Spring 2015 Plenary II: Going Global
Building International Research Capacity and Global Data Collaborations – Lessons Learned

- Yuri Quintana, PhD
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Building International Research Capacity and Global Data Collaborations

Lessons Learned

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May 1, 2015
Global Health Challenges

- Rising chronic diseases
- Aging population
- Late or no diagnosis
- **Lack of trained healthcare workers**
- Lack of essential medicines
- Lack of appropriate equipment
- **Poor or no integration of health IT systems**
- **Lack of reliable data at local, regional & national level**
- Poor coordination of healthcare delivery
- Rising costs of healthcare
Case Study: Central America

- 1980s: Few pediatric oncologists,
  - civil wars, earthquakes, floods and hurricanes
  - childhood cancer survival rates below 20% [1]

- 1990s: Specialized centers form
  - training via site visits and annual regional meeting
  - survival rates climb slowly to over 20% [2]

- 2002-2014: Cure4Kids.org launched to provide online education and collaboration tools
  - weekly online meetings to discuss best practices
  - survival rates climb to 48% [3]

Community of Practice

- A community of practice (CoP) is a group of people from a common profession or interest area that share knowledge and experiences with each other so that they can grow personally and professionally.
Communities of Practice

- Local Group
- Regional Societies
- National Professional Societies
- International Professional Societies

- **Challenge:** Limited Frequency of meetings, cost of travel, limited depth of collaborations
Communities of Practice

- People with Common Needs
- Join a List
- Create a Discussion Forum
- Share Best Practices
- Create New Knowledge
- Collective Intelligence
Cure4Kids is a website dedicated to improving health care for children in countries around the globe. A resource, portal and bridge of knowledge, Cure4Kids provides continuing education and global communication tools to health care professionals who treat children with cancer and other catastrophic diseases. Explore this free resource and start collaborating worldwide!

Tour Cure4Kids
Content is presented in the form of online seminars and conferences with audio narration, electronic full-text books and journals, and online self-paced courses. Click below to get a visual tour of Cure4Kids.

Sample Content
Cure4Kids contains hundreds of seminars, courses, and conferences. All material can be easily used and downloaded for reference and educational purposes. Click below to preview some of our content.

Oncopedia
Oncopedia is an interactive area on Cure4Kids with complex hematology / oncology cases, chapters, and images with expert commentary from our editorial board. Cure4Kids users can interact with other users and the editorial board by posting opinions and questions about the content.

Learning and Collaboration Platform

Online Learning Platform
- Online Seminars
- Self-Paced Courses
- Instructor Led-Courses
- Care Guidelines
- Competency-based curriculums linked to online educational resources
- Clinical Case Library

Online Collaboration Platform
- Online web meeting services
- Group shared documents
- Online teaching classes
- Online clinical case discussions for second opinion on care treatments
- Online meeting minutes notes
- Recorded meetings archive
- Shared collaborative projects tools

Online Live Group Clinical Discussions

• 400 groups formed worldwide for live online group meetings

• Over 200 groups remain active


Case Study: Central America

- Online meetings for
  - Continuing education
  - Second opinion on case management
  - Program administration development

- Key Success Factors
  - Regular meeting time
  - Multi-disciplinary team participation
  - Involvement and mentoring of new staff
Oncopedia - Asynchronous Clinical Forum

Global Data Sharing

Virtual Sites
- El Salvador
- Honduras
- Guatemala
- Nicaragua
- Costa Rica
- Panama

Shared Library
- Protocols
- Forms
- Reports
- Charts
- Documents

Global Data Sharing

Case Study: Central America

Connect

- AHOPCA pediatric oncology society annual meeting
- Access to continuing education on Cure4Kids.org
- Access experts via Web meetings on Cure4Kids.org

Collaborate

- Develop common protocols on Cure4Kids.org
- Disseminate new knowledge via weekly meetings on Cure4Kids

Trust

- Data sharing for quality improvement on POND4Kids.org
- Second opinion consultation
Case Study: Central America

Focus on sharing not Credit

Developed common protocols adapted to local resources

Weekly meetings to discuss clinical cases

Common needs

Clear goals

Access to continuing education on Cure4kids.org

Shared data and outcomes on POND4Kids.org

Peer-to-Peer Collaborations

Expanded from 1 to over 30 communities in entire region
- Clinical Protocols
- Nursing
- Palliative Care
- Laboratory Medicine
- Data Management
- Clinical Improvement

Central America Outcomes

- **Increased survival rates** from 20% to over 50% for common types of cancer in some low income clinics

- Expanded Communities of Practice to **other disciplines**

- Expanded **Multi-Disciplinary** Teamwork

- **Multiplier effect** – impact beyond ped-onc unit

- **Quality Improvement Initiatives**
  - Late Referrals (community outreach)
  - Toxic deaths (adapting protocols)

Sources:


Evolution of Communities

Connect
People Connecting with Common Needs
Access to Continuing Education
Access Best Practice Guidelines

Collaborate
Peer to Peer Support
Develop New Best Practices and Guidelines
Disseminate new knowledge

Trust
Mentoring Networks (Senior – Junior member)
2nd Opinion Networks (advice giving in real time)
Data Sharing for Quality Improvement

Facilitators

- Transparent and Inclusive Leadership
- Open to Innovation
- Supportive Community
- Renewal of Leadership
- Evolving and Relevant Goals
- Creation of New Communities
- Common Tools and Language
- Supportive and Responsive Community
- Focus on Sharing not Credit
- Critical Mass of People
- Common Needs
- Clear Goals

Barriers

- Misaligned Goals and Needs
- Inflexible and Non-Transparent Leadership
- Dominating Personalities Focused on Credit
- Hidden Agendas
- Lack of Access to Knowledge
- Institutional Rigidity
- Infrequent Meetings
- Non-Responsive Community
- Non-Returning Membership
- Irrelevant Mission and Goals

Connected Information Systems

- Early Diagnosis
- Patient Referrals
- Community Health Indicators

- Optimizing Clinical Care
- Creating Peer Networks

- Patient Reported Data
- Family Care Networks

Global Health Informatics
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Technical Challenges

• Trying to collect too much data
• Tools Import of legacy data
• **Tools and processes for data quality assurance**
• Conversion of international units
• Managing diverse medical vocabularies & taxonomies
• Granularity of data access controls
• **Offline tools that can synchronize**
• Inconsistent bandwidth
People Challenges

- Availability of technical staff (security)
- **Lack of training in local languages**
- Retention of staff
- Sustainable funding
- Inconsistent communications
- **Cultural differences**
- Semantic differences (“urgent”, “minor”, “abandonment”)
- Lack of Governance models for data sharing
- **Lack of Trust**
Lessons Learned

- Need achievable plan give local resources
- Agreed on objectives, target outcomes, timelines
- Design programs to meet regional needs
- Long term commitment
- **Training and career ladders are key**
- Incentives, rewards, recognition
- **Locally appropriate change management approach**
- **Easy to use platforms that can scale to larger size**
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