

OME 2013  
SUMMARY OF PITCHES



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THEMES

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# DATA COLLECTION

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## LEARNING FROM FAILURE

Ninety-five percent of drug clinical trials fail. However the law currently does not allow the Food and Drug Administration (FDA) to make data from these failed trials public nor do pharmaceutical companies have any incentive to share it. Because of this, researchers may be tackling the same problem unbeknownst to each other and ultimately, patients have no way of knowing if they are in a clinical trial of a failed drug or if another trial is going on replicating failed data.

Learning From Failure proposes to make this data public by taking the steps to make a change in legislation and develop an agreement with major bio-pharmaceutical companies and research universities to make this information available. By having an agreement across the board, no one is at a competitive disadvantage.

There is a way to celebrate cures and lower the economic burden of getting a drug to market. Additionally, the FDA is also open to thinking about this.

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## BRINGING ME FOR YOU TO LIFE

Me For You is a social media campaign to raise awareness and understanding of precision medicine among the public through a new microsite. This project brings precision medicine to life through a video story of a girl who may develop breast cancer and encouraging users to think about the people they care about and to dedicate themselves to their health. MeForYou.org is a new movement that proposes widespread sharing of health data to empower patients to advance the field of precision medicine.

If patients are given control of the data, they can begin the sharing cycle within the larger systems. It's an opportunity to revolutionize the health system if people can understand and get excited about it.

The challenge will be getting institutions to share this data as they currently have no incentive to do so today. However, if an institution such as UCSF can lead by example, the value of this process can be demonstrated. This would include freeing data on the clinical side – UCSF's Michael Blum has already promised to give back EMR data within a year – as well as working to incentivize faculty researchers to share data back to their participants.

# DATA COLLECTION

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## DATA DONOR DRIVE

The Data Donor Drive, or D3, will set out to collect 1 million genetic data sets to help develop a database as a launching pad for precision medicine's knowledge network.

By tapping into people's sense of volunteerism and philanthropy and underscoring the importance of open access and security (anonymity through donation), this grassroots campaign will start with those already involved in precision medicine – health care practitioners, employers, patient advocacy groups and encourage them to bring in at least one additional donor. The drive will also leverage similar current government efforts at the Veterans Affairs Medical Center.

Ultimately, this drive will not only build a strong database, but will more importantly raise public awareness around precision medicine through engaged participants.

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## SMART TOILET

Precision medicine needs to be made easy and passive, so people don't have to change their behavior. The Smart Toilet is designed to analyze stool samples, which are a key health indicator. Enormous amounts of information can be drawn from looking at stool, such as understanding overall diets, personal genome, microbiome, etc. The Smart Toilet could collect and analyze data on a daily basis, then make it available for mining to get genomic and microbiome information.

This "lab in your toilet" would use the data to make a real-time dashboard for family members to monitor their own health and well-being and could be shared with their caregiver, who could help with intervention early on. For example, data could be analyzed from the hundreds of HIV-positive patients at San Francisco General Hospital and Trauma Center and it could tell that patient population about bacteria or parasites that they might have. The data also could be compiled and sent anonymously to researchers studying public health implications, to help identify prevailing infectious diseases before they reach an epidemic scale.

The estimated funding request for this project is \$1.5 million.

# DATA STORAGE

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## BLOOMBERG OF GENOMICS

Imagine a scenario in which a patient with lung cancer is being treated in the community. The physician says, “I’ve sequenced the DNA of your tumor cells.” The physician then pulls up a globally based profile showing other patients with similar demographics, clinical history and genomic sequences. Those would be linked to various possible treatments, with data on patients’ drug responses and outcomes, linked to their genetic data. Together, those tools give the physician the ability to assess which treatment would benefit this particular patient.

Components of housing the data as described above are already in place. Phenotypic records are increasingly available already, and genomic sequencing methods have become more accurate and inexpensive. What is missing is the “Bloomberg of Genomics” – a global database of clinical and genomic data. Just as Bloomberg aggregates financial information, then vulcanizes that information worldwide for its members to tap into, health care needs an entity to aggregate and vulcanize health-related data.

The Bloomberg of Genomics would create a set of standards in a non-profit entity that would assume stewardship of this project and would index all the data. That would generate an ecosystem of different companies with different tools and different needs, but all with the ability to access the highest quality clinical and genomic data.

This data could be accessed through a simple web portal, which could be used by everyone, from patients interrogating their own information to researchers gathering and providing further data. This knowledge and distributive database would be free and open and not owned by any one company.

The request is for everyone to help build this machine.

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## WORLDWIDE BIO CONSORTIUM

Research data is stuck in this time of “Betamax versus VHS,” in which two different groups could be working on research for the same disease, such as Alzheimer’s, but the data can’t communicate to each other. Based on what the W3C did for the Internet, the Worldwide Bio Consortium aims to do the same by establishing standards for collecting and analyzing biological data.

The consortium would convene volunteer representatives from academic institutions, pharmaceutical companies, biotechnology companies and other cross collaborators to meet and think about establishing standards. Initially, this would be done at scale by focusing on a few pilot disease areas, such as cancer or neurological diseases, and selecting specific data types for which the consortium would set initial standards.

Currently UCSF, Sanofi and Quintiles are signed up and looking for more interested organizations in collaborating on this data standards consortium.

## DATA ANALYSIS & TECHNOLOGY DEVELOPMENT

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### PRECISION MEDICINE TECHNOLOGY FOUNDATION

The Precision Medicine Technology Foundation is a non-profit foundation that would certify precision medicine technology for early reimbursements.

Typically, there is a six-year cycle to bringing ideas to market, but money often runs out after the first couple of years. By reducing the timeframe to four years – two years of research and development and two years of trials – the project can demonstrate clinical validity, clinical utility and an economic model of reduced costs and better care, it can get promising projects on an accelerated track and reduce risk for investors.

This foundation could be funded by major health care providers (Humana and Aetna are already exploring this space) and advised by industry knowledge leaders.

Additionally, in an effort to pinpoint new precision medicine ideas, new projects could receive a certificate of approval after two years of demonstrating potential opportunity.

## DATA USE

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### IMMERSIVE VISUALIZATION

The Immersive Visualization pilot is intended to develop a computational database with a unique user interface to manipulate complex data sets. The system would create a way to visualize multiple, complex data sets to accelerate the pace of scientific discovery for neurodegenerative diseases.

In his research group, UCSF neuroscientist William Seeley focuses on neurodegenerative diseases, all of which target a significant, large-scale distributive brain network. Bill and his team have developed research tools to measure and monitor brain network connectivity over time to determine how potential treatments are working. However, the sheer magnitude of patient data is outpacing their ability to interactively visualize, explore, understand and effectively use these data as research tools.

Bill is currently partnering with Oblong Industries and Lawrence Berkeley National Laboratories (LBNL) on the Immersive Visualization project. Oblong is helping Bill develop a prototype to develop a system that would allow researchers to share data from their laptop, mobile or other device through the cloud seamlessly and collaboratively with each other, with an ultimate goal of putting a new user interface on every computer in the world.

At the same time, Lenny Olikier, at the LBNL, is looking to apply sophisticated mathematical techniques to help further mine and manage the data. Specifically, they are augmenting visualization with high-performance analytics and sophisticated mathematical techniques in statistics, image processing, graphic theory and machine learning.

There is 10 years' worth of patient data from this research collected at UCSF and a need for financial support to keep this collaboration going.

# DATA USE

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## SHINE A LIGHT

In 2011, **Nature** magazine published one of the first reports of the human genome and since then, there has been even more information about what is in the genome.

The Shine A Light project plans to help individuals make use of that information by building a stronger and better lever and fulcrum to connect the patient to the information needed to make precision medicine a reality.

The project relies on three questions: Do I need to know it? Can I understand it? Can I trust it?

And is proposed in three parts:

- Connect to your specific information
- Ability to translate difficult literature into forms that are meaningful to you
- Two-part rating system: one that rates understandability, how difficult the material is, and one that rates how credible and trustworthy is the information derived from experts in the field

Shine A Light would make available a translation system that will break down the research literature, and how difficult it is from high to low.

Currently, UCSF, Institute of Medicine, Kaiser and Stand Up to Cancer have committed to help and are looking for more communities of passionate people to say “I’ll help in translating that.”

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## PRECISION MEDICINE HEALTHCARE GROCERY STORE

To realize the promise of precision medicine it will take investment and time. The Precision Medicine Healthcare Grocery Store will serve as the financing source to accomplish everything discussed at OME 2013.

Currently health care represents 17 percent of the US economy. This project takes into consideration the concept and efficiency of free markets - when markets are free to work, costs go down and quality goes up. By creating an integrative health system, all data goes into a resource pool. A standard is established and then each individual is incentivized and given the tools to meet that with intervention applied as needed.

For example, take weight management. A standard is established like BMI (Body Mass Index), individuals are given tools to meet their target, such as diets, counseling, etc., and then incentivized to meet their goal. This provides a process in which the patient becomes more accountable and creates a marketplace, giving the savings to lower the cost even further.

Health care today has limited or no cost and quality information. The plan for this movement is to enlist people who are willing to lead. Many large blue chip companies who are open to innovation have already started down a similar path and would be key partners in implementing elements of this with their employees. Additionally, the government is an enabler in this process.

# DATA USE

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## GPS

Most drivers these days rely on a GPS (Global Positioning System) or maps to help them navigate to their destination. Unfortunately, there is no directional guide in health care. Check ups are intermittent and reactive at best.

With a health care GPS system or Guided Patient Strategy, health care can become more proactive and continuous by leveraging precise tools to help patients reach their “target destination.”

By using a smart integration of information, elements of artificial intelligence and freeing up constrained data sets, this health care GPS is a dashboard personalized based on your personality, location, genetics and is connected to social networks with other patients in it. It essentially will provide you with your own check engine light, tailored to you.

This smart integrated patient dashboard is also connected to your clinician to help provide situational awareness. For example, not every Type 2 diabetes patient is treated similarly. By optimizing personalized information to then optimize pathway to treatments, this dashboard can further help physicians determine the best course of treatment.

In order to realize this, there is a need for data donors and for drug companies, pharmaceutical companies, and universities to cross-fertilize to reinvent how precision medicine is seen.

