

BMJ Open Care coordination across healthcare systems: development of a research agenda, implications for practice, and recommendations for policy based on a modified Delphi panel

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ABSTRACT

Objective For large, integrated healthcare delivery systems, coordinating patient care across delivery systems with providers external to the system presents challenges. We explored the domains and requirements for care coordination by professionals across healthcare systems and developed an agenda for research, practice and policy.

Design The modified Delphi approach convened a 2-day stakeholder panel with moderated virtual discussions, preceded and followed by online surveys.

Setting The work addresses care coordination across healthcare systems. We introduced common care scenarios and differentiated recommendations for a large (main) healthcare organisation and external healthcare professionals that contribute additional care.

Participants The panel composition included health service providers, decision makers, patients and care community, and researchers. Discussions were informed by a rapid review of tested approaches to fostering collaboration, facilitating care coordination and improving communication across healthcare systems.

Outcome measures The study planned to formulate a research agenda, implications for practice and recommendations for policy.

Results For research recommendations, we found consensus for developing measures of shared care, exploring healthcare professionals' needs in different care scenarios and evaluating patient experiences. Agreed practice recommendations included educating external professionals about issues specific to the patients in the main healthcare system, educating professionals within the main healthcare system about the roles and responsibilities of all involved parties, and helping patients better understand the pros and cons of within-system and out-of-system care. Policy recommendations included supporting time for professionals with high overlap in patients to engage regularly and sustaining support for care coordination for high-need patients.

Conclusions Recommendations from the stakeholder panel created an agenda to foster further research,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Coordinating patient care across different healthcare delivery systems presents considerable challenges for healthcare professionals, and we convened a 2-day stakeholder panel, preceded and followed by surveys and informed by literature, to formulate concrete recommendations for research, practice and policy supporting healthcare organisations.
- ⇒ Some of the practice and policy recommendations may be aspirational for some organisations; however, panellists took limited organisational resources into account throughout the process and prioritised recommendations to identify the most important steps to meaningfully improve and support care coordination across healthcare systems.
- ⇒ While we used a structured and framework-driven approach to stakeholder selection and convened a large panel with a broad range of stakeholders, undoubtedly, some perspectives of the complex care coordination between systems will have been missed, and we hope that future research will further investigate care coordination established across healthcare systems and different care delivery organisations.

practice and policy innovations in cross-system care coordination.

INTRODUCTION

Care coordination has received much practical and research attention, and its role in integrating clinical services is of critical importance to ensure safe and effective patient care.¹ The care coordination literature derived from integrated delivery systems often focuses on coordination within a single healthcare system, such as improving interaction between primary care and specialty



care providers. Efforts within systems include shared software and business processes to foster interdepartmental coordination. However, as demonstrated by network analyses that capture patient sharing between healthcare providers, care coordination across healthcare systems is an increasingly common clinical scenario.² Such coordination may include management of chronic conditions by primary care with periodic input from external specialists.³ Other common areas of collaboration between healthcare delivery systems are cancer care⁴ and palliative care.⁵

Care coordination across healthcare systems cannot always use the same approaches as those used within a single system and instead may include introducing new software designed to facilitate coordination, such as web-based communication tools that can be accessed by healthcare professionals from all systems.⁶ These online tools create a secure, virtual space for care professionals and sometimes include patients and caregivers in the communication. Results across evaluation studies are mixed, with some authors concluding that tool implementation is feasible but sometimes of limited use to healthcare professionals. An evaluation of an accountable care organisation concluded that formal clinical integration may be insufficient to improve patient outcomes.⁷

We engaged stakeholders in an expert panel process to articulate an agenda for improving care coordination across healthcare delivery systems, from the vantage point of a large integrated healthcare system needing to coordinate care with external healthcare entities that do not share administrative or medical infrastructure. We formulated concrete recommendations for research, practice and policy.

METHODS

We developed a detailed workplan that guided a 1-year process. The modified Delphi stakeholder panel used online surveys and video-assisted, moderated discussions and was informed by a rapid literature review.

Rapid review

A rapid review aimed to identify examples of care coordination approaches between healthcare systems and organisations to learn more about tested communication tools and strategies. There is no accepted nomenclature for care coordination, and the existing literature is dominated by coordination approaches within healthcare systems; hence, we applied a strategic search to identify relevant studies. We used four key publications selected by project staff to represent different aspects of care coordination research (clinical integration, implementation of technological advances, social network analysis of provider relationships and interpersonal relationships between providers) as seed articles for a forward search.^{1 2 6 7} We screened studies included in 127 systematic reviews on care coordination to obtain a broad range of care coordination approaches.^{3-5 8-131} The reviews addressed

common chronic conditions managed in primary as well as specialty care, cancer care, palliative care, comorbidity and complexity, personnel specialising in care coordination, frameworks and strategies to promote coordination, technology supporting coordination, settings for temporary care such as emergency departments and care models applied to specific populations. The online supplemental appendix describes the methods and results of the rapid review in detail. We used the rapid review to prepare for the stakeholder panel meetings, made the results of the review available to stakeholders and summarised the findings during the panel meetings.

Analytical model

The project team designed an analytical model that anchored the care coordination discussions with three scenarios and that introduced the idea of a main integrated organisation with external healthcare professionals providing additional care outside of the primary network. Throughout the study, we used the Veterans Health Administration (VHA) as an example of a main healthcare delivery organisation that has significantly expanded its network of external providers over the years, allowing patients to use selected external healthcare providers to reduce waiting times and otherwise address patient needs, in particular since the introduction of the Maintaining Internal Systems and Strengthening Integrated Outside Networks Act.¹³² However, the panel's goals were to advance care coordination across systems, an objective relevant not just to VHA but also to private-sector integrated delivery systems whose patients may receive out-of-system care (eg, for emergencies or when the main system contracts with an external organisation to deliver care).¹³³

Our analytical framework is depicted using three scenarios in figure 1. The scenarios capture the multi-level aspect of care coordination, which includes patients, healthcare professionals, and the main healthcare delivery system or organisation. For simplicity, coordination is depicted as occurring across two systems, with the understanding that, for complex situations, coordination may need to occur across more than two entities. We also developed a glossary of key terms for panellists, also shown in the online supplemental appendix. The three care coordination scenarios include

- ▶ Scenario 1: intense care coordination—coordinating the care of individual, high-need patients who require frequent and high levels of care across different healthcare delivery systems.
- ▶ Scenario 2: ad hoc care coordination—an unexpected need to communicate across healthcare delivery systems (eg, abnormal lab value is identified by one professional that should be communicated to the other healthcare professional).
- ▶ Scenario 3: high overlap in patients—coordinating care between two healthcare professionals in different healthcare delivery systems who share a large number of patients.

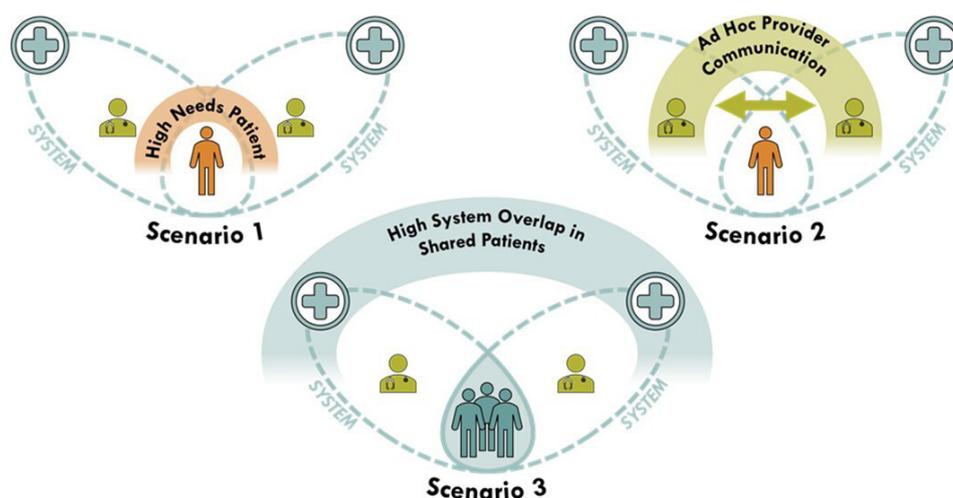


Figure 1 Analytical framework.

We hypothesised that the scenarios may warrant different approaches to care coordination; for example, there may be differences in the amount of investment into care coordination improvement and technology.

Stakeholder panel

We reviewed stakeholder engagement models and adopted a model appropriate for public health, which includes four types of stakeholders: *health services providers*, *decision makers*, *community representatives* and *research representatives*.¹³⁴ Within stakeholder categories, we approached potential representatives and ensured that the panel was multidisciplinary and represented different levels within organisations. The online supplemental appendix table documents all 16 participating panellists.

Consensus finding

The consensus-finding procedure adhered to principles of consensus methods for medical and health services research: anonymity (private ranking or voting to avoid dominance issues in the group), iteration (multiple rounds to allow individuals to change their opinions after discussions), controlled feedback (feedback of the group response after each rating round) and statistical group response (provision of summary measures of the group response).¹³⁵ We used an online prepanel survey to elicit input from panellists to prepare the panel meeting. Fifteen panellists provided prepanel input (response rate 94%). The survey addressed available communication methods (formal and approved methods in the organisation as well as workarounds not sanctioned by the organisation but used to ensure communication with the external care professional), experience with approaches to foster informal interaction between healthcare professionals to support coordination, unintended consequences of care coordinated between multiple healthcare professionals, and the different aspects and layers of care coordination. All survey questions were open to all panellists, as all panellists were felt to have sufficient insight into care coordination processes (eg, patient representatives,

although not engaging in ‘provider to provider’ communication, stated their preference for how they preferred their providers to communicate with one another). The panellists also received the results of the rapid review, and we made key resources available on a secure site for all team members and panellists. Results of the survey were presented during the panel in aggregate format, including points of agreement and disagreement across panellists.

We convened two panel meetings of 5 hours each. Although originally planned as an in-person meeting, both meetings were held online due to COVID-19 restrictions. The two meetings were held in the same week, on the first and last days of the week. The first panel meeting included presentations and discussions, while the second panel meeting asked panellists to vote on themes identified in the first meeting. The first panel meeting provided panellists with some background on the topic; an introduction of all team members and panellists; the status of the Veterans Health Administration Health Information Exchange, a system designed to support care coordination across VHA and (external) community providers; the findings of the rapid literature review; a presentation of the three coordination scenarios; results from interviews conducted within VHA with a specific focus on rural health; feedback from the prepanel survey; and a summary of the panel goals.

Three formal rounds of discussions in the first panel meeting focused on strategies for informal relationship-building among providers from different healthcare systems; communication methods; and the present state of care coordination across systems, focusing on what is working and what is not working for care coordination with current methods and approaches, from the panellists’ perspectives. Five discussion rounds on the second panel meeting day addressed the domains of care coordination, unintended consequences of (poor) coordination, the future research agenda, implications for practice and recommendations for policy. Discussions were

moderated by experienced moderators who ensured that a variety of perspectives were heard and panellists stayed on topic. Following an approach used for RAND appropriateness panels, no attempt was made to force the panel to consensus. Instead, the discussions explored all viewpoints and tried to clarify terms and concepts. We used online technology to provide instant feedback. The panel meetings were attended by the panellists as well as five observers and two external presenters who added to the discussions.

A postpanel survey consolidated the findings of the panel meeting. Eleven panellists (69%) completed the postpanel survey. The survey was completed by each panellist individually to avoid situational groupthink and to consolidate the panel findings independently. To orient panellists, we used VHA as an example of a *main healthcare system* and termed professionals and community providers delivering outside care *external healthcare providers*. However, the input was geared towards making recommendations that are not specific to a selected organisation but that are applicable to different healthcare delivery systems that share care. The survey included recommendations for research, practice and policy drafted by the review team following the panel discussions. The survey used a 5-point rating scale throughout that assessed the importance of the presented items, ranging from not important (1) to very important (5). We used a cut-off of a mean value of 4.5 across panellists to select items as important. For the method of communication, one-way analysis of variance was performed to test for differences in means between the three coordination scenarios.

RESULTS

Data were collected in the prepanel meeting survey, during the meeting and the postpanel meeting. Here we present the final results, that is, those that are based on the last consolidating round of panel input, preceded by a round of prepanel ratings and video-assisted discussions during the panel meetings.

Dimensions of care coordination

We asked panellists about the importance of 16 dimensions of care coordination, all based on published literature, suggestions from individual panellists and panel discussions. Panellists rated the *method of communication*, the *organisational mechanism*, the *urgency of communication*, the *scope of coordination*, the *interpersonal aspect of coordination* and *organisational culture* (the healthcare system support for coordination) as key aspects of coordination (see figure 2).

Communication methods

The most commonly used method of communication between healthcare professionals to achieve coordination was *phone calls* (87%). A large proportion of the panellists used *secure messaging* (53%), *email* (47%), *in-person communication* (40%) and *shared software* (40%). The use of a *web platform for care coordination* (33%), *call centre* (33%), *fax* (27%), and *letter/mail* (27%) was also selected multiple times (table 1).

Panellists' preferences for interprofessional communication included phone, in-person, direct communication, email, secure messaging, text, shared online portal, video, shared web-based services, commercial collaboration software (Microsoft Teams), commercial communication software (Epic messaging), and a platform that allows



Figure 2 Care coordination domains. Domain content (mean (SD)) on a scale from 1 to 5.

Table 1 Frequency and preference for communication methods used in care coordination

Modality	Frequency of use (%)	Preference ranking scenario 1 (intense coordination)	Preference ranking scenario 2 (urgent, unplanned communication)	Preference ranking scenario 3 (high overlap)
Phone call	87	4.10	4.30	4.18
Secure messaging	53	4.60	4.50	4.60
Email	47	4.10	4.00	3.91
In-person communication	40	4.20	4.20	4.00
Shared software	40	4.40	4.40	4.36
Web platform for care coordination	33	4.30	4.50	4.36
Call centre	33	3.30	3.30	3.00
Fax	27	2.67	2.60	2.55
Letter/mail	27	2.80	2.50	2.55
Email list	20	3.90	3.90	3.82
Pager	13	2.60	2.70	2.36
Text messaging (personal phone)	20	2.30	2.60	2.45
Text messaging (work phone)	13	4.00	3.80	3.64
Smart phone app	7	4.30	4.10	4.00
Messenger (third party)	13	3.11	3.00	2.82
Patient-held records	20	2.60	2.60	2.64
Video coordination (organisational system)	13	3.90	3.70	3.55
Commercial video (Zoom)	7	3.70	3.30	3.36
Duplicate health record	20	3.40	3.00	2.64
Other, query-based exchange in health information exchange system	7	3.80	3.50	4.00
Other, Veterans Health Information Exchange	7	4.00	3.40	3.91
Other, Microsoft Teams	7	3.78	3.80	3.91

uploading of information and other electronic health information exchange capabilities. Some panellists indicated that the preferred method depended on the type of information, the situation or the purpose. Among all 22 communication modalities, there were no significant differences in mean preference ranking between the three scenarios; that is, we found no evidence that the communication method differed systematically by the three scenarios (*intense care coordination*, *ad hoc care coordination* and *high overlap in patients*). One panellist preferred phone calls for ‘real-time issues’, and another panellist responded that some conversations warrant face-to-face interaction; otherwise, calls and emails work. One panellist indicated it depends on the urgency of the need, and urgent issues required calls; otherwise, email would work. Panellists indicated it depends on whether the purpose is communication, coordination or collaboration. For collaboration, a platform that allows uploading information is needed (ideally with video or phone interface); for other purposes, phone calls are fine.

Furthermore, we asked about healthcare professionals’ use of strategies of communication and coordination that are not approved in their healthcare delivery system. Examples of these ‘workarounds’ were texting and using email. This included using day-to-day communication tools such as smartphones, for example, to check with another provider whether a patient had followed through and had made an appointment as suggested, or to check whether results of tests were coming on time for an upcoming appointment. Reasons for using workarounds were typically ease of use of the standard tools in time-pressing matters and the availability to communicate quickly without additional sign-in procedures when there were no confidentiality concerns because no details had to be shared.

Support to foster collaboration

Twenty per cent of panellists indicated that there was only minimal or no support in their respective organisations for external communication, care coordination and

collaboration such as web portals, and pager and phone arrangements to make healthcare professionals accessible to partners in other health systems.

Participants reported very few informal initiatives for cross-system communication, that is, occasions characterised by informal interaction and relationship-building without focus on a particular patient or a specific care issue to solve. Similarly, only few studies identified in the rapid literature review described relevant initiatives. Where studies mentioned initiatives, these were most often informal gatherings such as meet-and-greet lunches^{136–139} or training and didactic sessions for topics of shared interest.^{140–143} Other studies relied on a shared care facility promoting communication due to proximity.^{144–148}

Unintended consequences

While the literature cited many examples of the positive effects of care coordination, panellists also noted some unintended consequences. We differentiated between potential unintended consequences for patients and for healthcare professionals, and asked panellists to consider both perspectives. For professionals, panellists addressed *burden*, *role confusion*, *miscommunication* of health information leading to inaccurate care plans, *patients pitting healthcare professionals* against one another and *healthcare professionals pitting patients* against another professional.

For patients, panellists rated *ambiguity* of whom to contact for care needs, *uncertainty* of care processes, *mixed messages* from different professionals, *delays in care* (eg, professionals may wait to discuss care plans with each other first), *miscommunication* leading to misunderstandings, enhanced communication and collaboration *disliked by patients* (eg, patients not appreciating being the subject of discussion among providers), and *confidentiality concerns*. Although all items were rated as somewhat

important, none met the prespecified threshold, indicating that the item is ‘very important’.

Recommendations

A key aim of the stakeholder panel was to identify targets for research, practice and policy. Panellists rated a large number of potential recommendations shown in the online supplemental appendix. The recommendations were based on the reviewed literature and the panel discussions on the first panel meeting day.

Figure 3 documents the 10 research recommendations selected by the panel. Recommendations for research centred around needed data on and measures of shared care and workflow, the role of patients in care coordination and explorations into better understanding healthcare provider needs. Throughout the study, recommendations stressed that needs may well be different for different care scenarios (eg, frequency of likely coordination needs). Specifically, identified research recommendations targeted the development of *measures of shared care* between professionals in the main healthcare delivery system and the external healthcare professionals such as the proportion or absolute numbers of patients shared between two care providers. Further research is needed that *identifies coordination scenarios* in which the additional expense and time associated with team care are warranted. Studies should evaluate *patient experiences* of care coordination across separate healthcare delivery systems. We also need more information on the proper and improper *uses of patient engagement* to coordinate care, that is, to determine how much we should expect patients to participate in care coordination versus how much should be owned by the providers/systems caring for the patient. Studies are further needed to understand the *external professionals’ needs* and preferences better in relation to interfacing with the main healthcare delivery system’s services.



Figure 3 Recommendations.

Furthermore, organisations should evaluate *roles/responsibilities* of the main healthcare delivery system's clinicians, administrators, external care and third-party administrators, for example, look for gaps or overlap. To advance care coordination, we need to conduct ongoing, *real-time evaluation of changes* to care coordination processes being implemented in the field, given that care coordination and available tools is a fast-moving field. The panel also agreed that it is imperative that studies produce replicable *care coordination data and data validation*, such as organisations tracking referrals and follow-up. Furthermore, organisations should evaluate their *workflow practices* to ensure closed-loop communication. Finally, the panel agreed that evaluating the *comparative effectiveness* of interventions to improve care coordination is a research priority.

The panel also made eight recommendations that should be implemented in routine practice (see [figure 3](#)). Recommendations addressed education of healthcare professionals in the main healthcare system as well as educating the external providers. Specifically, panellists agreed that it is critical to educate main and external healthcare professionals *how to use the latest communication technology*, including electronic health information exchanges. Panellists also stressed that it is critical to ensure that external practices *keep communication options up to date*, including keeping contact details of the primary contact at the practice up to date. Furthermore, panellists agreed on the importance of determining the best *point of contact* phone numbers for different healthcare professionals, teams and clinics to be reached by external professionals, including embedding the contacts in the appropriate software so that they are seen by external care providers. Further recommendations included educating external healthcare professionals about patient demographics and the *care approach* in the main healthcare system (discussed examples included the use of opioids for pain management). The panel stressed that it is critical to educate the main healthcare delivery system providers about what the *roles and responsibilities* are for all parties involved with outside care coordination; multiple experiences indicated that roles and responsibilities are not always clear or do get lost over time. One concrete recommendation to increase local relationship-building activities that panellists agreed on was to *initiate team meetings/huddles for professionals of both healthcare delivery systems* that share a group of patients with complex care coordination needs, including determining which team members need to be involved in the meetings. Panellists also agreed that organisations should implement *quality improvement routines* such as audit and feedback to check that coordination mechanisms are working as intended. A final agreed recommendation was to *help patients better understand the pros and cons* of care within the main system and externally, in particular as patients may have unrealistic expectations about care options within or outside the healthcare system.

Finally, the panel prioritised five recommendations to direct policy (see [figure 3](#)). Panellists were aware that policy

recommendations are often a trade-off between multiple important goals, and the panel determined priorities for policy by taking into account that the selected recommendations will take precedence over other targets of policy. Agreed-on recommendations included increasing *investment in healthcare professionals' education* about the coordination challenges between healthcare professionals. Increasing *investment in healthcare professionals' education about tools* to support coordination between professionals was also agreed upon. Care coordination and available tools is a rapidly developing field, and using tools requires investing in practitioners to keep up with new developments. Panellists also agreed on dedicated time and *resources for care coordination training*. Further, organisations need to be prepared to *support time* for professionals with high patient overlap to engage regularly, for example, engaging in huddles and relationship-building activities between professionals. Finally, panellists agreed that policy makers should provide and *sustain support for care coordination resources* for high-need patients.

Policy recommendations included supporting time for professionals that have high overlap in patients and need to engage regularly, as well as sustaining support for care coordination for high needs patients. Such support can be reflected in workload credit, countering financial disincentives for care coordination and designating administrative staff to support providers who coordinate care.

DISCUSSION

The stakeholder panel successfully explored many different aspects of care coordination, and panel discussions resulted in concrete recommendations for research, practice and policy. Some recommendations are general in nature, while other recommendations address specific gaps in research, practice and/or policy identified in each of the three coordination scenarios included in our analytical framework. For example, the practice recommendation to initiate team meetings or huddles for professionals in both main and external healthcare systems to coordinate care for high-need patients addresses scenario 1 (the specific challenges in coordinating care of high-need patients across systems), whereas the research recommendation to develop measures of shared care between professionals in the main healthcare system and the external system addresses scenario 3 (coordination challenges associated with high system overlap in shared patients). Recommendations relating to scenario 2 (ad hoc communication between healthcare professionals across systems) were indirectly addressed by practice recommendations relating to keeping contact information up to date and educating providers in the main healthcare system and external systems about the latest communication technology.

It was noteworthy that despite the number of publications suggesting new tools with advanced, secure, online technology for sharing information between healthcare



professionals,^{14 33 35 50 65 73 88 102 104 122} professionals still rated phone calls as the most frequently used form of communication. This raises the question whether the mixed results seen in effects of health information exchange approaches¹⁴⁹ are in part attributable to professionals not being ready for the technology or, alternatively, that the technology is insufficiently user friendly. The broad range of communication mechanisms used by providers is also striking. Although some of this range may be responsive to differences in patient and coordination needs and urgency, this range may also indicate the lack of best practices or standardisation for communication, coordination and collaboration across healthcare systems.

The exploration of domains of care coordination showed that the organisational mechanism, the method of communication and the urgency of the communication are key components that influence care coordination. We specifically addressed support mechanisms and approaches to foster informal contact between coordinating professionals and identified approaches included shared events such as journal clubs that bring professionals together without directly discussing patients but potentially fostering relationships. These approaches need to be sufficiently attractive to draw healthcare providers in who tend to have already busy schedules (eg, offer continuing medical education credits). However, there are potential regulatory issues, given that the coordination is typically between two healthcare delivery systems, of which one serves as the external provider or 'vendor' offering additional care. Panellists stressed the importance of relationship-building activities towards improving care coordination for existing patients while avoiding the use of the meetings as a method of 'advertising' or 'marketing' by the 'vendors' (in particular, in the context of the VHA's government contractual obligations for an external community care network). Finally, although separate systems may view themselves as competing for patients, a growing shortage of healthcare providers may foster innovative approaches for collaboration across systems.

The panel discussed potentially unintended consequences of care coordination at length, which require thoughtful consideration yet do not preclude the need for improved care coordination. Panellists debated passionately whether issues such as administrative burden and role confusion are an indication of poor coordination, simply a result of receiving care from multiple care providers, or a challenge that coordination is precisely aiming to address. These discussions did point to the need for both patients and providers to consider the pros and cons of seeking care external to the main healthcare system. The proposed research methods will support eventual analyses to inform such considerations.

This work was exploratory and therefore subject to limitation. While we used a structured and framework-driven approach to stakeholder selection and convened a large panel with a broad range of stakeholders, undoubtedly, some perspectives of the complex care coordination

between systems will have been missed. In addition, the panellists were predominantly familiar with the VHA, Keck Medicine at the University of Southern California (USC) and the Los Angeles County+USC Medical Centre. Due to the small sample, we could not systematically explore differences in responses based on individual panellists' characteristics. The panel was informed by research evidence, but the rapid review showed a research literature that is dominated by care coordination within system, and there are numerous aspects of coordination between systems that make this field even more complex. We hope that future research will further investigate care coordination established across healthcare systems and different care delivery organisations.

Panellists selected recommendations from a large pool of potential recommendations. Any recommendation needs to consider that there are usually multiple competing goals for organisations. The current study purposefully refrained from assembling a long and unrealistic 'wish list', and panellists discussed barriers to implementing recommendations critically. The research recommendations aimed to provide explicit direction and outlined areas for which we have little information to date, including measures of shared care, the role of patients in care coordination and exploring healthcare provider needs. Some of the practice and policy recommendations may be aspirational for some organisations (eg, providing protected time for care coordination education); however, panellists took limited organisational resources into account throughout the process and prioritised recommendations to identify the most important steps to meaningfully improve and support care coordination across healthcare systems. Our 10 concrete recommendations for research, 8 for practice and 5 for policy makers provide the first step in better understanding of care coordination between systems.

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Patient and public involvement Patients and/or the public were involved in the design, conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants. The panel included health service providers, decision makers, research and community representatives including patients. The University of Southern California's institutional review board determined the study to be exempt. The participants gave informed consent to participate in the study before taking part.

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