SLIDE 2

So my talk today is about how to encourage more data sharing across the Caribbean

I want to start by looking at our regional data challenges

And these challenges will lead me into a new hierarchy of data needs for the Caribbean

I then want to explore the importance of data sharing and data re-use

And this will lead me into our current project - called CaribData - which is all about encouraging Caribbean data sharing through storytelling.

So let’s press on…

SLIDE 3

We’ve all seen data gaps from our own work—and regional reports keep sounding the alarm.

Back in 2020, PAHO flagged data gaps as a major barrier to evidence-based decisions.

In 2022, the UN asked—without baseline data, how can we measure progress?
In 2023, the Institute of Migration highlighted how little we know about migration flows in the region.
And just this year, the OECD stressed that better Caribbean data is key to designing good policies.

Now these aren’t isolated complaints—they reflect real struggles to *find* data. But they’re also scattered, across sectors, across countries. And that’s part of our challenge: we don’t have a clear regional picture of our data gaps.

So as we talk about data sharing today, let’s keep that in mind. If we want to move forward, we’ve got to start by knowing what’s missing—and where its missing.

SLIDE 4

Let’s take a quick look at one of the biggest data challenges we face in the Caribbean—data availability. Of course without data, nothing else works.

This slide shows how much SDG data is available across world regions. You’ll see two dots—blue for 2018, white for 2022.

At the bottom in orange are the Small Island Developing States – the SIDS, including the Caribbean. We had the lowest availability of SDG data in both years. That’s despite having very different development profiles than parts of Africa, which had fewer data gaps.

Now the SDGs get a lot of global attention and support, so we imagine this is a best-case scenario. And when we look at broader indicators—like 900 gender-stratified metrics—it's even worse. Only one-third of those indicators were available for SIDS in 2022, compared to about two-thirds or more for other regions.

So there’s solid evidence of major data gaps that make it harder for us to plan, act, and track progress effectively.

SLIDE 5

If data is available - accessibility then asks whether we can actually get our hands on that data in the right formats.

And again this is a situation we've all encountered - data does exist but its in messy spreadsheets, or worse as hard copy.

Open Data is a good proxy for data accessibility, and the Open Data Inventory – ODIN for short - reports the openness of official statistics for 195 countries.

And just like data availability, the SIDS have the lowest level of data openness in the world.

So just like availability, there’s very good evidence of low data accessibility across the Caribbean

SLIDE 6

Who controls our data? It might seem like an odd question, but it’s an important one.

In the Caribbean, a lot of our research is done in collaboration with international partners. That’s great when it leads to high-quality data, stored securely. But too often, the data ends up overseas, on systems we don’t control, with unclear rules about access or preservation. That’s a risk—especially for long-term projects.

Let me share a story. The Barbados Eye Studies began back in 1987. Over 4,000 people took part, and the data transformed how we understand eye disease in African-descent populations. There were follow-ups, major findings, and dozens of publications. This data even helped shape global policies on eye care.

But after 2010, the funding ended. The team moved on. The systems aged. And now... the data is gone. No one knows where it is. That's a big loss—for science, and for the region.

And this is why some level of local control matters. If we want to protect our region's data, we need systems and stewards that we trust. Caribbean libraries and archives have always protected our stories—and we can help them safeguard our data future too.

SLIDE 7

You've probably heard of the Global Burden of Disease study—it's one of the world's biggest efforts to track health loss across countries.

In 2015, it made headlines by announcing that Barbados had the healthiest diet in the world. As local researchers, this raised eyebrows. It didn't match what we were seeing—or the findings from our national nutrition survey.

So we looked into it. The GBD claimed its data was nationally representative. But the dataset they used came from just 280 Barbadians receiving cancer treatment. A valuable study for sure, but not one that speaks for the whole country. It took real digging to figure that out. There were no local researchers involved, and no transparency about the data sources.

We wrote a letter pointing this out—saying, first, it was hard to tell where the data came from, and second , that interpreting the data without local input can lead to misleading conclusions. Our letter made little noise. The original paper, though, was cited and shared very widely.

And that's the point. Without Caribbean voices at the table, global narratives can miss context—or worse, get it wrong. That's why data sovereignty isn't just an academic principle. It's a safeguard.

SLIDE 8

The last bottleneck I want us to think about is fragmentation.

At the peak of the COVID-19 pandemic, our team worked with CDEMA and CARPHA to produce daily surveillance summaries for CARICOM—23 separate reports every morning, over 650 reports each month. We like to think that the final product appeared fairly seamless, but the daily process behind it was anything but straightforward.

SLIDE 9

Each morning, for CARICOM member states, this involved gathering data from four key aggregation sites and cross-checking them against 15 national sources.

The six associate member states required an entirely different method of data collection.

In total, we had to access 26 different websites to compile essential COVID-19 statistics.

So this highlights regional data fragmentation as a critical issue. In settings with limited statistical infrastructure, scattered data becomes a daily challenge. Fragmentation slows decision-making, it burdens teams, and creates risks of misinformation. To effectively respond to health crises, we must invest in coordinated data systems that empower, rather than exhaust, our health professionals.

SLIDE 10

We've looked at four major data bottlenecks across the region—and I want to bring them together into a framework our team has found useful: a data needs hierarchy built specifically for the Caribbean.

At the bottom are our foundational needs. First up: availability. Is the data even being collected and stored reliably?

Then comes accessibility. Can we access the data when we need it?

Then sovereignty. Who owns the data, who controls it, and who gets to interpret the results?

After that, we shift into the aspirational layers. Can we connect data across systems, ministries, and countries?

Can we build a culture where data is routinely shared, not siloed?

And finally—reuse. Can we apply the data beyond its original purpose, to unlock new insights and policies?

Right now its fair to say, many of us are grappling with the foundational needs. But if we're serious about collective progress, we need to build systems that support this whole ladder—from reliable collection all the way up to meaningful reuse.

SLIDE 11

And this aspiration of data re-use across the Caribbean is the ultimate goal of the CaribData project, which I'll talk more about in a while.

SLIDE 12

Data sharing sounds great in theory—but in practice, it's not always easy.

We teamed up with Yale to run a regional survey, asking Caribbean researchers about their experiences and concerns with data sharing.

And while there was broad agreement that sharing is important——most people had multiple concerns that make them hesitate.

Top of the list? Confidentiality. People want to make sure their data won't expose individuals or communities.

Next came misuse. Not necessarily malicious misuse—sometimes it's just misinterpretation. But that still causes harm, especially when local insight is missing.

Then there's the practical stuff: getting permission, having enough time, and securing funding. These are familiar challenges, especially in low-resource settings.

So yes—there are lots of barriers. And when you look at them all at once, it can feel overwhelming. But we shouldn't let that stop us.

Because if we only focus on the risks, we lose sight of the huge benefits that can come from sharing.

So let's shift perspective—and explore what's possible when we do share.

SLIDE 13

This slide highlights three great examples of what open data can do.

First up—the Johns Hopkins COVID-19 dashboard. We all remember how essential it became. Its real power was in pulling data from multiple sources and making it available in one place—so researchers, policymakers, and the public could respond in real time.

Second, the National Hurricane Center. We almost take it for granted during storm season—but it's built on open data. It powers the apps, alerts, and forecasts that help us stay safe and plan ahead.

And third—OpenStreetMap in Haiti, after the 2010 earthquake. Volunteers stepped up and using freely available satellite images— —they built a detailed map of Port au Prince in just 3 weeks. That open map data was critical for getting aid and rescue teams where they were needed most.

These are powerful reminders that open, reusable data can drive action and save lives.

And we have home grown examples from our own work – here's just a couple I've chosen.

SLIDE 14

In an analysis for PAHO, we joined mortality data from the WHO with population data from the UN to explore life expectancy trends across the Americas. We focussed on the elderly and this was part of a wider review of aging and NCDs in the Americas.

And we saw that over the past 2 decades the years of remaining life for 60 year-olds in the Americas increased from 21 to almost 23 yrs – higher than any other world region. That sounds very positive, but regional averages as always will hide important evidence.

When we compare Barbados to the regional average we start to wonder if something else is going on. The yrs of remaining life is still increasing, but at a much lower rate.

And in fact – when we include every Caribbean country on this chart we see that 27 of the 32 Caribbean territories have a lower LE than the regional average, with only 5 higher than the regional average.

SLIDE 15

There's a lot more on this story, and you can download the full report here…

Broadly though, a much higher burden of CVD, diabetes, cancer and particular concerns around the health of the region's men are contributing to this LE stagnation.

So completely open data, and it allows us to gather important country-level information on the burden of disease in the Caribbean.

SLIDE 16

So that first example involved Caribbean countries supplying data each year to WHO for subsequent sharing.

This second example involves researchers coming together to combine and share multiple research datasets.

This chart you're seeing for Jamaica comes from a regional project called Globorisk-LAC. For the first time, we've developed cardiovascular risk scores specifically for our populations—using local data from cohort studies, including over 21,000 people.

Until this work, all the risk scores used in our region were based on data from Europe and North America—populations that don't reflect our genetic backgrounds, lifestyles, or health systems.

Thanks to data sharing, we now have risk charts tailored to each of 31 countries, including 14 Caribbean countries, helping doctors better identify who's at highest risk of heart disease or stroke. It's a great example of regional collaboration leading to tools that are not just scientifically robust, but actually useful for clinical practice.

SLIDE 17

So we've heard that data sharing and reuse are aspirational goals for many, and that these aspirations are blocked by data bottlenecks and data concerns that we've already explored.

It's so easy for these administrative and technical hurdles to feel overwhelming. But we also know that just naming these hurdles doesn't move us forward.

What does help is seeing it work. Seeing that folk like us, in a setting like ours, shared their data and something good came from it. That can build confidence. It sparks ideas. It shows us what's possible.

And that's at the heart of the CaribData project—we're sharing real Caribbean stories driven by responsible data analytics. Sometimes – just maybe - all it takes to shift a mindset is the right example.

Now CaribData is a journey, and it's a journey partly because of the many data hurdles that we must overcome. Its small steps and we're confident, so let's me just explain what we're planning.

SLIDE 18

And broadly. We're building a set of resources to enable and encourage Caribbean data sharing and data re-use.

. We're setting up an online infrastructure to enable easier data collection, data sharing and re-use.

. We're developing a training program and longer-term mentoring to increase capacity in data handling and data communication.

. We're developing a data communications web platform. This is all about actively communicating the stories around the data we all produce. And at the same time, advocating for data re-use.

. And we're actively training data stakeholders, and building collaborations to develop a sustainable team of data storytellers.

So how does CaribData help to solve the issues we've highlighted in our Data Needs Hierarchy?

SLIDE 19

On the left side of this slide is our Data Needs Hierarchy—a visual reminder that good data isn't just about collection; it's about making data accessible, acceptable, shared, and reused in ways that work for the Caribbean.

On the right, you'll see how the CaribData project is structured to meet those needs.

Our infrastructure work tackles the foundational data needs — making sure data is actually *available*, *accessible*, and that we retain acceptable *sovereignty* over it. Without strong, local infrastructure, everything else becomes shaky.

SLIDE 20

Then we have training, which builds the skills needed to access and manage data, understand sovereignty, break down fragmentation, and start building a culture of *sharing*. This is where we start to move from isolated data efforts to coordinated action.

SLIDE 21

Storytelling comes in at the higher levels of the hierarchy — helping people make sense of data and use it in ways that are meaningful, sharable, and reusable. Because data only has power when it connects with real people and real decisions.

SLIDE 22

And networks cut across the entire hierarchy — creating the relationships and trust needed to connect data, people, and purpose. Networks make collaboration possible, and collaboration is what gets us to *collective impact*.

Together, these four components (we would say) form a whole-system approach to tackling our biggest data bottlenecks and our highest aspirations.

SLIDE 23

I want to think for a moment about our data storytelling process.

On the left, we have the science — collecting, analyzing, and visualizing data to understand what really matters.

On the right, we have the art — shaping that evidence into clear, compelling stories that connect with people. This is also where we're starting to use AI tools to help speed up that process — but that's a conversation for another time.

Now in the middle, there's often a gap. Scientists may struggle to tell stories, and storytellers might not feel confident with data.

That's where the *data editor* comes in — someone who bridges both worlds. And that's the heart of the CaribData project: helping data professionals tell better stories, and helping storytellers use data well — so we can share stronger, more meaningful Caribbean stories.

SLIDE 24

Here's a quick look at our training programme.

It's an 8-week course, and together with our data platform, it forms the core of the CaribData project.

Each week builds skills — from spotting bias and verifying data, to graphing, modelling, and linking analysis with narrative.

We learn from journalism, apply those lessons in real-world settings, and wrap up with a Storython — a practical, hands-on final project.

The aim is simple: help data professionals tell clearer stories, and help storytellers work with data more confidently.

And at the centre of it all is a new kind of role — the data editor — someone who connects science and storytelling.

SLIDE 25

So let me wrap up… And I could have started with this slide, but I decided instead to use it as a very broad summary.

Right now in the Caribbean, I think it's fair to say that much of our data landscape sits somewhere between *disorder and confusion* and *individual impact*.

We have brilliant people and powerful data, but it's often siloed, fragmented, and hard to access. And while there are pockets of excellence, they often operate in isolation, with limited reach or long-term influence.

SLIDE 26

With the CaribData initiative, we're building a path to something more ambitious that we might call *collective impact*. That's the fourth stage in this journey, where data isn't just collected or analysed for individual gain, but shared, trusted, and used to shape decisions that benefit the entire region.

To get there, we're not just talking about systems or platforms — we're talking about building an infrastructure of trust and collaboration. Our training programmes build the skills we need to work together. Our focus on storytelling makes data relatable and actionable. And through all of this, we're working to grow a new kind of professional — the *data editor* — someone who can link silos, align incentives, and move us forward.

So the vision for CaribData is clear: it's not just about data. It's about creating a shared culture of evidence in the Caribbean, where data moves from confusion to collaboration — from isolation to impact. That's the future we hope we'll manage to build.