

CEI Shared Learning Group Event



Delivering CEI across multiple settings



Tuesday 5 November 2024

Hosted by the NIHR CEI Team, Global Surgery
Unit and RESPIRE



Programme

Chair's welcome, introductions and housekeeping

Introducing Global Surgery Unit and RESPIRE

The journey of establishing CEI across multiple settings: Case studies

Break

Key learnings and advice

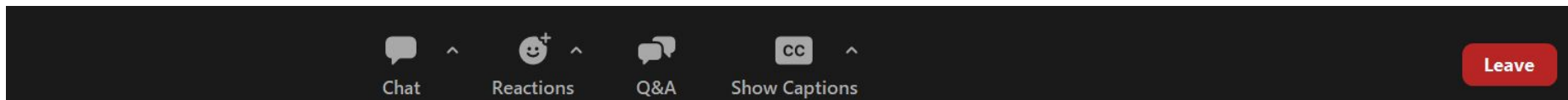
Q&A

Final thoughts and close

Housekeeping

- This session will be **recorded**
- **Closed captioning** is available if needed
- **Slides and recording** will be shared after the event
- If you have any questions for the speakers, please use the **Q&A function** to ask your question
- The **chat function** can be used to introduce yourself, comment on presentations and for NIHR to share resources with you

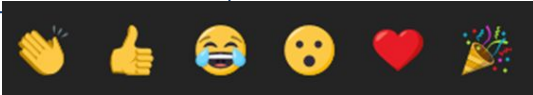
Zoom controls



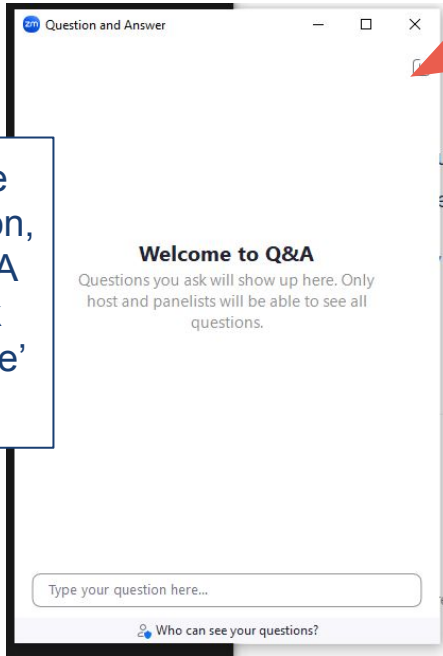
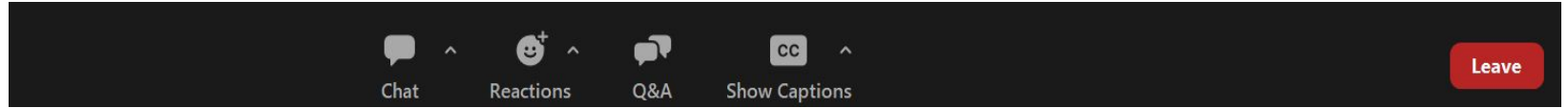
You can view links/resources that will be shared during the presentations.

You can enable captions if required.

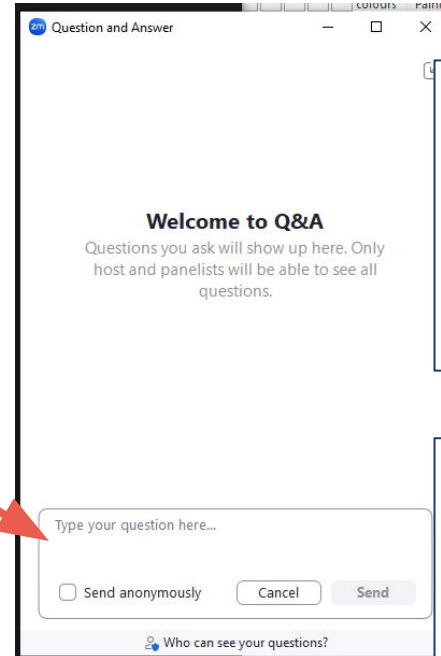
You can react to the presentations/ answers to the Q&A with an emoji.



Zoom controls - Q&A



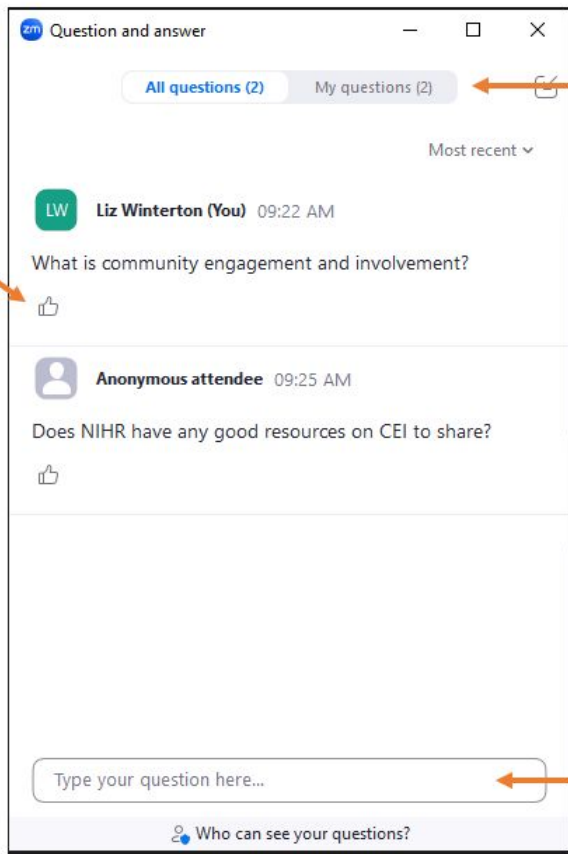
If you would like to ask a question, click on the Q&A button and click in the 'Type here' box.



Select 'Send anonymously' if you do not want your name to be associated with your question.

Once you have finished, click 'Send' to submit your question.

Select the 'thumbs up' icon to upvote a question and increase the chances it will get answered by the panellists.



You can use these tabs to either view All questions, or view only your own.

Submit a new question.

Poll

- 1) In which continent are you based?
 - Asia
 - Africa
 - North America
 - South America
 - Europe
 - Australia
- 2) What level of CEI experience do you have?
 - None / limited experience
 - Some experience
 - A lot of experience

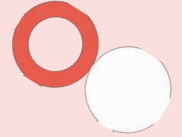
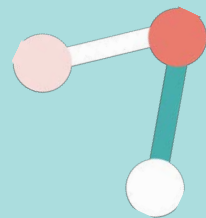


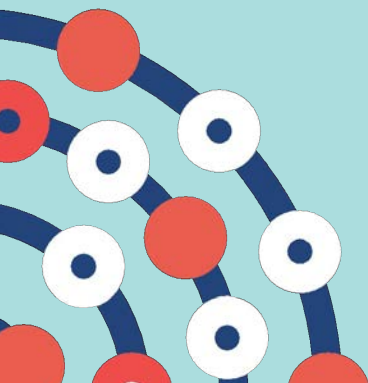
Photo credit: Alexander Kumar. This project is part of the NIHR Global Health Research Unit on Neglected Tropical Diseases [16/136/29](#)



What does NIHR mean by community engagement and involvement (CEI)?

Ms Heidi Surridge

Senior Research Manager, Community Engagement and
Involvement



What do we mean by CEI?

Across the NIHR Global Health Research portfolio, CEI is understood to mean:

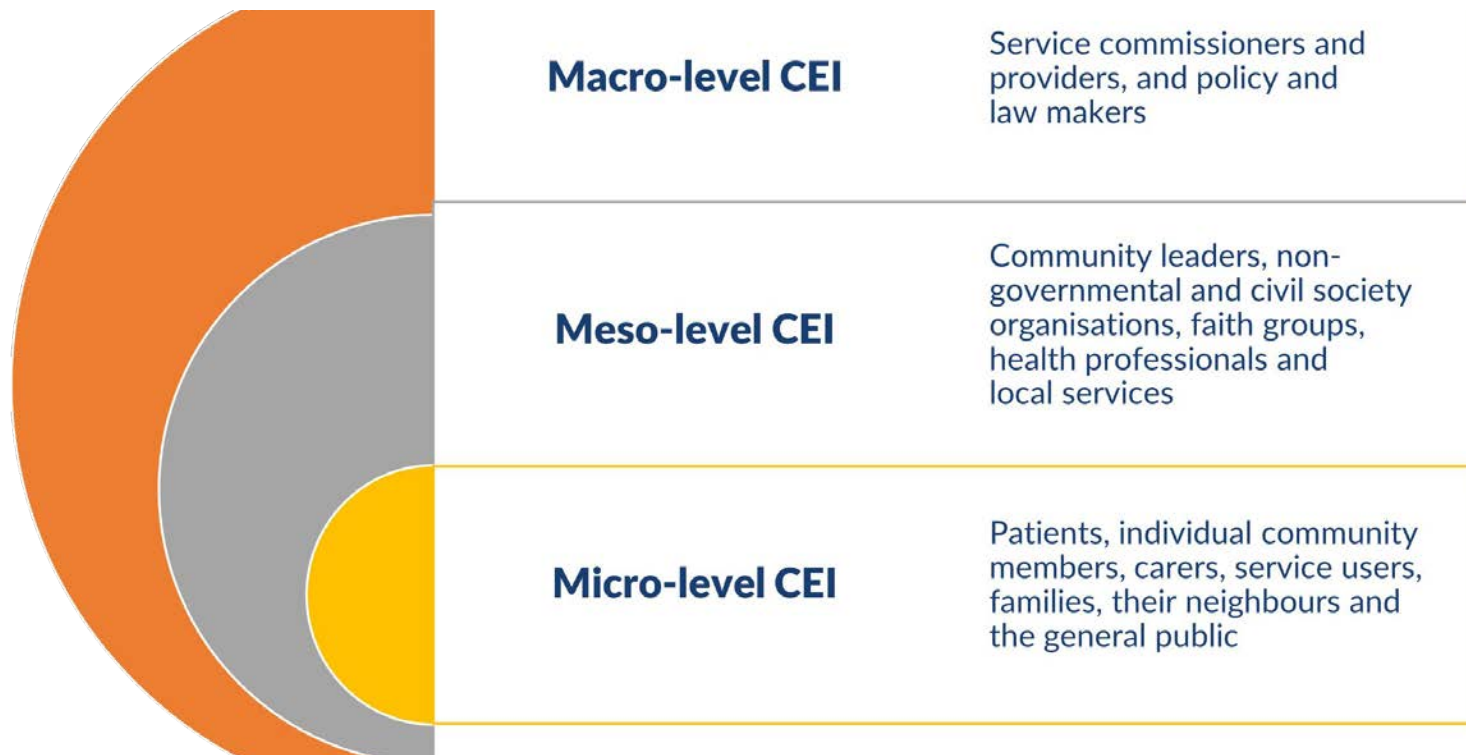
- an **active involvement** of the community throughout the research process, using **participatory approaches** and **working in partnership** with all key stakeholders
- a range of activities which involve interactions between researchers, community members and stakeholders

These aim to improve the relevance, value, and conduct of health research.

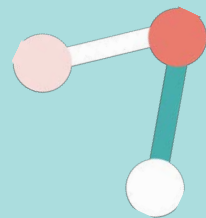


Who are the community?

Localities where the research is undertaken



Introducing Global Surgery Unit & RESPIRE

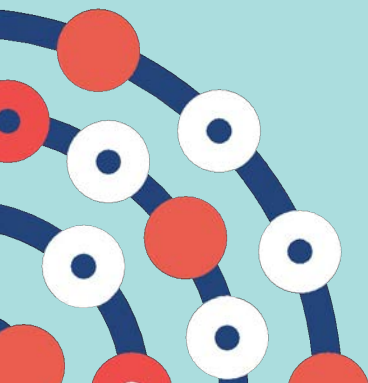


Global Surgery Unit

Michael Bahrami-Hessari
Prof Ismail Lawani

RESPIRE

Dr Dominique Balharry
Dr Genevieve Fernandes





NIHR Global Health Research Unit on
Global Surgery



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Introducing...

The NIHR Global Surgery Unit



Michael Bahrami-Hessari

CEI Manager
NIHR Global Surgery Unit

Prof Ismail Lawani

Benin Hub Director and CEI Workstream Lead
NIHR Global Surgery Unit

The largest global research network in science

Cohort studies

GlobalSurg /
CovidSurg studies

>500,000

Patients

1677

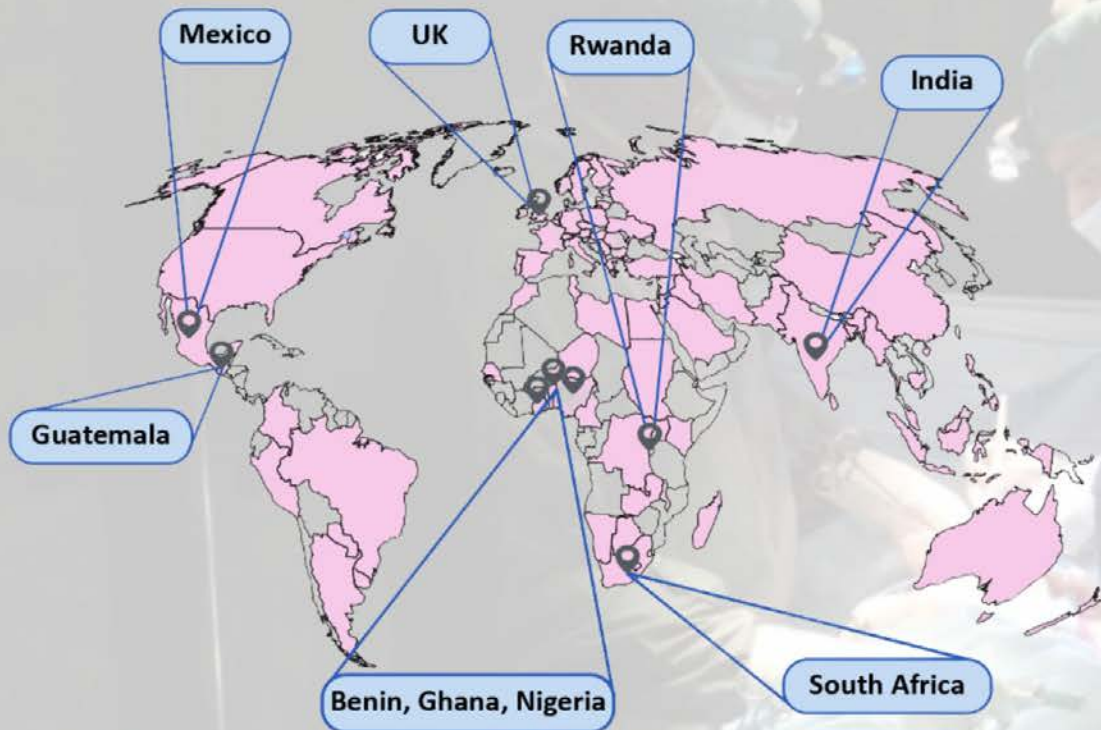
Hospitals

116

Countries

15,025

Collaborators



RCTs

NIHR Global
Surgery Unit

>25,000

Patients

>90

Hospitals

8

Countries

>1,000

Collaborators



Largest scientific collaboration (Guinness World Records 2021)

SURG-WEEK Largest global cohort studies in surgery (GlobalSurg-CovidSurg Week, 2021)
PROSPECTIVE INTERNATIONAL COHORT STUDY

FALCON Largest randomized controlled trial in surgery (Falcon, The Lancet 2021)
RCT

CHEETAH Largest cluster randomized controlled trial in surgery (Cheetah, The Lancet 2022)
CLUSTER RCT

Research influencing health policy...

Routine sterile glove and instrument change at the time of abdominal wound closure to prevent surgical site infection (ChEETAh): a model-based cost-effectiveness analysis of a pragmatic, cluster-randomised trial in seven low-income and middle-income countries



NIHR Global Health Research Unit on Global Surgery*



Summary

Background Surgical site infection (SSI) is a major burden on patients and health systems. This study assessed the cost-effectiveness of routine change of sterile gloves and instruments before abdominal wall closure to prevent SSI.

Lancet Glob Health 2024;
12: e235-42

*The writing committee is listed at the end of the Article and a



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THE 100-4-100 PROJECT

£100m for secure, clean energy for 100 hospitals
in the Global South

[https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(23\)00538-7/fulltext?uid=uid%3A23274118-4096-44f5-8b9f-3a7b63244630](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(23)00538-7/fulltext?uid=uid%3A23274118-4096-44f5-8b9f-3a7b63244630)



NIHR Global Health Research Unit on
Global Surgery



So where do **patients, carers**
and **communities** fit into all
this?

Why surgery?



Five Billion

World's population without access to safe and affordable surgical and anesthesia care



143 Million

Additional surgical procedures needed in low- and middle-income countries each year



33 Million

World's population face catastrophic expenditures paying for surgery and anesthesia annually



Investing in Surgery

Is affordable, saves, and promotes economic growth



Surgery

Is an indivisible, and indispensable part of health care

Lancet Commission on Global Surgery (Meara et al., 2015)

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)60160-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60160-X/fulltext)

0-X/fulltext

HOWEVER...

How is surgery seen by communities in the Global South?

- “LUXURY”
- INACCESSIBLE
- with FEAR and MISTRUST



Take surgery from the operating theatre and into the community!!!



How does GSU bring surgery into the community?

- **Task-shifting**
 - CHW training
 - Empowering non-surgeon physicians
- **Patient education** for self-management
- Understanding the **patient journey** at accessing surgical care



CEI governance structure in GSU

- **Hub-and-Spoke model**

- **Hub-** main hospital; **Spokes-** “satellite” hospital
- CEI structure varies per country
- Each Hub (country) named CEI lead(s)

- **Benin, Rwanda, Mexico-** national CEI steering committee

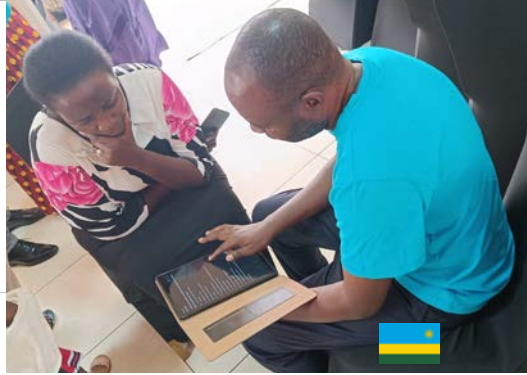
- **Ghana-** regional CEI groups and stoma support groups connected to missionary hospital

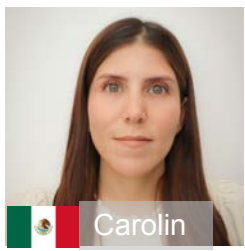
- **Nigeria-** Hub (Lagos) initially working with 5 larger spokes with capacity

- **India-** Hub (Ludhiana) + 2 Sub-Hubs (Kolkata+ Vellore)

- **Unit Level steering committee:** Workstream lead + CEI manager + Patient co-applicant (chairs) + Hub CEI leads (members)







Carolin



Ismail



Emmy



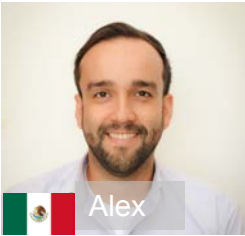
Ebenezer



Ritu



Deepak



Alex



Nalelly



Josette



Vivienne



Emmanuel



Moyo



Miguel



Anna



Omolara



Covalic



Dhruv



Atul



Ami



Amandeep

Online CEI course using GSU Examples



Scroll down to view a list of the CEI learning resources!

A certificated course is also available which covers a similar range of learning objectives, select the button below to enrol.

Join certificate course

List of learning resources for:

Community Engagement and Involvement

This page provides links to a collection of stand-alone learning resources on community, engagement and involvement (CEI) in the context of surgical research

No. of resources: 9

Authors: NIHR GSU Faculty

VIEW / START

Cookie preferences

<https://education.globalsurgeryunit.org/course/cei-resources>

Additional modules on **Health Economics, Qualitative Methods, Research Management and Statistics** in **SURGICAL RESEARCH**

Thank you



<https://www.globalsurgeryunit.org/>



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Community and Stakeholder Engagement

Approach, Case Studies and Lessons Learned

RESPIRE Team

Date: 5 November 2024



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Introducing RESPIRE

To reduce the impact and number of deaths caused by respiratory diseases in Asia



RESPIRE is delivered by collaborative, equitable partnerships across 8 countries



www.ed.ac.uk/usher/respire

 @RESPIREGlobal

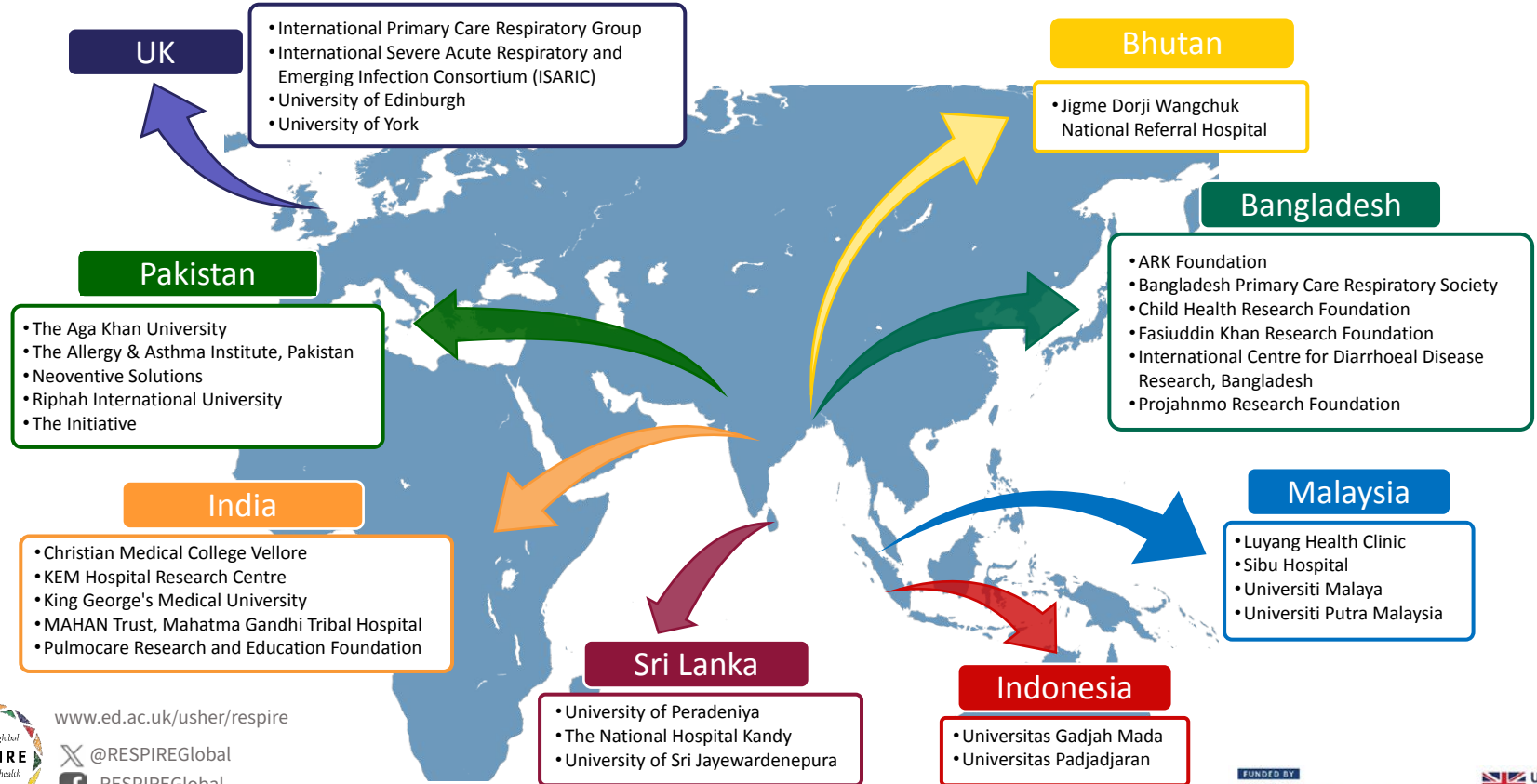
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RESPIRE: Partnerships

8 Countries
30 Partners



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Ethos of equitable partnerships

“in 15 years of collaborative research with international partners, this is the first time I have been asked what would I like to do”

- RESPIRE Partner (Asia)



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RESPIRE



- Deliver **low-cost, scalable policy and clinical interventions** to reduce respiratory morbidity and mortality in Asia
 - Focus on disadvantaged populations
 - Focus on multi-centre, multi-country studies



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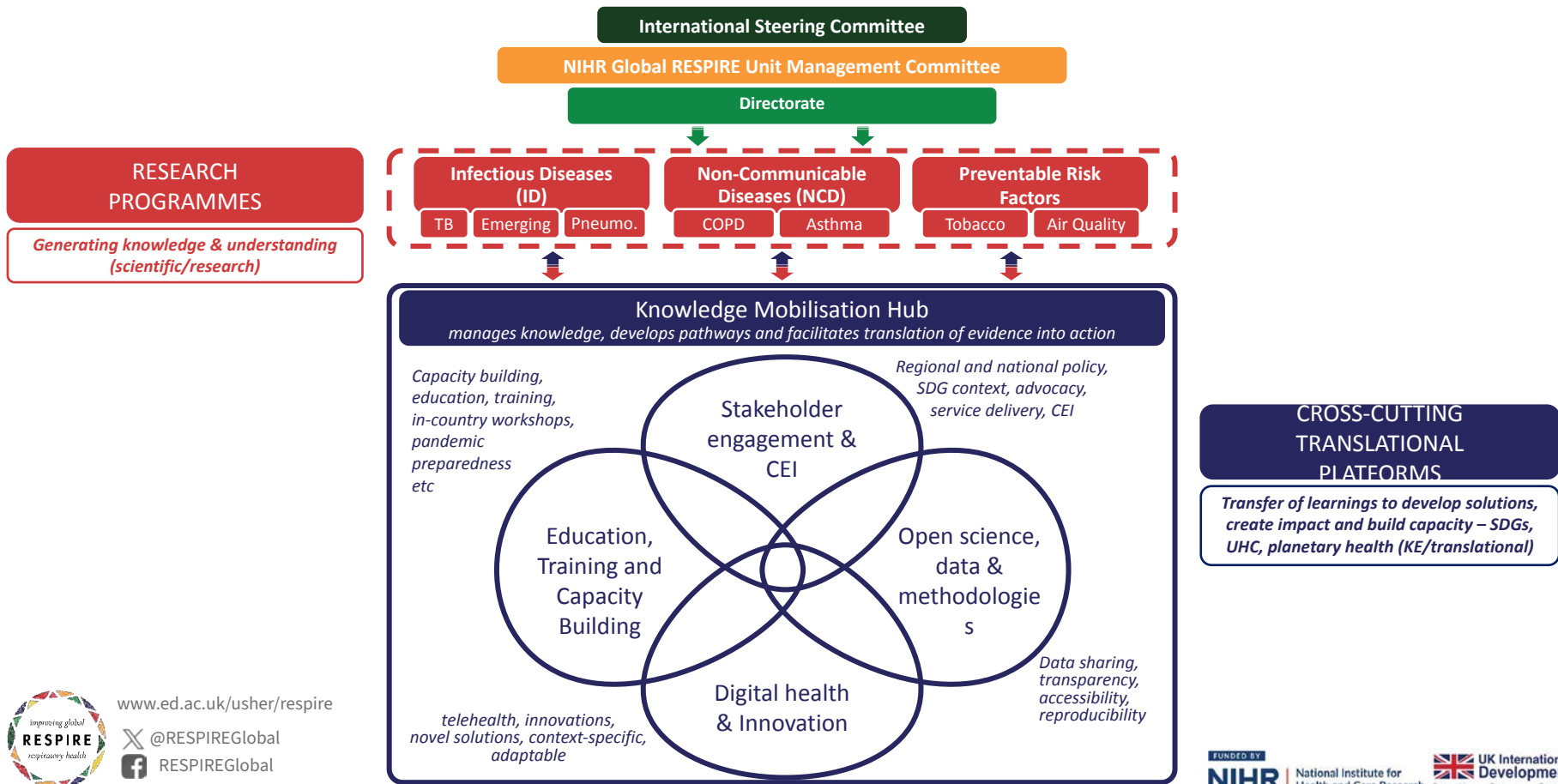
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RESPIRE: How we deliver impactful Research



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ark foundation
advancement through research and knowledge



འཕེལ་ལྡན་འབྲུག་གཞུང་།
ལེན་གཤམ་མེད་རྗེ་རི་དབང་ལྷུན་གྲུབ་ཡོངས་ལེན་འབྲིན་ལྷན་ཁང་།
Jigme Dorji Wangchuck National Referral Hospital
Thimphu :: Bhutan



Child Health Research Foundation
CHRF *Prevent Infections, Save Lives*



PURE
Pulmocare Research & Education Foundation



icddr,b

Projahnmo
Research Foundation

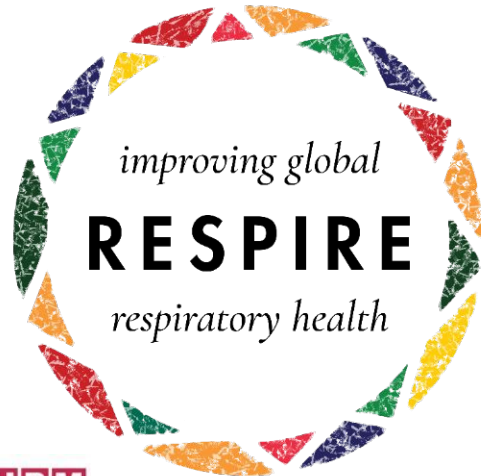


USJ
University of Sri Jayewardenepura
Sri Lanka



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IMPROVEMENT & SAFETY



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தேசிய வைத்தியசாலை கண்டி
The National Hospital Kandy



Neoventive Solutions

UPM
UNIVERSITI PUTRA MALAYSIA

ISARIC

IPCRG
International Primary Care
Respiratory Group

The Initiative



HOSPITAL SIBU
Patient Safety Our Priority



UNIVERSITY of York



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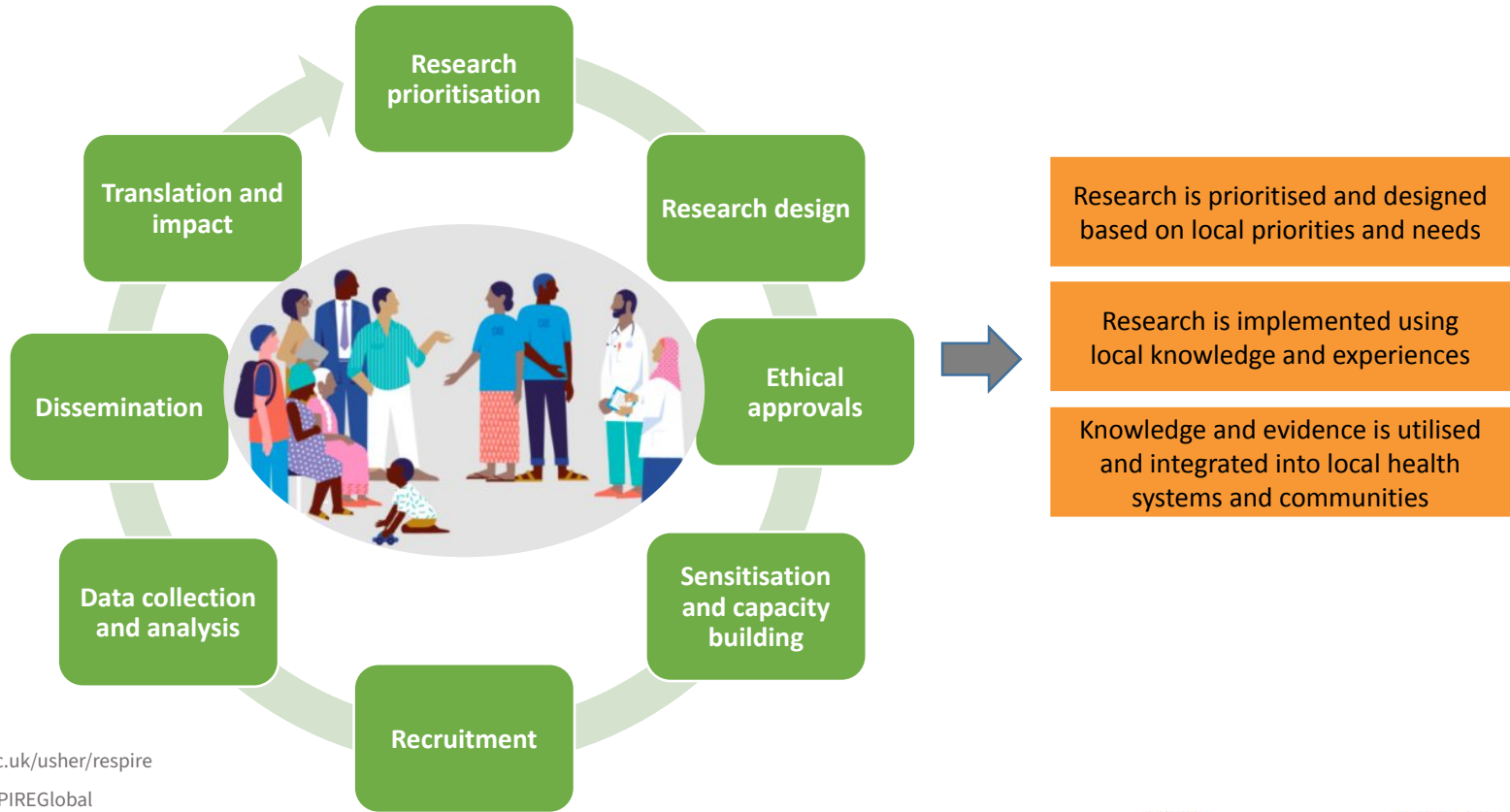
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Community and Stakeholder Engagement Platform: Our Aims



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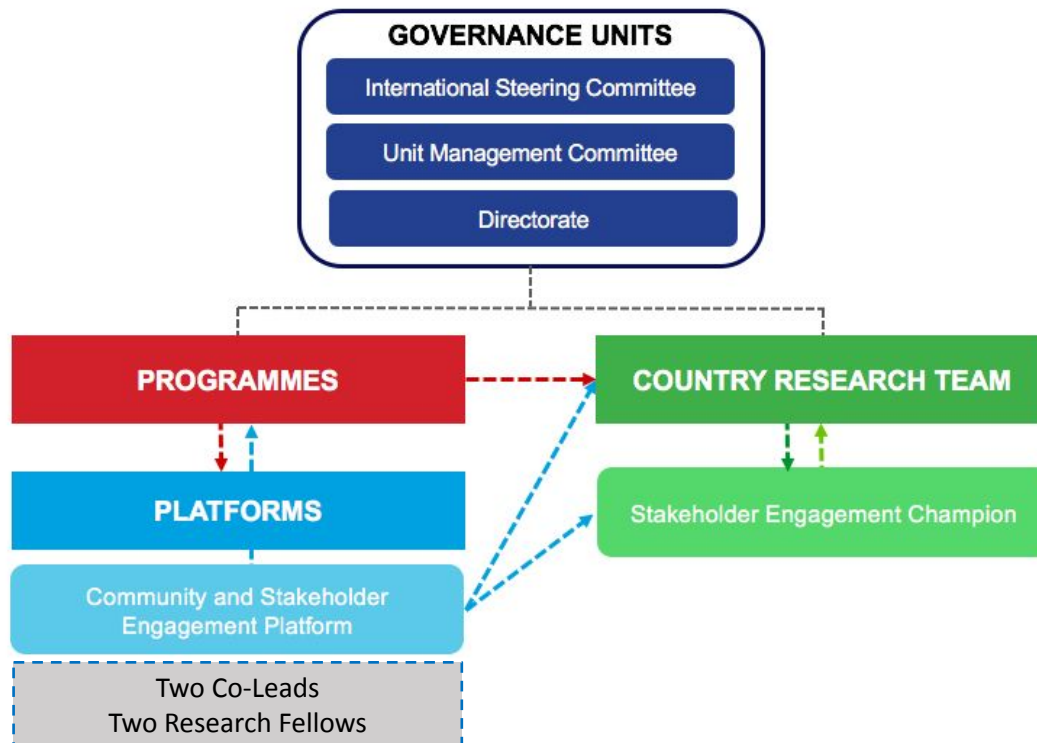
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RESPIRE: Organisational Structure



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Community and Stakeholder Engagement: RESPIRE approach



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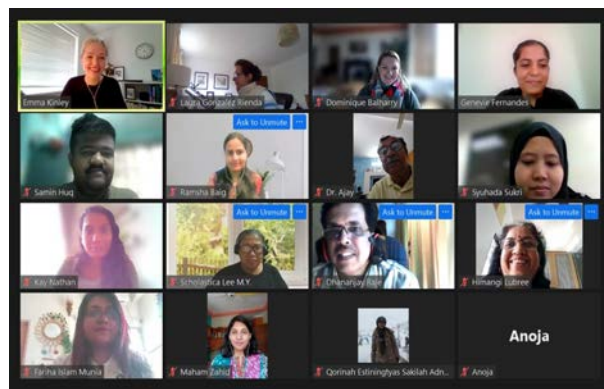
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RESPIRE: Stakeholder Engagement Champions



*Abdullah Rafi
Ajay Kumar Roy
Anoja Wimalasekara
Dhananjay Raje
Fahmeda Akter
Fariha Islam Munia
Farishtey Muanka
Harsh Regi
Himangi Lubree
Jayakayatri Jeevajothi Nathan
Kazi Sarmad Karim
Maham Zahid
Naila Muzzafar
Nursyuhada Sukri
Ramsha Baig
Samin Huq
Seema Khan
Qorinah Adnani*



Images: Stakeholder Engagement Champions monthly meetings and annual in-person training workshop in Jakarta (2023) and Colombo (2024).



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Curating and sharing best practices: RESPIRE Resource Guide



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[Link to the RESPIRE Resource Guide](#)

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Thank you!

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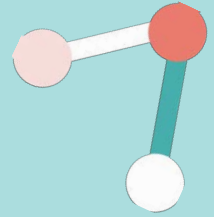
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The journey of establishing CEI across multiple settings: Case studies



Global Surgery Unit

Dr Ebenezer Amofa

Dr Dhruv Ghosh

Atul Suroy

Emmanuel Munyaneza

Dr Omolara Williams

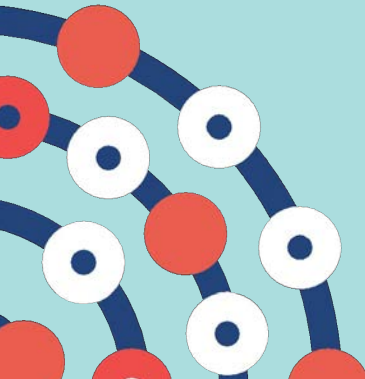
Nallely Ortiz

RESPIRE

Kazi Sarmad Karim

Dr Rizawati Ramli

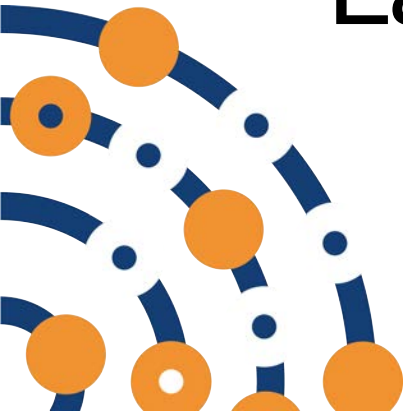
Dr Jayakayatri (Kay) Jeevajothi Nathan





GSU Case Study 1 (The TIGER Trial):

Start Strong and Engage Early for Lasting Community Buy-In

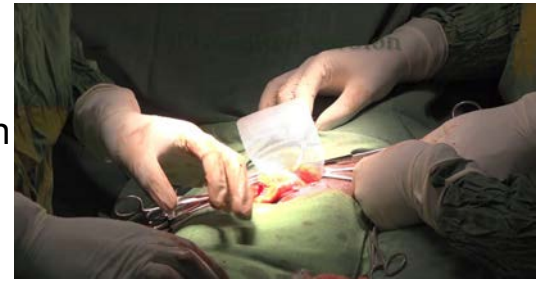


Dr Ebenezer Amofa

Ghana Hub CEI Lead
NIHR Global Surgery Unit

The need...

- 3.15% prevalence of inguinal hernia in general Ghanaian population
- Estimated hernia repair rate is 30 per 100,000 patients
- **Backlog of 1 MILLION hernia repairs needed in the next 10 years! (Beard et al., 2013)**



The challenge...

- Ghana doctor-to-population ratio- **1.4:10,000** (2022)
- WHO minimum recommendation- **2.5:10,000**
- **WORKFORCE SHORTAGE!**



The proposed solution...

- Task-shifting inguinal repair to **non-surgeon physicians (NSPs) like GPs**
- **TIGeR- Task shifting InGuinal hernia Repair** between surgeons and non-surgeon physicians
- **But what do patients, carers and communities think about this?**



Reference: <https://onlinelibrary.wiley.com/doi/10.1007/s00268-012-1864-x> (Beard et al, 2013)

TIGeR- Task shifting InGuinal hernia Repair between surgeons and non-surgeon physicians

- **Question:** Is task-shifting inguinal hernia repair to non-surgeon physicians(NSPs) **acceptable to the community?**
- **What was done? Consultations in Tamale, Ghana** (31 hernia patients, 2 Chiefs (community leaders), a community finance officer and a local politician) **and Ludhiana, India** (5 patients and carers; 5 surgeons; 6 medical students; 15 community health workers)



TIGER CEI Paper:

<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-021-00270-5>

TIGeR- Task shifting InGuinal hernia Repair between surgeons and non-surgeon physicians

What did we find out? TIGeR was acceptable to communities consulted in Ghana but NOT in India

WHY?

GHANA

- Patients felt it was a need and did not mind who performed hernia repair as long as they get better

INDIA

- Hernia surgeries readily accessible and not a pressing problem
- Indian law prohibits hernia repairs to be performed by non-surgeons
- When patients asked if they are happy to have it done instead by newly-qualified surgeons (as opposed to experienced ones) they had apprehensions

Impact of community input on TIGeR trial (Ghana):

- Amended protocol to include women
- Validated study relevance, feasibility, and acceptability
- Supported ethics approval process
- Highlighted need for accurate translation of patient documents
- Identified key patient information for recruitment (risks, options)

- Translation and localisation of PROM (**HerniaQ tool**)
 - QoL focus- staple meals without digestive issues, return to work, marital intimacy
 - Spouses/friends with surgery history increase patient consent (peer consent, snowballing)
 - Added recruitment poster with navel-to-thigh photo, recommending reproductive organ coverage

Read full report here: <https://impact-surgery.org/index.php/pub/article/view/68>

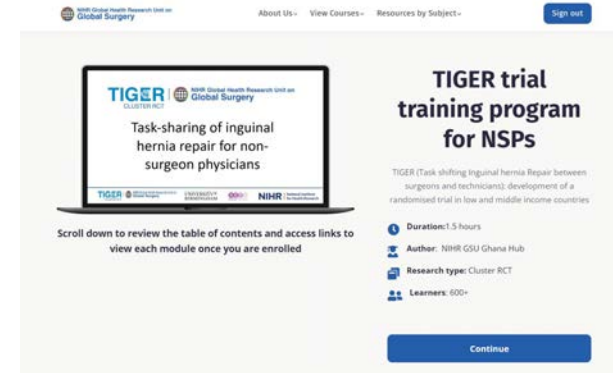


Input from NSPs on TIGeR Trial (Ghana)

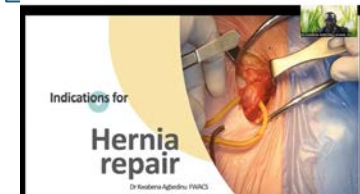
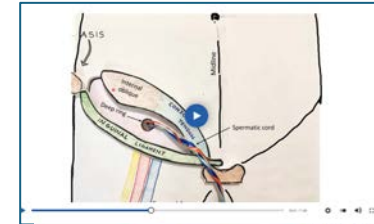
Consultations for review of training videos

Participants: **2 medical interns and 2 GPs**

- The content was considered **informative**
- The demonstration of the **anatomy of the inguinal canal** was described as easier to appreciate than in an anatomy book
- Participants wanted a **step-by-step demonstration** of the surgical procedure with commentaries by the operating surgeon



The screenshot shows the homepage for the TIGER trial training program. At the top, there are navigation links for 'About Us', 'View Courses', and 'Resources by Subject', along with a 'Sign out' button. The main heading is 'TIGER trial training program for NSPs'. Below this, a laptop displays the course title: 'TIGER Task-sharing of inguinal hernia repair for non-surgeon physicians'. To the right, a description states: 'TIGER (Task sharing inguinal hernia Repair between surgeons and technicians): development of a randomised trial in low and middle income countries'. Key details include: Duration: 1.5 hours, Author: NIHR GSU Ghana Hub, Research type: Cluster RCT, and Learners: 500+. A 'Continue' button is at the bottom right.



Access TIGER training resources for NSPs here: <https://education.globalsurgeryunit.org/course/tiger4nsp>

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Listening to the priorities of urban slum communities in Bangladesh

Kazi Sarmad Karim, Research Manager, Fasiuddin Khan Research Foundation (FKRF)

Nov 05, 2024



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Fasiuddin Khan Research Foundation (FKRF)

- The Fasiuddin Khan Research Foundation (FKRF), a pioneering social enterprise established in 2009, is dedicated to enhancing healthcare access, with a particular focus on palliative care and respiratory health in Bangladesh.
- We have been providing palliative care treatments and pulmonary rehabilitation as part of our services in 12 urban slums located in Uttara locality of Dhaka.
- In RESPIRE2 we are currently involved in the research study titled “Pulmonary Rehabilitation in Bangladesh, Bhutan, and Pakistan” being conducted in Cox’s Bazar, Bangladesh.



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Fasiuddin Khan Research Foundation staff



Dr Farzana Khan
CEO & President of FKRF



Kazi Sarmad Karim
Research Manager



Mohd. Saiful Hoque
Scientific Officer



Hasina Karim
Psychologist



Abida Sultana
Research Officer



Nazmul Huda
Physiotherapist



Ritu Akter
Research Officer



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Community consultations



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Conducting cleanliness drive



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Benefits of listening to community priorities first



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Cleanliness drive

**Location: Takepara Slum
located in Dhaka North City
Corporation (DNCC), Dhaka,
Bangladesh**



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Thank you!

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GSU Case Study 2 (Project REACH)

Empowering Community Health Workers: Navigating Gatekeepers and Focusing on Impact

Dr Dhruv Ghosh

Unit Co-director and India Hub Director
NIHR Global Surgery Unit

Atul Suroy

India Hub Manager
NIHR Global Surgery Unit

Emmanuel Munyaneza

Rwanda Hub CEI Lead
NIHR Global Surgery Unit



Community Health Workers (CHWs)

Traditional Roles:

- Maternal, neonatal health, infectious disease
- Slowly expanding into surgical care

Roles in Surgical Care:

- Screening, linkage to care, and post-op care

Challenges and Opportunities:

- Most studies in HICs.
- **Can CHW-enhanced surgical care model be done in LMICs?**

Project REACH:

- **RE**sources for surgical **cA**re training of **C**ommunity **H**ealth Workers
- Train CHWs in recognising SSIs to assist with post-op care
- Top-up UKRI funding received for pilot



Project REACH: The India Hub Experience



ASHA Workers (India):

- Approved by Punjab National Health Mission
- SSI training **not prioritized**
- Focus on top 3 cancers: Oral, Cervical, Breast

Training:

- Targeted Ludhiana district & rural areas
- Topics: Cancer risk factors, symptoms, treatment, prevention, *brief mention of SSIs*

Challenges:

- Balancing funder (NIHR) & NHM-Punjab priorities

Impact Measurement:

- Knowledge assessed at 3 time points: before, immediately after, 3-6 months post-training
- Multiple-choice visual quiz



Full report here:

<https://impact-surgery.org/index.php/pub/article/view/72>

Project REACH: The India Hub Experience



Training sessions:

- 30 Sessions; >1800 ASHAs

Assessment results:

- Pre-training- 38.99% (≥ 4 out of 6 questions)
- Post-training 71.14% (≥ 4 out of 6 questions)

Post-training Engagement:

- 24/7 hotline number with 16 different WhatsApp for each village group
- **31 patient referrals made for further screening**

Future plans

- Submit 1st phase report to NHM Punjab, request for second district Jalandhar.
- Implement similar model of training & delivery in another states of India.

NIHR Global Health Research Unit on
Global Surgery

CEI

Name _____ Designation _____
Mobile No. _____
Address _____
City Area _____

QUESTIONNAIRE

Instructions: Tick on options that are applicable.

1. Which of these are the common risk factors for cancer?

a) Male gender b) Smoking
c) Family history of cancer d) Diabetes
e) Increasing age f) Alcohol consumption

2. Which of these should alert you regarding the possibility of cancer in a patient?

a) Pain b) Fever
c) A non-healing wound d) Weight loss
e) A lump or a mass f) A change in bowel pattern

3. Which of the following behaviours can help prevent cancer?

a) Regular exercise b) Eating softness food
c) Keeping indoors d) Taking regular medication

4. Curative treatment of cancer beliefs?

a) Surgical removal of the tumour b) Chemotherapy
c) Radiotherapy d) All of the above



Project REACH: The Rwanda Hub Experience

Scoping work: PIGEON

- *Im*Proving surgical care outcomes throuGh the active involvEment of cOmmunity healthworkers in RwaNda
- Mixed method study to get perceptions of CHWs about surgical care and research
- **Survey (n= 184) and 4 FGDs (n =42)**

PIGEON results:

- **72%** reported encountering post-operative patients requiring follow-up care in their communities.
- **99%** expressed confidence in their ability to contribute to post-operative follow-up
 - Identified post-surgical care CHWs can provide:
accompanying to health facility (42%); assist in general body hygiene (9%); medication administration (7%) and simple dressing change (60%)



Project REACH: The Rwanda Hub Experience

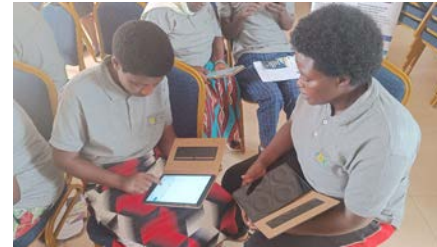
SSI Training for CHWs

- “Train the trainer” model
- Senior CHWs trained on 1) SSI concepts; 2) obtaining informed consent and 3) qualitative interview skills
- Training cascaded to other CHWs
- Assessments done at 3 points: pre-, post- and 3-6 months after training

Assessment results:

- 256 CHWs total trained
 - Recognising SSI symptoms
 - Pretest- 92%
 - Post-test- 98%
- Paper on this pilot being written

Full report here: <https://impact-surgery.org/index.php/pub/article/view/78>



Project REACH: Lessons Learned




1. **Scope** and learn the “**lay of the land**” (**PIGEON**)
2. **Balancing act** between gatekeeper buy-in (Indian MoHFW) and funder (NIHR)
3. **Incentivise CHWs** (payment for time, transport)
4. **Follow-up** is essential – engage beyond the event (WhatsApp group; phone hotline)




Cancer Awareness and Home Care

Venue: Premashraya auditorium
Time: 4 pm to 5 pm
Date : 22/02/2024

- Cervical Cancer Awareness
HPV vaccination
- Breast Cancer Awareness
- Post surgery wound care management at home





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RESPIRE 1

The Malaysian Asthma Hajj Study

5 November 2024



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Dr Rizawati Ramli
Primary Care Medicine Department
Universiti Malaya
Malaysia



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The Malaysian Asthma Hajj Study



In memory of Prof Dr Liew Su May

Rizawati Ramli¹, Nik Sherina Hanafi¹, Norita Hussein¹, Ping Yein Lee², Sazlina Shariff Ghazali², Ai Theng Cheong², Ahmad Ihsan Abu Bakar³, Azah Abdul Samad⁴, Suhazeli Abdullah⁴, Hilary Pinnock⁵, Aziz Sheikh⁵, Ee Ming Khoo¹ on behalf of the RESPIRE Collaborators⁴

¹Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, Malaysia, ²Faculty of Medicine and Health Sciences, University Putra Malaysia, Malaysia, ³Hospital Pusrawi Pvt Ltd, ⁴Ministry of Health, Malaysia, ⁵Usher Institute, University of Edinburgh, United Kingdom



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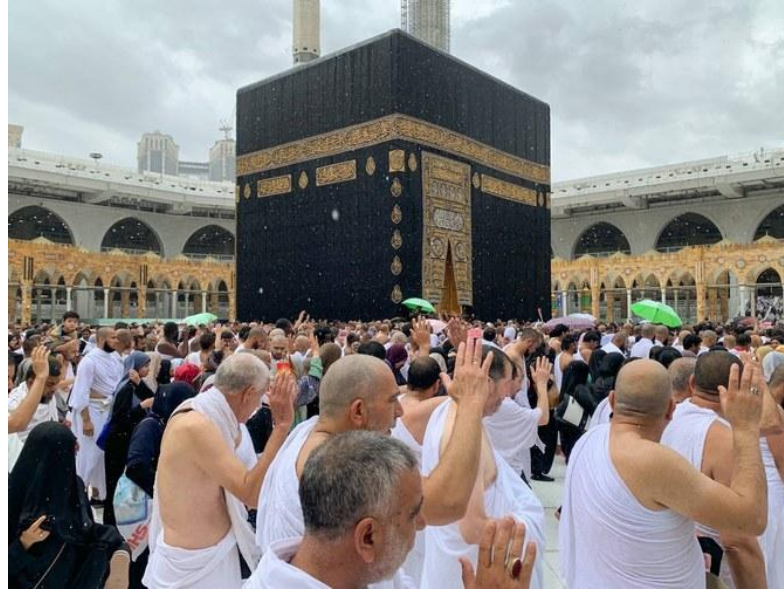
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Asthma and Hajj



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STUDY PHASE	DESIGN	STAKEHOLDERS
Pre-Hajj health examination	Ethnographic observation of the pre-Hajj health examination programme at 14 MOH health clinics	<ol style="list-style-type: none"> 1. Hajj Board (health unit, Hajj department) 2. Ministry of Health, public health higher officers 3. District health office, public health officers 4. Health clinics and family medicine specialist
Healthcare provider's perceptions of pre-Hajj health examination on asthma	In-depth interviews with 21 stakeholders on the barriers and facilitators to asthma care for pilgrims	<ol style="list-style-type: none"> 1. Public health clinics <ul style="list-style-type: none"> • Family medicine specialists and medical officers. 2. District health office <ul style="list-style-type: none"> • Public health officers 3. Private general practitioners 4. Hajj Board ground staff
Asthma control and incidence of unscheduled care among Malaysian pilgrims attending the Hajj in Saudi Arabia	<p><u>Pre-Hajj</u></p> <ul style="list-style-type: none"> • Face-to-face survey using a structured questionnaire to collect data face-to-face on pilgrims with self-reported asthma who attended health examinations at health clinics. <p><u>Post-Hajj</u></p> <ul style="list-style-type: none"> • Telephone survey on the same group of pilgrims within three months of return from pilgrimage 	Hajj pilgrims with asthma.
	<p><u>During Hajj</u></p> <p>Obtaining secondary quantitative data on : Unscheduled asthma care among pilgrims performing Hajj (including nebulization, admission, ICU care and death)</p>	<ol style="list-style-type: none"> 1. Hajj Board 2. Ministry of health.



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HAJJ FUND BOARD



The key institution that provides facilities for the welfare of Malaysian Hajj pilgrims.



Hajj Department



Pilgrims health unit

- Small unit
- 2 -3 staff with medical background



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MINISTRY OF HEALTH



KEMENTERIAN KESIHATAN
MALAYSIA

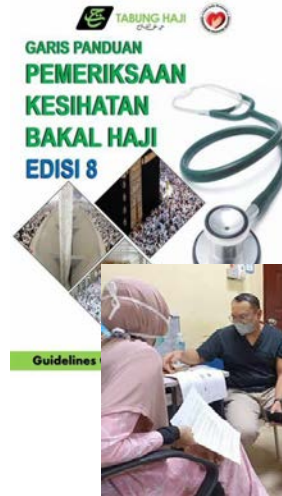
Ministry of Health (MOH) supports various aspects of pilgrim's healthcare in the homeland and during the pilgrimage.



PUBLIC HEALTH



DISEASE CONTROL DIVISION



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EARLY STAKEHOLDER ENGAGEMENT

- Ministry of Health and Hajj Fund Board approval - conduct of studies involving their facilities and resources, including participation of their staff.
- The research design of and development of research tools - guided by the input obtained from series of discussion between researchers, healthcare providers, Hajj fund board personnel, patients and public (PPI) involvement.



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ENGAGEMENT WITH THE HAJJ BOARD

Challenges in data collection

- Access to Hajj fund board data was not permissible
- Formal request for specific data – send a letter via email
- Request to a different department - several layers of approval from the higher officers
- More than one request as received incomplete data following the earlier request



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ENGAGEMENT WITH THE HAJJ BOARD

Challenges in data collection


1. Data privacy and security concerns
2. Data ownership issues
3. Lengthy approval processes
4. Lack of clear communication channels

Lesson learned

- obtaining protective data from other authorities indeed a challenging process
- require planning including backup or alternative strategies.



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POTENTIAL STRATEGIES

- Clarify legal and ethical guidelines
- Streamline approval processes
- Use data sharing agreements



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ENGAGEMENT WITH THE HAJJ BOARD

WORKSHOP FACULTY



Honorary Professor
Dr Khoo Ee Ming



Professor Dr Liew Su May



Dr Rizwati Raml



Dr Azah Abdul Samad



Dr Suhazali Abdillah

2

PROGRAMME

Workshop 1 (17th September 2021, Friday)

0900 - 0910

Welcome, ice-breaking and introduction
by Honorary Prof. Dr Khoo Ee Ming/Prof. Dr Liew Su May

Attendees - family medicine specialists, medical officers, and health unit staff of the Hajj board

PENJAGAAN ASMA JEMAAH HAJI DI TANAH SUCI
Asma terkawal, Haji Sempurna

PENCETUS ALAM SEKITAR

- Kota Mekah 40°C
- Gurun berhabuk, kering dan panas.
- Cuaca sepanjang tahun yang sangat tinggi, suhu pada waktu siang boleh melebihi 40°C.
- Asap kenderaan yang banyak menjejaskan kualiti udara.
- Bulu dan najis burung merpati berterbangan.
- Bilangan jemaah yang ramai dan sesak meningkatkan risiko mendapat pengikutan virus.

PENCETUS AKTIVITI FIZIKAL

- Ulang-alik ke masjid Jarak antara hotel penginapan jemaah Malaysia ke Masjid Haram ialah antara 650m hingga 1 km.
- Tawaf Jarak mengelilingi Kaabah 7 pusingan ialah antara 500m hingga 1 km.
- Sole Jarak utang-Sum.
- Melantar Jarak utang-ke Jannah la.

TANDA SERANGAN ASMA

RINGAN/SEDERHANA

- Bermafas laju, beresak tajam, diletak, nafas berbunyi.
- Belah bercajak.
- Belah memuncuk apabila meng- 'tetas'.
- Belah berbarbing.

TERUK/SERIOUS

- Dada beresak sangat berat dan sangat sukar bermafas, nafas berbunyi.
- Percakapan tersakat-sakat.
- Tidak memuncuk apabila meng- 'tetas' yang sedang dilakukan.

TINDAKAN SEM

SEMAKIN BAIK

1 Mesti dicapai sebelum berangkat tanah suci

2 Dijaga sepanjang menjalani ibadah haji

3 Dikekalkan selepas pulang ke tanah air



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ENGAGEMENT WITH THE HAJJ BOARD

Challenges in the dissemination effort

Acquiring endorsement of the resources from MOH for Hajj Board pilgrims

- Multiple layers of bureaucracy
- Lengthy approval processes - time-consuming
- Lack of clear communication channels

Lesson learned

- Communicating the value of research to stakeholders could be a tricky process.



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POTENTIAL STRATEGIES TO OVERCOME CHALLENGES

1. Engage them early
2. Build relationships and engage continuously
3. Highlight mutual benefits
4. Showcase successes



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GSU Case Study 3 (Patient and Community Education Toolkit)

Stay Open: Relevant Research Sparks New Avenues for Engagement



Nallely Ortiz

Mexico Hub CEI Lead
NIHR Global Surgery Unit

Dr Omolara Williams

Nigeria Hub CEI Lead
NIHR Global Surgery Unit

The context:



NIHR CEI dissemination fund (2021)

- Targeted policymakers, medical practitioners, patients.
- Challenge: **How to make operating theatre-focused findings relevant to patients and carers?**
- **Solution: Engage the community!**

What we did:

- Engaged patients (29), carers (19), CHWs (88), community leaders (21) in 5 Hubs
- Explored knowledge on wound infections & self-management

What we learned:

- SSIs impact patients beyond hospitals
- Patients' experiences need more focus
- Low awareness & misconceptions about SSIs
- Patient education & self-management are key
- Need for plain, simple, localised educational materials

The GSU Patient and Community Education Toolkit



- Co-developed with community
- Initial focus: Surgical Site Infections (SSIs).
- Animated video in 8 languages (English, French, Spanish, Yoruba, Hindi, Marathi, Twi, Kinyarwanda)

Expanded to cover:

- Early cancer detection (India),
- Stoma care (Ghana, India, Nigeria, Rwanda),
- “Your Surgical Journey” (Mexico, Nigeria, Benin)

To be Disseminated and evaluated in SPECIES study:

- Trial-embedded mixed method study
- Assess **patient QoL** before/after surgery, **SSI awareness**, and **self-management**.
- Conduct interviews to explore post-surgical care.
- **Aim: Inform future Community Engagement and Involvement (CEI) activities.**



Engaging with communities: an important dilemma

The Mexico Hub Experience

- SSI education wasn't relevant to everyone in the community.
- Other health concerns raised include **cancer, NCDs (Diabetes, CVD), mental health**
- **Some issues fall outside the research scope (surgery)**

Dilemma:

- **How to address emerging community needs beyond your research remit?**
- Balance between funder requirements and community needs.
- Utilise these insights for future projects and collaborations.



What did we do?

Work with government to align with existing projects

- DIF (Mexico); Primary Care Board (Nigeria)

Reach out to private sector organisations and charities

- Membership in CEI advisory board

Be open to new engagement avenues and get CREATIVE

- “Hospitalito”
- First aid training for teachers + health checks

Identify future CEI collaborations

- Women’s health and breast cancer
- Paediatric cancer
- Stoma support group (Ghana)



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**Be creative, listen to stakeholders and involve them
in dissemination where appropriate and acceptable**

Dr. Jayakayatri Jeevajothi Nathan

Universiti Malaya

5 November 2024



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Involving and engaging public members around asthma in Malaysia

WORLD ASTHMA DAY 2021 | UNCOVERING ASTHMA MISCONCEPTIONS

FREE SKM RUN FOR 20 VIRTUAL ASTHMA 21
Run, walk or jog anytime & anywhere!

LET'S SPREAD ASTHMA AWARENESS!

- 1 REGISTER & RUN**
Register now at ticket2u.com.my/event/25059
5th May 2021 - 4th June 2021
- 2 SUBMIT**
Record using any running app & upload your result to Ticket2U by **4th June 2021**
- 3 REWARD**
Runners eligible for free T-shirt will be contacted by **11th June 2021**

T-shirt for first 500 finishers & e-certificate for all participants





"Physical activities help me stay well"

Sudhan Rayan prefers to be in control of his asthma by using an asthma action plan and keeping spare inhalers with his sports and work equipment. While previously having skipped on using his inhalers, he now knows that regular inhaler usage and discipline is what really helps him.

"Yes, you can do it!"

"To those with asthma who want to start doing some exercise I would say: yes, you can do it! Exercise is important for our overall health and can be done even with asthma. Having control over your symptoms is important, rather than letting them control you. It's a process but knowing your limitations and being patient with yourself is key, and soon enough you'll be able to get back out there and enjoy the physical activities you like."

"I was bullied in school."

Implementation Manager, Sudhan Rayan doesn't let having asthma stop him from exercising. "I was diagnosed when I was very young. As a child, I was hospitalised for asthma all the time. During school, I was bullied for being hospitalised frequently and started to smoke to prove that I wasn't 'weak.' It was a vice that was really bad for my asthma."

Sudhan Rayan did not realise just how badly asthma could affect him until he reached the age of 30. "It started with a cold. I became very ill at the time, but I kept putting off going to the doctor because of work. Before I knew it, I wound up in the hospital due to a serious asthma attack. If only I had listened to my body initially, it might not have gotten so bad. It was a wake-up call. I managed to get back on the right track to control my asthma."

At the age of 33, my friends encouraged me to join a marathon. Exercise is one of my triggers, especially running. However, it is entirely possible to maintain good physical health. When I go running, I make sure I have my reliever with me in a pouch under my T-shirt.

SUDHAN RAYAN, 40



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Engaging rural community around chronic respiratory health in India



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Involving patient members in communication campaign around pollen induced allergies in Pakistan



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Key Takeaways

- Creative Outreach
- Amplifying Patient Voices
- Adaptability and Cultural Sensitivity

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Thank you!

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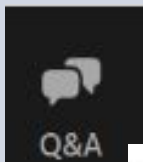
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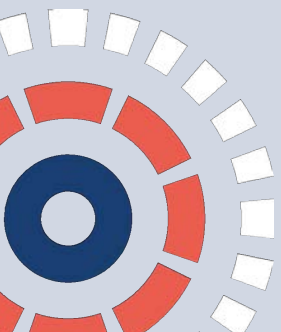
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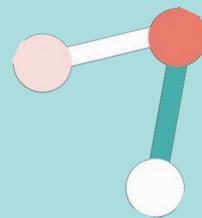
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Break



Please remember to submit your questions for the speakers via the Q&A button and 'upvote' any questions you particularly want answered by our panel.





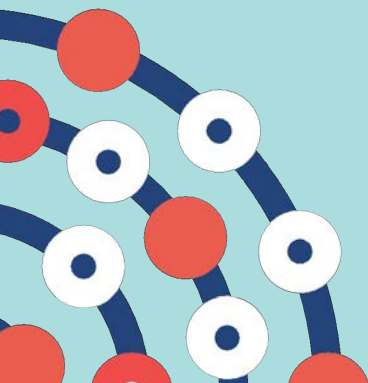
Key learnings and advice

Global Surgery Unit

Mr Michael Bahrami-Hessari
Prof Ismail Lawani

RESPIRE

Dr Dominique Balharry
Dr Genevieve Fernandes





NIHR Global Health Research Unit on
Global Surgery



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The NIHR Global Surgery Unit

...lessons learned in delivering CEI



Michael Bahrami-Hessari

CEI Manager
NIHR Global Surgery Unit

Prof Ismail Lawani

Benin Hub Director and CEI Workstream Lead
NIHR Global Surgery Unit

Lessons learned

- **Start early:** Buy-in from senior management, gate keepers and community is essential
- Never **underestimate** the **time** and **resources** needed to build relationships with the community
- Understand **motivations**: Different stakeholders have different goals. Use this to your advantage.



Lessons learned



- **Align CEI efforts with community needs**, even beyond research goals
- **Plan for future collaborations**: Use these differences to identify opportunities for future partnerships.
- Be **adaptable**: Be flexible and adjust to different work styles.



Thank you



<https://www.globalsurgeryunit.org/>



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Community and Stakeholder Engagement

What have we learnt?

RESPIRE Team

Date: 5 November 2024



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CHALLENGES

Contextual challenges

- Competing policy priorities
- Health system limitations
- Power dynamics
- Socio-economic, cultural and political barriers
- Limited networks
- Limited understanding of policy landscape
- Public health emergencies and crises derail activity

Process challenges

- Differentiating engagement in care delivery from engagement for research
- Clarifying who is the end user – a citizen, a patient, a clinician, a policy maker
- Identifying, utilising/building strategic communication capacity
- Going beyond the “usual customers” with limited funding
- Organisational limitations

Outcome challenges

- Linking engagement inputs with outputs/outcomes and better understanding the pathways
- How did the engagement change the research and at what stage of research cycle?
- How do you sustain engagement after the study ends?



LESSONS

Institutionalisation

Decentralisation

Tailored approach

Understand power dynamics

Internal and external stakeholder engagement needed

Building rapport, trust and relationships are vital

Non-linear, time-consuming and unpredictable, so be flexible



THANK YOU



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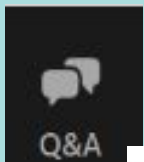
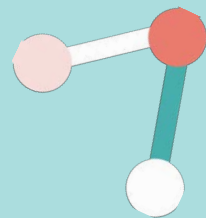
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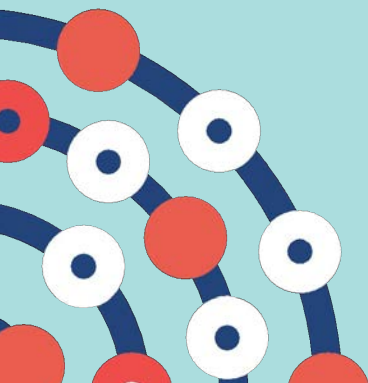
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Q&A



Please continue to submit your questions via the Q&A function and 'upvote' any questions you particularly want answered by our panel.

Any questions that are not answered will be compiled and their answers shared after the webinar.



Thank you!

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