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At Your Own Risk: User-Contributed Flu Maps, Participatory Surveillance, and an Emergent DIY Risk Assessment Ethic

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ABSTRACT

In this article, the author proposes that the emergence of digital, disease-tracking applications over the past ten years like HealthMap (healthmap.org) and Flu Near You (flunearyou.org) that allow non-experts to contribute information about emergent public health threats have facilitated a “do-it-yourself (DIY)” risk assessment ethic. Focusing in particular on Flu Near You (FNY), a crowdsourced, flu-tracking program, the author argues that some participants use the mapping feature to curate their own risk information experience in determining the preventative behaviors they may want to engage in (if any) to prevent flu. As outbreaks of infectious diseases increase (Smith et al., 2014), mHealth technologies like disease-tracking apps are evolving as an important risk assessment tool for both public health experts as well as non-expert, public audiences. Better understanding how non-experts use such information can inform not only the design of these apps but visual risk communication strategies more generally speaking.

Categories and Subject Descriptors

H.0 Information Systems: General

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Human Factors, Design, Documentation

Keywords

Visual rhetoric, mHealth, disease-mapping, risk communication, health apps, public health, data visualization

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PRACTITIONERS' TAKE AWAYS

- Risk communication research has long recognized fundamental differences in the ways that experts and non-experts perceive risk. Yet non-experts are still often assumed to be passive recipients of risk information.
- Crowdsourced, disease-tracking applications like HealthMap (healthmap.org) and Flu Near You (flunearyou.org) allow non-experts to contribute select health-related information about risks as well as access this information, which some Flu Near You participants use to curate their own risk information experience.
- Better understanding how non-experts use such information to conduct their own DIY risk assessments can inform not only the design of these apps but visual risk communication strategies more generally speaking.

INTRODUCTION

Following its inception in the 1980s, risk communication research initially focused on developing language-based strategies for conveying information about risks to non-expert audiences. Within the next couple of decades, however, increasing attention was directed toward visuals—more specifically, graphics that represent quantitative information about health-related risks (see Lipkus & Hollands, 1999; Ancker et al., 2006). Many of these studies have lent insight into the ways that non-experts perceive such information. Yet much of this research has also tended to position readers/viewers as merely passive recipients of risk information, playing no role in its collection, assembly, and/or construction.

In this article, I suggest that the emergence of digital, disease-tracking applications over the past ten years like HealthMap (healthmap.org) and Flu Near You (flunearyou.org) that allow non-experts to contribute information about emergent public health threats have facilitated a “do-it-yourself (DIY)” risk assessment ethic. Driven by the proliferation of social media and the widespread sharing of personal information as well as the increased emphasis on preventative medicine (e.g., Office of Disease Prevention

and Health Promotion, 2017), such programs do not replace risk information created by professionals. Rather I propose that non-experts use the information provided by these apps to enact agency over their risk assessment of some communicable and infectious diseases like flu. In making this argument, I focus in particular on the user-contributed mapping feature of Flu Near You (FNY), a crowdsourced, flu-tracking program. Drawing from select results of a user survey administered by the program and used in this article with permission, I argue that some respondents use the maps to curate their own risk information experience in order to determine the preventative behaviors they may want to engage in to prevent flu (if any).

As outbreaks of infectious diseases increase (Smith et al., 2014), mHealth technologies like disease-tracking apps are evolving as an important risk assessment tool for both public health experts and non-expert, public audiences. For instance, the World Health Organization describes its Zika app as “[d]esigned primarily for health care workers and responders” but also “a source of real-time information for the general public.” (WHO, 2017a). Better understanding how non-experts use such information can inform not only the design of these apps but visual risk communication strategies more generally speaking.

MHEALTH TECHNOLOGIES, SURVEILLANCE, AND FLU NEAR YOU

The proliferation of mHealth or mobile health technologies has enabled non-experts to collect, share, and evaluate personal health-related information in unprecedented ways. For instance, wearable health and fitness trackers allow users to monitor not only physical health indicators like diet, activity, and sleep but, in some cases, sophisticated mental health metrics like stress (e.g., Bellabeat’s Leaf, a smart jewelry device for women) and ‘mindfulness’ (e.g., iPhone’s Health app).

Many of these health-related behaviors and practices—diet and activity, for instance—have been linked to whether individuals develop chronic health conditions like diabetes, hypertension, and/or cardiovascular disease. Arguably increased attention to one’s health-related behaviors and practices increases awareness of potential health problems. Consequently, by using the applications linked to these devices, in theory, users can make better health-related decisions like eating a healthy diet and getting sufficient exercise, for instance, which can then mitigate their risk of developing many chronic health conditions as well as help them achieve and/or maintain better health overall.

These personal trackers provide information that individuals can use to manage their health, while other mhealth technologies allow users to contribute to and access health-related information about populations. For example, digital applications/programs that track infectious and communicable diseases like HealthMap (healthmap.org) and Flu Near You (flunearyou.org) solicit voluntarily contributed information directly from the public. HealthMap also collects information from other sources as described on their About page: www.healthmap.org/ site/about. Users can access HealthMap and Flu Near You (FNY) via each program’s website or smartphone app. HealthMap, for instance, encourages users to submit reports about potential outbreaks, which are then reviewed for veracity. Viewers can access the program’s global map of public health alerts that have been reported such as outbreaks of infectious and communicable diseases and instances of food-borne illnesses,

for example, as shown below in Figure 1. Each alert appears on the map as an individual dot. Users can view a list of alerts on the right hand side of the screen, which are classified by category—vectorborne, respiratory, and animal, to give a few examples—and the specific type of disease within each category. For instance, the vectorborne category includes Dengue Fever, West Nile Virus, and Malaria as well as the number of reports for each disease. Viewers can also zoom in on locations of interest and click on each dot to see more information about each alert as shown in Figure 2.

On the other hand, FNY, as the program’s name suggests, collects information from people in the United States, Canada, and Puerto Rico about a specific illness: flu symptoms that they may be experiencing. Created by a group of public health researchers and information technology professionals, FNY users agree to participate by registering via e-mail and providing select demographic information—gender, birth month and year, and zip code. Users then receive a weekly notification via e-mail and/or the program’s smartphone app prompting them to report any flu symptoms they and/or their family members (if users report for family members) may have experienced the week before such as sore throat, fever, cough (see Figure 3).

Both of these mHealth technologies—health and fitness trackers, and digital disease-tracking applications—involve participants actively monitoring or ‘surveying’ select health-related behaviors and practices. Indeed the term surveillance has been used in critical scholarship on mHealth technologies from a Foucaultian perspective (1977) to interrogate the ways that closely monitoring one’s body (or the body of someone else) creates a dissociative, objectifying gaze that enacts particular kinds of power relationships (e.g., see Ferenbok, Mann & Michael, 2016; Lupton, 2015; Lupton, 2012).

Surveillance, too, Elden (2002) argues in his analysis of themes across Foucault’s work, played a fundamental role in the creation of “a disciplinary society,” which he proposes is enacted “not in the total institution of the prison, but in the realm of public health” (p. 240). More specifically, surveillance practices during the eighteenth and nineteenth centuries were enacted to better understand in hopes of mitigating the spread of infectious and communicable diseases in hopes of mitigating their spread, which served to facilitate the institutionalization of medicine as well as establish control over the population. Indeed as Rosen (1993) puts in *A History of Public Health*: “Understanding the nature and cause of disease provides a basis for preventative action and control” (p. 85). Ultimately monitoring health-related practices and behaviors—either at the individual level by using personal health and fitness trackers or in the population by using disease-tracking apps—acts as a mechanism to control those practices and behaviors.

In public health today, however, the term has a very specific meaning that is fundamental to the discipline, referring to “the continuous, systematic collection, analysis, and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice” (WHO, 2017b). In other words, surveillance is a method of collecting data; it is the planned and ongoing process of gathering information about health-related activities among humans in order to make decisions designed to improve public health. To briefly illustrate, surveillance alerted public health officials to the potential link between microcephaly and Zika in the Western hemisphere in 2016. Surveillance also demonstrated a relationship between seat belt use and the reduced incidence of car accident-related injuries and deaths in the latter part of the twentieth century, leading to mandatory seat belt laws.

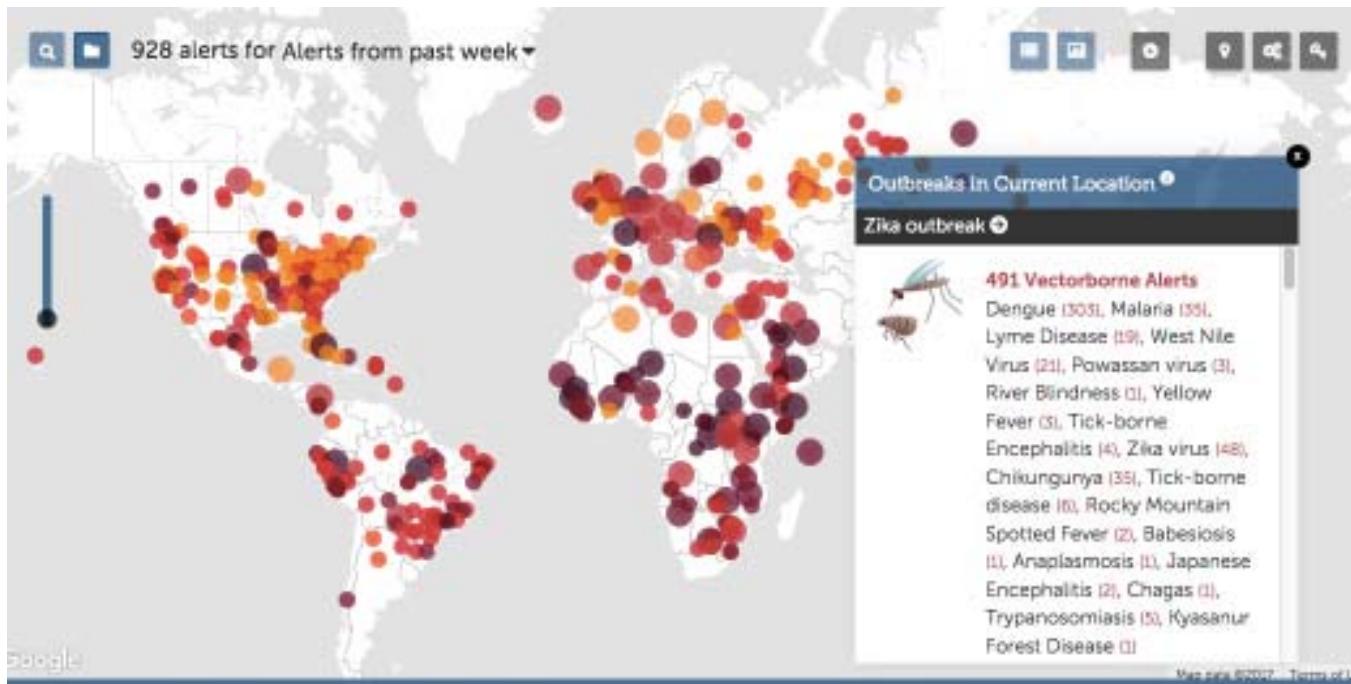


Figure 1. Screenshot of HealthMap homepage; used with permission.



Figure 2. Detail of HealthMap's homepage showing alerts in the Southeastern United States; used with permission.

Considered from a critical perspective, public health surveillance practices are not neutral. Indeed researchers who track information about Zika or car accident-related injuries and deaths make decisions about what information to ‘survey,’ how to survey it, and whom to survey (inclusion/exclusion criteria). The methodology of any research initiative shapes the ways that data are collected, analyzed, and subsequently interpreted, which in turn influences how public health risks are evaluated and the kinds of public health decisions that are made.

CDC conducts flu surveillance throughout the year from a range of data sources including lab reports, state health departments, and physician and hospital records (CDC, 2016a). However, reporting can be incomplete because not everyone who gets the flu is treated—in other words, not all cases get reported, and CDC’s flu reports are usually published about two weeks after information has been collected (Baltrusaitis et al, 2017).

Programs like FNY and HealthMap are forms of participatory surveillance, meaning that information about a particular public

Back

Flu Survey

Welcome Back

Did you experience flu-like symptoms this past week?

Symptoms include:

- Fever
- Nausea
- Diarrhea
- Night sweats
- Fatigue
- Vomiting
- Body aches
- Headache
- Cough
- Sore throat
- Chills
- Short breath

Yes

No

Health Report

06/20/2016 - 06/26/2016

Did You experience any of these symptoms since last Monday (06/20/2016)

I did not have any of the symptoms listed below

or

<input type="checkbox"/> Fever	<input type="checkbox"/> Cough
<input type="checkbox"/> Headache	<input type="checkbox"/> Sore throat
<input type="checkbox"/> Diarrhea	<input type="checkbox"/> Body aches
<input type="checkbox"/> Fatigue	<input type="checkbox"/> Chills/night sweats
<input type="checkbox"/> Nausea or vomiting	<input type="checkbox"/> Shortness of breath
<input type="checkbox"/> Rash	<input type="checkbox"/> Eye pain
<input type="checkbox"/> Yellow skin/eyes	<input type="checkbox"/> Joint/bone pain
<input type="checkbox"/> Red Eyes	<input type="checkbox"/> Dark, tea-colored urine

Submit

Flu Near You 2015 Terms & Conditions Privacy Policy

Contact Us: flunearyou@healthmap.org

[f](#) [t](#) [g](#)

Figure 3. Weekly flu survey; mobile app interface (left) and website (right; used with permission.)

health-related activity, event, or threat is collected directly from the population affected (or potentially affected), which can offer potentially useful supplementary information. For example, in the 1960s during the smallpox eradication campaign in rural areas of Africa where the virus was still endemic, healthcare workers often solicited information from local people about possible cases so they could focus their vaccination efforts in areas where the virus appeared to be spreading (see Foege, 2011).

Participatory surveillance efforts do not replace traditional surveillance systems. Indeed as FNY's developers have stated: "Although many established systems have the benefits of specificity and credibility, participatory systems offer advantages in the areas of speed, sensitivity, and scalability" (Smolinski et al., 2015, p. 2124). The program, they argue, "has the potential to serve as a viable complement to existing outpatient, hospital-based, and laboratory surveillance systems" (Smolinski et al., 2015, p. 2124).

Participatory surveillance, then, is not new. The emergence of digital programs like HealthMap and FNY, however, have made it easier for more people to contribute information (often without providing detailed identifying information) as well as broadened the quantity and the scope of data that can be collected. Further, such 'citizen scientist' efforts, which have become increasingly common over the past decade and tend to focus on conservation and environmental protection efforts (see McKinley et al., 2015), usually reflect a two-

fold purpose as Silvertown (2009) explains: engage non-experts in order to educate them about a specific topic, while also collecting information for a project. Indeed this sentiment reflects the goals of the Great Influenza Survey, the first participatory flu surveillance effort and a predecessor of FNY, which was conducted in the Netherlands during 2003-04 (see Marquet et al., 2006). As this program's creators explain: "ILI [influenza-like illness] was chosen as a vehicle to promote participation in an interactive enterprise in which the participant could experience the sensation of being a genuine scientist" (p. 2).

FNY accomplishes the first objective Silvertown (2009) identifies by providing links on both its webpage and mobile app to news stories about flu and other potential public health threats (e.g., Zika), a vaccine finder tool, and maps (Figure 4) that show flu activity collected by CDC (top) and user-contributed flu activity collected by the program (bottom). The CDC map shows the flu activity level—minimal, low, moderate, or high—in each state in the continental United States (top). FNY's mapping tool shows individual reports received by the program thus far for the week, which begins Monday and ends Sunday and the number of users reporting flu-like symptoms: fever and cough or sore throat as well as other symptoms (red circles), any symptoms that did not constitute influenza as classified by FNY (yellow circles), or no symptoms (blue circles) (Smolinski et al., 2015).

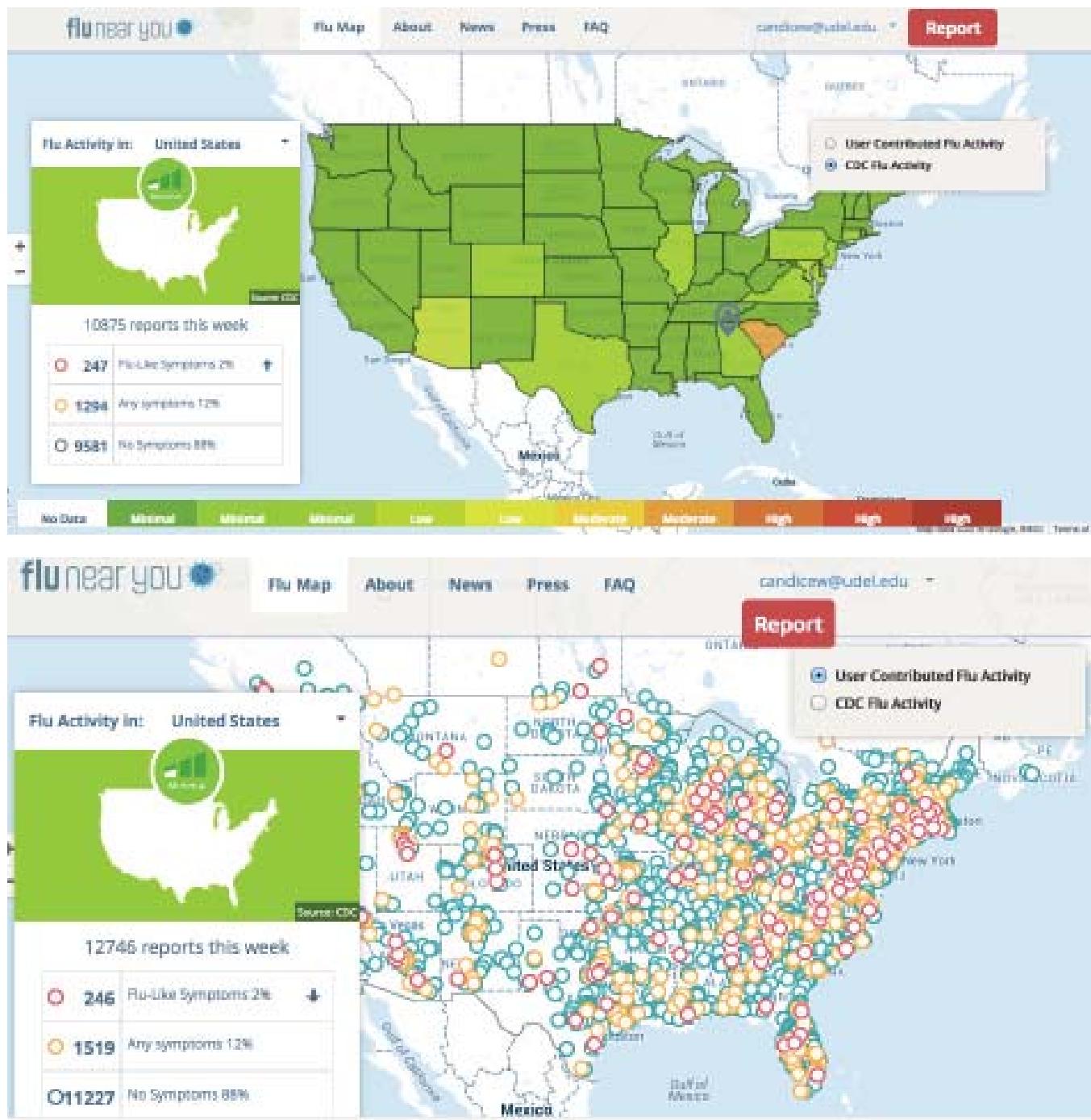


Figure 4. FNY's Mapping Features (CDC-contributed flu activity—top; FNY user-contributed flu activity—bottom; used with permission).

FNY endeavors to accomplish the second objective of collecting information for a particular project—in this case, about flu symptoms—by advancing the following pathos-based appeals on their splash page: “Help track the flu. Save Lives,” “Join the 60,000+ Flu Trackers reporting their symptoms,” “Help fight the flu in under 1 minute per week,” and “Protect yourself, your family & your community” (Figure 5). In other words, the program argues that users should participate because knowing how flu might be spreading benefits everyone (i.e., public health knowledge).

Yet while FNY meets both of Silvertown’s (2009) criteria, participatory flu tracking also differs dramatically from other citizen science research efforts. Rather than collecting information about a particular topic in a pre-defined natural environment (see McKinley et al. 2015), participants collect and report their own personal health-related information. This aspect, I argue in the next two sections by drawing on select results from a program-administered user survey as explained in more detail, fundamentally changes both the educational and the engagement component.

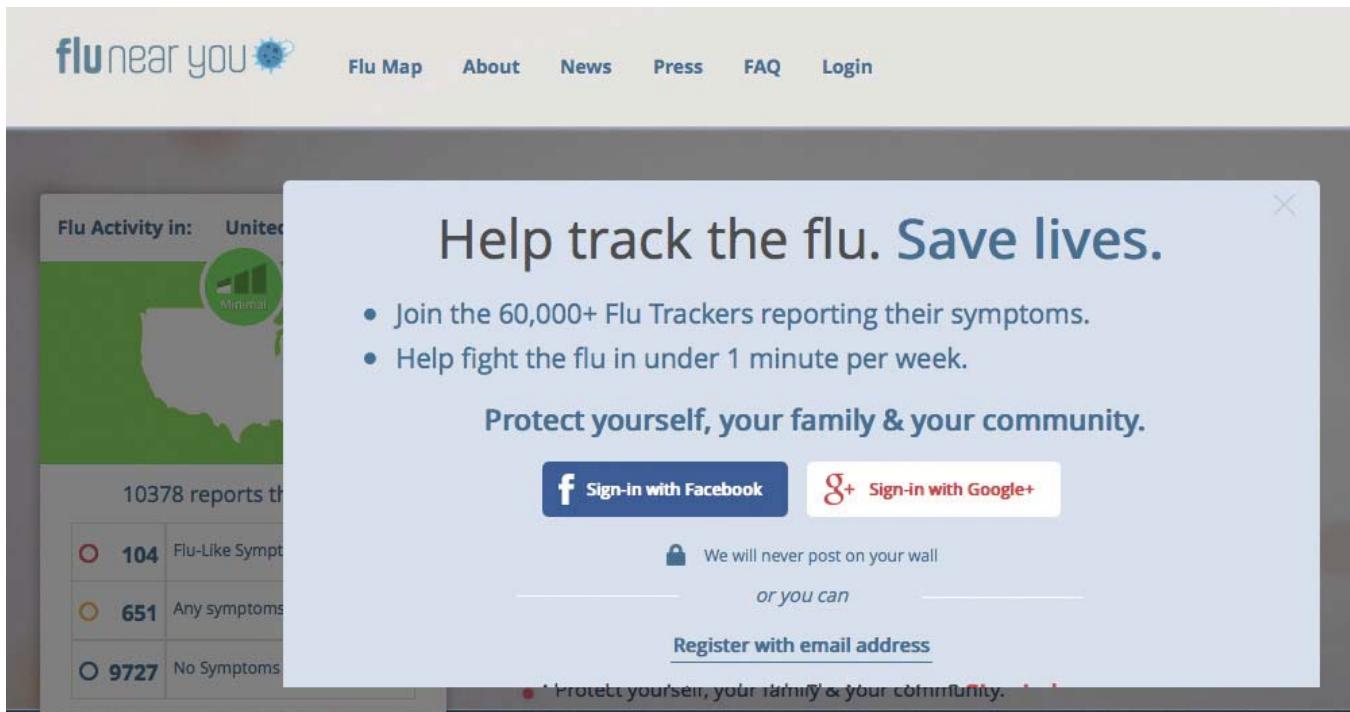


Figure 5. FNY splash page; used with permission.

AT YOUR OWN RISK: FNY'S USER-CONTRIBUTED MAPS

DESCRIPTION OF FNY'S PROGRAM

USER SURVEY

In May of 2016 FNY designed and administered a survey that sought to learn about users' participation habits and solicit feedback to improve participation rates. Select results from the survey were shared with me as an Excel file, some of which are reported in this section with permission from the program's developers (A. Crawley, personal communication, August 8, 2016). No identifying information for survey respondents was included in the file.

Program developers have reported that FNY participants tend to be female (Smolinski et al., 2015). The majority of respondents to the 2016 user survey reported being retired (34.04%), while the next most common responses were working in "health care and social assistance" (18.59%) and "professional, scientific, and technical services" (9.34%), respectively (Baltrusaitis et al., 2017, p. 7). These reports represent select results from user surveys administered in 2015 and 2016. Additionally, most respondents reported they had earned a bachelor's degree or higher (68.35%), and 12.41% had doctorates or other advanced degrees (Baltrusaitis et al., 2017, p. 7).

A total of 4,850 FNY participants responded to the 2016 user survey (Baltrusaitis et al., 2017, p. 7). The survey included 16 close-ended questions that gave respondents a list of responses to choose from and one final, open-ended question that asked: "Please share any other thoughts you may have about how we can improve Flu Near You to encourage more people to join the site and participate more regularly." I compiled and analyzed responses to this question by reading each response and assigning it to a general theme that I developed, which included the following

categories: advertising, friends, more info, other, problem, rewards (or incentive), simplicity, thanks (or praise), participant's usability pattern, usability complement, and usability improvement. Some responses were categorized as one or more themes. The purpose of my analysis was to identify comments that specifically discussed the maps. Of the 1705 responses to this open-ended question, only about 444 respondents provided a relevant suggestion. Some respondents may have misinterpreted or misread the question while others may have seen it as an opportunity to provide feedback on aspects of the program that are important to them and/or that they would like to see changed/improved. Indeed most respondents made unrelated comments such as thanking the developers for creating the program and/or describing a specific usability problem the user was experiencing.

Of the 1705 responses to this last question, 147 respondents specifically discussed the maps by praising the reports, suggesting design improvements, and/or otherwise critiquing the information shown. The following statement gives an example of the types of comments respondents made about the maps: "i [sic] definitely want to know about other diseases/viruses/foodborne illnesses. I would like to know what types of flu are circulating in what areas."

Such comments represent a fraction of the total number of responses to the last question and indeed to the survey as a whole. However, I propose that these comments lend rich insight into how some FNY participants perceive the maps because none of the survey questions asked about the maps. Indeed learning about how respondents use the maps was not the purpose of the survey. Consequently because respondents were not asked to offer their opinion about the maps, the comments that were made elucidate the importance of these visuals as a risk assessment tool for some participants.

The FNY program was reviewed by the Boston Children's Hospital Institutional Review Board and found to be exempt (A. Crawley,

personal communication, April 18, 2017). The University of Delaware's Institutional Review Board reviewed a protocol to include a discussion of the select results discussed in this article and found the project to be exempt.

FNY PROGRAM-ADMINISTERED USER SURVEY: ANALYSIS AND DISCUSSION OF SELECT RESULTS

Of the 147 comments about the maps, many noted the importance of being able to access information about the spread of flu in their area, for instance, which can only be acquired through the user-contributed mapping feature. For instance, one respondent stated: "I love 'Flu Near You.' I depend on it to let me know whom is ill and where." Another commented: "I find it helpful to see the map of what is being reported in my area."

While some comments were positive, many noted usability shortcomings and/or specific improvements that could be made to make the maps more useful for viewers. For instance, one respondent stated:

The map that pop us [sic] after reporting shows the whole US and is irrelevant to me. I want to know what's new in my area. I'd actually like an update at the end of the day on Monday. Is activity in my area increasing/decreasing/the same?

Two others stated: "Make the map easier to read," and "Make it easier to find graphs that plot the number of cases and in what part of the country," respectively.

Several other respondents stated that they have specific health problems and pointed to the value of the visual risk information provided by the maps. For instance, one respondent stated: "I have COPD and the flu is a major problem for me if it turns into Bronchitis. I like to gather info from as many places as I can." Another said: "I have three very serious lung conditions and I monitor your site very carefully to avoid potential illness. I have NOT had a flare-up in my conditions in over two years and I do consider your site as one of the reasons I haven't had a flare-up."

As many of these comments reveal, many respondents to the user survey who commented on the maps do not perceive their role only as contributors to a broader citizen scientist effort (i.e., participatory flu surveillance). While some may participate for educational purposes—that is, to learn more about flu through the program's links to news stories as well as where to get the vaccine through the vaccine finder tool—some also participate, as these responses indicate, specifically because they use the maps to assess flu risk. These participants may also be users who perceive getting the flu as particularly dangerous like those quoted above or they may be users who want to engage in preventative behaviors should the risk increase (as communicated via the maps). For instance, one respondent commented: "I think knowing where it is occurring so that one may avoid crowds or be highly careful is a selling point," while others stated: "Tracking helps us know when everyone is at risk locally and can take necessary precautions during outbreaks of food borne illness and disease, flu etc.," and "I like to see if my area-Neighborhood [sic] has the flu to see if I have to be overly careful."

The primary benefit of participatory flu surveillance systems for non-experts has been positioned primarily in terms of their

ability to "engage the public by communicating findings directly via the internet" (Wójcik et al., 2014, p. 1). Indeed as previously discussed, education and engagement are both goals of citizen science efforts. At the same time, the information non-experts glean about flu risk through FNY's maps as reflected in this discussion is more substantial than only "engaging" the audience. Indeed the FNY program meets two of the objectives that Rohrmann (1992) identifies for risk communication. First, the program increases awareness about flu both through its maps and educational components, "advancing/changing knowledge and attitudes," as he puts it (p. 170), about flu. Secondly, both of these sources of information as well as the vaccine finder tool seek to "modif[y] risk relevant behavior" (p. 170) by, arguably, prompting users to get the flu shot. Further, the participatory information FNY collects increases users' geographic awareness about where the flu may be spreading, which in turn provides users with information that they (rather than only the researchers involved in the project) can use to make their own risk assessments.

FNY's primary argument in favor of participation is articulated in the "How It Works" section, which states: "Reports are collected and mapped so that you know when the flu is around." Yet as the discussion in this section seeks to demonstrate, the user-contributed maps offer more than just letting users "know when the flu around," as the program's website puts it. More to the point, FNY's user-contributed maps give users information they can use to conduct their own risk assessments about flu, which they can then use to make their own decisions about what (if any) flu prevention behaviors they may want to engage in.

TOWARD A DIY RISK ASSESSMENT ETHIC

DIY or 'do-it-yourself' is a broad term that has tended to refer to non-professionals creating, modifying, and/or repairing something—an object, a device, a structure, or even a technological product like a software program or an app in the case of maker and hacker cultures, respectively. DIY efforts cannot always replace work done by professionals, particularly those that are too difficult or dangerous for non-professionals to execute correctly. At the same time, DIY can offer an alternative in situations where people want to save money, express creativity, invent something new, improve upon or customize an existing design, and/or otherwise address some kind of unmet need.

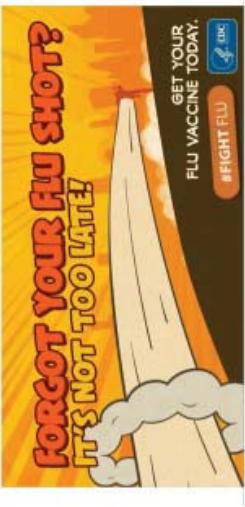
While DIY initiatives probably initially evolved for more practical purposes, today the movement is often characterized by strong undercurrents of individual autonomy, accountability, and sufficiency. Indeed invoking this DIY ethic is a common advertising strategy used by home improvement stores who have endeavored to capitalize on the do-it-yourself homeowner or property manager motivated by the potential savings. Companies who make wearable health and fitness trackers, too, promote these values through what Lupton (2013) refers to as "a discourse of 'healthism'" with its promise of individual "empowerment" and "the importance of 'taking responsibility' for one's health" (p. 397). For instance, Fitbit "motivate[s] you to reach your health and fitness goals by tracking your activity, exercise, sleep, weight and more" (2017), and Apple's watch is "the ultimate device for a healthy life" (2017).

As previously discussed, the tracking practices enabled by these technologies constitute a form of personalized risk assessment because users can make decisions based on the information they

T2: For best protection, everyone 6 mo & older should get a flu vax annually. I'm protected. Make sure you **#GetAFluVax** too! **#abcDrBchat**



It's not too late to get a **#flu** vaccine! As long as flu viruses are spreading a flu vaccine is your best protection against flu! **#NIVW**



T3: CDC director, Dr. Tom Frieden, tweets about getting the flu vaccine. **#FluVax**



Dr. Tom Frieden tweets about getting the flu vaccine. **#FluVax**



Figure 6. Tweets Promoting the Flu Vaccine, Fall 2016.

Panel 3: Dr. Frieden tweets numeric information about flu prevention during National Influenza Vaccination Week.

Panel 2: CDC tweets a reminder to get the flu vaccine during National Influenza Vaccination Week (12/4/16-12/10/16).

Panel 1: Dr. Tom Frieden, CDC director, tweets a photo of himself getting the flu vaccine in October, 2016.

collect, which can help lower their risk of developing chronic conditions. While the risk of developing a chronic disease can often be lowered by particular lifestyle choices like eating a healthy diet and getting sufficient exercise, the risk of contracting infectious and communicable diseases, too, can be lowered by engaging in particular behaviors—getting vaccinated for preventable diseases, and reducing exposure to germs by sanitizing hands and avoiding contact with sick people, for example.

Getting the vaccine is the most effective strategy for preventing flu (CDC, 2016b). FNY focuses on this line of prevention by indirectly promoting the flu vaccine in two ways: through its vaccine-finder tool; and through the weekly flu reports sent to program participants, which asks if they have received the shot. Once participants answer that they have, the program no longer asks this question.

CDC (2016c) recommends getting the flu vaccine in October in order to establish immunity early on. Indeed in October of 2016, then-CDC Director Tom Frieden (Figure 6; panel 1) promoted the flu shot by tweeting a picture of himself getting vaccinated that included a message advocating vaccination as the most effective prevention strategy. CDC promotes the vaccine via its social media accounts throughout the fall, and in December of this same year, during National Influenza Vaccination Week (12/4/16-12/10/16), the agency advised followers that they still had time to get the vaccine (Figure 6; panel 2). Dr. Frieden (as well as CDC Flu) also tweeted an infographic during this promotional week entitled “the benefits of flu vaccination,” which included the number of “illnesses,” “medical visits,” and “hospitalizations” that were averted during the 2015-16 flu season as a result of the flu shot (Figure 6; panel 3). This graphic compared these data to other numeric information that would be familiar to non-experts in order to provide context as well as facilitate viewers’ numeric literacy. For instance, the first panel of the infographic states that the vaccine prevented 5 million people from getting sick, which is the number of people who pass through the Denver airport every month. The second panel states that during the 2015-16 flu season the shot also prevented 2.5 million flu-related healthcare visits, which is the number of people who live in Portland, OR.

However, like many health-related risks, non-experts often perceive flu risk very differently from experts. Flu is often seen as a “minor nuisance,” while also being “a perfect paradigm of a risk that is serious technically but not so serious culturally—the sort of risk that kills people but doesn’t much upset them” (Sandman & Lanard, 2005, p. 4). Further, advocating the risk avoidance strategy shown in Figure 6 that is most likely to reduce the likelihood that the disease will spread in the population—getting the flu shot—emphasizes the way that experts perceive this risk—that is, primarily in terms of its numeric probability (Short, 1984; see American Chemical Society, 1998). Indeed every year in the United States, flu causes millions of illnesses, hundreds of thousands of hospitalizations, and potentially tens of thousands of deaths (CDC, 2016a). Figure 6, Panel 3 addresses three of these four numeric risks: people who become ill, people who then seek treatment, and people who are hospitalized. Number of flu deaths is the fourth area. The creators of the infographic may have decided that including this information would have been too alarming to disseminate to non-experts.

Fewer cases of flu means fewer people will be affected. Indeed the more people who are vaccinated, the lower the probability that the illness will spread in the population, and consequently the fewer people who will become ill, which also results in fewer flu-related

hospitalizations and deaths. Fewer cases of flu benefits everyone by reducing the overall numeric risk as Figure 6, panel 3 conveys. However because non-experts tend to evaluate risks through psychometric dimensions such as how familiar they perceive the risk to be as well as how potentially catastrophic—to give a couple of examples (see Covello, Peters, Wojtecki, & Hyde, 2001, p. 385; Fischhoff, Slovic, Lichtenstein, Read, & Combs, 1978; Sandman, 1987; Slovic, 1987)—such detailed numeric risk comparisons may not be compelling for this particular risk. More to the point, the flu vaccine prevented 2.5 million people from being hospitalized during the 2015-16 flu season. However, if viewers do not perceive that they are personally at-risk for hospitalization after getting the flu (and many healthy adults may not), then they may not interpret this risk information as applicable to them. Yet for people like the respondents to the open-ended survey question who reported having health problems exacerbated by flu, this information may be particularly relevant because for them getting the flu is particularly dangerous.

Both FNY and Healthmap focus on the second preventative behavior stated at the beginning of this section—reducing exposure to germs—through their mapping features, which allow users to view select public health threats by geographic area. More specifically, users of FNY can visualize CDC flu activity and user-contributed flu activity, while users of Healthmap can visualize a wide range of public health alerts that have been reported.

Many disease maps are static visual forms that depict the spread of a disease at a certain time within a defined geographic space. However, risk can quickly change as circumstances evolve and shift, particularly in the case of an illness like flu, which can spread differently across a flu season. The argument in Figure 6, panel 3 relies on an understanding of flu risk at some previous point in time in a particular place—presumably at the end of the 2015-16 flu season in the United States. mHealth technologies like FNY, which update the program’s user-contributed map in real time—that is, each time a user submits a report that week—reflect the fluidity of flu risk.

More specifically, these maps visually situate this aggregated risk information both temporally and spatially, prioritizing the geographic relationship between the variable(s) of interest shown. As Koch (2005) has pointed out, disease maps create a relationship grounded in proximity. They establish location as the most important risk factor in terms of the viewer’s potential exposure to the disease. Viewers need only identify the location(s) on the map relevant to them in order to customize this visual risk information about public health threats that may affect them. They can then use this risk information to make decisions about preventative behaviors they may want to engage in such as getting a yearly flu vaccine, sanitizing hands more frequently, and/or avoiding the area (if possible).

Everyone has some risk of developing chronic illnesses and contracting infectious and communicable diseases across her lifespan. But assessing these risks is often highly nuanced as well as specific to individuals. Some people can easily reduce their risk of developing a particular chronic condition like hypertension, for instance, by adhering to healthy diet and exercise habits across their lifetime. Others may be genetically predisposed, meaning they may still develop the condition regardless of how healthy their diet and exercise habits are.

Somewhat similarly, while generally healthy adults may not perceive that getting the flu is ‘risky,’ for someone with a lung condition, as a survey respondent commented, getting the flu can have serious health consequences. FNY’s maps then can be particularly useful for participants with particular types of health issues as well as users who may want to get the flu shot but cannot due to barriers such as cost and access, and/or health issues like previously having had an allergic reaction. Others may be influenced by social and cultural factors such as a distrust of vaccines and/or religious beliefs. Still others may doubt the vaccine’s efficacy, particularly if they were vaccinated but still contracted the flu.

On average the vaccine is between 50-60% effective during a given flu season (CDC, 2016d), which can substantially reduce the risk of contracting the disease. CDC also recommends engaging in other preventative behaviors discussed like sanitizing hands, staying home when ill, and not interacting with those who are sick (CDC, 2016b). The respondents to the user survey who commented “. . . knowing where it is occurring so that one may avoid crowds or be highly careful . . . ,” “take necessary precautions during outbreaks . . . ,” and “see if my area . . . has the flu to see if I have to be overly careful” suggest that they may be using the maps to determine, in part, if they might engage in some of these other preventative behaviors.

Much like participatory surveillance does not replace traditional surveillance methods, the information that non-experts glean through disease-tracking apps like FNY and HealthMap are not substitutes for expert-created risk information. At the same time, flu prevention strategies, for instance, tend to target a broad and homogenous non-expert audience. The information provided by disease-tracking apps can provide more individually-focused, location-specific information that aligns with the ways that non-experts perceive risk—that is, in terms of how the risk might personally affect them and/or their families. In this way, digital disease-tracking apps facilitate a DIY risk assessment ethic in which people potentially affected by a particular risk choose what information they want to collect about the risk and consequently formulate their own risk assessment, which they can then use to engage in specific actions designed to mitigate the risk.

Risk communication research has long recognized fundamental differences in the ways that experts and non-experts assess risk. Yet scholarship on visual numeric risk information has tended to focus on how non-expert viewers cognitively perceive this information (see Lipkus & Hollands, 1999; Ancker et al., 2006) with arguably insufficient attention directed to the wide range of other factors that shape how non-experts assess risk. Further, such research also tends to assume that numeric information is always important to non-experts, and that non-experts assess numeric information the same way that experts do—in terms of the likelihood that the risk will occur. Often non-experts do need to understand the mathematical probability that a particular risk will occur in order to make certain kinds of health-related decisions like weigh treatment options for a chronic condition or decide if they are likely to have an allergic reaction to the flu shot, for example.

However, as I have endeavored to argue in this article, non-experts are not passive recipients of risk information. Rather, they often draw from multiple and varied sources and mHealth technologies like disease-tracking apps and health and fitness trackers have facilitated their ability to collect more individualized risk

information. For instance, some users of FNY use the program’s maps to assess flu risk and consequently make more nuanced and personalized decisions about the flu prevention behaviors they may choose to engage in.

While this article does not explore specific design choices that could be made to improve the delivery of this information for non-experts, some survey respondents offered suggestions in this area. Consequently, future research might explore the specific types of visual information that non-experts would like to see as well as design changes that could be made. Better understanding how non-experts use such information can inform not only the design of these apps in general but visual risk communication strategies in other contexts.

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