

# Empowering consumers with improved immunization intelligence through technology and social frameworks

Michael L. Popovich<sup>1</sup> · Erich M. Daub<sup>1</sup> · Michelle Bonjour<sup>1</sup> · Colleen Crawford<sup>2</sup>

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**Abstract** Consumer engagement has emerged as a key factor contributing to improved health outcomes. Leveraging health information technology and social frameworks to provide consumers accurate and timely feedback offers the promise of better health. This chapter illustrates through historical evidence that individuals empowered with information are highly motivated, leading them to take actions that stem the spread of and eradicate preventable disease. It presents through applied practice a technical framework that links the health care community with consumers and through stories illustrates the value of public/private partnerships to engage consumers with their health records, specifically for immunizations. It concludes with the power of messaging and social media to extend individual involvement to engage larger communities and populations which returns full circle to the historical examples.

**Keywords** Consumer engagement · Health information technology · Immunization registries · Social media · Vaccine-preventable disease · Immunization ambassadors

## 1 Introduction

Anticipating that individuals travel and move great distances multiple times throughout their lifetime resulting in the use of

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✉ Michael L. Popovich  
Michael\_Popovich@stchome.com

<sup>1</sup> Scientific Technologies Corporation, 8444 N. 90th Street, Suite 100, Scottsdale, AZ 85258, USA

<sup>2</sup> 80531 Avenida San Felipe, Indio, CA 92203, USA

multiple healthcare providers over time, interest in providing individuals access to their personal on-line immunization information is growing in the United States and Canada. The ability to collect data measuring the frequency, circumstance, and point of contact of individuals accessing personal immunization information will be a value-added benefit of engaging individuals proactively in their healthcare. Over time, public health organizations will be able to research and draw conclusions about the economic and social impact of their services driving revision, improvement, and future expansion.

Educating healthcare professionals, public agencies, and the general public about the desirability and benefits of an individual's ability to access their personal medical and immunization information is critical. Accessibility of technology-driven immunization information is no guarantee that the community will use and benefit from preventive health services. Individuals need to understand how access to up-to-date medical information in near real-time is of personal value. Corporations need to understand how encouraging their employees to access health information will enhance profitability and business models. It is the perception of personal and economic value that will normalize and increase the frequency of immunizations for all ages but notable for adults who are at risk to vaccine-preventable disease.

## 2 Historical background

In the 20th century, an estimated 300 million people died from smallpox [1]. Sixty years ago polio was the most feared childhood disease. Today, disease still finds hosts and spreads within preferred social networks. Influenza causes 3 to 5 million cases of severe illness, and about 250,000–500,000 deaths worldwide each year [2]. The evolution of new organisms and strains of viruses and bacteria continues, creating new and sometimes more formidable diseases than we faced in

the past. Vaccines are critical to protecting populations and new ones are being researched and developed. The social and personal impact of vaccine-preventable disease on families, communities, and economies can be devastating as seen from recent global outbreaks.

Communication methods to increase awareness have evolved but the necessity for clear, timely, and effective access to information by individuals remains an imperative in effective, responsive public health programs. We have historical evidence that information in the hands of individuals has the ability and power to highly motivate and lead to actions that stem the spread of and eradicate preventable disease. Ultimately, the success or failure of any public health initiative or program is dependent upon individuals who are proactive in their own healthcare.

Below are historical examples of how effective communication of public health information motivated and empowered individuals and, ultimately, whole communities to take action effecting positive change and outcomes in public health.

In 1796, Edward Jenner successfully demonstrated how an inoculation from cowpox could prevent human Smallpox. Surprisingly, Jenner's research was initially rejected by the United Kingdom's Royal Society. It took leveraging of the social media of the day and a receptive social network to accelerate a public call for action and, eventually, to eradicate smallpox. With unwavering faith in his discovery's ability to eliminate the high personal and social costs of smallpox, Jenner self-published a pamphlet "*An Inquiry into the Causes and Effects of the Variolae Vaccinae, a Disease discovered in some of the Western Counties of England, particularly Gloucestershire, and known by the name of the Cow Pox.*" Although the pamphlet did not gain a large readership in the medical community, it garnered the interest of a well-respected London surgeon, Dr. Henry Cline, who successfully demonstrated that vaccination with cowpox prevented future smallpox infection in humans [3]. This peer validation of Jenner's research created media attention and general acceptance of smallpox immunization in the community; eventually, a widespread immunization program was adopted that, over time, eradicated the disease.



In 1918 the Spanish flu killed an estimated 50 million persons. Subsequently, influenza vaccines became a priority in

public health initiatives worldwide. The 2009 U.S. H1N1 outbreak and the 2013 Canadian H1N1 outbreak continued to demonstrate the necessity of immunizing large numbers of the general population starting with individuals who are at the greatest risk. These vast, time sensitive, immunization programs annually require public education, effective use of a variety of communication formats including social media, and personal action to be effective.



Polio disproportionately claimed children under the age of five, crippling and in some cases killing them with paralysis. Jonas Salk and a team of researchers created the polio vaccine in the early 1950's, saving and changing the lives of millions. As a result of a comprehensive public information campaign about the effectiveness of polio immunization, when polio vaccine became widely available in 1955, mothers everywhere raced to immunize their children. As a result of public information and personal action, by 1988 America was declared polio-free, and through a worldwide eradication effort, most countries are now free from its ravages.

### 3 Technology's role

Health Information Technology (HIT) is a powerful determinant of consumer engagement and evidence is accumulating to link HIT use with improved preventive health outcomes. The ability to empower consumers with immunization records that primarily exist in healthcare provider's record systems relies on three technology components. The first component is the initial capture of an individual's immunization at the time the event occurs in an on-line medical record system. Physician Electronic Medical Record (EMR) systems, hospital information systems, and pharmacy recordkeeping systems are examples of technologies increasingly being adopted in the developed world.

The second technology component is a population-based immunization registry or system that consolidates a patient's multiple immunization events into a single health record. Traditionally, as families grew, the family pediatrician was the single source of immunizations. However, immunization programs are now found in drug stores, retail health outlets, employer locations, at airports, and even drive up clinics. This diversity, while a benefit to access to care, poses a significant challenge to creating a consolidated patient immunization

record as many of these alternative immunization providers do not exchange their data with population-based registries. Combining multiple sources of records into a central resource creates a valuable health data asset for the individual consumer. Electronic record exchanges, processes to identify and combine patient information and maintain quality, and tools to analyze and report the information are all components of jurisdiction-wide immunization information systems (IIS).

The third technology component is a viable, easy to use consumer information access tool to provide individuals with their specific immunization histories. This may be accomplished through a smartphone application or a web interface that authenticates the individual for data access and provides them with the information needed to support future preventive health service actions. Two examples of such a tool, Immunize Canada [4] and My Immunization Record (MyIR™) in the United States, leverage some or all of these technology components. Immunize Canada is a smartphone application that allows individuals to enter their own immunization records but does not connect to a central registry. MyIR™ in the U.S. is an on-line and smartphone-optimized tool that connects consumers to their jurisdiction's public health IIS containing merged patient immunization records and tools to forecast past due and next due immunizations.

MyIR™ was originally deployed in five U.S. states in consumer-based pilot projects in 2013. To date these projects are expanding as the consumer empowerment model specific to vaccinate against preventable disease also expands. Through the third quarter of 2015, 7000 consumers registered for an account. Over 12,000 dependents are included on these accounts and over 100,000 unique immunization events are represented across a wide spectrum of users. As of October 2015, personal immunization records of participating consumers have been accessed over 24,000 times. As this user-community grows, significant consumer awareness and social impact will be evaluated to demonstrate the return on value for consumer engagement through technology.

Early results are encouraging. A series of national surveys to consumers who had acquired a MyIR™ account indicated that 40 % of these users discovered one or more family members were overdue for one or more immunizations. Of these, nearly 68 % of consumer-users reported that these discoveries led them to obtain the necessary immunizations or to consult their healthcare provider regarding their needs.

Based upon eighteen months of consumer engagement, there is substantial evidence of the synergy created with involvement of the individual and the growing power of social media. We know immunizations protect against disease. We know ministries and government health agencies work to protect their populations through educational campaigns. And we know preventive health will always be an individual decision, one that information technology and social engagement can affect. It is in this human element that there is real power.

## 4 Human role

Receiving information is often not enough to result in effective preventive health actions. Information must be linked to actions and barriers to action must be removed. Compelling stories that showcase the desired outcomes illustrate how this can be accomplished. Empowered individuals sharing how accessible immunization information was critical to the positive outcomes of their personal and corporate stories will evolve societal attitudes and ensure normalization of use. Ultimately, the success or failure of any public health initiative or program is deeply rooted in personal action. Effective, timely communication of personal immunization status empowers individuals to become proactive in their own healthcare increasing the probability they will seek initial immunization and ensure that immunizations are kept current.

### 4.1 Personal story 1

Michele, a young mother, told an audience of 440 U.S. immunization providers about a recent encounter at a healthcare provider to illustrate the power and value of knowing your family's immunization history.

Her daughter's immunization events had been reported by attending physicians to a centralized immunization registry. Michele had access to this registry through an on-line consumer application that allowed her to download the immunization records of her family.

Michele had previously been keeping track of her daughter's immunization records on paper forms and had recently used the consumer access tool to review the records on-line. She found that many of the immunizations on her paper forms were also in the on-line information system, although there were a few on her paper forms that were not included.

*She kept telling herself that one day she was going to bring in these paper records to her physician's office and have one of the nurses update the on-line system with the missing immunization events.*

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**What goes to school  
does not stay there.  
Immunize your children.**

“Well, I finally did it!” she told her audience. One of her daughter’s nurses validated the paper records and then entered these into the state’s on-line immunization registry. The nurse then came back to Michele to tell her that her daughter’s doses of varicella and MMR given three years earlier were invalid! You can imagine Michele’s surprise. The nurse explained that this happened because the time interval was too short between the administration of her daughter’s flu shot and those of other live vaccines. It was less than the minimum 28-day required interval based upon the decision support tools in the registry. This meant that the varicella and MMR immunizations that followed the flu shot were likely ineffective. For three years, her daughter had not been properly immunized and Michele did not even know it. Both Michele and her amazing immunization-champion pediatrician missed this – a reminder that this could happen to anyone.

Michele went on to tell the audience the value of empowering her as a consumer with health information that existed in on-line registries. This incident proved to Michele the importance of providing the individual consumer with knowledge-based health decision support tools enabled to evaluate the data. The incident provided her a critical lesson in the how the application of this knowledge could be used to better protect her family. The perception that everything is “fine” may not be true. In the case of immunizations to prevent disease, a mother’s responsibility to her family extends to her family’s community of relationships.

#### 4.2 Personal story 2

The flu season results in a rise in employee sick days. It is well known in public health circles that a larger percentage of influenza immunizations provided to employees is more likely to result in a significant reduction in sick days. Companies often hold workplace on-site flu clinics for their staff to encourage a larger number of their work force to immunize and thus reduce the potential impact of the flu on the business.

In one example that highlights the effectiveness of corporate action that supports strong partnership between business, community medical services, and individuals to reduce the spread of flu, a local CEO brought in a pharmacist from Walmart to provide on-site flu shots to employees. He knew from past years when over 70 % of employees were immunized a significant reduction in sick days was the result. He also knew that statistically the average percentage of employees that receive their flu shots from these events is usually in the 40–45 % range. So, to increase employee participation, the company used internal social media, engaged the HR team to make the event fun, and relied on techniques that leverage a small amount of peer pressure, such as texting “you did not get it from me” messaging.

Over 70 % of the company’s employees were immunized at the clinic as a result. Making this program a CEO priority,

engaging company resources, and integrating a full campaign made a huge impact on employee involvement. In each of the past three years, the achieved employee flu immunization rates have remained well above the initial 70 % which has made a positive impact on employee wellness, attendance, productivity and, ultimately, the profitability of the business.

In 2015, the immunization provided at the business was reported to a state immunization information system. The Walmart pharmacist electronically recorded the information for the forty (40) employees who received shots and as a result they were able to retrieve their individual information within 12 h using consumer access tools available on their smartphone.

Employees were more excited by the fact that their immunization was captured on-line, providing information about their future immunizations than they were about receiving the flu shot that would help protect them this season or for that matter the company once again hitting the commendable goal of >70 %. Employees now literally had this information in the palm of their hand and were heard to say, “I need to get my kids in for their flu shots.” The rapid exchange of information further empowered employees, encouraging them to have their families immunized and their records on-line and available.

#### 4.3 Personal story 3

Bartell Drug stores in the State of Washington implemented a program in 2014 to evaluate the impact of using a state-based immunization registry that pharmacists could access when an individual presented for an influenza immunization. Since most customers were adults – who are typically not aware of which immunizations they may need – Bartell wanted to see if using the registry would help identify persons in need of additional immunizations and just how identifying these patients could be applied to the customer service and patient care business models.

A research study was conducted across a subset of the Bartell pharmacy stores. Pharmacists discovered that 83 % of the patients presenting for an influenza vaccine were past due for one or more immunizations and on the average these adults were overdue for three immunizations. By presenting patient customers with this information, Bartell empowered them to make informed decisions leading to personal action. Some chose to receive additional immunizations from the pharmacists. Others indicated they would go to their regular doctor, and some just chose to have the pharmacist administer the influenza shot.

Based upon this experience Bartell Drug realized the value in consumer engagement, both for their immunization business model and for their patient loyalty program. They are now in the process of adding a customer portal to their website from which they will support their customers by proactively



encouraging immunization action through on-line immunization intelligence.

Clearly this is a win-win-win situation with benefits for the community, the pharmacy, and the individual. A key element of this story is that consumer empowerment begins with community partnership and a personal point of contact, in this case a pharmacist. When a consumer immunization component is added to a pharmacy's services, it offers consumers a mechanism by which they can stay informed about their immunization records. Better immunization supports other pharmacy programs such as prescription drug alignment and patient diabetes self-certification, while strengthening other comprehensive, assertive healthcare programs that align the efforts of the pharmacist, physician, and the patient to create patient wellness.

## 5 Social activism through individual action and social media

These stories provide insight into immunization care continuity. They are stories of people, families, businesses, and community partnerships empowered by easily accessible and up-to-date medical information, not physicians, organizations, or governments. The MyIR™ immunization application is helping to empower consumers interested in reducing their personal, their family's, and their community's risk to vaccine-preventable diseases.

The question is now: "How do we scale this empowerment so more individuals engage?" This can result in vaccine coverage "tipping points" that support the immunization care community in their drive to achieve herd immunity. Herd immunity is a disease outbreak risk-reduction strategy that focuses on immunizing large numbers of individuals in communities and encouraging them to remain current, thereby offering protection to others that are not immune.



**"This new data map shows that we've associated with 2307 people who are not up to date with their vaccinations."**

Consumers empowered to not only maintain their own immunizations but to advocate this message to their families and

friends can be consider the first scalability factor. However, now through the use of social media to message their stories to their networks, the scalability factor is significantly increased. A message sent to an individual that has 25, 50 or more friends extends this positive message beyond their traditional relative network.

Social empowerment, if effective, is also a means to combat the anti-vaccinators who rely solely on this framework to carry their messages. While a positive immunization conversation may occur through normal social communication, it is not normally a natural conversation. To assume individuals will simply begin to use social media to communicate they have received this year's flu shot is also not a normal electronic conversation. Therefore, empowering individuals to contribute to a cause requires that they also have a platform and forum through which to communicate.

Technology has enabled corporations to leverage their products and services through real-time communication with their customers. Technology-enabled consumers are looking for a place to voice their beliefs and impact the worldview of others. With so many companies and individuals on the internet it seems a natural to involve this media. The idea of spreading awareness about immunizations and vaccines through social media evolved through a program called Immunization Ambassadors [5].

Immunization Ambassadors is an emerging social network established in 2015 to specifically support consumer immunizations. The program's goal is to enable consumers to share their immunization stories so that others may be inspired to act. The Immunization Ambassadors program leverages social media to extend these consumer stories to a global audience and provide consumers a platform voice.

The goal of the Immunization Ambassadors program is to collaborate and create expanded awareness about the personal and social benefits of immunization through social media such as Twitter, Facebook, and Instagram and to have a little fun along the way. Ambassadors are individuals who are passionate about immunizations and want to spread the word to others; they are health care professionals (physicians and pharmacists), government officials, CEO's, authors, parents, students, and anyone who sees value in immunizations. The Ambassadors engage and collaborate with each other and share information with others while using the hashtag #WhyIVax. The hashtag not only allows Ambassadors to find information in one place but it also allows others to search for any relevant information regarding immunizations and vaccines in social media. Often an Ambassador will share content and connections from another Ambassador to advance their message, thereby generating a dialogue.

One Ambassador, an author from England, wrote a children's book *The Measly Virus* [6]. Another Ambassador used social media to share information about the book and now distribution of the book is provided to healthcare professionals

as an educational component of informational booths at health conferences. As part of the Immunization Ambassadors Program, a brand logo was created and added to pages on all social media sites producing a common theme and dialogue between Ambassadors and the general public.

To keep Ambassadors involved, and motivation going, a point system was put in place. Consequently, Ambassadors earn points for prizes and through social media create the ability to track an interaction. Diseases have no boundaries, neither do social networks. Measuring the effectiveness of using these networks to effect change will be the next step.

## 6 Call for change and consumer accessibility

In the past, it was assumed that it was in the best interest of public health that personal health information be safeguarded by the medical community. This may have been true at a time when consumers were less educated and information was more difficult to disseminate. However, it is now an antiquated policy and a paradigm that does not serve but impedes. The most recent statistics indicate that 30 % of Americans over the age of 25 hold at least a bachelor's degree and almost 11 % hold a graduate degree. Over 84 % of U.S. households own at least one computer and 73 % have internet access at home. Sixty-seven percent of Americans use social media. Over 87 % of Americans use the internet to seek medical information, while only 70 % requested information from a doctor or healthcare professional last year. What can we garner from

these statistics? At the very least, that Americans are ready, willing, and able to benefit from access to their personal medical information and they desire the ability to use that information to be proactive in their personal and family care.

**Compliance with ethical standards** This article does not contain any studies with human participants or animals performed by any of the authors.

**Conflict of interest** Michael L. Popovich, Erich M. Daub, Michelle Bonjour, and Colleen Crawford declare that they have no conflict of interest.

**Informed consent** Not applicable.

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