

Disease Demographics:

*How to determine the correct patient demographics
for the disease you are researching*



OREGON CLINICAL
& TRANSLATIONAL
Research Institute

Why is it important for me to understand the patient demographics of the disease I'm researching?

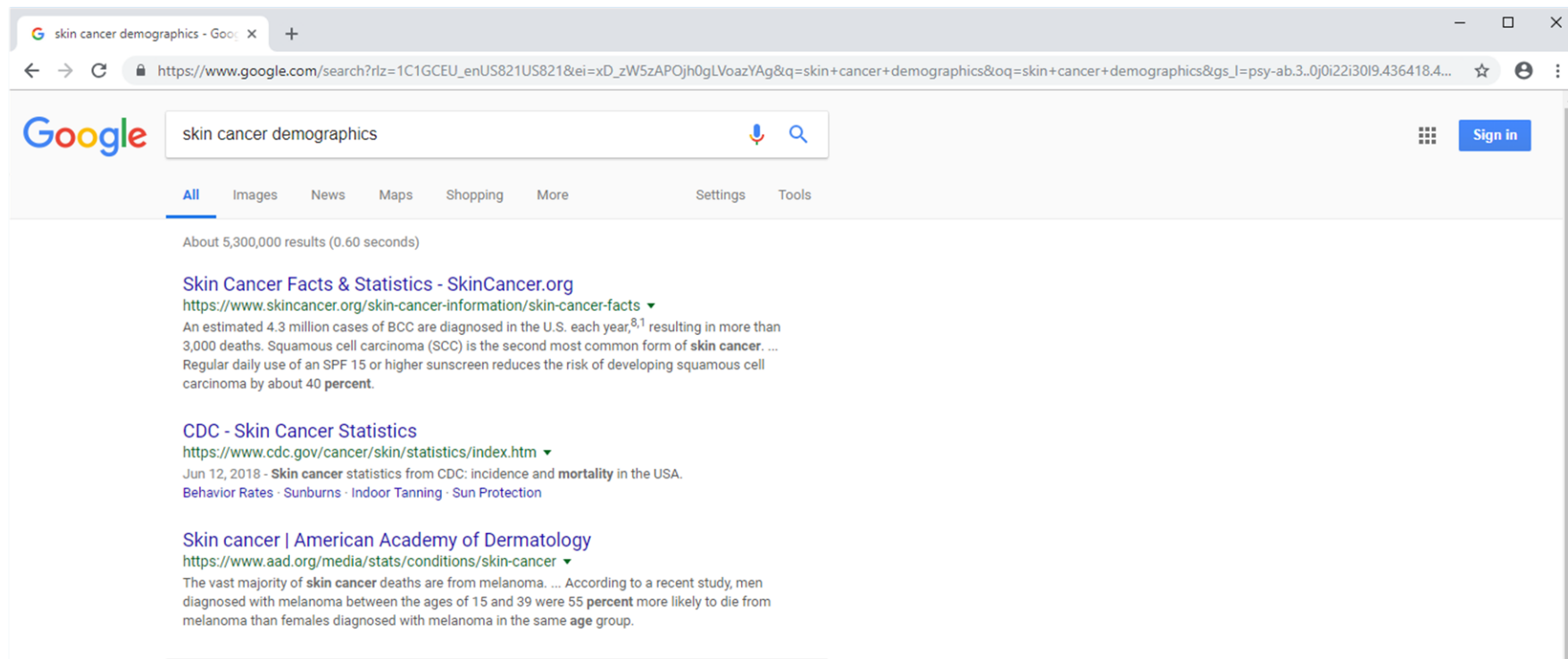
- To produce more reflective, comprehensive research results. By knowing the demographics of a disease, investigators can structure their study and inclusion criteria to have matching participant demographics.
- To be aligned with Federal regulations. As of January 25th, 2019, or later, the NIH will require grant applicants and awardees to submit de-identified participant-level data on sex/gender, race, ethnicity, and age from their funded studies ([NOT-OD-18-116](#)).

So how do I determine the demographics of the disease I'm researching?

There are many online resources available to the public that provide information on specific diseases and their statistics. Resources are often provided by government and government-related agencies, academic institutions, and health or disease-specific agencies or associations. The amount and specificity of the information varies by site.

So where do I start my search for disease demographics?

A great way to start your search is online with your favorite browser. Whether you prefer Google, Firefox, or Internet Explorer, a simple search of your disease focus + “demographics” will produce a list of resources to get you started.



I just want to get right to the data. What are some common sites for finding demographics?

Government and Government-Related Agencies

Organization	Website Link
Center for Disease Control – Data & Statistics	https://www.cdc.gov/datastatistics/index.html
Center for Disease Control – National Center for Health Statistics	https://www.cdc.gov/nchs/index.htm
World Health Organization – Health Data & Statistics	http://www.who.int/healthinfo/statistics/en/
Department of Health (per state) – Data & Statistics	https://www.oregon.gov/oha/ph/DataStatistics/Pages/index.aspx
HealthData.gov	https://healthdata.gov/
US Department of Health & Human Services	https://www.hhs.gov/ash/public-health-offices/index.html
National Institute of Health	https://www.nihlibrary.nih.gov/resources/subject-guides/web-search-thinking-beyond-google/health-statistics
NIH Genetic and Rare Diseases – Information Center	https://rarediseases.info.nih.gov/diseases

**Not an exhaustive list of websites*

Common Sites Continued...

Academic Institutions

Organization	Website Link
University of Michigan	https://guides.lib.umich.edu/c.php?g=283075&p=2694935
Johns Hopkins Medicine	https://www.hopkinsmedicine.org/healthlibrary/conditions/adult/
Oregon Health & Science University	https://www.ohsu.edu/xd/health/services/brain/in-community/brain-awareness/brain-health/disease-statistics.cfm

Health and Disease-Specific Agencies & Associations

Organization	Website Link
American Heart Association	https://www.heart.org/-/media/data-import/downloadables/heart-disease-and-stroke-statistics-2018---at-a-glance-ucm_498848.pdf
Alzheimer's Association	https://www.alz.org/alzheimers-dementia/facts-figures
American Lung Association	https://www.lung.org/lung-health-and-diseases/
Statista: The Statistics Portal	https://www.statista.com/topics/2070/diseases/
Global Genes Rare Diseases Project	https://globalgenes.org/rare-diseases-facts-statistics/

**Not an exhaustive list of websites*

Now that I know the disease demographics, what do I do?

Evaluate and redesign your study protocol as needed

- Is the inclusion age range reflective of the disease demographics?
- What about the inclusion race/ethnicity?
- And the inclusion sex/gender identity?
- Don't be afraid to engage experts to assist in study design. Experts can include specialists in the disease field or your institution's clinical trials office

Create (or update) a recruitment strategy that is tailored to the participant of the disease demographics

- Use multiple recruitment methods
- Adapt recruitment materials to the needed font size, language, reading level, etc. to make it reader friendly

Start researching!

For more information, additional resources, and to request a recruitment consultation, please visit our website at <https://www.ohsu.edu/octri> or email us at OCTRIrecruitment@ohsu.edu



OREGON CLINICAL
& TRANSLATIONAL
Research Institute