

Empowering Individuals through their Immunization Records

Abstract¹

Despite the promise of better healthcare through information-centric patient empowerment, little progress has been made. The issue is not that the data do not exist in a useable form, or that technologies that would enable access to this information are lacking. There are two primary challenges standing in the way of patient empowerment: (1) in the private sector there is no proven revenue model for providing this access, and (2) in the public sector the standard barrier is confidentiality of information, the possibility of misinterpretation, and existing policies. The lack of a priority by either private or public health providers to empower individuals will lead to these initiatives being consumer driven. However, through healthcare reform, and the transformation and modernization of information technology, a clear objective is emerging for the right of individuals to have their medical record information. Access to immunization records, a key component of medical information, through health informatics and supporting compunetics presents an easy-win opportunity to significantly empower individuals with their own health information.

Scientific Technologies Corporation (STC) has been implementing and supporting immunization registries in North America for over fifteen years. As an expert in this area, STC has developed a process for achieving successful large-scale access to personal immunization records with minimal investment. As a first step to empowering individuals with on-line access to their immunization records, the STC approach leverages the technical frameworks established for health insurance and third party payer environments linking to statewide immunization information systems. The individual is provided access to their records through their insurer's health portal. The portal is populated through electronic exports of member immunization records as retrieved from state or provincial registries that contain provider-supplied patient records, allowing individuals to utilize these hosted services or download their provider administered records into their personal health record. This is just one strategy. The movement toward Health Information Exchanges (HIE) in communities and states offers significant opportunity to engage individuals. Rapidly expanding social media, smart phone technology, and the second generation of personal health records (PHRs) all can play a key role in this process.

Keywords. Immunization record, personal health record (PHR), compunetics, patient empowerment, health informatics, Electronic Medical Record (EMR),

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Electronic Health Record (EHR), smart phone health, Health Information Exchange, my immunization history, vaccine schedules.

Background

Day in and day out there are press releases from healthcare providers, businesses, and departments of health stressing the value of individuals assuming a greater role in managing their health care. The economic cost impacts of a proactive health program are well known, and encouraging individuals to be a catalyst to accelerate for this is a win for all. Individuals require health information. They need to know what it means, and they need to know how to use it. They need to be able to make decisions, ask questions, and stay informed.

The provider community understands the value of historical and real time information to support healthcare decisions for their patients. They understand the need to share information as patients receive services from a variety of healthcare professionals. Providers address this need through information sharing. Through their expanding electronic medical and health record (EMR/EHR) environment and Health Information Exchange (HIE), a rapidly emerging technical infrastructure is becoming available to support the sharing of the individual's medical record and, correspondingly, the availability of this information to the individual. The question will become how to make this information available.

It is difficult for individuals to contribute to their own healthcare if they do not have ready access to their own personal health information. Patients empowered through information are more likely to understand the risks and benefits of certain activities (e.g., immunizations, disease screening) and are more likely to be proactive in their own healthcare. Health informatics together with medical compunetics² provides the tools for information to significantly shape an individual's personal healthcare environment. Accessible information will facilitate informed decision making and contribution by all members of the healthcare team: physicians, other healthcare partners (e.g., pharmacists, specialists), and most importantly, the patient. Better informed healthcare teams should translate into better personal care, providing a long term economic benefit for societies by preventing disease, mitigating direct healthcare costs, and promoting a healthy and more productive workforce.

Despite the promise of better healthcare through information-centric patient empowerment, little progress has been made. And although progress is being made to implement EMRs, significant barriers exist to enable widespread direct patient electronic access to this information. This paper presents an approach to achieve immediate real gains in patient empowerment by facilitating electronic access to a key component of an individual's personal health record: their immunization data.

² Compunetics in this sense is the combination of automation, data, and knowledge gained from the information.

The Universal Significance and Need for Personal Immunization Records

Access to immunization records through health informatics and decision support through health compunetics presents an easy-win opportunity to significantly empower individuals. Whether a vaccine for yellow fever, malaria, hepatitis, measles, or for emerging infectious diseases or chronic illnesses, immunizations are universally available in existing clinical medical records and in population-based immunization registries. They are not, however, easily or universally accessible by the individual nor or they easily understood. Understanding which immunization is required and the timing to maximize family protection from vaccine preventable disease (VPD) is complex. Figures 1 and 2 summarize immunizations currently recommended for children aged 0 – 6 and 7 – 18, respectively. Similarly there are recommendations for adults in the US all of which are subject to change through availability of new vaccines, research results on disease, and federal schedule recommendations.

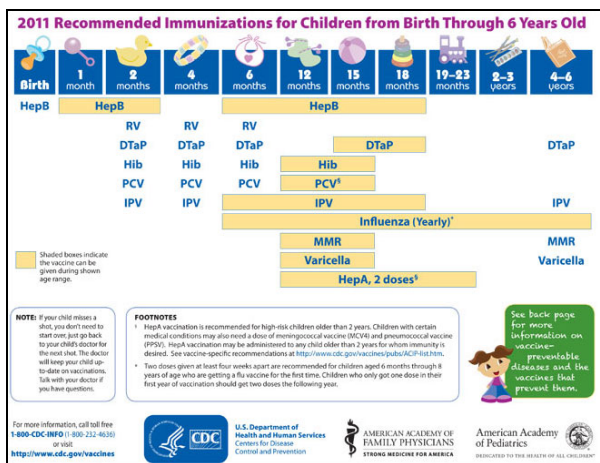


Figure 1. Recommended immunization schedule for persons aged 0 – 6 years, United States, 2011.

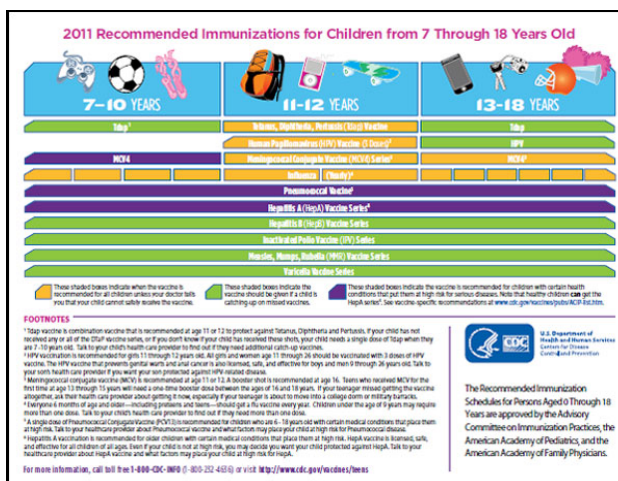


Figure 2. Recommended immunization schedule for persons aged 7 – 18 years, United States, 2011.

Immunizations are recommended and provided to new babies, adolescents, and adults, including the elderly. From Hepatitis B given at birth, to adult boosters including those for tetanus, pertussis, and influenza, and new vaccines for pneumonia and shingles, the need for immunizations persists throughout an individual's entire life. Therefore, a complete immunization history should be a required component of a person's health record. The value of health compunetics is that this record can then be evaluated to determine what risks an individual has to VPD. Having an immunization history and tools to determine risks will empower individuals to be proactive.

Immunization Recordkeeping and Patient Empowerment: the Gaps

An individual's immunization record needs to be complete to provide an accurate assessment of risk. Immunization records are retained by individual providers, but rarely consolidated into a single medical record across the patient's healthcare lifecycle. Each vaccine that is provided by a healthcare professional results in a paper or electronic record, retained in the custody of the primary provider. When individuals move and/or change physicians, records will exist in multiple locations, and often across state or public health jurisdictional borders.

With the advent of electronic health records, individual immunization data may eventually be consolidated under the patient's current provider, but these records are not likely to be as mobile as the patient. Patients can request from past providers copies of their families' immunization records, but often the effort required

to do this is seen as prohibitive, and for the provider such requests add administrative costs to search, retrieve, and provide this information.³

The first challenge is where or how to generate a single complete immunization record for an individual. Ultimately, there are three locations where complete records may be found. The most likely is in a home paper record kept by conscientious individuals themselves. The second location is with third party organizations that ultimately pay for the services. And finally, at least in North America, records may be in a consolidated regional immunization registry that is used by public health organizations to support VPD programs. For example, in the US, forty-nine of the fifty state health departments have implemented statewide immunization registries,⁴ and in Canada all provinces will be expected to implement immunization registries in the next few years. It is the state and provincial immunization registries where the combined patient records can be found and they will become the trusted source of this information. However, no or very little public access is available to this information. If it is available, this information is not leveraged to the extent that empowers the individual to act on their own behalf.

Personal immunization records must be easily accessible. With very few exceptions, individuals do not have access to their own immunizations records even if they exist in an electronic database. Without easy access it is difficult for an individual to review their own immunization status and that of their family. With access, the ability to know their immunization histories is only the first component. Knowledge is gained through the following building blocks for empowerment:

- Forecasting the immunization schedules at the time access is granted.
- Automatically notifying the individual through text messages, email, or phone updates to support adherence to vaccine schedules.
- Information alerts recommending age-appropriate immunizations.
- General vaccine and related disease information “newsfeeds.”

This is just the beginning. Empowering the individual through technology to report adverse reactions, communicate with experts and, for that matter, indicate immunizations not retained in the source files, begin to unlock the real power and energy of a consumer movement to support the public health mission to eliminate VPD.

The primary challenge standing in the way of such patient empowerment is the lack of priority by immunization data custodians to open their registries to the public. It is not necessarily their lack of want, but more often a lack of foresight in policy and procedures. Immunization registry data keepers must be sensitive to patient confidentiality. They also must be sensitive to how data is used once distributed. And they must be sensitive to the resources required to support their day-to-day

³ 2003 cost studies have shown economic impacts of \$5/chart to retrieve medical files.

⁴ American Immunization Registry Association, <http://www.immregistries.org/public.php/ImmRegs/regMain.php>

activities and objectives to assume this added responsibility. The desire to engage the public may be there, but the history to support this new vision is not. As such, there is a source for a combined patient record, but no mechanism for sharing this with the public. The challenge then becomes how to make available this resource – the second barrier to overcome.

Driven by good public health practice, economics, and national oversight, third party insurers – both private and government – have active immunization program efforts to encourage their provider networks to increase immunization coverage rates of their patient populations.⁵ Providers send immunization record information to their payee networks for reimbursement and to state health departments to maintain in their immunization registries.

The registries were the vision of the Centers for Disease Control and Prevention (CDC) in the early 90s and have since continued to evolve throughout the US. The registries are often robust and state-of-the art within health IT. They contain tools and resources to support electronic exchange of information, decision support, and access to large clinical care networks. The registries are population based with the first patient record being generated at the same time as a birth certificate, gathering immunization encounters to include the first immunization provided in the hospital. The registries focus on data quality as they combine immunization histories from multiple providers as the individual moves between clinicians; thus, requiring robust patient identification processes and deduplication including immunization deduplication. From a public health worker's perspective, these tools are key to successful state immunization program efforts.

To support the importance of immunization programs, the National Committee for Quality Assurance (NCQA)⁶ evaluates quality of care. Insurance companies provide reports annually on the level of their services. A key measurable criterion is immunization coverage determined from the immunizations histories of patients who are members of the insurance plan. A significant effort is made by insurance companies to gather this data, often through costly on-site provider visits involving the review of a random subset of patient records. With the implementation of statewide immunization registries at the health departments, insurance companies now can receive electronic copies of all their member records. This moves the data that is today contained in state immunization registries to primarily support clinicians and public health professionals' one step closer to the individual.

Electronic health records and health information exchange also are being facilitated through the Centers for Medicaid and Medicare Services (CMS) and the Office of the National Coordinator (ONC). Add the fact that the private sector, through health technology vendor offerings such as PHRs and health data vaults, means a

⁵ In the US individuals can choose to not receive required immunizations and opt out of these programs.

⁶ <http://www.ncqa.org/>

significant technical infrastructure is rapidly emerging across the US healthcare community. We should consider the occurrence and alignment of opportunity presented by the CDC, NCQA, CMS, ONC, and private business to be the perfect storm after a long drought which will germinate the seed that creates consumer empowerment. The seed is the immunization record.

Technical Recommendations for Sharing Immunization Records from a State Registry

Given the objective of empowering individuals and that the consolidated source of trusted immunization records is a state or regional-based immunization registry, there are a variety of technical strategies that can be deployed to provide data to the individual. Regardless of the technical strategy, the ability to provide the information is the first step to consider. Forecasting, automated reminders, and information exchange would follow.

Two of the technical approaches to consider are: web based and third party electronic exchange. Each requires HIPAA compliant tools and services to authenticate, select the appropriate record from the immunization system, and send accurate information to the individual.

The CDC has established a set of twelve minimal functional standards for an immunization registry⁷. In today's technical environment the systems are accessible through web-based client facing components with underlying relational database models and tools for electronic exchange, security, audit logging, and data quality. Data is accessible by enrolled providers through these web-based interfaces and through electronic exchange between the registry and the EHR.

The electronic exchange is emerging through a phased approach that currently is focusing on delivery of a patient immunization encounter through a one way HL7 message. This is supported by the current Meaningful Use initiative that encourages uptake of EHRs by Medicaid providers. Therefore, a bi-directional exchange that allows a provider to electronically query a state immunization registry to retrieve patient immunization histories is the next phase. Over the course of the next few years this will become more common, building infrastructure to support alternative parent access methods. However, currently a browser based user interface (UI) is the primary source of record access.

Establishing consumer accessibility to rapidly allow individual access to their immunization records in the state systems can be achieved by creating a separate UI. As mentioned earlier, there are a number of technical approaches, but given the fact that current immunization systems are secure and tightly managed, one

⁷ <http://www.cdc.gov/vaccines/programs/iis/stds/min-funct-std-2001.htm>

recommended approach separates the consumer-based access from the current provider approach. Specifically, a separate database and a separate UI that allows individuals to directly access their records (and those of their family) are optimal. This reduces the risk of unauthorized access into the immunization health records.

Creating a copy of the patient data that is synchronized daily outside a department of health firewall yet within a secure environment eliminates direct access to the primary data repository. It also allows some information to be removed as may be appropriate, or as required by state law (i.e., states have different legislation that governs what information can be captured in order to authenticate a user). This resource would contain all immunization records, although a policy could be established to remove some immunizations that might be considered sensitive. The point is that as the policy for immunization record sharing is implemented and evolves, the technical solutions also evolve. With this data, resource tools are required to enroll individuals, authenticate, monitor, and record actions. All such tools are in place with the current systems. Again these are specific only to the consumer-based data repository.

The next step is to implement individual access to their records. Access must be secure with only immunization history and forecasting provided with no presentation of identification or location data, and record access should be through any internet browser supported on computers, tablets, and smart phones. Parents and guardians should be able to access their family records after appropriate authentication. Figures 3 and 4 illustrate an example of a browser-based UI.

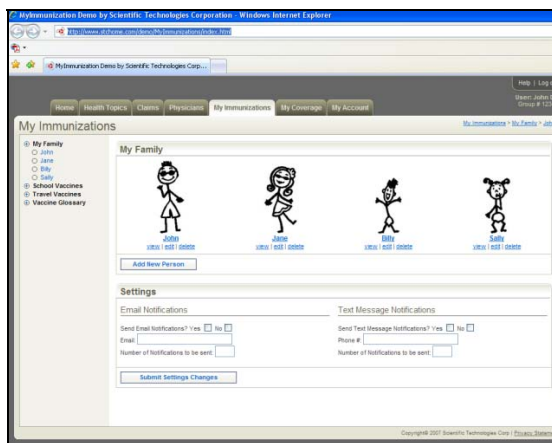


Figure 3. Example of a Browser-based UI.

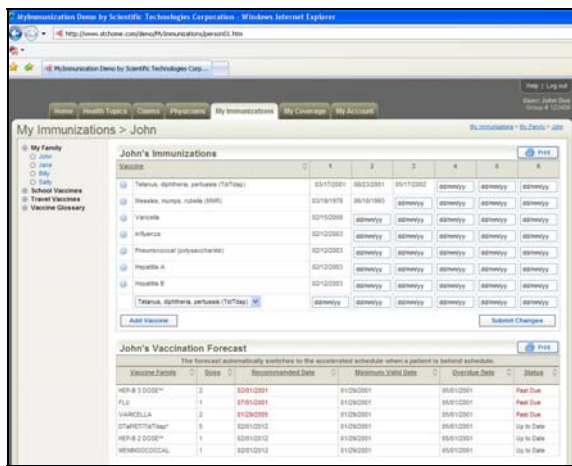


Figure 4. Example of an Individual Access Point to Immunization Records.

The second approach is a third party electronic exchange allowing for multiple avenues of distributing individual records. Before illustrating information to be disseminated to an individual, a technical approach to manage this community of users, and to request and deliver the actual record needs to be established.

The electronic exchange process can be identical to the current clinical EHR exchange processes. HL7 requests for information are processed by a state registry with the resulting record delivered to the requesting EHR if the patient matched the request. No record would be returned if the patient could not be found or uniquely identified. Expanding this to include individual requests significantly increases the volume and throughput, and expands the required resources to support this demand.

The solution is to move the exchange request to a third party broker or "middle man," thereby reducing the resources and the cost to support them. An option for this is to establish the third party broker as the single source from which a state registry would respond to a request for information from individuals, creating in effect an Immunization Record Exchange Service (IRES). The IRES would serve as the "clearinghouse" to manage all individual requests, eliminating the need for a state registry to manage a large number of new users. A single HL7 exchange between the IRES and the state system would be the pathway to providing the records.

The IRES would validate and authenticate a request and ensure that the full set of data necessary to uniquely identify the person is provided. Upon acceptance the IRES would issue a single HL7 query for the individual record. The state registry, again using a copy of the source system as recommended, would pull the record if available and return the information (or notification of no individual on file) through the standard HL7 message format.

The IRES then has the responsibility of delivering this information to the individual or requesting party. Requesting parties other than individuals would be expected to include insurance companies that provided enrolled member health record web portals (or PHRs), an HIE, a pharmacy or a grocery store that offered similar services to their community. It would not be necessary in every case for individual record retrieval to come through a single IRES. This could be one of a number of access methods allowing for similar direct requests from insurance companies, pharmacies, et al. However, there are advantages of using a single source access approach from which all requests are made — the most evident being one link into the state registry. A single access point increases the likelihood that record requests are complete as this source will manage all incoming requests and will ensure their accuracy and completeness before issuing a record request. In addition, this third party approach simplifies on-going communication by allowing more modern distribution mechanisms such as text messages and use of social media, thereby eliminating the need for state resources to manually engage in these activities, yet allowing for the services to be provided in partnership with the state. This third party approach offers all the advantages without any of the trouble.

Focusing on the individual immunization record delivery strategy becomes the responsibility of the IRES. Again this can be accomplished by the state or through any of the other electronic links that may be in place. It is not mutually exclusive although will be consistent. Immunization record delivery to the individual, once a request has been fulfilled, should not be constrained by a single technology. Records should and will be made available to health data vaults, PHRs, insurance company member-based web portals, consumer-based access points into HIEs, and kiosks in retail outlets such as pharmacies and grocery stores. Figures 5 and 6 illustrate two example record delivery options that are currently envisioned to be the most beneficial to empower individuals with their immunization records.



Figure 5. Example of a Smart Phone Application to Store and Access Records.

The first delivery option illustrated in Figure 5 shows the use of a smart phone on which the individual retains a copy of their immunization histories and those of their family. The data are stored locally on the phone and allow the individual to forecast what immunizations are past due, currently due, or next due. It would allow the

individual to request a record from a state in which they live. Optimally the request would be made through an IRES to ensure the information is complete and that the individual would receive alerts and information exchanges specific to immunizations through the most efficient and modern means available (i.e., text messages, social media).

The second example depicted in Figure 6 is the use of a tablet through a browser of which the user accesses their information from a web portal through their insurance company or a state registry with consumer access.



Figure 6. Example of Tablet Browser-based Access to a State Registry.

This application could also support expanded data collection such as adverse reaction, location information where immunizations were provided, and could offer the opportunity to expand the reach of public health by enlisting individuals to support a variety of data collection activities,⁸ any or all of which have the potential to support disease prevention programs ranging from obesity to VPD. In each case, the ease of use and access to information by individuals is where empowerment will surface.

Notable in any technical solution that allows individuals access to their information is the fact that all the technology and services currently exist. In short, technology is not a barrier. Cost is not a barrier either as the costs to implement them are insignificant when compared to the benefits that could be achieved. Sustainability costs will vary depending on the approach adopted and should include on-going user support functions such as Help Desk, Ask-the-Expert, 1-800, and social media exchange. Any expansion to include individuals should include a proactive campaign to educate and empower the individuals to support VPD programs.

⁸ Disease surveillance, dead animal reporting, foodborne illnesses, chronic disease reporting, lifestyle reporting.

Conclusion

Access to personal immunization data will have a number of direct benefits, including empowering individuals to improve their health and reducing the personal and societal impacts of disease. Furthermore, healthcare providers and insurers will experience a significant economic return on the limited investment required to implement such a solution.

Although there is ongoing debate relating to the potential costs and benefits associated with providing consumers access to their entire medical records, access to personal immunization records is a universally accepted concept. Enabling access to personal immunization records will provide a low-cost, low-risk, first step towards more broad-based access to personal health information. The economic and health benefits to individuals and communities associated with patient empowerment through information access will be profound. It will perhaps be the single most important health initiative to be implemented in the next decade.

About Scientific Technologies Corporation

Scientific Technologies Corporation (STC), an Arizona corporation established in 1988, provides domain expertise and information technology solutions to address complex real world problems in community, regional, state/provincial, and national public health programs. STC is committed to public health – our vision and mission is Advancing Health Outcomes through Information Technology with the goal to support worldwide disease management across all peoples and borders.

STC is an industry leader in developing, implementing, and supporting jurisdiction-wide public health information systems. The STC team offers a unique blend of health information technology engineers, systems architects, and developers as well as public health, clinical, and medical experts who excel in bringing state-of-the-art approaches and information to bear, while also creating new solutions, generating fresh collaborative insights, and producing an improved public health infrastructure.

STC is committed to the continuous improvement of our products and services through client feedback and on-going implementation and augmentation of emerging national standards and advancements in technology.

For more information, please visit www.stchome.com.