

Integrated Patient-Centred Health Information Systems

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Faculty/Presenter Disclosure

Faculty: Michael Graven

Relationships with commercial interests:

Grants/Research Support: None

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Consulting Fees: None

Other: Retired Faculty, Dalhousie University, Halifax NS, Canada

Employee of Bendcare LLC (Accepted invitation to speak at 28th ICP before being hired)

First International Congress of Pediatrics, Paris 1912

Professor Hutinel Opened Congress October 8, 1912 of behalf of **l'Association Internationale de Pédiatrie**

Jan Raczynski first shared evidence on relationship between seasonal lack of sunshine and rickets. He went on to experimentally show effect of absence of sunlight on newborn puppies developing rickets.

Raczynski built on the work of **Theobald Palm**, who observed geographic variability in rickets rates.

Over 104 years, their insights have been confirmed regarding bone mineralization, sunshine, and Vitamin D.

Raczynski J. Recherches Experimentales sur le Manque D'action au Soleil Comme Cause du Rachitisme. C. R. Assoc. Internat. Pédiatrie; Paris, France: 1913. pp. 308–309.

Palm T.A. The geographic distribution and etiology of rickets. Practitioner. 1890; 45:270-279, 321-342.

My Goals for the next 40 minutes

1. Show how to save lives and reduce suffering with health information systems.
2. Explain why health information systems currently do less than they could.
3. Describe examples of fully integrated health information systems
4. Outline critical issues that should guide health information policy in the future.

Therapeutic Gap

1. When it is known that a defined therapy is needed, but not yet provided.
2. To discretely identify a therapeutic gap, you must know all who need the therapy.
3. Identifying all who need the therapy requires knowing all who have received the therapy.
4. Fully integrated, patient centric, health information systems make knowing the gaps possible.
5. Minimizing or eliminating all therapeutic gaps requires such a health information system.

Why have Health Information Systems at all?

1. No need to record details of today's patient-provider encounter if they can't be used tomorrow
2. Clinic encounters are more effective if prior encounter records at that clinic are available
3. Clinical encounters are even more effective if encounter records from other clinics are available
4. Patients seen today will be seen in the future at multiple locations
5. Informatics value: human memory < hardcopy < electronically local < electronically distributed

Seven Fundamental Axioms on Health Information Systems

1. Humans need health services from multiple places at multiple times
2. Error rates rise whenever health data pass through human transmitters
3. All data without feedback have lower completeness and accuracy
4. Absence of feedforward will degrade informatics value over time
5. Excellence in management of common conditions decreases the rates of rare disasters
6. Patient-Centric \neq Technology Vendor-Centric \neq Administration-Centric
7. Absence of information must mean “not present” or “didn’t happen”

Multiple Care Loci: Common Examples in MCH

1. Prenatal care: Serial outpatient & pharmacy encounters, attached to inpatient delivery encounters
2. Well Child care: Serial outpatient with predictable rates of pharmacy and inpatient encounters
3. Chronic Condition care: Serial outpatient, inpatient and pharmacy encounters
4. Trauma/Accident care: Predictable rates of encounters at sites distant from home
5. Family Migration: Resetting any pattern of serial encounters at new location(s)

Information discontinuities between care loci degrade efficiency and effectiveness of all care

Multiple Care Loci: Example 1

Adverse Reactions to Prescribed Medications

- First reactions are more difficult to avoid
- Second and subsequent reactions can be avoided if all characteristics of adverse reactions are available wherever prescriptions are initiated or dispensed
- There are deaths daily in most countries from discontinuities between health records with reaction documentation and new prescriptions

Multiple Care Loci: Example 2

Prevention of Mother to Child Transmission of HIV (PMTCT)

- Prenatal care and delivery care nearly always are different places
- Prenatal care data (including HIV status) must be immediately available when a mother presents in labour
- Place where delivery will occur is often not known in advance
- Prenatal care data must, therefore, be available at as many places as possible where delivery might occur
- Prenatal records are often not available at the time of delivery

Multiple Care Loci: Example 2

PMTCT in Ethiopia 2004-2007

- *Medan Acts* Voluntary Testing and Counselling program expanded to include logistics of *Axios* donated antiretroviral medicines in 2004
- Contractually provided services for Addis Ababa Health Bureau in late 2004 for city of Addis Ababa. Expanded to most of Ethiopia through 2005
- Provided testing, counselling, and antiretrovirals for ~65,000 deliveries of HIV positive mothers 2005-2007.
- Program collapsed through lack of funds in early 2008, parts taken over by various NGO's, contracted aid agencies, and Ministry of Health, Government of Ethiopia

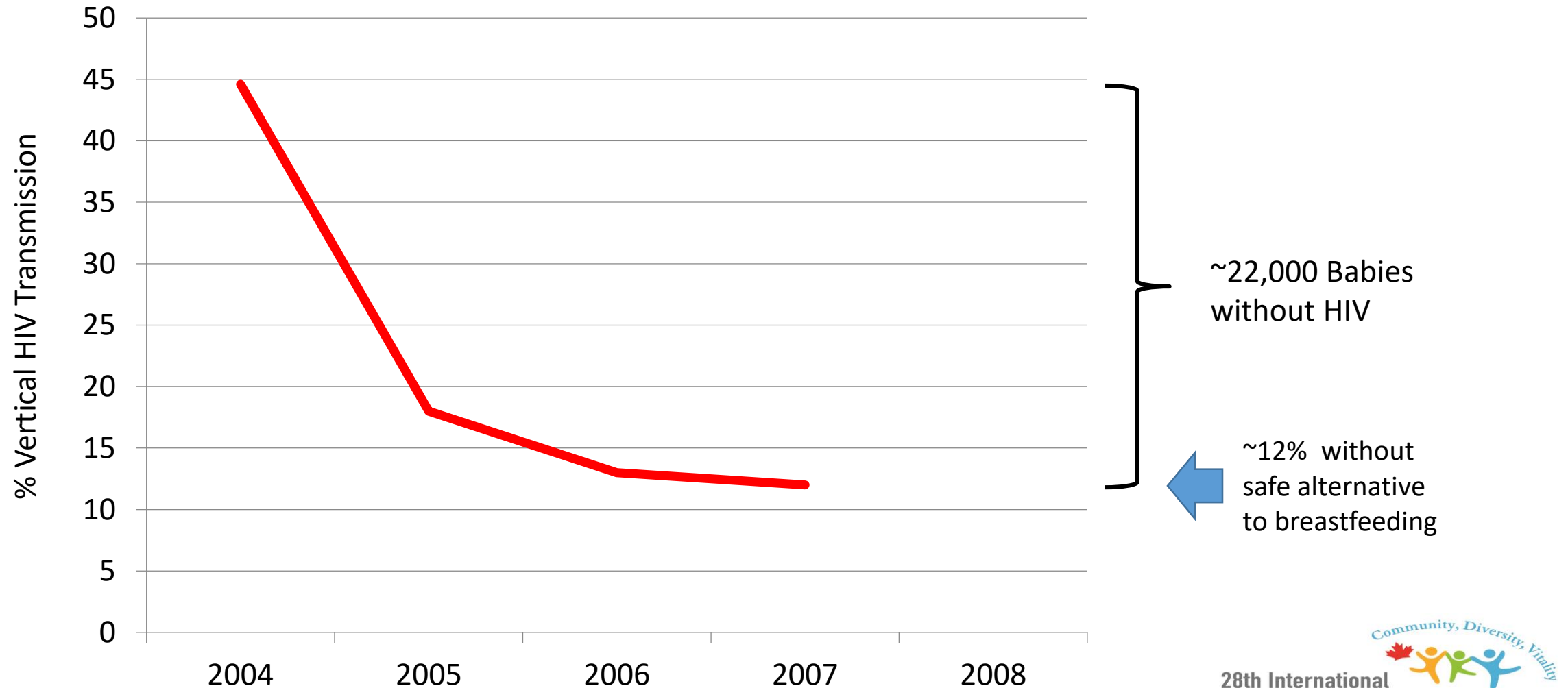
Multiple Care Loci: Example 2

Mathematical Requirements for Effective PMTCT

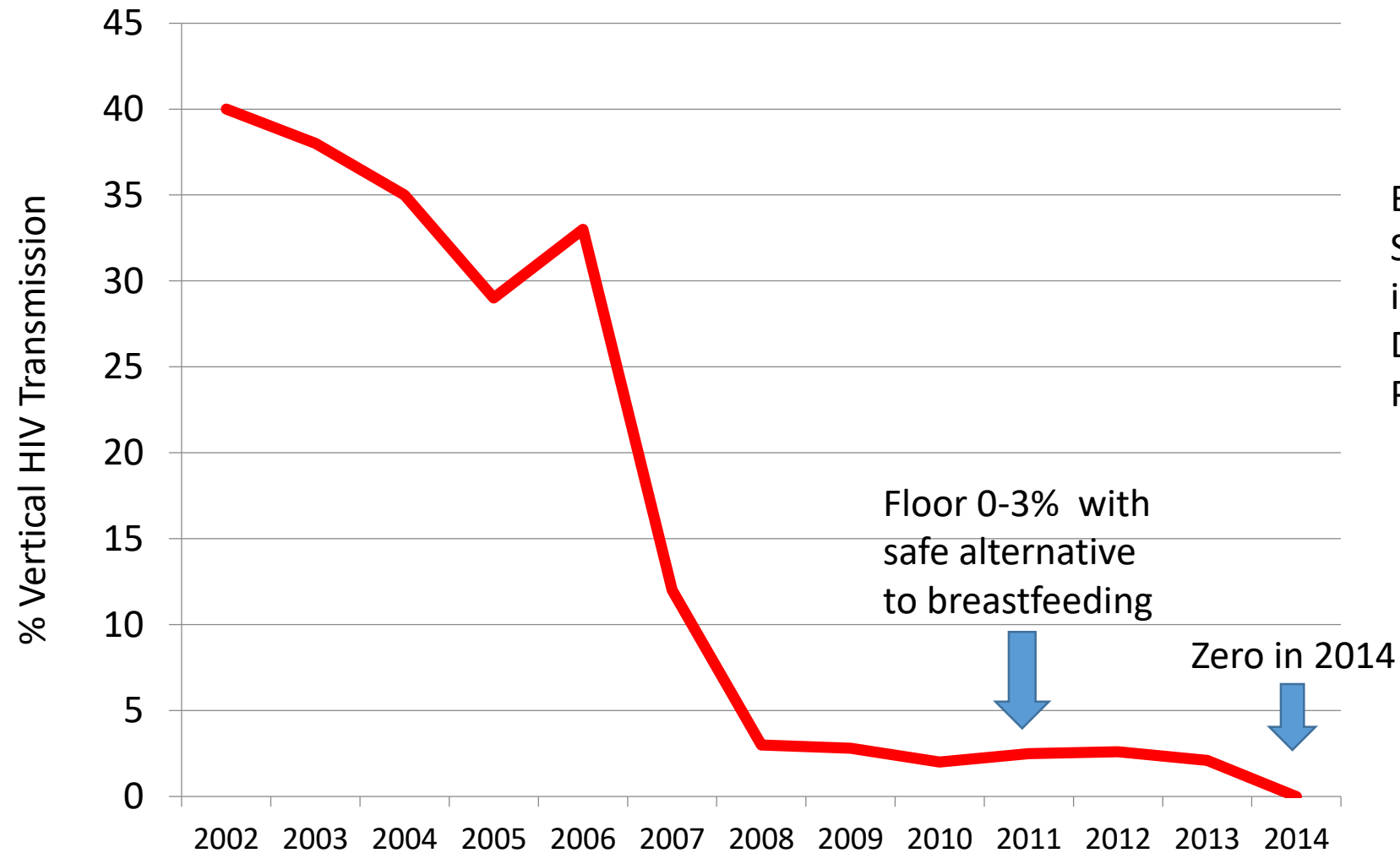
- Test everybody that might have HIV early in pregnancy
- Record HIV status safely, securely, but rapidly available wherever delivery might occur
- Rich countries: ARV's throughout pregnancy, at delivery, and for baby after delivery, with safe alternative to breast feeding: ~2-3% transmission to baby
- Poor countries: ARV's at delivery, and for baby after delivery with breast feeding in absence of safe alternatives: ~12% transmission to baby

Preventing Mother to Child Transmission of HIV in Ethiopia 2004-2007 (PMTCT)

(~65,000 Births to HIV+ Mothers Treated)

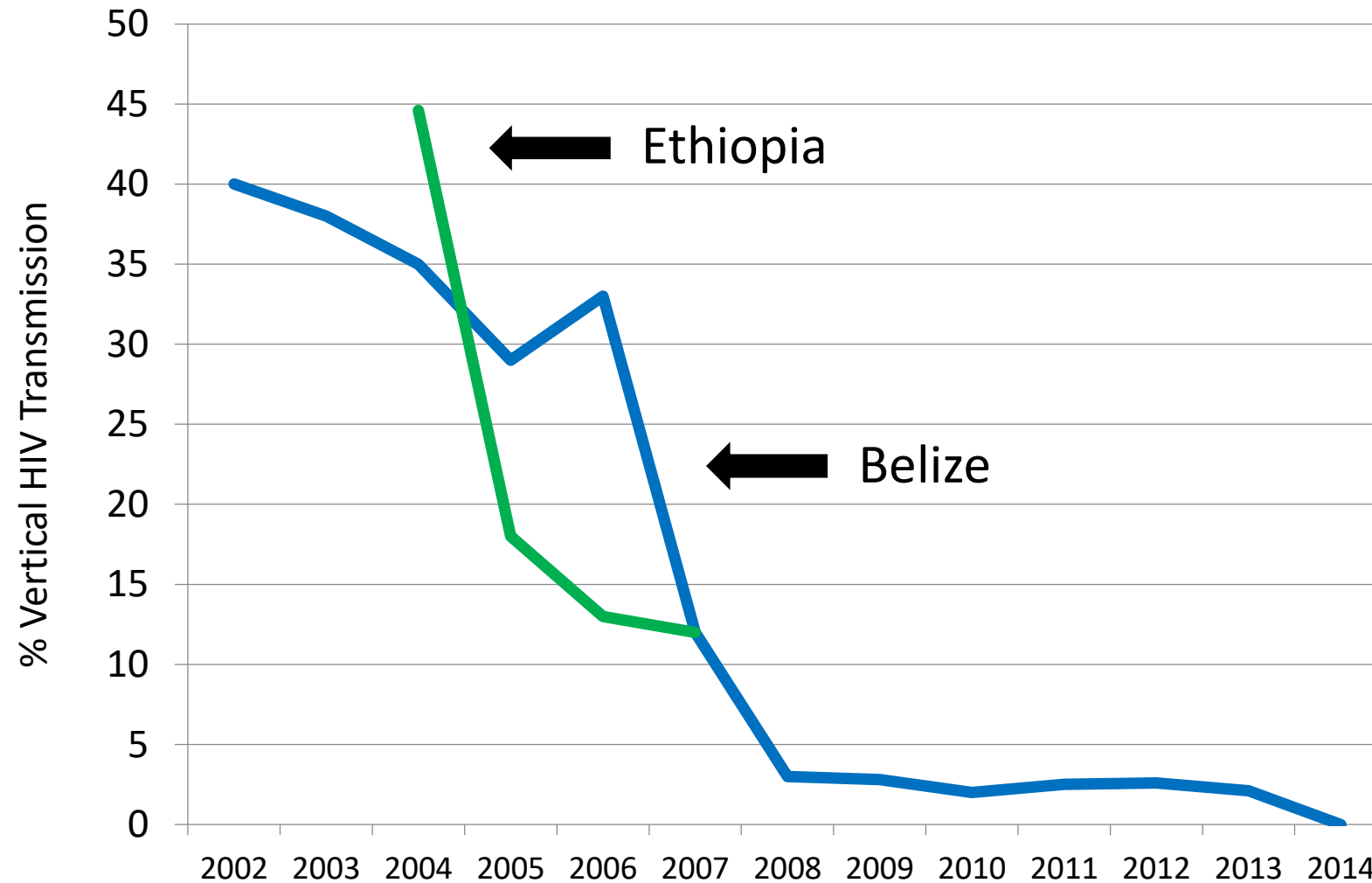


Preventing Mother to Child Transmission of HIV in Belize (PMTCT)



Belize Health Information System (BHIS) Deployed in 2007 with PMTCT Disease Management Protocols

PMTCT: Programs in Ethiopia and Belize



Sources of Human Data Transmission Error

- Memory of clinical information degrades with time
- Conditions like dyslexia alter digits and order
- Context shifts degrades ability to remember information
- Impaired vision can affect accuracy and precision of information taken by reading
- Handwriting variability affects ability to visually decode written information
- Sequential verbal transmissions rapidly degrade information content of clinical data
- Transition from short-term to long-term memory requires at least two sleep rem-cycles

Many Other Sources of Error Rate Variability

Human Data Transmitters: Example 1

In 1987 during a medical school clinical correlation discussion, a senior perinatologist asserted that there was zero error rate associated with the faxing of prenatal records from outpatient offices to inpatient labor & delivery service.

Based on that discussion, I set up an experiment with fax machines.

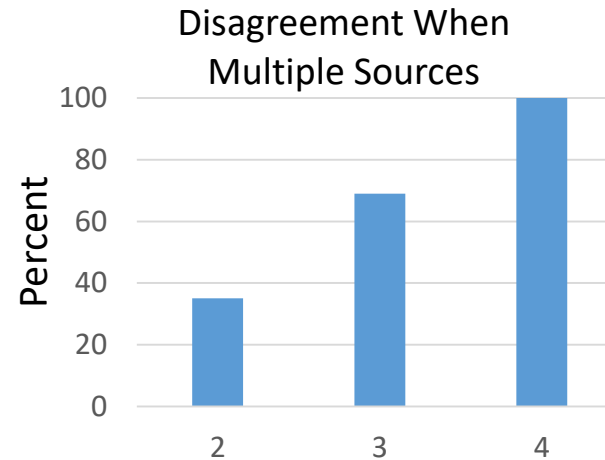
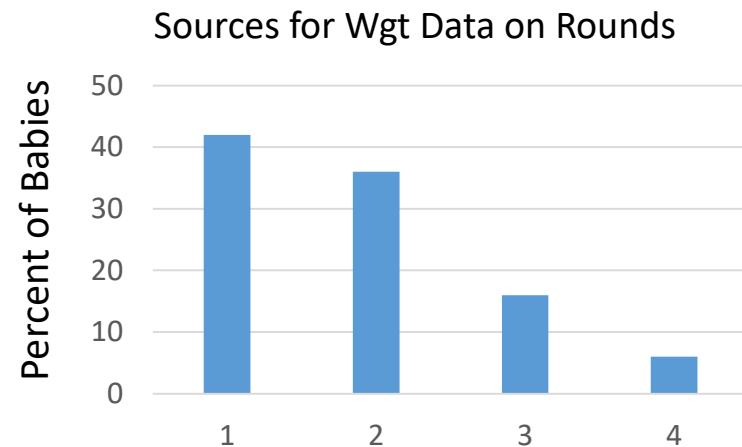
Design:

- 6 volunteer interpreters (3 men, 3 women, none needing vision correction)
- Faxed pages of random letters (no numbers or symbols) from one fax machine to another
- Two font sizes used on each page
- Each volunteer read and transcribed 100 random letters from each page, never from same original for each volunteer

Results: >50% error after third order fax, female error rate < male, larger font < smaller font

Human Data Transmitters: Example 2

In 2007 during a daily rounds in neonatal intensive care unit over 23 days continuous service, noted all times with disagreement among more than one source of baby weights taken and recorded that day.



Effects of Disagreement on Wgt

- 39% Extra time used on rounds
- 24% Change in Orders
- 11% Return to Bedside Later
- 3% Clinical change in patient

Classes of disagreement: memory vs. chart, two people's memory vs. chart, multiple places written

Feedback needed for Completeness/Accuracy

1. 137 Sequential NICU Discharge Summaries (2008-2009) where Diagnosis and Procedure Codes Assigned Decoupled from Clinical Staff:
 - Mean of 4.8 Diagnoses and 3.1 Procedures added per record
 - Mean of 1.8 Diagnoses changed from what was assigned in decoupled fashion
 - Not well received by Medical Records Department!
2. 44 Million Outpatient Encounter Records for 10 Million covered lives (1999-2000) with mean of 1.02 Diagnoses per encounter.
3. Chronic Conditions are separate class of diagnosis: Very Few systems treat separately (2 of 380)
4. Completeness/Accuracy is nearly never valued explicitly in Revenue Cycle Management, Despite nearly universal expectation of escalating amount and diversity of data collection for billing and regulatory/legal purposes

Limited Feedforward Processes

- New disease codes are introduced only after multiple, elaborate consensus exercises
- Introduction of current understandings of patient engagement and satisfaction are almost never part of the core health information system (3 of 380)
- Introduction of clinical pathways is rarely a structural part of health information systems (12 of 380)
- Integration of concurrent clinical outcomes with modification/update of clinical pathways is seen in only one health information system world-wide
- Safe/Efficient Feedforward requires orders of magnitude more analysis of health data than is possible under the IRB/Clinical Trials paradigm:

Must certify the ***Analyst***, rather than the ***Analysis***!

How Feedforward Should Work: Example Belize

Temporally Coupled Feedforward is Practiced Extensively by MCH Authorities in Belize (~7,000 Births/yr.)

- One case of maternal eclampsia gave rise to rapid investigation (same day, same work shift)
- MCH team discovered error in preparation document for magnesium sulfate.
- No cases of eclampsia have been seen in that health district (2009 to present)

Belize Officially Had Zero Maternal Mortality in 2013

Natural Distribution of Outcomes: Hypertension in Belize

1. BHIS connects all classes of health encounters, including dispensed pharmaceuticals, in real time
2. Essential Hypertension Management was among the first disease management protocols embedded within the BHIS
3. There are multiple steps to get approvals needed to safely deploy disease management systems
4. Deployed in 2007, protocol compliance steadily improved over the first two years.
5. The apparent relationship between protocols and reduced bad outcomes has been published:

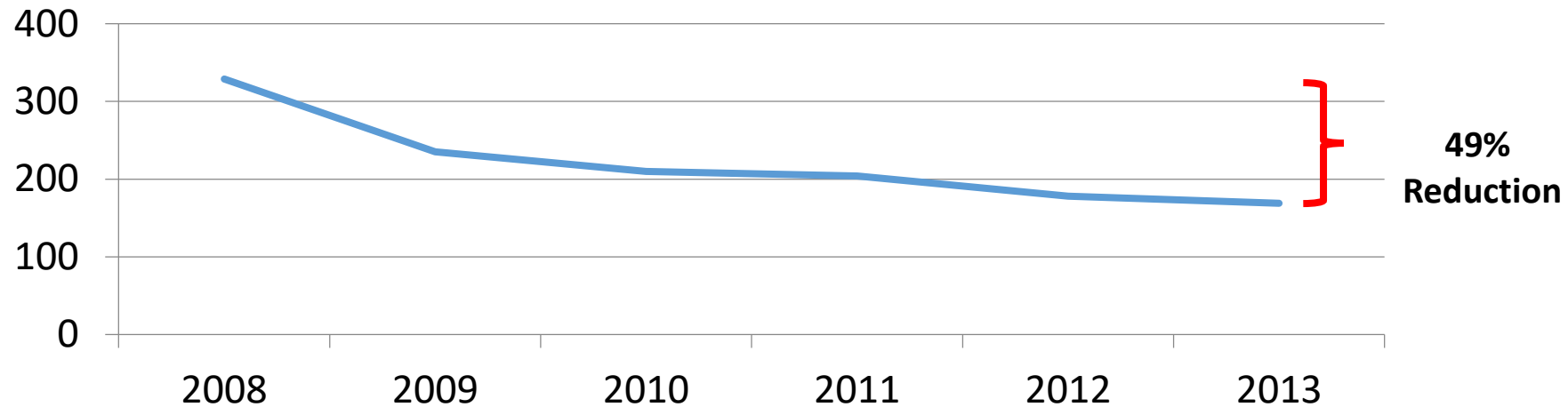
Decline in mortality with the Belize Integrated Patient-Centred Country Wide Health Information System (BHIS) with embedded program management. Graven M, Allen P, Smith I, MacDonald NE. Int J Med Inform. 2013 Oct; 82(10): 954-63

Hypertension in Belize

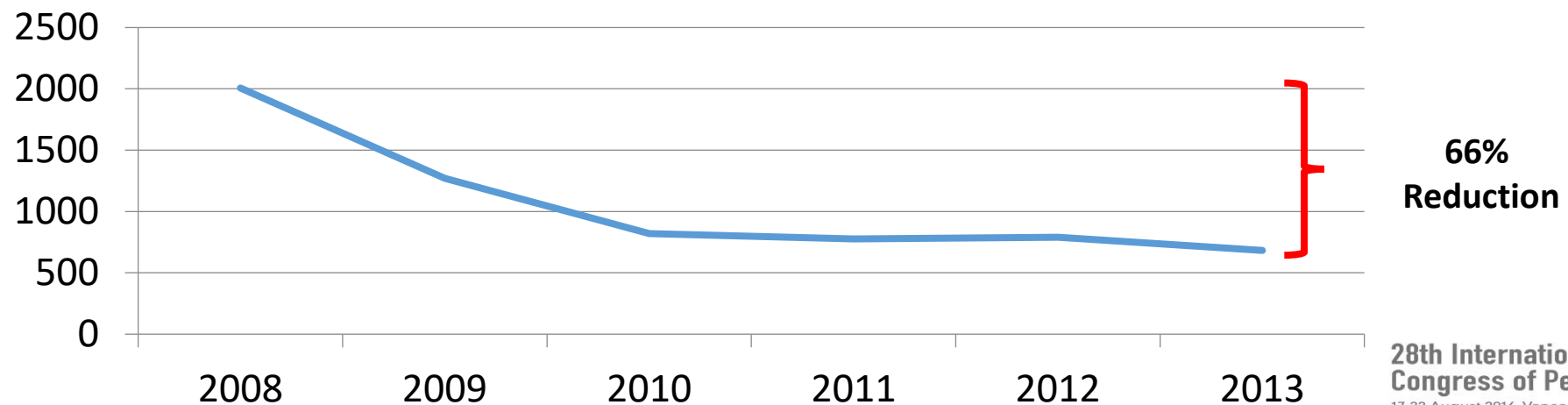
1. Effective outpatient management of chronic conditions like essential hypertension requires protocol driven care of serial blood pressure checks, with close attention to medications
2. Bad outcomes associated with essential hypertension require connection to emergency services encounters, inpatient encounters, post-hospitalization care, and mortality (if applicable)
3. Outpatient management encounters must be explicitly linked to all bad outcome encounters to evaluate program effectiveness (for feedback and feedforward)
4. There are orders of magnitude more outpatient than inpatient encounters for essential hypertension
5. Throughout most of the world, decoupled health information systems make outpatient history nearly unknowable, including prescribed medications, for new onset hypertension associated cerebral vascular disasters

Hospitalizations for Essential Hypertension Belize 2008-2013

Hospital Discharges



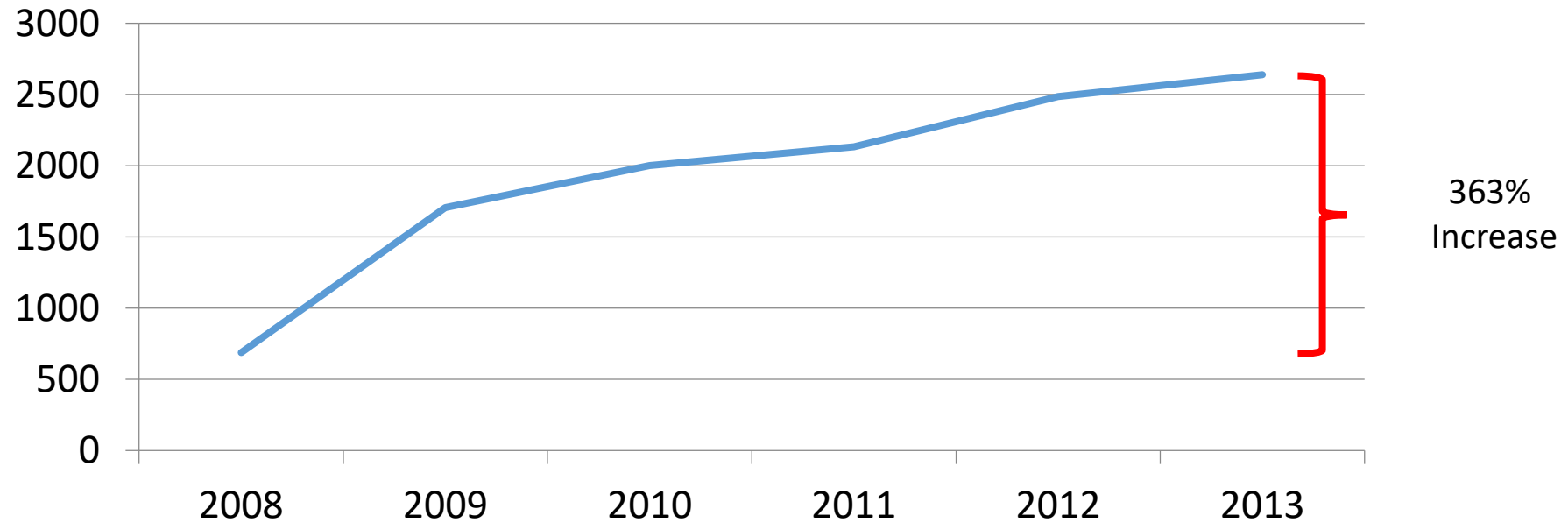
Hospital Days



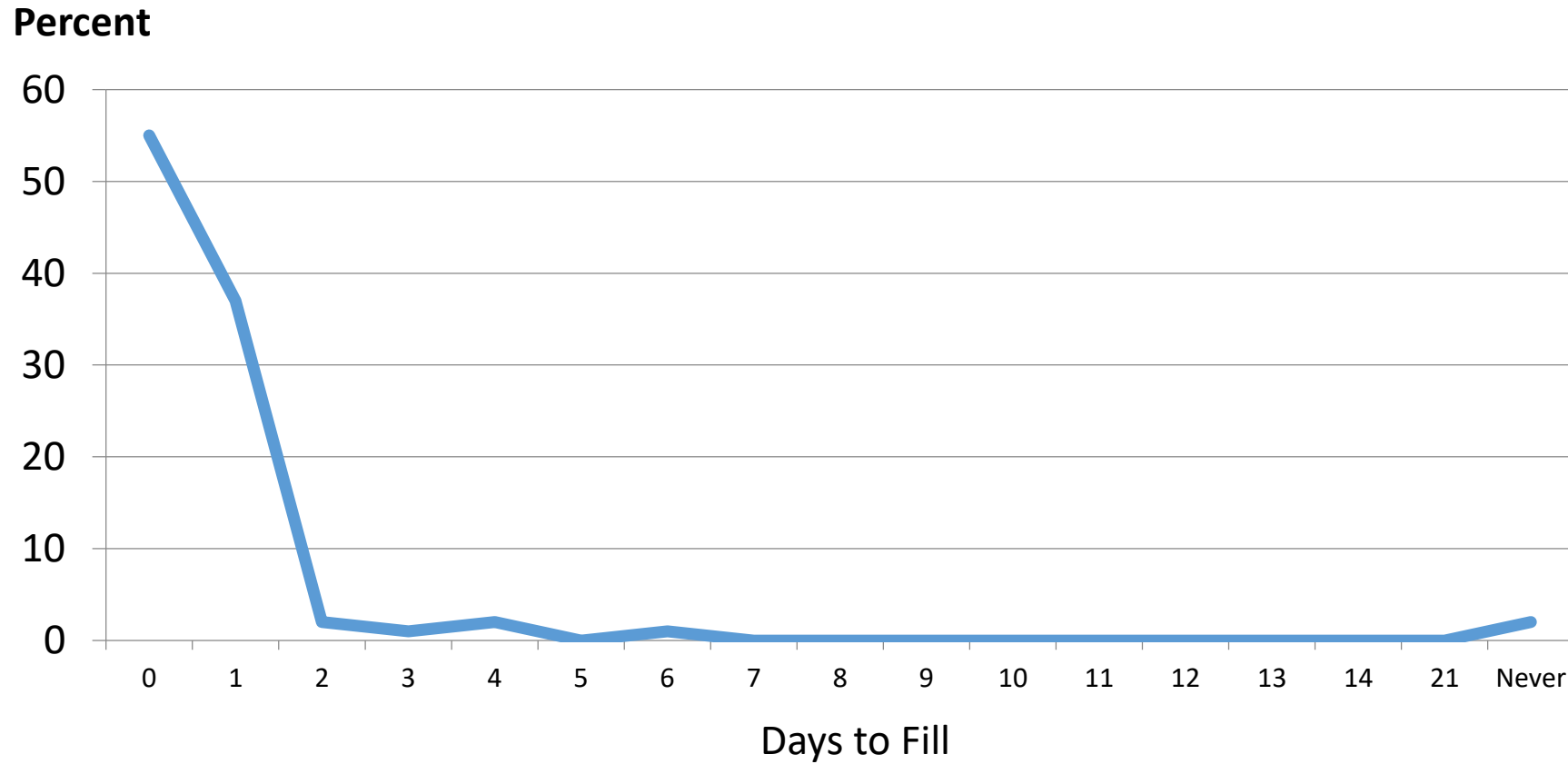
28th International
Congress of Pediatrics
17-22 August 2016, Vancouver, Canada

Outpatient Visits for Essential Hypertension Belize 2008-2013

Outpatient Clinic Encounters

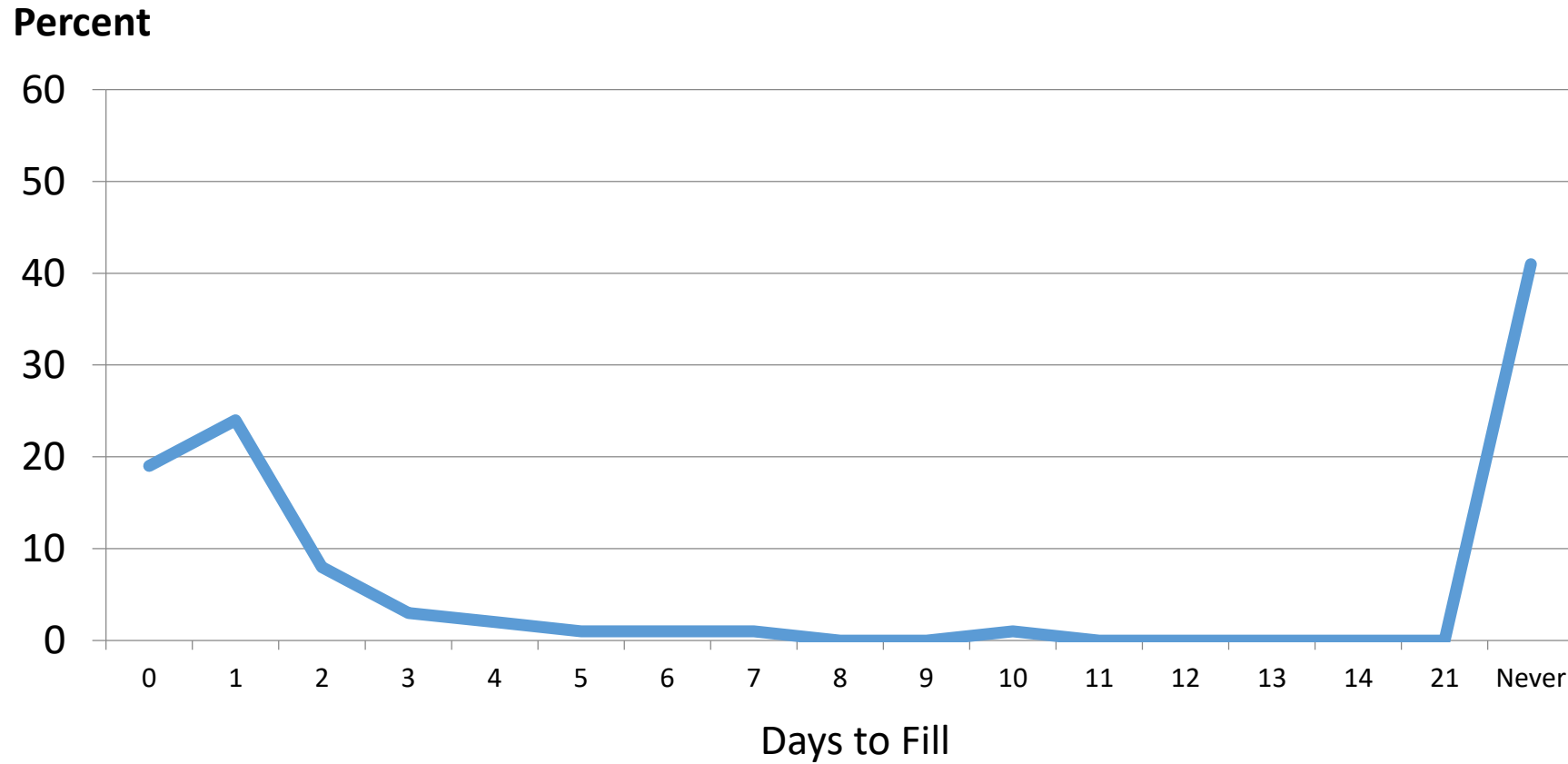


Days from Prescribed to Dispensed Antibiotics



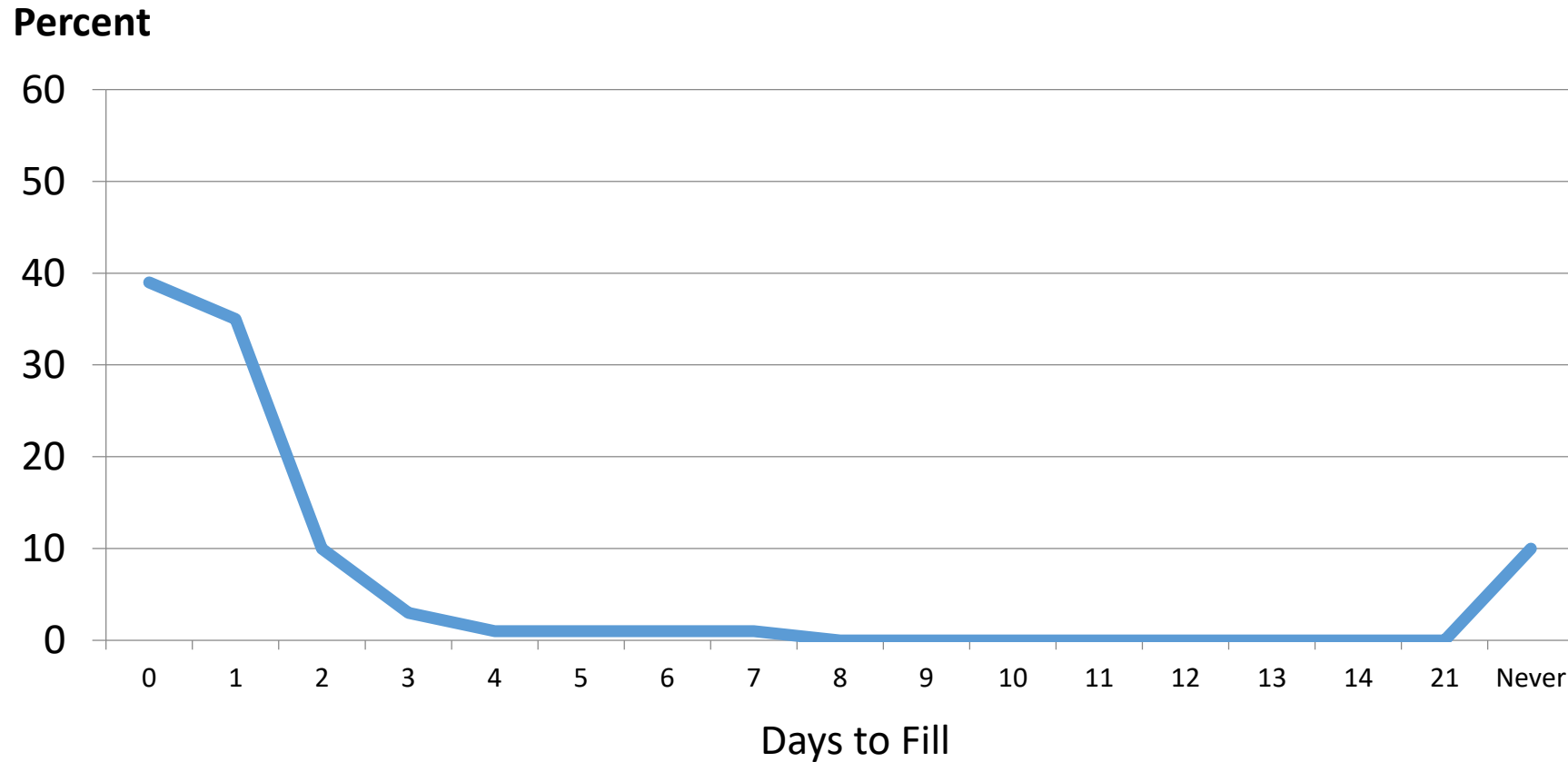
Days from Prescribed to Dispensed Anti-hypertensives

Belize 2008



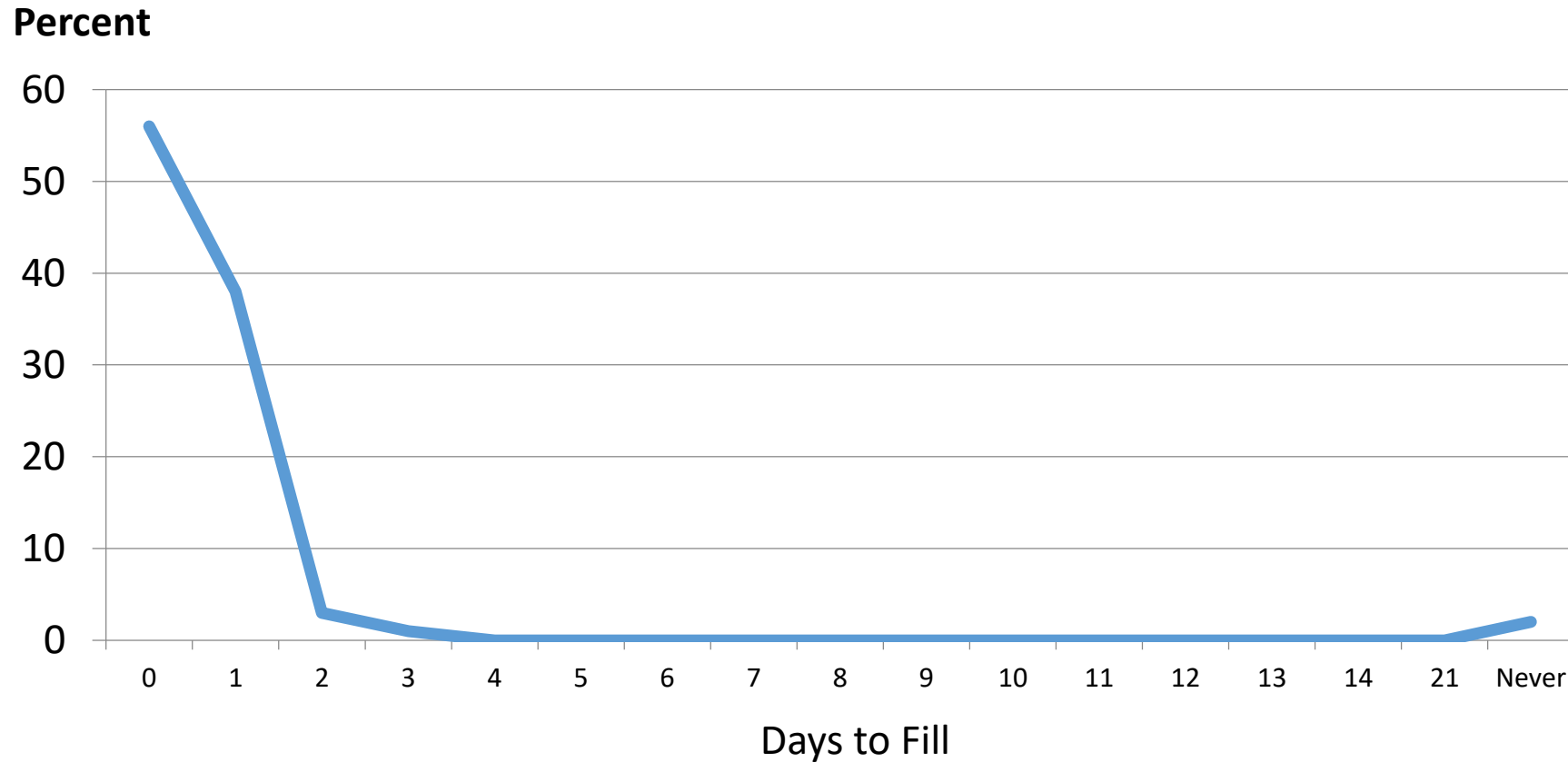
Days from Prescribed to Dispensed Anti-hypertensives

Belize 2009

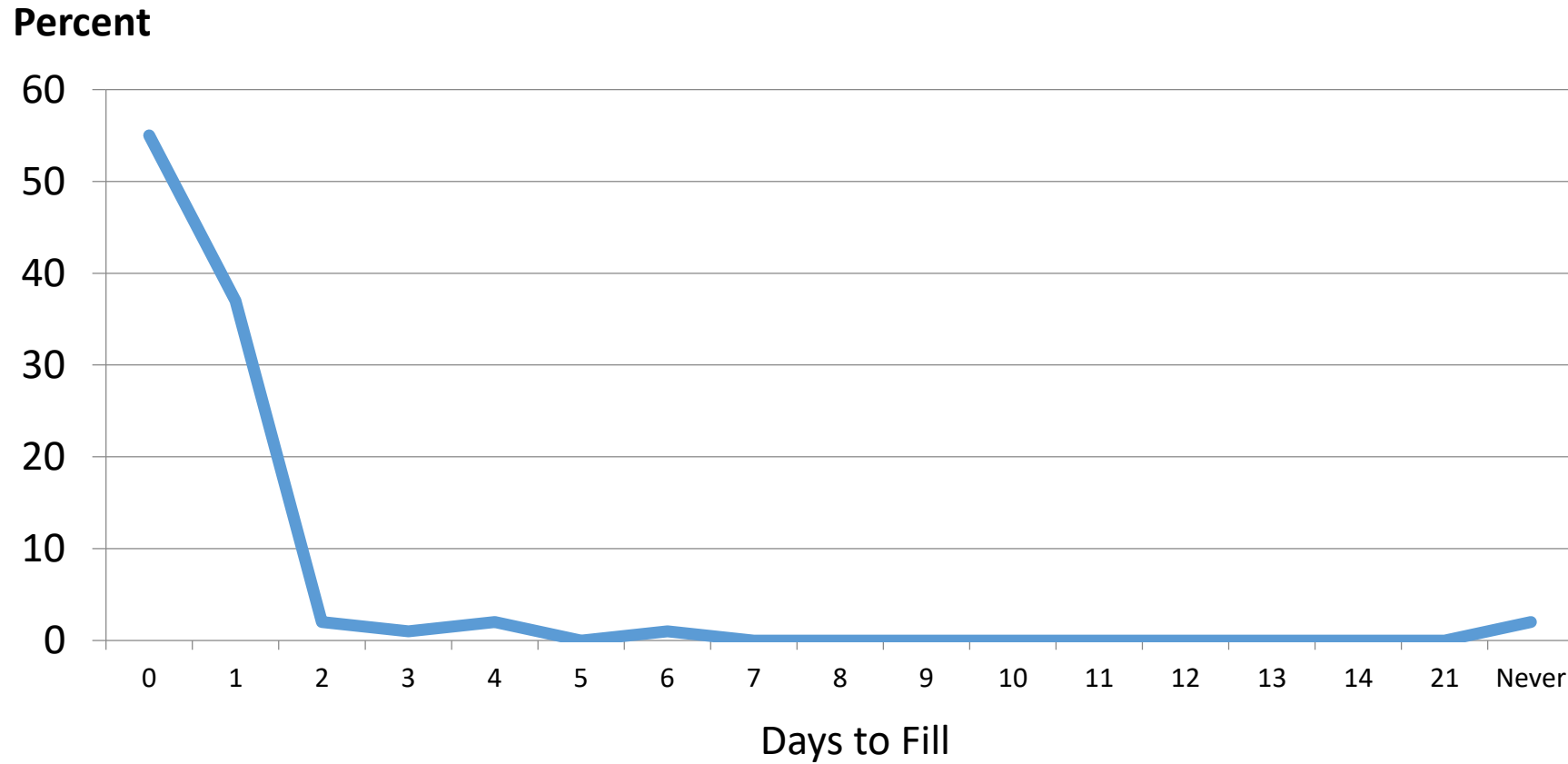


Days from Prescribed to Dispensed Anti-hypertensives

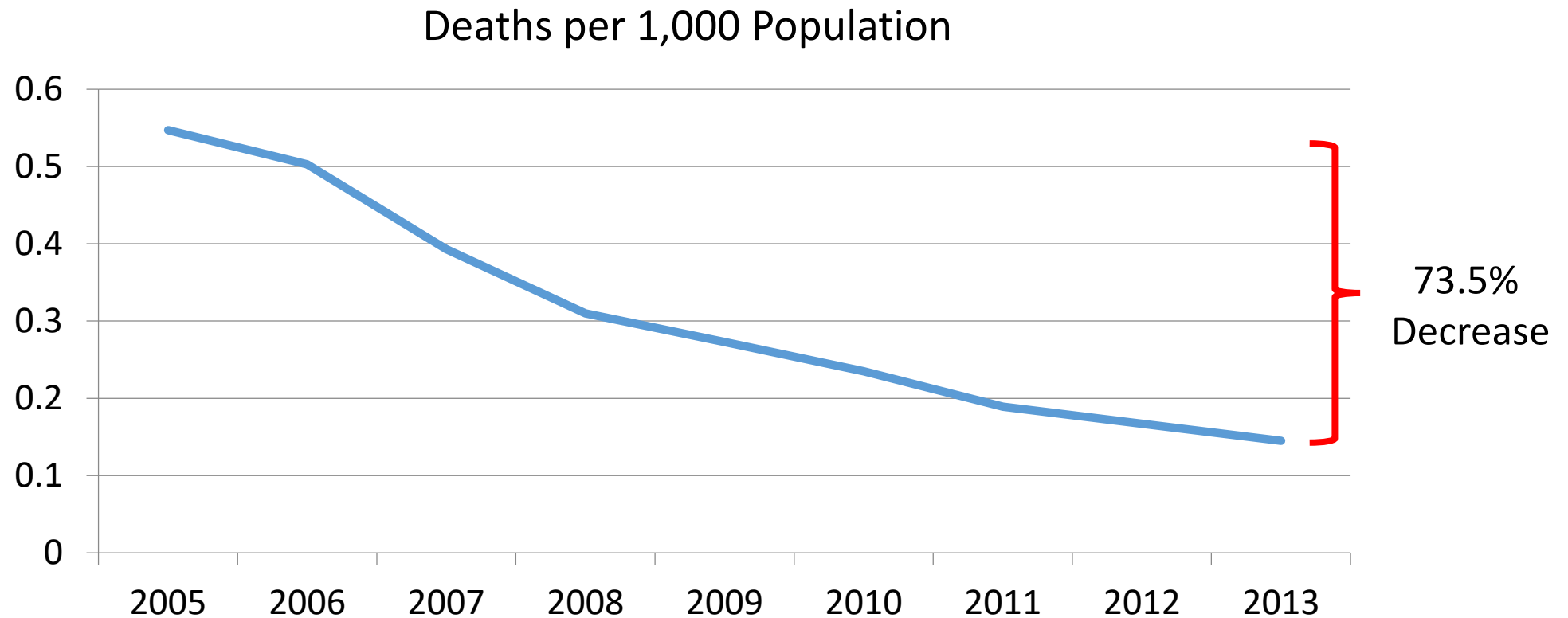
Belize 2010



Days from Prescribed to Dispensed Antibiotics



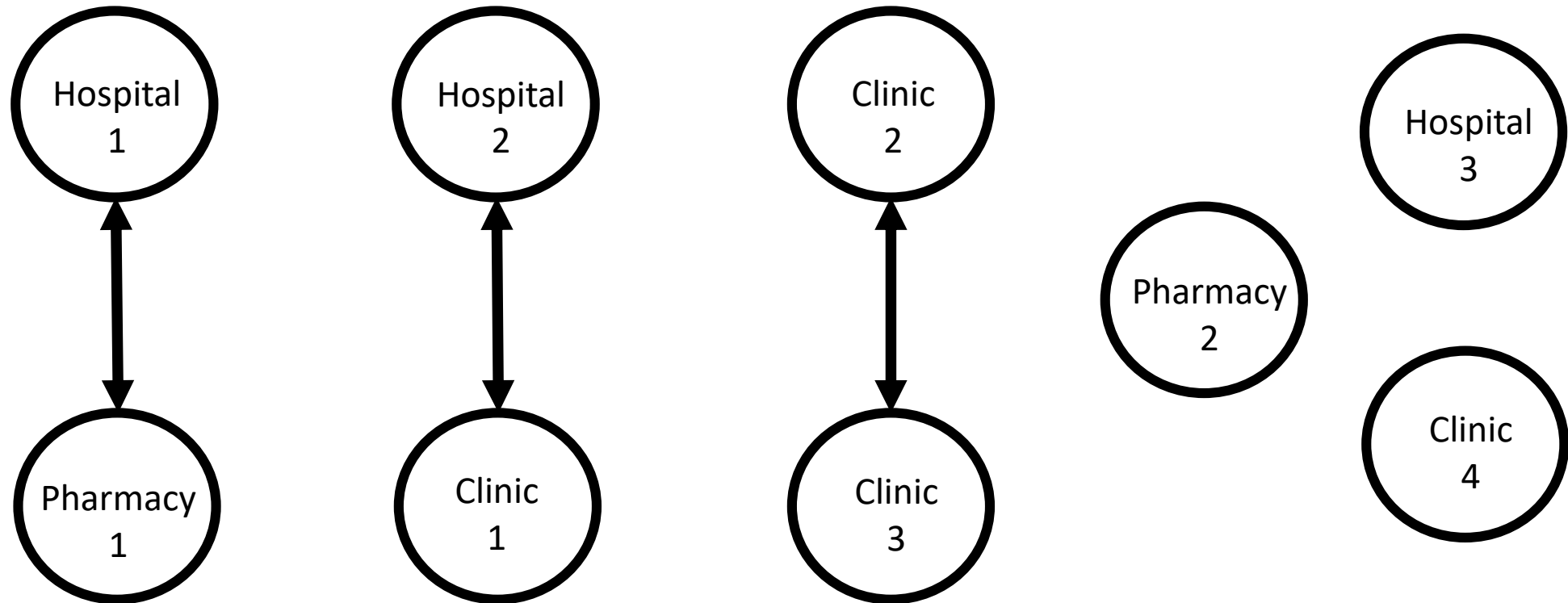
Essential Hypertension Crude Mortality: Belize 2005-2013



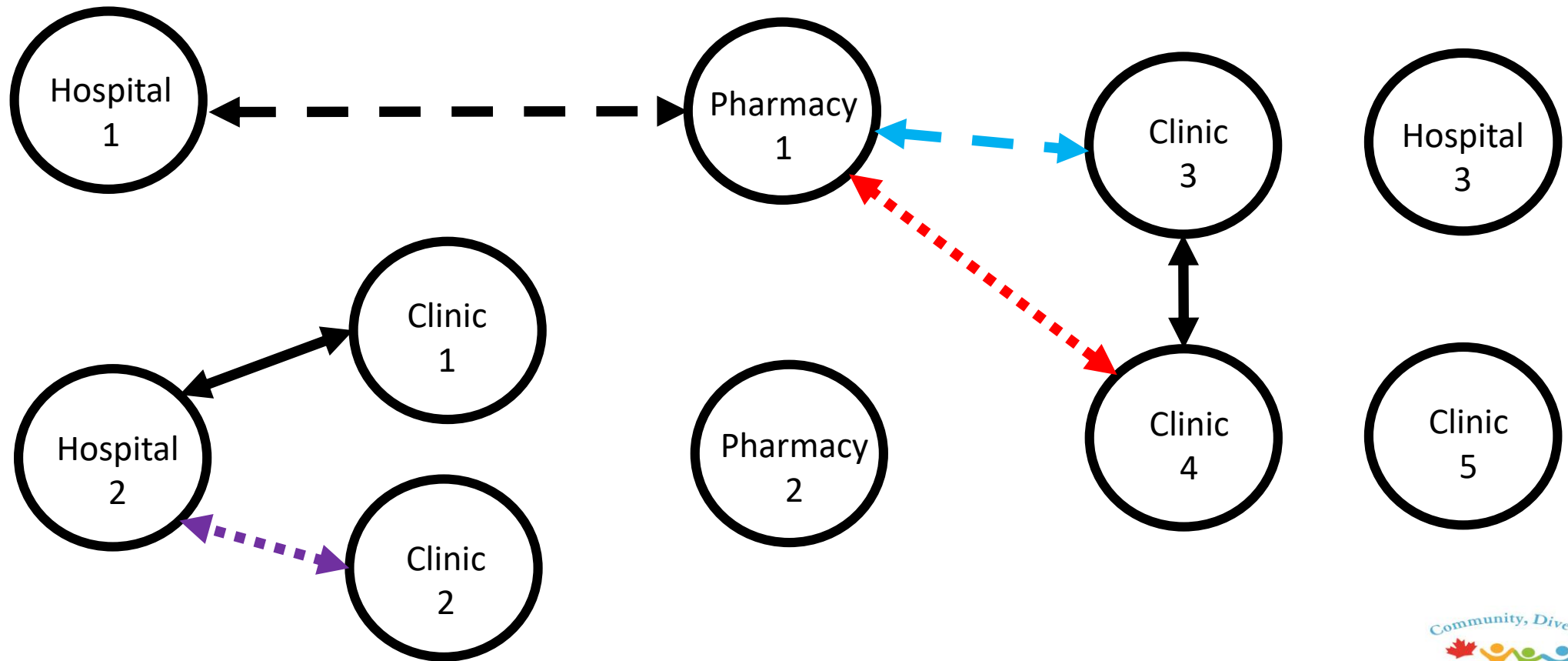
Reduced Mortality Seen In Belize 2005-2013

- Neonates and Infants up to 1 year of Age
- Children Age 1 - 5
- Acute Gastroenteritis \geq Age 5
- Acute Respiratory Infection \geq Age 5
- Maternal Mortality
- HIV, including PMTCT
- Essential Hypertension
- Serious Adverse Drug Reactions

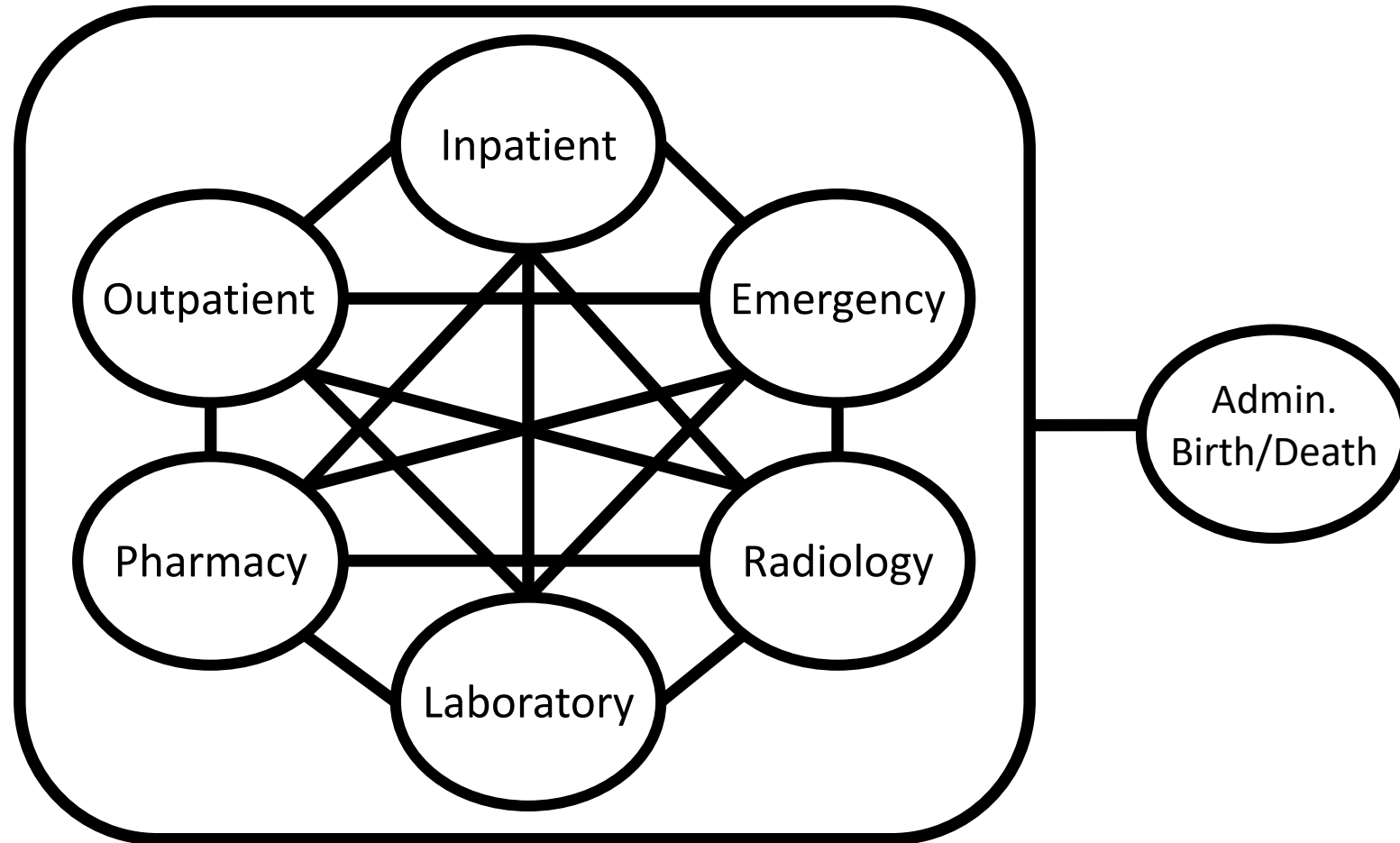
Administration Centric Model



Vendor Centric Model



Patient Centric, Fully Integrated Model

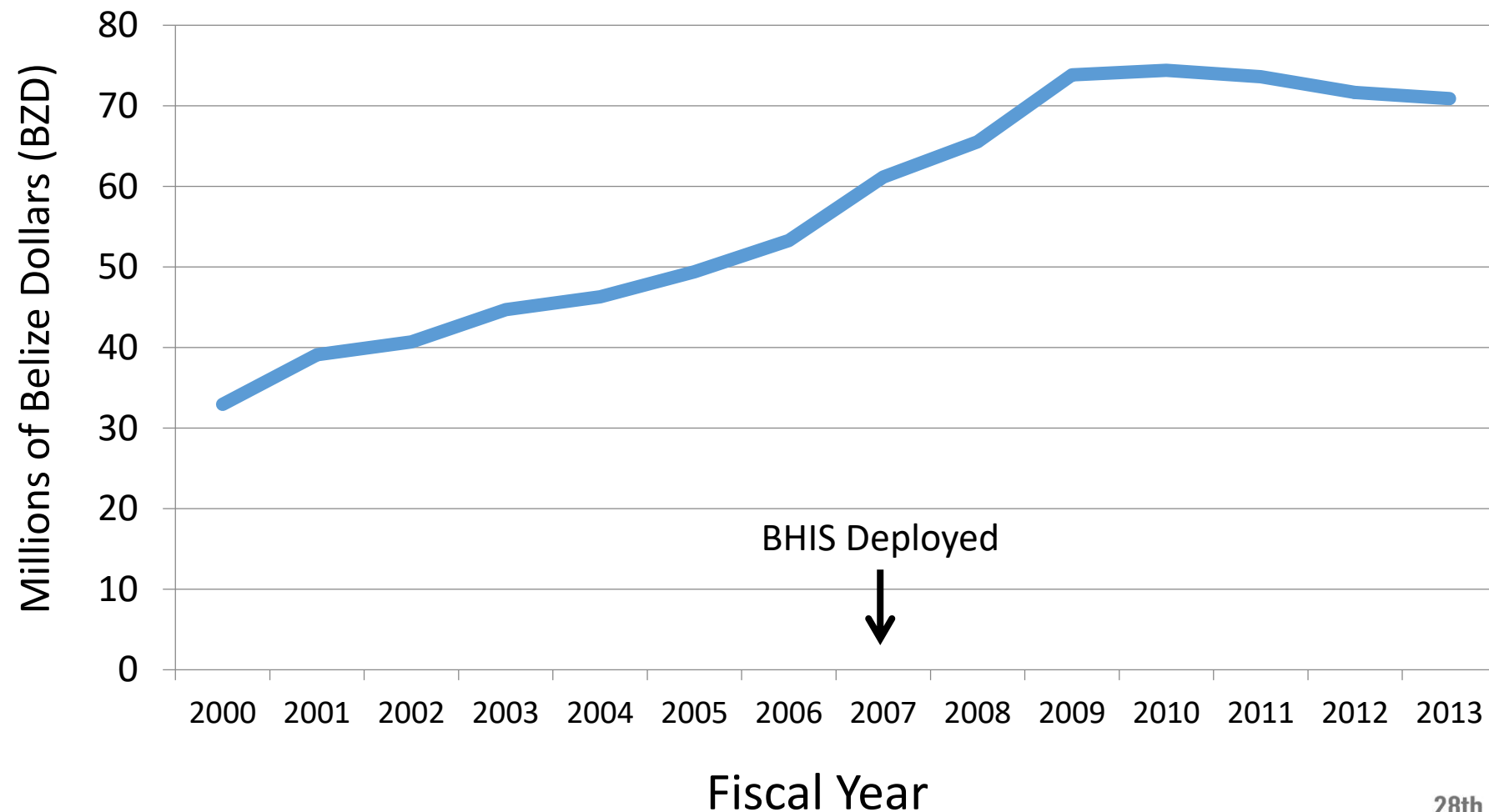


Information Content of “Absent from Record”

- With many system discontinuities, absence of condition from records limited to local only
- Fully Integrated systems make absence of condition means not present for patient
- Examples:
 1. Discontinuities in vaccine records means don't know who has, and has not, received vaccine
 2. Discontinuities in medication records means uncertainty wherever emergency care is provided
 3. Discontinuities in adverse reaction records yields predictable frequency of deaths

Probabilistic Certainty: Information System Discontinuities Increase Morbidity & Mortality

Belize Annual Public Healthcare Expenditures



28th International
Congress of Pediatrics
17-22 August 2016, Vancouver, Canada

Fully Integrated, Patient Centred, Health Information System

- Belize 2007 to Present:
 1. clinical, financial and administrative information within a system that supports data aggregation, real-time intelligence, embedded algorithms and reporting measures
 2. 99.99% up time: “never down” was a design requirement
- Currently used in:
 1. St Vincent and the Grenadines
 2. Barbados
 3. Several Canadian Provinces
- Cloud-Based
- Population-Health Management with Embedded Disease Management

Most Important Challenges for Health Information Systems

Temporality

Delay is a critical source of error

For Example, cancer will change stage if pathology results arrive late

Ordinality

Error rates multiply with every step of non-electronic transmission of data

For Example, digital weight of a sick baby changes as percentage with each pass person to person

Observations on Mathematics of System Discontinuities

- Countries with Fully Integrated Patient Centric Health Information Systems make possible a dramatically more complete approach to actuarial analysis
- Country epidemiologic data supports actuarial estimation of impact from use of fully integrated information systems
- Transition to a fully integrated health information system changes the shape of the statistical response surface that characterizes current health services utilization

You can achieve structural, population-wide, disease management

if and only if

you have a fully integrated patient centric health information system

Estimated Savings for 1 year, beginning 6 months after switch from discontinuous to fully integrated health information system

Australia	> 2	Billion Australian Dollars
Canada	> 11	Billion Canadian Dollars
Denmark	> 7	Billion Danske Kroner
Finland	> 1	Billion Euros
New Zealand	> 100	Million New Zealand Dollars
Norway	> 3	Billion Norsk Kroner
Sweden	> 4	Billion Svenska Kroner
United Kingdom	> 4	Billion Pounds Sterling
United States	Impossible To Estimate	

Structural Disease Management = Healthier People = Enormous Savings

Observations on Health Information System Initiatives

- High levels of system discontinuity shifts control to vendors, away from healthcare providers
- Change from one vendor system to another vendor holds legacy data hostage to high fees
- Most vendor systems severely limit access to core data
- Population-Specific Registries proliferate in presence of discontinuities, despite the critical weakness of being both temporally decoupled (often > 12 months after encounters) and composed of limited numbers of systematically harmonized variables

Fully integrated country wide health information systems are the **Universal Registry**

Regarding Stand-Alone Mortality Information Systems

Stand-alone mortality information systems:

1. Only count deaths
2. Temporally decoupled from clinical events preceding death, often months/years out of date
3. Involve a small, stylized, subset of clinical data
4. Does not include enough data to conduct clinical care

Fully integrated, patient centric, health information systems:

1. Help save lives and reduce suffering, rather than only count deaths
2. Fully temporally coupled with clinical events
3. Much richer clinical data
4. Includes more than enough data to accomplish birth and death registration

Mortality Systems \subset Clinical Information Systems

Factors Affecting Transition to Integrated Information Systems

- Cultural Acceptance
- Political Approval
- Financial Support
- Environmental Adaptation
- Healthcare Delivery Adoption
- Privacy
- Uniquely identifying patients

Structural Disease Management = Healthier People = Enormous Savings

Critical Barriers to System Deployment

1. Need master patient index
2. Privacy/confidentiality misrepresentation for political or financial gain (>95% of breaches inside jobs)
3. personalities
4. enormous amounts of money in broken-up model: it's a vicious business
5. power politics
6. systematic weakness of utilization data from the many discontinuities
7. Techno-arrogance

Structural Disease Management = Healthier People = Enormous Savings

Primum nil nocere in futurum

I hope this has been helpful

Questions  helping.when.possible@gmail.com