An Automated Communication System in a Contact Registry for Persons with Rare Diseases: Tools for Retaining Potential Clinical Research Participants

Rachel L. Richesson, PhD, MPH1, Ken Young1, Jennifer Lloyd1, Tim Adams1, Heather Guillette, MS1, Jamie Malloy, MS1, Jeffrey P. Krischer, PhD1

1Pediatrics Epidemiology Center, University of South Florida College of Medicine, Tampa, FL

Abstract
Strategies to enhance recruitment and retention are useful in clinical research network settings. Our network data center maintains a Contact Registry of patients who express a willingness to be contacted to enroll in clinical studies. An automated system generates periodic and customized communications to notify registrants of potential studies and network events. The majority of these communications are sent by email, although the system also supports postal communications. A database tracks the sending of all communications and facilitates reports of registry activity.

Background
The Rare Disease Clinical Research Network (RDCRN) consists of 10 clinical research consortia and a central Data and Technology Coordinating Center (DTCC). The RDCRN supports many studies in diverse and rare diseases. Tools and methods that enhance recruitment and retention are particularly valuable in this and other network settings.

Methods
The DTCC maintains a registry of patients who self-identify with a particular diagnosis and express a willingness to be contacted by the RDCRN to enroll in clinical studies. The registry is compliant with the Health Insurance Portability and Accountability Act (HIPAA). To protect the privacy of those in the registry, identifying information is not shared with individual investigators. Rather, RDCRN investigators use the DTCC as a vehicle to push information to potential research subjects for updates and upcoming trials. The information is customized by disease, age, gender, and geographic location.

Results
As of March 2007, over 3,100 individuals representing over 40 different rare diseases were enrolled in the RDCRN Contact Registry. This is impressive as the network is relatively young and has undertaken no formal marketing. Most of the registry enrollees to date joined via the Internet. These individuals overwhelmingly prefer to be contacted via email (69%).

To respond to this need, we extended our system to include automated updates of relevant network activities by email or mail, depending upon the registrants’ preference. These updates are automatically generated and sent out upon the opening of new protocols or new clinical sites. Reports of returned emails and letters facilitate the updating of contact information, potentially reducing attrition in the Contact Registry.

This poster and demonstration will outline our strategies for communicating with and maintaining valid contact information for those enrolled in the RDCRN Contact Registry. Updated data on those registered will also be presented.

Conclusions
The Contact Registry offers a means to accumulate potential study participants and has the potential to increase participation in RDCRN studies. This automated system provide rapid, economical, reusable, auditable, and scalable methods for Contact Registry Maintenance.

Acknowledgments
The project described was funded by Grant Number RR019259 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NCRR or NIH. The authors wish to thank the Office of Rare Diseases for their support and also Jamie Malloy of the PEC for her contributions.