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Evidence Check

Patient experience surveys for vulnerable families

An Evidence Check rapid review brokered by the Sax Institute
for the NSW Ministry of Health—February 2022

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This report was prepared by: Gina-Maree Sartore, Michelle Macvean, Catherine Wade, and Kate Spalding.

February 2022

Enquiries regarding this report may be directed to the:

Manager
Knowledge Exchange Program
Sax Institute
www.saxinstitute.org.au
knowledge.exchange@saxinstitute.org.au
Phone: +61 2 9188 9500

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Contents

Key messages

- This Evidence Check identified few patient-reported experience measures (PREMs) for use with people with both chronic or complex health conditions and social vulnerabilities
- Most of the studies (10 of 16) included in the review were conducted in the US
- All of the identified PREMs were psychometrically valid and reliable measures
- Most of the PREMs focused on integrated primary healthcare rather than integration across service systems or sectors
- Most of the PREMs were used with adults identified as having complex health concerns rather than people with multiple social vulnerabilities
- Many of the PREMs included domains or items relevant to integrated care or care coordination
- Few PREMs have direct applicability to populations with complex health and social needs or to cross-service sector models of care
- PREM selection should focus on use in integrated or coordinated care, but it may be suitable to look to beyond complex and vulnerable populations, as a wider selection of PREMs may be found in general healthcare
- PREM selection should consider ease of use; preferencing a short, simple, valid measure will reduce practitioner and client burden and increase likelihood of accurate and timely completion.

Executive summary

Background

People with chronic or complex health issues may experience a range of stressors in addition to their health concerns that place them in a position of increased vulnerability. In addition to their social issues, they are also vulnerable from fragmentation and gaps in the provision of services and supports to address their multiple needs.

The Healthy Homes and Neighbourhoods (HHAN) Integrated Care Initiative is intended to overcome barriers to accessing health and social care experienced by many families. HHAN is a co-located model of integrated care that provides multidisciplinary support to vulnerable people with chronic and/or complex health conditions and their families. The HHAN initiative is now being rolled out NSW-wide as the Vulnerable Families (VF) program. To better understand the experiences of patients accessing the VF program, the NSW Ministry of Health is developing a survey to capture information about patient experiences of the program, particularly with regard to service integration and care coordination.

This Evidence Check seeks to identify measures that report patients' experiences of integrated care using patient-reported experience measures (PREMs). The review's findings will support the development of a survey to use with families accessing the VF program.

Evidence Check questions

This Evidence Check aims to address the following questions:

Question 1: What validated patient reported experience measures (PREMS) have been used to measure the experience of vulnerable people and/or families accessing care coordination services?

Question 2: What PREMS, domains and questions from those identified in Question 1 may have applicability for clients of the NSW Vulnerable Families (formerly known as the Healthy Homes and Neighbourhoods) program?

Summary of methods

The authors employed systematic search and selection methods to identify English-language studies reporting PREMs for use with people with complex or chronic health conditions and social vulnerabilities, in the context of integrated or coordinated care. We searched six academic databases and 20 organisation and government websites in October 2021 to identify published and grey literature. We did not impose year or country limits on searches.

Studies were assessed for level of evidence and risk of bias and PREMs were assessed for their applicability for the VF program.

We identified 16 peer-reviewed publications reporting PREMs.

Key findings

Question 1: What validated patient reported experience measures (PREMS) have been used to measure the experience of vulnerable people and/or families accessing care coordination services?

We found 15 studies reporting 16 PREMs and one systematic review that summarised seven PREMs, three of which were also used by the authors of the single studies. Some of these papers assessed the psychometric properties of PREMs while others used PREMs to report on patient experience. All were valid and reliable measures, with more detail on validity and reliability reported in the papers focusing on psychometrics. Care coordination (integrated care) items appeared in many of the PREMs, while other domains covered were:

- Plans and protocols
- Messaging and communication
- Community resources/social needs
- Goals and outcomes
- Patient–clinician relationship
- Access to care
- Service/care transitions
- Cooperation between clinicians
- Patient-centredness and health promotion activities.

Question 2: What PREMS, domains and questions from those identified in Question 1 may have applicability for clients of the NSW Vulnerable Families (formerly the Healthy Homes and Neighbourhoods) program?

The majority of the studies included in this Evidence Check were published in the US and most of the PREMs were only available in English. Two studies were from the UK and one each from Canada, Italy and Spain, which may have more parallels to the NSW healthcare system.

All the PREMs were specifically used or for use in integrated or coordinated care and covered domains relevant to this context; however, most were in primary healthcare in populations with complex and/or chronic conditions, rather than those identified as having additional social vulnerabilities.

Gaps in the evidence

We found only a small number of PREMs that met this Evidence Check's inclusion criteria. Although all PREMs related to integrated or coordinated care, few had been used outside primary healthcare and few with populations with social vulnerabilities.

No PREMs were identified for use with Indigenous or First Nations peoples or people from culturally and linguistically diverse backgrounds who use a language other than English. We found two PREMs for use by parents to report on care of children, but not PREMs specifically for children and young people.

Applicability

While all the PREMs identified here are for use in integrated or coordinated care, few have direct applicability to the complex, vulnerable populations participating in VF or to the co-located, cross-service system VF model. The PREM with the most applicability to this context is Primary Care Quality–Homeless because of its use with people with a range of health and social vulnerabilities (not exclusively current homelessness) and use in integrated primary care and social services.

Conclusion

We identified few PREMs for use in integrated care with people with *both* chronic and/or complex health conditions *and* other vulnerabilities (and none for use with people with non-health vulnerabilities only). Most PREMs that we identified focused on primary healthcare for people with health concerns. In selecting a PREM for use in the VF context, it will be important to ensure the measure includes relevant domains and items for integrated care, but seeking PREMs in the health sector and not limiting to complex, vulnerable populations may be acceptable and may yield more options. To support use by practitioners and clients, a short, simple, valid measure is likely to be preferrable.

Background

People with chronic or complex health issues may experience a range of stressors in addition to their health concerns that place them in a position of increased vulnerability. This vulnerability relates not only to the effect of these common comorbid social issues such as homelessness or insecure housing, poverty, domestic and family violence, and literacy issues; vulnerability also arises from gaps in the provision of services and supports to address these multiple areas of need. Multiple health and social issues within families are likely to require the attention of multiple agencies, and a single intervention or service is unlikely to address all the needs of these families. Service integration and care coordination is vital. Aboriginal and Torres Strait Islander families and families from culturally and linguistically diverse backgrounds may experience additional barriers to accessing services.

Fragmentation of services means people and their needs sometimes slip through gaps in care provision.[1] Furthermore, poor streamlining of supports can lead to inefficiencies in service provision, with many highly vulnerable people and families missing out on care or receiving poorly timed or ineffective care. The *“lack of coordination, that spawns inefficient allocation of resources”* (p. S284) is a consequence of healthcare service fragmentation, with the most vulnerable in our communities bearing the greatest burden of gaps and inefficacies in healthcare.[2] Unnecessary service duplication can also result, particularly where multiple services connected to a family are not communicating with each other about their respective roles and service offerings.

The Healthy Homes and Neighbourhoods (HHAN) Integrated Care Initiative is intended to overcome the barriers many families experience accessing health and social care. Developed by Sydney Local Health District, HHAN is a co-located model of integrated care that provides multidisciplinary support to vulnerable families. HHAN provides whole-of-family health and social care coordination for families with a child below 18 years, where caregivers have complex/chronic health needs as well as complex psychosocial care needs. The HHAN is intended to ensure vulnerable families have their complex health and social needs met so they and their children remain safe and connected to society.[3] The HHAN initiative is now being rolled out NSW-wide as the Vulnerable Families (VF) program.

To assist in understanding the experiences of patients accessing the Vulnerable Families program (and potentially other care coordination services), the NSW Ministry of Health (NSW Health) is looking to develop a patient-report survey that will provide valid data from the end-users’ perspective about the quality of care received, particularly with regard to service integration and integrated care.

This Evidence Check identifies measures that report on patients’ experiences of integrated care as recorded using patient-reported experience measures (PREMs). PREMs are used to capture patient views about what happened to them during an episode of care and how it happened[4,5], and are used to collect data about healthcare quality and patient-centeredness from the perspective of the end-user. PREMs can be relational (e.g. ‘I felt listened to’) or functional (e.g. ‘The practitioner was good at letting me tell my story’). The information collected from PREMs is commonly used to inform quality improvement initiatives and for benchmarking the performance of services in meeting patients’ expectations of care.

NSW Health has devised a Patient Reported Measures Framework that includes consideration of the use of PREMs to support the delivery of ‘value-based healthcare’ (see https://www.health.nsw.gov.au/Value/Pages/prm-framework.aspx). The framework describes a set of principles within which PREMs (and other measures, including patient-reported outcomes measures—PROMs) will be used. The principles include that PREMs are co-designed with patients and care providers, they are integrated to cover the whole patient journey across care settings, and they provide universal coverage but also allow some variation to ensure suitability between distinct cohorts. The staged implementation of the Patient Reported Measures Framework across NSW is part of a long-term vision to collect and use PREM data across all sectors of the NSW health system.

This Evidence Check aims to identify PREMs used to evaluate integrated services—ideally, health and a range of social care services. Its findings will support the development of a survey to use with families accessing the Vulnerable Families program.

It was conducted by the Parenting Research Centre, commissioned by the NSW Ministry of Health via the Sax Institute.

Methods

Criteria for inclusion in this Evidence Check

The authors assessed papers identified through peer review database searches and other sources such as websites against the selection criteria listed in Appendix 1. Papers were eligible for inclusion in the Evidence Check if they were about a patient[*]-reported experience measure for use with vulnerable people. We excluded papers not matching these criteria. Consistent with the focus of the Vulnerable Families program, the preference was to identify measures for adult family members with complex or chronic health conditions who also presented with other social vulnerabilities, including substance use, domestic and family violence, mental health concerns, and financial and employment concerns. As VF also serves Indigenous and culturally and linguistically diverse peoples, we also scoped PREMs for these populations.

The Evidence Check sought PREMs that assessed experience with interventions that were aligned with the purpose of VF, including co-located services, multidisciplinary, cross-sector, interagency, integrated care and care coordination, with a preference for community-based settings. Residential settings were excluded. PREMs reporting experience of a condition, e.g. depression, were excluded, as were patient-reported outcomes measures (PROMs).

We excluded study protocols and conference papers and posters from the Evidence Check. Only English-language papers were included; however, no limits were placed on years of publication or place of publication.

Electronic database searches

We conducted systematic searches of six academic databases to identify peer-reviewed and grey literature. We searched the following databases on 8 October 2021: Criminal Justice Abstracts, Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, PsycInfo, SocINDEX and Sociological Abstracts (Table A1.1, Appendix 1). Search terms were designed to identify patient-reported experience measures used with vulnerable families in service contexts similar to VF. Search terms appear in Table A1.2, Appendix 1.

Searches were limited to English-language publications; however, no year limits were imposed.

Database search results were exported to Endnote and duplicate results removed. Titles and abstracts were screened for inclusion. Where these appeared relevant, we retrieved the full texts and assessed their eligibility for inclusion against the inclusion criteria. We resolved any eligibility

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[*] While typically referred to as ‘patient’-reported measures, the scope of this Evidence Check was not limited to respondents in a clinical context.

uncertainties via team review and discussion of papers. Final inclusions were determined by consensus.

Database searches produced 612 results. Following removal of duplicates and assessment against selection criteria, we included 16 papers from these searches (see the PRISMA flow chart of the literature selection process[6] in Appendix 2. All 16 papers were peer reviewed. No grey literature papers met the inclusion criteria.

Searching other sources

We searched 20 key organisation websites[†] for additional published and unpublished papers for inclusion in this Evidence Check (see Table A1.3, Appendix 1 for websites searched and Appendix 2 for the flow chart process for selection). Papers identified through website searches were also assessed for eligibility against the inclusion criteria specified in Appendix 1. We screened website search results live by using search functions where available[‡] and lists of publications or topics. We scanned titles and abstracts for executive summaries, with 36 potential papers downloaded to Endnote for confirmation of final inclusion in the Evidence Check. None of the papers found through website searches met the criteria for inclusion.

Included studies

The search yielded 16 publications. Data were extracted for each publication and can be found in tables A3.1—A.3.3 in Appendix 3. Included studies were narratively synthesised for findings relating to the two research questions. Table 1 presents an overview of studies, populations, interventions and the PREMs named. Where available, we have provided a copy of the measure, or a link to the measure, in Appendix 4.

We assessed the included studies' evidence using the National Health and Medical Research Council (NHMRC) Levels of Evidence[7] and the Mixed Methods Appraisal Tool (MMAT)[8] (see Appendix 5 for categories used). The NHMRC Levels of Evidence categorises studies according to six levels of evidence, from systematic reviews of randomised controlled trials (RCTs) to case series studies. The MMAT allows for the appraisal of study quality (risk of bias) for five categories of studies: qualitative research, RCTs, non-RCTs, quantitative descriptive studies and mixed methods studies.

To better answer Question 2, we also rated studies according to their overall applicability to the Evidence Check questions. Measures were rated as having low applicability if they had been tested on patients with a health vulnerability or social vulnerabilities only; of moderate applicability if they were tested on populations with a health vulnerability plus one other vulnerability; and of high

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[†] We used various approaches to website searches depending on functionality. This included use of search functions and screening publication and other lists. See Appendix 1 for further details.

[‡] Search terms used on websites varied based on the functionality of each website. In general, keywords used in website searches included: patient experience, patient reported, PREMs.

applicability if tested on populations with health plus multiple other vulnerabilities. Non-health vulnerabilities included:

- Domestic and family violence
- Child abuse and neglect
- Problematic substance use
- Mental illness
- Homelessness or insecure or inadequate housing
- Poverty
- Under-employment or unemployment
- Low literacy.

We identified few PREMs that crossed sectors or service systems and so this aspect of PREMs was not a key focus in determining applicability, although the population and setting types had relevance for service involvement.

We would also have considered PREMs designed or tested specifically for Indigenous/First Nations or culturally and linguistically diverse populations to be highly applicable, but we did not identify any.

Table 1—Overview of studies included in the Evidence Check

Study	Type	Country	Population	Intervention	PREM	Level of evidence
O'Loughlin 2017[9]	Uses PREM	Australia	Adult patients with complex or chronic health conditions	Synthesis of patient experiences of the Patient-Centred Medical Home model	Ambulatory Care Experiences Survey (ACES-SF) Components of Primary Care Index (CPCI) Consumer Assessment of Healthcare Providers and Systems Clinician and Group (CAHPS-CG) Diabetes Disease State Management Questionnaire (DDSM-QM) (a) Patient Assessment of Chronic Illness Care (PACIC) Primary Care Assessment Survey (PCAS) Survey of Healthcare Experiences of Patients (SHEP)	I
Noël 2021[10]	Uses PREM	US	Veterans Affairs patients with 4+ visits to clinic	Primary care: compare two strategies for improving integrated care	Health Care System Hassles Scale	II
Bonciani 2017[11]	Uses PREM	Italy	Adult patients with complex or chronic health conditions	GP-primary care co-location: determine if associated with patient satisfaction	Population survey of patient experiences	III-2

Gabrielian 2021[12]	Uses PREM	US	Primary care patients experiencing homelessness with serious mental illness	Integrating behavioural health and social services: determine if associated with patient satisfaction	Primary Care Quality–Homelessness (PCQ-H)	III-2
Gidengil 2017[13]	Evaluates PREM	US	Caregivers of children with complex chronic disease	Medicaid primary care	Family Experiences with Coordination of Care (FECC)	III-2
Joober 2018[14]	Evaluates PREM	Canada	Adults with at least one chronic condition	Family medicine clinics	Patient Experience of Integrated Care (PEICS)	III-2
Kertesz 2014[15]	Evaluates PREM	US	Veterans Affairs patients with experience of homelessness	Primary care	Primary Care Quality–Homelessness (PCQ-H)	III-2
Lloyd 2019[16]	Evaluates PREM	UK	Adults with long-term conditions	Primary care	Person-centred Coordinated Care Experience Questionnaire (P3CEQ)	III-2
Mastellos 2014[17]	Uses PREM	UK	Adults with type-2 diabetes and/or are aged 75+ years	Primary care: understand patient experience of integrated care	Pilot survey of integrated care experiences	III-2
Mira 2016[18]	Evaluates PREM	Spain	Young people and adults with at least one chronic condition	Primary care	Instrument for Assessing Patient Experience of Chronic Illness Care (IEXPAC)	III-2
Rogers 2020[19]	Uses PREM	US	Adult patients with complex or chronic health conditions	Ambulatory and primary care: understand patient attitudes to screening for social needs	Patient attitude survey	III-2
Singer 2013[20]	Evaluates PREM	US	Adults with two or more chronic conditions	Primary care	Patient Perceptions of Integrated Care (PPIC)	III-2

Ziniel 2016[21]	Evaluates PREM	US	Parents of children with complex medical, behavioural and educational needs	Primary care	Pediatric Integrated Care Survey (PCIS)	III-2
Zlateva 2015[22]	Evaluates PREM	US	Patients with multiple serious and/or chronic conditions	Primary care	Medical Home Care Coordination Survey (MHCCS)	III-2
Zulman 2019[23]	Uses PREM	US	Veterans Affairs patients	Integrated care plus multidisciplinary management including mental health/substance use support and intensive social work case management	Survey of Healthcare Experiences of Patients (SHEP) Patient Assessment of Chronic Illness Care (PACIC) Health Care Hassles Scale	III-2
Siantz 2020[24]	Uses PREM	US	Adult patients with more than one chronic care condition AND one behavioural health condition	Medicaid integrated physical and behavioural care	Focus groups[(b)]	--

(a) Excluded: disease-specific measure

(b) Included for relevant wording of discussion prompts

🟩 Low applicability: tested on patients with a health vulnerability or social vulnerabilities only

🟨 Moderate applicability: tested on populations with health vulnerability plus one other vulnerability

🟨 High applicability: tested on populations with health plus multiple other vulnerabilities

☐ Unable to rate: applicability depends on individual studies

Evidence grading

The same set of 16 publications was used to answer Questions 1 and 2. Of these, one was a level I review on the NHMRC Levels of Evidence (NHMRC 2009), one was a level II study (with randomisation at the site level) and 12 were level III-2 non-randomised studies (although for the seven studies evaluating a measure it is not clear that randomisation is an appropriate expectation). A single study was qualitative and could not be rated using the NHMRC scale. This is the basis of the 'evidence level' row of the data extraction table in Appendix 3.

Using the MMAT we rated six studies as being at relatively low risk of bias, four as being at medium risk of bias, and six studies as being at high risk of bias. The MMAT rates studies on the appropriateness of their methods and how well they were implemented, depending on their design (qualitative, quantitative randomised controlled trial, quantitative non-randomised, quantitative descriptive, or mixed methods). This is the basis of the 'evidence rating' row of the data extraction table in Appendix 3.

Using our own assessment of applicability based on the nature of the vulnerabilities to which patients were exposed, we rated one study as being of high applicability, two as being of moderate applicability and 12 as being of low applicability to the population of interest in this Evidence Check.

Findings

Question 1: What validated patient reported experience measures (PREMS) have been used to measure the experience of vulnerable people and/or families accessing care?

PREMs identified

We identified 16 PREMs in 15 individual studies, plus a review mentioning seven PREMs (three of which were already identified via single studies).

The individual studies identifying PREMs fell into two categories: psychometric studies that reported on the development and validation of measures, and evaluation studies that reported on the use of measures to assess health systems and patient attitudes. These are described separately below. We also identified a single review, which we have included with the evaluation studies.

Psychometric studies

We found eight studies that evaluated eight PREMs. Measures listed in bold below are those used in more than one of the studies we identified in all publications:

- Family Experiences with Coordination of Care (FECC)[13]
- Instrument for Assessing Patient Experience of Chronic Illness Care (IEXPAC)[18]
- Medical Home Care Coordination Survey (MHCCS)[22]
- Patient Experience of Integrated Care (PEICS)[14]
- Patient Perceptions of Integrated Care (PPIC)[20]
- Pediatric Integrated Care Survey (PCIS)[21]
- Person-centred Coordinated Care Experience Questionnaire (P3CEQ)[16]
- **Primary Care Quality–Homeless (PCQ-H).[15]**

These studies provided good information on measure validation. All authors concluded that the PREMs they developed exhibited good reliability and good validity on a range of psychometric measures (internal consistency, convergent and divergent ability, discriminant ability).

Evaluation studies

We found a further seven studies that used eight PREMs to evaluate programs or patients' experiences and attitudes. These PREMs were either stand-alone scales, qualitative measures or items relating to patients' experience in a larger survey:

- Focus groups on patient experience of the Behavioral Health Integration and Complex Care Initiative (BHICCI)[24]
- **Health Care System Hassles Scale**[10,**23**]

- Patient Assessment of Chronic Illness Care (PACIC)[23]
- Pilot survey of integrated care experiences[17]
- Population survey of patient experiences[11]
- **Primary Care Quality–Homeless (PCQ-H)**[12,15]
- Survey of Healthcare Experiences of Patients (SHEP)[23]
- Survey of patient attitudes to social needs screening and programs in ambulatory settings.[19]

These studies provided less information on PREMs validation. Some authors referenced the original publication for measures that may contain psychometrics; the one study that used a qualitative PREM reported on the development of questions and domains through suitable qualitative methods for validation including consultation and iterative coding of themes.

In addition, we found a single systematic review.[9] This assessed patients' experiences of Australian health services using a patient-centred medical home model, and cited studies using the following named measures. Again, measures identified in the preceding categories of papers are listed in bold, and these appear to be those that best match PREMs in an integrated care context. The PREMs included in the systematic review and their referencing papers are provided in the list of measures in Appendix 4. However, due to limited information available about these PREMs in the O'Loughlin review, we are not able to provide details of these measures in our Evidence Check:

- Ambulatory Care Experiences Survey (ACES-SF)
- Components of Primary Care Index (CPCI)
- Consumer Assessment of Healthcare Providers and Systems Clinician and Group (CAHPS-CG)
- Diabetes Disease State Management Questionnaire (DDSM-QM) (not described further in this evidence assessment as it is condition-specific)
- **Patient Assessment of Chronic Illness Care (PACIC)**
- **Primary Care Assessment Survey (PCAS)**
- **Survey of Healthcare Experiences of Patients (SHEP).**

Psychometric information was not listed for these measures in this review.

The full item set of these PREMs was provided for some of these studies (see Appendix 4 for further details), and in other cases we have provided links to sites with details of the PREM or a reference.

PREM items and domains

The PREMs we identified in the 15 individual studies ranged in length from six to 33 items (not including the qualitative measure and one measure where PREMs items were part of a larger survey and were not specified). The median number of items was 17.

The full list of domains mentioned as being covered by PREMs is available in the data extraction tables of Appendix 3. Not all studies gave detailed information on all domains. Grouping like with like, the most commonly covered domains (not counting the themes identified in the qualitative study) are:

- Care coordination (integrated care)
- Plans and protocols
- Messaging and communication
- Community resources/social needs

- Goals and outcomes
- Patient–clinician relationship
- Access to care
- Service/care transitions
- Cooperation between clinicians
- Patient-centredness and health promotion activities.

Question 2: What PREMS, domains and questions from those identified in Question 1 may have applicability for clients of the NSW Vulnerable Families (formerly the Health Healthy Homes and Neighbourhoods) program?

Country and setting

PREMs identified in this Evidence Check were predominantly used in or designed for primary care settings in the US:

- US (10 studies)
- UK (2 studies)
- Australia (1 review)
- Canada (1 study)
- Italy (1 study)
- Spain (1 study).

The UK, Canadian, Italian and Spanish healthcare systems would generally be considered closer in design and funding to the Australian context than would the US systems. On the other hand, most of the US studies that identified PREMs were set within the Medical Home Care model[22], which closely parallels the Australian equivalent of the Patient-Centred Medical Home.[9] The care systems in which these studies are embedded are thus similar to the NSW context. However, the health system alone is not a very close match to the VF program.

Settings described in the included studies were all some version of primary medical care, with varying levels of integration with other services. The settings and populations have been classified in Table 2.

Table 2—PREMs by setting

Setting	Study	Measure
Integrated primary healthcare	Bonciani 2017	Population survey
	Gidengil 2017	FECC
	Joober 2018	PEICS
	Lloyd 2019	P3CEQ
	Mastellos 2014	Population survey
	Mira 2016	IEXPAC
	O’Loughlin 2017	ACES-SF, CPCI, CAHPS-CG, PACIC, PCAS, SHEP
	Rogers 2020	Population survey
	Singer 2013	PPIC
	Ziniel 2016	PICS
	Zlateva 2018	MHCCS

Veterans Affairs integrated or intensive care	Gabrielian 2021	PCQ-H
	Kertesz 2014	PCQ-H
	Noël 2021	Health Care Hassles Scale
	Zulman 2019	Health Care Hassles Scale
		PACIC
		SHEP
Integrated physical and behavioural/substance use care	Siantz 2020	Focus groups

Population

The majority of the populations for which PREMs were tested and with which they were used were adults with complex and/or chronic health concerns. A small number of studies used PREMs with adult carers of children with chronic or complex health concerns, with adults with behavioural and/or substance use concerns in addition to health issues, adults requiring social support and adults with experience of homelessness (Table 3).

Table 3—PREMs by population

Setting	Study	Measure
Carers of children and young people	Gidengil 2017	FECC
	Ziniel 2016	PICS
Young people and adults with chronic health conditions	Mira 2016	IEXPAC
Adults with behavioural and/or substance use concerns plus health concerns	Siantz 2020	Focus groups
Adults with experience of homelessness	Kertesz 2014	PCQ-H
	Gabrielian 2021	PCQ-H
Adults receiving health and social support	Zulman 2019	Health Care Hassles Scale PACIC SHEP
Adults with complex and/or chronic health conditions	Bonciani 2017	Population survey
	Joober 2018	PEICS
	Lloyd 2019	P3CEQ
	Mastellos 2014	Population survey
	Noël 2021	Health Care Hassles Scale

	O’Loughlin 2017	ACES-SF, CPCI, CAHPS-CG, PACIC, PCAS, SHEP
	Rogers 2020	Population survey
	Singer 2013	PPIC
	Zlateva 2018	MHCCS

Six studies used measures in languages other than English (in some cases in parallel with an English-language version). None of the languages other than English were relevant to NSW community languages (with the exception of Italian), and we did not identify any English-language measures intended for people from culturally and linguistically diverse backgrounds or who have low literacy—where this was a consideration for study authors, they offered parallel versions in an appropriate language, such as English and Spanish.

Domains

The PREMs we identified covered a range of domains. For the VF context, the most relevant domains were those relating to client experience of the coordination of care, messaging and communication between professionals and between client and professionals, access to care (in this case, services) and transitions between services or care components. Clients’ perceptions of client-centredness, setting and meeting appropriate goals and outcomes, and their access to community resources were also relevant in this context.

Gaps in the evidence

We did not identify any PREMs for use by children, although we identified some for parents to report on the care experiences of children and young people.

We did not identify any PREMs specifically for use by Indigenous and First Nations peoples, or for use by people from culturally and linguistically diverse backgrounds using a language other than English. We did identify some PREMs in other languages, but these were for people to use in their preferred language. One of these languages, Italian, may be relevant to the NSW context.

Participants in some studies had experience of homeless, of mental health issues, and of behavioural issues including substance use. However, we did not identify any PREMs that were designed for or used with people who had experienced domestic and family violence, child abuse and neglect, unemployment, poverty or other hardship, or any other vulnerability of interest for the VF context.

While all PREMs were designed to capture an experience of integrated care, they were predominantly within a health context although a small number of studies investigated integrated physical and behavioural health (one study) or supplemented healthcare with social work case management (one study).

All PREMs were considered valid and reliable for the populations and contexts in which they were tested; we are not able to comment on their suitability for other populations and contexts, however.

Discussion

We identified 16 PREMs from 15 psychometric and evaluation studies. One further paper reported a review that included seven other PREMs, three of the most relevant of which had already been identified in individual studies. Most of the studies we identified (12 of the 15 individual studies) were level III-2 non-randomised designs, plus one level I review. Given many of these were psychometric studies, it would not be appropriate to expect them to use only randomised, quasi-randomised or controlled study designs. We rated six studies as being at relatively low risk of bias, four as being at medium risk of bias and six as being at high risk of bias (including the review).

PREMs ranged in length from six to 33 survey items (although one PREM was qualitative only and another formed part of a larger survey) and covered the following domains:

- Care coordination (integrated care)
- Plans and protocols
- Messaging and communication
- Community resources/social needs
- Goals and outcomes
- Patient–clinician relationship
- Access to care
- Service/care transitions
- Cooperation between clinicians
- Patient-centredness
- Health promotion activities.

The majority of PREMs were developed and used in the US, with two in the UK and one each from Canada, Italy and Spain. The review was of the Australian experience and used PREMs developed in a range of countries.

The care systems in which the studies in this review were embedded were similar to the NSW health context (even the US studies, given the kinds of health interventions in question). However, the ‘integration’ of care in the majority of studies referred to different health services. We found very little information on the use of PREMs for people experiencing services integrated across health and social support agencies. Given the domains covered by the PREMs we identified, they may be suitable for use in this broader context but we were not able to identify evidence of their suitability or otherwise.

The majority of populations taking part in these studies were adults with chronic/complex health concerns. We found limited evidence relating to PREMs for other populations: carers of children and young people, adults with mental illness and/or substance use issues, and adults experiencing homelessness or receiving intensive social work case management. Again, any of the PREMs identified may be suitable for any population of interest to the VF program, but we were not able to find evidence for or against that suitability.

The applicability of the PREMs we identified to the VF context is discussed further in the next section.

Applicability

The VF program works with families with complex or chronic health and social needs. In choosing PREMs, VF is seeking to balance validity and reliability with applicability factors such as purpose, clients' best interests, cost and administration requirements. Some key criteria for considering the applicability of measures include: relevance to the VF program and participants; administration; usability; and cost.

In this section, we report on the PREMs identified in the Evidence Check that appear to be the most applicable to the VF program. All the PREMs we identified were for use in an integrated or coordinated care context and so they are all suitable in that regard. Most of the PREMs were used in the context of primary care health services; few crossed sectors or service systems. Our principal focus in determining applicability was to consider the population match to VF, which also helps highlight multiple service system relevance.

Relevance to VF

We considered the applicability of PREMs to the outcomes intended to be measured and to the target population. This includes measures for adults with complex health and social needs including substance use, domestic and family violence, financial and employment concerns and mental health concerns. Use with children and young people was also a consideration.

Most of the PREMs we identified in this Evidence Check were of low applicability to the VF context as most related to health vulnerabilities rather than social vulnerabilities and most focused on health services rather than multiple providers.

We have rated two PREMS (reported in three studies) to be of moderate applicability to the VF population (health plus one non-health vulnerability) and one to be of high applicability (health plus multiple non-health vulnerabilities). Table 4 summarises these two most applicable PREMs.

Table 4—Most applicable PREMs based on population type

Measure	Population match	Setting and service match	Psychometrically sound	Method of use
Primary Care Quality–Homeless	People with experience of homelessness, poor health status, alcohol and other drug	Primary care and social services	Yes	English Clinician-administered 33 items

	use, serious mental illness			
Focus groups[(a)] on patient experience of the Behavioral Health Integration and Complex Care Initiative (BHICCI)	People with poor health status and a behavioural health condition	Integrated physical and behavioural care in a community setting	Yes	English Clinician-administered Six open-ended discussion prompts

(a) Focus group methodology is unlikely to be appropriate for the VF service delivery context, but the prompting questions may be of assistance in developing a survey measure.

Administration

A further factor to consider in applicability is the skills required to administer and score the measure, and the amount of time required (for both staff and clients). Ideally, measures need to minimise the administrative burden on staff and clients. The most applicable PREM noted above (Primary Care Quality–Homeless), is one of the longer quantitative measures. It may be that a less applicable, but shorter PREM might be chosen on the basis of ease of administration.

Usability

Consider measures that are appropriate for VF clients and reduce their cognitive burden, including easy-read versions for those with low literacy and translated versions. The qualitative PREM noted above as being applicable (focus group on patient experience of BHICCI) may be less intimidating and more useable for both clinicians and clients than many of the longer quantitative PREMs in the administration phase, but this must be balanced against the effort and lower objectivity of interpreting qualitative measures.

Cost

The cost of the tool itself (e.g. licensing) and of staff time and effort in administering and scoring should not be prohibitive. The PREMs we have identified are free to use but would represent either a time or an infrastructure cost to score and interpret.

Bottom line

The small number of PREMs identified in this Evidence Check are, on the whole, of low applicability to VF in terms of population type and services. They are all used in integrated care, however, and so they do consider coordinated aspects of service delivery that may be absent from PREMs used by single providers. Based on ease of administration and usability, as well as complexity of population, Primary Care Quality–Homeless[§] appears to be the most applicable.

[§] The population was referred to as people with experience of homelessness but they were not all homeless at the time. They were experiencing social vulnerabilities often associated with homelessness, however, such as serious mental illness, chronic conditions, alcohol and other drug use.

Conclusion

Question 1: What validated patient reported experience measures (PREMS) have been used to measure the experience of vulnerable people and/or families accessing care?

We identified 16 PREMs validated for use to measure patient experience of integrated care. This care was predominantly related to physical health, although a small number of measures were also used for health services integrated with behavioural health and with social work case management. Four additional PREMs were identified in a systematic review, but only minimal information was available on these.

Question 2: What PREMS, domains and questions from those identified in Question 1 may have applicability for clients of the NSW Vulnerable Families (formerly known as the Healthy Homes and Neighbourhoods) program?

Most PREMs identified in this Evidence Check had low applicability for clients of the NSW VF program. The Primary Care Quality–Homeless measure had the greatest applicability by client vulnerability. A qualitative measure for clients receiving integrated physical and behavioural care was also moderately applicable, but this needs to be balanced against difficulty of administration and, particularly, interpretation.

We found very little information on the use of PREMs for people receiving support from multiple co-located services or agencies, and no information on PREMs suitable for use with Aboriginal and Torres Strait Islander or culturally and linguistically diverse populations.

While selecting a PREM suitable for an integrated care context is ideal, it is possible that a short, simple and valid integrated care PREM exists that is not specifically for use with patients or families experiencing chronic or complex health conditions or social vulnerabilities.

Suggestions

Choosing a survey

We did not identify an ideal PREM for the VF context, although many covered relevant domains such as:

- Client experience of the coordination of care
- Messaging and communication between professionals and between client and professionals
- Access to care (in this case, services)
- Transitions between services or care components

- Clients’ perceptions of client-centredness
- Setting and meeting appropriate goals and outcomes
- Access to community resources is also of relevance in this context.

Measures in the literature tended to be quite long, which could be a burden on clients and practitioners. We suggest that the PREMs identified in this Evidence Check could be modified for use in the NSW VF context, with less relevant items omitted and those more relevant to key domains retained.

When looking at PREMs for potential adaptation, it would be helpful to look beyond measures identified for use with the most vulnerable populations. Expanding the population scope may help identify more suitable PREMs, even though they may not have been tested with a similar cohort to VF. It is likely to be more important to continue to match the intervention type (i.e. integrated care) than the population type when choosing or adapting a PREM, to ensure items are relevant to the VF multidisciplinary context.

We also suggest that any key outcomes of interest beyond patient satisfaction be determined before selecting or adapting a measure. These may include implications for wellbeing, client sense of control and self-efficacy, and willingness to maintain contact with services. Clarifying why patient experience is important in the local context and how this information is intended to be used—e.g. for annual reporting, practice improvement or assessing individual VF program components—may assist in choosing or developing the most appropriate measure.

Piloting the survey

Any adapted measure will need to be tested in the NSW VF population to ensure it retains the psychometric properties of the original. Any new measure should be piloted and its psychometric properties assessed. If the measure is short and able to be administered by clinicians frequently with minimal missing data, this has the potential to contribute to a new and valid measure of client experience that is not restricted to the healthcare context.

Administering the survey

Acknowledging the original intentions behind identifying a PREM for NSW VF, we suggest the voices of children and young people be captured as well as those of parents. It may be useful to administer a PREM through the practitioner rather than having a self-completed survey, to provide helpful context for all literacy levels and potentially for culturally and linguistically diverse clients. Administering the PREM as part of a clinical conversation may itself contribute to a positive client experience. These considerations should be balanced against the possibility of response bias, where clients may feel constrained to give only positive feedback to their care professionals.

It may be helpful to administer any survey via digital means such as a tablet, to facilitate data collection. Responses could be collected using a pictorial Likert-type scale as long as such a scale has the same discrete options as the original response scale. Combining verbal questions with digital responses may minimise response bias if the practitioner can reassure the client that their individual digital responses will not be seen by the practitioner.

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Appendices

Appendix 1—Search strategy

Criteria for inclusion in this Evidence Check

Publications not meeting the following criteria for types of participants, interventions, settings, outcomes and study type were excluded. Overall reasons for exclusion (according to these broad categories) are provided in Appendix 2.

Types of participants

- People or families who are vulnerable or accessing care coordination services
- Primary interest is families with children prenatal to 18 years
- Primary interest is adults experiencing complex or chronic health conditions with other social vulnerabilities.

Types of interventions or care

- Preference for services as close to VF as possible, including: co-located services, multidisciplinary, cross-sector, interagency, care coordination
- Various services that may be accessed by vulnerable people or families engaged in care coordination, and may include: family services, healthcare, allied health, mental health, housing, disability, financial assistance, education, justice, drug and alcohol
- Papers were excluded if they reported PREMs related to the experience of a condition rather than an intervention
- Papers were excluded if they described patient-reported outcomes measures (PROMs).

Setting

- Community settings
- Residential settings were excluded
- Hospital settings may be considered based on the relevance and availability of other studies.

Types of outcomes

- Measure properties, items, development, administration
- Validity and reliability of measures
- Acceptability, uptake and use of measure (e.g. response rate, barriers to implementation, who is the respondent)
- Measure scoring—how to score, ease of use, limitations.

Types of studies

- English language
- Peer-reviewed or grey literature
- No year limits
- No limits on place of publication
- Papers were excluded if they were conference abstracts, posters or study protocols.

Search sources and search terms

Table A1.1—Databases searched

Database	Platform
Criminal Justice Abstracts	EBSCO
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	EBSCO
MEDLINE	Ovid
PsycInfo	Ovid
SocINDEX	EBSCO
Sociological Abstracts	ProQuest

Table A1.2—Search terms used across platforms

Platform	Search terms
Ovid	1. (Patient report* experience measures or PREMs).mp. 2. Patient* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 3. Family adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 4. Families* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 5. Parent* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 6. Carer* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 7. Caregiver* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 8. Mother* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 9. Father* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 10. Consumer* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti. 11. Client* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

12. Child* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

13. Adolescen* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

14. Teen* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

15. Youth* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

16. Young person* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

17. Young people* adj2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback).ti.

18. (vulnerab* or complex* or fragile or multi-problem or at-risk or troubled or multi-risk or multi-stress* or multi-need* or multiple-problem* or multiple-stress* or multiple-need* or multiple-risk* or chronic*).mp.

19. ((domestic or family or interpersonal or intimate or intimate partner or ex-partner or spous* or relationship* or couple* or partner* or marital) adj2 (violen* or abus* or conflict*)).mp.

20. (child* adj2 (abuse* or neglect* or maltreat* or violen* or protect* or welfare or at risk or at-risk or mistreat*)).mp.

21. ((substance abuse* or substance use* or substance misuse* or substance addict* or drug use* or drug addict* or drug abuse* or drug misuse* or alcohol abuse* or alcohol misuse* or alcohol use* or alcoholic* or alcoholism) adj2 (parent* or mother* or father* or child* or adolescent* or youth* or teen* or young people* or young person*)).mp.

22. ((mental illness* or mentally ill or mental health or psychiatric*) adj2 (parent* or mother* or father* or child* or adolescent* or youth* or teen* or young people* or young person*)).mp.

23. (Aborigine* or Aboriginal* or Torres Strait Islander* or Maori* or American Indian* or Alask* Nativ* or Nativ* Alask* or Nativ* Hawaiian* or Hawaii* Nativ* or Americ* Nativ* or Americ* Samoa* or Samoa* Americ* or Eskimo* or Inuit* or Aleut* or Metis or First Nation* or Indigenous).mp.

24. (cultur* divers* or cultur* linguistic* divers* or CALD or emigrant* or immigrant* or refugee* or cultural competenc* or LOTE or language* other than English or race* or ethnic*).mp.

25. ((disabil* or disabl* or impair* or retard* or handicap*) adj2 (parent* or mother* or father* or child* or adolescent* or youth* or teen* or young people* or young person*)).mp.

26. (poverty or impoverish* or low-income* or poor or disadvantag* or hardship or welfare or unemploy* or un-employ* or underemploy* or under-employ* or job loss or homeless* or transient or shelter* or unsheltered or vagran* or destitute* or street* or sleep* rough or skid row).mp.

27. ((hous* adj1 (inadeq* or insecur* or unfit* or derelict* or instab* or unstab*)) or (income adj1 (insecur* or low or inadeq* or instab* or unstab* or limit*)) or (employ* adj1 (insecur* or instab* or unstab* or irregul*))).mp.

28. ((illitera*) or (litera* adj2 (low or poor or insuffic* or inadeq* or limit* or suffic* or below))).mp.

29. ((care adj1 (coordinat* or manage* or conferenc* or planning)) or (case adj1 (coordinat* or manage* or conferenc* or planning)) or (service adj1 (coordinat* or manage* or conferenc* or planning)) or (social adj1 work*) or (team adj1 (multidisciplinary or interdisciplinary or multi-disciplinary or interdisciplinary or transdisciplinary or trans-disciplinary)) or (work adj1 (multidisciplinary or

	interdisciplinary or multi-disciplinary or interdisciplinary or transdisciplinary or trans-disciplinary))).mp. 30. (casework* or case-work* or wraparound or psychosocial or inter-agency or interagency or multiagency or multi-agency or coordinating council* or community response* or community-based or community based or place based or place-based or locally based or locally-based or area based or area-based or integrate* or colocat* or co-locat* or collocat* or cross-sector*).mp. 31. (survey* or questionnaire* or assess* or measure* or scale* or report* or self-report* or tool* or instrument* or checklist* or check-list*).ti. 32. or/1-17 33. or/18-28 34. or/29-30 35. and/31-34
EBSCO	1. (Patient report* experience measures or PREMs) 2. Patient* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 3. Family N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 4. Families* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 5. Parent* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 6. Carer* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 7. Caregiver* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 8. Mother* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 9. Father* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 10. Consumer* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 11. Client* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 12. Child* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 13. Adolescen* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 14. Teen* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 15. Youth* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 16. Young person* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 17. Young people* N2 (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback) 18. (vulnerab* or complex* or fragile or multi-problem or at-risk or troubled or multi-risk or multi-stress* or multi-need* or multiple-problem* or multiple-stress* or multiple-need* or multiple-risk* or chronic*)

	19. ((domestic or family or interpersonal or intimate or intimate partner or ex-partner or spous* or relationship* or couple* or partner* or marital) N2 (violen* or abus* or conflict*)) 20. (child* N2 (abuse* or neglect* or maltreat* or violen* or protect* or welfare or at risk or at-risk or mistreat*)) 21. ((substance abuse* or substance use* or substance misuse* or substance addict* or drug use* or drug addict* or drug abuse* or drug misuse* or alcohol abuse* or alcohol misuse* or alcohol use* or alcoholic* or alcoholism) N2 (parent* or mother* or father* or child* or adolescent* or youth* or teen* or young people* or young person*)) 22. ((mental illness* or mentally ill or mental health or psychiatric*) N2 (parent* or mother* or father* or child* or adolescent* or youth* or teen* or young people* or young person*)) 23. (Aborigine* or Aboriginal* or Torres Strait Islander* or Maori* or American Indian* or Alask* Nativ* or Nativ* Alask* or Nativ* Hawaiian* or Hawaii* Nativ* or Americ* Nativ* or Americ* Samoa* or Samoa* Americ* or Eskimo* or Inuit* or Aleut* or Metis or First Nation* or Indigenous) 24. (cultur* divers* or cultur* linguistic* divers* or CALD or emigrant* or immigrant* or refugee* or cultural competenc* or LOTE or language* other than English or race* or ethnic*) 25. ((disabil* or disabl* or impair* or retard* or handicap*) N2 (parent* or mother* or father* or child* or adolescent* or youth* or teen* or young people* or young person*)) 26. (poverty or impoverish* or low-income* or poor or disadvantag* or hardship or welfare or unemploy* or un-employ* or underemploy* or under-employ* or job loss or homeless* or transient or shelter* or unsheltered or vagran* or destitute* or street* or sleep* rough or skid row) 27. ((hous* N1 (inadeq* or insecur* or unfit* or derelict* or instab* or unstab*)) or (income N1 (insecur* or low or inadeq* or instab* or unstab* or limit*)) or (employ* N1 (insecur* or instab* or unstab* or irregul*))) 28. ((illitera*) or (litera* N2 (low or poor or insuffic* or inadeq* or limit* or suffic* or below))) 29. ((care N1 (coordinat* or manage* or conferenc* or planning)) or (case N1 (coordinat* or manage* or conferenc* or planning)) or (service N1 (coordinat* or manage* or conferenc* or planning)) or (social N1 work*) or (team N1 (multidisciplinary or interdisciplinary or multi-disciplinary or interdisciplinary or transdisciplinary or trans-disciplinary)) or (work N1 (multidisciplinary or interdisciplinary or multi-disciplinary or interdisciplinary or transdisciplinary or trans-disciplinary))) 30. (casework* or case-work* or wraparound or psychosocial or inter-agency or interagency or multiagency or multi-agency or coordinating council* or community response* or community-based or community based or place based or place-based or locally based or locally-based or area based or area-based or integrate* or colocat* or co-locat* or collocat* or cross-sector*) 31. (survey* or questionnaire* or assess* or measure* or scale* or report* or self-report* or tool* or instrument* or checklist* or check-list*) 32. or/1-17 33. or/18-28 34. or/29-30 35. and/31-34
ProQuest	1. (Patient report* experience measures or PREMs) 2. (perspective* or opinion* or experience* or satisf* or acceptab* or view* or perception* or preference* or feedback)

3. (vulnerab* or complex* or fragile or multi-problem or at-risk or troubled or multi-risk or multi-stress* or multi-need* or multiple-problem* or multiple-stress* or multiple-need* or multiple-risk* or chronic*)

4. ((violen* Near/1 (domestic or family or interpersonal or intimate or partner* or ex-partner* or spous* or relationship* or couple* or marital)) or (abus* Near/1 (domestic or family or interpersonal or intimate or partner* or ex-partner or spous* or relationship* or couple* or marital)) or (conflict Near/1 (domestic or family or interpersonal or intimate or partner* or ex-partner* or spous* or relationship* or couple* or marital)))

5. child* Near/2 (abuse* or neglect* or maltreat* or violen* or protect* or welfare or at-risk or mistreat*)

6. (substance abuse* or substance use* or substance misuse* or substance addict* or drug use* or drug addict* or drug abuse* or drug misuse* or alcohol abuse* or alcohol misuse* or alcohol use* or alcoholic* or alcoholism)

7. (mental illness* or mentally ill or mental health or psychiatric*)

8. (Aborigine* or Aboriginal* or Torres Strait Islander* or Maori* or American Indian* or Alask* Nativ* or Nativ* Alask* or Nativ* Hawaiian* or Hawaii* Nativ* or Americ* Nativ* or Americ* Samoa* or Samoa* Americ* or Eskimo* or Inuit* or Aleut* or Metis or First Nation* or Indigenous)

9. (cultur* divers* or cultur* linguistic* divers* or CALD or emigrant* or immigrant* or refugee* or cultural competenc* or LOTE or language* other than English or race* or ethnic*)

10. (disabil* or disabl* or impair* or retard* or handicap*)

11. (poverty or impoverish* or low-income* or poor or disadvantag* or hardship or welfare or unemploy* or un-employ* or underemploy* or under-employ* or job loss or homeless* or transient or shelter* or unsheltered or vagran* or destitute* or street* or sleep* rough or skid row)

12. ((hous* Near/1 (inadeq* or insecur* or unfit* or derelict* or instab* or unstab*)) or (income Near/1 (insecur* or low or inadeq* or instab* or unstab* or limit*)) or (employ* Near/1 (insecur* or instab* or unstab* or irregul*)))

13. ((illitera*) or (litera* Near/2 (low or poor or insuffic* or inadeq* or limit* or suffic* or below)))

14. ((care Near/1 (coordinat* or manage* or conferenc* or planning)) or (case Near/1 (coordinat* or manage* or conferenc* or planning)) or (service Near/1 (coordinat* or manage* or conferenc* or planning)) or (social Near/1 work*) or (team Near/1 (multidisciplinary or interdisciplinary or multi-disciplinary or interdisciplinary or transdisciplinary or trans-disciplinary)) or (work Near/1 (multidisciplinary or interdisciplinary or multi-disciplinary or interdisciplinary or transdisciplinary or trans-disciplinary)))

15. (casework* or case-work* or wraparound or psychosocial or inter-agency or interagency or multiagency or multi-agency or coordinating council* or community response* or community-based or community based or place based or place-based or locally based or locally-based or area based or area-based or integrate* or colocat* or co-locat* or collocat* or cross-sector*)

16. (survey* or questionnaire* or assess* or measure* or scale* or report* or self-report* or tool* or instrument* or checklist* or check-list*)

17. or/1-2

18. or/3-13

19. or/14-15

20 and/16-19

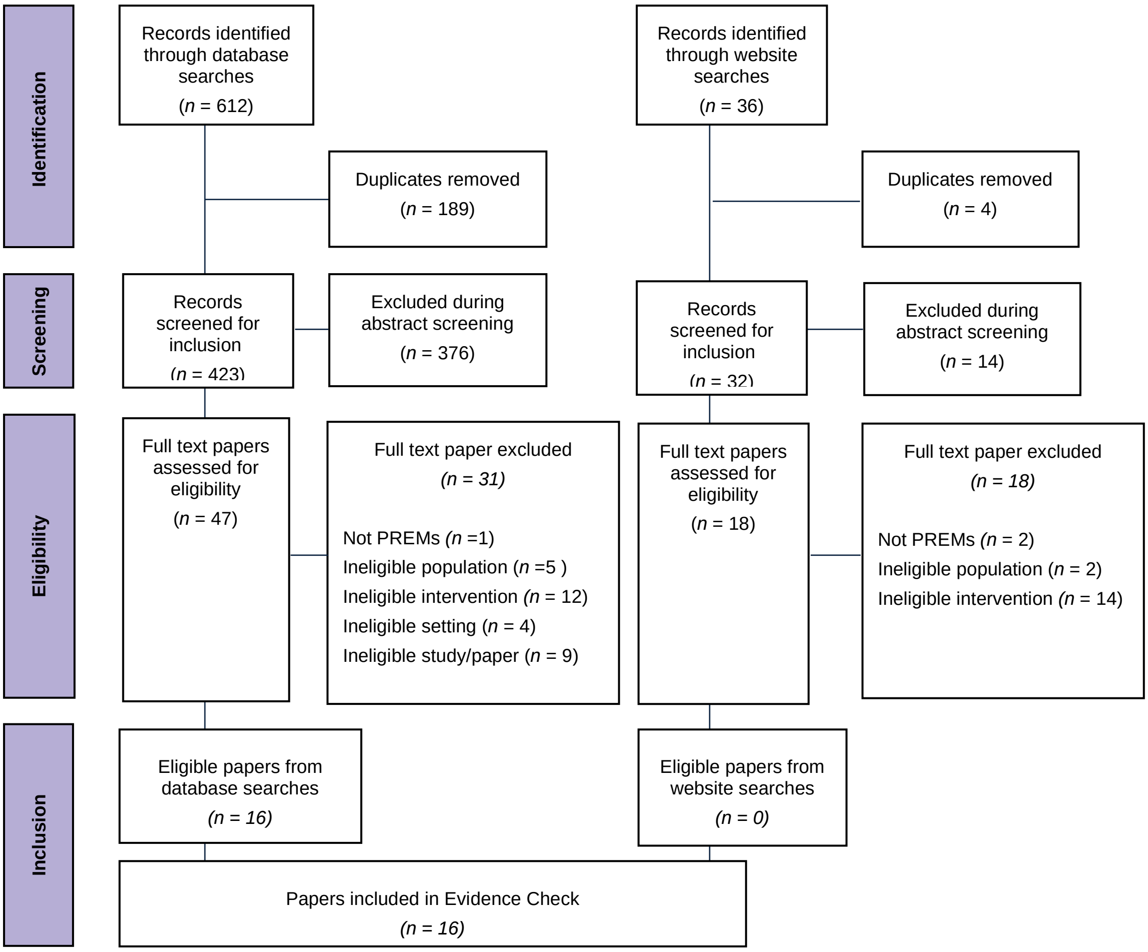
Table A1.3—Website searches

Organisation	Website	Search strategy
Analysis and Policy Observatory	https://apo.org.au	Entered search term ‘Patient experience’ into search function AND Selected ‘health’ from menu
Australian Commission on Safety and Quality in Health Care	https://www.safetyandquality.gov.au	Entered search term ‘Patient experience survey’ into search function
Australian Government Department of Health	https://www.health.gov.au	Entered ‘Patient experience survey’ into search function; selected health sector as filter for results AND Selected resources/publications/report/health sector from menu then searched ‘patient experience’
Australian Indigenous HealthInfoNet	https://healthinfonet.ecu.edu.au	Searched publications using search terms ‘patient AND experience’ in title & abstract
Australian Institute of Family Studies	https://aifs.gov.au	Searched publications catalogue using search terms ‘patient AND experience’ in all fields AND Also entered search term ‘patient experience survey’ using search function on main site
Australian Institute of Health and Welfare	https://www.aihw.gov.au	Entered search term ‘Patient experience survey’ using search function on main site, then filtered by releases/report
Canadian Institute for Health Information	https://www.cihi.ca/en	Entered search term ‘Patient experience survey’ using search function on main site
Centre for Effective Services	https://www.effectiveservices.org	Entered search terms ‘Patient experience survey’ and ‘Patient

		experience' using search function on main site Screened all reports in the resource library
European Commission	https://ec.europa.eu	Selected Topics/public health; then consumers, and screened titles AND Entered search term 'Patient experience survey' using search function on main site. Filtered by PDF and 'health wellbeing & consumer protection' and 'last year'
Health Quality and Safety Commission New Zealand	https://www.hqsc.govt.nz	Entered search term 'Patient experience survey' using search function on main site
National Institute for Health and Care Excellence	https://www.nice.org.uk	Selected menu items Evidence search/patient experience survey/filter by 'quality indicators' 'Community health "patient experience survey"'
National Institutes of Health	https://www.nih.gov	Entered search term 'Patient experience survey' using search function on main site
NSW Ministry of Health	https://www.health.nsw.gov.au	Entered search term 'Patient experience survey' using search function on main site
Productivity Commission	https://www.pc.gov.au	Entered search term 'Patient experience survey' using search function on main site, filtered by research report
QLD Department of Health	https://www.health.qld.gov.au	Entered search term 'Patient experience survey' using search function on main site
SA Department of Health	https://www.sahealth.sa.gov.au	Entered search term 'Patient experience survey' using search function on main site

Social Care Institute for Excellence	https://www.scie.org.uk	Entered search term ‘Patient experience survey’ using search function on main site
UK Department of Health and Social Care	https://www.gov.uk/government/organisations/department-of-health-and-social-care	Entered search term ‘Patient experience survey’ using search function on main site Filtered by ‘health and social care’ and filtered by ‘research and innovation in health and social care’
US Department of Health and Human Services	https://www.hhs.gov	Entered search term ‘Patient experience survey’ using search function on main site
Vic Department of Health	https://www.health.vic.gov.au/	Entered search term ‘Patient experience survey’ using search function on main site AND Checked menu items: Publications/report, Publications/standards and guidelines, Publications/frameworks

Appendix 2—PRISMA flow chart



Appendix 3—Data extraction tables

Table A3.1—Studies evaluating a measure

	Gidengil (2017) **Family Experiences with Coordination of Care (FECC)**	**Joober (2018)** **Patient Experience of Integrated Care (PEICS)**	**Kertesz (2014)** **Primary Care Quality–Homeless (PCQ-H)**	**Lloyd (2019)** **Person-centred Coordinated Care Experience Questionnaire (P3CEQ)**
Country	US	Canada (Quebec)	US	UK
Setting	Medicaid services in two US states	Family medicine clinics (one rural, one urban)	Primary care, VA and non-VA facilities	Primary care
Purpose	Further development of measure of quality of care of children with medical complexity	Validation of measure of quality of care of adults with chronic conditions	Development and validation of a primary care questionnaire for homeless patients	Development and validation of a patient-centred care experience measure for adults with long-term conditions
Population	Caregivers of children aged 0–17 years with complex chronic disease, eligible for Medicaid and with Medicaid provider, who had made at least 4 healthcare visits (including hospital) in preceding year.	Adults with at least one chronic health condition. Native French speaker Mean age 58 33% male 48% high income	Homeless-experienced clients of Veterans Affairs primary care programs 85% male; 58% African American, 2% Native American, Asian, Pacific Islander, 5% Hispanic/Latino	Adults with long-term conditions 54% male Modal age group 75–84 years Slight skew to higher educational attainment,

	Caregivers: 95% female, 92% parents, 70% aged 25–44. 60% white, 21% Hispanic Children: 11% <2 years, 22% 2–5 years, 30% 6–10 years, 38% 11–17 years		68% chronically homeless in preceding year 43% health status fair/poor 34% illicit drug use in preceding 3 months 23% alcohol use in preceding 3 months	modal attainment secondary school level
Findings	FECC was feasible to implement; respondents to mailed version less likely to be minority, more likely to speak English, more likely to complete in English compared with telephone version Lower quality of care reported by mixed-mode/mail respondents	PEICS showed good psychometric properties and is suitable for primary care or use in research	PCQ-H is an accessible and robust measure for those who have experienced homelessness	P3CEQ has strong face, construct and ecological validity and is a valid and reliable measure of patient-centred care experience
Psychometrics	1209 respondents of 2967 eligible caregivers Not validated against existing measures Items developed using Delphi method and caregiver focus groups	159 respondents at T1, 50 at T2 Internal consistency: Cronbach's alpha = 0.88 (0.85–0.91) Test–retest validity (2-week interval): intraclass correlation coefficient = 0.91 (0.64–0.90)	Interviews with clients and care providers to identify question content themes prior to item generation and selection Internal consistency high across subscales (Cronbach's alpha 0.75—0.92) and high for	Internal consistency: person-separation reliability = 0.756, 0.672 (2 subscales). Cronbach's alpha = 0.829, 0.783 Face/ecological validity: co-design workshops with stakeholders during development. Able to detect changes in care

		Concurrent validity: against Continuity of Care from Multiple Clinicians (3 domains) Spearman’s rank correlation coefficient varied from 0.44–0.54	complete scale (Cronbach’s alpha = 0.96 Convergent validity: good correlation with comparable scale (r = 0.73) Divergent validity: some evidence, modest inverse correlation with distress measure (r = -0.13)	experience pre-post a care coordination intervention, confirmed through semi-structured staff and patient interviews
How administered	By phone or by mail with phone follow-up Binary and ordinal scoring	Generally single time point; two time points used for test–retest reliability In person and by phone (researcher completed)	In-person, clinician administered	By mail, patient completed
Number of questions	20 items	17 items	33 items	11 items
Domains	Care coordination services (8 items) Messaging (9 items) Protocols/plans (3 measures)	No sub domains reported. Comparison measure covers coordination role, comprehensive knowledge of patient, team relational continuity	Patient–clinician relationship (15 items) Cooperation (3 items) Access/coordination (11 items) Homeless-specific needs (4 items)	Information and communication Care planning Transitions Goals and outcomes Decision making
Children and young people	For parents/carers about young people	Not tested	Not tested	Not tested

Languages other than English (LOTE)[a]	Spanish	French	Not tested specifically for LOTE speakers	Not tested specifically for LOTE speakers
Use and validity for priority groups	Low applicability[b]	Low applicability	Moderate applicability	Low applicability
Evidence level	III-2	III-2	III-2	III-2
Evidence rating[c]	Medium	High	High	Low

a. Languages cited are for language of the measure, not for LOTE populations.
b. Low applicability: health vulnerability only; Moderate applicability: health plus one other vulnerability; High applicability: health plus multiple other vulnerabilities.
c. Evidence rating from MMAT evidence quality tool, based on method appropriateness and overall risk of bias.

Table A3.1 continued—Studies evaluating a measure

	Mira (2016) **Instrument for Assessing Patient Experience of Chronic Illness Care (IEXPAC)**	**Singer (2013)** **Patient Perceptions of Integrated Care survey (PPIC)**	**Ziniel (2016)** **Pediatric Integrated Care Survey (PICS)**	**Zlateva (2015)** **Medical Home Care Coordination Survey (MHCCS)**
Country	Spain	US	US	US
Setting	Primary care	Primary care	Primary care for children and youth with special healthcare needs	Primary care
Purpose	Develop and validate a self-report measure of patient experience of integrated chronic care	Develop and pilot a measure of care integration as experienced by patients	Develop and validate a measure of family-reported experiences	Develop and validate a self-report measure of care coordination in primary care
Population	Patients older than 16 years with at least one chronic condition 53% male Mean age 66.5 Modal education level: basic studies	Patients 18+ years with two or more chronic conditions 85% prefer English 66% female 34% aged 55+ years 60% white 15% Black 22% Hispanic 53% with high school or 2-year degree	Parents of children with complex medical, behavioural, health and educational needs	Patients 18+ years with at least one of: 2+ ED visits in past year, hospitalisation in past year, multiple serious chronic conditions 57% female 61% white 71% aged 50+ years Healthcare teams (primary care providers, nurses, administrative staff at community healthcare provider

Findings	Reliable and valid measure of how patients perceive integrated care, emphasising the patient’s experience of care	Potentially useful for measuring patient experience, but authors suggest item rewording and reduction and refinement of domains Suggestion of selection bias	Provides a good measure of a family’s experience of care integration across a team regardless of institutional affiliation, practitioner type, type of intervention or location of care	Reliable and valid measure of care coordination within a patient-centred medical home care model. Authors argue both patient and staff input is needed to assess quality of care
Psychometrics	Reliability and convergent validity: composite reliability indices > 0.7 Internal consistency: Cronbach’s alpha = 0.76 for full scale Confirmatory factor analysis used to identify latent factors and reduce number of items	Factor analysis for item and domain confirmation Reliability: internal scale consistency estimates. Six of seven empirically derived factors met or ‘nearly met’ conventional standards (Cronbach’s alpha > 0.70): range from 0.62—0.80	Developed from focus groups and expert consensus, based on the Patient Perceptions of Integrated Care survey Exploratory factor analysis to determine item inclusion Test–retest reliability: Cohen’s kappa showed substantial agreement on 10 items and moderate agreement on 9 items Construct validity: using PICS scores for healthcare needs to differentiate respondents led to expected directional differences on other domains	Delphi consensus procedure to establish content validity (10 experts) Patient measure Internal consistency: ESEM testing to trim items. Cronbach’s alpha = 0.893—0.909 for patient domains Good discriminant ability with low correlations with patient education level or ethnicity (apart from communication domain). Good predictive validity based on correlation with self-rated health
How administered	Online, paper-and-pencil, phone	By mail	Paper and online	Paper and online

Number of questions	11 items	29 items (plus demographics)	19 items	13 items (patient), 32 items (healthcare team)
Domains	Productive interactions New relational model Person's self-management	Information flow to your doctor Information flow to your specialist Information flow to other providers Coordination with home and community resources Post-visit information flow to patient Patient-centredness	Access to care Communication between team and parents Family impact of healthcare needs Care goal creation Team functioning	Patient measure Plan of care Communication Link to community resources Care transitions
Children and young people	Validated for young people (>16 years)	Not tested	Parents of children and young people	Not tested
LOTE	Available in a range of languages	English, Spanish, Portuguese versions	Not tested	Not tested specifically for LOTE speakers
Use and validity for priority groups	Low applicability	Low applicability	Low applicability	Low applicability
Evidence level	III-2	III-2	III-2	III-2
Evidence rating	High	Low	Medium	Medium

Table A3.2—Studies using a measure to evaluate an intervention or service

	Bonciani (2017) **Population survey of patient experiences**	**Gabrielian (2021)** **Primary Care Quality–Homeless (PCQ-H)**	**Mastellos (2014)** **Pilot survey of integrated care experiences**	**Noël (2021)** **Health Care System Hassles Scale**
Country	Italy	US	UK	US
Setting	GP–primary care co-location	Veterans Administration integrated healthcare system	Primary care	VA primary care
Purpose	Determine if co-locating general practice within a multidisciplinary team is positively associated with patient satisfaction	Determine if tailoring primary care teams for homeless patients and integrating behavioural health and social services results in higher satisfaction with care	Understand the experiences of patients joining the Integrated Care Pilot in North West London	Compare two strategies for improving care coordination
Population	GP patients aged 18+ years 48% male 37% aged 18–45 years, 29% aged 65+ years 52% highest education level (high school or degree) Self-reported health: 47% fair 32% self-reported chronic conditions	Primary care patients experiencing homelessness with serious mental illness Homeless-patient aligned care teams (H-PACT) vs mainstream care H-PACT respondents more likely to be younger, male and unmarried compared with mainstream, with more history of chronic homelessness and drug problems. No differences	Patients with type-2 diabetes and/or are aged 65+ years 22% over 75 and with diabetes 49% over 75 only 32% diabetes only Other demographics not reported	Patients with 4 or more primary care visits to assigned clinic in preceding 12 months Other demographics not reported

	9% were in co-located GP AND had experience with multidisciplinary team; 28% in co-located GP with no experience of team (remainder with GPs no in MDT)	on number of chronic medical conditions		
Intervention	GP co-located with other services versus not co-located	Compared: High integration H-PACTs (3–4 embedded services) Low integration H-PACTs (0–2 embedded services) Mainstream services	Participating practices offered incentives to develop specific, tailored care plans in consultation with patient, with multidisciplinary case discussion meetings to coordinate services across primary and secondary care	Online toolkit plus weekly coaching (high intensity) vs online toolkit alone (lower intensity)
Findings	Patients with GPs co-located within a multidisciplinary team were more satisfied with their care, especially frequent service users	Assignment to an H-PACT was associated with more favourable experiences compared with mainstream primary care. Availability of behavioural health services was not associated with positive or negative experiences, but more embedded services (highly integrated clinics including social services) were associated with favourable perceptions of clinic access	Patient satisfaction higher among participants who were aware they had a care plan (only 22% aware)	Both versions of the intervention were associated with fewer reported client hassles Coaching provided no additional benefit to the online toolkit alone for patient reported outcomes

Psychometrics	Not reported for measure	Referenced for measure but not cited in study	Not reported for measure. Items developed through consensus among research team (sociologists, psychologists, clinicians). Face validity assessment in weekly meetings and via participant feedback	Referenced for measure but not cited in study
How administered	Computer assisted telephone interview	Postal, with telephone follow-up for non-responders	Pen-and-paper	Postal
Number of questions	60 items in full measure—unclear how many directly related to experiences with the co-located service	33 items	19 items	16 items
Domains	Access to practice Primary care professionals associated with practice Communication and relationship with GP GP involvement with health promotion activities	Access/coordination Patient–clinician relationship Perceived cooperation among clinicians Homeless-specific needs	Integrated care Care planning	Lists problems encountered with healthcare in general
Children and young people	Not tested	Not tested	Not tested	Not tested
LOTE	Not applicable (Italian study using measure in Italian)	Not tested	Not tested	Not tested

Use and validity for priority groups	Low applicability	High applicability	Low applicability	Low applicability
Evidence level	III-2	III-2	III-2	II (site randomisation)
Evidence rating	High	High	Low	Medium

Table A3.2 continued—Studies using a measure to evaluate an intervention or service

	Rogers (2020) **Survey of patient attitudes to social needs screening and programs in ambulatory settings**	**Siantz (2020)** **Focus groups on patient experience of Behavioral Health Integration and Complex Care Initiative (BHICCI)**	**Zulman (2019)** **Survey of Healthcare Experiences of Patients (SHEP)** **Patient Assessment of Chronic Illness Care (PACIC)** **Health Care Hassles Scale**
Country	US	US	US
Setting	Ambulatory and primary care	Integrated physical and behavioural care	VA intensive primary care
Purpose	Develop and use a new survey measure to assess patient perceptions and experience of the health impact of social needs, and the degree of support for addressing social needs within the health system	Understand patient experience of integrated care within a Medicaid managed care plan system	Determine whether augmenting a Patient Aligned Care Teams (PACTs) model with an intensive management program (PIM) increases patient satisfaction with and perceived access to care
Population	Patients aged 18+ years 66% female 79% <= 60 years 70% non-white 50% Hispanic 33% high school graduate or less 17% reported at least one social need in previous year	Patients with >= one chronic care condition AND one behavioural health condition Aged 18+ years speaking English or Spanish	Mean age 65 (PIM) 64 (PACT) 90% male 50% / 48% white 55+% some college or colleg/more 50% low income

Intervention	Not applicable—attitude survey	Clinics create multidisciplinary teams of: • Care manager (support patient to identify and achieve wellness goals) • Care coordinator (screen, assess, ensure information sharing and coordination • Behavioural health clinician (provide evidence-based treatment for mental health and substance use conditions)	Supplement the PACT with a program (PIM) of regular interdisciplinary team meetings, medication management, home visits, mental health/substance use assessment and support, health coaching and intensive social work case management
Findings	Most patients see connection between social needs and overall health, whether or not they had personally experienced such a need. Patients' attitudes to health system addressing needs varied according to the nature of the need	Care coordination is valued by patients, causes some resourcing challenges for providers Patients wanted more involvement in their own care planning and need a formal mechanism for conveying feedback to providers	No difference between PACT and more intensive PIM in coordination of, access to, or satisfaction with care Patients receiving PIM were more likely to report having a trusted provider and being asked about their health goals and have higher mean scores for chronic care
Psychometrics	Based on patient and clinician focus groups. Not otherwise reported	Six focus groups conducted across five program sites, 54 participants Conducted in English or Spanish Grounded theory, open coding Provider groups also conducted	Not reported for measures
How administered	Paper and electronic	In person	Paper and telephone
Number of questions	8 items	6 open-ended discussion prompts	SHEP not reported

			PACIC 6 items Hassles not reported
Domains	Prior experience with social needs Perceptions of how social needs affect health Perception of their (private) healthcare system’s role in addressing social determinants of health, including which needs should be screened and assessed Attitudes towards health system investment in addressing social needs	Nature of care received Changes to care with new model Describe a good/helpful interaction How does your team involve you in planning and decisions? Describe an aspect of service delivery that could be improved	Health goals Things that make it hard to care for health Medication and care coordination Care coordination for chronic illnesses Challenges in receiving healthcare
Children and young people	Not tested	Not tested (in this study)	Not tested
LOTE	Not tested	English and Spanish	Not tested
Use and validity for priority groups	Low applicability	Moderate applicability	Low applicability
Evidence level	III-2	Not on NHRMC scale, qualitative only	III-2
Evidence rating	Low	High	Low

Table A3.3—Review

	O’Loughlin (2017) **Various measures**
Country	Australia
Setting	Patient-Centred Medical Home (PCMH) (Health Care Home in the Australian context)
Purpose	Assess literature in which adult patients report their experiences of using health services with PCMH model of care
Population	Adult patients, any country
Intervention	Key attributes of the Health Care Home/PCMH model: 1. Each patient has a primary care physician responsible for delivering whole-person coordinated care 2. Physician is part of a wider practice team working collaboratively to support the patient 3. Care is coordinated 4. Care is accessible 5. Patients are encouraged to participate in care decisions
Findings	Evidence for PCMH improving patient experience is mixed, with improvements demonstrated in some studies but not others. Better measures are needed to evaluate patient experience in the Australian context 24 studies used validated tools, 5 used non-validated ones
Measures named	Ambulatory Care Experiences Survey (ACES-SF) (Fishman 2012) Components of Primary Care Index (CPCI) (Nutting 2010) Consumer Assessment of Healthcare Providers and Systems Clinician and Group (CAHPS-CG) (Agency for Healthcare Research and Quality 2017) Diabetes Disease State Management Questionnaire (DDSM-QM) (Shawn McFarland 2014) Patient Assessment of Chronic Illness Care (PACIC) (Carvajal 2014, first mention in table) Primary Care Assessment Survey (PCAS) (Christensen 2013) Survey of Healthcare Experiences of Patients (SHEP) (Nelson 2014)

Evidence level	I
Evidence rating	Low (MMAT does not cover, but method states scoping methodology. No indication of grey literature search, restriction to RCT, double screening, or assessment of risk of bias)

Appendix 4—Measures

ACES-SF: O’Loughlin 2017

See Reid RJ, Fishman PA, Yu O, Ross TR, Tufano JT, Soman MP, Larson EB (2009) Patient-centered medical home demonstration: a prospective, quasi-experimental, before and after evaluation. The American Journal of Managed Care 15, e71–e87 (cited in O’Laughlin 2017, limited details available).

CAHPS-CG: O’Loughlin 2017

See Kern LM, Dhopeshwarkar RV, Edwards A, Kaushal R (2013) Patient experience over time in patient-centered medical homes. The American Journal of Managed Care 19, 403–410 (cited in O’Laughlin 2017, limited details available).

See also: https://www.ahrq.gov/cahps/surveys-guidance/cg/index.html

CPCI: O’Loughlin 2017

Nutting PA, Crabtree BF, Stewart EE, Miller WL, Palmer RF, Stange KC, Jaén CR (2010) Effect of facilitation on practice outcomes in the National Demonstration Project model of the patient-centered medical home. Annals of Family Medicine 8(Suppl. 1), S33–S44. doi:10.1370/afm.1119 (cited in O’Laughlin 2017, limited details available)

See also: https://innovation.cms.gov/innovation-models/comprehensive-primary-care-initiative

FECC: Gidengil 2017

Items in Appendix 4 in the paper (page 23).

Health Care Hassles Scale: Noël 2021, Zulman 2019

See Parchman, ML, Noël PH, and Lee, S (2005) Primary care attributes, health care system hassles, and chronic illnesses. *Medical Care* 43 (11) 1123

Scale is 4-point, not a problem at all—very big problem

Lack of information about my medical conditions

Lack of information about treatment options

Lack of information about why my medications have been prescribed to me

Problems getting my medications refilled on time

Uncertainty about when or how to take my medications

Side effects from my medications

Lack of information about why I've been referred to a specialist

Having to wait a long time to get an appointment for specialty doctors or clinics

Poor communication between different doctors or clinics

Disagreements between my doctors about my diagnosis or the best treatment for me

Lack of information about why I need lab tests or x-rays

Having to wait too long to find out the results of lab tests or x-rays

Difficulty getting questions answered or getting medical advice between scheduled appointments

Lack of time to discuss all my problems during scheduled appointments

Having my concerns ignored or overlooked by my health care providers

Medical appointments that interfere with my work, family, or hobbies

IEXPAC: Mira 2016

Scale available at http://www.iemac.es/iexpac/ Choose English-language version.

5-point Likert scale never–always

1. They respect my lifestyle

The professionals who care for me listen to me and ask me about my needs, habits and preferences to adapt my treatment and care plan.

2. They are coordinated to offer me good care

The professionals who care for me at the health centre and those who care for me at the hospital talk to each other and coordinate to improve my wellbeing and quality of life.

3. They help me become informed via the internet

The professionals who care for me inform me about reliable websites and internet forums that I can consult to better understand my disease, its treatment and the consequences they may have on my life.

4. I now know how to look after myself better

With the support of my professionals, I feel now that I have more confidence in my ability to take care of myself, manage my health problems and keep my autonomy.

5. They ask me about and help me follow my treatment plan

I review the adherence to my treatment and care plan with the professionals who care for me, and if I have questions, they answer them.

6. We agree on objectives to lead a healthy life and to control my health problems better

I've been able to agree with the professionals who care for me on specific objectives regarding diet, physical exercise and medication to control my health problems better.

7. I use the internet and my mobile phone to consult my clinical record

I use the internet and my mobile phone to consult my clinical record, test results, scheduled visits and to access other services on my health service's website

8. They ensure that I take my medication correctly

The professionals who care for me review with me all the medications I take, how I take them, how they make me feel, and I can ask them about the questions I have.

9. They are concerned about my wellbeing

The professionals who care for me are concerned with my quality of life and I feel they are committed to improving my wellbeing.

10. They inform me about health and social resources that can help me

The professionals who care for me inform me about the health and social resources available (in my neighbourhood, town or city) that I can use to improve my health problems and take better care of myself.

11. They encourage me to talk with other patients

The professionals who care for me encourage me to participate in patient groups to share information and experiences on how to care for ourselves and improve our health.

If you have been hospitalised in the last 6 months, please respond to the following statement:

12. They care about me upon my arrival home after being in hospital

After being discharged from hospital, they have called or visited me at home to see how I was and what care I needed.

If you have received emergency care in the last 6 months, please respond to the following statement:

13. They counsel me on how to avoid a new emergency

After having been in the emergency room, the professionals who care for me know what has happened to me and advise me on how to avoid a new emergency.

If you have received healthcare in your home in the last 6 months, please respond to the following statement:

14. They care for me well in my home

The professionals who care for me in my home try to solve my health problems in coordination with the professionals of the health centre and the hospital.

If you have received care from the social services in the last 6 months, please respond to the following statement:

15. Social services are coordinated with the health services to provide me with good care. The professionals who care for me in social services talk to and coordinate with the healthcare professionals to provide me with good care.

MHCCS: Zlateva 2015

Patient and healthcare provider versions listed as available at supplementary materials page: https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-015-0893-1#Sec12

P3CEQ: Lloyd 2019

Items not in publication.

Original publication: Sugavanam T, Fosh B, Close J, Byng R, Horrell J et al. Codesigning a measure of person-centred coordinated care to capture the experience of the patient: the development of the P3CEQ. J Patient Exp 2018;5(3):201–11. doi:10.1177/2374373517748642.

Free to use, but authors require a user agreement to release items. Corresponding author: Helen Lloyd, Plymouth University Peninsula Schools of Medicine and Dentistry, Room N10, ITTC Building, Davy Road, Plymouth Science Park, Derriford, Plymouth PL6 8BX, United Kingdom. Email: helen.lloyd-1@plymouth.ac.uk

PACIC: Zulman 2019

Patient Assessment of Chronic Illness Care (PACIC)

See: Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). Med Care 2005 May;43(5):436–44. doi: 10.1097/01.mlr.0000160375.47920.8c. PMID: 1583840.

PCQ-H: Gabrielian 2021

Items not in publication. See Kertesz for PCQ-H.

PCQ-H: Kertesz 2014

Items available in the paper (p. 738). Survey form and scoring worksheet available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4620084/

4-point agree/disagree Likert plus ‘don’t know’

Q1. My primary care provider never doubts my health needs.

Q2. My primary care provider takes my health concerns seriously.

Q3. My primary care provider makes decisions based on what will truly help me.

Q4. I feel my primary care provider has spent enough time trying to get to know me.

Q5. I can get in touch with my primary care provider when I need to.

Q6. I can get enough of my primary care provider’s time if I need it.

Q7. If my primary care provider and I were to disagree about something related to my care, we could work it out.

Q8. My primary care provider makes sure healthcare decisions fit with other challenges in my life.

Q9. I worry about whether my primary care provider has the right skills to take good care of me.

Q10. I can be honest with my primary care provider if I use drugs or alcohol.

Q11. I worry my primary care provider might report my health information to the authorities.

Q12. My primary care and other healthcare providers need to communicate with each other more.

Q13. I have been frustrated by lack of communication among my primary care and other healthcare providers.

Q14. My primary care and other healthcare providers are working together to come up with a plan to meet my needs.

Q15. My primary care provider helps to reduce the hassles when I am referred to other services.

Q16. I have to wait too long to get the healthcare services my primary care provider thinks I need.

Q17. Someone from my primary care provider’s office returns my phone or pages.

Q18. At this place, I have sometimes not gotten care because I cannot pay.

Q19. If I could not get to this place, I think the staff would reach out to try to help me get care.

Q20. f I walk into this place without an appointment, I have to wait too long for care.

Q21. This place is open at times of the day that are convenient for me.

Q22. This place helps me get care without missing meals or a place to sleep.

Q23. It is often difficult to get healthcare at this place.

Q24. This place tells me about what services are available.

Q25. The healthcare services I need are close to each other.

Q26. If my primary care provider is unavailable there is someone else that can help me.

Q27. When I need information about my healthcare, like test results, I can get it easily.

Q28. The staff at this place listen to me.

Q27. This place tries to help me with things I might need right away, like food, shelter or clothing.

Q30. The people who work at this place seem to like working with people who have been homeless.

Q31. If I miss an appointment, this place still finds a way to help me.

Q32. At this place, I always have to choose between healthcare and dealing with other challenges in my life.

Q33. Staff at this place treats some patients worse if they think that they have addiction issues.

PEICS: Joober 2018

Items available (English version) in the paper, p3.

1. Have all your needs been assessed?

☐ All of my needs have been assessed

☐ Almost all my needs have been assessed

☐ Some of my needs have been assessed

☐ Few of my needs have been assessed

☐ None of my needs have been assessed

2. Were you as involved as you wanted to be in decisions about your care and support?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

3. Was your family or carer as involved in decisions about your care and support as you wanted them to be?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

☐ There were no family or carers available to be involved

☐ I don’t want or I don’t need my family or my carers to be involved

4. Overall, do you feel that your carer/family received support from health and social services as needed?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

☐ There were no family or carers to support

5. Did health and social care staff tell you what will happen next?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

6. When health or social care staff planned care or treatment for you, did it happen?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

7. Were your care and support reviewed as they should be?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

8. Was your medication thoroughly reviewed as it should be?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

9. Did you know who to contact if you needed to ask questions about your condition or treatment?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

10. If you had questions, could you contact the people treating and caring for you?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

11. Did all the different people treating and caring for you work well together to give you the best possible care and support?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

12. Did health and social care services help you live the life you want?

☐ Completely

☐ A lot

☐ Moderately

☐ A little

☐ Hardly

13. Did health and social care staff give you information about other services that are available to someone in your circumstances, including support organisations'?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

14. Was information given to you at the right time?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

15. Was information provided in a way that you could understand?

☐ Always

☐ Often

☐ Sometimes

☐ Rarely

☐ Never

16. Could you meet/phone/email a professional when you needed to ask more questions or discuss the options?

□ Always

□ Often

□ Sometimes

□ Rarely

□ Never

17. If you still needed contact with previous services/professionals, would it be possible?

□ Always

□ Often

□ Sometimes

□ Rarely

□ Never

PICS: Ziniel 2016

Questions and scoring instructions in supplementary materials of the article.

Population survey: Bonciani 2017

Items not in publication. Measure in Italian.

Population survey: Mastellos 2014

Items not in publication. Protocol paper (Greaves F, Pappas Y, Bardsley M, Harris M, Curry N et al. Evaluation of complex integrated care programmes: the approach in North West London. Int J Integr Care 2013;13:e006. Available from: URN:NBN:NL:UI:10-1-114283.) does not have survey items either. Contact corresponding author if scale needed: Nikolaos Mastellos, Research Associate, Department of Primary Care & Public Health, School of Public Health, Imperial College London, Reynolds Building, St Dunstan’s Road, London W6 8RP, UK, Phone: +44 (0)20 7594 7455; Fax: +(0)20 7594 0854, email: n.mastellos@imperial.ac.uk

Population survey: Rogers 2020

1. Within the last year, have you personally had any of the following social needs? (*Check all that apply*)
    - Not being able to afford healthy food
    - Housing problems or homelessness
    - Not being able to find or afford transportation to get to work or medical care
    - Not being able to afford basic expenses
    - Being alone or isolated from friends, family or others
    - Trouble understanding written medical information
    - I haven't personally had any of these needs
2. Which of these social circumstances do you think may have an impact on health? (*Check all that apply*)
    - Not being able to afford healthy food
    - Housing problems or homelessness
    - Not being able to find or afford transportation to get to work or medical care
    - Not being able to afford basic expenses
    - Being alone or isolated from friends, family or others

Trouble understanding written medical information
I don’t know / Unsure
I don't think social circumstances have an impact on health

3. Which of the needs below should the health system ask all patients about? (*Check all that apply*)

    Not being able to afford healthy food
    Housing problems or homelessness
    Not being able to find or afford transportation
    Not being able to afford basic expenses
    Being alone or isolated from friends, family or others

    Trouble understanding written medical information
    Other (*Please specify*):

4. Which needs should the health system help its patients with, if they want help? (*Check all that apply*)

    Not being able to afford healthy food
    Housing problems or homelessness
    Not being able to find or afford transportation
    Not being able to afford basic expenses
    Being alone or isolated from friends, family, or others

    Trouble understanding written medical information

5. Please indicate how much you agree or disagree with the following statements: (*strongly agree—strongly disagree*)
    a. I support Kaiser Permanente using social needs information to improve care for its patients
    b. Kaiser Permanente should dedicate part of its budget to help patients with their social needs
    c. Kaiser Permanente should help patients with their social needs even if that could increase my healthcare costs

Plus demographic questions

PPIC: Singer 2013

Survey (print-ready format) available here: https://www.hsph.harvard.edu/ppic/ppic-resources/the-survey/ with contact details for scoring instructions.

Qualitative measure: Siantz 2020

Focus group questions.

1. What made you start coming to this clinic? When?

2. How much of your health care do you receive at this organization?

3. How many health providers do you see at this clinic? Probe for when they started seeing multiple providers.

4. When you come to see your providers, what does a typical health visit involve for you? Probe for experience with BHICCI core elements: medical, behavioral, physical reconditioning, alternative therapy, care management

5. Thinking about the care you are currently receiving—how have services changes since before BHICCI officially began (which will vary by clinic)?

6. Describe a time you found your healthcare providers (with the providers mentioned in previous question) to be especially attentive and helpful to needs? Probe for examples or what could have improved if not positive.

7. In what ways does your healthcare team involve you in the planning and making decisions about your healthcare options?

8. If you could improve one healthcare issue in the delivery of your services, what would that issue be?

SHEP: Zulman 2019

Survey of healthcare experiences of patients (SHEP). Unable to locate.

Appendix 5—Evidence grading

NHMRC Levels of Evidence

Level	Evidence type, for screening interventions
I	A systematic review of level II studies
II	A randomised controlled trial
III-1	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)
III-2	A comparative study with concurrent controls: • Non-randomised, experimental trial • Cohort study • Case-control study
III-3	A comparative study without concurrent controls: • Historical control study • Two or more single arm studies
IV	Case series

Mixed Methods Appraisal Tool

SCREENING QUESTIONS	S1. Are there clear research questions? S2. Do the collected data allow you to address the research questions?
1. QUALITATIVE STUDIES	1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3. Are the findings adequately derived from the data? 1.4. Is the interpretation of results sufficiently substantiated by data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
2. RANDOMISED CONTROLLED TRIALS	2.1. Is randomisation appropriately performed? 2.2. Are the groups comparable at baseline? 2.3. Are there complete outcome data? 2.4. Are outcome assessors blinded to the intervention provided? 2.5 Did the participants adhere to the assigned intervention?
3. NON-RANDOMISED STUDIES	3.1. Are the participants representative of the target population? 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? 3.3. Are there complete outcome data? 3.4. Are the confounders accounted for in the design and analysis? 3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
4. QUANTITATIVE DESCRIPTIVE STUDIES	4.1. Is the sampling strategy relevant to address the research question? 4.2. Is the sample representative of the target population? 4.3. Are the measurements appropriate? 4.4. Is the risk of non-response bias low? 4.5. Is the statistical analysis appropriate to answer the research question?
5. MIXED METHODS STUDIES	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? 5.2. Are the different components of the study effectively integrated to answer the research question? 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?