PROJECT INFORMATION

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Determining the Best Methods for Using Patient Registry Data in Clinical Research

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Organization

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What was the research about?

Researchers can use data from patient registries to look at which medicines or other treatments work best. Registries store data about people with a specific health problem. The data may include the health care and medicines patients receive over time and patient reports of their health status.

To find out patients' health status, registries ask patients to fill out surveys at different times during treatment. Researchers can compare survey results from when patients first take the survey with results from surveys taken after treatment. They can then find out how well a medicine works. But patients may not always take the first survey before they start a new medicine. Sometimes, they don't take the first survey until after starting treatment. When this happens, it is hard to know how well the medicine works.

In this study, the research team looked at different ways to use data from patient surveys in registries. The team wanted to learn which way would give the most accurate understanding of the effects of a new medicine. The study also looked at patients' views on taking part in registries.

What were the results?

Estimating the effects of medicines. The most accurate understanding of a medicine's effects came from using surveys completed at the time closest to the start of a new medicine. It didn't matter if patients completed the survey before or just after they started to take the new medicine. Both ways worked well when used for predicting if the medicine will work.

Patient views on taking part in registries. Patients said they would take part in registries if

- They knew they were helping others
- Their own care might benefit
- Taking the survey was easy

Patients who spoke Spanish reported concerns about taking part in registries. Concerns included being guinea pigs and not trusting the translators.

Patients under age 45 preferred receiving surveys by email, internet, or phone app. Those older than age 65 preferred mailed paper surveys. Patients aged 45–65 had mixed preferences.

What did the research team do?

The research team created a computer program. The program compared 13 different ways to include data from patient surveys in registries. The team wanted to see which way worked best to learn a medicine's effects. To check the results of the computer program, the team looked at real registry data for patients with rheumatoid arthritis, or RA.

Then, the team gave a survey to 150 registry patients with RA and 169 registry patients with inflammatory bowel disease, or IBD. The survey asked for patients' views about taking part in registries. In each group, 95 percent of people who took the survey were non-Hispanic white. In addition, 83 percent of patients with RA were women, and 62 percent of patients with IBD were women. The average age of patients with RA was

62; the average age of patients with IBD was 43. Patients lived in Boston, Massachusetts.

What were the limits of the study?

The study only looked at one type of data from patient surveys for two health problems. The results may differ for other types of data. Future studies could look at using patient survey data from patient registries for other health problems.

Most people who took the survey were non-Hispanic white. Results may be different for people of other races and ethnicities. Future research could ask

people from other races and ethnicities about taking part in patient registries.

How can people use the results?

The results of this study may help researchers use patient survey data from patient registries to get the most accurate understanding of a medicine's effects. Researchers may also use the results to encourage people to take part in patient registries.

To learn more about this project, visit www.pcori.org/Solomon106.