Challenges for Implementation of Multicentric Registries of Pediatric Cardiac Surgery in Latin America

Nestor Sandoval R.
Fundación Cardioinfantil-Instituto de Cardiología
Bogotá, Colombia

Member Steering Committee IQIC.
Member WDSPCHS
Background

Congenital heart surgery is rapidly evolving in developing nations with increasing surgical volumes and better outcomes.

limited infrastructure and trained personnel, few dedicated pediatric cardiac programs, suboptimal funding and lack of health insurance policies.

There is no a database that attracts and reaches all countries, and many centers.

There is now a desire or interest from “established Societies” to involve centers in developing countries (LA) in these databases projects.
Why implementation of a multicentric registry so important

- Using clinical data drives the best practice.
- Guidelines for clinical practice.
- Clinical research. (publications)
- Public reports outcomes. (important for patients, families, government, and insurance companies.)
- A Good “competition”.
- Generates commitment and responsibility.
Essential elements of a database

1. **Nomenclature**: Use of a common language and nomenclature.
2. **Database structure**: Defined and uniform core data set.
3. **Complexity stratification**: Mechanism to evaluate case complexity. (Rachs-1 STAT)
4. **Data verification**: Mechanism to assure data accuracy.
5. **Subspecialty collaboration**: Cardiology, CV surgery, anesthesia, critical care.
6. **Longitudinal follow-up**: Mechanism for lifelong follow-up.
7. **Quality improvement**: Mechanism for measurement of performance and improvement.
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STS/EACTS Latin America Cardiovascular Surgery Conference 2017
41,100 new child need any treatment

Sandoval N et al. World Journal for Pediatric and Congenital Heart Surgery 2010 1: 321
60% children have no any treatment

Sandoval N et al. World Journal for Pediatric and Congenital Heart Surgery 2010 1: 321
Cardiac units per million in South America
(418,000,000)

140 centers
1 Ped Cardiac Center /2´900.000
Pediatric Databases with impact in Latin America

CHSS
STS
ECHSA
IQIC
WDSPCHS
Limited Cost

STS/EACTS Latin America Cardiovascular Surgery Conference 2017
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- Free ?
- Verification ?
- was the first to try to involve Latin America.
- Complete medical information
- Lack of direct relation to centers

ECHSA Database Growth

STS/EACTS Latin America Cardiovascular Surgery Conference 2017
Society for Thoracic Surgery Congenital Cardiac Surgery Database

- Largest database in the world
- 125 centers in the US and 8 in Canada
- Verified audited data
- Risk adjusted data
- Platform for QI and transparency
- National Quality Forum endorsement

Growth in the STS Congenital Heart Surgery Database
Cumulative operations over time

STS/EACTS Latin America Cardiovascular Surgery Conference 2017

Society for Thoracic Surgery
Congenital Cardiac Surgery Database

- Limited mainly to US and Canada and ????
- “Expensive” for LA countries.
- Hard to fill all the variables

STS/EACTS Latin America Cardiovascular Surgery Conference 2017

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- Free
- Webinars and meetings
- Verified audited data
- Limited medical information
- Mortality 30 days
- Publications
- Future?
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Participating Centers (21 countries) 2016

- Russia: 2
- China: 4
- India: 11
- Brazil: 6
- Argentina: 2
- Peru: 1
- Colombia: 2
- Uganda: 1
- Mexico: 2
- Guatemala: 1
- El Salvador: 1
- Nicaragua: 1
- Costa Rica: 1
- Georgia: 1
- Serbia: 1
- Bulgaria: 1
- Ukraine: 1
- Afghanistan: 1
- Pakistan: 2
- Bangladesh: 1
- Vietnam: 1
- Malaysia: 1
- Afghanistan: 1
- Pakistan: 2

Founding Sites

- UNICAR, Guatemala City, Guatemala
- Clinica Medellin, Medellin, Bogota*
- Frontier Lifeline Hospital, Chennai, India
- National Children’s Cardiac Surgical Center, Minsk, Belarus*
- Armed Forces Institute of Cardiology, National Institute of Heart Disease, Rawalpindi, Pakistan

*No longer enrolled
Currently Participating (18)

- It is free if one surgeon is member of the WSPCHS
- Easy to fill
- Complete medical information.
- Longitudinal follow up.
- Open for everybody.
Joint effort to link this two databases.
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- International Quality Improvement Collaborative for Congenital Heart Surgery in Developing World Countries
- Link compatible allow the migration of information that several databases can be included
Conclusions

• Databases have produced a overwhelming amount of information to offer the better treatment to our patients, and will allow developing congenital heart surgical programs to evaluate outcomes and compared to themselves and peers.

• All databases are good

• Not need to have more than one database system.

• We need a safe database over time !!!!!!!
Conclusions

• We need to create a platform that allows for the linkage of currently existing continental subspecialty databases
• Leaders.
• Commitment and support of institutions.
• International support.
• Cost is a barrier.

Once you have used it you can not live without it
Let's all get addicted to database
Linking Databases
Thank You