Health Business Group
Sustainability Planning for ISCC
Discussion Document
September 20, 2013
Questions to discuss today

• What is sustainability?

• What we are trying to sustain?

• How are we going to address sustainability for ISCC?

• What are different models of sustainability?

• What can we learn from other case studies?
What is sustainability?

- Creating a model for a mission or organization to become financially self-supporting of its own activities

- In today’s economic and political environment, a business-like approach can greatly enhance the likelihood of success
  - Understand the stakeholders and their interests and needs
  - Be explicit about what value is created and how that translates into a focused set of activities
  - Demonstrate that benefits delivered can justify the amount of funding from stakeholders
  - Consider diversified funding streams and a wide constituent base to provide greater stability

- Sustainability isn’t a static state and must evolve over time to meet changing needs
  - Need to re-evaluate regularly, especially given the rapid evolution of health care
What are we trying to sustain?

• Need to determine up front what aspects of ISCC should be maintained
  
  o *The mission?*
  
  – “To improve genomic literacy of physicians and other practitioners and to enhance the practice of genomic medicine through sharing of educational approaches and joint identification of educational needs”

  o *The broad facilitation and sharing of practices/resources?*
  
  – “The group facilitates interactions among medical professional societies and the NIH ICs to exchange practices and resources in genomic education and clinical care”

  o *The activities within the charge of some or all of the workgroups?*

  o *Other?*
How are we going to address sustainability for ISCC?

**Key issues to research:**

1. Should the ISCC transition from a task force/project to a permanent model? If so, how? When?
2. What should the scope of activities be?
3. What staffing and budget are required to sustain the desired scope?
4. Who should the stakeholders include?
5. How should the organization be funded? What funding model?
6. What organizational form should it take?
7. How should the organization be governed?
8. What risks should be evaluated and considered – financial, political, commercial?
9. What comparable organizations should be studied as sources of best practice?
How are we going to address sustainability for ISCC?

Our approach:

- Review existing materials/documents
- Interviews with workgroup chairs
- Develop list of issues to research
- Interviews with external industry players/experts
- Primary and secondary research
- Develop strategic options
- Evaluate other considerations (e.g., funding models, governance)
- Survey member to get prioritization/feedback on options/considerations
- Synthesize findings and develop recommendations
Examples of strategic choices to be evaluated

<table>
<thead>
<tr>
<th>Scope of services</th>
<th>Mission of professional genomic literacy</th>
<th>Facilitation/convening/sharing best practices</th>
<th>Curation of third-party educational products</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Creation of content</td>
<td>Consulting services</td>
<td>Health policy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Funding model</th>
<th>Membership dues</th>
<th>Program funding</th>
<th>Fee-for-service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Royalties</td>
<td>Grants</td>
<td>Donations</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Specialty medical societies</th>
<th>Specialty medical boards</th>
<th>Government agencies</th>
<th>Foundations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medical education providers</td>
<td>Industry (e.g., genetic testing companies/labs, pharma)</td>
<td>Patient advocacy groups</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organizational form</th>
<th>Subsidiary of existing organization</th>
<th>Independent 501(c)3</th>
<th>For-profit entity</th>
</tr>
</thead>
</table>
What are some different models of sustainability?

• Public-private partnerships
  o Forum for Collaborative HIV Research
  o Biomarkers Consortium
• Multi-stakeholder collaborations
  o AF4Q alliances
  o NRHI alliances
• Subsidiaries of medical societies and other health care non-profits
  o TransforMED
  o Massachusetts eHealth Collaborative
• Medical society collaborations or associations
  o Council of Medical Specialty Societies (CMSS)
  o American Association of Medical Society Executives (AAMSE)
Funding model considerations

Funding models must be aligned with the activities being provided and the value created

Other factors will influence the most appropriate funding models for an organization

• Types of stakeholders and their ability to pay
• Size of organization
• Maturity of organization
• Familiarity and comfort with a particular model
## Overview of funding models

<table>
<thead>
<tr>
<th>Funding model</th>
<th>Description</th>
<th>Representative activities that may be in aligned with funding model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership dues</td>
<td>Members desire to “belong to the organization” and benefit from or support most/all of the activities</td>
<td>Convening, facilitation, learning collaboratives</td>
</tr>
<tr>
<td>Program funding</td>
<td>Design programs that organizations and/or individuals deem worthy of supporting on a more independent basis</td>
<td>Programming around given clinical condition</td>
</tr>
<tr>
<td>Fee-for-service funding</td>
<td>Commercialize services/products, and sell them directly to target clients</td>
<td>Publications, educational seminars/conferences, consulting services</td>
</tr>
<tr>
<td>Royalty</td>
<td>Licensing content or intellectual property</td>
<td>Licensing own content to third-parties, reselling third-party content</td>
</tr>
<tr>
<td>Grants and/or donations</td>
<td>Approach government agencies, foundations or large donors who share a common mission</td>
<td>Seed funding, research programs, consumer education/engagement</td>
</tr>
</tbody>
</table>
## Funding model pros and cons

<table>
<thead>
<tr>
<th>Funding model</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership dues</td>
<td>• Predictable revenue/cost</td>
<td>• Formulas become complex or outdated</td>
</tr>
<tr>
<td></td>
<td>• Ability to respond to emerging priorities</td>
<td>• Members may be uncomfortable with autonomy</td>
</tr>
<tr>
<td></td>
<td>• Equitable</td>
<td></td>
</tr>
<tr>
<td>Program funding</td>
<td>• Tied to specific priorities</td>
<td>• Have to raise funds on an ongoing basis</td>
</tr>
<tr>
<td></td>
<td>• Can come from different budgets</td>
<td>• Less predictability</td>
</tr>
<tr>
<td></td>
<td>• Can broaden the base of shareholders</td>
<td>• Large contributors can dominate</td>
</tr>
<tr>
<td>Fee-for-service</td>
<td>• Introduces commercial discipline</td>
<td>• Members may resist payment</td>
</tr>
<tr>
<td>funding</td>
<td>• Demonstrates value added</td>
<td>• May stray from mission</td>
</tr>
<tr>
<td>Royalty</td>
<td>• A byproduct, requiring little ongoing</td>
<td>• Can complicate governance</td>
</tr>
<tr>
<td></td>
<td>attention</td>
<td></td>
</tr>
<tr>
<td>Grants and/or</td>
<td>• Sponsor can support an issue important to</td>
<td>• Grants generally have a limited life</td>
</tr>
<tr>
<td>donations</td>
<td>them</td>
<td>• Requires resources for grant writing</td>
</tr>
<tr>
<td></td>
<td>• Motivation is largely mission-based</td>
<td>• Hard to have predictable long-term revenue stream; Often requires an</td>
</tr>
<tr>
<td></td>
<td></td>
<td>endowment to create financial buffer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Some grants are more pass-through</td>
</tr>
</tbody>
</table>
### Possible commercial partners for marketing/distribution

<table>
<thead>
<tr>
<th>Clinical user base</th>
<th>Medscape</th>
<th>UpToDate</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Over 550,000 active U.S. physicians and 600,000 nurses across all specialties</td>
<td>• Over 550,000 active U.S. physicians and 600,000 nurses across all specialties</td>
<td>• Over 700,000 clinicians in 157 countries.</td>
</tr>
<tr>
<td>• Over 2.6M physician visits and 3.6M nurse visits per month in the US</td>
<td></td>
<td>• Integrated into clinical workflows in over 25,000 institutions and practices</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current</th>
<th>Medscape</th>
<th>UpToDate</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Limited information in genomics today</td>
<td>• Limited information in genomics today</td>
<td>• Generally does not have separate genetics topics, with some exceptions (e.g., breast cancer)</td>
</tr>
<tr>
<td>• Has their own editorial staff and also licenses/distributes partner content</td>
<td>• Has their own editorial staff and also licenses/distributes partner content</td>
<td>• The genetic medicine section editor attends editorial meetings 3-4 times per year to discuss how genetics/genomics fits in more broadly</td>
</tr>
<tr>
<td>• Formats into knowledge-based content (written and video) and performance-based content (case studies)</td>
<td>• Formats into knowledge-based content (written and video) and performance-based content (case studies)</td>
<td></td>
</tr>
<tr>
<td>• Much of third-party content distribution is funded by grant-based programs</td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Future</th>
<th>Medscape</th>
<th>UpToDate</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Very interested in discussions with ISCC</td>
<td>• Very interested in discussions with ISCC</td>
<td>• Recognizes need to go deeper on genomics. Looking for “current, true, clinical applications.” Views genetics as still early. Trying not to be cutting edge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Interested in seeing the ISCC outputs to determine clinical usefulness</td>
</tr>
</tbody>
</table>
What can we learn from case studies?

• Forum for Collaborative HIV Research
• Aligning Forces for Quality Program Alliances
• Biomarkers Consortium
Mission
• The Forum for Collaborative HIV Research is a public/private partnership including government agencies, industry, HIV researchers and clinicians, payers, foundations and the HIV patient advocacy community
• Mission is to facilitate and enhance HIV research
• Apply HIV collaborative model to HCV

History
• Started as a Keystone dialogue – with no expectation of permanence
• Founded in 1986
• 1 year funding (HHS) extended by 1 year
• 5 year multi-stakeholder funding - NIH, CDC, HRSA, CMS, pharma
• Expand focus internationally
• Expand funding base – biotech, foundations
• Expand focus to include HCV
• New programs include: internship/fellowship program, didactic courses, collaboration with other schools, executive level short-courses
### Members-Partners-Collaborators

#### Government Agencies
- **USA**
  - CDC
  - FDA
  - HHS/OASH
  - HRSA
  - NIH
    - NIAID
    - NIDA
    - NIMH
    - OAR
  - OGAC
  - USAID
  - VA
- **Europe**
  - ANRS
  - EMA

#### Academia / Providers
- **HIV**
  - ACTG
  - INSIGHT
  - Epi / Stats
  - Immunology
  - Virology
  - Women’s Health
- **Foundations**
  - BMGF
  - amfAR
  - EGPAF
- **Professional Societies**
  - AAN
  - IAS
  - HIVMA
  - IDSA
  - EASL
  - AASLD

#### Industry
- **HIV**
  - Abbvie
  - Abbott Mol.
  - Alere
  - BD
  - Bio-Rad
  - BMS
  - Genentech
  - Gilead
  - Illumina
  - Janssen
  - Merck
  - Monogram
  - Orasure
  - PacBio
  - Quest
  - Quintiles
  - Roche MS
  - Tobira
  - Viiv
- **HCV**
  - Abbvie
  - Abbott Mol.
  - Achillion
  - Biocartis
  - BI
  - BMS
  - DDL
  - Genentech
  - Gilead
  - GSK
  - Hoffman La Roche
  - Idenix
  - Janssen
  - Merck
  - Monogram
  - Novartis
  - PPD
  - Quest
  - Quintiles
  - Roche MS
  - Vertex
  - Virco

#### Community / Advocacy
- **HIV**
  - ATAC
  - CAB-ACTG
  - CAB-INSIGHT
  - EATG
  - NGMAC
  - TAG
- **HCV**
  - HCAB
  - NATAP
  - NVHR
  - PWB+HCV
  - TAG
- **Insurers**
  - Kaiser Permanente
Forum Model & Principles

- **Collaboration**
  - achieve optimal resource utilization
- **Ownership**
  - of the process by all stakeholders
- **Independence**
  - from bias
- **Credibility**
  - scientifically & ethically sound principles
- **Productivity**
  - avoid duplication
- **Accountability**
  - to all the stakeholders
- **Accessibility**
  - of products to all members & the public

Government Agencies

Academia

Foundations

Professional Societies

Industry

Community

Advocacy Organizations

Health Insurers
About the program

• Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation’s (RWJF) signature effort to lift the overall quality of health care in targeted communities, reduce racial and ethnic disparities and provide models for national reform

• AF4Q asks the people who get care, give care and pay for care to work together toward common, fundamental objectives to lead to better care

• Focus in 16 geographically, demographically, and economically diverse communities that together cover 12.5% of the U.S. population

• Project areas
  o Care Across Settings
  o Cost and Efficiency
  o Equity
  o Measurement and Reporting
  o Consumer Engagement
Best practice organizations have a diversified portfolio of funding streams

Revenue by funding model

<table>
<thead>
<tr>
<th>Percent of Funding</th>
<th>Alliance A</th>
<th>Alliance B</th>
<th>Alliance C</th>
<th>Alliance D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program funding</td>
<td>51</td>
<td>75</td>
<td>42</td>
<td>85</td>
</tr>
<tr>
<td>Fee-for-service (includes contracts and events)</td>
<td>4</td>
<td>25</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Membership dues</td>
<td>20</td>
<td>25</td>
<td>56</td>
<td>85</td>
</tr>
<tr>
<td>Grants/contributions</td>
<td>2</td>
<td>25</td>
<td>56</td>
<td>5</td>
</tr>
</tbody>
</table>

Alliance A, Alliance B, Alliance C, Alliance D
### Number of Membership Levels

<table>
<thead>
<tr>
<th>Alliance</th>
<th>Few</th>
<th>Many</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alliance A</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Alliance B</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Alliance D</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Alliance C</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

**Pro**
- Simpler
- Promotes equity across all organization types
- More mission-based

**Con**
- Lower levels are sometimes needed to attract smaller organizations

**Pro**
- Intended to represent ability to pay
- Sometimes an additional level is available to allow for commercial entities who seek sponsorship and recognition

**Con**
- Can be more complicated to explain to members
## Range of Membership Dues

<table>
<thead>
<tr>
<th>AF4Q Alliance</th>
<th>Total dues (approx)</th>
<th>Number of membership levels</th>
<th>Number of members</th>
<th>Maximum membership amount</th>
<th>Minimum membership amount</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>$1.9M</td>
<td>7</td>
<td>150</td>
<td>$60,000</td>
<td>$100</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>$800K</td>
<td>1</td>
<td>28</td>
<td>$26,000</td>
<td>$2,500-10,000</td>
<td>Beginning to experiment with a lower level for smaller MD groups</td>
</tr>
<tr>
<td>A</td>
<td>$380K</td>
<td>11</td>
<td>69</td>
<td>$54,616</td>
<td>$182</td>
<td>Being revamped to address economic challenges of community</td>
</tr>
<tr>
<td>D</td>
<td>$73K</td>
<td>5</td>
<td>62</td>
<td>$5,000</td>
<td>$100</td>
<td></td>
</tr>
</tbody>
</table>
Mission
- The Biomarkers Consortium projects serve to develop and qualify promising biomarkers in order to help accelerate the delivery of successful new technologies, medicines and therapies for prevention, early detection, diagnosis and treatment of disease
- Designed to enable improvements in drug development, clinical care, and regulatory decision-making

History
- Formally launched in late 2006
- Founders:
  - Foundation for NIH
  - National Institutes of Health
  - Food and Drug Administration
  - Pharmaceutical Research and Manufacturers of America
- Other parties instrumental in the implementation of the Consortium:
  - Centers for Medicare & Medicaid Services
  - Biotechnology Industry Organization
- Broad participation from stakeholders across the health field, including government, industry, academia and patient advocacy and other non-profit private sector organizations
Organizational structure

- An initiative of the Foundation of the NIH

Funding model

- Exclusive funding from private sector funds
  - Membership model to support organizational core, maintain strategic direction as well as to develop new project ideas
    - Government
    - 14 life sciences companies
    - 16 non-profit organizations
  - Separate program funding both from Consortium members and non-members

- Coordinates efforts of over 250 research scientists and has launched 13 projects worth over $40 million in cancer, neuroscience, diabetes, cardiovascular disease, osteoarthritis, and other major diseases