Health Business Group
Sustainability Planning for ISCC

Discussion Document

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HealthBusiness GROUP

101 Federal Street
Suite 1900
Boston, MA 02110
(617) 648 3828
HealthBusinessGroup.com

For additional information contact Karen Donovan
kdonovan@healthbusinessgroup.com or (617) 512-4582

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

Scope of services	Mission of professional genomic literacy	Facilitation/convening/sharing best practices	Curation of third-party educational products	
	Creation of content	Consulting services	Health policy	

Funding model	Membership dues	Program funding	Fee-for-service	
	Royalties	Grants	Donations	

Stakeholders	Specialty medical societies	Specialty medical boards	Government agencies	Foundations
	Medical education providers	Industry (e.g., genetic testing companies/labs, pharma)		Patient advocacy groups

Organizational form	Subsidiary of existing organization	Independent 501(c)3	For-profit entity

What are some different models of sustainability?

- **Public-private partnerships**
  - **Forum for Collaborative HIV Research**
  - **Biomarkers Consortium**
- **Multi-stakeholder collaborations**
  - **AF4Q alliances**
  - **NRHI alliances**
- **Subsidiaries of medical societies and other health care non-profits**
  - **TransforMED**
  - **Massachusetts eHealth Collaborative**
- **Medical society collaborations or associations**
  - **Council of Medical Specialty Societies (CMSS)**
  - **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

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

Funding model pros and cons

Funding model	Advantages	Disadvantages
Membership dues	• Predictable revenue/cost • Ability to respond to emerging priorities • Equitable	• Formulas become complex or outdated • Members may be uncomfortable with autonomy
Program funding	• Tied to specific priorities • Can come from different budgets • Can broaden the base of shareholders	• Have to raise funds on an ongoing basis • Less predictability • Large contributors can dominate
Fee-for-service funding	• Introduces commercial discipline • Demonstrates value added	• Members may resist payment • May stray from mission • Can complicate governance
Royalty	• A byproduct, requiring little ongoing attention	• Need to control use; sometimes is not worth the trouble
Grants and/or donations	• Sponsor can support an issue important to them • Motivation is largely mission-based	• Grants generally have a limited life • Requires resources for grant writing • Hard to have predictable long-term revenue stream; Often requires an endowment to create financial buffer • Some grants are more pass-through

Possible commercial partners for marketing/distribution

	Medscape	UpToDate
Clinical user base	• Over 550,000 active U.S. physicians and 600,000 nurses across all specialties • Over 2.6M physician visits and 3.6M nurse visits per month in the US	• Over 700,000 clinicians in 157 countries. • Integrated into clinical workflows in over 25,000 institutions and practices
Current	• Limited information in genomics today • Has their own editorial staff and also licenses/distributes partner content • Formats into knowledge-based content (written and video) and performance-based content (case studies) • Much of third-party content distribution is funded by grant-based programs	• Generally does not have separate genetics topics, with some exceptions (e.g., breast cancer) • The genetic medicine section editor attends editorial meetings 3-4 times per year to discuss how genetics/genomics fits in more broadly
Future	• Very interested in discussions with ISCC	• Recognizes need to go deeper on genomics. Looking for “current, true, clinical applications.” Views genetics as still early. Trying not to be cutting edge • Interested in seeing the ISCC outputs to determine clinical usefulness

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
- 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.

HCV (cont.)
- Achillion
- Biocartis
- BI
- BMS
- DDL
- Genentech
- Gilead
- GSK
- Hoffman La Roche
- Idenix
- Janssen
- Merck
- Monogram
- Novartis
- PPD
- Quest
- Quintiles
- Roche MS
- Vertex
- Virco

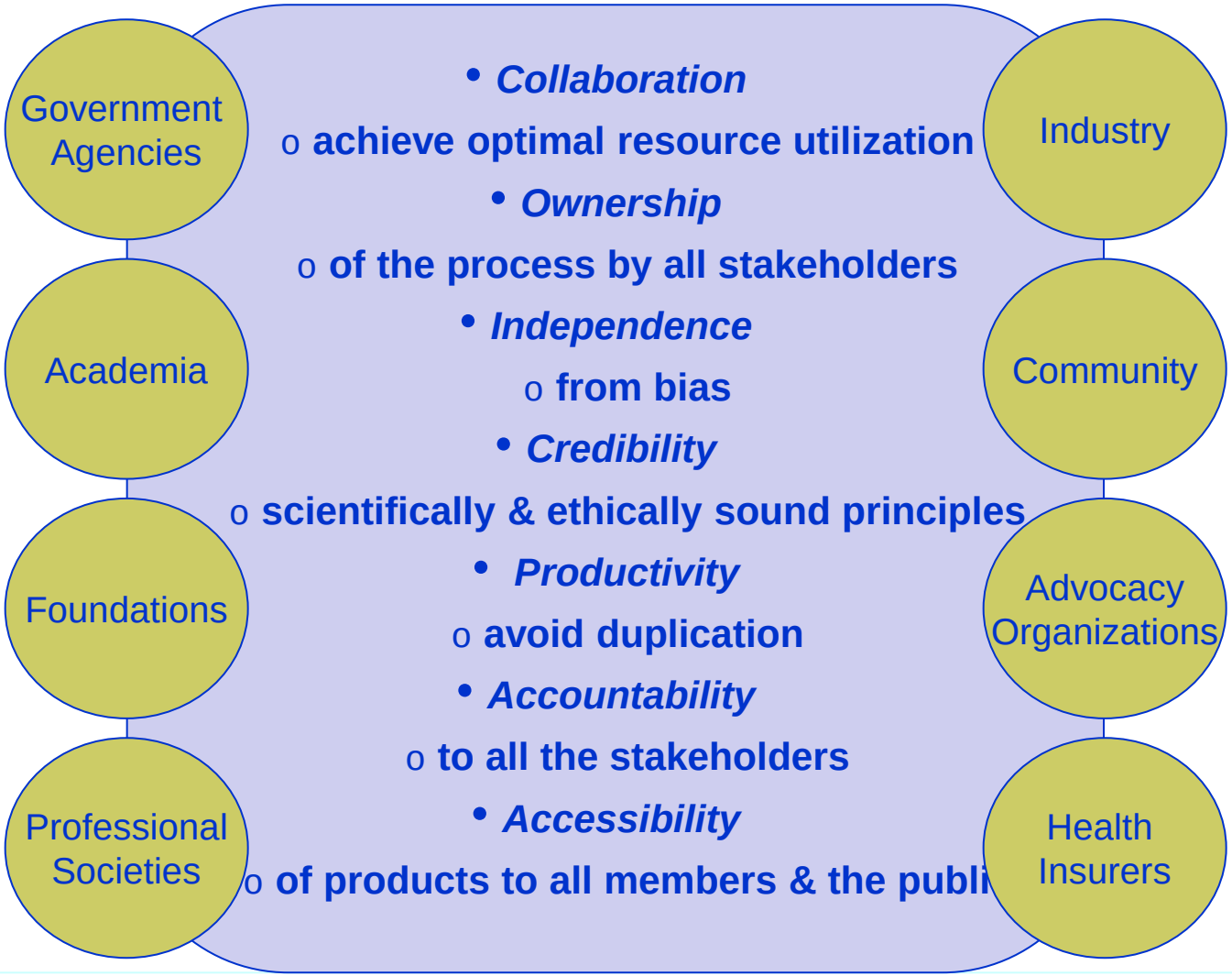
Community / Advocacy

HIV
- ATAC
- CAB-ACTG
- CAB-INSIGHT
- EATG
- NGMAC
- TAG

HCV
- HCAB
- NATAP
- NVHR
- PWB+HCV
- TAG

Insurers
- Kaiser Permanente

Forum Model & Principles

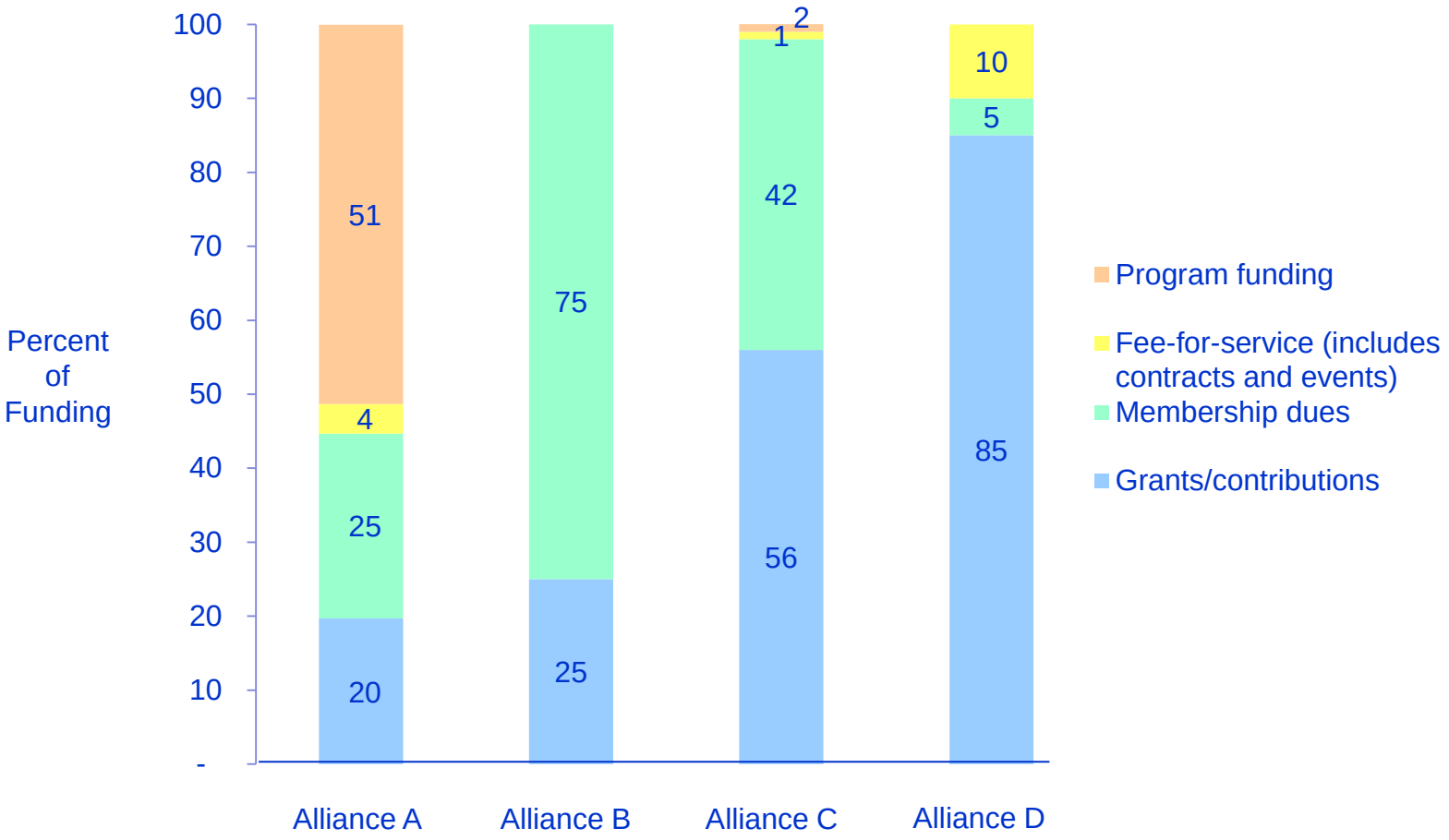


About the program

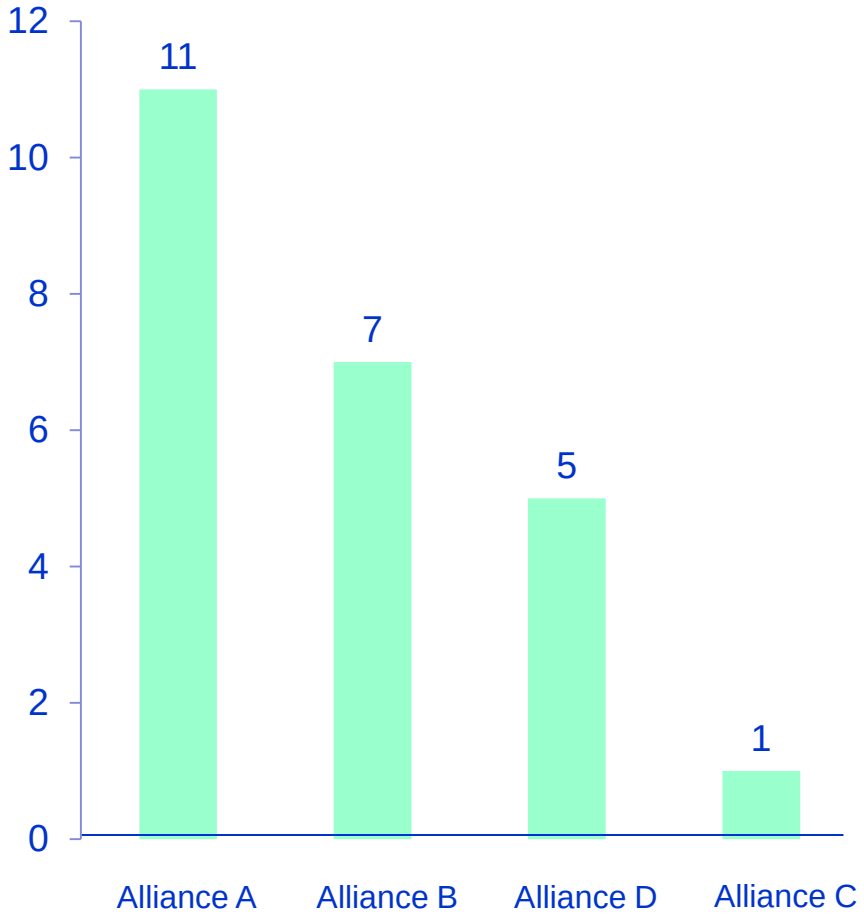
- **Aligning Forces for Quality (AF4Q) is the Robert Wood Johnson Foundation's (RWJF) signature effort to lift the overall quality of health care in targeted communities, reduce racial and ethnic disparities and provide models for national reform**
- **AF4Q asks the people who get care, give care and 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**
  - **Care Across Settings**
  - **Cost and Efficiency**
  - **Equity**
  - **Measurement and Reporting**
  - **Consumer Engagement**

Best practice organizations have a diversified portfolio of funding streams

Revenue by funding model



Number of Membership Levels



	Few	Many
Pro	• Simpler • Promotes equity across all organization types • More mission-based	• Intended to represent ability to pay • Sometimes an additional level is available to allow for commercial entities who seek sponsorship and recognition
Con	• Lower levels are sometimes needed to attract smaller organizations	• Can be more complicated to explain to members

Range of Membership Dues

AF4Q Alliance	Total dues (approx)	Number of membership levels	Number of members	Maximum membership amount	Minimum membership amount	Comments
B	$1.9M	7	150	$60,000	$100	
C	$800K	1	28	$26,000	$2,500-10,000	Beginning to experiment with a lower level for smaller MD groups
A	$380K	11	69	$54,616	$182	Being revamped to address economic challenges of community
D	$73K	5	62	$5,000	$100	

THE biomarkers CONSORTIUM

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

THE biomarkers CONSORTIUM

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