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# E-mental health interventions for informal caregivers

*Development with a focus on implementation*

CHELSEA COUMOUNDOUROS



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### Abstract

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The four studies within this thesis contributed to the identification of key factors to be considered when designing and implementing e-mental health (e-MH) interventions for informal caregivers.

Study I was a mixed-methods systematic review to examine factors related to the effectiveness and implementation of e-MH interventions for informal caregivers of adults with chronic diseases. A thematic synthesis with deductive coding using the Consolidated Framework for Implementation Research (CFIR) identified 152 implementation barriers and facilitators. Barriers and facilitators primarily related to intervention and user characteristics. Exploration of barriers and facilitators related to the implementation setting or wider context was limited.

Study II was a cross-sectional survey to examine contextual factors related to informal caregivers (e.g. intervention preferences, caregiving situation) to inform the development of a cognitive behavioural therapy (CBT) self-help intervention to support the mental health of informal caregivers of people living with chronic kidney disease (CKD). The majority of participants were caring for a male spouse or partner living with CKD, and over half were experiencing at least mild depressive symptoms. Informal caregivers reported preferences for CBT self-help interventions to be delivered via the internet, a workbook, or individually in-person, with additional support provided in-person or via email by a trained professional at a non-profit organisation.

Study III was a qualitative study to explore the perspectives of professionals (i.e. potential implementers) anticipated to play key roles in the future implementation of an e-MH intervention for informal caregivers of people living with CKD regarding the intervention's design, delivery, and implementation. Manifest content analysis with primarily deductive coding using the CFIR led to identification of 29 generic categories representing implementation determinants. Potential implementers considered an e-MH intervention as fitting within some existing healthcare delivery models and work routines, however, capacity to be involved with intervention delivery was low. Equitable support access was important to ensure intervention acceptability.

Study IV was a qualitative study to explore informal caregivers' experiences of accessing and receiving support while caring for someone living with CKD. Reflexive thematic analysis generated three themes: (1) "Systems seem to get in the way" – challenges within support systems, describing challenges encountered when navigating complex systems; (2) Relying on yourself, describing how informal caregivers relied on their own skills and networks to find support; and (3) Support systems can "take the pressure off", describing how support systems were perceived as supportive when empathetic and reliable.

**Keywords:** informal caregiver, e-mental health, mental health, implementation, chronic kidney disease

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*“We have such a long way to go”, sighed the boy*  
*“Yes, but look how far we’ve come”, said the horse*

- Charlie Mackesy, The Boy, the Mole, the Fox and the Horse



# List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- Ia. Coumoundouros, C., von Essen, L., Sanderman, R., Woodford, J. (2020) Implementation of e-mental health interventions for informal caregivers of adults with chronic diseases: a protocol for a mixed-methods systematic review with a qualitative comparative analysis. *BMJ Open*, 10(6): e035406
- Ib. Coumoundouros, C., Mårtensson, E., Ferraris, G., Zuidberg, J.M., von Essen, L., Sanderman, R., Woodford, J. (2022) Implementation of e-mental health interventions for informal caregivers of adults with chronic diseases: mixed methods systematic review with a qualitative comparative analysis and thematic synthesis. *JMIR Mental Health*, 9(11):e41891
- II. Coumoundouros, C., Farrand, P., Hamilton, A., von Essen, L., Sanderman, R., Woodford, J. (2023) Cognitive behavioural therapy self-help intervention preferences among informal caregivers of adults with chronic kidney disease: an online cross-sectional survey. *BMC Nephrology*, 24(1):4
- III. Coumoundouros, C., El Arab, R.A., Farrand, P., Hamilton, A., Sanderman, R., von Essen, L., Woodford, J. Potential implementers' perspectives on the development and implementation of an e-mental health intervention for caregivers of adults with chronic kidney disease: a qualitative study. *JMIR Human Factors*. Accepted.
- IV. Coumoundouros, C., Farrand, P., von Essen, L., Sanderman, R., Woodford, J. "Systems seem to get in the way": a qualitative study exploring experiences of accessing and receiving support among informal caregivers of people living with chronic kidney disease. Submitted

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# Abbreviations

CBT	Cognitive behavioural therapy
CFIR	Consolidated Framework for Implementation Research
CHERRIES	Checklist for reporting results of internet e-surveys
CKD	Chronic kidney disease
COPD	Chronic obstructive pulmonary disease
DASS-21	Depression, Anxiety, and Stress Scale – 21 items
e-MH	e-mental health
GDPR	General Data Protection Regulation
i-PARIHS	integrated Promoting Action on Research Implementation in Health Services
MRC	Medical Research Council
NHS	National Health Service
PRECIS-2	Pragmatic explanatory continuum indicator summary 2
PRESS	Peer review of electronic search strategies
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
QCA	Qualitative comparative analysis
RCT	Randomised controlled trial
SRQR	Standards for Reporting Qualitative Research
TIDieR	Template for intervention description and replication
UK	United Kingdom

# Introduction

Informal caregivers, also referred to as caregivers, provide unpaid care and support to partners, family members, or friends with care needs, often due to the presence of a physical and/or mental health condition. In Europe, 8% to 43% of people are a caregiver, however, estimates vary by country and obtaining accurate estimates is challenging [1, 2]. Caregivers can have a wide range of responsibilities such as providing support with personal care (e.g. bathing, dressing), medical care (e.g. communicating with the medical care team, managing medications), household tasks (e.g. cleaning, cooking), and emotional support [3, 4]. Although every caregiver's situation differs, being a caregiver can amount to a full-time job, with some providing 30 hours of care or more each week [5–7]. Providing informal care can also be financially burdensome due to out-of-pocket costs (e.g. medication, transport) and income loss (e.g. absenteeism, reduced work hours) [8, 9].

Demand for informal care is expected to increase in the future [10, 11] as a result of the growing proportion of older adults in society [11], the rising prevalence of a number of chronic health conditions commonly requiring informal care (e.g. cancer, chronic kidney disease) [12–14], and healthcare policies increasingly favouring community-based care [15]. Although demand is rising, caregiver availability is decreasing. This decreased availability is related to demographic and societal changes such as changing family structures (e.g. geographic spread of families, more divorced/unmarried people, more people without children), changing societal roles (e.g. increased employment among women), and demographic changes resulting in fewer working-age adults (who often take on a caregiving role) in comparison to the number of older adults (who often need informal care) [10, 11, 16, 17].

Caregiver availability is also impacted by caregivers' motivation and willingness to provide care, which are influenced by several factors (including some societal changes mentioned above). Practical factors such as caregivers' competing demands (e.g. employment, other familial responsibilities), financial stability, geographic proximity to the care recipient, and the presence or absence of others who are able to take on a caregiving role, can influence caregivers' motivation and willingness to provide care [18–20]. Motivation and willingness to provide informal care are also impacted by quali-

ties related to the caregiver-care recipient relationship (e.g. affection, family values, relationship quality, reciprocity), and the caregiver's individual characteristics (e.g. ability to cope, perceptions regarding the care recipient's illness, skills) [20]. Factors influencing motivation and willingness to provide care can change throughout the caregiving period, increasing or decreasing motivation to provide care [20].

As demand for informal care continues to exceed supply, more people may be left without access to informal care. To meet this demand, it is vital to maximise caregiver availability by ensuring caregivers are motivated and willing to take on a caregiving role. Developing psychological interventions to support caregivers' well-being, while mitigating the potential negative impacts associated with informal care provision, may provide a way of enhancing motivation and willingness to care.

## Impact of informal care

Caregivers can experience positive impacts related to the caregiving role such as an improved relationship with the care recipient, personal growth, and a sense of accomplishment [21–23]. However, providing informal care can also have a negative impact on the quality of life, and physical, emotional and financial well-being of the caregiver [3, 23, 24]. Caregivers often experience higher levels of mental health symptoms compared to non-caregivers [25, 26]. Among adults in the general population, the prevalence of depressive symptoms has been estimated at around 8-10% [27, 28], although this varies by country and some evidence suggests prevalence has increased during the COVID-19 pandemic [29]. The prevalence of depressive symptoms among caregivers is notably higher at 42% and 31%, respectively, for cancer and dementia caregivers [30, 31]. The prevalence of anxiety symptoms is similar to that of depression with 47% and 32% of cancer and dementia caregivers, respectively, experiencing anxiety symptoms [30, 32]. Experiencing mental health problems can impact an individual's physical health, social network, and employment [33–35]. Additionally, the mental health of the caregiver can impact the mental health of the care recipient [36–39], and the quality of informal care provided [40, 41].

## Caregivers' access to mental health support

Although caregivers commonly experience mental health problems such as depression and anxiety, research suggests few access mental health support. Studies from Sweden and the United States suggest only a small proportion of caregivers (around 10% or less) access services to support themselves

(e.g. support groups, respite services) [42, 43]. Another study among cancer caregivers in the United States showed that although all participants experienced psychological distress, only around 26% accessed mental health services [44]. In contrast, among the general population in high-income countries, 19% to 61% of people with depression (depending on treatment type) [45], and 36% of people with anxiety disorders [46] received treatment (e.g. treatment from mental health or general health services). This suggests caregivers may be less likely than the general population to access mental health support. Additionally, among cancer caregivers experiencing psychological distress, 29% of those who did not access mental health services indicated interest in receiving support [44], suggesting access barriers may be present that impede caregivers' ability to seek and/or access support.

A number of barriers make it challenging for individuals to seek and/or access mental health support. Barriers can be grouped into three levels: (1) individual-level barriers related to the person experiencing a mental health problem; (2) provider-level barriers related to healthcare professionals; and (3) system-level barriers related to the healthcare system [47]. Individual-level barriers include stigma, lack of time, lack of awareness of support options, and inaccurate perceptions regarding the severity of mental health problems being experienced [47, 48]. At the provider-level, lack of skills and willingness to assess and manage mental health problems, lack of time, and stigma discussing mental health are challenges to primary care providers discussing mental health with patients [47]. Finally, at the system-level, barriers to providing mental health support include guidance focused on pharmacotherapy, lack of awareness of effective treatment options, lack of integration between mental health and primary care services, and limited availability of mental health providers [47]. Financial barriers also prevent individuals from accessing mental health support [48, 49].

These barriers can also make it challenging for caregivers to access mental health support. For example, common barriers reported by caregivers include a lack of information about available support, not perceiving a need, viewing mental health support as only appropriate for individuals with severe mental health problems, negative views and experiences with mental health treatments and care providers, and stigma [49, 50]. However, caregivers also experience a number of access barriers related to their caregiving role, for example, difficulties navigating healthcare systems that can be complex and disjointed, feelings of guilt for spending time on themselves rather than the care recipient, and lack of time [49–51]. Another barrier relates to caregiver identification given (1) caregivers may not self-identify as a caregiver; (2) providers often fail to take a proactive approach to identify caregivers; and (3) systems are not in place for providers to document caregiver needs [52–54]. Challenges identifying caregivers may mean caregivers do not seek

available support, and providers are unable to identify caregivers who may benefit from support services [52–54]. To improve caregiver access to mental health support, interventions meeting caregivers' needs with flexible delivery are necessary.

## E-mental health – a potential solution?

E-mental health (e-MH) interventions are mental health interventions delivered using internet-based technologies (e.g. mobile application, website) [55, 56]. e-MH has the potential to improve access to mental health support given interventions can be accessed flexibly from multiple locations (e.g. in an individual's home), without needing to travel to attend an appointment [56]. e-MH interventions can also provide greater anonymity which can facilitate disclosure of challenges experienced by caregivers [56, 57]. Additionally, the internet-based format provides opportunities to tailor intervention materials (e.g. content, graphics) and information delivery formats (e.g. audio, video) to meet caregiver needs [58]. Therefore, e-MH interventions could provide a way to improve caregiver access to mental health support by better accommodating caregiving responsibilities and helping overcome access barriers such as lack of time, guilt, and stigma.

e-MH interventions are effective in adult populations, with controlled trials of supported e-MH interventions versus face-to-face psychological therapies demonstrating equivalent overall effects for a number of common mental health problems, including depression and anxiety disorders [59–61]. The amount of support provided to users ranges from completely self-administered interventions, to users receiving regular support from a trained professional [62]. Although self-administered e-MH interventions can be effective at reducing symptoms of anxiety and depression [63], support from a trained professional is associated with higher effect sizes [60]. There is also evidence that e-MH interventions can be effective at improving caregiver mental health [64–68]. Meta-analyses of e-MH interventions for caregivers show small, positive, effect sizes for depression, however, evidence is generally of low to moderate quality [66, 69]. Tailoring interventions to specific caregiver groups may represent a way to enhance the effectiveness of e-MH interventions for caregivers [66]. Caregivers also express a preference for interventions tailored towards their needs and caregiving situation [70–72]. Future e-MH development should therefore focus on tailoring and personalising interventions to better meet caregiver needs and potentially enhance effectiveness.

## Implementation of e-MH interventions

Despite evidence supporting the effectiveness of e-MH interventions, implementation remains challenging [73]. Case studies and systematic reviews have explored factors influencing whether e-MH interventions for the general population are implemented into routine practice [74–76]. Key facilitating factors include the presence of systems and policies that facilitate implementation (e.g. IT system to support e-MH solutions, national mental health policies that include e-MH), relationships with external organisations that can support implementation within the care system, good monitoring and feedback systems to track performance and safety, multiple patient referral options (e.g. self-referral), and support/training for practitioners involved in intervention delivery [74–76]. Professional stakeholders report differing views regarding e-MH that are both positive (e.g. reduce individual access and structural barriers, potential for personalisation), and negative (e.g. digital exclusion, lack of personal contact) [77].

Although some e-MH interventions are integrated into routine practice for the general population [74, 75], implementation of interventions tailored towards caregivers remains limited. One study found only 3% of psychosocial interventions (i.e. educational and/or psychological interventions, including non-internet-based interventions) for dementia caregivers were implemented into practice [78]. Another study examined twelve internet-based interventions providing education and/or mental health support for dementia caregivers and found few were accessible to the general public and they were generally not “implementation-ready”, primarily due to a lack of information regarding staff support and other resources (i.e. training) needed for implementation [79]. Two reviews examining the implementation of any internet-based intervention for caregivers (i.e. including interventions not targeting mental health), showed implementation determinants related to the implementing organisation and wider context were commonly not explored [80, 81]. Together, these studies indicate more attention on the implementation of e-MH interventions for caregivers is needed to enable integration into routine practice.

## An approach to designing for implementation

The Medical Research Council (MRC) framework for the development and evaluation of complex interventions is a well-established resource for planning the development of complex interventions [82]. Complex interventions can involve (1) multiple intervention components; (2) behaviour change from intervention providers and/or users; (3) flexible intervention components/delivery modes; and/or (4) interactions between the intervention and

implementation context [82, 83], with e-MH interventions possessing all of the above characteristics.

The MRC framework was created in 2000 and has continued to be revised over the last 20 years [82]. The first iteration of the MRC framework had a strong focus on evaluating intervention effectiveness [84]. The second iteration published in 2008 continued to have a focus on intervention effectiveness, however, it also focused on feasibility and pilot testing before starting more substantial evaluation work, and included process outcomes (e.g. acceptability) within the evaluation phase [83]. In 2021, the most recent version of the MRC framework was published [82]. The framework consists of four phases (1) develop (or identify) intervention; (2) feasibility; (3) evaluation; and (4) implementation (Figure 1) [82]. Intervention development should move back and forth across phases as needed, rather than following each phase in a linear path [82]. Throughout intervention development, feasibility, evaluation, and implementation, a focus on understanding why and how interventions work, considering intervention theory and contextual factors that may influence intervention effectiveness and/or implementation are highlighted [82]. A noticeable addition to the latest MRC framework is a list of core elements to be considered at all four phases. Core elements include (1) considering context; (2) developing, refining, and (re)testing programme theory; (3) engaging stakeholders; (4) identifying key uncertainties; (5) refining intervention; and (6) economic considerations [82]. These core elements highlight a new emphasis within the framework on implementation. While implementation has been included in all iterations of the MRC framework [82–84], only in more recent guidance [82, 85], does implementation seem to have a similar importance as effectiveness.

Core elements guide researchers to directly explore implementation factors (i.e. key uncertainties and context) during the intervention development phase [82]. Exploring context during the intervention development phase can allow for key factors that may influence future implementation to be incorporated into intervention design and planning. Context refers to features relating to the situation in which an intervention is being developed and implemented [82, 86]. Context can be broken into three levels: (1) micro level (e.g. patient/user attitudes, needs, preferences); (2) meso level (e.g. organisational culture, readiness for change); and (3) macro level (e.g. policies, networks, regulation within the wider environment) [86]. Additionally, some factors span all levels of context such as social networks (e.g. the social structure and ties between individuals and/or organisations), resource availability (e.g. time, money), and leadership [86]. According to realist principles, intervention context is important to explore given certain elements of context may interact with the intervention, influencing intervention outcomes [87]. Following the MRC framework during intervention development can help



ensure contextual factors influencing future implementation are considered early in the development process, thus facilitating the development of interventions suited to the context in which they will later be implemented.

Studying implementation during intervention development can be guided by existing implementation theories and frameworks providing structured approaches to (1) describe implementation determinants (e.g. Consolidated Framework for Implementation Research (CFIR) [88, 89], and integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) [90]); (2) describe the process of translating research into practice (e.g. Knowledge to Action Framework [91]); and (3) evaluate implementation (e.g. PRECEED-PROCEED [92]) [93]. Considering implementation during intervention development is becoming increasingly common [94–96]. For example, during the development of a mental health intervention for people living with chronic obstructive pulmonary disease (COPD), intervention users’ and professional stakeholders’ perspectives on the intervention (e.g. content) and implementation (e.g. delivery mode, provider training) were explored [95]. Exploring implementation determinants during intervention development may also facilitate the later selection of implementation strategies to promote intervention uptake based on key implementation determinants relevant to the intervention and implementation context (e.g. audit and feedback, facilitation) [97]. Given the infrequent implementation of e-MH interventions for caregivers, following MRC guidance to consider factors that may influence future implementation during intervention development is essential to improve the translation of research into practice.

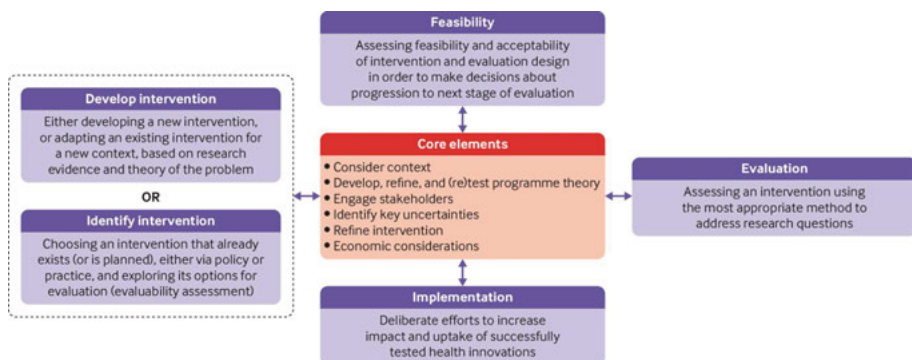


Figure 1: The Medical Research Council framework for the development and evaluation of complex interventions. Reproduced with permission from Skivington et al, 2021 under the Creative Commons CC BY 4.0 licence. (2021). BMJ. All rights reserved.

## Context

Within this thesis, Studies II, III, and IV explore contextual factors that may influence the development of an intervention specifically designed to (1) fit within the context of the United Kingdom (UK), and (2) meet the needs and preferences of caregivers of adults living with chronic kidney disease (CKD). To frame this work, the intended implementation setting and primary population of interest are described below.

### UK context

In the UK, an e-MH intervention for caregivers would likely be placed within the publicly funded National Health System (NHS), or the non-profit sector (e.g. community organisations/charities). Within the NHS, mental health interventions are provided at the primary, secondary, and tertiary care level at no cost to service users. For common mental health problems such as depression and anxiety, care is provided at the primary care level via the NHS Talking Therapies for Anxiety and Depression programme which follows a stepped care model, offering high and low-intensity interventions based on main presenting difficulties, and preferences [98, 99]. Within NHS Talking Therapies, e-MH interventions are available as an option for people experiencing depression or anxiety via different online platforms (e.g. SilverCloud) [100, 101].

Additional mental health support is available at the secondary and tertiary care level, for example, support can be available to individuals coping with specific health conditions through their care unit (e.g. psychosocial support is available for people with CKD within kidney care units) [102]. Community mental health teams are also in place within the secondary care level to support individuals with severe mental health needs [103]. Non-profit organisations (e.g. Kidney Care UK, Macmillan Cancer Support) provide support directly to people living with different health conditions and caregivers, including information, support groups, and counselling [104–107]. Therefore, both the NHS (e.g. NHS Talking Therapies, kidney care units) and non-profit organisations may play important roles in the implementation and delivery of an e-MH intervention for caregivers in the UK.

### Population of interest

CKD impacts approximately 10% of people worldwide [108], and over 2 million people in the UK are living with CKD [109, 110]. Mortality from CKD has increased globally [108], and prevalence is expected to increase as the proportion of older adults and the prevalence of conditions increasing CKD risk (e.g. diabetes, obesity) rise [12, 13]. CKD is an incurable disease

which is classified into five stages based on an individual's estimated glomerular filtration rate which measures kidney function [111]. Stage 5 CKD (also referred to as kidney failure) may be treated with renal replacement therapy which includes dialysis (e.g. haemodialysis, peritoneal dialysis), or a kidney transplant [112]. People living with CKD may also take medication to manage related conditions (e.g. diabetes, high blood pressure) and involve changes to diet and activity levels to better manage the condition [112].

CKD is a highly complex condition which can make it challenging for caregivers to provide care. The complexity is due to the frequent presence of comorbidities such as cardiovascular conditions and diabetes [113, 114], the need for treatment utilising both pharmacological and non-pharmacological approaches (i.e. lifestyle interventions) [115], and the many different medications people living with CKD take [113]. Additionally, given healthcare professionals working in different sectors (e.g. general practitioners, pharmacists, renal healthcare professionals including nephrologists, nurses, social workers) can be involved in providing care for people living with CKD, communication challenges can arise [116]. These challenges and complexities can impact the caregiver as they navigate complex healthcare systems while managing the different treatments and lifestyle changes the person living with CKD may be coping with [117].

Caregivers of adults living with CKD can experience burden, poor quality of life, and mental health problems as a result of informal care demands [4, 118–120]. Research is limited, however, studies have shown the prevalence of depressive symptoms among caregivers of adults living with CKD can range from 30-60% [118, 120], similar to the prevalence of depressive symptoms among cancer and dementia caregivers [30, 31]. Despite caregivers of adults living with CKD experiencing mental health problems, there is a lack of research regarding intervention development for these caregivers [121, 122] compared to other informal caregiving populations [123–125]. This motivated Studies II, III, and IV to focus on developing an intervention for caregivers of adults living with CKD.

# Aims

The overall objectives of this thesis were to (1) identify factors that could influence the implementation of e-MH interventions for caregivers; and (2) explore key factors related to implementation and intervention design that will inform the development of an e-MH intervention tailored for caregivers of adults living with CKD in the UK.

The overall aims of each study were:

- I. Examine factors related to the effectiveness and implementation of e-MH interventions for caregivers of adults with chronic diseases
- II. Examine contextual factors related to caregivers (e.g. intervention preferences, caregiving situation) to inform the development of a cognitive behavioural therapy (CBT) self-help intervention to support the mental health of caregivers of people with CKD
- III. Explore the perspectives of professionals (i.e. potential implementers) anticipated to play key roles in the future implementation of an e-MH intervention for caregivers of people living with CKD regarding the intervention's design, delivery, and implementation
- IV. Explore caregivers' experiences of accessing and receiving support while caring for someone living with CKD

# Ethical considerations

## Study I

This study did not require ethical approval given it did not involve research participants and no primary data was collected. Professional stakeholders were consulted for their professional feedback on the results of the thematic synthesis, however, this involvement was a form of consultancy rather than in a research participant capacity.

## Study II

This study took place in the UK, led by the University of Exeter and received ethical approval from the Psychology Research Ethics Committee at the University of Exeter (UK) (Reference: 492915). Electronic informed consent was obtained before any data collection. All data were anonymous with no specific personal information collected, therefore data were not subject to the General Data Protection Regulation (GDPR). The online survey platform (Qualtrics) did not store participant IP addresses. Given data were anonymous, caregivers experiencing mental health problems were not identifiable. Therefore, all participants were provided with a list of mental health support services. Data were stored on secure University of Exeter servers. Given data were not subject to GDPR, and the study took place in the UK, Swedish ethical approval was not required. Public contribution activities were carried out at a consultancy level with two caregivers to obtain feedback on study materials. Public contribution in the form of consultation does not require ethical approval in the UK [126].

## Study III & IV

Ethical approval was obtained from the University of Exeter Psychology Research Ethics Committee (Reference number: 513911) for interviews with caregivers and stakeholders from non-profit organisations. Ethical approval for interviews with NHS staff was obtained from the University of Exeter Psychology Research Ethics Committee (Reference number: 510971) and the Health Research Authority (IRAS: 308682). Ethical approval for all in-

terviews was also obtained from the Swedish Ethical Review Authority (Dnr: 2022-03068-01) to facilitate remote data collection and processing from Sweden. To minimize the risk of harm, participants were informed they could stop the interview at any time and they did not have to discuss anything they did not wish to. Interviews took place in a private setting to prevent bystanders from over-hearing interview discussions.

During caregiver interviews, although the mental health of participants was not formally assessed, risk protocols from the University of Exeter were used in the event that risk of harm to self or others became apparent. All caregivers were provided with contact information for free mental health services they could access if they needed support.

# Methods

## Study I

A mixed-methods systematic review with a qualitative comparative analysis (QCA) and thematic synthesis was conducted to:

- 1) Explore the combinations of intervention (e.g. presence of support) and implementation (e.g. presence of regular supervision and feedback) characteristics that are sufficient for e-MH interventions for caregivers of adults with chronic diseases to be effective
- 2) Identify barriers and facilitators to the implementation of e-MH interventions for caregivers of adults with chronic diseases

The review was registered on PROSPERO (CRD42020155727) and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines [127]. Methods used are summarized below with further detail available in the published protocol [128] and paper [129].

## Study eligibility criteria

Study eligibility was framed in accordance with PICOS (population, intervention, comparator, outcome, study design):

- 1) **Population:** adult (18 years old or older) caregivers supporting an adult with cancer, COPD, dementia, diabetes, heart disease, or stroke.
- 2) **Intervention:** e-MH interventions targeting the treatment of common mental health problems (anxiety, depression, psychological distress, stress). Interventions delivered solely via e-mail, telephone or video (e.g. video call) were excluded.
- 3) **Comparator:** For the QCA, randomised controlled trials (RCTs) with non-active controls (e.g. treatment as usual, wait list, attention control, information about the care recipient's health condition) were

included. For the thematic synthesis, studies with or without any type of control were included.

- 4) **Outcome:** For the QCA, studies had to report on the caregiver's mental health (anxiety, depression, psychological distress, stress). For the thematic synthesis, studies had to report on any aspect of implementation - defined as any factor within the CFIR [88] or the implementation outcome framework [130].
- 5) **Study design:** For the QCA, only RCTs were included. For the thematic synthesis, any study type was eligible for inclusion.

## Search strategy

Six electronic databases (CINAHL, the Cochrane Library, EMBASE, PsycINFO, PubMed and Web of Science) were searched from January 1, 2007 to July 6, 2022. Secondary search strategies included: forward and backward citation searching, using the "Find Similar" function in PubMed, screening reference lists of relevant systematic reviews, searching two clinical trial registries, searching OpenGrey (a grey literature database), and contacting experts in the field.

The search was developed with assistance from an academic librarian and reviewed by two researchers with experience conducting systematic reviews in similar areas following the Peer Review of Electronic Search Strategies (PRESS) guidance [131]. Search terms included were related to (1) caregivers; (2) the chronic health conditions of interest in this review; (3) e-health; (4) mental health; and (5) types of mental health interventions.

## Study selection

Database searches were first de-duplicated [132], followed by the screening of titles and abstracts by two independent reviewers. Studies included after title/abstract screening had their full text reviewed by two reviewers. Screening decisions were based on the PICOS. Conflicts between reviewers were discussed, with a third reviewer consulted if needed. Abstracts, reviews, protocols, theses, books, commentaries, editorials, and letters to the editor were excluded. Authors of relevant protocols were contacted to see if unpublished data could be obtained.

Secondary search strategies (outlined above) were conducted by one reviewer. Results from an update search conducted from October 2021 to July 2022 (n = 1858 de-duplicated records) were only screened by one reviewer due to resource limitations.



## Assessments of randomised controlled trials

RCTs were assessed for bias using the Cochrane Risk of Bias 2.0 tool which has five domains: bias arising from the randomisation process, bias due to deviations from intended interventions, bias due to missing outcome data, bias in the measurement of the outcome, and bias in the selection of the reported result [133].

RCTs were also evaluated to determine how pragmatic the trial design was using the PRagmatic Explanatory Continuum Indicator Summary 2 (PRECIS-2) tool [134]. PRECIS-2 evaluates trial design based on nine domains: eligibility criteria, recruitment, setting, organisation, flexibility (delivery), flexibility (adherence), follow-up, primary outcome, and primary analysis [134]. Each domain is scored from 1 (very explanatory) to 5 (very pragmatic) [134].

For both assessments, two reviewers evaluated each RCT independently before discussing scores together, consulting a third reviewer as needed.

## Data extraction

Data were extracted from each included full-text related to (1) study participants; (2) study design; (3) intervention characteristics; and (5) relevant outcomes. Data were generally extracted by one reviewer with a second reviewer double-checking the extraction for accuracy and completeness. Data used for the QCA analysis (e.g. quantitative outcome data) were extracted by two reviewers. Data from six full texts retrieved from the search update conducted from October 2021 to July 2022 were extracted by one reviewer. Data for the thematic synthesis were transferred to NVivo for analysis.

## Data synthesis

### QCA analysis

A crisp-set QCA analysis [135] was conducted to identify sets of conditions sufficient for e-MH interventions to be effective. Conditions could be related to intervention (e.g. presence of peer support) or implementation (e.g. presence of training) characteristics. First, a data table was created to classify (1) the conditions within each RCT, and (2) RCT effectiveness. Conditions were classified as being present or absent. RCTs were classified as effective or not effective based on the standardised mean effect size (Hedges'  $g$ ) for the primary outcome identified in the study. If no primary outcome was identified, outcome data for depression was used. Studies with a Hedges'  $g$  of at least 0.3 were classified as effective. This cut-off was based on meta-analyses of e-MH interventions [136–138]. Second, truth tables were created to show all

possible combinations of conditions and illustrate what proportion of interventions with each combination of conditions were effective. Consistency and coverage of at least 0.75 were required to proceed with Boolean minimization [135].

### **Thematic synthesis**

A thematic synthesis [139] was conducted to identify barriers and facilitators to implementation. Data related to the implementation of e-MH interventions were primarily deductively coded using the 41 CFIR constructs (Figure 2) [88]. The CFIR framework defines factors that influence implementation, with a focus on the meso and macro level of context [86]. The CFIR was selected as it has been commonly used in reviews exploring barriers and facilitators to implementation [80, 140] and was developed by combining multiple implementation theories into one consolidated framework [88]. Although most coding was deductive, inductive codes were developed if needed. Quantitative data was integrated into the thematic synthesis by creating narrative summaries of the quantitative findings which were subsequently coded. Two reviewers independently coded 10% ( $n = 4$ ) of included full-texts. The coding process was discussed and codes were clarified in consultation with a third reviewer before the remaining full-texts were coded by one reviewer with regular discussion with a second reviewer. After data was coded to the CFIR framework, barriers and facilitators to implementation were derived within each CFIR construct with an inductive coding process. Identified barriers and facilitators (with all supporting data) were reviewed by a second reviewer. Barriers and facilitators were refined based on feedback from the second reviewer and shown to a third reviewer for additional feedback.

The final list of barriers and facilitators was shown to professional stakeholders ( $n = 4$ ) with experience working with e-health and e-MH for expert feedback regarding (1) whether they have encountered the barriers and facilitators identified; and (2) whether barriers and facilitators were missed in the literature.

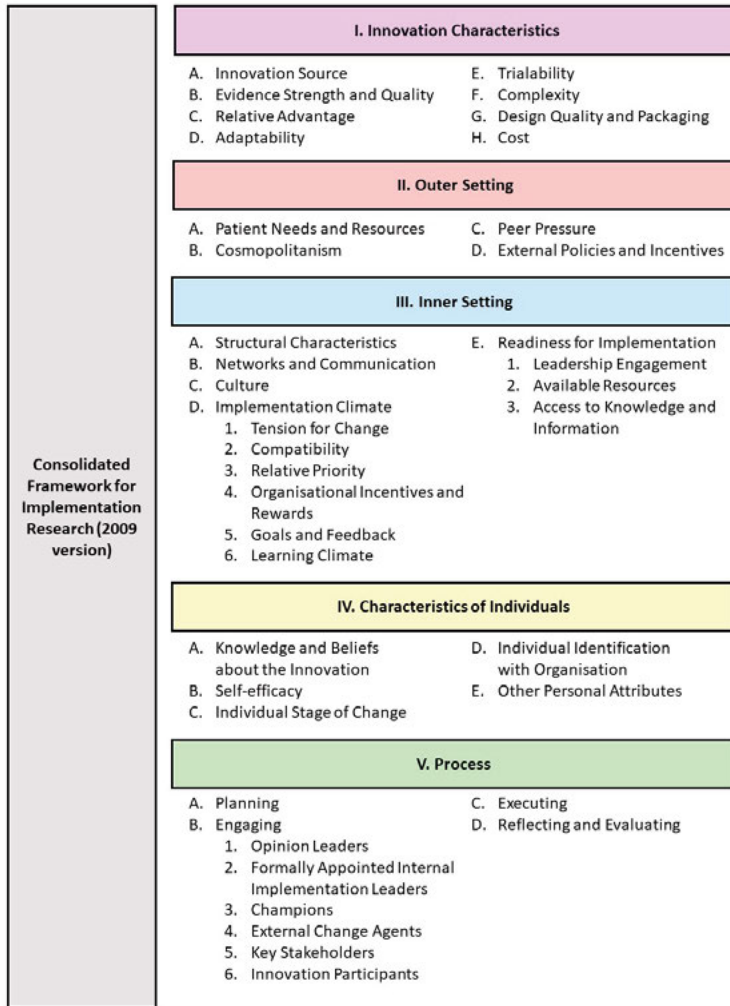


Figure 2: Consolidated Framework for Implementation Research constructs and domains from Damschroder et al, 2009

## Study II

An anonymous online cross-sectional survey hosted on the online survey platform Qualtrics to:

- 1) Describe the situation of caregivers of adults living with CKD (e.g. what type of informal care activities they do, who they care for) and caregiver's mental health symptoms

## 2) Examine caregivers' CBT self-help intervention preferences

Caregivers ( $n = 2$ ) acting as public contributors were consulted for feedback on the study materials (e.g. information sheet, survey) prior to recruiting participants. Reporting followed the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [141]. See the publication for full details of the information summarized below [142].

Intervention preferences were obtained in relation to a CBT-based intervention given CBT is an evidence-based approach to treat mental health problems [143], is in line with the National Institute for Health and Care Excellence guidelines for treating anxiety and depression in the UK [144, 145], and is used in NHS Talking Therapies services [98, 99]. Intervention preferences were not specifically focused on e-MH interventions (i.e. internet-based delivery) as we did not want to assume this delivery format was acceptable to caregivers.

### Eligibility criteria

Individuals had to be (1) at least 18 years old; (2) living in the UK; (3) providing unpaid care and support to someone living with CKD; and (4) the person with CKD had to be at least 18 years old.

### Recruitment

Caregivers were recruited via (1) advertisements on digital platforms (e.g. social media pages, website, online newsletters) of non-profit organisations focused on people with CKD and/or caregivers; (2) advertisements on a study Facebook and Twitter page; (3) a magazine article; (4) a podcast episode; and (5) paid Facebook advertisements.

### Procedure

Informed consent was obtained electronically via Qualtrics before data collection. After informed consent was obtained, potential participants completed four screening questions to ensure they met the eligibility criteria described above. Only participants meeting all eligibility criteria could proceed to the survey.

### Survey items

The survey comprised four main sections:

1) **Caregiver characteristics** including their (1) age; (2) gender; (3) country of residence; (4) first half of their postcode; (5) ethnicity; (6) marital status; (7) number of dependent children; (8) employment status; (9) education level; (10) time spent in caregiver role; (11) informal care activities; (12) how well they are coping; (13) presence of other caregivers; (14) care recipient's receipt of formal care; (15) receipt of Carer's Allowance (financial support payment from the UK government available to caregivers meeting eligibility criteria [146]); and (16) other caregiving responsibilities.

2) **Care recipient characteristics** including their (1) age; (2) gender; (3) relationship to the caregiver; (4) residence of care recipient relative to the caregiver; (5) frequency of contact between the caregiver and care recipient; (6) approximate time of diagnosis with a kidney condition; (7) kidney condition type/cause; (8) type of treatment; (9) whether the care recipient is terminally ill; and (10) number of chronic conditions.

3) **Intervention preferences** including (1) how likely it is they would use CBT self-help interventions if they experienced mental health problems; (2) if they have ever sought help from a self-help intervention for mental health problems; (3) how likely it is that they would use a CBT self-help intervention based on the delivery format (e.g. audio-based, internet-based, in-person) (8 sub-items); (4) when they would like to receive information about CBT self-help interventions; (5) who they would like to receive information about CBT self-help interventions from; (6) when they would like to start using a CBT self-help intervention; (7) who they would want to work through the intervention with (e.g. alone, with the person they care for); (8) how they would like content to be available (e.g. all the time or time-released); (9) presentation methods (e.g. text, video, images); (10) devices they would use to access the CBT self-help intervention if there was online content; (11) content preferences; (12) whether they would like to receive support from a trained professional; (13) what mode of support they would want (e.g. personal email, telephone) (6 sub-items); (14) where they would like support to be provided; and (15) who they would want to receive support from.

4) **Caregiver mental health** was assessed using the 21-item Depression, Anxiety, and Stress Scale (DASS-21) [147]. The DASS-21 is made of three subscales that measure depression, anxiety, or stress, and all subscales have shown good internal consistency [147]. Each item is scored from 0 (Did not apply to me at all) to 3 (Applied to me very much or most of the time) [147].

## Data analysis

Descriptive statistics (e.g. mean, frequency) were calculated for all survey items. For each DASS-21 subscale, the value of missing items was imputed as the average of all other items within the subscale if only one item was missing. Participant's responses within a subscale were first added together, then multiplied by two to determine their individual score, before calculating the sample mean for each subscale. Quantitative data analysis was performed in RStudio. Qualitative data provided in open text-boxes were coded and similar codes were grouped into categories.

## Study III

A qualitative description study [148] using semi-structured interviews and manifest content analysis [149] to:

- 1) Explore the perspectives of potential implementers regarding the design, delivery, and implementation of an e-MH intervention for caregivers of people living with CKD.

Potential implementers refer to professionals who could potentially have a role in the implementation, delivery, and/or endorsement (e.g. referral) of an e-MH intervention for caregivers of people with CKD. Pragmatism was adopted as the overall research paradigm with results considered transferable to other settings and methods selected to best suit the end result of the research (i.e. intervention development) [150]. Reporting followed the Standards for Reporting Qualitative Research (SRQR) [151] with full details provided in the manuscript [152].

## Recruitment

Professionals (i.e. potential implementers) working in settings where an e-MH intervention for caregivers of people living with CKD could potentially be implemented (i.e. kidney care, mental healthcare, non-profit organisations) were recruited. Variation sampling was used to recruit professionals working in different roles and settings [153]. Recruitment occurred via four NHS Trusts, professional networks, social media advertisements, and word of mouth. Informed consent was obtained prior to data collection.

## Data collection

Semi-structured, video-call interviews ( $n = 18$ ) were conducted using an interview guide informed by the CFIR [88] which explored topics such as

compatibility of an e-MH intervention within potential implementers' workplace, evidence needs, and barriers and facilitators to intervention usage. Potential implementers were also provided with a short text-based description of the e-MH intervention prior to the interview. Audio recordings of interviews were transcribed verbatim by a professional transcription company.

### Sample characteristics

The majority of potential implementers were female ( $n = 14$ ) working in England ( $n = 14$ ) with a mean of 7 years ( $SD = 5$ ) experience in their current role. Potential implementers worked in kidney care ( $n = 9$ ), general mental healthcare ( $n = 3$ ), or at non-profit organisations ( $n = 6$ ).

### Data analysis

Manifest content analysis [149, 154] with primarily deductive coding using the updated CFIR [89] (Figure 3) was conducted, with NVivo used to support data management. First, all transcripts were read by author 1 (CC), and a subset of transcripts ( $n = 7$ ) were read by author 2 (RAEA) to support data familiarisation. The initial subset of transcripts ( $n = 7$ ) were independently coded by both authors using the CFIR as a codebook. Regular discussions were held to enhance understanding of CFIR constructs and reflect on the application of constructs to the data. The remaining transcripts were coded by CC. Codes were then inductively organised into generic categories and sub-categories by CC and reviewed by RAEA and author 7 (JW). After subsequent revision of generic and sub-categories, author 3 (PF), who was not involved in data analysis, provided peer examination, informing the development of the final list of categories. Rigour was created through regular discussions with multiple team members, coding involving two research team members, peer examination, and maintaining an audit trail of initial impressions of the data [155].

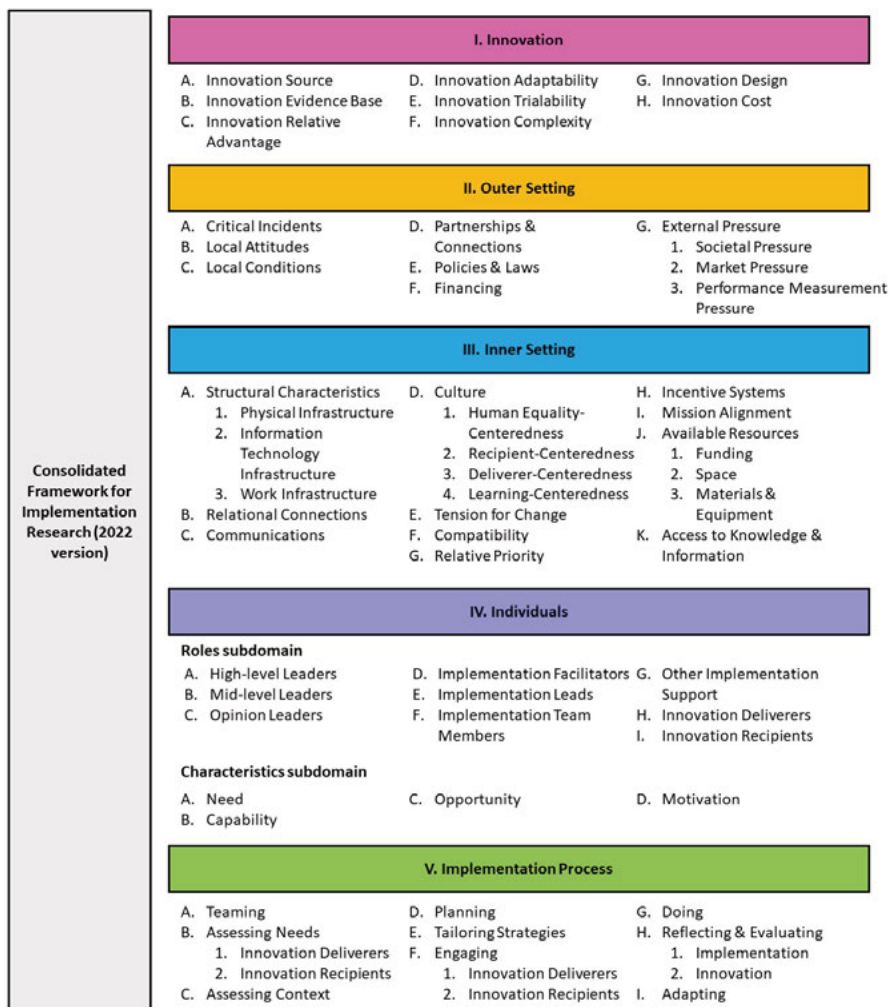


Figure 3: Domains and constructs in the updated version of the Consolidated Framework for Implementation Research from Damschroder et al, 2022

## CFIR tailoring

The CFIR was tailored to the context of this study in three ways. First, a construct from the previous version of the CFIR [88] (Figure 2), *Knowledge and beliefs about the innovation*, which was removed from the updated CFIR [89], was re-added to the codebook to capture individual's beliefs about the intervention. Second, given this study focused on the hypothetical implementation of an intervention and the exact role professionals would have during the implementation and delivery of the intervention were unknown (e.g. whether they would lead implementation, or endorse the inter-



vention), the more generic role of “potential implementer” was created and used within the *Individuals* and *Implementation Process* CFIR domains. Third, given it was unknown which setting would implement and deliver the intervention (e.g. *Inner Setting* within the CFIR), in contrast to settings that may only be involved in intervention endorsement (e.g. *Outer Setting* within the CFIR), constructs within the *Inner* and *Outer Setting* domains were merged into a single *Inner/Outer Setting* domain reflecting the overall implementation context.

## Study IV

A qualitative study using semi-structured interviews and reflexive thematic analysis [156] to:

- 1) Explore the experiences of accessing and receiving support among caregivers of adults living with CKD

Reporting followed the SRQR [151], with additional details in the manuscript [157].

## Recruitment

Caregivers were recruited via (1) online adverts shared by CKD/caregiver-specific non-profit organisations; (2) study social media pages; (3) paid social media adverts; and (4) caregivers who took part in Study II who indicated an interest in other research opportunities. Caregivers had to be an adult (aged 18 years or older) caring for an adult living with CKD in the UK. Informed consent was obtained prior to data collection.

## Data collection

Semi-structured interviews via telephone (n = 1) or video call (n = 12) were conducted using an interview guide informed by related research [49, 158, 159] which explored topics such as needs, experiences receiving support from different sources (e.g. family and friends, healthcare professionals, non-profit organisations), and factors influencing support access. Audio recordings of interviews were transcribed verbatim by a professional transcription company.

## Sample characteristics

All caregivers were female (n = 13), with the majority living in England (n = 12) and having a white ethnic background (n = 11). Caregivers had been

caring for their spouse/partner (n = 8), sibling (n = 3), child (n = 2), or parent (n = 1), for an average of 7.2 years (SD = 7.6). Two caregivers were supporting more than one person living with CKD. Concerning how caregivers were coping with the caregiving role, about half of caregivers felt they were doing neither well nor unwell (n = 6), with the rest feeling they were either coping well/very well (n = 4) or not well/very unwell (n = 3).

## Data analysis

Reflexive thematic analysis with a critical realist perspective was used for data analysis [156, 160, 161], with NVivo used for data management. First, author 1 (CC) read all interview transcripts and recorded impressions as memos to facilitate data familiarisation. CC then inductively coded interviews by primarily considering semantic meanings. Across the data set, shared meanings of codes were used to generate an initial thematic map of themes and sub-themes. After a discussion of the initial thematic map with author 5 (JW), a revised thematic map was produced and applied to the data to facilitate reflection regarding the fit between generated themes and the dataset. The revised thematic map, with descriptions of themes and sub-themes, was peer-examined by JW for additional feedback. After incorporating feedback into the thematic map and theme descriptions, these materials were peer-examined by author 2 (PF) who had not previously been involved in the data analysis, leading to the production of the final thematic map. Rigour was established through dialogue with research team members, peer examination, and memo-taking to maintain an audit trail [155].

# Results

## Study I

### Study characteristics

A total of 53 reports, representing 29 interventions, were included in the review (Figure 4). Interventions focused on dementia caregivers (55%, 16/29) [67, 72, 162–189], cancer caregivers (38%, 11/29) [71, 190–210], and stroke caregivers (7%, 2/29) [68, 211]. Interventions were based on different theories, primarily CBT or stress and coping theory. Interventions were often supported (76%, 22/29), with standardized support (n = 9) such as reminders [71, 172, 176, 177, 183, 191–196, 199, 200, 209–211], or full guidance from a trained professional (n = 7) [68, 72, 162–164, 168, 169, 171, 173, 185–189, 202] being the most common types of support.

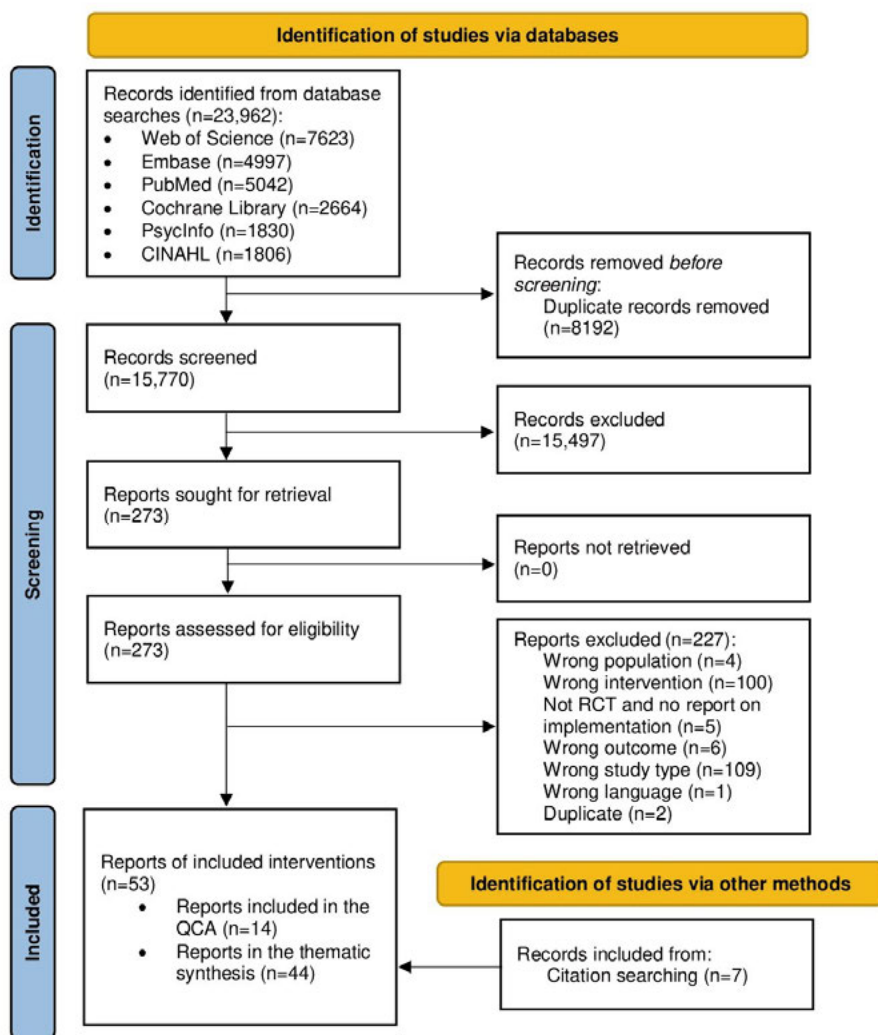


Figure 4: PRISMA flowchart of the study screening process

RCTs (n = 14) contained a mixture of pragmatic and explanatory design features, with all RCTs having a PRECIS-2 score above 3. The most pragmatic domains were flexibility of intervention delivery, and flexibility of adherence (Figure 5). The most explanatory domains were eligibility criteria, organisation of the intervention, and follow-up (Figure 5). Most RCTs (13/14, 93%) had an overall high risk of bias [68, 166, 168, 170, 171, 174, 183, 187, 194, 196, 206, 210], with bias in the measurement of the outcome most frequently evaluated with a high risk of bias due to lack of blinding,

and bias from the randomisation process and deviations from the intended intervention being most frequently evaluated as having low risk of bias.

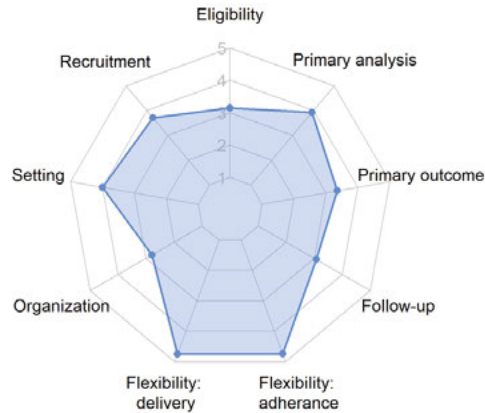


Figure 5: Mean PRECIS-2 scores for RCTs (n = 14). Each domain was scored from 1 (very explanatory) to 5 (very pragmatic).

## QCA analysis

The QCA included 14 RCTs, of which five were classified as effective based on having a Hedges'  $g$  of at least 0.3. Three conditions were explored in the QCA: (1) the presence of professional support; (2) the presence of peer support; and (3) the presence of select persuasive design features (reminders and/or tunnelling). However, no combination of these conditions had high enough consistency and coverage to continue with the analysis.

## Thematic synthesis

The thematic synthesis included 44 reports and resulted in the identification of 152 barriers and facilitators to implementation. The majority of barriers and facilitators related to the *Innovation Characteristics* and *Characteristics of Individuals* (e.g. caregiver) domains within the CFIR. All barriers and facilitators were found to fit within the CFIR constructs. The term stakeholder used below represents any professionals (e.g. healthcare professionals, staff) involved in the implementation and/or delivery of e-MH interventions.

### **Summary of select barriers**

e-MH interventions did not always meet caregivers' information and support needs [71, 72, 162, 165, 166, 172, 177–179, 185, 186, 190–193, 197, 201, 203, 207, 209]. Some interventions lacked personalized support [72, 166, 178, 191, 192] and the format of communication (e.g. written) between caregivers and providers could be challenging [180, 185, 188, 207]. Interventions could lack tailoring to caregivers' caring situation (e.g. relationship to the care recipient, stage of illness), and to caregivers' language and culture [71, 72, 163, 164, 166, 172, 178, 179, 185, 186, 191, 200, 201]. Stakeholders reported being uncertain of caregivers' needs [188, 189] and felt population-level interest in internet-based interventions was low [189]. One implementation challenge was poor integration of the intervention into existing systems (e.g. electronic medical records) [207, 208]. There was also a general lack of leadership engagement and resources to support implementation [186, 188, 189] [161,163,164]. There were a variety of negative views related to e-MH interventions such as perceiving e-MH as impersonal [72, 166, 169, 185, 192, 193, 200], concerns about privacy [188, 190, 203, 205, 207, 208], and feeling interventions could have a negative impact on caregivers' well-being [165, 185, 186, 190, 203]. There were also challenges to caregivers using e-MH interventions such as low digital literacy [72, 165, 172, 179, 185, 186, 188, 189, 191, 200, 205], low internet access [166, 172, 186, 191, 205], and caregivers having too many other responsibilities to participate [72, 163, 169, 172, 175, 179, 186, 192, 193, 195, 197, 200, 201, 209]. Finally, there was a need to engage a wide variety of people to implement the interventions, including intervention users (i.e. caregivers), key stakeholders, leaders, and champions [172, 188, 189].

### **Summary of select facilitators**

Stakeholders valued pragmatic evidence regarding e-MH interventions to feel confident interventions would be effective outside of research settings [162, 209]. The internet-based format made interventions convenient and more easily accessible [72, 162, 177, 178, 185, 186, 190, 193, 200]. Interventions contained useful information that caregivers could apply to their lives [71, 72, 162–166, 169, 172, 174, 175, 177–179, 181, 184–186, 188, 191–193, 195, 197, 198, 200–203, 207, 209]. Opportunities for contact with other caregivers and/or seeing examples of how other caregivers managed different situations were valued [72, 163, 164, 172, 178, 179, 185, 186, 190–193]. Implementation was facilitated by increasing digitalization in other sectors [189] and the fit between the intervention and existing policies (both within the implementing organization and wider society) [162, 188, 189]. e-MH interventions were able to fit within stakeholders' existing workflows [179, 180, 186, 188] and flexibility regarding how stakeholders could use the intervention facilitated intervention use [186, 208]. Caregivers and stake-

holders viewed e-MH interventions as benefiting caregivers in many ways (e.g. reducing isolation, normalizing lived experiences, increasing knowledge and skills, and improving well-being) [71, 162–164, 166, 167, 169, 175–178, 180, 185, 186, 189, 190, 192–195, 198, 202–204, 209, 211]. Strategies to engage diverse groups of caregivers in the interventions [175, 179, 189] and early engagement of caregivers and stakeholders with the intervention [179, 189] were also viewed as important for implementation.

## Study II

### Sample characteristics

A total of 65 caregivers of adults living with CKD participated in the study. They were mainly women (55/65, 85%) with a white ethnic background (63/65, 97%), aged 56 (SD = 13). Care recipients were often men (50/65, 77%), aged 52 (SD = 16) receiving kidney replacement therapy (e.g. dialysis, transplant) (44/65, 68%), regular follow-up with a clinician (42/65, 65%), and/or medication for the kidney condition (41/65, 63%). Caregivers were often caring for a spouse or partner (48/65, 74%), and had been providing informal care for 8.2 years (SD = 8.0). Common care activities included providing emotional support to the care recipient, attending medical appointments with the care recipient, running errands, cleaning/gardening, cooking, and managing the care recipient's symptoms. According to DASS-21 scores, depression was the most prevalent mental health problem with 58% (37/64) of caregivers experiencing at least mild depressive symptoms. Anxiety and stress symptoms were experienced by 38% (24/64), and 46% (30/65) of caregivers, respectively.

### Intervention preferences

Almost half of caregivers (31/65, 48%) were likely or very likely to use a CBT self-help intervention. Caregivers preferred to receive information and use a CBT self-help intervention when the care recipient was diagnosed (30/61, 49%). However, flexible intervention access was considered important, including having information regarding the intervention available at all stages of the caregiving journey. Caregivers were interested in being informed about the intervention through many pathways including an information sheet and being provided information from non-profit organisations, healthcare professionals (nurses, doctors, psychologists), and peers.

Internet-based interventions were the most preferred intervention delivery format (39/61, 64%), followed by a workbook (34/61, 56%) or an individual in-person intervention (33/61, 54%). Caregivers expressed interest in several

caregiving related topics, especially living with CKD (93%, 57/61), caregiver support services (93%, 57/61), caregiver physical health (e.g. sleep) (87%, 53/61), and diet (82%, 50/61). Caregivers commented that additional topics of interest not mentioned within the survey were (1) financial support; (2) self-care; (3) coping strategies (e.g. coping with changes, coping with emotions); and (4) self-help resources for the care recipient.

Just over half of caregivers (38/61, 62%) preferred a supported CBT self-help intervention, with the most interest in support provided in-person (32/49; 65%) or via personal email (32/49, 65%). Caregivers preferred support provided by a trained professional at a non-profit organisation (20/49, 41%) knowledgeable about CKD.

### Study III

Overall, 29 generic categories related to 17 CFIR constructs were identified (Figure 6).



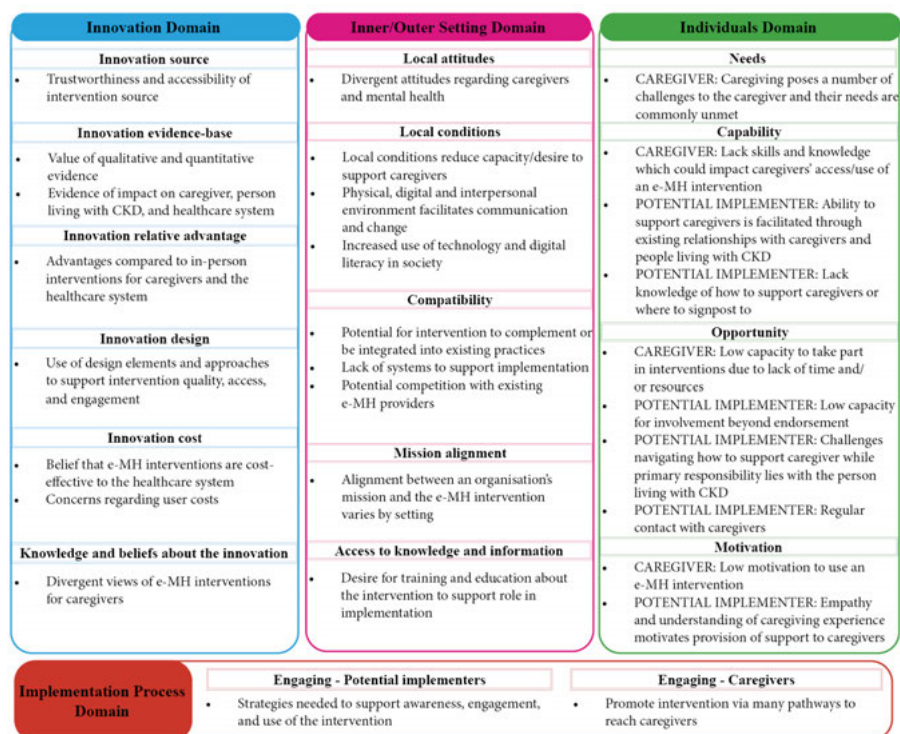


Figure 6: CFIR domains and constructs, with generic categories related to the implementation and development of e-MH interventions for caregivers of people living with CKD.

## CFIR Domain: Innovation

Eight generic categories were identified that connected to six constructs within the *Innovation* domain.

*Innovation source*: Potential implementers felt the trustworthiness of the innovation source was important to facilitate intervention implementation. Examples of trustworthy innovation sources included the healthcare system and non-profit organisations. Private companies were viewed negatively given they were perceived as being motivated by profit generation.

*Innovation evidence-base*: Evidence regarding the clinical and cost-effectiveness of e-MH interventions was important to potential implementers, with qualitative and quantitative evidence valued. Additional outcomes of interest included measures of the implementation process (e.g. uptake), intervention acceptability, and secondary benefits interventions have on people living with CKD.

*Innovation relative advantage:* e-MH interventions were viewed as having several advantages compared to in-person interventions such as providing flexible and immediate intervention access, and requiring fewer resources from the healthcare system (e.g. staff) to be implemented and delivered.

*Innovation design:* Strategies to design interventions collaboratively with caregivers and other stakeholders, ensuring interventions accommodate different user needs (e.g. tailoring content or features) and skills (e.g. digital literacy), and creating strong safeguarding protocols were important to potential implementers. The provision of support within the intervention was viewed as a strategy to enhance user engagement and understanding of intervention content.

*Innovation cost:* e-MH interventions were thought to provide cost-savings to the healthcare system, however, it was important to potential implementers that there was no cost to users given cost was a perceived barrier to intervention access for caregivers.

*Knowledge and beliefs about the innovation:* There were divergent views related to e-MH interventions. Potential implementers felt e-MH interventions would benefit caregivers (e.g. improve well-being and knowledge), however, they also felt e-MH interventions could be impersonal.

## CFIR Domain: Inner/Outer Setting

Nine generic categories were identified that connected to five constructs within the *Inner/Outer Setting* domain.

*Local attitudes:* The value of caregivers and how caregivers can influence the well-being of people living with CKD was recognised. However, potential implementers were aware that some kidney healthcare professionals view caregiver support as outside the scope of their role. Decreasing societal stigma regarding mental health may facilitate implementation of an e-MH intervention as discussing mental health was becoming normalised.

*Local conditions:* Capacity issues such as poor funding, sustained service disruptions from the pandemic, waitlists for support, and the low priority of caregivers in society were perceived barriers to implementation. Environmental factors such as the digital, physical, and interpersonal environment within workplaces (e.g. good relationships with colleagues), as well as increasing societal digital literacy were perceived as potentially facilitating intervention implementation.

*Compatibility:* Potential implementers perceived a good potential fit between an e-MH intervention for caregivers and some healthcare delivery models (e.g. the stepped care model), and that the intervention was a way to enhance current caregiver support referral practices. However, the absence of systems to track caregiver needs and referral to support services could make implementing an e-MH intervention challenging. Additionally, potential implementers working in non-renal-specific settings felt it would be challenging to identify caregivers of people living with CKD. The presence of competing e-MH providers in the general mental healthcare system was viewed as a potential implementation barrier.

*Mission alignment:* Non-profit organisations were the only setting in which an e-MH intervention for caregivers was viewed as aligning with the organisation's mission. There was potential for the intervention to align with the mission of the mental healthcare system to increase access to mental health interventions. However, mental healthcare professionals acknowledged caregivers were not currently considered a priority population in that setting.

*Access to knowledge and information:* Access to training and information regarding the purpose and content of an e-MH intervention, and the ability to access the intervention themselves was important to potential implementers. Potential implementers also felt access to materials to promote the intervention (e.g. information sheet), and having a contact point for more information were important.

## CFIR Domain: Individuals

Ten generic categories were identified that connected to four constructs within the *Individuals* domain.

*Needs:* Potential implementers felt caregivers often had unmet needs and that given the challenges caregivers can experience, could benefit from support.

*Capability:* Caregivers were viewed as potentially lacking skills needed to use an e-MH intervention (e.g. digital literacy). Potential implementers also felt caregivers may lack awareness of being in a caregiving role, impacting whether they would access an intervention designed for caregivers. Kidney healthcare professionals had long-term relationships with caregivers which could help them identify those in need of support, however, kidney and mental healthcare professionals lacked knowledge regarding available caregiver support.

*Opportunity:* Potential implementers anticipated caregivers would lack the capacity (e.g. time, energy, resources) to use an e-MH intervention. Potential

implementers felt they would have the opportunity to endorse the intervention given they often came into contact with caregivers, however, involvement with implementation beyond endorsement was not considered possible. Challenges navigating existing relationships with the person living with CKD to provide support to the caregiver were anticipated.

*Motivation:* Potential implementers felt caregivers would have low motivation to take part in an intervention as other responsibilities often take priority and they may have negative views of mental health interventions. Potential implementers' empathy for caregivers, stemming from their own caregiving experience and/or working closely with caregivers, motivated them to support caregivers.

## CFIR Domain: Implementation Process

Two generic categories were identified that connected to two constructs within the *Implementation Process* domain.

*Engaging – potential implementers:* Strategies to build awareness and encourage potential implementers to engage with an e-MH intervention were viewed as important for implementation, for example, creating an efficient referral process, reminders for potential implementers about the intervention, and ensuring healthcare professionals working in a wide range of roles within kidney care are informed about the intervention.

*Engaging – caregivers:* Potential implementers suggested key strategies that could encourage engagement with an e-MH intervention, including diverse pathways for caregivers to learn about the intervention (e.g. adverts, newsletters), and promoting the intervention in a wide range of settings (e.g. kidney units, non-profit organisations).

## Study IV

Three themes with nine sub-themes were generated (Table 1): (1) “Systems seem to get in the way” – challenges within support systems; (2) Relying on yourself; and (3) Support systems can “take the pressure off”.

Table 1: Thematic structure

Theme	Summary	Sub-themes
“Systems seem to get in the way” – challenges within support systems	Caregivers had to navigate complex health and social care systems while seeking and obtaining formal and informal support which presented several challenges for caregivers	<ul style="list-style-type: none"> <li>• “Pushed from pillar to post” – finding your way through health and social care systems</li> <li>• Changing social networks</li> <li>• Systems don’t meet our needs</li> <li>• People don’t understand CKD</li> </ul>
Relying on yourself	Caregivers had to identify and access support independently to meet their support needs. However, such self-reliance may leave support access barriers unaddressed	<ul style="list-style-type: none"> <li>• Leveraging existing skills and networks</li> <li>• “We can’t just go out and find it”</li> <li>• When beliefs get in the way</li> </ul>
Support systems can “take the pressure off”	Support systems could reduce the stress and burden caregivers were experiencing if they possessed certain qualities	<ul style="list-style-type: none"> <li>• Empathetic support that “instinctively knows” what you need</li> <li>• Support you can count on</li> </ul>

### Theme 1: “Systems seem to get in the way” – challenges within support systems

Support systems included both formal (i.e. health and social care systems) and informal (e.g. family, friends, neighbours) sources of support. This theme describes challenges caregivers encountered when navigating complex systems that failed to meet their needs.

*“Pushed from pillar to post” – finding your way through health and social care systems:* Health and social care systems were viewed as complex and disjointed, with caregivers experiencing challenges navigating these systems (e.g. lack of follow-up, communication challenges). Healthcare systems were perceived as strained, influencing caregivers’ support-seeking behaviours. For example, caregivers were efficient when asking questions, or chose not to access support.

*Changing social networks:* Caregivers lost or reduced contact with network members due to COVID-19 related social distancing, changing priorities, network member discomfort discussing the caregiving situation, or differing cultural beliefs. These network changes negatively impacted the availability of social support.

*Systems don't meet our needs:* Caregiver support needs were often unmet, especially regarding CKD information, and support at specific phases of the CKD journey (e.g. while waiting for a transplant). Culturally sensitive support was perceived as lacking by caregivers with a South Asian background.

*People don't understand CKD:* Poor CKD understanding among social network members and non-renal healthcare professionals led to unsatisfactory and negative experiences with support as caregivers had to explain the impact of CKD on the care recipient to others. This was contrasted to perceived higher levels of societal understanding of cancer and heart attacks.

## Theme 2: Relying on yourself

This theme illustrates how caregivers used their own skills and resources to find support in response to the challenges encountered when interacting with support systems (Theme 1). However, self-reliance to access and receive support left support access barriers unaddressed.

*Leveraging existing skills and networks:* Caregivers expressed how they had to be resourceful to receive support which involved leveraging their skills (e.g. ability to find information, self-care skills), and networks (e.g. social network members with medical training) to maintain their well-being and meet their information needs.

*"We can't just go out and find it":* Seeking support was challenging for caregivers given they could lack knowledge regarding available support. Seeking support was time-consuming and was not compatible with the caregiver's caring responsibilities and other demands such as childcare. Concern was expressed for caregivers lacking the skills and resources to independently identify and access support.

*When beliefs get in the way:* Caregivers held negative beliefs regarding support programs. For example, mental health support was viewed as emotionally challenging, and caregivers felt undeserving of support and that they would be taking support away from others.

### Theme 3: Support systems can “take the pressure off”

This theme describes how support systems could help caregivers cope with the caregiving role if systems were perceived as empathetic and reliable. Although systems could provide caregivers with support which was valued, experiences with empathetic and reliable support did not necessarily compensate for the challenges caregivers experienced navigating health and social care systems (Theme 1).

*Empathetic support that “instinctively knows” what you need:* Empathetic support was valued as it provided support perceived as appropriate and sensitive to the challenges caregivers were experiencing. Empathy and understanding were displayed through network member’s actions such as accommodating caregiver needs, learning about CKD, and showing an interest in the well-being of the caregiver and care recipient.

*Support you can count on:* Reliable support reassured caregivers that they could obtain support when needed. Reliability was built through effective communication with network members, such as having a consistent contact point within the healthcare team and quick responses to caregiver concerns and needs, fostering trust among network members.

# Discussion

## Summary of main findings

In Study I, 53 reports were identified exploring the effectiveness and/or implementation of e-MH interventions. Of these reports, 14 were RCTs which were included in a QCA analysis. However, the QCA analysis could not proceed due to low consistency and coverage. 152 barriers and facilitators to implementation were identified in a thematic synthesis. These barriers and facilitators were most often related to the *Innovation Characteristics* and *Characteristics of Individuals* (i.e. intervention users and stakeholders involved in implementation) domains. Comparatively few barriers and facilitators were identified related to the *Outer Setting*, *Inner Setting*, and *Process* domains.

In Study II, 65 caregivers of adults living with CKD completed the survey. Caregivers often had a white ethnic background and were female caring for a male spouse/partner with CKD. Over half of caregivers were experiencing at least mild depressive symptoms. Almost half of caregivers were likely to use a CBT self-help intervention if experiencing a mental health problem. Caregivers preferred an internet, workbook, or individual in-person CBT self-help intervention, with additional support provided in-person or via email by a trained professional at a non-profit organisation. CBT self-help interventions containing information on caregiving related topics such as living with CKD, support services, physical health, and diet, to supplement evidence-based techniques from CBT, could better meet caregiver information needs.

In Study III, 18 potential implementers working in renal care, mental healthcare, or non-profit organisations participated in an interview. Overall, 29 generic categories were identified that related to 17 CFIR constructs. Within the *Innovation* domain, the trustworthiness of the innovation source and designing interventions to ensure equitable access were key implementation determinants. Within the *Inner/Outer Setting* domain, capacity challenges and a lack of systems to support implementation were some anticipated barriers to implementation. However, there was potential for the intervention to fit well within existing healthcare delivery models. Within the *Individuals* domain, potential implementers perceived caregivers have a need for mental health support and their existing relationships with caregivers could



facilitate intervention endorsement. However, potential implementers were unsure whether caregivers would have the time, motivation, and skills to use an e-MH intervention. Within the *Implementation Process* domain, potential implementers stressed the importance of using diverse strategies and pathways to promote the intervention to caregivers and potential implementers.

In Study IV, 13 caregivers of people living with CKD participated in an interview. Three themes were generated: (1) “Systems seem to get in the way” – challenges within support systems described the challenge of navigating complex health and social care systems, the changes that occurred within social networks, the inability of systems to meet caregiver needs, and the lack of understanding of CKD; (2) Relying on yourself described how, in response to the challenges described in Theme 1, caregivers had to rely on their own skills and networks to find support, however, self-reliance left support access barriers such as negative beliefs and practical access barriers (e.g. lack of time) unaddressed; and (3) Support systems can “take the pressure off” described how support systems had the potential to help caregivers cope with the caregiving role if they exhibited empathetic and reliable support.

## Study-specific discussion

### Study I

e-MH interventions were primarily tailored towards caregivers of people with dementia and cancer, with few interventions focused on caregivers of people with other chronic health conditions (e.g. COPD, diabetes, stroke). Intervention descriptions commonly lacked details that would potentially be needed to implement and deliver interventions in practice. Incomplete intervention reporting in accordance with the Template for Intervention Description and Replication (TIDieR) checklist [212] is common, with a review of reviews showing that a number of TIDieR items, such as information about intervention providers and intervention tailoring, were frequently inadequately reported in clinical trials [213].

RCTs included in the QCA analysis contained a mixture of pragmatic and explanatory elements in the trial design, and the majority of RCTs had a high risk of bias. One domain of the PRECIS- 2 evaluation that was the least pragmatic was organization, referring to the resources (e.g. equipment, staff), training, and expertise needed to deliver the intervention [134]. The low score for this domain reflects how most trials were conducted in academic settings with little reference to how the intervention would fit within routine practice. The domain of the Risk of Bias 2.0 tool which often had a

high risk of bias was bias in the measurement of the outcome, which was primarily a result of a lack of participant blinding. Blinding is challenging in the context of trials for mental health interventions [214] and although a useful tool to evaluate efficacy, blinding is not representative of real-world conditions. In the QCA analysis, solutions representing combinations of conditions with adequate consistency showed low coverage given solutions were based on 1 to 2 RCTs. Therefore, conclusions could not be drawn from the QCA analysis.

Several barriers and facilitators were identified in this review, primarily connected to the *Innovation Characteristics* and *Characteristics of Individuals* CFIR domains. e-MH interventions tended to be well-designed and often incorporated feedback from different stakeholders (e.g. caregivers, and healthcare professionals) during the development phase. However, despite including stakeholder perspectives to inform intervention design, few studies explored stakeholders' perspectives regarding factors influencing implementation related to the *Outer Setting* and *Inner Setting* CFIR domains. The limited reporting on implementation barriers and facilitators regarding the implementation setting reflects how existing literature focuses on acceptability and intervention development research, indicating a gap in understanding e-MH intervention implementation within the caregiving literature. Other reviews focused more broadly on e-health interventions for dementia caregivers have reported similar gaps regarding intervention implementation [80, 81]. As per the MRC framework [82], contextual factors related to implementation should be explored at all stages, including intervention development. Early consideration of implementation could facilitate better implementation planning and ensure interventions are designed to fit within their intended implementation setting.

The thematic synthesis included data from both intervention users (i.e. caregivers) and professional stakeholders. After the thematic synthesis was completed, an addendum to the CFIR framework was published stating the use of the CFIR is only appropriate with data from stakeholders involved in intervention delivery and/or implementation [215]. Therefore, unless the intervention user is involved in intervention delivery and implementation, their data is considered out of the scope of the CFIR. In light of this addendum, data included in this thematic synthesis derived from intervention users may not have been considered to fit within the CFIR. However, other reviews on implementation have included data from intervention users when identifying implementation determinants [80, 81], and perspectives of intervention users may be considered an important element of context that could impact the implementation and sustainability of e-MH interventions in practice.

## Study II

Recruitment of caregivers was low, a common challenge in the literature, with a systematic review showing RCTs involving caregivers of people living with CKD recruited only 38 to 105 participants [121]. The small sample size may have been expected given studies using similar recruitment methods, but including caregivers of people with any health condition, recruited 226 to 229 participants [216, 217]. Recruitment strategies involving direct contact with caregivers (e.g. face-to-face recruitment at kidney care units) may enhance recruitment [218, 219] and should be explored in future studies.

Caregivers were primarily women, aged 56 with a white ethnic background. Although population-level data regarding caregivers of people living with CKD are not available, a sample of caregivers from the UK Census showed similar proportions of female and male caregivers, with 10% of caregivers having other ethnic backgrounds, primarily Indian, Pakistani, or Black Caribbean [220, 221]. This suggests the survey sample is unlikely representative of the population of caregivers of adults living with CKD in the UK.

Over half of caregivers were experiencing at least mild depressive symptoms. In other countries, the prevalence of depressive symptoms among caregivers of people with CKD has been found to be 30-60% [118, 120], with current study findings falling within this range. Meta-analyses have shown that caregivers of people with cancer, dementia, and stroke have a prevalence of depressive symptoms of 42%, 31%, and 40%, respectively [30, 31, 222]. Despite caregivers of adults living with CKD having similar levels of depressive symptoms, there are comparatively few mental health interventions for this caregiver group [121, 123–125]. Thus supporting the need to develop interventions tailored to caregivers of adults living with CKD.

Caregivers of adults living with CKD preferred a CBT self-help intervention delivered via the internet, workbook, or individually in-person, with support from a trained professional at a non-profit organisation. However, existing interventions for caregivers of people living with CKD are typically group-based, with support provided by researchers, psychiatric nurses, or other healthcare professionals with experience in kidney care [121]. Non-profit organisations in the UK (e.g. Kidney Care UK, Popham Kidney Support, National Kidney Federation) offer different support such as information booklets, telephone information and counselling, and in-person peer support [105, 106, 223]. However, none of the support currently available fully aligns with the intervention preferences identified in this study.

Offering a CBT self-help intervention through a non-profit organisation, as per caregivers' preferences, may provide a means to improve access and reduce the stigma associated with mental health support, which has been observed with community-based mental health outreach for older adults [224]. Kidney patient organisations have existing resources that could complement a CBT self-help intervention, and staff have a high level of knowledge regarding CKD, facilitating the provision of support that is empathetic to the challenges of caring for someone with CKD. Future research should focus on exploring factors that would influence the implementation of a CBT self-help intervention in non-profit organisations.

There was strong interest in additional topics related to caregiving being included in a CBT self-help intervention such as living with CKD and support services. A recent review focused on caregivers of people with end-stage kidney disease found a number of unmet information needs, and a lack of tailored information specific to caregivers of people living with CKD [225]. Caregiver needs can also change over time as the health of the care recipient changes [226, 227], further highlighting the importance of intervention tailoring. Internet-based interventions can provide a means to tailor intervention content and delivery mode (e.g. audio, video, text) to meet these needs and preferences [58]. Provision of tailored intervention content and flexible modes of content delivery were important for intervention acceptability during the development of interventions among other caregiver populations [71, 164, 172, 185], and should be explored as an approach to enhance intervention acceptability among caregivers of adults living with CKD.

### Study III

An e-MH intervention for caregivers showed the potential to fit within existing healthcare delivery models (e.g. stepped care) and work routines in potential implementation settings, which is important for facilitating implementation [186, 207]. Existing social networks of potential implementers could also be leveraged to support e-MH implementation. Healthcare professionals' relationships with caregivers could facilitate the identification of caregivers with support needs and referral to an e-MH intervention. Additionally, potential implementers' relationships with other professionals could facilitate information dissemination about the e-MH intervention. Social networks of potential implementers should be explored further to inform who to strategically involve in implementation to enhance dissemination and uptake of the intervention [228, 229].

The capacity to implement an e-MH intervention was low, with many potential implementers lacking time to support the implementation of an e-MH

intervention. Potential implementation settings were also perceived as having low capacity to support caregivers due to resource limitations (e.g. lack of staff, lack of funding), and the absence of systems to identify caregivers and provide support referrals. Identification of caregivers is a reported challenge in several healthcare settings [52, 54, 230], resulting in several policy recommendations supporting the development of a systematic approach to identify caregivers [231, 232]. To enhance implementation capacity, the provision of training and educational materials to increase self-efficacy among potential implementers could also be beneficial [188].

Finally, to enhance the acceptability of the e-MH intervention, consideration of equity and accessibility during intervention development and implementation was important. Potential implementers valued an intervention which would be accessible to caregivers with different skills and resources (i.e. digital and health literacy), suggesting the importance of developing interventions with different delivery modes (e.g. digital and non-digital versions). Future research should apply an equity lens to intervention development, for example using the PROGRESS framework, to consider inequities related to intervention access [233].

## Study IV

Complex health and social care systems made it challenging for caregivers to access and receive support, especially regarding the receipt of information from healthcare professionals. Caregivers of people living with CKD often report unmet information needs, such as not receiving sufficient information about CKD [158, 225, 234, 235]. The complexity of CKD in terms of the different treatment options and frequent presence of comorbidities may also contribute to unmet information needs given caregivers can interact with a wide range of healthcare professionals who may not have renal expertise or adequate resources for caregivers [114, 236, 237]. Communication training for caregivers and healthcare professionals could be a strategy to improve conversations between caregivers and professionals to better meet caregiver information needs [238, 239]. Integrating system navigation support within the renal healthcare system could also improve caregivers' experiences of receiving support. Existing roles, such as the Assistant Wellbeing Practitioner (Renal) role which supports provision of psychosocial renal care [240], could be leveraged to help caregivers navigate systems and identify support.

Empathetic support was valued and met caregiver support needs. Empathy is a key component of competency frameworks for mental health professionals [240, 241] and has been identified as important in relation to e-MH intervention development [163, 191]. Strategies to build empathy into interventions should be utilised such as public contribution and user-centered design [242–

244]. Tailoring interventions to better reflect caregivers' situations (e.g. CKD treatment and stage, relationship to the care recipient) and backgrounds (e.g. cultural background) could also help caregivers identify with intervention content and is often an important element of intervention design [71, 164, 245]. Tailoring interventions for caregivers of people living with CKD can be challenging given the wide range of care situations among this group of caregivers. Further research is needed to understand which sub-groups of CKD caregivers interventions should be tailored to.

Finally, the reliance on caregivers to independently seek support, and the presence of support access barriers, raise concerns regarding whether caregiver support access is equitable. Inequities in mental health support access have already been identified [246–248] and some dimensions of equity are often unaddressed during caregiver intervention development [249, 250]. Therefore, similar to Study III findings, the use of an equity framework to guide intervention development could support consideration of all dimensions of equity during intervention development [233]. Consideration of culture, one dimension of equity, may be particularly important given we found support experiences were impacted by caregivers' cultural background, and other research has shown consideration of culture within interventions can enhance effectiveness [251, 252].

## Limitations

There are several limitations that should be considered when interpreting the findings of this work.

### Study I population

Due to unforeseen changes in the design of Studies II, III, and IV that occurred after beginning Study I, the systematic review did not include literature related to caregivers of adults living with CKD. Population inclusion criteria in Study I were based on chronic physical health conditions commonly requiring informal care and contributing most to disability-adjusted life years, which takes disease prevalence into account [253]. By focusing on more prevalent chronic health conditions, caregivers of people with less prevalent chronic health conditions, such as CKD, were excluded. However, Study I findings and wider literature [123–125] have shown that a significant number of interventions exist for caregivers of people with more prevalent health conditions (e.g. cancer, dementia). As such, focusing on the development of an intervention for caregivers of adults living with CKD in Studies II, III, and IV provides greater potential for research impact given few interventions have been developed for this group of caregivers [121, 122]. Final-

ly, a systematic review published in 2021 of interventions for caregivers of adults living with CKD did not retrieve any e-MH interventions [121], suggesting it is unlikely there was literature related to e-MH interventions for caregivers of adults living with CKD that could have been included in Study I.

## Assessment tools

Within Study I, RCTs were assessed for risk of bias using the Cochrane Risk of Bias 2.0 tool, however, this tool has been shown to have poor interrater reliability [254] which may mean other researchers would have evaluated the risk of bias in the included studies differently. Retrospective assessment of RCTs with the PRECIS-2 tool relies on assumptions by the review team given the intended implementation context is rarely reported in trials, impacting the PRECIS-2 scores reported in this study.

## Analytical approach

Studies I and III used a framework identified a priori to guide deductive coding given theories and frameworks are well-established in the implementation science field [93]. Using the CFIR during qualitative data analysis ensures a thorough consideration of factors that can influence implementation, resulting in the categorisation of findings within a commonly used framework which facilitates comparison with related literature. However, using a framework for qualitative data analysis can lead to data being forced into the pre-defined framework constructs, limiting the potential identification of new categories not contained within the framework [255].

Studies II and III obtained caregiver and potential implementer views of mental health interventions for caregivers based on a general written description of CBT self-help interventions (Study II) or e-MH interventions (Study III). Views related to intervention preferences and implementation barriers and facilitators could change if participants were presented with a more fully developed intervention or if prototypes had been produced to share with participants when eliciting preferences [191]. Additionally, in Study III potential implementers did not have any formal roles or responsibilities in relation to intervention implementation, therefore, their views could change as their implementation role becomes more concrete (e.g. if they are responsible for intervention delivery or if they only need to endorse the intervention).

## Generalizability and transferability of findings

The sample size of Study II was small, limiting the generalizability of study findings. Although we do not know specific population-level characteristics

of caregivers of adults living with CKD in the UK, based on population-level data [220, 221, 256], it is unlikely the sample was representative. Additionally, the online survey format means participants likely had some level of digital literacy, potentially influencing intervention preferences.

Study IV findings may have limited transferability given the sample was composed of all women and the majority of the sample had a white ethnic background. Future research should explore the specific needs and support experiences among caregivers with diverse genders and ethnic backgrounds. Additionally, the sample included caregivers of people living with CKD at any stage and receiving any type of treatment. However, needs and experiences receiving support may vary based on the CKD stage and treatment modality, therefore, future research should explore the specific needs of different sub-groups of CKD caregivers.

## Public contribution

This work may have benefitted from collaborative public contribution at all stages of the research process (e.g. selection of research questions, study design, analysis, and interpretation and dissemination of results). The public (e.g. caregivers, professional stakeholders) were involved as consultants in the work described above to inform (1) the interpretation of results in Study I; and (2) the development of study materials (e.g. recruitment materials, survey) in Study II. However, involvement occurred only within Studies I and II at one time-point, and related to only one stage of the research process, rather than sustained public contribution throughout each study. Studies III and IV did not include any public contribution activities. Involving the public throughout the research process, especially when decisions regarding research questions and study design were made, may have improved the quality and societal relevance of this work [244].

## Clinical implications and future directions

The results of this work provide a foundation for the development of an e-MH intervention for caregivers of people living with CKD. The information needs identified in Study II and IV can be used to inform intervention content, with Study II providing additional insights into preferred information delivery modes (e.g. having videos with experts, and support provision via email or in-person). The next steps based on this work could include creating intervention prototypes to facilitate the co-design of the e-MH intervention with caregivers and other stakeholders [257, 258]. Additionally, implementation barriers and facilitators identified in Study I and III could be used to guide the selection of implementation strategies to support future implemen-



tation initiatives [97]. Acceptability, feasibility, and implementation barriers and facilitators should continue to be explored as intervention development continues.

Findings of this work also highlight future directions that research focused on support for caregivers of people living with CKD or any other chronic health condition should consider.

## Caregiver support pathways

To implement interventions for caregivers, support pathways need to be developed. Currently, caregivers are not adequately integrated within healthcare teams [259–261], which can lead to variation in the provision of information and support [225, 261, 262]. Several barriers to the inclusion of caregivers into healthcare systems have been identified including challenges identifying caregivers, lack of time to address caregiver concerns, and communication challenges [52, 54, 230, 261–263]. Efforts to improve caregiver integration within healthcare teams such as education and healthcare professional training, policy and practice changes (e.g. establish system navigators for caregivers, incentivize healthcare professionals to support caregivers), and development of systems to screen/assess caregiver needs are necessary to ensure caregivers are identified and appropriate support referrals are made [54, 263, 264].

## Ensuring equitable access to support

Equitable support access was raised as an important consideration when developing e-MH interventions by both caregivers and professional stakeholders. Within physical and mental healthcare systems, individuals with low socioeconomic status and/or ethnic minority backgrounds commonly access fewer services, receive lower quality care, and experience more persistent mental health problems [265–267]. Among caregivers, low socioeconomic status and having an ethnic minority background are also associated with higher levels of burden and more unmet needs [250, 268–270]. Socioeconomic status, ethnic background, and other dimensions of equity (e.g. disability) are seldom considered when developing interventions for caregivers [249]. Therefore, although e-MH interventions have the potential to enhance access to mental health support by eliminating the need to travel to appointments and offering greater privacy, effort is still needed to ensure e-MH intervention access is equitable [56, 271].

Multiple strategies could be used to support equitable access to e-MH interventions for caregivers. To address the potential that e-MH interventions exclude caregivers with low digital literacy or lacking internet access, strate-

gies such as the provision of IT equipment, training on the use of technology and the e-MH intervention, and development of a non-digital version of the intervention could be used to improve access [271, 272]. To ensure e-MH interventions are acceptable to people with different ethnic backgrounds, caregivers with diverse ethnic backgrounds should be engaged during intervention development to ensure content is culturally appropriate and develop strategies to better reach caregivers with diverse ethnic backgrounds [273–275]. Use of equity frameworks (e.g. PROGRESS framework, INCLUDE ethnicity framework) may help ensure different dimensions of equity are considered during intervention development and implementation [233, 276].

### Non-profit organisations as a potential e-MH implementation setting

In connection with building caregiver support pathways and providing equitable support access, non-profit organisations should be considered as a potential implementation setting for e-MH interventions for caregivers. Non-profit organisations in the UK already provide some mental health support to caregivers and people living with various health conditions [106, 223], and are accessed by caregivers to obtain information related to informal care and the care recipients' health condition. Additionally, within this work (Studies II and III), non-profit organisations were the preferred implementation setting of an e-MH intervention for caregivers of people living with CKD and were the only setting potential implementers identified as having a mission aligned with supporting caregivers. The potential for non-profit organisations to enhance the reach of mental health interventions given these organisations are already used for informational support has been identified in the literature [277] and should be explored further in future work.

### Leveraging social networks

Social networks are an important tool that can be used throughout intervention development and implementation to guide implementation planning. The work within this thesis began to explore the social networks of caregivers and professionals, suggesting that social networks can be leveraged to support the implementation of e-MH interventions for caregivers. For example, social network analysis methods could be used to gain a more detailed understanding of social networks within implementing organisations to identify key network members (i.e. professionals connected to many other professionals) to engage in the delivery and/or dissemination of interventions, and caregiver social networks could be explored to identify potential referral pathways based on caregivers' sources of support [228, 229, 278, 279].

## Identifying implementation strategies

Strategically selecting evidence-based implementation strategies to support intervention implementation is a key step in the implementation process. The Expert Recommendations for Implementing Change provides a list of 73 implementation strategies which have been linked with constructs of the CFIR framework to facilitate implementation strategy selection based on which CFIR constructs are identified as presenting a barrier to implementation [97]. Other work has outlined which implementation strategies are best suited to different stages of the implementation process (e.g. strategies for identifying what intervention is needed, or how to integrate an intervention into existing practice) [280]. Using implementation strategies selected based on identified implementation barriers and/or the stage of the implementation process may enhance implementation of e-MH interventions for caregivers into practice. Selection and operationalization of implementation strategies to support e-MH implementation should be considered in future research.

# Conclusions

Key conclusions from this work are:

- I. Numerous barriers and facilitators to the implementation of e-MH interventions for caregivers reported in the literature related to the characteristics of the intervention and individuals who use the intervention. However, stakeholders need to be engaged further to explore barriers and facilitators related to the implementing organisation (e.g. compatibility of the intervention with work routines) and wider context (e.g. impact of external policies on implementation).
- II. CBT self-help interventions, preferably delivered using the internet, a workbook, or in-person, were an acceptable form of mental health support for caregivers of adults living with CKD. Designing interventions to support flexible intervention access, with content and support tailored to caring for someone living with CKD were important to enhance acceptability.
- III. An e-MH intervention could fit within existing healthcare delivery models and potential implementers' regular interactions with caregivers. However, barriers such as low capacity would need to be overcome to facilitate implementation. The preferences potential implementers had regarding the evidence-base, design, and training about the intervention should be considered when planning implementation and evaluation. The anticipated barriers and facilitators identified can be used to inform selection of implementation strategies to support implementation.
- IV. Caregivers experienced a number of challenges when seeking support from complex and poorly connected systems, causing caregivers to rely on their own skills to receive support. Despite these challenges, support was valued when it was perceived as empathetic and reliable. Interventions to support caregivers should be built to embody positive support qualities (e.g. empathy), fit within caregiver support networks, and facilitate equitable support access.

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