Implementing post diagnostic dementia care in primary care: A mixed-methods systematic review

Rachael Frost[1], Greta Rait[1], Su Aw[2], Greta Brunskill[3], Jane Wilcock[1], Louise Robinson[3], Martin Knapp[4], Nicole Hogan[4], Karen Harrison Dening[5], Louise Allan[6], Jill Manthorpe[7], Kate Walters[1] and on behalf of PriDem team

[1]Research Department of Primary Care and Population Health, University College London, London, UK

[2]Saw Swee Hock School of Public Health, National University of Singapore, Singapore.

[3]Population Health Sciences Institute, Newcastle University, Newcastle-upon-Tyne, UK.

[4]Care Policy and Evaluation Centre (CPEC), Department of Health Policy, London School of Economics and Political Science, London, UK

[5]Dementia UK, London, UK

[6]Institute of Health Research, University of Exeter Medical School

[7]NIHR Policy Research Unit on Health and Social Care Workforce, Kings College London, London, UK

Word count – 4990

Implementing post diagnostic dementia care in primary care: A mixed-methods systematic review

Abstract

Objectives: Concentrating post-diagnostic dementia care in primary care may lead to better and more cost-effective care closer to home. We aimed to assess which intervention components and contextual factors may contribute to the successful delivery and implementation of primary care-led post-diagnostic dementia care.

Methods: Mixed-methods systematic review. We searched five databases (inception-March 2019) with reference list screening and citation tracking. We included studies evaluating post-diagnostic dementia care interventions where primary care had a significant role in dementia care, which assessed one or more implementation elements (acceptability, feasibility, adoption, sustainability, reach, costs, appropriateness or fidelity). Two authors independently critically appraised studies.

Results: Out of 4528 unique references, we screened 380 full texts and included 49 evaluations of services collecting implementation process data. Most services had high acceptability ratings. The most acceptable components were information provision, social and emotional support and links to community organisations. Feasibility was chiefly influenced by provider engagement and leadership, building dementia care capacity, sufficient resources/funding and collaboration. Care quality was maximised through adding capacity from a dementia-specific health professional. On the basis of limited data, costs for various primary care-led models did not substantially differ from each other.

Conclusion: A range of primary care-led dementia care models appear feasible and acceptable. Future services should: add dementia-focussed health professionals into primary care, develop primary care leadership and provide sufficient funding and collaboration opportunities. Information, community service links and social and ongoing support should be part of services. Further exploration of service reach and formalised fidelity assessment are needed.

1   Introduction

Dementia is a syndrome including a range of cognitive, psychological and behavioural symptoms such as memory loss, reasoning or communication problems and personality changes, which progressively impair a person's ability to carry out activities of daily living (Pink et al., 2018). Approximately 43.8 million people worldwide are living with dementia (Nichols et al., 2019), and this is rising with increasing longevity. The later stages of dementia often require intensive health and social care support. Global costs are estimated at US$ 818billion, across medical, social and unpaid care (Prince et al., 2015). Considering this, the World Alzheimer Report (2016) recommended a task-shifted model of post-diagnostic dementia care, moving from secondary to primary care-led health care. Post-diagnostic dementia care encompasses initial treatment, continuing support and end of life care (Prince et al., 2016).

Primary care is defined as first-contact, accessible, continued, comprehensive and coordinated services (World Health Organisation, 2019). However, so far, the optimal way to provide these primary care-led dementia services is unclear and current guidelines do not favour any particular service model. Previous systematic and scoping reviews have found mixed results for primary care-led models, with suggestions that case management may improve some outcomes but with little ability to highlight effective components (Backhouse et al., 2017; Khanassov et al., 2014; Prince et al., 2016; Reilly et al., 2015).

However, even where dementia trials were successful, the services tested are not always implemented, for various reasons. As well as demonstrating effectiveness, it is important that new services can be implemented easily, as an intervention's effectiveness depends on it being sustained in practice (Proctor et al., 2011). Based on the diffusion of innovation model, one review found that low case management intensity, larger caseload and a reactive approach negatively influenced implementation of primary care case management, with a clear need to outline the necessary skills and responsibilities (Khanassov et al., 2014). A multitude of primary care models, in addition to adding case management roles, have been implemented worldwide, e.g. Primary Care Memory Clinics in Canada (Lee, Hillier, Heckman, et al., 2014) and the Gnosall Memory Clinic in the UK (Benbow et al., 2013). Data collected from even limited evaluations of these services may offer important messages for developing new primary care-led services.

Considering this, our review aimed to explore intervention components and contextual factors that appear to contribute to delivery and successful implementation of primary care-led post-diagnostic dementia care.

2   Methods

We undertook a mixed-methods systematic review. The protocol is registered on Prospero (ID CRD42018104128). In light of the heterogeneous data collected across studies, we included those which measured any aspect of Proctor et al's (2011) implementation framework (Proctor et al., 2011) (Table 1) to provide a more complete picture. The framework was modified to incorporate qualitative data reflecting feasibility (not listed in Proctor et al 2011).

[table 1 about here]

2.1   Inclusion criteria

- Studies of services providing multicomponent post-diagnostic dementia care which was led, coordinated by or substantially involved a primary care provider in the care of a person living with dementia ('substantially involved' defined as active participation in decisions regarding one or more aspects of the person's care)
- Studies providing process data on any implementation dimension, as defined by Proctor et al (2011) after delivering a service in a trial or real-world situation (see Table 1). This could include service evaluations (evaluations assessing how well a service is achieving its intended aims, with the aim of judging the current service only, to benefit the people using that service and to inform local decision-making (Twycross & Shorten, 2014)) in addition to formal research projects.

Exclusion criteria:

- Studies of secondary care-led interventions (i.e. healthcare provided in hospitals (National Institute for Health and Care Excellence, 2020)); interventions with no to minimal primary care involvement (e.g. community-based dementia case management with a single letter to the primary care provider); care home staff-led interventions; interventions focused on improving diagnosis rates or dementia prevention; educational interventions focused on increasing professional knowledge, confidence or adherence to guidelines
- Studies to develop interventions (e.g. exploratory qualitative work), reviews, cost-only modelling studies, standalone surveys, quality improvement initiatives, descriptions of intervention implementation where data were not formally collected and analysed (e.g. the authors' experiences of implementing a service)

2.2 Searches

We searched MEDLINE, PsychINFO, EMBASE, Web of Science and CINAHL (inception to March 2019) and deduplicated studies using Mendeley. One author (XX or YY) screened titles and abstracts, with 10% checked independently by a second reviewer (XX or YY). Two authors (YY and XX or ZZ) screened all full texts, with disagreements resolved through discussion and consultation with two team members (WW and VV) where necessary. There were no language restrictions - full texts in another language were screened by a native speaker where possible, with results sections translated where necessary. We did not include full texts in another language if an English language full text was available.

One author (YY) screened reference lists and tracked citations of included papers and conducted searches of Ethos and trials registers. Protocols, trials register entries and conference abstracts were followed up through author searches and emails if the full text had not already been found through review searches.

2.3 Data extraction and quality assessment

Data were extracted on study type, sample, intervention characteristics (according to the TIDIER checklist (Hoffmann et al., 2014)) into a form designed for this review. Two authors (YY and ZZ) assessed study quality using the Cochrane Risk of Bias Tool (Higgins et al., 2011) for RCTs; ROBINS-I for non-randomised interventional studies (Sterne et al., 2016); Critical Appraisal Skills Programme checklist for qualitative and mixed-methods studies (Critical Appraisal Skills Program, 2010); National Institute for Health tool for pre-post test studies (NIH National Heart Lung and Blood Institute, 2019); Mixed Methods Appraisal Tool (MMAT) for quantitative descriptive studies (Hong et al.,

2018); and Consensus on Health Economic Criteria checklist (Evers et al., 2005) for economic evaluations. Disagreements were resolved through discussion and related largely to checklist interpretation rather than the strengths and weaknesses of individual studies.

2.4   Synthesis

Models of care were classified independently by two authors (YY and ZZ) and refined through discussions with VV and WW. Both independently classified interventions according to the configuration of healthcare professionals involved, with specialist care defined as a specific branch of medicine that could be based in either hospital or community settings. We intended to use this as a framework to compare different implementation aspects, however due to the consistency of findings across models, we draw upon these only where differences were evident.

We used Proctor et al's (2011) framework of implementation outcomes (Table 1) to organise our data. Quantitative data were tabulated and narratively synthesised, following the Centre for Reviews and Dissemination (2008) framework for narrative synthesis. Qualitative data were coded inductively in NVivo 12 (QSR International Pty Ltd., 2018) by YY. The thematic descriptive framework generated was reviewed by ZZ (who had read all studies as part of quality assessment) and agreed with a small number of codes added. Analytical themes were developed and discussed across the main research team (YY, VV, WW).

3   Results

Out of 4528 titles and abstracts, we screened 377 full texts and included 68 papers, of which 49 provided primary data and 19 provided supplementary information (e.g. protocols, service descriptions) (Figure 1). The 49 papers were of 38 separate studies (e.g. RCT paper and associated process evaluation) evaluating 27 different services.

[Figure 1 about here]

3.1   Summary of included studies

Implementation studies were all evaluations that included data on any of the implementation outcomes. Studies were quantitative (n=37), mixed-methods (n=6) or qualitative (n=6). Twelve were RCTs with associated process data, 10 were quasi-experimental studies with process data, 21 were service evaluations (11 quantitative, six qualitative, four mixed methods) and six were pre-post test studies with process data.

Studies were carried out in the US (n=19), Germany (n=8), UK (n=6), Canada (n=8), Netherlands (n=5), Singapore (n=2) and Sweden (n=1). Studies included a variety of models that could be configured according to healthcare professional, including those led solely by a primary care provider (n=7, PCP); those led by a primary care provider (PCP) with additional process improvements such as structured visit notes (n=2, PCP+); those led by a primary care provider with increased consulting support from a specialist, e.g. neurologist (n=4, PCP-SP); local collaborative networks of dementia care (typically including primary care physicians, practice nurses, case managers, and community nurses but including representation from medical, care and welfare staff, n=3, network); case managers collaborating closely with primary care providers (N=20, PCP-CM); primary care based dementia clinics (n=12, PCDC, which could include specialists working in a primary care setting with PCPs for a clinic, or training up PCPs to become more specialised in dementia with support from a specialist); and shared group visits (n=1, SGV).

3.2 Quality

The overall quality of the evidence was highly variable. All RCTs had at least three domains at low risk of bias, with one to three domains at high risk (Appendix 2, Table 1). Participant blinding could not be achieved in any study. Quasi-experimental controlled studies were generally poor quality (at serious to critical risk of bias) (Appendix 2, Table 2). Quantitative service evaluations were of moderate quality (Appendix 2, Table 3), whilst service evaluations using primarily qualitative or mixed methods approaches were better quality, with most meeting all criteria apart from reflexivity (Appendix 2, Table 4). Pre-post test studies were of poor quality overall (Appendix 2, Table 5). Economic evaluations associated with trials met the majority of quality criteria; those calculating healthcare costs from services met fewer, but still most, of the criteria (Appendix 2, Table 6).

3.3 Feasibility and adoption

Ten studies assessed feasibility quantitatively (Table 2). Only one study concluded a case manager based in primary care was not feasible, in a UK context (Iliffe, Robinson, et al., 2014), due to recruitment and implementation difficulties, although it is likely that other models demonstrating a lack of feasibility are not published.

Case manager referral rates from PCPs were moderate across two studies (49% (Reuben et al., 2013a); 63.6% (Menn et al., 2012)) (Table 2) and seemed to depend highly on PCP engagement (Menn et al., 2012; Reuben et al., 2013a). Some case management services documented appointments attended, which were sufficient in three US studies (Callahan et al., 2006; Fortinsky et al., 2014; Mavandadi et al., 2017), but low in one UK study, with high variation by case manager (Iliffe, Robinson, et al., 2014). Primary care memory clinics had on average 48.6 patients per clinic and saw patients an average of 1.2 times over an average of nine and a half months (Lee, Hillier, Heckman, et al., 2014), with only 2/22 patients not attending appointments in one UK service evaluation (Greening et al., 2009). One study documented an average of 1.5 month wait time to assessment across 1113 patients (Lee et al., 2017).

[table 2 about here]

Uptake of other components besides case management could be fairly low, including (unpaid) carer education (Mavandadi et al., 2017; Noel et al., 2017), support groups (Callahan et al., 2006; Menn et al., 2012; Noel et al., 2017)) and community service referrals (<20% before and after case management (Cherry et al., 2004)). Services including specialist consulting support for PCPs did not increase the additional support services utilised compared to usual PCP care (Menn et al., 2012). There was mixed evidence as to whether primary care-led services had significant differences compared to specialist-led care with regards to referral to community and home care services (Aupperle, Blume, MacPhee, Sanchez, & Coyne, 2004; Aupperle & Coyne, 2000; Garcia-Ptacek et al., 2017; Meeuwsen, Melis, Meulenbroek, & Olde Rikkert, 2014; Parmar et al., 2014).

3.4 Sustainability

Six studies of three types of services provided quantitative sustainability data (Table 3). Overall information on sustainability was limited. There were high levels of sustainability for between six and 23 months in one primary care dementia clinic in Canada across three service evaluations (Lee et al., 2017; Lee, Hillier, & Weston, 2014; Lee, Hillier, Heckman, et al., 2014). Most dementia networks were sustained in one multiple case study (14/17) (Richters et al., 2018) and those that *were* sustained showed better integration scores per year. However, involvement in comprehensive PRODEM services varied over seven years and related primarily to funding (Hesse, 2005). One study

which looked at the sustainability of components in a primary care-led model found that the only sustainable component was referrals to local Alzheimer's or dementia associations (Reuben et al., 2010).

[table 3 about here]

3.5   Feasibility and sustainability: qualitative data

There were eight studies reported in nine papers contributing qualitative data regarding feasibility and sustainability. Studies evaluated primary care dementia clinics (n=4), collaborative network approaches (n=2), primary care-led approaches with specialist support for consultation (n=1) or case management partnership models (n=1 study, 2 papers).

3.5.1   Primary care engagement and leadership.

Greater primary care physician leadership was associated with feasibility, sustainability (Iliffe, Waugh, et al., 2014) and meeting quality improvement goals (Richters et al., 2018):

> *Patterns showed that networks with highly involved PPs [primary providers] performed better than those without or with only little involvement.* (Richters et al., 2018)

This was particularly important where additional services were being provided in primary care (e.g. case management) as referral or endorsement affected uptake of these services (Menn et al., 2012; Reuben et al., 2013a). Engagement varied widely between individual physicians despite good awareness of the services provided (Lee, Hillier, & Weston, 2014), and was influenced by financial incentives (although these were not sustainable (Hesse, 2005)) and leadership by other primary care physicians (Lee et al., 2010):

> *A physician champion was perceived as important for the successful establishment and sustainability of a memory clinic. This physician secured support from other physicians within the practice and instilled confidence among patients and their families as well as among the interprofessional team members interested in the care of elderly adults.* (Lee et al., 2010)

Two lead primary care physicians to coordinate a dedicated dementia clinic and work with services whilst sharing the workload was considered ideal (Lee, Hillier, & Weston, 2014).

3.5.2   Resources and funding

Primary care-led dementia care was considered a better and more efficient use of healthcare resources (Iliffe, Waugh, et al., 2014; Lee, Hillier, & Weston, 2014; Lee, Hillier, Heckman, et al., 2014; Richters et al., 2018), although in one UK study staff were sceptical that it may instead represent a cost-saving exercise (Dodd et al., 2015). Models in which PCPs felt their own time was saved were those that were felt to be most feasible (Bamford et al., 2014; Dodd et al., 2015; Lee et al., 2010; Lee, Hillier, Heckman, et al., 2014), and care coordination was considered to be difficult to provide by primary care providers alone with no further support (Dodd et al., 2015). Services based on a template required less resources to implement:

> *Having the tool kit was a big help. We just took and ran with it. It [memory clinic] wasn't a huge project to establish. It didn't take a huge amount of resources just to get it going. [IDA11#2]* (Lee, Hillier, & Weston, 2014)

As may be expected, adequate service funding was a major determinant of feasibility and particularly sustainability, which could be affected by the level of local area support (Hesse, 2005; Lee, Hillier, & Weston, 2014; Michalowsky et al., 2017). Staffing problems were common, such as lack of some professionals, insufficient administrative support or time slots (Lee, Hillier, & Weston, 2014), or finding case management time amongst other roles (Iliffe, Waugh, et al., 2014):

> *…primary care colleagues rarely recognized the legitimacy of time spent on case management, creating additional difficulties: "with (Case Manager 4) for example, the last time I went to see her she was pulled out to do two practical procedures in the middle of our meeting, even though they knew I was doing supervision" (Mentor)* (Bamford et al., 2014)

Urban settings with higher provider density appeared to lead to more sustainable dementia networks in Germany (Michalowsky et al., 2017), but this was not the case for integrated clinics in Canada, which were implemented successfully in rural areas (Lee et al., 2017). One Dutch study suggested practices with smaller catchment areas were able to collaborate more closely as these were less complicated environments involving fewer professionals who were more familiar to each other (Richters et al., 2018).

3.5.3 Building primary care dementia capacity

Healthcare professionals felt capacity was best increased in primary care through facilitating access to consultative specialist support for supervision and for complex cases (Dodd et al., 2015; Lee, Hillier, & Weston, 2014; Lee & Hillier, 2016; Richters et al., 2018; Sheiban et al., 2018), rather than extra training, which had associated practical difficulties regarding time and attendance (Dodd et al., 2015). Training was mainly considered valuable when focussed practically on how to replicate service delivery in their own practice (Lee, Hillier, & Weston, 2014). Access to specialist expertise was associated with feelings of increased PCP confidence and knowledge (Iliffe, Waugh, et al., 2014; Lee et al., 2017; Lee & Hillier, 2016; Richters et al., 2018):

> *The PCCMCs [primary care collaborative memory clinics] were viewed as assisting family physicians with challenging aspects of care such as assessing fitness to drive and identifying appropriate community services and supports for patients and caregivers.* (Lee & Hillier, 2016)

3.5.4 Collaboration

Close collaboration within and between primary care and specialist care was considered essential to making services work (Iliffe, Waugh, et al., 2014; Lee, Hillier, & Weston, 2014; Lee, Hillier, Heckman, et al., 2014; Richters et al., 2018; Sheiban et al., 2018). Long lasting collaborations could facilitate improvements in dementia, whilst divergent visions for care provision inhibited quality improvement (Richters et al., 2018). This was particularly important where case managers and PCPs needed to closely collaborate (Iliffe, Waugh, et al., 2014):

> *Good communication among all professions facilitated the implementation of the clinics' model so that each member was comfortable to provide input into the discussion of the assessment results and treatment recommendations.* (Lee, Hillier, & Weston, 2014)

One key facilitator was sharing the same IT system, particularly across different sectors (Lee et al., 2019; Lee & Hillier, 2016; Richters et al., 2018) and having sufficient administrative support (Iliffe, Waugh, et al., 2014; Lee, Hillier, & Weston, 2014). One study developed its own information system, including a structured decision aid, which was received well by case managers (Eichler, Thyrian, Fredrich, et al., 2014). Another key element was role clarity, although there were reports of difficulties knowing how involved different staff members should be in different processes and concerns raised about overlap with other services or existing roles (Bamford et al., 2014; Dodd et al., 2015; Iliffe, Waugh, et al., 2014).

3.6   Acceptability and appropriateness: quantitative data

Seventeen studies collected quantitative acceptability data (Table 4). Acceptability was most frequently assessed for models of memory clinics delivered in primary care and case management partnership models. High ratings were given across all service types, indicating that a range of models is acceptable to people living with dementia, carers and primary care physicians. A small number of studies compared case management models to baseline or to a usual primary care control group and found higher satisfaction levels.

[table 4 about here]

3.7   Appropriateness of a primary care setting: qualitative data

Eight papers of seven studies qualitatively explored the appropriateness of primary care dementia services. Primary care-led post-diagnostic care was considered appropriate due to the local location (Greening et al., 2009; Iliffe, Waugh, et al., 2014; Lee et al., 2017, 2018; Lee, Hillier, Heckman, et al., 2014; Lee & Hillier, 2016) and the potential for more holistic and comprehensive services:

> *"I think just the ability to have a one stop sort of intensive visit that incorporates the medical story and the family story and the social setting, and sort of looking at all of that in one sitting for a comprehensive plan is certainly the most beneficial part of that"* (Lee & Hillier, 2016)

One study concluded that primary care may not be the most appropriate setting for case management given multiple barriers to implementation (such as poor integration with the primary care team, lack of time around other duties), despite positive evaluations from service users (Bamford et al., 2014). Primary care was considered most suitable where dementia cases were less complex (Dodd et al., 2015). More positive views tended to be from service configurations where additional professionals were integrated into primary care. Where care was provided by existing healthcare professionals with little additional support or training, there were concerns that primary care was mostly appropriate only for more straightforward cases of dementia (i.e. not young onset, comorbidities or accompanying psychosis), could include limited post-diagnostic support or might represent a cost saving exercise rather than an improvement in patient care (Dodd et al., 2015).

3.8   Acceptability: qualitative data

Twelve papers from nine studies (Bamford et al., 2014; Clark et al., 2013; Dodd et al., 2015; Greening et al., 2009; Iliffe, Robinson, et al., 2014; Iliffe, Waugh, et al., 2014; Khandelwal et al., 2015; Lee, Hillier, Heckman, et al., 2014; Lee et al., 2017, 2018; Lee, Hillier, & Weston, 2014; Sheiban et al., 2018) contributed to the qualitative acceptability analysis (Table 5). This data primarily came from primary care dementia clinic services and services where a case manager worked in partnership with primary care staff.

[table 5 about here]

3.9   Fidelity and service content delivered

Sixteen studies contained process data assessing fidelity or intervention content delivered (Table 6). Most of these related to documenting care processes and quality rather than comparing how well an intervention was delivered compared to a service manual. Some studies involving case managers documented processes of care: 4/8 non-pharmacological protocols were triggered per patient in one large US RCT (Callahan et al., 2006); at least one case management action was recorded for 32% of people with dementia's unmet needs and 50% carers' unmet needs in a small UK feasibility study (Iliffe, Robinson, et al., 2014); and the great majority of those at the end of life had at least one goal of care conversation documented (Jennings, Turner, et al., 2019). Common areas for triggering response included behavioural symptoms (Callahan et al., 2006), financial and legal support and physical wellbeing and medication support (Iliffe, Robinson, et al., 2014). Daily living support was least likely to have an action recorded (Iliffe, Robinson, et al., 2014). There were lower levels of anti-dementia medication prescribing compared to specialist care (Aupperle et al., 2004; Aupperle & Coyne, 2000; Garcia-Ptacek et al., 2017; Meeuwsen et al., 2014), but these were greater when further support was added to primary care (Callahan et al., 2006; Kohler et al., 2014; Lee, Hillier, Heckman, et al., 2014).

The ability to improve quality scores in PCP-led care alone, e.g. through structured visit notes and educational materials, was limited (Belmin et al., 2012; Reuben et al., 2010). Adding a case manager led to higher care quality than a primary care provider alone, regardless of whether or not additional specialist input was present (Ament et al., 2015; Cherry et al., 2004; Jennings et al., 2016; Reuben et al., 2010, 2013b), and typically case managers scored highly on care quality assessments (Jennings et al., 2016; Noel et al., 2017). There were no clear patterns in which aspect of care improved most. Third sector referrals were also associated with higher quality scores (65% vs 41%) (Reuben et al., 2010). Use of a digital information system to structure assessment by a dementia care manager was associated with identifying more areas to intervene (5.75 vs 1.64 per person with dementia) (Eichler, Thyrian, Dreier, et al., 2014). Other service types, such as primary care dementia clinics, did not provide data on maximising care quality and fidelity.

[table 6 about here]

3.10   Costs - economic evaluations

Six studies included economic analyses of sufficient quality to draw conclusions (Table 7). Two were randomised trials, neither reporting any health (or health and social care) cost differences between primary care provider-led care and <mark>memory clinic care, or primary care provider-led care with and without specialist consulting support</mark>. The non-randomised studies suggested cost savings for primary care-led approaches relative to the various comparators, but only one examined cost-effectiveness compared to memory clinic care; and a randomised trial showed that, although memory clinics are cheaper than usual PCP care, the latter is more effective. Intervention costs for case management primary care dementia clinics were more cost-effective than memory clinics in a Singaporean case-control trial (Saxena et al., 2018). Two additional studies reported basic intervention costs for primary care led approaches involving case managers ($1000 per patient/year in one RCT (Callahan et al., 2006), and $1279 per patient/year in one service evaluation (Noel et al., 2017)).

[table 7 about here]

3.11 Reach

No studies compared the demographics of those including/receiving the service with the eligible population in the local area.

4 Discussion

We reviewed 49 studies collecting process data on interventions where primary care had a leading or substantive role in dementia care, across a range of (mostly high income Western) countries. Most services had high acceptability ratings, across a range of models. Qualitative data suggested a comprehensive approach including information, social and emotional support and links to third sector services was the most acceptable. Maximising care quality appeared to be most feasible through adding in other disciplines rather than through practice changes to improve PCP-led care. Little fidelity data was available. Feasibility was primarily influenced by: primary care provider engagement and leadership, building capacity for primary care dementia care, resources and funding and collaboration. Costs for PCP-CM and PCDC models were typically either similar or led to modest cost savings in the studies compared to usual primary care or memory clinics. Only one study found a cost-effectiveness difference.

Similar factors affect the implementation of dementia case management approaches with differing levels of primary care professional involvement. Communication and collaboration were identified as key factors, with optimal implementation recommended to be high intensity case management with a caseload of 50-60 dyads/case manager (Khanassov et al., 2014). Grey literature from local UK primary care dementia service evaluations confirm our findings that primary care engagement is a key factor and highlight further issues such as staff turnover, defining staff remit and problems around integrating computer systems (Bristol Dementia Wellbeing Service, 2016; Gill, 2016). In a realist review of primary care chronic care models, clear protocols for disease management were associated with effective management, whilst team-based approaches were more successful when they had highly skilled members, good communication, opportunities to collaborate, training and dedicated members to support patients or providers (Kastner et al., 2018). Kastner et al also found that having a case manager as a primary contact was more successful than a primary care professional. Within another review, caseload, location and contact level did not impact upon effectiveness; only lack of supervision and a nurse case manager improved effectiveness (Backhouse et al., 2017). Most services in this current review were highly acceptable on quantitative ratings, however, few studies had a control so it is difficult to draw conclusions from this.

Our review took a rigorous approach to literature searching and drew upon a range of study types and information to develop a comprehensive body of evidence. We did not restrict searches or inclusion by language. In contrast to many reviews focussing solely on primary care case management, we included evidence from a wider range of models. We also used an implementation framework to organise results and draw clear conclusions in each area. However, this was challenging given the conceptual overlap in primary study (particularly qualitative) data. Few studies were designed to collect implementation data and most were of limited quality. There is also a high likelihood of publication bias, particularly for smaller service evaluations – those that were unsuccessful or not re-commissioned are unlikely to have been written up and published. Similarly, service evaluations are more likely to be published in the language of origin and may not have been located through our searches, so the results are most likely to apply to UK, US and Canadian populations. It should also be noted that the countries included cover a range of types of healthcare

system and have different underlying social and political forces that are likely to affect implementation of dementia services. However, as the primary studies included in this review often focussed on local funding and resource issues, we were unable to clearly illuminate these wider societal factors. We did not conduct thorough grey literature searches, although some reports were identified through reference list screening.

The main finding arising from this review is that similar factors influence primary care-led dementia service implementation, regardless of whether this is a case management intervention or a primary care dementia clinic. To improve feasibility, service quality and sustainability, new primary care led dementia services need to consider adding specialist dementia staff or clinic time into primary care, to provide dedicated dementia expertise for patient contact and build expertise in existing staff through providing consultations where needed. Current cost and quality data suggest that adding further specialist support into primary care through the addition of a healthcare professional is not likely to cost significantly more, and in some models may present modest cost savings. However, economic data on this topic are still limited at present and conclusions may change in the future, particularly across different healthcare systems. This approach is likely to be more acceptable to professionals than providing dementia training, although training on new service implementation appears to be valued. In addition, clear collaborative structures and good leadership from primary care physicians needs to be in place for these approaches to be successful. The most acceptable services were those with good community service links, who could provide information and social and emotional support over time.

No studies evaluated service reach and few formally assessed fidelity to a service manual. Further studies need to evaluate these areas of implementation, particularly whether primary care-led services might increase or reduce service accessibility or inequalities for the wider local population affected by dementia, and whether they can be consistently delivered to an adequate level.

5   Conclusion

From this review of 49 studies, we found that common factors affect the feasibility and sustainability of primary care-led dementia services, regardless of care model: building dementia care capacity, primary care engagement and leadership, resources and funding and collaboration. Maximising fidelity and care quality appears to be most feasible through adding dementia-focussed healthcare professionals into primary care services rather than through trying to change the practice of primary care providers. . Different models are acceptable, providing they deliver information, links to community services and social and ongoing support. There may be some modest health and social care cost savings. Further work on the reach of services needs to be undertaken.

Supplementary files

1. List of search terms
2. Quality tables
   a. Table 1 Risk of bias summary for trials
   b. Table 2 Risk of bias summary for non-randomised intervention studies
   c. Table 3 Mixed Methods appraisal tool ratings for descriptive quantitative studies
   d. Table 4 CHEC ratings for economic evaluations
   e. Table 5 CASP ratings for qualitative research

f. Table 6 NIH Before and after study ratings

6 References

Ament, B. H. L., Wolfs, C. A. G., Kempen, G. I. J. Md., Ambergen, T., Verhey, F. R. J., & Vugt, M. E. (2015). The benefit of a geriatric nurse practitioner in a multidisciplinary diagnostic service for people with cognitive disorders. *BMC Research Notes*, *8*(1), 1–7. https://doi.org/10.1186/s13104-015-1189-6

Aupperle, P. M., Blume, J., MacPhee, E. R., Sanchez, B., & Coyne, A. C. (2004). Health Service Utilization by Alzheimer's Disease Patients: A 2-Year Follow-Up of Primary Versus Subspecialty Care. *Journal of Geriatric Psychiatry and Neurology*, *16*(1), 15–17. https://doi.org/10.1177/0891988702250507

Aupperle, P. M., & Coyne, A. C. (2000). Primary vs. subspecialty care: A structured follow-up of dementia patients and their caregivers. *American Journal of Geriatric Psychiatry*, *8*(2), 167–170. https://doi.org/10.1097/00019442-200005000-00012

Austrom, M. G., Hartwell, C., Moore, P., Perkins, A. J., Damush, T., Unverzagt, F. W., Boustani, M., Hendrie, H. C., & Callahan, C. M. (2006). An integrated model of comprehensive care for people with Alzheimer's disease and their caregivers in a primary care setting. *Dementia*, *5*(3), 339–352. https://doi.org/10.1177/1471301206067108

Backhouse, A., Ukoumunne, O. C., Richards, D. A., McCabe, R., Watkins, R., & Dickens, C. (2017). The effectiveness of community-based coordinating interventions in dementia care: a meta-analysis and subgroup analysis of intervention components. *BMC Health Services Research*, *17*(1), 717. https://doi.org/https://dx.doi.org/10.1186/s12913-017-2677-2

Bamford, C., Poole, M., Brittain, K., Chew-Graham, C., Fox, C., Iliffe, S., Manthorpe, J., & Robinson, L. (2014). Understanding the challenges to implementing case management for people with dementia in primary care in England: A qualitative study using Normalization Process Theory. *BMC Health Services Research*, *14*(1), 1–12. https://doi.org/10.1186/s12913-014-0549-6

Belmin, J., Min, L., Roth, C., Reuben, D., & Wenger, N. (2012). Assessment and management of patients with cognitive impairment and dementia in primary care. *Journal of Nutrition, Health and Aging*, *16*(5), 462–467. https://doi.org/10.1007/s12603-012-0026-z

Benbow, S., Jolley, D., Greaves, I., & Walker, E. (2013). Closing the diagnosis gap and improving care: The primary care memory clinic. *Progress in Neurology and Psychiatry*, *17*(6), 27–30.

Bristol Dementia Wellbeing Service. (2016). *Bristol Dementia Wellbeing Service*.

Callahan, C. M., Boustani, M. a, Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., Fultz, B. A., Hui, S. L., Counsell, S. R., & Hendrie, H. C. (2006). Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*, *295*(18), 2148–2157. https://doi.org/10.1001/jama.295.18.2148

Centre for Reviews and Dissemination. (2008). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. University of York. http://www.thelancet.com/pdfs/journals/laninf/PIIS1473309910700657.pdf

Cherry, D. L., Vickrey, B. G., Schwankovsky, L., Heck, E., & Yep, R. (2004). Interventions to Improve Quality of Care: The Kaiser Permanente–Alzheimer's Association Dementia Care Project. *The American Journal Of Managed Care*, *10*, 553–560.

Clark, M., Moreland, N., Greaves, I., Greaves, N., & Jolley, D. (2013). Putting personalisation and integration into practice in primary care. *Journal of Integrated Care*, *21*(2), 105–120. https://doi.org/10.1108/JFM-03-2013-0017

Critical Appraisal Skills Program. (2010). *Making sense of evidence about clinical effectiveness: 10 questions to help you make sense of qualitative research*. http://www.casp-uk.net/wp-content/uploads/2011/11/CASP_Qualitative_Appraisal_Checklist_14oct10.pdf

Dodd, E., Fear, T., Cheston, R., Ismail, S., Gatting, L., Jefferies, R., Gray, R., & Cullum, S. (2015). Primary care-led dementia diagnosis services in South Gloucestershire: Themes from people and families living with dementia and health care professionals. *Dementia*, *15*(6), 1586–1604. https://doi.org/10.1177/1471301214566476

Donath, C., Grässel, E., Grossfeld-Schmitz, M., Menn, P., Lauterberg, J., Wunder, S., Marx, P., Ruckdäschel, S., Mehlig, H., & Holle, R. (2010). Effects of general practitioner training and family support services on the care of home-dwelling dementia patients--results of a controlled cluster-randomized study. *BMC Health Services Research*, *10*(1), 314. https://doi.org/10.1186/1472-6963-10-314

Eichler, T., Thyrian, J. R., Dreier, A., Wucherer, D., Köhler, L., Fiß, T., Böwing, G., Michalowsky, B., & Hoffmann, W. (2014). Dementia care management: Going new ways in ambulant dementia care within a GP-based randomized controlled intervention trial. *International Psychogeriatrics*, *26*(2), 247–256. https://doi.org/10.1017/S1041610213001786

Eichler, T., Thyrian, J. R., Fredrich, D., Köhler, L., Wucherer, D., Michalowsky, B., Dreier, A., & Hoffmann, W. (2014). The benefits of implementing a computerized Intervention-Management-System (IMS) on delivering integrated dementia care in the primary care setting. *International Psychogeriatrics*, *26*(8), 1377–1385. https://doi.org/10.1017/S1041610214000830

Evers, S., Goossens, M., de Vet, H., van Tulder, M., & Ament, A. (2005). Criteria list for assessment of methodological quality of economic evaluations: Consensus on Health Economic Criteria. *International Journal of Technology Assessment in Health Care*, *21*(2), 240–245. https://doi.org/10.1017.S0266462305050324

Fortinsky, R. H., Delaney, C., Harel, O., Pasquale, K., Schjavland, E., Lynch, J., Kleppinger, A., & Crumb, S. (2014). Results and Lessons Learned from a Nurse Practitioner-Guided Dementia Care Intervention for Primary Care Patients and Their Family Caregivers. *Research in Gerontological Nursing*, *7*(3), 126–137. https://doi.org/10.3928/19404921-20140113-01

French, B. D. D., Lamantia, M. A., Livin, L. R., Herceg, D., Alder, C. A., & Boustani, M. A. (2014). Healthy Aging Brain Center Improved Care Coordination And Produced Net Savings. *Health Affairs*, *4*, 613–618.

Garcia-Ptacek, S., Modéer, I. N., Kåreholt, I., Fereshtehnejad, S. M., Farahmand, B., Religa, D., & Eriksdotter, M. (2017). Differences in diagnostic process, treatment and social Support for Alzheimer's dementia between primary and specialist care: Resultss from the Swedish Dementia Registry. *Age and Ageing*, *46*(2), 314–319. https://doi.org/10.1093/ageing/afw189

Gill, A. (2016). *Transforming Dementia Care with the Golden Ticket: Qualitative Service Evaluation. The Patient, Carer and Staff Experience*.

Greening, L., Greaves, I., Greaves, N., & Jolley, D. (2009). Positive thinking on dementia in primary care: Gnosall Memory Clinic. *Community Pract*, *82*(5), 20–23.

Grossfeld-Schmitz, M., Donath, C., Holle, R., Lauterberg, J., Ruckdaeschel, S., Mehlig, H., Marx, P., & Wunder, S. (2010). Counsellors contact dementia caregivers--predictors of utilisation in a longitudinal study. *BMC Geriatrics*, *10*, 24.

Hesse, E. (2005). PRO DEM: A Community-Based Approach to Care for Dementia. *Health Care*

Financing Review, *27*(1), 89–94.

Higgins, J., Altman, D., Gotzsche, P., Juni, P., Moher, D., Oxman, A., Savovic, J., Schulz, K., Weeks, L., & Sterne, J. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*, *343*, d5928. https://doi.org/10.1136/bmj.d5928

Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., Altman, D. G., Barbour, V., Macdonald, H., Johnston, M., Lamb, S. E., Dixon-Woods, M., McCulloch, P., Wyatt, J. C., Chan, A.-W., & Michie, S. (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ*, *348*(March), g1687. https://doi.org/10.1136/bmj.g1687

Hong, Q. N., Pluye, P., Sergi, F., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Marie-Pierre, G., Griffiths, F., B, N., O'Cathain, A., Rousseau, M.-C., & Vedel, I. (2018). Mixed Methods Appraisal Tool (MMAT), version 2018. *McGill Department of Family Medicine*, 1–11. http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf

Iliffe, S., Robinson, L., Bamford, C., Waugh, A., Fox, C., Livingstone, G., Manthorpe, J., Brown, P., Stephens, B., Brittain, K., Chew-Graham, C., & Katona, C. (2014). Introducing case management for people with dementia in primary care: a mixed-methods study. *British Journal of General Practice*, *64*(628), e735–e741. https://doi.org/10.3399/bjgp14x682333

Iliffe, S., Waugh, A., Poole, M., Bamford, C., Brittain, K., Chew-Graham, C., Fox, C., Katona, C., Livingston, G., Manthorpe, J., Steen, N., Stephens, B., Hogan, V., Robinson, L., Austin, A., Katona, C., Bamford, C., Poole, M., Steen, N., … Knapp, M. (2014). The effectiveness of collaborative care for people with memory problems in primary care: Results of the CAREDEM case management modelling and feasibility study. *Health Technology Assessment*, *18*(52). https://doi.org/10.3310/hta18520

Jennings, L. A., Laffan, A. M., Schlissel, A. C., Colligan, E., Tan, Z., Wenger, N. S., & Reuben, D. B. (2019). Health Care Utilization and Cost Outcomes of a Comprehensive Dementia Care Program for Medicare Beneficiaries. *JAMA Internal Medicine*, *179*(2), 161–166. https://doi.org/10.1001/jamainternmed.2018.5579

Jennings, L. A., Tan, Z., Wenger, N. S., Cook, E. A., Han, W., McCreath, H. E., Serrano, K. S., Roth, C. P., & Reuben, D. B. (2016). Quality of Care Provided by a Comprehensive Dementia Care Comanagement Program. *Journal of the American Geriatrics Society*, *64*(8), 1724–1730. https://doi.org/10.1111/jgs.14251

Jennings, L. A., Turner, M., Keebler, C., Burton, C. H., Romero, T., Wenger, N. S., & Reuben, D. B. (2019). The Effect of a Comprehensive Dementia Care Management Program on End-of-Life Care. *Journal of the American Geriatrics Society*, *67*, 443–448. https://doi.org/https://dx.doi.org/10.1111/jgs.15769

Kastner, M., Cardoso, R., Lai, Y., Treister, V., Hamid, J. S., Hayden, L., Wong, G., Ivers, N. M., Liu, B., Marr, S., Holroyd-Leduc, J., & Straus, S. E. (2018). effectiveness of interventions for managing multiple high-burden chronic diseases in older adults: A systematic review and meta-analysis. *Cmaj*, *190*(34), E1004–E1012. https://doi.org/10.1503/cmaj.171391

Khanassov, V., Vedel, I., & Pluye, P. (2014). Case management for dementia in primary health care: A systematic mixed studies review based on the diffusion of innovation model. *Clinical Interventions in Aging*, *9*, 915–928. https://doi.org/10.2147/CIA.S64723

Khandelwal, C. M., Prentice, A., Fisher, J., Parrott, R., & Sloane, P. (2015). Treating dementia with shared group visits. *Family Practice Management*, *MAY-JUNE2015*, 16–21.

Klingenberg, A., Szecsenyi, J., Hesse, E., Habs, M., Schaper, G., Bolley, J., & Kreisch, M. (n.d.). *PRO DEM - ein Projekt zur regionalen Versorgung Demenzkranker und ihrer pflegenden Angehörigen Erfahrungen und Ergebnisse*.

Kohler, L., Meinke-Franze, C., Hein, J., Fendrich, K., Heymann, R., Thyrian, J., & Hoffmann, W. (2014). Does an Interdisciplinary Network Improve Dementia Care? Results from the IDemUck-Study. *Current Alzheimer Research*, *11*(6), 538–548. https://doi.org/10.2174/1567205011666140618100727

Lai, S. H., Tsoi, T., Tang, C. T., Hui, R. J. Y., Tan, K. K., Yeo, Y. W. S., & Kua, E. H. (2019). An integrated, collaborative healthcare model for the early diagnosis and management of dementia: Preliminary audit results from the first transdisciplinary service integrating family medicine and geriatric psychiatry services to the heart of patients' ho. *BMC PSYCHIATRY*, *19*. https://doi.org/10.1186/s12888-019-2033-7

Lee, L., & Hillier, L. M. (2016). Family physicians' perspectives on memory clinics in primary care. *Neurodegenerative Disease Management*, *6*(6), 467–478. https://doi.org/10.2217/nmt-2016-0031

Lee, L., Hillier, L. M., Heckman, G., Gagnon, M., Borrie, M. J., Stolee, P., & Harvey, D. (2014). Primary care-based memory clinics: Expanding capacity for dementia care. *Canadian Journal on Aging*, *33*(3), 307–319. https://doi.org/10.1017/S0714980814000233

Lee, L., Hillier, L. M., Stolee, P., Heckman, G., Gagnon, M., McAiney, C. A., & Harvey, D. (2010). Enhancing dementia care: A primary care-based memory clinic. *Journal of the American Geriatrics Society*, *58*(11), 2197–2204. https://doi.org/10.1111/j.1532-5415.2010.03130.x

Lee, L., Hillier, L. M., & Weston, W. W. (2014). Ensuring the success of interprofessional teams: Key lessons learned in memory clinics. *Canadian Journal on Aging*, *33*(1), 49–59. https://doi.org/10.1017/S0714980813000652

Lee, L., Hillier, L., Molnar, F., & Borrie, M. (2017). Primary Care Collaborative Memory Clinics: Building Capacity for Optimized Dementia Care. *Healthcare Quarterly*, *19*(4), 55–62. https://doi.org/10.12927/hcq.2017.25011

Lee, L., Lu, S. K., Hillier, L. M., Gregg, S., & Kaufman Carlin, G. (2019). Improving access to community support and services for persons living with dementia: Integration of home care services into primary care-based memory clinics. *Geriatrics and Gerontology International*, *19*(1), 81–82. https://doi.org/10.1111/ggi.13572

Lee, L., Slonim, K., Hillier, L. M., Lu, S. K., & Lee, J. (2018). Persons with dementia and care partners' perspectives on memory clinics in primary care. *Neurodegenerative Disease Management*, *8*(6), 385–397. https://doi.org/10.2217/nmt-2018-0024

Mavandadi, S., Wright, E. M., Graydon, M. M., Oslin, D. W., & Wray, L. O. (2017). *A Randomized Pilot Trial of a Telephone-Based Collaborative Care Management Program for Caregivers of Individuals With Dementia*. *14*(1), 102–111.

Meeuwsen, E. J., Melis, R. J. F., Meulenbroek, O., & Olde Rikkert, M. G. M. (2014). Comparing content of dementia care after diagnosis: Memory clinics versus general practitioners. *International Journal of Geriatric Psychiatry*, *29*(4), 437–438. https://doi.org/10.1002/gps.4064

Meeuwsen, E., Melis, R., Van Der Aa, G., Golüke-Willemse, G., De Leest, B., Van Raak, F., Schölzel-Dorenbos, C., Verheijen, D., Verhey, F., Visser, M., Wolfs, C., Adang, E., & Rikkert, M. O. (2013). Cost-effectiveness of one year dementia follow-up care by memory clinics or general practitioners: Economic evaluation of a randomised controlled trial. *PLoS ONE*, *8*(11).

https://doi.org/10.1371/journal.pone.0079797

Menn, P., Holle, R., Kunz, S., Donath, C., Lauterberg, J., Leidl, R., Marx, P., Mehlig, H., Ruckdäschel, S., Vollmar, H. C., Wunder, S., & Gräßel, E. (2012). Dementia care in the general practice setting: A cluster randomized trial on the effectiveness and cost impact of three management strategies. *Value in Health*, *15*(6), 851–859. https://doi.org/10.1016/j.jval.2012.06.007

Michalowsky, B., Wuebbler, M., Thyrian, J., Holle, B., Graeske, J., Schaefer-Walkmann, Flessa, S., & Hoffmann, W. (2017). Finanzierung regionaler Demenznetzwerke: Determinanten einer nachhaltigen Finanzierung am Beispiel spezialisiserter Gesundheitsnetwzwerke. *Gesundheitswesen*, *79*, 1031–1035.

National Institute for Health and Care Excellence. (2020). *Glossary*. https://www.nice.org.uk/Glossary?letter=S

Nichols, E., Szoeke, C. E. I., Vollset, S. E., Abbasi, N., Abd-Allah, F., Abdela, J., Aichour, M. T. E., Akinyemi, R. O., Alahdab, F., Asgedom, S. W., Awasthi, A., Barker-Collo, S. L., Baune, B. T., Béjot, Y., Belachew, A. B., Bennett, D. A., Biadgo, B., Bijani, A., Bin Sayeed, M. S., … Murray, C. J. L. (2019). Global, regional, and national burden of Alzheimer's disease and other dementias, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, *18*(1), 88–106. https://doi.org/10.1016/S1474-4422(18)30403-4

NIH National Heart Lung and Blood Institute. (2019). *Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control group*. https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

Noel, M. A., Kaluzynski, T. S., & Templeton, V. H. (2017). Quality Dementia Care: Integrating Caregivers into a Chronic Disease Management Model. *Journal of Applied Gerontology*, *36*(2), 195–212. https://doi.org/10.1177/0733464815589986

Parmar, J., Dobbs, B., McKay, R., Kirwan, C., Cooper, T., Marin, A., & Gupta, N. (2014). Diagnosis and management of dementia in primary care: Exploratory study. *Canadian Family Physician*, *60*(5), 457–465.

Pink, J., O'Brien, J., Robinson, L., & Longson, D. (2018). Dementia: Assessment, management and support: Summary of updated NICE guidance. *BMJ (Online)*, *361*(June), 1–6. https://doi.org/10.1136/bmj.k2438

Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). World Alzheimer Report 2016 Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future. In *Alzheimer's Disease International*.

Prince, M., Wimo, A., Guerchet, M., Ali, G. C., Wu, Y. T., Prina, M., & Alzheimer's Disease International. (2015). *World Alzheimer Report 2015. London, UK*. https://doi.org/10.1111/j.0963-7214.2004.00293.x

Proctor, E., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., Griffey, R., & Hensley, M. (2011). Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health and Mental Health Services Research*, *38*(2), 65–76. https://doi.org/10.1007/s10488-010-0319-7

QSR International Pty Ltd. (2018). *NVivo qualitative data analysis software. Version 12.* (No. 12). QSR International Pty Ltd.

Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D., Orrell, M., S., R., C., M.-C., R., M., J., H., S., T., & D., C. (2015). Case management approaches to home support for people with dementia. *The Cochrane Database of Systematic Reviews*, *1*(6), CD008345.

https://doi.org/https://dx.doi.org/10.1002/14651858.CD008345.pub2

Reuben, D. B., Ganz, D. A., Roth, C. P., McCreath, H. E., Ramirez, K. D., & Wenger, N. S. (2013a). Effect of nurse practitioner comanagement on the care of geriatric conditions. *Journal of the American Geriatrics Society*, *61*(6), 857–867.

Reuben, D. B., Ganz, D. A., Roth, C. P., McCreath, H. E., Ramirez, K. D., & Wenger, N. S. (2013b). Effect of nurse practitioner comanagement on the care of geriatric conditions. *Journal of the American Geriatrics Society*, *61*(6), 857–867.

Reuben, D. B., Roth, C. P., Frank, J. C., Hirsch, S. H., Katz, D., McCreath, H., Younger, J., Murawski, M., Edgerly, E., Maher, J., Maslow, K., & Wenger, N. S. (2010). Assessing care of vulnerable elders - Alzheimer's disease: A pilot study of a practice redesign intervention to improve the quality of dementia care. *Journal of the American Geriatrics Society*, *58*(2), 324–329. https://doi.org/10.1111/j.1532-5415.2009.02678.x

Richters, A., Olde Rikkert, M. G. M., Nieuwboer, M. S., van der Marck, M. A., Melis, R. J. F., & Perry, M. (2018). Longitudinal multiple case study on effectiveness of network-based dementia care towards more integration, quality of care, and collaboration in primary care. *Plos One*, *13*(6), e0198811. https://doi.org/10.1371/journal.pone.0198811

Saxena, N., George, P. P., Teo, K. W., Tan, W. S., Ng, C., Heng, B. H., Yeo, C. Y. Y., Anthony, P., Tan, C., Low, K. Y., Wu, V., Ali, N. B., & Chong, M. S. (2018). Evaluation of an integrated primary care-led dementia shared care program in Singapore: An effectiveness and cost-effectiveness study. *Geriatrics & Gerontology International*, *18*, 479–486. https://doi.org/10.1111/ggi.13196

Sheiban, L., Stolee, P., McAiney, C., & Boscart, V. (2018). Health care provider experiences in primary care memory clinics: A phenomenological study. *BMC Family Practice*, *19*(1), 1–9. https://doi.org/10.1186/s12875-018-0756-z

Sterne, J. A., Hernán, M. A., Reeves, B. C., Savović, J., Berkman, N. D., Viswanathan, M., Henry, D., Altman, D. G., Ansari, M. T., Boutron, I., Carpenter, J. R., Chan, A. W., Churchill, R., Deeks, J. J., Hróbjartsson, A., Kirkham, J., Jüni, P., Loke, Y. K., Pigott, T. D., … Higgins, J. P. (2016). ROBINS-I: A tool for assessing risk of bias in non-randomised studies of interventions. *BMJ (Online)*, *355*, 4–10. https://doi.org/10.1136/bmj.i4919

Tan, Z. S., Jennings, L., & Reuben, D. (2014). Coordinated care management for dementia in a large academic health system. *Health Affairs*, *33*(4), 619–625. https://doi.org/10.1377/hlthaff.2013.1294

Thyrian, J. R., Eichler, T., Pooch, A., Albuerne, K., Dreier, A., Michalowsky, B., Wucherer, D., & Hoffmann, W. (2016). Systematic, early identification of dementia and dementia care management are highly appreciated by general physicians in primary care - Results within a cluster-randomized-controlled trial (DelpHi). *Journal of Multidisciplinary Healthcare*, *9*, 183–190. https://doi.org/10.2147/JMDH.S96055

Twycross, A., & Shorten, A. (2014). Service evaluation, audit and research: What is the difference? *Evidence-Based Nursing*, *17*(3), 65–66. https://doi.org/10.1136/eb-2014-101871

World Health Organisation. (2019). *Primary health care: Main terminology*. http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology

7   Tables

Table 1 Implementation outcomes used in this review (modified from Proctor et al (2011))

Implementation outcome	Description	Example
Acceptability	Satisfaction with one or more aspects of the intervention (e.g. content, complexity, comfort, delivery, and credibility)	Quantitative satisfaction data, qualitative data regarding which components of the intervention are most or least acceptable
Appropriateness	Perceived fit, relevance and suitability of an intervention	Qualitative data regarding the relevance of the intervention, quantitative data regarding usefulness of a component or model
Feasibility	Actual fit, utility, suitability and practicability of a service	Qualitative data Survey, administrative data
Sustainability	The continuation, maintenance or routinisation of a service	Duration service is commissioned for, number of services ongoing after X years, qualitative data regarding factors affecting sustainability
Adoption	The uptake, utilisation, initial implementation or intention to try a service	Uptake of service components such as referrals to community services or a dementia case manager
Fidelity	Delivery as intended, adherence to protocol or quality of program delivery	Percentage quality indicators met; percentage components delivered
Reach	Reach and spread of intervention	Comparison of study or service sample to wider relevant population
Costs	Costs of intervention delivery, including marginal cost, cost-effectiveness and cost-benefit	Intervention costs, cost-effectiveness evaluations

Table 2 Feasibility and adoption quantitative outcomes

Review ID Study name Location	Study design Service type N	Feasibility
Grossfeld-Schmitz 2010 (Donath et al., 2010; Grossfeld-Schmitz et al., 2010) IDA Germany	RCT process evaluation PCP-led care vs PCP-SP N=97 with >=1 contact	29 family members (30%) had no personal contact with study counsellor, 33 (34%) had one contact and 35 (36%) had >1 over 2yrs. Usage increased 3.8x after PCP recommendation.
Mavandadi 2017(Mavandadi et al., 2017) USA	Pilot RCT PCP-CM partnership model vs usual Veterans Affairs care N=38 carers (25 completed) - CGs treated as main part of patient-carer dyad	Case manager contacts mean 3.5 contacts (range 1–7) over 3 months.
Callahan 2006(Austrom et al., 2006; Callahan et al., 2006) USA	RCT process evaluation PCP-CM vs usual primary care N=84 (intervention arm)	Case manager contacts mean 14.4 (8.9), median 13 (range, 0-51) over 12 months. Half face-to-face, half telephone.
Lee 2014b (Lee, Hillier, Heckman, et al., 2014) PCMCC Canada	Mixed methods service evaluation PCDC N=729	582/729 referred to the clinic (mean 48.6 patients/clinic), 79.8% (n=582) assessed (mean 38.8 (SD = 23.3) patients/clinic). 97 patients were awaiting assessment and 50 were not assessed due to patient refusal, death prior to appointment, and acute illness. During the average study period of 9.6 months (mo), average appointments were 1.2 per patient (SD 0.63, range 1-6).
Lee 2017(Lee et al., 2017) PCMCC Canada	Service evaluation PCDC 1113 patients assessed, 34% (n=383) dementia diagnosis, 27% (n=303) mild cognitive impairment diagnosis, 5% other issues.	Average wait time to assessment 1.5 months (1553 patients referred over 23 mo), 9% referred for geriatrician or neurologist assessment.
Lee 2014a(Lee, Hillier, & Weston, 2014) PCCMC Ontario	Mixed methods service evaluation PCDC n=529 Referrals and service tracking for up to 23mo (mean (SD) 9.6mo (5.9))	74.2% were seen in 2 months of referral (mean 1.4 mo), with specialist referrals for 8.9% patients.
Fortinsky 2014 (Fortinsky et al., 2014) PPDC USA	CCT process evaluation PCP-CM vs usual primary care N=31	16/21 (76.2%) completed all 12 case management sessions over a 12 month period. Mean visit length 75 minutes (SD = 21 minutes, range = 30-225 minutes).
Reuben 2013a (Reuben et al., 2013b) ACOVE-2 USA	Pre-post test PCP-CM vs PCP N=485 randomly selected from 658 screened positive for 1+ conditions and aged >75 (N dementia unclear).	49% saw a NP for co-management of >=1 study condition. 82% others lacked medical record referrals.
Iliffe 2014a (Bamford et al., 2014; Iliffe, Robinson, et al., 2014; Iliffe, Waugh, et al., 2014) CAREDEM UK	Feasibility trial PCP-CM N=29 carers and N=28 patients	Recruitment: 29/44 target recruited. Retention: 89% Case manager contacts with PWD mean 1.08 (range 0-8) and with CGs 1.42 (range 0-6) over 4 months, differing significantly by case manager.
Greening 2009 (Greening et al., 2009) Gnosall Memory Clinic UK	Service evaluation PCDC N=22 patients	2/22 patients did not attend memory clinic appointments
Eicher 2014a (Eichler, Thyrian, Fredrich, et al., 2014) Delphi-MV Germany	RCT process evaluation PCP-CM before and after implementation of a digital information management system (IMS) by case managers 96 pre-IMS group, 33 IMS group, 4 case managers	IMS identified more areas to intervene than case manager alone (1.64/PWD interventions compared to 5.75/PWD; 78.8% additional needs not identified).
Noel 2017(Noel et al., 2017) MemoryCare USA	Service evaluation PCP-CM N= 967 patients, 3251 carers	139 caregivers completed Caregiver College education programme and 38 attended peer support groups, 40% utilised resource centre.

Table 3 Quantitative sustainability data

Study, setting, service model	Study design	Sustainability
Reuben 2010(Reuben et al., 2010) ACOVE-AD USA, California and Washington, 2 large practices PCP	Pre-post study comparing before and after practice redesign in two practices Survey of components in June 2009 (unclear how long post intervention)	Dementia case finding discontinued but use of fax referral sheets for local Alzheimer's Association sustained in one practice.
Hesse 2005(Hesse, 2005; Klingenberg et al., n.d.) PRODEM Germany PCP-CM	Service evaluation Number of practices and people participating in the project over time	16/32 primary care practitioners across 20 practices participated at one time or another (since 1998). Decreased after industry payments for participation stopped and physicians needed to be an association member. Nine now cooperate intensively.
Lee 2014a(Lee, Hillier, & Weston, 2014) PCMCC Central and Southwestern Ontario, Canada 16 Family Health Teams (FHT) PCDC	Service evaluation Referrals and service tracking for up to 23mo (mean (SD) 9.6mo (5.9)) Number of family health teams continuing memory clinic	15/16 sustained their memory clinic (1 disbanded due to high specialist support in the area).
Lee 2014b(Lee, Hillier, Heckman, et al., 2014) PCMCC Ontario, Canada, 13 FHT-based memory clinics PCDC	Service evaluation Number practices sustaining a memory clinic at follow up (overlap with Lee 2014a).	13/14 sustained clinic over time (one limited management support and well served by geriatricians).
Lee 2017(Lee et al., 2017) PCMCC Ontario, Canada, 41 FHTs and 5 community health centres PCDC	Service evaluation Sustainability - continuing to assess patients for >6 months	44/46 teams trained established a PCCMC (1 did not start, 1 not sustained) across 517 primary care practices and 659,702 patients.
Richters 2018(Richters et al., 2018) DementiaNet The Netherlands PCP-S	Longitudinal mixed methods multiple case study 17 dementia networks evaluated over time	4/17 networks discontinued during first year (lack of motivation (e.g. initiated by local government) or lack of time). Out of those sustained network maturity (level of integration) increased by 2.03 times per year.

Table 4 Acceptability survey ratings across included studies

Study and intervention type	Population	Acceptability rating
Greening 2009 (Greening et al., 2009) PCDC	Patients and caregivers (N not reported)	High PWD and CG satisfaction with the preparation for, conduct and outcomes of the clinic (figures not reported), particularly to avoid travelling to hospital. More interest in frailty and ageing support group than PWD support group.
Clark 2013 (Clark et al., 2013) PCDC	Patients and caregivers (N not reported)	Positive feedback from patients and carers on contacts with Dementia Advisor and consultant, sensitivity and attentiveness to their views and the provision of information and support (figures not reported)
Saxena 2018 (Saxena et al., 2018) PCDC	Caregivers (MC n = 89, PCDC n = 86, other polyclinics n = 51)	Odds of caregiver satisfaction at 12-months similar between PCDC and MC, but higher in the PCDC group vs usual primary care polyclinics (figures not reported).
Lai 2019 (Lai et al., 2019) PCDC	Caregivers (n=402)	99.5% caregivers requiring support felt their needs had been met after intervention
Callahan 2006 (Callahan et al., 2006) PCP-CM	Caregivers (n=153)	Higher satisfaction than in usual primary care (82.8% very good/excellent vs 55.9%, p=.002), 6 mo after intervention ended, not significantly different (70% very good/excellent vs 62%, p=0.27).
Noel 2017 (Noel et al., 2017) PCP-CM	Caregivers (n= 203/400, 51% RR)	98% overall satisfied, 95% felt knowledge improved, 90% felt ability to manage behaviour improved, 83% felt helped keep PWD at home longer, 85% felt fee acceptable for services
Mavandadi 2017 (Mavandadi et al., 2017) PCP-CM model	Caregivers (n=38)	Three case management contacts over three months was considered acceptable
Khandelwahl 2015 (Khandelwal et al., 2015) SGV	Patients and caregivers (N not reported)	High satisfaction in survey following programme completion (data not reported)
Lee 2010 (Lee et al., 2010) PCDC	People living with dementia (60%RR) and caregivers (42.5%RR) (n=523)	Mean satisfaction ratings 5.8/7 (1.1) (n=523). >84% PWDs and CGs agreed they could obtain appointments in good time, better understood their symptoms and conditions, would recommend to others and thought it was a valuable addition to regular family physician care.
	Physicians (n=8, 72.7%RR)	Very satisfied with timeliness and quality of assessment, diagnostic and treatment recommendations, and availability of team for consultation (all mean ratings over 4.5/5).
Lee 2014a (Lee, Hillier, & Weston, 2014) PCDC	People living with dementia, caregivers (95, 47.3% RR)	PWD and CG mean satisfaction rating = 6.2/7 (SD 0.95) (n = 68).
	Physicians (n=27, 35.5% RR)	Referring physicians all rated satisfaction ≥4.0/5 and felt more likely to consider and manage cognitive impairment, that consultation notes were meaningful and helpful and their patients were better informed, felt better supported and that the clinic was an effective use of health care system resources.
Fortinsky 2014 (Fortinsky et al., 2014) PCP-CM	Patients (n=14), caregivers (n=19)	Mean satisfaction scores for all items for all respondent groups ranged from 3.5/4 to 4.0/4. CGs gave highest rating to relevance of PPDC program material, PWD on the question of the interventionist's ability to help them feel better about the future.
	Primary care physicians (n=18)	Most satisfied with effects on patient mood and outlook, slightly less satisfied with interventionist's monthly meeting reporting of patients' progress.
Tan 2014 (Tan et al., 2014) PCP-CM	Caregivers (52%RR of total 519)	90% intake visit time well spent, 94% DCM listened to their concerns, 87% decisions made were important to the patient, 59% considered referral programmes helpful, 96% felt supported in their role, 95% would recommend the program to other caregivers.
	Physicians (37%RR, total N not reported)	82% felt program provided valuable behavioural and social recommendations; 87% would recommend for other patients.
Cherry 2004 (Cherry et al., 2004) PCP-CM	Caregivers (n=83, 100% RR)	CG satisfaction higher 3-6 month after implementation (very satisfied 40% vs 17%, satisfied 39% vs 51% (P<.05))
	Physicians (n=126, 37% RR)	Physician satisfaction increased non-significantly
Lee 2016 (Lee & Hillier, 2016) PCDC	Physicians (n=78, 46%RR)	95% frequently referred patients to memory clinic, ratings 3.8/5 to 4.6/5 for referral process, assessment timeliness and comprehensiveness, care plan recommendations and implementation, documentation, follow-up, memory clinic team expertise, availability for consultation. Between 67.6% and 93.2% agreed care

Study and intervention type	Population	Acceptability rating
		plan, documentation, support in caring for PWD, less burden, added value, optimise secondary care usage, ensures timely access to assessment
Reuben 2013 (Reuben et al., 2013b) PCP-CM model	Physicians (n=12)	64% physicians rated dementia as relevant or extremely relevant to their patients and were more frustrated with managing dementia than other conditions
Thyrian 2016 (Thyrian et al., 2016) PCP-CM model	Physicians (n=40, RR 50.6%)	>79% agreed DCM recommendations appropriate, satisfied with DCM care, PWD satisfied with DCM care, cooperation time with DCM useful investment, high DCM competence, would like to permanently cooperate with DCM, DCM should be routine care >60% agreed information letter good communication tool, delegation of tasks helpful, CGs relieved by DCM care, DCM supported them in caring for PWD, care situation has improved >50% agree home visits necessary, pharmacist's recommendations useful
Eichler 2014a (Eichler, Thyrian, Fredrich, et al., 2014) PCP-CM model	Dementia care managers (n=4)	Use of digital information system for case management (all rated 1-10) helpfulness 9.5, user-friendliness 6.8, willingness to implement 9.0.

Table 5 Acceptability of different care components

Component	Description	Quote(s)
Information provision	Information provision was considered particularly important and could lead to changes in knowledge (Clark et al., 2013; Lee, Hillier, Heckman, et al., 2014), though the level of information desired varied between individuals (Dodd et al., 2015; Lee et al., 2018). Information was valued more highly when given directly from healthcare professionals, as opposed to written leaflets or handouts (Iliffe, Waugh, et al., 2014), although some wanted a 'roadmap' for different types of dementia (Lee et al., 2018)	*Access to information about dementia was crucial in enabling participants to manage the practicalities and uncertainties of the condition and to empower patients and carers to understand their condition and plan for the future (Iliffe, Waugh, et al., 2014)*
Greater involvement from community services	The ability to connect people living with dementia and carers to community and voluntary sector services, through information provision and referrals, was felt to add further value to the service (Lee et al., 2010, 2018; Lee, Hillier, & Weston, 2014), overcome access difficulties (Lee et al., 2018), improve care quality and ongoing support (Lee et al., 2019) and enable a greater range of issues, such as welfare, to be addressed (Iliffe, Robinson, et al., 2014).	*"I find it hard to navigate community resources. They're changing all the time and they aren't always integrated … I know that my patients have been referred to some fantastic community resources through memory clinic that I wouldn't have known about otherwise…" (Lee & Hillier, 2016)*
Social and emotional support	Emotional support was an important dimension for patients and caregivers (Iliffe, Robinson, et al., 2014). Services in which people living with dementia and caregivers felt supported by a case management role received positive evaluations (Clark et al., 2013; Iliffe, Waugh, et al., 2014)**,** although this could also be achieved in primary care dementia clinics (Clark et al., 2013; Lee et al., 2018).	*"The people that look after me here are very, very caring and respectful. . . Well, just the way they approach you and the way they talk to you. They're good.[Person with dementia 11]"(Lee et al., 2018)*
Medical support	There were mixed views as to the value of dementia medication among healthcare professionals, people living with dementia and families, but medication reviews were valued (Dodd et al., 2015; Lee et al., 2018). Within other studies, cognitive and other medical and physical support was rarely discussed by people living with dementia and caregivers.	*"I think there is far too much emphasis on diagnosis and handing out tablets that give false hope to patients and carers [female HCP]"* (Dodd et al., 2015)
Ongoing support	Longitudinal support was highly valued as a safety net (Iliffe, Robinson, et al., 2014), with people living with dementia and carers in one study of primary care dementia clinics expressing appreciation of planning for future care, which was facilitated by consistency of team members (Lee et al., 2018). Ongoing	*"perceived and actual benefits of a case manager from the patient and carer perspective included acting as a first point of contact and also as a 'safety net' for all concerns, potentially providing a one-to-one, therapeutic relationship for*

	monitoring through testing was less acceptable (Lee et al., 2018).	*future ongoing support and offering information and direct links to the practice and other services"* (Iliffe, Waugh, et al., 2014)
Driving issues	Concerns about driving were thought to be difficult to raise and overcome by both people living with dementia (Dodd et al., 2015) and primary care professionals, particularly in more rural locations (Lee, Hillier, & Weston, 2014; Lee, Hillier, Heckman, et al., 2014; Sheiban et al., 2018).	*"several of the memory clinics noted that dealing with automobile driving safety had been a stressful and challenging aspect of the memory clinic assessment."* (Lee, Hillier, & Weston, 2014)

Table 6 Fidelity data reported in studies

Review ID Study name Location	Study design Service type N	Fidelity and content of services delivered
Callahan 2006(Austrom et al., 2006; Callahan et al., 2006) USA	RCT process evaluation PCP-CM vs usual primary care N=84 (intervention arm)	BPSD protocol most common (89% patients triggered at >1 protocol, mean 4/8 protocols total triggered per patient). 56% PWD and CGs attended >1 support group counselling session. More likely to receive CHEIs (79.8% vs 55.1%, p=0.002) and antidepressants (45.2% vs 27.5%, p=0.03), no differences in memantine (8.3% vs 8.7%, p>0.99), antipsychotics (13.1% vs 7.3%, p=0.29) or hypnotics (9.5% vs 10.1%, p>0.99).
Meeuwsen 2014 (E. J. Meeuwsen et al., 2014) Netherlands	RCT process evaluation PCP vs memory clinic care N=160 (N=83 memory clinic, n=77 PCP)	Lower medication use in follow up (45% PCP vs 71% MC, p=0.001) and at 12 mo (83% vs 78%, p=0.02). Lower information provision (41% vs 63%, p=0.02).
Grossfeld-Schmitz 2010 (Donath et al., 2010; Grossfeld-Schmitz et al., 2010) Germany	RCT process evaluation PCP vs PCP-S N=97 with >=1 contact	No differences in medication.
Belmin 2012(Belmin et al., 2012) USA	Controlled clinical trial (CCT) process evaluation PCP+ vs PCP 34 with newly identified cognitive problems, 101 with incident or prevalent dementia	No difference in care quality (44% vs 41%, P=.67). Most quality care components delivered for <30% people.
Kohler 2014 (Kohler et al., 2014) Germany	Controlled clinical trial PCP-S N=235	Higher proportions seeing a neurologist (21.3 % vs. 8.5 %; p=0.046), but no differences in attending additional services (e.g. physical therapists). Intervention group increased in frequency of anti-dementia drug treatment (34 % to 50.5 %), remained stable in control (34 % vs. 35.8%).
Cherry 2004(Cherry et al., 2004) USA	Pre-post study PCP-CM vs usual ==primary== care N=42	Significant increase in all quality indicators, some differences by professional (e.g. social workers most likely to document an ADL assessment (32%), depression noted most frequently by primary care physicians (39%), physicians more frequently documented capacity assessment).
Iliffe 2014a(Bamford et al., 2014; Iliffe, Robinson, et al., 2014; Iliffe, Waugh, et al., 2014) UK	Feasibility trial PCP-CM N=29 carers and N=28 PWD	>=1 action recorded for 32% of PWD's unmet needs and 50% of carers' unmet needs (varied significantly by type of need for carers (P<0.001) but not for PWD).
Lee 2014b (Lee, Hillier, Heckman, et al., 2014) Canada	Pre-post mixed methods study PCDC N=729	Recommendations related to cholinesterase inhibitors (initiation, change, or plans to initiate) were made for 67.4% patients diagnosed with dementia (baseline not reported).
Reuben 2010(Reuben et al., 2010) USA	Pre-post study PCP+ 47 pre- and 90 post-intervention records	Increase in quality indicators met (38% to 46%, p=.05). Increase in assessing functional status (20% vs 51%), discussing risks/benefits of antipsychotics (32% vs 100%), referring to Alzheimer's Association (AA) (0 vs 17%) and counselling caregivers (2% vs 30%), but not cognitive assessment, medication review or neurological examination. Referral to AA associated with higher quality scores (65% vs 41%), including receiving driving counselling (50% vs 14%), CG counselling (100% vs 15%), and specify a surrogate decision-maker (75% vs 44%).
Reuben 2013a (Reuben et al., 2013b) USA	Pre-post test PCP-CM vs PCP 485 randomly selected from 658 screened positive for 1+ conditions and aged >75. N for dementia unclear (only eligible quality indicators, not people).	Co-management led to non-significantly higher quality indicators for dementia (59% vs 38%), with higher annual cognitive evaluations (75% vs 50%), caregiver support (52% vs 29%), and BPSD monitoring (70% vs 45%).
Garcia-Ptacek 2017(Garcia-Ptacek et al., 2017) Sweden	Cross-sectional analysis PCP vs memory clinic care Memory clinic n=5734, PCP n=3891.	No significant differences in cholinesterase inhibitor prescribing (OR 0.98 (0.89 to 1.08)). Lower memantine prescribing (OR 0.46 (0.39 to 0.53), neuroleptic

Review ID Study name Location	Study design Service type N	Fidelity and content of services delivered
		prescribing (OR 0.76 (0.60 to 0.86)) and higher anxiolytics and/or hypnotics prescribing (OR 1.31 (1.14 to 1.51)).
Aupperle 2000 (Aupperle et al., 2004; Aupperle & Coyne, 2000) USA	Cohort study PCP vs specialist care 31 PCP, 27 specialist at 1 yr 22 PCP and 17 specialist at 2 years	Lower donepezil prescribing rates at 1 and 2 yrs (35.5% vs 64.5%, p<0.005; 45.5% vs 76.5%,p=0.05).
Ament 2015(Ament et al., 2015) Netherlands	Cohort study (historical reference comparator) PCP-CM vs PCP N=181	Lower concordance with care plan advice (71.3% vs 82.1%, p<0.001). Lower for medication (p=0.014), hospital referrals (p<0.001) and healthcare professional referrals (p=0.002).
Parmar 2014(Parmar et al., 2014) USA	Retrospective chart review PCP vs geriatric assessment team N=81 records for same person compared across teams	Less likely to assess basic and instrumental ADLs (17% vs 100%, p<0.001), driving status (99 vs 30%, p<0.001), wandering (88 vs 17%, p<0.001), personal directives (99 vs 6%, p<0.001), power of attorney (99 vs 10%, p<0.001), explore decision-making capacity (39 vs 5%, p<0.001), assess decision making capacity assessment (36 vs 4%, p<0.001), explore elder abuse (26 vs 1%, p<0.001), identify BPSD (100 vs 46%, p<0.001), explore caregiver stress/coping (53 vs 20%, p<0.001) or refer to community care (57 vs 16%, p<0.001)
Noel 2017(Noel et al., 2017) USA	Service evaluation PCP-CM N= 967 PWD, 3251 caregivers	All charts met best care criteria.
Jennings 2016(Jennings et al., 2016) USA	Service evaluation PCP-CM N=797 PWD.	92% passed quality indicators, with case manager pass rates between 90–96%. Counselling and assessment quality indicators high (>80%), treatment lower (69%) with wider variation. 98% received ACP counselling.

28

Table 7 Costs reported in included studies

Study	Comparison	Intervention costs	Estimated cost differences	Cost-effectiveness
Meeuwsen 2013 (E. Meeuwsen et al., 2013) €2009 RCT N=160 patient-carer dyads	PCP vs usual memory clinic care	Not reported	No significant cost differences	€41,442 per QALY lost for memory clinic care compared to usual PCP care, but difference not significant
Menn 2012 (Menn et al., 2012) RCT €2008 N= 383	PCP (A) vs PCP-S (B) vs PCP-S plus caregiver counselling and support group (C)	Not reported	No significant cost differences between trial arms	Cost-effectiveness analysis not reported 'because neither cost nor effects differed significantly between groups' (p.857).
Jennings 2019 (Jennings, Laffan, et al., 2019) USD $2013 Case control study N= 3249	PCP-CM vs matched cohort with dementia not receiving services	$1268 per patient per yr	Cost-saving or cost-neutral depending on programme costs. $601 USD less per quarter (excluding programme costs). Net cost of -$284 USD per programme participant per quarter.	Not undertaken
French 2014 (French et al., 2014) Cohort study USD $2012 N=1756	PCP-CM vs patients with a diagnosis who had not enrolled in programme	$618 per patient per year	$3,474 per patient risk-adjusted (health care costs only). Total saving of $1.05 million annually based on cohort of 303 patients; average annual net cost saving per patient of $2,856.)	Not undertaken
Saxena 2018 (Saxena et al., 2018) CCT S$2012 N=240 (6 months) N= 226 (12 months)	PCDC vs PCP vs usual memory clinics	Not reported	$1600 lower direct medical costs for PCDC compared to polyclinics at 6mo, no difference compared to memory clinics. No significant difference in societal costs between groups.	PCDC cost-effective at 12 mo compared to memory clinics (cost per QALY gained compared to MC was $S29 042). Cost-effectiveness not computed for PCDC v usual primary care.
Clark 2013 (Clark et al., 2013) Service evaluation N=19 new patients, 61 follow up contacts (in sixth year of programme) Costing year not reported	PCDC vs published data	£11,500 compared to estimated £133k if secondary care-based	£116k savings for mental health services and £450k savings for all secondary care	Not undertaken