

# All of us together

UK Health Data Research Alliance Symposium

Tuesday 1 December 2020  
09:30 - 17:00

## International open research and data sharing

Chair: Georgina Humphreys, Wellcome Trust

Panellists: Phaik Yeong Cheah, University of Oxford; Gary Saunders, ELIXIR; Tim Smith, CERN; Rachel Plachcinski, HDR UK Public Advisory Board

**HDRUK**  
Health Data Research UK

UK Health Data  
Research Alliance

Health Data Research  
Innovation Gateway

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[hdruk.ac.uk/HDRAlliance20](https://hdruk.ac.uk/HDRAlliance20)

@HDR\_UK  
#HDRAlliance20



# HDRUK: International open research and data sharing

Gary Saunders, Human Data Coordinator, ELIXIR

1st December, 2020



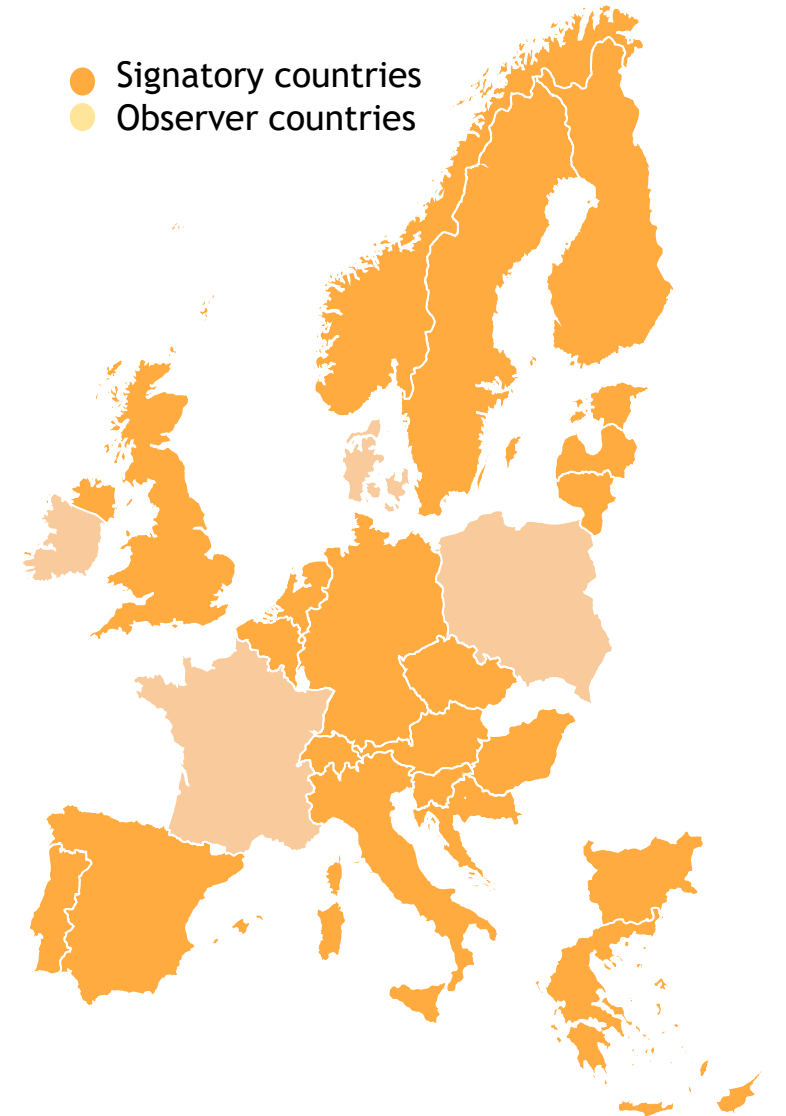
[gary.saunders@elixir-europe.org](mailto:gary.saunders@elixir-europe.org)

# Who are winners of data sharing?

## Citizens



- Signatory countries
- Observer countries

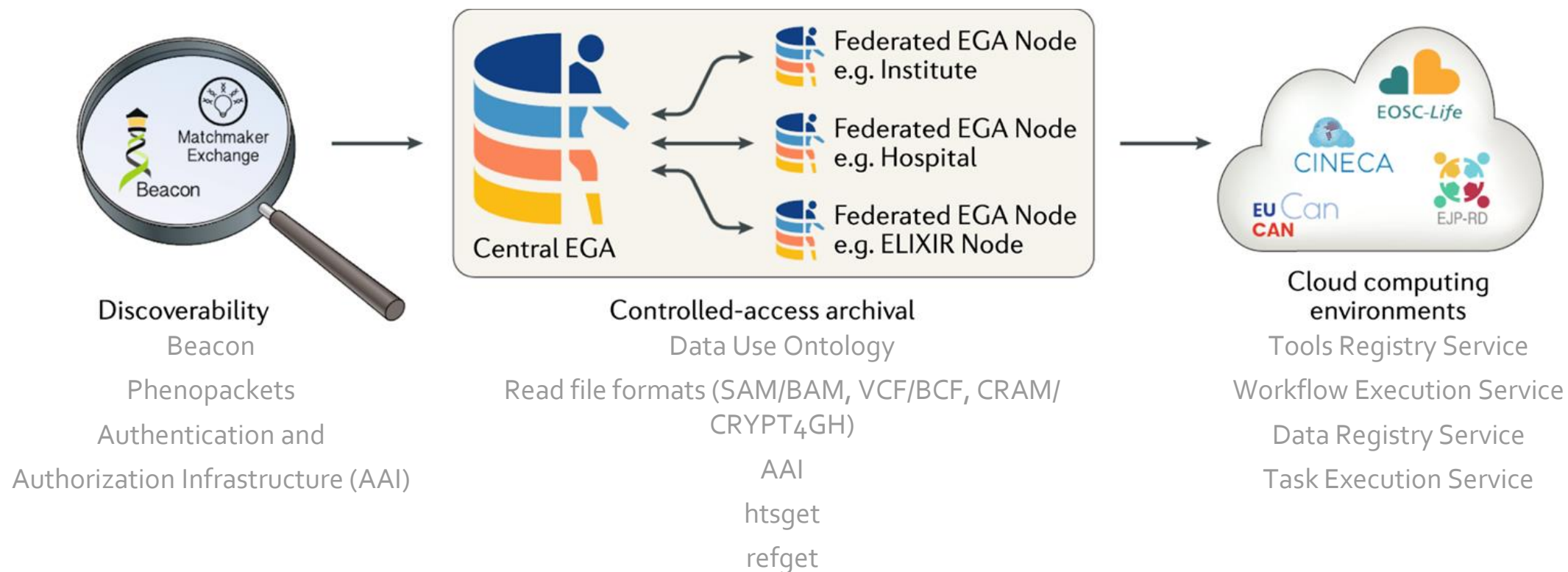


Need to demonstrate impact and socio-economic benefit

# What works well?

## Collaborate On Standards, Compete On Implementation

Driving interoperability using GA4GH standards



Connect via a standards-based federation - innovative implementations

# What comes next?

## *Federated Data Analysis & Implementations Sustained Nationally*



Shared vision and roadmaps for a coordinated European infrastructure





# Services at CERN Open Data



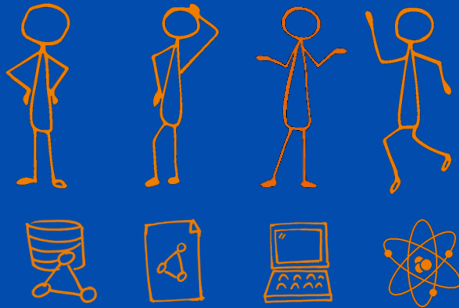
Tim SMITH



UK Health Data Research Alliance Symposium – 2020/12/01

# CERN Open Data

Education



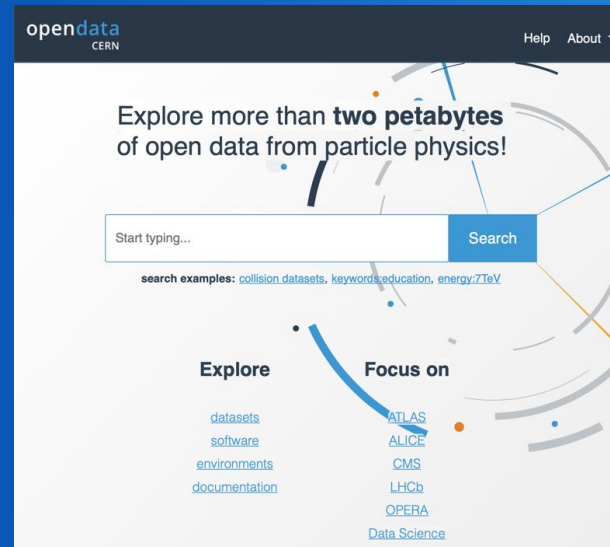
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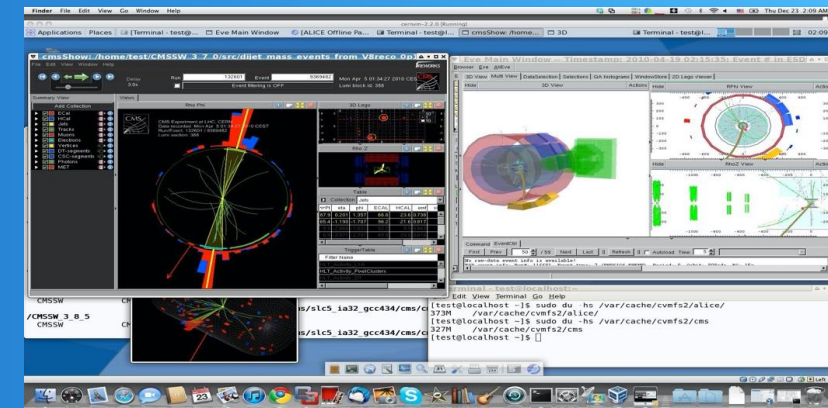
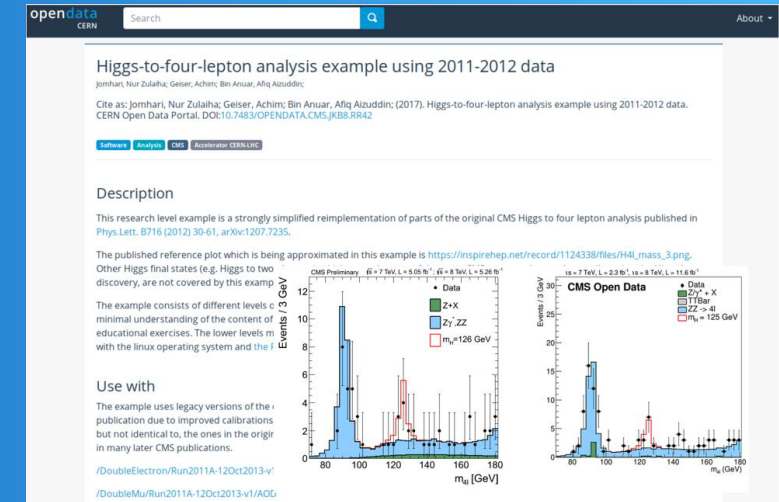
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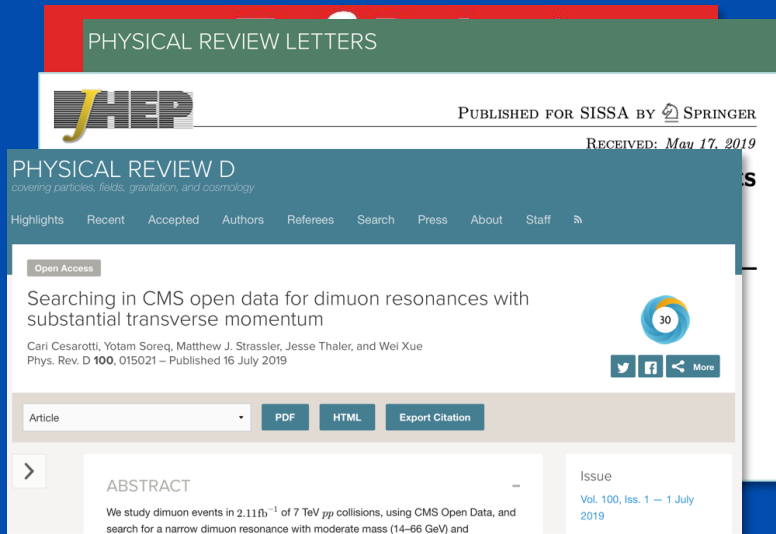
<http://opendata.cern.ch>



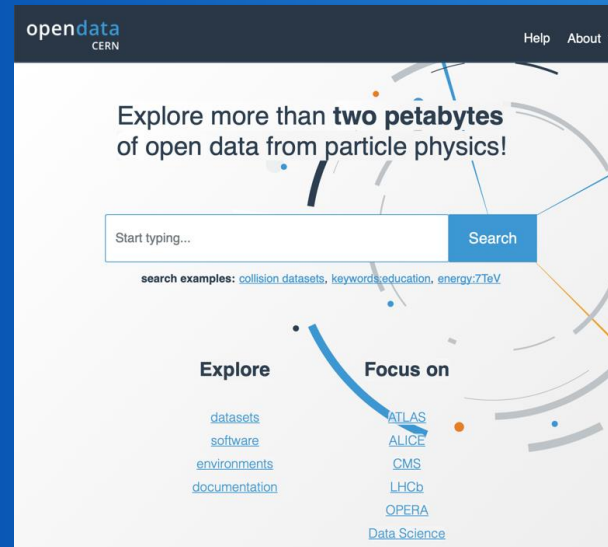
Research



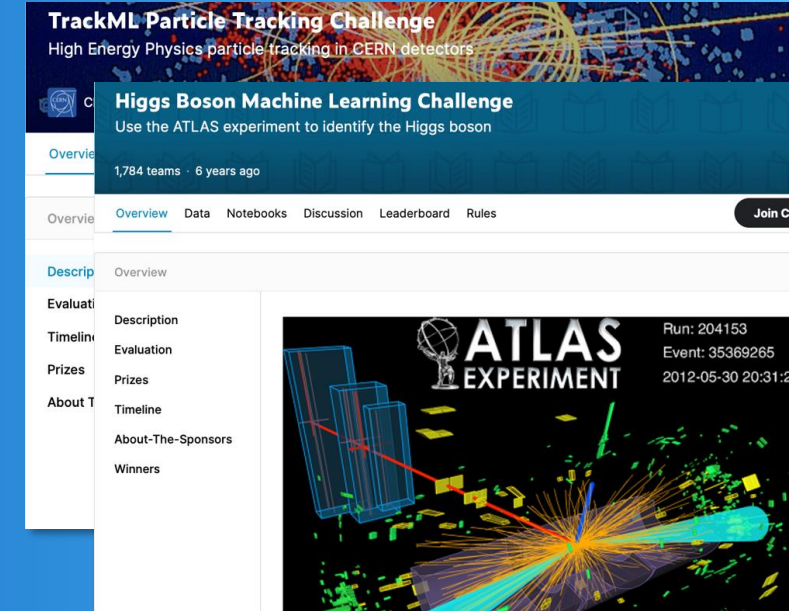
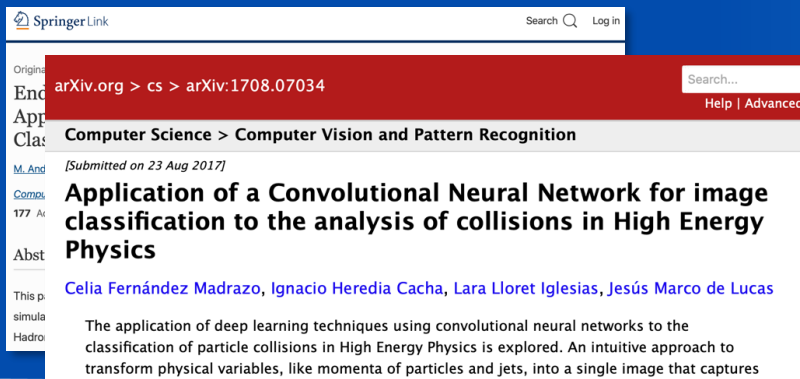
# For Everyone !



New theories



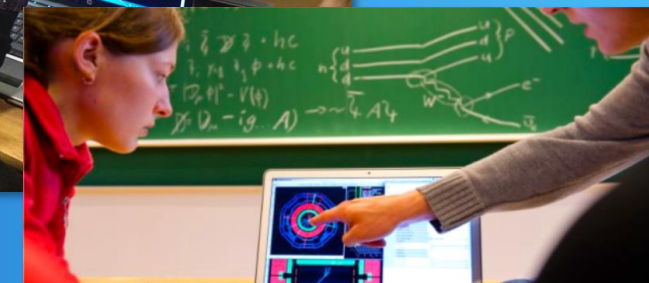
Machine/Deep Learning



New Communities



Next Generation



@TimSmithCH







The background is a dark blue space filled with a dense cloud of glowing blue particles and dust. A bright, curved arc of light and particles sweeps across the right side of the image, creating a sense of motion and energy.

opendata  
CERN

zenodo

INVENIO

# International involvement of patients and the public

*Rachel Plachcinski*  
*Cochrane Consumer Network Executive*  
*HDR-UK Public Advisory Board*

Trusted evidence.  
Informed decisions.  
Better health.





**1,790 consumers, across 79 countries**



# What's worked

- Consumers have been part of Cochrane since it began in 1993
- A supported network, with opportunities for training and strategic involvement
- Statement of Principles for Consumer Involvement developed in 2016, based on equity, inclusion and partnership
- The Consumer Network Executive developed its first strategy this year



# Who wins?

- People using healthcare – consumer input helps shape research so it answers the questions important to users
- The organisation – rooted in the experiences of both researchers and patients
- Researchers – when done well, consumer involvement helps shape researcher development





# What's next?

- Evaluating the implementation of the Statement of Principles
- Attracting more consumers from LMICs
- Tech solutions for those accessing documents via smartphone or tablet
- Time and support for those who speak English as a second language
- Aligning national and international approaches and standards, eg payment/ reward



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Coming up next...

16:00-16:40 Closing plenary

16:40-17:00 Networking session

Find the links to join in your brochure or at [hdruk.ac.uk/symposium-links-20](https://hdruk.ac.uk/symposium-links-20)

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