Research Data Use Scenario Template

Multi-Stakeholder Research Data Use Scenario Development Form to Gather Examples of Scenarios from Stakeholder Group

Purpose:

To provide work group stakeholders with additional opportunities to provide input and to augment our activities during the work group meetings, we would like to collect sample research data use scenarios directly from individual group members that can be further developed into detailed scenarios and use cases. We would also like to use these ideas to build a roadmap for the coming meetings, so the work group knows in advance what topics will be covered.

We would like these initial descriptions to take the form of narratives that describe real life situations you have encountered related to patient-centered outcomes research. Once we collect these scenarios, we will collaborate with the work group to identify the underlying requirements and develop the associated use cases.

If you would like to submit a scenario of interest, we have provided a template below to help guide you, and to help standardize the responses. Thank you in advance for your contributions.

Instructions:

- Below, we provide you with a sample scenario presented in a recent meeting as a template, and a text box for you to enter your own scenario.
- As you describe your scenario, please be detailed in specifying the core issue, the users, and the information flow.
- We have also included a list of questions for you to consider when developing your scenario that we believe are highly relevant to the development of use cases, as well as the eventual legal and ethical framework.
- If you have any questions, please contact Katherine Donaldson and Donaldson-Katherine@norc.org

Sample Scenario:

Max Researcher at Advanced Research Institute obtains approval from the Advanced Research Institute's IRB for the Human Nature protocol.

Using the list of approved patients identified by their research unique identifier, Max loads the list into the Research Information System and submits the list in an electronic request to the Coordinating Center. The request specifies the patients enrolled in the protocol using the research unique identifier, assigned by Coordinating Center.

Advanced Research Institute has a Data Use Agreement with a set of Data Sites. The agreement specifies that various data sites (i.e., covered entities) will provide a "minimum data set" of health information to be used in the Human Nature research study (a study containing only data analysis one protocol).

Once the Coordinating Center System receives the request for data sets from Advanced Research Institute (on behalf of Max Researcher), it does the following:

1. It correlates patient research unique identifiers supplied in the request with data-site-specific identifiers for each intended data site and it identifies four sites that store relevant data sets.
2. It adds a technical criteria corresponding to the approved data set to be supplied by each site.
3. It submits separate requests to each of four data sites.
    - Each data site will receive a list of patients using the site local identifier and return the matching set of records defined in the Data Use Agreement.
4. The Coordinating Center System processes the responses (success/failure) and the data returned from each data site and returns the data sets to Advanced Research Institute system (Research Information System).

The Research Information System combines the data such that Max Researcher can accomplish the goals of the protocol for the Human Nature study.

Core Issue: Combining data sets from multiple sites governed by data use agreements.

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