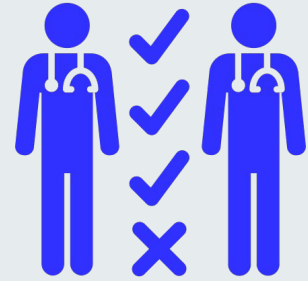


# Wikiproject Clinical Trials



WIKIPEDIA

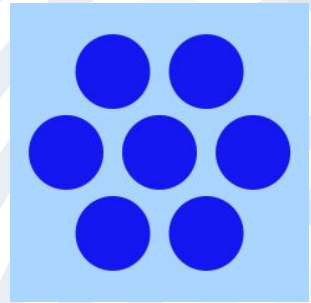
# Lane Raspberry

Wikimedian in Residence

School of Data Science

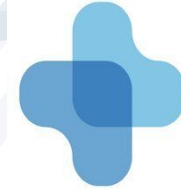
University of Virginia

user:blueraspberry



# Thanks to project contributors

- Duke University, Sheri Tibbs
- ClinWiki
  - William Hoos
  - Amy Westermann
- Vanderbilt University
  - Steven James Baskauf
  - Clifford Anderson
  - Philip Walker
- PCORI, Jeffrey Keefer
- Scholia
  - Daniel Mietchen
  - Finn Årup Nielsen
  - Egon Willighagen
- Wikimedia Bangladesh, Tanvir Rahman
- University of Virginia, Cherrie Kwok
- Wellcome Trust



# Agenda

1. What did we do with clinical trials?
2. What does this bring to our Wiki?
3. Background on Wiki + medicine
4. How did we do this?
5. What next?

**We imported  
ClinicalTrials.gov  
to Wikidata  
and curated it wiki style**



# Statistics

356,831 - Number of clinical trials

356,536 - Links to ClinicalTrials.gov

177,420 - Number of clinical trial phases links

report from



# Sample clinical trial

NIH U.S. National Library of Medicine

*ClinicalTrials.gov*

Find Studies ▾

About Studies ▾

Submit Studies ▾

Resources ▾

Ab

[Home](#) > [Search Results](#) > Study Record Detail

## A Study of Induction and Maintenance Treatment of Advanced Non-squamous Non-Small Cell Lung Cancer



The safety and scientific validity of this study is the responsibility of the study sponsor and investigators. Listing a study does not mean it has been evaluated by the U.S. Federal Government. Read our [disclaimer](#) for details.

ClinicalTrials.gov Identifier: NCT00789373

Recruitment Status ⓘ : Completed

First Posted ⓘ : November 11, 2008

Results First Posted ⓘ : July 18, 2011

Last Update Posted ⓘ : December 14, 2018

### Sponsor:

Eli Lilly and Company

### Information provided by (Responsible Party):

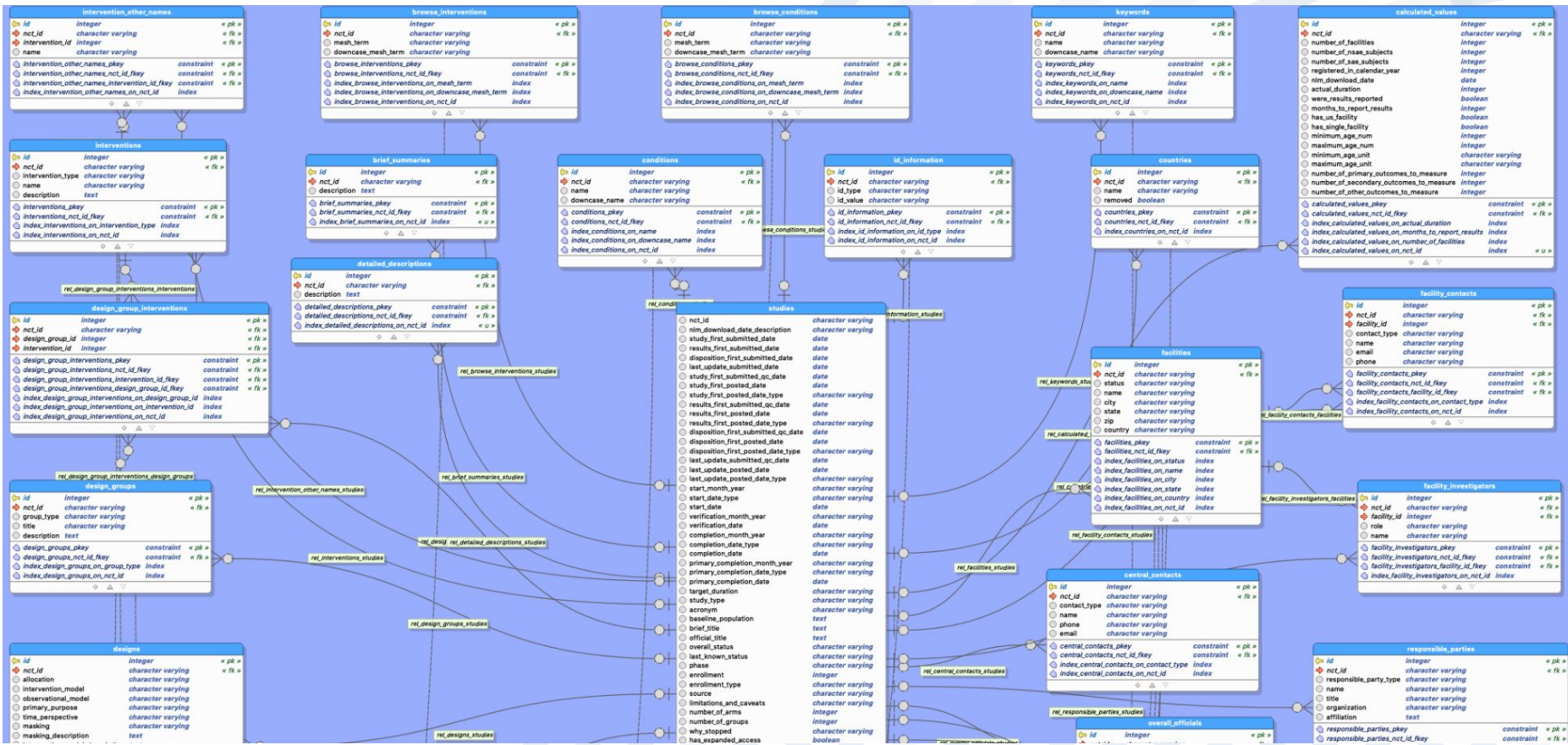
Eli Lilly and Company

# Basic information

- disease treated
- drug used
- who managed
- sponsors
- research sites
- when
- how many people
- phase
- status
- catalog numbers



# Data schema



# Wiki style data curation

- disambiguation
- placement in ontology
- remixing with other datasets
- language translation

# Visit WikiProject Clinical Trials

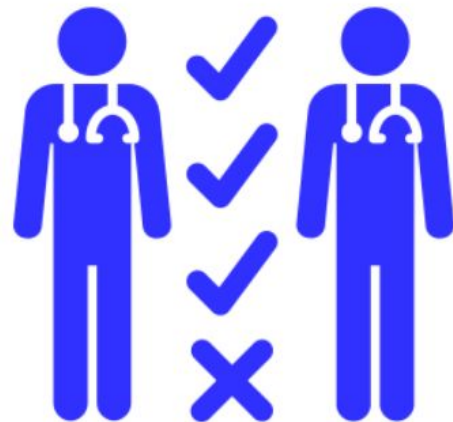
## Wikidata:WikiProject Clinical Trials

[Home](#)[Models](#)[Queries](#)[Members](#)[About](#)[Discuss](#)

**WikiProject Clinical Trials** is a Wikidata community project to curate [Wikidata's](#) collection of information on clinical trials.

### **Contents** [\[hide\]](#)

- 1 [Typical activities](#)
- 2 [Objectives](#)



**This matters because it  
brings medical  
knowledge to new users**



# Wikidata Query Service



## Wikidata Query Service



```
1 #defaultView:BubbleChart
2 SELECT (COUNT(DISTINCT ?trial)
3 WHERE {
4     ?trial wdt:P31 wd:Q30612 .
5     { ?trial wdt:P8329 ?PI .}
6
7     { ?PI wdt:P108 ?org }
```



Wikip-e-tan

# Requests we can make

Show me clinical trials...

- for a particular disease
- with a particular drug
- in my city
- sponsored by an organization
- headed by a particular person



# Requests we can make

Show me clinical trials...

- studying COVID
- researching malaria vaccines
- in cities with low population
- sponsored by new companies
- headed by non-scientists



# Typical clinical trial

what happens

1. company sponsors
2. institute hosts
3. scientist manages
4. volunteers join
5. experiment happens
6. results published
7. drug developed

data of interest to wiki

1. link list from article
2. university profile
3. show in biography
4. show on map
5. linked data to science
6. link to WikiCite
7. linked data to medicine



# Wikipedia is a highly popular, high quality medical information resource



“

The literature positions Wikipedia as a prominent health information resource...  
Wikipedia's health content is accessed frequently...

Smith DA (2020) [Situating Wikipedia as a health information resource in various contexts: A scoping review](#). PLoS ONE 15(2): e0228786.



**WIKIPEDIA**  
The Free Encyclopedia

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[Random article](#)

Article

[Talk](#)

# Health information on Wikipedia

From Wikipedia, the free encyclopedia

The [Wikipedia online encyclopedia](#) has, since the late 2000s, served as a primary source of health information. Wikipedia are popularly accessed as [results](#) from [search engines](#), which means that many people who seek **health information on Wikipedia**, the scope of health information available on Wikipedia is largely determined by the results of search engines.



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The Free Encyclopedia

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Article [Talk](#)

# Wikipedia coverage of the COVID-19 pandemic

From Wikipedia, the free encyclopedia

The [COVID-19 pandemic](#) is covered in [Wikipedia](#) extensively, in real-time, and across many languages, with many existing articles being amended to take account of the [pandemic](#)'s effect on them. Wikipedia achieved that coverage – received widespread media attention for its comprehensiveness, reliability,

**Contents** [\[hide\]](#)

# Scholia Profile of Health & Wikipedia

Wikidata Query Service

topic: content:span

### Recently published works on the topic

Show 10 entries

Date	Work	Topics
2021-09-29	Wikipedia in Health Professional Schools: from an Opponent to an Ally	Wikipedia // evidence-based medicine // health information on Wikipedia
2021-09-28	Representing COVID-19 information in collaborative knowledge graphs: The case of Wikidata	Wikidata // COVID-19 pandemic // SARS-CoV-2 // COVID-19 // Knowledge graph // WikProject COVID-19 // Wikidata's response to the COVID-19 pandemic // collaborative curation
2021-08-14	An overview of the COVID-19 related content of Wikidata projects	COVID-19 pandemic // SARS-CoV-2 // COVID-19 // Wikidata project // Wikidata's coverage of medical topics // WikProject COVID-19 // Wikidata's response to the COVID-19 pandemic
2021-07-01	Wikipedia for multilingual COVID-19 vaccine education at scale	Wikipedia // health education // scifiability // health information on Wikipedia // maintenance // vaccine hesitancy // COVID-19 vaccine // vaccine education // COVID-19 // COVID-19 pandemic
2021-06-16	Developing a scalable framework for partnerships between health agencies and the Wikimedia ecosystem	scifiability // medical organization // health information on Wikipedia // partnerships // Wikimedia project
2021-04-19	Assessing the quality of health-related Wikipedia articles with generic and specific metrics	health information on Wikipedia // data quality
2021-04-01	Does the packaging of health information affect the assessment of its reliability? A randomized controlled trial protocol	Wikipedia // health information on Wikipedia // DISCERN
2021-03-25	FAIR and open multilingual clinical trials in Wikidata and Wikipedia	Wikipedia // English Wikipedia // Wikidata // open data // clinical trial // health information on Wikipedia // ClinicalTrials.gov // FAIR data
2021-03-01	Meta-Research: Citation needed? Wikipedia and the COVID-19 pandemic	Wikipedia // COVID-19 pandemic // COVID-19 // Wikidata's response to the COVID-19 pandemic
2021-01-01	Expanding Reach of Occupational Health Knowledge: Contributing Subject-Matter Expertise to Wikipedia as a Class Assignment	health information on Wikipedia // Wikidata in education

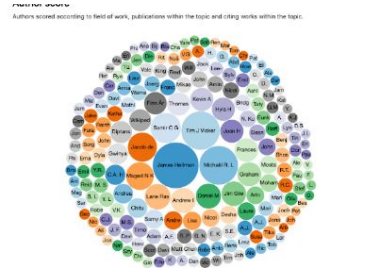
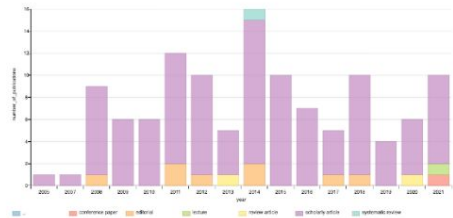
Wikidata Query Service

topic: recently-published-works:span

Showing 1 to 10 of 119 entries

Previous 1 2 3 4 5 ... 12 Next

### Publications per year

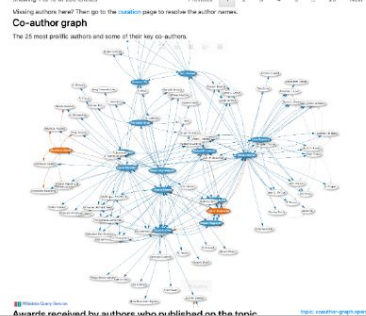


Wikidata Query Service

topic: author:score:graph:span

Show 10 entries

Score	Author	Example work
8700	James Heilman	Does the packaging of health information affect the assessment of its reliability? A randomized controlled trial protocol
6230	Michael R. Lachner	Wikipedia: a key tool for global public health promotion
6100	Tim J. Vickers	A gene walk for community annotation of gene function
3820	Samir C. Ghorri	Wikipedia: a key tool for global public health promotion
3520	Jacobs de Wolff	Wikipedia: a key tool for global public health promotion
3230	Maged H. Kameel	Scope, completeness, and accuracy of drug information in Wikipedia
2700	Lawe Heberly	FAIR and open multilingual clinical trials in Wikidata and Wikipedia
2620	Andrew I. Su	A gene walk for community annotation of gene function
2620	David Meehan	FAIR and open multilingual clinical trials in Wikidata and Wikipedia
2620	Jim Oates	Internet encyclopaedia: go head to head

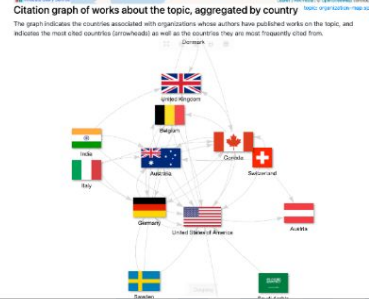
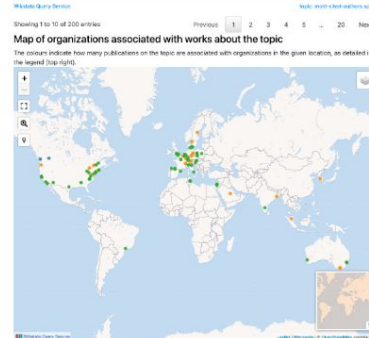


Wikidata Query Service

Number of citations

Search:

Number of citations	Author	Cited work example
54	James Heilman	Wikipedia: a key tool for global public health promotion
52	Michael R. Lachner	Wikipedia: a key tool for global public health promotion
52	Tim J. Vickers	Wikipedia: a key tool for global public health promotion
29	Samir C. Ghorri	Wikipedia: a key tool for global public health promotion
29	Jacobs de Wolff	Wikipedia: a key tool for global public health promotion
29	Maged H. Kameel	Wikipedia: a key tool for global public health promotion
26	Jim Oates	Internet encyclopaedia: go head to head
21	Gradyen Beards	Wikipedia: a key tool for global public health promotion
19	Joan H. Drenthkamp	Scope, completeness, and accuracy of drug information in Wikipedia
19	Hyun H. Park	Scope, completeness, and accuracy of drug information in Wikipedia



- 119 scholarly papers
- subtopics known
- authors tracked

# Why no clinical trials on Wikipedia?



WIKIPEDIA  
The Free Encyclopedia

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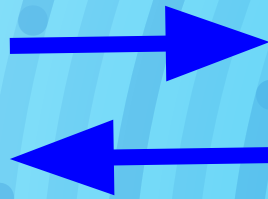
## RV 144

From Wikipedia, the free encyclopedia

**RV 144**, or the **Thai trial**, is the name of an [HIV vaccine clinical trial](#) combining HIV until July 2006,<sup>[1]</sup> publicly releasing efficacy findings in September 2009.

Only very unusual clinical trials are a good fit for Wikipedia.

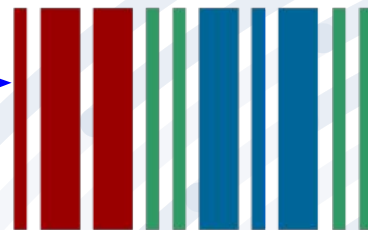
**Data remixing  
=  
new models for  
knowledge production**



ClinicalTrials.gov



CLINICAL TRIALS TRANSFORMATION INITIATIVE



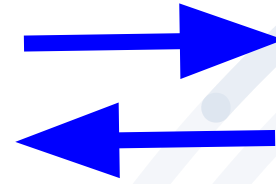
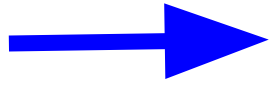
WIKIDATA

end time	P582	Point in time	end time: time an item ceases to exist or a statement stops being valid	Use of Dalfampridin in Primary Lateral Sclerosis <end time> January 2020	-
sponsor	P859	Item	sponsor, <i>Tabula gratulatoria</i> and research sponsor: organization or individual that sponsors this item	Opioid Prescribing After Cesarean Delivery <sponsor> Vanderbilt University Medical Center	-
main subject	P921	Item	topic, matter, topic of a work and subject: primary topic of a work (see also P180: depicts)	Use of Dalfampridin in Primary Lateral Sclerosis <main subject> motor neuron disease	-
number of participants	P1132	Quantity	number of participants: number of participants of an event, e.g. people or groups of people that take part in the event (NO units)	Opioid Prescribing After Cesarean Delivery <number of participants> 160	-
title	P1476	Monolingual text	original title and title: published name of a work, such as a newspaper article, a literary work, piece of music, a website, or a performance work	PARAMOUNT trial <title> A Study of Induction and Maintenance Treatment of Advanced Non-squamous Non-Small Cell Lung Cancer	-
short name	P1813	Monolingual text	abbreviation: short name of a place, organisation, person, Wikidata property, etc.	PARAMOUNT trial <short name> PARAMOUNT trial	-
medical condition treated	P2175	Item	disease that this pharmaceutical drug, procedure, or therapy is used to treat	Use of Dalfampridin in Primary Lateral Sclerosis <medical condition treated> motor neuron disease	di u:

Thanks Sheri Tibbs

Duke UNIVERSITY





- patient-centered wiki community
- patients and families edit trial records
- open data shared in Wikidata

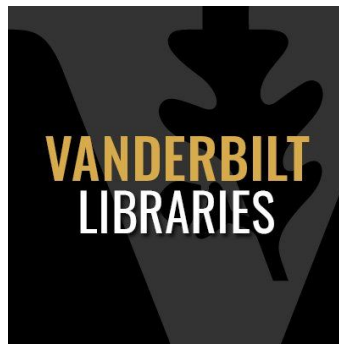
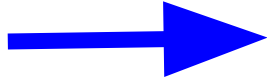
Thanks

William Hoos

Amy Westermann

ClinWiki volunteer editors

VANDERBILT  
UNIVERSITY



Vanderbot



- library profiles all university researchers
- library transfers profiles to Wikidata
- cross-reference with clinical trials

Thanks

Steven James Baskauf

Clifford Anderson

Philip Walker

- papers from PIs
- trials at Vanderbilt

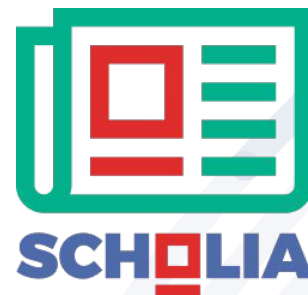
# pcori



- Patient-Centered Outcomes Research Institute
- Patient-focused clinical trials
- shared funding data not otherwise in C T.gov

Thanks

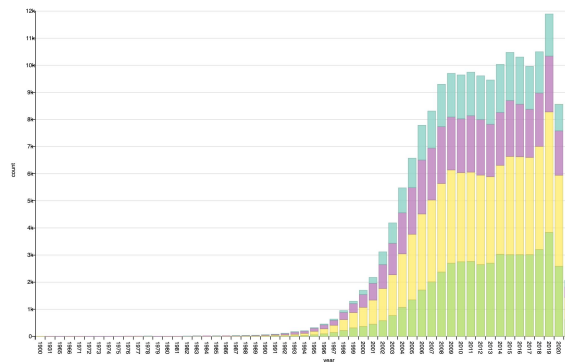
Jeffrey Keefer



- no data added
- data visualized!

Thanks  
Daniel Mietchen  
Finn Årup Nielsen  
Egon Willighagen

Phases



Medical conditions

Show  entries

Count	Medical condition	Example trial
10,093	<a href="#">diabetes</a>	<a href="#">Atherosclerosis Risk in Communities</a>
7,433	<a href="#">syndrome</a>	<a href="#">Serum Metabolomics Study of Polycystic Ovary Syndrome</a>
5,613	<a href="#">carcinoma</a>	<a href="#">Randomized Phase 1/2 Open-Label Trial of PR104 and Sorafenib in Patients with Advanced Hepatocellular Carcinoma (HCC)</a>

Interventions

Show  entries

Count	Intervention
5,180	<a href="#">cyclophosphamide</a>
3,187	<a href="#">paclitaxel</a>
3,182	<a href="#">Anesthetics, Combined</a>
2,625	<a href="#">cisplatin</a>
2,323	<a href="#">carboplatin</a>



বাংলা

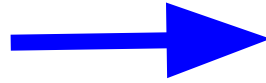


উইকিপিডিয়া  
একটি মুক্ত বিশ্বকোষ

- translation of English terms into Bangla
- For Wikidata, also migrates into Wikipedia
- রোগীভিত্তিক পরীক্ষণ for everyone

Thanks

Tanvir Rahman



- documentation
- interpretation
- management

Thanks

Cherrie Kwok

## FAIR and open multilingual clinical trials in Wikidata and Wikipedia

▼ [Lane Raspberry](#), [Daniel Mietchen](#)

### Abstract ▲

This project seeks to conduct language translation on metadata labels for research publications, attribution data, and clinical trials information to make data about medical research queriable in underserved languages through Wikidata and the Linked Open Web. This project has the benefit of distributing content through Wikipedia and Wikidata, which already have an annual userbase of a billion users and which already have established actionable standards to practice diversity, inclusion, openness, FAIRness, and transparency about program development. The impact will be localized access to basic research information in various Global South languages to integrate with existing community efforts for establishing the same. Although Wikidata development in this direction seems inevitable, the cultural and social exchange required to establish global multilingual research partnerships could begin now with support rather than later as a



Thanks  
Wellcome  
Trust

# What next?

## Curation for communities



# Next steps

Probably curation by university

1. import all researchers
2. disambiguate all research sites
3. showcase of research
4. connect with grant databases
5. match papers published



# Next steps

More consideration  
of FAIR and open data  
in Wikidata and in general

# Thanks to project contributors

- Duke University, Sheri Tibbs
- ClinWiki
  - William Hoos
  - Amy Westermann
- Vanderbilt University
  - Steven James Baskauf
  - Clifford Anderson
  - Philip Walker
- PCORI, Jeffrey Keefer
- Scholia
  - Daniel Mietchen
  - Finn Årup Nielsen
  - Egon Willighagen
- Wikimedia Bangladesh, Tanvir Rahman
- University of Virginia, Cherrie Kwok
- Wellcome Trust
- Presentation template by SlidesCarnival



# Any questions?

Lane Raspberry

user:blueraspberry

rasberry@virginia.edu

