The increasing challenge of chronic disease

Public health challenges are characterized by multiple interacting behavioral, social, and environmental causes that go beyond traditional sectors or organizational divides. From obesity to respiratory health, addressing complex public health problems that affect diverse populations requires broad community participation. The rising prevalence of chronic diseases represents one of the most pressing public health problems facing the United States. According to recent reports, chronic disease accounts for 86% of the total healthcare costs (see Figure 1) and 7 of the top 10 causes of death in the US. With the prevalence of chronic disease projected to increase to nearly 48% of the population by 2020, public health officials and healthcare providers are seeking new approaches to combat these alarming trends.

Limitations of current chronic disease management

The current model for chronic disease management relies largely on primary care physicians to provide care to patients within increasingly shorter face-to-face visits. A physician spends just 15 minutes on average with each patient, which limits the opportunities for patients and physicians to go over their treatment plan, talk about lifestyle changes and root causes of their disease, or engage in collaborative decision-making about treatment modifications. Physicians also rely on self-reported data from patients about their medication and treatment adherence. These recall-based assessments of chronic disease are often susceptible to bias and errors, which limit providers from accurately understanding their patients’ current health status and their opportunities to optimize care. Additionally, patients often receive treatment plans and advice that include medical jargon or language beyond their reading comprehension, which makes following treatment plans challenging, especially for patients with limited English proficiency or literacy. Together, these factors, among others, have undermined the capacity of primary care providers and patients to address the growing chronic disease epidemic across the country.

People living with chronic diseases face similar, numerous barriers to successfully manage their condition. As such, people managing a chronic disease can feel frustrated, overwhelmed by the many obstacles, and exhausted from the required behavior changes, activity limitation,
and medication regimens, and the emotional or psychological burden that results from living with the disease. This is all compounded by the fact that many people manage their chronic disease in relative isolation, further magnifying feelings of frustration and lack of control.

Mobile health tools to track and support disease self-management

One way that providers and patients have attempted to overcome these challenges and to support chronic disease self-management is through the use of technology to track health indicators and symptoms outside of office visits. Using a variety of digital tools, from clinical decision support software to portable diagnostic technologies or sensors, providers can integrate the information to deliver more data-driven care. Through remote monitoring, providers are able to track patients’ symptoms in real time, better prioritize patient outreach, collect patient-reported outcomes, and make medication and treatment adjustments, without requiring an in-person visit. Learning about patients’ disease status and experience in between office visits can enhance providers’ ability to deliver more personalized care, which is especially valuable when caring for patients who live in rural settings or who have multiple chronic diseases that may limit their mobility.

Patients also now have many digital tools at their fingertips that have helped transform the way that they are able to manage their chronic diseases. An estimated 500 million people have installed health applications on their mobile devices, which support self-management, track symptoms and medication use, provide tailored education, feedback, and reminders, and connect with peers through larger social networks. Beyond mobile health apps, more sophisticated tools including wearable devices and medical sensors, such as those developed by Propeller Health (propellerhealth.com), now allow real-time, passive tracking of medication use, symptoms, and other relevant health data, all of which can be shared between patients and their providers. Using these digital health tools, patients are able to monitor and track their condition in a way that positions them as active participants in their treatment plan, ultimately helping to strengthen the partnership between the patient and provider teams.

From the individual to the collective: how data sharing leads to improved understanding and self-management

These types of tools have begun to revolutionize how patients share and participate as active citizen scientists in their own health experience. From websites and patient social networks to blogs and social media, patients now have multiple avenues to learn, share, and gain insight from other people living with the same chronic disease. A recent survey suggests that 80% of Internet users have looked on the Internet for health information, 34% have read about someone else’s experience about health or medical issues on a website or blog, and 25% have watched an online video about a health issue.

Online chronic disease communities represent one way that patients have used technology to shift from monitoring and managing their chronic disease in isolation to benefiting from insights generated by people living with the same disease around the globe. In recent years, a number of online chronic disease communities have been created by patients, patient organizations, providers, and nonprofits, which have helped fulfill the informational and social needs of patients and amplified the discoveries and experiences of individual patients in a way that has never been possible before.

One of the most successful online communities, PatientsLikeMe, currently supports 2,500 different disease communities and serves over 350,000 members. Founded over a decade ago, PatientsLikeMe was created to promote information-sharing between patients within disease-specific communities and to provide an online quantitative personal research platform to share patient-reported outcomes, find patients who have similar demographic and clinical characteristics, and learn from aggregated data reports.
From PatientsLikeMe to many other online communities and platforms, patients are beginning to explore how the health data that they collect can contribute to and help inform research studies. One site in particular, Crohnology, a self described “patient-powered research network” for patients with Crohn’s disease and colitis, offers patients the ability to ask and help answer research questions and participate in studies.

With over 7,000 patients in 87 countries around the world, Crohnology has helped capture 53,980 years of patient experience—significantly enhancing our collective understanding of self-management strategies for Crohn’s disease and colitis and contributing patient collected data towards a cure. These types of technology-based platforms can enable data collection at a more rapid pace and at a larger scale than traditional clinical studies. In a similar way, the Patient-Centered Outcomes Research Institute developed a national research network, PCORnet, which includes multiple patient-powered research networks that allow patients and family caregivers to help prioritize research questions, investigate their own health experience, and support the dissemination of results. We are only just beginning to see how patient-driven health data collection and research can transform the rate and scope of knowledge creation and rapidly move chronic disease research forward.

The value of digital health tools and asthma

The use of digital tools to collect patient-generated data and to inform health research is gaining particular traction within the respiratory disease community. Asthma, one of the most prevalent respiratory diseases in the country, has received significant attention recently from healthcare providers, public health officials, academic researchers, and patients for the opportunity to use digital health to empower patients to improve their self-management, reduce symptoms, and learn more about individual and community level asthma burden. Despite the availability of effective medications and compelling national guidelines, many studies have shown medication adherence rates to be under 30%, and nearly 60% of adults with asthma are uncontrolled. Poor adherence and the corresponding negative health impacts contribute to $56 billion in direct and indirect healthcare costs, making it one of the costliest diseases in the country.

This issue is further magnified by the fact that traditional data sources and data collection methods available for asthma management are severely limited in scope, time sensitivity, and functionality. Asthma diaries, which require patients to write down their symptoms, remain the primary mode of data collection, yet are completely dependent on unreliable patient recall. On a population level, reports from healthcare organizations on emergency room visits and hospitalizations remain limited despite the existence of an active and robust National Asthma Control Program. When available, these sources of data are often aggregated at the zip code level, have limited to no geographical information, and typically are over a year old, which limits the ability of public health departments to address local respiratory disease burdens.

In order to combat the variety of data limitations, digital tools have emerged to fill these gaps and to better support asthma management. From SMS-based medication reminder systems to multi-component management platforms that provide education, feedback, and communication between patients and providers, digital tools for asthma management play an important role in supporting patients to track and collect data about their disease status, and ultimately reduce symptoms, improve control, and enhance management. A growing body of literature has demonstrated positive results in self-management and clinical outcomes among patients using digital tools for asthma.
With advances in technology, new opportunities now exist to support real-time remote monitoring of asthma symptoms without burdensome diaries and record-keeping. Sensors placed on inhalers, such as those developed by Propeller Health, allow passive, objective collection of when and how frequently patients use their medications. When paired with a smartphone, these sensors can track the geographic location of inhaler use and corresponding weather and air quality data at the time of use. These data can then be transmitted to mobile apps and online platforms, which help display the information and provide insights on patterns of use and associated environmental triggers, all in real-time. By simply continuing to use their inhaler equipped with a sensor, patients now have access to a more complete picture of their medication use and symptom experience. With a tool like this at their disposal, patients have new opportunities to experiment, learn, and discover new insights and trends about their health experience and expand the knowledge of community level asthma burden.

An exciting project in Louisville, Kentucky, has begun to use Propeller Health’s sensor technology, paired with the growing citizen scientist movement, and a supportive and forward thinking municipal government, to engage citizens in helping to better understand and address asthma within the community. In recent years Louisville has been ranked in the top 20 “most challenging places to live with asthma” in the US and was named the #1 “Spring Allergy Capital” (AAFA). A whole host of social and environmental factors make Louisville and the surrounding Jefferson County difficult for the residents with asthma. As Louisville sits in the Ohio River valley, pollution from nearby coal and oil-burning industrial facilities and car emissions can accumulate, reducing the air quality and creating conditions that can trigger asthma symptoms. Reduction in tree canopy and rising temperatures also contribute to making Louisville a challenging place for residents with asthma to live, work, and play. On top of this, a recent health report by Louisville Metro Public Health and Wellness highlights a variety of additional social factors such as poverty and unemployment rates that limit access to healthcare and opportunities to lead healthy lives. The combination of these factors contribute to the high prevalence of asthma in Jefferson County, where over 10% of the population has asthma and asthma is the 4th leading cause of hospitalization.

Leaders in Louisville have grown concerned with the burden that asthma places upon the health, economic vitality and quality of life in their city, and recognize that it is a very important problem that needs to be addressed at the community level. Despite a strong commitment to improve the health of its citizens and to address the larger asthma burden, city leaders have been limited by the data available to track asthma within their community. Currently the city relies upon healthcare utilization data to assess the burden of asthma, however these data only offer information about where and how frequently residents go to the ER or hospital, not where they are experiencing asthma symptoms. In order to better understand local factors that impact asthma, city leaders have sought innovative approaches to collect data in a way that provides a more real-time and precise picture of citizens’ experience with asthma. In 2012, the City of Louisville, including Mayor Greg Fischer and Chief of Civic Innovation, Ted Smith, formed a public-private collaboration with Propeller Health and three local foundations including the Owsley Brown Charitable Foundation, Norton Healthcare Foundation, and the Foundation for a Healthy Kentucky, to find out whether an innovative asthma surveillance program that equipped local citizens with sensors to collect real-time data on inhaler use could help improve citizens’ daily symptoms and directly inform local policy decision-making.

Working closely with stakeholders across various sectors, this pilot program aimed to engage citizens of Jefferson County...
in collecting data to support their own asthma management, and to help fill the data gap on asthma burden at the community level. Over the course of 13 months, local citizens volunteered to be a part of the pilot program. Citizens were recruited through a number of avenues including Walgreens Pharmacies, community programs like the Family Scholar House, community events such as Healthy Hoops, and specialty clinics like Family Allergy and Asthma. By the end of the recruitment period, 140 citizens had volunteered to use the Propeller sensor for a year. During the year of data collection, the 140 citizens continued living their lives as they normally would—working, going to school, and playing in the community and taking their medication as needed. Each time citizens in the program took their medication the sensor captured the date, time, and number of puffs, and if the citizen had a smartphone, the location of use. These data were presented back to citizens in the form of a mobile application and web-based dashboard, both of which provided information on their current level of asthma control, medication adherence, personalized education, and the community burden of asthma.

Armed with a passive data collection tool and the analytical capabilities available on the app and dashboard, citizens had a new, data-driven opportunity to improve their asthma management and to support efforts to improve the breadth and scope of asthma surveillance data available in Jefferson County. At the individual level, the citizens in the program became more informed and aware of their asthma—from identifying specific asthma triggers to tracking their medication use—citizens benefited greatly from their involvement in the pilot program. Participants also benefited from the data collection efforts of their fellow citizens who were involved in the pilot program as their data could be shared at an aggregated, de-identified level to show where others in the community were experiencing symptoms. In this way, residents had access to valuable information beyond the scope of their own

Figure 6. AIR Louisville website. AIR Louisville https://www.airlouisville.com/
experience, which could help inform them about environmental risks present in the community.

At the community level, citizens contributed significantly to filling the surveillance data gap. Over the course of the program, the citizens’ sensors collected thousands of inhaler use events and tens of thousands of person-days of data. This data collection method has lead to the creation of the largest, most detailed database of asthma inhaler use in existence. By combining the aggregated, de-identified data with local socioeconomic and environmental data layers, city leaders were able to see patterns emerge about where, when, and why we see clusters of asthma activity across Jefferson County. Further, the sensor data paired with local data layers allowed city leaders to begin to test associations, identify specific social and environmental drivers of asthma, and ultimately see the great potential these data offer for informing city plans and strategies aimed at reducing asthma burden.

The pilot program’s promising results inspired leaders to explore opportunities to expand the program in order to reach a larger segment of the Jefferson County population with asthma. Thanks to a grant from the Robert Wood Johnson Foundation, an expansion of this pilot program, AIR Louisville (www.airlouisville.com), is currently underway with the goal of recruiting more than 2,000 participants, making it the largest citizen-science, community-focused asthma program ever implemented. AIR Louisville involves the City of Louisville, the Mayor’s office, the Institute for Healthy Air Water and Soils (IHAWS), Propeller Health, Louisville Metro Public Health and Wellness, the Community Foundation of Louisville, local employer partners, such as Brown-Forman and Papa Johns, local health plans such as Passport Health Plan, and local asthma specialty clinics, such as Family Allergy & Asthma. The collaborative program is adding new partners every day.

The primary goals of AIR Louisville are to improve citizens’ asthma self-management, to reduce asthma-related healthcare utilization and cost, to identify regional environmental drivers of asthma and to use the citizen-generated data to directly influence Louisville’s policy-making and intervention strategies. More specifically, city leaders are interested in using these data to help determine where to focus their attention and funding in order to have the most meaningful impact on asthma burden. For instance, using the pilot program data, city leaders in Louisville have begun to explore what the specific impact of improving air quality could be for residents with asthma. How many asthma attacks could be prevented if specific intervention were implemented to address the most relevant environmental triggers in the community? Where should the city plant trees within the county to have the greatest impact reducing asthma symptoms? These questions, among many others, can be explored in greater detail thanks to the aggregated, de-identified data collected through the AIR Louisville program. In this way, this data-driven approach for reducing asthma burden at the individual and community level can offer city leaders new opportunities improve the health and well-being for all of its citizens.

This direct connection between data collection and policy decision-making will strengthen the ties between citizens’ health experience and meaningful policy action. Accordingly, using the sensor and corresponding mobile app and dashboard, citizens in this program are able to play a larger role in the data collection and discovery process, both in terms of better understanding their own self-management and gaining valuable insights on drivers of asthma within Jefferson County. The larger community is also

Figure 7. AirBare. Future directions: citizen health scientists contribute asthma data to nationwide efforts.
able to benefit from this program thanks in part to the work of AIR Louisville’s nonprofit partner, IHAWS, which is distributing a number micro air pollution sensors across Louisville to capture more detailed data about air pollution levels. These data will be displayed on IHAWS open-source, open data portal to increase transparency and public awareness. A public art installation called AirBare, located in downtown Louisville combines the air quality data with the citizen-generated inhaler use data to display a real-time look at air quality in the city and how this can impact asthma. Making these data publicly available through visualizations in the AirBare art installation, citizens throughout Jefferson County have the opportunity to become more aware of local drivers of asthma and see the value and insights that citizen generated data can provide local city leaders.

With the promising results and potential of the program in Louisville, there is great interest in expanding this type of citizen-science, community-focused asthma program to additional locations across the country. Earlier this year, Propeller Health announced that it would build a national Asthma Risk Map for the United States, through which citizens can track how climate change may affect the frequency and severity of respiratory disease. Using the program in Louisville as a model, the company expects to partner with city leaders and local stakeholders to equip residents with sensors to collect crowd-sourced data on the time and location of inhaled medication use in cities around the country. Fueled by the citizen-generated data and using predictive spatial modeling techniques and open government data resources, Propeller Health will aim to identify areas in US cities where the impacts of climate change will likely be felt most acutely by people with chronic respiratory disease over the next 10 to 100 years and beyond. In this way, citizens will not only contribute to better understanding their own self-management and burden in their own community, but also help drive greater understanding and valuable insights related to the health impacts of climate change at a national scale.

**Conclusion: promise of citizen science for chronic disease management and prevention**

Advances in technology have begun to open the door for broader community participation in tracking chronic diseases. With sophisticated digital health tools in the hands of citizens, we are only just beginning to see the promise of how improved data collection and analysis tools can empower citizens to play a more significant role in informing their own self-management, enriching the understanding of chronic disease phenotypes by sharing their data within patient social networks, and guiding policy action. As key investigators of their own health experience, citizen health scientists are redefining the role that patients can play in advancing the treatment and understanding of chronic diseases, and substantially informing and rapidly moving chronic disease research forward.

Kelly Henderson, MPH, is passionate about exploring ways that digital health tools can support self-management of chronic illnesses, as well as address social and environmental determinants of health in communities. Prior to joining Propeller Health as a research coordinator, she worked at a social media data analytics company leading a collaborative project focused on analyzing real time social media data to inform public health communication and campaigns. She received her Bachelors degree from Duke University and her Masters in Public Health from University of California Berkeley.

Meredith Barrett, PhD, is passionate about using technology to better understand the intersection of health and the environment. She was a Robert Wood Johnson Foundation Health & Society Scholar at the University of California Berkeley School of Public Health and UC San Francisco Center for Health and Community, where she first began collaborating with Propeller Health. She completed her PhD in Ecology at Duke University, where she was a National Science Foundation Graduate Research Fellow.

Olivier Humblet, PhD, is a data scientist who is passionate about combining technology with data analytics to improve health. He was a Robert Wood Johnson Foundation Health & Society Scholar at the University of California Berkeley School of Public Health and UC San Francisco Center for Health and Community, and completed his doctorate in Epidemiology and Environmental Health at the Harvard School of Public Health.

Chris Hogg, MBA, is a digital health advocate interested in how new forms of health data are changing the relationship between physician and patient. As COO, he leads the company’s San Francisco office with an emphasis on product, data and implementation. Prior to Propeller Health he co-founded 100Plus, a mobile health company using personalized analytics to promote healthy behaviors, which was acquired by Practice Fusion in 2013. At Practice Fusion he built a data science group that created data products leveraging the company’s 80+ million patient clinical database. Prior to 100Plus Chris led the Cardiovascular Commercial Strategy group at Gilead Sciences. Chris holds a Degree in Molecular and Cell Biology from Brown University and an MBA from The University of Chicago.

David Van Sickle, PhD, is the co-founder and CEO of Propeller Health, a Madison, WI based company that is pioneering effective new digital health solutions to chronic respiratory disease. Previously, Van Sickle was a Robert Wood Johnson Foundation Health and Society Scholar at the University of Wisconsin School of Medicine and Public Health. From 2004-2006, he was an Epidemic Intelligence Service officer at the Centers for Disease Control and Prevention in Atlanta, where he was assigned to the Air Pollution and Respiratory Health Branch. Van Sickle received his PhD in medical anthropology from the University of Arizona in 2004. In 2011, he was named a Champion of Change by the White House for his work on innovation.
References


3. S.Y. Wu and A. Green, Projection of Chronic Illness Prevalence and Cost Inflation (Santa Monica, Calif.: RAND, October 2000)


7. https://www.patientslikeme.com/


