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





Health Data Research Innovation Gateway

→ Join the conversation:

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

Who are winners of data sharing?

Citizens

DECLARATION OF COOPERATION

Towards access to at least 1 million sequenced genomes in the European Union by 2022







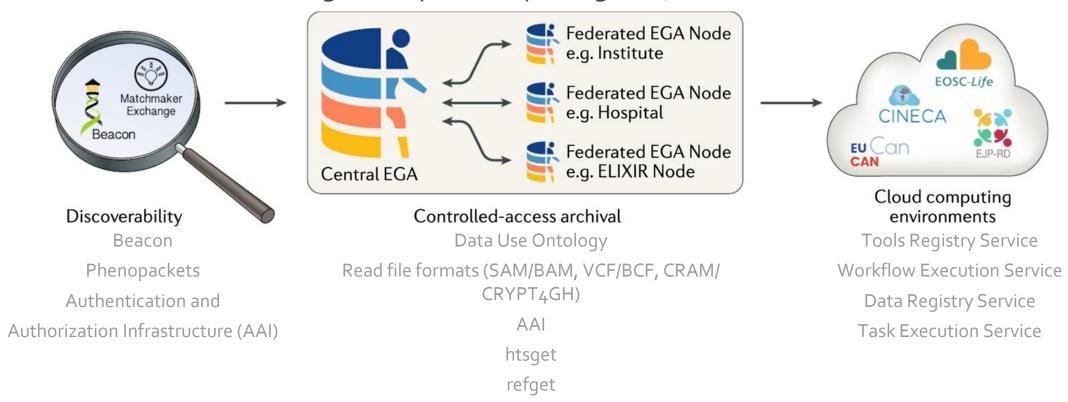
Need to demonstrate impact and socio-economic benefit



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

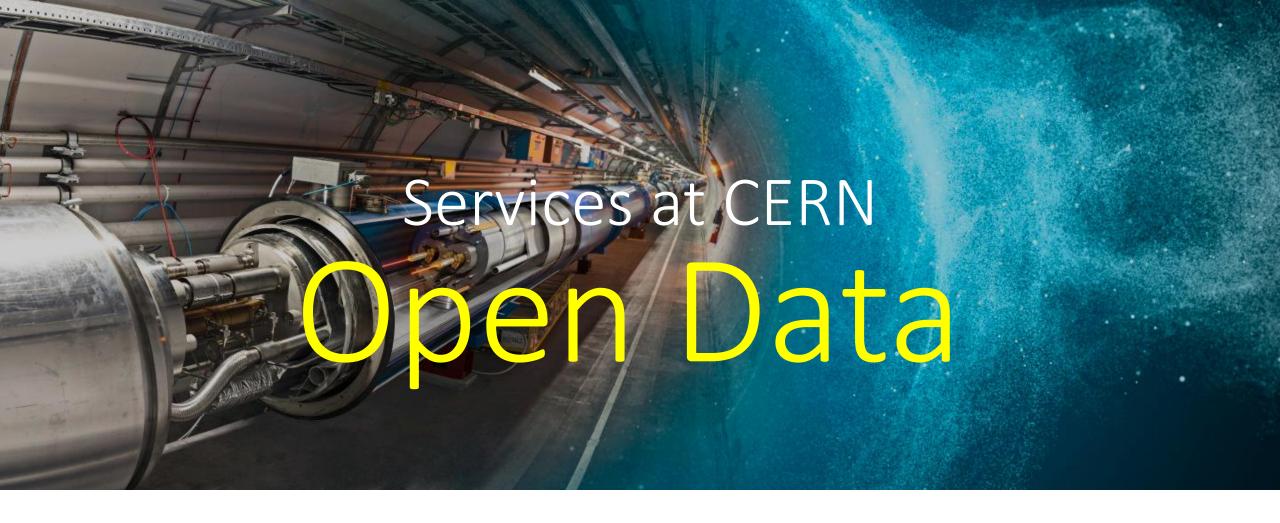


predominantly research-driven activity to one driven through health care as many countries in Europe now have nascent precision medicine programmes. To maximize the value of the genomic data generated, these data will need to be shared between institutions and across countries. In recognition of this challenge, 21 European countries recently signed a declaration to transnationally share data on at least 1 million human genomes by 2022. In this Roadmap, we identify the challenges of data sharing across borders and demonstrate that European research infrastructures are well-positioned to support the rapid implementation of widespread genomic data access.



Shared vision and roadmaps for a coordinated European infrastructure







Tim SMITH



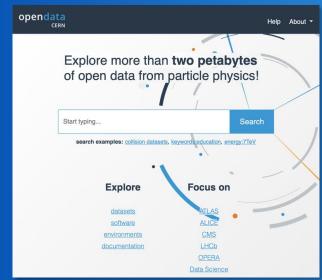
CERN Open Data

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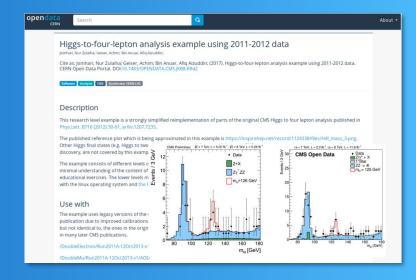
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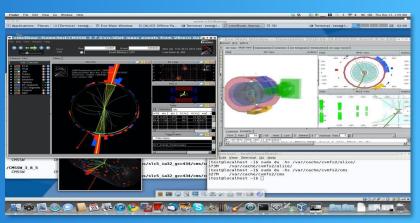




http://opendata.cern.ch

Education





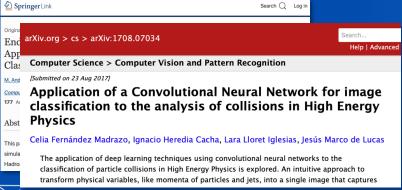
Research



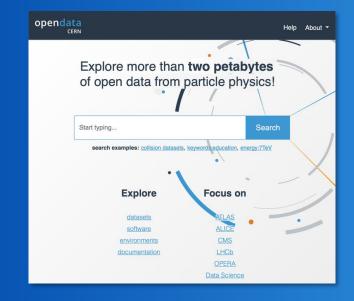
PHYSICAL REVIEW LETTERS PUBLISHED FOR SISSA BY SPRINGER RECEIVED: May 17, 2019 PHYSICAL REVIEW D Covering particles, fedds, grantation, and cosmology Highlights Recent Accepted Authors Referees Search Press About Staff is Searching in CMS open data for dimuon resonances with substantial transverse momentum Cari Cesarctit, Yotam Soreq, Matthew J. Strassler, Jesse Thaler, and Wel Xue Phys. Rev. D 100, 015021 – Published 16 July 2019 Article PDF HTML Export Citation Issue Vol. 100, lss. 1 — 1 July 2019 We study dimuon events in 2.11fb. 1 of 7 TeV pp collisions, using CMS Open Data, and search for a narrow dimuon resonance with moderate mass (14-66 GeV) and

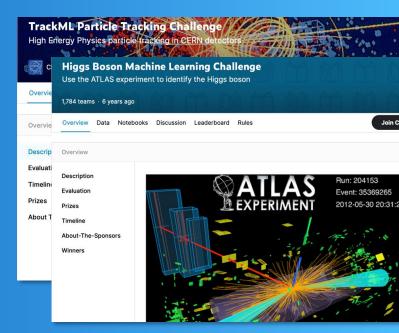
New theories

Machine/Deep Learning



For Everyone!



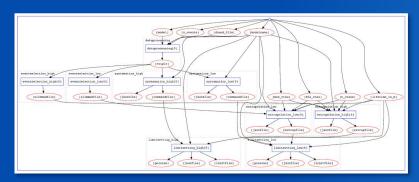


New Communities

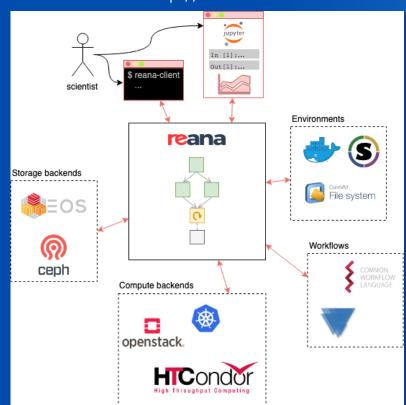


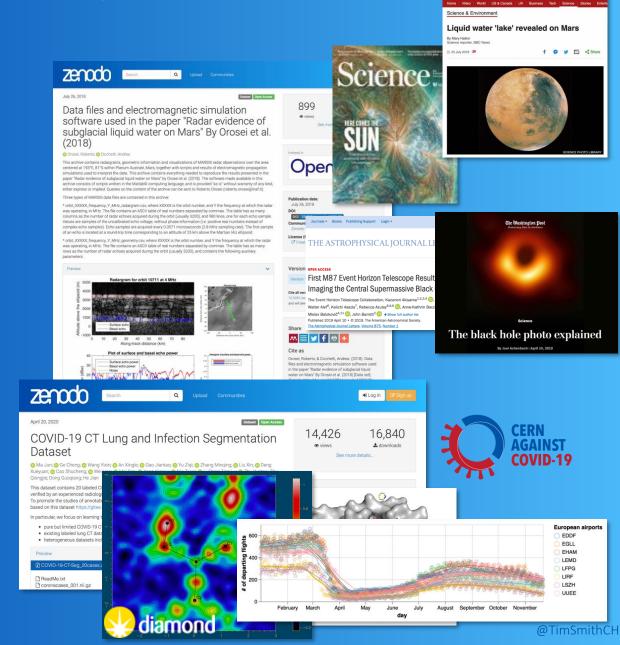


Reusability



http://reana.io





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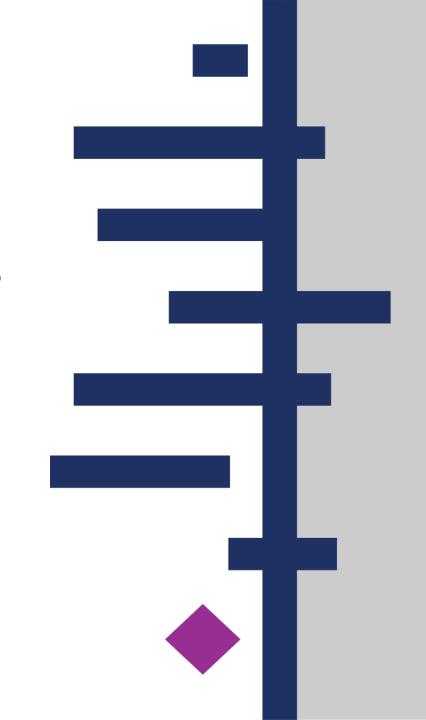
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International involvement of patients and the public

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



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→ Join the conversation: