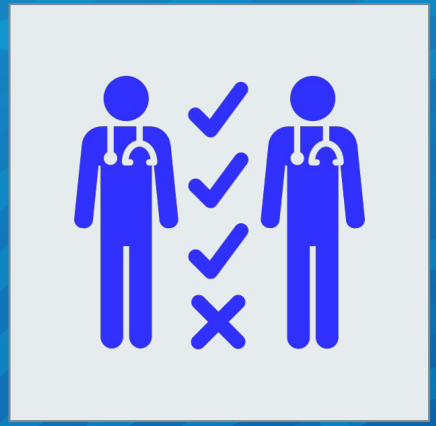
# Wikiproject Clinical Trials



# Lane Rasberry

## Wikimedian in Residence

School of Data Science
University of Virginia
user:bluerasberry

# 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 ▾ Abo

Home > Search Results > Study Record Detail

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

ClinicalTrials.gov Identifier: NCT00789373

⚠ 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.

Recruitment Status ℹ : Completed
First Posted ℹ : November 11, 2008
Results First Posted ℹ : July 18, 2011
Last Update Posted ℹ : December 14, 2018

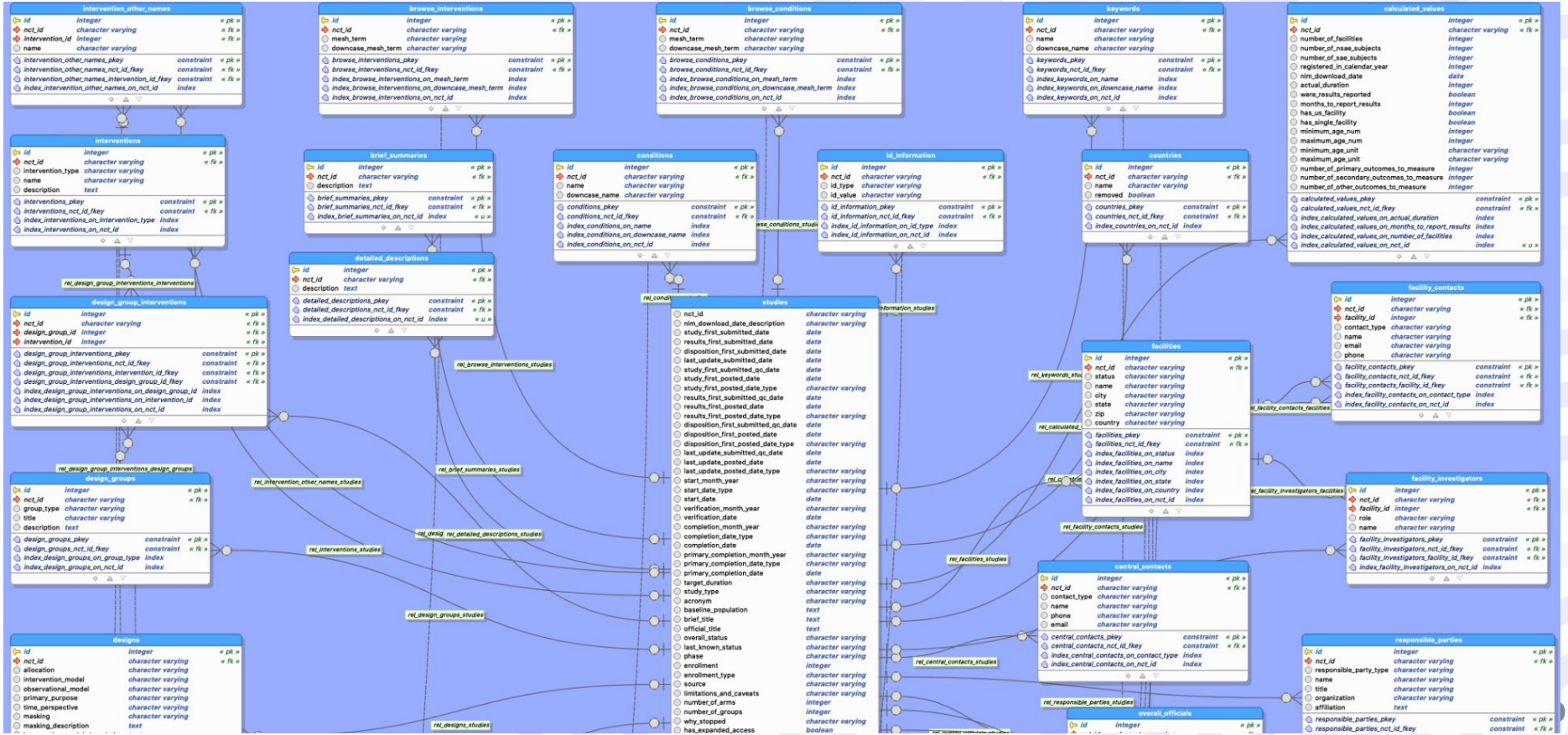
**Sponsor:**
Eli Lilly and Company

**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


intervention_other_names
browse_interventions
browse_conditions
keywords
calculated_values
interventions
brief_summaries
conditions
id_information
countries
detailed_descriptions
studies
facility_contacts
design_group_interventions
facilities
design_groups
facility_investigators
central_contacts
designs
responsible_parties
overall_officials

# 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 }
```

Wikipe-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

Main page
Contents
Current events
Random article

Article Talk

# Health information on Wikipedia

From Wikipedia, the free encyclopedia

The Wikipedia online encyclopedia has, since the late 2000s, served a
Wikipedia are popularly accessed as results from search engines, whi
people who seek **health information on Wikipedia**, the scope of hea

WIKIPEDIA
The Free Encyclopedia

Main page
Contents
Current events
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About Wikipedia
Contact us

Article Talk

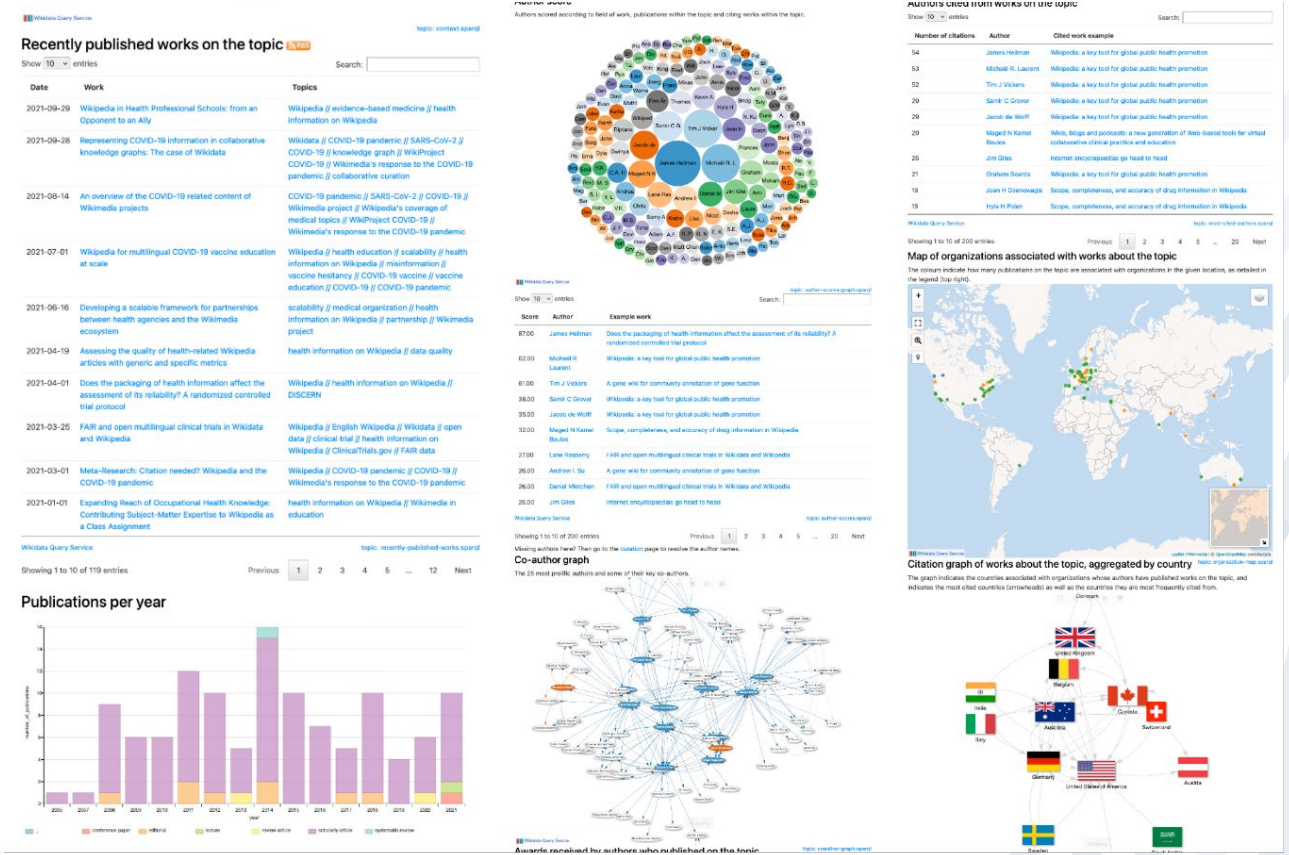
# Wikipedia coverage of the COVID-19 pandemic

From Wikipedia, the free encyclopedia

The COVID-19 pandemic is covered in Wikipedia extensively, in real-time, and across many langua
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, reliabilit

**Contents** [hide]

# Scholia Profile of Health & Wikipedia

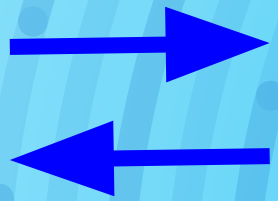



- 119 scholarly papers
- subtopics known
- authors tracked

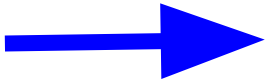
# Why no clinical trials on Wikipedia?

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

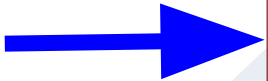
# Data remixing
# =
# new models for knowledge production



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, Tabula gratulatoria 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 | d u |

Thanks Sheri Tibbs

Duke UNIVERSITY

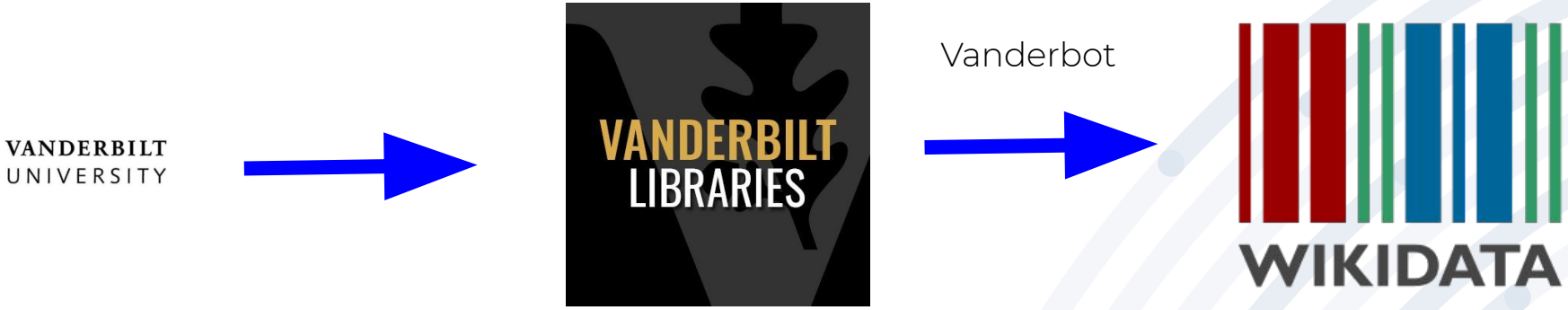
- patient-centered wiki community
- patients and families edit trial records
- open data shared in Wikidata

Thanks

William Hoos

Amy Westermann

ClinWiki volunteer editors

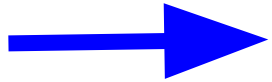



- library profiles all university researchers
- library transfers profiles to Wikidata
- cross-reference with clinical trials

Thanks
Steven James Baskauf
Clifford Anderson
Philip Walker

- papers from PIs
- trials at Vanderbilt

pcori

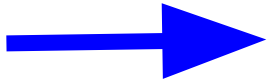


WIKIDATA

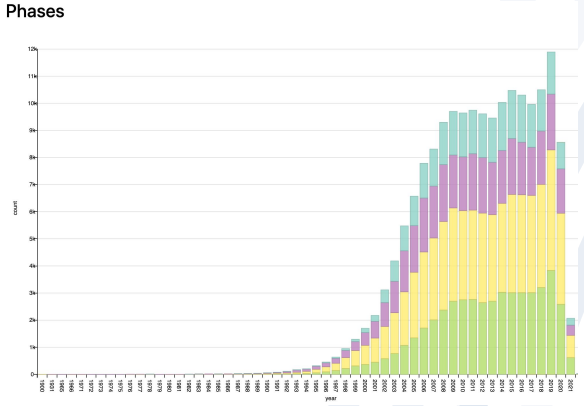
- Patient-Centered Outcomes Research Institute
- Patient-focused clinical trials
- shared funding data not otherwise in C T.gov

Thanks

Jeffrey Keefer



- no data added
- data visualized!




Medical conditions

Show 10 entries

| Count | Medical condition | Example trial |
|---|---|---|
| 10,093 | diabetes | Atherosclerosis Risk in Communities |
| 7,433 | syndrome | Serum Metabolomics Study of Polycystic Ovary Syndrome |
| 5,613 | carcinoma | Randomized Phase 1/2 Open-Label Trial of PR104 and Sora Carcinoma (HCC) |

Interventions

Show 10 entries

| Count | Intervention |
|---|---|
| 5,180 | cyclophosphamide |
| 3,187 | paclitaxel |
| 3,182 | Anesthetics, Combined |
| 2,625 | cisplatin |
| 2,323 | carboplatin |

Thanks

Daniel Mietchen

Finn Årup Nielsen

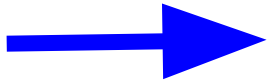
Egon Willighagen

বাংলা

- 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 Rasberry, 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
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- PCORI, Jeffrey Keefer
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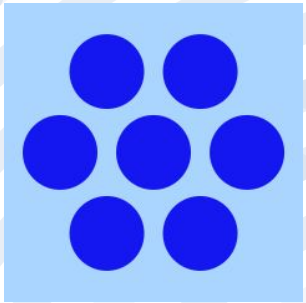
  - Daniel Mietchen
  - Finn Årup Nielsen
  - Egon Willighagen
- Wikimedia Bangladesh, Tanvir Rahman
- University of Virginia, Cherrie Kwok
- Wellcome Trust
- Presentation template by SlidesCarnival

# Any questions?

Lane Rasberry
user:bluerasberry
rasberry@virginia.edu