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Original Research

Health Information Exchange Organizations and Their Support for Research: Current State and Future Outlook

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Abstract

Federal investment spurred health information exchange organization (HIO) development and maturation to provide third-party approaches to electronic health information exchange across disparate electronic health record (EHR) systems. By creating opportunities for data aggregation across multiple medical institutions, HIOs also spur research. Using data from a 2015 national web-based survey of HIOs (N = 64), we identified HIOs supporting or not supporting research, and compared characteristics of the 2 groups. We found that 15 (23%) of the 64 HIOs reported supporting research, 30 (47%) reported planning to support research, and 19 (30%) did not support research. Research-supporting HIOs were more likely than nonresearch supporting HIOs to offer advanced functionality, such as allowing users to query and retrieve data from multiple sources. Our study offers encouraging preliminary evidence that HIOs are supporting research, which could offer a solution to current challenges in creating comprehensive longitudinal clinical data sources for research.

Keywords

longitudinal patient data source, cross-institutional clinical information, health information systems, health information exchange, and health information organization

Background and Significance

Federal investment through the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act[1] spurred the development and maturation of health information exchange organizations (HIOs), which offer third-party approaches to enable electronic health information exchange (HIE) across disparate electronic health record (EHR) technologies. While some HIOs were in operation prior to the federal investment, the number of operational HIOs has grown steadily, from 32 in 2007 to 119 in 2012.[2,3] In parallel, medical institutions' participation in HIE has grown, with 11% of hospitals reporting engaging in HIE with unaffiliated providers in 2011,[4] increasing to 30% in 2014.[5]

The explosion of EHR implementation and growth of HIOs create opportunities for aggregating clinical data to support research. Much research has been published with EHR data as the primary data source, and researchers continue their efforts to evaluate the use of EHR data for research, develop tools and methods to address their limitations, and create guidance for EHR developers to incorporate necessary functionality for research in EHR systems.[6-10] A key challenge with using EHR data for research, however, is that the data needed to track care episodes are often distributed across multiple EHR systems, such that multiple systems need to be accessed to capture all relevant clinical data accurately. Because they connect providers with disparate EHRs in a community, HIOs can provide a mechanism to aggregate electronic health information across multiple medical institutions. In addition, as providers join HIOs to support clinical care, HIOs have an opportunity to foster research by supporting functions needed for research, and by engaging institutions that traditionally would not have provided data to support research, including many community-based hospitals, physicians' private practices, urgent-care centers, home health agencies, rehabilitation facilities, and nursing homes.

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However, leveraging HIOs for research comes with challenges common to sharing data across distinct institutions, as well as unique issues specific to the use of exchanged data for research. To exchange health information electronically, HIOs must accurately identify the patient and health care provider receiving the information, transmit the information according to recognized industry standards regardless of the sending and receiving EHR technology, and ensure appropriate safeguards for the privacy and security of the protected health information throughout the process. Leveraging HIOs for research requires additional functionality, including the ability to create data sets representing multiple patients across multiple institutions with differing data structures; to incorporate data standardization strategies that provide consistent representation of data among institutions; to de-identify health information when requested by data providers; to implement policies assuring appropriate use of data for research; and to create a governance model to review, approve, and monitor research requests. A recent systematic review of HIO research support found that only 7 HIOs were involved in published research that used HIO data to address a specific research question.[11] Two other recent systematic reviews that assessed use and impact of HIOs on the delivery and quality of health care found similar results: Only a limited number of HIOs supported research beyond the direct evaluation of the impact of exchanging data on clinical outcomes (eg, reductions in redundant testing).[12,13] These studies suggest that the research potential of HIOs has yet to be fully realized and point to the importance of ongoing assessment of the research capabilities of HIOs.

New Contribution

HIOs can be important partners in research, because they are a potential source of clinically relevant, cross-institutional clinical information. Since HIOs were developed to support the delivery of health care, information is shared synchronously, potentially decreasing the time and cost of providing clinical information to researchers. An assessment of the degree to which HIOs are willing and able to support research can serve to inform policymakers concerned with the development and sustainability of HIE. Promoting research using digital health data is an important policy priority. Insights into how HIOs are supporting research also serve to inform development efforts of other HIOs that are considering or planning support for research. HIOs' involvement in research could serve as a pathway to support their own sustainability, via the inclusion of important, multipurpose functionalities that increase the HIOs' value to a diverse array of stakeholders.

Objectives

The objectives of this study are to assess the extent to which HIOs in the US report supporting research, identify characteristics that differentiate HIOs that report supporting research from those that do not, and describe the specific infrastructure and policies used by HIOs that report supporting research.[14] Although the cross-sectional nature of the survey data does not inform assessment of causality, we hypothesized that HIOs reporting support for research would have more advanced technological infrastructure and functionalities, as well as more mature organizational infrastructure, compared with nonresearch supporting HIOs.

Methods

Data Source

We used data from a 2015 national survey of organizations that support clinical data exchange between independent entities. This ongoing national survey has been conducted 5 times between 2007 and 2015, with a high response rate (80% in the 2015 survey).[2,15,16] Full methodological details of the most recent (2015) survey, conducted between December 2014 and April 2015, have been described elsewhere.[14] The web-based survey was sent to the Executive Directors of organizations identified as supporting HIE, including all organizations from the 4 previous surveys, using Qualtrics, an online survey software. New organizations supporting HIE that emerged after 2012 were identified using Web searches as well as personal references and contacts. Consistent with previous iterations of the survey, HIE networks created by EHR vendors, such as Epic's CareEverywhere[17] and CommonWell Health Alliance,[18] were excluded.

Inclusion/Exclusion Criteria

The survey instrument included screening questions to ensure that the respondents met the definition of an HIO; inclusion criteria included facilitating or planning to facilitate the exchange of clinical data among entities with no shared financial structures or governance.[14] The 2015 survey included a new set of questions designed to characterize involvement in research. These questions included introductory text that defined research as "any investigation or analysis to address a specific question regarding patient or population health that is not part of the data exchange mission of the HIE effort, and is not used to support treatment/payment/operations/quality improvements." We also provided the following examples of research: "determining the use and effectiveness of a clinical treatment or intervention, or describing disparities and trends in the utilization of health services." For organizations responding that they support or plan to support research, additional questions determined the level of participation in research, existing restrictions related to their participation in research, and capacity to support researchers. Organizations indicating

Table 1. Organizational, Functional, and Delivery System Reform Support Characteristics of Health Information Organizations (HIOs).

Characteristic	N[a]	Number (%)	Supporting research, or planning to do so	Not supporting research	Chi-square *P* value
Total number of organizations	64	64 (100)	45 (70)	19 (30)	
Organizational demographics					
Independent organization	64	53 (83)	38 (84)	15 (79)	.60
Multiple competing entities can participate	64	36 (56)	27 (60)	9 (47)	.35
Duration of operation ≥ 5 years	59	35 (59)	23 (56)	12 (67)	.45
Participants cover 100% of operating expenses	64	39 (61)	25 (56)	14 (74)	.17
Functionalities					
Currently provides master patient index*	64	49 (77)	38 (84)	11 (58)	.02
Currently provides clinical data repository*	64	46 (72)	37 (82)	9 (47)	<.01
Query retrieves data from multiple other sources*	60	52 (87)	39 (93)	13 (72)	.03
Unidirectional messaging into electronic health record	60	53 (88)	36 (88)	17 (90)	.85
Unidirectional messaging into an inbox outside an electronic health record system	56	56 (100)	39 (91)	17 (90)	.88
Supports data level interoperability	63	52 (83)	37 (84)	15 (79)	.62
Currently provides provider directory	64	38 (59)	29 (64)	9 (47)	.20
Delivery system reform support capacity					
Provides technical infrastructure to support delivery system reform	64	31 (48)	25 (56)	6 (32)	.08
Provides data to networks or providers for their analysis	64	27 (42)	22 (49)	5 (26)	.09
Supports accountable care organizations	57	40 (70)	29 (74)	11 (61)	.31
Supports patient-centered medical home	55	39 (71)	29 (76)	10 (59)	.19
Integrates data from multiple sources	64	36 (56)	26 (58)	10 (53)	.70
Performs analytics	64	23 (36)	18 (40)	5 (26)	.30
Provides consulting on design or operations	64	20 (31)	15 (33)	5 (26)	.58
Incorporates technology and workflow redesign	64	30 (47)	22 (49)	8 (42)	.62
Can profile providers about cost or quality metrics	64	24 (38)	15 (33)	9 (47)	.29

[a]Respondents were not required to answer each question.
*$P < .05$.

that they do not plan to support research were not asked the questions related to research. To proceed with the remainder of the survey, respondents were not required to answer questions related to their support for research.

Sample

Of the 127 organizations that participated in the survey, 64 (50%) classified their organization as a HIO. Respondents were able to select multiple organizational types, including HIO, state government, state Medicaid agency, health care delivery organization, and academic institution. We limited our analyses to organizations that self-identified as HIOs, because we were interested in organizations whose primary mission is HIE. We included any respondent that self-identified as a HIO regardless of whether it was the sole selection or one of many.

Measures and Statistical Analysis

We created a dichotomous outcome variable reflecting whether HIOs reported supporting, or not supporting, research. We defined an HIO as supporting research if it allows exchanged clinical data to be aggregated and used for clinical, health services, or epidemiologic research. For this variable, HIOs indicating a plan to support research were also considered to support research. We then compared 20 characteristics between the 2 groups, using chi-square tests. We considered $P \leq .05$ to be statistically significant (see Table 1).

We determined the proportion of HIOs that reported that they support, or plan to support, research and then identified the characteristics that differentiate them from HIOs that reported that they did not support research and had no plan to do so. Statistical differences between the 2 groups were identified using chi-squared analysis with $P \leq .05$ classified as statistically significant. We examined 3 types of characteristics: organizational factors (eg, duration of operation), functional capabilities (eg, types of HIE that they support), and whether and how they support health care system reform (eg, providing technical infrastructure). Finally, for research-supporting HIOs, we described the extent to which they have in place any of 15 types of infrastructure and policies that specifically facilitate research (eg, data use agreements allowing use of HIO data for research). Statistical differences between HIOs supporting research and those planning to support research were identified using chi-squared analysis with $P \leq .05$ classified as statistically significant. The University of Michigan's Institutional Review Board (IRB) determined that this study was exempt from review.

Results

Fifteen (23%) of the 64 responding HIOs reported currently supporting research, 30 (47%) reported that they do not

Table 2. Research Infrastructure for Health Information Organizations (HIOs) Supporting, or Planning to Support, Research.

Characteristic	Number (%)	Involved in research	Planning to support research	Chi-square *P* value
Total number of organizations (denominator for percentages)	45 (100)	15 (33)	30 (67)	
Creates multi-institution data sets	40 (89)	12 (80)	28 (93)	.07
Creates de-identified data sets	38 (84)	13 (87)	25 (83)	.80
Data use agreements allow use for research*	28 (62)	14 (93)	14 (47)	.00
Research part of business model, strategic priorities, or mission	28 (62)	12 (80)	16 (53)	.08
Restricts direct interaction with system to employees of HIO or participating providers	28 (62)	9 (60)	19 (63)	.47
Evaluates requests from researchers on case by case basis	28 (62)	9 (60)	19 (63)	.28
Policies and procedures in place*	26 (58)	13 (87)	13 (43)	.01
Requires written data use agreement	25 (56)	10 (67)	15 (50)	.29
Permits data to leave the firewall	24 (53)	10 (67)	14 (47)	.12
Creates limited data sets that can be relinked to patients with their consent	23 (51)	9 (60)	14 (47)	.61
Requires approval by an Institutional Review Board	21 (47)	10 (67)	11 (37)	.06
Requires approval of research proposal from oversight body*	19 (42)	10 (67)	9 (30)	.02
Requires written approval from stakeholders	18 (40)	4 (27)	14 (47)	.20
Restricts access to data for research to participating stakeholders	6 (13)	2 (13)	4 (13)	.28
Requires approval from a specific, designated Institutional Review Board	4 (8.9)	2 (13)	2 (6.7)	.46

* $P < .05$.

currently support research but plan to do so in the future, and the remaining 19 HIOs (30%) do not currently support research and have no plans to do so, or are unsure of their future plans regarding research.

Organizational, Functional, and Delivery System Reform Support Characteristics

Table 1 displays organizational characteristics, differences in functionality, and support for delivery system reform efforts for the HIOs, based on their involvement in research. The HIOs have similar *organizational characteristics*. Most (83%) are independent organizations, more than half (56%) allow multiple competing entities to participate in the HIO, more than half (59%) have been in operation for at least 5 years, and almost two-thirds (61%) indicated that their participants collectively cover 100% of their operating expenses.

The two groups demonstrated statistically significant differences in three *functional capabilities*, with the 45 research-supporting organizations more likely to provide a master patient index (84% vs 58%, $P = .02$), a clinical data repository (82% vs 47%, $P \leq .001$), and the ability to query data from multiple other sources (93% vs 72%, $P = .03$), compared with the 19 organizations that do not support research. The remaining 4 functional capability measures did not differ between the 2 groups.

HIOs supporting research were also more likely to *support delivery system reform efforts* such as Patient-Centered Medical Homes (PCMH)[19] and Accountable Care Organizations (ACO)[20] which are 2 common strategies to coordinate care across the health care continuum, by providing technical infrastructure (56% vs 32%, $P = .08$) and by providing data to networks or providers for their analysis (49% vs 26%, $P = .09$). The remaining 7 delivery system reform measures did not differ statistically between the 2 groups.

Research Infrastructure

When we examined the research-specific infrastructure and policies in place within the 45 research-supporting HIOs, we found that some were widely adopted, whereas others were not. Table 2 shows specific policies and technical infrastructure capabilities between the 15 HIOs currently supporting research, compared with 30 HIOs planning to support research but not currently doing so. The most widely adopted infrastructure element was the ability to create multi-institution data sets (89%). Creating de-identified data sets (84%) was second most common. Four infrastructure elements were tied for the third most common element at 62%: incorporating the use of exchanged data for research in data use agreements; including research as part of the business model, strategic priorities, or mission; restricting direct interaction with the HIE technology to employees of the HIO or participating providers; and evaluating requests from researchers on a case by case basis.

Between the 2 groups, HIOs still in the planning phase were more likely to report having the ability to create multi-institution data sets (currently supporting, 80%; and planning to support, 93%, $P = .07$). Creating de-identified data sets was reported at similar rates for the 2 groups (currently supporting, 87%; and planning to support, 83%, $P = .80$). HIOs currently supporting research were significantly more likely to report incorporating the use of exchanged data for research in data use agreements (currently supporting, 93%; and planning to support, 47%; $P \leq .001$). Including research as part of the business model, strategic priorities, or mission (currently supporting, 80%; and planning to support, 53%;

$P \leq .1$) while restricting direct interaction with the HIE technology to employees of the HIO or participating provider (currently supporting, 60%; and planning to support, 63%; $P = .47$) and evaluating requests from researchers on a case by case basis (currently supporting, 60%; and planning to support, 63%; $P = .28$) were reported at similar rates.

The least commonly adopted infrastructure and policies were those related to requiring IRB approval from a specific, previously approved IRB (8.9%), restricting access to exchanged data to participating stakeholders (13%), written approval from stakeholders to use their data for research (40%), and approval from an oversight body to ensure that the research protocol is valid and appropriate (42%), although HIOs currently supporting research were much more likely to require approval from an oversight body (67% vs 30%; $P = .02$).

Discussion

HIOs can be important partners in research, because they are a potential source of clinically relevant, cross-institutional clinical information; nonetheless, there is little systematic data about their research capabilities. In this study, we found that more than 70% of HIOs reported that they currently support, or plan to support, research. Although less than a quarter (23%) of the 64 HIOs currently support research, a significant fraction of HIOs plan to support research (47%). Although we found that HIOs that support research did not differ from those that do not in terms of general organizational characteristics such as duration of operation and whether the HIO allows competing entities to participate, research-supporting HIOs were more likely to have advanced functional capabilities, as well as efforts to support reform of health care delivery, such as the development of ACOs and PCMH. Almost all of the HIOs supporting or planning to support research reported the ability to create multi-institutional and de-identified data sets, both important for research. Other complementary policies and infrastructure were also widely adopted; almost half of HIOs involved in research reported having data use agreements that allow the use of clinical information for research and have the necessary policies and procedures in place. Taken together, our results indicate that HIOs report being more involved in research than previously thought[11] and offer advanced capabilities that can create value beyond HIE for clinical care alone. Since our cross-sectional data cannot inform conclusions about causality, it is unclear whether an interest in supporting research is prompting HIOs to develop these enhanced capabilities, or whether HIOs that provided these capabilities for other reasons now recognize the opportunity to maximize the use of the capabilities by including support for research.

Supporting research might provide HIOs with a mechanism to create additional value for participating providers and partnering organizations. Health care providers can accomplish point-to-point HIE through their own EHR systems—using, for example, ONC's Direct protocol or HL7 interfaces directly connecting to data providers such as hospitals and labs. HIOs that can differentiate their role from these other options may thus be best positioned for sustainability. A 2014 systematic review found that measuring HIE's value was the fifth most cited barrier to its implementation.[21] Similarly, prior work based on this national survey found that 64% of respondents identified the "lack of agreement on what HIE [health information exchange] includes" as the most substantial barrier to progress.[14]

We examined whether HIOs supporting research were also more likely to support new models of care delivery under the hypothesis that some of the same capabilities may enable HIOs to support both use cases. Our survey found that HIOs supporting research also support these reform efforts by providing technical infrastructure, integrating data from multiple sources, providing analytical support, preparing data for networks to analyze themselves, and providing consultation about design or operational approach. PCMHs are certified by The Joint Commission, the accrediting organization for hospitals and health care systems, to signify that ambulatory practices meet "each patient's physical and mental health care needs, including prevention and wellness, acute care and chronic care" and are "coordinated across the broader health care system."[19] ACOs are networks of providers who work together to provide Medicare beneficiaries with coordinated care of high quality.[20] Supporting delivery system reform models such as PCMH and ACO requires an HIO to have a diverse network of participating institutions that send and receive a significant amount of electronic health information and maintain a robust technical infrastructure. Consistent with this, we found that HIOs supporting research, and a significant proportion of those planning to support it, can integrate health care data across multiple providers, perform health care analytics such as modeling and predictive analytics, and provide data to participating providers for their own analysis. That is, the ability to support research and the ability to support new models of care delivery have certain core HIE-related capabilities in common, so this association did not surprise us.

Supporting research requires high trust levels among participating providers for sharing their data with researchers. Medical institutions are stewards of their patients' health information, so HIOs must develop trust with and among their customers, to create appropriate exchange. HIOs must demonstrate to their customers that their technologies and procedures ensure that clinical data are handled consistently with respect to federally and state-mandated privacy and security protections for health information. Developing such trust takes time and, once established, could extend to additional sharing of health care data such as required to support research. Our survey results help to illustrate how this trust can be transformed into policies and infrastructure. Specifically, we found that most HIOs supporting research have invested in the implementation of policies and procedures governing research-related activities, have created data

use agreements that allow the use of exchanged data for research, and have established or work with oversight bodies to evaluate research proposals prior to receiving HIO support. This suggests that they are putting into place what is needed to ensure that they can enable research in a way that, in turn, helps to ensure customers' trust.

Some results surprised us. For example, we anticipated that 100% of the HIOs currently supporting research would require IRB approval, but only 46% responded that they did, and only 9% indicated that they required documentation from a list of preapproved IRBs. It is possible that a portion of the HIOs not requiring IRB documentation are at the initial stages of supporting research or limit their support to the provision of IRB-exempt, de-identified data sets of which almost all the HIOs report the capacity to create. Similarly, the supporting and planning-only HIOs differed in terms of whether they required approval from an oversight body, with 67% of supporting HIOs, and 30% of planning HIOs, having such a requirement in place. Oversight bodies are useful for reassuring provider organizations contributing health information to the HIO that research using their data has a valid foundation and that the researchers have provided plans to protect the confidentiality of the research participants and the safety of their data. We suspect that this result reflects a learning curve in which planning-only HIOs may not yet realize the value of the use of this institutional mechanism to review researchers' requests for data.

HIOs have an opportunity to complement existing efforts to make EHR data available for research.[22] Research is currently ongoing to determine whether the information collected and shared through HIOs results in an accurate, representative, and comprehensive foundation for clinical and epidemiological research activities.[12,23-28] Even if HIOs are found to be valuable research partners but not sufficient as a primary data source for research, the opportunity to facilitate aggregation of data across providers could address some of the limitations of current partnerships to share EHR data for research. For example, the Clinical and Translational Science Awards program that is funded by the National Institutes of Health and based at medical research institutions created a network of sites called Accrual to Clinical Trials, to share data and thereby improve recruitment for clinical research studies.[29] Similarly, the Patient-Centered Outcomes Research Institute created the PCORnet, a network that combines data available in EHRs with patient-generated data, to support clinical research.[30] New efforts are also emerging, such as the Strategic HIE Collaborative's Patient-Centered Data Home that seeks to facilitate HIE among HIOs that treat the same patient population, and because of their scale, these new efforts could prove even more valuable to support research.[31] With appropriate measures in place to ensure research participants' confidentiality, privacy, and informed consent, HIOs' participation in these efforts can greatly expand the number and types of health care organizations contributing health care data, and the pool of potential research participants, promoting greater generalizability of their findings.

Progress toward leveraging HIOs to support research could be sped by some key policy actions. First, updates to the Common Rule that make it easier to use data collected for health care delivery for research would facilitate the process for researchers requesting HIO data and reduce the administrative burden for HIOs managing these requests. Second, creating standard Data Use and Reciprocal Support Agreements would reassure data providers that such use of health care data meets human subject protections, complies with privacy and security standards, and adheres to terms and conditions broadly accepted as protecting the rights and interests of both the health care providers and their patients. Finally, efforts to standardize health care data stored electronically to support interoperability between health care providers would enable linking data from multiple data sources, a function beneficial to research, as well as directly address a key resource issue as HIOs currently manage data structures that are essentially unique to each data contributing organization.[32,33]

Our study has limitations. First, we relied on self-reported data and were not able to verify the accuracy of the responses independently. In addition, this was the first time that the survey included questions about research. Further work is required to understand the reliability and validity of these survey questions. While the same definitions were provided to all respondents, respondents were directors of HIO organizations and might not have had research training or experience. As a result, respondents' interpretations of the questions might have differed. An example of this might be the question related to IRB: respondents might have been uncertain about the nature of an IRB, its purpose, or its requirements, which could have contributed to the unexpectedly low number of HIOs that reported needing IRB approval. Second, given the cross-sectional design, it is not possible to know the temporality of the associations identified—Thus, we do not know whether these attributes preceded an interest in research, or vice versa. Third, the multiple independent statistical tests could have resulted in an increase in Type 1 errors. Finally, while the survey team incorporated multiple sources to identify all HIOs in the country, some might have been missed or might not have received the survey. Although only 20% of targeted HIOs did not respond to the survey, we do not know whether responders and nonresponders differed significantly.

This work describes the level of HIO support for research and identifies characteristics and barriers associated with this support. Future iterations of the survey should assess the reliability of the questions (eg, in test-retest evaluations), conduct further investigation into perceived barriers, and determine the reasons behind the decision of HIOs that do not support research. Engaging HIOs' Executive Directors in one-on-one interviews or focus groups could serve as complementary approaches to address these issues. Future research is also needed to confirm

that the reported administrative and technological infrastructure in place is functioning. In particular, it would be valuable to validate that a researcher can access HIO data, as well as assess the costs, restrictions, and limitations. It would also be useful to collect data that indicate whether an HIO facilitates the development of a multi-institution data set or whether the effort to use an HIO is comparable with securing data from each participating organization separately. Finally, further investigation into whether the information collected and shared through HIOs results in an accurate, representative, and comprehensive foundation for clinical and epidemiological research is needed.

Conclusion

In the first systematic effort to collect data about HIOs' support for research, we found that most responding HIOs reported supporting, or planning to support, research. Such support should result in additional value created by third-party approaches to HIE. Among HIOs that reported support for research, the types of research support that they offer likely vary. This was reflected in their infrastructure preparation and data use requirements. Policymakers pursuing the development and growth of HIE can use the results of this survey to promote HIOs' involvement in research as a mechanism to enhance the return on the federal investment in EHR systems and HIE. For those running HIOs, these results may inform the development efforts required to support research and increase the value provided by the HIO to its members.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: JAM serves on the advisory board for QPID Health. CP, MW, and MR have no conflicts of interest to declare. The views expressed in this article are those of the authors and do not necessarily represent the views of the US Department of Veterans Affairs.

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