

Patient Registry

A patient registry is a collection of information about individuals, usually those with a specific diagnosis or with specific risk factors for a disease. Some patient registries seek people with varying health levels who may be willing to take part in research about a particular disease. Registries can be funded and/or managed by government agencies, non-profit organisations, clinics, or commercial organisations.

Patient registries have multiple uses. For example, registries for rare diseases can be used to establish the basic characteristics of the disease, how it is managed in clinics, and what outcomes people experience. Other uses include helping to measure clinical effectiveness of treatments in 'real world' settings, and investigating quality of patient care.

Clinical trial registries collect basic health information from people who agree to be contacted about taking part in future clinical trials. Volunteering for a registry does not mean a person has signed up for a clinical trial. Volunteering for a disease registry can sometimes become a first step toward taking part in a clinical trial, but registries and specific trials are not directly linked.