Achieving Data Liquidity in the Cancer Community: A Coalition of All Stakeholders

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What’s data liquidity and why is it needed in cancer research?

Data Liquidity = Rapid, seamless, secure exchange of useful, standards-based information among authorized individual and institutional senders and recipients.

Value in cancer research and care:

Inform care decisions  Fuel research  Reduce costs, measure impact
Why don’t we have widespread data liquidity yet?

- Collecting the ‘right’ data
- Non-uniformity of data
- Quantity of data
- Privacy concerns
- Data ownership
- Intellectual property
- Misaligned incentives
- Health IT limitations
- Incentives

Red = technical obstacles
Blue = legal/cultural obstacles

*Graphic based on image from European Biopharmaceutical Review, Jan 2012*
What’s the opportunity if we get it right?

Personalized Cancer Medicine

Prevention, diagnosis and treatment that reflects patient’s unique biological and disease characteristics as well as values and preferences.

Rapid Learning Healthcare System

Information-based biomedicine in which all data about clinical care are applied to fuel and facilitate research and development, and all research data are rapidly translated into knowledge to improve clinical care.
The path forward: An idea to overcome the digital dilemma by...

- **LEVERAGING** the successes of the pioneers
- **EXPLOITING** existing assets/capabilities
- **PLAYING** to the strengths and needs of each constituency in biomedicine
The concept: Introduced at the IOM in February 2012

DRAFT: Achieving Data Liquidity in the Cancer Community: Proposal for a Coalition of All Stakeholders

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In Process

* Members of the IOM National Cancer Policy Forum’s Workshop on Informatics Needs and Challenges in Cancer Research Planning Committee
The Coalition is...

A non-profit membership organization comprised of all stakeholders in the cancer community who are deeply committed to actualizing a common vision of data liquidity to achieve personalized cancer medicine and the rapid learning healthcare system.
Proposed Coalition principles

- Research and clinical care can benefit from collection and analysis of all relevant (and potentially relevant) information, recorded in standards-based formats and curated through appropriate governance structures.

- Biomedical innovation and achievement of personalized cancer care can be accelerated and improved by facilitating connectivity and seamless data exchange among research and care collaborators.
Proposed Coalition principles, cont’d

- Open information technology frameworks – which define standards by which technology components can interoperate – provide such capability through open interfaces, enabling researchers to seamlessly capture, aggregate, integrate, analyze, interpret and transmit data.

- Progress toward a connect biomedical community that benefits all health care stakeholders can best be implemented in a pre-competitive setting, where all participants are free to contribute and partake of components.

- Open technology frameworks – which can facilitate the interface between open source and/or commercial components – must be shared freely.
Coalition strategy

- Encompass…

- Energize…

- Execute…
The Need
- Academic or commercial organization needs an IT platform for conducting biomarker-driven clinical trials.
- That organization makes a contribution to coalition for some or all of the following steps:

Step 1: The Plan*
- Coalition develops a plan that defines the requisite IT capabilities

Step 2: The Technical Foundation*
- Coalition develops pre-competitive specifications and expands standards as needed

Step 3: Implementation*
- Coalition develops requisite software for an open framework
- Coalition shares the framework with all coalition members

Step 4: Ongoing Operations*
- Coalition maintains the common infrastructure, accessible to all

* The Coalition could select the most appropriate vendors from among its members and/or from the larger community of academic/commercial providers.
Range of potential Coalition activities

- Convene
- Advocate
- Mobilize participation
- Serve as honest broker
- Select and apply standards; catalyze standards development where none exist
- Catalyze the building of capabilities that serve immediate needs, via contracts to members or others
- Leverage successful models of research-enhancing data exchange
- Act as “sherpa” to advance projects through to completion
- Coordinate/integrate capabilities leading up to a national system
How would all this roll up to a national system of data liquidity?

- Coalition members would make a commitment of time/resources, and would be vested in the success of the resulting capabilities.
- Each capability would address a specific problem defined by the user; once delivered, the capability would be shared across the community.
- The Coalition would consistently seek to integrate and promulgate the capabilities, rather than viewing them as one-off examples.
- Those who use the effective digital frameworks would gain competitive advantage (and vice versa).
- As in virtually all other industries, biomedical users are likely to overwhelmingly demand/expect the benefits of interoperability once they get used to it.
The impact of the Coalition

- Identify/validate biomarkers
- Identify patient sub-groups
- Share ADRs globally

- Share patient health info with researchers
- Link biobanks for querying

- Develop products/services for biomedical market
- Gain ‘common market’ of users; reduce risk by leveraging gov’t investment

- Clinical trials infrastructure that doesn’t ‘waste’ encounter data

- Share clinical data with collaborators
- Speed insights into clinical practice

- Accelerate studies
- Advance new approaches of evidence generation

Researchers and Product Developers

IT/Software firms

CROs

Patient groups

Comparative Effectiveness and Public Health Researchers

Providers
The impact of the Coalition

The Coalition could achieve benefits for all constituencies
Next steps

- Convene Steering Committee
- Establish Coalition governance
- Launch website environment for community involvement
- Develop business plan
- Seek funding
- Drive membership
- Identify/develop practical projects

To participate and stay informed, contact Marcia.Kean@fkhealth.com
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