

Appendix 1. Interview/Focus group guide for moderators in study I (ADHD)

KIND

CENTER OF NEURODEVELOPMENTAL
DISORDERS AT KAROLINSKA INSTITUTET



Introduction (± 10 min)

In a first step, you introduce yourself and the group assistant(s), after which all participants introduce themselves. Then you explain the procedure of the session and the objective of the study:

On behalf of my colleagues I would like to welcome you to today's group discussion where you will share your experiences of living with ADHD. First, some information concerning the procedure: As mentioned in the information sheet, we will be recording the group discussion. During the recording, my colleagues will be taking notes.

You have agreed to have the group discussion be recorded by signing the consent form. I would like to emphasize that for the transcription your name will be replaced by a code number. To protect your identity the recordings will be destroyed after the evaluation of the data. Do you have any questions so far?

Obtain nonverbal and verbal feedback.

OK! We will now start the recording.

Turn on the recorder.

The group discussion will take between one and one and a half hour. About half way through, we will take a small break.

Now, to the project itself: Having a diagnosis of ADHD has a great impact on everyday life. We are interested in your experiences regarding everyday functioning in relation to ADHD. You can give us information regarding everyday problems or troubles having to do with ADHD. What are the problems and troubles that are especially relevant for those with ADHD? To explore this question, we would like to consult you, since you have first-hand experience. You can give us a good impression of what obstacles and problems people with ADHD have to face in their everyday lives.

I would like to begin with a short introduction of all participants. My name is [insert your name], I am a [insert your profession] and I work at [insert your clinic/institution]. I will conduct and moderate today's discussion. Please briefly introduce yourself.

Introduction of all participants clockwise.

Thank you for introducing yourselves. Now I will introduce the questions for the group discussion.

You initiate the discussion about problems associated with ADHD using the seven open-ended questions in the topic guide.

During the discussion I will ask you several questions concerning functioning and impairment related to ADHD. These questions are intended to be broad and general and they may include anything that you feel is relevant in your life with ASD. Altogether, we will be discussing seven questions in the group. First, I will give you an overview of all seven questions so that you can see which topics we will be discussing. Here are the seven questions.

Read all seven questions out loud.

Regarding the single questions, I am interested in all factors concerning ADHD which are especially relevant for you. We will discuss each question one by one. We are interested in all of your personal experiences with ADHD. It is important for you to know that there are no correct or incorrect opinions or views. Each of you should feel free to share the problems or troubles you experience. It is also important that within the group, you discuss your views and exchange opinions.

Please respect the following rules of discussion:

- *Each opinion is important and of interest!*
- *Please don't interrupt your partners!*
- *Please don't talk at the same time!*
- *Please deal with the current subject!*
- *Please talk about your own experiences!*

Discussion (±70 min, incl. 10 break)

You begin the discussion by showing the first question on the screen and reading it out loud. The examples given in the text here can be used as necessary to clarify the question. You can also use the chapters of the ICF-CY (e.g., in Body functions: mental functions, sensory functions, etc.) for inspiration for examples.

Let's begin with the first question:

How does your ADHD affect the way your body and your mind works? /How does ADHD affect the way the body and the mind of people with ADHD works?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, it could happen that you get restless or that you can't stop yourself from

moving around all the time. Perhaps you also have difficulty concentrating on your schoolwork, or you forget your books and homework.

You have mentioned several factors regarding the question of what doesn't function on the bodily level. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

In which parts of your body does your ADHD give you problems?/In which part of the body does ADHD give people with ADHD problems?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, you could experience that your head feels busy or crowded with thoughts. Maybe you get pain somewhere in your body when you are forced to sit still for a long time (e.g., sore muscles), or you experience pain in other situations or specific parts of your body (e.g., in your stomach, your arms, your shoulders).

You have mentioned several aspects regarding the question in which parts of the body can give problems. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

How does your ADHD affect the things you can and cannot do in your everyday life?/How does ADHD affect the things people with ADHD can and cannot do in their everyday lives?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, it could happen that you have difficulty paying attention to what the teacher is saying during a lesson in school. Perhaps you have difficulty planning your day, keeping appointments, doing schoolwork, and other activities. It could also happen that you have frequent conflicts with friends or family.

You have mentioned several aspects regarding the question of what are common problems in daily life. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

What and/or who in the environment where you live and work/go to school make everyday life with ADHD difficult for you?/ What and/or who in the environment where they live and work/go to school make everyday life difficult for people with ADHD?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, your classroom at school might be too big and there are too many

students so that it gets hard for you to concentrate and get easily distracted during lessons. Or perhaps someone you know will get angry with you for being “too loud” or they might have high demands on you.

You have mentioned several aspects regarding the question of what makes life with ADHD more difficult. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

What and/or who in the environment where you live and work/go to school is helpful and supportive in your everyday life with ADHD?/What and/or who in the environment where they live and work/go to school is helpful and supportive in the everyday lives of people with ADHD?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, an assistant or special educator in school who helps you with things like planning your day. You could experience that medication has a positive effect on your everyday functioning. Perhaps you have good eating and sleeping routines that help you get through the day.

You have mentioned several aspects regarding the question of what can be helpful or supportive. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the next question:

When you think about yourself and the person you are, what helps you to handle your everyday life with ADHD?/When you think about the personal characteristics of individuals with ADHD, what helps them to handle their everyday life with ADHD?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, physical activities like doing sports could make it easier for you to handle the difficulties you experience with your ADHD. Perhaps you are interested in many things and enjoy trying new things in life, which makes it easy for you to make friends.

You have mentioned several factors regarding the question of what is important about you/them and the way you/they handle your/their ADHD. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Now to the final question:

What can be the positive sides of living with ADHD?

Here we are interested in all factors regarding ADHD which you regard as being especially relevant. For example, you may be creative and full of imagination. Perhaps you are really good at sports or you can think faster than most people.

You have mentioned several factors that may be positive about having ADHD. For example [summarize (some of) the subjects discussed so far]. Is there anything you would like to add regarding this question?

Closing (±10 min)

Finally, you thank all participants for their engagement in the study and briefly give information of what will happen next.

I would like to take this opportunity to thank you for your participation in the group discussion. We were able to collect and discuss several interesting aspects which are relevant to you as a person with ADHD/to people with ADHD. In the coming time we will be analyzing the information that we collected today and that is collected in the other focus group discussions. Once the analyses are completed we will write a report about our findings that will be published in a scientific journal. If you are interested we will be happy to send the report to you after publication. Please sign up on this list to receive the report.

Show the list and place it where participants can sign up (for example, on their way out of the room).

Finally, we want to show our gratitude for your participation in this focus group by giving you this gift card.

Hand out the gift cards.

Thank you once more for your participation!

Debriefing

After each focus group a debriefing with your group assistants should take place to review the focus group process. We encourage all of you to also share your experiences during the focus groups with the other study sites involved in the study, so that we can all learn from each other.