

Equitably Harnessing the Power of Health Data

Time for Action and Collaboration
April 2021

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1. Speakers and contributors

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Trudie Lang, Professor of Global Health Research; Director of The Global Health Network and Senior Research Scientist in Tropical Medicine, Nuffield Department of Medicine; Research Fellow, Green Templeton College: Prof. Lang works to drive better health outcomes in vulnerable communities by enabling local leadership and ground-up implementation of high-quality research. She has over 20 years' experience in running clinical trials and has worked in industry, academia and for UN organisations. She founded and heads [The Global Health Network](#).

Dr Luiza Lourenco, Regional Coordinator, REDe (Brazil), The Global Health Network: Dr Lourenco is the Brazilian Regional Coordinator of [REDe](#), a network focused on research capacity building in Latin America and the Caribbean. She is based in Brazil where her work aims to improve health research and education.

Dr Michael Makanga, MD PhD FRCP: EDCTP Executive Director: Dr Makanga is a clinician-scientist who has spent 28 years working on health and poverty-related infectious diseases affecting Africa. Before joining [EDCTP](#) Dr Makanga was in clinical practice, academia, clinical research and research management. He has served on advisory boards for the development of medical products for poverty-related and neglected diseases.

Professor Andrew Morris, Director, Health Data Research UK: Prof. Morris is the Director of [HDR UK](#) - the UK national institute for health data science. He is seconded from his position as Vice Principal of Data Science at the University of Edinburgh. Prof. Morris chairs the Scottish COVID 19 Advisory Group which provides analysis to the Scottish Government. He was Chief Scientist at the Scottish Government Health Directorate.

Dr David Mukanga, Senior Program Officer, Africa Regulatory Systems at the Bill and Melinda Gates Foundation: Dr Mukanga's supports the development of harmonised, transparent and predictable regulatory systems covering the lifecycle of medical products in Africa, as well regulatory emergency preparedness.

Dr Aliya Naheed, Head of the Initiative for Noncommunicable Disease, icddr,b: Dr Naheed heads the Initiative for Noncommunicable Disease at the [icddr,b](#), international research organisation in South Asia. Her research focuses on the prevention and control of NCDs through strengthening local health systems. She has led large scale NCD studies in Bangladesh, Pakistan, India and Sri Lanka.

Dr Thomas Nyirenda, Strategic Partnerships and Capacity Development Manager of EDCTP: Dr Nyirenda is a public health physician and research scientist with 26 years' experience of working in sub-Saharan Africa. He chairs the [Africa Academy of Sciences](#) Advisory Board on Clinical Trials Capacity Data Base programme (CTC).

Dr Carla Saenz, PhD, Regional Bioethics Advisor Department of Health Systems and Services, Pan American Health Organization: Dr Saenz is an international expert in bioethics and is responsible for [PAHO's](#) Ethics Review Committee (PAHOERC). Dr Saenz is a board member of the International Association of Bioethics, and serves on the steering committee of the Global Forum on Bioethics in Research.

2. Executive Summary

Health research offers immense opportunities for improving world health and mitigating the impact of both COVID-19 and other major diseases. Impactful work is happening in many countries but much needs to be done if research and therefore, evidence-based healthcare, are to flourish everywhere.

The *Equitably Harnessing the Power of Health Data* symposium brought together expert contributors, and nearly 540 participants, from many countries and continents to exchange experience, outline examples of good practice and explore the challenges and solutions.

This report outlines the key issues they examined and their suggested ways forward.

The financial, human and infrastructural barriers to research must be overcome

The lack of financial, human and infrastructural resources are among the greatest barriers research and all inhibit advances in care. In some cases it is essential to develop stronger relationships with policymakers and political representatives to persuade them of the benefits of evidence-based healthcare.

Research must be local, global – ubiquitous – to mitigate future health emergencies

All countries need a robust research infrastructure with sufficient resources, skills and capacity. This is essential for tackling the everyday health challenges of their local populations. It is equally necessary for ensuring that there is a worldwide system able to swiftly identify and respond to emergent pathogens. Only by investing in the day-to-day can we be ready to stand up to the great challenges of tomorrow.

With a worldwide network of teams able to immediately pivot their focus to characterise and learn about new threats, rapidly sharing the data, it is more likely that we can stop a localised outbreak becoming an international emergency.

At the same time, the potential of health data research can only be fully realised by building strong and inclusive international networks, alliances and collaborations. Each must be able to access and work on data across and between all partners, geographies and diseases.

High quality data is the essential foundation for high quality healthcare

High quality care is underpinned by high quality data. Studies need to be well designed and executed by suitably-trained researchers gathering information from all relevant sections of the community. In many parts of the world there is a need to build capacity, developing lasting and capable teams.

All roles engaged in healthcare delivery can be supported in undertaking research where good questions can be set to gain vital evidence and working closely with the local community to ensure relevant new treatments and practice in every setting.

Communities must be at the heart of everything we do

Research must be of social benefit and yield improvements in health and care. This can only happen if research is embedded within healthcare systems and communities, identifying their needs and carrying out research that tackles those needs. Not only do communities have to be central to the research process but they must also be part of the whole cycle to ensure they benefit

from the results of the findings and ensure that the ensuing recommendations are implemented to deliver better care.

Ethical standards, trustworthy behaviour and fair sharing are essential at all stages

Harnessing the potential of health data and guaranteeing equity requires a fair, balanced and trusted research eco-system. The current pandemic and previous crises have shown the need for close collaboration on research and the open, fair sharing of results and the benefits of research. Without ethics, fairness and trust at every stage there is a risk to future co-operation.

Ethical standards and effective governance are needed at all stages of the research cycle in order to build public trust, and trust between countries and institutions. Progress can be made through commitments to open science and the transparent stewardship of data. These are areas in which governments, donors and research bodies have an important role to play.

Public trust is equally important. If science and research are to be valued and trusted by society not only must the public be directly involved at all stages but they must have confidence that all health data is being managed and exploited for the individual and collective benefit.

We must learn from experience and from each other

The response to COVID-19 has often been deeply flawed, partly because of a failure to learn lessons from past major disease outbreaks. There have, though, been many examples of outstanding excellence in health data science research that can be built on and adapted in new locations and circumstances. COVID-19 must be treated as a call to sustained action to engage and to realise our potential so we are better prepared for future pandemics and health challenges.

- The symposium was organised by [ICODA](#) (the International COVID-19 Data Alliance) in partnership with [TGHN](#) (The Global Health Network) as part of the [CUGH](#) (Consortium of Universities for Global Health) March 2021 *Virtual Conference Addressing Critical Gaps in Global Health and Development*.

3. Foreword

Professor Trudie Lang, Director of The Global Health Network

COVID-19 is the latest in a series of pandemics including Ebola, Zika and SARS that have all highlighted the urgent need for a worldwide health research network that can swiftly unite in response to major disease outbreaks. At the same time we have to find better ways to generate the research needed to overcome the rampant health inequalities.

The best way to be able to respond quickly is to ensure that the necessary infrastructure, skills and resources are in place permanently, working on the everyday diseases affecting their areas of the world. In the event of a broader emergency they would be ideally positioned to pivot and face the threat – enabling a fast local response that can also be harnessed globally.

There are many remarkable research initiatives and collaborations already taking place that could provide the building blocks for such a network – some of which I am very familiar with through The Global Health Network (TGHN).

However, if we are to truly harness the power of health data research to improve and save lives, many other difficulties and inequalities have to be overcome.

‘Right now 90% of health research benefits just 10% of the world’s population. This is wrong. It has to change. It can be changed.’

Prof Trudie Lang

It is in everyone’s interests for this to happen but it can only be done if there is true equity in research and its benefits.

Our experience at TGHN shows that the major difficulties that face researchers in achieving their goals include a lack of resources, training, skills, collaboration and support. There are also issues around access, benefits, ethics, trust, fair sharing, priorities, regulation and governance if an effective global health research network is to be established. Despite these enormous challenges, there are amazing examples of important and inspiring work being driven across the global south that show us the potential that we could deliver if we were able to come together.

All types of health research data are important if we’re going to learn how to characterise diseases, understand the threats, and then test and implement interventions to address them.

This symposium, which brought together more than 500 people from Africa, the Americas, Asia and Europe revealed an abundance of goodwill and commitment – it also served to reinforce that an approach led by those operating at the front line across the world offers the greatest potential for meaningful and sustained impact.

4. Introduction

Professor Andrew Morris, Director of Health Data Research UK

Evidence-based decision making is essential across all institutions and nations if we are to find better treatments for diseases and save lives.

The better the evidence, the more informed the decisions that can be taken – and this requires data sharing.

A lack of data sharing will undermine the effectiveness of our response to the current pandemic and future threats to human health.

On the day of this symposium the WHO reported that 113 million COVID-19 cases had been confirmed and 2.5 million deaths reported. Probably an underestimate. In the UK, where I am based, we are struggling. There have been 123,000 deaths, 5% of the global total.

We all have much to learn. As this report shows, the [ICODA](#) (International COVID-19 Data Alliance) symposium on *Equitably Harnessing the Power of Health Data* contributed to that learning process.

The symposium brought together a talented group of international contributors. Their experience is wide and varied, but they share the energy, determination and practical ideas to bring positive change. They have a willingness and desire to learn from each other and all argue that this demands equity and trust in health data research.

Only if we have a global, learning health system will we be able to suppress this pandemic and tackle future major disease challenges.

ICODA, which is convened by Health Data Research UK (HDR UK), is working towards a globally coordinated, health data-led research response to COVID-19 and is paving the way for ongoing collaboration. We are in the foothills of where we need to be and this event showed how we can move forward by looking at examples of best-practice in the generation and harnessing of data.

Success demands partnership in order to:

- build an inclusive, collaborative international alliance
- develop a trustworthy data eco-system
- prioritise public and patient engagement
- be transparent around data stewardship.

This may not be easy, but it is necessary and as Nelson Mandela said: “It always seems impossible, until it's done.”

5. Research must be local, global – ubiquitous – to mitigate future health emergencies

Healthcare research has the potential to provide global solutions to many of humanity's greatest care and treatment needs – but only if there is worldwide collaboration. Equally, healthcare research can provide solutions to many of humanity's most localised care and treatment needs, but only if researchers work with the affected communities.

To achieve the best for communities, nations, regions and the world we have to bring together the local and the global.

Contributors at the *Equitably Harnessing the Power of Health Data* symposium gave examples of how scientists, research organisations and donors are increasingly recognising the new approaches are needed if healthcare research is going to bring benefits for all.

Countries such as Bangladesh face their own specific challenges – a poor and rapidly-ageing population with limited access to affordable care – but researchers there believe there is huge potential in bringing together highly localised and Pan-Asian initiatives (see *Case Study 1*).

Dr Aliya Naheed of the [icddr](#), is emphatic about the need to make sure that research is designed to include representative samples of all relevant populations. A specific and deliberate effort must be made to send researchers into hard-reach-areas such as island, hill-top and coastal communities to collect data.

'When we identify research sites we need to be vigilant and honest about picking up vulnerable groups in remote areas and identify what proportion of the population should be represented in the sampling. This is the only way to do justice to the entire population.'

Dr Aliya Naheed

Unless this is done then the research is not comprehensive, meaning that the healthcare model that results cannot be comprehensive either.

This perspective was reinforced by Dr Luiza Lourenco, Brazilian Regional Coordinator of the REDe network who argued that whatever the advances we are making in technology, we can never understand people's needs without going out and talking to them.

'We can sit here and think of smart ways to do things with Artificial Intelligence, but really we need to be sensitising people to the issues in remote areas and make them understand the need to go out to these places and talk to the people there.'

Dr Luiza Lourenco

There is a recognition among donors such as the Bill & Melinda Gates Foundation of the need for grassroots research that feeds into national policymaking and international investment.

Dr David Mukanga, from the Foundation, said that from the perspective of international donors it is vital for voices from the grassroots to be heard at the highest level in order to guide investment.

‘The priorities of communities and the policymakers at country level really need to be the engine of the research agenda.’

Dr David Mukanga

6. Case Study 1 – from local to Pan-Asian

Bangladesh has a pressing need to get a better understanding of the diseases affecting its people, and their severity. The country is small but has a dense, growing and rapidly ageing population of 160 million – many on low incomes.

Healthcare is expensive but some 63% is paid for directly from patients' own pockets, something that will be increasingly problematic as the population is expected to surpass 200 million by 2050, with a growing proportion aged over 60 and often having little money.

As head of the Initiative for Non-Communicable Diseases at the country's [icddr](#) research institute, Dr Aliya Naheed is at the forefront of efforts to ensure the right data is gathered and made available to provide universal healthcare services.

'We need comprehensive health data to generate the evidence that will give us immediate information to identify solutions. And for that we need to create an infrastructure for accessing data.'

Dr Aliya Naheed

Health data about older people is very limited but it is known that some 80% suffer from a disease and there is a high incidence of multimorbidity, with chronic illnesses such as diabetes, dementia and hypertension being common. Dependency on children for support will grow and there will be increasing pressure on the country's health and care systems. Dr Naheed believes that a strong and effective research structure has to be developed if Bangladesh is going to fulfil its needs for evidence based clinical practice.

Crucial questions have to be answered including about the type of treatments people are paying for now, the risk factors to their health and wellbeing and the illnesses they are experiencing. This is a challenge as there is no system in place to collect and analyse the comprehensive health data that is needed from a representative sample of the population.

But there are hopes that the country can find ways to access and make use of the patient data that is collected daily by hospitals all across the country. Dr Naheed is optimistic that progress can be made – pointing to innovative initiatives that have charted a way forward.

One, in conjunction with a medical university in Bangladesh and the British Medical Journal set out to create a platform to promote clinical research. Notably, it brought clinicians and the public and researchers to the same table, giving them opportunity to learn how to design research, build data collection tools, carry out analysis and disseminate the results in real time.

What has subsequently emerged is the highly ambitious Stand by Me (**Streng**Thening and **Accelerating the Global Respo**Nse to COVID-19 **BY** Sharing **M**ethods and Knowledge Between Countries, **NE**tworks and Organisations) programme.

This aims to revitalise the previously established clinical research platform and also to set up an Asian Knowledge Hub for the wider dissemination of COVID-19 and other data across the continent. The objectives of Stand by Me are to develop pan-Asian collaboration in order to:

- Identify common health issues
- Find common solutions
- Agree fast and cost-effective interventions
- Improve quality of care.

Dr Naheed also believes that the Stand by Me model could be adopted and adapted for use on other continents.

7. High quality data is the essential foundation for high quality healthcare

The ability of research to pave the way for healthcare providers and policymakers to improve care and treatment relies on the quality of the initial data. In many parts of the world there is a need to build capacity, ensuring a suitable cohort of well-trained researchers. They in turn need a perspective that embraces the local and the global.

Dr Michael Makanga described the work of the EDCTP in investing in the development of the whole continuum of researchers from the junior to the very senior. At one level this aims to ensure that African countries are equipped to generate meaningful research questions that are locally relevant. At another level, it aims to make sure that the researchers are linked into global networks. They think both locally and internationally, generating regular data that is relevant locally and applicable internationally.

At the same time the EDCTP has been promoting international cooperation between African countries and research institutions, through regional networks of excellence and with collaborations between regions.

Regardless of the quality of the researchers Dr Luiza Lourenco, the Brazilian Regional Coordinator of [REDe](#), emphasised the need to put people and communities at the heart of every project (see *Case Study 2*). Only by doing this is it possible to be confident that you are addressing the right issues.

Research barriers

Event participants were asked about the most frequent barrier researchers in their setting encounter that prevent them from doing their own research, those who responded said:

- Lack of training and/or experience 11%
- Lack of access to health research literature 3%
- Lack of resources (financial, human or infrastructure) to support data management 50%
- Limited collaboration or isolation 10%
- All of the above 23%
- Other 3%

'We have to understand the needs of the population. If we don't then we can't ask the right questions. Before we think about the importance of sharing data we have to know what data is relevant and what should be shared first.'

Dr Luiza Lourenco

It was only through workshops with affected communities that researchers identified that many families of children who had Zika-related disabilities could not afford the wheelchairs that could have a transformative benefits. Knowing the issue allowed researchers to ask the appropriate questions.

'You gather really good data because you've asked the right question in the right place.'

Prof. Trudie Lang

Prof. Trudie Lang of TGHN identified a series of characteristics that determine a good study. These included:

- Checking with the community that the right questions are being asked
- Designing the study to suit the setting
- Using the evidence to form recommendations
- Taking the recommendations back to the community for implementation.

For this to happen there needs to be an eco-system of research that sees it in terms of a lifecycle, beginning and ending with the community. This in turn means identifying and overcoming the barriers that exist to research – including those identified in a poll of our event participants (see *box*).

8. Case Study 2 – communities at the heart of research

The [REDe](#) network and the [Fiocruz](#) public health foundation offer outstanding success stories for health research in Latin America and the Caribbean.

The two are close collaborators. Both champion equity – something they see as essential to ensuring that research is high quality and relevant, generating the reliable data needed to inform decisions. They also share a deep commitment to involving all those with a stake in research – and on emphasising projects that address the needs of the population.

‘Research should be led from the perspective of the community, including both healthcare professionals and patients.’

Dr Luiza Lourenco

According to Dr Luiza Lourenco, Regional Coordinator of [REDe](#) (Brazil), the success of Fiocruz rests on three pillars:

- Its closeness to, and deep relationship with, vulnerable communities
- Being one of Brazil’s few institutions with dedicated research roles
- A positive working relationship with the Ministry of Health and national lawmakers.

The Fiocruz Foundation’s mission is to produce, disseminate and share knowledge and technologies to improve health. This inevitably involves addressing issues about who can access research and data, on what terms, and how the resulting benefits are distributed.

In 2014 Fiocruz took a significant step forward in promoting and practicing equitable research practices with the introduction of an open science policy. This led to the establishment of an online platform where all research undertaken at Fiocruz is shared openly and freely. Others are being encouraged to follow suit but, Dr Lourenco warned, this will only happen if people are convinced that the open science movement is going to lead to more equitable research instead of more inequity.

One of the important issues REDe has been addressing is capacity building. In 2019 it ran a series of workshops intended to address another important challenge – that of capacity. It attracted 239 participants, many without previous experience in health research. A third had no previous research experience and more than half were looking for career development opportunities. Dr Lourenco described it as simple initiative with a strong positive impact on the community. Crucially, it was only possible because they could partner with local teams and experts and focused on attracting a diverse group of participants.

REDe, Fiocruz and GNH are also working together to facilitate access to research through the highly sophisticated Zika Findings Project. This will involve an online platform with built-in artificial intelligence able to translate research findings and turn them into accessible information for the wider community, researchers from other areas and policymakers. In doing this it establishes a full knowledge cycle, making sure that information goes back to the community that first generated the data.

9. Ethical standards, trustworthy behaviour and fair sharing are essential at all stages

The emergence and rapid spread of new COVID-19 variants in different parts of the world has demonstrated the need for fast, effective research and the immediate sharing of data. If we are going to respond well to this crisis, and those that lie ahead, symposium contributors argued that three issues have to be addressed:

- Fairness
- Trust
- Ethics

Failure to do so can threaten willingness to participate with potential partners and collaborators fearing that neither the data nor the benefits of the research will be shared fairly.

Dr Carla Saenz said the during the Zika outbreak there was a need to share samples and data because samples and data were not available to those doing research. To the extent that COVID-19 is a pandemic, and researchers all over the world have had access to samples and data because there have been cases all over the world, there has been no need to share so far. In the Latin America region, there has been no talk about sharing because of that. It is only now, with variants and populations immunized with different vaccines, that we face the need to share and are starting to talk about such need. Yet we are still immensely better than we were before zika, because some of the essentials of sharing samples and data, namely broad consent for future use in research, have been introduced and promoted since the Zika outbreak.

'Latin America has made a remarkable contribution to vaccine research but there has been a very slow return on the benefits from that research.'

Dr Carla Saenz

Despite having hosted a number of important COVID-related clinical trials the region has not had the returns it anticipated. Changes in approach, such as having strong transfer agreements in place from the start that advance fair sharing. These, and other measures, are essential in order to generate trust.

'Trust needs to build up, maybe by doing small things first, exercising data sharing in your smaller projects to begin with.'

Dr Jackeline Alger

In Honduras Dr Jackeline Alger has been overcoming the barriers to trust by starting small and gradually increasing the scope and types of collaboration with colleagues from across Central America.

Donors can make a major contribution by supporting the creation of structures that will enforce fair sharing and ethical practices. They can also have a far reaching impact by making grants conditional on fair sharing – something that is being pushed forward in Africa by the EDCTP (see *Case Study 3*). Institutions carrying out research need to address their own arrangements. Their willingness to share with others not only builds trust but can increase efficiency by eliminating the need for pointless duplication of effort.

There are many other hurdles to sharing – some of which were identified in a poll of symposium participants (see *box*).

In Brazil the Fiocruz Institute has taken a large step forward by implementing an open science policy (see *Case Study 2*). There has also been widespread recognition of the need for a greater emphasis on the need to strengthen ethical research, for example by Pan American Health Organization ([PAHO](#)).

Public trust is equally important. If science and research are to be valued and trusted by society, then society must be involved at all stages of the process. And that demands having the right infrastructure in place. The guiding principle needs to be that all health data is managed for the individual and collective benefit.

Hurdles to sharing

Symposium participants were asked about their greatest hurdle when sharing research data with other researchers – respondents said:

- Lack of infrastructure 12%
- Lack of data management personnel 8%
- Lack of incentive to share 13%
- Governance issues 22%
- Concerns that recognition will not be given to the researchers who generated the data 10%
- Other 3%
- All of the above 31%

10. Case Study 3 – co-operation and sharing

Moves towards the fair sharing of health research data are starting to gain traction in Africa. Dr Thomas Nyirenda, Strategic Partnerships and Capacity Development Manager of EDCTP (European and Developing Countries Clinical Trials Partnership), is among those driving the process forward.

The EU-funded organisation has invested €800 million to support 274 clinical studies in 41 African countries and involving 244 African institutions. It also supports African researchers through fellowships and has programmes to strengthen ethics and regulatory systems. Despite its success in promoting research and researchers there have been serious problems with lack of co-operation and sharing.

'Projects close and the researchers no longer have access to the data, they never see it again.'

Dr Thomas Nyirenda

Initially it was hoped that these challenges could be tackled through the establishment of regional networks of excellence - groupings of institutions that received funding based on their own choice of partnerships. These were set up in Eastern, Southern, Central and Western Africa but it did not result in efficient and sustainable systems for access and sharing. The [Pan-African Clinical Trials Registry](#) was also set up and has had a degree of success in getting trials registered in Africa.

But July 2017 saw an important new development when EDCTP signed a joint statement on the public disclosure of results from clinical trials. Since then anyone receiving grants has been required to give free and open access to scientific publications and research data. The EDCTP now also insists that research into epidemics and public health emergencies must be available for third parties to access, mine, exploit, disseminate and reproduce for free. Importantly, this must be done within 30 days of the data being generated.

Since then the EDCTP has worked with TGHN to set up the [EDCTP Knowledge Hub](#). The hub provide researchers with the tools and guidance to undertake high-quality health research. It offers a:

- Protocol Development Toolkit
- Data Management Portal
- Data Sharing Toolkit.

The hub guides researchers from start to finish, from research question through to sharing their data.

At present the evidence suggests that many researchers feel that data sharing is still not common practice. But it is hoped that the hub will change this by promoting free and straightforward access to research that is open to scientists and citizens alike.

11. Infrastructure – creating the right eco-system

Harnessing the potential of health data and guaranteeing equity requires the development of a fair and balanced research eco-system.

There are many outstanding programmes across the world that are responsible for highly agile and creative data science. But symposium contributors agreed that there is a long way to go in building an infrastructure fit to fully address global health needs.

This demands an eco-system that is healthy at every point of the cycle – from involving the community in designing the research, through the execution of the project and on to the sharing of the outcomes with the original community so it can benefit from the findings. For this to happen all stakeholders need to identify and address their own barriers to research.

Dr Jackeline Alger outlined the situation in Honduras where she works in the main public hospital and university and collaborates with the Honduran Medical Association ([Colegio Médico de Honduras](#)). The country is one of the poorest and most unequal in the Latin American and Caribbean region. One consequence is that many people need two, even three jobs to get by – making it incredibly difficult to develop and sustain effective research environments. There are also few opportunities for mentoring. Added to this is an absence of well-equipped data centres and well-trained data management staff.

There is, though, a great deal of interest in the development of research skills among students and young professionals. Substantial numbers take online courses and these tie them into global initiatives.

‘The other elements needed for healthy research system exist in Honduras but need to be improved.’

Dr Jackeline Alger

Many university students, including those in clinical specialities, now require research skills in order to graduate. Formal regulations govern research projects and there are peer reviewed journals and annual science events that allow research to be scrutinised and shared.

In order to make progress in Honduras and elsewhere Dr Alger believes there needs to be a greater recognition that research is vital to providing better health care, preventing disease and creating a healthy academic sector.

Measures also have to be taken to support good practice in low and middle income countries where resources are more limited. This is something ICODA is attempting to address by acting as a provider of tools and services in a way that is genuinely accessible to researchers everywhere.

A healthy eco-system is also one where values (such as the fair sharing of data) are practised from start to finish. This means that technical issues over software, data gathering, storage and dissemination have to be confronted. The sharing of data can never be fair if it is not made available in a form that is readily useable by third parties.

The symposium also discussed regional data centres of excellence, something has proved successfully with laboratories. These could make a valuable contribution to strengthening both the research infrastructure and the perceived importance of research.

Ultimately the objective needs to be an open and collaborative international alliance where what Prof. Morris referred to as “nodes of excellence” are linked up to maximise the benefits that research brings to the public.

12. We must learn from experience and from each other

Today's research should be tomorrow's care. But this is far from always being true, not least because of a lack of fair sharing and a chequered history in learning from experience.

There has been [substantial criticism](#) of COVID-19 data management and reuse. Additionally our response to the current pandemic may have been hampered by the difficulty in finding, accessing and reusing relevant research from past outbreaks such as Ebola. Organisations like TGHN and ICODA are addressing this head on and argue the need for research to focus on questions that are important for communities, policymakers and system leaders.

'If we don't complete the circle and bring the results of research back to the people then the very reason we use to justify that research disappears.'

Dr Carla Saenz

Dr Carla Saenz expressed the issue in terms of a duty to do research of social value. She said there is also an imperative to make sure the mechanisms are in place to guarantee that research is used to improve health. This, she believes, requires a change in mindset. The use of research is too often seen as "a single event" when we need to arrive at a situation where every policy and every clinical guideline is based on evidence, and that evidence has been gathered using an appropriate methodology.

The research community itself might also need encouragement to learn from past good practice, with Dr Thomas Nyirenda citing the quality of participatory guidelines produced for HIV studies.

Many barriers exist that militate against research resulting in health impact. In Bangladesh and elsewhere in South Asia Dr Aliya Naheed said the value of research data is often not appreciated with little dialogue between public health researchers and clinicians.

'Using local data for identifying local solutions and changing policies is something that is totally missing in most developing countries and could be an eye-opener for everyone.'

Dr Aliya Naheed

One way through this could be to empower our institutions, such as small hospitals, to create their own data hubs. This would allow them to gather and analyse the evidence to understand problems that directly affect them and those they serve, and from that to develop low-cost solutions.

It is also essential to persuade political decision makers that healthcare is better when informed by science.

'We need to seduce them, showing that policies based on scientific evidence are more effective, save money and will get them more votes.'

Dr Luiza Lourenco

This can potentially be done by putting more effort into demonstrating to politicians the benefits that research has brought to a community.

Dr Alger believes this type of work matters for another reason and that there is a clear need for more and better implementation science and research. Solutions developed in a controlled environment do not necessarily work as hoped in real life.

Going back to stakeholders to learn what impact an intervention has had will not only generate better healthcare research in the future but is ultimately a means by which to build confidence that the best healthcare is built on science.

13. The way ahead

The *Equitably Harnessing the Power of Health Data* symposium offered many perspectives on challenges, solutions and the way forward. The potential benefits for every community and country are enormous. Despite many examples of excellence in practice and in outcomes, there is an enormous distance yet to travel.

The current pandemic has once again shown the need for far greater and closer collaboration - extending from the grassroots to the global. This can only happen if data, research and the benefits of research are fairly shared. Hopes were expressed that the symposium would act as a catalyst for mutually-beneficial co-operation.

Organisations, such as ICODA and TGHN, have been bringing people together to provide a collective response to COVID-19 and hope that this will provide a basis for researchers, donors, policymakers and communities to work together in the future.

'A great coalition is required just like we have started during COVID.'

Dr David Mukanga

One way this can be done is by having permanent, strong, effective and adequately resourced research teams at work in every part of the world carrying out work into the priority healthcare issues of their areas.

When disease outbreaks occur that threaten wider international society (such as we experienced with HIV, Ebola, Zika and now COVID-19) they would immediately be able to pivot to provide a response to the crisis that was simultaneously global and local.

The symposium identified the need for a world-wide health data research eco-system founded on fairness and trust and where all health data is managed for the individual and collective benefit. This requires good governance and ethical behaviour at every stage in the research lifecycle.

In future we need to:

- Put communities at the heart of everything that is done
- Ensure that research addresses the real health needs of the public
- Conduct projects so they fully represent all relevant populations – especially in hard-to-reach locations
- Share data quickly, fully, fairly and openly so it can be reused and freely exploited
- Return research to the communities where the data was gathered
- Guarantee that contributing communities reap the health benefits of research
- Study the effectiveness of the resulting health interventions.

Achieving these aims will also contribute to the likelihood of success in meeting the wider challenge of persuading politicians, policymakers and the rest of society that healthcare is better and more cost-effective when it is based on scientific evidence.

14. About ICODA and TGHN

The **International COVID-19 Data Alliance (ICODA)** provides a co-ordinated international platform to enable researchers to access global data to derive rapid insights about COVID-19 and speed up the development of treatments. It is an open and inclusive global collaboration of leading life science, philanthropic and research organisations that have come together to harness the power of health data to respond to the pandemic.

ICODA is convened by Health Data Research UK (HDR UK), the national institute for health data in the UK and funded by the [COVID-19 Therapeutics Accelerator](#) Programme. The founding members bring their collective data assets, expertise and funding, and include the Bill & Melinda Gates Foundation, Minderoo Foundation, Wellcome, African Academy of Sciences, HDR Network Canada, Genomics England, and the Infectious Diseases Data Observatory.

The Global Health Network (TGHN) works across all aspects of health research to:

- embed health research in places, diseases and regions where evidence is lacking by bringing support, training and guiding faster, easier and better research processes
- drive equity in who takes part and who benefits from health research by enabling the open movement of health research information, data and know-how between diseases areas, regions, organisations and communities
- build lasting capable research teams in low-resource settings to lead research studies and compete internationally for recognition, reward, engagement and visibility.

15. Useful Links

- Bill & Melinda Gates Foundation <https://www.gatesfoundation.org>
- The EDCTP <https://www.edctp.org>
- Fiocruz Foundation <https://portal.fiocruz.br/en>
- The Global Health Network <https://tghn.org>
- HDRUK <https://www.hdruk.ac.uk>
- ICODA <https://icoda-research.org>
- PAHO <https://www.paho.org/en>
- REDe <https://rede.tghn.org>

16. Thanks and acknowledgements

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17. Contact details

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