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Let's Get Healthy! Health Awareness Through Public Participation in an Education and Research Exhibit

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Abstract

Background—Health information technology (HIT) offers a resource for public empowerment through tailored information.

Objective—Use interactive community health events to improve awareness of chronic disease risk factors while collecting data to improve health.

Methods—*Let's Get Healthy!* is an education and research program in which participants visit interactive research stations to learn about their own health (diet, body composition, blood chemistry). HIT enables computerized data collection that presents participants with immediate results and tailored educational feedback. An anonymous wristband number links collected data in a population database.

Results and Lessons Learned—Communities tailor events to meet community health needs with volunteers trained to conduct research. Participants experience being a research participant and contribute to an anonymous population database for both traditional research purposes and open-source community use.

Conclusions—By integrating HIT with community involvement, health fairs become an interactive method for engaging communities in research and raising health awareness.

Keywords

Education; nonprofessional; community health research; community-based participatory research; rural population; health care technology assessment; health care evaluation mechanisms health care quality; access public health

Health fairs provide opportunities for the public to gather information and undergo screening for a variety of common medical conditions.^{1–5} However, traditional health fairs are often limited in the range of topics they reach, their ability to tailor information to individuals, and the ability for communities to use the resulting screening information to improve community health. Although health fairs provide a valuable resource for collecting

data for scientific purposes,^{2,3,6} their value in facilitating community–research partnerships remains largely unexplored.

Lack of time and resources are common challenges for developing and sustaining community research partnerships.⁷ HIT may provide an inexpensive framework for targeted resource delivery and rapid data collection.⁸ The field of consumer health informatics highlights the role of HIT and using computers to provide individuals with tailored health⁹ Tailored, personalized information stimulates greater cognitive activity than standard health education information¹⁰ and is increasingly used to support health education and research in community settings.⁸

This paper describes how communities and research organizations can leverage health fairs and HIT to develop ongoing partnerships through the collection of population-level data that community groups can use. A health fair model can allow communities to tailor their event experience to address local needs,¹¹ and a flexible technology platform supports the event framework, provides interactive learning, facilitates assessment of health knowledge, and supplies immediate feedback on health results. The resulting data collected at health events could then be used to by community groups to improve local health as part of ongoing community–research partnerships. Thus, with the addition of HIT, the health fair can become a fun and interactive method for engaging communities in research.

METHODS

Development of Nutrition World

The initial impetus for an interactive health education and research exhibit stemmed from a preserved body exhibit at the Oregon Museum of Science and Industry (OMSI) in 2007. Oregon Health & Science University (OHSU) hosted a series of educational displays at OMSI,¹² one of which was an interactive nutrition exhibit (developed by MKI, JQP, and JS, a pharmacist, endocrinologist, and nutritional epidemiologist, respectively). This exhibit—originally titled *Nutrition World*—was designed to engage the public in learning how human participation in research advances science. The exhibit invited attendees to enroll as research participants and learn about the quality of their diet, body composition, and cardiovascular risk factors while contributing anonymously to a population database. This database was originally intended to help investigators describe eating habits and body size as they relate to chronic disease risk and particular genetic profiles in the population. A key feature of *Nutrition World* was that it provided participants with immediate feedback based on their measurements and responses to questionnaires, so that both participants and scientists would leave the event with useful information to improve health. All education and research activities were reviewed and approved by the OHSU Institutional Review Board (IRB; protocol #3694). *Nutrition World* recruited participants from a subset of attendees at the OMSI exhibit. Attendees aged 4 years and older were eligible to participate. Each attendee was given an age-appropriate information sheet. If they assented to participate, they received a color-coded wristband imprinted with a random barcode number. The barcode number anonymously linked all collected data in a database as participants visited research stations in any order.

Research Modules and Tailored Feedback

At the entry kiosk, participants scanned their wristbands and entered their age, gender, race, and ethnicity. They could then visit the following voluntary research stations, scanning their wristband at each to link all collected data.

- *Dietary Assessment.* A short, computer-based diet screener (<5 minutes) resulting in immediate, tailored feedback based on age (Nutrition Quest).¹³ This station used

questionnaire responses on the frequency and consumed portion sizes of various foods to provide estimates of daily intake of fat, fiber, fruit, vegetables, and—for children under 18 years—sugar-sweetened beverages.

- *Body Composition.*— Height was measured by a trained volunteer using a portable stadiometer (SECA 213), and waist circumference was determined using a measuring tape held at the navel. Weight, body fat percentage, and body mass index were calculated using a Tanita scale (TBF-410GS) with precision within 0.2 lb (0.1 kg). The Tanita uses bioimpedance to determine percent body fat given a measured height. All measurements were recorded by a trained volunteer. Participants received immediate feedback based on national recommendations.^{14–17}
- *Blood Chemistry.* Adult participants (aged 18 years) could obtain blood pressure, nonfasting blood glucose, and lipid level measurements (total cholesterol, high-density lipoprotein cholesterol, calculated low-density lipoprotein cholesterol, and triglycerides). Because of the frequently noisy background environment, two Spacelabs model 90207 automated blood pressure cuffs were used in addition to manual auscultation. Blood glucose and cholesterol measurements were obtained through a fingerstick assessment (Cholestech LDX). This station was developed in partnership with the OHSU/Oregon State University College of Pharmacy. A data collection form modified from a previous program¹⁸ assessed cardiovascular risk factors and medications. Individuals received personal consultation by a medical professional to discuss their results according to national recommendations.^{19–21}
- *Salivary (Buccal Cell) Sample Collection.* Adult participants (aged 18 years) had the option of providing an anonymous saliva sample for future genetic research. Because these samples were linked through the wristband number, genetic associations between dietary intake and physiologic measures could be assessed. Interested participants swished with 10 mL of Scope Original Mint mouthwash for 30 seconds to slough cheek cells.²² The mouthwash was then returned to 50 mL conical tube and frozen (–20°C) within 24 hours of collection. DNA could then be extracted from the sample (Gentra Puregene Buccal Cell Kit; Qiagen, Hilden, Germany) and stored (–80°C) for future analyses.

Ongoing Community Interest Prompts Community Partnerships

Although the exhibit was intended only as an academic week-long venture, the popularity of *Nutrition World* at OMSI prompted invitations from various community groups to bring the program to local health fairs. OHSU's Community & Practice Research Program provided seed money to make *Nutrition World* a travelling community research program. The hope was to make data collected through the exhibit available to investigators, students, or others with approved research proposals. Rural community requests by health organizations, churches, and community centers stimulated further expansion. Furthermore, a series of 12 previously developed museum exhibits related to nutrition and physical activity^{23,24} were miniaturized in collaboration with OMSI and made portable for future outreach. The anticipated growth of the program to areas outside of nutrition prompted a name change to *Let's Get Healthy!* in 2009. The Health Discoveries Program was formed at the same time to run the exhibit, maintain IRB and regulatory compliances in place since program inception, and manage the resulting data from *Let's Get Healthy!* events. In collaboration with OHSU's Oregon Rural Practice-based Research Network (ORPRN) program,²⁵ which has a long history of working with rural Oregon communities to develop research programs based on community participation and interest,²⁶ two of ORPRN's long-term community partners were identified who would implement the academic exhibit in community settings.

A community representative selected by the community (often a nurse or health care administrator) helped to implement events at local sites (often using school gymnasiums as a venue). An information packet provided station descriptions and a sample of possible offerings. Program staff and community representatives then worked together to tailor the event. Communities identified a date and location that would pair the 4- to 6-hour health event with another widely attended community event (e.g., cancer screenings, bicycle repair and rodeo, fitness events, annual health fairs). Communities also identified local health issues important to them (e.g., head injury prevention, alcohol awareness, cancer prevention, improving access to care) so that additional groups could be included (e.g., local police/fire departments, regional educational programs, low-cost clinics, support groups/centers).

OHSU staff initially ran the exhibit; however, with more frequent events and longer distances to travel, the program worked with the IRB to develop a new model of inviting community volunteers to run the exhibit. Central to this development were training procedures and protections for both volunteers and participants. An online registration form (Wufoo) allowed program staff to manage applications of volunteers who wanted to serve as researchers at local health fairs. Although all volunteers were accepted, their applications enabled staff to place volunteers at appropriate stations based on their interest, background, and age. *Let's Get Healthy!* staff brought equipment and supplies and trained community volunteers before the event. Training lasted approximately 1 hour and included research ethics (Responsible Conduct of Research), maintaining privacy (Health Insurance Portability and Accountability Act), and training on the volunteer's assigned research station. Volunteers signed Individual Investigator Agreements, which allowed community volunteers to be approved community researchers that were covered under OHSU's Federalwide Assurance,²⁷ an agreement that provides ethical oversight for federally funded research. After each event, volunteers were sent an online, anonymous survey link to assess their research experience.

A secure, firewalled, and SSL-encrypted server stores all anonymous data, with access managed by Health Discoveries Program staff under a companion repository protocol (OHSU IRB# 7068). After each event, summary data are returned to the community for use in identifying health issues and/or developing community grants. Researchers and community organizations interested in accessing all or a portion of the raw data must submit a signed data use agreement with instructions for use. Because the data are completely anonymous, users do not need additional IRB approval for its use.

RESULTS AND LESSONS LEARNED

Study Design

A total of 6,827 people participated in the *Nutrition World/Let's Get Healthy!* cross-sectional study from July 2007 through May 2011. Although the health fair model is often used as an education-only event, Table 1 illustrates that HIT-based health fairs such as *Let's Get Healthy!* can be used to rapidly collect community-level data and reach a broad audience. Demographic characteristics of the dataset are comparable to the state of Oregon,²⁸ although this model could be applied to deliver resources to target populations. The frequency of station participation was not greatly affected by age, gender, race, or ethnicity, suggesting that individuals felt comfortable participating in the voluntary research regardless of their demographic background. Efforts to better understand participant comfort with anonymous human subject research are ongoing.

The health fair/event format has been very popular, with 26 events held in response to 71 community requests. Organizations requesting the event were typically public health or advocacy groups (e.g., churches, community centers, health organizations). Event requests

are now managed with a free online tool (Wufoo), with priority given to underserved sites with high health need, as determined by obesity rates, low socioeconomic status, and limited access to health care. With increasing number of requests, however, it has become clear that an application system to match communities with a finite number of events is needed. These efforts are currently in development and overseen by the program's advisory board, whose members represent community, research, school, bioinformatics, and public health perspectives.

Although *Let's Get Healthy!* has been used primarily as a cross-sectional data collection tool, it has also been used as a recruitment tool for longitudinal and prospective cohort studies, one of which has concluded²⁹ and two more of which are ongoing. The program's ability to incorporate new education and research modules (e.g., sleep, cancer risk, and cognitive assessments) has increased appeal to participants and provided additional linked data for scientist and community use. To date, the data are being used by 11 scientists, 9 communities, and 7 students. Efforts to tailor the program to include culturally relevant material are underway in collaboration with a local health and service center and the program is now available in five languages. The ability to leverage the HIT applications of this program to select participants at high risk for chronic disease to enroll them in targeted interventions remains an unexplored application of this work.

Community Participation in Research Planning and Data Collection

Although the exhibit began as a short-term academic venture, the health fair format provided unexpected opportunities for developing partnerships. Community groups are familiar with the health fair format, which allows organizers to be involved in the planning process from the very beginning. In addition to being comfortable with the format, community organizations knew that their community members would receive immediate feedback and that the organization would receive the anonymous research data after the event, all of which supported initial collaboration activities and fostered partnership development. Because health fairs are often viewed as education only, it is critical that community organizations and the public are well-informed that research is to be conducted. Failure to adequately inform individuals has the potential to erode initial trust needed for long-lasting partnerships. To aid in this endeavor, a venue agreement form is provided with the information packet that must be signed by the head of the organization to acknowledge that research can occur. This, together with the assent process described in the methods, helps to ensure all parties are aware of the research aspect of the health fair model.

Communities now have full autonomy in determining the content of their events, including which research stations and other partnering groups they want to include. *Let's Get Healthy!*'s modular format has enabled 22 resource groups to partner with the program, thereby leveraging the educational, logistical, and financial resources of multiple public health programs. These partnerships include education programs with a statewide mission (e.g., Area Health Education Centers, university extension services, health promotion programs) as well as new research programs who leverage *Let's Get Healthy!*'s HIT and programmatic infrastructure to conduct separate research studies. To date, four researchers have developed new IRB-approved protocols, covering research areas of orthopedics, cognition, and cancer prevention. All use the HIT infrastructure provided by the wristband number to link demographic data with their own data collection components. Again, as the communities determine the content of their event, no research occurs without community invitation.

In addition to planning their event, community members participate in the collection of their anonymous local data. Through 2011, 314 individuals volunteered with *Let's Get Healthy!*, representing a wide variety of backgrounds as community members (44%), health

professionals (35%), and/or students (56%, predominantly undergraduate). This inclusion of community members in the data collection process has been particularly valuable in rural locations, which often lack opportunities for individuals to conduct or participate in research. A total of 92 volunteers have completed the post-fair survey. Of the 81.5% who were first-time volunteers ($n = 75$), most agreed or strongly agreed that they felt well-trained to manage their station (89.2%) and would volunteer again (91.0%). These data highlight initial first steps needed for transferring ownership to community partners.

Community Use of Data

It is often expensive and time-consuming to collect research data in communities. The ability of *Let's Get Healthy!* to use HIT to rapidly and inexpensively collect population-level data for use by communities and scientists alike has been an appealing motivator for community organizations who are interested in assessing local health indicators to determine where to devote efforts and resources. In the first year, the rural community of Madras, Oregon (population 6,046; 51.4% non-Hispanic White),²⁸ partnered with OHSU to write a community health grant using their collected data. Although this community was familiar with the research process through ongoing partnerships with ORPRN and other community-based participatory research projects,²⁶ the majority of other visited communities have been new to the research process. One such community in Canby, Oregon (population 15,829; 74.7% non-Hispanic White),²⁸ reported that *Let's Get Healthy!* did "a phenomenal job creating an interesting, interactive presentation; this was just what we were looking for and so much more." The demographics of the Canby community are comparable with the population-level data shown in Table 1 as well as the state of Oregon.

Although community requests have typically been for a single event to assess local health, the popularity of *Let's Get Healthy!* with the public has resulted in most communities requesting return events, with several communities requesting the exhibit to visit annually. The health fair model likely provides the familiarity and comfort needed to engage new communities in research. Moreover, it provides an unanticipated benefit of helping to develop the initial trust needed to develop ongoing research partnerships with communities. The extent and sustainability of these new partnerships remain to be seen, because a challenge of implementing the health fair model has been to balance ongoing collaborations with additional requests from new communities. Assuming limited resources, this will continue to be a challenge as the number of requests for events steadily increases. Moreover, it remains to be seen the extent to which community groups are able to use the resulting data. Although summary statistics are provided and program staff answer community questions on an individual basis, there is not yet a formal mechanism for assisting communities with transforming and interpreting the raw data. ORPRN can connect communities with researchers to aid in this endeavor and develop new projects; however, this currently remains an unexplored partnership opportunity.

CONCLUSION

Health fairs often take place in communities, yet are largely unexplored as a tool for developing community–research partnerships, especially when paired with HIT. *Let's Get Healthy!* represents a new method for catalyzing community–research partnerships and builds on the process of community-based decision making. Communities implement their own HIT-based health events to raise awareness about health issues while collecting anonymous local data that can be used for grants and to inform policy decisions that improve public health within the community. Community members are able to explore the process of human subject research (as volunteer researchers and as research participants) and directly benefit from implementation of research in their community. Thus, an HIT-

based health fair model can provide a fun and interactive method for engaging communities in research.

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Table 1
Demographics of Participants Completing *Let's Get Healthy!* Research Modules

	Entry Station <i>n</i> (%)	Dietary Assessment <i>n</i> (%)	Body Composition <i>n</i> (%)	Blood Pressure <i>n</i> (%)	Blood Chemistry <i>n</i> (%)	DNA Sample <i>n</i> (%)
Gender						
Female	3,874 (56.7)	1,924 (57.2)	1,978 (58.1)	1,312 (57.9)	626 (64.3)	795 (63.4)
Male	2,953 (43.3)	1,440 (42.8)	1,424 (41.9)	953 (42.1)	347 (35.7)	459 (36.6)
Age (yrs)						
< 18	3,970 (58.2)	1,847 (54.9)	2,008 (59.0)	1,347 (59.5)	0 (0)	0 (0)
18	2,857 (41.8)	1,517 (45.1)	1,394 (41.0)	918 (40.5)	973 (100.0)	1,254 (100.0)
Race						
White	5,191 (76.0)	2,600 (77.3)	2,619 (77.0)	1,776 (78.4)	760 (78.1)	1,028 (82.0)
Asian	303 (4.4)	183 (5.4)	158 (4.6)	118 (5.2)	52 (5.3)	66 (5.3)
Black	159 (2.3)	66 (2.0)	88 (2.6)	32 (1.4)	27 (2.8)	31 (2.5)
> 1 Race	356 (5.2)	197 (5.9)	184 (5.4)	112 (4.9)	26 (2.7)	21 (1.7)
Other	181 (2.7)	92 (2.7)	69 (2.0)	49 (2.2)	23 (2.4)	28 (2.2)
No answer	637 (9.3)	226 (6.7)	284 (8.3)	178 (7.9)	85 (8.7)	80 (6.4)
Ethnicity						
Hispanic	771 (11.3)	303 (9.0)	270 (7.9)	179 (7.9)	88 (9.0)	88 (7.0)
Non-Hispanic	2,964 (43.4)	1,422 (42.3)	1,540 (45.3)	1,119 (49.4)	175 (18.0)	205 (16.3)
No answer	3,092 (45.3)	1,639 (48.7)	1,592 (46.8)	967 (42.7)	710 (73.0)	961 (76.6)
Total	6,827 (100.0)	3,364 (49.3)	3,402 (49.8)	2,265 (33.2)	973 (14.3)	1,254 (18.4)

Note. Percent of participants completing each station was calculated based on total through entry booth ($n = 6,827$). Demographics for station participation were calculated based on total participation for each station. Twenty-six events were held in 15 communities between July 2007 and May 2011. The data suggest that the HIT-based health fair model can rapidly collect data from participants of all ages, genders, races and ethnicities. No individuals under age 18 years were permitted to participate in the blood chemistry or DNA sample stations.