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

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National Cancer Policy Forum

"Informatics Needs and Challenges in Cancer Research"

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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 coalition is…

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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.

What's data liquidity?

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

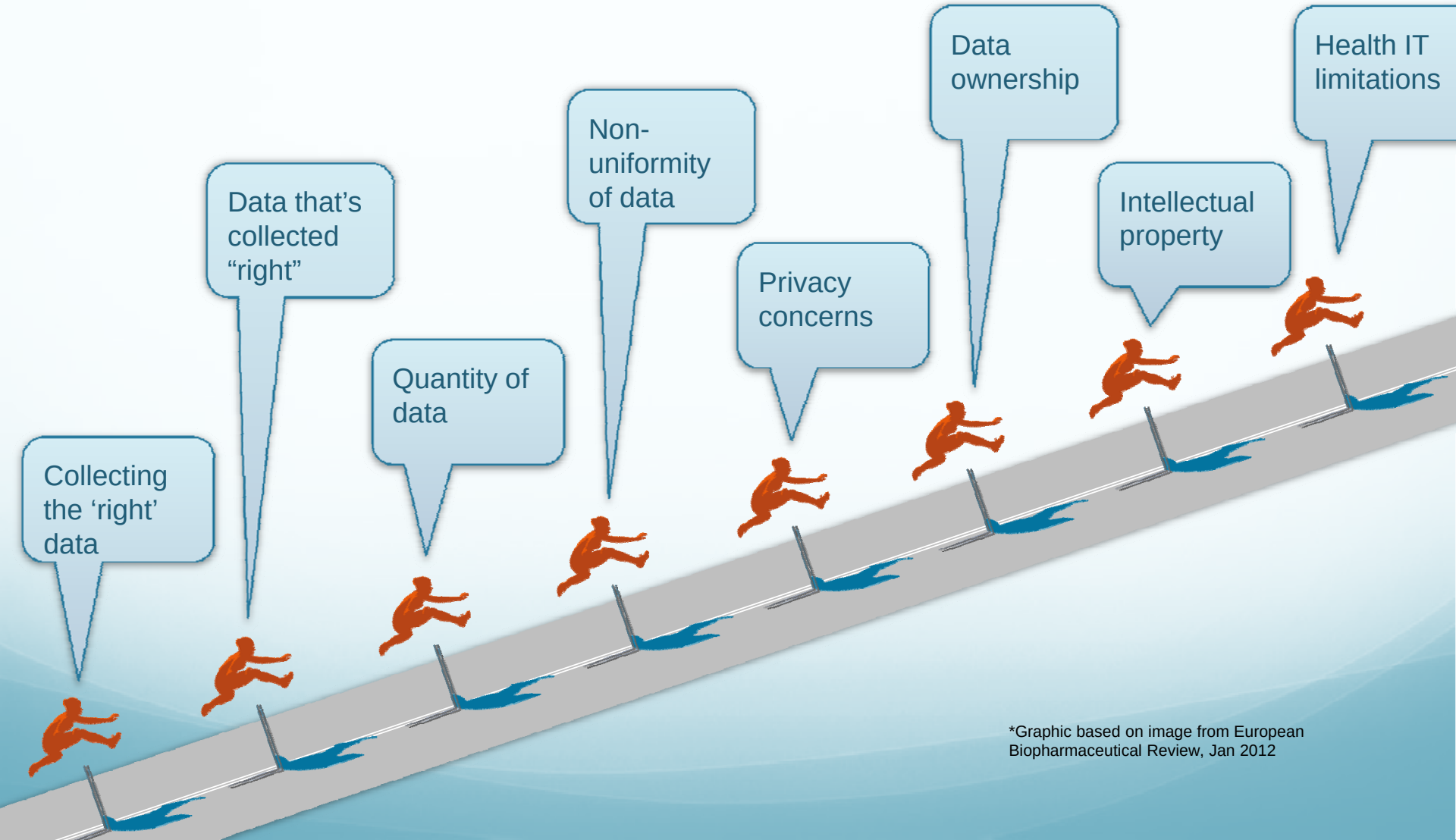
Some exemplars of data exchange

- The Cancer Genome Atlas

- BRIDG (Biomedical Research Integrated Domain Group)

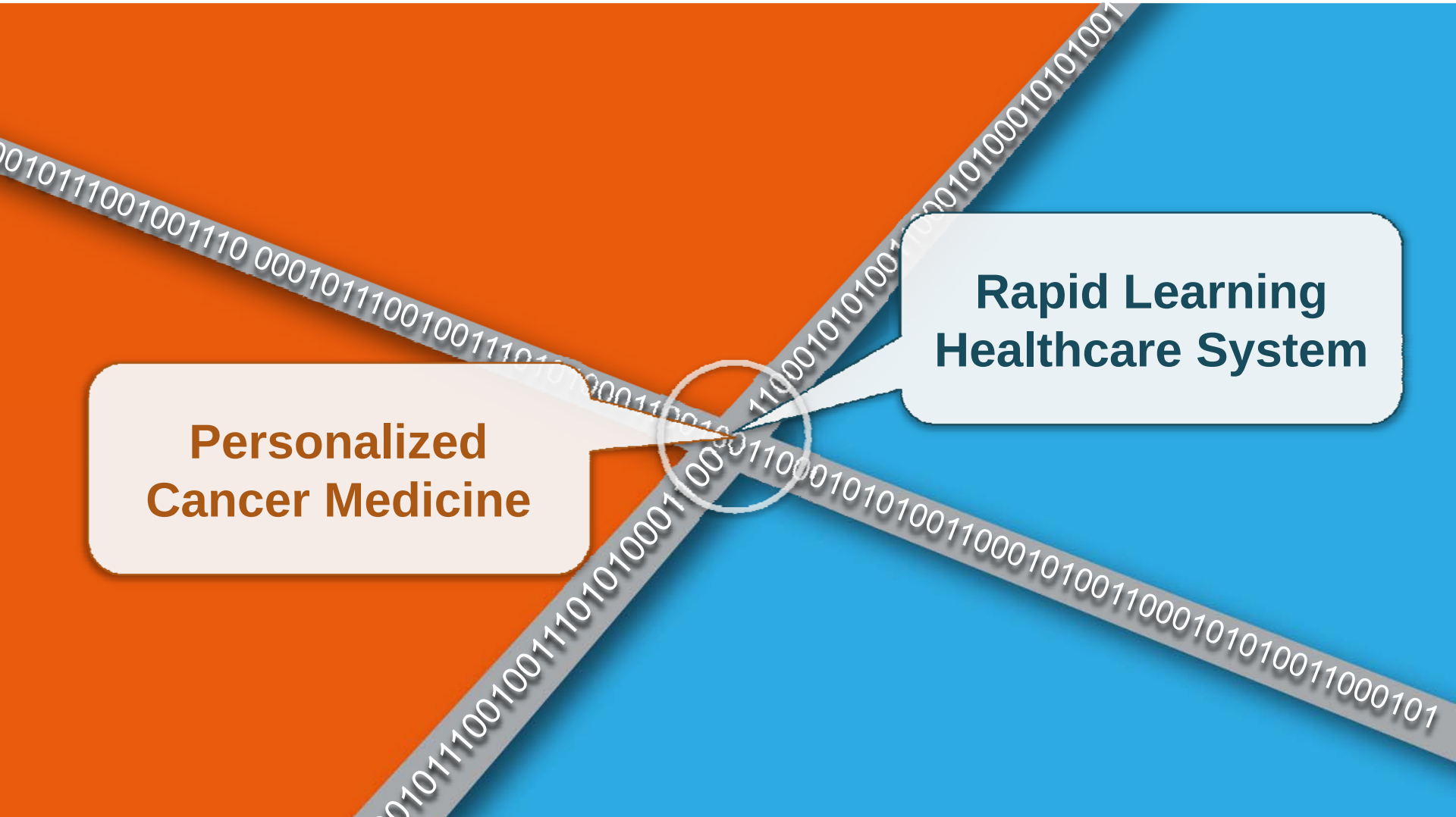
- I-SPY 2 Trial

Why don’t we have widespread data liquidity yet?



*Graphic based on image from European Biopharmaceutical Review, Jan 2012

What's the opportunity if we get it right?



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.

The coalition could deliver rapid, seamless data exchange…

- Facilitated by interoperability…
- Driven by just-in-time standards…
- Implemented in small-scale capabilities that are open at the interfaces…
- Developed incrementally and iteratively…
- To address specific and immediate needs…
- And then integrated in a coordinated, systematic way…

So that over time those capabilities roll up to a national system

The strategy is to build capabilities that address specific, acute problems

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
- Provide consulting and project management services, via contracts to members
- 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

Coalition governance

- Non-profit to preserve ‘honest broker’ role
- Potential for 501(c)(6) to imitate Chamber of Commerce
- Board of Directors with representatives from multiple constituencies

Coalition funding/sustainability

- Membership fees, on a sliding scale
- Consulting fees
- Project management fees
- Foundation grants
- Government support

How would all this roll up to a national system of data liquidity?

- Coalition members would be making 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

How would the coalition be different?

What it is…

- Hybrid model in which all gain the benefit of data exchange through open interfaces, while commercial IT companies can be remunerated for their proprietary products/services
- A testbed for executing interoperability
- An open forum that seeks members from all constituencies
- A way to augment the role of ASCO, AACR, et al.
- A vehicle for ensuring that one-off models contribute to an overall national capability
- A strategy for building on whatever has already been developed

What it's not…

- A data aggregator
- A way to benefit just one single constituency
- A competitor to standard-setting bodies
- An initiative 'owned' and led by government
- A way to undermine or disrupt proprietary software systems
- A way to force data-sharing where it is not desired
- A universal collection of perfected standards that are developed without intent for practical usage

The impact of the coalition

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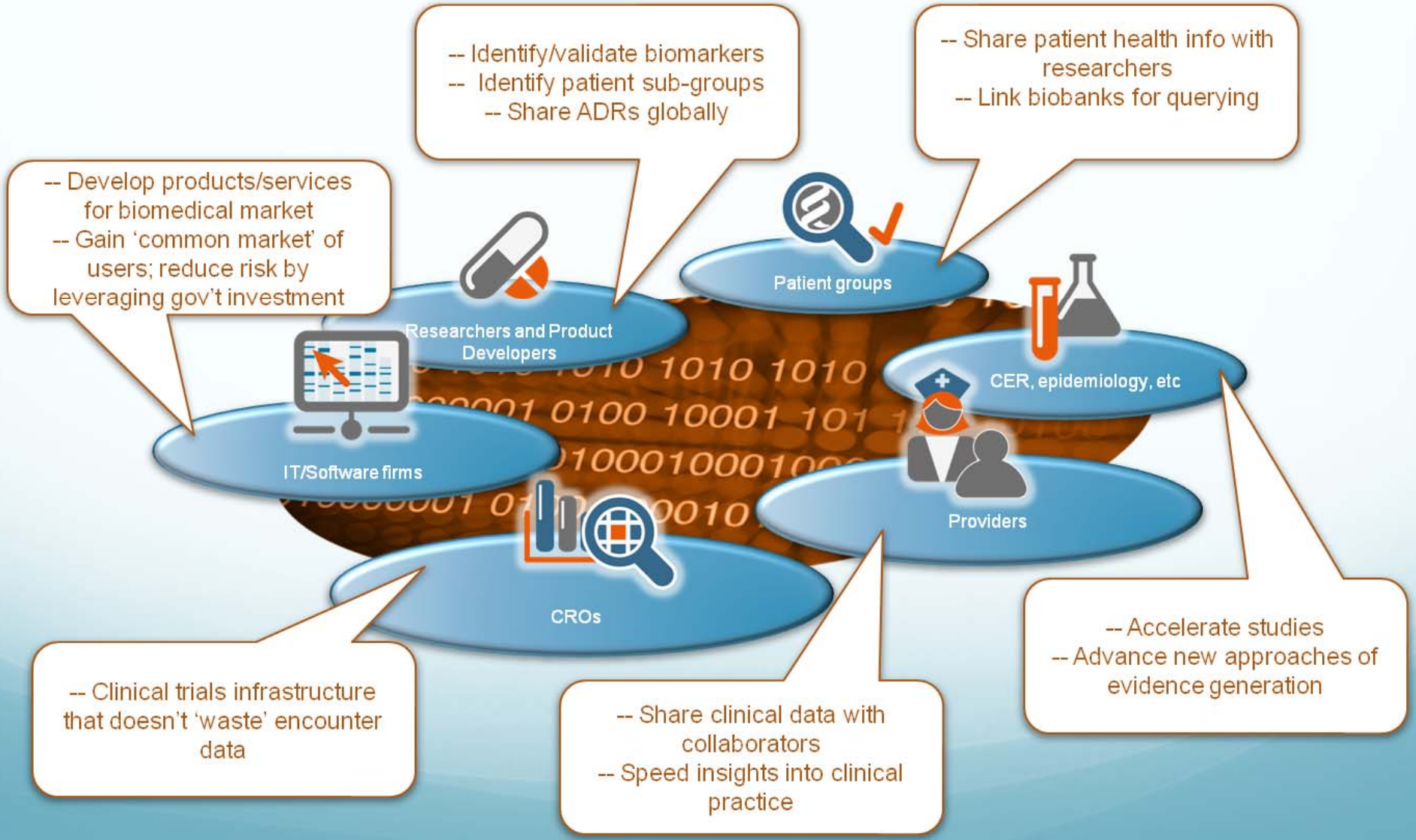

The impact of the coalition

The Coalition could achieve benefits for all constituencies

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