

**Title:** Differing Perceptions of Risks and Benefits

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**Description:** A researcher conducts a non-therapeutic study with young adults with Tourette's Syndrome and their families. The participants' perceptions of risks and benefits differ from those of the researcher.

**Headings:** Study Design and Risk-Benefit Analysis; Risks and benefits; Special Populations and Cultural Competence; Community or consumer representation; Mental health disorders, participants with (including addictive disorders and developmental disabilities)

**Case Type:** Decision making

### **Differing Perceptions of Risks and Benefits**

You are a researcher planning a non-therapeutic, exploratory study on young adults diagnosed with Tourette's syndrome (TS) and their family members in order to investigate the impact of the disease on family functioning. You will conduct focus groups and in-depth interviews with individuals and family members and plan for the household to be the unit of analysis. You plan to use this research to ultimately determine ways of helping families manage patients with TS by developing a family-based behavioral intervention program. Data will be used to seek funds to test the program using an experimental study design.

In the IRB application and the participant consent form, which are both approved by your institution's IRB, you list the following risks and benefits for participation:

- benefits: opportunity to learn more information about TS (for example, educational materials will be provided to all participating families); contribution to the knowledge base regarding the management of TS
- risks: potential psychological pain involved with discussing unpleasant or painful family memories, situations

As you begin to enroll individuals diagnosed with TS and their family members in the study, you discover that they express hopes of getting different benefits than those you had considered, including: "free counseling and social services," "getting to know other families dealing with TS," and "improved functioning" for the adolescent/young adult with TS. You begin to think that even though this is a nontherapeutic study, maybe because of the lack of research on TS, the families mistakenly believe the focus groups and interviews are group/family therapy and/or support groups. Several individuals and family members have also mentioned their eagerness to contribute to the search for the cause of and/or cure for TS. None have seemed concerned about the potential risks.

**Given that participants seem to be misinterpreting the benefits of participation, can you continue the study? If you decide to continue, what modifications can/should be made in order to better inform families about risks and benefits?**