






# Joining the dots: Day to day challenges for practitioners in delivering integrated dementia care

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## Abstract

Despite the increasing policy focus on integrated dementia care in the UK, little is known about the opportunities and challenges encountered by practitioners charged with implementing these policies on the ground. We undertook an extensive, mixed-methods analysis of how a contemporary multidisciplinary dementia pathway in the UK was experienced and negotiated by service providers. Our pragmatic mixed methods design incorporated three types of research interaction with practitioners: (a) Semi-structured interviews ( $n = 31$ ) and focus group discussions ( $n = 4$ ), (b) Practitioner 'shadowing' observations ( $n = 19$ ), and (c) Service attendance and performance metrics reviews ( $n = 8$ ). Through an abductive analysis of practitioner narratives and practice observations, we evidenced how inter-practitioner prejudices, restrictive and competitive commissioning frameworks, barriers to effective data sharing and other resource constraints, all challenged integrative dementia care and led to unintended consequences such as practice overlap and failure to identify and respond to people's needs. In order to more successfully realise integrated dementia pathways, we propose innovative commissioning frameworks which purposefully seek to diffuse power imbalances, encourage inter-provider respect and understanding, and determine clear lines of responsibility.

## KEYWORDS

commissioning, Dementia, integrated care, mixed methods, practitioner perspectives, pragmatism, third sector

## 1 | INTRODUCTION

'Without integration at various levels, all aspects of healthcare performance can suffer. Patients get lost, needed services fail to be delivered, or are delayed, quality and patient satisfaction decline, and the potential for cost-effectiveness diminishes.' (Kodner & Spreeuwenberg, 2002, p. 2).

Central Government commissioning structures and strategies, such as Integrated Commissioning Partnerships and the Better Care Fund (BCF), are placing increasing funding emphasis on the planning and delivery of more fully integrated health and social care provision across England (Charles, Wenzel, Kershaw, Ham, & Walsh, 2018; Department of Health & Social Care & the Ministry of Housing, Communities & Local Government, 2019a, 2019b). From Sustainability and Transformation Partnerships through to more recently piloted

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Integrated Care Systems, NHS England have set ambitious demands and targets in their efforts to implement sustainable, intersectoral partnerships and systems which aim to transform healthcare practice and place England at the forefront of the Western world in integrated provision (Forder et al., 2018; Ham, 2018; NHS England, 2019).

While current integration strategies are centrally guided, frameworks for delivery are non-prescriptive and encourage geographical regions to draw on the needs of local people, communities, as well as pre-existing care provision and commissioning structures (e.g., NHS England, 2019). As a result, there is no prototype of local service provision, rather an eclectic mix of different forms of integration happening in different ways, over varied time phases, and to mixed effectiveness (Forder et al., 2018; Charles et al., 2018; National Audit Office (henceforth, NAO), 2017). Moreover, since integrated services and systems are still in their infancy, to date there have been limited efforts to evaluate and evidence the effectiveness and parity of these different models and, where such evaluations have occurred, only marginal improvements in some piloted areas have been identified (Charles et al., 2018; Forder et al., 2018; NAO, 2017).

A further challenge in our understanding of contemporary integrated care partnerships and systems is that our endeavours to evaluate effectiveness are focused on implementation experiences at the leadership, strategic and structural levels (such as, senior NHS, local government & third sector management; e.g., Alzheimer's Society, 2018a, 2018b; Charles et al., 2018; Ham, 2018). As such, we lack nuanced understanding of the extent and complexity of barriers practitioners face at the ground level in their efforts to successfully work and communicate in integrated ways. We propose that to fully understand such challenges, it is essential we broaden our evaluative lens to encompass perspectives and experiences at the inter-practitioner level and not just at the inter-agency and leadership level.

## 1.1 | Integrated pathways in dementia care

An area where important integrated care provision remains underwhelming in terms of development and evaluation is in the field of dementia. The historical and forecasted escalation in dementia support and treatment costs in the UK and worldwide (Knapp et al., 2014; Luengo-Fernandez, Leal, & Gray, 2010; Wittenberg, Hu, Barraza-Araiza, & Rehill, 2019) has prioritised the need for evidence-based, multi-disciplinary and equitable dementia care pathways (Bragato & Jacobs, 2003; NHS England, 2017; Samsi & Manthorpe, 2014). While not anchored in a singular definition (Samsi & Manthorpe, 2014), dementia care pathways aim to uphold best integrated health and social care practice principles and are thought to be pivotal in directing and coordinating appropriate intervention and rehabilitative services for people, families and carers affected by dementia (Banerjee, 2010; Brooker, 2006; Department of Health, 2016; NHS England, 2017). In reality, contemporary 'pathways' usually consist of statutory older people mental health and social care services, often commissioned alongside third sector care practitioners, with the main aim of providing integrated support; from assessment and diagnosis through to end of life care (Department of

### What is known

- The prevalence of dementia experiences and the cost of dementia care will continue to dramatically escalate in the next 20 years
- At a strategic level, commissioning frameworks in the UK are prioritising effective integrated, multidisciplinary working
- We know very little about the challenges encountered by practitioners at the ground level

### What this paper adds

- Unique interpretative analysis of the views and perspectives of a range of dementia service practitioners
- Insights into how current commissioning frameworks risk accentuating inter-practitioner prejudices, communication breakdown and practice overlap
- Suggestions of how commissioning frameworks could proactively diffuse inter-agency prejudices. For example, through encouraging statutory and third-sector service providers to form consortia bids and to build relationships through shadowing and shared office space.

Health, 2016; Department of Health & Department for Communities and Local Government, 2017; NHS England, 2017).

## 1.2 | The current study

While significant investment into health and social care provision is planned (Department of Health & Department for Communities and Local Government, 2017; Department of Health, 2016), we remain unclear about the efficacy of current community-based services, and the types and breadth of challenges we are faced within providing or accessing integrated disciplinary models of care. Dementia care practice is one particular example of integrated care provision which requires closer scrutiny if it is to fulfil its potential to fully support people with dementia and their families in the community, and to help people remain outside of acute services (Banerjee & Owen, 2009; Forder et al., 2018; NAO, 2017; Torjesen, 2020; Wittenberg et al., 2019). In the absence of good evaluative data, integrated care is at risk of being premised upon idealised principles (and rhetoric), which in turn can detrimentally impact on health and well-being outcomes and treatment costs for people affected by dementia (Banerjee, 2010; Banerjee & Owen, 2009; NAO, 2017).

This paper offers insights from a commissioned independent review of a dementia care pathway in the South East of England. The review aimed to understand and evidence the finer workings of the dementia provision with a view to help future local service configurations. To do so, the review adopted a pragmatic mixed-methods approach (Morgan, 2007) to explore how the current multidisciplinary dementia pathway was experienced and negotiated by service

providers and recipients. A pragmatic mixed-methods approach 'organically' develops understanding and evidence through flexibly, and reactively, utilising a methods framework in response to the research context as it evolves (e.g., Feilzer, 2010; Morgan, 2007), rather than rigidly applying a fixed method design (e.g., Creswell & Plano Clark, 2007). The mixed methods framework in question, included: interviews and focus group discussions; practitioner 'shadowing' observations, and service attendance and performance metrics, which were used to explore the barriers to effective integrated and collaborative practice for older people mental health services, as well as other statutory and third sector dementia service providers. This paper presents our understanding of the challenges in operationalising an integrated pathway from the service provider perspective. A forthcoming publication will present service user experiences.

## 2 | METHODS

### 2.1 | Design

The current analysis was part of a *process evaluation* (Robson, 2000) commissioned by an Integrated Commissioning Unit in South East England. The research team consisted of the authors and research assistants ( $n = 9$ ). A 'pragmatic' mixed-methods framework (Feilzer, 2010; Morgan, 2007) was utilised to capture engagement and practice experiences of people with dementia, their carers and pathway practitioners. As such multiple research methods were incorporated 'organically' and 'in situ' (i.e., a methods framework was utilised reactively in response to the research context as it developed, rather than prescriptively applied; Morgan, 2007). The methods framework included: semi-structured and structured interviews, focus groups, practitioner 'shadowing' and a quantitative review of service attendance and performance metrics. Adopting and adapting these methods 'organically' meant that researchers aimed to validate and challenge findings through evidence emerging from the multiple sources of data throughout the study (Morgan, 2007), e.g., shadowing observations and service attendance and performance

metrics could be used to inform interview questions for both people affected by dementia and service providers, as well as challenge practitioners' answers and other initial findings (see *Sources of data & Procedures* for fuller description). Due to resource and time restraints our analyses did not address 'end of life' or nursing and residential care experiences.

The NHS Health Research Authority and the University of East London ethically approved the study. All interviews and focus groups were conducted in a quiet and confidential setting, either within participants' places of work or at the premises of the host University for the study.

### 2.2 | Contextualising the pathway

A dementia pathway funded by an integrated commissioning unit in the South East of England formed the basis for the independent dementia pathway review. At the time data collection for this review was completed (May, 2017), approximately 2,142 residents (out of a population of 210,000) were estimated to live in the City area with some form of dementia; 55% (1,178) mild, 32% (685) moderate and 13% (279) severe). Of these, 78% (1,669) were reported as living outside of residential care, with approximately 65% (1,392) being female and 2% (50) people having early onset dementia (i.e., below the age of 65). The dementia pathway consisted of Older People Mental Health (OPMH) services offering dementia diagnosis & memory clinics (bi-annual outpatient consultations for people with dementia and carers), community and intermediate nursing teams and acute psychiatric hospital care; GP & Adult social care support, and a breadth of commissioned third sector specialist dementia initiatives and practitioners (fuller details Table 1).

### 2.3 | Sources of data and procedures

There were three main types of review interactions: (a) Semi-structured interviews ( $n = 31$ ) and focus group discussions ( $n = 4$ ),

**TABLE 1** Participants, services, practitioner roles and methods incorporated in the review (<sup>1</sup>Semi-structured interviews; <sup>2</sup>focus groups; <sup>3</sup>shadowing; <sup>4</sup> attendance & performance metrics;  $n =$  no. of interactions)

Statutory specialist dementia services	
Older People Mental Health Service <sup>4</sup> [service manager <sup>1 (n = 2)</sup> ; Memory clinic psychiatrist <sup>1 (n = 2), 3</sup> ; memory clinic nurse practitioner <sup>1</sup> ; Intermediate community team nurses <sup>1, 2, 3 (n = 2)</sup> ; Community psychiatric nurses <sup>1 (n = 2), 2</sup> ]	
Adult Social Care [Manager <sup>1</sup> ; Dementia social worker <sup>1 (n = 2), 3</sup> ]	
General Practitioners [Senior GP dementia leads ( $n = 2$ ) <sup>1 (n = 2)</sup> ; Practice manager <sup>1</sup> ]	
Statutory commissioned third sector specialist dementia practitioner teams	
Reablement team <sup>4</sup> [Manager <sup>1</sup> ; Reablement Practitioners ( $n = 2$ ) <sup>1, 3 (n = 3)</sup> ; Dementia Advocacy Nurse <sup>1 (n = 2), 3 (n = 2)</sup> ; Dementia advisor (DA) team ( $n = 4$ ) <sup>4</sup> [Manager <sup>1 (n = 2), 3</sup> , DA Practitioners <sup>2, 3</sup> ]	Carer Centre [Practitioner <sup>1</sup> and manager <sup>1</sup> ]
Statutory commissioned third sector specialist dementia services	
Memory Cafés <sup>4</sup> [manager <sup>1</sup> ; facilitators <sup>1 (n = 2), 3 (n = 2)</sup> ; volunteers <sup>1, 3 (n = 2)</sup> ]; day centres ( $n = 2$ ) <sup>4</sup> [manager <sup>1 (n = 2)</sup> ]; Cognitive stimulation therapy (CST) groups ( $n = 2$ ) <sup>4</sup> [facilitators <sup>1 (n = 2), 3 (n = 2)</sup> participant <sup>1</sup> ]	
Third Sector self-funded specialist dementia services	
Outreach dementia rehabilitation workers ( $n = 2$ ) <sup>4, 1 (n = 2)</sup> ; Singing & veteran activity groups ( $n = 3$ ) <sup>4, 3 (n = 1)</sup> ; Early onset group <sup>4, 2</sup> ; Volunteer group facilitators ( $n = 2$ ) <sup>1, 3 (n = 2)</sup>	

(b) Shadowing observations ( $n = 19$ ), and (c) Service attendance and performance metrics reviews ( $n = 8$ ). All participating practitioners gave informed consent before review interactions commenced.

1. Interviews and focus groups concentrated on service aims and practitioners' perspectives on their roles and experiences when working with people with dementia, family carers and other service providers. All pathway service provider managers were interviewed at least once. Other interviews and focus groups were with practicing professionals, which were either prearranged with the managers, or initiated after shadowing observations in the field. Questions were guided by previous shadowing observations and performance metrics. Where possible, or necessary, practitioners were interviewed on more than one occasion (Table 1). For example, service managers were initially interviewed and asked to outline the aims of their services, how they were implemented and their remit in relation to other services. These scoping interviews were used to inform team practitioner interview questions and shadowing observations and, on some occasions, re-interviewing of managers e.g., if practitioner role clarification was needed.
2. Shadowing observations were pre-agreed with service provider managers and their team members. These involved practitioners being observed in their day-to-day roles by one or more researchers. Where possible the same practitioners were observed by two different researchers on separate occasions. Shadowing observations were inductive and interpretative (Quinlan, 2008) and focused on the quality of practitioner interactions with people with dementia and carers, as well as on inter- and intra-service relationships with colleagues. Data generated from these sessions included informal discussions with practitioners and service users which were written up with observation notes after session interactions were completed. The accuracy and quality of observations were verified between observers and the participants being shadowed; either less formally at the time of observation or more formally elsewhere (e.g., subsequent interviews or focus groups that followed the shadowing; further detail below).
3. Attendance and performance metrics of core services included recorded outcome measures captured by providers for quarterly and annual commissioner reports and internal audits, e.g., service attendance and satisfaction metrics.

## 2.4 | Analyses

Interview transcriptions, shadowing observation notes, as well as performance indicators were collated. A variant of Thematic Analysis (Braun & Clarke, 2006) was used to systematically identify emergent patterns and themes within and between multiple data sources. Analysis was *abductive* and therefore integrated in the data gathering (Morgan, 2007), where emergent knowledge and theory were interrogated 'through action' throughout the course of the study,

e.g., emergent findings from shadowing observations informed subsequent interview questions and analyses for service providers, and, likewise, earlier service manager interview narratives (e.g., outlining roles and aims of service) were used to inform shadowing observations. The main analysis of data was conducted by MC, but there were regular research team meetings throughout the study where themes and research directions were discussed, challenged and negotiated between co-researchers. Consistent with the data gathering approach, final analysis was *abductive*; shifting between inductive and deductive interpretative approaches to develop and triangulate emergent themes (Jick, 1979). Our findings were finalised after sharing our analysis with local dementia pathway commissioners and practitioners as well as wider stakeholder audiences (e.g., Chase, 2019).

## 3 | FINDINGS

Drawing on multiple data sources in the analyses (interviews, focus groups, shadowing and attendance and performance metrics), the following themes concerning barriers to effective integrated and collaborative practice were identified (Table 2).

Throughout the review, people and carers affected by dementia spoke highly of the expertise, compassion and commitment of dementia practitioners involved in their lives. However, our analyses raised important questions about the efficacy of provision across services; particularly with respect to integrative and collaborative working. Barriers to optimal practice identified were *Attitudinal* and *Practical & Policy* driven (Table 2). These were observed to lead to: service overlap (e.g., where two or more services were identified to be doing the same job); recognised and unnecessary demands on people with dementia and their carers to repeat their needs or re-tell their stories to different professionals; information or intervention overload (at a time when people with dementia and carers may not be ready, or equipped to assimilate it); and missed practice opportunities (e.g., times when practice was duplicating a service already provided, rather than helping people meet other important needs).

**TABLE 2** Barriers to effective integrated and collaborative practice

For statutory and <i>third sector</i> dementia service providers
<b>Attitudinal</b>
'Professionals' Vs. 'Para-professionals'
'Pilot' Project fatigue
'Contractual competitiveness'
<b>Practical &amp; policy</b>
Ambiguities in interpretation of roles and financial responsibilities
Data sharing challenges
Systems Incompatibility
Risk aversion
Integrating practice & data sharing through shared office space
Crisis resolution Vs. preventative support

### 3.1 | Attitudinal barriers to effective integrated and collaborative practice

#### 3.1.1 | 'Professionals' Vs. 'Para-professionals'

Effective integrated and collaborative practices were, at least in part, restricted by 'attitudinal barriers'. Interview and observational data evidenced tacit and explicit prejudices between different providers; not least when there were distinctions in professional training and standing. In particular, a 'para-professional' Vs. 'professional' attitudinal barrier was noticeable in statutory providers' communication and interactions with commissioned third sector workers; where registered trained practitioners (e.g., general hospital and community psychiatric nurses) appeared to be less accommodating of practitioners working in the third sector whose training was perceived to be less stringent and professionally recognised.

'Para-professional' attitudinal concerns resonate in the following interview narrative of third sector reablement practitioner, SB. SB was originally trained as a dementia specialist nurse and, after a number of years working in the NHS, was now establishing herself in the dementia pathway as an advocacy nurse for a third sector organisation:

"I'll be very honest, working in charity and not in a local authority or NHS, you lose that kind of "authority" and you always need to try harder to prove yourself [...] It is a culture, and to change the culture is hard." (Interview, Dementia Voice Nurse)

Similar attitudinal challenges were exemplified in shadowing observations of third sector reablement practitioners working with people with dementia admitted to the local general hospital (e.g., as a result of a fall or urinary infection). While some hospital nurses understood and welcomed *third sector* efforts to advocate and negotiate care arrangements for patient discharge, other were reticent

and less than helpful to requests for important information which reablement workers did not have direct access to (e.g., patients' discharge dates or next of kin's contact details; see e.g., Figure 1). Although hospital practitioners' workloads appeared to be an important factor, so too were practice attitudes; a theme explored and verified in subsequent interviews with the affected reablement practitioners.

"Unfortunately, we still face disinterest from some ward staff when highlighting key patient needs." (Interview, Reablement Manager)

"I think it depends on the individuals, it depends on whether or not they [ward nurses] like what you do; I think it depends on how busy they are... because we are still not able to access personal details without having somebody with us." (Interview, Reablement Practitioner 2)

#### 3.1.2 | 'Pilot' project fatigue

Elsewhere in community rehabilitation services, a key 'attitudinal barrier' faced by *third sector* practitioners resulted from what was termed 'pilot project fatigue' (resistance to embrace, and refer on to, dementia support services which had only temporary status). It was something recognised and acknowledged in both statutory and non-statutory practitioner interviews.

"A lot of the funding for these [pilot] schemes are all ad hoc or on a pilot basis and people, senior clinicians, quickly realise that when anything is run as a pilot or on a project basis, they would worry that these will not last long and [consider] whether they should be referring patients or not." (Interview,

It was agreed between two separate shadowing observers today that K & S [third sector reablement practitioners] were consistently confronted by a lack of engagement and response by hospital staff members (in particular nurses and ward managers) in their efforts to advocate for patients or to retrieve contact information for them to contact relatives to negotiate ward discharge arrangements. This is undoubtedly influenced by ward staff being very busy people... but for some of the doctors and nursing staff their reluctance to engage with their advocacy and information requests appears partly driven by their detachment or prejudices. – some barely wanted to acknowledge them; a number dismissed them. Nevertheless K & S remained persistent.

**FIGURE 1** Shadowing field notes: 'professional' vs. 'para-professionals'

(*Third sector, Reablement Practitioners, shadowing notes; MC & SK*)

NHS, Older People Mental Health Consultant  
Psychiatrist)

The result was a default 'in-house' referral and signposting process which had a preference to drawing on the knowledge and services of the "established" (but resourced-stretched) statutory Older People Mental Health community teams; when commissioned third sector services could have 'shared the load' e.g., dementia advisors and rehabilitation practitioners were not being used for generic monitoring support and signposting advice.

The reluctance for statutory health and social care providers to formally recognise and make referrals to third sector services was subsequently explored and evidenced in other ways in the review. For example, in interviews it was identified that no statutory commissioned practitioner was able to accurately describe the remit of a third sector pathway provider (despite their acknowledgement of their existence), and no statutory provider was observed referring or signposting on any service user to a third sector practitioner (despite possible need being evident) when there was possibility to do so (e.g., Memory Clinic outpatient appointments).

"[W]e are used to referring to people who have accountability for their actions and at the moment we don't feel Dementia Advisors have sufficient accountability..." (Interview, NHS, General Practitioner 2)

### 3.1.3 | A 'contractual competitiveness'

Attitudinal barriers were evident in other ways. Contracted for only one or two years, locally commissioned third sector 'pilot' providers were concerned about their longer term employment and were acutely aware of how 'competing' service providers were a threat to contract extensions. While less apparent in interview data at the manager level (e.g., managers maintained their staff had an understanding of roles of other pilot services, and were willing and keen to communicate and work effectively with them), shadowing observations and interviews with practitioners 'on the ground' evidenced limited knowledge of, and willingness to promote, other third sector providers (Figure 2).

Attitudinal barriers and resistance to working and signposting effectively between third sector providers was further evidenced through interview data at a managerial level:

"[W]hen I started I found a huge resistance to working with other organisations and agencies which I found quite difficult because I have never worked in this way and I don't see the point; you know that leads to duplication... I found, you know, that there is a lot of professional jealousies and things like that..." (Interview, Dementia Advisor Team Leader).

## 3.2 | Practical and policy barriers to effective integrated and collaborative practice

### 3.2.1 | Ambiguities in interpretation of roles and financial responsibilities

For statutory health and social care practitioners (e.g., social workers and community psychiatric nurses), lack of clarity of roles and budgetary responsibilities provided tensions in collaborative practice.

"There is always that underlying, not sure what word to use, conflict between health and social care..."  
(Interview, Council Adult Social Care Social Worker)

A key barrier was how the eligibility criteria for social care support needs were differently assessed or interpreted by health and social care practitioners. For example, community psychiatric nurses expressed their concerns about people who 'presented well' in social care needs assessments (administered by social care social workers), and yet, in their view, were in need of additional care or monitoring support to prevent unnecessary hospitalisation, e.g., someone who was able to wash and dress themselves was sometimes judged to not require care support, despite their inability to judge time of day, hunger or their need to take prescribed medication.

"They [people with dementia] can still function to get washed and dressed but they can't cope with the complexities of taking their medication..." [Community psychiatric nurse 1].

"... or they stop eating and drinking then there will be a problem. And they want us to keep them out of general hospital and most times they will end up in there because their physical [health] has gone down." [Community psychiatric nurse 2]. (Focus Group 2; Community Psychiatric Nurses)

### 3.2.2 | Data sharing challenges: Incompatible systems and risk aversion

Technical, ethical and political obstacles to sharing information across health and social care provisions (statutory and third sector) were further impacting on effective collaborative working between organisations. All statutory Older People Mental Health practitioners shadowed or interviewed stressed the challenges of accessing and sharing information across (statutory-based) data systems. Databases were not fully compatible and the reliance on third parties to 'chase up' or coordinate care plan or referral details meant that practice was often slower, more cumbersome and ineffectual

Visited, with K (third sector reablement practitioner), LB (male living with dementia) and SC (LB's wife and carer) in the community. LB was four weeks out of hospital and it was planned to be K's last visit. K asked each individually how they were doing and appeared to have a good rapport with both of them. In preparation for their discharge, K was enthusiastically disseminating information in the form of leaflets and verbal summaries of services that were available to them both. This appeared to be too much information, too quickly, and neither LB nor SC seemed to welcome or understand the barrage of information and activity. Interestingly, the information provided no mention of the dementia advisors or memory cafés as possible resources until I mentioned them at the end; these fellow pilot services would have been more local and appropriately suited to monitor the wellbeing of LB and SC following their discharge from the reablement team.

*(Third sector, Reablement Practitioners, shadowing notes; MC)*

In a follow up interview, K was asked about why she had not signposted the Dementia Advisors (DAs) to LB & SC in her final visit (DAs could, in contrast to K's reablement team, provide non-time limited support and advisory service). In her response K demonstrated, at the very least, a mistaken understanding of the remit and role of the Dementia Advisor:

*"It appears that the Dementia Advisor is only going in the once and I think just doing very similar to what we are doing, which is giving lots of detail about what's on in the area...."*

*(Interview, third sector, Reablement Practitioner 1)*

## FIGURE 2 Shadowing field notes: contract competitiveness

than necessary. Emphasis was placed on mainframe health and social care systems, but examples of the impact of incompatible hospital-based and community NHS data systems were also evident following discharge.

"I find it particularly confusing when someone is discharged and we are involved and the PR [hospital rehab team] are involved, sometimes there is duplication...they are on XXX, but they are on a different XXX. So you have to access that to see what they are doing...." (Interview, NHS, Intermediate Care Team Practitioner).

"Because I am a charity, information sharing for me is the biggest problem.... If I could get into the system, like Social Services have XXX and the NHS have

YYY, then I can type in what I am doing and they know straight away." (Interview, Dementia Voice Nurse)

Shadowing observations further identified that existing local data and patient protection protocols meant that commissioned third sector rehabilitation and advisory support services were unable to directly access health service databases and contact details for new existing people diagnosed with dementia. They were therefore reliant on referrals from general hospital admissions, GP and memory outpatient clinics appointments, or self-referrals. Consequently, commissioned third sector services failed to run at capacity, with a large amount of their practitioner time spent networking at community events or setting up 'stalls' in locations likely to elicit self-referrals e.g., targeted GP surgeries and memory clinic reception areas.

### 3.2.3 | Integrating practice & data sharing through shared office space

Examples of more effective integrated practice and data sharing were observed in one Older People Mental Health community team, where, in a 'piloted' initiative, a team of NHS community and intermediate psychiatric nurse team members and a local City Council funded social worker were practicing in the same office space. In this shared environment health and social care providers were able to follow-up clients' details (housed on different data systems) for their colleagues, as well as share thoughts and experiences before jointly negotiating care plan challenges. The environment also served to dismantle previously established attitudinal barriers and practice misunderstandings.

"I think what is good is they can see exactly where I am coming from, and why I need to do certain things in a certain way; so instead of it being a social worker who is holding up the process, they can see what has to happen, even for a small request for funding." (Interview Council Adult Social Care Social Worker)

### 3.2.4 | Crisis resolution Vs. preventative support

Over the period of the review, important macro health policy and austerity factors placed additional strains on integrated practice in the local dementia pathway services; in particular, the contact opportunities for people to access specialist dementia medical outpatient support. For example, with increasing emphasis on early dementia diagnoses, current NICE guidelines for additional screening of people living with Alzheimer's on the drug Memantine (National Institute for Health & Care Excellence, 2018), and the growing number of frailer or less mobile outpatients who needed to be visited in their own homes (approximately 40%–50% according to a local clinical lead), meant that the frequency of memory clinic appointments for the vast majority of people was due to be reduced from once every six months to once a year. It was a concern for senior practitioners:

"I think people need to be seen more frequently but it is just capacity... we all know from experience that a lot can change in one year." (Interview, NHS, Older People Mental Health psychiatrist)

These macro contextual factors, alongside the less than optimal integrative working which the independent review identified, meant that the local dementia services 'pathway' had evolved into a 'reactive' collection of services which focused on crisis resolutions. Referral outcome and observation data evidenced that contact with statutory and third sector rehabilitation services was predominantly limited to: diagnosis provision;

outpatient Memory Clinics (now once per year); crisis response adult social care or Older People Mental Health community support services; or third sector services providing initial signposting following diagnosis or short-term reablement support in home-based environments following a recent crisis (e.g., general hospital visit). Consequently the 'pathway' had little capacity for preventative approaches to accompanying people on their 'journeys' and promoting and enabling people to 'live well with dementia' (Banerjee, 2010).

## 4 | DISCUSSION

All community service providers interviewed and observed were committed, motivated and skilled practitioners who made positive differences to people's lives. However, core barriers, in the form of communication, practitioner prejudice, restrictive commissioning frameworks and resource constraints, challenged effective integrative dementia services and multidisciplinary working. These barriers resulted in observed practice overlap and inefficiencies. These, coupled with the strains imposed by austerity, meant that the dementia pathway under review had evolved into a collection of disjointed services which, after initial diagnosis and signposting, prioritised crisis management over crisis prevention.

Given the current and predicted prevalence figures for people affected by dementia in communities in the UK (Knapp et al., 2014; Wittenberg et al., 2019), and what we know about the geographical disparity in dementia services quality (e.g., Care Quality Commission, 2018), these findings raise clear concerns for service planning and development. In line with current preferred integrated practice (Department of Health & Social Care & the Ministry of Housing, Communities & Local Government, 2019a, 2019b; NHS England, 2017), a core recommendation, and clear challenge, for current pathway services is to meet the increased needs of people diagnosed with dementia with comprehensive integrated care packages which flexibly monitor and chaperone people to 'live as long and as well with dementia' as they can. To do this, the identified core barriers to engagement and practice need to be addressed.

Identified inter-service prejudices and attitudinal barriers are difficult to challenge. While they are likely to be helped by improved communication and data sharing channels between agencies (Ham & Walsh, 2013; NAO, 2017), the establishment of clear support frameworks at the commissioning level is more likely to ensure services integrate in meaningful ways. For example, core to recommendations to local commissioners of the current study was that, at the very minimum, statutory and non-statutory providers shadow each other's services and become actively involved in team building and collaborative workshops and training. Moreover, commissioners were encouraged in their consideration of future commissioning of consortiums of service providers (whereby third sector and statutory providers amalgamate specialisms



and collaboratively bid for tenders), and the clear benefits to integrated health and social care teams working in shared office spaces (Department of Health & Department for Communities and Local Government, 2017; Milbourne & Cushman, 2012). Alongside these initiatives, it was highlighted how 'pilot fatigue' and 'contract competitiveness' could be alleviated by extending commissioning tenders (e.g., to 3 + years; Milbourne & Cushman, 2012; Rees, Mullins, & Bovaird, 2012).

Data sharing systems and protocol problems plagued efforts for "better" (Department of Health, 2016; Department of Health & Department for Communities and Local Government, 2017; NHS England, 2017) multidisciplinary practice between and within the statutory and third-party support providers; with too much time spent either identifying client need (as was the case with third sector providers) or chasing client information across statutory health and social care agencies. While, in part, a widely acknowledged technical problem (of developing ways for different types of information systems to communicate with each other; Department of Health, 2013; House of Commons Science & Technology Committee, 2016) it was also indicative of an ubiquitous "culture of anxiety" around sharing information which permeates the health and social care sector in the UK (Department of Health, 2013). Important shifts in this *culture* are a necessity if 'person centred' care is to be encouraged and maintained, and practitioner barriers dismantled: "To care appropriately, you must share appropriately" (Department of Health, 2013, p. 35).

#### 4.1 | Study limitations

A pragmatic and abductive data-driven mixed-methods approach (Morgan, 2007) was used to develop a deeper understanding of how a dementia services pathway works and was experienced in one locality in the UK. A particular strength of the chosen methodology (over mono or more 'fixed' approaches) was that it allowed, within a team or researchers, reactive 'triangulation' of data generated from multiple methods (e.g., shadowing observations could be used to validate interview data). In this way, we were able to delve beneath the 'surface layer' of how people and practices worked; and are confident in the internal validity of findings and the level of practice understanding which emerged.

While we acknowledge that our analysis represents only one geographical area in the UK (e.g., NHS England, 2019), and data collection was completed in 2017; we are aware that health and social care commissioning frameworks remain essentially similar across the UK (Department of Health & Social Care & the Ministry of Housing, Communities & Local Government, 2019a, 2019b; Milbourne & Cushman, 2012; Rees et al., 2012). With our final analysis being disseminated and verified at various local and national dementia stakeholder events (e.g., Chase, 2019), we are confident that our

core findings maintain external validity and that service providers' identified barriers to integrative practice in the current study hold current relevance in other geographical areas in the UK (Milbourne & Cushman, 2012; NAO, 2017).

#### 4.2 | Implications

With current local dementia pathway services struggling to accommodate demand at a time of scant financial support, effective integrated health and social care working is essential to accommodate need, alleviate strains on services and to encourage 'preventative' over crisis-response modes of practice (Alzheimer's Society, 2018a; Ham & Walsh, 2013; NAO, 2017, 2020). At the strategic level, we propose at least three core areas for improvement. Firstly, commissioning contractual frameworks should prioritise the diffusion of practitioner 'power', prejudice, and competitiveness. These should include: contractually encouraging inter-provider shadowing and team building, through to longer term consortium tenders; which straddle statutory and third sector agencies and encourage shared working spaces (Department of Health & Department for Communities and Local Government, 2017). Secondly, as we continue to wait for technical data systems solutions (House of Commons Science & Technology Committee, 2016), it is essential that the risk averse data sharing culture that has evolved in health and social care is replaced with one which authentically places the needs of people affected by dementia at the forefront of their care (Forder et al., 2018; NAO, 2017). A final recommendation relates to situating the voices of people affected by dementia at the centre of decisions for how best to configure and commission dementia care pathways and keep people out of hospital (Alzheimer's Society, 2018b), an issue which is picked up and discussed further in the subsequent paper by the same authors.

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#### CONFLICT OF INTEREST

The authors report no conflicts of interest.

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