

### **SUMMIT REPORT**

June 6–7, 2016



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Imagine a world where every child has an equal opportunity to survive and thrive. Imagine a world where we harness data, from cells to cities, to provide innovative approaches that improve the health of populations. Imagine a world where Precision Public Health can bring better health for all.



# Opening Remarks

There are two big reasons why this summit had to happen. The first is that we face a threat that precision medicine will further increase inequities in health at home and abroad. The second is that, despite this threat, we have an opportunity to use big data and other precision medicine technologies for everyone's benefit.

The world has made great progress in the past 15 years, but nearly 6 million children under the age of 5 still died in 2015, mostly because they were born into poverty. They lived in communities where infectious diseases are still prevalent, health care is still limited, and nutrition is often still poor.

Not every global health problem requires delivering or developing new medicines, but solving these problems always involves gathering good information about what is driving them. It may be that a population has many babies that are dying from diarrhea or pneumonia, which we can guard against by promoting an intervention as low-tech as breastfeeding.

Gaining knowledge about why children in poor countries die will enable us to get the right interventions to the right people in the right places to save lives. Any discussion about health in the first thousand days of life has to include not just infectious disease and preterm birth, but also malnutrition. This means using a precision approach to understanding micronutrient deficiencies and the most efficient ways to target them.

These are just a couple of examples of how better data can lead to better outcomes. This approach works as well in urban America as it does in rural Africa. Whatever the context, and whatever differences we may have, we can agree that the better we understand the causes of the problems we are trying to solve, the more effective our responses to them will be.

### Susan Desmond-Hellmann, MD, MPH

CEO, Bill & Melinda Gates Foundation



# Opening Remarks

As we identify examples of the type of innovation we seek in Precision Public Health, they share three qualities: They tap into data and technology to reveal solutions and break down barriers to cooperation. They enable new partnerships to arise. And they focus on solving real problems for real people.

The President has challenged us to build a new structure that fundamentally changes the way research is done – how we understand prevention – so that the benefits of science will be accelerated for everyone.

This has several important principles: the availability of data and new technologies, bringing diverse collaborators together, and engaging the people who are most affected the problems that are under study.

We are here to scale what innovators in the public and the private spheres have already created, to explore how data and technology can speed their work and to bring all the different actors who can play constructive roles together.

If we work together and find ways to harness all the data and technologies that are emerging, we can shift from admiring our problems to solving them. And we can make sure every child can survive and thrive.

"

### Claudia Williams, MS

Senior Advisor, White House Office of Science and Technology Policy



# Opening Remarks

To date, precision medicine has focused on increasing the precision and the number and types measurements on the individual – telescoping down with increasing clarity to define the biology of the individual person that can help us understand their health and more specifically how to prevent and treat disease.

In this summit, we will spend some time telescoping down, but we will spend more time telescoping back out – to understand the individual in the context of their family, their community, and the social, environmental, and behavioral factors that we also know are important to health.

These are not opposing approaches – in fact, only through being able to telescope down to the genome and the microbiome and then back out to the family and the community will the power of precision medicine come into focus.

# These are amonging concepts acch of voluments

These are emerging concepts – each of you will see them and understand them from your own perspective. We are not presenting a finished product here; rather, we're asking you to contribute your voice to defining what's possible.

All of us who have worked to organize this meeting feel a compelling sense of urgency to address our most important public health challenges. And we believe bringing the best in innovation to bear on these problems will yield important solutions.

### Kirsten Bibbins-Domingo, MD, PhD, MAS

Professor of Medicine and Epidemiology and Biostatistics, University of California, San Francisco Director, UCSF Center for Vulnerable Populations



## Who Attended?

The attendees of the Precision Public Health Summit came from a wide range of fields and brought with them a variety of perspectives. Representatives from public health, academia, community, government, technology, and philanthropic foundations traveled to the University of California, San Francisco (UCSF), from across the US and around the world to discuss the state and future of Precision Public Health. This unique mix participated in provocative and productive discussions and breakouts that furthered the field in new and exciting ways.









### Summit Statistics

Attendees came together from all over the spectrum of Precision Public Health. Over the course of the summit, they connected, discussed, and shared ideas. Many committed to next steps to move the field of Precision Public Health forward.





**PUBLIC HEALTH** AND COMMUNITY





## Key Themes

The summit's presentations and discussions spanned a range of topics, but a spirit of inspiration and motivation infused all of the discussions.

More important, a sense of urgency about the public health challenges to be addressed in the first 1,000 days of life – and the need to bring together the best minds to address these challenges in innovative ways – permeated the summit.















### Theme 1: Social Justice

### OVERVIEW

Big data has the potential to empower disadvantaged communities with empirical evidence of social inequity to inform the health of the communities. Drawing upon lessons learned from the Flint water crisis, the question for communities becomes, "Who will help me once I have the data to prove there is a public health issue? Who are the advocates for social good?"

Through equitable inclusion and attention, Precision Public Health has the potential to be a democratizing force. The more comprehensive information we have, the better we will be able to serve everyone and target meaningful intervention and prevention.

Social justice becomes a research calibration tool, aligning the work of precision medicine and public health in shared goals and action. We need to align on standard metrics for health and its social determinants in order to ensure that this data is collected every time and in all circumstances.

#### **RELATED BREAKOUT DISCUSSIONS**

Return on Health (ROH): Defining a New Evaluation Metric (#4)

Identifying Ways to Partner Neighborhood Investments with Public Health (#8)

Defining a New Socio-Emotional Sensor (#10)

### Theme 1: Social Justice

### "

I think when you understand what is happening, knowledge gives us the power to intervene. It's like, 'This is something I can take and sound the alarm on it and use to find solutions that are going to work.' "

### Nadine Burke-Harris, MD

### "

So you see you have a high rate of asthma [in a neighborhood], what do you do? Who do you tell? Who cares? "

### **Hope Williams**

### "

I like the idea that we can use big data and digital health approaches, even in potentially for-profit ways, and still have an end-goal of disparities reduction. In fact, big data won't work unless there is social justice. "

### **Courtney Lyles, PhD**

### Theme 2: Data Infrastructure and Integration

### OVERVIEW

Creating data infrastructure is about building knowledge networks within which researchers in precision medicine and public health can quickly discover, easily access, and seamlessly integrate relevant data, and learn from and build on the knowledge and experience of others.

An integrated data hub is highly contingent upon the purpose, use, and expected goal of the outcomes. However, it also needs to incorporate large swaths of seemingly disparate data sets because we simply do not know what surprising and useful patterns may emerge until we look at the data in aggregate and apply precise public health solutions to solve the problems that emerge.

Successful infrastructure will support reliability and refinement. In order to ensure that we are accessing good data, the hub will need some measure of ensuring "minimum viable reliability." Moreover, as new knowledge emerges in a particular space, the data will need to be constantly refreshed to represent the best available information.

### RELATED BREAKOUT DISCUSSIONS

Virtual 1,000 Days: Integrating Data into Decision Support (#5)

Civic Informatics for Health: Defining a Governance Framework (#6)

Defining Success Criteria for Precision Public Health Infrastructure (#7)

Defining a Child Health Collective Impact Hub (#9)

### Theme 2: Data Infrastructure and Integration

### "

It's not sexy to create or to fund a hub, but it's necessary to make Precision Public Health a reality. "

### Anda Kuo, MD

### "

How do you fund infrastructure when everything is in terms of projects? What is the role that everyone takes? There's a disconnect between what's needed and who will fund what. This is about nodes and spokes. "

### **PPHS Attendee**

### "

You have to go from silo to ecosystem. You have to have systems imagination first, not just delivery imagination. "

**Richard Tyson** 

### Theme 3: Scope and Alignment

#### **OVERVIEW**

A shifting perspective in health care has been emerging in recent years – from providing treatment for individuals to advocating for prevention across diverse populations, from managing symptoms to uncovering disease mechanisms. Precision Public Health offers the opportunity to bring together these emerging trends in health care with innovative advances in public health, building new partnerships, sharing tools and methods and lessons learned, rather than continuing to operate in traditional silos. Precision Public Health focuses on the holistic interplay of biological, environmental, and social determinants of health. With this emerging definition comes the opportunity to create new tools for capturing the data needed to measure the environmental and social aspects of health at the population level.

Precision Public Health is an emerging movement, gaining definition as it grows. A working understanding of Precision Public Health will focus on specific and actionable principles rather than attempting to arrive at an allencompassing definition. All constituents must participate in building out this space in order to ensure equal representation across the sciences and community. Establishing a shared language can help integrate the different groups, combining the needs and perspectives of precision medicine and public health, thereby creating a platform for collaboration, best practices, and success. In order for Precision Public Health to be successful, we must become involved in the doing, not just the defining. We bring definition to the space of Precision Public Health through our actions, moving our work forward with a unified perspective. Many of us are already doing this work; we must leverage our knowledge and experience within this space, share it with others, and shine light on the areas that need focus.

#### **RELATED BREAKOUT DISCUSSIONS**

Building a Working Definition of Precision Public Health (#1)

Return on Health (ROH): Defining a New Evaluation Metric (#4)

Defining Success Criteria for Precision Public Health Infrastructure (#7)

Defining a New Socio-Emotional Sensor (#10)



### Theme 3: Scope and Alignment

### "

The paradigm is shifting on what medicine is. For so long, medicine was treating people once they were sick, but medicine should be about keeping people healthy. "

### Elizabeth Baca, MD, MPA

### "

Socioeconomic status is the most powerful predictor of disease, disorder, injury, and mortality we have. "

### Tom Boyce, MD

### "

Schools, pharmacies, stress, income levels, housing...Precision medicine discussions reaching elements that really impact our health. "

### Atul Butte, PhD, MD

### Theme 4: Data Sharing

### OVERVIEW

There is a growing culture shift toward data sharing. From knowing what data is being captured and how to access it, to volunteering an organization's or individual's data sets, people want to give and be given access to the data that exists. Researchers and public health advocates cannot provide the most meaningful interventions and policy recommendations without a holistic view of an issue. We cannot have social justice and community engagement without giving citizens access to their own data.

We need to think about the ethics of data sharing and rethink who owns and controls data. Precision Public Health is not achievable without comprehensive data sharing and, to varying degrees, accessing community-level and self-reported data. Doing that requires social license for government agencies to combine and mine public data sets. However, when working with vulnerable populations – depending on the data being collected and analyzed – negative consequences could ensue without appropriate protections. In order to safeguard vital resources, it is necessary to establish clear ethics surrounding the data. Intelligibility is just as important as accessibility. It's not just about making data accessible, but also ensuring that the data is clearly understood. Just because data is sharable does not mean it is actionable. We must be mindful of the types of data and the presentation of that data with respect to audience and outcome.

#### **RELATED BREAKOUT DISCUSSIONS**

Integrating Environmental Data for Government Changes (#3)

Civic Informatics for Health: Defining a Governance Framework (#6)

Attack Asthma: Integrating EHR and Legal Case Data to Identify Intervention Targets (#11)



### Theme 4: Data Sharing

### "

The role of the government is to make data available to people. "

### Tracey Woodruff, PhD

### "

Until today, I had no idea they had all that data. "

Robert Kahn, MD

### "

Five percent of the budget has to be used to make data. "

Atul Butte, PhD, MD

### "

I have birth data in San Francisco, and I want to make it useful. "

Tomás Aragón, MD, DrPH



### Theme 5: Community Engagement

#### OVERVIEW

Community leaders must be engaged in the design of research and intervention in order for them to be meaningful and effective to the populations they aim to serve. Educating and actively partnering with communities – using relevant tools, best practices, and participatory design methods – will ensure success.

Community members already are doing inspiring work. Moving beyond the frustration with particular civic and political processes, communities and their leaders have used new technology and data to take matters into their own hands and improve local health issues and outcomes. Precision Public Health partners have an opportunity to build upon this foundation and empower and engage communities by creating visibility and accessibility of research and data resources while gaining a hyper-local perspective within a community-defined problem area. Establish best practices and principles to ensure consistent and equitable practice when engaging with communities. To avoid "reinventing the wheel," there is an opportunity to craft and share what we know about how to engage with communities and their leaders in a respectful, ethical, and productive manner. Funders also could be encouraged to include requirements that help drive forward some of these best practices of community engagement.

#### **RELATED BREAKOUT DISCUSSIONS**

Design Principles for Engaging Communities in Precision Public Health (#2)

Identifying Ways to Partner Neighborhood Investments with Public Health (#8)

Precision Social Justice Tool Kit (#12)



### Theme 5: Community Engagement

### "

In order for Precision Medicine to succeed, we need the population to participate. "

### Nancy Adler, PhD

### "

For us, it's not about research that's being done to people or to public health, it's about research being done with people and with public health. "

### Laura Jelliffe-Pawlowski, PhD

### "

Sometimes I feel like we don't necessarily need new pots of money, we need a different set of design principles for these public health services. "

### Claudia Williams, MS

### Theme 6: Meaningful Partnerships

#### **OVERVIEW**

Precision Public Health cannot emerge in a silo. It is, by definition, interdisciplinary, spanning across public and private sectors, penetrating aspects of academic research, clinical medicine, urban planning, and social engagement. Partnerships might be aimed at exploring the bounds of current practice, sharing relevant data sets, generating new funding sources for future projects, and investigating desired outcomes at the individual, family, and community levels.

Knowing that each partner will have distinct but legitimate goals and drivers, the goal will be to create partnerships that are imbued with shared significance and meaning. We must share and learn from past partnership failures in order to build a foundation for success of new and future partnerships.

Attention to the social determinants is currently underemphasized in existing partnerships. In order to ensure that the promise of social justice is realized, we need to establish principles of partnership that are grounded in an understanding of the social determinants of health. Working at a hyperlocal level in community-academic partnership (e.g., UCSF and Bay Area) provides further opportunity to integrate relevant social determinant research and insight.

### **RELATED BREAKOUT DISCUSSIONS**

Attack Asthma: Integrating EHR and Legal Case Data to Identify Intervention Targets (#11)

Identifying Ways to Partner Neighborhood Investments with Public Health (#8)

Design Principles for Engaging Communities in Precision Public Health (#2)



### Theme 6: Meaningful Partnerships

### "

One of the major speed bumps in this field is the lack of appropriate partnerships and multiple perspectives coming together to create ideas that no single perspective can produce. "

### Tom Boyce, MD

### "

Above all, everything we do depends on partnership – and we all need to play to our strengths. "

### Susan Desmond-Hellmann, MD, MPH



## Breakout Groups

Through the unconference format, summit attendees decided which topics and initiatives excited them and selected 12 breakouts from a list of 21. Each of the breakouts prompted healthy discussion and established relationships, laying the groundwork for solid progress to continue after the summit.











### Breakout 1:

# Building a Working Definition of Precision Public Health

### DESCRIPTION

At stake in crafting this definition was not only a mutually agreed upon alignment in terms of the bounds and scope of Precision Public Health but also attaching action, direction, and orientation to the definition so it could truly become a working definition for practitioners in the field.

#### GOAL

Explore the creation of a definition of Precision Public Health that includes scope, limits, context, overlap, and differences.

#### **BREAKOUT LEADERS**

**Tarun Weeramanthri, PhD** Chief Health Officer, Western Australian Department of Health

### Katherine Hempstead, PhD

Senior Advisor, Robert Wood Johnson Foundation

#### Jimmy Rosen, MPH, MBA

Deputy Director, Program Related Investments, Bill & Melinda Gates Foundation

#### FACILITATOR

#### Lindsey Mosby, MS

Executive Strategy Director, Health Practice Lead, frog









### **Breakout Outcomes:**

# Building a Working Definition of Precision Public Health

### **KEY THEMES AND DISCUSSIONS**

Participants explored crucial concepts and built a diagram and a working definition from which future iterations could stem.

Clear divisions emerged between clinicians and academics on the side of precision medicine and public health practitioners, resulting in the adoption of a hybrid reconciliation term: "Precision Health." Other terms discussed included "Precision Population Health."

"Precision Health" sits at the intersection of two perpendicular lines – one that moves from Precision Medicine to Precision Public Health, and another that moves from Personal Health to Population Health. This diagram is intended to be instrumental in helping to assess current initiatives and build out the constitutive elements surrounding each point.

#### **NEXT STEPS**

Establish team governance, clarify the mandate, and ensure participation is sanctioned by all necessary individuals.

Compare working definition against existing initiatives or organizations, and pilot this definition on one of these programs (e.g., low infant birthweight), placing it at the center of the diagram to see if all pieces are there, and identify gaps.

Present diagram and definition at various conferences, summits, and workshops to add more voices, opinions, and insights into the evolution.



### **Breakout 2:**

Design Principles for Engaging Communities in Precision Public Health

#### DESCRIPTION

Community engagement has emerged as an essential element in Precision Public Health. However, initiating and maintaining these partnerships requires careful attention to a variety of factors in order to ensure a safe, successful, and mutually beneficial engagement.

#### GOAL

Define design principles and best practices necessary to build community – academic partnerships for health equity.

#### LEADERS

**William Riley, PhD** Director, Office of Behavioral and Social Sciences Research, National Institutes of Health

**Paula Fleisher** Navigator, UCSF

### FACILITATORS

**Megan Bontempo** Visiting Healthcare Strategist, frog

**David Steuer** Executive Director, Healthcare Practice Lead, frog





### **Breakout Outcomes:**

Design Principles for Engaging Communities in Precision Public Health

### **KEY THEMES AND DISCUSSIONS**

Fostering a culture of trust, safety, and respect is paramount to community engagement. Research scientists and academic collaborators should approach new partnerships with social sensitivity and acknowledgment of structural and situational barriers that might impede or limit interactions.

Garnering the support of local public officials is vital to the success of community partnerships. It will be important to identify thought leaders within the target community to generate interest and build trust as well as work with regional governing bodies that can help sanction and support activities.

Crafting a shared language and adopting a communication style that is intelligible and accessible to all participants will help drive successful community engagements with a focus on empathetic listening and storytelling practices.

#### **NEXT STEPS**

Build community engagement models into research proposals and drafts of new initiatives.

Identify sympathetic funding sources within the community that can help with the logistical and structural barriers to engagement that communities might face.

Capture best practices from proxy Precision Public Health initiatives such as the Preterm Birth Initiative (PTBi) at UCSF and apply them to another public health challenge.



### **Breakout 3:**

# Integrating Environmental Data for Government Changes

### DESCRIPTION

Influenced by the presentation of many successful models layering environmental and social data, this session was convened to think through how individuals might leverage existing data technologies to illuminate problems, garner support, and drive change within their communities.

#### GOAL

Define three to five strategies to engage communities with their environmental data in order to influence government change.

#### LEADERS

#### Tim Dye, CCM

Sr. Vice President, Chief Business Development Officer, Sonoma Technology, Inc.

#### **Tracey Woodruff, PhD, MPH** Director, Program on Reproductive

Health and the Environment; Professor, UCSF

### FACILITATOR

**Brian Pridgen MD** Visiting Healthcare Specialist, frog

**Carlos Elena-Lenz** Principal Technology Strategist, frog





### **Breakout Outcomes:**

# Integrating Environmental Data for Government Changes

### **KEY THEMES AND DISCUSSIONS**

Creating sensor-rich environments and leveraging environmental data to create change will require sensitivity to privacy.

Establishing a shared language will be vital to ensuring effective communication between research scientists, communities, and the public.

Extract best practices from existing community-based applications (e.g., Tinder, Kickstarter, etc.) to apply toward the development of an open-source data-sharing and crowdfunding platform.

#### **NEXT STEPS**

Review current and existing tools (e.g., Humanitarian Data Exchange, Cal Enviro Screen) to identify which might be useful to share with breakout leaders and participants to further the work.

Drawing insights from the Opportunity Project and Cal Enviro Screen, create a similar open-source, data-sharing platform focused on generating peer-to-peer support and connecting communities with research scientists, academic institutions, and relevant organizations to help address problem areas.

Look to analogous social media apps to think through and create a space for connecting community members with vested subject-matter experts and relevant affiliates.

Leverage existing platforms for crowdfunding initiatives to help generate visibility, momentum, and support for initiatives, as well as quantifiably demonstrate the value of a given initiative.

Use social communication tools like hashtags to help community members raise awareness and become a backchannel for scientific, academic, and governing stakeholders who want to keep "an ear to the ground" of the community.



### **Breakout 4:**

### Return on Health (ROH): Defining a New Evaluation Metric

#### DESCRIPTION

The annual expenditure on health care in the US is nearly 4 trillion dollars. How do you make the case for allocating money to things like mold-free housing and safe neighborhoods? In what sense can that be considered healthcare?

#### GOAL

To create a new universal metric beyond simple financial measures.

#### LEADER

lya Khalil, PhD Chief Commercial Officer, Executive Vice President and Co-Founder, GNS Healthcare

#### FACILITATOR

Tim Morey, MBA Vice President, Innovation Strategy, frog













### **Breakout Outcomes:**

### Return on Health (ROH): Defining a New Evaluation Metric

### **KEY THEMES AND DISCUSSIONS**

Return on Health (ROH) is a modern metric that encompasses the emerging holistic sensibilities of health – from survival to thriving.

ROH can be used to justify spending to prevent chronic conditions instead of waiting for them to develop and then treating them (e.g., preventing the conditions in people's homes that cause asthma rather than waiting for children to get asthma).

ROH is a long-term measure that may not pay off for decades, and this is at odds with the needs of organizations and payers to realize the returns on their investments more quickly.

ROH can become the gold standard by which every organization seeks to optimize its actions.

#### **NEXT STEPS**

Create a formula or web-based tool to provide clinicians, academic researchers, and other relevant stakeholders a new way to calculate the value of health.

Do concept testing with this new formula or web-based tool. Take it out to providers, patients, and communities for validation. Iterate and further refine based upon findings.

Once a successful working model has been established, evangelize it to the industry (e.g., white paper or tool kit).



### **Breakout 5:**

# Virtual 1,000 Days: Integrating Data into Decision Support

### DESCRIPTION

Expanding upon an existing data-simulation and prediction tool, this session focused on identifying relevant types of data and possible outcomes and generating models to help extend the project.

#### GOAL

Identify key features and data necessary to create a decision-support tool.

#### LEADER

**Donald S. Burke, MD** Dean, Graduate School of Public Health, University of Pittsburgh

#### FACILITATOR

David Sherwin Frog Fellow













### **Breakout Outcomes:**

# Virtual 1,000 Days: Integrating Data into Decision Support

### **KEY THEMES AND DISCUSSIONS**

As a prediction tool informed by real data, this type of simulation can generate actionable knowledge for parents, providers, and policymakers to inform decision-making and help focus and target interventions.

Adding a text-based input from parents and caregivers could serve as an excellent platform enhancement, adding an additional predictive layer to existing data through the incorporation of real-time insights and feedback.

#### **NEXT STEPS**

The the city and county of San Francisco has a large amount of relevant birth data that could be plugged into this platform to either be used as a hypothesis generation tool for researchers or guide decision-making surrounding initiatives targeting the first 1,000 days.

Connect interested parties (e.g., Dell, Rafael Lopez) with Don Burke to build and extend models.

Identify other key sources of regional or geographically specific data that could be incorporated into the existing model and implemented to begin informing policy and change at a local level.



### **Breakout 6:**

### Civic Informatics for Health: Defining a Governance Framework

### DESCRIPTION

Comparing and contrasting between the UK and US political and social climates, the group examined the potential benefits of a civic informatics framework that would make use of licensed data sets shared among stakeholders to drive widespread and interconnected outcomes.

#### GOAL

To define a governance framework for actionable, high-resolution information on preventive interventions, community-wide.

#### LEADER

**Iain Buchan, MD** Clinical Professor in Public Health Informatics, University of Manchester

### FACILITATOR

**Richard Tyson** Principal Strategy Director, frog






# Civic Informatics for Health: Defining a Governance Framework

# **KEY THEMES AND DISCUSSIONS**

Civic informatics is a concept that merges system data (top down) and community data (bottom up). A Precision Public Health initiative should be informed and supported by a civic informatics commission that helps unlock relevant data and drive collective social action.

We need to have a holistic civic imagination that is both inclusive and aware that there are multiple layers of benefits of actions taken at the individual level. In this way, public health is converted into civic health when citizens help set the agenda for what types of government data should be combined and tracked to prioritize health issues that matter most to the community.

Differences in social, political, and governing conditions create different possibilities for enacting public health solutions.

Community engagement and transparency regarding use and benefit are key accessing to community health-related data that is essential to the informatics framework.

#### **NEXT STEPS**

Identify funding sources to develop a pilot program of connected "sister cities" that are already engaging in aspects of a creating civic informatics (e.g., Cincinnati, Manchester UK).

Use lessons learned through the sister-city pilot program to develop an exportable tool kit that can help inform programs of this kind in other areas.

Interested parties could reach out to Rob Kahn and Iain Buchan to discuss the possibility of connecting Cincinnati and San Francisco under this sister-city pilot program.



# Breakout 7:

# Defining Success Criteria for Precision Public Health Infrastructure

# DESCRIPTION

This group primarily focused on how to bridge the gap between big-data processing and the promise of new insights given the lack of public health technology infrastructure to implement proposed changes.

## GOAL

Define "infrastructure," identify the constitutive elements, and begin to establish success criteria.

#### LEADER

**Mike Fried, MS** Chief Information Officer, Baltimore City Health Department

## FACILITATOR

**Richard Tyson** Principal Strategy Director, frog









# Defining Success Criteria for Precision Public Health Infrastructure

# **KEY THEMES AND DISCUSSIONS**

Given the multiple layers of infrastructure necessary to support change related to Precision Public Health data, the unity of action will likely begin at the city level.

A movement from siloed data, knowledge, and action toward a systemic and shared model is necessary to connect the diverse stakeholders.

How can public health agencies can take the lead in Precision Public Health? An early conceptual framework (loosely termed the "maturity model") outlined what types of proficiencies public health agencies might need to enhance/acquire to take a leadership role in this movement, such as better data infrastructure and new data scientist roles, increased capacity for building and maintaining partnerships across local government agencies, and new funding streams to increase the visibility and capacity of their work.

#### **NEXT STEPS**

Identify exemplars of infrastructure.

Develop the conceptual model based upon the criteria outlined by the group.

Publish and present this model to be shared with multiple stakeholders.

Apply the model to an actual on-the-ground program within a pilot city.



# **Breakout 8:**

Identifying Ways to Partner Neighborhood Investments with Public Health

# DESCRIPTION

With more than \$200 billion invested annually in low-income communities and more than 4,000 community developers that do not currently take health into account, this session focused on looking at opportunities, barriers, and metrics that public health experts could use to help guide these investments and demonstrate efficacy and impact.

# GOAL

Identify most effective ways to partner neighborhood investments with public health, medical researchers, and practitioners.

# LEADER

**Doug Jutte, MD, MPH** Executive Director, Build Healthy Places Network

# FACILITATOR

**Stephanie Lewis** Creative Director, frog





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Identifying Ways to Partner Neighborhood Investments with Public Health

# **KEY THEMES AND DISCUSSIONS**

Any investment in a community should involve the community; it is therefore important to identify a community ambassador to liaise with public health officials and generate recommendations.

There needs to be a shift in focus from affordable housing to affordable communities. Investment recommendations should be expanded to include accessibility, food scarcity, and availability of green spaces.

Collecting data at the community level is crucial to informing new initiatives and demonstrating impact, but including a social justice angle is essential. We need residents to support the data collection, but many people do not trust the government or organizations that would collect the data. There a belief that data can't be safeguarded. How might we create transparency without penalty?

#### **NEXT STEPS**

Identify similar best-practice collaboration model (e.g., Aging in Place).

Identify trusted intermediaries that can safely gather, analyze, and report personal data.

Make actionable connections (e.g., HopeSF and the Purpose Built Communities).



# **Breakout 9:** Defining a Child Health Collective Impact Hub

## DESCRIPTION

This session looked at collective impact using the precision medicine lens to help focus and narrow it. The group developed a model for what a collective impact hub would like and what it should include.

# GOALS

Identify key functions of a collective impact model through a Precision Public Health lens; identify stakeholders and potential barriers and opportunities.

## LEADER

**Ivor Horn, MD, MPH** Medical Director, Center for Diversity and Health Equity, Seattle Children's Hospital

**Anda Kuo, MD** Director, Child Health Equity Collective; Professor of Pediatrics, UCSF

# FACILITATOR

David Sherwin frog Fellow













# Defining a Child Health Collective Impact Hub

# **KEY THEMES AND DISCUSSIONS**

The collective impact model is about community interventions that could have clinical impact.

Building trust among stakeholders could present a significant challenge to a successful partnership. Start with existing partnerships with strong foundations and where the parties are already aligned on metrics and outcome measures.

Use quantitative data and predictive models to build support and drive consensus among stakeholders and potential funders.

#### **NEXT STEPS**

Conduct a detailed literature review to see if this approach has been used, and extract any lessons learned, or identify the reasons for failure.

Pick the top two or three issues in pediatrics with community partners who are considering doing a collective impact approach to generate a community-based intervention that could have potential clinical impact.

Extract the model and extend it into the funding and implementation phase.

Research, Publish, Pilot – stress-test the model and build the collective infrastructure, publish the model in a white paper, and pilot the program in a smaller city; learn-iterate-improve.

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# Breakout 10:

# Defining a New Socio-Emotional Sensor

# DESCRIPTION

Although socio-emotional exposures are just as important and prevalent in terms of risk factors for early development and health, most monitoring is focused on physical-chemical exposures. To address this disparity, the session brainstormed a broad range of technological solutions, both existent and aspirational.

## GOAL

Generate ideas for the measurement of risk of protected factors at three levels: individual child, family and caregivers in contact with that child, and communities and neighborhoods that surround that family.

## LEADER

Tom Boyce, MD Chief, Division of Developmental Medicine, UCSF

# LEADER

**Tim Morey** Vice President, Innovation Strategy, frog







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# Defining a New Socio-Emotional Sensor

# **KEY THEMES AND DISCUSSIONS**

Existing sensing technologies and infrastructures potentially can provide valuable data on psychosocial and emotional well-being (e.g., Binky 2.0).

Reciprocity, or ensuring that useful and appropriate information is being fed back into the community, is one of many crucial design elements.

Data analysis should be converted into "parent-friendly language," rather than charts and graphs, to help inform decision making and behavioral changes within the home.

### **NEXT STEPS**

Conduct some community-based participatory and user-centered design research to identify the kinds of approaches for measuring socio-emotional environments that would be acceptable to communities.

Begin mapping existing data that could be built into the approach, including electronic medical records, Google street views, Google searches, etc.

Develop a prototype of a minimally viable product that would begin to approach this kind of measurement.

Identify infrastructure and material goods that could be embedded with sensors or become monitors that would could be useful to families.



# Breakout 11:

# Attack Asthma: Integrating EHR and Legal Case Data to Identify Intervention Targets

## DESCRIPTION

Born out of a desire to replicate and build upon the successful work by of Dr. Robert Kahn of Cincinnati Children's Hospital, participants thought through the logistics of using a layered data strategy to target interventions for asthma beyond biological or clinical means. The group worked to define outcomes, identify funding partners, and talk through possible data sources.

## GOAL

Eliminate environmental causes of asthma due to deficiencies in housing.

#### LEADER

**James Hayden, MBA** Global Executive, Dell Healthcare and Life Sciences

## FACILITATOR

**Megan Bontempo** Visiting Healthcare Strategist, frog









Attack Asthma: Integrating EHR and Legal Case Data to Identify Intervention Targets

## **KEY THEMES AND DISCUSSIONS**

Asthma is a condition with side effects and associated morbidities that disproportionately affect lower-income and disadvantaged communities. Due to the high rate of control and stability among more affluent populations, this disease often does not garner focus or attention.

Due to recent advancements in technologies aimed at layering data to identify disease determinants (e.g., Dr. Rob Kahn's Community Map) it is possible to demonstrate new connections and target specific areas for interventions.

By leveraging these technologies and partnering with community stakeholders, it will be possible to decrease the disproportionate disease burden of this chronic condition through a series of easily implementable interventions.

## **NEXT STEPS**

Craft a public health announcement and a communication strategy aimed at bringing awareness around asthma and generating funding and support for tech and data-driven interventions.

Interested parties could reach out to Dr. Robert Kahn to help identify data sources and help lead the development of analogous systems and technologies within other communities.



# **Breakout 12:** Precision Social Justice Tool Kit

# DESCRIPTION

The value of this tool kit lies primarily in developing a mobile, portable set of practices and provocations that can be used by scientists, clinicians, and public health practitioners so each initiative does not have to "reinvent the wheel." The tool kit would be designed to be attentive to local needs, history and sociality, with the aim of maximizing participation of those most affected by health disparities.

## GOAL

To develop a toolkit of concepts, practices, and orientations to Precision Public Health that can be used across locales, disease domains, and initiatives to address inequities in health care.

## LEADER

#### Ruha Benjamin, PhD Assistant Professor, Department of African-American Studies, Princeton University

## Keith Yamamoto, PhD

Vice Chancellor for Science Policy and Strategy; Vice Dean for Research, School of Medicine, UCSF

## FACILITATOR

Brian Pridgen MD Visiting Healthcare Specialist, frog

**Carlos Elena-Lenz** Principal Technology Strategist, frog













# Precision Social Justice Tool Kit

# **KEY THEMES AND DISCUSSIONS**

A rethinking of the impact of the term "stakeholder" when identifying participants, and a recommendation for its exclusion to ensure that we are not succumbing to historic blind spots when it comes to identifying individuals who should be "at the table."

Borrowing from a similar strategy used by some of the participants, the group distilled its strategy down into the following action words: Learn-Engage-Enact-Embed.

Develop tools for creating a shared language and ensuring a multidirectional accountability of communication.

### **NEXT STEPS**

Build social justice into educational paradigm so these principles are reflected in curriculum and instruction.

Look for relevant materials to be disseminated to this group so that the participants can carry on this work in an actionable way (e.g., Keith Yamamoto's classroom modules, frog's Collective Action Tool Kit).

Petition a large, philanthropic, and granting organization to create a funding requirement around the clear demonstration social justice considerations and impact.

Consider how to borrow and build upon knowledge from other successful initiatives. Look to Australia for analogous experience and best practices in this space and then take these ideas and "test them at home."



# Next Steps

For many attendees, the activities and discussions at the Summit inspired them to continue working on the initiatives that inspired them over the two days. Many left the summit with new or renewed motivation to take steps, no matter how small, toward furthering the movement of Precision Public Health.



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# Next Steps

# Vision & Strategy

Continue to set out a bold vision, strategy, and action plan for Precision Public Health, both internally within local organizations and communities as well as externally among larger spheres of influence.

# **PPH Community**

Encourage connection and action among an engaged and passionate community of Precision Public Health advocates across health, technology, government, community and philanthropy.

# **Local Projects**

Lead local projects that activate and engage local communities, leaders, and partners in order to research and reduce health disparities, while defining best practices for Precision Public Health at large.

# **Data Sharing & Integration**

Create infrastructure, knowledge networks, and pilot program best practices that make it easier to access, share, and integrate highquality data across biological, social, and environmental health determinants.

# **Thought Leadership**

Demonstrate leadership within Precision Public Health by influencing and aligning strategies, principles, and best practices among key advocates and stakeholders.

# VisioEducation & Training

Exemplify principles for Precision Public Health by integrating them into education and training for future leaders in this field.



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# Closing Remarks

# "

Do not underestimate the power of this meeting and the opportunity it has created for all of us to make a difference. You all came because you are leaders. If all of you serve as ambassadors of the ideas we developed here, you will not only leave here changed – open to new and different ways of thinking – you also will be able to change others as well.

I would ask you to keep several concepts in mind. First, think about scalability. How can the next neighborhood, the next community benefit from the work we've discussed? Can we come up with a framework, a tool kit, a set of principles that is tried and true? At the same time, remember that every community does not need to be forced to adopt our ideas. What we're offering is a framework. It's important how you listen and how you engage communities. Second, consider how these ideas could be funded. At the Bill & Melinda Gates Foundation, we have a concept that we call 'market failure,' which is when innovators are not tackling a problem because they don't see how they can make money from it. This is common in vaccine development. So, we are always looking for ways to address it. For example, tiered pricing made HIV drugs more affordable to low-income countries. We need to adopt this kind of creativity to make precision public health a reality.

In other words, we need to be thinking about actionable ways to make change.

# Susan Desmond-Hellmann, MD, MPH

CEO, Bill & Melinda Gates Foundation



# Closing Remarks

We're at this intersection of data and technology. Naturally, the question is, 'How are we using that to think about our own individual lives?' We should fundamentally believe as a nation that a technology is neither radical nor revolutionary unless it benefits every single American. We're very good at building really creative technology. We have to make sure it benefits everybody simultaneously, to provide the value proposition that we have to have going forward.

# **DJ** Patil

US Chief Data Scientist, White House Office of Science and Technology Policy





#### CONVENER

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# BILL& MELINDA GATES foundation

### HOST

#### FACILITATOR





University of California San Francisco

frog



# Thank You



# Appendix



# Agenda



# June 6: Day of Immersion and Inspiration

### FISHER BANQUET ROOM Registration & Breakfast\_

\_8:00am\_9:00am

#### ROBERTSON AUDITORIUM

Welcome & Opening Remarks \_\_\_\_\_\_9:00am-9:10am Sam Hawgood, MBBS (Chancellor, UCSF)

# Opening Keynote

\_9:10am\_9:30am

Susan Desmond-Hellmann, MD, MPH (CEO, Bill & Melinda Gates Foundation) Claudia Williams, MS (Senior Advisor, White House Office of Science and Technology Policy)

Summit Goals & Day 1 Activity Overview \_\_\_\_\_9:30am-9:40am Kirsten Bibbins-Domingo, MD, PhD, MAS (Director, Center for Vulnerable Populations; Professor of Medicine, UCSF)

Precision Public Health: Introduction to the First 1000 Days and the Potential for Precision Public Health\_\_\_\_\_9:40am\_10:00am Tom Boyce, MD (Chief, Division of Behavioral Pediatrics, UCSF)

# Precision Public Health in Action:

#### Neonatal Morbidity

\_\_\_10:00am\_11:15am

Rebecca Dineen, MS (Assistant Commissioner, Maternal and Child Health, Baltimore City) Eric Dy, PhD (Co-Founder and CEO, Bloom Technologies)

#### Panel: UCSF Preterm Birth Initiative

Moderator: Larry Rand, MD (Director of Perinatal Services, UCSF) Michael Snyder, PhD (Professor and Chair, Genetics, Stanford University School of Medicine) Monica McLemore, PhD, MPH, RN (Assistant Professor, UCSF School of Nursing) Laura Jelliffe-Pawlowski, PhD, MS (Associate Director, UCSF Preterm Birth Initiative, California, UCSF)

Jenee Johnson (Program Director, San Francisco Black Infant Health Program)

#### ROBERTSON AUDITORIUM

## Precision Public Health in Action:

#### Early Childhood Adversity\_

Robert Kahn, MD, MPH (Professor of Pediatrics, Associate Chair of Community Health, Cincinnati Children's Hospital Medical Center) Margaret Laws, MPP (President & CEO, HopeLab)

Panel: Flint Michigan Water Crisis
Moderator: Tracey Woodruff, PhD, MPH (Director, Program on Reproductive Health and the Environment; Professor, UCSF)
Lee Anne Walters (Community Activist, Flint Michigan)
Marc Edwards, PhD, MS (Professor of Environmental and Water Resources Engineering, Virginia Tech)

#### FISHER BANQUET ROOM

Lunch

#### OPTIONAL BREAKOUT

Data Exploration for Public Health Research:

### San Diego County as a Case Study

(a partnership between UCSD, the National Science Foundation and the Robert Wood Johnson Foundation)

Kevin Patrick, MD, MS (Director, Center for Wireless and Population Health Systems, Qualcomm Institute/Calit2; Professor of Family Medicine and Public Health, UCSD)

#### **ROBERTSON AUDITORIUM**

Building Healthy Data Ecosystems <u>1:30–3:00pm</u> Lindsey Mosby, MS (Executive Strategy Director, Healthcare Practice Lead, frog) Atul Butte, MD, PhD (Professor; Director, Institute for Computational Health Sciences, UCSF) John Brownstein, PhD (Chief Innovation Officer, Boston Children's Hospital and Professor, Harvard Medical School) Tim Dye, MS (Sr. Vice President, CBDO, Sonoma Technology, Inc.) Anita Zaidi, MD (Director, Enteric and Diarrheal Diseases (EDD) Program, Gates Foundation) Howard Look (President and CEO, Tidepool)

Breakout Ideation Session & Voting\_\_\_\_\_3:00pm-4:45pm Facilitator: Lindsey Mosby (Executive Strategy Director, Healthcare Practice Lead, frog)

# Closing Remarks & Day Two Framing\_\_\_\_\_

Kirsten Bibbins-Domingo, MD, PhD, MAS (Director, Center for Vulnerable Populations; Professor of Medicine, UCSF)





4:45pm-5:00pm

# June 7: Day of Action – Designing a Roadmap for the Future

#### **FISHER BANQUET ROOM** Breakfast & Breakout Signups\_ (Breakout Leader Coaching)

#### **ROBERTSON AUDITORIUM**

Opening Remarks & Day Two Framing\_ 9:00am-9:15am Susan Desmond-Hellmann, MD, MPH (CEO, Bill & Melinda Gates Foundation) Kirsten Bibbins-Domingo, MD, PhD, MAS (Director, Center for Vulnerable Populations; Professor of Medicine, UCSF)

# Opening Keynotes

9:15am-10:00am

Perspectives from NIH and CDC William Riley, PhD (Director, Office of Behavioral and Social Sciences Research National Institutes of Health) Muin Khoury, PhD, MD (Director, Office of Public Health Genomics, CDC) Reimagining Child Health Moderator: Rafael Lopez, MPA (Commissioner, Administration on Children, Youth and Families, HHS Robert Kahn, MD, MPH (Professor of Pediatrics, Associate Chair of Community Health, Cincinnati Children's Hospital Medical Center)

Nick Macchione, FACHE (Agency Director, Agency Director)

8:00am-9:00am

various rooms Breakout #1	10:00am-12:00p
<b>гізнег валоџет гоом</b> Lunch & Breakout Signups	12:00pm-1:00pr
<b>various rooms</b> Breakout #2	1:00pm–3:00pm
ROBERTSON AUDITORIUM Breakout Presentations	3:00pm-4:00pm
FISHER BANQUET ROOM AND LAWN Closing Remarks and Social Mixer	4:00pm-5:00pm

DJ Patil, PhD (Chief Data Officer, White House Office of Science and Technology Policy)



















# Organizers





# Kirsten Bibbins-Domingo, MD, PhD, MAS

DIRECTOR, CENTER FOR VULNERABLE POPULATIONS; PROFESSOR OF MEDICINE

UCSF



Sue Desmond-Hellmann, MD, MPH **CHIEF EXECUTIVE OFFICER** Bill & Melinda Gates Foundation



# Claudia Williams, MS

#### **SENIOR ADVISOR** White House Office of Science and Technology Policy

#### **UCSF STEERING COMMITTEE**

Kirsten Bibbins-Domingo, MD, PhD, MAS Nancy Adler, PhD Tomás Aragón, MD, DrPH Mike Blum, MD Atul Butte, MD, PhD Bob Hiatt, MD, PhD India Hook-Barnard, MD Sharat Israni, MS, PhD Laura Jelliffe-Pawlowski, PhD, MS Anda Kuo, MD Courtney Lyles, PhD Aric Prather, PhD Larry Rand, MD Tracey Woodruff, PhD, MPH Jaime Sepulveda, MD, DSc, MPH Keith Yamamoto, PhD



Speakers





# Kirsten Bibbins-Domingo, MD, PhD, MAS

DIRECTOR, CENTER FOR VULNERABLE POPULATIONS; PROFESSOR OF MEDICINE

UCSF



# John Brownstein, PhD

**CHIEF INNOVATION OFFICER** Boston Children's Hospital



Sue Desmond-Hellmann, MD, MPH **CHIEF EXECUTIVE OFFICER** Bill & Melinda Gates Foundation



# Tom Boyce, MD

CHIEF, DIVISION OF DEVELOPMENTAL MEDICINE UCSF



# Atul Butte, MD, PhD

**PROFESSOR; DIRECTOR, INSTITUTE FOR COMPUTATIONAL HEALTH SCIENCES** UCSF



# Rebecca Dineen, MS

ASSISTANT COMMISSIONER, MATERNAL AND CHILD HEALTH Baltimore City Health Department





# Eric Dy, PhD

**CO-FOUNDER & CEO** Bloom Technologies



# Marc Edwards, PhD, MS

**PROFESSOR OF ENVIRONMENTAL** AND WATER RESOURCES ENGINEERING Virginia Tech



# Laura Jelliffe-Pawlowski, PhD, MS

ASSOCIATE DIRECTOR, UCSF PRETERM BIRTH INITIATIVE, CALIFORNIA

UCSF



# Tim Dye, MS

**SENIOR VICE PRESIDENT**/ CHIEF BUSINESS DEVELOPMENT OFFICER Sonoma Technology, Inc.



# Sam Hawgood, MBBS

CHANCELLOR UCSF



# Jenée Johnson

**PROGRAM DIRECTOR** San Francisco Black Infant Health





# Robert Kahn, MD, MPH

#### PROFESSOR OF PEDIATRICS, ASSOCIATE CHAIR OF COMMUNITY HEALTH

Cincinnati Children's Hospital Medical Center



# Margaret Laws, MPP

**PRESIDENT/CEO** HopeLab



# Rafael López, MPA

## COMMISSIONER

Administration on Children, Youth and Families, US Department of Health and Human Services



# Muin Khoury, MD, PhD

#### DIRECTOR, OFFICE OF PUBLIC HEALTH GENOMICS

Centers for Disease Control and Prevention



Howard Look

**PRESIDENT AND CEO** Tidepool



# Nick Macchione, FACHE

## AGENCY DIRECTOR

Health and Human Services Agency, County of San Diego





Monica McLemore, PhD, MPH, RN

**ASSISTANT PROFESSOR** UCSF School of Nursing



# DJ Patil, PhD

#### **DEPUTY CHIEF TECHNOLOGY OFFICER FOR DATA POLICY** AND CHIEF DATA SCIENTIST

White House Office of Science and Technology Policy



Larry Rand, MD DIRECTOR OF PERINATAL SERVICES

UCSF



# Lindsey Mosby, MS

#### EXECUTIVE STRATEGY DIRECTOR, HEALTHCARE PRACTICE LEAD

frog



# Kevin Patrick, MD, MS

DIRECTOR, CENTER FOR WIRELESS AND **POPULATION HEALTH SYSTEMS, QUALCOMM INSTITUTE/CALIT2; PROFESSOR OF FAMILY** MEDICINE AND PUBLIC HEALTH

UC San Diego



# William Riley

DIRECTOR, OFFICE OF BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

National Institutes of Health





# Michael Snyder, PhD

**PROFESSOR AND CHAIR, GENETICS** Stanford University School of Medicine



# Claudia Williams, MS

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# Anita Zaidi, MD

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Bill & Melinda Gates Foundation



# Lee Anne Walters

**COMMUNITY ACTIVIST** Flint, Michigan



# Tracey Woodruff, PhD, MPH

DIRECTOR, PROGRAM ON REPRODUCTIVE HEALTH AND THE ENVIRONMENT; PROFESSOR UCSF

