with treatment as usual (TAU).

Methods

The three WPs were undertaken between 2014 and 2023, with activity seriously impacted by the COVID pandemic.

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia, and development of the Best Practice Tool and Best Practice Resource Kit

A systematic literature review was undertaken, building on previous work, to investigate the impact of crisis teams for PwD on reducing hospital admissions and other related outcomes. An online scoping survey of managers explored the current use of older adult crisis teams in England to identify the range of different arrangements in place.

To examine current practice, qualitative studies were undertaken. Interviews were undertaken with 60 participants in 5 TMCDs. This involved 30 staff, 15 PwD and 15 carers. Qualitative questionnaires were also completed by 57 participants at a public engagement event to gain their understanding of crisis and preferences for service response. Focus groups were undertaken with 44 people, including TMCD staff, carers, PwD and other stakeholders, such as health and social care providers.

Data from the interviews and focus groups, systematic review and scoping survey were used to develop standards reflecting effective TMCD working. These standards were refined and reduced during a process of consultations, a 1-day consensus conference and modified Delphi process to produce a Best Practice Tool (BPT). This measured best practice and gave teams a score out of 100. It was field tested by 12 TMCDs and 5 Community Mental Health Teams (CMHTs) to examine scoring and validity.

From these standards, a Resource Kit was created containing a Home Treatment Package (HTP); the BPT; resources and training templates. The Resource Kit was tested by four teams over a 4-week period, after which feedback was obtained and the Resource Kit finalised for the feasibility study.

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Four sites were recruited, each covering several teams, purposively selected from across England providing a total of 40 staff in TMCDs and 54 PwD and carers. TMCD staff completed online training in the use of the AQUEDUCT Resource Kit, and each team completed the BPT. Teams implemented the Resource Kit over an 8-week period and then, at the end, completed the BPT. Feedback was provided by team members. Information was collected at recruitment and follow-up from older people and carers using a range of measures. Data from the feasibility study were also reviewed by patient and public involvement and clinical staff reference group members to shape the trial and intervention design.

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Building on the literature, surveys, intervention design and feasibility study, a multisite pragmatic RCT was undertaken to compare the effectiveness and cost-effectiveness of the Resource Kit, used by TMCDs, with TAU.

A full RCT was undertaken across 24 TMCDs in England. Eligible teams were managing dementia mental health crises, offering urgent mental health assessment and intervention for PwD in the community. The primary outcome was admissions to psychiatric hospitals over a 6-month period in the geographical region of the TMCD, according to postcode, and was analysed using a Poisson regression model to estimate the treatment effect quantified by incidence rate ratio (IRR). Secondary outcomes related to PwD and their carers, and TMCD staff used multilevel mixed-effects models. Qualitative interviews and questionnaires with team members, PwD and carers were used to ascertain their experience of the intervention.

Results

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia, and development of the Best Practice Tool and Best Practice Resource Kit

Seventy-four full-text articles were identified in the systematic review, and of these, three were included, plus four from a previous review. The systematic review demonstrated some indication of a positive effect of crisis teams on hospital

admissions, although there was a need for high-quality evidence and a full RCT. The material from the review also contributed towards the items defining standards of best practice used to create the BPT.

Sixty-two managers representing a range of areas in England undertook the online survey of TMCDs. Most managed CMHTs or Home Treatment Teams and reported considerable variation in ways of working. Both the systematic review and the scoping survey highlighted the need for a more standardised approach to managing crises for PwD in the community.

Qualitative work with staff, PwD, carers and other stakeholders indicated that services operated to a variety of models and that there was no clear shared definition of a crisis in dementia care. Carers particularly valued supportive interventions and crisis management that went beyond addressing the immediate pressure for hospital admission towards preventive goals such as improved coping strategies and talking through their lived experience. Thus, effective crisis intervention required accessible, expert services providing practical and emotional support, coordination with other services, and a person-centred approach that involves family members. The data from all these studies contributed to the development of standards for the BPT.

An initial 165 BPT standards were reduced and refined using consultation groups, a consensus conference and adjusted Delphi process. The final version of the BPT contained 50 items covered three areas: the crisis service, rapid assessment and intervention, and service resources. The BPT was field tested in early 2018 by 12 TMCDs and 5 non-crisis CMHTs and refined for the feasibility study.

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

The feasibility study was completed on time in March 2020, as the first period of lockdown associated with COVID-19 commenced. Findings indicated a degree of sensitivity to change over time of the BPT scores within teams, and different development choices by teams of domains in the Resource Kit. Due to non-use by teams the HTP was removed as a core feature of the Resource Kit. As expected, there were difficulties in recruitment and data collection from PwD and carers during crises. There was a positive response from staff in TMCDs. The choice of primary outcome as psychiatric hospital admissions was confirmed, with quality of life and well-being measures as secondary outcomes, reflecting the data collection environment imposed by COVID-19.

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Twenty-three TMCDs were successfully randomised from different geographical locations in England. For logistical purposes only, once consent was obtained, TMCDs were entered into a remote web-based randomisation system, which allocated them to either intervention or control arm with equal probability. This should not be confused with a cluster trial since the primary outcome data were collected at Team level. Blinding of TMCDs was not possible, but PwD, carers, outcome assessors and statisticians were blinded to TMCD arm allocation until the data analysis was completed. These included information from 238 staff and 75 PwD and their carers. Hence, staff members within the TMCDs were individually recruited, consented, and analysed as individual participants.

The intervention had no significant effect at the primary end point of 6 months on psychiatric hospital admissions. After adjustment for differences at baseline, the control group estimated IRR was 1.18, slightly, but not significantly, favouring the intervention group. The 95% confidence interval ran from 0.81 to 1.79 (p = 0.37). Adjusted analysis also showed no significant effect on secondary outcomes for PwD, their carers and staff. The intervention was well received by TMCD staff who engaged positively with the process. Qualitative work suggested that PwD and carers valued team clinical interventions, access to help in crisis and support from staff. However, there was a lack of cross agency integrated care.

Conclusions

The Resource Kit co-produced with staff, carers and PwD offers the possibility for audit, quality improvement and greater harmonisation of TMCDs with potential to improve support for PwD and their carers at home at critical times. There was visible staff commitment to service improvement in this area.

Recommendations for future research

Future work could examine quality improvement comparable to initiatives such as the Memory Services National Accreditation Programme in England, using the Resource Kit in conjunction with process measures more closely aligned to its immediate areas of impact.

Trial registration

This trial is registered as ISRCTN42855694.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Programme Grants for Applied Research programme (NIHR award ref: RP-PG-0612-20004) and is published in full in *Programme Grants for Applied Research*; Vol. 13, No. 11. See the NIHR Funding and Awards website for further award information.

Synopsis

Background

Worldwide, around 47 million people live with dementia, including an estimated 850,000 people in the UK.[1,2] Dementia is a significant threat to global health, the leading cause of disability and dependency among older people, and a condition principally managed through the provision of personal assistance.[3–5] Services for people with dementia (PwD) in the UK cost £21B a year (at 2019 prices), and the costs to carers are a further £14B a year.[6] In future decades, with an ageing population, increasing numbers of PwD are likely to live at home. As in many countries, improving dementia care is a key priority in England, and policies for the care and treatment of people living with dementia are geared towards supporting them to live in their own homes for as long as possible and reducing the need for inpatient hospital admission, often through specialist clinical teams that respond to crises in community settings.[7–10] However, fluctuations in the health and social circumstances of the person with dementia and their family carers may lead to crisis, breakdown in home care and admissions to hospital or long-term care. Indeed, in one study, one in ten respondents reported a relative with dementia admitted to hospital unnecessarily due to lack of access to community support.[2] Admissions to inpatient settings are associated with a further loss of independence through a decline in mobility and ability to complete activities of daily living with significant increase in costs compared to the person with dementia who has been able to remain at home.[11–13] Nevertheless, it is not generally the severity of dementia that predicts hospital admission, but other factors including multiple health conditions, polypharmacy and dependency, alongside domestic instability.[14,15]

Focused approaches to manage these problems may sustain care at home, improve quality of life (QoL) and reduce costs. For the working age population with mental health problems, Crisis Resolution Teams, designed to avoid inappropriate hospital admission, have shown some reduction in hospital admissions and improvements in patient and caregiver satisfaction although requiring better-defined service models.[16–21] In contrast, PwD and their carers experiencing crisis are often supported through a variety of different services varying in nomenclature, staff mix and operational procedure. These services include Community Mental Health Teams (CMHTs), Crisis Resolution and Home Treatment Teams (HTTs) and generic older people's rapid response teams. Similar services have also emerged elsewhere including Australia, USA, Norway, and Belgium and therefore research into their effectiveness has international connotations.[22,23] These Teams Managing Crisis in Dementia (TMCDs) in the UK are multidisciplinary teams (MDTs), usually provided by Mental Health Services, based in the community as either independent teams or as part of a CMHT or memory assessment service (MAS). Their typical mode of working involves a rapid assessment to establish the needs of the person with dementia and carers, most often following referral from primary care in response to a crisis, and an intensive short-term intervention to manage or reduce risk of admission while appropriate long-term support is arranged with other community health and social care services. However, unlike services for younger adults, there appears to be less evidence and no guidance as to how such teams, or crisis resolution services for older people including those with dementia, should be designed or operate.[22,24] This lack of guidance is a likely contributor to the large variation seen across the UK in crisis services for older people, specifically for those living with dementia.[22]

People with dementia, caregivers and practitioners appear to value a more co-ordinated approach to crisis management which is responsive to the unique features of each crisis.[25] Home Treatment Packages (HTPs) have been used to help teams manage crises for PwD and their family carers, with specialist older people's crisis services identified as providing valuable expertise.[26–28] A systematic review and a scoping exercise of crisis interventions in dementia found modest evidence that specialist crisis teams effectively managed crises and reduced hospital admissions. However, a more clearly defined model of best practice and randomised controlled trial (RCT) was needed, as well as more focused assessment of different home treatment models.[29] Thus, crisis intervention approaches could reduce admissions to psychiatric hospitals for PwD, but stronger evidence and a more clearly defined model of best practice was needed, and this informed the development of the Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT) research programme.

The relevance and salience of developing dementia crisis care were highlighted in more recent work since the AQUEDUCT study commenced, with studies confirming the importance of clarifying operational processes in TMCDs and identifying key components of intervention.[23,30–32]

The AQUEDUCT programme was designed to improve QoL and well-being of PwD and their carers who experience a crisis, through identifying and defining best practice; developing a Resource Kit, including a best practice measure, for TMCDs; and to evaluate impact in a RCT. The overall objective was to improve the health and care experience and QoL for PwD who experience a crisis.

The programme consisted of three sequential interconnected work packages (WPs): moving from intervention development in WP1; through feasibility testing in WP2; to evaluation in WP3. A research pathway diagram of the stages and development of the interconnecting workstreams and how they contributed to the whole programme is shown in *Figure 1*. WP1 used a literature review, a survey of teams addressing crises in dementia, consultations and a consensus workshop, and qualitative work with TMCD staff, PwD and carers to develop a BPT providing a set of measurable standards of best practice for TMCDs. A Resource Kit was subsequently developed which contained the Best Practice Tool (BPT) and materials and resources to help teams improve their performance. WP2 undertook a feasibility study of a trial to examine the impact of the Resource Kit in practice. WP3 constituted a multisite RCT of the Resource Kit. The research was undertaken between September 2014 and November 2023 and inevitably was subject to marked disruption by the COVID pandemic. Within each workstream, patient and public involvement (PPI) was crucial to the effective collection and dissemination of evidence. We worked together both with the

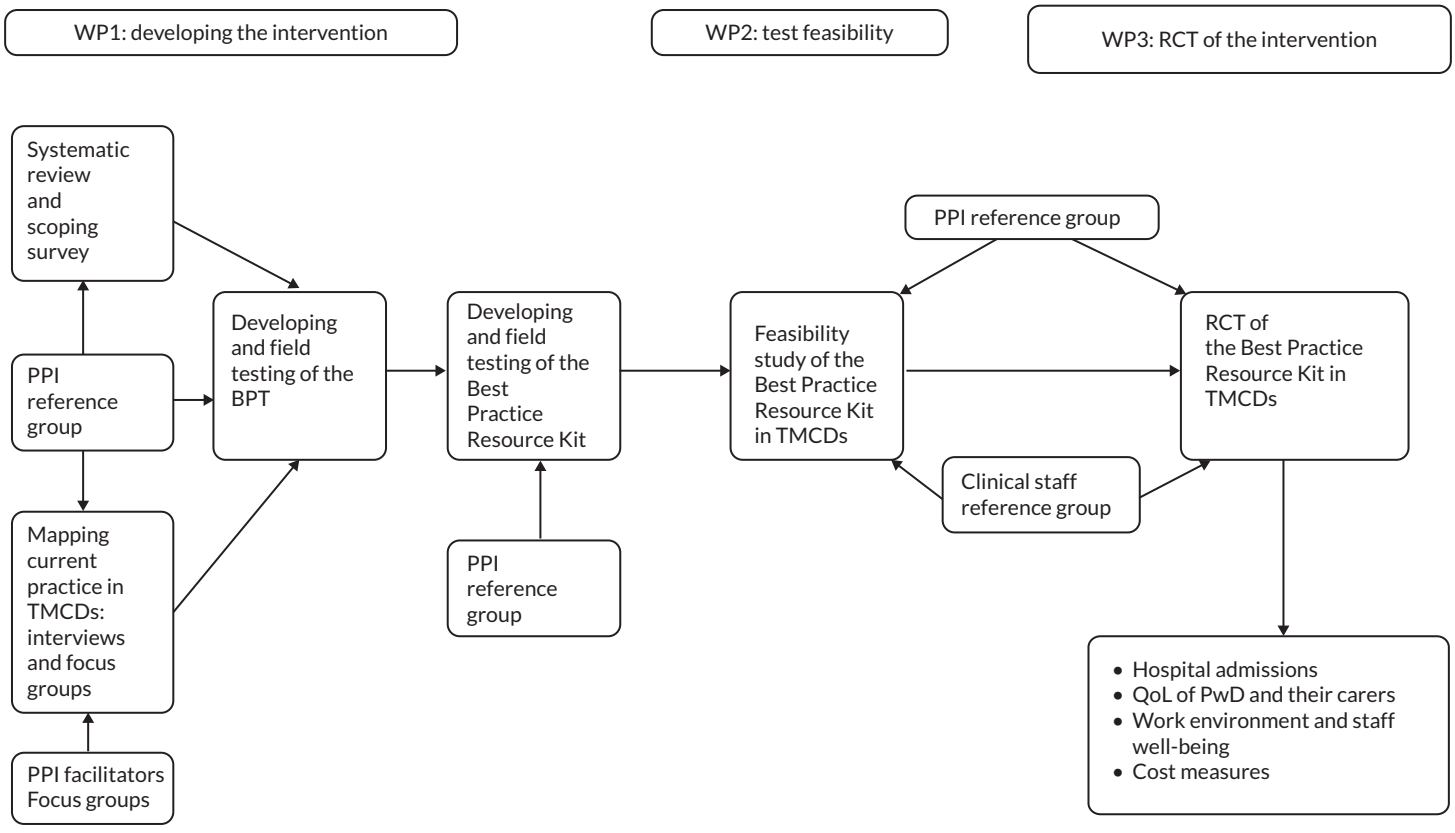


FIGURE 1 Achieving Quality and Effectiveness in Dementia Using Crisis Teams research pathway diagram.

programme-specific group and other established groups to design the individual studies, plan and undertake data collection and interpret and disseminate findings.

Research summary page

The research plan had to adapt to circumstances and events both endogenous and exogenous. The main endogenous change was the relocation of the Chief Investigator (CI) from London to the University of Nottingham at the very beginning of the programme. The grant was originally awarded to North-East London NHS Foundation Trust, commencing in September 2014. The move required changes in the hosting arrangements to the Nottinghamshire Healthcare NHS Foundation Trust in March 2015 and of the responsible Clinical Trials Unit from Bangor University to the University of Nottingham Clinical Trials Unit (NCTU). With the move pending no further staff were appointed to the London based research team in 2014–5 and there was a concomitant delay in staff recruitment, including that of the key post of Programme Manager. However, continuity was managed through the CI and one researcher transferring from London to Nottingham.

During the early phase of WP1, some refinement was made to categorise more precisely the stages of the work and the target group for engagement with the study. The stages of WP1 are categorised in this report. The terminology used to describe the target population teams changed from 'Dementia Crisis Teams' to 'Teams Managing Crisis in PwD' (TMCDs) to reflect the fact that while these teams are managing crises in dementia, they may not necessarily be dementia-specific and may also see people with other mental health conditions. They also used varied nomenclature, including HTT, Dementia Intensive Support Team, Intensive Recovery Intervention Service, and Crisis Resolution Team, so that a generic term was required.

A second endogenous factor which happened later in the programme was the move away from engagement with the NCTU in the study. This became evident during WP2, the feasibility study for the intervention. In the process of developing the protocol for the RCT in WP3, some differences in views about the most appropriate strategy for completion of the programme emerged. It was agreed in April 2020 that NCTU would no longer be involved and that methodology and statistics support for the main trial would now be provided through the East Midlands NIHR Applied Research Collaboration. The AQUEDUCT research team took over responsibility for preparing the protocol for the trial.

The key exogenous influence, to which the programme had to adapt, was the impact of the COVID pandemic. This impacted both the timing and the content of the research. Following the feasibility study and consultation with PPI and clinical staff reference groups, the design of the trial was shaped to be feasible and safe given the impact of the COVID pandemic and the research environment of the NHS immediately post pandemic. This is described in the trial protocol.[33] The design of and data collected in the trial were shaped in response to circumstances to adapt to the immediate post-COVID research environment. It thus relied upon secondary data for the primary outcome and self-report measures collected remotely for clinical staff, PwD and their carers. Following completion of the feasibility study, NHS trust research and development (R&D) departments were not able to consider set-up of non-COVID-related studies as they needed to divert their resources to manage the pandemic. During this time, some R&D staff who were also clinically trained were redeployed to support clinical services and dementia crisis teams (the focus of the AQUEDUCT programme) were unable to engage with research at the height of the pandemic. This led to delays between late 2021 and spring 2022 in recruiting teams. The research team maintained regular communication with interested teams (a pre-recruitment process via virtual meetings) so that preliminary work was nevertheless undertaken with over 20 teams before commencement.

Programme management and governance

A Programme Steering Committee oversaw the entire programme with a Data Monitoring and Ethics Committee approved by NIHR, as a subcommittee overseeing the trial on an at least annual basis, with additional e-mail and

telephone correspondence as required. The Programme Steering Committee included members with expertise in PPI, dementia care, old-age psychiatry, health services research, nursing, psychology and trials. A Programme Management Group comprising co-applicants for the AQUEDUCT programme met every 6 months to review progress and to provide critical input regarding subsequent stages of research. A Trial Management Group, consisting of sponsor representative and co-applicants met monthly from the commencement of the feasibility study in WP2 and liaised with the Programme Steering Committee and Data Monitoring and Ethics Committee on matters relating to the trial.

A PPI reference group was created with seven members and met on a regular basis, at 6 monthly intervals with investigators and the Programme Manager. The membership was refreshed following the impact of the COVID pandemic. A parallel clinical staff reference group was created in WP2 to advise on implementation and met on a 3-monthly basis. On an operational basis, the programme was managed through the Programme Management Group.

Work package 1: investigation of best practice in Teams Managing Crisis in Dementia, and development of the Best Practice Tool and Best Practice Resource Kit

The objectives of WP1 were:

1. To determine best practice in Teams Managing Crisis for PwD (TMCDs) by drawing on the perspectives and experiences of service users (SUs), carers, professionals and experts, culminating in a consensus process to achieve synthesis of these sources of evidence (WP1.1, WP1.2, WP1.3).
2. To formulate an evidence-based conceptual model and guidance for achieving best practice in the organisation and operation of TMCDs to guide research and practice (WP1.3).
3. To develop and validate a fidelity measure to assess to what extent TMCDs achieve this best practice (WP1.3).
4. To develop a Best Practice Resource Kit to achieve high-quality and effective TMCD care, which included the HTP; best practice guidance for TMCD organisation and the BPT fidelity measure (WP1.4).

The WP1 consisted of four stages. The first two stages (WP1.1 and WP1.2) were concerned with a process of gathering evidence. This involved a systematic literature review of the impact of TMCDs on outcomes (WP1.1), an online scoping survey completed by managers of TMCDs to understand current organisation and experience of teams (WP1.1) and interviews and focus groups with various stakeholders to understand current practice in TMCDs (WP1.2). The latter included the views from PwD and their carers supported by TMCDs during a recent crisis.

The third stage used evidence from WP1.1 and WP1.2, following the principles of the US evidence-based practice (EBP) project, to formulate an evidence-based conceptual model – the Best Practice Model for TMCDs.[34] The EBP model includes the development of resource kits, including manuals, training materials and guidance on implementation, designed to help teams achieve best practice. Central to the EBP method is assessment of the extent to which evidence-based interventions are delivered as planned (i.e. with fidelity to the protocol). Consistent with the EBP model, a fidelity measure known as the BPT was developed in WP1.3. The process was informed by empirical evidence on components of the model associated with effectiveness and by stakeholder consensus. The work to develop this measure also built on the methodology used in the NIHR Crisis team Optimisation and RElapse prevention (CORE) study which focused on mental health crises in working-age adults.[35] The BPT was developed and validated to measure how far TMCDs follow best practice guidance, including their internal organisation and operation. The tool was designed to incorporate a degree of flexibility around the structure and leadership of teams to enhance the capabilities of teams that were already working well locally rather than attempting to reorganise teams. This approach had worked successfully with the implementation of quality standards for memory services in the UK Memory Services National Accreditation Programme (MSNAP), in which the CI (Martin Orrell) had a key role.[36] A validated conceptual framework for assessing implementation was employed: the Theoretical Domains Framework, which considers a range of motivational and capability factors influencing behaviour.[37] The BPT was then field tested with TMCDs.

In the fourth stage, a Resource Kit was developed incorporating the BPT and training resources. The Best Practice Resource Kit was then field tested and subsequently employed as the intervention for the feasibility study (WP2). A

modified version was used for a full RCT (WP3). *Figure 2* shows the stages in WP1, and these are described in more detail in the text below.

Work package 1.1: systematic review of the impact of teams managing crisis in dementia in older people and scoping survey of current practice in these teams in England

A systematic review of the impact of Teams Managing Crisis in Dementia in older people on outcomes

As part of WP1, a systematic review was undertaken, which aimed to investigate the impact of crisis teams for PwD on reducing hospital admissions and other related outcomes compared with usual care. The review was designed to build upon a previous systematic review undertaken as part of the Support at Home: Interventions to Enhance Life in Dementia (SHIELD) NIHR programme grant (RP-PG-0606-1083).[26] The previous review included studies which took place during the time period 1965–2008, and in the current review, the period was updated to January 2008–27 July 2015. Previous findings suggested low-quality evidence (Grade C Oxford Centre of Evidence Based Medicine guidelines) that crisis resolution/HTTs are effective in reducing numbers of admissions to hospital but with no well conducted RCTs included. It concluded that there was a lack of evidence for the efficacy of crisis resolution/HTTs, and

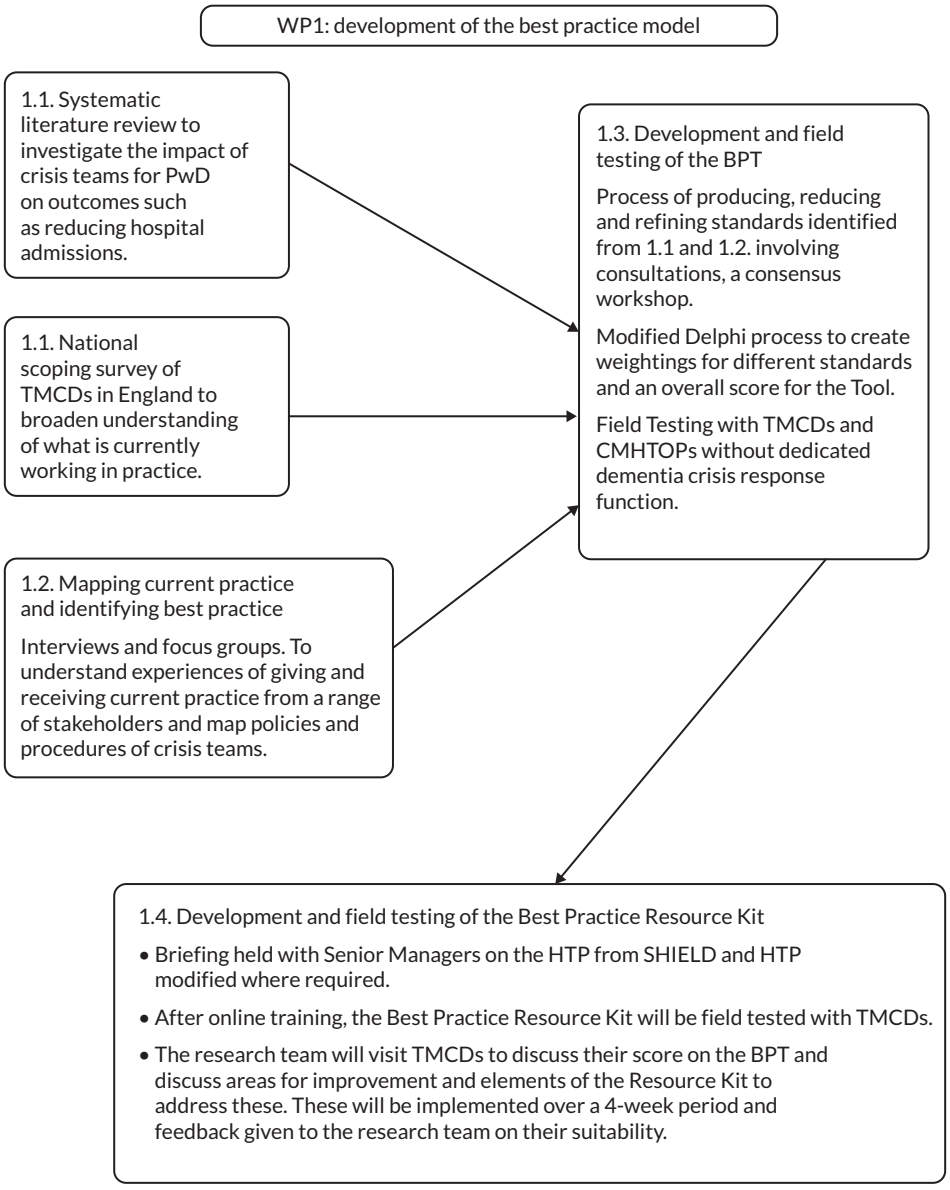


FIGURE 2 Work package 1: development of the Best Practice Model. CMHTOPs, Community Mental Health Teams for Older People.

a RCT was needed as well as more focused assessment of the different home treatment service models which have developed in the UK.[29]

Searches of electronic databases: MEDical Literature Analysis and Retrieval System; Excerpta Medica database; PsycInfo® (American Psychological Association, Washington, DC, USA), Cumulative Index to Nursing and Allied Health Literature; Latin American and Caribbean Health Sciences Literature; and grey literature sources were undertaken on 27 July 2015. The search terms used were those from the previous systematic review and aimed to be broad terms to include as many relevant studies as possible.[29] Study participants needed to meet the inclusion criteria of being aged 65 years or older, with a diagnosis of dementia and living in the community. Eligible methodologies included RCTs, controlled before and after studies, interrupted time series, observational studies, theoretical papers and government frameworks and policies. To be included, a crisis experienced by a person with dementia needed to be 'an urgent need for an assessment and intervention for a person living in the community'. For included studies, the experimental groups consisted of older PwD in receipt of any mental health crisis resolution/home treatment intervention while control groups could be TAU, waiting list or matched controls. A range of outcome measures were included. Primary outcomes included the number of hospital admissions, length of hospital stays, maintenance of community residence and patient QoL. Secondary outcomes included patient cognition, activities of daily living, mortality rates, medication use, level of patient and/or carer satisfaction, level of service use and health and social care costs.

Titles and abstracts were reviewed against the defined inclusion criteria by one researcher, and those not meeting this were removed. Full text was obtained for any papers deemed relevant, and when necessary, further information was obtained from the paper's authors. Two researchers independently rated papers against a methodological quality measure the Critical Appraisal Skills Programme checklist for cohort and case-control studies which rated the evidence into three categories: low, acceptable or high.[38] For any studies where there was a difference of opinion on the checklist, the researchers discussed this until an agreement was reached.

The results of the systematic review are reported elsewhere (see Publications from programme: *Appendix 1*).[39] The initial search identified 5344 items. This was reduced to 74 following a process of removing duplicates and screening of titles and abstracts. Seventy-four full-text articles were screened and assessed for eligibility. Of these, 71 were removed because they did not include PwD, or they were not focused on PwD experiencing a crisis. Seven studies were included in this review, three from the current search and four from a previous review.[29] Only one study was rated as high-quality, four were deemed acceptable and two studies were considered low quality. There were no high-quality studies, such as RCTs, but mainly cohort studies were included which used previous years of running the service or a comparison group from a previous completed study. Samples mixed both PwD with those with mental illness, and older age groups with those of working age and there was no separation of these mixed samples in the reported analysis. Overall, the review found some evidence that crisis services for older people with mental health problems had a positive impact on reducing hospital admissions, readmissions, length of stay and mortality rates, but this should be interpreted with caution given the lack of statistical rigour, variable study designs and small number of studies found. It was not possible to synthesise the results across the seven studies in a meaningful way.

The findings from this updated systematic review demonstrated some indication of a positive effect of crisis teams on hospital admissions. However, it highlighted a gap in the literature of high-quality evidence and demonstrated the need for a higher-quality RCT study. The evidence gathered from the review contributed towards the development of the 165 standards of best practice which were used to create the BPT (WP1.3). The systematic review is summarised in *Figure 3*.

An online scoping survey of current practice in Teams Managing Crisis in Dementia in England

An online scoping survey addressed a gap in the existing literature by exploring the current use of older adult crisis teams in England. It involved contacting teams responsible for managing crises in PwD in England to gain a clearer understanding of what is happening in current working practice. Relevant NHS Trusts providing mental health and community dementia services were identified (using NHS England's website) and contacted to identify the appropriate service lead or manager who could provide details of the scope and nature of crisis/intermediate care services for PwD and implementation issues (via an electronic survey). The contact details of these leads and managers of relevant services were obtained. These services were checked against the Care Services Improvement Partnership combined

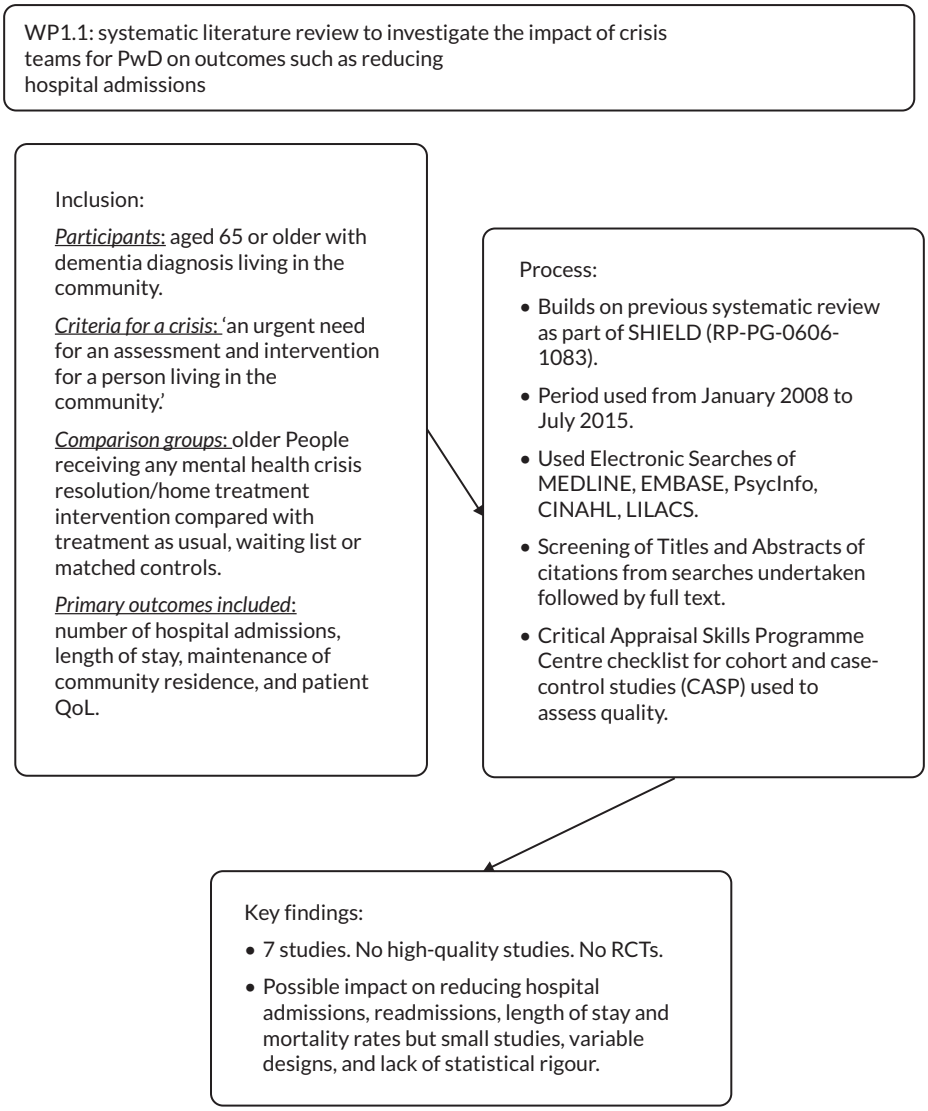


FIGURE 3 Systematic literature review of the impact of crisis teams for PwD. CINAHL, Cumulative Index to Nursing and Allied Health Literature; LILACS, Latin American and Caribbean Health Sciences Literature.

mapping framework of mental health services and the Personal Social Services Research Unit (PSSRU) database of Community Mental Health Teams for Older People (CMHTOPs).[40] The PSSRU survey included over 400 CMHTOPs in England and achieved a response rate of 88% (376 teams).[41]

The scoping survey contained 29 questions and was conducted using Survey Monkey software and covered questions on type of service, organisational details, primary diagnosis and primary needs of those entering the service, details of referrals, use of a care pathway, interventions and assessments used, and challenges and benefits of delivering home treatment. Respondents who indicated that crisis management was not within the remit of their service were automatically excluded from the survey. Telephone and e-mail reminders were used to prompt non-responders and teams were also contacted for further details about any identified relevant initiatives in their area and whether these had been evaluated. The survey aimed to:

- Map the policies and operational procedures of crisis teams, including referral/discharge procedures, processes, and pathways and the interface, to establish a detailed national picture of the range of practices, and the multidisciplinary skill mix.
- Map the local social services, voluntary sector and NHS resources.
- Investigate the diversity of models.

The scoping survey is summarised in *Figure 4*. Of 234 individual services potentially managing crises in PwD, 200 had available contact details for service managers and were sent e-mail invitations to take part in the survey. At this stage, it was not clear how many services would be dealing with cases of dementia and meet the criteria for TMCDs; however, from an early stage it was clear that that many of the services did not meet the criteria for TMCDs. Although the research team was not able to confirm the total number of TMCDs, 62 managers representing a range of areas in England commenced the online survey. Two of these were automatically excluded by the software for not giving consent and three exited the survey, thereby excluding themselves voluntarily.

Respondents were divided into three groups according to their response to the type of service they led. Twenty-seven respondents reported managing a CMHT or similar, 24 reported managing a HTT or similar and 6 reported managing a MAS. The findings suggested high variability across the three identified groups. There was variability in which days services operated, with HTT's mostly operating extended hours outside weekdays. The proportion of time spent doing profession-specific work also varied with MAS team members spending on average 80% of their time carrying out this work compared with 40% CMHTs and 70% HTTs. This may have been related to differing primary needs of patients entering these three groups of services. Both the MASs and HTTs had behavioural and psychological needs as the highest-ranking primary needs of referred patients and environmental factors as the lowest ranked need. For CMHTs this was reversed with environmental factors being ranked highest and behavioural and psychological needs lowest. Median number of referrals per week varied with MASs having 18 (range 6–20); HTTs having 10 (range 0–50) and

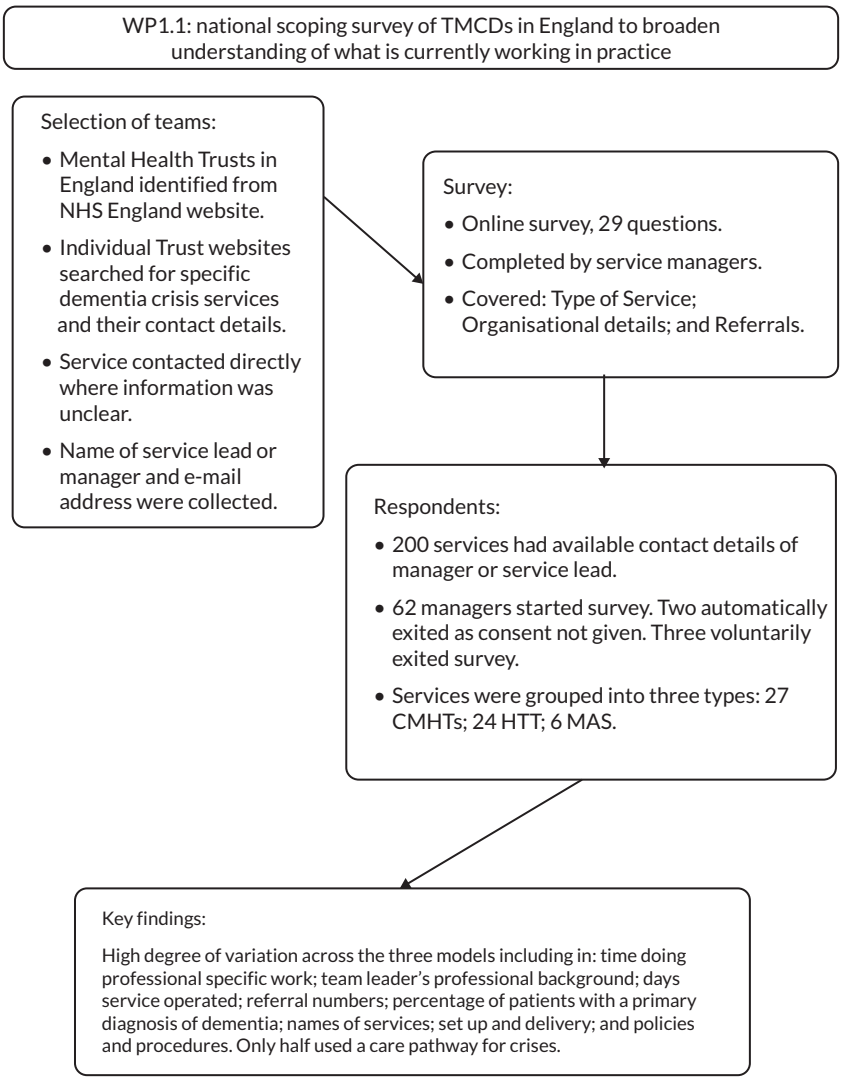


FIGURE 4 National scoping survey of TMCDs in England.

CMHTs having 10 (range 0–25). Care pathways and protocols were infrequently used in all three types with only half (51.8%) of the teams reporting using one.[39]

Both the systematic review and the scoping survey highlighted the need for a more standardised approach to managing crises for PwD in the community as a measurable intervention to evaluate the effectiveness of these services. The diversity in service procedures and caseloads found in the survey suggested that clearly defined protocols could help to ensure that PwD receive the best care and achieve better outcomes.

The evidence gathered from the survey of current practice contributed towards the development of the 165 standards which were used to create the BPT (WP1.3). The survey also helped to identify services suitable/willing to be involved in other aspects of the AQUEDUCT programme and any relevant unpublished data.

There were several limitations in the study. The study relied on obtaining the correct contact details for managers, but identification and access sometimes proved difficult. Some managers, especially those with a wider remit who managed several teams, may not have been able to provide a detailed picture of the service at ground level because of their broader roles. Some non-completers may have ruled themselves out inappropriately because of the emphasis in the introduction to the survey on dementia crisis. Since services varied greatly, they may in fact have been eligible to participate.

Work package 1.2: mapping current practice and identifying best practice for Teams Managing Crisis in Dementia

Aims

The aim of this component of WP1 was to identify the content of current practice in managing crises for PwD, the nature of crisis and to scope what constituted best practice from the perspective of a wide range of stakeholders. These included staff providing crisis services, other professionals with whom they interfaced, those managing and commissioning services, PwD and their carers and the wider public.

Method

The method is described in detail elsewhere (see Publications from programme: *Appendix 1*).[42] It comprised qualitative work involving interviews, questionnaires and focus groups and is summarised in *Figure 5*.

Interviews were undertaken with 60 participants in total ranging across 5 TMCDs. This involved 30 staff, 15 PwD and 15 carers. For team members the interviews addressed the operational process of working, interface with other

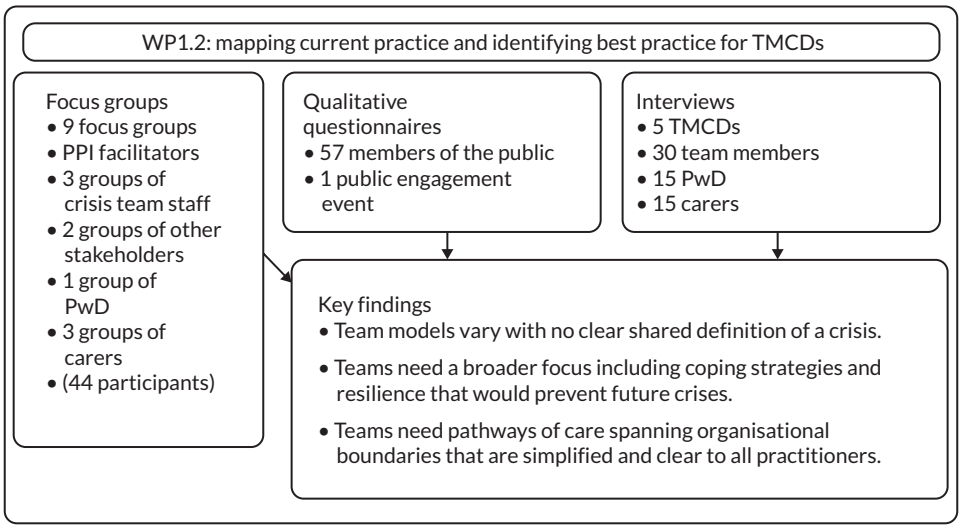


FIGURE 5 Components of WP1.2.

organisations, good practice, barriers and capacity to innovate practice. For SUs and carers, interviews addressed positive experiences of crisis help, the way support was managed and possible changes to the way teams responded.

Qualitative questionnaires were completed by 57 participants at a public engagement event to elicit understandings of crisis, and preferences for how a crisis intervention team should operate and co-ordinate with other services.[43]

Focus groups were undertaken with 44 participants in groups of between 2 and 6 people. These comprised: three groups of TMCD staff members, three groups of carers, one group of PwD and two groups of stakeholders (including other health and social care providers). The groups addressed the nature of crisis, ranked identified aspects of good practice, the nature of engagement by teams and barriers and facilitators to good practice. The focus groups were led by the research team in partnership with PPI facilitators.

Key findings

A key aim was to identify quality indicators of a good service and best practice which could be produced as items for the BPT. The development and use of these items are described in the next section of this report.

In addition to item generation, it was clear from interviews with team staff that services operated to a variety of models and that there was no clear shared definition of a crisis in dementia care. Some appeared to define a crisis by behavioural and psychological symptoms of the person with dementia and others by crises experienced by carers and failure of the support network, and to focus their work accordingly. It seemed that effective crisis services needed to address both these domains, and the relational interaction between them and the wider care network. The importance given to such supportive care by family caregivers was particularly evident.[44]

The qualitative questionnaires indicated the importance of an approach to crisis management that went beyond addressing the immediate pressure such as hospital admission towards wider goals of regaining control, autonomy and creating coping strategies that mitigate against future crises. It suggested that effective crisis intervention required accessible, expert services providing practical and emotional support, co-ordination with other services, and a person-centred approach that involves family members. It appeared that: crisis intervention services should set clear expectations of their role; require resources and capacity to not only prevent admission to hospital but also set in place crisis prevention measures; pathways of care spanning organisational boundaries should be simplified and understood by practitioners, and effective crisis intervention services should be accessible with clear referral routes.[43]

Focus groups with staff in TMCDs indicated the importance of effective engagement of all parties, the person with dementia, carers and the crisis team, particularly in the light of the short length of contact between the parties.[45] Differing definitions of crisis between carers and TMCDs could make engagement more difficult. Direct support for carers and individual one to one engagement by the team with the person with dementia were seen as assisting engagement and addressing the different perspectives of the members of a caring dyad.[46] It seemed that making SUs aware of the support provided by crisis teams before needed could help promote a positive therapeutic relationship and effective care management.

Interface with rest of the programme

This set of qualitative studies directly informed the development of the BPT in the later stages of WP1, contributing to the development of the domains and items therein. In addition, work undertaken in association with the programme in relation to researcher capacity development also provided important contextual material in relation to quality of care for the BPT.[47–49]

Work package 1.3: development and field testing of the Best Practice Tool for Teams Managing Crisis in Dementia

Analyses from the interviews and focus groups (WP1.2), and systematic review and scoping survey (WP1.1) were used to develop 165 standards that captured the essential elements of effective working in TMCDs. *Figure 6* shows the stages undertaken in WP1.3. The 165 standards were reduced to 50 through a process of consultations and a 1-day consensus conference. An iterative process of drafting and re-drafting potential items refined these in response to emerging evidence and feedback. The process of developing the BPT is described elsewhere (see Publications from Programme: *Appendix 1*) and summarised below.[50]

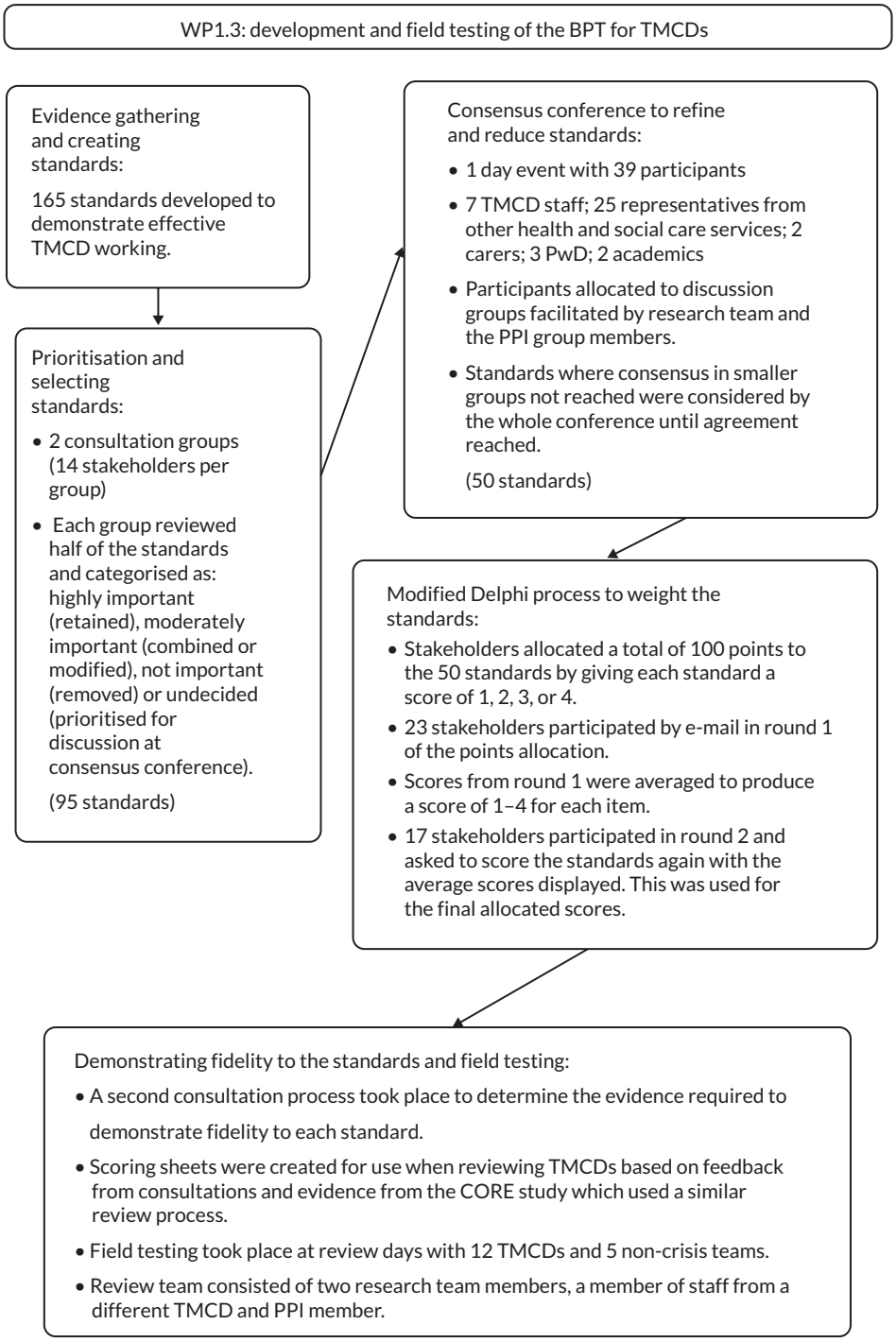


FIGURE 6 Development and field testing of the BPT for TMCDs.

Method

Two consultation groups were held each with 14 stakeholders. Stakeholders represented 'critical friends to the project' and were clinicians in TMCDs or other health and social care services and members of the PPI group. Each consultation group was asked to rate half of the 165 standards. Groups were facilitated by members of the research team. Participants rated each standard as: highly important; moderately important; not important; and undecided. Highly important rated standards were retained, moderately important standards were revised or combined with others, not important standards were removed and decisions about undecided standards were made at a subsequent consensus conference. The research team provided contextual information from the systematic review, scoping survey and qualitative work to ensure that any alterations were grounded in the evidence and relevant to diverse experiences of care and support. At the end of the consultations the number of standards was reduced to 95.

A 1-day stakeholder consensus conference was held in November 2017. The event involved 39 participants (including PwD, carers for PwD, TMCD staff members at varying grades, senior Trust managers, stakeholders who interface with TMCDs from primary and secondary care, academics) in 5 groups reviewing standards. A systematic process considered whether a standard was required to achieve a good TMCD, whether the wording needed to be clarified, whether the standard could be combined with another standard and if anything was missing. Each standard was then edited and clarified as necessary. The importance of selected standards being measurable, specific to TMCDs, and defining best practice fully and concisely was stressed. Following the consensus conference which reduced the number of standards to 50, the research team ensured that there was no duplication, no missing elements and that the standards fitted with current practice based on the knowledge obtained in WP1.1 and WP1.2.

Following the consensus conference, a modified Delphi process was used to create a hierarchy of standards using a weighting system, recognising that the contribution made to best practice varied across the standards. Twenty-three stakeholders were involved in a points allocation process and were asked to allocate 100 points to the 50 standards by giving each standard a score of 1, 2, 3 or 4. Stakeholders participated by e-mail and consisted of participants from the consensus conference, stakeholders from the consultation groups, members of the PPI group and academics. Scores were then collated and averaged to produce a score for each standard. A second round of points allocation was then undertaken with 17 participants and, additionally, participants considered the average score from the first round. Following the second points allocation, scores were again collated and averaged for each standard.

A third consultation group was then undertaken to determine the types of evidence required to demonstrate each standard was met. Standards previously excluded from the final 50 were reviewed and where relevant refined as potential indicators of evidence. The research team used feedback from the consultation groups and evidence gained from the CORE study, which used a similar methodology, to develop scoring sheets for use when reviewing each TMCD against the BPT standards.[35]

The Best Practice Tool

The BPT comprises 50 weighted statements designed to capture the core of best practice in a TMCD. It was designed to be used by TMCD managers to assess their team's performance against the standards and identify areas for improvement. The tool allocates a score out of 100 to each team. The final version of the BPT covered three areas: the crisis service, rapid assessment and intervention, and service resources as shown in *Box 1* and the full 50 statements

BOX 1 Best Practice Tool components

The Crisis Service: 22 standards relating to the services' purpose, values, procedures and improvement.

Examples:

- The service has a system for prioritising risk and assessing required levels of support for PwD.
- Each service has a senior qualified 'duty worker' (shift co-ordinator) who allocates work each day and who oversees all calls about patients.

Rapid Assessment and Intervention: 14 standards relating to accessibility, assessment, and intervention.

Examples:

- The service operates outside normal working hours and signposts to other community-based support when the service is closed outside of these hours.
- Following referral, the service makes initial contact on the same day and the person with dementia is seen within the next working day for appropriate crisis referrals.

Service Resources: 14 standards relating to staffing, joint working with other services and team base.

Examples:

- The service has administrative support that is sufficient to meet current demand.
- The service is embedded within established pathways of care and policies exist for working with all other relevant agencies, to include social care, emergency services, charities, and the voluntary sector. Other agencies and services have an accurate perception of the crisis service and its remit.

are shown in *Appendix 1*. Prior to completing the BPT teams are asked to complete a series of questionnaires/checklists to help them put together the required information to complete the BPT. These consisted of: a manager questionnaire; a staff member questionnaire; other service staff questionnaire; a case note review checklist; a paperwork review checklist and a visual check of the team base; a person with dementia questionnaire; and a carer/family questionnaire.

Field testing

Between February 2018 and March 2018, field testing was undertaken of the BPT in 12 TMCDs and in 5 non-crisis CMHTs. Each team was visited by a research team consisting of two members of the AQUEDUCT team, a member of a different TMCD, and a member of the PPI group. Teams were contacted beforehand to explain the process and to enable them to prepare. The process was based on that used in the CORE study.[35] On the review day, evidence was collected and activities arranged to fit in with the team's needs. At the end of the day, reviewers met to complete the BPT scoring sheet and provided a total score and feedback to the team in the form of a report. The process allowed teams to clarify information later and any subsequent changes to the score were agreed by the reviewing team. The non-crisis CMHTs provided a comparison group for the purpose of checking face and content validity. Scores between the TMCDs and non-crisis teams were compared to determine discriminant validity of the measure, to assess floor or ceiling effects and to determine face validity of the Best Practice Model.

Following the field-testing, changes were made to the criteria required to achieve the maximum scores for each standard in the BPT in response to ceiling effects occurring in scoring across both types of teams. This change made it more difficult for teams to achieve high scores and allowed greater variation in scores across the teams. Scores between the two types of teams varied with TMCDs scoring highest suggesting good discriminant validity (TMCDs median 74.5, range 67–92; non-crisis teams median 60, range 48–72). This analysis was based on 11 TMCDs and 5 non-crisis CMHTs.[50] Feedback from managers suggested that the BPT was realistic in identifying good practice, had good face validity and the processes including identification of areas for improvement were useful and non-threatening, albeit time consuming.

Limitations

One limitation of the study was that it was undertaken in England and the resulting research and Best Practice Model were based on services provided there. Although it may be applicable to the devolved nations of the UK, this has not been tested and its applicability beyond the UK is also unknown.

There was an attempt to avoid being overly prescriptive in precise definitions of the standards so that local context and factors, such as case mix, which influence best practice could be considered. However, this can impact on reliability of the Tool and some standards are quite general. However, field testing of the BPT found validity in the presence of lower scores on the Tool for non-crisis teams.

A further limitation was that the psychometric properties of the BPT were not investigated during the development process. The small numbers of teams in the field testing meant that statistical comparisons were not possible. Test–retest reliability could not be established because of the burden of the review day on teams. On the review days not all the evidence was present. Inter-rater reliability could not be established because of limited staff numbers and time, and no single reviewer was able to look at all the evidence gathered. There was necessarily no exploration of the criterion validity of the tool since it is unknown how well a score on the tool relates to clinical outcomes for PwD and carers.

Following the field testing and modification to the scoring, the final version of the measure developed in WP1.3 was incorporated into the Best Practice Resource Kit. The Best Practice Resource Kit is described in the following section.

Work package 1.4: development and field testing of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

The Best Practice Resource Kit consisted of three components: the HTP; the BPT developed in WP1.3; and resources and training templates which teams could use to reach the best practice standards of the BPT. *Box 2* shows the components of the Resource Kit and its development is summarised in *Figure 7*.

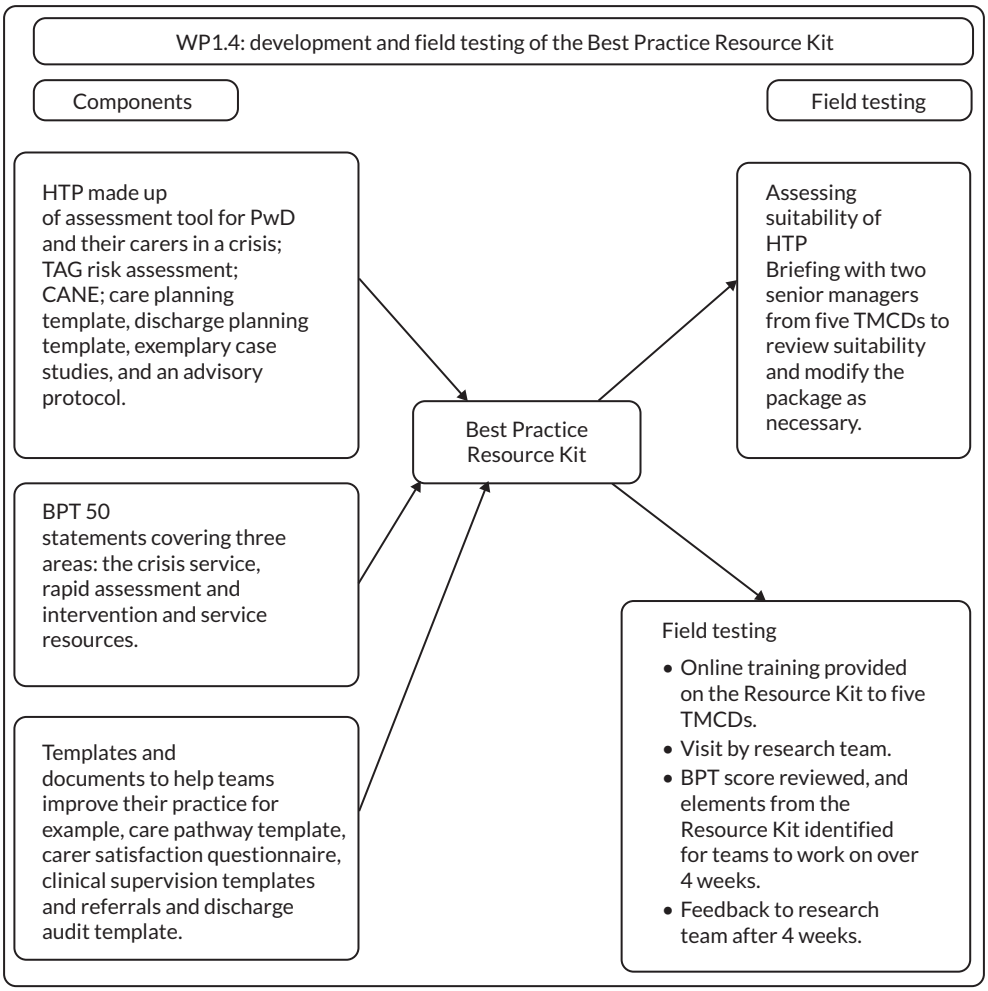


FIGURE 7 Development of the Best Practice Resource Kit. CANE, Care Assessment Need Evaluation; TAG, Threat Assessment and Guidance.

BOX 2 Components of the Best Practice Resource Kit

- The BPT to measure performance against 50 standards.
- Training and resources that teams could use to help achieve the individual standards on the BPT.
- Training in the use of the HTP for individual care planning and needs assessment.

The HTP incorporated in the Best Practice Resource Kit was developed from a previous NIHR Programme Grant led by Martin Orrell – SHIELD.[26,51] The HTP underwent feasibility testing as part of SHIELD programme, but it was further refined following field testing as part of WP1.4. The detailed contents of the HTP are shown in *Box 3*.

A half day briefing day on the HTP was held with two senior members of five TMCDs to provide training in and determine the suitability for use and ease of completion of the HTP using case study examples. This allowed any modifications to the HTP to be undertaken before it was used as an element in the Resource Kit. As part of the review staff used their own clinical experience to complete the HTP and provided feedback to the research team on the process of using it.

The Resource Kit was then field tested by five TMCDs. Online training was provided by the research team to staff members in the teams on the use of the Resource Kit. Following this training members of the research team visited the staff and discussed their score on the BPT and areas for improvement. The team members then agreed elements from the Resource Kit that they would focus on during a 4-week period. Over the 4 weeks teams were contacted weekly by an AQUEDUCT researcher to record usage of the Resource Kit elements. At the end of the 4 weeks feedback was obtained from the five teams on the process of using the Resource Kit and this was used to finalise the version of

BOX 3 Components of the HTP

- A guide to using the HTP and key steps to be followed.
- HTP advisory protocol pathway, which shows the key stages of the assessment and care planning procedure as a flow diagram.
- HTP advisory protocol checklist which records the assessments completed and indicates the level of need for implementing the home treatment interventions.
- Threshold assessment grid score sheet to assess risk for the person with dementia.[52]
- Short Camberwell Assessment of Need in the Elderly completed with the person with dementia and family carer.[53]
- Glossary of interventions ranked most likely to be useful in a crisis.
- Care Planning tool in which the unmet needs and interventions will be documented in order of priority for action.
- Evaluation and Discharge care planning tool in which the unmet needs are evaluated, and preventative interventions will be documented to reduce risk of further crises occurring.

the Best Practice Resource Kit for use in WP2 the feasibility study. Overall, TMCDs from NHS Trusts across England engaged in WP1 reflected a wide geographical spread, urban and rural locations, and affluent and less affluent areas. Following WP2 the Resource Kit was further modified for the subsequent RCT. These changes are discussed in WP2 below. The Best Practice Resource Kit was made available with password protected access on a website (http://www.dementiacrisisresource.co.uk/)

Work package 2: feasibility study of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Work package 1 consisted of the development of a Model of Best Practice comprising 50 best practice statements in a BPT, and a Resource Kit to facilitate enhanced management of and response to crises in dementia care by clinical teams tasked with that responsibility.[42,50] Subsequently, 12 TMCDs and 5 non-crisis older adult mental health teams field-tested the AQUEDUCT BPT and Resource Kit. The feedback from these teams was used to further improve the Resource Kit for use in an evaluation of its feasibility. This feasibility study constitutes WP2.

Aims

The aims of WP2 of the AQUEDUCT research programme were to:

1. Conduct a feasibility study of use of the Resource Kit in relation to practice, care outcomes, and costs.
2. Gather feedback from participants about the acceptability and feasibility of the research procedures.
3. Refine the Resource Kit for use in the RCT.

This latter refinement was to: (a) determine the feasibility of recruitment to a large-scale RCT; (b) refine the eligibility criteria for TMCDs for a future definitive RCT; (c) determine the relevance and acceptability to NHS practitioners; (d) determine the acceptability to PwD, carers, and NHS practitioners of the trial procedures; (e) assess the ability of the NHS sites to implement the Resource Kit; (f) assess the training and support needs for NHS practitioners using the Resource Kit; (g) evaluate Resource Kit uptake and fidelity when used through NHS services; (h) assess follow-up and outcome completion rates; (i) determine the relevance and acceptability of a range of outcome measures to inform selection of the primary outcome for the main trial; and (j) evaluate the utility and acceptability of resource use questionnaires for use in an economic evaluation in a future RCT.

Method

Work package 2 was a feasibility study assessing the acceptability of the BPT's design within TMCDs and the process's feasibility. The study protocol is described in detail elsewhere and the components of WP2 are shown in *Figure 8*.[54]

Four sites were recruited, each covering several teams, purposively selected from across England to ensure a diverse range of TMCD models and SU demographics. From these sites a total of 94 participants – staff in TMCDs, PwD and carers were to be recruited.

For the intervention, participating practitioners completed online training in use of the AQUEDUCT Resource Kit and a post training self-assessment to provide information about the effectiveness of the online training. Each team was given

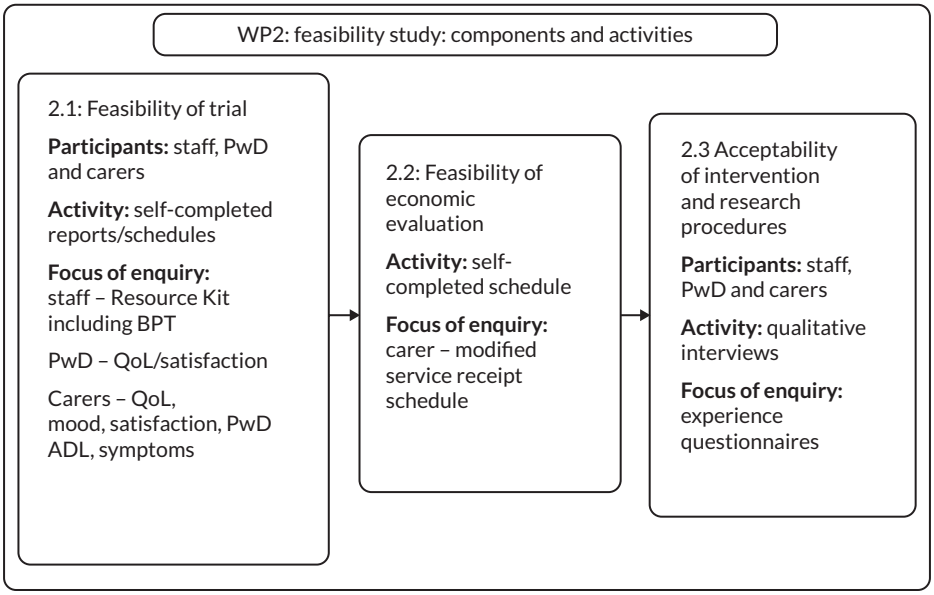


FIGURE 8 Feasibility study: components and activities. ADL, activities of daily living.

3 weeks to complete the BPT before the implementation phase, to determine areas in which the TMCD could improve practice. The team then implemented relevant elements of the Resource Kit that could assist them in improving practice during an 8-week implementation phase. The team then recompleted the BPT at the end of the implementation phase.

Data were collected at two time points for PwD and carers. Upon recruitment, demographic information and baseline questionnaires were completed; follow-up questionnaires were completed at the end of the period during which the person with dementia and the carer had received team input. One of the main aims of the feasibility study was to determine the most suitable outcome measures for the subsequent RCT. A range of outcome measures were collected and are listed in *Box 4*.[54]

In addition, carers were approached to assess the feasibility of resource data collection for economic evaluation using a bespoke version of a standard cost data collection tool along with information about the additional costs of

BOX 4 Outcome measures for PwD, carers and TMCDs used for the feasibility study

PwD

- Self-completed and proxy versions of the Dementia Quality of Life Questionnaire (DEMQOL and DEMQOL-Proxy)[55]
- Client Satisfaction Questionnaire (CSQ)[56,57]
- The Neuropsychiatric Inventory (NPI) completed by carers[58]
- Bristol Activities of Daily Living Scale (BADLS)[59]

Carers

- EuroQol-5 Dimensions, five-level version (EQ-5D-5L)[60]
- Hospital Anxiety and Depression Scale (HADS)[61]
- NPI severity of symptoms manifestations and to determine caregiver distress associated with neuropsychiatric symptoms[58]
- CSQ[56,57]

TMCDs

- BPT scores (start and end or implementation phase)
- Number of Hospital Admissions for the TMCDs (during the 8-week implementation phase)
- Number of referrals received (during the 8-week implementation phase)
- Number of dementia-specific crisis referrals received (during the 8-week implementation phase)
- Number of inappropriate referrals (during the 8-week implementation phase)
- Staff absenteeism (during the 8-week implementation phase)
- Total number of hospital beds available to the TMCDs (during the 8-week implementation phase)

implementing the Resource Kit.[62] Team level data were collected which included hospital admissions during the study period, BPT scores, and measures of organisational process such as referral rates and absenteeism.

Qualitative work was also undertaken, using self-report questionnaires, to evaluate the experience of applying the research methodology in wider research and clinical practice and the acceptability and relevance to staff of using the Resource Kit and for PwD and carers receiving input from TMCDs. An important aim was to improve the research experience for all participants, particularly PwD and carers, to mitigate and reduce the demands associated with taking part in this research.

A Trial Management Group was established early in the feasibility study, to review procedures and outcomes on an ongoing basis; monthly meetings took place throughout the study and allowed opportunity for data inspection and consideration of best outcome measure(s) for the main trial.

The protocol for WP2 was developed in consultation with the AQUEDUCT PPI reference group, and all study documentation and participant recruitment procedures were reviewed by PPI representatives.

A clinical staff reference group was also established during the feasibility study since the Resource Kit intervention impacted on practitioners working in dementia crisis teams. This met on several occasions during the feasibility study. The input of group members proved to be particularly valuable in helping to refine the timing of procedures for the main trial.

Key findings

The feasibility study received Research Ethics Committee (REC) and Health Research Authority approval in July 2019, and the study was implemented in four TMCDs across England from September 2019. In total, 77 practitioners, 17 carers and PwD took part.

Recruitment across the four sites included:

- **Site One:** 21 practitioners and 7 carers were recruited.
- **Site Two:** 21 practitioners were recruited, 0 PwD or carer.
- **Site Three:** 10 practitioners, 2 PwD, and 1 carer were recruited.
- **Site Four:** 25 practitioners, 2 PwD, and 5 carers were recruited.

Each site was asked to complete the BPT assessments before and after implementing the Resource Kit (RK). Baseline and follow-up scores observed were:

- **Site One:** Initial score of 77; no follow-up score was received.
- **Site Two:** Initial score of 67; follow-up score of 80, indicating improvement.
- **Site Three:** Initial score of 57; follow-up score of 57, indicating no change.
- **Site Four:** Initial score of 68; follow-up score of 81, indicating improvement.

These findings suggest the BPT was sensitive to change, as evidenced by improvements in Sites Two and Four.

Across the 4 sites, 13 different items from the Resource Kit were utilised, with sites advised to implement a minimum of 4 items to modify their practices. The specific items included:

Items the teams selected from templates and documents in the Resource Kit

SITE 1	SITE 2	SITE 3	SITE 4
Admission to referrer template	Referral form	Carer satisfaction questionnaire	Care pathway template
Basic information card template	Basic information card	Patient satisfaction questionnaire	Operational policy
Care pathway template	Carer Satisfaction Questionnaire	Sharing of personal information consent form	MDT meeting individual patient
Handover daily checklist	Referral and discharge audit template	Daily handover checklist	Discharge letter

Teams Managing Crisis in Dementia practitioners in the four sites received training in use of the Resource Kit and employed it with all instances of dementia crises screened into their service during a 2-week recruitment period. Outcome measures were completed with PwD and carers, where possible, to test outcome measure sensitivity, with the aim of carrying the most sensitive measure(s) forward to the main trial. TMCD/service relevant outcome measures were collected and assessed for the same reason.

The study additionally included a feasibility testing of the economic evaluation to be used in the main trial, using the Client Service Receipt Inventory. However, only three professional carers and two informal carers were recruited, with the questionnaires being completed by just one carer. These findings showed that collecting data for an economic evaluation during crises was not feasible.

No teams in the feasibility study used the HTP component of the RK. The primary reason cited was the additional burden of routinely collecting extensive data, which was deemed too onerous in crisis situations. This showed that incorporating the HTP into a larger trial would not be practical.

The feasibility study was completed on time at the end of March 2020, just as the period of lockdown associated with the COVID pandemic commenced. Findings indicated a degree of sensitivity to change over time of the BPT scores within teams, and different development choices by teams of domains in the Resource Kit. *Box 5* summarises the main conclusions from the study which were further shaped by the impact of the COVID pandemic.

The study was successful in informing the design and procedure of the main trial; in particular, difficulties in recruiting PwD and carers at times of crisis were highlighted and with input from the AQUEDUCT PPI reference group and clinical reference group adjustments were made to amend the procedure for the main trial. Overall, WP2 data collection was completed within 1 week of the commencement of the first lockdown for COVID-19. The conclusions from this feasibility work fed into the planning for the RCT and these plans had to ensure the research was responsive to and feasible within the changed NHS research environment created by the pandemic. This included changes to both the types of data collected and the means of data collection, with a necessary reduction in face-to-face activity. The detailed protocol for the trial is outlined in the following section.

Work package 3: randomised controlled trial of the Best Practice Resource Kit for Teams Managing Crisis in Dementia

Following the completion of the Best Practice Resource Kit (WP1) and the subsequent feasibility study in WP2, a full RCT was conducted.

Findings from the WP1.1 systematic review provided some evidence that specialist crisis teams effectively manage crises and may reduce hospital admissions, although study numbers were low, and the evidence was of variable quality with methodological weaknesses.[39] The need for both more rigorous evidence and a clearly defined model of best practice was identified in this review. This had previously been highlighted in the systematic review conducted as part of the SHIELD programme.[26] The trial protocol was published in *Trials* in 2022 and gives full details of the trial procedures.[33] The paper also gives details of the sample size estimation for the primary outcome. A summary of the methodology and initial results are given below.

BOX 5 Work package 2: key learning from feasibility study

- Recruitment of PwD and carers very difficult in context of crisis and exacerbated with the arrival of COVID-19.
- Practitioner recruitment successful and positive engagement.
- As Resource Kit is a team intervention, staff outcome measures valuable.
- Routine outcome measures at team level offer best primary outcome indicators.
- HTP not employed by teams and therefore not employed as a core part of the Resource Kit in main trial.
- The revised Resource Kit in the main trial had two components: BPT and resource templates.
- Patient reported outcome measures (questionnaires that would be completed by the person with dementia and/or carer) should be secondary outcomes.
- Economic data needed to be collected on a reduced list basis as not feasible from carer self-report.

Operational management of the trial was undertaken by a Trial Management Group which met monthly during the setup of the trial and monthly or bimonthly subsequently. Its remit included: ensuring compliance with the research plan and monitoring progress against targets for recruitment; supporting PPI involvement during WP3; considering and acting on advice from the REC where relevant; and resolving concerns regarding the intervention and the research. Membership included chief investigator, co-investigators, programme/trial manager, experts by experience and researchers involved in the development and operation of the trial.

Aims

The aims of the AQUEDUCT trial were:

- To evaluate the Resource Kit in practice by conducting a RCT with a representative sample of TMCDs across England examining the impact upon hospital admissions, costs and upon PwD, carers and staff compared with treatment as usual (TAU).

Method

The trial was designed as a pragmatic RCT of an online Resource Kit for use by TMCDs. The teams were allocated into a two-arm parallel group, TAU controlled trial. In the intervention arm, TMCDs implemented the Best Practice Resource Kit for 6 months. Prior to implementation, AQUEDUCT researchers provided these teams with training in the use of the Best Practice Resource Kit. Each intervention team completed the BPT measure to identify areas for improvement. Based on the outcome of the BPT measure at baseline, four relevant templates from the Resource Kit were identified by teams to implement over the following 6-month intervention period.

Access to the Best Practice Resource Kit was online and TMCDs were instructed 'You must use a minimum of **FOUR** templates and/or documents from the list below. Please note, your computer system may require you to save these documents to your computer before opening them'.

The Resource Kit included the following items:

1. Admission letter to referrer template. This template can be used to send a letter to the referrer, to inform them that you have accepted the patient onto your caseload and to let them know about the expected treatment plan.
2. Basic information card template. This template can be used to produce a card that is given to PwD and/or carers or to other services, with the team's contact details. It is small enough to be easily portable so that someone can carry it with them at all times.
3. Bid to funders template. This template can be used by teams when they are considering altering their team working and when they are applying for funding for the changes they wish to make.
4. Business meeting minutes template. This template can be used to record business meeting minutes – some possible issues for discussion are suggested.
5. Care pathway template. This template can be used to illustrate the team's place in the dementia care pathway, showing who refers into the team and the destinations of discharge. This diagram could be used in the operational policy or in the staff induction pack to inform new staff members.
6. Carer satisfaction questionnaire. The template for this carer satisfaction questionnaire is specific to crisis working. The questionnaire should be completed after discharge from the team. It is advised that a team member completes this questionnaire with the carer by telephone within a week of discharge, to give the best chance of a true account of the person's experience with the team. You may decide to add questions that will help to evaluate further the team's practice.
7. Clinical supervision template – Driscoll. This clinical supervision template uses Driscoll's model, to enable structured reflection on a particular case or event in practice. This form ensures that clinical supervision is well documented and provides the opportunity to identify when staff require further support.
8. Clinical supervision template – Gibbs. This clinical supervision template uses Gibb's model, to enable structured reflection on a particular case or event in practice. This form ensures that clinical supervision is well documented and provides the opportunity to identify when staff require further support.
9. Compliments slip template. This template can be personalised with the team's information, to be used whenever a written note is required, for example, a thank you note.

10. Daily handover checklist. This template can be used to ensure that all necessary information is discussed during handover meetings.
11. Daily handover template. This template can be used to record the minutes of daily handover meetings, to inform staff of updates and the actions to be performed that day.
12. Discharge letter to referrer template. This template can be used to send a letter to the referrer, to inform them of the treatment received by the person referred to the team and future actions required post discharge.
13. Information leaflet template. This template can be used to produce a patient-facing leaflet which describes all the information a SU/carer should know about the team.
14. Managerial supervision template. This template can be used to document managerial supervision sessions – some possible topics for discussion are suggested.
15. MDT meeting plan – individual patient template. This template can be used for reporting and updating on an individual patient on the team's current caseload.
16. MDT meeting plan – all patients. This template can be used for reporting and updating on all patients on the team's current caseload.
17. Operational policy template. This operational policy template is designed to encompass all the AQUEDUCT Best Practice Statements and to support the team in achieving best practice. This document may require alteration based on the particular remit of your service.
18. Overview of service presentation. This template can be used to produce a presentation that can be shared with other services with which the team regularly liaises. It gives an overview of the team, including eligibility criteria, the team purpose, and what the team does.
19. Patient information summary form. This template can be used for patient handover. It may be used in instances such as a change in staffing, or it could be kept at the patient's residence for reference purposes.
20. Patient satisfaction questionnaire. The template for this patient satisfaction questionnaire is specific to crisis working. The questionnaire should be completed after discharge from the team. It is advised that a team member completes this questionnaire with the patient by telephone within a week of discharge, to give the best chance of a true account of the person's experience with the team. You may decide to add questions that will help to evaluate further the team's practice.
21. Plan-Do-Study-Act and Model for Improvement template. This template can be used by teams when considering small-scale changes in their practice, covering how to formulate ideas, implementation and evaluation.
22. Quality Improvement example. This is a poster created by a Team Managing Crisis in Dementia; it gives an example of a Quality Improvement project.
23. RAG traffic light system template. This template can be used by teams to stipulate criteria for categorising the intensity/urgency of intervention required. This could be helpful for triage, or the RAG system could be circulated to referring services so that they are aware of the parameters of the team's response times.
24. Referral form template. This template can be adapted and given to services that commonly refer into your team, or it can be used by team staff when taking referrals, to ensure all necessary triage information is collected.
25. Referrals and discharge audit template. This Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) file can be used by the team to record referrals and discharges. This could help the team to monitor inappropriate referrals, the average amount of time patients stay with the team, and discharge destinations. These data could be used, for example, to justify bids for extra funding or to track changes in referral rates. All columns are pre-populated, to make it easier to complete and record the information.
26. Sharing of personal information consent form template. This template can be used to record patient consent for information sharing.
27. SMARTER goals template. This template can be used to enable staff members to be more specific when goal setting.

The BPT measure was then completed again at 6 months. In the TAU group, team members had no access to and did not use the Resource Kit. The trial initially aimed to recruit 30 teams managing mental health crises in dementia in community settings which were randomised equally between the Resource Kit intervention and TAU. Randomisation was undertaken using a web-based randomisation system set up and managed by the University of Nottingham and separate from the research team (further information can be found in Coleston-Shields *et al.*[33]). TMCDs in the intervention arm were required to use a minimum of four items from the Best Practice Resource Kit.

The primary outcome in the study was admissions to psychiatric hospitals of PwD in the team's catchment area, according to post-code. This was assessed over a 6-month period following randomisation. Secondary outcomes used in the study were:

- Acute/general hospital admissions for PwD were measured based on TMCD catchment area (as defined by post codes).
- Measures of satisfaction and well-being for PwD and their carers which involved use of the Client Satisfaction Questionnaire (CSQ-8), EuroQol-5 Dimensions, five-level version and the General Health Questionnaire (GHQ-12).[56,57,63,64]
- Practitioner measures for TMCD staff involved two measures of the work environment: the Work Acceptance and Action Questionnaire (WAAQ) to measure psychological flexibility in the workplace; and the Utrecht Work Engagement Scale (UWES) to measure staff engagement in work.[65–67]
- Practitioner measures of well-being were also collected: the GHQ-12 and staff sickness as a proxy for work well-being.[64]
- The quality of each TMCD's practice in managing crises was also recorded for each team in the intervention arm only using the score on the BPT.

Measures of psychiatric admissions per team caseload and acute hospital admissions were recorded at baseline and 6-month follow-up for each of the corresponding antecedent 6-month periods. Measures of satisfaction and well-being for PwD and their carers were recorded at 6 months follow-up only. Practitioner measures were recorded at baseline and 6-month follow-up. The BPT fidelity measure was recorded by each team in the intervention arm only, at baseline and at 6-month follow-up.

Five resource use measures were also collected for the comparison of cost in the two study arms. Cost information was collected using a 'reduced list' approach to costing, reflecting the necessary parsimonious adaptation of methodology required following the COVID-19 pandemic.[68] Those included were: Psychiatric and acute hospital admissions for PwD within the TMCD's catchment area (defined by post codes) at baseline and 6-month follow-up point for the preceding 6-month period; and, to indicate use of other high-cost resources during the intervention period, the number of permanent care home admissions and respite care admissions from each TMCD. To capture the marginal cost of the intervention, staff time use in implementing the Resource Kit and associated support time were collected.

Teams were recruited from NHS Trust sites in England using professional and research networks and from contacts made during the earlier part of the AQUEDUCT programme where managers had expressed willingness to be contacted about participating in further research work. The study aimed to recruit 6 staff members per team (180 overall). PwD and their carers were identified via new referrals to the individual teams and team practitioners invited them to participate in the study. The study aimed to recruit a total of 450 PwD and their carers (225 per study arm).

Ethical approval was obtained on 9 March 2021 from West Midlands – Coventry and Warwickshire Research Committee (Ref 21/WM/0004). Each participating team identified two members of their staff to act as research co-ordinators, enabling them to recruit PwD or carers into the study. The co-ordinators gave study information to colleagues and obtained consent from their team staff. For PwD and their carers, appropriate information sheets were provided by team staff, and they were given up to three days to decide to participate. Consent was obtained from PwD and their carers to participate by team staff. Consent from PwD and their carers was considered a continuous process to comply with the Mental Capacity Act 2005 and reviewed at each meeting and all participants were made aware of their right to withdraw from the research at any time for any reason.[69]

A qualitative component explored the participants' experience of engaging with the Best Practice Resource Kit intervention. Forty-five TMCD practitioners (3 staff members per team) were approached to complete self-administered questionnaires and researchers also conducted semi-structured interviews remotely via telephone or multimedia, with up to 12 PwD or their carers. The latter were PwD or their carers who had received input within the previous 6 weeks from a TMCD in the intervention arm.

Changes to protocol

The AQUEDUCT independent Programme Steering Committee approved any significant changes in the protocol. The COVID pandemic and associated lockdowns had a major impact on the timeline for the main trial resulting in significant delays to the work and subsequent extensions to the programme. During the latter part of 2020 to early 2022, although teams expressed an interest in the AQUEDUCT main trial and the research team kept in contact, many NHS Trust R&D departments were not able to move forward to set up non-COVID-related studies. Some R&D staff who were also clinically trained were redeployed to support clinical teams. Dementia crisis teams were also unable to engage with the research while they focused their attention on clinical need and teams were under staffing pressures due to sickness and self-isolation. Despite this, by September 2022, 19 TMCDs were recruited, although 1 subsequently dropped out, and 9 of these had completed follow-ups. During the following months, the decision was made to reduce the number of teams required to participate in the trial from 30 teams to the minimum sample required of 24 teams. Although 30 had been the initial target, it was still possible to achieve 80% power with a sample of 24 teams.

There were also difficulties during the trial in acquiring the expected number of CSQs and cost schedules from PwD or their carers following contact with the crisis team. The reasons for this included: carers remained stressed after the completion of the crisis team involvement and hence team staff were reluctant to ask for further information; many PwD in crisis were too impaired to complete the survey; teams were under such pressure that they were unable to prioritise following up people after discharge; and after discharge it was sometimes difficult to follow up people who have gone to other services. In view of this, the Trial Management Group decided to reduce the projected numbers required to 10 per team.

The changes in the study's methodology continued to support the validity of the results through its robust design, which included a RCT approach, a well-defined intervention (the Best Practice Resource Kit), and a comprehensive set of outcome measures. By randomising participants and using standardised tools to measure key outcomes, the study minimised biases and confounding factors, ensuring that the observed effects were attributable to the intervention itself. Additionally, the use of both primary and secondary outcomes allowed for a nuanced evaluation of the intervention's impact, enhancing the overall reliability and generalisability of the findings, even in the context of external disruptions. Changes in the Statistical Analysis Plan can be found in *Report Supplementary Material 1*.

Key findings

A Consolidated Standards of Reporting Trials flow diagram of the trial is shown in *Figure 9*. Following recruitment to the trial 24 TMCDs in different geographical locations in England were recruited and 23 TMCDs were successfully randomised. These included 238 staff within teams and 75 SUs, consisting of PwD and their carers. The overall research programme was received well by most teams, partly indicated by follow-up response rate, observing an overall average of 88.5% returns across all TMCDs. Similarly, the intervention was well received by TMCD staff and detailed findings are shown in *Appendix 2*. However, there was no statistical evidence that it reduced hospital admissions nor improved the well-being or service satisfaction of PwD and carers or staff well-being on the measures employed. Interestingly, there was a decrease in the median number of hospital admissions in the intervention group. However, the small sample size may have limited the statistical power of the regression model, which used constituency-level population with dementia as an offset variable, reducing the ability to detect a significant effect. Given the scale of effect noted on the primary outcome, it is unlikely that this could be attributed to the trial being underpowered. Qualitative work with PwD and their carers (shown in *Appendix 3*) indicated they valued TMCDs offering some clinical interventions, such as medication management, knowing who and where to contact in emergencies, and supportive talking with team members. However, it did not appear that team support successfully integrated health and social care at the patient/carer level.

Factors which are likely to have influenced these findings are the nature of the research and the COVID pandemic. First, the trial was focused upon and took place during particularly difficult circumstances for PwD and their carers, namely a crisis in dementia care. Crises are inherently the worst time to engage people and expect to gather research information from them when they are under stress and distracted, thereby affecting participation. The presence of the COVID pandemic can only serve to have amplified this and shaped final research design and data collection. The

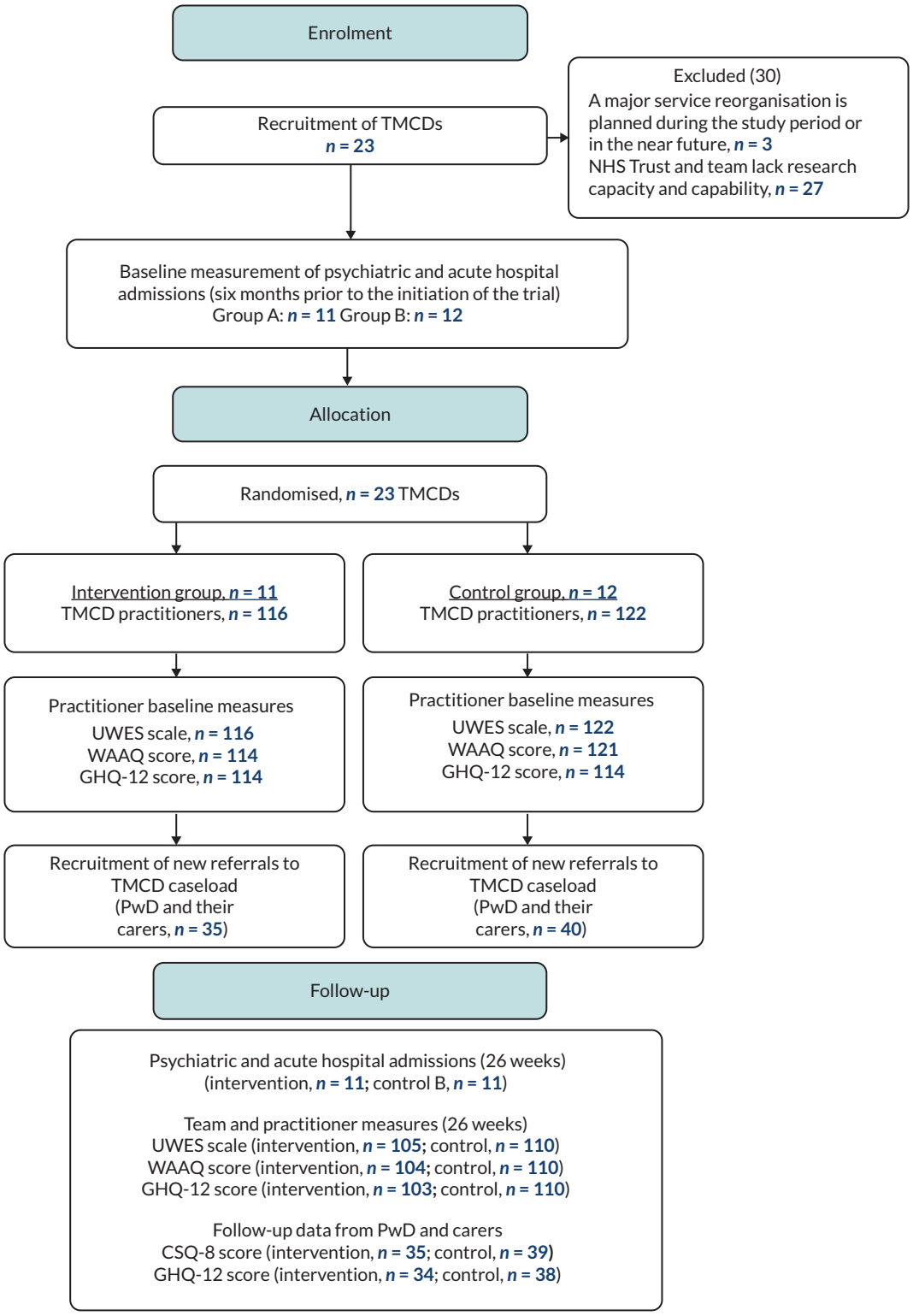


FIGURE 9 Consolidated Standards of Reporting Trials flow diagram.UWES, Utrecht Work Engagement Scale; WAAQ, Work-related Acceptance and Action Questionnaire.

primary outcome measure was one which could be collected remotely in the context of the pandemic and its aftermath, but one which could only be impacted indirectly from the intervention whereby changes in team process could affect patient and carer experience and thereby hospital admissions. Particularly following the pandemic, patterns of hospital admission, and the contribution of complementary and substitute services, were in a state of flux whereby the marginal contribution such as the AQUEDUCT intervention could be at best limited. Nonetheless, the study also demonstrated strengths and lessons for the future. First, the Best Practice Resource Kit, particularly the BPT, provides a quality

improvement resource which could be used for team development and evaluation and the harmonisation of ways of working. Second, the approach used to successfully complete running a trial during and just after a pandemic indicated ways in which routine data and remote means of data collection can be employed with some degree of economy and efficiency in research.

Patient and public involvement

Patient and public involvement was integral to the development and operation of the programme from its inception. Their contribution has been active and taken the form of advice and guidance, commentary and peer researcher roles. A related activity was also to create a clinical staff reference group more widely than the participating sites to provide perspectives from that group.

One of the study applicants is a PPI member with previous caregiving experience who is also a member of the Programme Steering Group. PPI members have contributed to the recruitment of the research team through participation in interview panels. They have also been involved in the development of the protocol for WP1 by offering advice drawn on life experiences, and by providing comments on drafts of the protocol. In addition, the charitable sector is represented on the Programme Steering Group, to facilitate further public engagement, particularly with people who have experience of dementia.

A PPI reference group was created at an early stage of the programme with clear terms of reference to ensure PPI was embedded into the programme. Members were involved as Peer Researchers in WP1. Two training days for PwD and carers of PwD were held in February 2017, to promote learning about research and specifically about co-facilitating focus groups. These training days were attended by 14 people. Nine focus groups with PwD, carers of PwD, stakeholders, and staff members of teams that manage crises were conducted, and all were co-facilitated by a peer researcher with dementia or a peer researcher who cares for a person with dementia. Peer researchers asked sensitive and insightful questions and enriched the data collection process. The Chair of the PPI reference group was a member of an interview panel to appoint a researcher for this activity. In addition, peer researchers helped to facilitate discussion at the Stakeholder Consensus Workshop for the development of the BPT. As part of the field testing of the BPT, TMCDs and non-crisis dementia teams were visited by a PPI representative as well as a researcher and a clinician, to score the TMCD on current practice according to the BPT. The PPI peer researchers received training, both in use of the BPT and in their role as PPI peer researcher.

The PPI reference group also advised on development of the protocol for WP2, met regularly during the feasibility study and was instrumental in guiding the research team regarding timing of measures to be used in the main trial, to reduce participant burden while also ensuring optimal data collection.

The programme has also engaged with a wider PPI group at the University of Nottingham to assist with dissemination and this group also received the quarterly programme PPI newsletter. In addition to PPI engagement, a parallel clinical staff reference group of four members was also established who advised on development of the protocol for WP2 and met twice during the feasibility study, to discuss possible outcome measures with the AQUEDUCT research team. Both this group and the PPI reference group contributed to development of the protocol for WP3, ensuring the research burden for PwD, carers and clinical staff would be minimised in the main trial given the impact of COVID-19, with data collection nonetheless accurately reflecting the day-to-day practice of clinical staff working in NHS dementia crisis management.

The COVID pandemic undoubtedly brought unique challenges for the programme regarding PPI. Just before the start of lockdown, when it was becoming clear that COVID-19 would make direct contact infeasible, the research team met remotely with both reference groups and arranged communication via telephone, online platforms, e-mail and newsletters, thus maintaining the health and safety of all concerned. However, this inevitably impacted on engagement, and following the pandemic some new members were recruited in partnership with the programme PPI lead. The duration of a lengthy study will inevitably challenge continuing inclusion of SUs, carers and members of the public, with

their own life and health demands. We were therefore especially grateful for the extended commitment of several PPI members in a variety of roles, including research and recruitment.

Dissemination and developing research capacity

An overall dissemination strategy was developed for the AQUEDUCT programme describing its aims, the process for decision-making and the range of planned activities. The goals of this strategy were to: promote and increase understanding of the research by stakeholders and maximise recruitment of participants to the study; to identify individuals and groups who may have an interest in the research topic; to identify potential collaborators and maximise awareness of the data from the programme and the possibility for developing future studies; to ensure that information was provided in a format appropriate to the user needs, preferences and requirements and that outputs met the needs of the intended audience; and to identify and monitor indicators of dissemination activity, reach and impact. A programme-specific logo, branding and promotional materials were developed early in the programme to give the study a recognised identity.

Various dissemination methods were used to provide information. The AQUEDUCT team developed a programme-specific Twitter account (@AqueductIMH) in June 2016, which has 242 followers and was used to promote several newsletters from the programme of work, the ongoing research activities and milestones in WP1 and promote other related research. A programme-specific website was developed as a sub-section of the University of Nottingham Institute of Mental Health website providing updates on the work. Academic publications from the programme have been published in open access high-quality peer-reviewed journals (Additional information). The research was presented locally at NHS Trusts R&D and at national and international conferences. Examples of these events and other dissemination activities are listed below:

- Poster presentation and the AQUEDUCT programme was featured in the Institute of Mental Health 10 Year Anniversary Event Film in May 2016.
- Poster presentation at the *British Psychological Society: Faculty of the Psychology of Older People (FPOP) Annual Conference 2016*, Oxford on 11–12 July 2016.
- Members of the research team attended the *Healthy Brains at Every Age Event* at the University of Nottingham in October 2016 to inform members of the public about the research and to gain public and patient opinions.
- Presentation at *Bridging the Gap in Evidence-Based Dementia Care* at the Yorkshire and Humber Clinical Research Network at the University of Bradford in December 2016.
- The programme was promoted on *BBC Radio Nottingham* which was an opportunity to recruit more local PPI members.
- A blog post was written and published on the *Dementia Day to Day* blog, hosted by the University of Nottingham.
- *8th Research and Innovation Event* organised by Coventry and Warwickshire Partnership NHS Foundation Trust in June 2017 where the programme was shortlisted in the top three for a prize for involving clinical staff who have not previously participated in research.
- Oral poster presentation at *28th Alzheimer's Europe Conference Making Dementia a European Priority* on 30 October 2018 Barcelona Spain.
- Oral presentation, AQUEDUCT update at *Dorset Healthcare University NHS Trust Research Event*, April 2018.
- Oral poster presentation, 'Achieving QUality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT)' at North-East London NHS Foundation Trust Research and Development Day, May 2018.
- Poster, 'Let me in': Researching together with members of the Centre for Dementia PPI group' accepted for *'PPI in Research' Conference 2018* at Newcastle University, November 2018.
- Oral presentation, 'Development of Best Practice for Dementia Crisis Teams – the AQUEDUCT Research Programme', *Centre for Dementia seminar series*, *Institute of Mental Health*, University of Nottingham, May 2019.

The importance of keeping PPI members sufficiently informed to fully contribute was recognised: to retain their involvement particularly during the COVID pandemic; to recruit new members; and to maximise the gain to the programme from the PPI involvement. PPI dissemination specifically included: updating members using various

mechanisms including a quarterly newsletter advising on the current research activities, research staff changes and meeting dates; and making mutually informative links with local charities such as Forget Me Not, local Memory Cafes and the Alzheimer's Society.

The programme was able to offer opportunities to two researchers to work alongside the research team. Alessandro Bosco (Economic and Social Research Council award holder) – Study title: *The Social Understanding of Mental Health Crisis in Dementia* and Dr Kaanthan Jawahar (Trainee psychiatrist on a clinical academic fellowship) – Study title: *What Is the Optimum Team Configuration for Best Crisis Team Working in Dementia?* Both individuals also helped with data collection which provided them with useful experience.

The programme also offered opportunities for clinical staff in TMCDs to learn about and get involved in research, including participation in the RCT. Two staff members from each team were trained as co-ordinators to take a leading role in taking consent from their team colleagues and in providing new staff, who joined the team during the RCT, with information and training on the research. All team members were involved in explaining the research to PwD and their carers and obtaining their consent. There was a strong interest in the AQUEDUCT programme and desire to become involved expressed by staff working in TMCDs and the study was able to reach and offer experience of research to a group of clinical staff not frequently involved in research.

The arrival of the COVID pandemic in 2020–1 and its aftermath with the necessary lack of face-to-face contacts, travel restrictions and adjustments to new and changed ways of communicating had some impact on both the programme's dissemination strategy and opportunities for developing research capacity However, it also provided new learning how research partnerships could be built, and new research skills fostered.

Reflections on what was and what was not successful in the programme

From the start of the programme, NHS Staff, stakeholders, SUs and carers were very enthusiastic about the relevance of the programme and the research team met with a great deal of openness and interest when engaging with participants. Recruitment for the three WPs was excellent and both WP1 and WP2 recruited to target. Involved TMCDs and other clinical services were keen for the programme to be a success in further developing crisis working and to learn from innovative practices in other services. Indeed, on occasions when the research team brought people from different services together this resulted in sharing of knowledge and practice approaches among attendees. From the beginning, the good response to WP1 produced a rich source of data which fed into the development of the trial intervention, ensuring this was evidence based and grounded in practice.

Patient and public involvement in AQUEDUCT was successful with PPI members working alongside the researchers at various stages of the research and supporting the team in various activities throughout. These have been discussed more fully earlier but included co-facilitating consensus discussion groups and being members of reviewing teams. One challenge was ensuring the correct governance was in place for PPI members, particularly when acting as co-researchers. Many PPI members were learning to use technology such as iPads and computers and using different software to complete governance checks was at times difficult for them. The research team worked closely with the Volunteering Manager at the Sponsor Trust and with the Trust Research and Innovation Department to develop processes that were acceptable to different Trusts in the study. The process was lengthy and at times delayed their involvement. Despite these challenges, PPI members made a significant contribution to the research bringing new insights into discussions and creating a deeper level of empathy with carers and SUs than otherwise might have been the case.

The relocation of the Chief Investigator to the University of Nottingham, early in the programme, led to a change of Clinical Trials Unit from Bangor University to the Clinical Trials Unit at the University of Nottingham (NCTU). This presented a challenge, and the new trials unit's subsequent involvement was not successful, reflecting differing perspectives on the use of routine data as primary outcome measures. Consequently, NCTU ceased involvement prior to the commencement of the trial. Work originally planned as the responsibility of the NCTU was successfully managed by the AQUEDUCT research team which made additional demands upon the research team with the Programme Manager responsible for drafting the RCT protocol and work in recruiting alternative statistician support.

The arrival of the COVID-19 pandemic in early 2020 towards the end of the feasibility study (WP2) provided a major challenge to the research team, TMCDs, PPI members, PwD, their carers, and other stakeholders. The AQUEDUCT research method had been planned to place considerable reliance on the input of NHS staff; the programme involved contacts with groups at high risk from COVID; and the trial outcome measures were admissions to hospital which was disrupted during the initial phase of the pandemic. The work was thus seriously impacted by COVID-19 and there was as a result a real risk of non-completion of the RCT. It was a success of the AQUEDUCT programme, that despite these challenges, and with continued support from NIHR, the team was able to adapt the trial design in a manageable and safe way that allowed the work to be completed. This success provided helpful lessons as to how research design can be constructively modified in the context of major external changes.

Equality, diversity and inclusion

The issues of equality, diversity and inclusion were addressed at different levels and stages throughout the study. These are in PPI and the research process, access to study information and geographical and population representativeness of the study. In undertaking research with PwD, the study was focused upon a group of people often under-represented in research.

In terms of population representativeness, 30 NHS Trusts from across England engaged with WP1. These Trusts reflected a wide geographical spread, from County Durham in the north to Devon in the south, from Shropshire in the west to Suffolk in the east, as well as demographic variability encompassing both urban and rural locations, across more and less affluent areas. Similarly, the trial in WP3 engaged with 24 Trusts across different geographical and sociodemographic areas.

In the research process, the trial was designed in conjunction with both PPI and clinical staff reference group members to minimise the demands on participants, reflecting the twin unique circumstances of research undertaken at a time of personal crisis and overshadowed by the impact of COVID-19 on people and the NHS. Furthermore, the study PPI members contributed to ensure their voice was heeded, working in a range of roles such as co-researchers, advisers and appointment of staff.

Regarding access to information, as well as information made available to research, policy and practitioner groups through media, such as journal articles and local, national and international conferences, the study team produced newsletters and worked with local PPI groups and wider focused not for profit organisations to publicise the work of the study for interested members of the public who would otherwise lack access to information.

Despite these efforts, we recognise that the design of the research may not have permitted the inclusion of salient groups of people. Members of the team had undertaken research with ethnic minorities and on the issues surrounding uptake of services for PwD by members of the South Asian community and are aware of their lower uptake of services and use of services at a later stage in their illness.[70–72] Since the sample of PwD was from referrals to the TMCDs this may have excluded groups such as these who may have been unable to participate because of more advanced illness and or who sought help elsewhere. This is something that we were unable to address in this programme but should be a focus of future research, such as whether there are differential approaches to a crisis by PwD and their carers from ethnic minorities and if care pathways to TMCDs differ by ethnic minority groups. Again, it has been observed that dementia research has tended to focus on people with carers or close support and neglected those who are more isolated. Here too, recruiting people from service engaged groups, in this case crisis services, may have excluded more isolated individuals undergoing crisis.

Limitations

The programme examined the work of TMCDs based in England and while it may also be representative of the other three devolved nations in the UK, it has not been tested there and may also not be applicable internationally. It is also possible the programme excluded some groups in the analysis who were less likely to take up community mental health

services such as ethnic minorities and people living alone, and that these groups may well have required a different approach to managing crises to engage with services. This was not explored in the study.

Some limitations have been discussed previously for WP1. There may have been some methodological limitations in the scoping survey (WP1.1) associated with lack of access to appropriate managers, variation in their direct knowledge of services, and some respondents excluding themselves from the survey due to design issues. In WP1.3, there was a lack of full psychometric testing and statistical analysis of the Best Practice Fidelity Tool primarily reflecting to the small numbers in the field testing and its application in the intervention.

There are likely to have been limitations upon the RCT which were imposed by the context in which it was undertaken, the immediate aftermath of COVID-19. In this context, a feasible primary outcome had to be chosen, psychiatric hospital admission rates, which would not have been the chosen outcome in the absence of the pandemic. However, first, it may be the case that patterns of admissions both prior to the intervention and subsequently were changed in ways that differed from usual care due to the pandemic and influenced the results. Second, it is possible that there were changes in the operation of complementary and substitute services in study localities in response to COVID-19 such that probabilities of admissions to hospital of PwD were reduced. Finally, it is possible that a more complex and sophisticated method of standardising admission rates may be required, taking account not just of population but bed numbers and substitute services, if admissions are to be employed as an outcome measure in studies.

Recommendations for future research

The programme has highlighted the limited knowledge base regarding the most appropriate support for people addressing crises in dementia. Arising from WP1, there are questions regarding the operation of TMCDs. These include: whether crisis responses are better managed as a role within CMHTOPs or as specialist services; the most effective linkages between primary, secondary care and social care in addressing crises; and staff mix within crisis teams. Arising from the BPT is work to further examine its structure and psychometric properties. From the trial there are questions regarding the issue of continuity of care and the effective delivery of supportive engagement with PwD and carers. More generally, there would appear to be room for further consideration of the differential form and impact of dementia crisis and crisis management strategies in different sub-groups in the population. These could include minority ethnic populations, likely to access services at a later stage of dementia, people living alone, and the impact of rurality.

Implications for practice

Findings from the systematic review showed a lack of good evidence on impact to guide practice for those practitioners caring for PwD during a crisis and the scoping survey highlighted the variability in arrangements for crisis management in dementia across respondents and lack of use of a care pathway by nearly half of teams. Further qualitative work (WP1.2) also highlighted variability in teams and the need for a better defined and broader role to respond to crises, a clearer definition of a crisis and care pathway which linked with other services and understood by all stakeholders. This was confirmed by a strong positive interest in the research by TMCD staff committed to improve their practice. This suggests that a national evidence-based intervention offering standards and guidance would be welcomed by practitioners. In a policy context advocating care at home standards to improve practice and maintain community tenure have immediate salience for practitioners, managers, commissioners, and PwD and their carers.[10]

Prior to the AQUEDUCT research programme, there were no practice standards for TMCDs. With the development of the 50 statement BPT, TMCDs can measure their current level of performance against best practice standards and develop strategies to improve specific aspects of their practice. The 50 standards could provide national level benchmarking data about practice and variation in TMCD services which would be useful for both policy makers and service planners, providing a basis for quality standards, service development and audit, even if the impact on outcomes is more subtle than that found in the trial.

Conclusions from the programme

The programme was devised as an integrated whole with a clear linear logic pathway flowing from multi-source evidence scoping, to tool design and refinement, design and validation of intervention, through to testing the intervention in a RCT. Bringing these results together and reflecting upon research findings and process we may conclude:

- The literature review, scoping survey and qualitative work with team staff, PwD and carers and other stakeholders produced a picture of the operation and scale of TMCD. This mapping of the different structures and ways of working of services managing crises for PwD and their carers, and the perspectives of these different stakeholders on the nature of crises and what is helpful has value for commissioners and managers.
- The aim of producing an evidence-based model of best practice via the Best Practice Resource Kit for practitioners was successfully achieved, as evidenced by the development of the BPT with its 50 Standards has potential wider utility and could be employed in quality improvement as in the MSNAP in England.[36] However, the RCT found no evidence that the use of the Resource Kit impacted psychiatric hospital admission rates, according to the geographical postcode region in which the TMCD operate, or other secondary outcomes.
- The pragmatic randomised trial of the Best Practice Resource Kit found no evidence of effects on psychiatric hospital admission rates or of effects on other secondary outcomes (such as the self-reported psychometric changes observed in QoL, satisfaction or staff well-being within the TMCD). The intervention was implemented successfully, and qualitative evidence suggests that it was well received, and people felt engaged with it. There are lessons from the study regarding outcome measure choice and processes of data collection.
- Data collection in crisis is inherently difficult due to the circumstances of people in highly stressful situations. Research in crisis teams, which are frequently short-term interventions, makes engagement and follow-up more difficult. Furthermore, reflecting the circumstances of the COVID pandemic, the necessary choice of a routine data source (psychiatric hospital admissions) as the primary outcome (perhaps more distant from the intervention than ideal) and collecting secondary outcomes of well-being and satisfaction remotely is likely to have affected sensitivity to the effects of the intervention and response numbers, respectively.
- The unique context of the COVID pandemic and its legacy raised lessons for research in relation to adaptability since there was a real risk of non-completion of the RCT. For example, health economic data, initially planned for inclusion in the AQUEDUCT programme, were not collected due to the COVID pandemic and the feasibility study showing that that it was not feasible to collect cost-related data.
- The adaptation of the trial design enabled us to successfully complete the study. This provided helpful lessons as to how research design can be constructively modified in the context of major external changes beyond the control of the research team.
- A related success was the continued involvement of PPI and reference groups during the pandemic by adapting the modes of contact. Just before the start of lockdown, when it was becoming clear that COVID-19 would make direct contact infeasible, the research team met remotely with PPI and clinical staff reference groups and arranged communication via telephone, digital platforms, e-mail and newsletters, thus maintaining the health and safety of all concerned.
- Finally, it is evident that the salience of dementia crisis care can be seen in work published since the AQUEDUCT programme commenced with studies confirming the importance of clarifying operational processes in TMCDs and identifying key components of intervention in care at home.[23,30–32] The AQUEDUCT programme, by developing quality standards of best practice for TMCDs, has contributed to and complemented this knowledge base.

Additional information

CRediT contribution statement

Martin Orrell (https://orcid.org/0000-0002-1169-3530): Conceptualisation (lead), Funding acquisition (lead), Investigation (lead), Methodology (lead), Project administration (lead), Resources (lead), Supervision (lead), Validation (lead), Writing – original draft (equal), Writing – editing and reviewing (equal).

Donna Maria Coleston (https://orcid.org/0000-0002-6381-8518): Investigation (lead), Methodology (lead), Project administration (equal), Supervision (equal), Writing – editing and reviewing (equal).

Linda O'Raw (https://orcid.org/0000-0001-5265-2885): Data curation (equal), Methodology (equal), Project administration (lead), Supervision (lead), Writing – editing and reviewing (equal).

Emma Broome (https://orcid.org/0000-0001-7733-0583): Investigation (equal), Methodology (equal), Writing – editing and reviewing (equal).

David Challis (https://orcid.org/0000-0002-6464-2286): Conceptualisation (lead), Funding acquisition (lead), Investigation (equal), Methodology (equal), Supervision (equal), Writing – original draft (lead), Writing – editing and reviewing (lead).

Tom Dening (https://orcid.org/0000-0003-3387-4241): Conceptualisation (equal), Funding acquisition (equal), Investigation (equal), Writing – editing and reviewing (equal).

Boliang Guo (https://orcid.org/0000-0002-1844-705X): Data curation (lead), Formal analysis (lead), Supervision (equal), Validation (equal), Writing – editing and reviewing (equal).

Juanita Hoe (https://orcid.org/0000-0003-4647-8950): Conceptualisation (equal), Funding acquisition (equal), Investigation (equal), Writing – editing and reviewing (equal).

Brynmor Lloyd-Evans (https://orcid.org/0000-0001-9866-788X): Conceptualisation (equal), Funding acquisition (equal), Investigation (equal), Writing – editing and reviewing (equal).

Esme Moniz-Cook (https://orcid.org/0000-0002-7232-4632): Conceptualisation (equal), Funding acquisition (equal), Investigation (equal), Writing – editing and reviewing (equal).

Magdalena Opazo Breton (https://orcid.org/0000-0002-1226-7541): Data curation (lead), Formal analysis (lead), Visualisation (lead), Writing – editing and reviewing (equal).

Fiona Poland (https://orcid.org/0000-0003-0003-6911): Conceptualisation (equal), Formal analysis (equal), Funding acquisition (equal), Investigation (equal), Methodology (equal), Supervision (equal), Validation (lead), Writing – editing and reviewing (equal).

David Prothero: Funding acquisition (equal), Writing – editing and reviewing (equal).

Marcus Redley (https://orcid.org/0000-0001-8866-7990): Data curation (equal), Formal analysis (equal), Writing – editing and reviewing (equal).

Miriam R Stanyon (https://orcid.org/0000-0003-4326-0286): Investigation (equal), Writing – editing and reviewing (equal).

Angela Worden (https://orcid.org/0000-0003-0585-1472): Writing – original draft (lead), Writing – editing and reviewing (lead).

Jennifer A Yates (https://orcid.org/0000-0001-9451-1175): Investigation (equal), Methodology (equal), Writing – editing and reviewing (equal).

Steve Morris: Conceptualisation (equal), Funding acquisition (equal).

Acknowledgements

It has been a long road to get this project completed and we are very grateful to all the participants and all the others involved and thank them for all their contributions and time. This project would not have been possible without the full and energetic support of the Teams Managing Crisis in Dementia and especially during the COVID pandemic and its aftermath which had a huge impact on the staff who already had a challenging workload and had the additional stress of other staff being off sick with COVID-19 or self-isolating due to being a contact. We also thank the local research offices of each of the Trusts involved who often helped us get the projects set up despite ongoing challenges to the clinical services. We would like to thank our PPI reference group which has undergone a number of changes over the years but has provided a valuable line of support, advice and commentary. We also thank all the members of our Programme Steering Committee: Dr Jonathan Waite; Dr Emma Barton; Professor Clare Goodman; Theresa Allen; and chaired by Prof Ken Laidlaw; and all the members of our Data Monitoring and Ethics Committee: Dr Jane Burgess and Mona Kanaan; chaired by Prof Jan Oyebode. Big thanks to Chrissy Bailey who has provided very kind, efficient and professional administrative support over the many years. Thanks to Robert Allen for his role as the Nottinghamshire Healthcare NHS Foundation Trust sponsor representative including his contribution to the Programme Management Group meetings and thanks to Natasha Jumbu and Daniel Simpkins for the setting up and oversight of the database. Lastly, thanks to the NIHR for funding this research programme continuing to believe in it despite the many challenges and especial thanks to our NIHR Programme Manager Saima Siddiqui for her ongoing advice, support and encouragement.

Patient data statement

This work uses data provided by patients and collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from people's patient records, to understand more about disease, develop new treatments, monitor safety and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it's important that there are safeguards to make sure that they are stored and used responsibly. Everyone should be able to find out about how patient data are used. #datasaveslives You can find out more about the background to this citation here: https://understandingpatientdata.org.uk/data-citation

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

Ethics approval for WP1 was granted by the West Midlands-Black Country Research Ethics Committee (ref:16/WM/0273) on 4 August 2016 for this study. Data collection began in October 2016 and was completed by the end of August 2018. Ethical approval for the Public Engagement Event in October 2016 was obtained from the University of Nottingham, School of Psychology Ethics Committee at Nottingham in September 2016. Ethical approval for a study of

coping styles and experience in PwD and their carers and how these impact on care management (Bosco *et al.* 2020) (reported in WP1) was obtained from East Midlands – Derby Research Ethics Committee (ref:18/EM/0023) on 27 March 2018. Ethical approval for WP2 was granted by the West Midlands–Coventry and Warwickshire Research Ethics Committee (ref:19/WM/0132) on 14 July 2019. Ethics approval for WP3 was obtained from the West Midlands – Coventry and Warwickshire Research Ethics Committee (ref: 21/WM/0004) on 9 March 2021 for this study.

Information governance statement

Nottinghamshire Healthcare NHS Foundation Trust is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, Nottinghamshire Healthcare NHS Foundation Trust is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here researchsponsor@nottshc.nhs.uk. Data are kept according to the NHS Code of confidentiality as well as GCPR and GCP guidelines. The AQUEDUCT team adhered to the SOPs issued by the sponsor trust. CI Prof. Martin Orrell acts as data custodian for data generated by the research.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/KGRQ1188.

Primary conflicts of interest: David Challis reports funding from the AQUEDUCT programme to support the current manuscript; Boliang Guo reports voluntary membership of Data Monitoring Committees and Trial Steering Committees outside the submitted work; Juanita Hoe reports book royalties (Cambridge University Press), an honorarium for associate editorial duties (Journal of Aging and Mental Health) and Travel costs to Chile for presentations from Universidad Andrés Bello; Brynmor Lloyd-Evans reports funding from the AQUEDUCT programme; Magdalena Opazo Breton reports funding from a grant from the Medical Research Council outside the submitted work and an NIHR Committee Member Development Scheme role at the NIHR Public Health Research Funding Committee; Mirium Stanyon reports funding from an NIHR grant and provision of study materials; Angela Worden reports funding from the AQUEDUCT programme to support the current manuscript.

Copyright and credit statement

Publications

Work package 1

Systematic review of the impact of teams managing crisis in people with dementia in older people and scoping survey of current practice in these teams in England
Streater A, Coleston-Shields DM, Yates J, Stanyon M, Orrell, M. A scoping review of crisis teams managing dementia in older people. *Clin Interv Aging* 2017;**12**:1589–603. https://doi.org/10.2147/CIA.S142341

Mapping current practice and identifying best practice for Teams Managing Crisis in Dementia
Stanyon M, Streater A, Coleston-Shields DM, Yates J, Challis D, Dening T, *et al.* Development of an evidence-based: protocol for a qualitative study. *JMIR Res Protoc* 2021;**10**:e14781. https://doi.org/10.2196/14781

Redley M, Poland F, Coleston-Shields DM, Stanyon M, Yates J, Streater A, *et al.* Practitioners' views on enabling people with dementia to remain in their homes during and after crisis. *J Appl Gerontol* 2022;**41:**2549–56. https://doi.org/10.1177/07334648221118557

Bosco A, Schneider J, Coleston-Shields DM, Orrell M. Narrative inquiry on case studies of crisis in dementia. *Qual Ageing Older Adults* 2020;**21**:181–91. https://doi.org/10.1108/QAOA-02-2020-0002

Yates JA, Stanyon MR, Redley M, Coleston-Shields DM. Conceptualising dementia crisis and preferences for resolution: a public perspective. *J Prim Care Community Health* 2020;**11**:1–7. https://doi.org/10.1177/2150132720925946

Bosco A, Schneider J, Di Lorito C, Broome E, Coleston-Shields DM, Orrell, M. Involving the person with dementia in crisis planning: focus groups with crisis intervention teams. *Int J Environ Res Public Health* 2020;**17**:5412. https://doi.org/10.3390/ijerph17155412

Bosco A, Schneider J, Coleston-Shields DM, Jawahar K, Higgs P, Orrell M. Agency in dementia care: systematic review and meta-ethnography. *Int Psychogeriatr* 2019;**31**:627–42. https://doi.org/10.1017/S1041610218001801

Bosco A, Schneider J, Coleston-Shields DM, Orrell M. Dementia care model: promoting personhood through co-production. *Arch Gerontol Geriatr* 2019;**81**:59–73. https://doi.org/10.1016/j.archger.2018.11.003

Bosco A, Schneider J, Coleston-Shields DM, Higgs P, Orrell M. The social construction of dementia: systematic review and metacognitive model of enculturation. *Maturitas* 2019;**120**:12–22. https://doi.org/10.1016/j.maturitas.2018.11.009

Work package 2

Protocol for work package 2

Broome E, Coleston-Shields DM, Dening T, Moniz-Cook E, Poland F, Stanyon M, *et al.* AQUEDUCT intervention for crisis team quality and effectiveness in dementia: protocol for a feasibility study. *JMIR Res Protoc* 2020;**9**:e18971. https://doi.org/10.2196/18971

Development and field testing of the Best Practice Tools

Yates J, Stanyon M, Challis D, Coleston-Shields DM, Dening T, Hoe J, *et al.* Developing a model of best practice for teams managing crisis in people with dementia: a consensus approach. *BMC Psychiatry* 2020;**20**:505. https://doi.org/10.1186/s12888-020-02899-0

Work package 3

Coleston-Shields DM, Challis D, Worden A, Broome E, Dening T, Boliang G, *et al.* Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT): a study protocol for a randomised controlled trial of a Resource Kit. *Trials* 2022;**23**:24. https://doi.org/10.1186/s13063-021-05995-y

Orrell M, O'Raw L, Coleston DM, Opazo Breton M, Guo B, Dening T, *et al*. Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT): a randomized controlled trial evaluating the impact of a best practice Resource Kit used by teams managing crisis in dementia. *Nat Commun* 2025;**16**:6414. https://doi.org/10.1038/s41467-025-61537-z

References

1. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. Alzheimer's Disease International. World Alzheimer Report 2015. In *The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends*. London: Alzheimer's Disease International; 2015. URL: www.alz.co.uk/research/WorldAlzheimerReport2015.pdf (accessed 27 October 2023).
2. Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera M, *et al*. *Dementia UK: Update*. London: Alzheimer's Society; 2014. URL: https://kclpure.kcl.ac.uk/portal/en/publications/dementia-uk-update (accessed 27 October 2023).
3. World Health Organization. *Dementia: A Public Health Priority*. Geneva: World Health Organization; 2012. URL: www.who.int/publications/i/item/dementia-a-public-health-priority (accessed 1 August 2019).
4. Alzheimer's Disease International. *Policy Brief for Heads of Government. The Global Impact of Dementia 2013–2050*. London: Alzheimer's Disease International; 2013. URL: www.alzint.org/u/2020/08/GlobalImpactDementia2013.pdf (accessed 6 March 2025).
5. Prince M, Prina M, Guerchet M. *World Alzheimer Report 2013 Journey of Caring. An Analysis of Long-Term Care for Dementia*. London: Alzheimer's Disease International; 2013. URL: www.alz.co.uk/research/WorldAlzheimerReport2013.pdf (accessed 21 November 2023).
6. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. *Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom 2019–2040. CPEC Working Paper 5*. London: London School of Economics and Political Science; 2019. URL: www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf (accessed 27 October 2023).
7. Department of Health. *The Prime Ministers Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015*. London: Department of Health; 2012. URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf (accessed 21 May 2021).
8. Department of Health. *Prime Minister's Challenge on Dementia 2020: Implementation Plan*. London: Department of Health; 2016. URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf (accessed 20 May 2021).
9. Department of Health. *Living Well with Dementia: A National Dementia Strategy*. London: TSO; 2009. URL: https://assets.publishing.service.gov.uk/media/5a7a15a7ed915d6eaf153a36/dh_094051.pdf (accessed 21 May 2021).
10. Department of Health. *Prime Minister's Challenge on Dementia 2020*. London: Department of Health; 2015. URL: https://assets.publishing.service.gov.uk/media/5a80d3ce40f0b62302695b8c/pm-dementia2020.pdf (accessed 31 October 2023).
11. Covinsky KE, Palmer RM, Fortinsky RH, Counsell SR, Stewart AL, Kresevic D, *et al*. Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: increased vulnerability with age. *J Am Geriatr Soc* 2003;**51**:451–8. https://doi.org/10.1046/j.1532-5415.2003.51152.x
12. Sampson EL, Leurent B, Blanchard MR, Jones L, King M. Survival of people with dementia after unplanned acute hospital admission: a prospective cohort study. *Int J Geriatr Psychiat* 2013;**28**:1015–22. https://doi.org/10.1002/gps.3919
13. National Audit Office. *Improving Services and Support for People with Dementia*. London: The Stationery Office; 2007. URL: www.nao.org.uk/report/improving -services-and-support-for-people-with-dementia/ (accessed 30 April 2020).
14. Shepherd H, Livingston G, Chan J, Sommerlad A. Hospitalisation rates and predictors in people with dementia: a systematic review and meta-analysis. *BMC Med* 2019;**17**:130. https://doi.org/10.1186/s12916-019-1369-7

15. Perlman CM, Law J, Luan H, Rios S, Seitz D, Stolee P. Geographic clustering of admissions to inpatient psychiatry among adults with cognitive disorders in Ontario, Canada: does distance to hospital matter? *Can J Psychiat* 2018;**63**:404–9. https://doi.org/10.1177/0706743717745870
16. Johnson S, Nolan F, Hoult J, White IR, Bebbington P, Sandor A, *et al*. Outcomes of crises before and after introduction of a crisis resolution team. *Br J Psychiatry* 2005;**187**:68–75. https://doi.org/10.1192/bjp.187.1.68
17. Johnson S, Nolan F, Pilling S, Sandor A, Hoult J, McKenzie N, *et al*. Randomised controlled trial of acute mental health care by a crisis resolution team: the north Islington crisis study. *BMJ* 2005;**331**:599. https://doi.org/10.1136/bmj.38519.678148.8F
18. Glover G, Arts G, Suresh BK. Crisis resolution/home treatment teams and psychiatric admission rates in England. *Br J Psychiatry* 2006;**189**:441–5. https://doi.org/10.1192/bjp.bp.105.020362
19. Jethwa K, Galappathie N, Hewson P. Effects of a crisis resolution and home treatment team on in-patient admissions. *Psychiatr Bull* 2007;**31**:170–2. https://doi.org/10.1192/pb.bp.106.010389
20. Tyrer P, Gordon F, Nourmand S, Lawrence M, Curran C, Southgate D, *et al*. Controlled comparison of two crisis resolution and home treatment teams. *Psychiatrist* 2010;**34**:50–4. https://doi.org/10.1192/pb.bp.108.023077
21. Wheeler C, Lloyd-Evans B, Churchard A, Fitzgerald C, Fullarton K, Mosse L, *et al*. Implementation of the Crisis Resolution Team model in adult mental health settings: a systematic review. *BMC Psychiatry* 2015;**15**:74. https://doi.org/10.1186/s12888-015-0441-x
22. Johnson S. Crisis resolution and home treatment teams: an evolving model. *Adv Psychiatr Treat* 2013;**19**:115–23. https://doi.org/10.1192/apt.bp.107.004192
23. Westera A, Fildes D, Grootemaat P, Gordon R. Rapid response teams to support dementia care in Australian aged care homes: review of the evidence. *Australas J Ageing* 2020;**39**:178–92. https://doi.org/10.1111/ajag.12745
24. Joint Commissioning Panel for Mental Health. *Guidance for Commissioners of Older People's Mental Health Services. 2013*. London: Joint Commissioning Panel for Mental Health; 2013. URL: www.slideshare.net/jcpmh/jcpmh-olderpeopleguide (accessed 21 May 2021).
25. Toot S, Hoe J, Ledgerd R, Burnell K, Devine M, Orrell M. Causes of crises and appropriate interventions: the views of people with dementia, carers and healthcare professionals. *Aging Ment Health* 2013;**17**:328–35. https://doi.org/10.1080/13607863.2012.732037
26. Orrell M, Hoe J, Charlesworth G, Russell I, Challis D, Moniz-Cook E, *et al*. Support at Home: Interventions to Enhance Life in Dementia (SHIELD) – evidence, development and evaluation of complex interventions. *Programme Grants Appl Res* 2017;**5**:1–184. https://doi.org/10.3310/pgfar05050
27. Dibben C, Saeed H, Stagias K, Khandaker GM, Rubinsztein JS. Crisis resolution and home treatment teams for older people with mental illness. *Psychiatric Bull* 2008;**32**:268–70. https://doi.org/10.1192/pb.bp.107.018218
28. Cooper C, Regan C, Tandy A, Johnson S, Livingston G. Acute mental health care for older people by crisis resolution teams in England. *Int J Geriatr Psychiatry* 2007;**22**:263–65. https://doi.org/10.1002/gps.1650
29. Toot S, Devine M, Orrell M. The effectiveness of crisis resolution/home treatment teams for older people with mental health problems: a systematic review and scoping exercise. *Int J Geriatr Psychiatry* 2011;**26**:1221–30. https://doi.org/10.1002/gps.2686
30. Rubinsztein J, Hatfield C, High L, Krishnan R, Arnaoutoglou N, Goulia P, *et al*. Efficacy of a dementia intensive support (DIS) service at preventing admissions to medical and psychiatric wards: qualitative and quantitative evaluation. *BJPsych Bull* 2020;**44**:261–65. https://doi.org/10.1192/bjb.2020.24
31. Hopkinson J, King A, Young L, McEwan K, Elliott F, Hydon K, *et al*. Crisis management for people with dementia at home: mixed-methods case study research to identify critical factors for successful home treatment. *Health Soc Care Community* 2021;**29**:1072–82.

32. Hopkinson JB, King A, Mullins J, Young L, Kumar S, Hydon K, *et al*. What happens before, during and after crisis for someone with dementia living at home: a systematic review. *Dementia (London)* 2021;**20**:570–612. https://doi.org/10.1177/1471301220901634

33. Coleston-Shields DM, Challis D, Worden A, Broome E, Dening T, Guo B, *et al*. Achieving Quality an Effectiveness in Dementia Using Crisis Teams (AQUEDUCT): a study protocol for a randomised controlled trial of a Resource Kit. *Trials* 2022;**23**:54. https://doi.org/10.1186/s13063-021-05995-y

34. Torrey WC, Bond GR, McHugo GJ, Swain K. Evidence-based practice implementation in community mental health settings: the relative importance of key domains of implementation activity. *Adm Policy Ment Health* 2012;**39**:353–64. https://doi.org/10.1007/s10488-011-0357-9

35. Lloyd-Evans B, Christoforou M, Osborn D, Ambler G, Marston L, Lamb D, *et al*. Crisis resolution teams for people experiencing mental health crises: the CORE mixed-methods research programme including two RCTs. *Programme Grants Appl Res* 2019;**7**:1–102. https://doi.org/10.3310/pgfar07010

36. Doncaster E, McGeorge M, Orrell M. Developing and implementing quality standards for memory services: the Memory Services National Accreditation Programme (MSNAP). *Aging Ment Health* 2011;**15**:23–33. https://doi.org/10.1080/13607863.2010.519322

37. Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci* 2012;**7**:37.

38. Critical Appraisal Skills Programme (CASP). *CASP Checklists CASP*; 2016. URL: www.casp-uk.net/#!checklists/cb36 (accessed 30 October 2023).

39. Streater A, Coleston-Shields DM, Yates J, Stanyon M, Orrell M. A scoping review of crisis teams managing dementia in older people. *Clin Interv Aging* 2017;**12**:1589–603. https://doi.org/10.2147/CIA.S142341

40. Verbeek H, Worden A, Wilberforce M, Brand C, Tucker S, Abendstern M, Challis D. Community mental health teams for older people in England: variations in ways of working. *Int J Geriatr Psychiatry* 2018;**33**:475–81. https://doi.org/10.1002/gps.4775

41. Wilberforce M, Tucker S, Abendstern M, Brand C, Giebel CM, Challis D. Membership and management: structures of inter-professional working in community mental health teams for older people in England. *Int Psychogeriatr* 2013;**25**:1485–92. https://doi.org/10.1017/S104161021300077X

42. Stanyon M, Streater A, Coleston-Shields DM, Yates J, Challis D, Dening T, *et al*. Development of an evidence-based best practice model for teams managing crisis in dementia: protocol for a qualitative study. *JMIR Res Protoc* 2021;**10**:e14781. https://doi.org/10.2196/14781

43. Yates JA, Stanyon MR, Redley M, Coleston-Shields DM. Conceptualising dementia crisis and preferences for resolution: a public perspective. *J Prim Care Community Health* 2020;**11**:1–7. https://doi.org/10.1177/2150132720925946

44. Redley M, Poland F, Coleston-Shields DM, Stanyon M, Yates J, Streater A, Orrell M. Practitioners' views on enabling people with dementia to remain in their homes during and after crisis. *J Appl Gerontol* 2022;**41**:2549–56. https://doi.org/10.1177/07334648221118557

45. Bosco A, Schneider J, Di Lorito C, Broome E, Coleston-Shields DM, Orrell M. Involving the person with dementia in crisis planning: focus groups with crisis intervention teams. *Int J Environ Res Public Health* 2020;**17**:5412. https://doi.org/10.3390/ijerph17155412

46. Bosco A, Schneider J, Coleston-Shields DM, Orrell M. Narrative inquiry on case studies of crisis in dementia. *Qual Ageing Older Adults* 2020;**21**:181–91.

47. Bosco A, Schneider J, Coleston-Shields DM, Jawahar K, Higgs P, Orrell M. Agency in dementia care: systematic review and meta-ethnography. *Int Psychogeriatr* 2019;**31**:627–42. https://doi.org/10.1017/S1041610218001801

48. Bosco A, Schneider J, Coleston-Shields DM, Orrell M. Dementia care model: promoting personhood through co-production. *Arch Gerontol Geriatr* 2019;**81**:59–73. https://doi.org/10.1016/j.archger.2018.11.003

49. Bosco A, Schneider J, Coleston-Shields DM, Higgs P, Orrell M. The social construction of dementia: systematic review and metacognitive model of enculturation. *Maturitas* 2019;**120**:12–22. https://doi.org/10.1016/j.maturitas.2018.11.009

50. Yates J, Stanyon M, Challis D, Coleston-Shields DM, Dening T, Hoe J, *et al*. Developing a model of best practice for teams managing crisis in people with dementia: a consensus approach. *BMC Psychiatry* 2020;**20**:505. https://doi.org/10.1186/s12888-020-02899-0

51. Hoe J, Ledgerd R, Toot S, Orrell M. Crisis and Assessment of Need in Dementia: Development of a Home Treatment Package. In Hoe J, Orrell M, editors. *CANE: Camberwell Assessment of Need for the Elderly*. 2nd edn. London: Cambridge University Press; Royal College of Psychiatrists; 2021. pp. 62–76. https://doi.org/10.1017/9781911623373

52. Slade M, Powell R, Rosen A, Strathdee G. Threshold Assessment Grid (TAG): the development of a valid and brief scale to assess the severity of mental illness. *Soc Psychiatry Psychiatr Epidemiol* 2000;**35**:78–85. https://doi.org/10.1007/s001270050011

53. Orrell M, Hancock G. *Needs Assessment in Older People: The Camberwell Assessment of Need for the Elderly*. London: Gaskell; 2004.

54. Broome EE, Coleston-Shields DM, Dening T, Moniz-Cook E, Poland F, Stanyon M, Orrell M. AQUEDUCT intervention for crisis team quality and effectiveness in dementia: protocol for a feasibility study. *JMIR Res Protoc* 2020;**9**:e18971.

55. Mulhern B, Rowen D, Brazier J, Smith S, Romeo R, Tait R, *et al*. Development of DEMQOL-U and DEMQOL-PROXY-U: generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health Technol Assess* 2013;**17**:v–xv, 1.

56. Attkisson CC, Zwick R. The client satisfaction questionnaire. Psychometric properties and correlations with service utilization and psychotherapy outcomes. *Eval Program Plann* 1982;**5**:233–7. https://doi.org/10.1016/0149-7189(82)90074-X

57. Attkisson C, Greenfield T. The UCSF Client Satisfaction Scales: The Client Satisfaction Questionnaire-8. In Maruish ME, editor. *The Use of Psychological Testing for Treatment Planning and Outcomes Assessment*. 3rd edn. Mahwah, NJ: Lawrence Erlbaum Associates; 2004. pp. 799–811.

58. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology* 1994;**44**:2308–14. https://doi.org/10.1212/wnl.44.12.2308

59. Bucks RS, Ashworth DL, Wilcock GK, Siegfried K. Assessment of activities of daily living in dementia: development of the Bristol Activities of Daily Living Scale. *Age Ageing* 1996;**25**:113–20. https://doi.org/10.1093/ageing/25.2.113

60. Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, *et al*. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res* 2011;**20**:1727–36. https://doi.org/10.1007/s11136-011-9903-x

61. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67**:361–70. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

62. Beecham J, Knapp M. Costing Psychiatric Interventions. In Thornicroft G, Brewin C, Wing J, editors. *Measuring Mental Health Needs*. Oxford: Oxford University Press; 1992. pp. 163–83.

63. Janssen MF, Pickard AS, Golicki D, Gudex C, Niewada M, Scalone L, *et al*. Measurement properties of the EQ-5D-5 L compared to the EQ-5D-3L across eight patient groups: a multi-country study. *Qual Life Res* 2013;**22**:1717–27. https://doi.org/10.1007/s11136-012-0322-4

64. Goldberg D, Williams P. *A User's Guide to the General Health Questionnaire*. Windsor: NFER-Nelson; 1988.

65. Bond FW, Lloyd J, Guenole N. The work-related acceptance and action questionnaire (WAAQ): initial psychometric findings and their implications for measuring psychological flexibility in specific contexts. *J Occup Organ Psychol* 2013;**86**:331–47. https://doi.org/10.1111/joop.12001

66. Schaufeli WB, Salanova M, Gonzalez-Roma V, Bakker AB. The measurement of engagement and burnout: a confirmatory factor analytic approach. *J Happiness Stud* 2002;**3**:71–92. https://doi.org/10.1023/A:1015630930326

67. Schaufeli WB, Bakker AB. *UWES: Utrecht Work Engagement Scale: Preliminary Manual*. Utrecht: Occupational Health Psychology Unit, Utrecht University; 2004. URL: www.wilmarschaufeli.nl/publications/Schaufeli/Test%20Manuals/Test_manual_UWES_English.pdf (accessed 8 April 2021).

68. Knapp M, Beecham J. Reduced list costings: examination of an informed short cut in mental health research. *Health Econ* 1993;**2**:313–22. https://doi.org/10.1002/hec.4730020404

69. House of Commons. *Mental Capacity Act 2005. Chapter 9*. London: House of Commons; 2005. URL: www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf (accessed 21 May 2021).

70. Giebel CM, Zubair M, Jolley D, Bhui KS, Purandare N, Worden A, Challis D. South Asian older adults with memory impairment: improving assessment and access to dementia care. *Int J Geriatr Psychiatry* 2015;**30**:345–56. https://doi.org/10.1002/gps.4242

71. Nielsen TR, Vogel A, Phung TKT, Gade A, Waldemar G. Over-and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *Int J Geriatr Psychiatr* 2011;**26**:1128–35. https://doi.org/10.1002/gps.2650

72. Cooper C, Spiers N, Livingston G, Jenkins R, Meltzer H, Brugha T, *et al*. Ethnic inequalities in the use of health services for common mental disorders in England. *Soc Psychiatr Psychiatr Epidemiol* 2013;**48**:685–92. https://doi.org/10.1007/s00127-012-0565-y

73. Mills CW. *The Sociological Imagination*. Oxford: Oxford University Press; 1959.

74. Parsons T. *The Social System*. Glencoe, IL: The Free Press; 1951.

Appendix 1 Achieving Quality and Effectiveness in Dementia Using Crisis Teams 50 Best Practice Tool statements

The crisis service

Service purpose

1. The service provides a timely and intensive level of support, working with PwD and carers/families to reduce risk, including inappropriate hospital admission.
2. The service communicates a clear, flexible definition of crisis and its own aims to other services, PwD and their carers/families.
3. The service has a definition of when a crisis is resolved to a point where intensive support from the service is no longer required.
4. Service operational policies outlining the purpose and eligibility criteria are accessible by service staff.

Service values

5. The service is person-centred and care is planned to meet the needs of the person with dementia and their carers/families. Service staff are caring, approachable and professional, and treat people with empathy and understanding.
6. Service staff work to build a rapport with the person with dementia and their carers/families to ensure they are involved in decision-making.
7. All service staff feel confident to contribute to decision-making in an open and supported process.
8. Service staff explain the care to be delivered to the person with dementia and their carers/families at the start and throughout their involvement. Information is timely, accurate and relevant to the needs and wishes of the person with dementia and their carers/families.
9. PwD and their carers/families have the opportunity to speak with service staff separately and together; they are not rushed during face-to-face contact.
10. Staff are aware of cultural and minority group issues that may affect PwD and their carers/families, and know how to enhance their approach to support them.

Service procedures

11. PwD and their carers/families have a named worker to support consistency of staff working with them.
12. The service has a system for prioritising risk and assessing required levels of support for PwD.
13. Each service has a senior qualified 'duty worker' (shift co-ordinator) who allocates work each day and who oversees all calls about patients.
14. Service staff are able to make day-to-day decisions autonomously, in keeping with their levels of experience and in line with their professional competencies where relevant.
15. Service staff have the means to communicate effectively using established documentation that is organised to avoid duplication and is up to date.
16. A daily handover takes place to communicate information about PwD between service staff.
17. The service uses a centralised diary system led by the shift co-ordinator to know where service staff are and availability for new referrals.
18. Case load, mix and flow are measured and used to assist the organisation and planning of the service, with the staff working rota allowing for flexibility regarding staff absence and working patterns.

Service advancement

19. Service satisfaction information is collected from PwD and their carers/families using an appropriate measure. The whole service is aware of how it is evaluated in terms of satisfaction and performance, and how these results are acted upon. The service has a process to manage all feedback.
20. Service staff are informed of and involved with quality improvement initiatives, affording the flexibility to think creatively.
21. All service staff have regular clinical supervision that is separate from managerial supervision and is in accordance with professional and NHS Trust standards.
22. All service staff have regular opportunities for continuing professional development to support clinical and non-clinical skills related to the range of crises that affect older PwD.

Rapid assessment and intervention

Accessibility

23. The service operates outside normal working hours and signposts to other community-based support when the service is closed outside of these hours.
24. The service communicates its referral process to PwD, their carers/families, and other relevant organisations.
25. Following referral, the service makes initial contact on the same day and the person with dementia is seen within the next working day for appropriate crisis referrals.
26. At a minimum, the service is accessible by telephone and if an answerphone or voicemail system is used, calls are returned and responded to according to risk.
27. Service staff can see the person with dementia at their usual place of residence.

Assessment

28. Service staff use a comprehensive assessment that includes standardised measures where appropriate, risk assessments, and the views of the person with dementia and their carers/families to inform care planning.
29. The purpose and outcomes of assessments used by service staff are clearly explained to the person with dementia and their carers/families.

Intervention

30. Service staff take a holistic approach, considering physical health, mental health and social needs.
31. Service staff provide information and education relevant to the specific dementia diagnosis, tailored to individual needs, to help carers/families support the person with dementia at home.
32. Service staff provide interventions to improve QoL for the person with dementia and their carers/families by providing practical assistance and problem-solving techniques.
33. Service staff review medication and monitor its effectiveness. Service staff have access to prescription of medication and are able to dispense it.
34. Service staff engage in interventions to prevent further crisis; these may include assessment, advice and support for other professionals.
35. Service staff signpost and facilitate referrals to other services including respite care.
36. PwD and their carers/families are involved in the decision to discharge, are adequately prepared for discharge, and are aware how to re-access the service if necessary. Verbal and written information is offered which includes information about onward services organised by the crisis service.

Service resources

Staffing

37. The service takes a multidisciplinary approach and has awareness of, and immediate access to, other relevant professional disciplines.
38. The clinical lead for the service has specialist knowledge and skills relevant to working with older people and with dementia.
39. Service staff have specialist dementia knowledge and skills through training and/or appropriate clinical experience.
40. The service has administrative support that is sufficient to meet current demand.
41. The service has an operational plan which includes staff mix and bandings, and roles and responsibilities.
42. Service staff understand all relevant legislation.

Joint working

43. The service is embedded within established pathways of care and policies exist for working with all other relevant agencies, to include social care, emergency services, charities, and the voluntary sector. Other agencies and services have an accurate perception of the crisis service and its remit.
44. Agreements are in place to support cross-boundary working across geographical and commissioning areas, for example, with neighbouring health services and local authorities.
45. The service liaises with the person with dementia's general practitioner (GP). The service is explicit with GPs about what timely information is required in a referral, and what physical health checks should be undertaken prior to referral. The service includes GPs in decision-making where relevant and through correspondence.
46. The service has good communication with other services involved in the care of the person with dementia and their carers/families to avoid unnecessary duplication of assessments.
47. Joint visits between service staff and professionals from other agencies take place when necessary.
48. Service staff and professionals from other services attend each other's meetings when necessary, and appropriate escalation procedures are established and shared when required for complex cases.

Team base

49. The service has access to appropriate space to facilitate MDT meetings, and for staff to complete paperwork and conduct telephone calls of a confidential and/or sensitive nature.
50. There is provision of Information Technology resources and associated IT support appropriate to the needs of the service. This includes access to computer systems, including electronic notes, to enable working remotely from various location.

Appendix 2 Achieving Quality and Effectiveness in Dementia Using Crisis Teams trial results

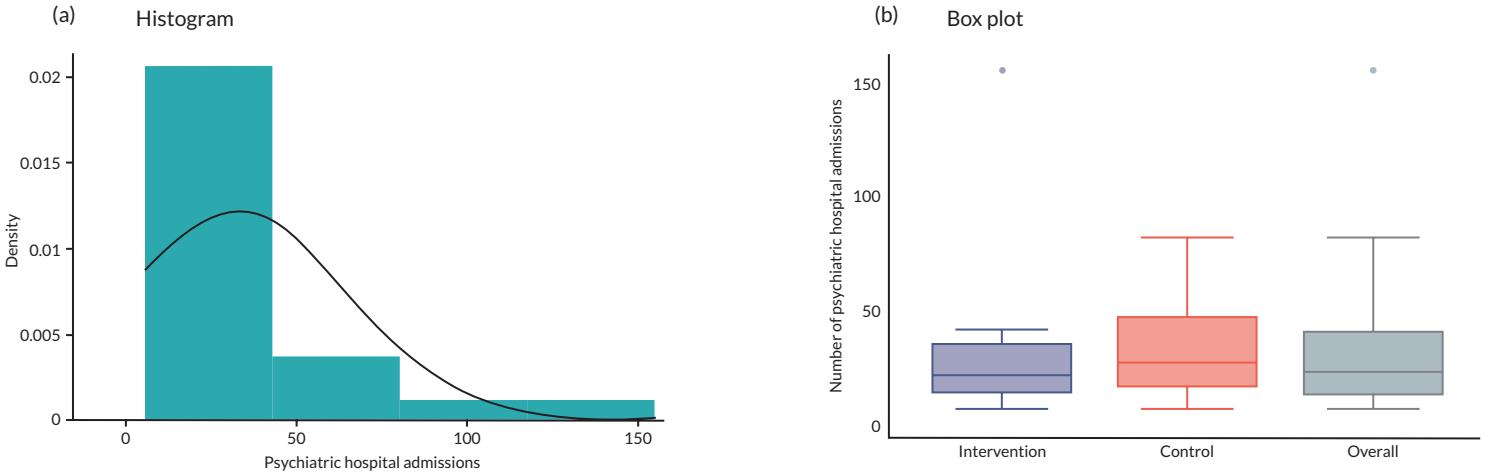
In this appendix, we provide a summary of key findings from the AQUEDUCT trial. The information is organised by primary and secondary outcomes.

Further trial results can be viewed in the below reference, in keeping with the NIHR Embargo Policy:

Orrell M, O'Raw L, Coleston DM, Opazo Breton M, Guo B, Dening T, *et al*. Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT): a randomised controlled trial evaluating the impact of a best practice Resource Kit used by teams managing crisis in dementia. *Nat Commun* 2025;**16**:6414. https://doi.org/10.1038/s41467-025-61537-z

Primary outcome

The primary outcome was admissions to psychiatric hospitals in TMCD catchment areas in the 6-month period before and after the intervention, standardised by respective parliamentary constituency-level population with dementia. The distribution is shown in *Figure 10* and descriptive statistics in *Table 1*.



Mean	Median (Q1, Q3)	Variance
32.8	22.5 (13, 41)	1077.1

FIGURE 10 Distribution of the primary outcome: psychiatric hospital admissions at 6 months. Mean = 32.8; mean (Q_1, Q_3) = 22.5 (13, 41); variance = 1077.1.

TABLE 1 Descriptive statistics for the primary outcome by group at baseline and 6 months

	Intervention		Control	
	Baseline	6 months	Baseline	6 months
Primary outcome				
1. Psychiatric hospital admissions for PwD				
Mean (Standard deviation)	34 (27.4)	34.4 (43.7)	28.4 (22.6)	31.4 (22.2)
Median (Q_1, Q_3)	30 (11, 44)	21 (13, 35)	26.5 (7.5, 43)	26 (15.5, 47)
Total TMCD observations	11	10	12	12

The group comparisons are shown both for those cases with complete data and on an intention-to-treat basis, using multiple imputation controlling for area-level estimated dementia prevalence. *Tables 2* and *3* show estimated incidence rate ratios (IRRs) using a negative binomial model, complete-case and multiple imputation, respectively, 95% confidence interval (CI) and *p*-values for psychiatric hospital admissions for PwD to mental health beds in the geographical catchment area of the TMCD at 6 months by group, using constituency-level population with dementia as an offset variable.

A sensitivity analysis was conducted of these results to control for variations in pre-existing hospital admission rates. *Tables 4* and *5* show these analyses with estimated IRRs using a negative binomial model, complete-case and multiple imputation, 95% CI and *p*-values for psychiatric hospital admissions for PwD to mental health beds in the geographical catchment area of the TMCD at 6 months by group, using baseline psychiatric hospital admissions as an offset variable.

Reflecting the presence of outliers in the dependent variable, an additional sensitivity analysis was conducted excluding those with admission rates > 150. *Tables 6* and *7* show estimated IRRs using a negative binomial model, complete-case and multiple imputation, 95% CI and *p*-values for psychiatric hospital admissions for PwD to mental health beds in the geographical catchment area of the TMCD at 6 months by group, using constituency-level population with dementia as an offset variable and excluding outlier observations (psychiatric admission at 6 months > 150).

A summary of these primary outcome results is provided in *Figure 11*. It shows intention-to-treat, complete-case, sensitivity and outlier exclusion for psychiatric hospital admissions for PwD to mental health beds in the geographical catchment area of the TMCD at 6 months by group.

Primary outcome complete-case and sensitivity analysis between intervention and control can be seen in *Report Supplementary Material 2*.

Secondary outcomes

Two categories of secondary outcomes are compared, outcomes for PwD and their carers and outcomes for TMCD staff. For the former, comparisons were made of responses to the 12-item GHQ[64] and the 8-item CSQ.[56,57] *Table 8* and *Figure 12* show the distribution of these two indicators after 6 months' experience of TMCDs. These outcome measures were only recorded at 6 months for PwD.

The group difference at 6 months was tested using linear regression for GHQ-12 score and quantile regression for CSQ-8 scores in PwD and their carers, 95% CI and *p*-values and is shown in *Table 9*.

TABLE 2 Primary outcome results: complete cases

Group	IRR	*p*-value	95% CI	
Intervention (reference)				
Control	0.75	0.434	0.37	1.54
Total observations (*N*)				22

TABLE 3 Primary outcome results: intention to treat

Group	IRR	*p*-value	95% CI	
Intervention (reference)				
Control	0.74	0.397	0.37	1.48
Total observations (*N*)				23

Note
Computed using multiple imputation in Stata (20 imputations).

TABLE 4 Primary outcome sensitivity analysis: complete cases

Group	IRR	*p*-value	95% CI	
Intervention (reference)				
Control	1.20	0.367	0.81	1.79
Total observations (*n*)				22

TABLE 5 Primary outcome sensitivity analysis: intention to treat

Group	IRR	*p*-value	95% CI	
Intervention (reference)				
Control	1.18	0.435	0.78	1.77
Total observations (*N*)				23

Note
Computed using multiple imputation in Stata (20 imputations).

TABLE 6 Primary outcome extra sensitivity analysis: complete cases

Group	IRR	*p*-value	95% CI	
Intervention (reference)				
Control	1.26	0.459	0.68	2.35
Total observations (*N*)				21

TABLE 7 Primary outcome extra sensitivity analysis: intention to treat

Group	IRR	*p*-value	95% CI	
Intervention (reference)				
Control	0.74	0.476	0.32	1.72
Total observations (*N*)				23

Note
Computed using multiple imputation in Stata (20 imputations).

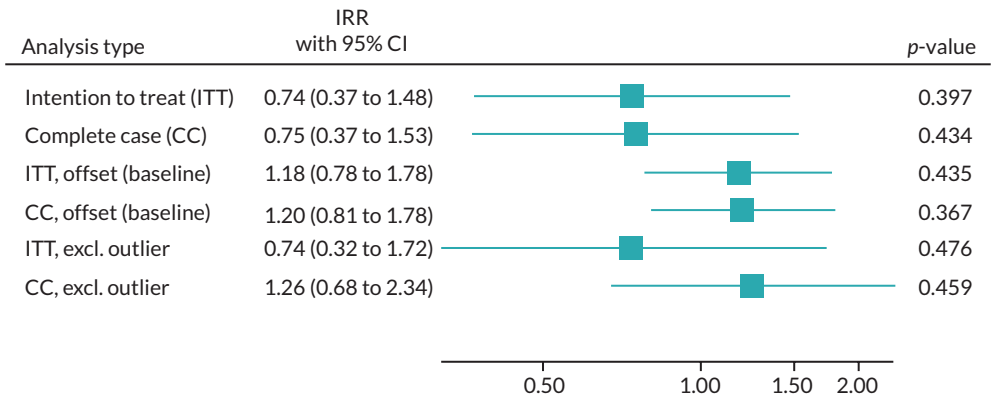


FIGURE 11 Summary of primary outcome results.

TABLE 8 Distribution of secondary outcome variables for PwD and their carers at 6 months

	Intervention		Control	
	Baseline	**6 months**	**Baseline**	**6 months**
CSQ-8 score				
TMCD staff, mean		30		28
(Q_1, Q_3)		(25, 32)		(24, 31)
(*n*)		(*n* = 35)		(*n* = 39)
GHQ-12 score				
TMCD staff, mean		15.1		16.86
(Standard deviation)		(5.8)		(7.5)
(*n*)		(*n* = 34)		(*n* = 38)

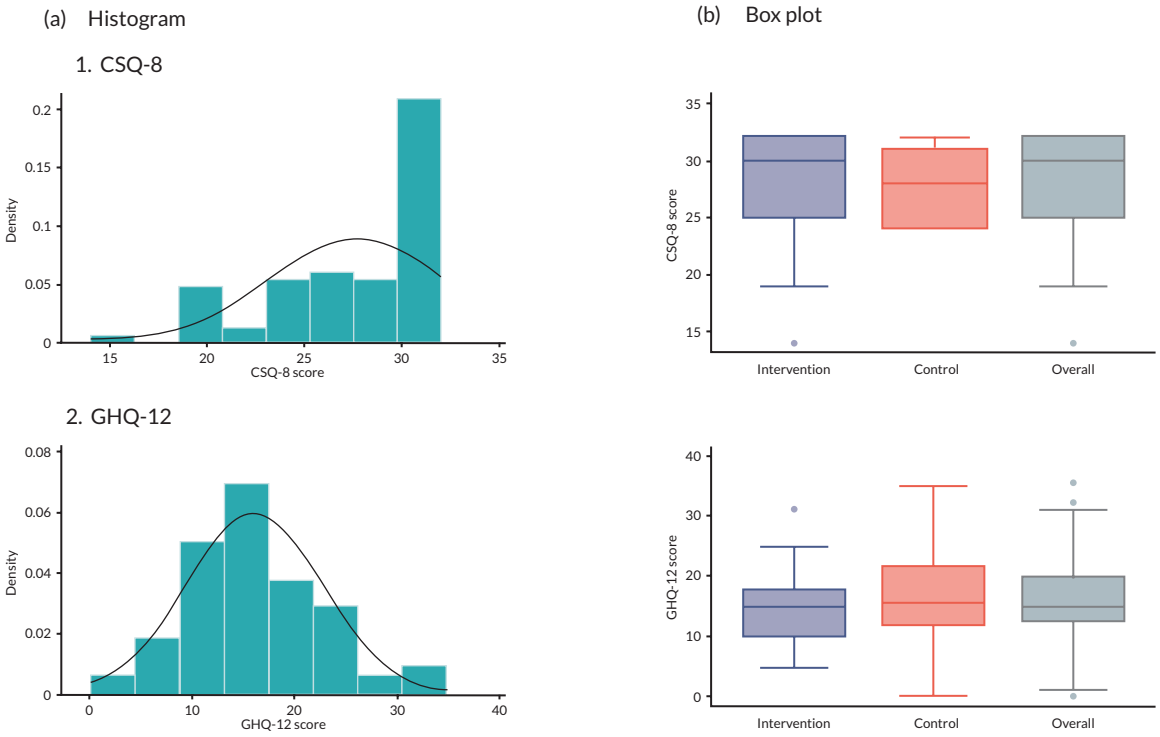


FIGURE 12 Distribution of secondary outcome variables for PwD and their carers at 6 months.

Secondary outcomes for TMCD practitioners were examined using three variables: the 12-item GHQ-12[64]; the WAAQ[65]; and the UWES.[66,67] *Table 10* and *Figure 13* show the distributions of these at baseline and 6 months, respectively.

Tables 11 and *12* show the estimated differences for TMCD practitioners' secondary outcomes at 6 months by group using mixed linear models adjusted by baseline scores. The first shows these analyses for complete cases (see *Table 11*) and the second (see *Table 12*) using multilevel multiple imputation.

TABLE 9 Secondary outcome analysis GHQ-12 and CSQ-8

Group	Coefficient	*p*-value	95% CI	
GHQ-12 score				
Control	1.74	0.276	−1.42	4.90
Total observations (*N*)				72
CSQ-8				
Intervention (reference)				
Control	−2.00	0.189	−5.01	1.01
Total observations (*N*)				74

Note
Missing items in scores and scales were imputed using pro-rating. Quantile regression for CSQ-8 at the median (P50 = 29). IRR is showed via coefficient > 1, favouring the intervention arm, while an IRR < 1 suggests a benefit of the control arm.

TABLE 10 Distribution of secondary outcome variables for TMCD practitioners at baseline and 6 months

	Intervention		Control	
	Baseline	6 months	Baseline	6 months
GHQ-12 score				
TMCD staff, mean	12.4	11.2	12.1	11.6
(Standard deviation)	(4.7)	(5.0)	(5.5)	(4.2)
(*n*)	(*n* = 114)	(*n* = 103)	(*n* = 122)	(*n* = 110)
WAAQ score				
TMCD staff, mean	36.4	36.2	37.0	36.1
(Standard deviation)	(5.5)	(6.1)	(6.5)	(6.7)
(*n*)	(*n* = 114)	(*n* = 104)	(*n* = 121)	(*n*)
UWES				
TMCD staff, mean	71.7	72.6	74.0	71.3
(Standard deviation)	(12.7)	(11.2)	(11.9)	(12.3)
(*n*)	(*n* = 116)	(*n* = 105)	(*n* = 110)	(*n* = 110)

Conclusions

Results of the main trial did not demonstrate any evidence of benefit from using the Resource Kit in reducing hospital admissions or improving well-being or functioning for PwD, their carers, or staff within teams. While the intervention was positively received, no measurable impact was observed on the specified outcomes, and this is unlikely to be due to the trial being underpowered. However, there are several constraining factors and successes from the trial which should be noted.

There are two broad constraining factors, the context in which the intervention took place and the COVID-19 pandemic. The trial was focused upon and took place during particularly difficult circumstances for PwD and their

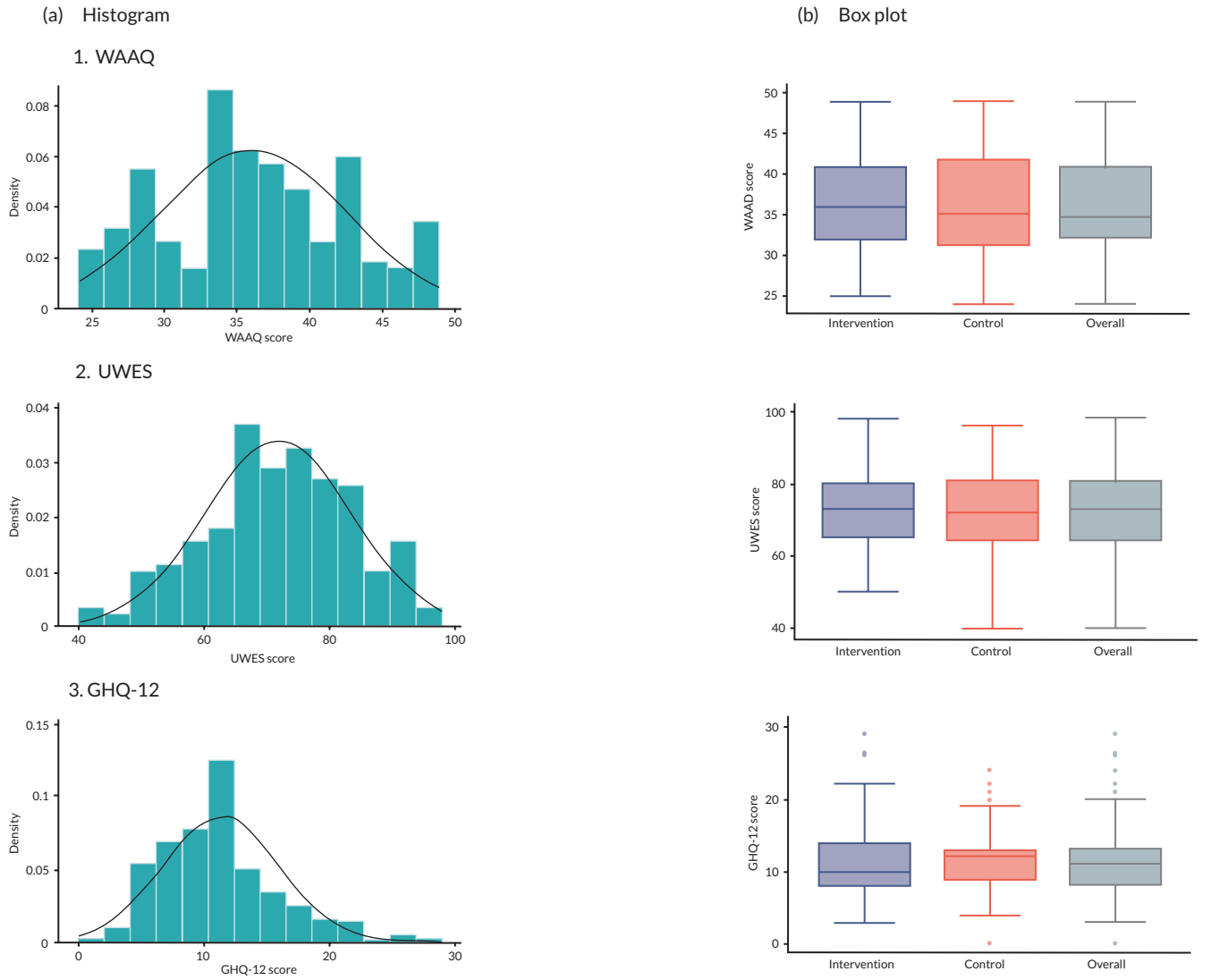


FIGURE 13 Distribution of secondary outcome variables for TMCD practitioners at 6 months.

TABLE 11 Secondary outcome results TMCD practitioners: complete cases

Group	Coefficient	*p*-value	95% CI	
GHQ-12				
Intervention (reference)				
Control	0.71	0.376	−0.86	2.29
Total observations (*N*)				211
WAAQ				
Intervention (reference)				
Control	0.17	0.885	−2.14	2.48
Total observations (*N*)				212
UWES				
Intervention (reference)				
Control	−2.29	0.338	−6.98	2.40
Total observations (*N*)				215

Note
Missing items in scores and scales were imputed using pro-rating. IRR is showed via coefficient > 1, favouring the intervention arm, while an IRR < 1 suggests a benefit of the control arm.

TABLE 12 Secondary outcome results TMCD practitioners: intention to treat

Group	Coefficient	*p*-value	95% CI	
GHQ-12 score				
Intervention (reference)				
Control	0.83	0.319	−0.80	2.46
Total observations (*N*)				238
WAAQ				
Intervention (reference)				
Control	0.06	0.962	−2.24	2.35
Total observations (*N*)				238
UWES				
Intervention (reference)				
Control	−2.56	0.316	−7.56	2.44
Total observations (*N*)				238

Note
Missing items in scores and scales were imputed using pro-rating. Missing scores and scales were imputed through multilevel multiple imputation using jomo R package [2] and calculating *p*-values (20 imputations). Post-estimation analyses were performed to check the conversion of parameters generated by Markov Chain Montecarlo (MCMC) modelling used in these imputations. IRR is showed via coefficient > 1, favouring the intervention arm, while an IRR < 1 suggests a benefit of the control arm.

carers, namely a crisis in dementia care. Crises are inherently the worst time to engage people and expect to gather information from them when they are under stress and distracted. This was perhaps even more difficult when in many cases they were receiving support from teams whose responsibility was short term and time limited and therefore would find it difficult to encourage people to provide follow-up information well after their involvement had ended. The presence of the COVID pandemic can only serve to have amplified these factors. The primary outcome measure was one which could be collected remotely in the context of the pandemic and its aftermath, but one which could only be impacted indirectly from the intervention whereby changes in team process could affect patient and carer experience and thereby hospital admissions. Particularly following the pandemic patterns of hospital admission, and the contribution of complementary and substitute services, were in a state of flux whereby the marginal contribution such as the AQUEDUCT intervention could be at best limited. Finally, the way in which the trial itself, a psychosocial intervention, had to be implemented may have attenuated any impact of the intervention. Specifically, in order to recruit teams and gain their consent there had to be discussion about ways of working and that the intervention was a quality improvement initiative. As such it is possible that control group teams had acquired a heightened awareness of the issues and thereby shaped and improved their practice.

The study also demonstrated certain strengths and lessons for the future. First, the Best Practice Resource Kit, particularly the BPT, provides a quality improvement resource which could be used for team development and evaluation and the harmonisation of ways of working. Second, the approach used to successfully complete running a trial during and just after a pandemic indicated ways in which routine data and remote means of data collection can be employed with some degree of economy and efficiency in research.

Appendix 3 Qualitative data summary

What can be learnt about the lived experience of engaging with the Resource Kit from the interview data

Preface

Within the AQUEDUCT programme, there has been a small but significant element of qualitative research. This aimed to understand the lives of people living with dementia and how those supporting them, both family members and supporting practitioners in TMCDs, understand their responsibilities and efforts. It indicates that services operate to a variety of models and that there was no clear shared definition of a crisis in dementia care.[39,44] Carers particularly valued supportive interventions and crisis management that went beyond addressing the immediate pressure for hospital admission towards preventive goals, such as improved coping strategies.[43] Effective crisis intervention appeared to require accessible, expert services providing practical and emotional support, co-ordination with other services, and a person-centred approach that involves family members. The data from all these studies contributed not only to the development of standards for the BPT but also towards its evaluation and, the collection and analysis of qualitative data reported below.

Introduction

A small but diverse sample as shown in *Table 13* provided an illustrative rather than an exhaustive account of what it is like to care for a family member living with dementia and to experience using TMCDs informed by the AQUEDUCT Resource Kit. The final version of the Resource Kit had two components: a BPT to measure practice covering three areas: the crisis service, rapid assessment and intervention, and service resources and materials providing administrative support and pathways of care and policies to link to other agencies and services. This study provides evidence both on the experiential context and reasons for carers evaluating these in the way they did.

The interviews demonstrated how differences in people's circumstances, their physical and mental health, proximity of supportive relatives, the availability to them of community services, their financial situation, their values and, importantly individual resilience in the face of adversity, could differ greatly. Our data therefore provide a well-developed resource for evaluating the experiences of family carers who, in response to a crisis, received support from TMCDs with access to the AQUEDUCT Resource Kit. The respondents, family carers supporting a spouse or parent living with dementia, give accounts of 'personal troubles'[73] which emerge from the practical and emotional demands of caring framed within the context of receiving support from human services. The broader spectrum of service support reported here included: GP surgeries, NHS memory clinics, NHS inpatient care for physical and mental health conditions, adult social care, and providers of residential care, as well as the focus of the AQUEDUCT trial, NHS TMCDs. These teams, along with the other human services providing health and social care support for persons with

TABLE 13 Qualitative interview respondent characteristics

Code	Carer caring for	Cared for person's current residence
SA-77–20	Wife caring for husband	In general hospital awaiting discharge to community residential home
LY-RI-012	Husband caring for wife	In own home
HB-78–20	Husband caring for wife	Resident in nursing home considered too far away for regular visits
CN-20–79	Wife caring for husband	In own home
01–01	Wife caring for husband	In own home
01–02	Daughter caring for mother	Mother living alone in own home
RW-20–78	Male caring for long-term female partner	In own home

dementia, aimed to help people remain in their own homes for longer, despite encountering the challenges of dementia-related changes in their everyday lives. The aim of supporting people to remain for longer at home has been designed to address a long-standing social problem, namely reducing the costs of in patient admissions.[9,73] More specifically, TMCDs, when responding to crises, provide intensive short-term support to enable family carers to continue providing care in a person's own home.

Findings

The data reveal how, when relating to community services, many respondents struggled to differentiate and identify the roles of Memory Clinics, TMCDs, and, in some instances, whether a practitioner worked in adult social care or a CMHT. Instead, respondents spoke more broadly of gaining help through visits to GP surgeries and inpatient services, but often without distinguishing between general and psychiatric hospitals, and when referring to specific practitioners, used their first names and the task they had undertaken with them. Even when pressed to be more specific, respondents continued to speak in these terms, struggling to name a practitioner's title, professional background, and the service where they worked. The terms in which these respondents framed their references to community services, rather than referring to specific services delivered by attending at specific sites (a hospital or surgery), underlined how respondents have a specifically lay understanding of who may have been supporting them: 'Jane', 'the consultant' who 'arranged a brain scan'.[74] In keeping with this lay perspective, when asked about how and when the TMCD become involved, respondents talked in similarly vague language. The only exception to this was one respondent who specifically reported that the TMCD were involved when her husband was discharged following detention under the *Mental Health Act* (MHA). Detention under the MHA cannot be taken as a definitive predictive marker of TMCD involvement, as another respondent was less than sure it was the TMCD who were involved when his wife returned home following detention in the local psychiatric hospital. What respondents were able to report and describe with greater certainty were those interventions that enabled the person in their care to remain at home. These interventions were: (1) prescribing the medication, 'pills' in respondents' language, that they experienced as having reduced a person troublesome behaviour. Only one respondent was able to name the prescribed medication, but not the symptoms it addressed; and (2) the reassurance that came with being provided with emergency telephone numbers, so that should the situation deteriorate, a member of the care team would call round. Carers expressed their appreciation of practitioners' visits, described as occasions where medication was reviewed, especially identifying and helping manage unwelcome side effects, patients having blood and urine samples taken, and the carer's ability to cope was checked.[44] When specifically asked if the TMCD had offered guidance on the practical aspects of providing care, all respondents answered in the negative. What practical advice they reported receiving (such as going along with, rather than challenging a person's delusions, and removing the knives from the kitchen) came from other services. Carers were, in the main, keen to keep the person they cared for at home, referring to how unhappy the person had been when in a residential service (a temporary expedient when the principal carer, a daughter, had COVID-19) or when in hospital.

When asked to reflect on what it was like providing care, respondents mainly acknowledged that it was demanding but saw themselves as 'able to cope', at least in the short term. Coping with and caring for a person with dementia, was seen as becoming do-able once any challenging behaviours were managed with medication. Some respondents reported that they had previously, cared for a parent or parent in-law with the condition. Carers did not see it as easy for them to care for a spouse or parent, neither for the carer, nor for the person needing caring. Carers were 'managing' and 'coping', and the person being cared for was seen as 'unhappy' or 'struggling'. What carers described as being unable to cope with and when they therefore came to accept a decision that a person could not remain at or return home following an inpatient admission, was when that person had become incontinent and/or had lost mobility. Taking the decision that a person should move into residential care came with troubles of its own, namely in finding a suitable care home within reasonable travelling distance. None of the respondents where a person was in residential care or where a move to a residential home was planned had found such a service as removing those troubles from the carer. In sum, the move to residential care did not bring an end to a person's caring responsibilities, it merely shifted those responsibilities into a different domain. It was a feature of respondents' accounts of their troubles, that these persistent troubles included troubles with care services. With respect to TMCDs, these troubles occurred in that aspect of the service that all carers valued, chatting. One respondent thought the practitioner seeing her, on account of her husband's violent outburst, was putting words in her mouth to justify the practitioner putting her husband in a residential service. Following a complaint this practitioner was no longer visiting the person concerned. Another respondent reported that despite the support he had received, he was contemplating walking out of the home he shared with his partner as he was no longer able

to cope with the demands of caring. He, and his partner's children, believed their mother should not be in a residential service; however, it was the view of the visiting practitioner that this woman could only be placed in a residential service as she wished to move and had the capacity to make such a decision. Another example of a service featuring in a respondent's talk of their troubles concerned their receiving poor advice. When her husband was admitted to hospital for a chest infection, this respondent reported being told she must challenge and correct her husband's deluded thoughts. This was a practice, which, following her husband's discharge, led to several violent outbursts at home and detention under the MHA. It was while detained on a psychiatric ward, that this respondent was told she should go along with her husband's delusions and she related how, to keep the peace with them, she had become a quick-witted and accomplished liar. Other accounts of trouble with human services (but not TMCDs), involved telephones, including emergency numbers not being answered, and domiciliary care where a person was not being washed and dressed. The TMCDs Resource Kit-supported service was therefore at times not seen to address the range of troubles carers encountered, particularly those outside their remit, nor clearly seen as offering a distinctive service with distinctive or comprehensive longer-term relief to carers' troubles.

Conclusions: Teams Managing Crisis in Dementia and efforts to reduce inpatient admissions

Carers in receipt of a service from a TMCD may have very little idea where different community services begin and end, may be unaware when they are receiving support from TMCDs; the most impactful interventions from a carer's perspective is medication for managing challenging behaviour, and knowing that there is a particular service they can telephone in a crisis. Although carers may be committed to supporting a spouse or family member at home, this is experienced as a demanding set of responsibilities, and becomes less possible for carers when dementia is coupled to incontinence and physical dependence. Involvement from a TMCD may sustain a person at home, but still places significant demands on the carer, demands that continue once the TMCD has withdrawn. This inescapable fact, along with carers' inability to distinguish between the broader range of community services beyond recalling the changing identities and frequencies at which practitioners visit, means these respondents are poorly placed to evaluate specific services. What respondents can do is describe how specific service-providing individuals have addressed or added to the troubles they face. This is not to say that TMCDs along with other services are not making a useful contribution towards addressing the social problem – reducing the cost of inpatient admissions – but at the individual-level, their successes commonly mean one frail older person is being sustained as the carer of another frail person. This reveals a range of issues which may be relevant in scoping expectations of the impact and sustainability of TMCD interventions, or of the degree of overlap between carer concerns and perceptions of their ability to mitigate their situation. The pressures carers were experiencing when recognised as being 'in crisis' impinged on their lives – but those pressures experienced as important to them in managing could not necessarily be picked up by the TMCDs and remained unaddressed beyond the time of the crisis intervention. These constraints upon what the services provided may also have limited the sustainability of the effects of the intervention on admission to longer-term care of the person with dementia.

EME
HSDR
HTA
PGfAR
PHR

Part of the NIHR Journals Library
www.journalslibrary.nihr.ac.uk

Published by the NIHR Journals Library