ResearchMatch

What is ResearchMatch?

It is a registry of volunteers willing to learn about, and possibly participate in, research studies. Research needs both volunteers and researchers. ResearchMatch helps bring these two groups together in a secure and convenient way.
Presentation Overview

- What is ResearchMatch?
- Who uses ResearchMatch?
- ResearchMatch Connections
- How Do You Get Started?
- How Can You Make This a Better Resource?
What Is ResearchMatch?

- A national partnership to create a centralized, web-based recruitment registry connecting individuals who are interested in participating in research with researchers nationwide
  - No cost to users
  - Disease-neutral
  - Study-neutral
  - CTSA collaborative activity
    - 40+ participating CTSA sites
  - IRB oversight by Vanderbilt University
  - Funded by CTSA Informatics grant in 2008
### What is ResearchMatch.org? (cont)

<table>
<thead>
<tr>
<th>What it is</th>
<th>What it is NOT</th>
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<tbody>
<tr>
<td>- A tool matching volunteers with research studies</td>
<td>- NOT the end-all solution to participant recruitment</td>
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<td>- A free, complementary recruitment resource for researchers</td>
<td>- NOT a replacement for existing recruitment efforts</td>
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<td>- A safe &amp; secure registry promoting volunteer choice at all levels</td>
<td>- NOT a tool that permits ‘cold calling’ volunteers</td>
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<td>- Disease-neutral</td>
<td>- NOT a final product – evolving based on user feedback</td>
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<td>- Anyone residing in the US can join</td>
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**Who Uses ResearchMatch?**

[Logos: Case Western Reserve University, CTSC, ResearchMatch]
Who is using ResearchMatch?

- **3 key stakeholders:**
  - **Volunteers - Everyone!**
    - Anyone of any age and condition can register on ResearchMatch
    - Parents can register children under 19
    - Caregivers can register those who can’t register themselves
  - **Researchers - Any PI or Proxy**
    - Proxy: This includes research coordinators, research staff assistants, research nurses or any other key study personnel
  - **Liaisons**
    - Person who manages ResearchMatch at the institution, approves access for researchers, and helps get volunteers registered

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Stakeholders: Volunteers

- **5-10 minute registration process**
  - Self
  - Parent/Guardian/Caretaker

- **Questions include:**
  - Basic contact information (protected)
  - Secure username/password
  - Basic information (age, race, gender, height, weight, etc.)
  - Voluntary entry of health/medical conditions and medications
  - Preference page (e.g. how far are you willing to travel)

- Currently, volunteers cannot search for studies in ResearchMatch.
Stakeholders: Researchers
Who can register as a researcher?

- Any key study personnel **authorized** to recruit for a study can register. These "other" people we call "Proxies"
  - Principal Investigator (PI)
  - "Proxy" name used for other study personnel – PI MUST verify proxy’s registration via email

- **Multiple users can register for the same study**
  - After the first person has registered the study into ResearchMatch, we can notify any additional users someone has already registered the study and ask if they wish to join

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Stakeholders: Researchers (cont)
What type of access exists?

- **Feasibility Access**
  - View aggregate information for grant-writing purposes or hypothesis generation
  - You will be able to run searches of the registry and receive aggregate data
  - No IRB approval necessary

- **Recruitment Access**
  - You need to be a Principal Investigator (PI) or a “proxy” for the study
  - You need to upload the IRB-approved study letter
  - Once approved, you will be able to search the registry for potential matches to your study
  - You can send a recruitment message to potentially matching volunteers once volunteers authorize the release of their contact information via email
Stakeholders: Researchers (cont)
What next after registering to recruit?

- If a Principal Investigator (PI): request is routed to the Liaison for review
- If a PROXY: request is sent to the PI
  - PI MUST approve your access request before it is routed to Liaison for review.
- You will receive an email stating your study is pending review
- You will receive an email with the Liaison’s review decision
  - If APPROVED: Accept this access through a link in the confirmation email.
  - If DENIED: Notified via email with opportunity to resubmit/edit

Researcher Search Options

- You can perform searches based on the following criteria:
  - Location
  - Demographics
    - Age
    - BMI
    - Ethnicity
    - Gender
    - Height
    - Multiple Birth Status
    - Race
    - Tobacco User
    - Weight
  - Health Status
    - Medical Conditions
    - Healthy Volunteer
  - Medications
Stakeholders: Liaisons

- Each participating site has at least one Institutional Liaison who will be responsible for managing researcher requests from their institution through ResearchMatch.

- Liaison approval consists of reviewing registered information & uploaded IRB approval letter from researcher.

- Liaison is responsible for setting ResearchMatch access expiration date to match that of the IRB approval letter expiration date.
  - Liaison Approval – automatically notifies researcher of recruitment access privileges.
**Volunteer & Researcher Connection**

**Step 1:** Volunteers (or their parents/caretakers) self-register to be contacted for research studies.

**Step 2:** Researchers search database for individuals (identifiers suppressed) based on study inclusion criteria.

**Step 3:** Researchers send IRB approved recruitment message to ‘matched’ volunteers.

Volunteers may then opt to share identifiable information for direct contact.

**Step 4:** Researchers contact interested volunteers and follow normal study consent procedures.

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**Liaison & Researcher Connection**

**Step 1:** Researcher (PI or PROXY) registers and provides information regarding IRB-approved protocol — Researcher must receive Liaison approval before recruitment access.

**Step 2:** Researcher can search registry with feasibility access (aggregate data) while recruitment request pending liaison review.

**Step 3:** Liaison receives access request. Approves request by setting expiration date to match IRB approval expiration.

**Step 4:** Researcher is notified of approval via email and can begin to search registry and contact potential matches for their study.
How Do You Get Started?

How do you get started?

From your web browser, go to the following link:

http://casemed.case.edu/ctsc/researchmatch/
How Can You Make This a Better Resource?

Boosting Volunteer Count

- A registry is only as good as its available volunteers!
  - Ideas for helping populate:
    - Post flyers in your office, department
    - Wear "Ask me about ResearchMatch.org!" button
    - Give ResearchMatch business cards to patients
    - Use ResearchMatch appointment reminder cards
    - Register as a volunteer yourself
    - Display brochure

For material requests email:
ct-sc-research-concierge@case.edu
Partnering with Organizations

- Partnering with organizations reaches more potential volunteers!
  - If you have contacts within organizations let them know about ResearchMatch.org or send their contact information to info@researchmatch.org

- Currently ResearchMatch is partnered with:
  - The National Parkinson’s Foundation
  - The Organic Acidemia Association
  - The Sarcoidosis Center
  - GARD – the Genetic and Rare Disease Information Center
  - The National MS Society
  - Sudden Cardiac Arrest Association

Providing Feedback

- ResearchMatch is a living resource and wants to continue to be valuable, let us know how we can do that!
  - Email with any questions, comments, feedback and ideas

- Let us know where we should be posting ResearchMatch material

- Reach out if you are having technical problems or confusion

Email: ctsc-research-concierge@case.edu