

Health Information Needs Assessment of Adult Learners in PEI

Submitted to: Adult Knowledge Learning Centre

Submitted by: PEI Literacy Alliance

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Executive Summary

The PEI Literacy Alliance aims to improve health literacy for Islanders. To help reach this goal, we conducted a health information needs assessment of people with low-literacy skills. We focused on people enrolled in an adult education classes who we estimated to have level 2 literacy skills.

We formed an advisory committee to guide our work on this project. Using focus groups to gather information, we identified health information needs of adult learners.

When we asked participants where they get health information, we got many responses. Doctors and pharmacists were named most frequently. The Internet was a popular place to get more health information after visiting the doctor. Although most people had good experiences getting health information from pharmacists, this was not the case with doctors.

Doctors need to improve the way they communicate health information. They need to use plain language, be supportive, and spend more time with patients. One participant said, “I asked him [the doctor] to explain it again, he did, but I still didn’t understand and then he was out the door.”

This research project is the first step in a larger plan. The Literacy Alliance hopes to conduct a needs assessment of those working in the health field. We want to find out what will enable them to communicate more effectively with their clients, especially those with low-literacy skills. We will then be equipped to make clear recommendations to policy-makers to improve health literacy for Islanders.

Health Information Needs Assessment of Adult Learners in PEI

“My doctor gave me very little information, just enough to scare me”

~ Quote from a participant

Description of the Research

Background

The PEI Literacy Alliance held a Health and Literacy Summit in March 2007. Participants represented adult learners, health professionals, community workers, and health policy people. During the Summit, important discussions took place across these sectors. There was a consensus that before we could move forward with recommendations for policy makers, a needs assessment specific to PEI was needed.

This project is a Health Information Need Assessment of Adult Learners. In the spring of 2008, we plan to work on a needs assessment of health professionals and others working in the field of health literacy.

Our goal is to improve the health literacy of Islanders.

Target Audience:

We chose to look at the needs of adult students in GED prep and Levels courses for these reasons:

1. We estimated they have level 2¹ literacy skills
2. They were easy to recruit because we knew where to find them
3. They met our requirements of a well-defined and specific group
4. They represent 28.8%² of Islanders who have level 2 literacy skill

¹ According the International Adult Literacy Survey, people at level 2 can read but not well, can deal with material that is simple and clearly laid out, and they often do not recognize their limitation.

² *The Importance of Literacy for the Labour Force and the Labour Market, Human Resources and Social Development Canada*

Methodology

We formed an advisory committee to help guide our research. Members of the committee are:

- Donna Murnaghan, Associate Professor, UPEI School of Nursing
- Barbara Macnutt, Director, PEI Literacy Initiatives Secretariat
- Rod Stanley, Communications Officer, PEI Department of Health
- Charlotte Comrie, CEO, Heart and Stroke Foundation of PEI
- Nishka Smith, Evaluator, Atlantic Evaluation Group
- Dianne Smith, owner and operator, Smith Lodge, a community care facility
- Catherine O'Bryan, Executive Director, PEI Literacy Alliance
- Norm Finlayson, Health Literacy Coordinator, PEI Literacy Alliance
- Jinny Greaves, Researcher, PEI Literacy Alliance

We considered using questionnaires, surveys and one-on-one interviews. However, we decided focus groups would create more in-depth information and allow for more exploration of answers. We also had a limited amount of time to complete the research and had to choose a method to provide rich information and that could be completed within two months.

The committee agreed that four focus groups held across the Island would be the best way to get the information we needed. To conduct successful focus groups we needed 4 to 8 participants, group guidelines, good open-ended questions that were not leading, and a strong facilitator.

The researcher met with Natalie Worthen, Program Manager of Adult and Community Education at Holland College, to identify instructors to help recruit participants. The researcher contacted the instructors and explained the project. The researcher then sent a recruitment package to these instructors. In this package was a letter explaining to the instructor what was being asked of them, a consent statement that each instructor read to their class, and consent forms for participants. The letter, statement and form are attached.

Our research goals

1. To define the health information needs of adult students
2. To create a list of suggestions from adult learners on how to improve the communication of health information

Questions for our Focus Groups

The researcher facilitated the focus groups with the help of a note-taker. Three questions were used to guide the discussions:

1. When you need health information, where do you go to get it, and why?
2. What has been your experience getting health information from _____ (places and people named in question 1)?
3. How could health information be easier for you to get and use?

Limitations of Research

This research project looked only at the needs of adult students who have approximately level 2 literacy skills. There are many adults who have level 2 literacy skills who are not enrolled in an adult education program. These adults may have different health information needs than our target audience. Also, this project does not look at those who have level 1 literacy skills. These people may have different health information needs.

Key Findings

We gathered a lot of information from participants during our four focus groups. This section summarizes what the participants said about where they get health information and what their experiences have been.

Participants said they got their information from these sources which are listed in order of number of responses:

- Doctors
- Pharmacists
- Specialists
- Internet
- Medical Books
- Nurse/Dietician/Nutritionist/Nurse Practitioners
- Community Groups
- Friends and Family

Doctors

More than half of the participants said they went to the doctor first because the doctor knows the diseases, symptoms and cures. Although some participants felt their doctor gave them good health information and explained it so they could understand it, most disagreed.

This quote from one participant sums up what many said, “my doctor gave me very little information, just enough to scare me.” Many said

they simply received a diagnosis and a prescription and were sent on their way. Most did not receive any printed information.

Even those that had good experiences getting information said “you have to ask, if you don’t, they don’t tell you much.” One participant said “I feel like he [the doctor] doesn’t want me to know too much because I’m young.” Many participants also said the doctor used complex terms: “they don’t use our language.” “I asked the doctor to explain it again, he did, but I still didn’t understand.” Participants said they felt rushed and that they could only ask about one specific problem even if they had several health problems.

About half of the participants distrust doctors. There were many experiences of being mis-diagnosed. Many people talked about going to the doctor first and then researching the diagnosis and what they could do on their own. This research involved looking through medical books, searching the internet and talking to friends and family. Most found the information they were looking for and said it was helpful.

Pharmacists

Everyone said that pharmacists were good at communicating health information. Reasons given were they:

- explain things in simple terms
- are approachable
- take the time to explain
- use demonstrations
- give out videos
- have lots of pamphlets.
- are always there and you don’t have to make an appointment
- can be called
- offer information sessions

A few people said they also had an experience with the pharmacist where they did not get enough information. The examples given were not being told what food or over-the-counter drugs to avoid when taking their medication.

Specialists

Most who had visited a specialist doctor said they received good health information. They received printed information and the doctor explained the health issue in detail and in easy-to-understand words. Others felt they did not get good health information from the specialists because of lack of plain language or that they were given too much information leaving them feeling confused and scared.

Internet

Many said after going to the doctor they would use Google to search for health information. They said there was lots of good information online but that it could also be overwhelming. They liked the internet because of the ease of using it. Most have a computer in their homes. “On the Internet you can read at your own pace.” Video or audio clips can also be found online as well as diagrams – good for visual learners. Some participants didn’t use the internet at all for health information. There was discussion at each focus group about the reliability of websites and that there could be a risk of mis-diagnosing yourself.

Medical Books

The few that said they used medical books said it was either as a starting-point or to learn more after seeing the doctor. They said information was easy to get and that learning more helped them feel in control.

Nurse/Dietician/Nutritionist/Nurse Practitioners

These are grouped together because participants that used these sources to get health information said the same thing about each. These people were approachable, took the time to explain and made sure the patient understood. They gave them printed material and were very supportive. They spent a lot of time getting all the details from the patient.

Community Groups

Only a few people said they got health information from community groups. One participant talked about getting a huge pile of information about breast cancer. She found it overwhelming, scary and offensive and didn’t understand half of what she read. She was told to read it and make a decision about treatment. She felt she had little support.

Others said they read their pamphlets but found some to be confusing “there’s too much information jammed in one pamphlet”. The TV ads by the Heart and Stroke Foundation caught most people’s attention but they noted that they were about specific problems and that the information was vague.

Some participants had used some community group websites and found some information to be good, but some of it was too hard to understand.

Friends and Family

Many participants talked to friends and family whose opinion they trusted. These people were approachable and knowledgeable and explained things in simple terms.

Suggestions on How to Improve the Communication of Health Information to Adult Learners

A summary of what we heard:

“Health information, whatever its form, needs to be easier to understand, more accessible and there needs to be more support in analyzing it.”

Health Promotion

- raise awareness of where you can get health information
- avoid the use of medical terms, they only put people off
- place pamphlets in schools, grocery stores, and other high traffic places
- use plain language and clear design for all pamphlets
- hold information sessions/guest speakers in schools about smoking, alcohol, sexually transmitted infections, exercise, healthy eating, etc.
- place an anonymous question box in schools with answers posted weekly
- teach kids about stress management
- increase awareness about how parents should talk to their kids about cancer or death

Health Protection

- make WHMIS³ more accessible but offering it to anyone free of charge
- increase awareness about the risks of using toxic cleaning products
- raise awareness of the availability of WHMIS Data Sheets at stores where toxic products are sold
- raise awareness of what cleaning products are safest to use
- increase the responsibility of drug companies so they clearly list all side effects and health risks
- improve the communication of test results - doctors need to call their patients back
- increase awareness about how to help someone who is in a violent relationship

Disease Prevention

- raise awareness of common diseases through TV ads/documentaries, posters - things that catch people's attention
- hold information sessions available free to everyone
- use plain language and clearly designed pamphlets on all common diseases
- allow patients to address all their health issues at one time when visiting the doctor

Health Care and Maintenance

Specific to doctors and how they can improve the way they communicate health information:

- give more guidance on how patients can take control of their health
- spend more time with patients so they can ask more questions
- use plain language
- give printed information about conditions
- explain conditions in more detail

³ The Workplace Hazardous Materials Information System (WHMIS) is Canada's national hazard communication standard. The key elements of the system are cautionary labelling of containers of WHMIS "controlled products", the provision of material safety data sheets (MSDSs) and worker education and training programs.

- explain how a drug works, what the side effects are and what alternatives are available
- make sure patients understand what they are being told
- recommend where they can go to get more information

Generally:

- place pamphlets in doctors' offices
- use pamphlets that are in plain language and use clear design
- use pictures
- create a reliable health information website using clear design, plain language and visual learning tools (videos, audio clips, images)
- hold more information sessions on specific conditions
- have health information available at Access PEI
- create a 1-800 # where people can call and talk to a nurse
- avoid giving patients too much written information as this may overwhelm them
- help patients analyze the information so they can make the best choice
- bring nurse practitioners to the Island

Systems Navigation

- improve signage at hospitals by using plain language and clear directions
- improve forms at the hospital and doctors' offices by using plain language and clear design
- allow public access to mental health information at the McGill Centre as they have excellent resources that currently only clients can access
- Family Health Care Plan should clearly list what drugs are covered

Conclusion

Using focus groups to gather information on the needs of adult learners was an effective and efficient way to do our research. Hearing the stories and experiences of participants getting and using health information put a real face on the issue of health literacy. We will use the suggestions we have gathered from the participants to form recommendations for policy makers.

Attachments:

- [Consent Statement and Form](#)
- [Letter to instructors](#)
- [Literacy Levels](#)
- [Press Release](#)



Literacy for All – Learning for Life

Informed Consent Statement

Invitation for you to participate

We invite you to take part in a focus group as part of our Needs Assessment Project. This research project will identify health information needs of adult students. We are doing this research so that we can make recommendations to government and health professionals to improve health information and communication.

We will hold focus groups in Charlottetown, Summerside, Westisle, and Montague.

Before you agree to be a part of a focus group, please listen to this information. Feel free to ask questions if you don't understand something.

What you will be asked to do

If you decide to take part, we will ask you to participate in a focus group. The focus group is a 1½ hour discussion between adult students. We will use questions to guide the discussion. We want your thoughts, opinions or experiences. There is no right or wrong statement.

Benefits to you

The information that comes out of the focus group will be used to encourage government to take action and make health information easier to get and use. All Islanders will benefit from better health information.

If you agree to participate, we will give you \$25 at the end of the focus group.

Confidentiality

We will protect your privacy at all times. You will not be identified in any way. The information we collect will be used as part of a report. Your name will not be recorded in the notes or in any other document

We may use a tape recorder to help make sure the notes are accurate. After the notes are completed, we will erase the tape.

Voluntary Participation

Participants in this focus group are volunteers. If you don't want to participate it will not have any negative effects for you. If you attend the focus group, you may at anytime, for any reason, leave the meeting without any negative consequences.

PO Box 20107

Charlottetown, PE C1A 9E3

project@eastlink.ca

tel: 902-368-1810 fax: 902-368-3269

web: www.pei.literacy.ca

Focus Group Consent Form

Please consider this consent form carefully before you sign it.

| Focus Group Details |
|---------------------|
| Date: |
| Time: |
| Place: |
| Room: |

I have read or listened to the above information and agree to participate in the focus group on _____.

Your Signature: _____

Please print your name: _____

Today's Date: _____

If you have any questions please contact:

Jinny Greaves
Researcher with the PEI Literacy Alliance
Phone: 902-368-1810
Email: project@eastlink.ca

A copy of this form will be kept by the researcher for at least five years.

This is your copy to keep

PEI Literacy Alliance
P.O. Box 20107
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November 20, 2007

Catherine Griffin
Holland College Adult & Community Education
c/o Western School Board
P.O. Box 57
Elmsdale, PE
C0B 1K0

Dear Catherine,

I am asking for your help in recruiting 4 to 8 adult students to be participants in our focus group.

We are holding these focus groups to identify health information needs of adults with level 2 literacy skills. We will use the information we gather to make recommendations to Government and policy makers. Our goal is to improve the communication of health information so all Islanders can maintain or improve their health.

Please read the attached **Informed Consent Statement** to your class and ask those interested in volunteering to sign **2 forms each**. Those interested can keep the yellow form and consent statement (also on yellow paper). The white form is for our records. Please hold on to these white forms and I will pick these up when I come to Montague to do the focus group.

I have included 14 copies in case you have more than 8 students interested. We can only take a maximum of 8 students, so if there are more than 8 interested, I will draw their names from a hat.

Focus Group Details:

Date: November 29, 2007

Time: 10:00 am

Place: Western School Board Elmsdale Office

Room: Boardroom

Honorarium: We will give each volunteer \$25

Your help is greatly appreciated. If you would like to receive a copy of our final report just let me know and I will mail you one once it is completed.

Sincerely,

Jinny Greaves
Researcher

Literacy Skill Levels

According to the International Adult Literacy Survey (IALS) 1996

Level 1

- people at this level have great difficulty reading and usually know they have a problem

Level 2

- people at this level can read, but not well
- they can deal with material that is simple and clearly laid out
- they often do not recognize their limitation

Level 3

- people at this level can read well, but have some problems with more complex tasks
- many jobs require a higher skill level

Level 4 and 5

- people at this level have a high level of literacy and can meet most reading demands

For Immediate Release

December 19, 2007

“They gave me just enough information to scare me”

A research report by the PEI Literacy Alliances puts a spotlight on the issue of health literacy. Health professionals may think they are helping their clients, but do these clients understand what they are being told?

The PEI Literacy Alliance aims to improve health literacy for Islanders. To help reach this goal, they conducted a health information needs assessment of people with low-literacy skills. They focused on people enrolled in an adult education classes who they estimated to have level 2 literacy skills.

They formed an advisory committee to guide their work on this project. Using focus groups to gather information, they identified health information needs of adult learners.

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Doctors need to improve the way they communicate health information. They need to use plain language, be supportive, and spend more time with patients. One participant said, “I asked him [the doctor] to explain

it again, he did, but I still didn't understand and then he was out the door."

This research project is the first step in a larger plan. The Literacy Alliance hopes to conduct a needs assessment of those working in the health field. They want to find out what will enable them to communicate more effectively with their clients, especially those with low-literacy skills. The Alliance will then be equipped to make clear recommendations to policy-makers to improve health literacy for Islanders.

This research was funded by the Adult Knowledge Learning Centre, the Literacy Initiatives Secretariat and the PGI Golf Tournament for Literacy.

To read the full report visit www.pei.literacy.ca.

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