

Enhancing Public Usability of ClinicalTrials.gov

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ClinicalTrials.gov

ClinicalTrials.gov is a registry and results database that provides potential participants, their family members, healthcare professionals, researchers and the public with access to information on publicly- and privately-supported clinical trials that are conducted around the world on a vast range of diseases and conditions.

Recent initiatives, ranging from the Cancer Moonshot to the 21st Century Cures Act, have reemphasized the vital role that ClinicalTrials.gov has to provide information about clinical trials to users with diverse needs. With these needs in mind, NIH and 18F initiated a discovery engagement in February 2017, which involved consulting with ClinicalTrials.gov stakeholders (e.g., regulatory bodies, researchers, journalists, journal editors, grant reviewers, and potential trial participants and their advocates) to learn how they use the site in order to improve the ability to search, display, and review information on ClinicalTrials.gov.



Average visitors per day*
87,000



Average new visitors per day*
59%



Top search queries*
Cancer immunotherapy drugs

- Nivolumab**
- Pembrolizumab**
- Atezolizumab**

*Data from June 7, 2017

User-Centered Research

We interviewed ClinicalTrials.gov stakeholders and observed them using the site (22 user interviews in the initial phase of this engagement). We assessed their past use of the site, gathered feedback about any uncertainties or barriers they have while using the site, and asked them to convey their needs and expectations for improving the site.

Generally, users are successful in obtaining the information they need. When they do have difficulties finding what they are searching for, it is usually because they: are unable to find desired information that exists on the site; misunderstand why certain results were returned; are unable to use the search tool as they wish; do not understand terminology used on the site; or assume that trials listed on the site are government approved and endorsed.

Examples of User Comments

"This database is 250K studies. I don't wanna miss a study. I wanna search in a way that I get every result." – Patient caregiver

[In reference to the National Clinical Trial (NCT) identifying number:] "That's the number everyone thinks of; I don't know why there wouldn't be a search by it." – Researcher

"I'd say [to patients looking for trials to participate in] your best bet is to go to ClinicalTrials.gov 'cause it's peer reviewed trials registered with government." – Patient advocate

*Note: The listing of a study on ClinicalTrials.gov does not reflect endorsement by NIH.

Selected Events That Have Shaped ClinicalTrials.gov

2017

- NIH/18F collaboration to enhance public usability of ClinicalTrials.gov
- ClinicalTrials.gov beta version launch

2016

- 21st Century Cures Act calls for stakeholder consultation to enhance ClinicalTrials.gov
- Final rule issued to implement FDAAA
- Final NIH policy issued on the dissemination of NIH-funded clinical trial information
- Cancer Moonshot launched

2014

- Proposed rule to implement FDAAA issued for public comment
- NIH draft policy on dissemination of NIH-funded clinical trial information issued for public comment

2008

- NIH/NLM launches enhanced registry and results database

2007

- FDA Amendments Act requires registration and results for specified drug and device trials

2000

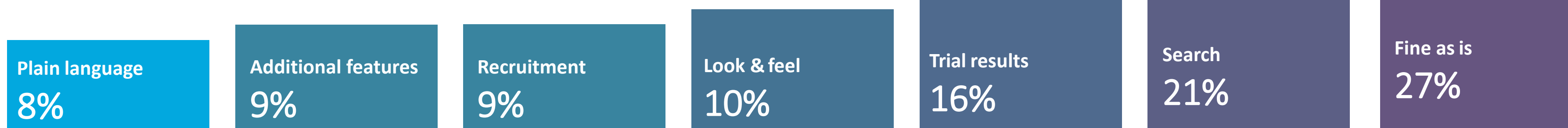
- NIH/NLM releases ClinicalTrials.gov

1997

- FDA Modernization Act requires registration of some drug trials

Improvement Survey

NIH's ForeSee Customer Satisfaction Survey measures users' expectations and perceptions of ClinicalTrials.gov by asking standard questions about site content, navigation, look and feel. Other questions ask about user demographics, reasons for visiting the site, and how health information is used from the site. From January 1 – August 16, 2016, responses to the request "Please suggest one improvement you would like to see on ClinicalTrials.gov," were characterized by 18F into the groups below. Of the 1,300 comments received, 1,073 were found responsive to the question and are depicted here.



Optimization Updates

In order to address gaps in information, search capabilities, and features provided on ClinicalTrials.gov and what users expect it to offer, 18F developed a set of recommendations for the homepage, search results page, and study record page. Site updates will be implemented incrementally and will focus on improving search capability, display, and information about trials registered on ClinicalTrials.gov. The first update was released on June 19, 2017.

June 19, 2017 Update – Homepage

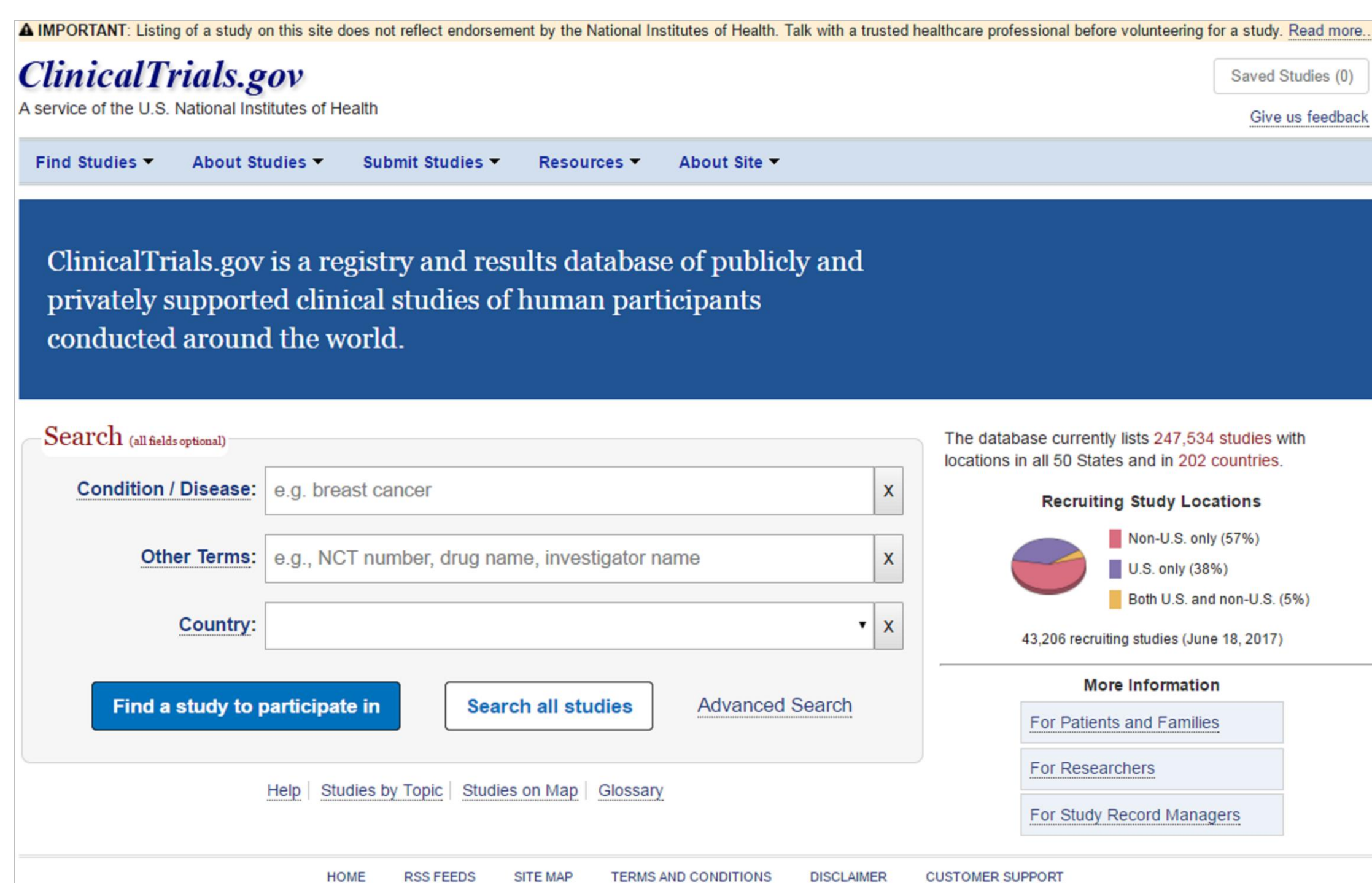
Changes to the site as of June 19, 2017

- Prominent language stating that registered studies are not necessarily endorsed by NIH
- Two optional search boxes added to the primary "Search" box
- Link added for potential study participants to easily find recruiting trials
- New ways to manage and refine results (e.g., additional search fields and expanded results filtering) and the ability to download data as a PDF
- Improvement to the look and feel of the site
- Web design adjusts to any monitor size, from desktop to mobile device

Next Steps

Additional changes to ClinicalTrials.gov developed as a result of this engagement will be launched by October 2017. Changes will be based on user validation via stakeholder interviews and testing.

Future enhancements to the site will be ongoing. User feedback will be collected and assessed through the continued use of the ForeSee Customer Satisfaction Survey (accessible via the "Give us feedback" link on the site homepage) and other public engagements.



Affiliations

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- NIH National Library of Medicine (NLM)
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