When Institutions Fail, Communities Get Busy: Putting Open Scholarly Data in the Hands of People Who Care.

Force 11 2023.

Professor Lucy Montgomery

CURTIN OPEN KNOWLEDGE INITIATIVE

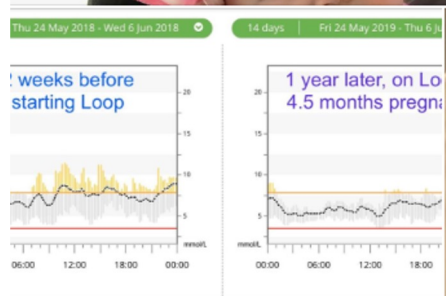
Tonight's Talk

- DIY Looping and #wearenotwaiting
- The **C**urtin **O**pen **K**nowledge **I**nitiative (COKI)

Melissa Ford Holloway
3 March at 06:46 ·

Yesterday Katie DiSimone passed away from glioblastoma. Looped and the wider diabetes world lost a leading light, mentor and friend. Katie's work on Loopdocs, Looptips, and her blog, plus her personal support in the Looped group helped me on my DIY looping journey and inspired me to be active in the community (#wearenotwaiting).

Before I started looping, I was on the fence about having a second child. After having James in 2015, I developed postpartum thyroiditis. For the ne... **See more**



You and 111 others 22 comments

Care Comment Share

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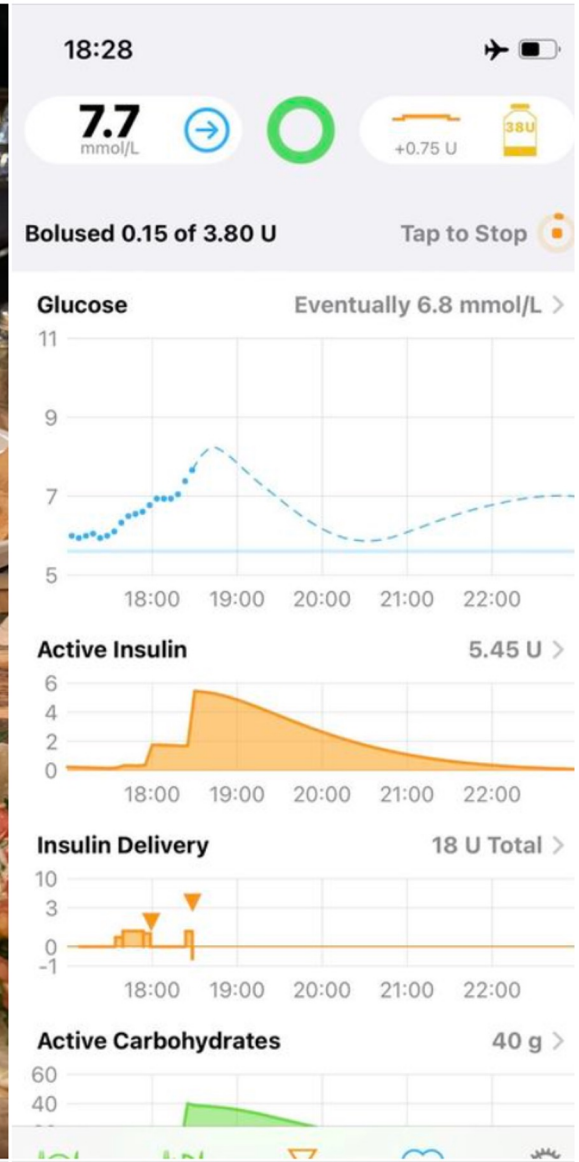
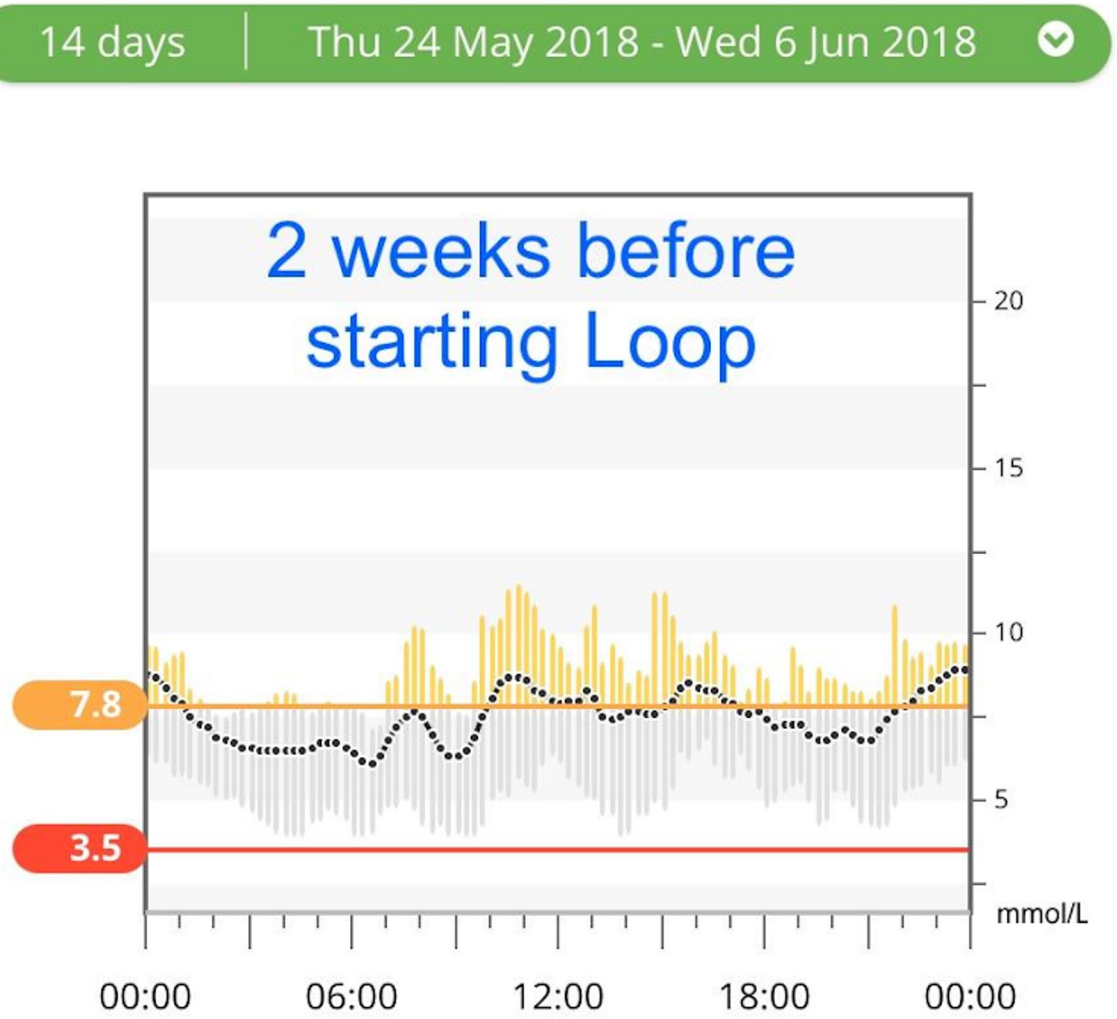
Stephanie Manson
It is never easy to say goodbye but so glad that she can be a bright light to inspire others as part of her legacy

Like Reply 1 w

Melissa Ford Holloway
16 November 2022 ·

Catching up on #WDD2022 posts because last night got away from me! Before my delicious fish taco dinner arrived on the table, I had a little rise from snacking on really great fresh tortilla chips, salsa and guacamole. The tacos had fresh corn tortillas (rather than flour) so I wasn't quite sure how they might hit me. I gave a slightly conservative bolus.




14 days
Thu 24 May 2018 - Wed 6 Jun 2018
2 weeks before starting Loop
20
15
10
5
7.8
3.5
mmol/L
00:00
06:00
12:00
18:00
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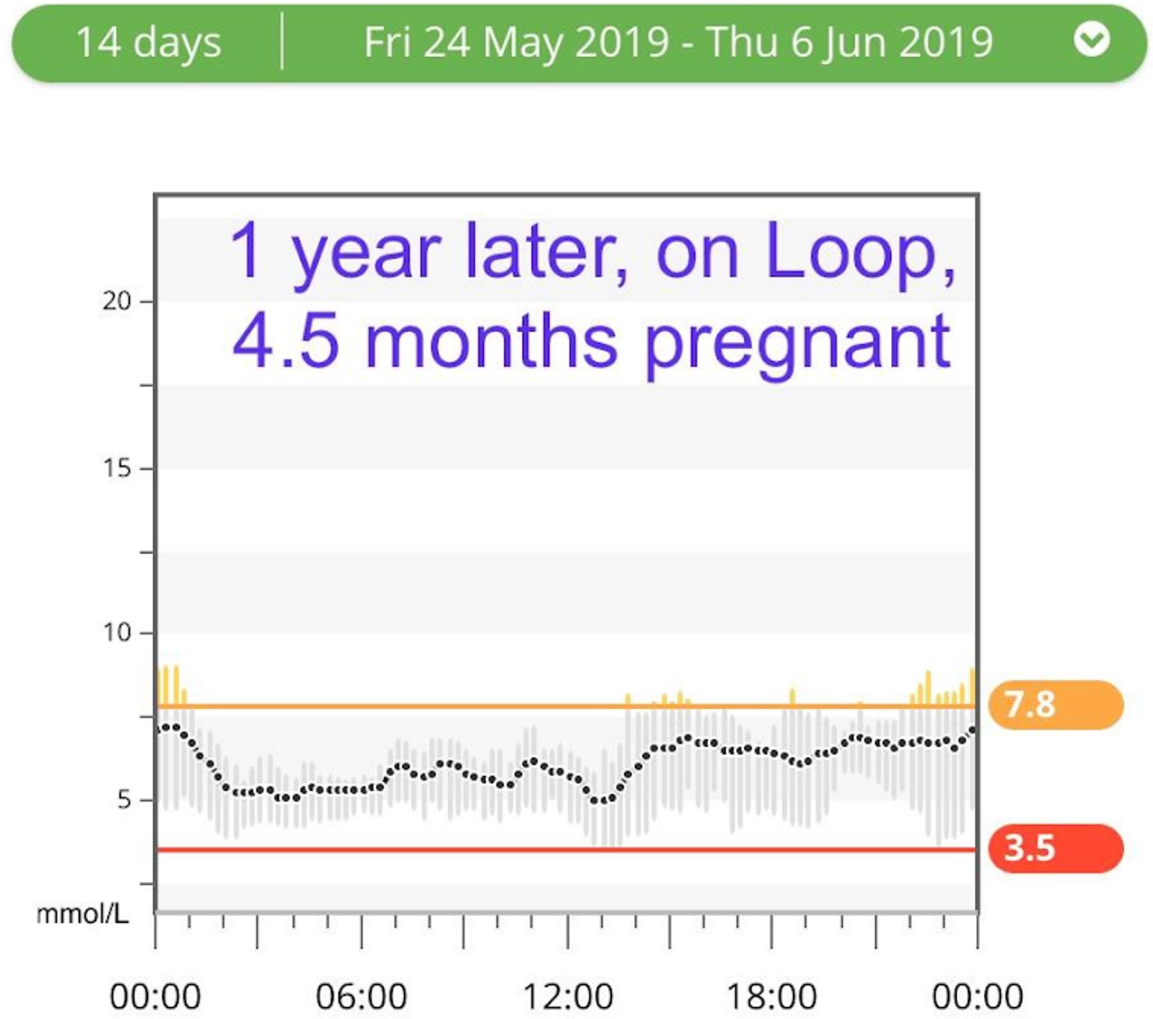
14 days
Fri 24 May 2019 - Thu 6 Jun 2019
1 year later, on Loop, 4.5 months pregnant
20
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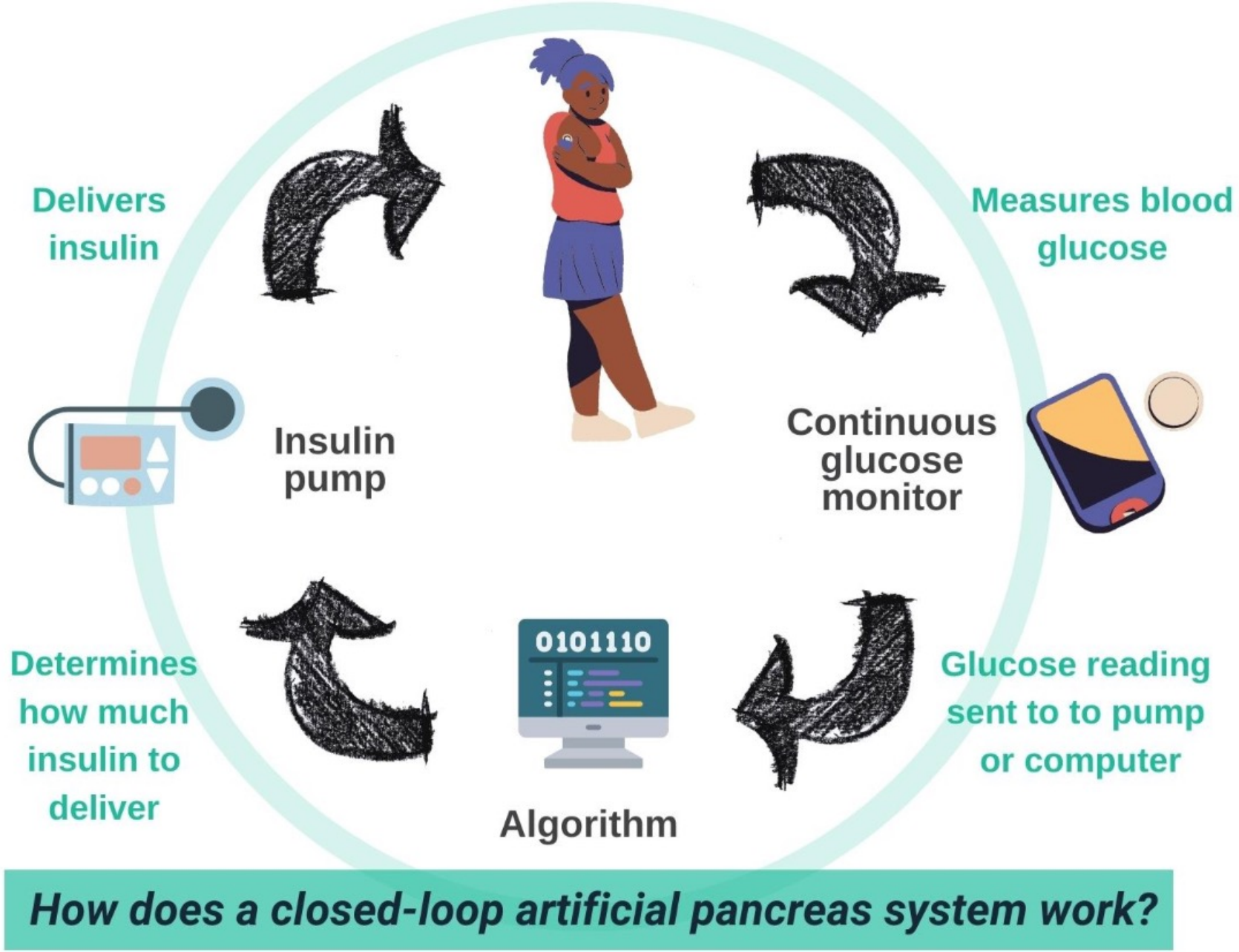

https://www.pslhub.org/learn/patient-safety-in-health-and-care/conditions/diabetes/how-safe-are-closed-loop-artificial-pancreas-systems-r5510/

Image CC-BY from: https://www.flickr.com/photos/vcucns/35019847795

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Businessweek | Feature

The $250 Biohack That's Revolutionizing Life With Diabetes

DIYers used a security flaw to bypass the $8.3 billion insulin delivery business with a cobbled-together artificial pancreas.

By Naomi Kresge and Michelle Fay Cortez

8 August 2018 at 17:00 GMT+8 Updated on 6 November 2018 at 03:02 GMT+8

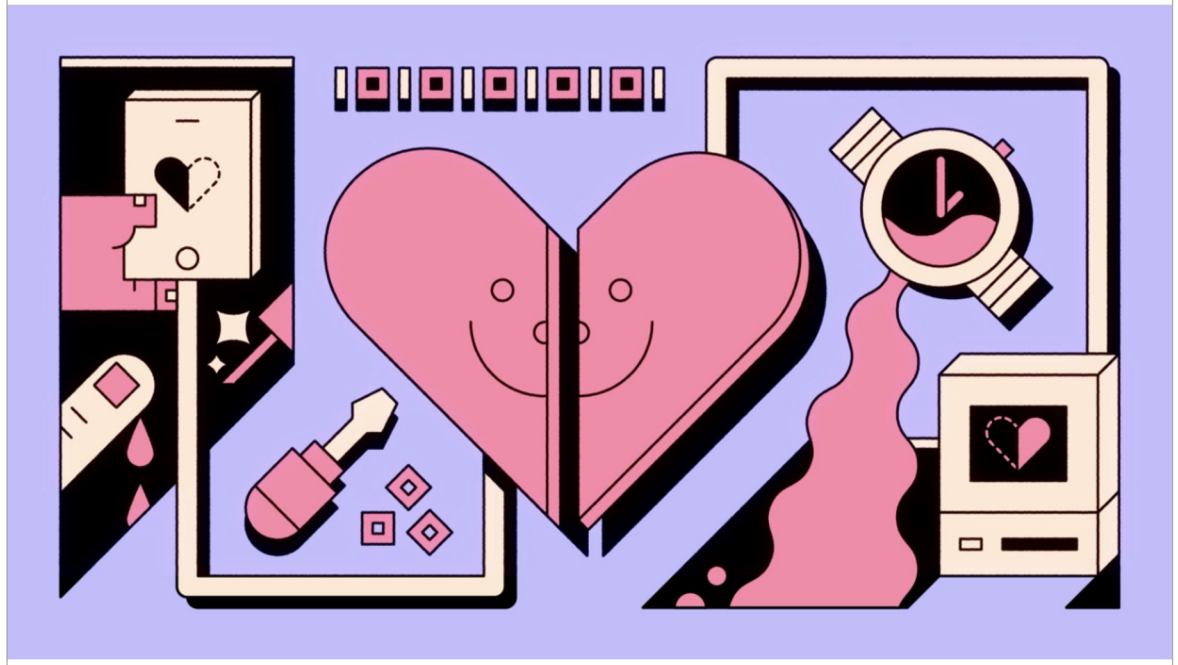

Illustration: Joel Plosz

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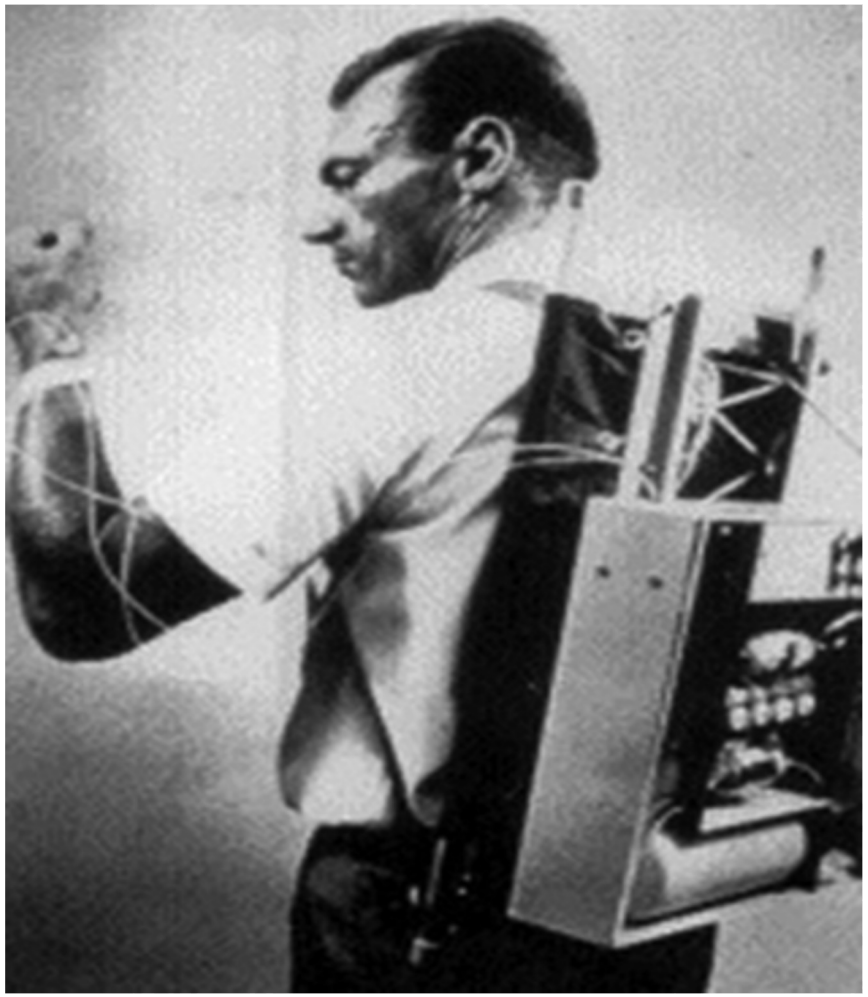
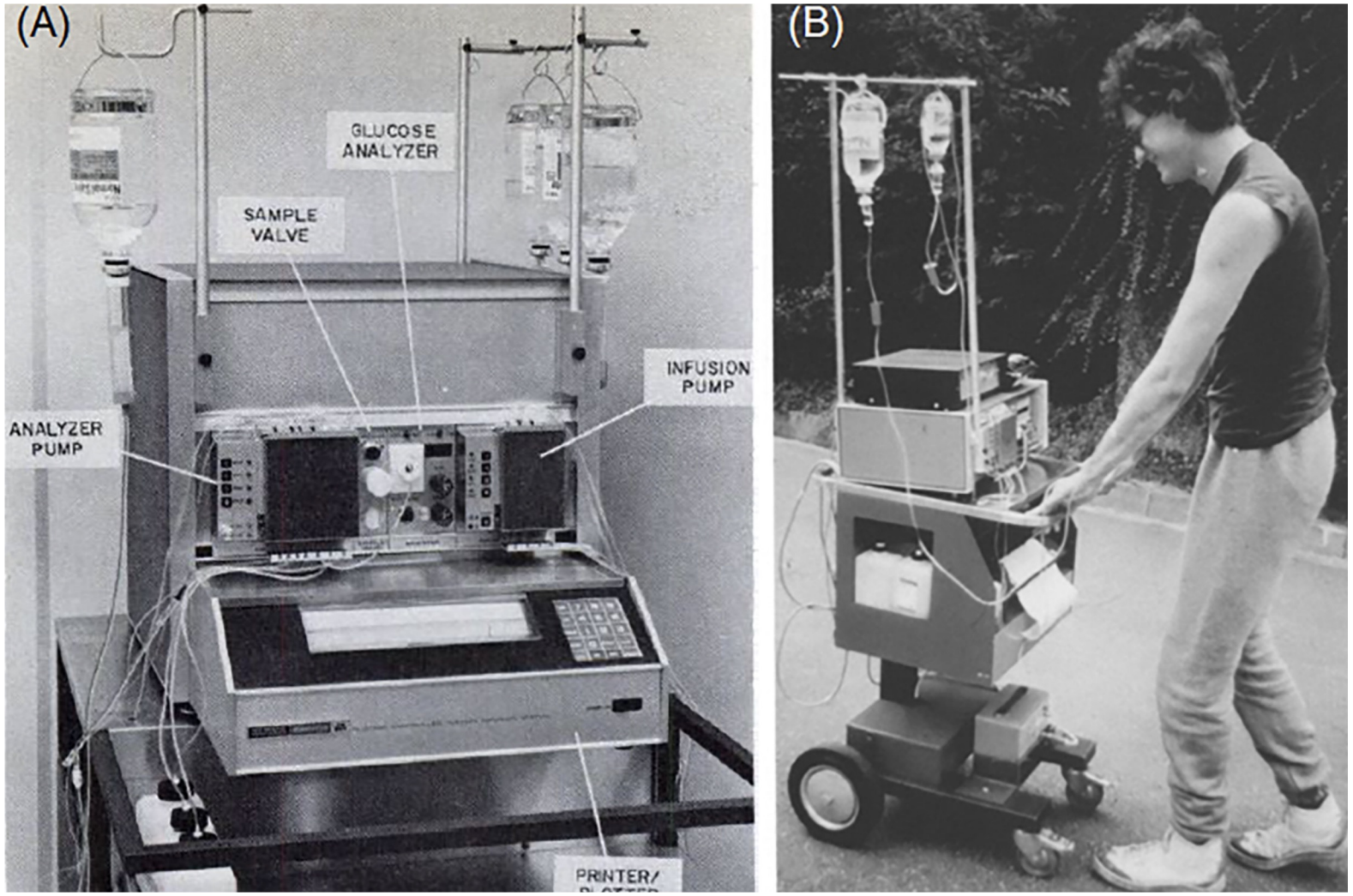
After our story ran, Bloomberg went back to the parents, coders and hobbyists who worked to hack together an artificial pancreas, and learn more about how they did it. It's the first episode in our first season of Prognosis, a podcast about people living on the edge of medical innovation. You can listen here.

Arnold Kadish's first closed-loop insulin pump device



Clinical Pharmacy Therapeu, Volume: 35, Issue: 2, Pages: 127-138, First published: 05 March 2010, DOI: (10.1111/j.1365-2710.2009.01048.x)

Biostator: A computer-based glucose-controlled insulin infusion system



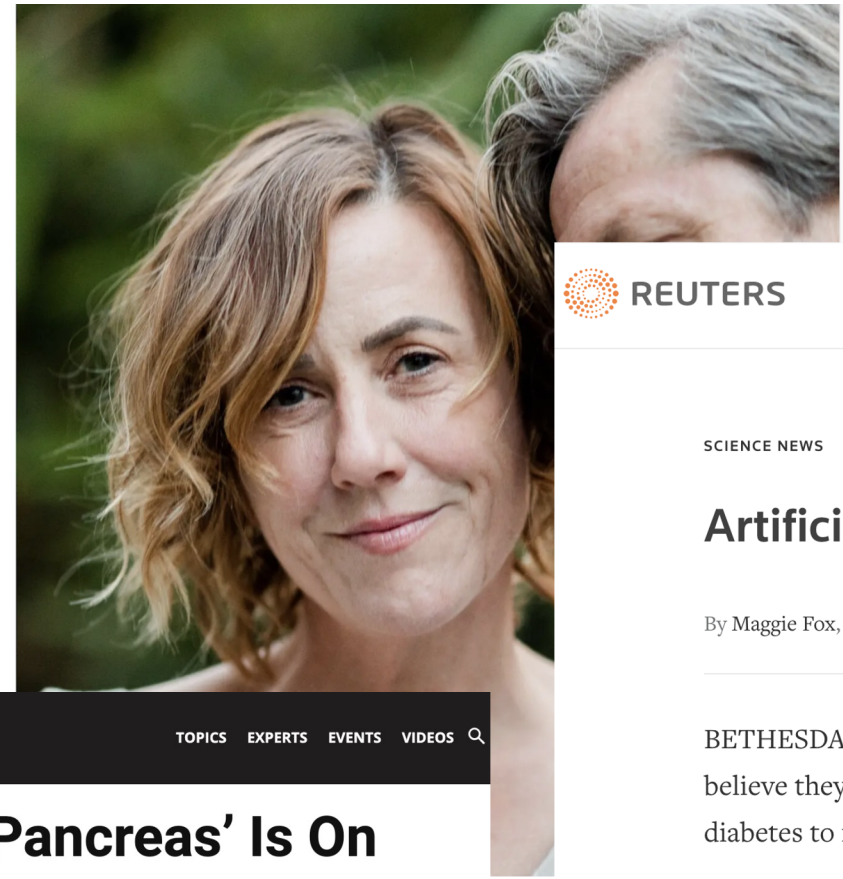
Closed-Loop Insulin Delivery Systems: Past, Present, and Future Directions
https://www.frontiersin.org/articles/10.3389/fendo.2022.919942#.ZDOV-64oqZg

The New York Times

Account

The Long, Long Wait for a Diabetes Cure

A documentary captures the desperation and frustration of Type 1 diabetes patients in a clinical trial.



REUTERS

World Business Markets Breakingviews Video Mo

SCIENCE NEWS JULY 26, 2008 / 10:25 PM / UPDATED 15 YEARS AGO

Artificial pancreas just years away, experts agree

By Maggie Fox, Health, Science Editor

5 MIN READ

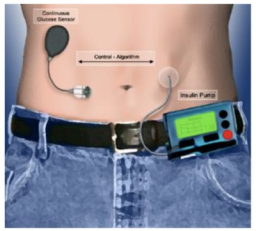
BETHESDA, Maryland (Reuters) - Researchers working on an artificial pancreas believe they are just a few years away from a nearly carefree way for people with diabetes to monitor blood and inject insulin as needed.

Singularity hub

TOPICS EXPERTS EVENTS VIDEOS

New Reports Show 'Artificial Pancreas' Is On Route To Treat Diabetes

By **Aaron Saenz** › July 7, 2010



The Artificial Pancreas is actually a combination of internal glucose monitor, insulin pump, and control software.

An 'artificial pancreas' developed with funding from the Juvenile Diabetes Research Foundation (JDRF) could allow diabetics to control their blood sugar automatically. Consisting of an insulin pump, continuous glucose monitor, and advanced control software, the artificial pancreas is part implant and part worn device. It will monitor blood sugar and vary insulin levels without a patient's need for constant calculation and adjustments. According to recent presentations at the American Diabetes Association Scientific Sessions in Florida, the artificial pancreas has shown great aptitude for treating diabetes overnight and after large meals – difficult times for many diabetics. The device may prove to be the best

English Edition

Medscape Monday, April 10, 2023

NEWS & PERSPECTIVE DRUGS & DISEASES CME & EDUCATION ACADEMY VIDEO

News > Medscape Medical News

Artificial Pancreas Will Become Reality Within 2 Years

Veronica Hackethal, MD

July 07, 2016

Not Waiting for...?

The folks involved summarize the movement with this powerful list:

#WeAreNotWaiting to bridge disconnected data islands.

#WeAreNotWaiting while our endocrinologist tries to assemble the disjointed pieces of the data puzzle.

#WeAreNotWaiting for competitors to cooperate.

#WeAreNotWaiting for regulators to regulate.

#WeAreNotWaiting for device manufacturers to innovate.

#WeAreNotWaiting for payers to pay.

#WeAreNotWaiting for peace of mind that our children with type 1 diabetes are safe.

#WeAreNotWaiting to get some decent sleep for the first time in years.

#WeAreNotWaiting for our child to be able to safely have a sleepover at friend's house.

#WeAreNotWaiting to give our child a better chance to succeed at school.

#WeAreNotWaiting for others to decide if, when, and how we access and use data from our own bodies.

#WeAreNotWaiting to build applications that focus on design and usability.

#WeAreNotWaiting to compel device makers to publish their data protocols.

#WeAreNotWaiting to insist that patients have access to their own diabetes data.

#WeAreNotWaiting to allow PWDs to have a choice in how they see their own diabetes data, and not be forced to use substandard software that comes with their device.

#WeAreNotWaiting to make it easier to get data off of devices.

#WeAreNotWaiting to bring together the best and brightest minds from around the world to help make things better for PWDs.

#WeAreNotWaiting for the cure.

Experience
Diabetes

Experience: I built my own pancreas

Having a computer make adjustments while I sleep is far safer than trying groggily to make decisions in the early hours

Dana Lewis

Fri 20 Jul 2018 18.59 AEST

143

Dana Lewis: 'More than 725 people worldwide have now built various types of DIY closed-loop systems.' Photograph: Annabel Clark for the Guardian

I was diagnosed with type 1 diabetes when I was 14. This means my pancreas no longer naturally produces insulin; and without insulin,

Image by Lisandra Santiago from Pixabay

NHS pilot of hybrid closed loop systems successful in improving lives of people with type 1 diabetes

Posted on 01 April 2022

Hybrid closed loop (or artificial pancreas) systems monitor and an insulin pump with a control algo amount of insulin, automa

Diabetes

NICE recommends hybrid closed loop tech for diabetics

The National Institute for Health and Care Excellence (NICE) is recommending the use of official hybrid closed loop systems to help patients with type 1 diabetes manage their blood glucose levels.

NICE has published new draft guidance for patients in England and Wales. It says that around 105,000 people in England are set to be offered the 'artificial pancreas' technology, which will allow them to go about their lives without having to continually monitor their blood glucose levels.

This article is more than **3 months old**

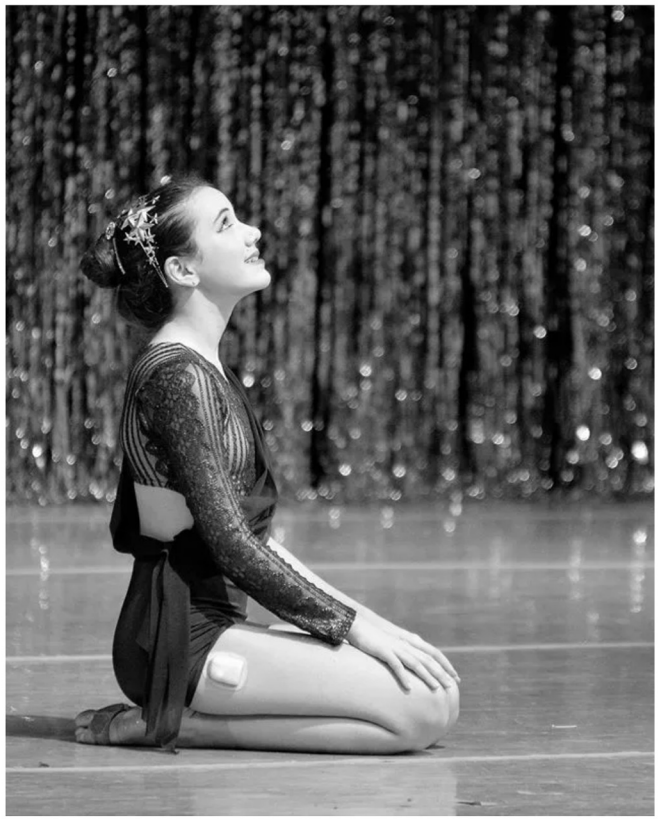
NHS in England to offer artificial pancreas to help manage type 1 diabetes

Successful trial of groundbreaking device, now approved by Nice, uses algorithm to determine amount of insulin needed

We finally have an “artificial pancreas” for diabetes. But it's a letdown.

By Julia Belluz | @juliaoftoronto | Oct 25, 2016, 6:00am EDT

SHARE



Endocrinetoday

By Regina Schaffer

+ Source/Disclosures

May 24, 2021 | 3 min read

SAVE

‘Loop’ artificial pancreas software safe, effective with community support

ADD TOPIC TO EMAIL ALERTS

CNET Your guide to a better future

Wellness > Medical

I Used Loop to Hack My Insulin Pump to Better Control My Blood Sugar Levels

Loop is a DIY automated insulin delivery system with more customization and features than FDA-approved systems on the market.

Justin Eastzer

April 13, 2022 5:00 a.m. PT

3 min read

COKI CURTIN OPEN KNOWLEDGE INITIATIVE

COKI Workshop, Mauritius, 2019

Curtin University

CAMPUS AND GLOBAL COMMUNITY

Curtin named among the world's top 250 universities

12 OCT 2022 | Yasmine Phillips

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RESEARCH

Curtin reaches new heights in prestigious QSWUR

09 JUN 2022 | Yasmine Phillips

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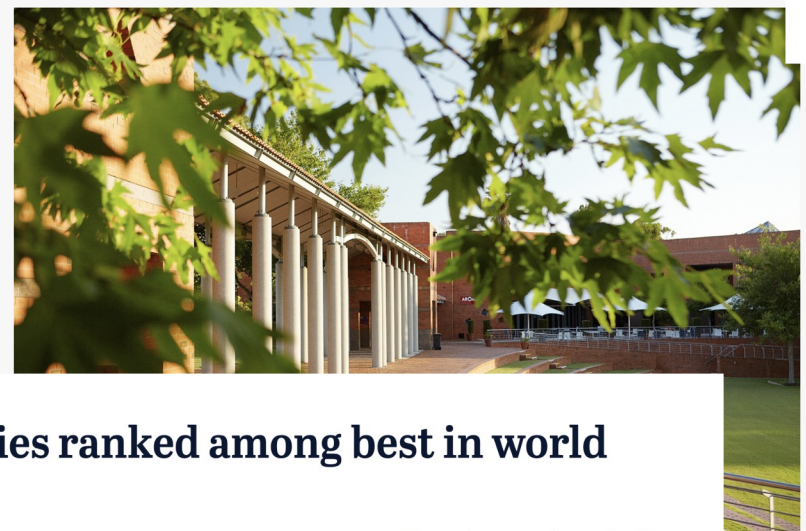

This was published 5 years ago

Two WA universities ranked among best in world

Hannah Barry

Updated August 15, 2017 — 4.20pm, first published at 11.50am

Save Share A A A

Two West Australian universities have been ranked among the best in the world, following the release of the results from the Academic Ranking of World Universities study on Tuesday morning.

R) by
ally.

This was published 2 years ago

Murdoch falls behind Edith Cowan to become WA's worst-ranked public university

Aja Styles and Natassia Chrysanthos

Updated September 3, 2020 — 2.39pm, first published at 1.12pm

Save Share A A A 8 View all comments

Murdoch University has plunged down the global university rankings, falling behind Edith Cowan University for the first time in its history.

Murdoch dropped to 501-600th position in the Times Higher Education's annual rankings after holding strong to 401-500th position for five years.

LIVE Search

The West Australian

NEW FOOTY TIPPING COMP! Cash in on your WAFL knowledge to win a whopping $10

Education | State Politics | WA News

Education Minister Tony Buti says University of WA's top 100 ranking under threat as SA leads way on mergers

Bethany Hiatt & Josh Zimmerman | The West Australian
Thu, 23 February 2023 12:37PM | Comments |

Education Minister Tony Buti has refused to buy into speculation an independent review of WA's universities will call for amalgamations, but conceded institutional size played a role in driving up world rankings.

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Curtin University

HORIZON EUROPE

The New EU Framework Programme for Research and Innovation

2021-2027

EUROPEAN OPEN SCIENCE CLOUD

National Science Foundation

OPEN SCIENCE IN CONVERSATION

Wednesday, March 30, 11:00 a.m. - 12:00 p.m. EDT

FOLLOW THE MONEY - FUNDING OPEN, DIVERSE, INCLUSIVE AND EQUITABLE SCIENCE

Eunice Mercado-Lara

Civic Science Fellow, Open and Equitable Model Funding Program

Open Research Funders Group

Kate Hertweck

Open Science Program Manager, Chan Zuckerberg Initiative

#OpenScienceinAction

Let's Talk About Openness & Equity in Grantmaking!

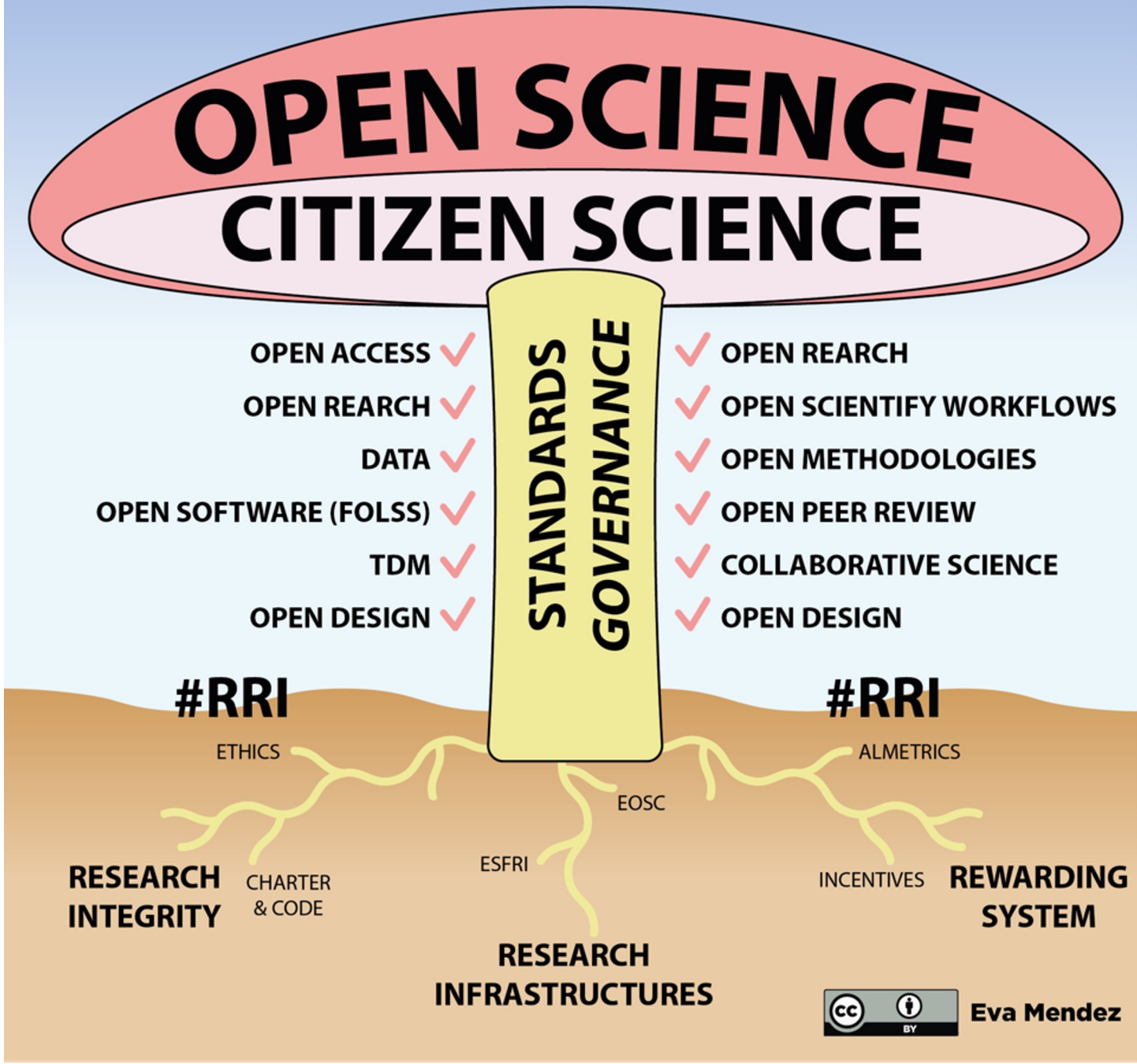
HOW WOULD YOU APPLY OPENNESS & EQUITY TO GRANTMAKING?

rfg Open Research Funders Group

Participate in the survey: rb.gy/9i1wqt

CURTIN OPEN KNOWLEDGE INITIATIVE

Australian open science mushroom by Libby Hepburn



An Open Knowledge Agenda

- What does Open Knowledge change?
- What would a University as an Open Knowledge Institution look like?
- What kinds of information might a University need to support a shift from closed to open?
- What kinds of information do funders, policymakers and research communities need to support an open agenda?

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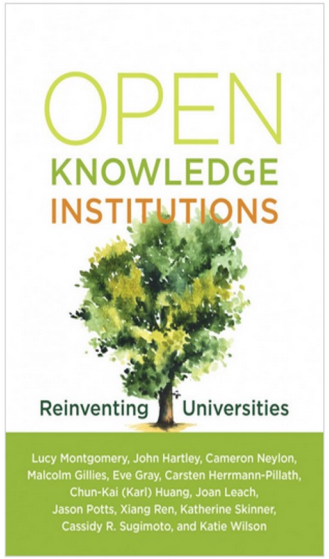
FOR COMPUTATION

Home | Education | General | Open Knowledge Institutions



Open Knowledge Institutions

Reinventing Universities

By Lucy Montgomery, John Hartley, Cameron Neylon, Malcolm Gillies, Eve Gray, Carsten Herrmann-Pillath, Chun-Kai (Karl) Huang, Joan Leach, Jason Potts, Xiang Ren, Katherine Skinner, Cassidy R. Sugimoto and Katie Wilson

The future of the university as an open knowledge institution that institutionalizes diversity and contributes to a common resource of knowledge: a manifesto.

Endorsements

"Can the contemporary university be reinvented with openness at its core, developing and sharing knowledge in service to the global public interest? The authors of *Open Knowledge Institutions* argue compellingly that such reinvention is not just possible but necessary, and they provide a crucial map of the work required to make it so."

Kathleen Fitzpatrick, Director of Digital Humanities and Professor of English, Michigan State University; author of Generous Thinking: A Radical Approach to Saving the University

"This book provides nuanced discussion around the moral, logistical, and practical challenges associated with embedding open science principles in public research organizations. With every syllable, I was nodding in agreement."

Gemma Derrick, Senior Lecturer in Higher Education, Lancaster University

"Laced with incisive case studies, this welcomed manifesto amounts to a fearless application of practical wisdom to revitalize the university by having it serve as a knowledge commons."

John Willinsky, Khosla Family Professor of Education, Stanford University

https://mitpress.mit.edu/9780262542432/open-knowledge-institutions/

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Outputs ~~125,948,412~~ 132,498,392

ORCIDs ~~3,513,542~~ 3,970,454

We are Crossref Metadata User

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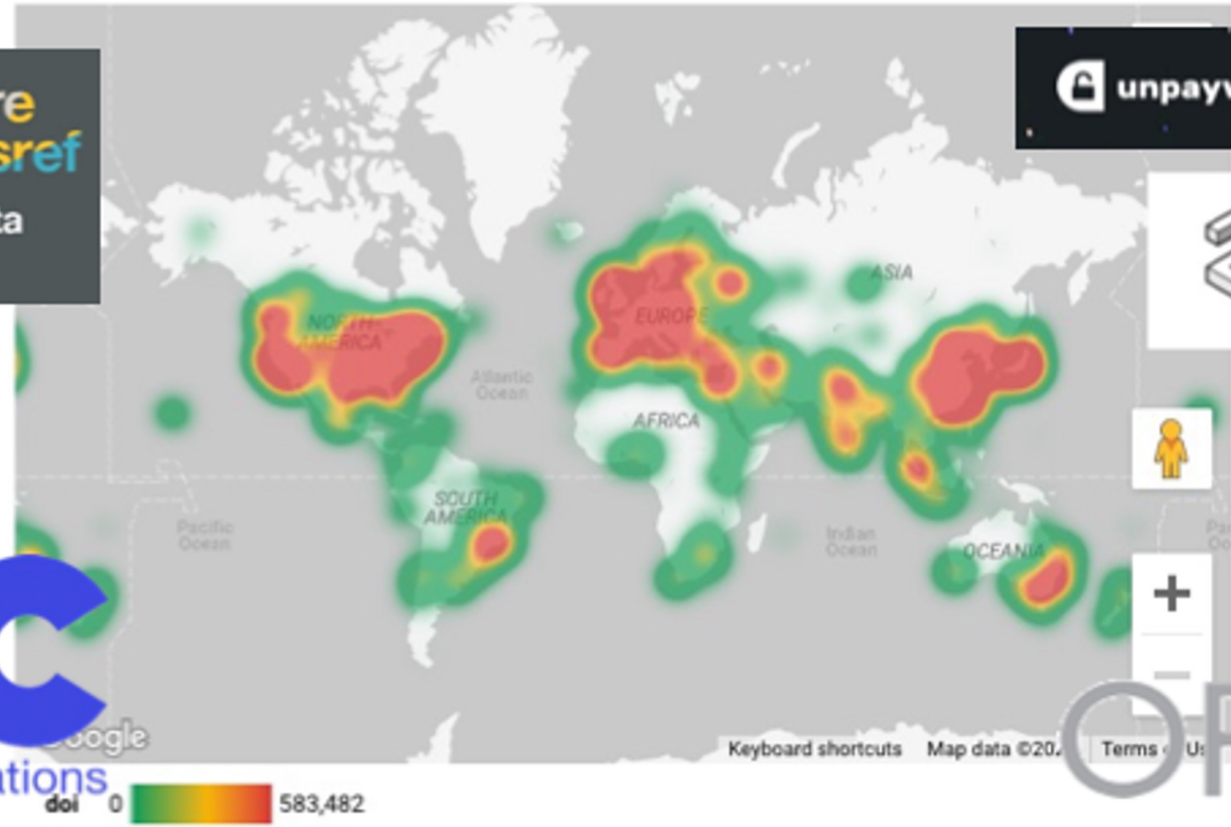
ROR .community



OpenCitations

ORCID

Institutions ~~19,887~~ 89,505

Countries 198

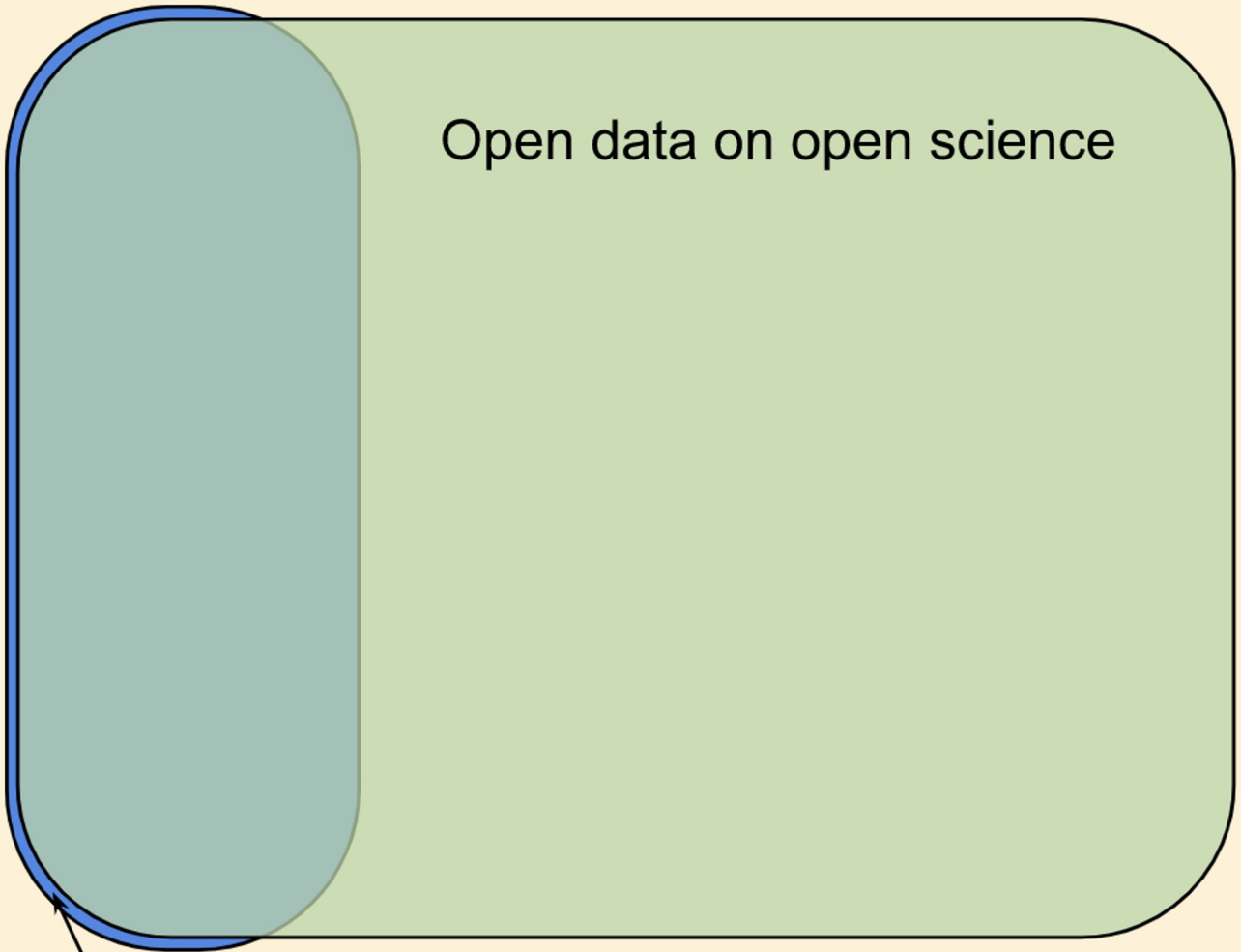
Publishers 77,935

Journals 100,456

Curtin University

Available data on open science

Unavailable data on open science



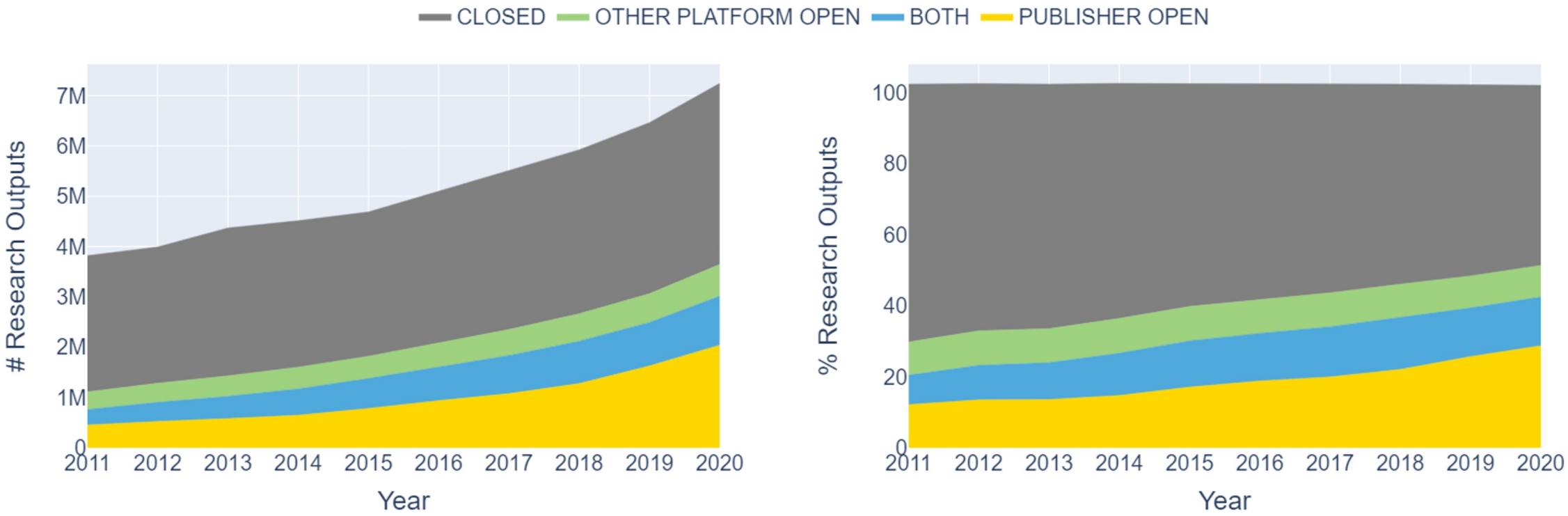
Currently unavailable data for which new approaches need to be developed (including qualitative)

Currently unavailable data that could be obtained with existing open approaches to produce open data (mainly quantitative)

Data on open science that is only available from closed / commercial sources

GLOBAL OPEN ACCESS LEVELS

TREND OVER 11 YEARS FROM 2010 TO 2020



COKI (2022) - https://doi.org/10.5281/zenodo.7059176

COKI CURTIN OPEN KNOWLEDGE INITIATIVE

Curtin University

AUSTRALIA

Australia, officially the Commonwealth of Australia, is a sovereign country comprising the mainland of the Australian continent, the island of Tasmania, and numerous smaller islands. Derived from Wikipedia licensed CC-BY-SA.

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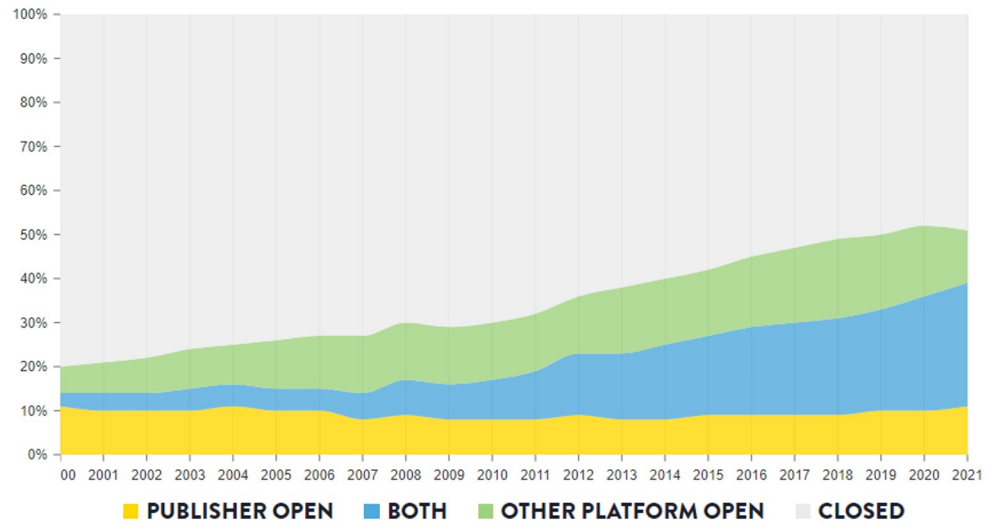
OPEN ACCESS PERCENTAGE	TOTAL PUBLICATIONS	TOTAL OPEN PUBLICATIONS	TOTAL CITATIONS
40%	1.4m	553k	37m

BREAKDOWN

PUBLISHER OPEN	BOTH	OTHER PLATFORM OPEN	CLOSED
9%	16%	14%	61%

PERCENTAGE OF OPEN ACCESS OVER TIME



Extracted from:
https://open.coki.ac

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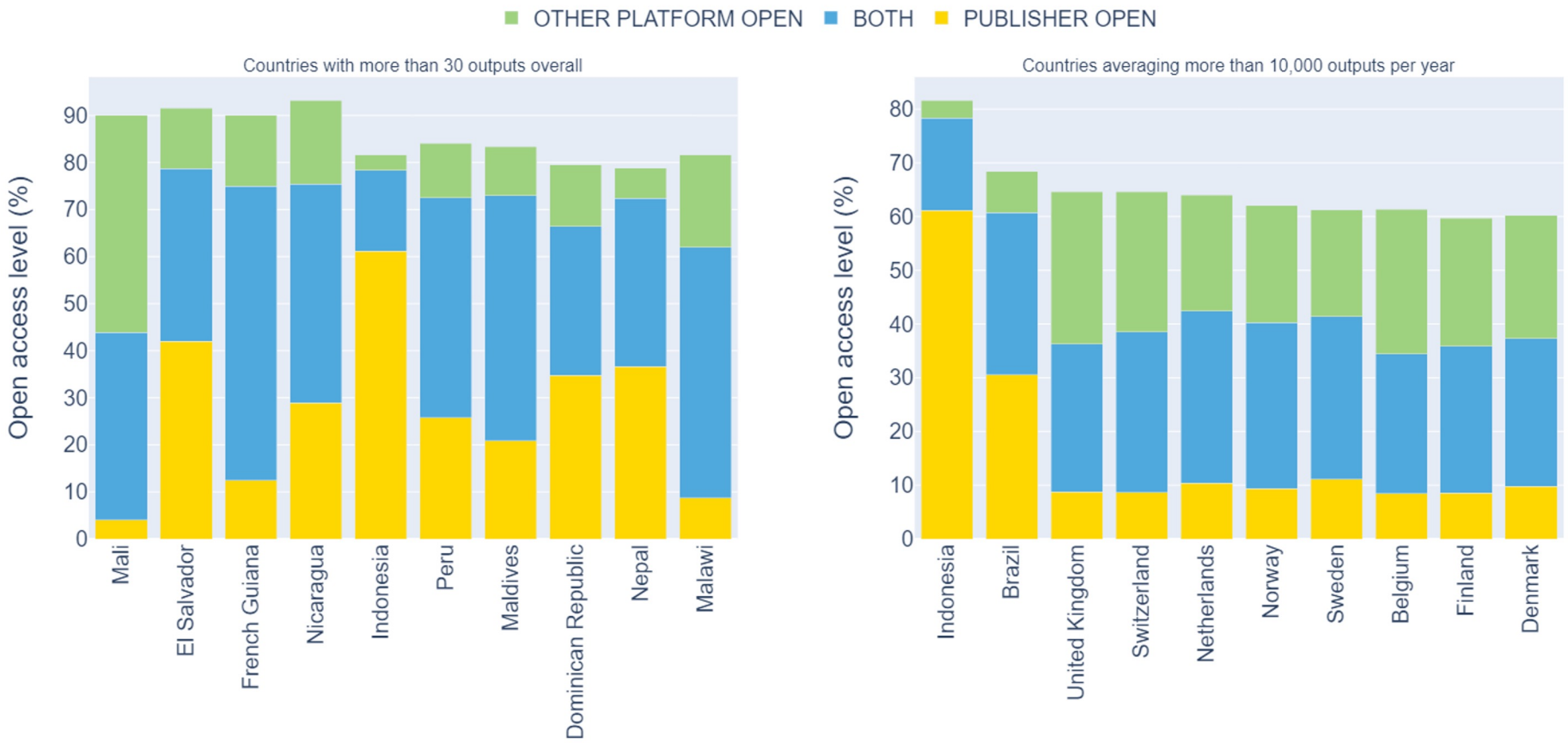
TOP 10 COUNTRIES BY OPEN ACCESS LEVELS

DATA OVER 11 YEARS FROM 2010 TO 2020



COKI (2022) - https://doi.org/10.5281/zenodo.7059176

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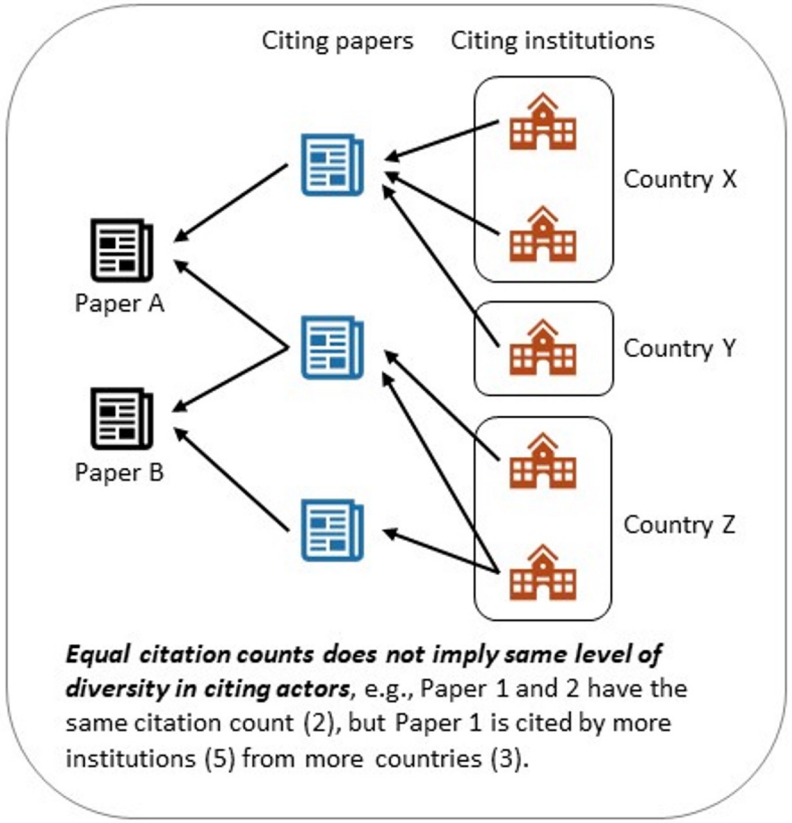
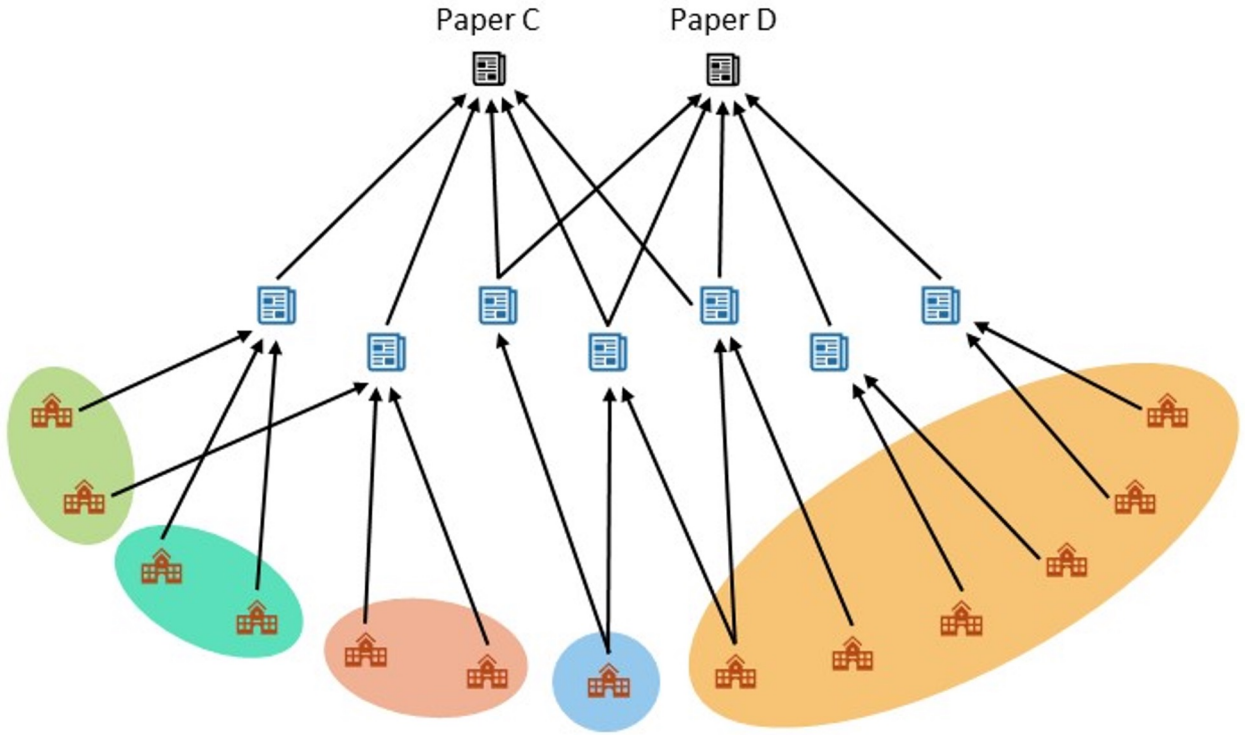
Q: We are all familiar with the open access citation advantage. Is there also an open access diversity advantage?



Equal citation counts does not imply same level of diversity in citing actors, e.g., Paper 1 and 2 have the same citation count (2), but Paper 1 is cited by more institutions (5) from more countries (3).

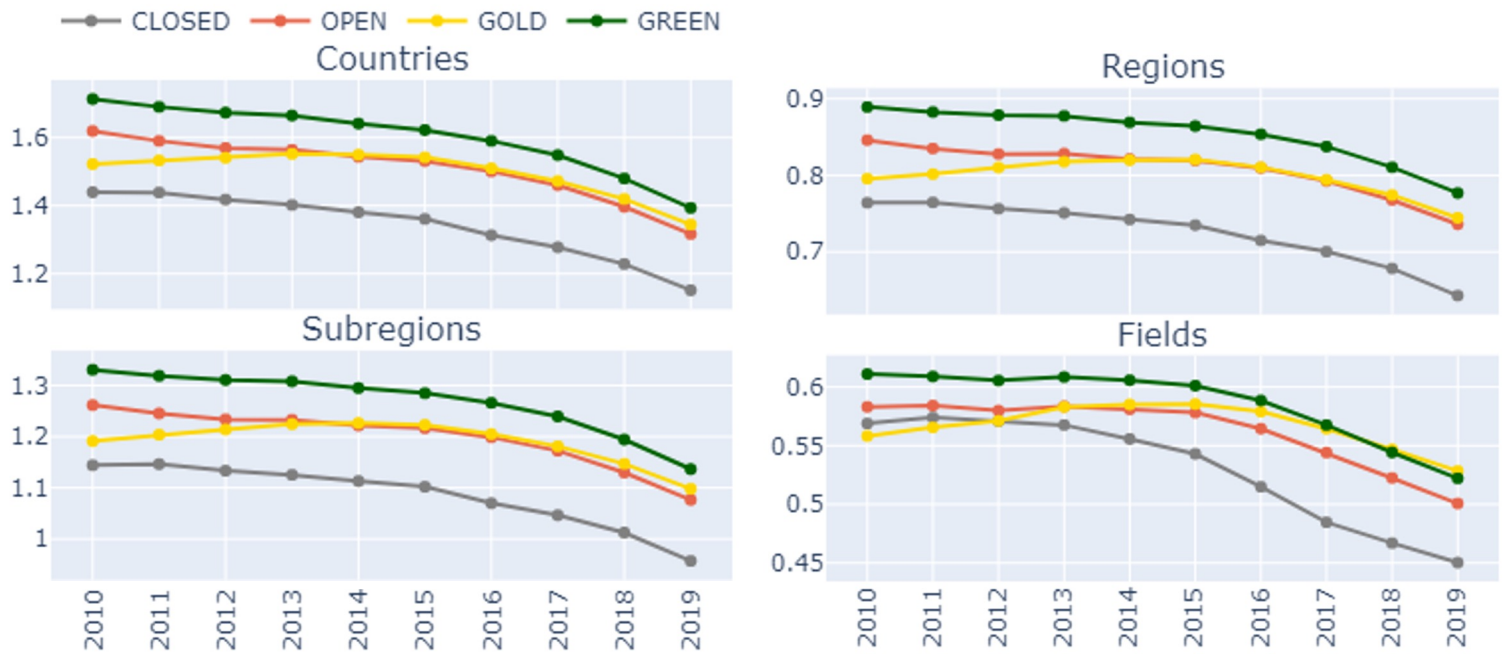


Paper	# Citations	# Citing institutions	# Citing countries	Gini-Simpson*	Shannon*
C	5	9	5	0.79	1.59
D	5	7	2	0.55	0.53

* Calculated based on grouping all "citing paper to citing institution" pairs by countries.

Does open access research connect with more diverse audiences?

Diversity of citations by countries, subregions, regions, and fields of research



CLIMATE CHANGE AND OPEN ACCESS DEMONSTRATION DASHBOARD

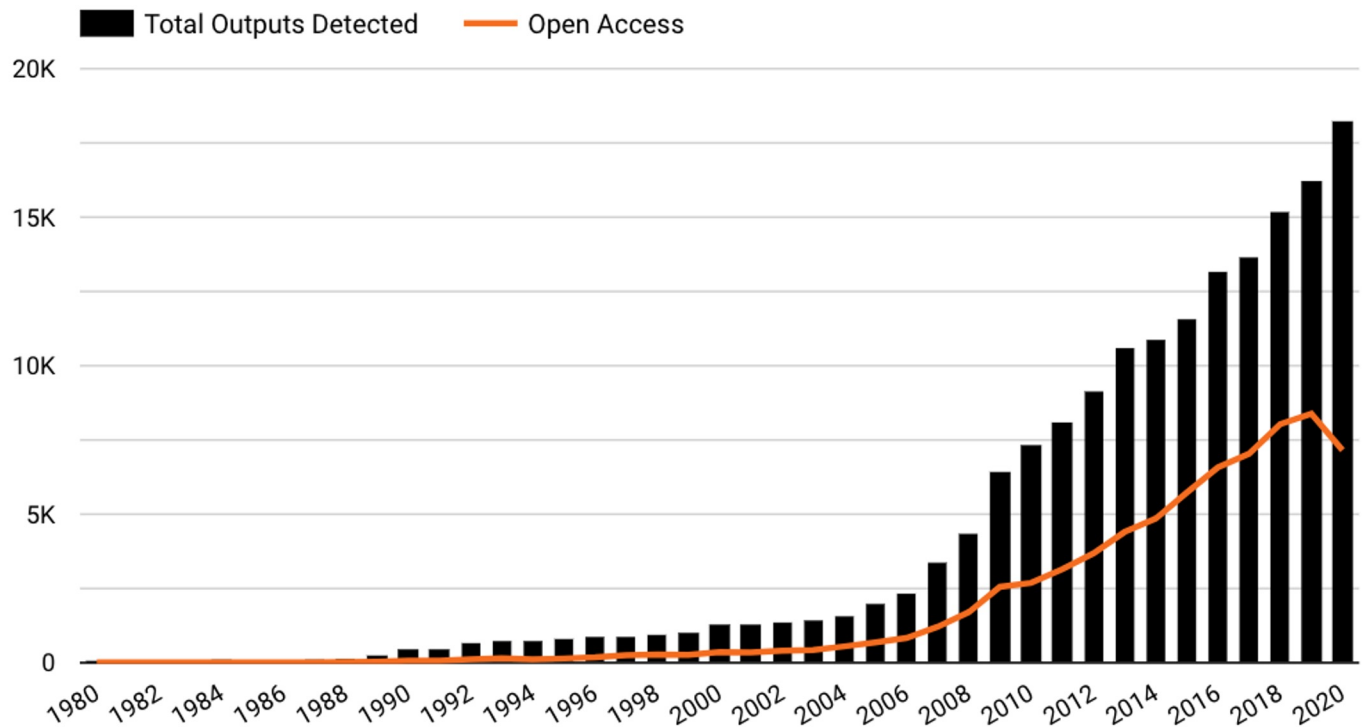
CURTIN OPEN KNOWLEDGE INITIATIVE

Total Outputs	Open Access	Open Access (%)
169,135	72,538	42.9

Year of Publication

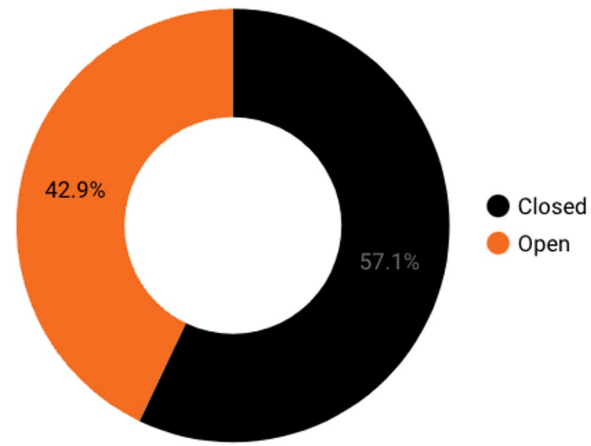
1,980 — 2,020

LITERATURE AND OPEN ACCESS OVER TIME

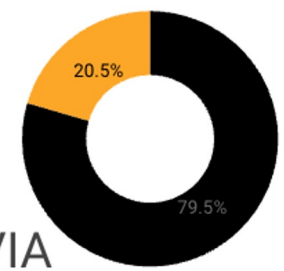


OA OVER SELECTED PERIOD

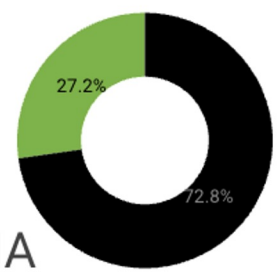
OVERALL ACCESS



OA VIA PUBLISHER



OA VIA REPOSITORY



Dashboard / AIATSIS - Overview

t and enhancemen ellbeing an trials evaluating its efficacy across range conditions. Based on PRISMA guideli

Rows per page: 50 1 of 10

AIATSIS - Summary

4940
Titles

4958
DOIs

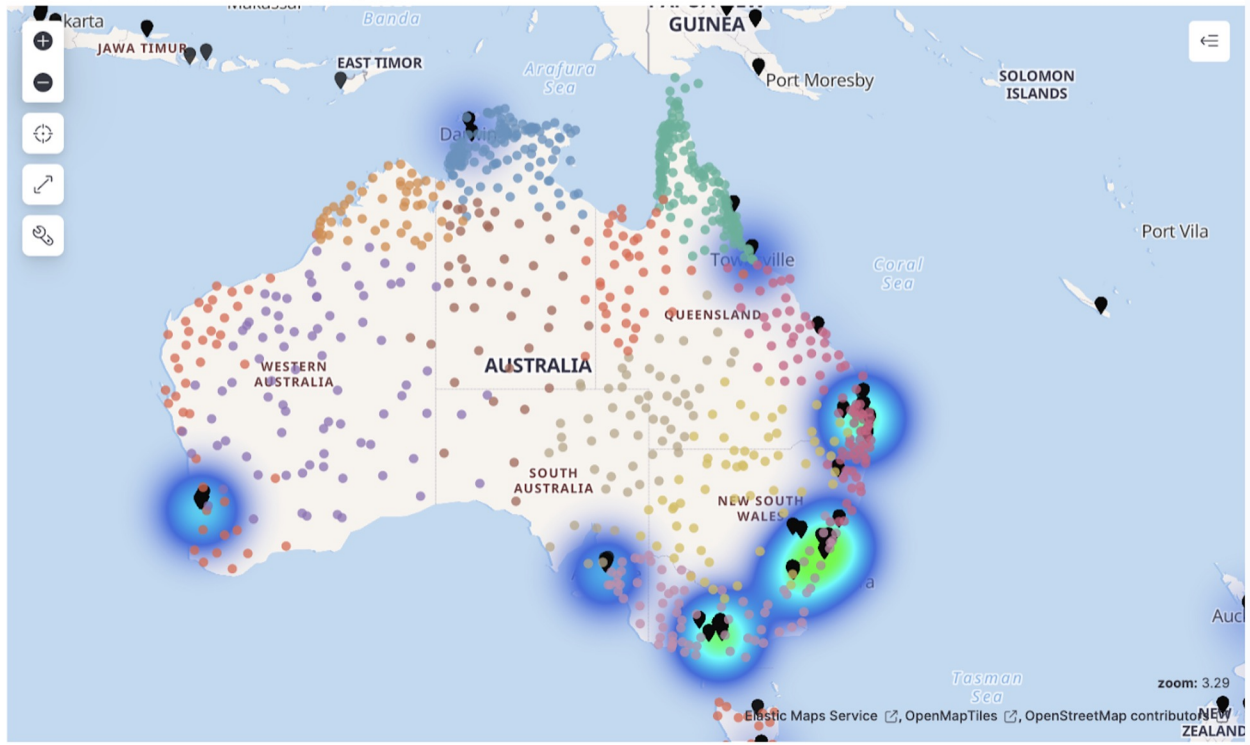
1492
Institutions

19
Disciplines

302
Publishers

799
Funders

Map of institution of authorship and AustLang data



AIATSIS - Publications

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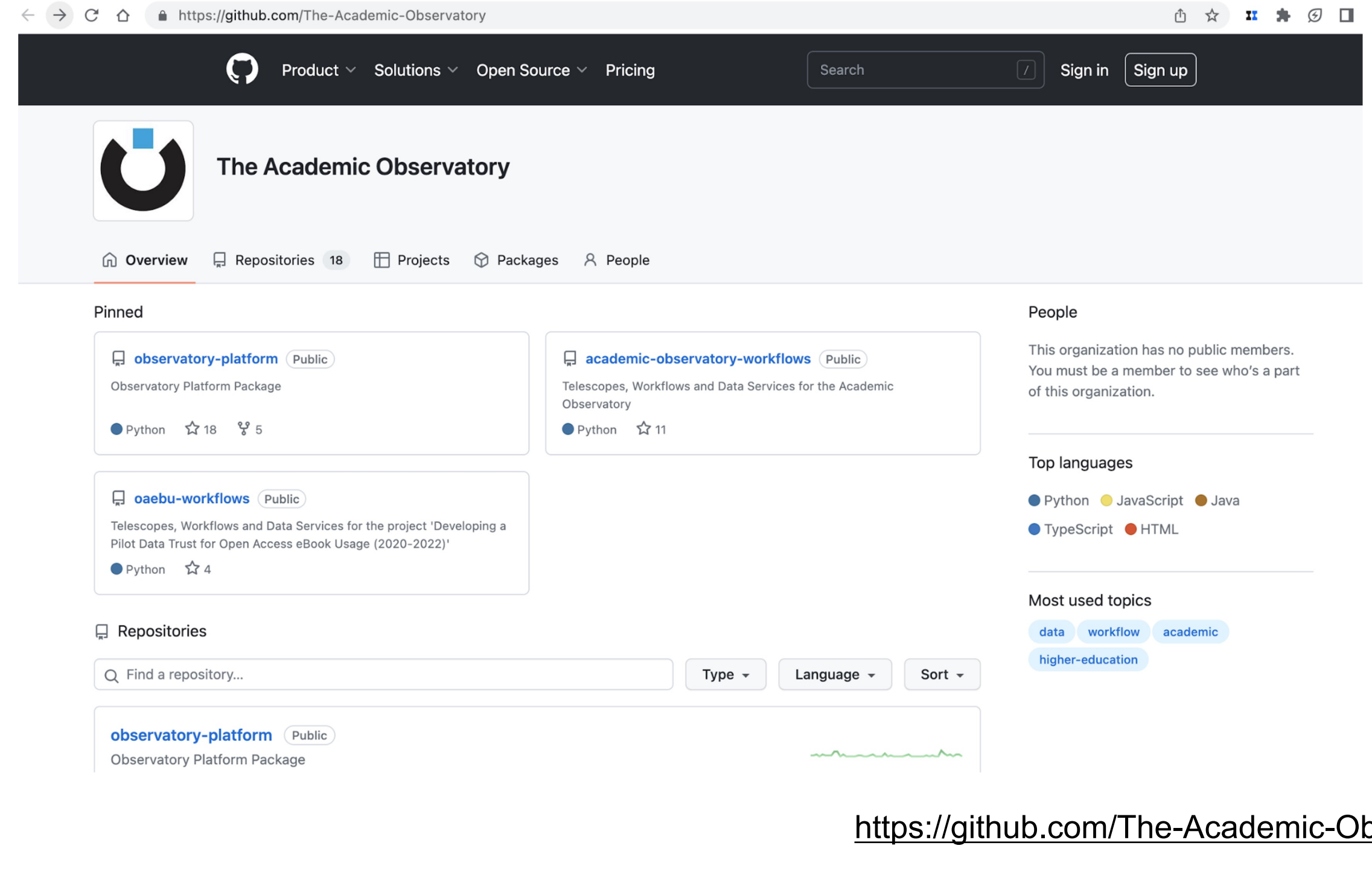
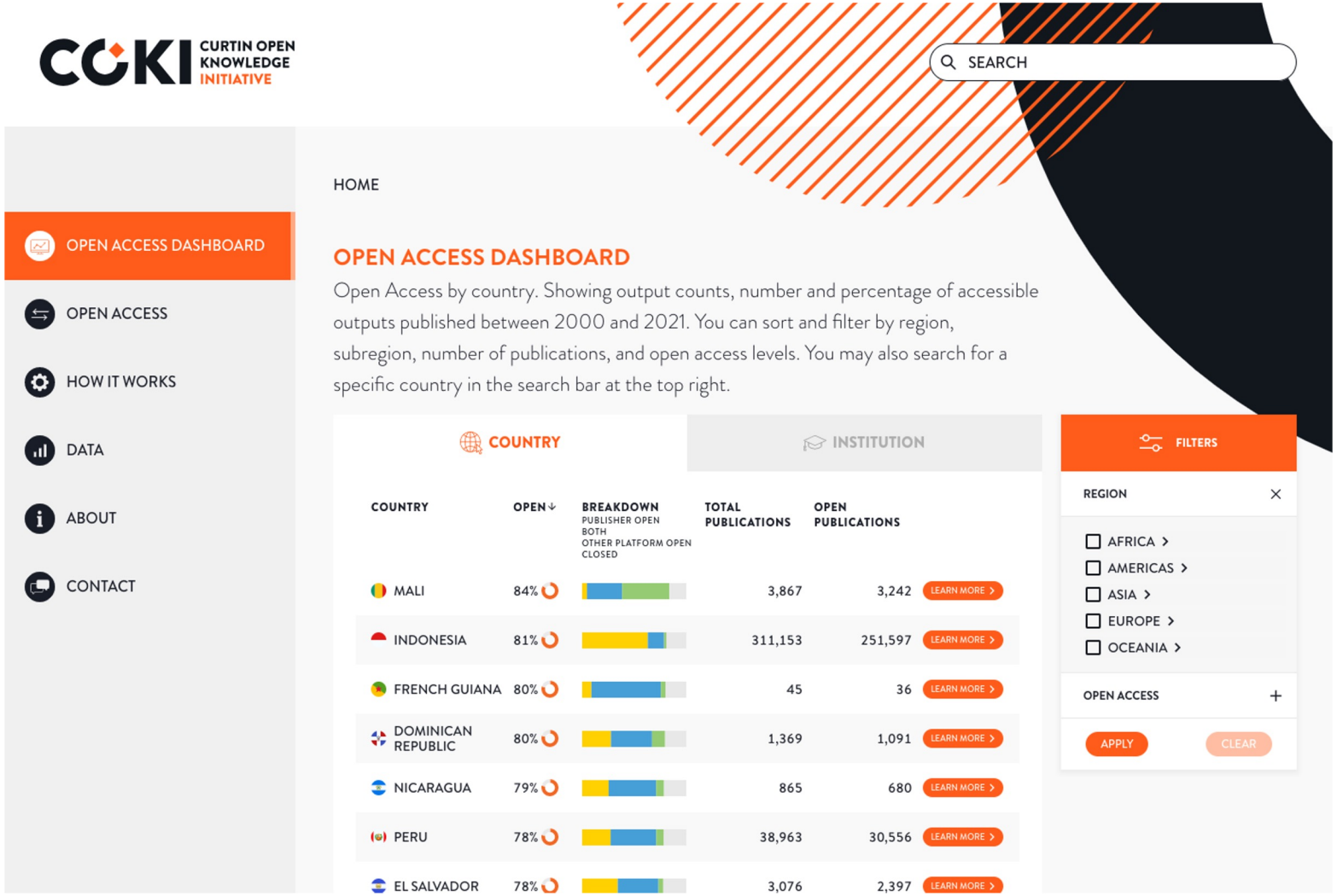


https://github.com/The-Academic-Observatory

OA Dashboard



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https://open.coki.ac/

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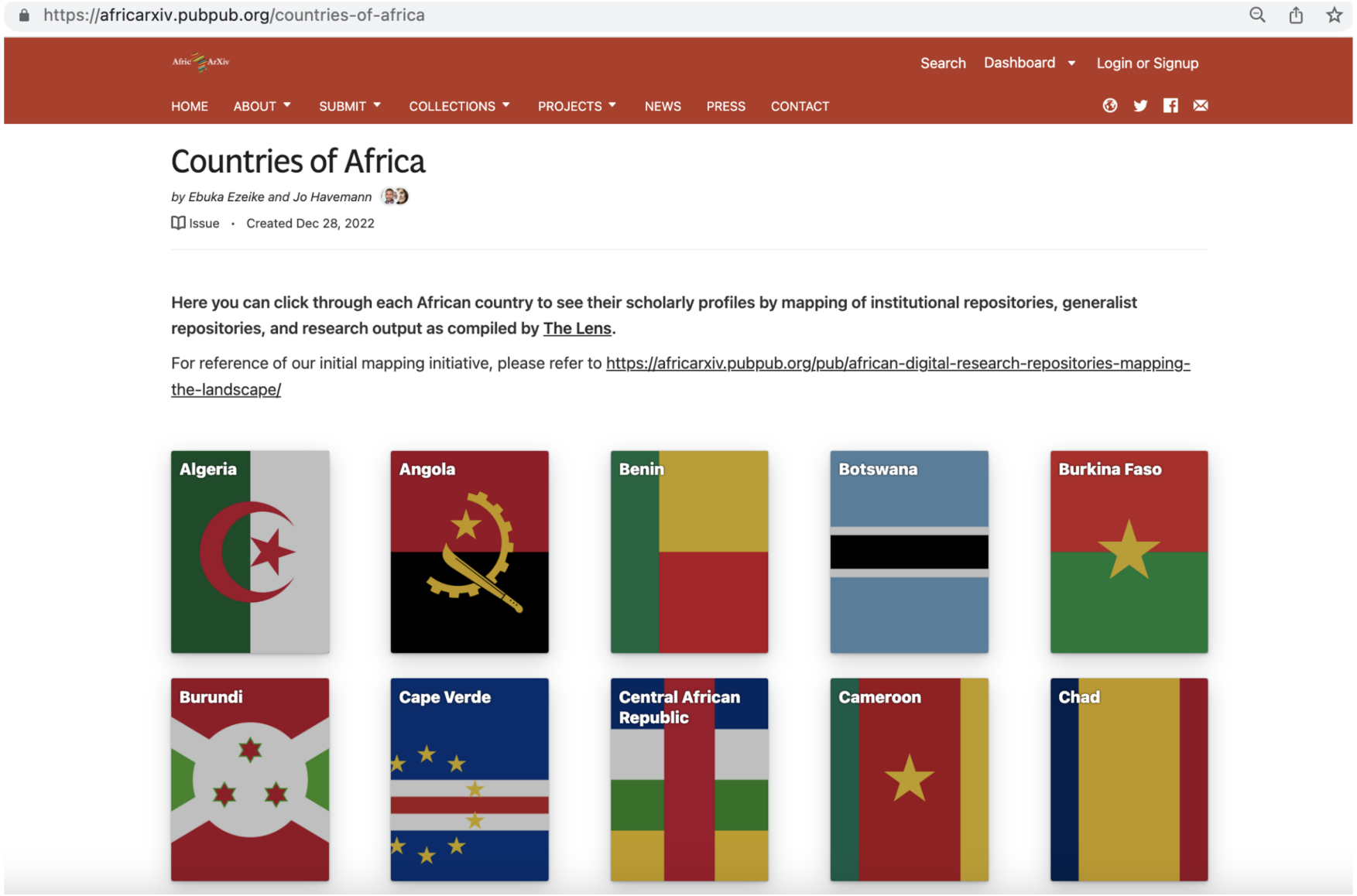
OA Dashboard



https://africarxiv.pubpub.org/countries-of-africa

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Thread

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The Principles of Open Scholarly Infrastructure

Governance

- **Coverage across the research enterprise** – it is increasingly clear that research transcends disciplines, geography, institutions and stakeholders. The infrastructure that supports it needs to do the same.
- **Stakeholder Governed** – a board-governed organisation drawn from the stakeholder community builds more confidence that the organisation will take decisions driven by community consensus and consideration of different interests.
- **Non-discriminatory membership** – we see the best option as an "opt-in" approach with a principle of non-discrimination where any stakeholder group

Thank You…. Questions?

USEFUL LINKS

- Curtin Open Knowledge Initiative: https://openknowledge.community/
- COKI Open Access Dashboard: https://open.coki.ac/
- Open Knowledge Institutions: Reinventing Universities: https://mitpress.mit.edu/9780262542432/open-knowledge-institutions/
- Open access research outputs receive more diverse citations: https://doi.org/10.5281/zenodo.7081036
- COKI GitHub: https://github.com/The-Academic-Observatory
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