



Registry and Biobank Boot Camp

Seattle, WA

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9:00 AM **Introductions** **and goals for the day**

In this session, we welcome participants and preview the day, using a cooking metaphor. Participants will be asked to introduce themselves, and describe their registry goals: something you know and something you would like to learn. This session will also provide a general overview of registries in the context of GRANDRx, and the important role of advocacy organizations in leading these research initiatives.

9:30 AM **Recipe for a registry or biobank**

This session provides a comprehensive review of practical things to consider when creating a registry or biobank. Areas of focus include determining what you want to collect, understanding what you need to collect, and an introduction to questionnaire development and design.

10:15 AM **Cooks in the kitchen - working with your advisors**

This session provides guidelines and best practices for identifying appropriate advisors and strategies for working with your advisors while developing your questionnaire.

10:30 AM **Ingredients and measurement I - introduction to questionnaire design**

This session introduces the basics of question types, answer types, standard vocabularies, and implications of questionnaire design on data mining. We will explore different sources of questions, and their advantages and disadvantages.

11:00 AM **Ingredients and measurement II - introduction to sample collection**

This session introduces the basics of sample collection. We will explore common collection strategies, different sources of biological specimens, and their advantages and disadvantages.

11:15 AM **Kitchen equipment - vendors and software solutions**

This session explores different types and vendors, characteristics of a good vendor and partner, and reviews key considerations when assessing

vendors. Areas of focus include registry capacity, scalability, quality of information, and ability to adapt to standards.

- 11:45 AM **Discussion from morning sessions**
- 12:15 PM **Networking lunch**
- 1:30 PM **Grand opening - organizational capacity and operations**
This session will discuss the organizational resources and planning needed to make your registry a reality, including appropriate staffing models. An assessment tool will provide insight on areas of strength and those that could be improved.
- 2:00 PM **Good governance**
This session provides practical information on complex legal issues surrounding registries and repositories. Areas of focus include governance, ownership, privacy, IRBs, and the process of informed consent.
- 2:30 PM **Repeat customers - recruitment and retention**
This session provides strategies for engaging your community, and obtaining high participation rates and low attrition rates.
- 3:00 PM **Developing your organization's action plan**
This session is an opportunity for each participant to develop a plan complete with measurable action items to make your organization's registry a reality.
- 4:00 PM **Final thoughts and Adjourn**