

The Basics for Quitlines: Questions to Ask of Researchers who Request Data

WHO is requesting the data?

Who are all of the parties involved (identify any subcontracts the research will require as well as vendor, funder, administrative involvement)?
Who will have access to the data (include both individuals and organizations)?
Who will serve as the key contact person for your organization, for the researchers/organization requesting the data, and for the quitline vendor (if needed)?
Who is responsible for funding the data request and/or project?

WHY

Why is the data being requested (include purpose, project summary, and a copy of the proposal)?

WHAT data are they requesting?

What data sets/variables will be shared? Is there a data dictionary, or will one need to be created to be able to appropriately interpret the data sets (this may also factor into cost)?
What is the funding commitment needed from the quitline in order to participate in the research project (e.g., staff time, administrative oversight of data sharing, changes needed to regular reports from service provider)?
What are the anticipated report deadlines (include in project timeline)? What reports are being requested? What information is necessary to capture to complete these reports?
What are the programming and/or software compatibility needs (e.g., version of Excel, Access, SAS, SPSS)? Is data shared electronically or in hard copy?

WHEN

When does the project request begin? When is the data needed? How many data pulls will they need and for how long (one-time, quarterly, annually)?
When does the data permission end (include in project timeline)?

WHERE

and

HOW

Can the researcher produce the IRB-approved protocol to show the research is approved for appropriate Human Subjects and HIPAA protections? Does the data request include data on vulnerable populations such as pregnant women, children, or prisoners and are these individuals included in the IRB approval?
Where is the IRB (ethics review) on record?
Where will the data be stored?
How will the requested variables be pulled from the complete data set? Who will do that work? Will a data dictionary be provided? Who will be responsible for follow-up requests for additional information or clarification?
How many quitlines are involved in this data project (consider data compatibility issues)?
How will the data be protected? How will caller information privacy be maintained (de-identification of the data set)?
How will the data be returned or destroyed at the end of the project?
How will data use be monitored (including subcontractors' data use)?
How will you be notified of a breach of privacy?
How will you be notified of the project's progress and results?