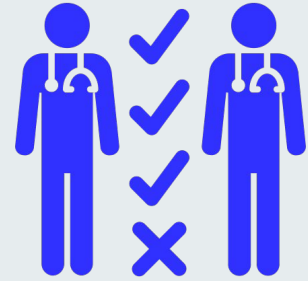


Wikiproject Clinical Trials



WIKIPEDIA

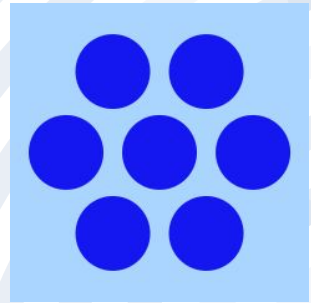
Lane Rasberry

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 ▾

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

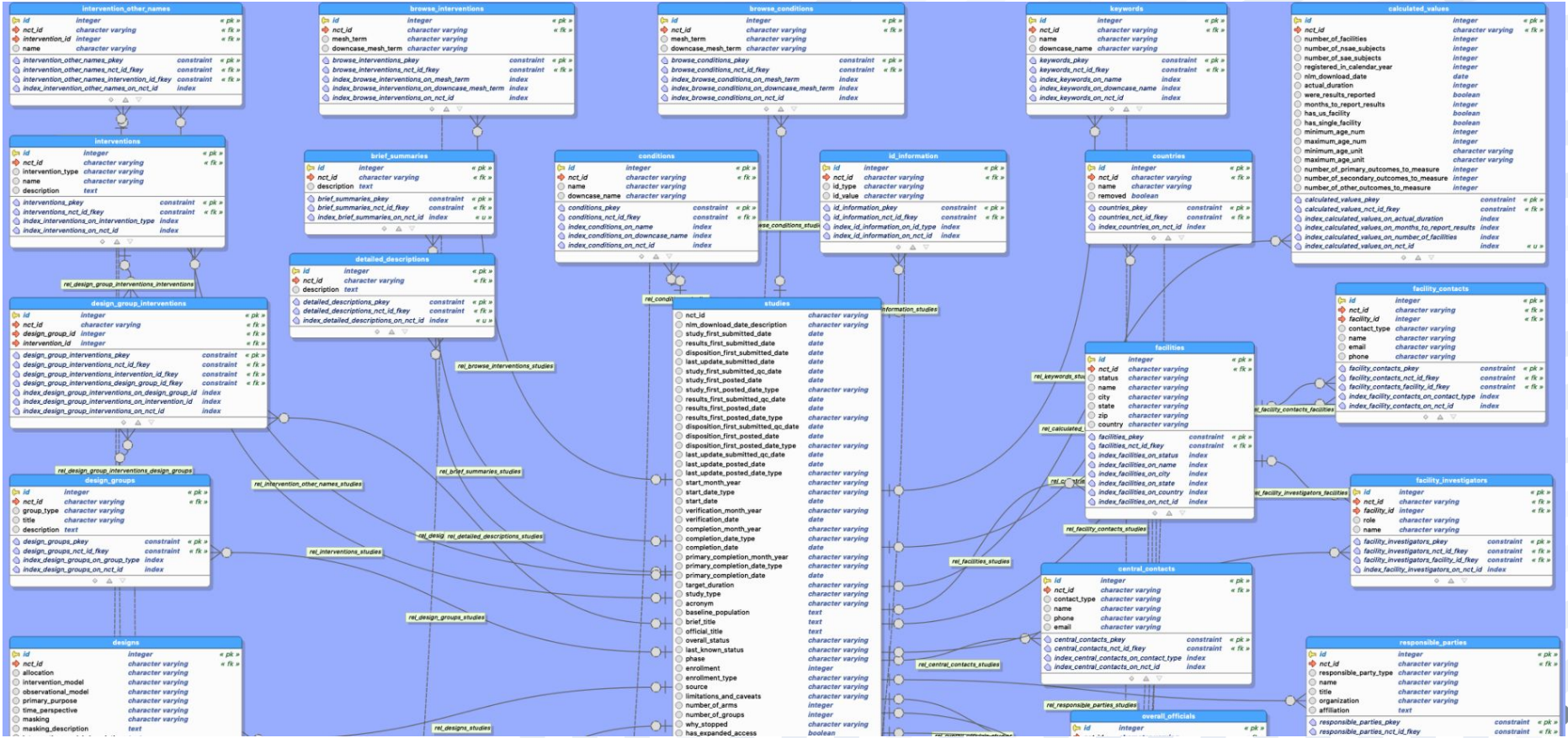
Information provided by (Responsible Party):

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](#)

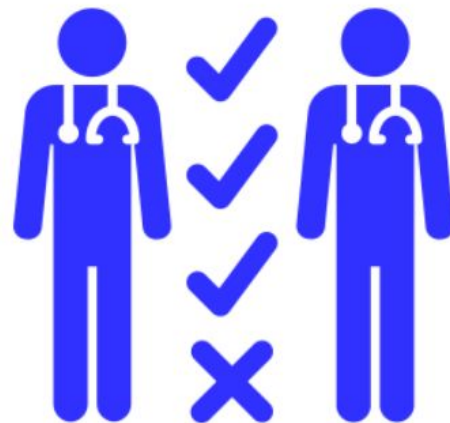
[Queries](#)

[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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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:spang

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 |

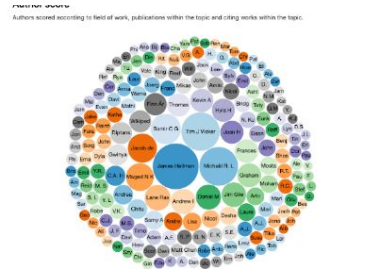
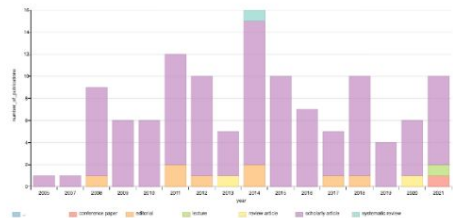
Wikidata Query Service

topic: recently-published-works:spang

Showing 1 to 10 of 119 entries

Previous 1 2 3 4 5 ... 12 Next

Publications per year

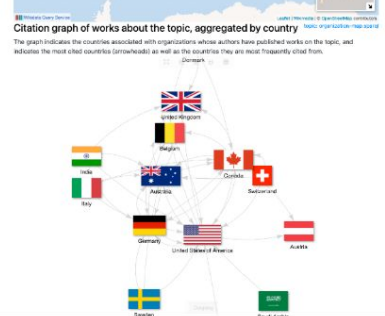
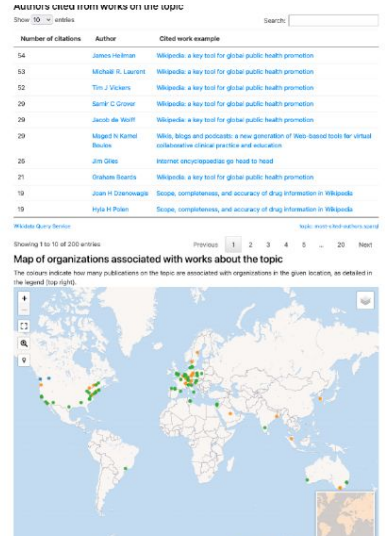
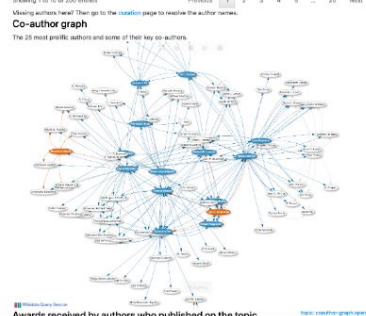


Wikidata Query Service

topic: author:recently-published-works:spang

Show 10 entries

| Score | Author | Example work |
|-------|--------------------|---|
| 8700 | James Helman | 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 wiki for community annotation of gene function |
| 3820 | Samir C. Grewal | Wikipedia: a key tool for global public health promotion |
| 3520 | Jacobs de Wolff | Wikipedia: a key tool for global public health promotion |
| 3230 | Maged N Kameel | Scope, completeness, and accuracy of drug information in Wikipedia |
| 2780 | Lawe Heberly | FAIR and open multilingual clinical trials in Wikidata and Wikipedia |
| 2680 | Andrew J. Su | A gene wiki for community annotation of gene function |
| 2630 | Daniel Meehan | FAIR and open multilingual clinical trials in Wikidata and Wikipedia |
| 2630 | Jim Oates | Internet encyclopaedia: go head to head |



- 119 scholarly papers
- subtopics known
- authors tracked

Why no clinical trials on Wikipedia?



WIKIPEDIA
The Free Encyclopedia

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[Talk](#)

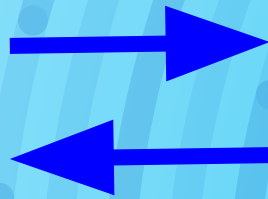
RV 144

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,^[1] publicly releasing efficacy findings in September 2009.

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

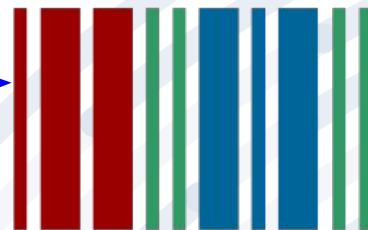
Data remixing
=
new models for
knowledge production



ClinicalTrials.gov



CLINICAL TRIALS TRANSFORMATION INITIATIVE

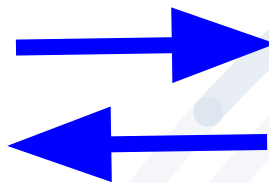


WIKIDATA

| | | | | | |
|---------------------------|-------|------------------|--|--|----------|
| 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

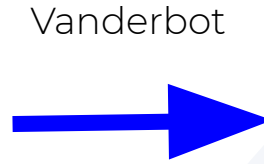
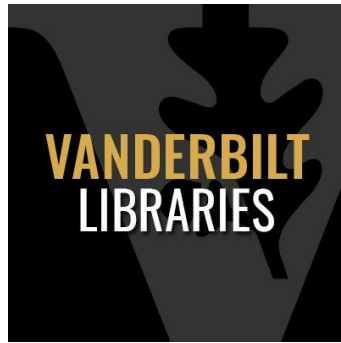
Thanks

William Hoos

Amy Westermann

ClinWiki volunteer editors

VANDERBILT
UNIVERSITY



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

Thanks

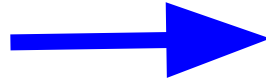
Steven James Baskauf

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

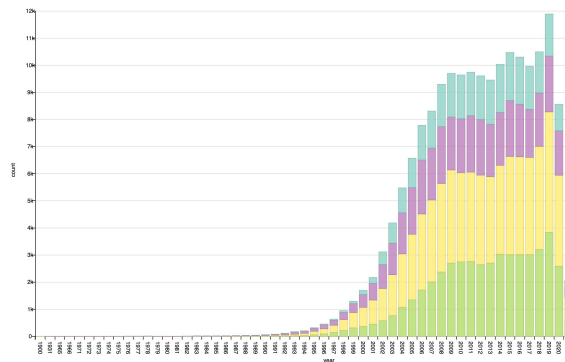
Jeffrey Keefer



- no data added
- data visualized!

Thanks
Daniel Mietchen
Finn Årup Nielsen
Egon Willighagen

Phases



Medical conditions

Show 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 Sorafenib in Hepatocellular Carcinoma (HCC) |

Interventions

Show 10 entries

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



বাংলা

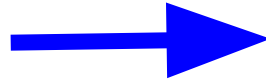


উইকিপিডিয়া
একটি মুক্ত বিশ্বকোষ

- 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

