ResearchMatch Update

Roxane Poskin, Manager Participant Recruitment
Manager, Participant Recruitment Services
UK ResearchMatch Liaison
roxane.poskin@uky.edu
Objectives

- Basic ResearchMatch functionality
- Conducting feasibility searches and adding research or survey studies
- ResearchMatch updates and future initiatives
What is ResearchMatch?

A national partnership to create a centralized, web-based recruitment registry connecting individuals who are interested in participating in research with researcher nationwide who are looking for participants.

• No cost to users
• Disease-neutral
• Study-neutral
• 61 CTSA collaborators, 45 other non-profit institutions
• IRB oversight by Vanderbilt University, funded by CTSA grant in 2008
• CCTS partnered in 2011
Who is using ResearchMatch?

3 Key stakeholders:

1. Volunteers – 78,252
   • 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

2. Researchers – 3,004
   • Proxy: this includes research coordinators, research staff assistants, research nurses or any other key study personnel
   • 518 research studies

3. Research Liaison
   • Manages ResearchMatch at the institution, approves access for researchers/proxy, and promotes to volunteers
Stakeholders: Volunteers

Registration process

• 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)
  - Conditions Connection (14 sub-registry) 8-12 additional questions

• Volunteers can look for studies (NEW)
  - Links to sites
  - UK Current Studies - UKclinicalresearch.com
  - Clinicaltrials.gov, now requesting NCT numbers
Stakeholders: Researchers

Researcher registration process:
• Any key study personnel authorized to recruit for a study can registry.
  - Principal Investigator
  - “Proxy” name used for other study personnel – PI MUST verify proxy 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 registered the study and ask if they wish to join
Researcher Access

- **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**
  - Principle Investigator or (approved) proxy for the study
  - Add to your Form B, Research Description, Section 5, Subject Recruitment Method *(See our example Form B)*
  - Approved flyer with no contact information
  - Upload approved IRB-approval *(ResearchMatch in memo line)*
  - Liaison will lift hold on study (you will receive an email)
  - Ready to search RM for potential matches
  - Send email (no contact information flyer) to potential volunteers
  - Once volunteers authorize the release of their contact information you can contact and provide more information about your study.
Stakeholder: Liaisons

Liaison access:
- Each participating site has at least one institutional Liaison
  - Roxane Poskin  University of Kentucky, Lexington Ky
  - Wayne Noble  Center of Excellence for Rural Health, Hazard Ky
  - Marti Gartner  Norton HealthCare, Louisville Ky
- Responsible for managing researcher requests from their institution through ResearchMatch
- Liaison approval consists of reviewing information:
  - IRB approval letter from researchers and
  - Setting IRB expiration date of study
- PI/Proxy will receive email notice of approval.

ResearchMatch trainings:
- Monthly ResearchMatch GoTo Researcher online trainings
- OR contact Roxane and schedule an individual or group training
Questions?

ResearchMatch.org/uky
Let’s check out ResearchMatch

Researcher or Proxy

ResearchMatch.org/uky
1. Condition Connections:
   condition specific sub-registries

1. Search distances from multiple locations

2. UK Initiatives
   1. URL for UK
   2. Partnership with YMCA

3. Upcoming RM initiatives
ResearchMatch Condition Connections sub-registry

What is it?
The RM Team developed a framework for researcher-driven question generation + volunteers review for condition specific sub-registry inclusion in the ResearchMatch platform.

How does it work?
When RM volunteers indicate a sub-registry condition in their health profile, they are invited to respond to the optional, targeted questions in the sub-registry. When a researcher queries a condition that has a sub-registry the responses from the volunteers are automatically made available to the researcher.
Current 14 Sub-registries

Anxiety
Autism
Ehler’s Danlos
Eosinophilic Esophagitis
Food Allergies
HIV Connections
Intellectual Disabilities

Migraine
Neuropathy
Patent Foramen Ovale (PFO)
Pomple
Postural Orthostatic
Tachycardia syndrome (POTS)
Sarcoidosis
University of Kentucky
ResearchMatch

Initiatives:

- ResearchMatch.org/uky
- CERH Hazard – search distance
- ResearchMatch Liaison – Wayne Noble
- Partnerships/Promotion
  - YMCA State
  - Pharmacy prescription bags
  - Norton HealthCare
Vanity Url: ResearchMatch.org/uky
RM at UK Center for Excellence in Rural Health (CERH)

- Search for volunteers based on their distance from CERH/Hazard
- ResearchMatch Liaison – Wayne Noble
Partnering with YMCA

20,783 members + program members from the past 12 months

Lexington YMCA 25,000+ people
ResearchMatch Banners

You can make a difference through research.

Through research you can make a difference.
University of Kentucky Initiatives!
Match Maestro Trophy
ResearchMatch/Vanderbilt University
Paul Harris, PhD, and Team

Future initiatives:
• ResearchMatch app
• Study screening survey forms

Past initiatives:
• ResearchMatch
• RedCap
• IRB Share