

Seniors and Diabetes Focus Group Guide

Prepared by The Atlantic Seniors Health Promotion Network

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Attitude Makes a Difference Project

Focus Group Guide
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Table of Contents

Introduction	4
Part One: Reference Guide for Focus Groups	5
About the Organizations Sponsoring the Focus Group	5
Purpose of the Focus Groups (Statement of Purpose)	5
Definition of Diabetes	6
Statement Concerning Confidentiality	6
Definition of Diabetes Educator.....	6
Role of the Provincial Coordinator as Moderator/Facilitator.....	7
Planning the Focus Group	7
Tips for Moderating/Facilitating a Focus Group.....	7
Qualities of Good Questions.....	8
Tips for Reporting (including transcribing from recording and taking notes during and after the meeting)	9
<i>Transcribing the Focus Group Discussion</i>	9
<i>Who Takes Notes?</i>	9
<i>Some Tips for Recorders on Taking Useful Notes</i>	9
Part Two: Focus Group Guide and Timetable	10
Welcome and Overview of Project and Focus Group (5 minutes).....	10
Introductory Questions for Participants (15 minutes)	11
Questions Concerning Diabetes/Pre-Diabetes (40 minutes)	11
(Diabetic) Refreshment Break (15 – 20 Minutes).....	13
Continue Questions Concerning Diabetes (40 minutes).....	13
Concluding Questions (25 minutes).....	15
Evaluation Questions for Participants	15
Evaluation Questions for Moderator/Coordinator	15
Part Three: Check List for Focus Group	16
One Month Before	16
Two Weeks Before	16
One Hour Before	16
Half Hour Before.....	17
Focus Group Start.....	17
End of Focus Group.....	17
Within a Week Following Focus Group.....	17
References and Resources	18
Books and Articles.....	18
Websites	18

Seniors and Diabetes Focus Group Guide

Introduction

An earlier version of this guide was designed for use in the Attitude Makes a Difference Project (Sponsored by the Atlantic Seniors Health Promotion Network and funded by the Canadian Diabetes Community-Care Program of Public Health Agency of Canada). It has been adapted for use in seniors and diabetes focus groups. The purpose of this guide is to help you prepare for, moderate and record focus groups in your community. The guide is divided into four parts:

Part One provides information and techniques that the moderators can use to prepare for and moderate their focus groups.

Part Two presents the questions and related timeframe for the focus groups.

Part Three is a checklist to use in preparing for and facilitating the focus groups.

Part Four contains materials and resources used in preparing this guide.

Part One: Reference Guide for Focus Groups

In the following paragraphs, the experience of the 'Attitude Makes a Difference' Project is used as examples of how a focus group can relate its purpose and actions to those attending such a session. These are noted in bold, as Example.

About the Organizations Sponsoring the Focus Group

Example: The Atlantic Seniors Health Promotion Network (ASHPN) was the Sponsor of the *Attitude Makes a Difference* Project, conducted between March, 2007 and March, 2008. ASHPN is an Atlantic-wide network of organizations and individuals who are working together to enhance the quality of life of seniors. ASHPN is devoted to working with all generations and encouraging communication between age groups. As an agent of support and change, ASHPN uses strategies of community development, research, education and advocacy to further programs, services and policies on behalf of older persons.

Community Links is the Administrative Organization for the Project. Community Links is a Nova Scotia voluntary organization with a membership of 190 seniors groups and seniors serving organizations. It works to promote healthy communities and to improve the quality of life for seniors and others in rural Nova Scotia through community development and volunteer action.

The *Attitude Makes a Difference* Project was funded by the Diabetes Community-Based Program of the Canadian Diabetes Strategy, through the Atlantic Regional Office of the Public Health Agency of Canada (PHAC). Projects funded by this Program must aim at increasing the knowledge and awareness of diabetes among high-risk populations and/or service providers within Atlantic Canada.

Purpose of the Focus Groups (Statement of Purpose)

Example: The purpose of the focus groups in the *Attitude Makes a Difference* Project is to discover what seniors know and want to know concerning diabetes, what helps and what is needed to prevent or manage diabetes and to understand how seniors see themselves as diabetic or pre-diabetic.

Based on the input of seniors throughout Atlantic Canada, ASHPN will prepare a report identifying key actions that are needed to enhance prevention, treatment and support, and identify ways to encourage and support positive attitudes towards diabetes.

Since ASHPN is concerned about those seniors at greatest risk for developing or having complications from diabetes, the focus groups will include older unattached women living in rural or semi rural areas with low incomes (receiving or eligible for partial or full Guaranteed Income Supplement (GIS). Focus groups would include persons diagnosed with pre-diabetes and type 2 diabetes.

Definition of Diabetes

Type 2 diabetes is a condition in which the pancreas does not produce enough insulin to meet the body's needs or the insulin is not metabolized effectively. *Pre-diabetes* is defined as having a fasting blood glucose (sugar) level that is near but not quite at the level to be defined as having type 2 diabetes. Not everyone with pre-diabetes will develop type 2 diabetes, but many will. Therefore identifying persons with pre-diabetes is very important. (Canadian Diabetes Association, Diabetes Dictionary, 2007:7)

Statement Concerning Confidentiality

Example: The Atlantic Seniors Health Promotion Network and those involved in this project assure those present at these focus groups of confidentiality. No one's name will be used in the report of the proceedings of this project. We want everyone to feel comfortable sharing their experiences and concerns, so please respect each other's privacy and do not repeat things heard at the meeting.

Definition of Diabetes Educator

A diabetes educator is a health care professional (nurse, dietitian, physician, pharmacist, social worker) who has expertise in diabetes management. A Certified Diabetes Educator (CDE) is a health care professional with an expertise in diabetes who meets eligibility requirements and successfully completes a certification exam.

Role of the Provincial Coordinator as Moderator/Facilitator

Example: An effective moderator/facilitator will keep the discussion focused on the issue of concern without discouraging the sharing of ideas. In preparing for the focus group, the Provincial Coordinators acting as moderators will need to be familiar with type 2 diabetes and the information in this focus group guide. The Provincial Coordinator will communicate with the Project Manager and Project Steering Committee in order to address questions or concerns.

Planning the Focus Group

Planning for a focus group meeting involves the following activities:

- Identify and invite participants
- Determine the location and time of focus group
- Order refreshments
- Arrange for travel expenses and honoraria
- Develop plan for evaluation and feedback
- Prepare or use guides for focus groups
- Develop questions and pilot questions with representative group
- Plan on how focus group will be recorded (tape recorder, notes or both).

Tips for Moderating/Facilitating a Focus Group

- Go over the Focus Group Guide so that you will feel comfortable and will be able to keep your attention on the participants rather than the Guide.
- Go over the questions, practicing with others so that the questions are presented in a clear and open manner (possibly pilot the questions with a representative group of seniors).
- Establish “ground rules” in order to encourage participation and help the discussion flow easily.
- Do not participate in the discussion unless you are asking for clarification or encouraging participation.
- Be impartial. Do not take sides with participants or try to argue your point of view or criticize theirs.
- Use simple language, asking one question at a time and allowing adequate time for responding.
- Be sensitive and patient – by your facial expression and body language, give the message that you are interested in what the participant is saying and allow time for their expression of ideas

- Be open and flexible – respond to what is important to the participant not to you.
- Be a good listener. Repeat what participants have said to make sure that you have understood what they meant. Use non-verbal strategies to show that you are open, comfortable and are waiting to listen to what each participant has to say.
- Encourage everyone to participate in discussion by using pauses, probes and re-enforcers.
- Pauses allow for a bit of silence so that participant can think more about the question and allows others to make comments.
- Probes encourage participation by asking follow up questions, such as “What was your experience?” Or “Could you give us an example of ...”.
- Re-enforcers communicate interest in what members share but do not suggest what is expected or acceptable. Re-enforcers may be non-verbal, nodding or making eye contact, or verbal, such as “I see” or “That is interesting”, but should avoid non-verbal actions, such as nodding the head after some responses, but not others and verbal, such as “ excellent response”.
- Use verbal and non-verbal techniques for encouraging shy or quiet participants to join in the discussion. Non-verbal techniques could include making eye contact with person or smiling at them, and using pauses or moments of silence to allow these persons to collect their thoughts. Verbal techniques could include directed questions such as “What was your experience with this?”
- Use verbal and non-verbal strategies to handle those who dominate the discussion, such as avoid eye contact with the talker, shift your eyes to the other participants and say, “Thank you, Mary. Let’s have some other comments”.

Qualities of Good Questions

- Clear, simple language. Use language the participants understand. Avoid asking questions that have several possible meaning or questions so long that they are difficult to follow.
- Short and open-ended. Use open-ended rather than yes/no questions. Examples of open-ended questions are; “How do you feel about.”, “What is your opinion of.”, and “Could you please describe”. Particularly effective are questions that begin with “how”. Beware of using a lot of “why” questions because they may lead participants to justify their actions or opinions and feel a little frustrated or think they are not giving the “right” answers.

- Pertinent to issues of concern. State in the ‘ground rules’ that it is important for everyone to participate and to focus on the questions/topic at hand, thus avoiding rambling off in different directions.
- Encourage openness and avoid bias. Avoid leading questions that lead respondents to answer in a particular way.

Tips for Reporting (including transcribing from recording and taking notes during and after the meeting)

Transcribing the Focus Group Discussion

- Make sure the tape recorder is working and you have extra tapes and batteries
- Locate the tape recorder so all participants can be heard
- Label tapes with date and location and number in the order in which they were used

Who Takes Notes?

Written notes should be taken by the Recorder. Although the Moderator may also take notes, they should be brief since losing the Moderator’s attention can disrupt the flow of the discussion and also give the impression that some person’s comments are worth writing down while others are not.

Some Tips for Recorders on Taking Useful Notes

- Write down well said quotes, word for word, using quotation marks and relevant question or conversational context
- Write down your observations, paying particular attention to non-verbal actions, such as head nodding or eye contact that would indicate a level of agreement, support or a difference of opinion between participants. Make note that these are your personal observations or opinions.
- If you have a question, make note of it and ask it when the time is right to do so.

Part Two: Focus Group Guide and Timetable

Welcome and Overview of Project and Focus Group (5 minutes)

- Welcome and housekeeping details. Point out the location of washrooms, the time of (diabetic) refreshment break and review the timetable for the focus group.
- Describe the Sponsor Organization.
- Describe the organization or agency which is funding the focus group.
- Describe The Purpose of the Focus group.
- Present a definition of type 2 diabetes and pre-diabetes. Note that when one says the word 'diabetes', it can refer to either pre-diabetes or type 2 diabetes (See *Part One: Reference Guide*).
- Make a verbal statement concerning confidentiality (See *Part One: Reference Guide*).
- Go over the 'ground rules':
- Give everyone a chance to talk.
- There is no right or wrong answer, everyone's opinion is important.
- What is said in this room stays here – please do not repeat things talked about today.
- We will work to stay 'on topic'. Although there are a lot of interesting things we could discuss, today we will be focusing on your experience and understand of type 2 diabetes.
- We are recording and taking notes today, but there will not be any names included in the report.

Introductory Questions for Participants (15 minutes)

1. Ice-breaker question. Sample ice-breaker questions are given below. Use whatever question you think will work best with your group if you think an 'ice-breaker question' is needed. You may want to use Question 2, below, as your ice-breaker.
 - What is your favorite season?
 - What is your favorite fall vegetable and favorite method of preparation?
2. Please tell us about yourself, your name and where you live.

Questions Concerning Diabetes/Pre-Diabetes (40 minutes)

Note: Use your judgment as to how you include the "issues and topics to cover" under each question in the time allotted. Ask follow up questions to probe or prompt answers to these topics..

1. Could you tell us about when and how you were diagnosed? Why were you tested?

Issues/topics to cover:

- Who made the diagnosis of diabetes
- How the diagnosis was made
- Length of time since diagnosis

2. What did you think about diabetes at that time? How did you *feel* about your diagnosis?

Issues/topics to cover:

- Knowledge of diabetes
- Attitude towards diabetes, did it make a difference in how you felt about yourself – including positive feelings such as ability to cope, strength, will power or negative feelings, such as fear, guilt, sadness, depression, anger, frustration.
- Impact on social relationships - how would diagnosis affect family – what would family or friends think of diagnosis.
- Attitude towards other seniors with diabetes – what did you think about other seniors who were diagnosed with diabetes.

3. What help, including information, were you given when you were diagnosed and who provided this help or information to you? Was help provided in the language of your choice? How long did you have to wait for this help, and if you had to wait for a longer time, what did you do in the meantime?

Issues/topics to cover:

- Information provided by physician
- Length of time between diagnosis and visit with diabetes educator (if such visit took place)
- Awareness of or information provided by diabetes educators, community health organizations, physicians, pharmacists, VON, etc.
- Awareness of or help (financial or technical) with diabetes medications and supplies
- Awareness of or help by support groups
- Help by family, friends, church, community organizations, etc
- Help from resources like the internet and television

4. In what ways, if any, has your attitude towards diabetes changed since you were diagnosed?

***Note:** This question is intentionally open-ended so it will not encourage a more detailed response or answer than a basic “Yes” or “No”.*

Issues/topics to cover:

- More acceptance of diagnosis
- More or less fear/worry about diabetes
- Greater awareness of the need for information concerning diabetes
- Re-evaluation of messages given in media, drug advertisements, in pharmacies etc.

5. How has your day-to-day life changed, if it has, since you were diagnosed? If it has changed, what do you think brought about this change?

Issues/topics to cover concerning change:

- Change in lifestyle – weight management, nutrition, exercise, meal planning,
- Change in social life – meals with family, friends, parties, etc.

- Change in cost of living – cost of medication, supplies, food, transportation

Issues/topics to cover concerning what affected change:

- Awareness of the complication of diabetes
- Information and support by physician
- Information and support by pharmacist
- Information and support by diabetes educators
- Support by family, friends or community support groups
- Ability to find answers to continuing questions/concerns
- Access to financial assistance with medication, supplies
- Information from other resources, such as the internet, television, pharmacy and grocery store programs, other health care professionals (including dieticians)

(Diabetic) Refreshment Break (15 – 20 Minutes)

Continue Questions Concerning Diabetes (40 minutes)

6. What concerns you most about diabetes?

Issues/topics to cover:

- Getting the information to help manage diabetes and getting answers to questions when you need them.
- Getting support/help with diabetes supplies - meters, injections, medications, etc.
- Impact on your health - complications from diabetes affecting your heart, eyesight, etc.
- Impact on emotions - worry, depression, etc.
- Impact on income/financial security - cost of diabetes supplies, cost of healthy food, etc.
- Impact on social life - how to carry on social life and live diabetes lifestyle
- Impact on family life – will other family members be diagnosed?
- Reading labels
- Concerns over medications being taken off the market, including the possibility that the medication I am taking might be taken off.
- Other

7. What helps you most to understand and manage your diabetes?

Note: *This was addressed in Question 2, but this question focused on the time of diagnosis and repetition of question is used to focus on what helps now.*

Issues to cover:

- Information provided by physician
- Information and support by diabetes educator in a one to one or group session (Note: ask if senior prefers a group setting or a one to one meeting)
- Information and support by community health organizations, pharmacists, nurse practitioner, VON
- Information provided by the Canadian Diabetes Association
- Assistance with diabetes medications and supplies (including financial assistance)
- Help from other health care professionals
- Help by support groups
- Help from family
- Help from friends, church, community organizations, etc.
- Information from media and/or internet

8. What additional help or support do you need?

Issues/Topics to cover:

- Information/support from physician
- Information/support from diabetes educator or on an ongoing basis (in a group setting or on a one to one basis)
- Financial support
- Transportation to physician, diabetes educator, pharmacy or other sources of diabetes information, medication and supplies
- Personal/social support (family and friends)
- Community support (support groups, help from church or other community groups)
- Other

Concluding Questions (25 minutes)

9. As a person living with diabetes, how do you see your future?

Issues/Topics to cover

- Overall health: living with diabetes, preventing or coping with complications
- Independence: perceived impact of diabetes on quality of life
- Finances: perceived impact of diabetes on cost of living
- Other

10. What is the most important advice you can give to a senior who has just been diagnosed with diabetes?

11. Do you have any final questions or comments?

Evaluation Questions for Participants

1. What did you like about the focus group?
2. Can you name one thing you would change?
3. How could the focus groups be improved?

Evaluation Questions for Moderator/Coordinator

- What did you think of the overall process of the focus group?
- Were the focus groups well organized?
- Did the information in the guide and the questions facilitate the process?
- Was there enough time to cover the questions?
- Did the focus group participants feel clear on their role?
- Did seniors feel comfortable participating in the group?
- Were the focus groups successful in bringing the target population together to discuss their attitudes towards diabetes itself and the services available?
- What parts of the focus groups, e.g. number of questions, content or wording of questions, timing, layout of room, should be changed?
- What suggestions do you have for changes?

Part Three: Check List for Focus Group

One Month Before

- Identify local organization/groups to help with focus group
- Meet with representatives from local organizations/groups
- Working with local organization, find accessible, affordable location for focus group.
- Set date and times
- Working with local groups, identify participants for session
- Call or send invitations to participants
- Order food for refreshment break

Two Weeks Before

- Meet with local organizations/groups to confirm focus groups plans
- Send letter or make call confirming time, date and place of Focus Group, including availability of transportation
- Confirm location of session
- Confirm food (remembering those coming are diabetics)
- Secure materials for session
- Tape recorder (extra tapes and batteries)
- Name tent (ask participants to print first names only)
- Pens/pencils and paper
- Flip Chart and markers
- Handouts

One Hour Before

- Arrange table and chairs
- Set up refreshments
- Set up tape recorder
- Set up name tents, paper and pencils for each participant

Half Hour Before

- Review introduction and questions
- Greet participants as they arrive
- Indicate the location of washrooms

Focus Group Start

- Welcome and Introduction
- Describe 'ground rules' for participation
- Participant introductions
- Beginning questions
- Refreshment break
- Continue questions
- Concluding questions

End of Focus Group

- Evaluation
- Thank participants
- Financial details (travel expenses/honoraria)
- Check tape recorder
- Gather notes from person doing recording and moderator
- Tidy up room

Within a Week Following Focus Group

- Check on tape recorder
- Go over notes with person recording session
- Recorder prepare written report based on tape recorded proceedings
- Moderator and recorder write down key points, valuable quotes, and put down observations, thoughts, opinions, noting these are your comments
- Send report to Project Manager and present report to Provincial Committee

References and Resources

Books and Articles

Atlantic Seniors Housing Research Alliance (ASHRA), Moderating Focus Groups: A Reference Guide for “Projecting the Housing Needs of Aging Atlantic Canadians Mount Saint Vincent University, Memorial University, University of Prince Edward Island, Dalhousie University, University of New Brunswick (Funded by Social Sciences and Humanities Research Council of Canada) April 5, 2007

Public Health Agency of Canada, National Diabetes Fact Sheet, 2007 (Available in English and French)

Health Communication Unit at the Centre for Health Promotion, Using Focus Groups, University of Toronto, June 30, 2002

Krueger, Richard A. and Mary Anne Casey, Focus Groups: A Practical Guide for Applied Research, (3rd Edition) London: Sage Publication, Inc. 2000

Walker, Rosemary and Jill Rodgers, Type 2 Diabetes: Your Questions Answered, London: DK Publishing, 2006.

Websites

www.caremapnb.ca Information on diabetes care and programs in New Brunswick is available on this website.

www.cdc.gov/dhdsp/cdcyergy/contest/resources/diabetes An example of a focus group guide designed for use for Native Americans with diabetes.

www.nscommunitylinks.ca Community Links website has the ‘Attitude Makes a Difference Report’ and other projects and services for seniors in Nova Scotia.

www.diabetes.ca The Canadian Diabetes Association website has links to all the Canadian Provincial CDA websites. It includes a wealth of information on diabetes.

www.diabetescareprogram.ns.ca Nova Scotia Diabetes Care Program Website.

www.gdiworld.com/tips.htm A brief introduction to focus group topics.

www.gohealthy.ca The “Achieving Health and Wellness: Provincial Wellness Plan for Newfoundland and Labrador: 2006-2007” presents the Wellness Plan for seniors in the Province, including the development of a Provincial Diabetes Strategy.

www.gov.nl.ca The Newfoundland and Labrador Provincial website includes links to programs and services for seniors in the Province.

www.gov.ns.ca The Nova Scotia Provincial website includes information on programs and services for seniors.

www.gov.pe.ca The PEI Government website has links to services and programs for seniors in the Province.

www.peidiabetes.pe.ca The Diabetes Program of PEI website.

www.peoplewithdiabetes.ca This website posts information on diabetes forums activities and concerns in Canada, including information on diabetes peer support groups.

www.mnav.com/qualitative_research A Manual on how to do focus groups.

www.unu.edu/unupress A manual on the use of focus groups.

www.cdc.gov/diabetes/pubs/index.htm A handbook for diabetes focus groups.

www.seniorsresource.ca The Seniors Resource Centre of Newfoundland and Labrador provides information on programs and services for seniors in the Province including information on the on seniors and diabetes, “Building On Our Strengths: Knowing What’s Good For Me”.