DISABKIDS – Focus Group manual version 4.2015

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2015

1. Aim of the research

To identify HRQoL dimensions and items from the perspective of the child or adolescent.

2. Limitations and pitfalls of focus groups

Focus groups are not useful for drawing inferences about larger populations.

Problems might arise due to personal expectations of the group members and group incompatibility or lack of respect.

Although group interaction is generally seen as an advantage of focus groups, there is always the possibility that the group setting may inhibit interaction - especially for certain individuals.

3. Flexibility

At the time of writing version 2 of this manual the focus groups are still an academic exercise.

When we come to running the actual groups we may find that it is necessary to change the procedure due to differences in facilities, cultures etc. It is important to keep the objective in mind and not the methodology.

4. Time table for the focus groups

Timetable	Start date
WP2 Start ♦ Identify families and children ♦ Decision on how to classify participants ♦ Classification of participants into mild, moderate and severe ♦ Invite for interview ♦ Organisation of staff and logistics ♦ Practice ICIDH-2 classification	Day 1
♦ Review Focus group manual ♦ Prepare for Focus groups	Day 30
♦ Translation of the moderators guideline and questions in your language ♦ Interviews start	Day 60
♦ Summarise findings ♦ Comparison with literature ♦ Extraction of items ♦ Summaries sent to focus group coordinator	Day 90

5. Severity classification

At our meeting in Hamburg, we decided to use only global judgements by physicians for the focus groups.

The medical staff in Lund have independently come up with this classification for the two conditions we will be looking at in the focus groups.

Diabetes

In Lund we have divided the group up into the three problem levels using their haemoglobin count (Hba1c) as a measure i.e. mild < 7%; moderate 7 to 10%; severe > 10 %. Of course there will be people in the severe group who have not yet had any problems but we felt we needed an objective measurement.

Epilepsy

In Lund we are working on the assumption that mild = takes medication but has no seizures; moderate = takes medication but occasional severe seizures (1 per year) and / or mild seizures; severe = frequent tonic-clonic seizures (1 per month).

6. Methodology

Each centre will undertake focus groups on one or two conditions. The conditions may have changed since this table was constructed.

Country	Focus Group 1	Focus Group 2 (if possible)
Netherlands	Asthma	Rheumatoid arthritis
France	Epilepsy	
Greece	Cystic Fibrosis	
United Kingdom	Cerebral Palsy	Epilepsy
Sweden	Diabetes mellitus	Epilepsy
Germany	Rheumatoid arthritis	
Austria	Diabetes mellitus	

Number of groups and age ranges.

The age range and group size are the most critical factors to the success of the focus groups. Therefore, we will aim at **six focus groups**.

(1) Condition one -- 4-6 participants (age 8-12) mixed gender and severity
(2) Condition one -- 4-6 participants (age 13-16) mixed gender and severity
(3) Condition one -- 4-6 participants (age 4-7) parents
(4) Condition one -- 4-6 participants (age 8-12) parents
(5) Condition one -- 4-6 participants (age 13-16) parents
(6) Condition one -- staff

In addition we would also like to get information from the fathers and siblings of the patients. This could be done via a telephone interview or a separate interview if they attend at the same time as the focus group.

(7) Condition one -- fathers
(8) Condition one -- siblings

Group size should be a minimum of four and maximum of six. There is no requirement for single gender groups and it is desirable that the members of the group are familiar with each other. See table below.

WP2 FOCUS GROUPS	First condition children				First condition parents*		
		Focus group 1	Focus group 2		Parents focus group 3	Parents focus group 4	Parents focus group 5
AGE	4-7	8-12	13-16		4-7	8-12	13-16
Mild	1	2	2		1	2	2
Moderate	2	2	2		2	2	2
severe	1	2	2		1	2	2
Total Children			16				

* Note - the parent interviews do not have to be from the focus group families.

1.1 Procedure

1. Letter to all potential participants to include: request to participate; information about the project; suggested dates and times for focus group; consent form; contact information.
2. Contact the participants parents by letter and follow-up phone call to ensure that they understand the procedures and will attend at the stated times.

The participating adults don't have to be parents of the children and adolescents in the focus groups, but mothers (or fathers) of children/adolescents in the relevant age groups.

1.2 Inclusion criteria

Participants have to:

- consent to participate in the study,
- fit the age requirements of the study
- have had the chronic condition under study long enough to be able to appreciate the health implications

1.3 Socio-demographic data

Socio-demographic data is to be gathered on a minimum level to verify that a wide range of profiles has been included in this phase of the study.

Socio-demograhic variables:

- Age
- Gender
- Number of brothers and sisters
- Type of school
- Grade
- Health Status - mild, moderate, severe
- Medication

7. Preparations for focus groups

- Recruitment of the moderators
- Translation of the moderators guidelines and the questions
- Obtain and check the tape recorder
- Book suitable room(s) for the focus groups

1.3.1 Recruitment of the moderators

Two moderators are required. One for managing the discussion and one for the technical as well as the co-moderating part (e.g. expressing the need for clarity concerning certain statements). Both moderators should be familiar with group discussions as well as with working with children.

1.3.2 Translation of the moderators guidelines and the questions

It is only necessary to translate the questions.

In this version I have avoided using the terms 'interviewer' and 'patient' in order to indicate that the focus group is not an interview and the subject is never a patient. The power relationship between the 'moderator' and the 'participant' is more equal. Please try to translate the guidelines using terms that show a more equal relationship.

1.3.3 Obtain and check the tape recorder

Make sure the moderators are familiar with the tape recorded before the focus group. The recording should not be emphasised. Become familiar and confident in using the recorder. Avoid checking the tape during the focus group.

1.3.4 Book suitable room(s) for the focus groups

Try to avoid the hospital setting as much as possible.

The seating should be comfortable and arranged so that everyone can see everyone else without having to turn around. A coffee room or common room would be ideal.

8. Training of the moderators

Moderators should be prepared well and read the instructions several times before carrying out the focus groups. A practice session will be useful.

It is important for the moderators to note that the questions are intended as more than a guide. They should be followed in the order given as this moves from general to specific questions. However, if the conversation is going well and is relevant then allow this to continue and come back to the questions if this is needed.

1.4 Characteristics of a good moderator

- Energetic
- Non-authoritarian
- Honest
- Calm
- Good timekeeper
- Flexible
- Prepared
- Reflexive
- Responsive

1.5 Attitude of a good moderator

- Don't interrupt
- Be patient
- Submit rather than dominate
- Listen attentively
- Reflect back the words and language of the participants

1.6 Language / phrases to be used.

The language should reflect that of the participants. Reflect back words or phrases that they use. Adapt your language to the age range of the participants. Avoid using phrases or words that they might not understand. Keep everything as simple as possible.

Don't re-interpret their words in your own 'research language'.

1.7 Objectivity

The aim of the focus group is to gather the information as objectively as possible – this means without influencing the person interviewed and without interpretations or pre-conceived ideas.

In other words, the interviewer should explore how the subjects' health state alters, affects his or her quality of life, and more precisely, identify any changes (positive or negative) related to the perceived health status in terms of physical, psychological and social aspects.

This is not a psychological interview aimed at therapeutic or diagnostic outcomes, but a collection of facts, thoughts, feelings and attitudes. The interviewer should only collect the elements (perceived health-related QoL) and not interpret them (do not try and define the subject's psychological profile, etc. These elements will be used to generate items for the future questionnaire.

1.8 Listen attentively

Even if the interview is being recorded, the participants must feel that he or she is being listened to and understood.

9. The focus groups with children

9.1 Materials for the focus groups

- Tape recorder or minidisk
- Tapes or discs pre-prepared with labels
- Index cards
- Flip chart or paper that can be stuck to the walls
- A4 paper for writing
- Pencils

9.2 Meeting the participants

All moderators should meet all the children and parents at an arranged time and place. The two moderators should then take the children to the interview room. Parents may wish to be in the near vicinity but it must be stressed that they are not to participate in the children's discussions.

9.3 Timing

The focus group should take about 60 to 90 minutes.

Part one should take no longer than 40 minutes to complete. There should then be a ten-minute break followed by part two, again not longer than 40 minutes. If you feel that all the points have been covered in a shorter time then end the group early.

Book the group room for longer so that there is no rush to leave at the end of the session. Do not end the group abruptly. Sum up the conversation and ask them what they thought of the activity. - Keep the tape recorder going -

9.4 Activity

	Minutes approx.	Purpose
Introductions	5	Warm up
Part 1 - structured questions	35	Getting the group to focus on health related quality of life
Break	10	
Part 2 - free form questionnaire construction	30	Getting the group to focus on the questionnaire
Evaluation of the list	10	Group evaluation and looking for anything missing

9.5 Introduction

General Introduction to the children / adolescents (after parents have left). From the beginning it is important to build up a good relationship with the children.

Given variations due to cultural differences we should attempt to make the group as equal as possible. So, if you suggest what to do always ask if they agree. If they have another suggestion or order for doing things then be prepared to try this out as well.

Suggested interviewer text for part 1 of the group. Keeping exactly to this text is not critical - we need to get them to start to talk about their lives and their experience of illness this is only a guide.

OK,

My name is _____ and this is _____ *(just first names*). We are working on the construction of a questionnaire about how children / adolescents see their health and quality of life. This is a unique opportunity for us and it is very important that it is you that we listen to. You are the experts and we want to learn from you.

This group will last approximately one to one and half hours including a 10-minute break, but you may stop at any moment if you no longer wish to continue.

We are going to record everything so that we don't miss anything that you said and it means that I can listen to you without having to think about making notes. The tapes will only be listened to by us and they will be wiped when we are finished.

- If I ask you a question that you don't understand then you tell me "I don't understand". If I don't understand something you say, then I will ask you explain it to me.

What we want is to find out more about how you experience X, so that we can help people in the future. In the future we want to have a questionnaire so we want to hear are your views about what to ask when constructing a questionnaire about X. We want the questionnaire to be in your words and for children of your age. You should mention anything that you think is relevant.

Is everyone happy with this ?

Lets start with introductions again. Please just say your name so we know who we are talking to.

I thought we could divide this discussion into two halves. Firstly, we are going to ask you some questions about what you think about life and being healthy or not healthy. Secondly, we are going to try to construct a questionnaire for other children / adolescents so that they can easily indicate how they feel about have X. Is that ok?

I have some paper and cards here - if you want to write anything down as we talk then please do.

9.6 Part one - structured questions.

Ask the questions and go round the group getting a response from everyone. If you drift off the question or jump to later questions don't worry as long as they come back to talk about quality of life and X. The idea here is to start with more general questions and focus in onto the main issues.

1. What kind of things keep you healthy? (coping styles / activities)

2. If you could make a wish (or several), what would you wish for in order to be happier ?

3. Tell me about X (e.g. epilepsy / diabetes / asthma / etc.)

4. How does X affect you at school
5. What would you like people to do or say at school to help?
6. How does X affect you at home?
7. What would you like people to do or say at home to help?
8. What would you like people to do or say at the hospital to help?

End of part one.

- Introduce objective of focus group again and the purpose of part 2 i.e.

- What should we put into a questionnaire - mention that they should think about some of the answers you gave in part one.

- If you judge the group able to write easily had out the cards so that they can work with these before part 2 starts. If the group is not able to write have a flip board where the second moderator can write up the comments.

9.7 - 10-minute break - if you can supply some soft drinks this would be very good.

_____

9.8 Part two - free form questionnaire construction

The second part is intended to offer the opportunity to the participants to begin to construct the questionnaire themselves.

Suggested interviewer text for part 2 of the group.

> Thinking about the quality of life questionnaire that we are going to write - what questions would you ask someone of your age with X ? Tell me everything you can think of.

If what is said is not clear ask the participants to say it another way "Can you say that in another way?". or "Can you say more about that?" or "How would this affect someone's daily life?" You can also get children to put it into the form of a story - "Can you tell me a story about that?"

* Remember to cover issues concerning:
  - family
  - siblings
  - medical treatment
  - school

9.9 - 10 minutes before the end or if the group seems to have run out of ideas:

1) Go through the list and ask if this is relevant to people of 8, 13 or 16 years. If it is relevant to one age group ask what would be relevant to the other age groups.

2) Ask the group which things are the most important. If they have been using the index cards get them to put these into order. These can be graded as 1. very important 2. important 3. Less important.

3) Ask for their opinion about the list -
   - ♦ will it make a good or bad questionnaire ?
   - ♦ Is there anything missing?

9.10 Closing

Thank the children/adolescents for their participation and close the session in a personal warm and friendly way.

Do not turn off the tape recorder.

At the end of the group - keep the tape recorder going. Close the interview and let people leave. The last few minutes are always important. Some children who felt inhibited to say something during the interview will take this opportunity to make the most valuable comment they have made all day.

9.11 Output

part 1:

- Tape of the group interview
- Notes of the moderators with specific statements / domains

part 2:

- Tape of the recorded discussion
- Notes of the moderators with specific statements / domains
- Cards or flip chart notes.
- A priority ranking of the issues / questions

9.12 Problems

1.8.1 Sensitive issues

Be sensitive to the mood of the group. Children have to have their problems acknowledged. If a certain issues appear to be painful for members of the group, the moderator should not insist on discussing these, but pass on to another issue.

1.8.2 Sense of failure

Avoid making participants feel that they have failed if they can't answer the questions.

1.8.3 Lies

Be honest at all times. If you think the participants are telling lies then DO NOT press them for the truth. Children always have a good reason for telling lies.

1.8.4 Privacy

A major difficulty will be in negotiating privacy. Parents may not understand the need for privacy; they may feel they need to be there to protect the child; they may feel that the child does not have the right to privacy (a white, middle class idea). If parents ask then one possible statement might be that privacy is an important element of the group process.

1.8.5 Power relations

There is a danger that the children may not open up and communicate fully if they perceive the focus group as being dominated by the moderator. This will happen if the moderator is seen as a teacher / parent / authority figure or if the structure of the interview is too rigid.

In order to avoid this the moderator should be reflexive, responsive and have fairly open ended goals that allow the children to talk about their daily lives and set the agenda (at least to some extent).

Actions to avoid dominating the focus group

a) Allow the children some control over steering the conversation. Don't expect that the conversation will be focused on the topic all the time. Some of the time they will want to talk about other things including the focus group process they are in at the time.
b) Encourage descriptions of events through getting them to tell the group a story of their day or anecdotes.
c) The moderator should let children and adolescents express themselves as freely as possible.
d) Be relaxed during the interviews this will relax the children as well.

10. Parents interview / group

In preparation

11. Transcription of the interview

All of the interviews are to be entirely recorded. A complete transcription (questions and answers) will be impossible. However, the main issues should be transcribed from the text in the language used. Conserve the exact expressions used by participants.

Compare this to the literature and forward the analysis to the John Chaplin at the Swedish centre.

12. Moderator evaluation of the group

- Did the children understand the instructions?
- Did you and your colleague keep to your roles?
- Did you go through the suggested interview structure?
- Did you get an adequate recording?
- Did the discussion flow smoothly?
- How much time (approximately) was spent off the topic?
- How did the session end?
- Where there problems with privacy ?
- What was the general atmosphere of the session?
- Did the participants like being in a group?

13. Data to be collected about the group

- Date
- Place
- How long did the group take
- Researcher's names
- Children's names
- Methods used - e.g. index cards