ALABAMA

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Increasing the Capacity for Research Using Quality Improvement

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: The ASCR utilizes cancer registry data for research as an important way to contribute to the health of all Alabamians. The ASCR strives to participate with researchers as much as possible; however, the number of active projects that can be undertaken is limited. Barriers to increasing the number of active projects include a lack of dedicated staff and delays in getting approvals from the Alabama Department of Public Health (ADPH) Institutional Review Board (IRB) and Legal Department.

In April 2016, the ASCR began a quality improvement (QI) project aimed at streamlining the research approvals process in order to meet the demand for research projects. The stated goal of this QI project was to reduce the time from receipt of the research application to data submission to the researcher. The goal for linkage studies was to have the linkage finished and data provided within three months of receipt of the application. The goal for research studies involving patient contact was to have the information available to the researcher within six to nine months of receipt of the application.

Over the course of several meetings, the QI team identified areas for improvement for both the research approvals process and for the way that ASCR performs research projects. These findings were presented to the ASCR Advisory Council (ASCRAC) as part of our annual meeting in August 2016. The ASCRAC approved the suggested changes, and the ASCR implemented these changes in January 2017. Since implementing these changes, the ASCR has had no limit on the number of projects, has met all stated goals for timeliness regarding approvals for research projects and transmission of data to researchers, and was able to effectively conduct the largest research mail out in ASCR history.

CHALLENGE: Like all NPCR registries, the ASCR is unable to spend awardee funds on research activities. As a result, the ASCR does not have dedicated staff to handle research requests. Prior to adding the research assistant position, the staff epidemiologist handled all aspects of research requests in addition to other job responsibilities. The lack of dedicated staff in addition to the lengthy and intensive process to obtain approvals led to the ASCR having to limit the number of active projects.

SOLUTION: The ASCR established a research assistant position that handles the more administrative portions (e.g. paperwork, contracts, mailings, scheduling, invoices, patient tracking, etc.) of the research processes. This position allowed the epidemiologist to focus on reviewing research proposals, performing linkages, and identifying potential study subjects for patient contact studies. If there is no research work available, the research assistant helps the ASCR by providing administrative support. This position is paid by the fees that the ASCR charges for participating with research.

In addition, the ASCR established a fee schedule for both linkage studies and patient contact studies. Further, after consulting with the ADPH Legal Department, the ASCR created a template for Memorandum of Agreement contracts (MOAs) between ADPH and the researchers. There is a separate template for linkages studies and for patient contact studies. Additionally, the research assistant undergoes annual training on the ADPH contract system to be up to date with all departmental policies.

After a review of the previous process by the QI team, an improved process was designed. The new process allows the ASCR to perform research tasks concurrently when possible to help reduce project time. For linkage studies, the ASCR performs the linkage as soon as approvals have been received so that data may be transmitted to the researcher as soon as the MOA has been executed. For patient contact studies, the ASCR identifies potential study subjects while the project is undergoing review by the ADPH IRB. This allows the ASCR to begin the physician consent process immediately after receiving ADPH IRB approval. The physician consent process is performed concurrently with the MOA approval process. The MOA would be fully executed within the time frame that the ASCR requires for the physician consent process, enabling the ASCR to transmit the names and contact information for potential study subjects to the researcher as soon as the physician consent is completed.

A significant improvement was creating a combined ASCRAC and ADPH IRB research application. Formerly, researchers would have to submit a research application form to the ASCR/ASCRAC and then would have to submit a different application form for ADPH IRB. Additionally, the research assistant scans all items of the research packet into a ".pdf" that can then be transmitted electronically to both the ASCRAC and the ADPH IRB. The staff epidemiologist was also added as a member of the ASCRAC.

Finally, the ASCR met with the ADPH IRB to discuss whether or not linkage studies that already have an IRB approval from another source should even require ADPH IRB approval. As part of these discussions the ASCR agreed to add a member of the ADPH IRB to the ASCRAC. Adding this member has allowed for linkage studies to be approved without requiring a full ADPH IRB review.

RESULTS: The ASCR has seen dramatic improvements since implementing these changes. By utilizing electronic communication, having the staff epidemiologist added to the ASCRAC, creating the research assistant position, and using the new combined research application, the amount of time needed for approvals from the ASCRAC and the ADPH IRB has been greatly reduced. Both linkages and patient contact studies are reviewed and approved by the ASCRAC within two weeks of the receipt of the completed research packet. Linkage studies are often approved by the ADPH IRB within two weeks. Patient contact studies can still take from six weeks to three months to get approval from the ADPH IRB. However, this is a significant improvement as patient contact studies used to take a minimum of six months to get ADPH IRB approval. As such the ASCR has been able to perform all linkage requests within three months of the receipt of the research packet, and has been able to perform patient contact studies within six months. The ASCR has had no limit on the number of active research projects since the changes were implemented.

SUSTAINING SUCCESS: The ASCR continues to work with the Advisory Council and the ADPH IRB to ensure research projects are approved within a reasonable time frame. The ASCR continues to work with the ADPH Legal Department to ensure our MOAs are up to date and are processed efficiently. The research assistant undergoes annual training with the ADPH contract system to keep up to date on any changes. Additionally, the research assistant maintains a log of all active research projects, contracts, and invoices in order to allow the ASCR to process research projects faster and thus be able to participate with all reasonable research requests.

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