

BRIDGE: An Open Infrastructure for the Acceleration of Medical Discovery

THE PROBLEM:

The current system of drug discovery is a primitive one severely hampered by the crude models we have of the diseases we try to treat. Typically, single researchers, or closed teams of researchers, pursue a molecular target or disease pathway understanding in isolation until perhaps years after the discovery when the new ideas are transmitted as scientific papers or patents. Moreover, traditional players in academia and industry are not incentivized to share with each other, let alone with patients to build informative disease models. In this closed medical information system, data is controlled by companies to protect intellectual property (IP), and by individual researchers to protect publication and grant-raising ability. The system is designed as if every new program is destined to deliver an approved drug long before there is a reasonable probability of success.

A major contributing factor to this problem is the current reward structure of the medical-industrial complex. We believe that it is important to enable research where data and models of disease are jointly evolved. We also believe that recognition should be gained by tracking who uses what data and tools. This recognition will need to be driven by everyday citizens, whose primary focus is on impacting disease, not climbing academic ladders or making profits. Our goal with the platform, Bridge, is to redefine the reward structures around sharing medical information in an effort to build better models of disease that re-imagine the traditional roles that patients, researchers and funders play.

The goal of this current project is to pilot three seed projects- Fanconi Anemia Project, Real Names Discovery Pilot (Parkinson's) and Breast Cancer Project - through this platform that will enable us to test new ideas and understand better how to bring the open source movement to medical discoveries and drive systems change around eliminating disease by activating citizen-patients and shifting scientists to share data and models. This will help us gain a deeper understanding to identify an alternative reward architecture to build bridges between citizen-patients, researchers and investors through real-time access to knowledge.

SOLUTION: BRIDGE

BRIDGE is a customized Open Growth platform for building models of disease where everyone engages at each stage for maximum impact.

Key aspects of BRIDGE are:

- **Democratization of building smart therapies.** Bridge allows for breaking out of classical roles; redefining the reward structures around sharing medical information in an effort to build better models of disease that re-imagine the traditional roles that citizens-patients, researchers, and funders play. Smart therapies determine who needs to be treated with

what, identify new biomarkers and targets for new therapies, and new models of disease. The platform gives everyone an important role to play.

- **User-friendly “bridge” to building collaborative models of disease (Synapse).** This platform extends the functionality of existing activated communities. A user-friendly, non-restrictive, central disseminator of information for all interested citizen-patients, researchers, and investors.
- **Extending/expanding activation of citizen-patients.** Bridge allows for expanding the role of organizations/disease groups that are powerful activated citizen-patient communities and enable those that are earlier in the “activation” lifecycle. Bridge is enabling and accelerating the role of citizen-patients beyond being passive recipients to now participants who are able to share clinical details and problems worth solving, and can track how and where their data is helping research.
- **Promotion of transparency.** Citizen-patients, researchers, and investors are all equally powerful. This platform enables recognition beyond publishing and provides value beyond sharing “what did not work.”
- **Research 2.0.** Real-time interpretation of citizen-patient data. Bidirectional conversation between researchers and citizen-patients, which is open and shared.
- **Collaborative competitions.** Citizen-patient involvement in network approaches to solving problems including sourcing problems worth solving and building integrated models of diseases.

Bridge is planned in three phases. Phase I includes the customized design, development, and launch of the platform at the Sage Congress in April 2012. Phase II includes the testing of the pilot phase of the marketplace for three “activated” communities from April 2012 until April 2013. Phase III will be launched in 2013 to drive individual participation.

The three key activities in this pilot proof of concept phase are (1) framing and design of the customized platform, (2) identification of “activated” disease communities and competitions to be run on BRIDGE and (3) identification of alternative incentives to influence the current medical-industrial complex. We have established an Advisory Council for BRIDGE with experts who include John Abele, Boston Scientific, Inc.; Jeff Hammerbacher, Cloudera; Josh Knauer, Rhiza Labs; Peter Kapitein, Inspire2Live; Dr. Susan Love, Army of Women; Dr. Eva Guinan, Harvard and Sharon Terry, Genetic Alliance. This pilot project is supported by The Robert Wood Johnson Foundation.

Framing and design of the platform is critical to allow for collaboration across patient groups, researchers and funding organizations in a manner that questions the status quo and expands these archetypal roles. Citizen-patients are not only able to help identify problems worth solving, but follow the progress of research projects and their individual data. Researchers are posed collaborative challenges on “crowdsourced” problems vetted by a Research Council that appropriately frames the challenge. The challenges are run on Synapse, a computational space that provides an open source environment rich in curated and standardized data combined with

analytical support. In this new discovery system, everyone relies on everyone and information becomes non-hierarchical, catalyzing a trust network and offering shared value. Additionally, when information is openly available through BRIDGE to everyone; all involved in developing new models of disease become accountable to the world. The platform encourages smarter allocation of resources emphasizing collaboration. This will lead to the development of new reward structures that drive innovation in medical discovery.

INTENDED RESULTS

Our goal is to deliver an Open Growth platform at the Sage Congress in April 2012 that will initially host three, preselected projects - Fanconi Anemia, Real Names Discovery Pilot (Parkinson's), and Breast Cancer. A successful pilot will enable a platform capable of accepting the data needed for the challenges, interfacing with Synapse where the computational models will be built through collaborative competitions, and providing the tracking for the projects as needed for scientists, citizen-patients and investors. Each seed project will report back at the Sage Bio-Congress in April 2013 with the lessons learned and progress achieved, culminating in the development of a more robust BRIDGE.

AUDIENCE

Citizen-patients, researchers and funders are the three primary audiences for this project. Core to the platform are tools that allow researchers to transparently define, track and report on their progress fostering trust and credibility for all three stakeholders. BRIDGE allows for real-time collaboration and knowledge-sharing that maximizes efficiency and accelerates discovery.

DEFINITION OF SUCCESS

Success is defined by the creation of a framework that makes the progress of novel discoveries transparent to all, accountable to all, and aided by all. In particular, where current granting mechanisms by governments and foundations discount the participation of patients as citizen-scientists, BRIDGE will encourage the evolution of ideas to be understandable, comparable, credible and public so everyone can better understand their return on investment. The platform will foster an environment in which researchers (in Synapse) are more accountable to each other, to their communities, to investors and to the citizens. Our overall goal is to transform the culture and practice of biomedicine's closed information systems around building models of disease while aligning with and supporting health outcomes.

For the identified diseases, BRIDGE should provide sufficient insights to give clues as to which patients will respond to various approved therapies and thus help build better models of disease. BRIDGE will also bring about shift in the mentality of patients away from being resigned and excluded from the discovery process, and instead provide an active role to play in achieving new understanding. In turn, scientists supported within BRIDGE will begin to have reward

structures encouraging them to share data in real time with incentives coming directly from the participating patients who follow their projects.

Please contact us with any questions:

Dr. Stephen Friend, President, Sage Bionetworks. Email: friend@sagebase.org

Chitra Krishnan, Ashoka Changemakers. Email: krishnan@ashoka.org