## Consumer Engagement

Key Points

- PHAs will face greater expectations on behalf of consumers for population, community, and even individualized data about their health, prevention, and risks.
- Providing consumers with data requires both a high level strategy and technical considerations to ensure information is useful and properly interpreted.
- As a matter of strategy, strive to make complex ideas easier to understand: choose pilot projects thoughtfully, talk to consumers to solicit their feedback, and, if possible, leverage other efforts such as consumer access to their EHRs and open government data initiatives.

The surge in consumer access to data will continue to sweep across the health and healthcare ecosystem. For public health, this means greater expectations on behalf of consumers for population, community, and even individualized data about their health, disease prevention, and risks. Social media will add yet another dimension to consumer health, where citizens use their social networking activity to construct their *own* depiction of health issues,[1] assemble their *own* health education material[2] (which may or may not have efficacy), or even tip off public health about adverse events.[3] Public health agencies (PHAs) need to be prepared to serve these new consumer markets with reliable and responsive data and advice. Public health data ranges from the individual to the aggregate, and across many domain areas.

Why do consumers want access to public health data? Parents want to get immunization histories (and forecasts) for their children for child care, camp, or school enrollment as easily as possible,
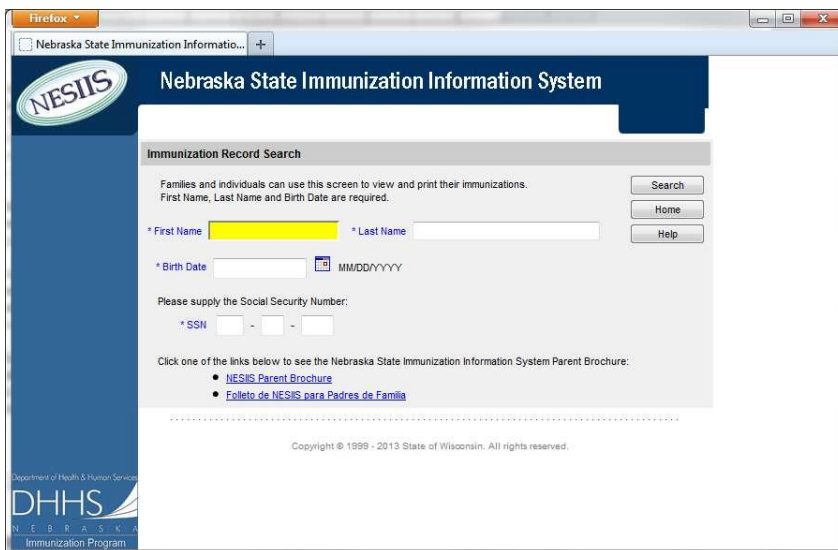
without provider involvement (see sample of consumer access to Nebraska State Immunization Information System). Cancer patients want to understand whether there are higher than normal occurrences of a particular disease in a particular location. Consumers want to know if their favorite restaurant has failed an inspection, or if their local hospital has higher (or lower) morbidity or mortality for particular procedures.

[1] For example, see https://flunearyou.org/

[2] For example, see http://www.patientslikeme.com/

[3] White RW, et al., *Web-scale pharmacovigilance: listening to signals from the crowd*, J Am Med Inform Assoc 2013;20:404-408.

Many people have a thirst for medical knowledge related to specific symptoms or conditions and increasingly turn to the Internet (as opposed to a healthcare professional) for this information. There are many other examples.

Providing consumers with data should be approached deliberately. Will they interpret the data correctly? Will the PHA be able to authenticate a consumer to ensure that, if the data is individualized, a consumer only sees their own personal data and data for their dependents? What if the PHA goes through all this trouble to make public health data available and no one looks?

There are technical considerations as well. Personal health records (PHRs) of various models continue to have relatively slow uptake. On the other hand, smart phones, tablets, and other mobile technologies continue to proliferate and provide handy, personalized tools for data access. Secure email products like Direct are starting to be deployed for physician-to-physician interaction and soon physician-to-patient interaction. Health Information Exchanges (HIEs) are beginning to aggregate data and make it available to consumers themselves. Meaningful Use will soon require providers to make encounter data available electronically to patients whether they ask for it or not.

Action Steps for State and Local PHAs

- **Develop an overall strategy for consumer engagement.** This strategy may be developed in conjunction with a larger jurisdiction-wide consumer data access initiative, and should include your jurisdiction's use of social media to engage with consumers, as well as more traditional online resources.
- **Make complex ideas easier to understand.** Most consumers do not have experience interpreting complex data and statistical information. Public health data offerings have to be straightforward and useful. Expect to experiment and revisit projects and approaches.
- **Choose pilot projects thoughtfully.** It is important for PHAs to experiment with consumer access applications without picking too many paths or going too far in any one direction. Survey the landscape to determine where the largest need seems to be, recognizing that consumers will articulate divergent and varied desires. Include in the scan any open government data initiatives to identify existing public infrastructure that might be leveraged.
- **Talk to consumers.** Consumer feedback is crucial to structuring useful services, but don't expect to necessarily get consistent opinions, let alone consensus. Examine consumer feedback critically and be sure to develop a thick skin!
- **Don't forget providers.** Providers will continue to be the gateway to consumers in most cases. They should be integrally involved in consumer health initiatives as they will likely be on the front line of explanation and support to their patients. It is also important not to allow initiatives to emanate from public health that cannot be readily supported in the community. Stage 2 Meaningful Use will drive the deployment of provider portals which will play an important role in consumer access to health information over the next few years.
- **Leverage other efforts and information.** For both individualized data and aggregate population data, the PHA does not necessarily need to be the face of public health data access. PHRs, HIE portals, and provider EHR systems will offer increasing opportunities for consumer

access to personal health data. Open government data initiatives provide third party developers the opportunity to create applications that engage consumers in ways that government applications often don't. A wealth of healthcare information is available on the Internet, though often it is not curated or conflicting. With limited resources, it is wise for PHAs to continue doing what they do best; provide legitimate, high-quality access to public health data to their traditional customers (providers, health plans) and encourage consumer access through those secondary sources.

Leadership Steps for National Agencies and Organizations

- Participate in national initiatives around consumer engagement, and be prepared to advise your stakeholders about emerging national activities.
- Work across agencies and organizations to ensure a more coherent face to consumers for the initiatives, activities, and information being aimed towards them in this arena.

More Information

http://www.healthit.gov/patients-families
http://www.naphsis.org/Pages/WebbasedDataQuerySystemsWDQS.aspx
http://www.healthit.gov/sites/default/files/consumer_mediated_exchange.pdf
http://www.healthdata.gov/

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