

Dear [Name],

Thank you for agreeing to participate in this focus group study to help us better understand the perspectives of those affected by Tourette syndrome and other tic disorders. In preparation for the focus group session, we would like to provide you with some background and logistical information. **At the bottom of this letter, there is a link to a brief survey that takes less than 5 minutes to complete.** Information from this survey will help us as we prepare for and analyze the focus group discussion.

Background Information

Tourette syndrome affects 1% of the global population. It is defined by the presence of motor and vocal tics. In addition to tics, many with Tourette syndrome experience mental, social, and physical health problems. Ninety percent of individuals with Tourette syndrome have at least one psychiatric diagnosis. One third of adults with Tourette syndrome say they lack adequate support from their families, and many more avoid social situations. Individuals with Tourette syndrome are at heightened risk of cardiovascular disease, accidents, substance abuse, and global perceived disability. They have a 2-fold higher risk of premature death compared to the general population.

Despite evidence of impaired mental, social, and physical health in Tourette syndrome populations, many studies narrowly focus on tics in childhood. More information is needed on adults with Tourette syndrome to improve understanding of and treatments for the disorder and, ultimately, to help improve the quality of life of adults with Tourette syndrome.

Our research team at _____ is planning a study to gather information from adults with Tourette syndrome and other chronic tic disorders. This study will be called the Adult Tourette Syndrome Registry. During the study, participants will share information about their tics, mental health, physical health, lifestyle habits, socio-economic factors, stressors, and quality of life. Information will be gathered over time, through structured interviews, standardized questionnaires, and cognitive tasks. Those who participate in the Adult Tourette Syndrome Registry will be asked to complete an assessment each year.

The upcoming focus group is a key step in development of the Adult Tourette Syndrome Registry. As we plan the Registry, we need input and suggestions from you. We want...

- to ensure we are asking questions and collecting data that matter to adults with Tourette syndrome and other chronic tic disorders
- to identify ways to improve recruitment and retention for the registry

Logistical Information

The focus group will involve 6-10 participants, a moderator, and several members of the research team. The moderator will introduce him/herself at the beginning of the session, provide some housekeeping details and ground rules, and then ask questions for the group to answer and discuss. Questions will address some of the following topics:

- *Researchers can ask many questions about Tourette syndrome to guide their work. What do you see as the most important questions for researchers to be working on?*
- *There is evidence suggesting that adverse childhood experiences, such as abuse, influence mental and physical health in adulthood. We intend to ask registry participants questions about their own adverse childhood experiences. How willing are you to honestly answer questions about adverse or traumatic experiences in your childhood?*
- *We would like to understand the most effective mode of survey delivery. What are some of the advantages and disadvantages to completing a paper version using postal mail? What are some advantages and disadvantages to using online surveys? What would be your preference? Why?*
- *Most studies in Tourette syndrome enroll individuals from large medical centers in big cities. Individuals from minority populations, from rural areas, and/or without insurance are often not well-represented in these studies. What suggestions do you have for improving recruitment of these under-represented populations?*

The focus group will last 90 minutes. A Zoom link will be emailed to you within 24 hours of your focus group session. If you should have technical issues with the link, please contact rebecca@redcap.org. Please also contact rebecca@redcap.org with any questions or concerns that arise before or after the focus group,

Survey Link

Please click on the link and complete the brief survey in preparation for the focus group session.
[REDCap link]

Thank you again for agreeing to participate in this study. We very much look forward to hearing your thoughts and experiences at the upcoming focus group session.

Sincerely,

Supplementary Material 2 - Moderator Script

Document: Moderator Script

Study Title: Focus Groups for Development of Adult Tourette Syndrome Registry

Version Date: 10/28/2021

Introduction

I am [moderator name], and I will be moderating today's focus group.

I will first give background on the reason we are conducting this focus group.

Tourette syndrome affects 1% of the global population. It is defined by the presence of motor and vocal tics. In addition to tics, many with Tourette syndrome experience mental, social, and physical health problems. Ninety percent with Tourette syndrome have at least one comorbid psychiatric diagnosis. One third of adults with Tourette syndrome say they lack adequate support from their families, and many more avoid social situations. Individuals with Tourette syndrome are at heightened risk of cardiovascular disease, accidents, substance abuse, and global perceived disability. They have a 2-fold higher risk of premature death compared to the general population.

Despite evidence of impaired mental, social, and physical health in Tourette syndrome populations, many studies narrowly focus on tics in childhood. More information is needed on adults with Tourette syndrome to improve understanding of and treatments for the disorder and, ultimately, to help improve the quality of life of adults with Tourette syndrome.

Researchers at _____ are planning a study to collect information from adults with Tourette syndrome and other chronic tic disorders. This registry will collect information about tics, mental health, physical health, lifestyle habits, socio-economic factors, stressors, and quality of life. Information will be gathered over time, through structured interviews, standardized questionnaires, and cognitive tasks. We will ask study participants to complete an assessment each year.

As a next step in planning this study, we need input and suggestions from you. We want...

- to ensure we are asking questions and collecting data that matter to adults with Tourette syndrome
- to identify ways to improve recruitment and retention for the registry

Verbal Consent

I will now review the focus group logistics and ask for your verbal consent.

To participate in today's focus group, you must satisfy the following eligibility criteria:

- be 18 years of age or older
 - have received a diagnosis of Tourette syndrome, chronic motor tic disorder, or chronic vocal tic disorder
- OR
- be a caregiver of a child with a diagnosis of Tourette syndrome, chronic motor tic disorder, or chronic vocal tic disorder

We are requesting a waiver of documentation of consent for the [xxxx providers xxxx], given that the interviews involve no more than minimal risk and the primary risk to participants is the risk of disclosure of identity. We are requesting a waiver of documentation of consent for the [xxxx participants xxxx] since the research involves no more than minimal risk and would not negatively affect the rights or welfare of the [xxxx participant xxxx].

You do not have to participate in this focus group, and you are welcome to stop participating at any point.

The focus group will last 90 minutes. We are recording audio and video of this session so that the information can be transcribed and analyzed later. The transcribed information will be de-identified. We will take every precaution to maintain confidentiality of the data, but the nature of focus groups prevents researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in this focus group to others. We will be writing a report of the

information discussed today but I want to assure you that transcripts from this recording will be de-identified and your name will not be associated with what you say. So please feel comfortable to share openly.

As compensation for your time and effort, each participant will receive a \$50 Amazon gift card within 10 business days of the focus group.

Does anyone have any questions?

Introduction of Participants

Please introduce yourself by your first name only.

I would like to start by going over some ground rules:

1. One speaker at a time (no cross talk). Everyone will get a chance to share.
2. Please raise your hand (or hand icon) if you would like to speak.
3. Our time is limited so I might move on quickly to make sure I can ask everything we have planned.

Questions for Participants

Questions re: Content

- **Researchers can ask many questions about Tourette syndrome to guide their work. What do you see as the most important questions for researchers to be working on?**
 - **Are you more interested to learn about factors affecting quality of life or information on the causes of Tourette syndrome? Why?**
 - **What other questions can you think of that are important from your point of view as a person who experiences Tourette syndrome or as someone who cares for a child with Tourette syndrome?**
- **There is evidence suggesting that adverse childhood experiences, such as abuse, influence mental and physical health in adulthood We intend to ask registry participants questions about their own adverse childhood experiences.**
 - **How willing are you to honestly answer questions about adverse or traumatic experiences in your childhood? If you were asked such questions, would you be open to answering truthfully?**
 - **How uncomfortable would you be answering these questions?**

Questions re: Logistics

- **We plan for the first registry visit to last two hours. After that, registry participants will complete a one hour visit each year for as long as they are willing to remain in the study.**
 - **What are your thoughts about this time commitment?**
 - **Ask about potential barriers.**
 - **Do you believe this time commitment is reasonable?**
 - **If patients were compensated for their time, in what ways would that influence participation?**
 - **What amount of compensation would motivate you to participate?**
- **We would like to understand the most effective mode of survey delivery.**

- **What are some of the advantages to completing a paper version using postal mail (you would then mail back)? Disadvantages?**
- **What are some advantages to using online surveys? Disadvantages?**
- **What would be your preference? Why?**
- **For those who prefer online methods, do you prefer to answer surveys on your computer, your phone, or another electronic device? Why?**
- **Participants with smartphones (phones that have internet access, touch screens) will be asked if they would be willing to perform additional tasks with their phones, such as a timed 100-yard walk and a task testing the speed of their hand movements. These data would be reviewed by researchers.**
 - **Having said that, what would you need to know about these tasks/data before making a decision?**
 - **If you participated in the study, would you be willing to do such tasks?**
 - **If so, how frequently would you be open to performing such tasks? (e.g., monthly, weekly?)**
 - **What concerns do you have regarding collection of your smartphone data?**
 - **What other concerns would patients have?**
- **Most studies in Tourette syndrome enroll individuals from large medical centers in big cities. As a result, individuals from minority populations, from rural areas, and/or without insurance are often not well-represented in these studies. What suggestions do you have for improving recruitment of these under-represented populations?**
- **In studies that follow participants over time (so-called longitudinal studies), some participants decide to stop being in the study. When people drop out of a study, for whatever reason, this makes it more challenging to interpret study results. Thus, a major aim of all longitudinal studies is to retain, or keep in, participants until the study is finished.**
 - **What ideas do you have for improving retention of study participants?**

Questions re: Feedback

- **Is there specific feedback you would want from participating in the study we have described above?**
 - **For example, would you want to a copy of your answers on physical health or mental health questionnaires for your records? Why or why not?**
 - **Would you want to know how your answers compared to other study participants? Why or why not?**
- **If the study allowed you to choose to receive information about other research studies in Tourette syndrome, would you opt in or out?**
 - **Why? Why not?**
- **What other questions, concerns, and/or thoughts do you have regarding the registry?**

Closing

Thank you very much for participating in this focus group. Your input will be very helpful as we continue to develop this registry for adults with Tourette syndrome. If you have any follow-up questions or concerns regarding the focus group or the planned registry, please feel free to directly contact

Category

Label

1 Living with Tourette Syndrome

- 1.1 Disinhibition
 - 1.1.1 Vocal/Phonic
 - 1.1.2 Motor
- 1.2 Tic Triggers
- 1.3 Comorbid conditions
- 1.4 Times of symptom relief/what helps
- 1.5 Indicator of change
- 1.6 Directionality
 - 1.6.1 Tourette impacts health status
 - 1.6.2 Health status impacts Tourette
- 1.7 Change over time
- 1.8 Personal understanding of Tourette
 - 1.8.1 Has some degree of understanding
 - 1.8.2 Does not understand/limited
- 1.9 Resources/SDH
- 1.10 Age of symptom onset
- 1.11 Age of diagnosis
- 1.12 Hormonal Affects
- 1.13 Other

2 Quality of life

- 2.1 Relationships/interactions with others
 - 2.1.1 How people have responded
 - 2.1.2 Affect on relationships
 - 2.1.3 Reactions
 - 2.1.4 How explains condition to others
 - 2.1.5 Social Support
- 2.2 Recreational/activities
- 2.3 Travel
- 2.4 Pain/fatigue/sleep
- 2.5 Social isolation
- 2.6 Work/career
- 2.7 Diet
- 2.8 Financial
- 2.9 Cognitive load
- 2.10 Other

3 Coping with Tourette Syndrome

- 3.1 Problem based
- 3.2 Emotion-based

3.3 Avoidant

3.4 Other

4 Emotions and feelings

4.1 Fear/anxiety

4.2 Anger/frustration

4.3 Sadness/depression

4.4 Embarrassment

4.5 Trust

4.6 Mistrust

4.7 Happiness/positive emotions

4.8 Uncertainty

4.9 Stress

4.10 Other

5 Experience with health system

5.1 Diagnosis process

5.1.1 Misdiagnosis

5.1.2 Provides an estimate of how long it took

5.1.3 What went through to get diagnosed

5.1.4 Who made final diagnosis

5.2 Interactions with health system

5.2.1 Provider knowledge/capability

5.2.2 Attitudes by health system

5.3 Experience in other Studies

5.4 Family History

6 Characterization of treatments

6.1 Type of treatment/medications

6.1.1 Successful

6.1.2 Unsuccessful

6.2 Treatment needs

6.2.1 Day-to-day management needs

6.2.2 Needs better personal understanding of Tourette

6.2.3 Symptom management

6.3 Other

7 Barriers and facilitators

7.1 Barrier/challenge

7.1.1 Systems-level barrier/challenge

7.1.2 Person-level barrier/challenge

7.2 Specific concerns

7.3 Facilitator/advantage

7.4 Contingency/conditional

8 Attitudes and beliefs

8.1 Normative beliefs

8.2 Behavioral beliefs

8.3 Control beliefs

8.4 Comparisons

8.5 Self perception

8.6 Preferences

8.7 Expectation

9 Communication

9.1 Communication modalities

9.1.1 In-person communication

9.1.2 Telehealth/video call

9.1.3 Email communication

9.1.4 Social Media/Online Advertisement

9.1.5 Community Outreach

9.1.6 Flyers/posters

9.1.7 Postal Mail

9.1.8 Online Data Collection

9.1.9 Other modality

9.2 Frequency of communication

9.3 Quality of communication

9.4 Other communication

10 Results/status of registry or studies

10.1 Content

10.1.1 Individual level results

10.1.2 In Context

10.1.3 Collective/Group results

10.1.4 Findings/Conclusions of the collective/group

10.1.5 Details of the Participant Population

10.1.6 Future directions

10.1.7 Other

10.2 Scope of Information

10.2.1 Summary

10.2.2 All Research Details

10.2.3 Research implementation

11 Registry elements

11.1 Device

11.2 Walking

11.3 Survey

11.4 Phone Game

11.5 Duration of Task

11.6 How Often/Level of Involvement

11.7 Time Point

11.7.1 Time Point of Visit (initial)

11.7.2 Time Point of Visit (follow-up)

12 Registry involvement

12.1 Patient Engagement

12.2 Attrition

12.3 Incentives/Monetary

12.4 Title of Registry

12.5 Cohort/Longitudinal

12.6 Privacy/Anonymity

12.7 Most Important

12.8 Other

13 Specific example

14 Suggestions

15 Clarifying Question

Description

Uncontrollable emotions, behavioral impulses

Repetitive vocalization (e.g., Inappropriate language, shouting)

Repetitive movement (e.g., blinks, shrugging)

Discussion centers on triggers

e.g., bipolar disorder, ADHD

Participant discusses times in which s/he has experienced symptom relief

Discusses how s/he would know if her/his Tourette was changing (e.g., improving, worsening of symptoms)

How one aspect of personal condition affects another aspect

Impact on health status

Health status impacts on TS

Any change over time (e.g., coping mechanisms, emotions, symptom changes)

Discussions centers on participants' own understanding of her/his condition

Participant expresses that s/he has some degree of understanding of her/his condition

Participant expresses a lack of personal understanding of her/his condition

Access to resources (e.g., financial, transportation, insurance, etc.)

Symptom onset age

Diagnosis age

Discussion related to hormones or hormonal changes

Other discussion not listed above

Discussion centers on how this condition has changed her/his life

Discussion centers on how condition has impacted her/his relationships or interactions with others

Discussion centers on how people responded to her/his condition.

Discussion centers on how her/his condition affected her/his relationships. (e.g., family, friends, coworkers)

Participant describes how people react to her/his condition

Participant discusses how s/he explains her/his condition to others.

Discussion centers on social support (or lack of support)

Discussion centers on the complexity of planning activities, commitments, leisure, etc.

Discussion centers on travel or travel modification

Discussion centers on pain, nausea, and/or fatigue; includes effect on sleep

Discussion centers on social isolation as a result of Tourette

Discusses how Tourette affects her/his ability to work or earn a living

Discussion centers on diet or diet modification

Discussion centers on financial burden of having Tourette

E.g., constantly or very often thinking about Tourette (e.g., concerned about what others think of her/him)

Not listed above

Coping methods for living with TS

Conducts own research, modification of routines/environment, self-management techniques

E.g., meditation, prayer, therapy

E.g., alcohol, isolation, etc.

Other coping not listed above

Discussion centers on emotions or feelings

Discusses feelings of anxiety or fear

Discusses feelings of frustration or anger

Feelings of sadness or depression

Feelings of embarrassment

Discussion centers on trust

Discussion centers on feelings of mistrust

Discusses positive emotions or happiness

Discusses feelings of uncertainty

Feelings of stress

Other emotion not listed above

Discusses health system experiences

Discussion centers on how long it took for the participant to be diagnosed

Experienced misdiagnosis

Length of time to reach diagnoses

Process of diagnoses

Discussion centers on who made the final diagnosis

Participant discusses her/his interactions with the health system prior to diagnosis. S/he discusses lack of provider education and capability, and attitudes of providers such as being dismissive toward her/him.

Discussion centers on provider's knowledge of Tourette and capability in handling the condition

Participant discusses attitudes about Tourette that are expressed in the health system

Other research participation

Family history discuss

Participant discusses how s/he characterizes her/his treatment of Tourette so far

Discusses type of treatment/medications s/he had undergone/taken

Participant discusses aspects of treatment that s/he considers to be successful

Participant discusses aspects of treatment that s/he considers to be unsuccessful

Participants express treatment needs

Discussion centers on what would help participants manage the day-to-day experiences with Tourette better

Obtain a better understanding of her/his own condition-better explanation

What s/he thinks would help manage symptoms

Other treatment

Discussion centers on barriers, concerns, and facilitators related to Tourette or care

Discussion centers around a barrier or disadvantage

Systems-level barriers such as number of specialists

Person-specific barriers such as access to transportation, financial.

Expresses specific concern related to registry (e.g., data, privacy)

Discussion centers around a facilitator or advantages

A decision or choice depends upon specified factors

Discussion centers on attitudes and/or beliefs related to Tourette or registry

Value placed on registry overall or a specific element of registry

Causal attributions related to Tourette (internal and external) (e.g., I could have Tourette because it is genetic; external-Tourette was caused by abuse as a young person)

Discussion centers on sense of control, perceived behavioral control, and/or self efficacy

Any comparison made (e.g., social comparison, community comparison)

e.g., personality, outgoing, other self assessment

Any discussion of preferences related to registry or any aspect of care

Any discussion related to expectation

Discussion centers on modality and quality of communication

Discussion centers on communication modalities

Communication occurs/would occur in person (e.g., in-person meeting with provider/team)

Communication occurs/would occur via telehealth/video

Communication occurs/would occur via email

Social media discussion

Community outreach as communication modality

Communication via flyers or posters in clinic or community (outreach for registry)

Communication via postal mail

Online data collection methods

Other communication modality not listed above

Discussion centers on how often on results/status of study should be communicated

Discussion centers on how communication is presented in terms of quality(e.g., efficient, respectful)

Other communication topic not listed above

Results of registry or involvement

Discussion centers on what results the participants want shared with them.

Participants only wants her/his individual results. E.g., I just want my own data and no one else's data

Participant wants to receive her/his results in context of being compared to other participants

Participant wants to receive aggregate data about the group not specific to the her/him (general/broad group data)

Participant wants to receive results and conclusions from group data (e.g., Based on all data, here are our conclusions. Best treatment ___)

Participant wants descriptive of other participants (e.g., number of participants in the study, demographics of the participant population)

Participant would like to know plans for future research or strategies to improve patient's health following conclusion of the study

Other desired content not captured by the above codes

Discussion centers on how detailed the participants want the research results presented to them

Participants want a general summary of the research and conclusions (almost like an abstract)

Participants want all of the information available to them (includes academic paper, or expression for a general desire for 100% of the information that can be disclosed) includes goals and findings. Basic statement regarding the purpose of the study ("what they were looking for")

Participants want to know how the research will be used in the real world/its implications (ex. Best treatment available for a stroke)

Elements of this registry or elements of a cohort study overall

Device discussion

Walking activity

Survey activity

Phone game activity

Duration required of task

Level of involvement

Timepoint of meeting

Initial visit

Follow up visit

Involvement with registry

Patient as stakeholder

Discussion of retention or attrition

Incentives as motivator

Discusses terminology

Concept of cohort or longitudinal study

Privacy discussion

Most important focus for researchers

Other registry involvement

Actual or anecdotal

Any suggestion related to the registry

Participant asks a clarifying question