

**HOW CAN
IMPLEMENTATION
SCIENCE FRAMEWORKS
HELP NEWBORN
SCREENING IN AFRICAN
SETTINGS ?**

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Professor of Pediatric Hematology-
Oncology
Director of Pediatric Sickle Cell
University of Illinois at Chicago



ARISE

African Research And Innovative
Initiative For Sickle Cell Education

WELCOME BACK !

RE-CAP OF “INTRODUCTION & ORGANIZATION”



ARISE

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Initiative For Sickle Cell Education



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DISCLOSURES

- Research grants – AstraZeneca, Global Blood Therapeutics, Imara, Novartis, Pfizer.
- Consulting – Aruvant, AstraZeneca, Cyclorion, Emmaus, Emmi Solutions, Forma Therapeutics, Hilton Publishing, Global Blood Therapeutics, Novartis, Pfizer, Gerson-Lehman Group, Guidepoint, Slingshot, SmartAnalyst

I will discuss only publicly available information. I will discuss progress in sickle cell disease in general terms with no endorsement of commercial products.





LEARNING OBJECTIVES

Recognize

Recognize key features of newborn screening for SCD

Discuss

Discuss barriers and resources for large-scale newborn screening for SCD in your local region

Categorize

Categorize barriers and resources to large-scale newborn screening for SCD for different stakeholders using Getting To Outcomes framework

Predict

Predict how stakeholders' interests and resources could be aligned to promote successful large-scale newborn screening for SCD



READING ASSIGN 3 PAPERS. OTHER READING IS SUPPLEMENTAL

- Inusa, B.P.; Anie, K.A.; Lamont, A.; Dogara, L.G.; Ojo, B.; Ijei, I.; Atoyebi, W.; Gwani, L.; Gani, E.; Hsu, L. Utilising the 'Getting to Outcomes®' Framework in Community Engagement for Development and Implementation of Sickle Cell Disease Newborn Screening in Kaduna State, Nigeria. *Int. J. Neonatal Screen.* **2018**, 4, 33.
- Hsu L, Nnodu OE, Brown BJ, Tluway F, King S, Dogara LG, Patil C, Shevkoplyas SS, Lettre G, Cooper RS, Gordeuk VR, Tayo BO. White Paper: Pathways to Progress in Newborn Screening for Sickle Cell Disease in Sub-Saharan Africa. *J Trop Dis Public Health.* **2018**;6(2):260. doi: 10.4172/2329-891X.1000260. Epub 2018 Jul 10. PubMed PMID: 30505949; PubMed Central PMCID: PMC6261323.
- Wandersman A, Alia K, Cook B, Hsu LL, Ramaswamy R. Evidence-based interventions are Necessary but Not Sufficient for Achieving Outcomes in Each Setting in a Complex World: Empowerment Evaluation, Getting To Outcomes, and Demonstrating Accountability *Am J Evidence Aug* **2016** Vol 37 issue: 4, page(s): 544-561. DOI:10.1177/1098214016660613).

ACTIVITIES -

- **Think** of implementing large-scale newborn screening for SCD in your local region (city, state/province, maybe whole country).
- **Make a table** of what you imagine are 4 perspectives on newborn screening for SCD: (1) you as a doctor or researcher, (2) a family of a newborn baby, (3) primary care health provider, (4) health minister/hospital administrator whose leading worries are about costs and about COVID-19. In each perspective, list barriers and readiness features. Circulate to the other learners
- Think about how these 4 stakeholder perspectives could be aligned so that each group of stakeholders gets something that they want.
- **Write out plans to assess needs in your local region-** what would /could be done (probably not during global COVID-19 emergency). Circulate to the other learners



AT THE END: EVALUATION & OUTCOMES

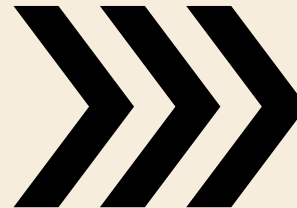
Evaluation:

- Were learning objectives achieved?
- Was virtual format Ok?
- What can be improved about format/ structure?
- What topics should be next?

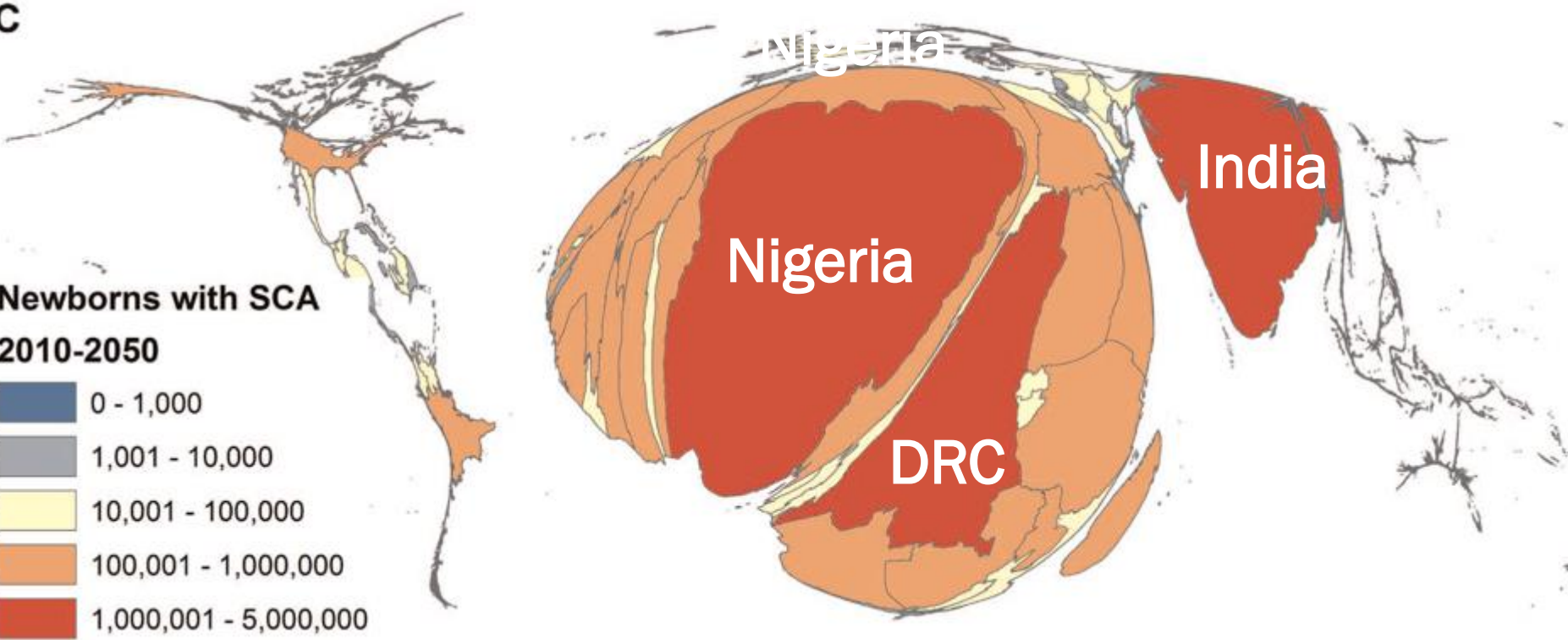


Outcomes:

1. Assemble reports and tables as a group work product for ARISE
2. Could this be a pilot / template for future ARISE virtual programs?
3. Possibly publish as “white paper” in a health policy journal? Or Int J Neonatal Screening?



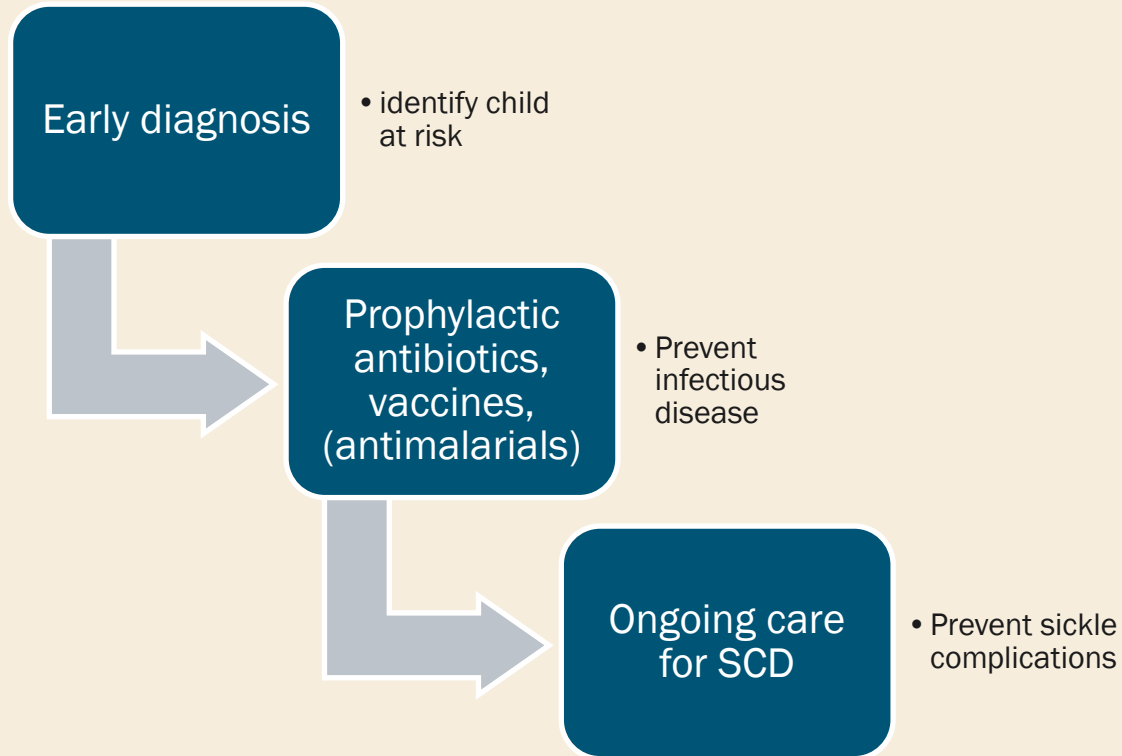
Sub-Saharan Africa leads the world in births with sickle cell disease (SCD) SCD is estimated to be 6th leading cause of death in children under 5yo. In Nigeria



Estimated number of newborns with SCA per country from 2010 to 2050.

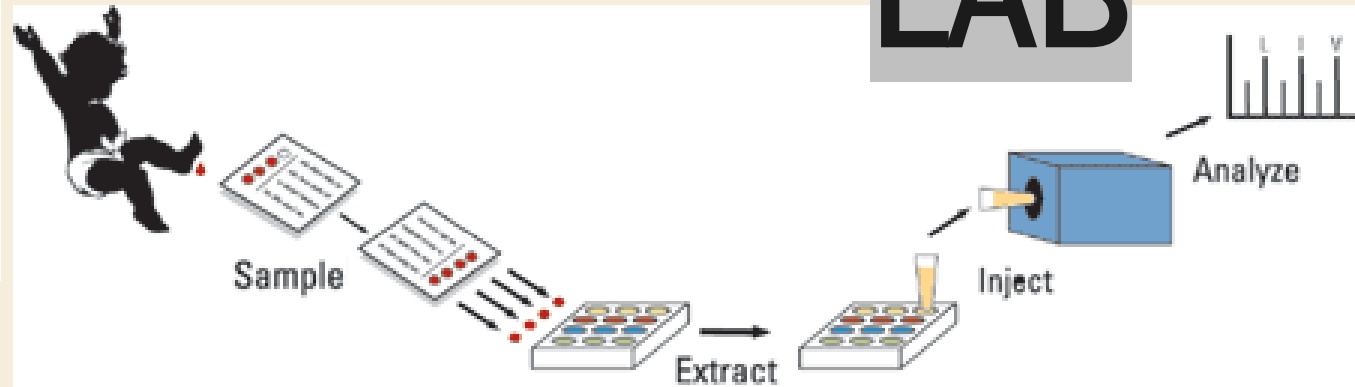
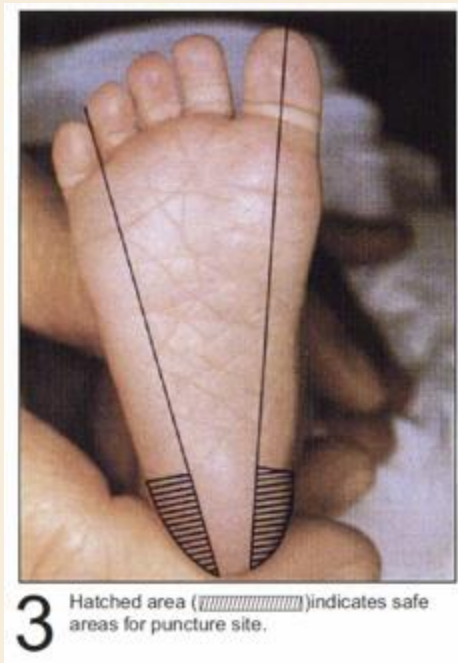
Piel FB et al. SCA Burden 2010-2050 PLOS Medicine 5 July 2013 10 (7)e1001484 Fig2.

WHY IS NEWBORN SCREENING CRUCIAL FOR SCD ?



WHAT IS NEWBORN SCREENING FOR SCD ?

- Heelstick blood sample on Guthrie Cards
- Government lab for large-scale testing



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https://mscdh.ms.gov/mscdh/site/_static/resources/4504.pdf

<http://pubs.acs.org/subscribe/archive/mdd/v05/i04/html/04willis.html>

So it's easy ... All we need for newborn screening are:

- (1) setting up a lab
- (2) buying Guthrie cards

Right ?

Perhaps we need more than that to succeed with newborn screening



NEWBORN SCREENING IMPLEMENTATION IN USA, BRAZIL, CARIBBEAN, UK, EUROPE ...



Find family for notification



Educate family



Link to medical care



Public health tracking to ensure follow-up



Build community awareness



Build medical care for lifespan

Maybe antenatal testing?
Maybe screen for carriers & counsel?

Also need to scale-up for 100-fold more births
with the resources in LMIC

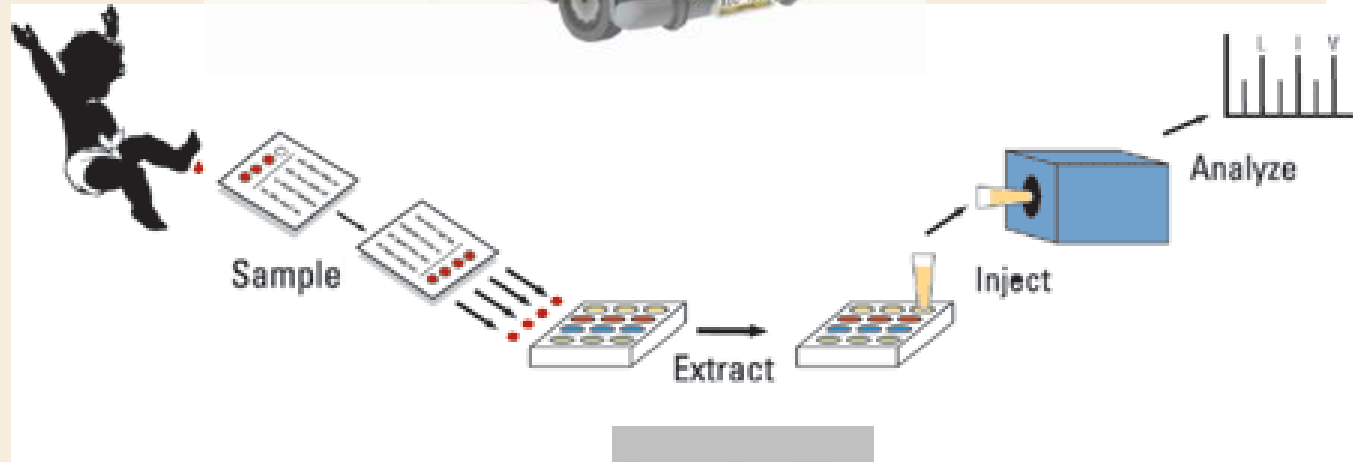
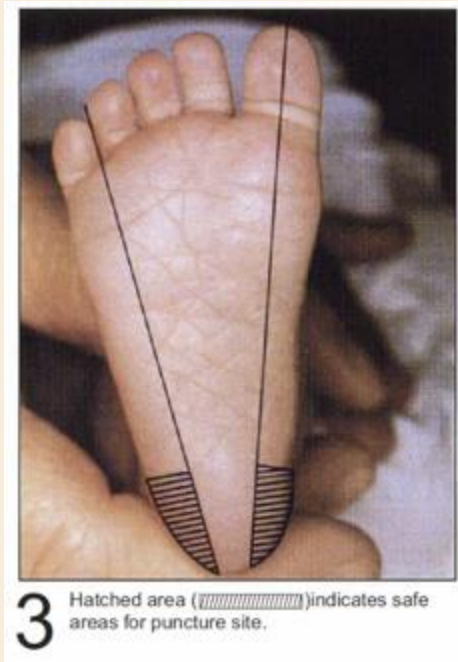
Build a new customized
infrastructure for sickle
cell care ?

Or adapt existing
healthcare
infrastructure



BUILD ON EXISTING INFRASTRUCTURE

- HIV screening uses Guthrie Cards
- Informal transport industry



FROM IDEAL SITUATION TO REAL WORLD

- Adapt clinical trial findings to local needs
- Adjust to changing conditions
- Overcome social determinants of health
- Optimize use of scarce resources
- Assess readiness for change
- Make the most use of stakeholder input....

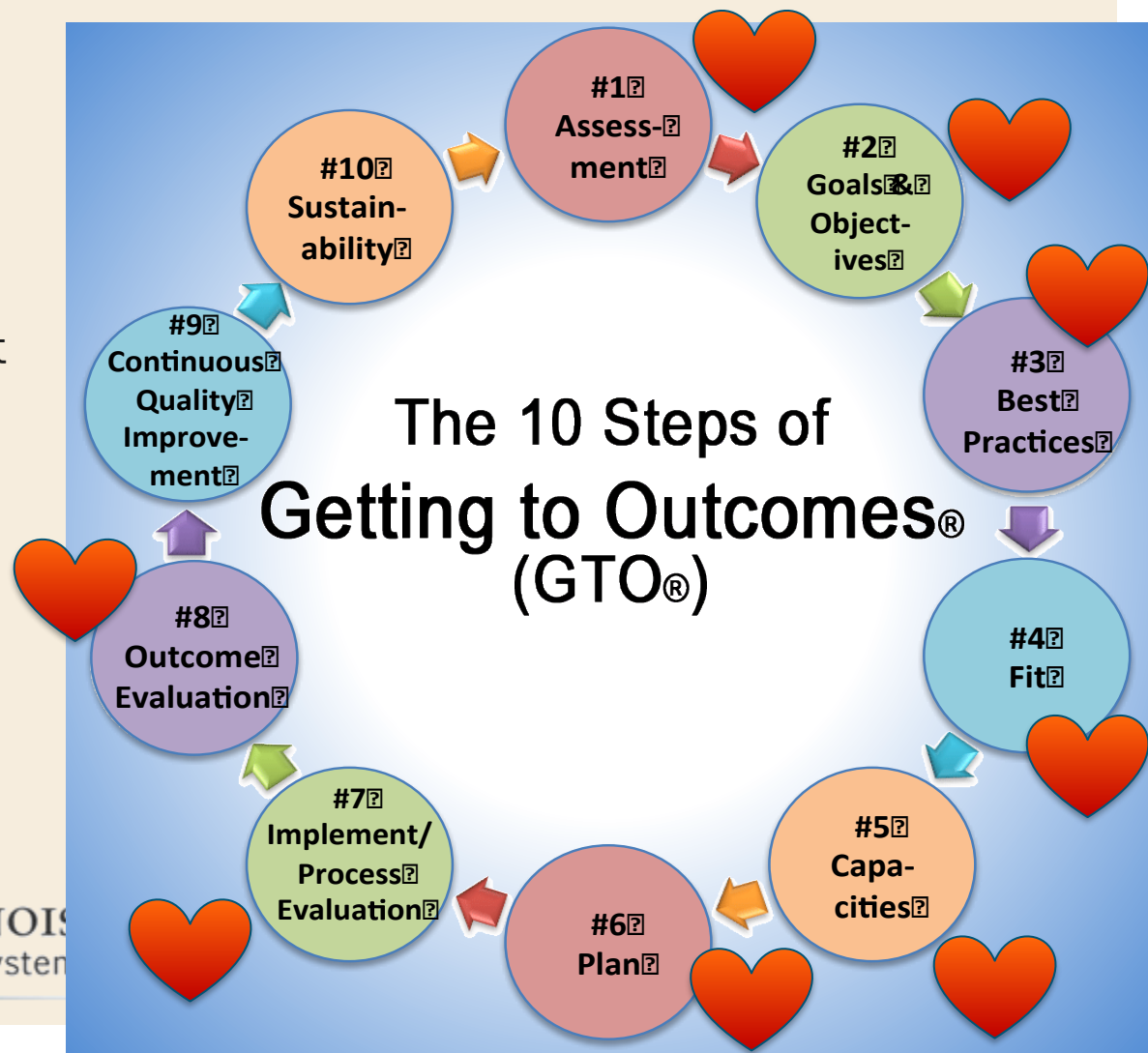


INCORPORATE STAKEHOLDERS INPUT

- Implementation Science framework *“Getting to Outcomes”*
 - Implement with quality,
 - Accountability = empowerment



Stakeholder involvement

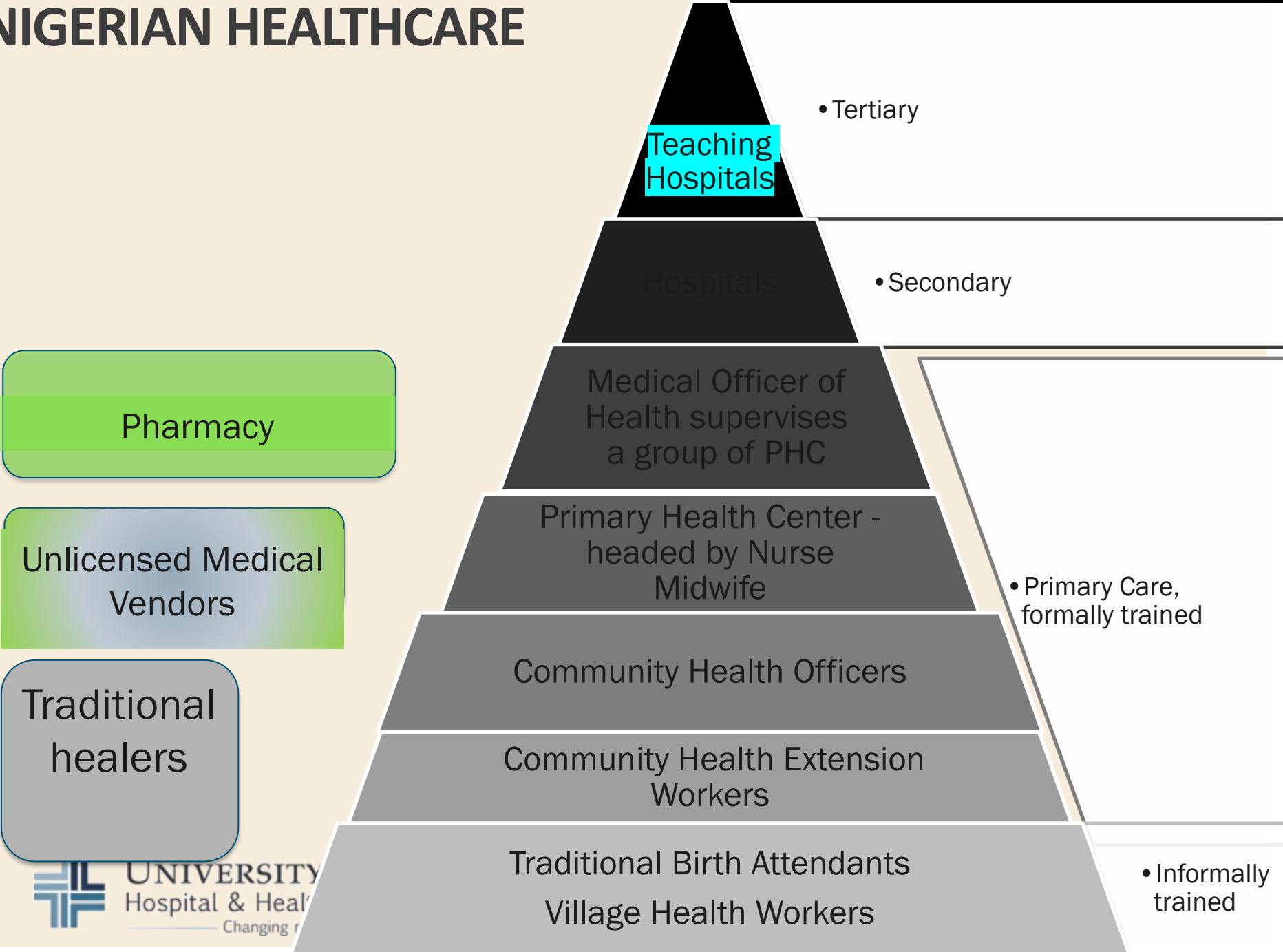


Getting to Outcomes results based approach to accountability

Implement with quality.

Accountability Question		Parent/Family/Home Sector	Medical Sector	Community Sector: Schools/Workplace
1	Needs/Resources			
2	Goals			
3	Best Practice			
4	Fit			
5	Readiness (Capacity X Motivation)			
6	Plan			
7	Process			
8	Outcome Evaluation			
9	Improve			
10	Sustain			

NIGERIAN HEALTHCARE



Getting to Outcomes results based approach to accountability

Implement with quality.


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Wandersman proposes that organizational readiness involves (a) the motivation to implement an innovation, (b) the general capacities of an organization, and (c) the innovation-specific capacities needed for a particular innovation.

JOURNAL OF
COMMUNITY PSYCHOLOGY

COMMENTARY

A PRACTICAL IMPLEMENTATION SCIENCE HEURISTIC FOR ORGANIZATIONAL READINESS: $R = MC^2$

Jonathan P. Scaccia , Brittany S. Cook, Andrea Lamont, Abraham Wandersman, Jennifer Castellow, Jason Katz, Rinad S. Beidas

First published: 13 April 2015 | <https://doi.org/10.1002/jcop.21698> | Citations: 54



WANDERSMAN PROPOSES $R=MC^2$ TO DESCRIBE
ORGANIZATIONAL READINESS
APPLY $R=MC^2$ TO SCD NEWBORN SCREENING IN AFRICA

- **Motivation**

- + High incidence,
- + families impacted
- + Health & economic burden
- stigma
- competing demands

- General capacity

- Specific capacity



APPLY $R=MC^2$ TO SICKLE NEWBORN SCREENING IN AFRICA

- Motivation

- **General capacity**

- + organized for HIV
- + organized for maternal health
- competing demands
- personnel
- +/- efficiency

- Specific capacity



APPLY $R=MC^2$ TO SICKLE NEWBORN SCREENING IN AFRICA

- Motivation
- General Capacity
- **Specific Capacity**
 - + trained lab for Hb testing
 - + trainer for CHEW & training plan
 - turnover of trained personnel
 - supplies
 - low awareness



Getting to Outcomes results based approach to accountability Implement with quality.

Accountability Question		Parent/Family/Home Sector	Medical Sector	Community Sector: Schools/Workplace
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10	Sustain			

A FOOD ANALOGY FOR READINESS



Recipe helps me understand my **Capacity** – do I have Ingredients ? stove or oven? Fuel ? Pot or pan ? Knife ? Time?



I also need **Motivation** – do I even want to cook?



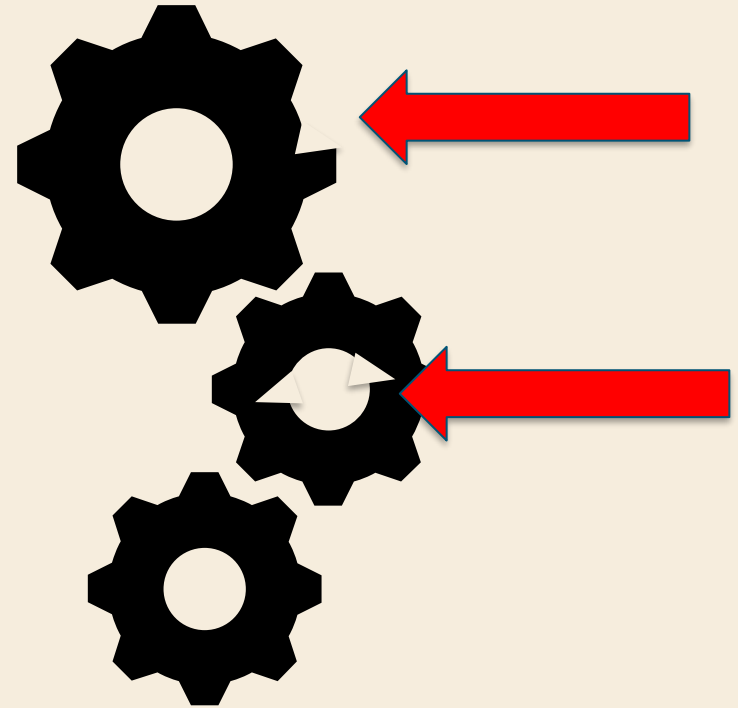
Getting to Outcomes results based approach to accountability

Implement with quality.

Accountability Question		Parent/Family/Home Sector	Medical Sector	Community Sector: Schools/Workplace
1	Needs/Resources			
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9	Improve			
10	Sustain			

EVALUATE AND SUSTAIN $R=MC^2$ TO SICKLE NEWBORN SCREENING IN AFRICA

- Motivation
- General Capacity
- Specific Capacity



ONGOING EVALUATION ANALOGY... CHECKING TEMPERATURE WHILE ROASTING MY TURKEY, RATHER THAN WAITING TO THE END

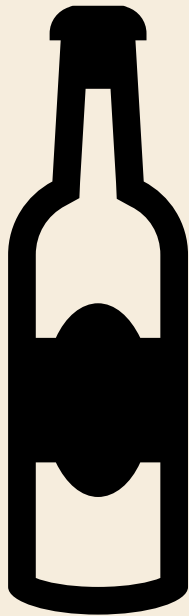


Getting to Outcomes results based approach to accountability

Implement with quality.

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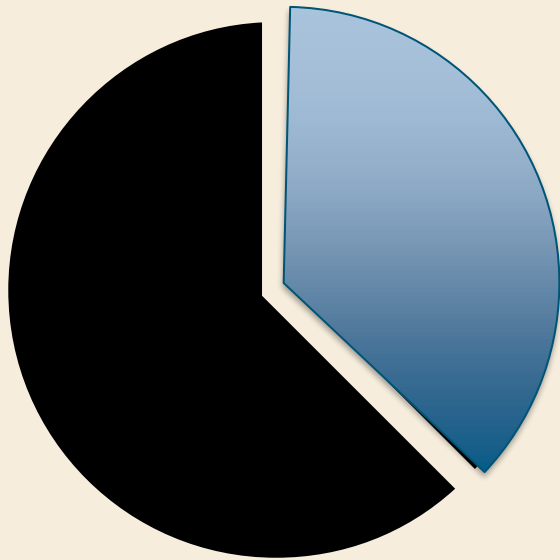
“REACH” IS LIKE “MARKETING”



- How many are buying?
 - **Number & percent = market share**
- Representativeness of the entire population
 - **Segmented market**



“REACH”



- How many of the target population participate?
 - Number & percent
- Representativeness of the entire population
 - Missed the men?
 - Missed those with lower education or literacy ?
 - Missed a whole religious group ?
 - Missed the “hard to reach” ?



INFOGRAPHICS

Infographics viewed in Nairaland by 999+

in 7 days

cost = USD\$ 0

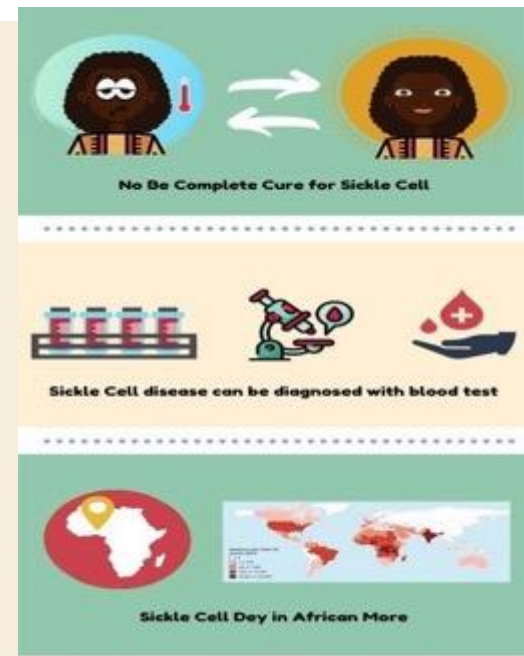
(~ 100 hours of unpaid time)



Infographics – Qualitative Feedback

- ❖ 31% wanted more Info for SCD Infographic #1
- ❖ 19% deemed SCDA COVID Infographic (#6) too cluttered or confusing
- ❖ 14.5% prefer changing language from pidgin to English

“Fit”



Social Adjustments & Response to COVID-19

Advice for People with Sickle Cell Disease & SCD Families

COVID-19, also known as Coronavirus, is a new respiratory illness that can be very serious.

We all need to do our part to protect ourselves and others, so the virus does not spread.

WHAT CAN YOU DO?

WEAR A MASK – When in public to reduce the spread of the virus.

PHYSICAL DISTANCING – Avoid close contact with others to reduce the spread of the virus.

FREQUENT HAND WASHING – At least 20 seconds with soap and water.

CALL YOUR PROVIDER – If you have symptoms.

AVOID

- Group Gatherings
- Responses
- Parties
- Visitors to your Home
- Constantly Watching the News

CAUTION

- Visit Grocery Store
- Get Take Out
- Pick Up Medications
- Mass Transit Systems
- Use open public areas
- Attending services
- Traveling

SAFE

- Hand Wash
- Play in your Yard
- Check out a Class
- Read a Good Book
- Listen to Music
- Cook a Meal
- Family Game Night
- Group Video Chats
- Stream a Favorite Show
- Check on a Friend
- Check on an Elderly Neighbor
- Virtual Religion Service

SCDA is committed to helping families get through this health crisis.

Sickle Cell Disease Association of America
1240 Parkway Drive
Suite 100
Hamden, MD 21074
www.scdaa.org
410.528.1555

Some D&I Frameworks

- Explanatory
 - Consolidated Framework for Implementation Research (CFIR)
 - Theoretical Domains Framework (TDF)
 - Greenhalgh Implementation Processes Model
- Directive/Applied
 - Reach Effectiveness Adoption Implementation Maintenance (RE-AIM)
 - Evidence-based Quality Improvement
 - Blended Facilitation
 - Replicating Effective Programs (REP/Enhanced REP)
 - Getting to Outcomes

RE-AIM FRAMEWORK

RE-AIM Precision (Personalized) Medicine Questions

Determine

- What percent and types of patients are **Reached**;
- For whom among them is the intervention **Effective**, in improving what outcomes, with what unanticipated consequences;
- In what percent and types of settings and staff is this approach **Adopted**;
- How consistently are different parts of it **Implemented** at what cost to different parties;
- And how well are the intervention components and their effects **Maintained**?

Pawson R, et al. *J Health Serv Res Policy* 2005;10(S1):S21-S39.

Gaglio B, Glasgow RE. Evaluation approaches...In: Brownson R, Colditz G, Procter E, (Eds). *Dissemination and implementation research in health: Translating science to practice*. New York: Oxford University Press; 2012. Pages 327-356



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IMPLEMENTATION RESEARCH HAS OVER 100 MODELS & FRAMEWORKS

www.dissemination-implementation.org

The screenshot shows the top navigation bar of the website. On the left, the title "Dissemination & Implementation Models in Health Research & Practice" is displayed in a grey box. Below the title are four navigation buttons: "Home", "Resources", "Submit Models", and "About Us". On the right, a blue box contains a "Need Help?" section with links for "Tutorial", "FAQ", "Glossary", and "Contact Us". Below these links is a "Google Custom" search bar with a magnifying glass icon.

This interactive website was designed to help researchers and practitioners to select the D&I Model that best fits their research question or practice problem, adapt the model to the study or practice context, fully integrate the model into the research or practice process, and find existing measurement instruments for the model constructs. The term 'Models' is used to refer to both theories and frameworks that enhance dissemination and implementation of evidence-based interventions more likely.



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Types of Outcomes in Implementation Research (Proctor, et al., 2010)

Implementation Outcomes	Service Outcomes	Client Outcomes
Acceptability	Efficiency Safety	Satisfaction
Adoption	Effectiveness	Function
Appropriateness	Equity	Symptoms
Costs	Patient-centeredness	
Feasibility	Timeliness	
Penetration		
Sustainability		

Proctor E, Silmere H, Hensley M, et al. Outcomes for implementation research: Administration and policy in mental health [serial online]. March 2011;38(2):65-76.

TIDIRC: Introduction to Dissemination & Implementation Science

TO LEARN MORE ONLINE...

TIDIRC
Training Institute for
Dissemination and
Implementation Research
in Cancer

has a series of talks on
YouTube and a website

The screenshot shows the NIH Implementation Science website. At the top, the NIH logo and 'NATIONAL CANCER INSTITUTE Division of Cancer Control & Population Sciences' are visible. A search bar is in the top right. Below is a purple navigation bar with 'Implementation Science' and a home icon. A dark grey menu bar contains links: 'IS Home', 'Funding Opportunities', 'Initiatives', 'Training & Education', 'Research & Practice Tools', and 'About IS'. The main heading is 'Training & Education' with a breadcrumb 'Home / Training & Education'. The main text describes collaboration with academic institutions and lists activities like a monthly webinar series, training programs, and an annual conference. To the right, there are two callout boxes: 'Implementation Science Webinars' with a 'VIEW WEBINARS' button, and 'Dissemination & Implementation Orientation Webinar' with a brief description. Below this is a 'TRAINING PROGRAMS' section with two entries: 'Training Institute for Dissemination and Implementation Research in Cancer (TIDIRC)' and 'Training Institute for Dissemination and Implementation Research in Health (TIDIRH)', each with a logo to its right.

NIH NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

SEARCH

Implementation Science

IS Home Funding Opportunities Initiatives Training & Education Research & Practice Tools About IS

Training & Education

Home / Training & Education


In collaboration with other academic institutions, professional organizations, and funding agencies, the Implementation Science team coordinates and supports several training and educational activities, including a monthly webinar series, training programs, and an annual conference. Collectively, these activities aim to increase the field's capacity to conduct rigorous implementation research.

Implementation Science Webinars
The Implementation Science Webinars series is a free, monthly webinar series focused on advanced topics in dissemination and Implementation (D&I) research.
[VIEW WEBINARS](#)


Dissemination & Implementation Orientation Webinar
Check out this webinar that provides an introduction and orientation to the science of dissemination and implementation for those new to this field.

TRAINING PROGRAMS

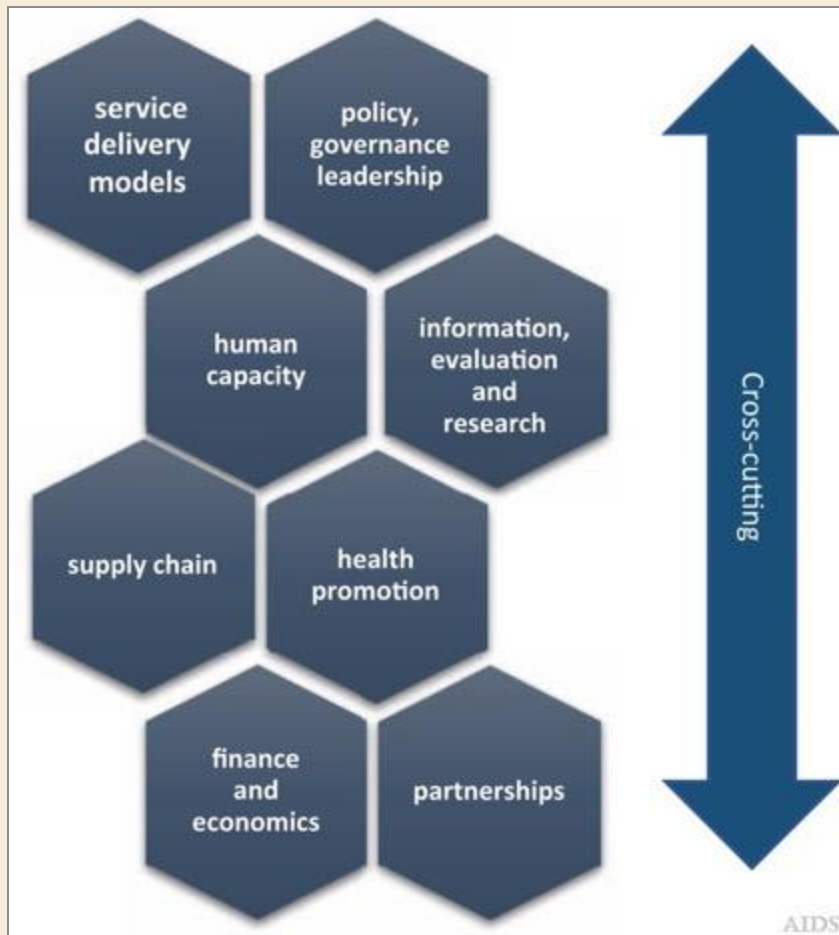
Training Institute for Dissemination and Implementation Research in Cancer (TIDIRC)
The [Training Institute for Dissemination and Implementation Research in Cancer \(TIDIRC\)](#) provides participants with a thorough grounding in conducting D&I research with a specific focus on cancer. All online training materials are open access. Applications for the facilitated program are accepted annually. [Learn more.](#)



Training Institute for Dissemination and Implementation Research in Health (TIDIRH)
The Training Institute for Dissemination and Implementation Research in Health (TIDIRH) was developed by the National Institutes of Health (NIH) to help build capacity in dissemination and implementation research. TIDIRH was held annually from 2011 through 2015 as a residential training program. From 2016 through 2020, TIDIRH has met in the Washington, D.C. area offered as a dual online and in-person training.



SUPPORT RESEARCH AND RESEARCH TRAINING IN IMPLEMENTATION SCIENCE USING A DISTRIBUTED APPROACH ACROSS FOGARTY'S PROGRAMS



Building on the HIV chronic care platform to address noncommunicable diseases in sub-Saharan Africa: a research agenda

Vorkoper, Susan; Kupfer, Linda E.; Anand, Nalini; Patel, Pragna; Beecroft, Blythe; Tierney, William M.; Ferris, Robert; El-Sadr, Wafaa M.; on behalf of the HIV/NCD Project
AIDS32:S107-S113, July 1, 2018.
doi: 10.1097/QAD.0000000000001898

Mapping the research article.

Readiness for “Scale up” and “Adaptation”



	SCD births/yr	Traditional Birth Attendants
Illinois	110	< 1%
Kaduna	~ 4,000	<10%
Niger	~ 3,000	60%

READINESS, FIDELITY AND ADAPTATION

- **Fidelity** = “extent to which the intervention was delivered as planned. It represents the quality and integrity of the program as conceived by the developers”
 - An evidence-based practice should be delivered as intended
 - Known costs, time, skill level, key components to deliver.

→ MANUAL of OPERATIONS. RECIPE
- **Adaptation** = adjust to local needs
 - Incorporate stakeholder inputs
 - Adjust for resources available

Will you lose effectiveness with program drift ?

SCALE UP AND ADAPTATION



<https://www.forbes.com/sites/aliciakelso/2019/07/09/customers-are-noticing-mcdonalds-significant-supply-chain-changes/#1674883e5962>



Language ▾ Sign Up for Email Careers

Q Search [Change Your Location](#)

[Order on Uber Eats](#)

Our Menu ▾ [McCafé](#) [About Our Food](#) [Deals & Our App](#) [Trending Now](#) [Locate](#)



Hamburger

250 Cal.

The original burger starts with a 100% pure beef patty seasoned with just a pinch of salt and pepper, then topped with a tangy pickle, chopped onions, ketchup and mustard. It contains no artificial flavors, preservatives or added colors from artificial sources.* Our pickle contains an artificial preservative, so skip it if you like.

*National sandwiches only. Excludes local and limited time options.

Fidelity



Idioma ▾ Únete a nosotros Carreras

Q Buscar [Cambia Tu Localización](#)

[Ordéna con Uber Eats](#)

Nuestro Menú ▾ [McCafé](#) [Nuestra Comida](#) [Ofertas & Nuestro App](#) [Lo Último](#) [Localizar](#)



Hamburguesa

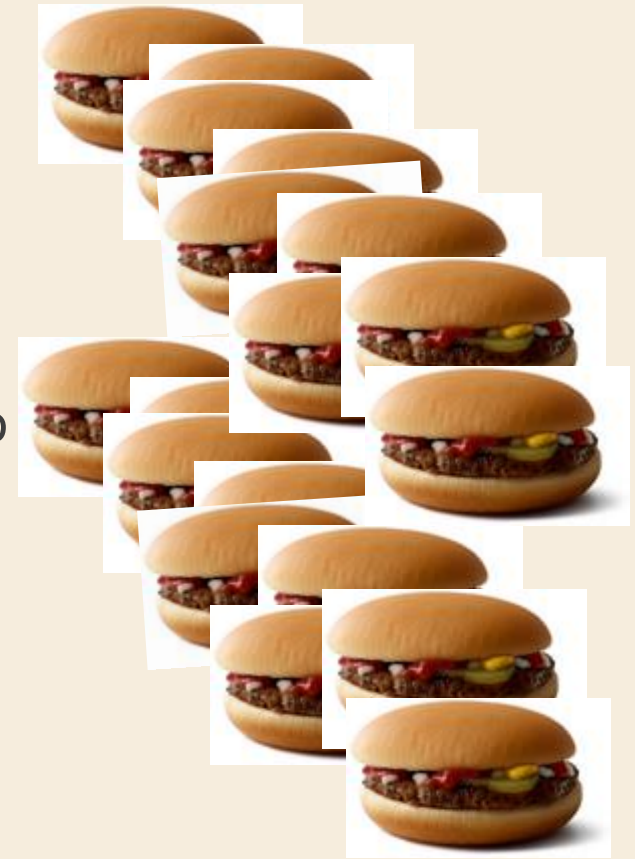
250 Cal.

La hamburguesa original comienza con un patty de 100% carne sazonado con una pizca de sal y pimienta. Viene cubierto con pepinillos crujientes, cebollas picadas, ketchup y mostaza. Se hace sin conservantes, colorantes ni sabores artificiales. No contiene sabores o conservantes artificiales ni colorantes agregados de fuentes artificiales*. Nuestros pepinillos contienen un conservante artificial, así que no lo ordenes si no quieres.

*Sándwiches nacionales solamente. Excluye las opciones locales y de tiempo limitado.

SCALE -UP

- **Start NBS in a region, then a state, then a country**
- Estimated annual number of babies with SCD to notify in Kaduna state is similar to the entire USA.
- **Backlogs could quickly become insurmountable**
 - What to do if the supply chain is interrupted?
 - What to do if there is a gap in staffing ?
 - How to maintain morale & avoid burnout ?
 - Build in redundancy and cross-check



Did they teach any of this in med school ?

Adaptation



screenshots used without permission, for educational purposes

FIDELITY VS ADAPTATION FOR SCD NEWBORN SCREEN

- Need HbC testing in West Africa, not East Africa
- Need beta-thalassemia detection in Middle East & Mediterranean
- Point of Care tests must tolerate humidity & heat
- Home visit by a nurse in uniform can create stigma
- Screening at a site close to home can create stigma
- Educational materials need relevance
- Transportation of Guthrie blood spot cards by courier



TRAINING WORKSHOPS AS OPPORTUNITIES

ENGAGEMENT, ADAPTATION, SCALE-UP



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USE TRAINING SCENARIOS TO LEARN ADAPTATIONS ?



Kaduna, Nigeria
Feb 20, 2018

TRAINING FOR NURSES AND COMMUNITY HEALTH EXTENSION WORKERS



TRAINING SCENARIO FOR COMMUNITY HEALTH EXTENSION WORKERS

- Grandparents of a baby with sickle cell anemia heard many rumors and stories about good treatments for sickle cell anemia: special herbs from the traditional healer or tortoise meat from a shop in Kano.
- The parents believe that prescription medicines from the clinic are the best treatment for sickle cell anemia.
- How could a CHEW help this family? (group discussion)





Discussing what CHEW
would do ...

Transformed

into acting out scenes of
the family dynamics:

**“IMPROVISED
THEATER”**





I LEARNED ABOUT THE VOLUNTEER COMMUNITY MOBILIZER NETWORK IN NIGERIA

- Selected from their respective settlements, 2,150 volunteers work as "change agents" in the community.
- Interventions house-to-house to generate demand for and acceptance of polio OPV and routine immunisation.
- Also worked on other maternal-child health issues



<https://www.comminit.com/polio/content/volunteer-community-mobilizer-network-nigeria>

VCM USE PICTORIAL EDUCATION, STORIES, SONGS, ...



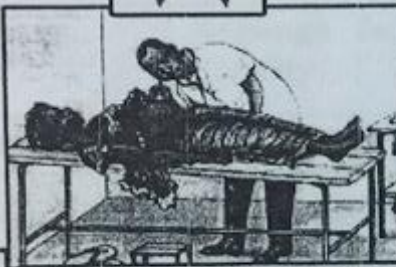
FEBRUARY 2018

TRAINING MANUAL

- Planning for emergencies (e.g. bleeding , prolonged labour etc)

To prepare the mother for labour, breast feeding and subsequent care of the baby

To ensure as much as possible that a mature, healthy and live baby is born



SCENARIOS FOR TRAINING NURSES

- The newborn blood spot card got wet because a nurse's cup of Hot tea spilled on the table where the card was drying.
- One blood spot is still untouched by the tea, but the other 5 spots are brown gritty smears and look like the hot tea has cooked the blood.
- The parents of the baby send messages asking when they will know the results of the blood test.
- What should be done? (group discussion)

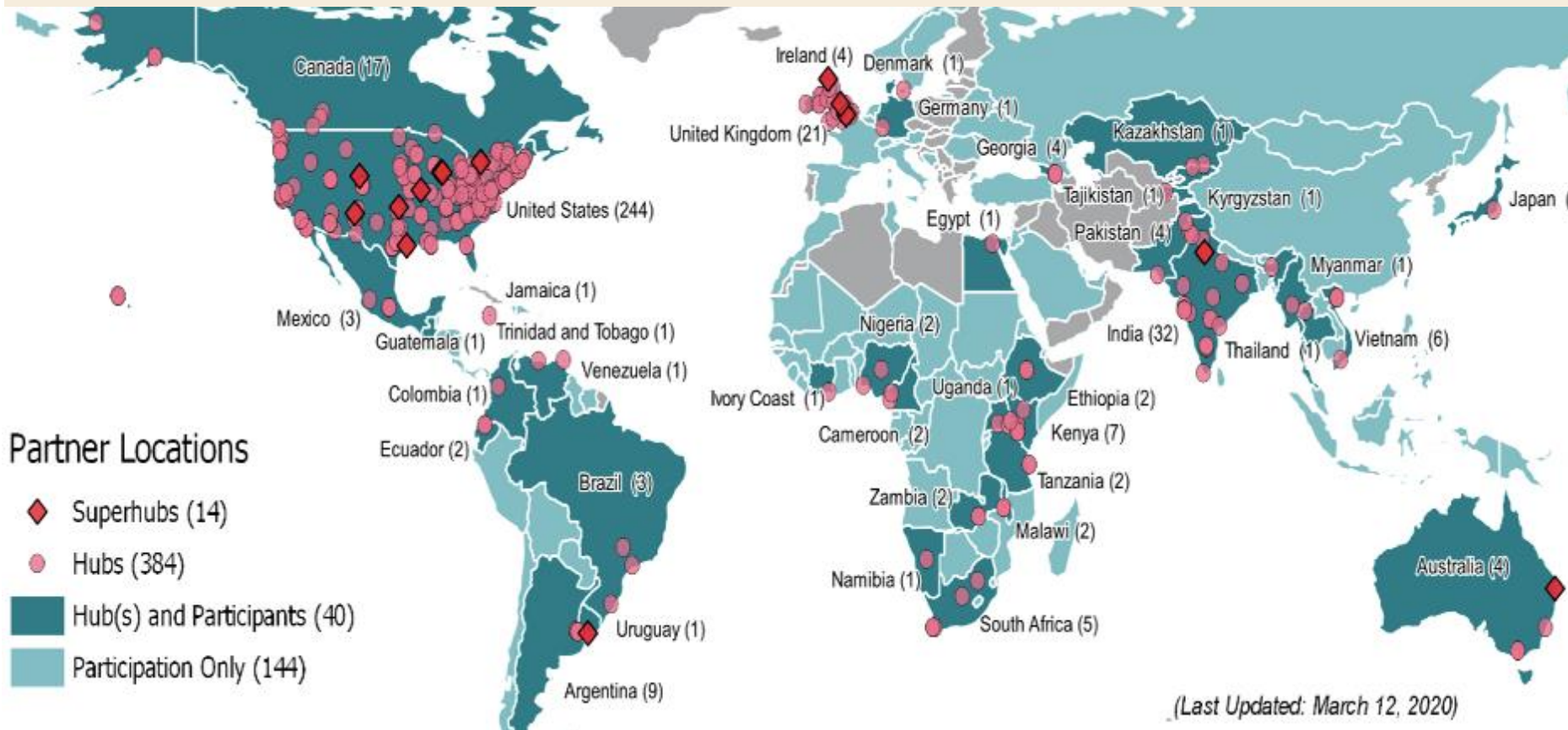




CAPACITY-BUILDING WITH *PROJECT ECHO*

MUTUAL e-TRAINING IN A CLINICAL SPECIALTY

“HUB AND SPOKE” NETWORKS



BUILD ENVIRONMENT COMMUNITY-PUBLIC ENGAGEMENT
ARISE-2 WILL HAVE 4 ***“ENGAGEMENT CENTRES”***

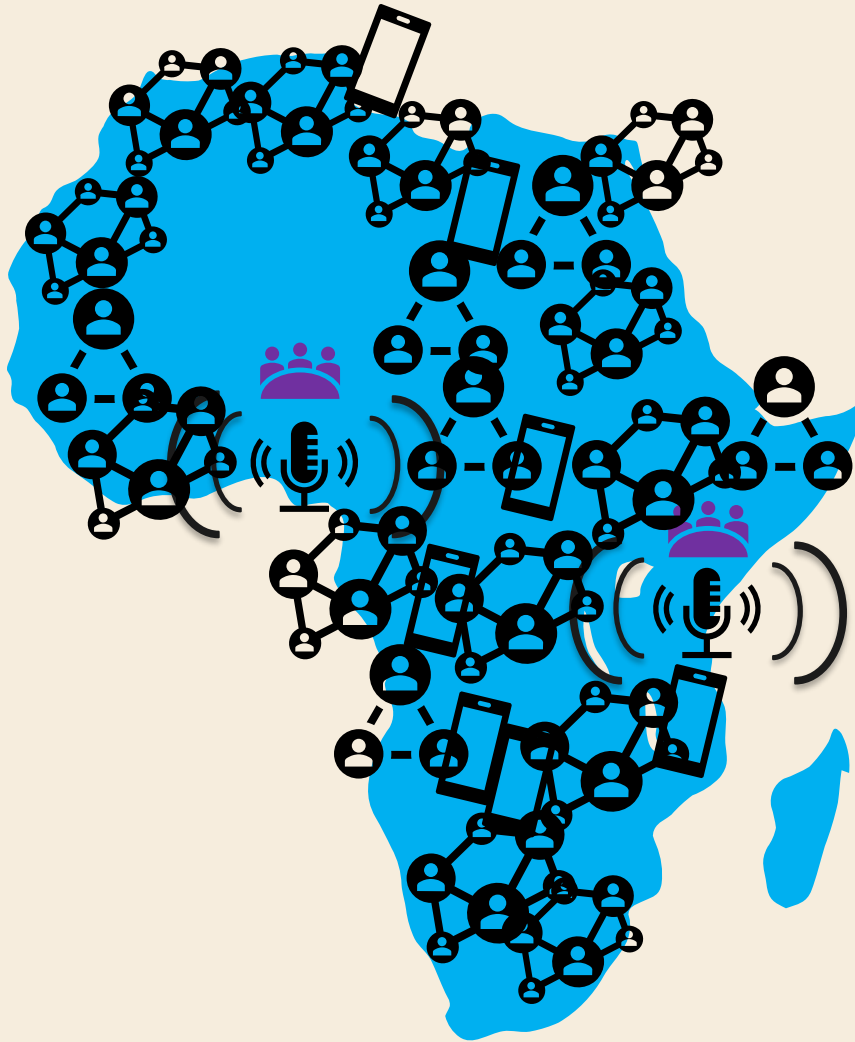


**Community, Students, Leaders,
Scientists, Clinicians**

- Hold conversations and debates about science and SCD in particular.
- Nurture a culture of shared decision-making, clarity and transparency
- Build trust early in the project process
- Catalyze new collaborations

BUILD ENVIRONMENT COMMUNITY-PUBLIC ENGAGEMENT

ARISE-2 WILL USE COMMUNICATION TECHNOLOGIES



1. distance learning for trainees
2. social media infographics and videos for public

DISSEMINATION & IMPLEMENTATION SCIENCE

1. Readiness
2. Capacity
3. Motivation
4. Reach
5. Fidelity
6. Adaptation
7. Scale-up



IS can guide LMIC to optimize use of scarce resources

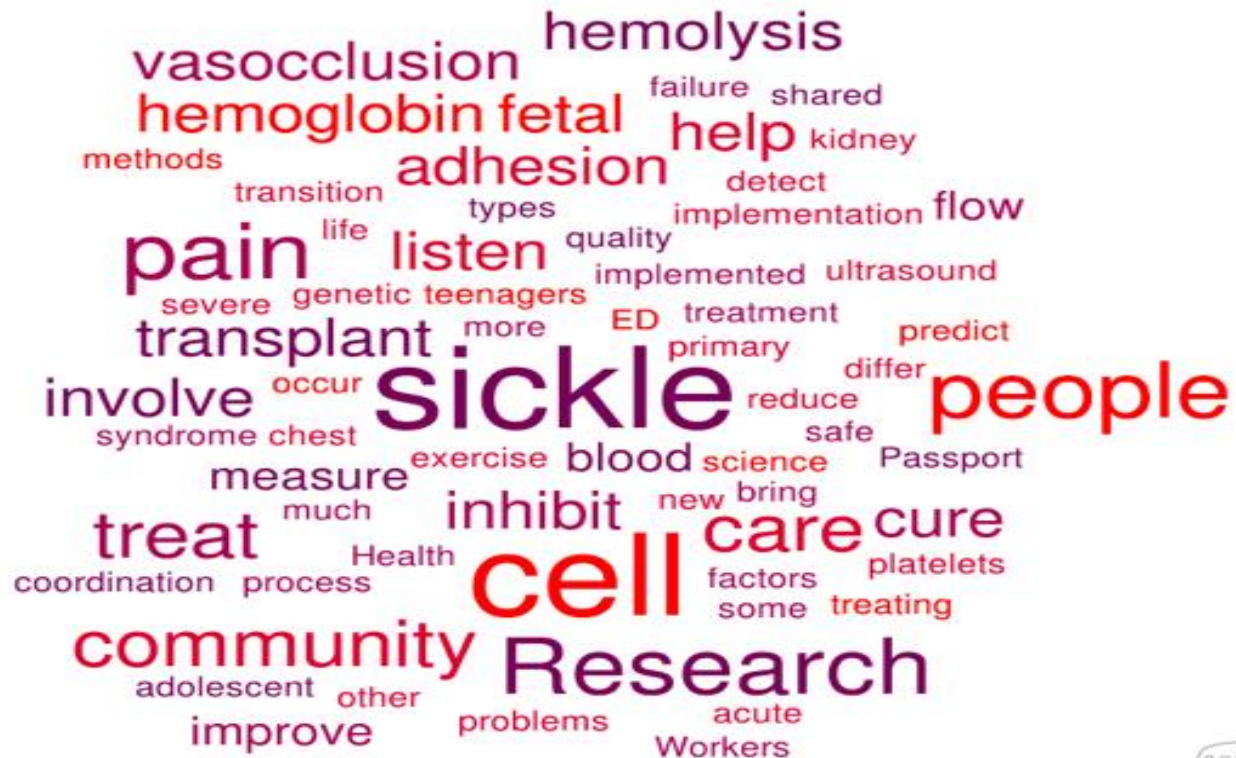
LMIC can drive progress in IS research

1. **Innovations thrive under constraints**
2. **“Reverse Innovation” = transfer novel approaches to all**
3. **Policy-makers open for collaboration with scientists**

Review by Yapa HM, Bärnighausen T. Implementation science in resource-poor countries and communities. *Implement Sci.* 2018;13(1):154.

2018 Dec 27. doi:10.1186/s13012-018-0847-1

DISCUSSION



WordItOut

