

# **My Research Assistant (MyRA)**

## **Needs Assessment**

Prepared by

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for the

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**Center for Clinical and Translational Science (CCTS)**

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### Mission

MyRA (My Research Assistant) is a Utah statewide Web research portal that provides resources and tools for and about research.

### Vision

MyRA is the central place where researchers go to explore, manage, initiate, and direct their research. It provides information and guidance at every step of the research process. MyRA answers questions, pushes relevant information to the user on a regular basis, invites exploration or directly supports rapid decision-making. It supports collaboration among various participants in the research process (e.g., senior or junior researcher, clinician, student, patient, and interested public). MyRA is the electronic entr ez to FURTHeR and other developed or collected tools, and is supplemented by a physical space that specifically assists researchers throughout their research processes.



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## Background

In the original grant proposal for the University of Utah's (U of U) CTSA award, the vision of a statewide Web portal that would act as an access point for researchers, clinicians, community providers, patients, and other CTSA programs and opportunities, institutional resources, and each other, was put in place. The portal would be the electronic (or virtual) entr ez to FURTHeR, a standardized query table for accessing the rich clinical data of U of U and its partner institutions, and would be supplemented by a physical office with staff that specifically assists researchers throughout the research process. The portal was to be called MyRA, My Research Assistant.

Though this part of the grant was not funded, the visionaries (Joyce Mitchell, Scott Narus, and Charlene Weir) did not lose sight of the need for a portal to information about other researchers, institutional procedures for performing research, and tools for collaborating. They put together a group (the MyRA Working Group) that asked that a needs assessment be performed in order to see what was needed or desired by users.

## Methodology

In preparation for querying University of Utah researchers about their needs, research was done to discover what tools are already available and being used by scientists, including those provided by other CTSA awardees.

***Tools used by other CTSA awardees.*** A list of tools used by other CTSA awardees was created by using the CTSA Biomedical Informatics Resource Inventory kept at the University of Pittsburgh (now maintained at the NIH and called the Clinical and Translational Resource Explorer) and by searching the awardees' CTSA-related websites. Evaluators of the first cohort of CTSA awardees were asked which tools were being used and what scientists were asking for. Tools were categorized into the following groups: Research/Collaborative, Educational, Administrative, Community outreach. The list, along with descriptions, can be found in Appendix 1.

***Social networking and collaborative tools.*** A list of social networking and collaborative tools developed for and used by research scientists was created by searching websites, science blogs, and through personal communication with science dissemination experts. This list was divided into the following categories of tools: Networking, Publication Sharing and Organizing, Data Sharing, Document Collaboration, Clinical Trials, and New Search Engines. This list, along with descriptions, can be found in Appendix 2.

***Survey and interview researchers for a needs assessment.*** Data was gathered on the needs of researchers at the University of Utah and its partner organizations through the use of surveys, interviews, and at a MyRA strategic planning session.



*CCTS Annual Survey.* A survey developed by Charlene Weir, PhD, RN, Associate Research Professor, was sent to all faculty and fellows in the University of Utah Health Sciences Center (n = 2,312). This was the first effort of an annual survey, so is considered baseline data. The survey is intended to study social networks across the institution and assess satisfaction and usage of CCTS services.

*Mark Thomason's Survey.* Mark Thomason, a PhD student in the Biomedical Informatics department, surveyed faculty on habits and factors that predict good collaboration. He also held focus groups of fellows and junior investigators that found strong needs for mentorship and support groups, especially for junior clinical researchers.

*MyRA Survey.* A survey instrument (Appendix 3) was prepared by Margaret Reich Consulting specifically for the MyRA needs assessment. It was intended to be sent only to senior researchers in an effort to distinguish it from the CCTS Annual Survey and Mark Thomason's survey. After reviewing the results of the CCTS Annual Survey, senior researcher interviews, and the persona exercise at the MyRA Strategic Planning meeting, it was decided that there was already enough information to start developing MyRA, and that a version of this survey could be used instead to assess the usefulness of MyRA after it was available for some time (e.g., 6-12 months).

*Interviews.* Twelve short, focused interviews were conducted by Margaret Reich, with help from Jean Shipman, Allyson Mower, and Kathleen Ann Amos. Interviewees, listed in [Table 1](#), were suggested by the MyRA working group members as representative of researchers and CCTS Core Directors who would be familiar with the CCTS and would have already given some thought to what they would like to see offered as assistance to researchers. Interviewees were sent an early version of the MyRA mission and vision to review before the interview. The interviews were fluid, and questions were added or deleted based on the interviewees' familiarity with the project, and the answers to early questions. The base questions are listed in [Table 2](#).

*Strategic Planning Persona Exercise.* An exercise was devised for the MyRA Strategic Planning meeting held January 25, 2010, in which volunteer attendees were asked to take on a specific persona and describe their needs from the persona's point of view. The personas were: Student, Fellow, Junior Researcher, Senior Researcher, Statistician, Librarian, and Community. Persona needs were placed on flipcharts labeled with the following categories: Hypotheses Generation, Protocol Development, Approval, Data Gathering, Data Analysis, Publish, and General. Attendees and their personas at the Strategic Planning meeting are listed in [Table 3](#).

## Results

Responses ([Table 4](#)) to the CCTS survey and interview questions, as well as the persona exercise ([Table 5](#)), point to the need for a clearinghouse for information that the proponents of MyRA had envisioned. Requests for assistance or for more information fell into the following categories:



data, grant writing and IRB navigation, statistical and technical resources, collaboration, physical space/staff.

**Data.** This topic was the source of the most frustration from senior researchers interviewed. It also comes up often in the open comments from the CCTS survey. The respondents express an appreciation for the wealth of clinical data that exists at the various institutions in Salt Lake City, and their inability to effectively use that data. Even after going through the process of getting permission to use the data, the lack of standard fields, coding, and search queries makes it nearly impossible to run replicable experiments. This is really the purview of the FURTHeR project, and the plan is that MyRA will act as a portal to the FURTHeR database, along with providing training and promotional materials so that investigators are aware of the improvements.

**Grant writing/IRB process.** Another frequent source of frustration in respondents' comments was the lack of centralized, clear information about the process of grant application and management, and related IRB procedures. Concomitant with this is the lack of administrative support for grant writing and management, which has become extraordinarily complicated at every level, particularly at the funding agencies themselves.

Some departments have very successfully built their own infrastructure for grant preparation and management. The benefit of interviewing the more senior scientists working in these departments was that they could recognize and speak to the frustrations of their less experienced colleagues (some whom they were mentoring), and could suggest the types of resources that would be useful. Some of these senior scientist expressed a willingness to offer their knowledge and services to CCTS/MyRA, if the result would benefit all. Their suggestions are included in Table 4.

**Statistical and technical resources.** A sense of confusion about what resources are available and a lack of understanding about how to access and use them came through especially in the persona exercise done at the strategic planning meeting. A complementary sense that potential users were unaware of their services or confused about them came from those involved with the Cores providing these resources. A real need for an awareness and training campaign became apparent during these interviews.

**Collaboration.** When taken in the larger context of researchers finding like-minded researchers, this topic came up as a need more readily and frequently for the junior personas in the persona exercises. Dr. Weir's knowledge of this need came mainly from Mark Thomason's focus groups with fellows and junior investigators, in which a great desire for finding effective mentors was expressed.

Not surprisingly, the senior researchers interviewed did not bring this up as a need, but discussed it only when prompted by questions about collaborative software and social networking tools. When prompted, senior researchers said they would use collaborative software, and expressed a



desire for the popular eRoom software to be made freely available. There were fewer positive remarks about social networking tools, although two interviewees would like to see a sophisticated search tool that would know their interests and push appropriate information about other researchers and opportunities to them. Most others were not comfortable or familiar with these tools. There seemed to be a particular aversion to the creation of another researcher database like the MBM system or Find a Researcher, because interviewees found the existing systems onerous to use or so out of date and that they were not useful. Interviewees were leery of being asked to create and maintain a profile in yet another database. Some wondered why such a database couldn't be auto-populated with data already available (e.g., lists of publications, funded grants).

***Physical space/staff.*** When prompted, a majority of interviewees thought that having a physical office for MyRA is a good idea. All but one thought it would be best housed in the Eccles Library. A few expressed a desire for a more social meeting space, where one could meet those they wouldn't necessarily seek out. One could envision a space with meeting rooms that also allowed small receptions and made other refreshments available, especially during orientations and training sessions.

The need for more support staff was expressed by many of those interviewed, but when prompted, all liked the idea of a MyRA support person, who could direct investigators to information they needed (i.e., a Research Concierge).

### **Building an Informational Website—MyRA's Foundation**

The MyRA Strategic Planning Meeting was held on January 25, 2010. Its goal was to make some decisions about building MyRA, knowing that whatever is done can evolve into something more complicated and sophisticated as users come to the site, give feedback, and express their needs.

Dr. Adi Gundlapalli, Assistant Professor in the Division of Epidemiology and the Department of Biomedical Informatics, gave a presentation of the CRISP (Clinical Research Informatics Systems Plan) research that was done to review current processes for clinical and translational research with a view toward finding information technology solutions to breach barriers. Some of the recommendations from his work speak to the need for an informational website about research procedures. The website could eventually provide automated tools, such as project scheduling tools, but would be extremely useful even if just informational at the start.

The group was extremely impressed with the flowchart presented by Dr. Gundlapalli that outlined all of the stages from idea to grant submission (Figure 1). There was consensus that it should be used on the MyRA website, with links coming from the flowchart to pages or sites with information about that stage of the process. There should also be an alphabetical and a hierarchical list of links to information, so that visitors to the site have a choice about how to browse or search.



The University of Utah already has a wealth of informational sites (i.e., Office of Sponsored Projects (OSP), VP for Research, Research Administration Training Series (RATS), the Research Portal) that describe resources offered at the University. There are also outside resources that would be appropriate to link to (i.e., NIH--grants.gov). MyRA would be the portal, clearinghouse, one-stop shop, pointing to useful information in an organized, easy-to-find way. [Table 6](#) is a list of informational sites to link to, in a suggested structure that is a starting point for discussion.

Highlighting a few of these U of U resources, the VP for Research office recently created the Grant Writer Network (GWN) to help departments on campus write grants collaboratively. Boilerplate language (e.g., university and departmental descriptions), one of the requests made by interviewees, will be compiled in a shared repository via the UNITE system, described below.

In February 2010, the Brain Institute rolled out their UNITE tool, which uses Vignette/Open Text software to assist collaboration, with links to investigators' calendars, email, and wikis. Researchers will be able to create and maintain private and team workspaces and communities and facilitate collaborative document authoring. Use of UNITE will be free to all U of U researchers with a U-ID. Brain Institute staff have agreed to consult with departments that want to set up their own instance of UNITE, and training will be done through the RATS.

As there is already very good information residing on these sites, as well as the U of U's Research portal, MyRA as an informational site would act as an umbrella site, seamlessly pointing to all of this information. Even if access to some of this information requires a U-ID login, there should be a link to it (with a definition of what it is and a note that it will require a login) from the MyRA portal, which is open to all, so that visitors will know it is there.

Another recommendation that came from the CRISP research was to develop and implement a formal research orientation for new investigators as part of their employment orientation, including an introduction to the grant preparation process. Orientation materials should be included on the MyRA website and the face-to-face orientation should point investigators to the MyRA portal, as a one-stop shop containing links to much of what they need to know throughout their research careers. MyRA working group members would also like to see orientation material presented in videos placed on YouTube, and linked to from the MyRA site.

The attendees at the Strategic Planning Meeting also liked Dr. Weir's idea of including a place to leave your questions, needs, or suggestions on the MyRA site. The comments and questions would then be used to develop an FAQ list, and this is an excellent way to get feedback for future development of the site. If there is any indication on the site that questions will be answered, however, someone will have to be put in charge of responding helpfully in a timely manner, so that visitors will have a good experience with the website, and be more likely to return.



**University of Washington Case Study.** The Strategic Planning group was impressed with a website of another CTSA awardee, The University of Washington's Institute of Translational Health Sciences (ITHS). A clear and uncluttered website (<http://www.iths.org/>) with the following tabs: Discover ITHS, Request a Consult, Find a Resource, Get Funding, Find Training, Find People, and Get Involved. Each tab leads to a page of some information and many links to more information.

For any visitor who cannot find the information they are looking for or who needs help navigating the site, each page also has a feature box that leads the visitor to the ITHS Portal Consultant. This link may lead to a form asking for information, or a link to a staff member at the appropriate Core, or to the Portal Consultant itself. Havivah Schwartz, Associate Director of the ITHS, explained that they were just in the process of hiring a full-time Portal Consultant. While other CTSA awardees with this type of function have successfully used a combination of administrative staff and faculty, the ITHS decide to hire a scientist who would have the hands-on experience to help an investigator navigate the University of Washington's resources while putting together a research study. The Portal Consultant would also be charged with training and outreach to make the appropriate people at the University aware of their services.

The resources available from the ITHS portal and through the Portal Consultant are general to all researchers at the University, not just those funded by the ITHS. But to take advantage of full benefits of the ITHS, one is encouraged to become a member. Membership requirements and benefits can be found here: [www.iths.org/membership](http://www.iths.org/membership). Filling out a membership application gives the ITHS information about investigators and their research, which can be used to build a profile for that investigator. Other CTSA awardees have similar applications on their sites.

**MyRA-like sites on other CTSA sites.** [Table 7](#) contains a list of all CTSA grant recipients, and whether or not they have a MyRA-like portal as part of their website. Every Center created with CTSA funds has some kind of website highlighting who they are and what they do. They get a Yes in the MyRA column only if the website has links to resources for all researchers, such as funding opportunities, grant writing and IRB resources, and collaboration resources. If it is simply information about the CCTS (or equivalent) and its Cores, or links only to contact information of individuals, it is not considered a MyRA-like site.

## **MyRA Evaluation**

After the MyRA site has been developed and available for some time (i.e., 6 months), it should be evaluated for recognition, usefulness, ease-of-use, and improvements. The following tools can be used:

- CCTS annual survey
- The survey questions in Appendix 3 can be amended to evaluate MyRA



- The “suggestion box” or “ask a question” element on the MyRA website will be a constant source of feedback on what is working, not working, and what is needed

Other quantifiable metrics for measuring MyRA’s effectiveness would be comparing the rate of success of certain processes that MyRA hopes to help improve. Baseline data for questions such as

- How many times do grants get bounced back for technical issues?
- How many mistakes are made on IRB applications?

would need to be collected now in order to see if MyRA’s existence improved these metrics.

As a web-based portal, MyRA can be improved at any time. Links to important information can be added, pages that are confusing can be simplified, and information can be clarified.

### **MyRA Evolution**

MyRA as an informational site should be so clear, easy to navigate, and useful that it becomes a popular destination for visitors looking for information to help them with their research. With the trust of the user community, MyRA will be able to reach some of its more sophisticated goals, namely:

- Home to a highly developed researcher database
- Social networking tools to push information and relationships to users based on their profiles, or personas, which will be recognized upon logging in

MyRA will be able to take advantage of and link to tools being developed and set up by others, including the NIH, other CTSA awardees, and other departments at the University of Utah. One of the challenges inherent in using the tools on sites built at different times in different departments is that they were built using different software, and reside in databases that do not talk to each other. For instance, the IRB system uses ERICA, and the OSP uses PeopleSoft to store data. An evolution of MyRA could be to form a layer over both these systems, using the information collected in the Document Summary Sheets (DSS), so that researchers only have to fill out a DSS once for any given project.

As MyRA matures, it might also take advantage of tools being developed by other CTSA for finding investigators and information about their research, such as VIVO, created at Cornell, and now being developed into a national platform by the University of Florida Health Science Center Libraries, with funding from the NIH; or LatticeGrid, built on existing social networking and knowledge management platforms, at Northwestern University.

The feedback feature box and FAQ list can evolve into forums, much like the Harvard Catalyst advice forum (<https://grants.catalyst.harvard.edu/grants/spring/advice>). Expert investigators can





be asked to write blogs, that can lead to interesting—perhaps provocative—and helpful discussions that lead more visitors to the site.

## **MyRA Implementation**

The following is a list of suggested first steps that need to be taken in order to build the MyRA site:

- Review elements of other CTSA awardees' MyRA-like pages (“yes” entries, Table 7)
- Review internal websites: GIS, OSP, Research Portal, VP for Research
- Organize the “About CCTS” page, with diagram of Cores and Partners, and how they work together.
- Decide on structure of the portal—keep it simple for ease of navigation (Table 6)
- Collect links to information and resources and decide where they are linked to from within the structure of the portal (Table 6)
- Get baseline data for evaluation metrics
- Design web portal
- Import content and links into design
- Set up physical space, hire staff
- Launch portal, with PR campaign, reception
- Collect feedback and begin evaluation
- Ongoing maintenance and improvement
- Ongoing addition of features



**Table 1. MyRA Needs Assessment Interviewees**

|                    |   |
|--------------------|---|
| Elsayed Ahmed      | Research Associate, CCTS, Translational Technologies & Resources Core             |
| Joe Biskupiak      | Research Associate Professor, Associate Director, PORC                            |
| Carrie Byington    | Professor, Pediatric Administration, Administrative Core                          |
| Kathleen Digre     | Associate Professor, Department of Neurology                                      |
| Per Gesteland      | Assistant Professor, Pediatric Administration, Biomedical Informatics             |
| Tom Greene         | Professor, Division of Epidemiology, Design & Biostatistics Core                  |
| Carrie McAdam-Marx | Research Assistant Professor, Outcomes Research Center, PORC                      |
| Mollie Poynton     | Assistant Professor, College of Nursing   |
| Lucy Savitz        | Research Associate Professor, Division of Epidemiology, Community Engagement Core |
| Jackie Smith       | Professor, College of Nursing   |
| Mark Supiano       | Chief, Division of Geriatrics   |
| Michael Varner     | Professor, Department of Obstetrics and Gynecology                                |



**Table 2. Interview Questions**

**MyRA 20-minute interview**

**Interviewee**

**Mission.** MyRA (My Research Assistant) offers Web-based access to various CTSA resources and tools. MyRA is unique, in that it is a Utah statewide Web portal with access points for biomedical researchers, clinicians, community providers, patients, and other CTSA personnel.

**Vision.** MyRA is the central place where researchers go to explore, manage, initiate, and direct their research. It provides information and direction at every step of the research process. MyRA answers questions, pushes relevant information to the user on a regular basis, invites exploration or directly supports rapid decision-making, and connects people together. It “knows” what type (i.e., senior or junior researcher, clinician, student, patient, interested public) the user is. MyRA is the electronic entr ez to FURTHeR and other developed or collected tools, and is supplemented by a physical space that specifically assists researchers throughout their research processes. MyRA also provides virtual collaborative working spaces for the various local CTSA units and for their network of researchers.

**Introduce MyRa briefly. Interview questions:**

1. What one thing do you need most from a resource like MyRA?
2. What have you needed the most help with, when planning a research program or while doing your research?

**Suggestions if they can’t find an answer:**

- a. Finding information about what the CCTS is doing
  - b. Finding out about CCTS opportunities (eg, funding)
  - c. Finding out what resources are available to me
  - d. Finding collaborators
  - e. Making my way (or mentoring my students/post docs) through the research process
  - f. Sharing data and manuscript stages with collaborators
3. Do you use any social networking tools, like Facebook?

**If answer is yes, then:**

- a. Have you applied any of these to your research? Which ones?

**If answer is no, then:**

- b. What are the biggest barriers—or annoyances—to getting research done at the University?
4. Would you prefer that MyRA was mostly virtual—including virtual “space” where you could hold “meetings” and share information with collaborators—or a combination of virtual and physical space, staffed with people who could direct you toward information you need?



**Table 3. Strategic Planning Meeting Attendees**

| <b>Attendees</b>                      | <b>Persona</b>    |
|---------------------------------------|-------------------|
| Kathleen Ann Amos*                    |                   |
| Justin Cameron*                       | Student           |
| Tom Green                             | Biostatistician   |
| Adi Gundlapalli                       |                   |
| Nancy Lombardo                        | Librarian         |
| Randy Madsen                          |                   |
| Joyce Mitchell                        |                   |
| Allyson Mower*                        | Librarian         |
| Scott Narus*                          | Junior Researcher |
| Sadie Quinn                           |                   |
| Jean Shipman,* Meeting<br>Facilitator |                   |
| Amy Sikalis*                          | Senior Researcher |
| Louisa Anne Stark*                    | Community         |
| Mark Thomason*                        |                   |
| Charlene Raye Weir*                   | Fellow            |
| <b>Recorders</b>                      |                   |
| Margaret Reich                        |                   |
| Sherelyn Sandberg                     |                   |

\*Member of MyRA Working Group



**Table 4. List of Needs from Interviews and CCTS Annual Survey**

| <b>Collaboration</b>   |
|--|
| <ul style="list-style-type: none"> <li>• Free virtual collaborative software, (eg, eRoom. Google not secure enough)</li> <li>• Virtual meeting rooms</li> <li>• Sophisticated (knows your work and preferences) social tools for finding collaborators</li> <li>• Disadvantage of internal social network is you lose wider universe; consider subgroup on Facebook, for instance</li> <li>• Don't want another version of MBM, Find a Researcher</li> <li>• Auto populate researcher databases with publications from PubMed, funded grants from OSP or RePORT from NIH</li> <li>• Database of active grants</li> </ul>   |
| <b>Data</b>  |
| <ul style="list-style-type: none"> <li>• Need information about how to get access to data and tissue samples.</li> <li>• Need information about how to recruit patients.</li> <li>• Intermountain Healthcare's data are very useful. Need to write reporting tools to use the data. Very appealing to be able to do this state-wide. Learn from other people's search queries.</li> <li>• Need Utah population database to be accessible and organized as well as commercial data               <ul style="list-style-type: none"> <li>• Standardized fields</li> <li>• Valid codes</li> <li>• Data dictionary</li> </ul> </li> <li>• Need to be aware of cHIE and APD, to meet the needs of the state</li> </ul>  |
| <b>Grant Writing/IRB Proposals</b>   |
| <ul style="list-style-type: none"> <li>• Project management system               <ul style="list-style-type: none"> <li>• Grant writing timeline</li> <li>• Award management</li> </ul> </li> <li>• Calendar-based or Excel timeline that autopopulates deadlines based on grant</li> <li>• Provide boilerplate language for IRB applications, based on kind of study</li> <li>• Provide boilerplate language for grant applications</li> <li>• Excel spreadsheets templates for grant budgets</li> <li>• Tips and hints on winning proposals</li> <li>• Sample successful grants</li> <li>• Checklist for all grant requirements</li> <li>• Database of Foundations and funding opportunities</li> <li>• Mock study-section service</li> <li>• Grant administrator to review technical pieces of grant, budget, for compliance</li> </ul> |



|  |
|--|
| <b>Biostatistics and Technical Resources</b>   |
| <ul style="list-style-type: none"> <li>• More information about biostatistics resources</li> <li>• Help with scientific experimental design</li> <li>• Project management system</li> <li>• Link to their websites, information about their resources</li> </ul>   |
| <b>Physical Space/Staff</b>  |
| <ul style="list-style-type: none"> <li>• Physical space would be useful at the library—department neutral, up-to-date on technology, helpful &amp; friendly</li> <li>• Could be housed in the Research Center</li> <li>• Social, face-to-face contact, for “moments of serendipity,” faculty dining rooms</li> <li>• Co-locate with Collaborative Research Support Program from VP for Research program</li> <li>• More administrative, secretarial assistance. Without, even scheduling a meeting is a nightmare.</li> <li>• Research concierge—could be emeritus faculty or two who would know who is doing what and would serve as research matchmaker</li> </ul> |
| <b>Educational</b>   |
| <ul style="list-style-type: none"> <li>• Orientation for all new investigators about what services are offered to them, and how to find them</li> <li>• Overview of the services offered and examples of their successful use</li> <li>• Training investigators, how to work with biostatisticians <ul style="list-style-type: none"> <li>• How data should be organized</li> <li>• Basics about research</li> <li>• Why they need biostatistics</li> <li>• How best to design study (provide templates)</li> </ul> </li> <li>• Clearinghouse of seminars, integrated with calendar system and smartphone</li> </ul>   |
| <b>Miscellaneous</b>   |
| <ul style="list-style-type: none"> <li>• Clearinghouse of all output: publications, posters, grant awards; make it exposable, so Google can find it</li> </ul>   |



**Table 5. Persona Exercise Results from MyRA Retreat**

|                              | <b>Student</b>   | <b>Fellow</b>   | <b>Junior Researcher</b>   | <b>Senior Researcher</b> | <b>Statistician</b>  | <b>Librarian</b>   | <b>Community</b>  |
|------------------------------|--|---|--|--------------------------|--|--|---|
| <b>Hypotheses Generation</b> | <ul style="list-style-type: none"> <li>-What resources are available to me and at what cost?</li> <li>-Faculty sponsor?</li> <li>-Do I need a mentor, an advisor?</li> <li>-Directed toward funding sources</li> </ul> | <ul style="list-style-type: none"> <li>-Find mentors</li> <li>-List of IRB active studies related to inquiry</li> <li>-Collaborators</li> <li>-Estimate of time requirements</li> </ul> | <ul style="list-style-type: none"> <li>-Where do I start in order to develop a research program?</li> <li>-Are there peer research support groups?</li> <li>-How can I find a mentor?</li> <li>-Is there a formal mentorship program?</li> <li>-Inter-institutional partners, peer identification, and how communicate with them?</li> <li>-How to identify other projects?</li> </ul> |                          | <ul style="list-style-type: none"> <li>I need someone to help me formulate my research questions</li> <li>I need a statistician to be a member of my thesis committee.</li> <li>How can I find a statistician with the right expertise to collaborate with?</li> <li>How can I find a statistician to help me with my grant proposal?</li> </ul> | <ul style="list-style-type: none"> <li>-Help identify appropriate funding sources. What agencies, foundations, etc. Help from Development Office.</li> <li>-Do I need funding for my research project?</li> <li>-For hypothesis review, contacts in my own discipline to assist in refining my research questions</li> <li>-For hypothesis review, assistance from librarian on literature search to ensure idea is unique, not already “done” or published.</li> <li>-Means of discovering potential collaborators</li> </ul> | <ul style="list-style-type: none"> <li>-How do I write a grant proposal?</li> <li>-I’ve heard about a grant opportunity, what do I need to do to apply?</li> <li>-As a community leader I see “x” in my community who can I work with?</li> <li>-How do I find a researcher who studies “x” to work with our organization?</li> </ul> |
| <b>Protocol Development</b>  |  |   |  |                          | <ul style="list-style-type: none"> <li>-What do I need to do to get my data to the statistician?</li> <li>-I need a statistician to serve on a OSMB.</li> </ul>  | <ul style="list-style-type: none"> <li>-How do I manage the budget if I am funded? Is there someone who can help, eg. Budget personnel?</li> <li>-Where can I get help designing my research methods? I</li> </ul>   | <ul style="list-style-type: none"> <li>-What does all clinical research have in common – participants</li> <li>-I want to do a research project in schools. Who do I need to talk to?</li> <li>-How do I engage the</li> </ul>  |

|                       | Student                   | Fellow | Junior Researcher  | Senior Researcher   | Statistician  | Librarian                             | Community   |
|-----------------------|---------------------------|--------|--|---|---|---------------------------------------|---|
|                       |                           |        |  |   |   | want systematic methods.              | community that I want to study?<br>-Can I use other ways to obtain informed consent – like a video, computerized form?<br>-What can help me to obtain proper informed consent?<br>-Informed consent readability; less than 12 <sup>th</sup> grade reading level. Should it be written for colleagues or participants? |
| <b>Approval</b>       | -IRB help in every regard |        | -Am I under “covered entity” for HIPAA?  |   |   | -Assistance with steps in IRB and OSP | -What is the IRB? When do you need to go to the IRB?  |
| <b>Data Gathering</b> |                           |        | -I have an idea for a research project, but I don’t know where or how to get data. | -Approval levels of understanding – IRB and IACUC may not be the only ones needed. For example, to recruit patients – where and how do I start? | -I need help determining how to collect/organize my data for statistical analysis.<br>-How can I create a de-identified set of data that is easy for a statistician to analyze?<br>-Power analysis software and or links  |                                       |   |
| <b>Data Analysis</b>  |                           |        |  |   | -Is the statistical work on my project finished?<br>-I need another statistician for a second opinion.<br>-I need a statistician to oversee my own analyses<br>-I have questions about the analyses you did for me<br>-How can I find a statistician for short (30min-1Hr) consults?<br>-How can I find a statistician with research interests in my area to establish a collaboration?<br>-How can I get “emergency” stats help for something due tomorrow?<br>-What statistical software should I use?<br>-What statistician has been assigned to my project? |                                       |   |





|                | Student   | Fellow   | Junior Researcher   | Senior Researcher   | Statistician   | Librarian   | Community  |
|----------------|---|--|---|---|--|---|--|
| <b>Publish</b> |   |  | <ul style="list-style-type: none"> <li>-What's published by various institutions? Where is the research happening on a specific topic?</li> <li>-Research results dissemination options, what are they?</li> <li>-Report mechanisms – when are they due, in what format, etc.?</li> <li>-I don't know what to publish and who has published here at the U; how can I find out?</li> </ul>                             |   | <ul style="list-style-type: none"> <li>-Need a statistician to help me write my method and results section for a paper.</li> </ul>   | <ul style="list-style-type: none"> <li>-How do I identify the right journals?</li> <li>-How do I make enough time to write up my results?</li> </ul>  | <ul style="list-style-type: none"> <li>-Is there an online way for community members to find out study results?</li> </ul>   |
| <b>General</b> | <ul style="list-style-type: none"> <li>-Steps of research ...start to finish</li> </ul> | <ul style="list-style-type: none"> <li>-Education Classes Online</li> <li>-Support Group</li> <li>-Quality Improvement vs. research</li> </ul> | <ul style="list-style-type: none"> <li>-How can I discover what kinds of research are happening?</li> <li>-What resources are available for doing research?</li> <li>-What is the process timeline for tenure?</li> <li>-I saw this grant on the AHRQ website; what do I need to do to apply?</li> <li>-What's the process for initiating a grant?</li> <li>-Funding cycle?</li> <li>-Post award checklist</li> </ul> | <ul style="list-style-type: none"> <li>-Pre and post funding checklists for research flow</li> <li>-How to hire more staff (Craig's List), especially research assistants; what are recruitment opps</li> <li>-Mandatory data training and informed consent training especially for students</li> </ul> | <ul style="list-style-type: none"> <li>-Do I need to pay for stats support?</li> <li>-Need someone to teach me statistics</li> <li>-How can I find money to pay for stats help?</li> <li>-What stats book would help me to learn?</li> </ul>   | <ul style="list-style-type: none"> <li>-Clear outline of research process – start to finish – access to each tool or agency in the process</li> <li>-Links to “human advisors” for each step; email, phone, office</li> <li>-How do I get time to focus on research? – grant writing, project time if funded</li> </ul> | <ul style="list-style-type: none"> <li>-A researcher is approaching community members in ways that are not culturally appropriate or sensitive, who can I talk to?</li> <li>-Re language barriers for my community members who want to participate, what resources are available to me?</li> <li>-Health literacy tools</li> </ul> |
|                |   |  |   |   | <ul style="list-style-type: none"> <li>-What is the reason for doing research? Why should the community give of themselves? Nothing is ever brought back to the community.</li> <li>-Trusted resources for health information</li> <li>-FAQs generated in response to questions</li> <li>-Training in completing IRB research and understanding nuances of online form.</li> <li>-I want to be a participant in a study. How do I find out about one here at the U? Is there a list of studies at the U I can look at?</li> <li>-Educate researchers on how to be sensitive to the needs of participants. Rare diseases, cancer, phase one...</li> <li>-As a researcher, what resources are available to help me learn how to work with a specific community in a culturally sensitive way?</li> <li>-A researcher has approached me/my organization about participating in a research project. What questions should I ask them? How do we set up an equitable CBPR agreement? (UNPdocument)</li> </ul> |   |  |



## Table 6. Suggested Links from MyRA Portal

### Home Page Links

Sub pages links

### MyRA Home Page

CCTS, About (includes links to Leadership and Staff listings)

CCTS Cores

Need help? Ask the concierge (click to email)

Leave your question

### Funding Opportunities

Novel Clinical and Translational Methods Core

Pilot & Collaborative Studies Core

Funding Incentive Seed Grant Program

OSP, Limited Submission Opportunities

### Collaboration

Search for investigators by kind of research they are doing

Research portal, search by keyword

UNITE collaboration software

### Grant writing

CRISP flowchart

Checklists for Research Assistants

OSP

Research Portal

VP for Research

Grant and Proposal Writing Assistance Available at the University Writing Center (UWC)

Grant Writer Network (GWN)

Boilerplate language (description of U of U, the CCTS, etc, sample grant applications, budgets, schedules)

IRB, ERICA

Regulatory Knowledge and Clinical Research Ethics Core

External Links, Useful Grant preparation information:

PRIMER

Grants.gov

NIH Extramural Nexus online monthly newsletter

FASEB Horizons in Bioscience, articles that highlight research on the brink of clinical application and describe the pathway to discovery

FASEB Breakthroughs in Bioscience, longer articles documenting how basic research discoveries are translated into new therapies or medical technologies

[www.animalresearchcures.org](http://www.animalresearchcures.org)

Guide for the Care and Use of Agricultural Animals in Research and Teaching, 3<sup>rd</sup> ed.

### Data

FURTheR

Biomedical Informatics Core

Study Design and Biostatistics Center Core

Translational Technologies and Resources Core

### Community

Researchmatch.org

Database of clinical trials with U of Utah branding, but like clinicaltrials.gov

Links to results/outcomes of clinical trials

Links to Community organizations

Community Engagement Core

Participant Interaction Core (CCTS Research Nursing Unit)

### Training

Research Administration Training Series (RATS) Core

Online orientation

Orientation videos on YouTube

Come visit us! (invitation to use physical space/contact staff)



**Table 7. CTSA Awardee Websites**

| <b>CTSA</b>  | <b>MyRA-like Portal</b>                                     | <b>Url</b>   |
|--|---|--|
| <b>2006 Awardees</b>                                 |   |  |
| Columbia University Health Sciences                  | Yes   | <a href="http://irvinginstitute.columbia.edu/">http://irvinginstitute.columbia.edu/</a>  |
| Duke University                                      | Not really  | <a href="http://www.dtmi.duke.edu/">http://www.dtmi.duke.edu/</a>  |
| Mayo Clinic College of Medicine                      | Very nice, and highlights physical space                    | <a href="http://ctsa.mayo.edu/">http://ctsa.mayo.edu/</a>  |
| Oregon Health & Science University                   | Yes, great links for finding collaborators                  | <a href="http://www.ohsu.edu/xd/research/centers-institutes/octri/about/what-we-do/">http://www.ohsu.edu/xd/research/centers-institutes/octri/about/what-we-do/</a>  |
| Rockefeller University                               | Not really  | <a href="http://www.rockefeller.edu/ccts/">http://www.rockefeller.edu/ccts/</a>  |
| University of California, Davis                      | Some good elements  | <a href="http://www.ucdmc.ucdavis.edu/ctsc/">http://www.ucdmc.ucdavis.edu/ctsc/</a>  |
| University of California, San Francisco              | Yes! And use of blogs, forums                               | <a href="http://ctsi.ucsf.edu/">http://ctsi.ucsf.edu/</a>  |
| University of Pennsylvania                           | No  | <a href="http://www.itmat.upenn.edu/">http://www.itmat.upenn.edu/</a>  |
| University of Pittsburgh                             | Yes, very nice  | <a href="http://www.ctsi.pitt.edu/HomePage.shtml">http://www.ctsi.pitt.edu/HomePage.shtml</a>  |
| University of Rochester                              | Yes   | <a href="http://www.urmc.rochester.edu/ctsi/">http://www.urmc.rochester.edu/ctsi/</a>  |
| University of Texas Health Science Center at Houston | Not really  | <a href="http://ccts.uth.tmc.edu/">http://ccts.uth.tmc.edu/</a>  |
| Yale University                                      | No  | <a href="http://www.ycci.yale.edu/">http://www.ycci.yale.edu/</a>  |
| <b>2007 Awardees</b>                                 |   |  |
| Case Western Reserve University                      | Yes, nice   | <a href="http://casemed.case.edu/ctsc/">http://casemed.case.edu/ctsc/</a> , and nice Concierge definition: <a href="http://casemed.case.edu/ctsc/concierge/">http://casemed.case.edu/ctsc/concierge/</a>                     |
| Emory University                                     | Yes   | <a href="http://www.actsi.org/index.html">http://www.actsi.org/index.html</a> , see particularly leadership/staff pages: <a href="http://www.actsi.org/about/leadership.html">http://www.actsi.org/about/leadership.html</a> |
| Johns Hopkins  | Under construction  | <a href="http://ictr.johnshopkins.edu/ictr/">http://ictr.johnshopkins.edu/ictr/</a>  |
| University of Chicago                                | Most behind closed access                                   | <a href="http://itm.uchicago.edu/">http://itm.uchicago.edu/</a>  |
| University of Iowa                                   | Yes   | <a href="http://icts.uiowa.edu/">http://icts.uiowa.edu/</a>  |
| University of Michigan                               | Not really, links to who to contact                         | <a href="http://www.michr.umich.edu/">http://www.michr.umich.edu/</a>  |
| University of Texas Southwestern Medical Center      | Yes, but not particularly well done                         | <a href="http://www.utsouthwestern.edu/utsw/home/home/research/ctsa/">http://www.utsouthwestern.edu/utsw/home/home/research/ctsa/</a>  |
| University of Washington                             | Yes   | <a href="http://www.iths.org/">http://www.iths.org/</a>  |
| University of Wisconsin                              | Not really, links to staff help                             | <a href="https://ictr.wisc.edu/Home">https://ictr.wisc.edu/Home</a>  |
| Vanderbilt University                                | Not really  | <a href="http://www.mc.vanderbilt.edu/victr/pub/">http://www.mc.vanderbilt.edu/victr/pub/</a>  |
| Washington University                                | No  | <a href="http://icts.wustl.edu/">http://icts.wustl.edu/</a>  |
| Weill Cornell Medical College                        | Not really, point researchers to Research Team Facilitators | <a href="http://www.med.cornell.edu/ctsc/">http://www.med.cornell.edu/ctsc/</a>  |



| <b>2008 Awardees</b>   |  |   |
|--|--|---|
| Albert Einstein College of Medicine of Yeshiva University    | Yes  | <a href="http://www.einstein.yu.edu/ictr/page.aspx?ekmense15074e5e_942_944_btnlink">http://www.einstein.yu.edu/ictr/page.aspx?ekmense15074e5e_942_944_btnlink</a>   |
| Boston University  | Not really   | <a href="http://ctsi.bu.edu/">http://ctsi.bu.edu/</a>   |
| Harvard University   | Yes, some social networking tools                                      | <a href="http://catalyst.harvard.edu/home.html">http://catalyst.harvard.edu/home.html</a>   |
| Indiana University School of Medicine                        | Yes  | <a href="http://www.indianactsi.org/">http://www.indianactsi.org/</a>   |
| Northwestern University                                      | Yes, nice home page; also, collaboration database choices              | <a href="http://www.nucats.northwestern.edu/">http://www.nucats.northwestern.edu/</a><br><a href="http://www.nucats.northwestern.edu/investigators/find_collaborator.html">http://www.nucats.northwestern.edu/investigators/find_collaborator.html</a>  |
| The Ohio State University                                    | Yes, very nice   | <a href="http://ccts.osu.edu/">http://ccts.osu.edu/</a>   |
| The Scripps Research Institute                               | Not really   | <a href="http://www.stsiweb.org/">http://www.stsiweb.org/</a>   |
| Stanford University  | Yes, very nice   | <a href="http://sccter.stanford.edu/">http://sccter.stanford.edu/</a>   |
| Tufts University   | Must be member to access most  | <a href="http://www.tuftsctsi.org/">http://www.tuftsctsi.org/</a>   |
| The University of Alabama at Birmingham                      | No   | <a href="http://www.ccts.uab.edu/">http://www.ccts.uab.edu/</a>   |
| University of Colorado Denver                                | No   | <a href="http://cctsi.ucdenver.edu/Pages/index.aspx">http://cctsi.ucdenver.edu/Pages/index.aspx</a>   |
| University of North Carolina at Chapel Hill                  | Yes  | <a href="http://tracs.unc.edu/">http://tracs.unc.edu/</a>   |
| The University of Texas Health Science Center at San Antonio | No   | <a href="http://iims.uthscsa.edu/">http://iims.uthscsa.edu/</a>   |
| The University of Utah                                       | Yes  | At OSP and VP for Research sites  |
| <b>2009 Awardees</b>   |  |   |
| Medical University of South Carolina                         | Yes, using RedCap, Collexis. Check out Research Toolkit!               | <a href="http://sctr.musc.edu/">http://sctr.musc.edu/</a>   |
| Mount Sinai School of Medicine                               | Not really   | <a href="http://www.mountsinai.org/Research/Centers%20Laboratories%20and%20Programs/Institutes%20for%20Clinical%20and%20Translational%20Sciences">http://www.mountsinai.org/Research/Centers%20Laboratories%20and%20Programs/Institutes%20for%20Clinical%20and%20Translational%20Sciences</a> |
| New York University School of Medicine                       | Yes  | <a href="http://ctsi.med.nyu.edu/">http://ctsi.med.nyu.edu/</a>   |
| University of Arkansas for Medical Sciences                  | Yes  | <a href="http://www.uams.edu/cctr/default.asp">http://www.uams.edu/cctr/default.asp</a>   |
| University of Cincinnati                                     | Yes, a little cluttered, a lot password protected, but some good stuff | <a href="http://cctst.uc.edu/">http://cctst.uc.edu/</a>   |
| University of Florida  | Under construction   | <a href="https://www.ctsi.ufl.edu/">https://www.ctsi.ufl.edu/</a>   |
| University of Illinois at Chicago                            | Yes, minimal, but simple   | <a href="http://www.uic.edu/depts/mcam/CCTS/CCTS-home.html">http://www.uic.edu/depts/mcam/CCTS/CCTS-home.html</a>   |
| University of Texas Medical Branch                           | Not very complete, but nice FAQs                                       | <a href="http://www.its.utmb.edu/">http://www.its.utmb.edu/</a>   |





## Appendix 1. CTSA Tools Introduction

The attached document contains a list of tools being used by CTSA awardees to improve or streamline their research, or to start or improve collaborations across divisions, among CTSA, and in the communities surrounding them. It is not an exhaustive list. For example, I edited out the many tools being used for genomic research for the most part. The descriptions are taken from the CTSA websites and the Biomedical Informatics Resource Inventory (<http://biositemaps.ncbcs.org/cirwp/index.html>).

The tools are listed and described in the column headed “Tools,” with the name of the tool in bold face. The four columns to the right of the Tools column represent four functions of interest to the MyRA team. In these columns I have listed the names of the tools that are used for that function. The four categories of functions are as follows:

- **Research/Collaborative.** Tools used to search for collaborators, social networking tools, wikis, and clinical data management tools are listed here.
- **Educational.** Named educational tools, for researchers or the community, are listed here. Please note that almost all CTSA have some educational materials on their websites; they are listed here only if they have a formal name or structure.
- **Administrative.** Tools used to administer research projects are listed here, such as core facility management programs, protocol and IRB submission and review systems. If staff is mentioned as a formal way in which the CTSA administers its processes (eg, navigators, facilitators), that is listed here.
- **Community.** Any program or entity that was built for community outreach is listed here.

The tools are almost all data bases and software; however, when people are mentioned as a tool for collaboration, like the research navigators, or the creation of a consortium, they are listed, too.

As one might expect –and perhaps hope—some tools are used by multiple CTSA, and are worthy of special mention here, particularly those being developed by CTSA awardees or the NIH and its vendors specifically for use by the CTSA to further the mission of collaborative translational research.

Some tools that are used by a number of CTSA include Confluence wiki, Collexis BioMedExperts, Ingenuity, Mantis, Freezerworks, various LIMS programs, Click Commerce eIRB, Velos eResearch, and CRISP (although the CRISP system is no longer supported by the NIH, and has been replaced as of October 31, 2009, by the RePORT Expenditures and Results (RePORTER) query tool).



Many consortia also list the staff they have put in place as valuable tools in administering procedures and assisting researchers in finding the information and collaborations they seek. In fact, the Manager of Research Software Development at the University of Pittsburgh states that their Research Facilitators are the “most established” aspect of their CTSI, and that they represent the real “one-stop shop” for researchers to get assistance finding the services they need. Community, state-wide, or regional consortia are also mentioned by a number of CTSA, and seem to particularly fit the mission.

Lastly, there are a few tools developed for the CTSAs specifically that are being widely adopted by CTSAs. I will describe those in greater detail here.

**REDCap** (Research Electronic Data Capture), developed at Vanderbilt, is a suite of Web-based tools designed to support data capture and dissemination for clinical and translational research studies. REDCap gives research teams an easy way to collect, disseminate, and protect the privacy of study data. Vanderbilt has successfully exported REDCap to other institutions using a highly collaborative model in which Vanderbilt provides software and support to institutional partners at no charge in exchange for participation in a consortium. Features and functions of the system are enhanced weekly. REDCap provides: 1) an intuitive interface for data entry (with data validation); 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages (SPSS, SAS, Stata, R); 4) procedures for importing data from external sources; and 5) advanced features, such as branching logic and calculated fields. REDCap Survey is a powerful tool for building and managing online surveys. You can create and design surveys in your web browser and engage potential respondents using a variety of notification methods. Participant responses may be easily exported to Microsoft Excel or to common statistical analysis packages (SPSS, SAS, R, Stata). REDCap Survey allows for a variety of question types, such as Text Boxes, Multiple Choice (single and multiple answer), File Uploads, Yes/No, True/False, and Sliders (Rating Scales). There are also advanced question features that may be used, such as auto-validation, branching logic, and stop actions.

**WebCAMP** Suite of interconnected modules, developed at Cornell to support common management functions at GCRCs, CTSAs and similar centers supporting clinical/translational research projects. Modules currently include a CTMS ("Census and Protocol Tracking"), a protocol authoring and review system (ePAR), a core utilization tracking module that supports secure entry of core activity by designated core representatives, and both GCRC and CTSA annual reporting modules capable of drawing data from other modules. ePAR ColdFusion-based system for scientific protocol application, submission, and review, is included as an optional module in the WebCAMP system. It supports multiple customization features including site-defined "application types", permitting it to be used for a variety of purposes including requests for GCRC/CTSA resources, application to educational programs, and applications for pilot/planning and other similar awards. If used, it supports data flow with the Census and Protocol Tracking module and the CTSA Annual Reporting module.



**i2b2** (Informatics for Integrating Biology at the Bedside), is an NIH-funded National Center for Biomedical Computing based at Partners HealthCare System. The i2b2 Center is developing a scalable informatics framework that will bridge clinical research data and the vast data banks arising from basic science research in order to better understand the genetic bases of complex diseases. This knowledge will facilitate the design of targeted therapies for individual patients with diseases having genetic origins. The platform has been adopted by 12 CTSA's to repurpose hospital medical records. Another 6 are actively evaluating it.

**PRIMER**, provides links to online resources in six categories: (1) Building Collaborations, (2) Developing Proposals, (3) Starting up a Study, (4) Conducting and Managing Projects, (5) Disseminating and Closing Research, and (6) Resources for Training. The PRIMER project was funded through an administrative supplement to the University of Washington's Institute for Translational Health Sciences Clinical and Translational Sciences Award (CTSA) UL1 RR025014 from the NIH National Center for Research Resources (NCRR). PRIMER is endorsed by the Community Engagement (CE) Key Function Committee (KFC) of the CTSA consortium and is a joint project involving representatives from the University of Washington's Institute for Translational Health Science, the Duke Clinical Research Institute, and Wayne State University. The PRIMER team includes researchers from Practice-Based Research Networks and the HMO Research Network.

February 20, 2010





CTSA Tools

| CTSA Institution | Tools  | Research/<br>Collaborative | Educational | Administrative                      | Community     |
|------------------|--|----------------------------|-------------|-------------------------------------|---------------|
| Einstein         | <p>Web site is portal for info on research, with educational materials about performing clinical research. <b>Front Door</b> is help desk portal for protocol submission and service desk. Developed <b>Einstein Research Profiles</b> for researchers to find each other and collaborators, using Collexis BioMedExperts as a base. Community pages are about their community outreach, but are not designed for use by community per se. <b>Ingenuity Pathway Analysis (IPA)</b>, visual representation of molecular structure, interactions, and pathways. <b>Freezerworks</b> streamlines sample tracking and workflow. <b>LIMS</b> database helps manage shared facilities. <b>ICTR Protocol Submission and Review Application</b>, for IRB submission and review. The <b>Research Informatics Core (RIC)</b> is part of the Research Computing arm of Information Technology Services. It is also a Shared Resource of Albert Einstein College of Medicine. The RIC serves as the primary informatics resource for joint research efforts of the Albert Einstein College of Medicine and Montefiore Medical Center.</p>  | Einstein Research Profiles |             | Front door, Freezerworks, LIMS, RIC |               |
| Arkansas         |  |                            |             |                                     |               |
| Emory U          | <p><b>caArray</b>, aArray is an open-source, web and programmatically accessible array data management system. caArray guides the annotation and exchange of array data using a federated model of local installations whose results are shareable across the cancer Biomedical Informatics Grid (caBIG). <b>CR-Assist</b>, is a web application that is designed to assist research teams in managing participants and study visits, tracking recruitment effort, sharing study calendar, generating sample collection labels, inquiring on sample status, looking up CIS schedule and submitting electronic appointment requests to CIS schedulers. It also assists the CIS administrators in terms of resources planning and tracking. Microsoft <b>Sharepoint</b>, Collaboration and Virtual Workspace Environment. <b>ACTSI Request Submission Tool</b>, A web-based tool for allowing individual such as researchers, community physicians, community advocate submitting their requests to the ACTSI. <b>Nautilus</b> Laboratory Information Management System <b>LIMS</b> implementation with initial scope targeted at biospecimen management across clinical interaction sites in the ACTSI.</p> | CR-Assist, Sharepoint      |             | LIMS                                | ACTSI Request |
| Boston U         | <p><b>BMC-CDW</b>, BMC-Clinical Datawarehouse (BMC-CDW) is a comprehensive clinical datawarehouse (GE Centricity Physician Office EMR, Eclypsis Sunrise Clinical Manager (SCM), scheduling, billing, pharmacy and radiology). <b>INSPIR</b> Web-based IRB documentation and submission system for Boston University School of Medicine. <b>PCT System</b> The Paperless Clinical Trials (PCT) system can automatically create applications for electronic data capture and clinical trials data management based on common characteristics identified in research projects including: data entry, subject tracking, reports, electronic signature, and audit trails.</p>   | BMC-CDW, PCT System        |             | INSPIR                              |               |

CTSA Tools

| CTSA Institution | Tools   | Research/<br>Collaborative                                     | Educational | Administrative            | Community |
|------------------|---|--|-------------|---------------------------|-----------|
| Case Western     | <p><b>Oncore, Clinical Trial Management System (CTMS)</b> from Percipenz. Used in the Case Comprehensive Cancer Center, but available to the Cleveland CTSC as a member institution. Working out how data might be shared between this and other information systems for cancer and non-cancer studies. <b>CTSA Request Management System</b> (based on Multi-Modality, Multi-Resource Informatics Infrastructure, or MIMI), The RMS is based on a highly modified derivative of the Multi-Modality Multiresource Informatics Infrastructure (MIMI) framework. The system provides a single entry point for collaboration within the CTSC. The RMS guides researchers in issuing and tracking their requests to the CTSCs Cores. An investigator uses the system to request expertise via consultation resources. The system also allows core personnel to better manage incoming requests. Core administrators have the capability to forward requests to other cores or assign tasks from requests to consultation resource experts who then can consult with investigators to help address their research needs. The administrators can also note any changes or the current status of a request in a description box that is viewable to the requester. Consultation resource experts can access the system to update or complete any tasks that they have been assigned. The web-based CTSC RMS is also designed to support the daily operations of the <b>research concierge</b> in such a way that maximizes operational efficiency through cooperative, decentralized management of consultation resources. The research concierge remains in the loop in an administrative capacity or as a recipient of a request and can oversee existing requests and make sure that they have been triaged to the appropriate cores. Deployed at Imaging core, Proteomics core, Flow-Cytometry core, and in deployment for Concierge request management by directing investigators' requests to relevant consultants/resources and managing the life-cycle of such requests. <b>Confluence Wiki</b>, Web-based collaboration and communication Wiki used for the Cleveland CTSC (same as that used by the NCRR).</p> | <p>Oncore, CTSA Request management system, Confluence wiki</p> |             | <p>Research Concierge</p> |           |

CTSA Tools

| CTSA Institution     | Tools   | Research/<br>Collaborative                  | Educational   | Administrative                    | Community |
|----------------------|---|---|---|-----------------------------------|-----------|
| Cornell              | <p><b>GE Patient Protocol Manager</b>, Clinical Trials Management System. <b>BDVAL (Biomarker Discovery and Validation)</b>, a suite of tools to develop and validate predictive models from high-throughput data (gene expression, proteomics, methylation, etc). The domain of application is personalized medicine. This tools is being developed and tested in the context of the <b>MAQCII project</b> (Weill Cornell analysis team). Mapback Protein amino acid coordinates to genomic coordinate mapping tables. <b>TruData Data Dictionary</b> with Automated LOINC assignment and other advanced features for managing procedures, results, and other terminologies. <b>WebCAMP</b> Suite of interconnected modules to support common management functions at GCRCs, CTSA's and similar centers supporting clinical/translational research projects. Modules currently include a CTMS ("Census and Protocol Tracking"), a protocol authoring and review system (ePAR), a core utilization tracking module that supports secure entry of core activity by designated core representatives, and both GCRC and CTSA annual reporting modules capable of drawing data from other modules. <b>EpicCare Ambulatory EMR</b>, Electronic Medical Records (EMR) (interfaced to clinical trials management system). <b>EpicCare Clarity</b>, Clinical Data Warehouse. <b>COEUS</b>, IRB Administration. <b>RPS/POPS</b> (Cerebro) Investigator Profiles Registry. ePAR ColdFusion-based system for scientific protocol application/submission/review. ePAR is included as an optional module in the WebCAMP system. It supports multiple customization features including site-defined "application types", permitting it to be used for a variety of purposes including requests for GCRC/CTSA resources, application to educational programs, and applications for pilot/planning and other similar awards. If used, it supports data flow with the Census and Protocol Tracking module and the CTSA Annual Reporting module. See "WebCAMP" for more details about the overall software product. <b>Misc Computational and Micro Array Tools</b>, A long list of various computational bioinformatics and microarray utilities, databases, and other tools are provided for researchers.</p> | Patient Protocol Manager, WebCAMP, RPS/POPS |   | COEUS, ePAR                       |           |
| U of Colorado Denver | <p><b>Time Tracker</b>, Configurable web-based task &amp; time tracking system linked to invoicing for charge-back projects. <b>LAMP, Joomla</b>. Study Design / Manager Web-based clinical trials data management system with full audit trails. Interactive CRF design with automated DBMS table generation. ColdFusion &amp; MS SQL Server. <b>Orchard Harvest LIS</b>, Commercial LIS system being installed at CTSA core labs. <b>Introduction to Health Information Systems</b> -- course syllabus, Full course curriculum, including readings and assignments for a survey course of HIT geared toward Health Administration Masters students and first course for Informatics students. K12 Research Scholar Award application, Application forms for K-12 research scholar grants. <b>Informatics Seminar Series</b>, Slides and videos of monthly campus-wide Informatics presentations. Initial presentations have slides only. Later presentations have slides &amp; video</p>  | LAMP  | Intro to Health Information Systems, Informatics Seminar Series | Time Tracker, Orchard Harvard LIS |           |
| Duke U               | <p><b>caTRIP</b>, Allows users to query across a number of caBIG data services, join on common data elements (CDEs), and view their results in a user-friendly interface. Focus on enabling outcomes analysis. <b>Nautilus LIMS</b> Thermo Fisher Scientific Laboratory Information Management System. Includes biobanking module and integration with internal databases. <b>CRF Library</b> contains the data collection case report forms (CRFs) and other information about the data collected on trials conducted throughout the Duke Clinical Research Institute's history. Code, but not content, may be shared.</p>   | caTRIP, CRF Library                         |   | LIMS                              |           |

CTSA Tools

| CTSA Institution | Tools   | Research/ Collaborative          | Educational | Administrative                          | Community   |
|------------------|---|----------------------------------|-------------|---|---|
| Harvard          | <p><b>Harvard Catalyst</b> Web site is a simple tool for information and the online manifestation of Harvard Catalyst's three strategic goals: to create connections, to be at the cutting edge of every endeavor, and to nurture clinical and translational researchers. The Harvard Catalyst program includes three <b>research navigators</b> (staff). <b>HarvardTrials</b> is the Harvard view of ClinicalTrials.gov.</p>   | Harvard Catalyst, Harvard Trials |             | Research Navigators                     |   |
| Indiana U        | <p><b>caTissue Suite</b>, developed under the caBIG initiative is a tissue bank repository tool for biospecimen inventory, tracking, and basic annotation. Extensive support for barcode data entry and other tools for high volume specimen management, tightly integrated with <b>SPIN repository</b>. SPIN multi-organizational structured clinical data repository with patient and provider linkages. <b>DOCS4DOCS</b> @_ clinical messaging system. <b>RESNET</b>, Patient recruitment.</p>   | SPIN repository, DOC\$4DOCS      |             | caTissue suite                          | RESNET  |
| Columbia U       | <p><b>RASCAL</b> is web-based application developed to simplify the University's research compliance and research administration processes. <b>WorkWeb</b> is a suite of applications using wiki technology designed to help locate experts and collaborators at Columbia, request services for research, interact online by creating Web pages and sharing documents. Collaborative and Multidisciplinary Pilot Research (<b>CaMPR</b>) award program further encourages the establishment of new, multidisciplinary research teams. <b>TRANSFORM</b> (TRaining And Nurturing Scientists FOr Research that is Multidisciplinary) houses the Irving Institute's educational programs. Irving Institute's <b>Community Engagement Resource</b> partnered with its Biomedical Informatics Resource to begin conducting surveys, interviews, and focus groups in the surrounding community, to identify incentives and barriers to clinical research perceived by community leaders, non-academic health care providers, and patients. A new offsite community center was built.</p> | WorkWeb, CaMPR                   | TRANSFORM   | RASCAL                                  | Community Engagment Resource  |
| Johns Hopkins    | <p>The Institute for Clinical and Translational Research (ICTR) at Johns Hopkins University added two <b>research "navigators"</b> (staff), and Accelerated Translational Incubator Program (ATIP) pilot awards. ATIP applications are processed through <b>Connection Request</b>, the ICTR's custom software system designed to unify existing service request forms, create new ones, and manage workflow. Another technological solution is the <b>Clinical Research Management System (CRMS)</b>, a secure, Web-based application that organizes and streamlines clinical research management. An overarching ICTR goal is to enhance the image of study participation by emphasizing the social contribution made by study participants. <b>eIRB</b> is the electronic IRB approval system (linked to CRMS).</p>  | CRMS                             |             | Research Navigators, Connection Request | enhance image of study participation by emphasizing social contribution |

CTSA Tools

| CTSA Institution | Tools  | Research/ Collaborative               | Educational | Administrative                         | Community             |
|------------------|--|---------------------------------------|-------------|--|-----------------------|
| Mayo Clinic      | <p>Emphasis on community--mobile lab (van). <b>Practice-Based Research Network (PBRN)</b> pilot projects concern practice improvements in diabetes management, geriatrics, and end-of-life care. Research results can be quickly disseminated to health system practices in more than 70 communities. Mayo Clinic has also connected with eight regional CTSA's and IDeA (NCRR Institutional Development Award program) states to form the <b>Upper Midwest Consortium</b>, dedicated to sharing curriculum, resources, and best practices for research education and career development. At the national level, the Mayo Clinic CTSA continues its successful collaboration with the University of Pittsburgh Center for Minority Health in its work to eliminate health disparities. Mayo Clinic has also worked closely with Vanderbilt University on the development of the <b>REDCap</b> informatics solution for clinical trials management and volunteer registries. <b>IRBe</b>, Web based IRB review and approval system which includes a module for the RRRP review and approval process. <b>RRRP</b> is Mayo CTSA review panel for protocols intend to use the CTSA Research Resources for study implementation. <b>CTSA Service Tracking Tool</b>, Web based system for Mayo CTSA Service Center to track services provided to Mayo investigators. Information collected is also used to feed CTSA annual report. <b>CRU (Clinical Research Unit) Tools</b> A collection of integrated web applications organized into a web portal to support clinical study execution. The applications include protocol tracker, patient visit and staff scheduling, nursing task dictionary, nursing and laboratory flowsheet systems, computerized research order set, patient visit portal, and specimen collection tracking tool.</p> | Upper Midwest Consortium, REDCap, CRU |             | IRBe, RRRP, CTSA Service Tracking Tool | mobil lab (van), PBRN |

CTSA Tools

| CTSA Institution          | Tools   | Research/ Collaborative                    | Educational | Administrative                                | Community |
|---------------------------|---|--|-------------|---|-----------|
| U of Michigan             | <p><b>Velos eResearch</b>, Commercially-developed, regulatory compliant, web-based clinical research information system. <b>FreezerWorks</b>, Specimen management system that supports freezer inventory, sample management and sample tracking. Used by MCRU, formerly GCRC, and other research teams across the University of Michigan Health System. <b>Honest Broker Security</b> and integration informatics initiative that unites research and clinical care. Prototype securely links three clinical care systems and research database for research on co-morbidity of depression and cardiovascular disease, facilitating collaboration among community-based primary care physicians, cardiologists, and psychiatrists. <b>caTissue Suite</b>, Developed under the caBIG initiative is a tissue bank repository tool for biospecimen inventory, tracking, and basic annotation. Deployed at the University of Michigan as part of the Inter-SPORE Prostate Biomarker Study. Click Commerce <b>Proposal Management eResearch (eRPM)</b> is being developed as a new Web-based system to accommodate the electronic routing, approval, and submission of funding proposals to external sponsors, including Grants.gov. Deployed in pilot phase at the University of Michigan. <b>Engage</b>, Clinical Research Web Portal providing centralized access for all information regarding human subjects research for the University, including studies recruiting subjects, subject registries, required postings to public bulletin boards, such as clinicaltrials.gov, and general information about human subject research for investigators, patients and the community. <b>Tranche</b>, Free and open source filesharing tool that enables collections of computers to easily share and cite scientific data sets in a secure and scalable fashion. More than 5200 data sets on line as of mid-2008. Tranche is the filesharing link between PRIDE and Peptide Atlas for the Human Proteome Organization (HUPO) Plasma Proteome Project via ProteomExchange. Click Commerce <b>IRB, eResearch Regulatory Management</b> is the web-based system that centralizes the review and approval process for Human Subjects Research Applications and IBC Recombinant DNA Registrations. eResearch Regulatory Management was implemented across all University of Michigan campuses in July 2005.</p> | eResearch, Honest Broker Security, Tranche |             | Freezerworks, caTissue Suite, eRPM, Click IRB | Engage    |
| Mt Sinai                  |   |  |             |   |           |
| NYU                       |   |  |             |   |           |
| N Carolina at Chapel Hill | <p><b>VCGS</b>, Vocabulary and Concept Generation System is a text-mining and clustering tool capable of automatically extracting, ranking and associating key entities. <b>ENABLE</b>, An automated crawling, indexing, and searching tool suitable for developing a portal. <b>SAMI</b> (secure access to medical information), A research portal to UNC's clinical data warehouse (CDW).</p>   | VCGS, ENABLE, SAMI                         |             |   |           |

CTSA Tools

| CTSA Institution | Tools   | Research/ Collaborative   | Educational | Administrative                                     | Community |
|------------------|---|---|-------------|--|-----------|
| UT Southwestern  | <p><b>Athena: Remote Charge Capture System Software</b> acts as a remote charge capture system that can drastically reduce the time and effort necessary for collecting, processing, and accessing patient information. Demographic information can be downloaded to an abstractors laptop. <b>Human Resource Management System Software</b> (HRMS) is designed to serve the Budget, Human Resources, and Payroll functions of a major institution. All data collection for HRMS is done using online forms that can be entered at the source. <b>SAS</b>, The Center for Biostatistics and Clinical Science (CBCS) now offers a site license for Version 9.13 of SAS (Statistical Analysis Software) for Windows. This new version of SAS includes several enhancements. <b>Freezer Works</b>, Freezerworks Unlimited reduces the aggravation of managing thousands of samples. You can easily track what is being stored, moved, and tested across your organization. <b>Bad Bug Base</b>, a database of homologous coding sequences in infectious diseases. <b>eTBLAST and eTSNAP</b>, "eTBLAST is a unique search engine for searching biomedical literature. Our service is very different from PubMed. While PubMed searches for "keywords", our search engine lets you input an entire paragraph and returns MEDLINE abstracts. <b>FRISC</b>, "Faculty Research Interests Science Comparator, a pre-computed set of MedLine abstracts that are maximally similar to the research interests of UTSW investigators. FRISC uses eTBLAST as its engine. (experimental version for UTSW faculty.)" <b>TRITE</b> "Topical Research Interests Comparator. TRITE is a pre-computed set of Medline similarity hits that are topical. <b>ARGH</b>, a comprehensive catalog of biomedical acronyms and abbreviations extracted from MedLine abstracts. <b>IRIDESCENT</b>, A knowledge discovery engine designed for comprehensive identification and analysis of literature trends. <b>BioHealth Base</b>, to assist scientific researchers in their development of vaccines, therapeutics, and diagnostics. <b>ImmPort</b>, provides advanced information technology support in the production, analysis, archiving, and exchange of scientific data for the diverse community of life science researchers supported by NIAID/DAIT. <b>CLASSIFI</b> (Cluster Assignment for Biological Inference) is a data-mining tool that can be used to identify significant co-clustering of genes with similar functional properties (e.g. cellular response to DNA damage). <b>Deja vu</b>, The application of text similarity searching can robustly detect highly similar text records, offering a new tool for ensuring integrity in scientific publications. <b>EPIC</b>, Electronic Medical Record. Velos <b>eResearch</b>, Clinical Trials Management. <b>i2b2</b>, Clinical Reseach Data Warehouse. Cerner, <b>Laboratory Management Information System</b>. Click, Commerce <b>IRB Management</b>. <b>Biomaterial Tracking and Management - BTM</b>, A software application supporting the tracking and management of human tissue specimens for biobanking purposes. <b>Ingenuity</b>.</p> | Athena, eTBLAST and eTSNAP, FRISC, TRITE, ARGH, IRIDESCENT, BioHealth Base, eResearch, i2b2 |             | HRMS, SAS, FreezerWorks, Click IRB, BTM, Ingenuity |           |

CTSA Tools

| CTSA Institution | Tools   | Research/ Collaborative                         | Educational | Administrative                       | Community |
|------------------|---|---|-------------|--------------------------------------|-----------|
| Northwestern U   | <p><b>NOTIS (Northwestern Trial Information System)</b>, A web-based application for managing intra- and inter-institution research studies, participant accrual to studies, regulatory reporting, and supports clinical research reporting workflows. NOTIS is used at Northwestern to track roughly 400 studies and has more than 3000 trials and 80,000 patients with more than 500,000 research events entered. <b>Patient Study Calendar</b>, A standards based, open source, BRIDG-compliant, CDISC-harmonized Patient Study Calendar developed with the NCI for creating research study calendar templates and managing patient study calendars across institutions.</p> <p><b>Northwestern Clinical EDW</b>, A inter-institutional Data Warehouse encompassing encounter, scheduling, laboratory, pharmacy, billing and diagnostic data on 2.1 million patients seen in the McGaw health consortium, with more than 2.3 billion patient facts. ClickCommerce <b>eIRB</b> Supports IRB processing, and rudimentary clinical trials administration. We have been in negotiations with ClickCommerce (WebBridge) since 2002 and had our initial roll-out in June 2007. We are expecting to mandate entry into the system by Dec 2008 . <b>InfoEd</b>, A commercial grants management program. Replaced an in house system in 2007. <b>Surveyor</b>, A general purpose Ruby-on-Rails plugin engine for generating surveys or adhoc CRFs. <b>Publications and Interactions site</b>, A Ruby-on-Rails web app for mining PubMed given a list of faculty and departments, and build an interaction map. <b>NUgene</b>, A web-based system for managing a large genotype/phenotype biorepository at Northwestern.</p> | NOTIS, EDW, Publications and Interactions Suite |             | Patient Study Calendar, eIRB, InfoEd |           |



CTSA Tools

| CTSA Institution      | Tools  | Research/ Collaborative   | Educational | Administrative  | Community                               |
|-----------------------|--|---|-------------|---|---|
| Oregon Health & Sci U | <p>The Oregon Clinical and Translational Research Institute (OCTRI) has forged a partnership between Oregon Health &amp; Science University (OHSU) and the Kaiser Permanente Center for Health Research (KPCHR). Community-based research has been a cornerstone of OCTRI's efforts, and its Community and Practice Research program connects a group of practice-based research networks. The Human Investigations Program at OHSU provides comprehensive training for clinical and translational investigators, and has been instrumental in increasing the success rate of K award applications. Velos <b>eResearch</b>, Commercially-developed, regulatory compliant, web-based clinical research information system. <b>REDCap</b>, Electronic data capture and dissemination for research studies. <b>Consense</b>, Analytical framework in the statistical programming language R which provides metrics for interpretation and comparison of unsupervised learning algorithms. <b>Teleorm</b>, Document processing and automation solution. Surveyor Commerical CTMS. Surveyor provides tools for tracking subjects and studies, including tools for scheduling, budgeting, screening and reporting. <b>CRIS</b>, Internally developed resource scheduling and protocol tracking system. Content Management System Easy to administer web portal allows control of web based information and serves as an informational resource for investigators on their protocols via integration with CRIS. <b>JIRA</b>, A commercial bug and issue tracking project-management application. <b>Application Framework</b>, A core set of Delphi form classes and Firebird Database data structures that form a template for developing a client/server database application for a protocol's data management. <b>Mantis</b>, A free bug and issue tracking project-management application. <b>Erwin Enterprise data modeling tool</b>, allowing creation, visualization and other advance functionality across different databases. <b>Final Builder</b>, An automated build and release management tool. <b>Confluence</b>, A wiki package for collaboratively generating and maintaining information. Investigator Project Tracking This web-based tool tracks contacts between OCTRI and investigators regarding protocols that utilize OCTRI resources. The tool allows OCTRI staff to track information about investigators, their projects and the services provided by OCTRI. The tool also facilitates communication between units of OCTRI and serves as a central location for the status of service requests. The tool will be superseded by a more complex web-based information system that is currently under development. <b>Scientific Review Committee (SRC)</b>, Online Review Scientific review of protocols utilizing OCTRI resources is facilitated by the use of the online SRC page in the OCTRI Managed site. Documents for protocols that will be reviewed are made available online, which allows easy distribution and updates. Review members and OCTRI Program Directors can upload comments/reviews of the protocols. The meeting dates and agendas are also available, as well as the minutes which contain a summary of the comments about each protocol.</p> | eResearch, REDCap, Enterprise data modeling tool, Confluence wiki |             | Consense, Teleorm, CRIS, JIRA, Application Framework, Mantis, SRC | Community and Practice Research Program |
| Rockefeller U         | <p>Center for Clinical and Translational Science (CCTS) has developed electronic programs that facilitate study tracking, scheduling, and reporting; and an Advisory Committee for Clinical and Translational Science (ACCTS) that expands on the roles of previous committees and serves as the primary protocol reviewer and governance structure for the CCTS. Through the <b>Integrated Research Information System (iRIS)</b>, Rockefeller's CCTS offers <b>Study Assistant</b>, an electronic study management module that enables study personnel to generate inclusion/exclusion criteria checklists, order sheets, and worksheets for each protocol-specific study visit as well as to schedule participant visits, and <b>Review Board Assistant</b>, which permits electronic production and distribution of protocols to both the ACCTS and the institutional review board (IRB) and creates the underlying board databases. <b>Ingenuity Pathways Analysis</b>.</p>   | iRIS  |             | Study Assistant, Review Board Assistant                           |   |
| Med U of S Carolina   |  |   |             |   |   |

CTSA Tools

| CTSA Institution | Tools  | Research/<br>Collaborative       | Educational | Administrative               | Community   |
|------------------|--|----------------------------------|-------------|------------------------------|-------------|
| U of Washington  | <p>The Institute of Translational Health Sciences (ITHS) has sought resources outside the health science arena to enhance translational research, i.e., the Biomedical Informatics Core is partnering with Microsoft to evaluate using the <b>Amalga</b> tool to improve research access to medical record data. To help investigators translate concepts to the clinic, the ITHS Preclinical Research Development Network also partnered with academic business and law groups. Also used <b>Lean</b>, a data-driven, collaborative approach to increase efficiency, used for several years by one of the ITHS's key partners, Seattle Children's Hospital. To facilitate research with community partners, the Community Outreach and Research Translation (CORT) Core will publish a collaboration toolkit; a guide on best recruitment practices for multi-site studies; a data use agreement toolkit; and a data query, extraction, and standardization tool (<b>Data QUEST</b>). The CORT team also uses the Project to Review and Improve Study Materials (<b>PRISM</b>) readability toolkit (developed prior to ITHS funding)—a publicly available resource useful to anyone who wants to develop more participant-centered, reader-friendly research materials, such as consent forms, invitation letters, and HIPAA authorization language. And the Treuman Katz Center for Pediatric Bioethics at Seattle Children's developed the Bioethics Consult Application (<b>BECA</b>), a Web-based system to enhance the efficiency and quality of clinical and research bioethics consultation and improve communication with consult requestors. <b>WebTrial</b>, Web-based, .Net, SQL Server backend, handles "Standard" Case Report Forms. Legacy inhouse Electronic Data Capture system currently running some trials. Plan to move to more standard systems, but source code is available. <b>REDCap</b> Electronic data capture and dissemination for research studies, piloting support at ITHS. <b>OpenClinica</b> Open source platform for Electronic Data Capture (EDC), local installation being used to support clinical studies at the ITHS. <b>i2b2</b> Adaption and extension of the I2B2 data integration framework (www.i2b2.org) for a CTSA pilot project to integrate anonymized clinical data across three CTSA's. <b>Solstice</b>, Open source platform for surveys and other web content, basis for University of Washington Catalyst system, <a href="http://catalyst.washington.edu/">http://catalyst.washington.edu/</a>, which we are piloting for use in relatively simple Electronic Data Capture situations.</p> | Amalga, Lean, BECA, REDCap, i2b2 |             | WebTrial, Solstice           | CORT, PRISM |
| Ohio State       | <p><b>TOKEN</b>: Translational Ontology-anchored Knowledge Discovery Engine, A suite of data processing tools and a web application collectively used to generate, review, and annotate ontology-anchored relationships between phenotypic and bio-molecular data types in large-scale data repositories. <b>CIMS v2.0 PSC (Patient Study Calendar)</b>, A web-based clinical trial patient study calendaring tool (developed using web portlet / JSF technologies). <b>Information Warehouse (IW)</b>, Comprehensive, integrative data warehousing and business intelligence platform containing over 12 years of operational and clinical data for The Ohio State University Medical Center (developed using Oracle RDBMS/BI technologies). <b>ASAP (Automated Screening for Active Protocols)</b>, A data-warehouse anchored web application that supports the automated, pre-encounter screening of patients for clinical trials eligibility</p>   | TOKEN, Information Warehouse     |             | Patient Study Calendar, ASAP |             |

CTSA Tools

| CTSA Institution           | Tools  | Research/<br>Collaborative   | Educational | Administrative          | Community |
|----------------------------|--|--|-------------|-------------------------|-----------|
| Scripps Research Institute | <p><b>Genomic Medicine LIMS</b>, Oracle database containing sample inventory information, phenotype data, laboratory process status and genomic/genetic data. Accessible by internal web sites. Sequence Analysis Pipeline Custom scripts integrating Solexa/Illumina sequence analysis with LIMS, downstream alignment and variant detection packages. <b>C/NExT Tumor registry</b>, storing patient specific data including relevant patient details, DXs, ICDO (oncology specific coding), tumor size, grade, stage, and histologic tumor subtype. Software provided by State of California as part of the California Cancer Registry (CCR) program. <b>STSI website</b>, Website for the Scripps Translational Science Institute research projects, events, press, founders, more. <b>Clinic Data Warehouse</b>, Oracle data warehouse containing clinical data on roughly 2 million ambulatory/clinic patients, including DXs, demographics, clinic visits, and lab results. <b>Enterprise Data Warehouse</b>, SQL Server data warehouse containing clinical data on roughly 1.3 million hospital inpatients, including patient DXs, procedures (surgeries &amp; other), demographics, length of stay, charges &amp; applied costs. <b>GE Centricity</b>, Inpatient Electronic Hospital Record, (EHR) system with associated data repository.</p> | STSI Website, Clinic Data Warehouse, Enterprise Data Warehouse, Centricity |             | LIMS                    |           |
| Stanford                   | <p>The <b>CTR Support Portal</b> serves as a single entry for clinical and translational researchers to access key support services and technologies. Support is also coordinated by a "Study Facilitator." <b>CTP Image Anonymizer</b>, A DICOM image anonymizer that can receive images from any PACS workstation at Stanford, stripping out patient identifiers from DICOM headers. De-identified images are archived on a central server accessible to researchers throughout the enterprise via Web browser. Secondary capture images containing PHI "burned-in" are filtered out. <b>STRIDE Clinical Data Warehouse</b>, An HL7 RIM-based Warehouse of clinical data on 1.2 million patients seen at Stanford University Medical Center since 1995. <b>STRIDE Biospecimen Data Repository</b>, STRIDE J2EE-based biospecimen registration, management, tracking and distribution system.</p>   | CTR Support Portal, STRIDE   |             |                         |           |
| UC San Francisco           | <p>CTSI created a process to connect core managers across the university, providing detailed information about each core, and these data populated a widely used "cores search" tool rolled out by <b>CTSI's Virtual Home initiative</b>. CTSI formed an umbrella organization, the <b>Resource Allocation Program (RAP)</b>, to provide a single Web site for information on intramural funding opportunities and uniform proposal deadlines, application format, and review process. <b>Secure Data Environment</b>, Web based secure document storage and management service for research community. <b>THREDS</b>, Clinical Data Reporting service.</p>  | CTSI's Virtual Home Initiative, RAP  |             | Secure Data Environment |           |
| U of Chicago               | <p>U Chicago established the Institute for Translational Medicine (ITM, an administrative structure that oversees and implements the university's CTSA research support and training programs) and an affiliated Committee on Clinical and Translational Science (the academic unit responsible for graduate training in the ITM). The ITM's <b>Knowledge Translation Unit (KTU)</b> engages community-based clinicians in identifying high-priority clinical research questions, developing systems for efficient translation of new research findings into community-based clinical practice, and promoting the use of information technology for point-of-care access to the best research evidence to guide clinical practice. Also developing the <b>Collaborator Finder</b> that allows users to identify which University of Chicago faculty publish on topics most closely related to their own research. <b>Velos eResearch</b>, Commercially-developed, regulatory compliant, web-based clinical research information system. Esprit <b>Health eSphere</b>, Commercially-developed customized biospecimen management system. Epic Systems - <b>Clarity</b>, Commercial Electronic Health Record with associated data repository.</p>   | KTU, Collaborator Finder, eResearch  |             |                         |           |

CTSA Tools

| CTSA Institution        | Tools   | Research/ Collaborative    | Educational | Administrative                   | Community |
|-------------------------|---|----------------------------|-------------|----------------------------------|-----------|
| UT San Antonio          | <p>Collexis <b>Research Profiles</b>, a powerful tool for semantic searching and knowledge discovery. Collexis is an innovative tool to promote collaboration regardless of organizational affiliation. Collexis currently contains profiles for over 400 selected UT Health Science Center researchers. Profile information is compiled from federal grant information included in the <b>CRISP</b> database and publication information from PubMed. Users are able to search for collaborators by concept, name or full text. <b>Biomedexperts</b> , online community that connects biomedical researchers to each other through the display and analysis of the networks of co-authors with whom each investigator works to publish scientific papers. The comprehensive system of pre-populated expert profiles, coupled with the ability to analyze all associated professional connections within the co-author network, allows scientists and researchers across organizations the ability to share data and collaborate in ways never before considered. Collexis <b>Expert Platform for Translational Research (CPTR)</b>, aimed at supporting the individual scientists in their attempts to build translational research teams. The Collexis Expert Profiling Platform for Translational research allows for the first time to promote, explore and measure personal and institutional collaboration.</p>   | BiomedExperts, CPTR, CRISP |             |                                  |           |
| Tufts                   |   |                            |             |                                  |           |
| U of Alabama Birmingham | <p>UAB's Center for Clinical and Translational Science (CCTS) catalyzed creation of the Council of Center Directors, a monthly forum for UWIRC directors to discuss optimal use of resources and to coordinate efforts among centers. Also the Council for Translational Research meets monthly and represents all research administration offices, all schools on campus, and a range of investigators to streamline the institution's regulatory infrastructure and inform the development of a readily accessible electronic portal for grant submissions. Also has centralized the operation of UAB cores by facilitating development of the Office for Core Technologies within the Office of the Vice President for Research and Economic Development. <b>Horizon</b> - Ambulatory Electronic Health Record and Clinical Portal Internally developed web portal used across the UAB Health System for access to patient centered visit and clinical information. Includes all inpatient discharge and operative notes, and all outpatient transcribed documents and notes. Includes all laboratory and imaging results. Clinical and visit content is integrated with the enterprise Master Patient Index via a self-developed CORBA PIDS (Patient Identification Service) implementation. Includes additional information such as Policies and Procedures, Pyxis Stock, Renal Waitlist, Surgical Schedule, Medical Staff information, Patient Safety information, and access to an external evidence based clinical knowledge base. Oracle <b>Administrative suite</b>, Serves a broad range of university administrative needs, including Grants/Plant Accounting and Accounts Receivable for Sponsored Projects, GL, Purchasing, HR. Oracle <b>SiteMinder</b> Clinical Trial protocol management, budget creation, patient visits scheduling, tracking completion targets, and tracking expenses and billing. Primary focus to date has been financial management.</p> | Horizon                    |             | Administrative Suite, SiteMinder |           |

CTSA Tools

| CTSA Institution | Tools   | Research/ Collaborative   | Educational | Administrative  | Community |
|------------------|---|---|-------------|---|-----------|
| UC Davis         | <p>The IT staff and CTSC clinicians and researchers are making secondary use of clinical data a reality. The next generation of software will better collect data for disease registries, outcome and clinical effectiveness studies, clinical trials, and other types of health research. Early user of NIH-funded open-source software known as <b>i2b2</b> (Informatics for Integrating Biology and the Bedside). Data warehouse containing clinical data on over 150k patients, including outpatient DX, lab results, medications, and inpatient procedures. ETL processes authored to pull data from EMR and finance systems. <b>Telemedicine Network</b>, UC Davis partners with many community hospitals and clinics throughout Northern California to provide residents and their physicians with access to specialized medical care and education through the use of ISDN, TCP/IP, and satellite video communications technology. <b>Application Resource Use</b>, Web-based request form that collects and routes information concerning CTSC resource application for all cores within the UC Davis CTSC framework. <b>SUN Secure Global Desktop</b>, Secure remote desktop access management software. <b>Resources Website</b>, Web Site that contains a listing and links to numerous research-related functions at both UC Davis main campus and the UC Davis Health System. <b>Clarity data repository</b>, Oracle-based clinical data repository and custom data marts populated by nightly ETL from Epic EMR. <b>Velos eResearch</b>, Commercially-developed, regulatory compliant, web-based clinical research information system. <b>Atlassian Confluence</b>, Wiki Tool. <b>Atlassian JIRA</b>, Web-based Bug and Issue Management Tool.</p> | i2b2, Telemedicine Network, Resources Website, eResearch, Confluence wiki |             | Application Resource Use, Secure Global Desktop, JIRA |           |
| U TX Med Branch  |   |   |             |   |           |
| U of Wisconsin   | <p><b>BMIR Tracking System</b>, Tracking of Informatics projects. <b>ABNER</b>, ABNER is a software tool for extracting biological named entities from text documents. <b>OnCore</b>, ERM Clinical Trial Management System (CTMS) from Percipenz. <b>BARD Tracking System</b>, Tracking of Biostatistics projects. <b>Curve Analysis Tool</b>, Software for aligning and comparing gene-expression time series. <b>ICTR Webportal</b>, Local CTSA web portal/collaboration site. <b>Group Sequential Boundaries</b>, using the Lan-DeMets Method FORTRAN programs for the computation of boundaries and exit probabilities in the sequential analysis of clinical trials are described. The computations are appropriate for any trial based on normally distributed test statistics with independent increments, including those in which patients give a single continuous or binary response, survival studies, and certain longitudinal designs. Interim analyses need not be equally spaced, and their number need not be specified in advance. In addition to boundaries, power calculations, probabilities associated with a given set of boundaries and confidence intervals can be computed. <b>Mindtouch DekiWiki</b>, Web-based collaboration and communication Wiki. <b>EBarrays R</b>, software for identifying differentially expressed genes. ClickCommerce, <b>Multi-disciplinary eResearch Portal Software</b> for support services such as grants management, IRB processing, and clinical trials administration. This is currently in development with a tiered rollout program over the next few years. <b>SCRM2</b>, Software for identifying cis-regulatory modules in genomic sequences. <b>Sample Size</b>, Calculate sample size.</p>    | ICTR Webportal, Mindtouch dekiwiki  |             | Multi-disciplinary eResearch Portal Software          |           |
| U of Cincinnati  | <p><b>eProfessional</b>. Search for researchers, manage your own professional data, and generate CVs and Biosketches.</p>   | eProfessional   |             |   |           |
| U of Florida     | VIVO  | VIVO  |             |   |           |
| U of Illinois    |   |   |             |   |           |

CTSA Tools

| CTSA Institution | Tools  | Research/<br>Collaborative          | Educational | Administrative          | Community |
|------------------|--|-------------------------------------|-------------|-------------------------|-----------|
| U of Iowa        | <p><b>Loki</b> Research Profiles is a research networking tool. It allows researchers to share their research interests, keywords, MeSH headings and their publications with other researchers to discover new collaboration opportunities. <b>Wiki</b> is a wiki space for groups to collaborate across the campus and the nation asynchronously. The wiki can be used for lab notes, paper and grant writing, meeting planning, scheduling and brainstorming. New spaces and groups can be set up as needed. <b>HawkIRB</b>, locally developed, Web-based IRB process support system. <b>Epic</b>, Commercial Electronic Health Record with associated data repository. <b>caTissue Suite</b>, caBIG tissue bank support system. <b>WebCAMP</b>, web-based system supporting clinical research units. <b>Confluence Wiki</b>, commercial collaborative environment (same wiki as in use by CTSA consortium). <b>Oncore</b>, Commercial Clinical Trials Management System in use by Holden Comprehensive Cancer Center.</p> | Loki, Confluence Wiki, Epic, Oncore |             | HawkIRB, caTissue Suite |           |

CTSA Tools

| CTSA Institution | Tools  | Research/<br>Collaborative   | Educational         | Administrative  | Community |
|------------------|--|--|---------------------|---|-----------|
| U Penn           | <p><b>Trac</b>, Project management and ticketing. <b>Ingenuity</b> Pathways Analysis (IPA) is an all-in-one software application that enables researchers to model, analyze, and understand the complex biological and chemical systems at the core of life science research. <b>LearningLink</b>, A customized and internally branded version of the SumTotal Access Enterprise Suite. The system hosts enterprise-wide and focused training for employees as well as seminars, and other online learning modules. <b>Oncolog Registry</b>, Clinical Trial Management System, and Protocol Management for oncology-based studies. <b>TCL Inventory Management Tools</b>, A suite of tools for biological sample inventory management specifically tailored for the workflows of the ITMAT Translational Core Laboratory (TCL). <b>Freezerworks</b>, Installation of commercial application to support storage in Translational Core Lab. <b>OpenCMS</b>, Website content management. <b>Subversion</b>, Code tracking and version control. <b>Share</b>, Internally developed instance of a <b>Confluence wiki</b> for enterprise-wide academic research community. Allows department- and lab-based workspaces with full control by a PI over fluid content updates and permissions-based security. <b>HS-ERA</b>, Human Subjects Electronic Research Administration: is a secure web-based application for the Office of Regulatory Affairs (ORA) that manages protocols currently active or under review by the Institutional Review Board (IRB), Institutional Animal Care and Use Committee (IACUC), and/or the Safety Committee. It provides authorized users the ability to create, generate, and distribute agendas, minutes, and associated communications to investigators and IRB Board members. <b>CTSA Registration Online system</b>, for researchers to request services from CTSA-related cores, programs and centers. Tracks results of research (publications, patents, etc). Will be used to capture annual report data in future years. <b>BaseCamp</b>, Project management and collaboration. <b>myCTRC</b>, Online application for CTRC that will be developed as an add-on to HS-ERA; reduces investigator burden for applying for funding in the Clinical and Translational Research Center. <b>Redmine</b>, open source project management software. <b>Epic Clarity</b>, Clinical Data Warehouse. <b>TCL OMS</b>, Web-based system for researchers to place lab orders to the Translational Core Lab. Researchers provide data on samples and choose the assays they want run. Includes an administrative component for managing orders and workflow. Includes a billing component for automatic billing of research grants, and generating invoices for external researchers. <b>ITMAT LIMS</b>, A Web application for storing, organizing and describing data files resulting from high-throughput proteomics experiments. The ITMAT LIMS serves to archive and annotate such data, as well as act as the source for our data analysis pipelines. <b>ClickCommerce</b>, Multi-disciplinary eResearch Portal Software for support services such as grants management, IRB processing, and clinical trials administration. This is currently in development with a tiered rollout program over the next few years. <b>Fable</b>, <b>FABLE</b> mines the biomedical literature for information about human genes and proteins. FABLE v3 allows a user to find articles mentioning a gene of interest (Article Finder), to generate a list of genes associated with one or more keywords (Gene Lister), or use a local mirror of the UCSC Genome Browser with a literature track (LitTrack). <b>Clinical Trials Search</b>, Public search utility for finding clinical trials at PennMed and CHOP, using data from clinicaltrials.gov. <b>ITMAT Membership Management</b> Allows ITMAT members to update their research profile online. Publicly lists members and their profiles on the ITMAT website. Provides central management of membership data.</p> | <p>Oncolog Registry, Share Confluence wiki, BaseCamp, Redmine, Epic Clarity, FABLE</p> | <p>LearningLink</p> | <p>TCL Inventory Management, Freezerworks, HS-ERA, CTSA Registration online, TCL OMS. Lick commerce</p> |           |

CTSA Tools

| CTSA Institution | Tools   | Research/ Collaborative                      | Educational  | Administrative   | Community                       |
|------------------|---|--|--|--|---------------------------------|
| U of Pittsburgh  | <p>Partnership Award (SEPA) program. It has a mobile laboratory for visiting schools. Research facilitators help researchers navigate translational opportunities. CTSI is working with UPMC to bolster participation in clinical trials by developing an institutional registry of potential clinical trial participants. Pitt is undertaking a comprehensive communication campaign to spur researchers and other faculty to contact CTSI. <b>Honest Broker Service</b> (Request Tracking Tool) is an electronic tool for members to record data and/or tissue requests. It assists in ensuring compliance with specific regulatory agency guidelines, including the Office of Human Research Protection (OHRP) of the Department of Health and Human Services (HHS), the Health Insurance Portability and Accountability Act (HIPAA) and the UPMC/University of Pittsburgh Institutional Review Board (IRB) for the release of information, specifically PHI, involving data stored in applications developed, managed and/or utilized by CIS. <b>Internet-based studies in Education and Research</b>, This website provides users with a list of educational modules with lesson plans and quizzes for self-checks on learning. <b>Topaz</b> is a pipeline-based system for identifying clinical conditions from narrative clinical reports. It is built on the GATE framework and comprises three modules: (1) Identify clinical conditions. (2) Assign contextual properties to clinical conditions. (3) Integrate information from textual mentions. Topaz is available upon request. The GATE module for ConText is available on our NegEx page. <b>Cancer Clinical Trials</b> website is a website designed to provide educational resources to users. It provides several questions and answers in text and video format, and offers forums for users as well. <b>Open Clinical Report Repository</b> represents our leading role in designing the first large repository of de-identified clinical reports available for NLP researchers. Work with the AMIA NLP working group in designing annotation schemas and obtaining annotations, design a repository for shareable annotations, help design and execute a shared task in IE from clinical reports. <b>Faculty Research Interests Project application (FRIP)</b> is a search index of self-reported research interests of faculty at UPITT in the health sciences. <b>Digital Vita</b> is a software application that supports scientific networking for translational researchers. It focuses on managing data that comprises of researchers' CBs and biosketches. ConText Algorithm, ConText is based on a negation algorithm called NegEx. ConText's input is a sentence with indexed clinical conditions; ConText's output for each indexed condition is the value for three contextual features: Negation: affirmed or negated; Temporality: recent, historical, or hypothetical; and Experienter: patient or other Ontology Development and Information Extraction (ODIE), ODIE project aims to develop a toolkit that will provide the following functionality: 1. Build text processing pipelines that use ontologies to annotate documents, 2. Enrich ontologies with new concepts that are automatically discovered in documents. 3. Populate an information model automatically from information extracted from documents. De-ID, DE-ID is a software application which removes the 18 HIPAA identifiers from both narrative text and structured data so that the data can be used for research purposes without informed consent. It also provides an encrypted linkage file so that the identity of the patient can be retained by an honest broker. It integrates easily into data management systems to provide cost-effective and rapid de-identification of patient information in all forms of data, including discharge summaries, pathology, radiology and surgical reports, history and physical narrative and unstructured text in clinical information systems. Clinical Trial Management Application (CTMA), A web-based Java application for managing various aspects of clinical trials, research protocols, outcomes initiatives, statistical research analysis, as well as CTEP/CDUS reporting.</p> | Topaz, open clinical report repository, FRIP | Internet based studies in Education and Research, Cancer Clinical Trials website | research facilitators, Honest Broker Service, caTissue Suite | mobile lab for visiting schools |



CTSA Tools

| CTSA Institution | Tools   | Research/ Collaborative  | Educational | Administrative | Community                                |
|------------------|---|--|-------------|----------------|--|
| U of Rochester   | <p>The University of Rochester CTSI organized the Upstate New York Translational Research Network, a consortium of 13 major institutions from Albany to Buffalo. It has given rise to the Emergency Research Network of the Empire State, which brings together six emergency medicine departments to facilitate ER research. The CTSI's Community Engagement Key Function is building on a foundation of successful efforts to improve community awareness of clinical research, particularly among minority populations, through focus groups, surveys, interviews, and a clinical trials website designed to inform the public. Also built a building. <b>Clinical Data Warehouse</b>, Oracle data warehouse containing clinical data on over 10 million account level encounters, 4.2 million inpatient medication orders, 105 million lab results, 1.1 million microbiology reports, 3 million SoftMed reports and 1.8 million Radiology reports. This supports internal applications. <b>eRT Clinical Trials Data Management Software</b>, A clinical trials data management software solution that meets FDA regulatory requirements. <b>DSpace</b>, A repository for sharing documents from University of Rochester faculty to the rest of the world.</p> | <p>Upstate New York Translational Research Network, Clinical Data Warehouse, eRT, Dspace</p> |             |                | <p>Community Engagement Key Function</p> |
| UT Houston       | <p><b>i2b2</b> data warehouse, <b>Cayuse</b>, <b>iMedConsent</b>, <b>WebCamp</b>, Linux cluster, <b>iRIS</b>, <b>Genologics LIMS</b>.</p>   | <p>i2b2, WebCAMP</p>   |             |                |  |
| U of Utah        | <p><b>Dezign fort Databases</b>, A proprietary tool (Datanaminc Solutions, Netherlands) which creates and documents logical and physical data models for most of the commercial and open source relational database management systems commonly used. <b>CodeCharge Studio (CCS)</b> is a proprietary (YesSoftware, ) visual web application builder and code generator used for rapid application development using any of these languages: ASP,NET (C# and VB), ASP 3.0, PHP, Java Servlets, JSP, ColdFusion and PERL. <b>Find-a-Researcher</b> at mbm.uuhsc.utah.edu. <b>HUMUS</b> and <b>MBM</b> are other researcher data bases. <b>UNITE</b>, <b>eRoom</b> used for document sharing. <b>REDCap</b> being used by Bernie LaSalle, evaluated by College of Nursing. FURTHER experimenting with <b>i2b2</b> as front end.</p>   | <p>Find-a-Researcher, HUMUS, MBM, eRoom, UNITE</p>   |             |                |  |

CTSA Tools

| CTSA Institution | Tools  | Research/ Collaborative                     | Educational | Administrative | Community                       |
|------------------|--|---|-------------|----------------|---------------------------------|
| Vanderbilt       | <p><b>VICTR's Research Support Services</b> provides "one-stop" access to investigators experienced in initiating and conducting research by helping them address such issues as regulatory affairs, budgeting, contract negotiations and conflict of interest matters. The <b>StarBRITE Web-based portal</b> provides "one-stop" shopping for research needs. Content is organized around tasks and resources needed by research teams in the planning and conduct of scientific studies. StarBRITE also contains traditional portal offerings (e.g., template language and links to support research planning and implementation, and an integrated calendar of training events for researchers), as well as custom applications to support the research enterprise. To date, StarBRITE has received more than 400,000 hits from more than 5,000 users. The National Recruitment Registry (<b>ResearchMatch.org</b>) is a centralized, disease-neutral Web portal that will connect researchers with research volunteers across the nation. Hosted by V, but used consortium-wide. Fall 2009. Also developed at Vanderbilt, <b>REDCap (Research Electronic Data Capture)</b> is a suite of Web-based tools designed to support data capture and dissemination for clinical and translational research studies. REDCap gives research teams an easy way to collect, disseminate and protect the privacy of study data. Vanderbilt has successfully exported REDCap to other institutions using a highly collaborative model in which Vanderbilt provides software and support to institutional partners at no charge in exchange for participation in a consortium. The project currently supports approximately 3,000 researchers across 56 institutions, with users from 22 countries. Features and functions of the system are enhanced weekly. REDCap provides: 1) an intuitive interface for data entry (with data validation); 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages (SPSS, SAS, Stata, R); 4) procedures for importing data from external sources; and 5) advanced features, such as branching logic and calculated fields. <b>REDCap Survey</b> is a powerful tool for building and managing online surveys. You can create and design surveys in your web browser and engage potential respondents using a variety of notification methods. Participant responses may be easily exported to Microsoft Excel or to common statistical analysis packages (SPSS, SAS, R, Stata). REDCap Survey allows for a variety of question types, such as Text Boxes, Multiple Choice (single and multiple answer), File Uploads, Yes/No, True/False, and Sliders (Rating Scales). There are also advanced question features that may be utilized, such as auto-validation, branching logic, and stop actions. <b>Volunteer for Research Registry, Recruitment Registry + Matching Tools for Clinical and Translational Research Recruitment.</b> <b>CRISP</b> database contains information about all of the current Vanderbilt federal grants and is keyword searchable. Search results will provide a list of Vanderbilt investigators with active grants in the search area.</p> | StarBrite, ResearchMatch.org, REDCap, CRISP |             |                | Volunteer for Research Registry |

CTSA Tools

| CTSA Institution | Tools   | Research/<br>Collaborative | Educational | Administrative | Community |
|------------------|---|----------------------------|-------------|----------------|-----------|
| Washington U     | <p><b>caTissue Suite</b>, developed under the caBIG initiative is designed for biospecimen inventory, tracking, and annotation. This tool permits users to track the collection, storage, quality assurance, and distribution of biospecimens as well as data related to the participant and study protocol from which biospecimens are collected. It also allows users to find and request specimens that may be subsequently used for translational research studies. <b>ClinPortal</b> is a web-based, clinical studies data management system. Using a graphical front end, ClinPortal dynamically builds case report forms within the context of a user defined study calendar that drives the study's data collection workflow. ClinPortal may also be used to manage clinical data derived from disease oriented groups or disease-specific patient cohorts. An Oracle database on the backend securely stores PHI in compliance with HIPAA and IRB regulations. The query tool shares data among ClinPortal studies and across companion applications (caTissue and CIDER) rendering results in identified and de-identified fashion based on the authorization of the user. <b>caArray</b>, Microarray data management system, developed under the caBIG initiative guides the annotation and exchange of array data using a federated model of local installations. <b>caB2B</b> is a caGrid client that permits scientists to leverage caBIGTM compatible data services through a user friendly graphical user interface (GUI). A metadata-based query interface enables end users to search virtually any caGrid data service dynamically. The overarching goal of the tool is to aid translational scientists in combining data from tools like a caBIGTM biospecimen repository service like caTissue Core/Suite, with data from a microarray data repository like caArray and use the analytical services to analyze and visualize the results. <b>CIDER</b>, Clinical Investigation Data Exploration Repository termed CIDER is a comprehensive inpatient and outpatient research patient data warehouse. CIDER is designed to integrate diverse and complex biomedical data sets that include clinical information obtained from the patient, results of routine laboratory tests, imaging, biospecimens, molecular profiling (e.g. microarray analysis, proteomics, lipidomics, etc.), and genome annotation information. The aim of developing CIDER is to facilitate rapid advances in basic science to improvements in patient care and relay findings from clinical studies employing such new and increasingly customized diagnostics and therapeutics back to the bench for further refinement of the disease management process. <b>Function Express (FE)</b> is an integrated expression data analysis suite that offers: data management tools, data analysis algorithms, rich annotation, visualization tools, option to use clinical data during data analysis and visualization, and a data sharing platform between research groups. <b>CRS</b>, The Compatibility Review Software (CRS), co-developed by the Mayo Clinic and Washington University in St. Louis, has been developed to facilitate the task of ensuring that models meet the established Architecture and VCDE guidelines.</p> |                            |             |                |           |
| Yale             | <p>The Yale Center for Clinical Investigation (YCCI) has strengthened its core research facilities and organized them for easy access from a single website. By focusing on common ground and not trying to integrate every function, YCCI and YCC have been able to combine and share resources extensively. This collaboration has set the stage for tackling even bigger challenges, such as the selection and implementation of electronic clinical trial management and data capture systems. <b>WebCAMP</b>, WebCAMP is a Web-based system for the administrative management of clinical research centers. (Cornell University is the lead developer of WebCAMP.) <b>TrialDB</b>, A customizable Web-based clinical trials database system used for the creation of electronic case report forms and the storage and management of clinical data. <b>LIMS</b>, A comprehensive laboratory management information system for the CTSA Core lab is under development at Yale.</p>   | WebCAMP,<br>TrialDB        |             | LIMS           |           |

## SOCIAL NETWORKING, COLLABORATIVE SPACES FOR SCIENTISTS

There is an ongoing debate in blogs and elsewhere about whether or not social networking will become as popular among scientists as it has been outside the realm of science (e.g., Facebook, Twitter, LinkedIn). The NIH is actively studying the matter. Staff at CTSA's have reported that researchers are not asking them for collaborative tools, and when they are built, the researchers must be encouraged to use them through training and support from Deans and Core Directors. Still, it is intuitive that time-saving, easy-to-use tools that help researchers and clinicians find each other, share information, and collaborate are necessary to fulfill the promise of translational research. This document contains a list of social networking and collaborative spaces that were created for scientists and some popular tools that were created for the general public or the business sector, but are or could be used by scientists.

### NETWORKING

Tools that help researchers search for and be found by others. Some are more passively based on a user profile for building a network of colleagues (like LinkedIn). Others encourage more interaction (like Facebook). Many of the tools under the Networking heading include publication lists and organizational tools as part of creating a profile. So you will find some Networking tools in the Publication Sharing and Organizing section if the emphasis is on the publications rather than the people.

***BioMedExperts***, from Collexis. A scientific social network built from author lists in the literature, provided free of charge to researchers worldwide in an effort to increase collaborative biomedical research. BioMedExperts can be customized for an institution or group of institutions. CTSA Experts Platform (launched March 2009) allows researchers to identify partners from their organization and across the CTSA Consortia on any biomedical research topic. It will track and identify collaboration patterns among CTSA consortia members, allowing Collexis to give clients and NIH more information about how researchers collaborate and suggesting ways that NIH can improve the CTSA program. <http://www.biomedexperts.com/>

***COS (Community of Science)***, from Proquest. COS has been offering vital online information to support researchers and scholars since 1989. One of its flagship products, Scholar Universe, is used by academic libraries, publishers, government entities, and corporations all over the world who need to find and learn about potential collaborators, experts, peer-reviewers, consultants, and thought-leaders. Other COS services, including COS Funding Opportunities, COS Expertise, and Papers Invited, are used by academic research offices and libraries to support their researchers, faculty and students on the path to research success.

<http://expertise.cos.com/about/cosprofile.shtml>



**Research Gate.** Connect with colleagues and build your scientific network. Discover new methods, papers, and people with our comprehensive research based search engine. Collaborate using our suite of applications built specifically for researchers, such as ReStory, a file sharing and organizational tool. <https://www.researchgate.net/>

**Academia.edu,** uses the application programming interface (API) of Facebook in order to find people with similar research interests; keep track of the latest developments in your research area (papers, talks, blog posts and status updates); and create an easy-to-maintain academic webpage, listing research interests and any papers you have written. <http://academia.edu/>

**Sermo,** the largest online physician community in the US. Practicing US physicians—spanning 68 specialties and all 50 states—collaborate on difficult cases and exchange observations about drugs, devices and clinical issues. Sermo is a real-time meeting place where physicians get help with everything from patient care to practice management. Physicians on Sermo rank their colleagues for the value of their postings and the quality of their answers to posted questions. Highly ranked community members are turned to for respected answers and advice. <http://www.sermo.com/>

**LabRoots** is a free social networking site that enables scientists, engineers, and other technical professionals to connect, collaborate with, and learn from each other. LabRoots fosters world-wide scientific communication and incorporates the newest social networking technologies. <http://www.labroots.com/>

**BioCrowd,** a social network for students, scientists, business people, and others who share a passion for bioscience. BioCrowd was created to help bioscience professionals build relationships, exchange ideas, find jobs, and identify exciting new career opportunities. <http://www.biocrowd.com/>

**Laboratree** is a social networking tool for scientists and a research management tool. Laboratree allows you to grow your network by joining up with various colleagues, groups, and projects. Laboratree allows you to e-mail or send messages to all parts of your network. Laboratree allows you to manage a personal or group blog. Laboratree's latest feature allows you to share papers, documents, and other files with other people on Laboratree. Laboratree is a work and progress. <http://laboratree.org/pages/home>

**Pronetos** exists to connect scholars and their institutions and facilitate production of scholarly work. We offer a complementary set of products and services to help scholars collaborate, publish, and archive their scholarship. We remove technological barriers so scholars and researchers can focus on producing research in their respective fields. This site includes a Blog by its founder; social networking, including paper sharing and posting of course material; and open access publishing. <http://sn.pronetos.com/>



**SciLink.com** uses the information in your resume to help connect you with relevant people and information. You can search for a job at the job section by searching for a key word. Look through the people section to see the profiles of other users. You can browse through articles and save the ones that interest you. There is a news section where you can stay updated about the newest scientific technology. You can also search for funding opportunities. There is a scientific tree, which is similar to a family tree, where you can map out your career tree and how you are connected to your friends. <http://www.scilink.com/start.action>

**Epernicus** is a social networking site developed solely for the working scientist. You can list your present and past research advisors, projects you're working on, and even post full-text PDFs of publications you've authored. <http://www.epernicus.com/>

**OpenWetWare** is an effort to promote the sharing of information, know-how, and wisdom among researchers and groups who are working in biology and biological engineering. It provides a place for labs, individuals, and groups to organize their own information and collaborate with others easily and efficiently. This site has space to upload courses, protocols, and a space for blogs. [http://openwetware.org/wiki/Main\\_Page](http://openwetware.org/wiki/Main_Page)

**Nature Network**, a free, Facebook-like site by Nature Publishing Group, in which you create a profile for yourself that allows posting and messaging. Nature Network works on global and local levels. On the global pages, you can interact with scientists all over the world, form and join Groups (which can be public or private), participate in Forums and read about international science in the Blogs. There are also a number of local hubs - Boston, New York, and London - where you can meet local scientists, find events listings, seek jobs, and catch up on local news. Most items on the site are given keywords or 'tags', which link together similar information across the website. Add tags to your personal profile, forum topics, blog posts and events, and you'll receive a richer experience on Nature Network. <http://network.nature.com/>

## PUBLICATION SHARING AND ORGANIZING

The tools in this section emphasize the organization and sharing of published materials. These include scientific social bookmarking sites, some with networking functions, sites that review the published literature, and traditional reference manager software that is now sometimes web-based, and may include full-text content.

**eRoom** is an easily adopted web-based collaborative workspace that enables distributed teams to work together more efficiently. EMC Documentum provides a centralized repository for a library of clinical evidence, and eRoom creates a collaborative workspace for clinicians to review literature and make consensus-based decisions. <http://www.emc.com/products/detail/software/eroom.htm>



**Mendeley**, a reference management and article organizing and sharing tool, for the desktop and the web. You can also explore research trends and connect to other academics in your discipline. <http://www.mendeley.com/>

**Faculty of 1000, Biology and Medicine**, is an authoritative online service in which over 4,500 leading researchers and clinicians share their expert opinions by highlighting and evaluating the most important articles in biology and medicine. Not so much a networking tool per se, the services include: continuously updated selections and evaluations of the most important articles; attributed opinions and expert knowledge from global leaders in biology and medicine; site customization and email alerts based on user interests; and recommendations and interpretations based on the article's merits, not the journal's. <http://facultyof1000.com/>

**2collab**, from Elsevier. 2collab is a collaboration platform designed specifically for researchers in the science, technical, and medical communities. Intended for use by professional researchers in academic, government and corporate institutions, 2collab provides three types of features: (1) Online bookmarking and reference management; (2) Groups, for sharing with existing networks, or building new ones; (3) Networking, to find, evaluate and initiate contact with new people. Different privacy levels allow researchers to make content public or to share only certain content or share content within certain groups. Developers have found that among scientists using it, very little sharing is public. <http://www.2collab.com/about>

**Labmeeting** allows you to upload research articles, automatically match them to bibliographic records for reference management, search the full text of all your PDFs, mark them for fast retrieval and viewing, and recommend them to your colleagues. It also allows you to stay up to date on what's in top journals, get notified about papers relevant to your research, and collect the articles that interest you. You can also post articles for journal club, share protocols and data in a group notebook, and ask and answer questions and schedule events. <http://www.labmeeting.com/>

### **Traditional Reference Managers**

**Endnote**, now on Web.

**RefWorks**, now with full-text searching of PDFs.

**Connotea**, from Nature Publishing Group.

**Zotero**, full-text searching of PDFs.

**Papers**, (Mac only). Organizes pdfs you already have on your desktop, using PubMed for metadata.



## DATA SHARING

These tools/sites/publications allow the sharing of content that does not fall into the category of a traditional journal article, such as video, educational materials, and protocols.

*ebrary's DASH*, ebrary's scalable and reliable ISIS system turns PDF files into highly interactive databases where every word is identified as a separate entity. This "word-level" capability provides unprecedented searching and enables [InfoTools™](#), which networks every word with other online resources. DASH! allows users to create their own networked collections from their own collections of pdfs.

*DataCite*, assigns unique DOIs to data sets, so that they can be searched, found, and used independent of the mode of dissemination (article or publication)

*SciVee*, Enables researchers to combine video with documentation and data in a media rich format. Scientists can make their research more visible, shareable, and accessible throughout the research cycle. <http://www.scivee.tv/>

*JoVE* (Journal of Visualized Experiments), a peer-reviewed, PubMed indexed journal devoted to the publication of biological research in a video format. <http://www.jove.com/>

*Scholas* (in beta) lets you **store and cite** research notes, papers, slides, posters or seminar notes. <http://schol.as/>

*EQUELLA*, from The Learning Edge International, is a digital repository that incorporates learning objects, learning content management, and integrated content authoring. <http://www.thelearningedge.com.au/products.php>

## DOCUMENT COLLABORATION

This tool assists in the management and creation of documents, allowing co-authors, lab colleagues, and collaborators to securely share manuscript drafts, data, figures, including all the information gathered while preparing a paper, such as the results of literature searches.

**Microsoft Research Information Centre (RIC) Framework** is a Web-based platform for research project management and scientific collaboration. RIC Framework is a server-based application that runs on Microsoft® Office SharePoint® Server 2007. SharePoint Server 2007 is a powerful and flexible collaboration and information management platform, and has extensive developer and community support. RIC extends the generic SharePoint Server platform to provide a customized project-space that supports the needs of scientific researchers, including: managing a project's lifecycle; managing research-related information; obtaining funding; collaborating with team members and other colleagues; managing ongoing experiments; disseminating results; monitoring research news, searching the literature for interesting publication, and storing useful information such as bookmarks. RIC Framework provides a





central location for storing content such as grant applications and research papers; RIC Framework hosts tools such as forums, blogs, and wikis, to facilitate collaboration between colleagues. RIC Framework includes social networking features that allow you to share information and discover other scientists with related research interests. From a user perspective, RIC Framework can be used to manage two categories of information: (1) Personal--Each user has a personal portal that they can use to monitor research news and store information that is not necessarily tied to a particular project. Each user also has a personal profile, which supports the social networking features. (2) Project--Each project has a site that allows project owners and users to manage project-related information, interact with other project members through wikis and forums, and so on. <http://research.microsoft.com/en-us/research/default.aspx>

## NETWORKING TOOLS THAT WERE NOT BUILT FOR SCIENTISTS

These tools were developed for the general public, but many are used by scientists for networking and collaborating.

**LinkedIn**, mostly a business networking tool that has some following among scientists.

**Xing**, a business networking tool.

**Twitter**. About 600 “scientwists” follow [twitter.com/sciencebase](https://twitter.com/sciencebase). Also, [www.twibes.com](http://www.twibes.com) and [sciencepond.com](http://sciencepond.com). (Cold Spring Harbor Laboratory was forced recently to set a policy of no tweeting during scientific meetings, when results were being shared without speakers’ permission and were breaking journalists’ embargoes.)

**Facebook**, a social networking tool that has group applications used by some scientists, and that some scientist networking sites are modeled on.

**WordPress**, blogging software.

**Delicious**, social bookmarking site.

**Citeulike**, from Springer, scholarly social bookmarking.

**MediaWiki**, wiki software.

**FriendFeed** can combine all your social networking activity (Facebook, social bookmarking, twitter) in one spot. The Life Scientists is a room for all the life science types on FriendFeed. Topics tend to focus on bioinformatics and computational biology, but discussion from any area in biological sciences is welcome.



**Google groups**, where you can create your own discussion group based on a common interest.

**Yahoo groups**, where you can create your own internet forum or email list around a topic.

**Google wave**, combines social networking with email, instant messaging, wikis, and more.

**Google Docs**, document editing and sharing.

**Drupal**, open-source content management system for building websites.

**Wimba, AdobeConnect, gotomeeting**, video conferencing or webinar software.

## **SOCIAL NETWORKING FOR PATIENTS, CLINICAL TRIALS**

New websites developed by patient advocate groups or in some cases the patients' themselves, usually around specific diseases. Sites contain disease information and patient support groups, and are also used as ways for patients to sign up for clinical trials. Sites include: 23andMe, Diabetic Connect, Emerging Med Navigator, Healogica, iGuard, Inspire, PatientsLikeMe, Private Access, Sermo Panel Express, Susan Love's Army of Women, TrialX, Vision Tree/JDRF.

## **NEW SEARCH ENGINES**

**GoPubMed**, a semantic search engine using Gene Ontology (GO) and Medical Subject Headings (MESH) headings to structure the Medline data base, allowing more relevant searching.

**Deep Dyve**, DeepDyve is the largest online rental service for scientific, technical and medical research with over 30 million articles from thousands of authoritative journals. A DeepDyve user can rent an article and read its full-text for up to 24 hours for as little as \$0.99. These articles can only be viewed at DeepDyve and cannot be downloaded, printed, or shared.

**Eagle-i project**. The NIH has funded nine partner institutions to build a web site to help researchers find the tools and materials they need to accelerate biomedical research and enhance interdisciplinary collaborations. The Data Curation Team, lead by the OHSU Library, will build the ontologies and vocabularies used to describe research resources and make them easier to find.

*Descriptions of products and tools are copied or adapted from promotional materials, press releases, and websites.*



### Appendix 3. MyRA Survey

The University of Utah Center for Clinical and Translational Sciences (CCTS) wishes to learn about your needs in regard to finding information about translational research collaborations and opportunities and using collaborative tools during the research process. The CCTS particularly wants to know which tools and resources you would like to see offered by the CCTS.

Please respond to this brief survey, which should take no more than 10 minutes of your time. This information will be used to develop the CCTS website and My Research Assistant (MyRA) – a virtual collaborative space—in order to make it relevant to your work as a place to get information, streamline the research process, and find and work with others.

#### SURVEY QUESTIONS

1. How do you presently get information about the University of Utah's CTSA or CCTS, including funding and collaboration opportunities and support tools? Select all that apply.
  - a. I look on the website
  - b. I call/email someone at CCTS. If so, who? (fill-in box)
  - c. I contact a colleague
  - d. I receive email announcements or a newsletter
  - e. I am not interested in getting information
  - f. Other (fill-in box)
2. How would you like to get information about the University of Utah's CTSA or CCTS, including funding, and collaboration opportunities and support tools? Select all that apply.
  - a. I want to go to a website to search or browse for information
  - b. I want to be able to call/email a person in an administrative office
  - c. I want to easily be able to contact a colleague
  - d. I want to receive email or newsletter announcements
  - e. I want RSS feeds
  - f. I want to be part of an online community that I can share information with and that will feed me information
  - g. I am not interested in getting information
  - h. Other (fill-in box)
3. Do you use any of the following social networking tools for your work? Select all that apply.
  - a. Nature Network
  - b. BioMedExperts (Collexis)
  - c. Facebook
  - d. LinkedIn
  - e. Twitter
  - f. Google Wave
  - g. Tools developed by other CTSA awardees (e.g., WebCamp, REDCap, i2b2, PRIMER) please specify which ones (fill-in box)
  - h. Other (please list as many as you like) (fill-in box)

4. Do you use any of the following online publication and research information sharing tools?  
Select all that apply.
  - a. Mendeley
  - b. 2collab (Elsevier)
  - c. Connotea (Nature)
  - d. Papers (for Macs)
  - e. Del.icio.us
  - f. Google Docs
  - g. Other (please list as many as you like) (fill-in box)
5. Do you search for information using any of the following tools provided by the University of Utah?
  - a. Find a Researcher
  - b. MBM
  - c. Hummus
  - d. Faculty Activity Report
  - e. Other (please list as many as you like) (fill-in box)
6. Would you use a database listing researchers (and their research areas and interests) from the University of Utah and other institutions in the SLC area for browsing and searching for research ideas and collaborations?
  - a. Yes
  - b. No
  - c. Maybe
  - d. Comments (fill-in box)
7. Would you use a website that provides one-stop access to services for researchers to design, budget, and administer research projects, including all forms and instructions for IRB and other applications?
  - a. Yes
  - b. No
  - c. Maybe
  - d. Comments (fill-in box)
8. Would you contribute your grant/research project information (i.e., a brief description) to such a database?
  - a. Yes
  - b. No
  - c. Maybe
  - d. Comments (fill-in box)
9. Would you use the services of a person who could provide assistance with designing, budgeting, and administering research projects, including forms and instructions for IRB and other applications?
  - a. Yes
  - b. No
  - c. Maybe

- d. Comments (fill-in box)
10. Would you use an online database of clinical data for clinical studies?
- a. Yes
  - b. No
  - c. Maybe
  - d. Comments (fill-in box)
11. Would you use secure online collaborative tools for storing and sharing data such as lab notebook contents?
- a. Yes
  - b. No
  - c. Maybe
  - d. Comments (why not for instance) (fill-in box)
12. Would you use secure online collaborative tools for co-authoring of papers?
- a. Yes
  - b. No
  - c. Maybe
  - d. Comments (fill-in box)
13. Please rank in order of importance the tools you would like provided:
- a. Online database of funding opportunities
  - b. Online database of research-related educational resources and events
  - c. Online assistance in preparing and administering a research project
  - d. Secure collaborative website with coauthoring tools
  - e. Secure website with data sharing tools
  - f. Online database for searching and browsing researchers and their research areas and interests
  - g. Online database of clinical data
14. If a "physical" research support center (i.e., staffed by someone to help you with identifying potential funding sources, grant writing, developing evaluation procedures, biostatistics, literature reviews, results dissemination, etc.) was created at the University of Utah where you could go to get help with developing and conducting your research ideas, would you use it?
- a. Yes
  - b. No
  - c. Maybe
  - d. Comments (fill-in box)
15. Please provide any other desires or needs for research resources that are not mentioned in this survey. (fill-in box)
16. If you would like to take part in a focus group or interview regarding collaborative tools for scientific research, please provide your name and contact information:
- a. Name \_\_\_\_\_
  - b. Department \_\_\_\_\_
  - c. Email address \_\_\_\_\_
  - d. Phone number \_\_\_\_\_