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Survey of HIE Leaders: Assessment of HIE Research Participation and Perceptions

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**Survey of HIE Leaders: Assessment of HIE Research Participation and
Perceptions**

Brittany MacDonald, Kristin Rising, MD MS

Introduction: Health information exchanges (HIEs) allow for healthcare providers to effectively and securely access patient information from various healthcare networks. Some HIEs have acknowledged the important role they can play in research, however, this is not standard practice despite recognition that availability of research and outcomes data is a main limitation to evidence-based practice.

Methods: We created an electronic survey in collaboration with Health Share Exchange (an HIE in Philadelphia) with the aim of assessing HIE leader perceptions regarding the importance of and barriers to participation in research. The survey was disseminated via a Strategic Health Information Exchange Collaborative (the national association for HIEs) listserv that encompasses 70 HIEs in 49 states.

Results: Leaders of HIEs from Philadelphia, Georgia, Colorado, and Michigan responded to our survey (n = 4). All HIEs represented in this survey either participate in research currently or indicated an interest in participating in research, and all noted that they face barriers to participating in research, including (but not limited to) legal concerns, logistical barriers to sharing data, and reluctance from clients to allow sharing of data for research purposes. HIEs

that indicated the need for assistance with research participation noted that legal and policy-related support is needed to improve research participation.

Conclusions: The HIEs that participated in our survey indicated that although they are interested in participating in research, there are legal and logistical barriers that prevent them from doing so. Future work should survey additional HIEs across the U.S. and discuss solutions to the barriers acknowledged in this work.