

Making Connections: serving the public and the clinical research enterprise of the University of California

We respectfully submit our application for the 2022 UC Collaboration Award. Meet the UCSF Clinical and Translational Science Institute's Research Technology Team (CTSI's RT team). Our mission is to apply technical & product innovation to improve the efficiency and effectiveness of UCSF's clinical research infrastructure. We have developed, deployed, and supported software products now universally used at UCSF to support research collaboration and recruit research participants. Because of this success, UCLA, UCSD, Irvine, Davis, UC BRAID (UC Biomedical Research Acceleration, Integration & Development), and UC Office of the President have entrusted our team to build, host and manage software for their institutions. We have won 3 Gold Sautter awards and 1 honorable mention in the last 10 years.

What complex problems did we tackle?

1. The demands of research and publishing are time-consuming and make it difficult for researchers to keep up with published literature and the prior and current work of their colleagues and peers.
2. Failure to recruit adequate numbers of eligible and diverse participants is one of the most common reasons why clinical trials fail, resulting in delay, early termination, and not enough participants to generate statistically meaningful results.
3. Conducting a trial at multiple sites can promote participant enrollment but has additional impediments to starting the study: failure to identify suitable Principal Investigators (PIs) at each site creates delays, while engaging inexperienced investigators can result in low recruitment, poor data quality, and lower overall study quality.

Successes at UCSF

We started tackling problem #1 in 2010. At that time, even at a single institution like UCSF, it was difficult to know who was researching and publishing on specific topics. People relied on personal networks to find colleagues, and searched unfriendly government websites to find publications from UCSF. The RT team partnered with colleagues at Harvard to improve their beta open source software and launch [UCSF Profiles](#), the now-ubiquitous researcher networking software platform. Profiles is UCSF's "LinkedIn for researchers," featuring institutional provenance and automatically updated content, including demographics, publications, grants, and clinical trials. The first version of UCSF Profiles won a 2013 Gold Sautter award, and has subsequently continued to increase traction & value, extending far beyond its original researcher-networking vision with:

- 2 million web visits in 2021; worldwide traffic from potential partners, patients, study participants, journalists, & donors
- 500+ UCSF/UCSF Health websites link to it, including high-profile sites that use APIs to integrate Profiles data
- NYT, CNN, NPR, Washington Post, and other news organizations link to it — as well as 500+ UCSF.edu news stories
- 10,000+ researchers, 200K publications, and 2K clinical trials from UCSF are publicly available, making research visible to UCSF researchers, existing and potential funders, potential collaborators at other institutions, and the general public

In 2015-2016, RT addressed issue #2. UCSF needed a single comprehensive list of clinical trials, including studies at affiliated sites like Zuckerberg SF General Hospital and the Veteran's Administration. One could search the federal web site for registering clinical trials ([clinicaltrials.gov](#)), but it was cumbersome and incomplete. UCSF leadership, patients and referring physicians could not even answer the basic question: "How many and what clinical trials are we running?"

Clinical trials are required to register with [clinicaltrials.gov](#) but data are not standardized and are incomplete, e.g., "UCSF" is spelled out, abbreviated, and completely missing from studies at affiliated sites. The RT team wrote code to merge datasets and capture every variation of UCSF and its affiliated sites (including creative use of scanning zip codes and phone prefixes), to generate a comprehensive dataset. [UCSF Clinical Trials](#) was launched in 2016, creating a single easily searchable website of all trials at UCSF and providing a prominent call-to-action to prompt anyone interested in a specific study to contact study staff and ask to join the study. The site has been carefully designed for usability and now draws over 200K visits per year, referring 5,500+ people to studies annually, from veterans with PTSD to patients with breast cancer.

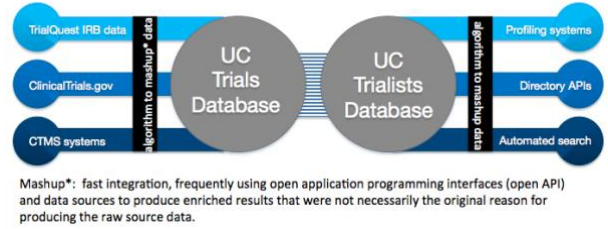
We then integrated UCSF Profiles and Clinical Trials, linking clinical trials to each researcher's web page on UCSF Profiles. Colleagues and patients can now find studies *and* learn much more about the researchers involved, including their interests, education, publications, and other clinical studies. Finally, we routinely employ search engine optimization (SEO) because our software products are meant to be used by the public as well as internally. RT has unique and deep expertise in SEO; we continuously adapt our products to keep up with evolving best practices for search engine results ranking, social media sharing, digital accessibility, and responsive mobile design.

Expansion to benefit the University of California System

The team's vision always included sharing our knowledge and experience across the UC system. By 2016, our networks of colleagues across UC were robust, largely thanks to UC BRAID, led by the CTSI Principal Investigators at the 5 UC Health campuses (Davis, Irvine, UCLA, UCSD, UCSF). Discussions with these leaders revealed that all five face similar challenges with a variety of unsuccessful initiatives. At one UC-wide conference, leaders said "No, we haven't solved the clinical trials inventory issue." Based on our successes at UCSF, we wanted to offer an effective suite of software products that would save time,

resources, and money for campuses (i.e., cheaper than using vendors and taking advantage of economies of scale), while reinforcing the UC-wide goal to have UC Health be a single health system rather than 5 systems at 5 distinct campuses.

We applied for and were awarded a \$650K NIH Grant in 2017 to address the complex problems described above. The 2-year grant funded the implementation of a UC-wide Clinical Trials finder, a UC-wide Principal Investigator finder, and individual campus-branded clinical trials sites and Profiles sites with cross-linking across all the web properties. With the UC-wide and other cross-linked sites, we made strides to address issue #3, making it easier to find a co-investigator at any UC and see their relevant clinical trials experience. We worked with leaders from each campus and ensured our grant application included critical funding for implementation at each participating UC campus. After receiving the grant, we established deeper working relationships with leadership, technologists, and administrators; with their support, we were successful in accessing HR and study data from each campus, gaining access to IT servers, figuring out campus communications culture, and navigating governance and decision making across the 5 partner sites. In addition, we trained each local team to provide level 1 client support and to improve usage and engagement, and we continue to provide communications templates, usage statistics, presentations and feature improvements. Between 2018-2019, we launched the following 9 websites:



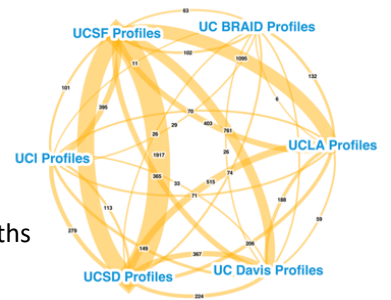
- **UC Davis:** [Profiles](#) and [Clinical Trials](#) (driving traffic to UCD’s main site)
- **UCLA:** [Profiles](#) only (UCLA runs their own trials recruitment site)
- **UC Office of the President/UC Health:** [UC Profiles](#) and [UC Clinical Trials](#)
- **UC Irvine:** [Profiles](#) and [Clinical Trials](#)
- **UC San Diego:** [Profiles](#) and [Clinical Trials](#)

This work attracted the attention of the **UC Cancer Consortium**. At their request, we created one more UC-wide site, [UC Cancer Consortium Clinical Trials](#) in 2019. And while all this development and implementation was supported by a grant, each group now finds enough value in our work that they have chosen to pay our team an annual innovation and maintenance fee.

Impact on a variety of levels

Impact is illustrated by web traffic/visit statistics, usage of services, and feedback from faculty, administrators, and patients:

- In 2021 we referred over 10,000 people to UC clinical trials, creating significant support for successful participant recruitment
- 2021 network traffic across UC Health’s Profiles sites enabled thousands of people from across the web to seamlessly jump between researcher profiles at UC Health campuses as they explore cross-UC research on COVID-19, prostate cancer, HIV/AIDS, and more. Line widths in the figure show relative counts of visits referred between each of the campus websites.



Our stakeholders, clients, and partners describe our impact best:

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| <p>"UCSD and UC BRAID see the value of the UC Clinical Trials Network and the promise that this work will support clinical trial recruitment and partnerships across UC. This light-weight, rapid deployment approach using public data is exactly the right way to do it. In fact, the NIH Accrual to Clinical Trials Network (ACT), which connects nearly 50 academic medical centers, has seen a demonstration of the platform and asked UC BRAID to expand it to the entire ACT network. It will be the gold standard for how we reach out to patients for clinical trials across the country." —Gary Firestein, MD, Senior Associate Vice Chancellor Health Sciences, UCSD</p> | <p>"The UC Drug Discovery Consortium (DDC) funds pilot awards across the UC system. We use the custom search of profiles for UC Health to find researchers with interests related to our specific target area for proposal calls. This focused approach ensures that most proposals are a good fit for our funding mechanism, significantly improving our review process." —Melanie Coco PhD, UC Irvine, Executive Committee UC Drug Discovery Consortium (UC DDC, funded by UCOP, aims to build a drug discovery community for UC.)</p> | <p>"Thanks to CTSI for being incredibly responsive to our request to add materials in the languages that are spoken by a substantial proportion of Californians, San Franciscans, and UCSF patients. This was one of the first official UCSF sites to include information in Spanish, Chinese, and Vietnamese in addition to English, making the site more welcoming and inclusive to the non-English speaking communities that UCSF serves." —Tung Nguyen, MD, Professor, Dept. of Medicine, UCSF, Chair, UCSF Differences Matter Initiative, on the UCSF Clinical Trials site</p> |
| <p>"This has been a terrific resource. A good percentage of those contacting us have gone on to enroll. We very much value this service!" —Annie Luetkemeyer, MD, on the UCSF Clinical Trials site</p> | <p>"By helping with the design and testing of the software, developing innovative new features, experimenting with novel ways of encouraging adoption, and presenting their work at scientific conferences, UCSF has played a major role in the success of Profiles at institutions around the world and demonstrated the benefits of open source code." —Griffin Weber, MD, PhD, Associate Professor of Medicine and Biomedical Informatics, Harvard University & Inventor of Profiles RNS</p> | |

In support of the UC Mission

Our journey has been rewarding and our work is valuable for researchers, clinicians, administrators, staff, and patients across the entire UC Health system and its 5 individual campuses. Our focus on accessibility and findability is key; these sites are all in the public domain, bringing research and advances in clinical care & health to serve all Californians and beyond.

--Anirvan Chatterjee, Brian Turner, Eric Meeks, Leslie Yuan (Submitter, CTSI CIO and RT Dir), Moisey Gruzman, Zeaid Noor