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Patient experiences of integrated care within the United Kingdom: A systematic review

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Abstract

Introduction: Integrated care and patient experience are central to the coordination and delivery of high quality health and social care in the UK, but their joint application is poorly understood. This systematic review aimed to gain an understanding of patient experience within current integrated care services in the UK, and specifically, whether they reflect person-centred coordinated care (PCCC).

Methods: Following PRISMA, electronic databases (ProQuest, EBSCO and Cochrane Library) were searched from 2012 to 2019 for primary, peer-reviewed literature. Papers were included where patients' or carers' experiences of integrated care were reported. Papers were excluded where they focused on acute integrated care interventions, measured experience via satisfaction scores only, or findings lacked sufficient depth to answer the research question. Quality was assessed using Mixed Methods Appraisal Tool, and findings synthesised using a framework approach, incorporating the Rainbow Model of Integrated Care and Measuring Integrated Care Patient Framework.

Results: Sixteen studies were included. Person-centred and shared responsibility experiences were most often discussed. Experiences were not always described as positive and some patients experienced a lack of PCCC. Clinical, professional/organisational and functional integration processes were associated with experiencing domains of PCCC.

Discussion: People with complex needs experience a lack of coordination across teams and wider community resources, and limited associations were made between integration processes and patient experience. Further research which gives context to individual experience, provides greater detail of integration processes and utilises validated patient experience measures of PCCC is required to understand the association between integration processes and domains of PCCC.

Keywords

Integrated health care system, healthcare delivery, United Kingdom, literature review

Introduction

People in developed countries increasingly have multiple chronic conditions and complex care needs, partly due to an ageing population,[1] which has led to increasingly specialised care that results in increased fragmentation of care.[2] This fragmentation occurs within and between providers, as well as at the interface between primary and secondary care or health and social care.[3] There is therefore continued emphasis internationally upon improving quality of care through improved coordination and integration of services.[4] Despite the benefits of integration often being cited as supporting the transition of care from hospital to community settings, improving self-care, reducing costs and reducing demand for acute care,[5] there has been limited evidence of its impact on patient outcomes within previous initiatives.[6]

The processes of integration have been organised into the level of system at which they operate within the Rainbow Model of Integrated Care, which highlights person-centred care as a central component.[7] Person-centeredness is a multifaceted concept, with three core values; considering the person's needs,

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wants, perspectives and individual experiences; offering people the opportunity to participate in their care; enhancing the partnership and understanding within relationships with health professionals.[8] However, it has been argued that these domains can sometimes lead to a tendency to define person-centred care through the behaviour of health professionals, such as care planning and shared decision-making skills,[9] rather than through the lens of the patient and their experiences.

Amid increasing acknowledgement of the need to measure patient experience as a quality outcome,[10] experience continues to be under-reported and poorly understood.[11] Patient experience data is not only an important measure of overall system performance,[12] it is also essential to improving quality, innovation in health care delivery redesign, and improving accountability.[13] However, there is continued debate regarding the effective measurement of patient experience[14] and the continued use of locally produced measures without proven validity or reliability.[15] Measurement of patient experience of integrated care is also limited, with systematic reviews identifying that the potential effects of integrated care on patient and carer experiences are under-researched in UK literature[11] and internationally.[16]

The aim of this systematic review is to develop an understanding of current integrated care models in the UK and determine whether evaluations of patient experience reflect a person-centred coordinated care approach.

Methods

This systematic review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for conduct and reporting.[17] As the term integration is used broadly within health and social care, careful consideration was given as to whether studies reported a change in the coordination or integration of service delivery. This could include changes within a single service or multiple services. Detailed consideration was also given to whether the studies did in fact report on the experiences of patients and carers (i.e. gave a thick and comprehensive description of the receipt of integrated care), as opposed to more one-dimensional assessments of the satisfaction or preferences of patients and carers alone.

Search strategy

Searches were conducted between June and July 2019 in ProQuest, EBSCO, and the Cochrane Library. Search terms represent the key concepts of the review and the most common indexing terms found during an initial scoping of the literature. Satisfaction was included as a search term since it may be used interchangeably with experience. The following terms were used to search within each database;

1. experience* OR satisfaction OR perce* OR value* OR perspective* OR view* OR feedback (ABSTRACT)

   AND

2. patient* OR client* OR user* OR consumer* OR carer* OR men OR women (ABSTRACT)

   AND

3. integrat* OR coordinat* OR co-ordinat* OR collabor* OR continui* OR joint OR multidisciplinary OR partner* OR "single point of access" (ABSTRACT)

   AND

4. health OR social OR system* OR care OR team* OR service* OR housing (ABSTRACT)

   AND

5. "United Kingdom" OR "UK" OR England OR Scotland OR Wales OR "Northern Ireland" OR "Great Britain" (ANYWHERE)

Inclusion/exclusion criteria and study selection

Inclusion criteria were:

- Studies of all patients/clients/users and their carers (male and female) of health and social care services of any age that included patient or carer reported experience after the introduction of the Health and Social Care Act.[18]
- Studies that focused on integrated care (defined as changes in integration/coordination of service delivery in order to improve patient outcomes and experience) involving health, social and/or third sector organisations within the UK.
- Any study design, English language, empirical studies published in peer reviewed journals.

Exclusion criteria were:

- Integrated care which focused on acute care episodes only, e.g. emergency care models or surgical care pathways.
- Experience consisted of satisfaction score only.

- Studies which did not address the quality issues specific to this review with sufficient depth. Therefore, were unable to add value to the findings.

All articles identified in the database searches were downloaded into a bibliographical software package (EndNote X8, *Clarivate Analytics*) to facilitate the study selection process. Duplicates were deleted before articles were sifted for eligibility based on title and abstract by LD. The full text of any articles which could not be included or excluded by abstract alone were then reviewed by LD. All articles identified as eligible for inclusion, and 20% (n = 23) of articles excluded on full text were reviewed by JS and NF, with discussion amongst all authors until agreement was reached. No reversal of decisions was required.

Data extraction

Data were extracted by LD using a data extraction form, which included country within United Kingdom, study design, aim and description of the intervention, target population, sampling process, participant characteristics, roles of involved providers, data collection and analysis (including validity/reliability/ethical issues), and summary of results. Separate forms were used to extract data on the integration processes involved and descriptions of patient centred coordinated care.

Quality assessment

The Mixed Methods Appraisal Tool (MMAT)[19] was used to appraise the overall methodological quality of included studies. Along with reliability and validity, careful consideration was given as to how fit for purpose and relevant the studies were in addressing the review questions. Studies which did not meet a minimum score of 10 out of 12 were deemed to lack sufficient depth and relevance, and therefore excluded.

Data synthesis

Integrated care is complex, multicomponent and multilevel, involving different groups and organisations which results in varied and multiple outcomes.[20] The number of components within integrated care make linking them with emergent system properties such as patient-centred coordinated care very challenging.[21] Therefore within this review, integrated care was viewed as a complex adaptive system; a living system of interacting parts capable of changing context for others through their actions.[22] A framework synthesis approach was used due to the exploratory nature of the review. The Rainbow Model of Integrated Care and subsequent taxonomy[7,23] were used to code the processes of integration data within the studies, whilst the Measuring Integrated Patient Care Framework[24] was selected to code data relating to patient experience. Table 1 provides an overview of the key concepts of the models used in the study.

Results

Sixteen studies were found to meet both the inclusion and quality appraisal criteria. The selection process is outlined in the PRISMA flowchart (Figure 1). Studies included within this synthesis are summarised in Table 2.

Study characteristics

Of the 16 studies included in the review, 11 were based in England,[25–35] three in Scotland[36–38] and one in Wales.[39] One study did not name the sites within the UK.[40] Only the English studies included services which had integrated across health and social care or between acute and primary care services. The Scottish and Welsh studies were focused on single conditions with limited or no organisational integration, whether formal or informal.[5] Twelve studies took a qualitative approach,[25,27,28,31–39] three studies took a mixed methods approach[26,29,40] and one took a quantitative approach.[30]

The focus of the studies reflected the potential of integrated care to address the needs of those with co-morbidities.[41] Seven studies looked at services which addressed the needs of those with, or caring for those at risk of complex co-morbid long-term conditions.[25,27,29,31–33,35] One study involved a service providing both a disease-focused approach (Type-2 diabetes) and those at risk of complex co-morbidities,[30] which was also the only study from an Integrated Care Pilot site. The remaining eight studies focused on services for people with a single condition such as a mental illness,[26,28,34,39] pregnancy,[40] chronic heart failure[36] and cancer.[37,38]

Integration processes

Vertical and horizontal integration. Three studies described full vertical and horizontal integration across the micro, meso, macro and supportive levels,[27,32,35] whilst three others described horizontal integration processes across all levels.[29,31,38] All six studies involved the integration of health, social care and/or wider community services, reflecting the complex needs of the populations targeted within the studies.

Clinical integration (micro level). All the studies described clinical integration processes (micro level), with having a named key worker, care coordination and

Table 1. Models used to develop the coding framework.

Model	Component/construct	Description
Rainbow Model of Integrated Care[7]	Clinical integration (micro)	Coordination of person-focused care in a single process across time, place and discipline
	Service/professional integration (meso)	Inter-professional partnerships based on shared competences, roles, responsibilities and accountability to deliver a comprehensive continuum of care to a defined population
	Organisational integration (meso)	Inter-organisational relationships (e.g. contracting, strategic alliances, knowledge networks, mergers), including common governance mechanisms, to deliver comprehensive services to a defined population
	System integration (macro)	A horizontal and vertical integrated system, based on a coherent set of (informal and formal) rules and policies between care providers and external stakeholders for the benefit of people and populations
	Functional integration (micro, meso and macro)	Key support functions and activities (i.e. financial, management and information systems) structured around the primary process of service delivery to coordinate and support accountability and decision-making between organisations and professionals in order to add overall value to the system
	Normative integration (micro, meso and macro)	The development and maintenance of a common frame of reference (i.e. shared mission, vision, values and culture) between organisations, professional groups and individuals
Measuring Integrated Patient Care Framework[24]	Coordinated within care team	The individual providers (which may include physicians, nurses, other clinicians, support staff, and administrative personnel who routinely work together to provide medical care for a specified group of patients, hereafter the "care team") deliver consistent and informed patient care and administrative services for individual patients, regardless of the care team member providing them.
	Coordinated across care teams	All care teams that interact with patients, including specialists, hospital personnel, and pharmacies and deliver consistent and informed patient care and administrative services, regardless of the care team providing them.
	Coordinated between care teams and community resources	Care teams consider and coordinate support for patients by other teams offered in the community (e.g., Meals on Wheels).
	Continuous familiarity with patient over time	Clinical care team members are familiar with the patient's past medical condition and treatments; administrative care team members are familiar with patient's payment history and needs.
	Continuous proactive and responsive action between visits	Care team members reach out and respond to patients between visits; patients can access care and information 24/7.
	Patient centred	Care team members design care to meet patients' (also family members and other informal caregivers') needs and preferences; processes enhance patients' engagement in self-management.
	Shared responsibility	Both the patient and his or her family and care team members are responsible for the provision of care, maintenance of good health, and management of financial resources.

self-management support the most frequently cited processes. This finding is indicative of recommendations to focus on reducing fragmentation of services, without the requirement for integration at the organisational or system level.[5,42] See Table 3 for details of the clinical integration processes described within each study.

Service/professional integration (meso level). The data once again reflected the recommended focus on clinical and service integration, with all but three of the studies[28,33,40] describing service/professional integration processes. The processes ranged from simply managing and following up referrals[38] to multidisciplinary teams making decisions and planning care together, of which

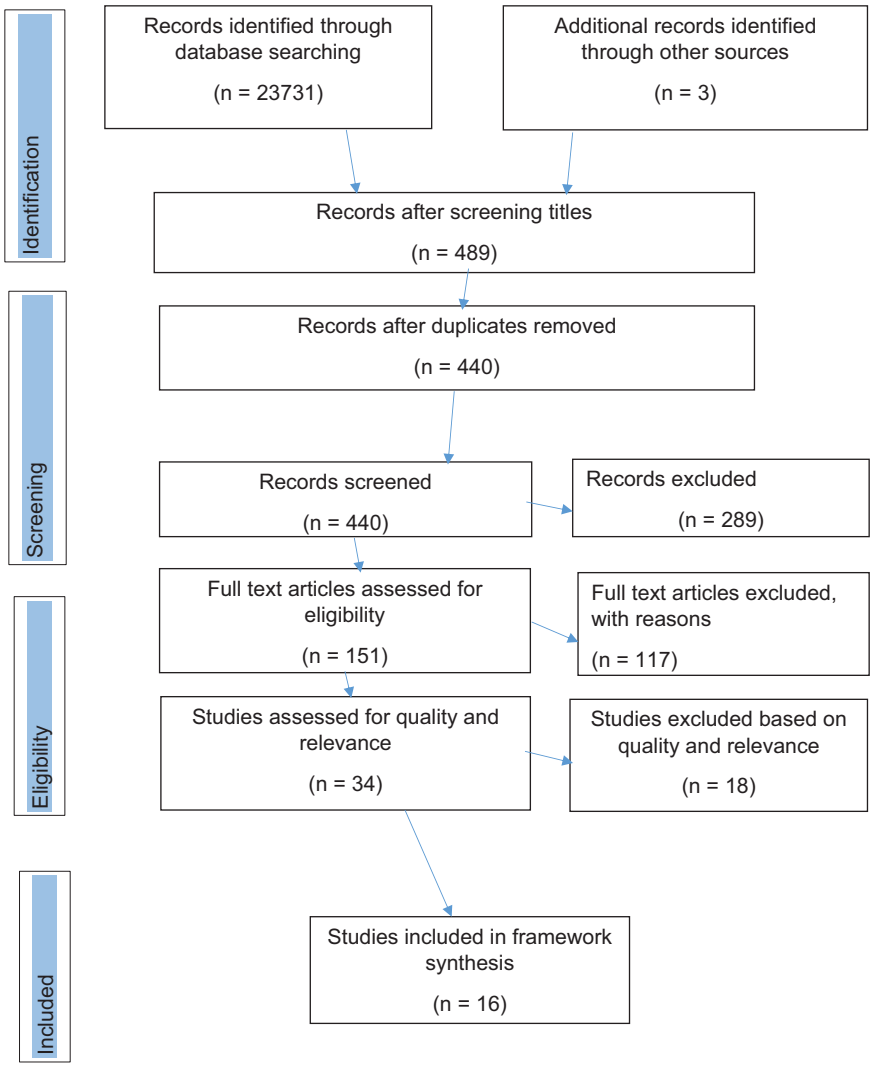

Figure 1. PRISMA flow diagram.

these were the most commonly described processes.[25–27,29,30,32,34,39] In Fairbrother et al.[36] service integration simply consisted of an Unscheduled Care Service taking over the weekend telemonitoring of people with chronic heart failure. Moule et al.[31] described an integrated team consisting of one professional (social worker), unqualified practitioners and a customer service officer with a team manager, working with trained assessors from other disciplines and teams to perform assessments, sign off and provide payments. Payne et al.[32] also described one of the hospices working as a hub for specialist palliative care services, supplementing primary care services and one consultant working across the hospital and hospice, while another hospice worked with specialist community heart failure nurses and community matrons to provide targeted services. In Wye et al.[35] professional integration focused on the role of a Discharge-In-Reach nurse who provided education and information to other professionals about end of life care and available services.

Organisational integration (meso level). Organisational integration was generally described in less detail if at all. In some studies organisational integration consisted of agreements to work across organisational boundaries providing support[27] and education.[28,31,32,38] In Hamilton et al.[28] assessors were trained across health, social care and voluntary organisations to perform assessments on behalf of the local authority. In other studies the multidisciplinary teams and/or key workers worked across organisational boundaries to deliver planned care.[30–32,34,35] Payne et al.[32] also described formal collaboration between hospices and other organisations with the use of similar paper-based records across one local care system. More formal arrangements such as co-location and/or management

Table 2. Characteristics and summary of studies included in the review, grouped by intervention type.

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
Interventions focused on people with or at risk of at least one long-term or age-related condition (n = 7)					
Boudioni et al. 2015[25]	Experience-based co-design (EBCD) using visual thematic approach.	Patients (65 years or over) in the community, mainly with long-term or complex range of age-related conditions in a London borough.	Partnership between local authority (LA) and primary care trust (PCT). PCT hosted a team of 8 integrated care social workers, managed by the LA and co-located within the community matron team.	Video recorded interviews (n = 7). Videos analysed by researcher with 2 independent service users trained in qualitative analysis.	Two main themes; 1. Overwhelming feelings and emotions across their journey. 2. The emotional journey and experience of powerlessness. Receiving extra integrated care reinstated feelings of control and power for most participants. Through integrated care, most participants obtained knowledge and skills required to manage condition and become active partners with professionals.
Gowing et al. 2016[27]	Qualitative	Patients at high risk of unplanned hospital admission in Northumberland.	Northumberland High Risk Patient Programme (NHRPP). Case finding of frail patients using a multidisciplinary team-led community case management programme and high-risk register.	Semi structured interviews (n = 23) in own home by independent academic GP trainee. Thematic analysis. Coding framework developed by team with diverse backgrounds.	Four main themes; 1. Awareness and understanding 2. Confidence in primary healthcare team. 3. Limitations of home care. 4. Active role of being a patient. Positive experience in general in terms of needs being met and having access to team members when needed. NHRPP experienced differently by different patients, especially those without informal carers, living alone with deteriorating health. Further integration is needed to meet complex health, psychological and social needs of frail older people, as well as reduce unplanned readmissions.

(continued)

Table 2. Continued

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
Hu 2014[29]	Mixed method post-implementation evaluation.	Older people requiring a defined range of community services across Cambridgeshire.	Locality integrated multi-disciplinary teams across four PCT areas.	Face to face/telephone administered questionnaire (n = 100) and semi-structured interviews (n = 27). Data analysed using SPSS and thematic approach by one researcher. Coding checked by supervisor.	Ten domains. Satisfaction with services; Waiting times for assessment and receiving services; Awareness of the Cambridgeshire Direct Contact Centre; Improvement in physical functioning of some users of occupational equipment; Promotion of faster recovery from illness; Meeting basic physical needs; Living in a clean and tidy environment; Control over everyday life; Being treated as an individual with respect; Having a say and control over services. Positive outcomes for some but not majority. Low level of satisfaction with social care associated with impact of agency work, aim of achieving maintenance/prevention outcomes and staff behaviour/attitudes. No evidence of more positive outcomes than other integration models, with or without structural changes.
Moule et al. 2014[31]	Qualitative	Carers of people eligible for and receiving provision from adult social care teams in Bristol.	Joint carers strategy supported by Bristol City Council and Bristol Clinical Commissioning Group. Integrated carers' teams work directly with carers to assess for one off direct payments to address outcomes identified. Also those funded by Continuing Health Care who do not have access to social workers.	Telephone interviews (n = 39) and home interview (n = 1). Interview schedule developed with input from 2 carer members of research team and project advisory board (carers and staff from both organisations). Thematic analysis using recognised framework.	Four themes; 1. Administration 2. Circumstances of the carers 3. The break 4. Effects of the break Assessment mostly positive experience but challenging to reach isolated group. Integrated approach to carer breaks should be maintained.

(continued)

Table 2. Continued

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
Payne et al. 2017[32]	Qualitative longitudinal organisational case studies.	Patients and families with cancer and chronic conditions requiring palliative care support in Northern England.	Integration between hospices and local health care providers to provide direct multidisciplinary patient care to one or more diagnostic groups (advanced airways disease/heart failure/cancer).	Semi-structured interviews (n = 47) 3 months apart, mostly at home. Interviewed by researcher. Secondary thematic analysis of data from Integrated Palliative Care in cancer and chronic conditions (InSuP-C) study. Coding checked by another researcher.	All valued continuity of care, integrated working and named professional as point of contact. Key area – information sharing. Highlights needs of patients with non-cancer diagnosis and multi-morbidities. Greater integration by hospices required to work with, rather than replace local providers. Priorities for integration identified as – single information system, skilled named professional to coordinate care and form meaningful relationships.
Randall et al. 2014[33]	Qualitative/Pragmatic	Patients with complex comorbid long-term conditions in a UK inner city PCT.	Case management by Community Matrons (CM), including care coordination, effective disease management and self-management support.	Semi-structured interviews (n = 21). Domains of case management used to guide framework analysis.	Four themes; 1. Visibility 2. Interpersonal relationships 3. Leadership 4. System/Professional boundaries Greatest impact – relating to person as a whole rather than dealing with single disease. Coordination role most valuable. Consistent approval of CM service from patients and carers. Reducing levels of hospital admission major challenge due to fragmented services and limited vision of working in partnership held by other professions.
Wye et al. 2014[35]	Realist evaluation	All palliative patients across North Somerset and Somerset.	Marie Curies Cancer Care's Delivering Choice Programme (DCP) working in partnership with local providers and commissioners to develop 24-hour services to meet local need.	Face to face and telephone semi-structured interviews (n = 43). Framework analysis. Local stakeholders attended hypothesis generation workshops.	Highly skilled, experienced, customer-focused palliative professionals are important. Willingness to have difficult conversations and access to community resources to support home care led to confidence and reassurance to patients. Inconsistency of referrals limited success and kept focus on those with cancer. Coordination Centres within

(continued)

Table 2. Continued

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
					social services on local authority premises and Discharge In Reach Nurses had most success accessing all eligible patients. 24 hour integrated palliative care services have an overview to steer families and patients through the system.
Interventions focused on those with a single condition/diagnosis ($n = 8$)					
Darwin et al. 2017[40]	Mixed method multisite evaluation informed by realistic evaluation.	Pregnant women from low income communities, two sites restricted to women from ethnic minority groups and third site has a large ethnic minority population.	Predominantly voluntary service organisations train volunteers from local community (doulas) to offer information, emotional and physical support. Work closely with existing services, facilitating communication and signposting to other services.	Questionnaires (n = 136) and semi structured interviews (n = 12). Discussions with key informants to develop topics and a priori hypotheses. Completed with assistance of researcher or interpreter or self-completed by post. Quantitative data analysed using descriptive statistics and chi-squared with Yates' continuity correction using SPSS version 20. Qualitative data analysed using content analysis.	Most reported positive impacts on emotional wellbeing; combating feelings of depression, fears allayed, increased confidence and self-esteem. Continuing support beyond 6 weeks should be considered. Negative experiences most commonly associated with lack of continuity. Volunteer doula services have potential to overcome barriers and facilitate access to improve outcomes of pregnant women with complex social factors.
Deslandes et al. 2015[39]	Qualitative case study	Patients with a diagnosis of mental illness attending a secondary care psychiatrist clinic in Wales.	A pharmacist supplementary prescriber working in partnership with five psychiatrists and patients to provide dose titration and medicine information.	Semi-structured interviews and self-completed diaries (n = 11) over 6 weeks. Code and retrieve analysis of interviews. Thematic content analysis of diaries. All transcribing and analysis by main researcher.	Interview themes; 1. Pharmacist-patient relationship. 2. Comparison to other professionals. 3. Time allowed for consultation. Diary themes; 1. Patient satisfaction. 2. Consistency of care. 3. Pharmacist accessibility. 4. Pharmacist knowledge. 5. Mental health patient. Positive experience associated with increased access to and continuity of healthcare professional and more active role for patients in decisions.

(continued)

Table 2. Continued

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
Fairbrother et al. 2013[36]	Qualitative	All patients with chronic heart failure(CHF) in the community in Lothian, Scotland.	Telemonitoring of patients at home by GP or CHF nurse.	Semi-structured interviews (n = 18) by 2 independent graduate researchers. Framework analysis.	Five themes; 1. Information, support and reassurance. 2. Compliance and dependence. 3 Changes and challenges. 4. Determining the criteria for patient applicability to telemonitoring. 5. Continuity of care. High level of satisfaction. Telemonitoring enhanced patients knowledge and understanding of condition and useful in management of CHF.
Firn et al. 2018[26]	Mixed method uncontrolled observational follow-up design.	Mental health patients in suburban West London Borough.	A hybrid model that incorporates practice and principles of Assertive Outreach (AO) into Community Mental Health Teams (CMHT).	Validated Team Attachment Questionnaire (TAQ) 12 months pre (n = 37) and post (n = 33) service change. Appreciative Inquiry method to free text responses.Change in measures of patient experience reported using mean change and 95% confidence intervals, paired t-tests to test significance.	TAQ scored highly in both services. Four themes; 1. Continuity. 2. Indifference to change. 3 Flexibility and freedom. 4 Reduction in contact and support. AO may have over provided care, nurtured dependency and continued beyond current need. Unnecessary dependence may explain concerns about reduced contact after integration.
Hamilton et al. 2016[28]	Qualitative	People eligible for publicly funded social care support within a mental health service. Across three local authority areas (rural South England, urban North England and London borough).	Social workers, occupational therapists and community psychiatric nurses work in partnership with client to assess personal budget needs on behalf of local authority.	In-depth semi-structured interviews (n = 52). Analysed using Interpretive Framework Approach in collaboration with advisory board of ten service user researchers.	One group of themes relating to power, choice and control. Generic local authority systems not well suited to people with mental health conditions whose level of need and capacity may fluctuate and may find process stressful.

(continued)

Table 2. Continued

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
Primeau et al. 2017[37]	Qualitative component of a randomised controlled trial (RCT).	Men with metastatic prostate cancer in Tayside, Scotland.	Multi-modal supportive care intervention (Thriver -Care) which includes: a holistic needs assessment with a prostate cancer specialist nurse (PCSN), individualised self-management care plans, group-based seminar and educational materials. Compared with standard care.	Semi-structured interviews at home or cancer centre (n = 26). Framework analysis. Data checked by peers to verify themes.	Overall high satisfaction with intervention. Perceived empowerment in their self-management. Important themes; being listened to by someone who could facilitate emotional expression; being provided individually tailored information; receiving practical help and evidence-based advice for managing consequences of cancer and it's treatment. Experienced less unmet needs than standard care group.
Thomson et al. 2018[34]	Qualitative component of larger randomised controlled trial.	People diagnosed with major depressive disorder across Nottinghamshire, Cambridgeshire and Derbyshire.	A collaborative and integrated psychobiosocial model. Joint assessments by psychiatrists and psychological therapists, with development of structured management plans.	Semi-structured interviews (n = 21) with experienced qualitative interviewer at 12-18 months after baseline. Inductive thematic analysis using grounded approach. Second researcher coded and themes checked by team.	Four themes; 1. Specific treatment components. 2. Individual qualities of clinicians. 3. Collaborative team approach. 4. Accessibility of treatment. Positive experiences centred on trusting relationships with therapists, stable and collaborative team, frequency and accessibility of sessions and ability to top-up/reinforce techniques learned over a longer period. Transition to usual care difficult for some.
Young and Snowden 2019[38]	Qualitative component of longitudinal mixed methods study.	People with a new diagnosis of cancer in Glasgow City Council area.	An integrated community-based supportive cancer service run by a joint health and social care board.	Semi-structured interviews (n = 20), mostly at home. Conducted by one researcher. Thematic analysis by two researchers.	Three themes; 1 One person, one place. 2. Routes to unexpected support. 3. Safety net. Beneficial for majority of participants. Positive impact associated with opportunity to discuss their concerns with someone separate to clinical environment/personalised guidance and support. Created confidence to self-manage.

(continued)

Table 2. Continued

Author(s)	Study design	Target population	Intervention	Data collection and analysis	Summary of results
Interventions which focused on people with a single diagnosis and those with age related conditions ($n = 1$)					
Mastellos et al. 2014[30]	A cross-sectional survey design.	Patients registered with the Integrated Care Pilot in North West London who had a diagnosis of diabetes and /or were aged over 75 years.	Practices were offered incentives to develop specific, bespoke care plans in order to identify those at risk of hospital admission and coordinate care across services in primary, secondary and community care.	Structured five-point Likert-scale questionnaire (n = 405). Paper-based and self-completed. Analysed using software and descriptive statistics used. Case analysis used for each variable to handle missing data.	Positive experience with Integrated Care Pilot. Benefits for those aware of having a care plan; increased involvement in decision-making, improved patient-provider relationship, better organisation and access to care, enhanced communication amongst healthcare providers. Incentive structures may be open to abuse. Provides empirical evidence integrated care has potential to improve patient experience.

of health and social care professionals under one organisation were found in three studies.[25,29,35] In Boudioni et al.[25] health (community matrons) and social care (social workers) professionals were co-located within the Primary Care Trust. However, social workers continued to be managed by the local authority. In Hu[29] professionals across health and social care for older people were employed directly by one Older People's Service.

System integration (macro level). Less than half of the studies described integration at this level, reflecting well-documented barriers which continue to exist regarding funding and lack of shared objectives.[43,44] Seven studies provided limited description of the following system integration processes; national policy or funding;[27,35,38] joint commissioning and a pooled budget;[29] legislation[28] and service level agreements.[32]

Normative and functional integration (supportive). Supportive processes are cited as important to achieving integrated care at all levels,[23,43] however only nine studies described any. The use of technology was the most frequently cited support process.[27,30,32,35] Other processes focused on creating shared culture,[29,40] learning[29,31,32,38] and governance.[29,31,34,35,38]

Experiences of person-centred coordinated care (PCCC). The experiences captured within the studies are summarised in Table 4. A positive experience is defined as when the patient or carer has described a beneficial or positive effect when experiencing a particular domain of care. Conversely, when experience of a domain has had a detrimental effect to the person it is recorded as a negative experience. Some of the comments and in particular the quantitative data only confirms the domain was experienced, without any indication of positive or negative views, these are recorded as neutral experiences. An opposing experience was recorded when a person described an experience which was the opposite of a particular domain e.g. they were not supported to share decision making or responsibility for their care. Only one study described patient experience of all domains of PCCC.[34]

Coordinated care within the team

This domain received limited descriptions of patient experience, which were mainly neutral.[25,27–31,34] Much of the coordination referred to within this domain relied on communication between team members and administrative processes, which are not always evident to patients and carers.

Table 3. Summary of clinical integration processes at the micro level.

Study	Care coordination	Care planning	Key worker	Remote monitoring	Self-management support	Supplementary prescribing	Total number of processes described
Boudioni[25]	•	•	•			•	4
Darwin[40]			•				1
Deslandes[39]					•	•	2
Fairbrother[36]			•	•	•		3
Firn[26]	•	•	•		•		4
Gowing[27]	•	•	•		•		4
Hamilton[28]		•					1
Hu[29]	•		•		•		3
Mastellos[30]	•	•			•		3
Moule et al.[31]		•					1
Payne et al.[32]	•		•				2
Primeau[37]		•	•		•		3
Randall[33]	•	•	•		•	•	5
Thomson[34]	•	•			•		3
Wye[35]	•		•		•		3
Young and Snowden[38]	•	•	•				3
Total number of studies	10 (63%)	10 (63%)	11 (69%)	1 (6%)	10 (63%)	3 (19%)	45 (47% of maximum number of processes available)

Coordinated care across teams

All studies except for three[36,38,39] included experiences of this domain. Only two studies included a negative experience.[26,29] For people with complex care needs the experience was generally positive.[27] In Wye et al.[35] a coordination centre put a care package in place to support a dying person at home. However, two studies described a lack of coordinated care across teams,[31,32] which was described as people being "too scared to cross each other's territories".[32]

Coordination of care across the team and between wider community services

Experience of coordination across the team and between wider community services received only negative descriptions in Firn et al.[26] and Hu,[29] while in Young and Snowden[38] they were all positive. The majority of negative experiences related to social care services and the often frustrating limitations in terms of time and quality of care provided. For example, in Hu[29] ten patients reported their basic physical needs had not been met due to a decline in social care quality. Positive experiences relating to social care involved carers feeling supported through the provision of overnight care[27] and home care packages to support dying at home.[35] Opposing experiences were described by palliative care patients regarding lack of communication and information sharing between health and social care providers.[32,35]

Continuous familiarity with a service over time

While there were mixed experiences of this domain, it was only described negatively in two studies where patients felt unsupported when a transition to another service or professional was required.[32,34] Some patients found it to be an important factor in establishing recovery, which points to a need for personalisation and flexibility in services.[34] While in Hu[29] social care experiences demonstrated a lack of continuous familiarity. For older people, those with complex conditions and those with a single condition, the value of access to a key worker who provided continuity featured in many positive experiences.[25,28,32,33,37–40]

Continuous proactive and responsive action between visits

The experience of this domain received mainly positive descriptions.[25,27,30,32–39] The experiences reflected a sense of reassurance from being actively followed up and being able to contact someone when needed, particularly older people with complex needs.[27] Where an opposing experience had been described it related to patients feeling they were still having to follow-up and coordinate care themselves.[25,32]

Table 4. Domains of integrated patient care measure.[24]

Study	Coordinated care within team	Coordinated care across team	Coordinated across team and community services	Continuous familiarity over time	Continuous proactive and responsive action between visits	Patient centred	Shared responsibility
Boudioni[25]	+	/ +		+	× +	× × / +	× / +
Darwin[40]				/ + + / + ×		/ + + × × +	+
Deslandes[39]				+ +	+	+	+ +
Fairbrother[36]					+	+ +	× +
Firn[26]		/ −	−	+ + +		+ + + − − −	
Gowing[27]	/ / /	/ +	+ − +		+ + +	+ + × − − + / + / +	+ −
Hamilton[28]	+	− − −				× + − × × +	+ − − − + × − × − −
Hu[29]	/ × +	+ +	− − − − −	× ×		+ / × ×	+ / ×
Mastellos[30]	/	/		/	/	/ / + / / ×	/ / ×
Moule[31]	/ ×	×				/ + + × / − + + /	
Payne[32]							
Hospice A		× + × + ×	−	+ / × + +		+	
Hospice B		×	+	+		+	
Hospice C		+ + /	×	+		/	
Hospice D		/ / + × ×	+	/	/ × +	+ ×	
Primeau[37]		/		/	/	+ + + /	/ /
Randall[33]		+ +		/	+ +	+	+
Thomson[34]	/	+	/	+ + −	+	+ + / +	/ + / / −
Wye[35]		+ + +	× +		+ + +	+	
Young and Snowden[38]			+ + + +	+ +	+ + + + + + +	× × / /	/

Key + denotes positive experience. − Denotes a negative experience./Denotes a neutral experience. × Denotes an opposing experience.

Patient/person-centred care

Patients and carers described the experience of person-centred care frequently and in all studies, which links to the focus on micro level integration within the studies. There were positive experiences across all studies and negative experiences in only four studies, related to lack of flexibility and personalisation in practitioners approaches.[26–28,31] For those with single conditions positive experiences centred on increased knowledge[37] and feeling listened to.[39] However, nine studies included experiences which demonstrated a lack of person centred care,[27–32,38,40] in particular when policy dictated when and for how long a service was available rather than individual need. For example, 33.1% of women receiving a doula service felt support ended too soon and at a difficult time.[40] In Mastellos et al.,[30] despite 78.8% of patients understanding how their care plan worked, only 36.4% were involved in creating the care plan.

Shared responsibility

The experience of shared responsibility was the second most described within the studies and reflects the frequency of self-management support in these studies.[25,27–30,33,34,36,39,40] However, three of these studies included negative experiences.[27,28,34] In Hamilton et al.,[28] people with mental health conditions felt overwhelmed by the expectation of shared decision-making regarding their personal budgets or felt pressured because they did not want to challenge the healthcare professional. Older people with complex needs also reported mixed experiences; some welcomed self-help as a good thing[27] and felt able to have a say in decisions, whilst others felt they did not have this right.[29]

Associations between integration processes and person-centred coordinated care

Associations between integration processes and experience of person-centred coordinated care were very limited in the included studies. Boudioni et al.[25] associated feelings of power and control, improving self-management skills and becoming active partners with professionals, with the overall service rather than a particular process. Hamilton et al.[28] acknowledged the experience of taking control was influenced by organisational culture and processes, as well as practitioner skills and attitudes. Positive experiences were associated with increased access to and continuity of healthcare professionals, along with a more active role in decisions,[39] individualised self-management interventions,[37] ability to accommodate preferences,[31,37] trusting relationships and a collaborative team[34] and increased access to community resources for home care.[35] Negative experiences were associated with a lack of shared organisational culture such as social care's focus on maintenance and prevention, as well as staff behaviour and attitudes.[29]

Discussion

Sixteen studies were identified which explored patient experience of integrated care within the UK since the introduction of the Health and Social Care Act.[18] Included studies examined varied types and levels of integration; some focused on single services, some explored changes to multiple services and others addressed the use of personal budgets to allow choice in services received. The breadth of integration processes examined, and the joint focus on integration and patient experience forms a key strength of this review.

Limited associations were made between integration processes and patient experience despite patient experience being a central component of integrated care.[7] Eight studies included in this review identified positive experiences of integrated care, with the majority of experience data focused on person centred care and shared responsibility. A negative experience of patient centred coordinated care occurred when integration did not allow for the flexibility and responsiveness required to meet individual needs[45] or when services try and fit people into a particular model that may not be appropriate.[40]

Despite evidence that integrating health and social care improves access to care for people complex and palliative care needs,[46] people with complex needs continued to experience a lack of coordination across teams and wider community resources.[32,35] Findings such as this strengthen the need to understand which integration processes are associated with patient centred coordinated care.[24] To facilitate this, research into integrated care would benefit from the use of a common framework or language regarding integration processes to improve shared understanding of links between implementation and patient experience.[47] Comparing individual patient experiences is challenging[48] and was found to be more achievable within studies where context and social factors were taken into account.[38,40]

Overall, the experiences of patients in this review support the view that person centred care is a core element of integrated care.[9,24] However, the argument that person centred care is often defined by the behaviour of health professionals[9] remains evident. While definitions of integrated care remain unclear, this review supports the findings of previous research[49] that patients are clear on the concept of patient-centred care coordination as their experiences reflect the importance of coordination (within, across and

with wider community resources), continuity, information sharing and engagement. As the patient can be the only person to have a holistic perspective of their care, particularly across multiple services, capturing data on their experiences is an important component towards understanding complexity, though patient experience data alone is insufficient for determining whether models of integration can be deemed successful.[50] The insights gained from this review affirm the potential of integrated care to provide PCCC but also reveal the potential for negative or opposing patient experiences when integration fails to go beyond the clinical level.

A potential lesson for other developed countries is the failure to treat healthcare systems as complex-adaptive, which has led to poor professional and organisational alignment, lack of funding incentives for collaboration and a continued top-down approach to management.[4] Integrated care requires the facilitation of strong relationships between providers and organisations over time,[4] which supports emergent collective insight and distributed control. However, confusion exists regarding the complex interactions between integration and integrated care which can occur at different levels of the health system.[51] In the UK, the Covid-19 pandemic has highlighted the need for a legislative framework which encourages provider collaboration and flexibility of service provision in order to effectively provide integrated care.

A limitation of this systematic review is that the data extraction process was completed by one researcher. However, the process was repeated to increase intra-rater reliability. A clear quality appraisal process enabled the identification of the most relevant studies for the review which also improved the overall validity of the findings. The exclusion of any non-empirical unpublished studies and low-quality studies does however mean this could not be considered a comprehensive review of all available data, but instead of only the highest quality data.

In conclusion, the findings of this review highlight the importance of measuring patient experience of integrated care, which could facilitate a shared understanding of experiences across health and social care. However, in order to compare experiences across such broad health, social and third sector services, far more focus on integration processes is required than were found within this review. The complexity of integration processes, which take many different forms and occur simultaneously at micro, meso and macro levels, pose key challenges in regard to conceptual clarity and practical application. As such, there is a need for greater consistency in the definition of this construct in order to facilitate its understanding and implementation. Likewise, future work should consider the use of validated measures of patient experience of PCCC in addition to in-depth qualitative methods. The review demonstrated the need for further work highlighting the processes which support integration more explicitly, in order to inform its operationalisation. Evidence on the relationship between integration and patient experience was shown to be scant, with this forming a key avenue for future research. In particular, the impact of organisational and system level integration for patients is currently very poorly understood, relative to more micro integration processes. The combined application of the Rainbow Model of Integrated Care[7] and the Measuring Integrated Care Patient Framework[24] within this paper provides a foundation for other work examining the links between integration processes and patient experience.

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References

1. Pearson WS, Bhat-Schelbert K and Probst JC. Multiple chronic conditions and the aging of America: challenge for primary care physicians. *J Prim Care Community Health* 2011; 3: 51–56.
2. Ling T, Brereton L, Conklin A, et al. Barriers and facilitators to integrating care: experiences from the English Integrated Care Pilots. *Int J Integr Care* 2012; 12..]
3. Glasby J, Dickinson H and Peck E. Guest editorial: partnership working in health and social care. *Health Soc Care Community* 2006; 14: 373–374.
4. Edgren L and Barnard K. Complex adaptive systems for management of integrated care. *Leadership Health Serv* 2012; 25: 39–51.
5. Goodwin N, Smith J, Davies A, et al. *Integrated care for patients and populations: improving outcomes by working together*. London: The Kings Fund, 2012.
6. Mason A, Goddard M, Weatherly H, et al. Integrating funds for health and social care: an evidence review. *J Health Serv Res Policy* 2015; 20: 177–188.
7. Valentijn PP, Schepman SM, Opheij W, et al. Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care. *Int J Integr Care* 2013; 13.
8. Ishikawa H, Hashimoto H and Kiuchi T. The evolving concept of "patient-centeredness" in patient–

physician communication research. *Soc Sci Med* 2013; 96: 147–153.
9. Greenfield G, Ignatowicz AM, Belsi A, et al. Wake up, wake up! It's me! It's my life! Patient narratives on person-centeredness in the integrated care context: a qualitative study. *BMC Health Serv Res* 2014; 14: 619.
10. Charles A, Wenzel, L, Kershaw, M, et al. *A year of integrated care systems: Reviewing the journey so far*. London: The Kings Fund, 2018
11. Baxter S, Johnson M, Chambers D, et al. Understanding new models of integrated care in developed countries: a systematic review. *Health Serv Deliv Res*. 2018; 6.
12. Salisbury C, Wallace M and Montgomery AA. Patients' experience and satisfaction in primary care: secondary analysis using multilevel modelling. *BMJ* 2010; 341: c5004.
13. Wong ST and Haggerty J. *Measuring patient experiences in primary health care: a review and classification of items and scales used in publicly-available questionnaires*. Vancouver: University of British Columbia Center for Health Services and Policy Research, 2013.
14. Goodwin N. How should integrated care address the challenge of people with complex health and social care needs? Emerging lessons from international case studies. *Int J Integr Care* 2015; 15.
15. Black N and Jenkinson C. Measuring patients' experiences and outcomes. *BMJ* 2009; 339.
16. Ouwens M, Wollersheim H, Hermens R, et al. Integrated care programmes for chronically ill patients: a review of systematic reviews. *Int J Qual Health Care* 2005; 17: 141–146.
17. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Ann Intern Med* 2009; 151: W-65–W–94.
18. Department of Health. *Health and Social Care Act*. London: Department of Health, 2012.
19. Hong Q, Pluye P, Fabregues S, et al. *Mixed methods appraisal tool (MMAT)*. Canada: Canadian Intellectual Property Office, 2018.
20. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* 2008; 337: a1655.
21. Anderson LM, Oliver SR, Michie S, Rehfuess E, et al. Investigating complexity in systematic reviews of interventions by using a spectrum of methods. *J Clin Epidemiol* 2013; 66: 1223–1229.
22. Greenhalgh T and Papoutsi C. Studying complexity in health services research: desperately seeking an overdue paradigm shift. *BMC Med* 2018; 16: 95.
23. Valentijn P, Boesveld I, van der Klauw D, et al. Towards a taxonomy for integrated care: a mixed-methods study. *Int J Integr Care* 2015; 15.
24. Singer SJ, Burgers J, Friedberg M, et al. Defining and measuring integrated patient care: promoting the next frontier in health care delivery. *Med Care Res Rev* 2011; 68: 112–127.
25. Boudioni M, Hallett N, Lora C, et al. More than what the eye can see: the emotional journey and experience of powerlessness of integrated care service users and their carers. *Patient Prefer Adherence* 2015; 9: 529–540.
26. Firn M, Alonso-Vicente M, Hubbeling D, et al. The replacement of assertive outreach services by reinforcing local community teams: a replication study reporting comparative outcomes and patient reported experience. *J Ment Health* 2018; 27: 157–163.
27. Gowing A, Dickinson C, Gorman T, et al. Patients' experiences of a multidisciplinary team-led community case management programme: a qualitative study. *BMJ Open* 2016; 6.
28. Hamilton S, Tew J, Szymczynska P, et al. Power, choice and control: how do personal budgets affect the experiences of people with mental health problems and their relationships with social workers and other practitioners? *Br J Soc Work* 2016; 46: 719.
29. Hu M. The impact of an integrated care service on service users: the service users' perspective. *J Health Organ Manag* 2014; 28: 495–510.
30. Mastellos N, Gunn L, Harris M, et al. Assessing patients' experience of integrated care: a survey of patient views in the North West London Integrated Care Pilot. *Int J Integr Care* 2014; 14.
31. Moule P, Pollard K, Clarke J, et al. An integrated approach for individualised support: carer's views. *J Integr Care* 2014; 22: 253–262.
32. Payne S, Eastham R, Hughes S, et al. Enhancing integrated palliative care: what models are appropriate? A cross-case analysis. *BMC Palliat Care* 2017; 16: 64.
33. Randall S, Daly G, Thunhurst C, et al. Case management of individuals with long-term conditions by community matrons: report of qualitative findings of a mixed method evaluation. *Prim Health Care Res Dev* 2014; 15: 26–37.
34. Thomson L, Barker M, Kaylor-Hughes C, et al. How is a specialist depression service effective for persistent moderate to severe depressive disorder?: A qualitative study of service user experience. *BMC Psychiat* 2018; 18: no pagination.
35. Wye L, Lasseter G, Percival J, et al. What works in 'real life' to facilitate home deaths and fewer hospital admissions for those at end of life?: Results from a realist evaluation of new palliative care services in two English counties. *BMC Palliat Care* 2014; 13: 37.
36. Fairbrother PBAM, Ure J, Hanley J, et al. Telemonitoring for chronic heart failure: the views of patients and healthcare professionals – a qualitative study. *J Clin Nurs* 2014; 23: 132.
37. Primeau C, Paterson C and Nabi G. A qualitative study exploring models of supportive care in men and their partners/caregivers affected by metastatic prostate cancer. *Oncol Nurs Forum* 2017; 44: E241E9.
38. Young J and Snowden A. A qualitative study on the perceived impact of using an integrated community-based supportive cancer service. *Eur J Cancer Care* 2019; 28: PAG.
39. Deslandes RE, John DN and Deslandes PN. An exploratory study of the patient experience of pharmacist supplementary prescribing in a secondary care mental health setting. *Pharm Pract* 2015; 13: 553.

40. Darwin Z, Green J, McLeish J, et al. Evaluation of trained volunteer doula services for disadvantaged women in five areas in England: women's experiences. *Health Soc Care Community* 2017; 25: 466–477.
41. Sanders T, Porter T, Grime J, et al. Living with multimorbidity: medical and lay healthcare approaches. *Int J Clin Rheumatol* 2015; 10: 111–119.
42. Curry N and Ham C. *Clinical and service integration*. The route to improve outcomes. London: The Kings Fund, 2010.
43. Cameron AM, Lart R, Bostock L, et al. *Factors that promote and hinder joint and integrated working between health and social care services*. London: Social Care Institute for Excellence, 2012.
44. Erens B, Wistow G, Mounier-Jack S, et al. Early findings from the evaluation of the integrated care and support pioneers in England. *JICA* 2017; 25: 137–149.
45. Clark M, Moreland N, Greaves I, et al. Putting personalisation and integration into practice in primary care. *J Integr Care* 2013; 21: 105–120.
46. Higginson IJ, Bausewein C, Reilly CC, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med* 2014; 2: 979–987.
47. de Stampa M, Vedel I, Bergman H, et al. Opening the black box of clinical collaboration in integrated care models for frail, elderly patients. *Gerontologist* 2012; 53: 313–325.
48. Wodchis W, Dixon A, Anderson G, et al. Integrating care for older people with complex needs: key insights and lessons from a seven-country cross-case analysis. *Int J Integr Care* 2015; 15.
49. Walker KO, Labat A, Choi J, et al. Patient perceptions of integrated care: confused by the term, clear on the concept. *Int J Integr Care* 2013; 13.
50. Hughes G, Shaw SE and Greenhalgh T. Rethinking integrated care: a systematic hermeneutic review of the literature on integrated care strategies and concepts. *Milbank Q* 2020; 98: 446–492.
51. Kodner DL and Spreeuwenberg C. Integrated care: meaning, logic, applications, and implications—a discussion paper. *Int J Integr Care* 2002; 2.