



Monday Morning Practice Pearls #58

I want to use a patient survey in my clinical research study, do I have to do anything first?

The simple answer is YES.

Here are 5 steps to follow to ensure that you can use a patient survey:

1. Determine if permission is needed.
 - a. Many surveys (e.g., QOL or other patient report outcomes) are under copyright protection and you may need to obtain permission prior to use. This permission is called licensing.
 - b. There are different levels of permission to use a survey:
 - i. No permission required: copyright holder licensed use for any purpose without permission
 - ii. Non-commercial/educational: copyright holder licensed use for non-commercial research without requiring you to obtain the permission
 - iii. Permission required: use of survey requires permission even if used for non-commercial research
 - c. If you don't seek permission, you may be violating on the owner's rights which may result in legal action.
2. Identify the owner.
 - a. Copyright holder is usually the creator of the survey, but they have transferred copyright to another entity (e.g., publisher, organization)
3. Identify the rights needed.
 - a. The owner controls a variety of rights related to the survey including if the survey can be modified.
 - b. Determine if the survey will be used in one or multiple protocols and over what timeframe.
 - c. Determine if you want to collect the survey via electronic means.
 - d. Determine if you want to just use the survey or also reproduce the survey (e.g., in the appendix of protocol or in publication).
4. Contact the owner and discuss the rights you need and negotiate whether payment is required.
 - a. Contact your AO to procure against the PI/Branch CAN.
5. Get your permission agreement in writing.

If you need help, please contact Liz Ness, nessel@mail.nih.gov.