Applying theory to characterize impediments to dissemination of community-facing family health history tools: a review of the literature

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Abstract

Uptake of community-facing family health history (FHH) tools to identify those at highest risk of disease and target prevention efforts has been consistently low. This review uses the diffusion of innovations (DOI) as a framework to organize the FHH evidence base and identify potential strategies to improve uptake of community-facing FHH tools. Methods for this literature review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines. We completed systematic searches in PubMed, Embase, and Web of Science databases for studies from 2009 to 2017 and hand searched bibliographies of relevant literature to identify additional articles. We abstracted and synthesized results, which were then organized by the DOI including the innovation–decision making process and characteristics of the innovation likely to influence diffusion (e.g., compatibility, relative advantage, complexity, trialability, observability). Of the 290 unique articles identified, 65 were eligible for full-text review after title and abstract screening; a total of 27 were included in the final abstraction. Eleven unique tools were identified. The most commonly used tool was the Surgeon General’s My Family Health Portrait ($n=9/27$). Only six studies directly evaluated participant perceptions shown to be associated with tool uptake. Studies tended to focus on improving compatibility by customizing tools to the target population’s needs and use of educational interventions. Results from this review suggest the need to evaluate strategies to increase the pace of uptake of community-facing FHH tools. These include pragmatic trials that compare different approaches to engage and evaluate participant perceptions of the relative advantage and complexity of tools. Ancillary support strategies may include collaborations with community networks to facilitate use and implementation study designs for rigorous evaluation.

Introduction

The use of family health history tools in clinical and community settings

Family health history (FHH) assessments are a well-established approach used to characterize genetic,

environmental, and behavioral risk factors shared among family members (Pyeritz 2012). FHH can identify those who may carry genetic mutations that greatly increase risk for inherited cancer and cardiovascular disease syndromes (Qureshi et al. 2009; Yoon et al. 2002), preventable disease (Moonesinghe et al. 2018; American Diabetes Association 2015; U.S. Preventive Services Task Force 2015), and non-preventable chronic diseases (Simmons et al. 2011; Falk et al. 2018; Haussmann et al. 2018). Accordingly, FHH assessment has been the frontline method for implementing evidence-based guidelines to refer high-risk subgroups to genetic counseling and genetic testing and, in turn, lifesaving prevention for mutation carriers (Pyeritz 2012; Guttmacher et al. 2004; Rose et al. 2004; Lucassen et al. 2001). FHH information also can inform tailored prevention and health promotion related to common chronic diseases (Qureshi et al. 2009; Yoon et al. 2002; Rich et al. 2004), and assist with interpreting variants of uncertain significance after genetic testing (Eccles et al. 2015).

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Traditionally, FHH information has been collected by health professionals as part of medical visits. However, patient's incomplete knowledge of their health histories and the time needed to collect FHH information are among the barriers health professionals cite for not collecting FHH information during office visits (Rich et al. 2004; Williams et al. 2011; American Medical Association 2018). In fact, a study that observed over 130 providers found that physicians spend under 3 min discussing FHH information. Only 51% of providers discussed FHH information during new-patient visits and 22% during established patient visits (Acheson et al. 2000).

Noting these barriers, a wide array of tools and initiatives have been developed and promoted nationally (Qureshi et al. 2009). These FHH tools and related awareness campaigns were aimed to facilitate collection of FHH information among individuals and family members outside of clinical settings (henceforth, community facing), improve translation of findings into public health action, and encourage dissemination of high-risk screening to the public (Valdez et al. 2010; Bates 2005). A systematic review published in 2011 identified 78 FHH tools and evaluated 47 of them for readability and complexity. Results indicated that most tools were written beyond the average reading level of individuals in the USA (Wang et al. 2011). With the proliferation of publically available tools, there have also been some efforts to catalog and evaluate quality, utility, and, importantly, the public's uptake and reach of these tools (Pyeritz 2012; Guttmacher et al. 2004; Welch et al. 2015a; Jackson Laboratory 2018; Global Alliance for Genomics & Health 2018). Indeed, past research has found that the majority of individuals believe that FHH is important to their health but also consistently show only a small proportion has actually collected health information from family members, and few (< 3%) have recorded this information using a FHH collection tool (Welch et al. 2015a; Awareness of family health history as a risk factor for disease—United States 2004; Yoon et al. 2003).

Previous reviews have predominately focused on characteristics of the tools themselves (e.g., quality and complexity of the tools) to identify tool-specific design characteristics that may reduce likelihood of adoption or use, evaluated tools designed to collect data for specific diseases, or focused on likelihood to adopt tools or improve uptake of FHH among providers in clinical settings (Wang et al. 2011; Awareness of family health history as a risk factor for disease—United States 2004; Kaphingst et al. 2012; Acheson et al. 2010). Relatedly, other research to explore the challenges of collecting FHH has emphasized the perceived difficulty in having conversations about FHH, family member's lack of willingness to disclose health issues to family members, and cultural and generational factors that shape health behavior and communication (Thompson et al. 2013; Malen et al. 2016; Thompson et al. 2015).

Overall, FHH research has largely been focused on barriers to clinical dissemination and atheoretical with few insights provided about how to address slow uptake of FHH. Well-accepted frameworks such as the diffusion of innovations (DOI) that offer insights into how to increase the pace of innovation dissemination have not been considered.

Applying the diffusion of innovations to explore FHH tool uptake

This review uses the DOI as a framework to organize the available evidence that could inform how to increase uptake of community-facing FHH tools. Accordingly, we reviewed the literature in alignment with key constructs of the DOI shown to be associated with the likelihood that, and pace at which, novel products are adopted by the public (Dearing 2009). The DOI holds that adoption of a new technology typically occurs along a predictable bell-shaped curve and begins with innovators (2.5% of the target population) which are followed by early adopters and the early majority. Eventually, an innovation reaches a saturation point at which it is considered ubiquitous and becomes self-sustaining; failed diffusion occurs when the innovation does not reach complete adoption by the population of interest.

Audiences targeted by the innovation pass through five discrete stages of adoption, beginning with awareness of an innovation through forming an attitude about the innovation. The movement between these stages involves a decision-making process of gaining knowledge, deliberating (persuasion and decision making), and acting (implementation and confirmation). Prior conditions such as previous experiences, felt need or problem, innovativeness, and interpersonal norms are thought to influence the decision-making process. Once an individual decides to take up an innovation, they may either continue to adopt or reject it until they reach the confirmation stage, which occurs when these adopters seek reinforcement for their decision or reverse their decision to adopt or reject the innovation. The final choice is the confirmation stage (either adoption or rejection) in which long-term adoption is achieved (Fig. 1).

Additionally, characteristics of the decision maker (e.g., socio-economic status, personality variables), innovation (e.g., relative advantage of the tool over alternatives, compatibility of the innovation with current lifestyle), and the adopter's perceptions about the innovation's characteristics influence both the likelihood and rate at which the innovation is adopted. Together, these elements of the DOI suggest important domains to consider when designing innovations for broad dissemination and help inform why innovations such as FHH tools may or may not be adopted.

Fig. 1 Innovation–decision making process. The *knowledge* stage occurs when an individual learns about an innovation and gains understanding about how it functions. This stage is influenced by the characteristics of the individuals making decision. Next, the *persuasion* phase occurs when an individual forms a favorable or unfavorable attitude toward the innovation. This process is influenced by the five innovation characteristics. Third, the *decision* phase occurs when an individual engages in activities that lead to a choice to adopt or reject the innovation. Adoption occurs when an individual proceeds with using the innovation as the best course of action. Rejection occurs when an individual does not adopt an innovation, which could be active rejection (tried it and decided not to adopt) or passive rejection (never

considered using innovation). Once an individual makes a decision, they will *implement* or use the innovation. At this stage, there may still be a degree of uncertainty about the innovation. Thus, there may be continued adoption or continued rejection based on the previous decision. It is also possible for an individual to move from adoption to discontinuance or an individual to move from rejection to adopting the innovation at a later point. Finally, *confirmation* occurs when an individual seeks reinforcement to the decision that they have already made or reverses their previous decision about adopting or rejecting the innovation if they are exposed to conflicting messages about the innovation. The final choice in the confirmation stage (adoption or rejection) will be the long-term effect.

One example of how the DOI has been used to understand poor uptake of innovations is in assessing the slow acceptance of e-health in primary care settings. The DOI framework suggests that adopters' perceptions that an innovation may have limited utility, be too complex, or lack relative advantage over existing practices can increase or decrease the rate of its adoption (MacVaugh and Schiavone 2010). Accordingly, poor uptake of e-health was influenced by patient's perceptions that e-health had low personal value and was incompatible with their needs (Zhang et al. 2015). Such findings suggest that greater effort should be taken to improve the perceived value of e-health and support rigorous research designs to evaluate different approaches to enhance uptake. Similar to findings in the e-health field, results from the present review could identify important gaps in the literature and provide opportunities for increasing the pace of uptake of FHH tools.

To this end, this review describes the community-facing FHH tool uptake by first systematically characterizing existing community-facing FHH tools and then summarizing research findings related to the use of these tools in step with the DOI framework. Specifically, we sought to consider the extent to which studies (1) considered adopter characteristics and progress through innovation-decision steps in the uptake of FHH tools, (2) described alignment of FHH tools with innovation characteristics known to increase uptake, and (3) measured users' perceptions of quality and utility of FHH tools.

Methods

Defining FHH tools as innovation

In this review, we consider community-facing FHH tools as the innovation. These tools were developed with the stated intention to be enhancements of standard clinic-based practice to collect FHH by reducing time burdens on clinical encounters, as well as improving comprehensiveness and accuracy (Welch et al. 2015b).

Data sources and searches

Methods for this literature review follow the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines (Liberati et al. 2009). We completed systematic literature searches in PubMed, Embase, and Web of Science databases for studies from January 2009 (since the previous FHH tool review (Wang et al. 2011)) to August 2017 (keywords included but were not limited to: family health history, family medical history, tool, questionnaire, instrument, survey) (see Supplemental Table 1 for full set of criteria). We also hand searched bibliographies of relevant literature to identify additional articles that were not captured in the initial database searches (Fig. 2). We used EndNote version X8 to organize and manage the review database.

Fig. 2 PRISMA statement

Study selection

The inclusion criteria for community-facing FHH studies were English language, published between 2009 (the year after the most current review) and 2017 inclusively, described a community-facing FHH tool, and used the tool to assess risk or to convey risk information to a target audience. Reviews, editorials, or reports that focused primarily on using FHH tools to identify prevalence of disease were excluded.

Using these criteria, we conducted initial title searches to identify articles to be included in abstract review. Next, one author (CGA) reviewed all titles and abstracts to identify those eligible for full-text review. Hand searches were completed during this phase to add relevant references to the abstract search. Finally, we completed full-text reviews to determine the studies to be included. Study selection and abstraction was completed by one reviewer (CGA) in consultation with a second reviewer (CMM), and all discrepancies were resolved through discussion and consensus.

Data extraction

We used the PICOTS framework to extract the following data from each article: aims/purpose, study population, methods/intervention, and study outcomes (Liberati et al. 2009). Studies were not explicitly required to cite DOI theory. DOI constructs were operationalized according to the definitions provided by Rogers to characterize the information available in the articles (Rogers 1962; Rogers 2003). For the purposes of this review, we extracted data about the individual adoption process, including knowledge, persuasion, decision,

implementation, and confirmation. We also identified study measures that indicated information about relative advantage of the FHH tool, compatibility, complexity, trialability, and observability. Additional extraction elements included details about the: target audience or population, how the tool was delivered (e.g., online, mailed, clinic), and indication of efforts to assess participant's perceptions of tool quality. One reviewer (CGA), trained in the systematic review process, coded all articles using MaxQDA qualitative software in consultation with other authors.

Operationalizing DOI constructs

Constructs from the DOI were operationalized using definitions derived from Rogers and agreed upon by the study team (Rogers 1962; Rogers 2003). The five stages of the innovation–decision making process were operationalized as follows: (1) *knowledge* was considered to be any mention of whether the individual in the study had previous knowledge of their FHH or had previously used FHH tools (i.e., previous exposure), (2) *persuasion* included attempts to demonstrate the value of using the tool or to assess whether participants were interested in knowing about the tool, (3) *decision* included mention of participant's engaging with the tool in order to decide whether to adopt or reject the innovation, (4) *implementation* was coded when an article described the ways participants used the tool once it was adopted (or rejected), and (5) *confirmation* was identified among studies that indicated adopters decision to continue using the innovation or not.

The innovation characteristics, which are influential in the innovation–decision making process, included the following:

(1) *relative advantage*: the degree to which the innovation was perceived as better than the idea it supersedes; (2) *compatibility*: the degree to which the innovation was perceived as being consistent with existing values, past experiences, and the needs of the adopters; (3) *complexity*: the degree to which the innovation was perceived as difficult to understand and use; (4) *trialability*: user's ability to test the tool prior to uptake; and (5) *observability*: the extent to which results or benefits of using the innovation were visible to adopters. We considered attempts researchers made to address each construct in the design of the tool, implementation of the tool or related intervention, and whether the research measured participant's perceptions about the DOI characteristic for each of the innovation characteristic.

Data synthesis and analysis

The results are organized by descriptions of included studies, characteristics of the tools, evidence of movement through the innovation–decision making process, tool alignment with innovation characteristics, and whether perceived quality and utility of tools are provided.

Results

Included study characteristics

We identified 447 articles (290 unique) from three databases (Fig. 2). Twenty-seven studies fit inclusion criteria for final data abstraction (Supplemental Table 2). One-quarter of studies were published in 2011 and another 25% in 2015. Study participants were primarily adults, with a small number of studies focused on adolescents and young adults (Foster and Smith 2015; Moore et al. 2012) and special populations such as Veterans (Arar et al. 2011; Hoyt et al. 2013). Some studies also focused exclusively on white participants (Acheson et al. 2010; Beadles et al. 2014; Buchanan et al. 2015; Newcomb et al. 2014; Orlando et al. 2016; Ruffin et al. 2011; Wallace et al. 2009), black participants (Murthy et al. 2011), or Hispanic participants (Kaphingst et al. 2011; Koehly et al. 2011). The number of participants ranged from 12 to 3876.

Most studies were cross-sectional and observational. Four compared multiple tools as part of the study design (Thompson et al. 2013) (Arar et al. 2013) (Moore et al. 2012) (Wang et al. 2015a), while the other 23 studies evaluated a single tool. Studies commonly introduced FHH tools as part of broader health-related interventions or education efforts (Thompson et al. 2013; Moore et al. 2012; Beadles et al. 2014; Newcomb et al. 2014; Ruffin et al. 2011; Wallace et al. 2009; Kaphingst et al. 2011; Imes et al. 2015; Orlando et al. 2013; Wang et al. 2015b), or assessed the impact of tool use on referrals and attendance to clinical

practice (Buchanan et al. 2015; Hulse et al. 2011; Murray et al. 2013; Wu and Orlando 2015; Yoon et al. 2009). Other studies used FHH as part of a broader risk assessment for multiple diseases (Orlando et al. 2016; Murthy et al. 2011; Koehly et al. 2011; Arar et al. 2013; Acheson et al. 2010).

Tools were primarily self-administered (i.e., not assisted by research assistant, or counselor) and were often a component of an intervention designed to increase discussion of FHH among participants or to improve the accuracy of FHH collection. Examples of delivery styles included: take-home assignments for students, part of FHH education sessions, and assistance from a lay health advisor or faith-based community nurse, web based, and delivered at a kiosk prior to clinical appointments. Fourteen tools were delivered electronically.

Description of community-facing FHH assessment tools

Among the 27 studies included, we identified 11 unique tools. The most commonly used tool was the Surgeon General FHH tool (My Family Health Portrait) ($n = 9$, 33%) (Arar 2011; Foster and Smith 2015; Kaphingst 2011; Newcomb 2014; Murray 2013; Wallace 2009; Arar 2013; Thompson 2013; Wang 2015a), which was developed in 2004 as a downloadable program to help organize family history information that could be printed and shared with a health care provider (Office of the Surgeon General 2016). The tool guides individuals to discuss FHH with their family members, enter health information, and save the information to be updated over time, and encourages sharing the information with family members.

Five studies used the Family Healthware tool ($n = 5$, 19%) (Ruffin et al. 2011; Koehly et al. 2011; Wang et al. 2015b; Yoon et al. 2009; Acheson et al. 2010), which was developed to help individuals learn about their risk, activate a personal prevention plan, and screen for early detection to help lead a healthy lifestyle. Family Healthware was initially developed by the Centers for Disease Control and Prevention and tested in primary care settings at three institutions. This web-based application collects familial risk information for six diseases and offers users a prevention plan and personalized recommendations using a Familial Risk Stratification algorithm (National Human Genome Research Institute 2016). In addition to a detailed health risk assessment and customized health score and screening recommendations, Family Healthware offers a personal prevention plan and subscription to a newsletter.

Five studies used MeTree ($n = 5$, 19%) (Beadles et al. 2014; Buchanan et al. 2015; Orlando et al. 2016; Orlando et al. 2013; Wu and Orlando 2015), which is a patient-facing

web-based tool designed by the Duke Center for Applied Genomics and Precision Medicine. In addition to collecting information on over 20 different diseases, the tool also directs the user to collect personal history on health behaviors in order to calculate risk scores (e.g., Framingham risk score). Results of the tool are intended to provide clinical decision support to medical providers and can be integrated into certain electronic health records.

Other studies ($n = 9$, 33%) developed and tested their own unique FHH collection tools: for example, a questionnaire to be used among veterans (Hoyt et al. 2013), questions delivered by a virtual counselor (Wang et al. 2015a), a tool called Health Heritage (Cohn et al. 2010), and the Family SHARE workbook (Koehly et al. 2015), among others (Moore et al. 2012; O'Leary et al. 2011; Murthy et al. 2011; Imes et al. 2015; Hulse et al. 2011). User engagement post-collection included providing risk assessments, direct linkage to electronic medical records for clinical decision support, and online engagement with continued opportunities to update health information. Diseases commonly assessed by these tools included coronary heart disease, stroke, diabetes, and ovarian, breast, and colon cancer.

Study findings informing the innovation–decision making process related to FHH tools

Our first research question addressed use of the innovation–decision making process, which involves five steps: knowledge, persuasion, decision, implementation, and confirmation.

Acquisition of *knowledge* about an innovation is the first step in the innovation–decision making process (Table 1). Most studies did not mention whether the participants had previous knowledge of FHH, any prior exposure to FHH tools, or had previously collected FHH information. Ability to use technology and trust in technology was assessed and found to be important in acquiring knowledge about FHH for tools that required computer access (Acheson et al. 2010; Arar et al. 2011; Buchanan et al. 2015; Arar et al. 2013).

Nineteen studies (70%) discussed the *persuasion* stage of innovation–decision making, or attempts to demonstrate the value of the tool to potential adopters. For example, Koehly (2015) aligned elements of their tool (Family SHARE workbook) with the Health Belief Model constructs to help improve the likelihood the tool would be of interest to the participants (Koehly et al. 2015). The workbook included information about risk factors for focal diseases (perceived severity), beliefs about the chances of getting a condition (perceived susceptibility), beliefs about the effectiveness of actions to reduce risk (perceived benefits), and strategies for initiating FHH-based risk reduction (cues to action) as part of a comprehensive evaluation effort. These strategies led to high levels of understanding and engagement with the workbook.

The next phase of the innovation–decision making process (the *decision* to adopt the innovation) was mentioned in 16 studies (59%). Some studies directly solicited feedback from participants about their experiences using tools (Kaphingst et al. 2011) (Murray et al. 2013). These studies showed that participants indicated a high percentage of reported use of the tool (Koehly et al. 2015) (Wallace et al. 2009) (Imes et al. 2015). For example, one study incorporated pre-post knowledge, attitudes, practice questionnaires, and a satisfaction survey as part of the overall evaluation. This study found that the FHH intervention was perceived to be feasible and acceptable Arar 2013. Additionally, a community study of individuals in Texas engaged to use My Family Health Portrait online tool found the majority felt like the items on the tool were easy to understand, that categories were relevant to their health (92%) and the tool was useful (97%) (Arar et al. 2011).

Some studies reported disadvantages of the tool that could impact individual's decision to use it. These included concerns about maintaining privacy and confidentiality, and not perceiving uptake to have personal value (Acheson et al. 2010; Arar et al. 2011). For example, semi-structured interviews with veterans using the Surgeon General tool showed that participants who were less likely to use the tool perceived the lack of privacy and confidentiality and unfamiliarity with relative's FHH were impediments (Arar et al. 2011).

Implementation was identified in seven studies (26%). These studies mentioned implementation in the context of future research opportunities to improve supporting systems (Wu and Orlando 2015) (Yoon et al. 2009) (Wallace et al. 2009) and broaden outcomes assessed (e.g., behavior changes over time) (Arar et al. 2013). Supplemental educational sessions appeared to enhance implementation and helped improve understanding of risk (Imes et al. 2015) and their ability to communicate with family members about FHH (O'Leary et al. 2011). Another study found that delivery by lay health workers was an effective way to implement My Family Health Portrait and improved the likelihood of implementation compared with standard delivery of FHH information (Kaphingst et al. 2011). Only two studies reported poor implementation as indicated by participants' perceptions that there was little added value in having the tool available (Newcomb et al. 2014) and no observed changes in patient's self-reported provider communication about FHH (O'Leary et al. 2011). Additionally, studies reported a lack of behavioral changes related to FHH (e.g., did not influence willingness to share feedback, did not increase likelihood to discuss FHH with family).

Confirmation was included in only one study (4%), which compared face-to-face instruction (intervention) to informational handout (control). A post-test FHH survey was sent 3 months after the intervention. This survey evaluated participant's recall of information about the

Table 1 Innovation–decision making process

Author (year)	Knowledge	Persuasion	Decision	Implementation	Confirmation
My Family Health Portrait					
(Arar et al. 2011)	✓	✓	+	0	0
(Foster and Smith 2015)	0	✓	0	0	0
(Kaphingst et al. 2011)	0	✓	+	+	0
(Murray et al. 2013)	0	0	0	0	0
(Murthy et al. 2011)	0	✓	+	0	0
(Newcomb et al. 2014)	0	✓	+	–	+
(Wallace et al. 2009)	0	✓	+	+	0
Family Healthware					
(Acheson et al. 2010)	✓	✓	–	0	0
(Koehly et al. 2011)	0	0	–	0	0
(Ruffin et al. 2011)	0	✓	0	0	0
(Wang et al. 2015b)	0	0	+	0	0
(Yoon et al. 2009)	0	✓	0	+	0
MeTree					
(Beadles et al. 2014)	0	0	0	0	0
(Buchanan et al. 2015)	✓	✓	0	0	0
(Orlando et al. 2013)	0	0	0	0	0
(Orlando et al. 2016)	0	✓	0	0	0
(Wu and Orlando 2015)	0	✓	+	+	0
Multiple tools (comparisons)^					
(Arar et al. 2013)	✓	✓	+	0	0
(Moore et al. 2012)	0	0	+	0	0
(Thompson et al. 2013)	0	0	+	0	0
(Wang et al. 2015a)	0	✓	0	0	0
Other tools*					
(Cohn et al. 2010)	0	✓	0	0	0
(Hoyt et al. 2013)	0	0	0	0	0
(Hulse et al. 2011)	0	✓	–	0	0
(Imes et al. 2015)	0	✓	+	+	0
(Koehly et al. 2015)	0	✓	+	0	0
(O’Leary et al. 2011)	0	✓	+	–	0

Knowledge: previous exposure or awareness of innovation (✓/0) where ✓ represents studies that included mention of knowledge assessment and 0 represents studies without mention of knowledge. **Persuasion:** efforts to persuade, formation of opinion (✓/0) where ✓ represents studies that included mention of persuasion and 0 represents studies without mention of persuasion. **Decision:** decision to adopt innovation after considering advantages, disadvantages (+/–/0) where + means study included a measure of decision and to use the tool was positive, – means study included a measure of decision and it was negative, and 0 indicates that study did not measure decision. **Implementation:** finalize decision to continue or discontinue use of innovation (+/–/0) where + means study included measure of implementation and it was positive, – indicates that study included measure of implementation and it was negative perception, and 0 indicates that study did not include measure of implementation. **Confirmation:** final decision to continue using innovation to full potential (+/–/0) where + means study included measure of confirmation and it was positive, – indicates that study included measure of confirmation and it was negative, and 0 indicates study did not include a measure of confirmation.

*Does it Run in the Family/Genetic Alliance Toolkit (O’Leary), Health Heritage (Cohn), independently developed FHH tool for Vietnam-era Veterans (Hoyt), Our Family Health (Hulse), My Family Medical History and Me (Imes), Families SHARE workbook (Kohley)

^Surgeon General, Does it Run in the Family (Thompson), “A Guide to Family Health History” and “A Guide to Understanding Genetics and Health” (Moore); Surgeon General, Virtual Genetic Counselor (Wang); GRACE program and Surgeon General (Arar, 2013)

My Family Health Portrait, use of the tool, and beliefs about the value of FHH information (Newcomb et al. 2014). Individuals in the intervention were more likely to state that they had heard of the tool and state that they

had written down and stored family health information after the intervention, indicating continued use.

Alignment of FHH tool properties with innovation characteristics

Our second research question was to identify the alignment of tool properties with the innovation characteristics known to increase uptake: relative advantage, compatibility, complexity, trialability, and observability.

Among the five innovation characteristics discussed by DOI, the *relative advantage* of a community-facing FHH tool was most commonly referenced ($n = 17$, 63%) (Table 2). In an effort to improve the tools' perceived relative advantage among users, researchers frequently attempted to enhance or automate previous tools (Acheson et al. 2010; Orlando et al. 2016; Arar et al. 2013; Orlando et al. 2013; Yoon et al. 2009; O'Leary et al. 2011). Other studies evaluated whether supplemental educational modules improved uptake. For example, Beadles (2014) conducted a hybrid type two implementation-effectiveness controlled clinical trial where individuals entered FHH information, received educational materials about FHH, and then updated FHH components in the tool. Efforts to improve perceptions of relative advantage included the tool being self-administered with built in real-time risk stratification and decision support. These efforts led to improved uptake and accuracy of FHH collection for cancer risk management.

Compatibility was also commonly referenced ($n = 11$, 41%). Efforts to improve tool compatibility included cultural adaptation, language translation, and customization of the tool to be community oriented (Moore et al. 2012; Murthy et al. 2011; Koehly et al. 2011; Arar et al. 2013; Orlando et al. 2013; Hulse et al. 2011; O'Leary et al. 2011). For example, one study provided booklets in collaboration with community partners. These booklets were developed based on an oral history method mimicking storytelling as a strategy to better understand individuals' experiences in describing, archiving, and telling their own health story (O'Leary et al. 2011). Data collection included usability questions that aligned with the compatibility construct of the DOI (e.g., "Did the booklets apply to your family?"). Only 50 of the 304 participants agreed that the booklets apply to their family demonstrating low levels of compatibility.

Attempts to lessen *complexity* of tools also were made. Several studies aimed to simplify tools by lowering reading level and applying plain language design features (Moore et al. 2012; Koehly et al. 2011; Wang et al. 2015a). These adaptations were frequently attributed to specific target group needs (e.g., using a lower reading level, plain language, or translating the tool to Spanish) and were perceived by users to be improvements. Examples of data collected about complexity included feedback from focus groups consisting of the target community's preferences regarding specific elements of a tool.

Trialability was not commonly described. In one study, participants were allowed to examine the tools prior to choosing which they would use (Wu and Orlando 2015). Two studies included measures related to *observability*: one publically provided the results of a previous evaluation of the tool (Murray et al. 2013) and the second mentioned user's prior observations of the tool. In both instances, FHH tools were well perceived as indicated by positive reactions and affirmation about utility of tool among participants.

Perceived quality of tools developed

Finally, we identified how often studies measured user perceptions of the quality and utility of the tools. Six studies (22%) included an evaluation of individual's perceived quality of FHH tools (e.g., satisfaction, user experience) (Thompson et al. 2013; Arar et al. 2011; Koehly et al. 2011; Imes et al. 2015; Wu and Orlando 2015; Koehly et al. 2015). These measures assessed facilitators of use, whether the tool enabled an accurate representation of the family, information seeking intentions spurred by the tool, and specific reactions to the tool (e.g., ease of use, ease of understanding). For example, one study determined perceived quality of the tool by assessing the likelihood of sharing information collected with a health care provider (Koehly et al. 2011). Other studies assessed the quality of the tool over another tool or previous practice and whether the tool was considered easy to use, understand, and navigate (Thompson et al. 2013; Wu et al. 2015). Although participants had positive reactions to the tools, these perceptions did not necessarily lead to better uptake of FHH information. For example, Thompson (2013) found that tools were perceived as collecting useful information and were considered to be of high quality but less than one-third of participants used the tool (Thompson et al. 2013).

Conclusions

Our goal was to review the evidence related to possible ways to improve the pace of uptake of community-facing FHH tools. We used the DOI framework to organize our review, as it is well accepted for guiding expectations about the uptake of innovations. We identified 11 unique FHH tools (2009 to 2017, inclusively) that were developed to improve upon clinic-based FHH collection.

Search criteria and inclusion and exclusion criteria used in this review were intentionally broad to allow for inclusion of a wide array of FHH tools, interventions, and evaluation methods. Despite efforts to be inclusive in our review, results showed that intervention studies about FHH tools were largely not designed to answer questions about FHH tool adoption or

Table 2 Innovation characteristics

	Compatibility		Relative Advantage		Complexity		Trialability		Observability	
	Attempt	Perception	Attempt	Perception	Attempt	Perception	Attempt	Perception	Attempt	Perception
My Family Health Portrait										
(Arar et al. 2011)	0	+	0	0	0	+	0	0	0	0
(Foster and Smith 2015)	0	0	✓	0	0	0	0	0	0	0
(Kaphingst et al. 2011)	0	0	0	0	0	0	0	0	0	0
(Murray et al. 2013)	0	0	0	0	0	0	0	0	✓	0
(Murthy et al. 2011)	✓	0	0	0	0	0	0	0	0	0
(Newcomb et al. 2014)	0	0	0	+	0	+	0	0	0	0
(Wallace et al. 2009)	0	0	0	0	0	0	0	0	0	0
Family Healthware										
(Acheson et al. 2010)	0	0	✓	0	0	0	0	0	0	0
(Koehly et al. 2011)	✓	0	✓	0	✓	0	0	0	0	0
(Ruffin et al. 2011)	0	0	✓	0	0	0	0	0	0	0
(Wang et al. 2015b)	0	0	0	0	0	0	0	0	0	0
(Yoon et al. 2009)	0	+	✓	0	0	+	0	0	0	0
MeTree										
(Beadles et al. 2014)	0	0	✓	0	0	0	0	0	0	0
(Buchanan et al. 2015)	0	0	0	0	0	0	0	0	0	0
(Orlando et al. 2013)	✓	0	✓	0	0	0	0	0	0	0
(Orlando et al. 2016)	0	0	✓	0	0	0	0	0	0	0
(Wu and Orlando 2015)	0	0	0	0	0	0	0	0	0	+
Multiple tools (comparisons)^										
(Arar et al. 2013)	✓	0	✓	0	0	0	0	0	0	0
(Moore et al. 2012)	✓	0	0	0	✓	0	0	0	0	0
(Thompson et al. 2013)	0	+	0	+	0	+	✓	0	0	0
(Wang et al. 2015a)	✓	0	✓	0	✓	0	0	0	0	0
Other tools*										
(Cohn et al. 2010)	0	0	✓	0	0	+	0	0	0	0
(Hoyt et al. 2013)	0	0	✓	0	0	0	0	0	0	0
(Hulse et al. 2011)	✓	0	✓	0	0	0	0	0	0	0
(Imes et al. 2015)	0	0	0	+	0	0	0	0	0	0
(Koehly et al. 2015)	0	0	0	0	✓	+	0	0	0	0
(O'Leary et al. 2011)	✓	0	✓	0	0	0	0	0	0	0

Attempt: mention of researcher's efforts to address this element of DOI in the design of the tool, implementation of tool, or intervention. *Perception*: mention of measurement of participant's perceptions about the DOI characteristic. Attempt (✓), positive perception (+), negative perception (−), or none included (0). *Compatibility*: degree to which innovation is perceived as being consistent with existing values, past experiences, and needs of potential adopters. *Relative advantage*: degree to which innovation is perceived as better than the idea it supersedes. *Complexity*: degree to which the innovation is perceived as difficult to understand and use. *Trialability*: degree to which innovation may be experiments with on a limited basis; ability to try out before adopting. *Observability*: Degree to which results of innovation are visible to others.

*Does it Run in the Family (Genetic Alliance Toolkit) (O'Leary), Health Heritage (Cohn), independently developed FHH tool for Vietnam-era Veterans (Hoyt), Hulse (Our Family Health), My Family Medical History and Me (Imes), Families SHARE workbook (Koehly), independently developed three-question FHH assessment

^Surgeon General, Does it Run in the Family (Thompson); "A Guide to Family Health History" and "A Guide to Understanding Genetics and Health" (Moore); Surgeon General, Virtual Genetic Counselor (Wang); GRACE program and Surgeon General (Arar, 2013)

uptake. Given the notable slow uptake of FHH tools in clinical and public health settings (Welch et al. 2015a; Awareness of family health history as a risk factor for disease—United States

2004; Yoon et al. 2003), it is surprising that there was little effort across studies to identify factors that might inform next steps for improving FHH tool uptake.

In contrast to the DOI framework, study designs did not routinely consider target audiences' perceptions about the innovation characteristics (e.g., relative advantage, compatibility, complexity). In fact, tools tended to be designed without consideration of perspectives from audiences intended to use them. Even among studies that used the most commonly cited and well-established Surgeon General's Family Health Portrait, addressing participant's perception of innovation characteristics of the tool were often not considered. Given the expansive literature supporting the DOI framework's conception of steps in optimal dissemination of innovations, the poor alignment between FHH tool deployment strategies, and constructs within the DOI shown in our review could, in part, explain the slow uptake of these tools.

Among the few studies that addressed tool characteristics in line with the DOI's innovation characteristics, researchers used cultural adaptation, language translation, and customization to help ensure the tool was appropriate for target users and was community oriented. Although some efforts were made that align with specific DOI constructs, few studies included appropriate measures to help understand whether they had achieved their goal (i.e., cultural adaptation) within the target population. Indeed, there is much opportunity to enhance both the use of DOI constructs and measurement of these efforts in future interventions designed to increase FHH tool use.

According to the DOI, one of the biggest obstacles to overcome related to uptake is an individual's uncertainty about engaging with a new innovation, which can be addressed through consideration of the compatibility of the tool with user needs (Noar et al. 2007; Qureshi et al. 2009; Acheson et al. 2006; Benjamin et al. 2003). Interventions included in our review that added educational modules tended to show increased engagement, uptake, and interaction with family members. Indeed, a growing body of literature supports the notion that brief educational modules that emphasize the utility of FHH to health can improve self-efficacy in collecting the information and increase the likelihood that individuals will engage in FHH conversations and tool use (Thompson et al. 2015; Rodriguez et al. 2016). Results of a few studies suggest that educational modules may help improve diffusion and uptake of FHH tools. Future research could extend these findings by comparing FHH interventions that include educational modules to adaptations that address other DOI constructs to assess which yields the highest uptake.

Further consideration should be given to differences in electronic versus paper administration of FHH tools on uptake. Currently, the majority of community-facing tools were designed to be self-administered online. Previous studies have found slow uptake of e-health tools in general, due to low literacy, lack of internet use, and poor perceptions of the utility of these technologies among targeted users (Zhang et al. 2015). The studies we reviewed did not assess factors related to electronic administration. This is particularly important as

e-health technologies likely would greatly increase the reach of FHH tools. Additionally, electronic administration can enable targeting to align with where an individual is along the innovation–decision making process. Another consideration would be for tools to be aligned with innovation characteristics that are most concerning to the user. For example, if perceptions of relative advantage (e.g., usefulness of completing FHH versus not completing FHH) were a major barrier to uptake, it would be possible for the electronic tool to be responsive to this concern and provide tailored education about the value of FHH prior to completing the tool.

DOI is joined by several other theories and conceptual models that could guide the future development and implementation of community-facing FHH tools (Nilsen 2015). The growing fields of dissemination and implementation science could inform the design, implementation, and evaluation of community-facing FHH tools. Prior studies have found an underutilization of dissemination and implementation science principles in developing tools and interventions for population health, calling for more convergence across health care, precision medicine, and implementation science (Roberts et al. 2017a; Chambers et al. 2016; Roberts et al. 2017b). Framing future development of FHH tools and interventions using DOI or other implementation theories would provide a more systematic way to understand slow uptake. In the long term, theory-based approaches could improve researcher's abilities to adapt tools to more closely fit the needs of the target users and implementers.

This review is not without limitations. First, our review only included tools that were part of published literature; this means that tools included only in gray literature may have been excluded. Additionally, we did not assess the quality of the FHH information collected using selected tools. This information would be particularly important when considering the utility of the commonly used tools, as most tools to date have not been formally evaluated and validated. Future studies may seek to confirm the validity of information collected as it relates to uptake using a framework like the ACCE model that has been applied in translation research related to genetic tests for use in clinical care (Valdez et al. 2010; Berg et al. 2009; Centers for Disease Control and Prevention 2010).

In light of these limitations, this review provides important information that could guide efforts to improve dissemination of community-facing FHH tools and, in turn, increase uptake of FHH tools. The DOI framework provided a useful structure for summarizing existing knowledge of participant perceptions of current tools to elucidate new strategies that could advance efforts to promote FHH taking among the public. Promoting the uptake of FHH at the population level will require addressing dissemination challenges, including enhancing tool design features, addressing public perceptions about the tools, and developing interventions that support interpersonal communication among family members about the

sensitive information needed for a complete and accurate FHH assessment.

Going forward, pragmatic study designs that enable rigorous evaluation drawn from dissemination and implementation science could be applied in order to more robustly consider constructs of the DOI framework. Additionally, we suggest that studies evaluating FHH tools include conceptually based process measures, and where possible standardize these measures, that can inform improvements in their approach in enhancing the FHH dissemination process.

Taken together, this review highlights gaps and opportunities to increase the reach of community-facing FHH tools. These efforts are greatly needed to realize the potential benefits of population screening to identify those at highest risk for preventable health conditions.

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Compliance with ethical standards

This is a review of existing literature. No informed consent was required.

Conflict of interest The authors declare that they have no conflicts of interest.

Human rights This article does not contain any studies with human participants performed by any of the authors.

Welfare of animals This article does not contain any studies with animals performed by any of the authors.

Informed consent This study does not involve human participants and informed consent was therefore not required

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