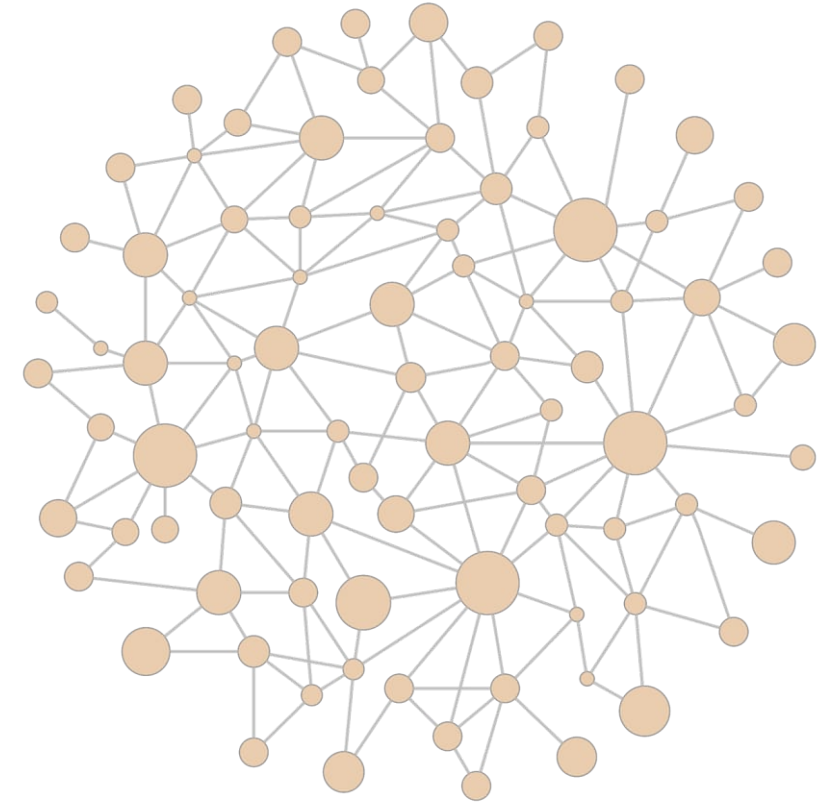


Sharing data for evidence-based storytelling

Ian Hambleton



Carib**Data**

The talk today

- Caribbean Data Challenges

Availability, Accessibility, Sovereignty, Fragmentation

- *A new data needs hierarchy* for the Caribbean

- The importance of data sharing and data reuse

- The CaribData project – data sharing & storytelling



Where's the data?



Pan American
Health
Organization

“Gaps in information systems and in the availability of data impede ... evidence-based decisions (2020).

“Across the region, data gaps precluded setting appropriate baselines, and measuring incremental progress (2022).



“There is a persistent lack of information and data on migration trends (2023).

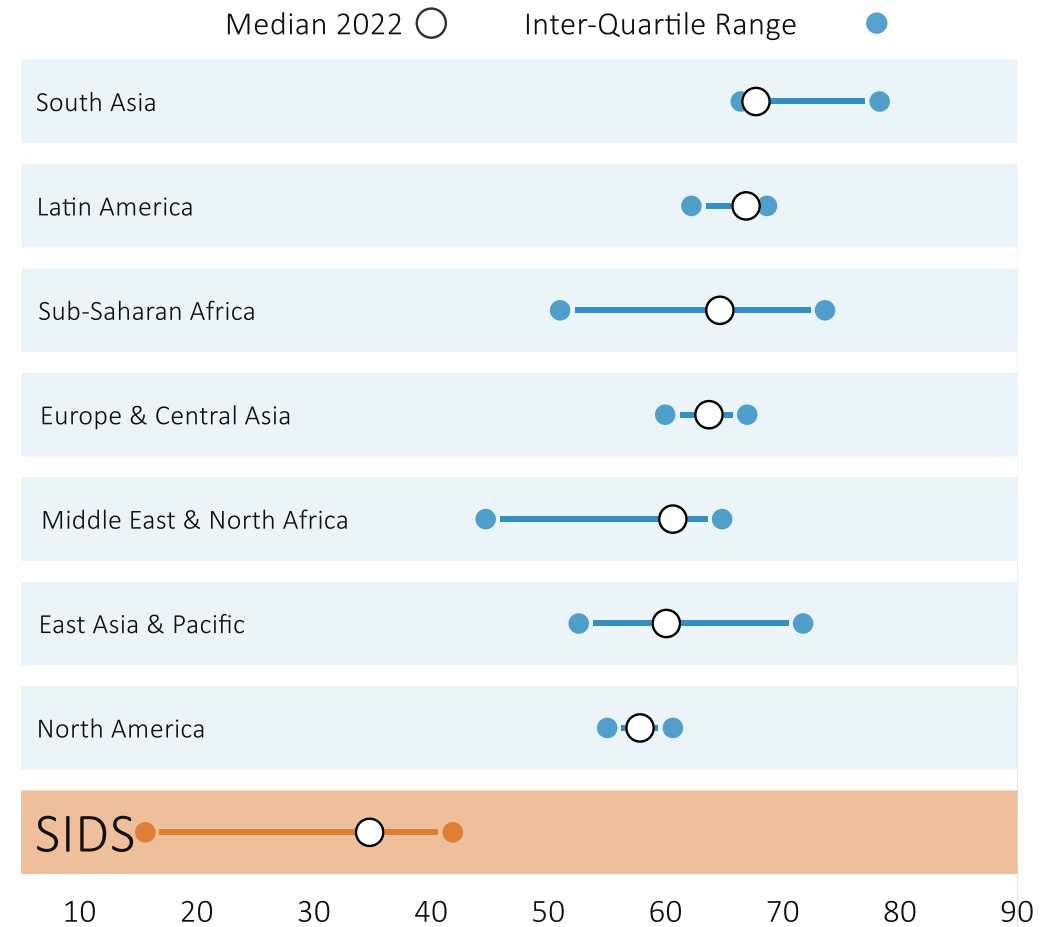
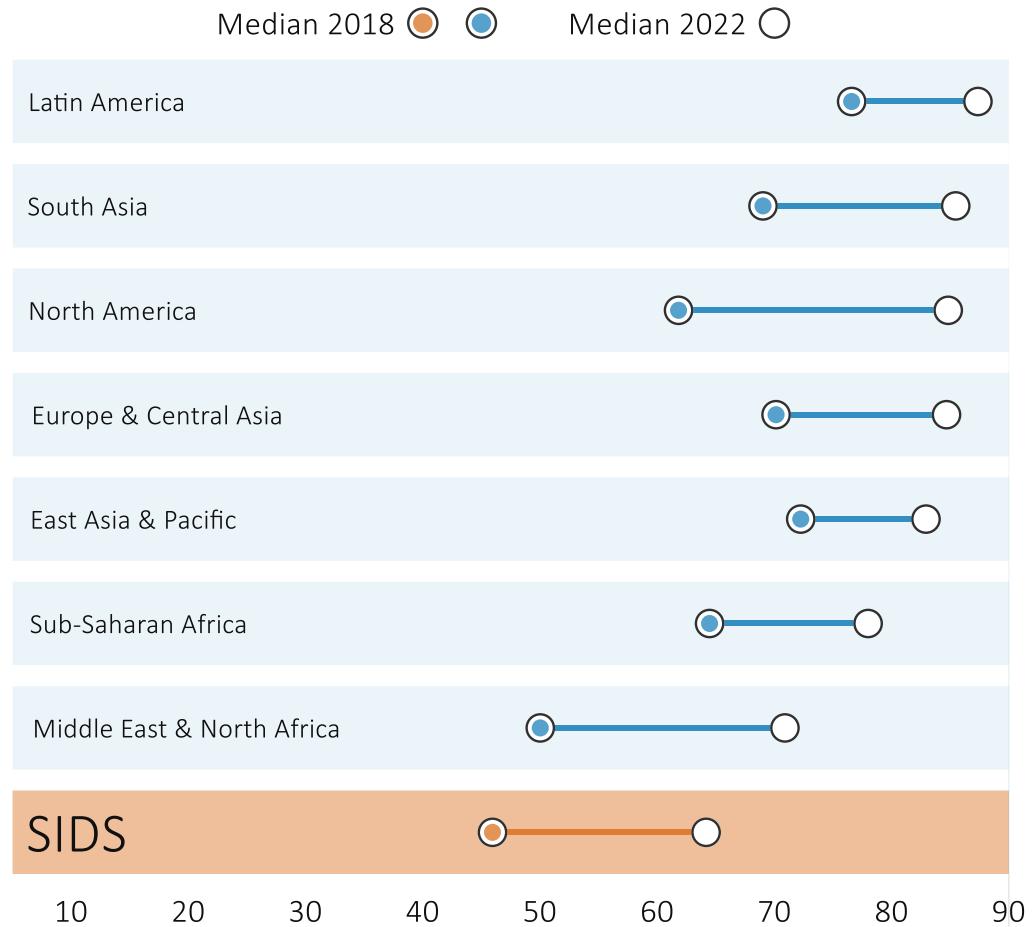
“Improving the quality and availability of data is paramount for informed policy design (2025).



Carib**Data**

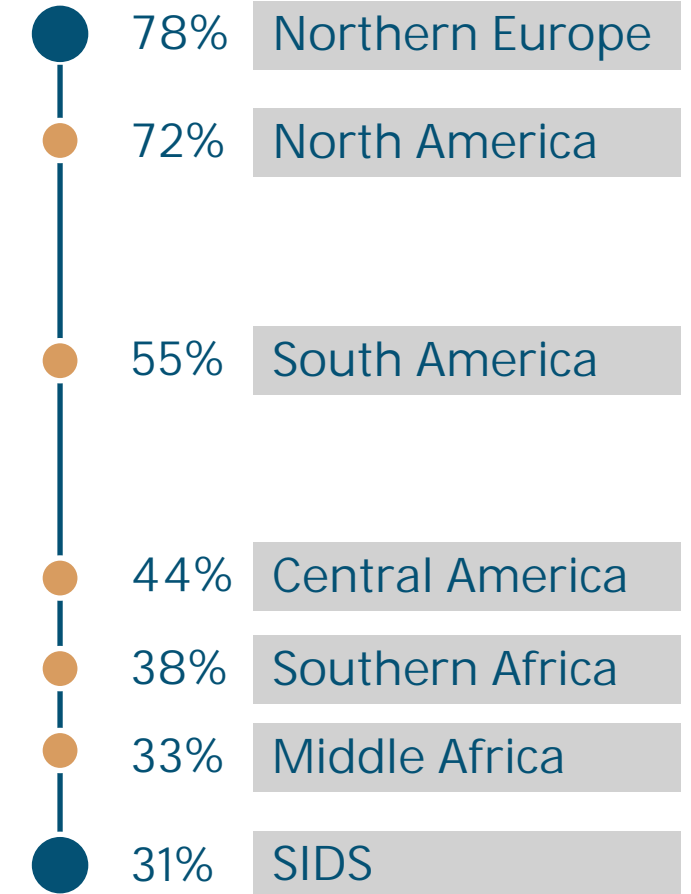
Data Availability

Is the data collected and stored reliably?



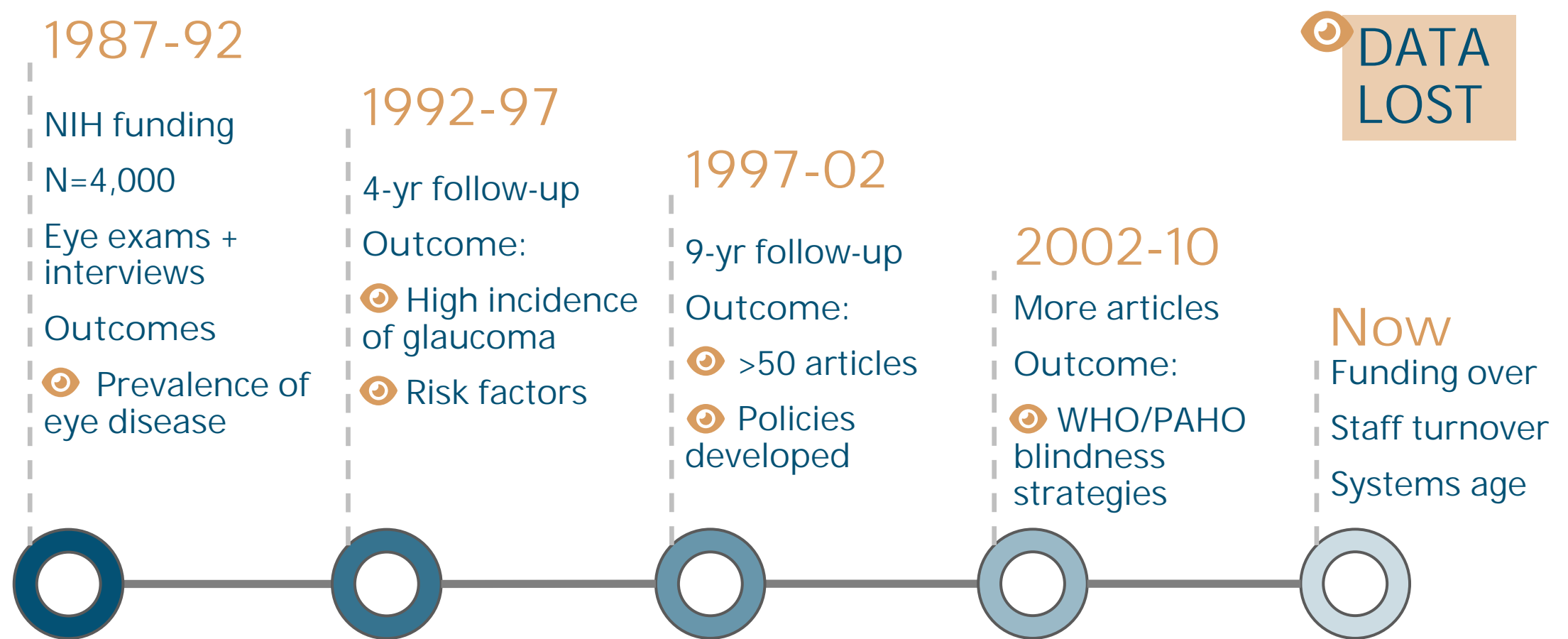


DATE	*	CLINICAL NOTES
29/1/50		V. 251 Painful lumb. migraine Circ. 110
5/11/50		Enure (C) 24 Pains ✓ " 24 Pains ✓ " 24 Pains ✓ " 24 Pains ✓
12.11.50		24 Pains 24 Pains (4 Pains)
20.11.50		Relief 24 Pains 24 Pains In case of 24 Pains
25.11.50		24 Pains 24 Pains
1/12/50		24 Pains 24 Pains
8/12/50		24 Pains 24 Pains
15/12/50		24 Pains 24 Pains
22/12/50		24 Pains 24 Pains
29/12/50		24 Pains 24 Pains
5/1/51		24 Pains 24 Pains
12/1/51		24 Pains 24 Pains
19/1/51		24 Pains 24 Pains
26/1/51		24 Pains 24 Pains
3/2/51		24 Pains 24 Pains
10/2/51		24 Pains 24 Pains
17/2/51		24 Pains 24 Pains
24/2/51		24 Pains 24 Pains
3/3/51		24 Pains 24 Pains
10/3/51		24 Pains 24 Pains
17/3/51		24 Pains 24 Pains
24/3/51		24 Pains 24 Pains
31/3/51		24 Pains 24 Pains
7/4/51		24 Pains 24 Pains
14/4/51		24 Pains 24 Pains
21/4/51		24 Pains 24 Pains
28/4/51		24 Pains 24 Pains
5/5/51		24 Pains 24 Pains
12/5/51		24 Pains 24 Pains
19/5/51		24 Pains 24 Pains
26/5/51		24 Pains 24 Pains
2/6/51		24 Pains 24 Pains
9/6/51		24 Pains 24 Pains
16/6/51		24 Pains 24 Pains
23/6/51		24 Pains 24 Pains
30/6/51		24 Pains 24 Pains
7/7/51		24 Pains 24 Pains
14/7/51		24 Pains 24 Pains
21/7/51		24 Pains 24 Pains
28/7/51		24 Pains 24 Pains
4/8/51		24 Pains 24 Pains
11/8/51		24 Pains 24 Pains
18/8/51		24 Pains 24 Pains
25/8/51		24 Pains 24 Pains
1/9/51		24 Pains 24 Pains
8/9/51		24 Pains 24 Pains
15/9/51		24 Pains 24 Pains
22/9/51		24 Pains 24 Pains
29/9/51		24 Pains 24 Pains
6/10/51		24 Pains 24 Pains
13/10/51		24 Pains 24 Pains
20/10/51		24 Pains 24 Pains
27/10/51		24 Pains 24 Pains
3/11/51		24 Pains 24 Pains
10/11/51		24 Pains 24 Pains
17/11/51		24 Pains 24 Pains
24/11/51		24 Pains 24 Pains
1/12/51		24 Pains 24 Pains
8/12/51		24 Pains 24 Pains
15/12/51		24 Pains 24 Pains
22/12/51		24 Pains 24 Pains
29/12/51		24 Pains 24 Pains
5/1/52		24 Pains 24 Pains
12/1/52		24 Pains 24 Pains
19/1/52		24 Pains 24 Pains
26/1/52		24 Pains 24 Pains
2/2/52		24 Pains 24 Pains
9/2/52		24 Pains 24 Pains
16/2/52		24 Pains 24 Pains
23/2/52		24 Pains 24 Pains
1/3/52		24 Pains 24 Pains
8/3/52		24 Pains 24 Pains
15/3/52		24 Pains 24 Pains
22/3/52		24 Pains 24 Pains
29/3/52		24 Pains 24 Pains
5/4/52		24 Pains 24 Pains
12/4/52		24 Pains 24 Pains
19/4/52		24 Pains 24 Pains
26/4/52		24 Pains 24 Pains
3/5/52		24 Pains 24 Pains
10/5/52		24 Pains 24 Pains
17/5/52		24 Pains 24 Pains
24/5/52		24 Pains 24 Pains
31/5/52		24 Pains 24 Pains
7/6/52		24 Pains 24 Pains
14/6/52		24 Pains 24 Pains
21/6/52		24 Pains 24 Pains
28/6/52		24 Pains 24 Pains
5/7/52		24 Pains 24 Pains
12/7/52		24 Pains 24 Pains
19/7/52		24 Pains 24 Pains
26/7/52		24 Pains 24 Pains
2/8/52		24 Pains 24 Pains
9/8/52		24 Pains 24 Pains
16/8/52		24 Pains 24 Pains
23/8/52		24 Pains 24 Pains
30/8/52		24 Pains 24 Pains
6/9/52		24 Pains 24 Pains
13/9/52		24 Pains 24 Pains
20/9/52		24 Pains 24 Pains



Who controls our data?

Caribbean data sovereignty – the Barbados Eye Studies



Who controls our data?

Caribbean data insights

Global Burden of Disease (GBD)

Largest global effort to assess health loss

204 countries



459 outcomes



90,000 datasets



607bn estimates



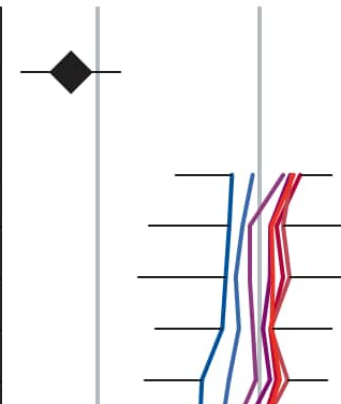
Articles

Dietary quality among men and women in 187 countries in 1990 and 2010: a systematic assessment

Fumiaki Imamura *et al.* (2015)

World, overall

Barbados
Seychelles
Mauritius
Chad
Greece



Two crucial issues.

Difficult to identify the data on which the results are based

The interpretation of data without the involvement of local researchers

The article

685

Citations

1,043

Captures

31

Mentions

218

Social Media

The response

5

Citations

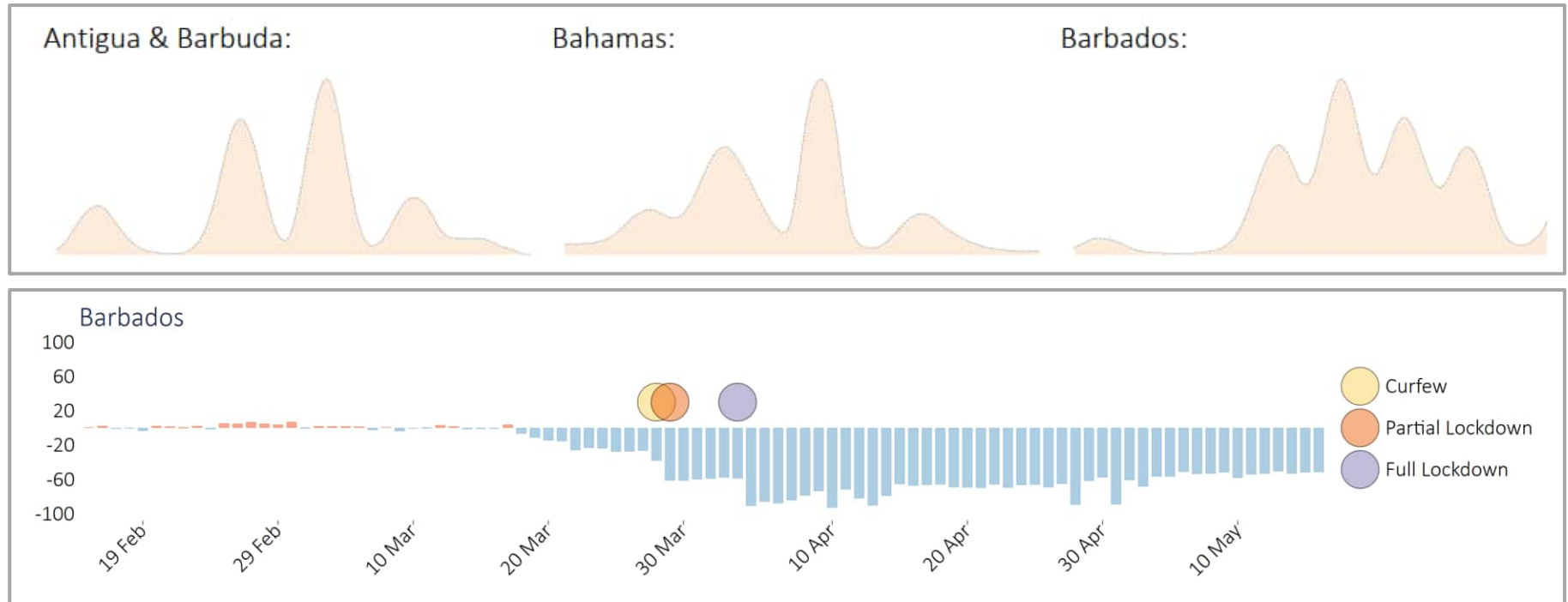
10

Captures

Data Living in Silos

Data fragmentation vs. integration

Covid-19
Surveillance



Daily

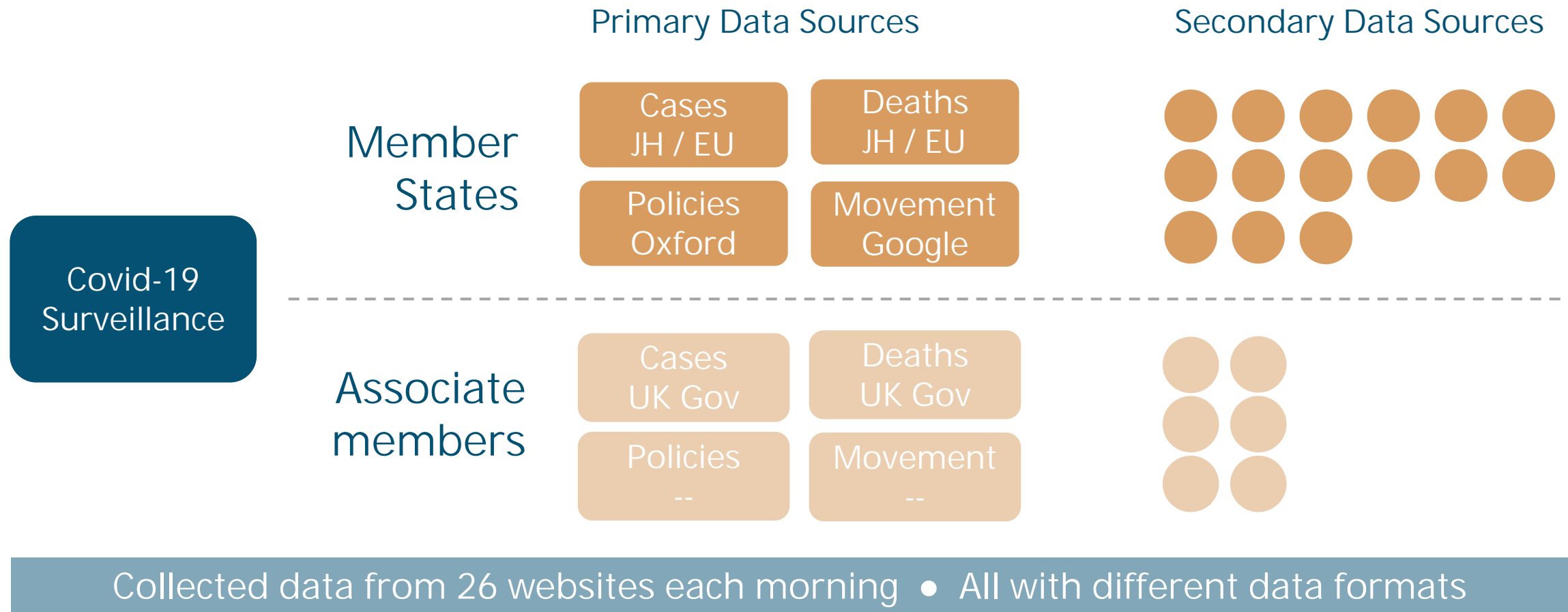
- ✳ CARICOM situation analysis
- ✳ Country report
- ✳ Slide deck
- ✳ 23 reports each morning. >650 per month.



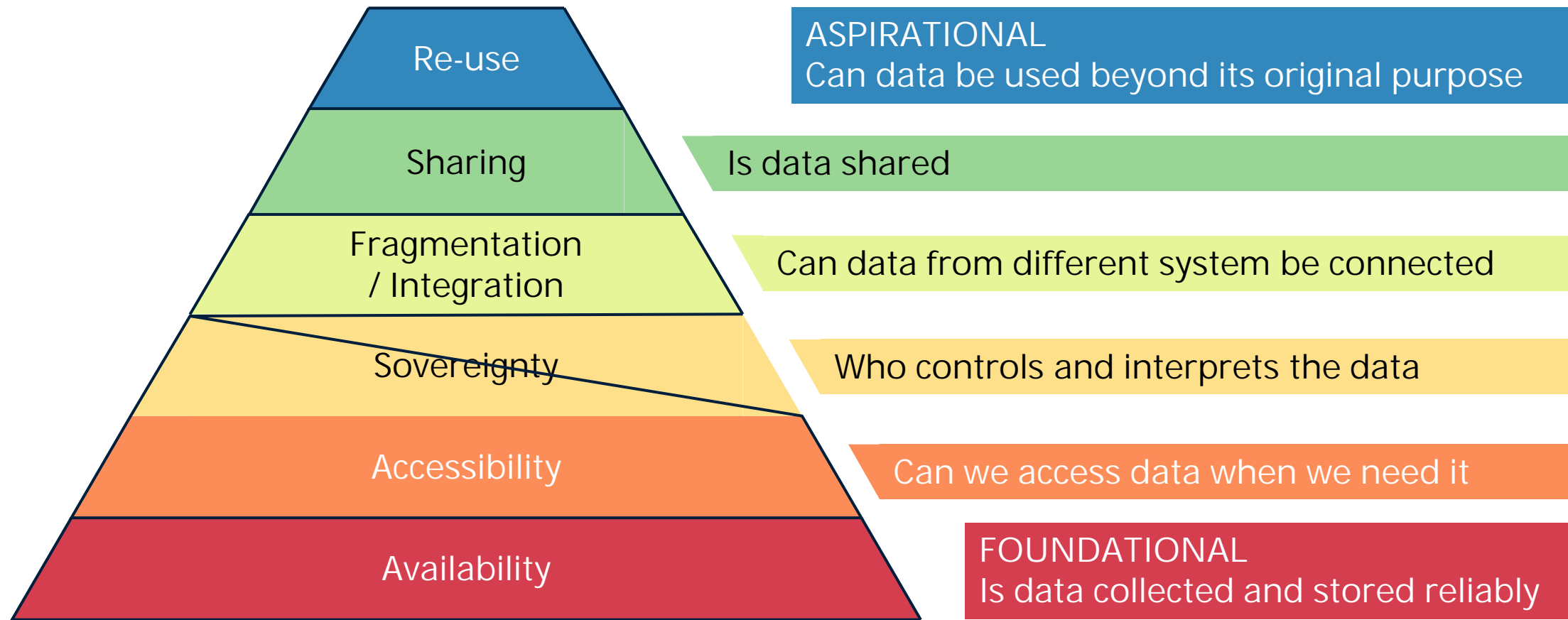
Carib**Data**

Data Living in Silos

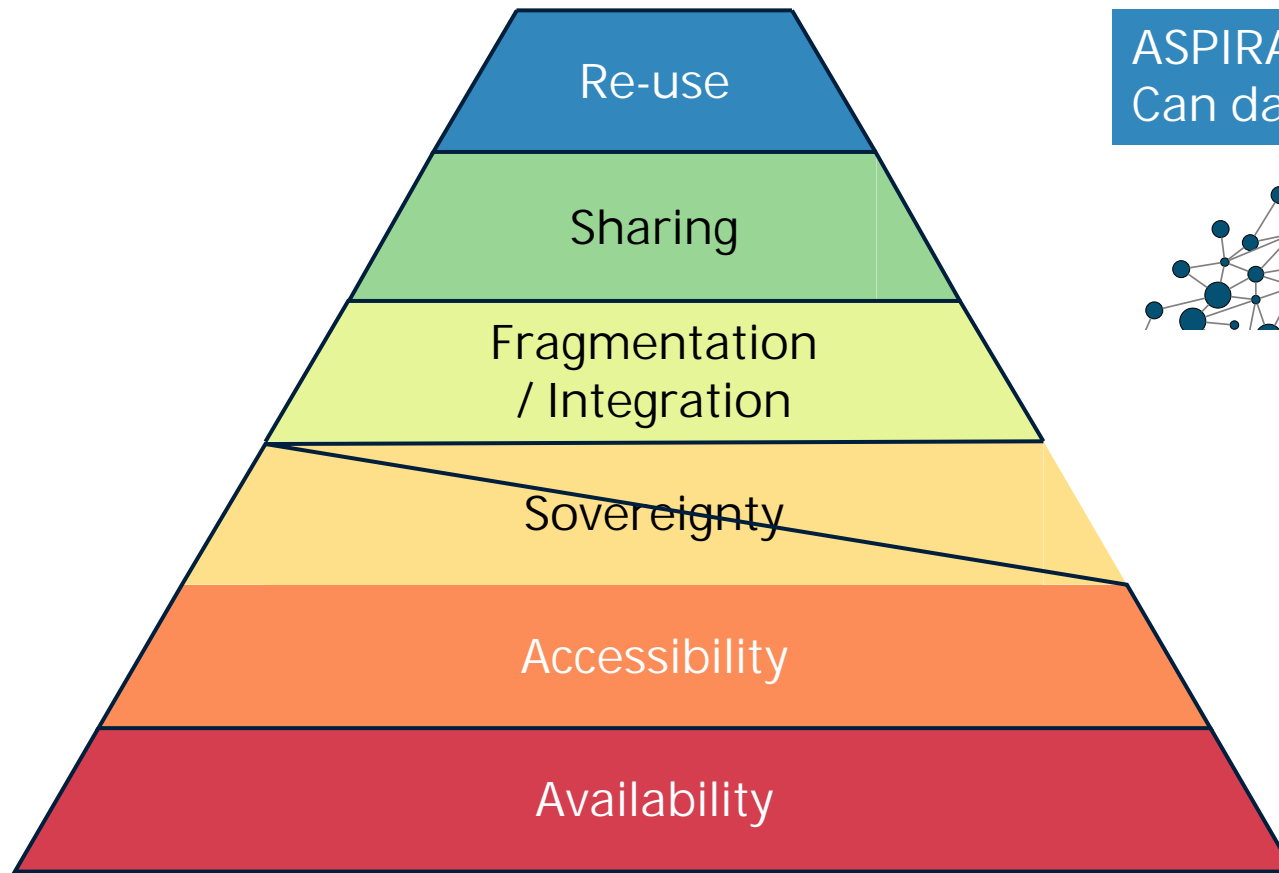
Data fragmentation vs. integration



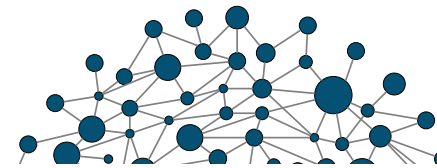
A data needs hierarchy for the Caribbean



A data needs hierarchy for the Caribbean



ASPIRATIONAL
Can data be used beyond its original purpose



CaribData

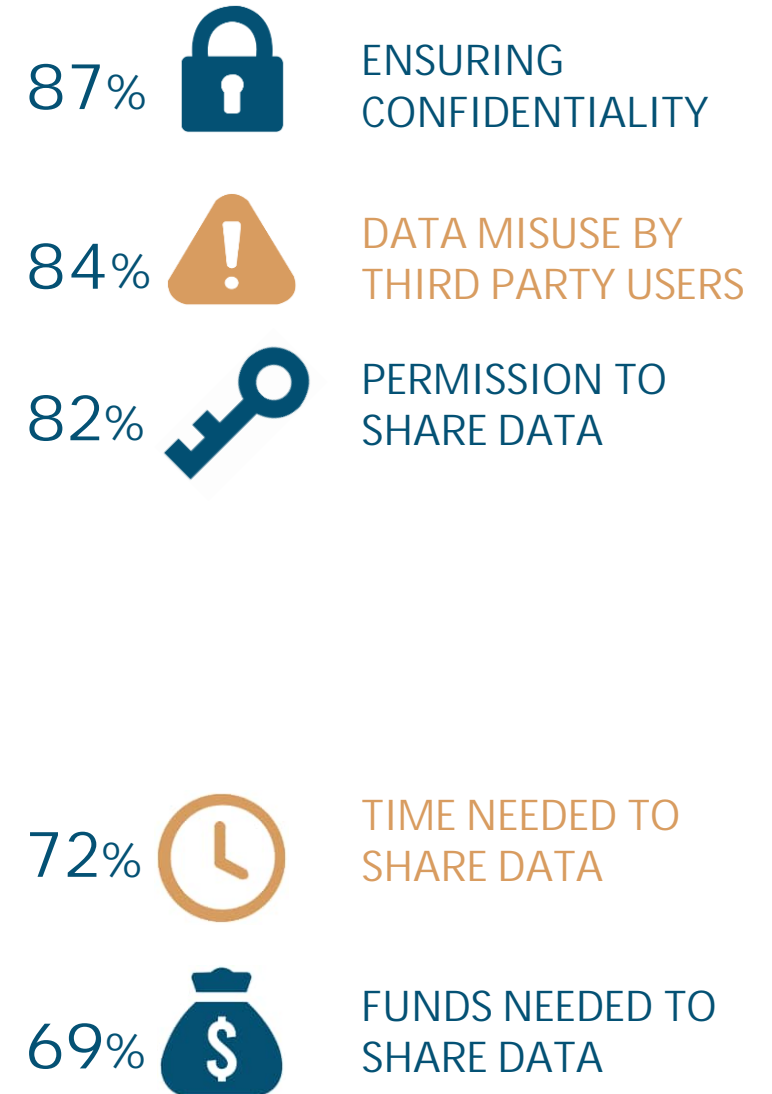


CaribData

Data sharing is hard

Data sharing concerns

Most survey participants agreed with the need to share data

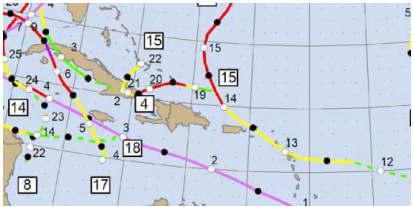


Data sharing matters

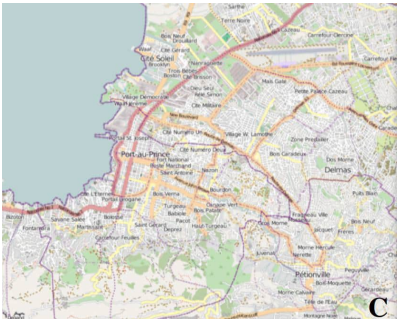
Johns Hopkins COVID-19 Dashboard



National Hurricane Centre

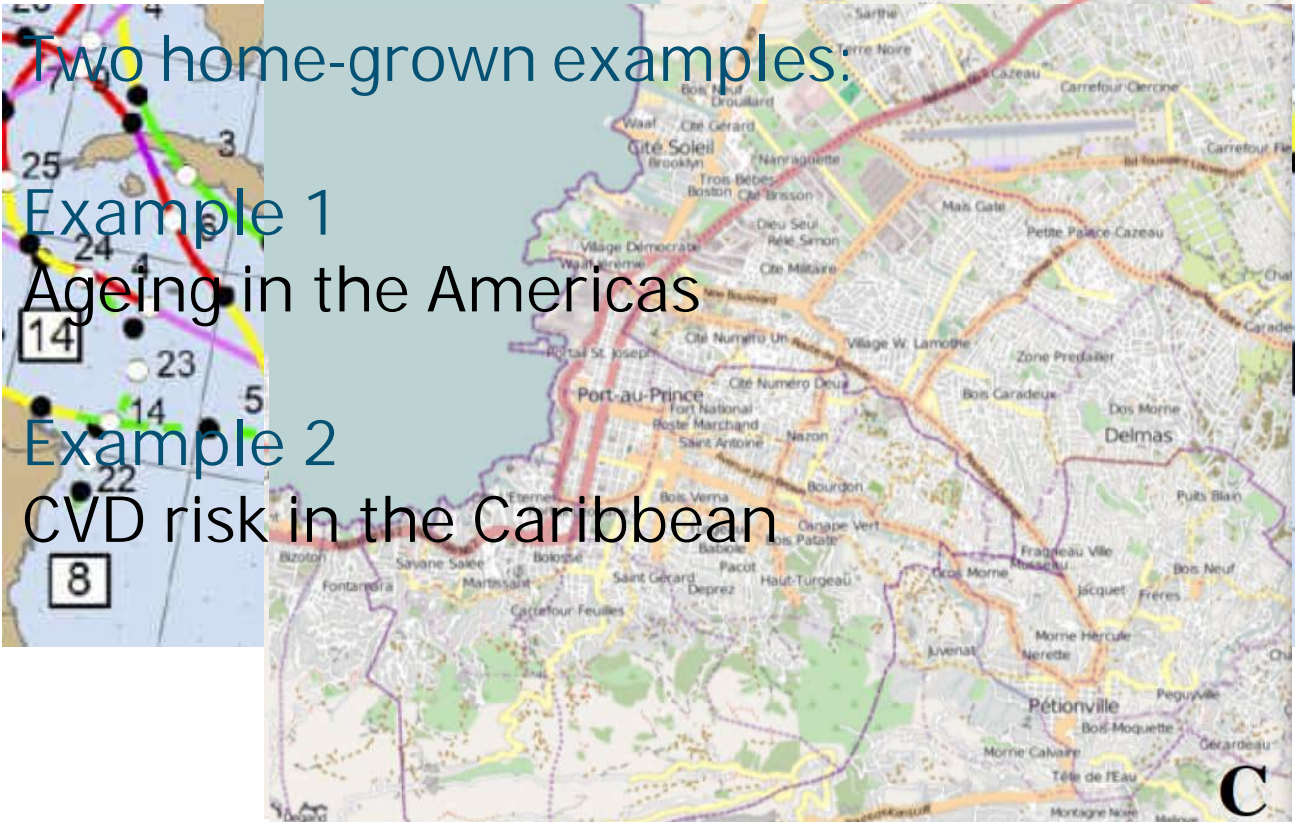


OpenStreetMap Haiti



OpenStreetMap Haiti COVID-19 Dashboard

Feb 02, 2020



Two home-grown examples:

Example 1

Ageing in the Americas

Example 2

CVD risk in the Caribbean

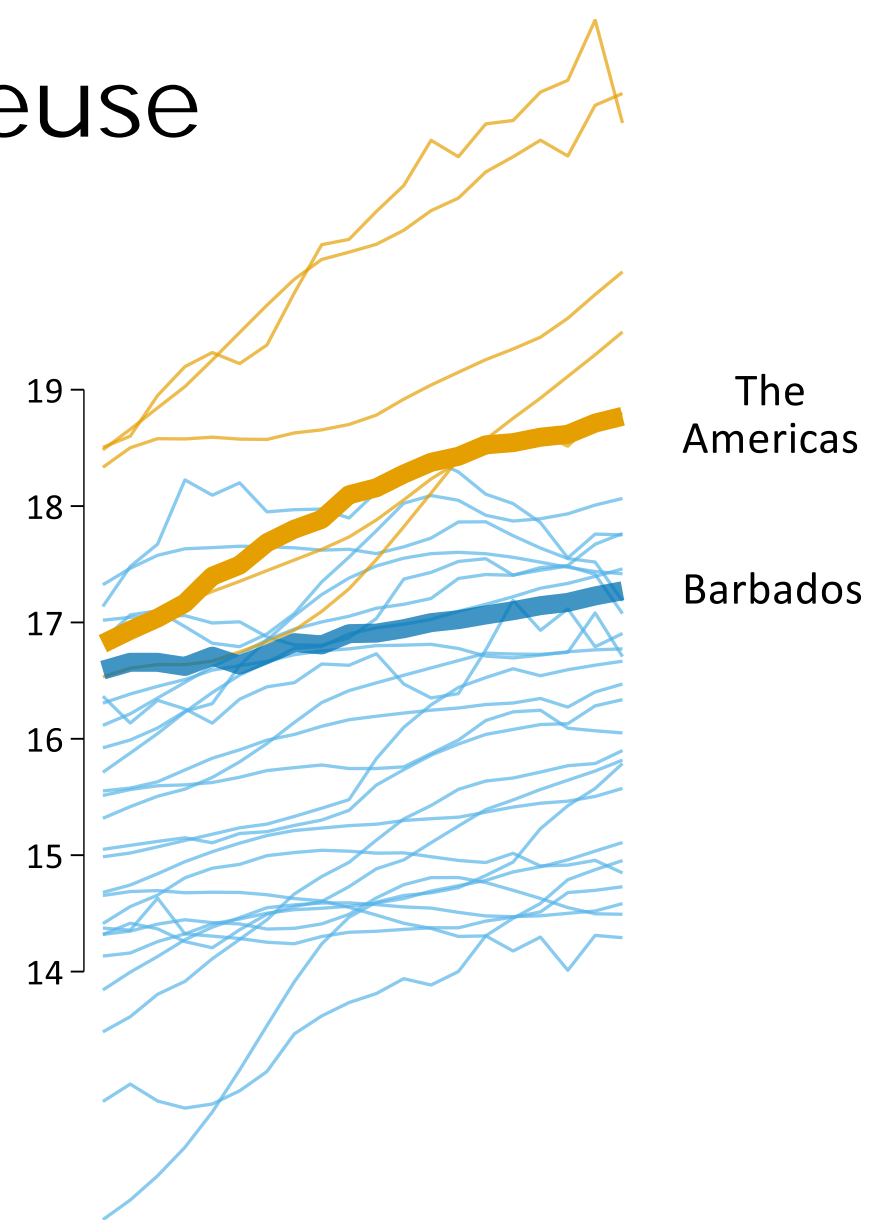
Data sharing leads to data reuse

Example – Ageing in the Americas

Among people reaching 60 years of age in the Americas, their years of remaining life increased from 21.1 years in 2000 to 22.7 years in 2019 – higher than any other world region

5 In 2019 → Higher LE at 65
In 2019 → Lower LE at 65

27



Data sharing leads to data reuse

Example – Ageing in the Americas

The rising burden of non-communicable diseases in the Americas and the impact of population aging: a secondary analysis of available data

Ian R. Hambleton,^{a,*} Roberta Caixeta,^b Selvi M. Jeyaseelan,^c Silvana Luciani,^b and Anselm J. M. Hennis^b

bit.ly/hambleton-aging

Leading causes of death
and disease burden
in the Americas

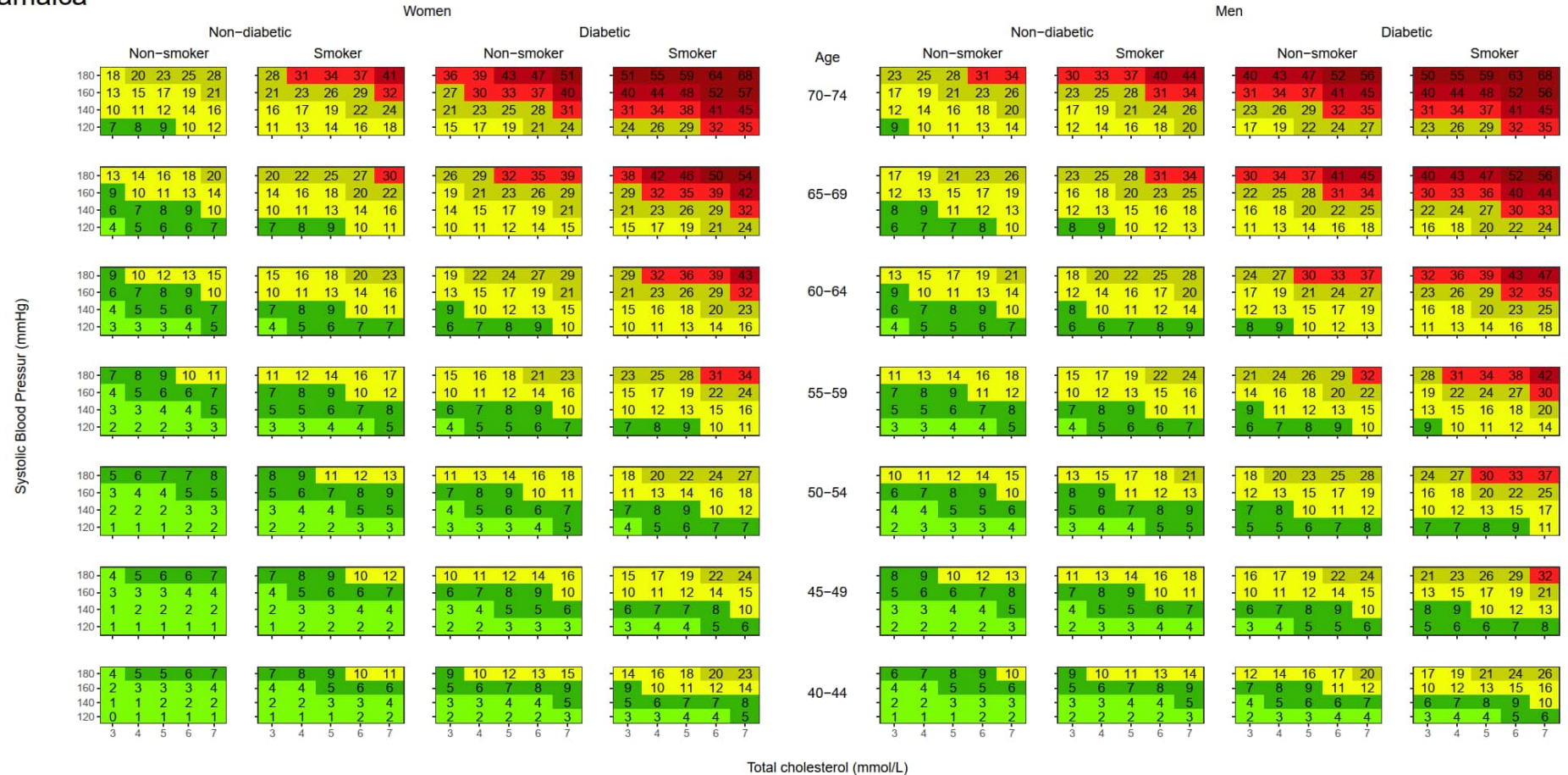
Noncommunicable diseases
and external causes

bit.ly/hambleton-paho-2024

Data sharing leads to data reuse

Example – CVD risk for the Caribbean

Jamaica



CaribData • Removing Data Bottlenecks



ENSURING
CONFIDENTIALITY



DATA MISUSE BY
THIRD PARTY USERS



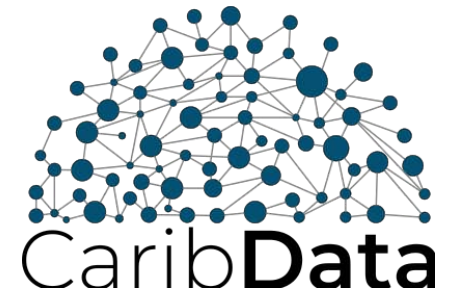
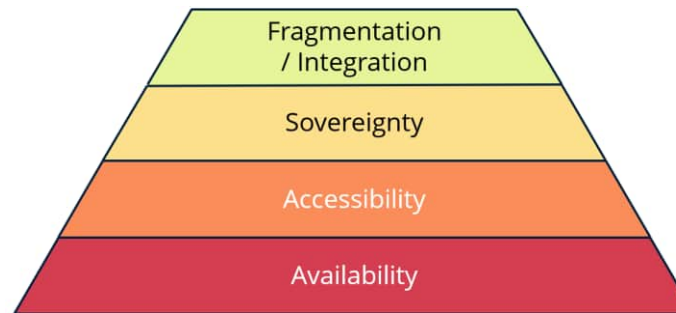
PERMISSION TO
SHARE DATA



TIME NEEDED TO
SHARE DATA



FUNDS NEEDED TO
SHARE DATA



CaribData • Data for Impact



Building
Infrastructure



Developing
training and guidelines

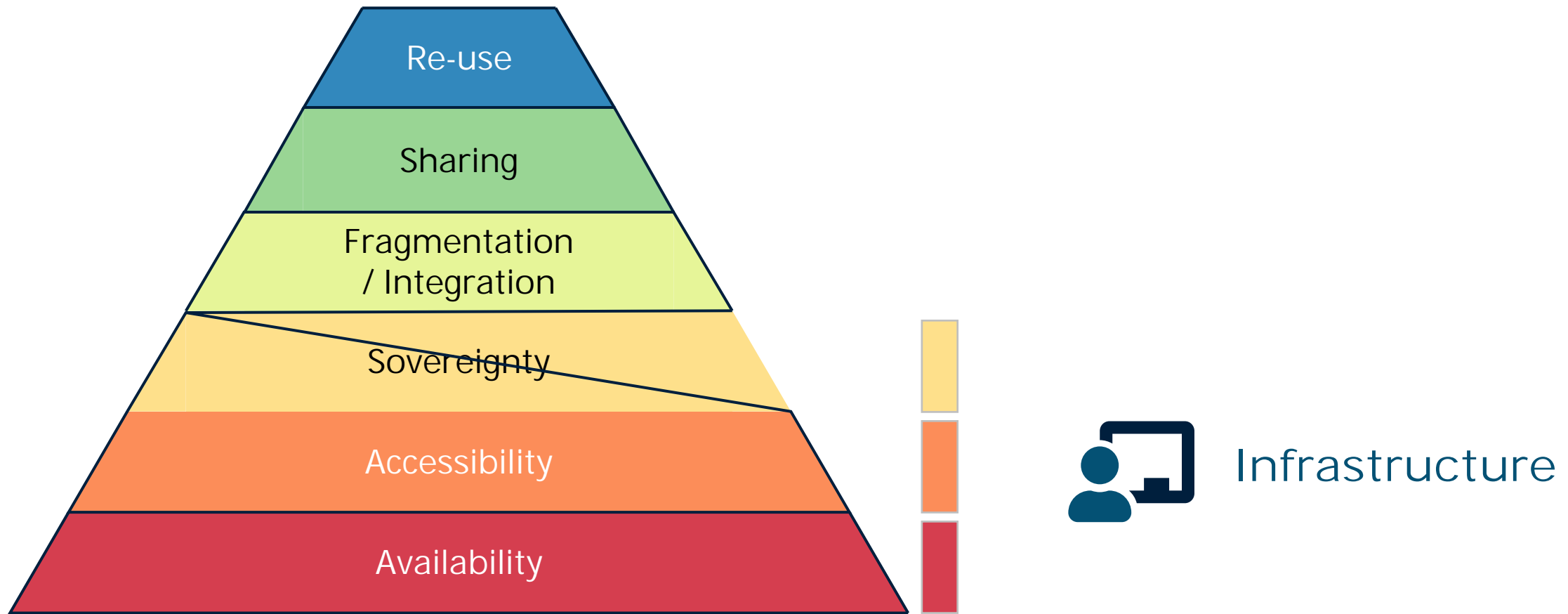


Analytics &
Communication

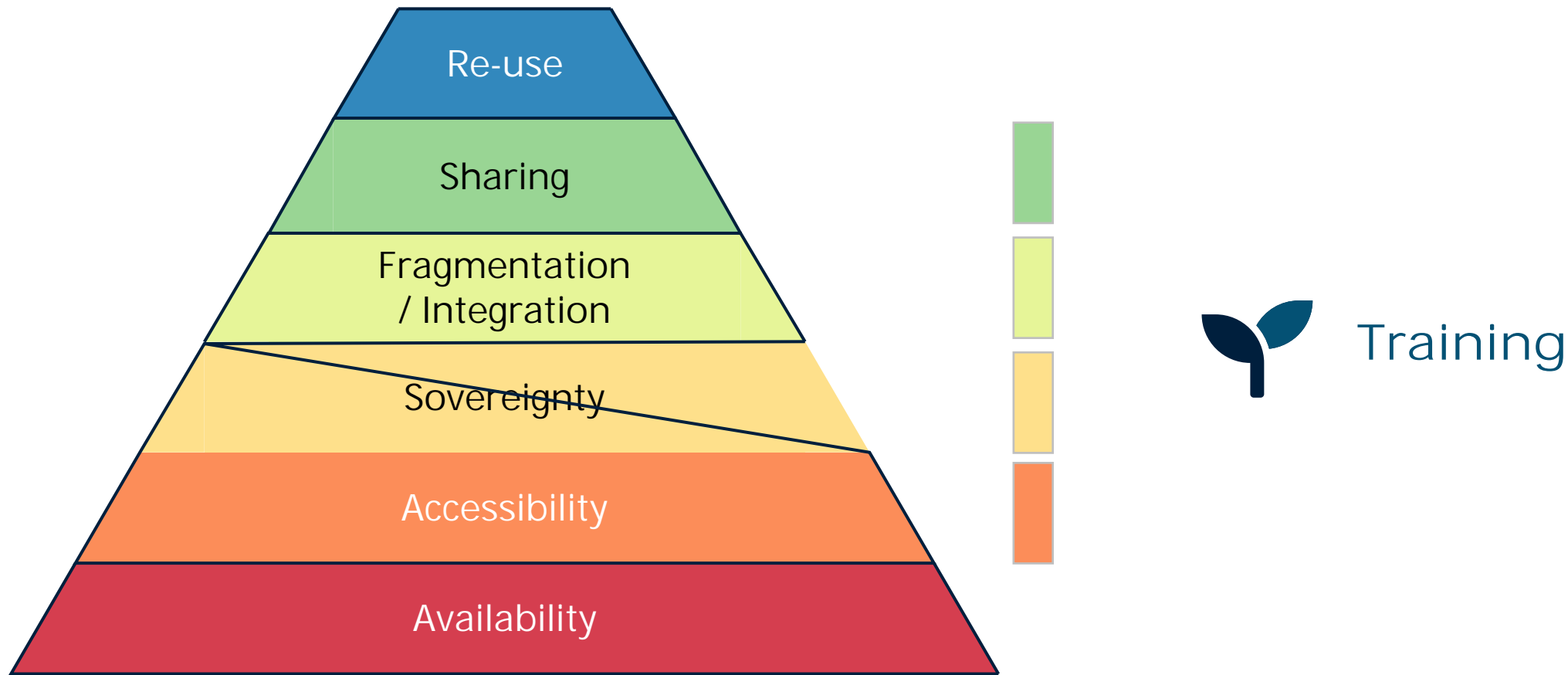


Establishing networks for
collaborative working

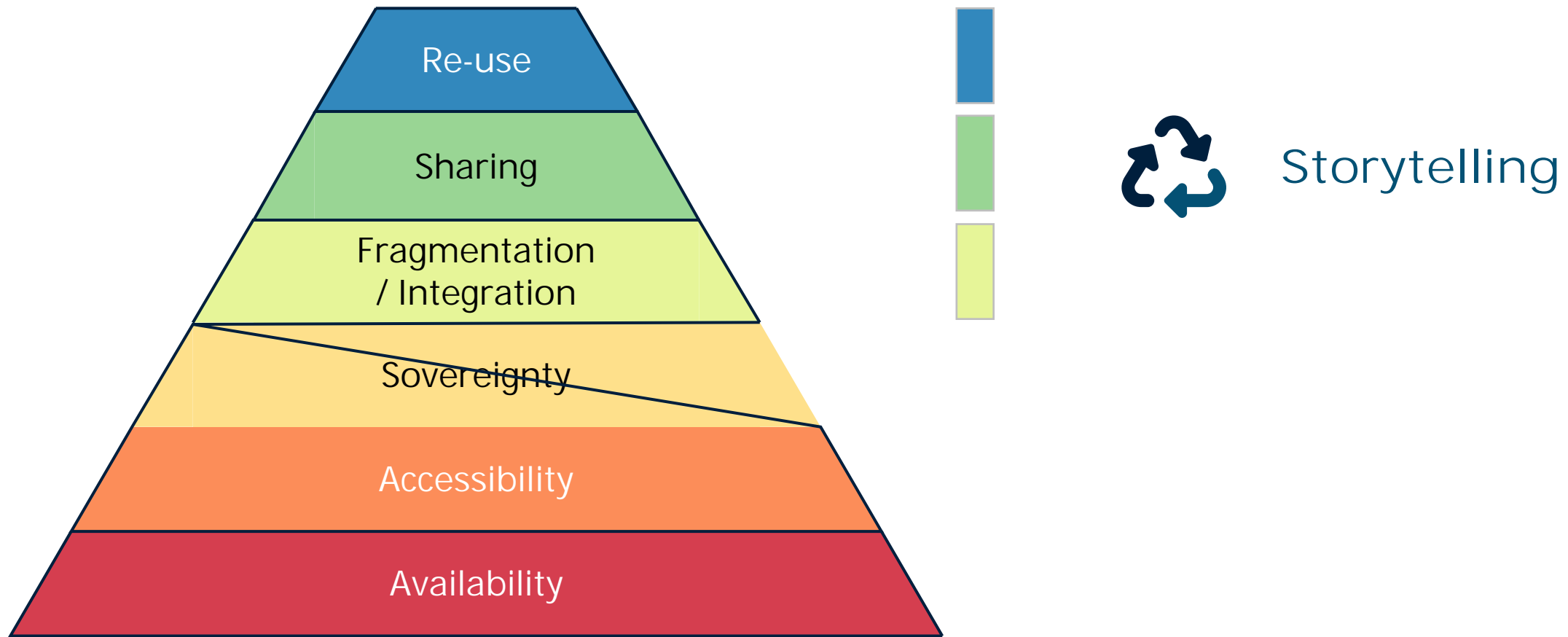
A data needs hierarchy for the Caribbean



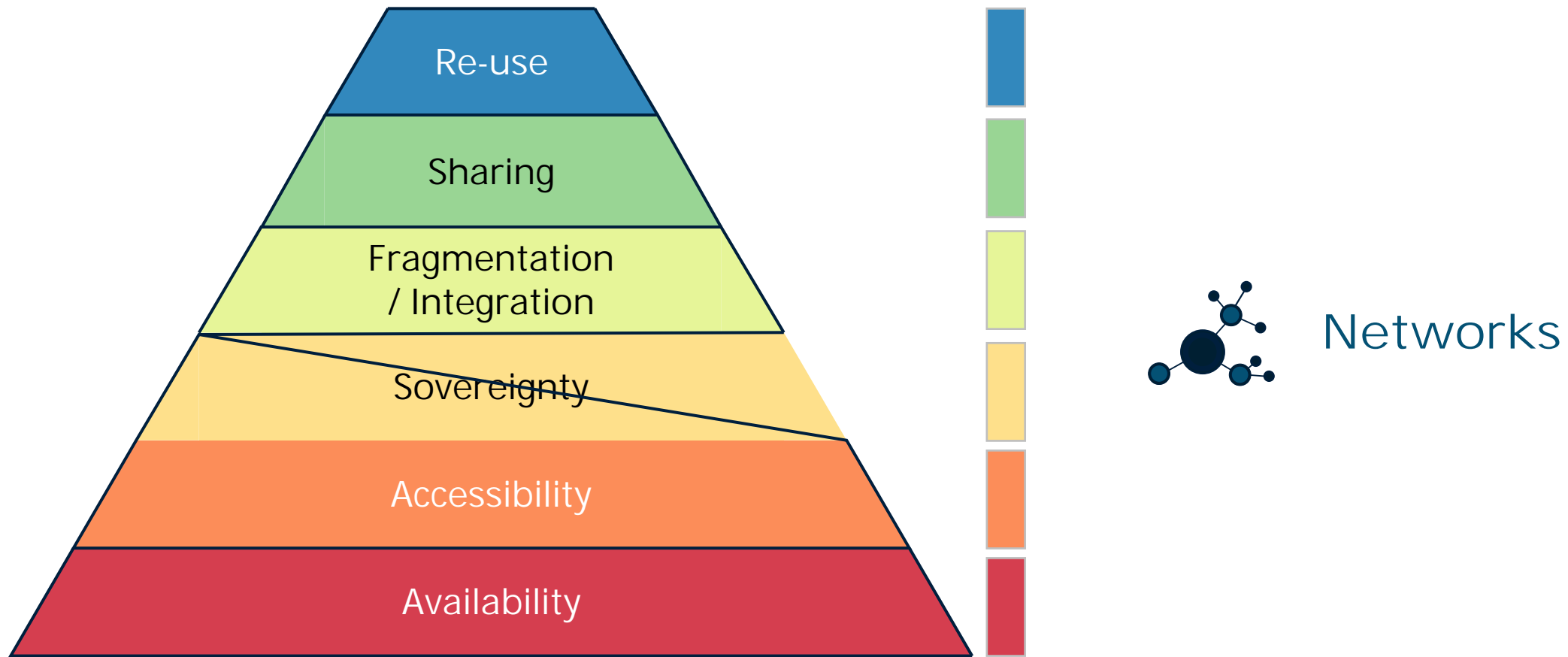
A data needs hierarchy for the Caribbean



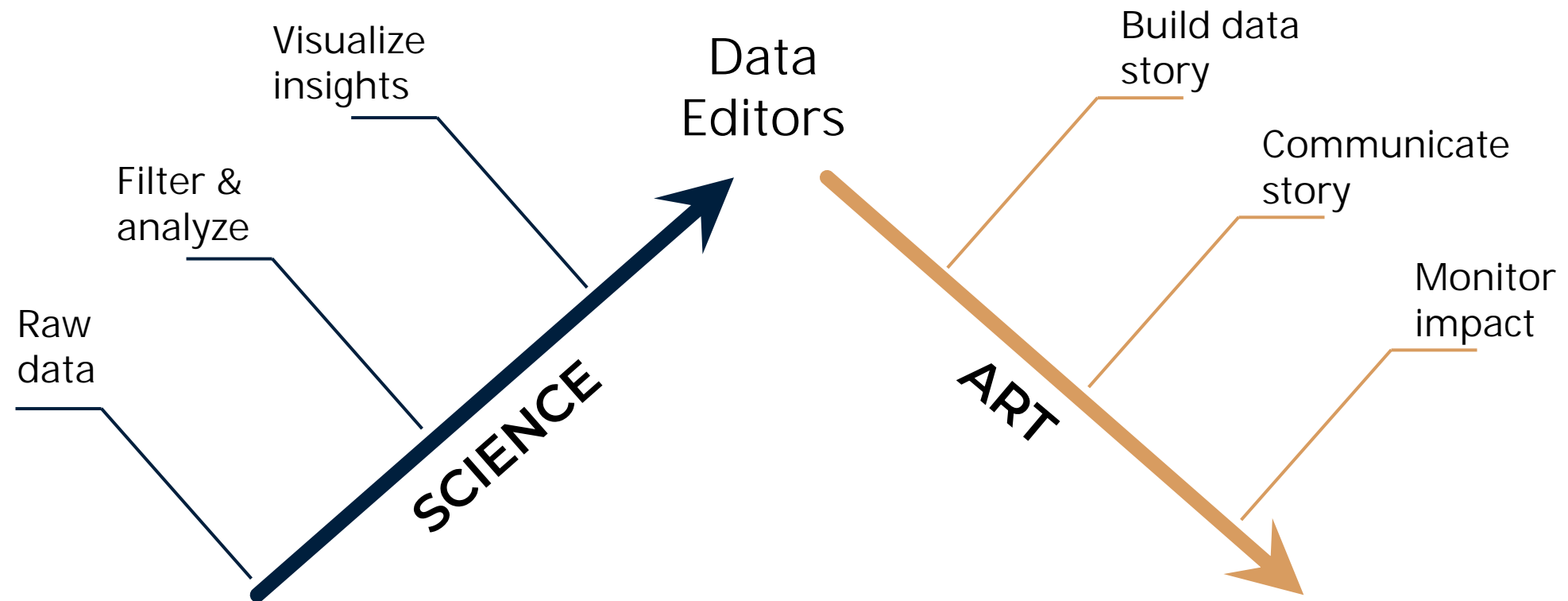
A data needs hierarchy for the Caribbean



A data needs hierarchy for the Caribbean



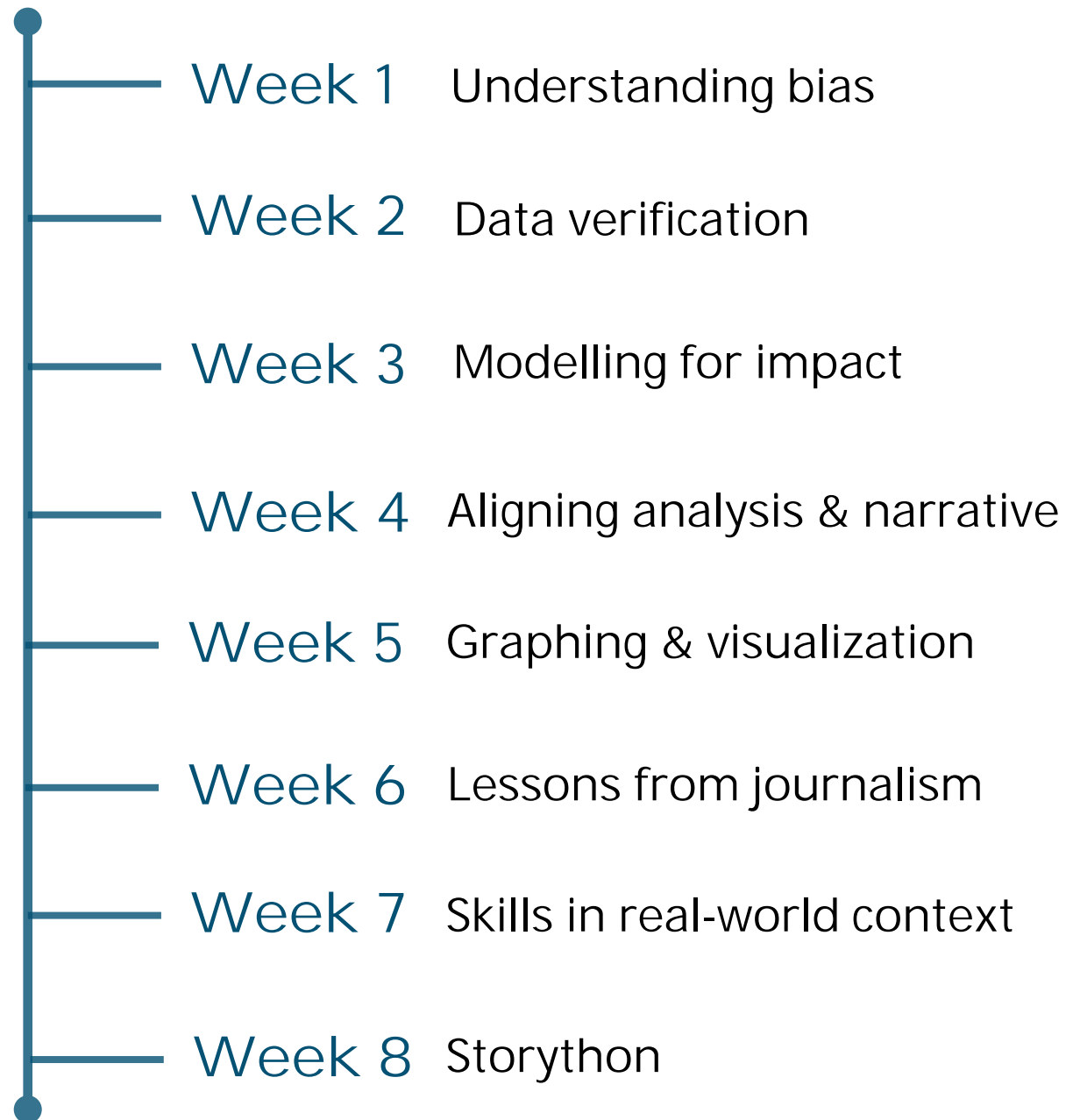
Linking data and stories



CaribData

The training

A Practical Guide to Data Storytelling, Visualization, and Audience Engagement

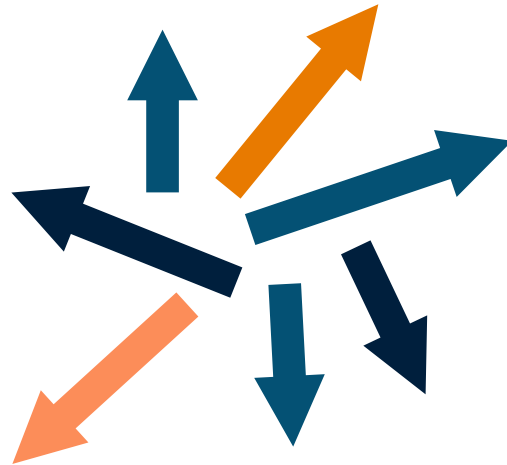


CaribData

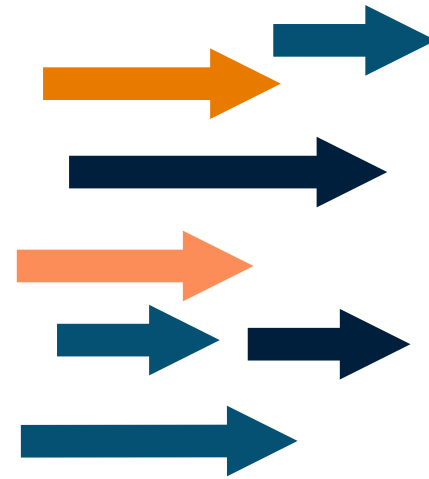
Collective data sharing



Disorder &
Confusion



Individual
Impact



Coordinated
Impact

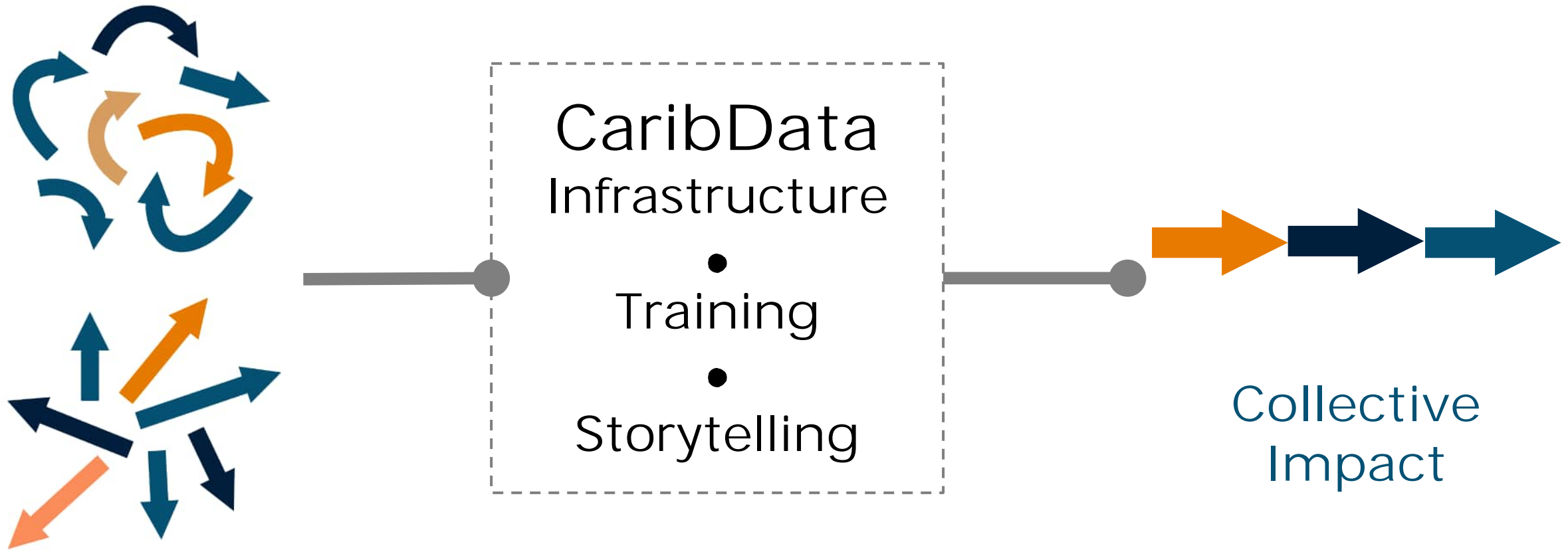


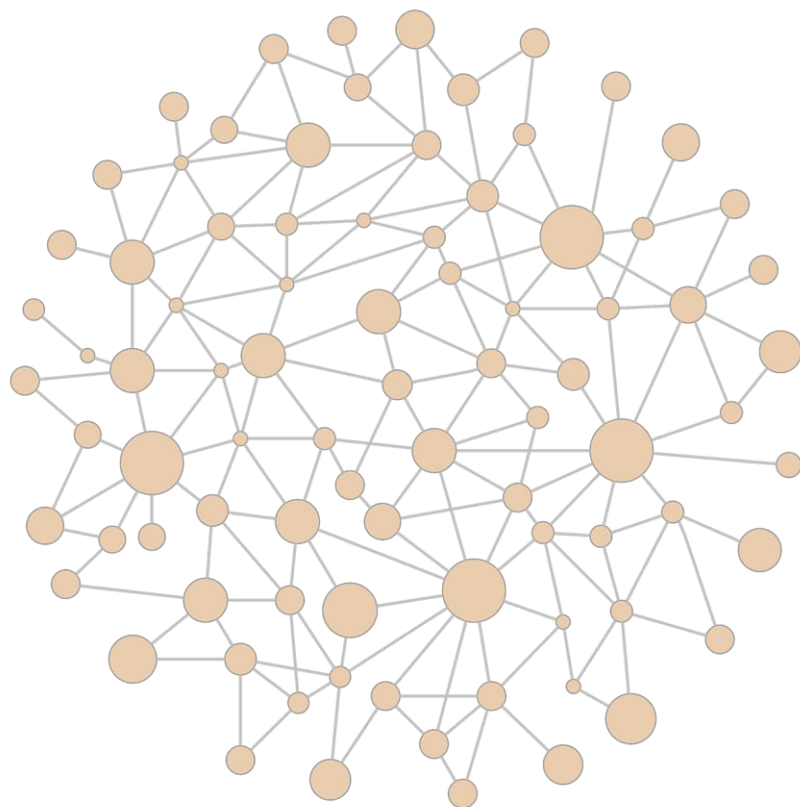
Collective
Impact



CaribData

Collective data sharing





Carib**Data**

Infrastructure



Training



Storytelling

