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Summary of Focus Group Findings Re: Privacy and Personal Health Materials Evaluation

Final Report

POR-03-80

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Submitted to:

Health Canada

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BACKGROUND

On January 1, 2004, the Personal Information Protection and Electronic Documents Act (PIPEDA) applied to organizations that handle personal information including personal health information, in the course of commercial actives.

To meet the consent requirements set out in PIPEDA, health care providers are required to inform patients of their privacy rights and to provide them with an opportunity to know what personal information is being collected, for what purpose, how it will be used, disclosed, and protected.

In preparation for PIPEDA, Health Canada has engaged in consultation with key national health care provider associations, other government departments and the Office of the Privacy Commissioner of Canada to better clarify how the Act applies to the health sector and to develop tools to assist the health sector in meeting their PIPEDA obligations.

Among these tools, a sample poster and pamphlet were developed. Health care providers will be able to download the information from the Internet and use "as is" or customize as they deem appropriate.

Since the intended audience is the general public, it is important to consult with average Canadians on the sample pamphlet and poster. There is a need to ensure that the poster and pamphlet are easily understood by patients/clients who clearly need to understand the content in order to provide informed/implied consent.

A component of the approved communications strategy is to evaluate/adjust the effectiveness of the outreach activities.

RESEARCH PURPOSE

- To solicit the viewpoint and appropriateness of content of tools developed regarding the privacy of personal health information from Canadians.

Research Objectives

- To assess the level of understanding of these issues outlined in the poster/pamphlet; and,

- To validate the effectiveness of these tools and/or understand what modifications may be necessary.

This research may also assist in the development of a pan-Canadian privacy framework.

METHODOLOGY

Four focus groups were held in Ottawa on February 2nd, 2004 with members the general public residing in the Ottawa-Gatineau region (Aged 18 and over). The groups were segmented by language and level of education (High/low). The groups were one and a half hours in duration and 10 participants were recruited per group for eight to show.

Participants were pre-screened to ensure a good mix of age and gender and to exclude anyone employed in the following areas:

- ☐ In an advertising agency
- ☐ A market research company
- ☐ The media, that is for TV, Radio or a newspaper
- ☐ A graphic design or Web-site design firm
- ☐ In Computer hardware and or software sales
- ☐ The federal government
- ☐ The health care sector (doctor/nurse)

KEY FINDINGS

Management of Personal Health Information

- Overall, participants demonstrated little or no knowledge about recent changes on how personal health information is managed.
- When asked which types of personal information they would regard as the most sensitive, participants tended to identify both their personal financial and health information.
- Participants agreed that it is very important that the personal information they provide to their physician is kept confidential.
- However, few participants exhibited any doubts, worries or concerns over the confidentiality of their personal health information within the hands of their GP. This low level of concern is directly related to their very high level of trust in their personal physician.
- Many participants indicated that they hadn't really considered how their personal information might be shared within the circle of care (primary care providers).
- Following the discussion on how their personal health information might be shared within the circle of care, participants understood the need to do so as part of the treatment process.
- Participants had a limited understanding of how their personal health information could be shared outside the circle of care to third parties such as different levels of government, academics and private companies such as insurance or pharmaceutical companies.
- Participants had a good understanding of why *some* primary care providers must share patient information as part of the treatment process. However, they were less knowledgeable about why others outside the circle of care such as insurance companies, academics or private companies would use their health data.
- When asked, participants are the most comfortable with those involved in primary health care and within the circle of care having access to their personal health information.
- Some participants felt that a secure and centralized database of personal health information should be accessible by physicians to facilitate timely and informed treatment in emergency rooms.
- Participants also tended to feel comfortable with those involved in research intended for the common good (tracking health trends, health planning and the development of new medications) having access to their personal health information, as long as it is anonymous.

- Participants were clearly less comfortable with private companies such as insurance or pharmaceutical firms having access to their personal information.

Consent

- Participant perceptions on the need for consent were influenced by who wishes to access personal health information and the intended purpose of access.
- Participants felt that at least initially physicians should discuss how the patient's personal health information might be shared within the context of care and treatment. Subsequently, most participants felt that consent may be considered as implied or "taken for granted" within the context of treatment.
- Aside from primary care or provincial health plans, participants said that they want to be consulted about any disclosure of their personal health information to those outside the circle of care.
- Many participants had problems with the term "implied consent " and felt that as a term it is too vague and ambiguous. Others felt that implied consent was linked to the assumption that physicians will communicate and exchange information with each other as part of the treatment process.

Perceptions of the Draft Brochure

- Overall, while participants felt that the brochure needed some additional work, they felt that it met their expectations of materials designed inform Canadians on how their personal health information is treated by health care professionals.
- The majority of participants gave the current draft of the brochure a "yellow light"[1] and felt that the brochure is on the right track and that it required some work to fine tune some aspects of the terminology and the amount of information provided to the readers.
- While English participants liked the conciseness, clarity and level of language used in the brochure, the French language participants felt that brochure contained too much information making the information difficult for readers to understand and digest.

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[1] Participants were asked to rate the readiness of the brochure for release by assigning the brochure a green, yellow or red light. A green light indicates that the brochure is ready for release; yellow indicates the brochure is good, but some additional work is required, while red means that the brochure would require have to be redone.

- The most problematic aspect of the brochure was the sections involving consent. Participants found the bullets relating to consent to be confusing and somewhat contradictory. Also, participants did not like or fully understand the terminology "implied consent".
- Concern about how effective the brochure is as a communications vehicle or the amount of brochure information is directly related to the difficulties associated with the issue of the privacy and confidentiality of personal health information. Specifically, the collection, control, disclosure and usage of personal health information. These difficulties include:
  - patient sensitivity to privacy, confidentiality and security;
  - heavy patient reliance on their personal physician to guard their personal health information; and,
  - requirements of end users (Medical research, tracking health trends, the development of new drugs vs. direct marketing) vs. privacy of personal health information.
- In many ways, it would be difficult for a brochure to address and alleviate all concerns that Canadians have about this sensitive issue.
- Participants felt that the readers should be directed to a 1-800 number or web site for further information on how their personal health information is managed.
- Currently, the brochure lacks a strong visual link to the health care sector. A image of a physician and patient provide the brochure with increased credibility, a stronger link to the health care sector

RECOMMENDATIONS

Content:

- State the purpose of the brochure within the context of the new legislation effective as of Jan 1 2004. Rationale will reassure participants that this is a positive and proactive initiative and not a cover up on the part of the government.
- Clearly state that this information targets all Canadians (including landed immigrants).
- Explain why information may be disclosed to others (e.g.: Ministries of Health and others, where required by law) – offer specific examples or circumstances – epilepsy or medical condition induced fainting.
- Be more specific about how assurances offered on last panel on the back of the brochure – participants question how these assurances can be offered or met.
- Boost information about how personal health records may be amended.
- Include more specific information on how a patient may complain. Participants said that it would be difficult to complain to your health care provider about personal health records in their care.
- (French Language Groups) Shorten the amount of information within the brochure.
- Include 1-800 number and web site address.
- Direct readers to 1-800 number or web site for detailed information on how their information is collected, stored, accessed and disclosed.

Boost visual appeal:

- Add additional polish (font type and colour).
- Change colour – moving away from "Tory" blue toward a green based colour scheme.
- Change font of title (brighter and more professional font).

- Break dense text in bullets to increase readability and interest of reader.
- Include picture of physician and patient in consultation on front page (see third bullet below).

Credibility and Stronger Link to Health Sector:

- Include Health Canada and Government of Canada logo/word mark.
- Include logos for health stakeholders' organizations (e.g.: Medical Associations).
- Include a picture of a physician and a patient in consultation to suggest a shared partnership, responsibility and decision-making.

Suggestions for Distribution:

- Through physicians - directly or indirectly (Placed in physician waiting rooms and offices);
- Pharmacies;
- Emergency rooms;
- Any health care providers/clinics; and,
- Direct mail along with government information or health private insurance companies (e.g.: Great West Life).

DETAILED FINDINGS

LEGISLATION: PROTECTION OF PERSONAL HEALTH INFORMATION

Overall, participants demonstrated little or no knowledge about recent changes to how personal health information is managed by health care professionals. One participant indicated that he had discussed how his personal health could be used with his dentist and pharmacist. Another participant discussed PIPEDA, but within the context of his business. This same individual was unaware that it also pertains to his personal health information.

PERSONAL HEALTH INFORMATION AND PRIVACY

Participants were asked to identify what types of information they consider to be personal information. For the most part, participants tended to identify their financial information first, followed by their health information, age, and marital status. When asked which of these types of personal information they would regard as the most sensitive, participants tended to identify both their financial and health information.

Definition of Personal Information

Lower Education

- financial information
- medical information
- criminal information
- ability to obtain life insurance

Higher Education

- name and address
- birth date
- marital status
- medical history
- age
- income
- social insurance number
- credit information/financial history

MANAGEMENT OF PERSONAL HEALTH INFORMATION

Perceptions of Privacy, Confidentiality and Security

Participants were asked what came to mind when they heard the terms privacy, confidentiality and security. Following the assessment of the brochure, participants were asked if their perception of these terms had changed and in most cases they had not.

Privacy

For most, the term privacy represented protection of personal or business information and the sense that personal matters and records are maintained "behind closed doors" and protected.

" *Maintaining records behind closed doors"*

"Ce qu'on est pas prêt a dévoiler au public"

Confidentiality

Participants felt that the term confidentiality represents a written or moral contract (interpersonal or business related), and the sense that personal conversations and personal information such as financial records remain confidential.

" *Something that is my business* "

" *Health and financial information* "

"Reste entre certaines personnes"

Security

This term had a broader connotation among participants. For most, it meant the protection of personal information and financial records. For some, security also meant that access to personal information is limited to those with authorized access. For others, the term security represents the heightened security measures in place since September 11th, 2001. A few said the word security relates to their personal security.

"[Security] Something that is necessary."

"Security of financial/banking information"

"Protéger l'accessibilité, la sécurité au niveau des - transmissions des info"

Participants with a higher level of education felt that the word security also suggests access to computers and electronic databases.

SHARING OF PERSONAL HEALTH INFORMATION

How Personal Health Information is Shared

Primary Health Providers

Participants agreed that it is very important that the personal information they provide to their physician is kept confidential. However, few participants exhibited any doubts, worries or concerns over the confidentiality of their personal health information within the hands of their GP. This low level of concern is directly related to their very high level of trust in their personal physician. Most said that they rely on their personal physician to manage and protect their personal health information.

"I am not worried, my doctors takes care of my personal information"

"My doctor cannot release my personal health information without my consent"

"I trust my doctor and other health care providers"

While most participants shared the same confidence that their physician protects the confidentiality of their personal information, higher education participants were somewhat less trusting and confident about the security of their personal health information.

Access to Personal Health Information

Many participants demonstrated a limited understanding of how their personal health information may be shared within the circle of care (primary care providers) and outside to third parties such as different levels of government, academics and private companies such as insurance or pharmaceutical companies. Participants mentioned that their personal health information might be shared with the following individuals or organizations:

- Other physicians such as specialists;
- Insurance companies;
- Spouse;
- OHIP – provincial health plans;
- Adoption information;

  - Pharmacists; and,
  - Emergency situations (ER/casualty).

When asked, many participants indicated that they hadn't really considered how their personal information might be shared within the circle of care (primary care providers). However, following the discussion on how personal health information might be shared within the circle of care, participants understood the need to share it as part of the treatment process. In fact, some participants felt that a secure and centralized database of personal health information should be accessible by physicians to facilitate timely and informed treatment in emergency rooms.

"In emergency situations, I think that emergency room doctors should be able access centralized health records for information on patients"

Outside of the circle of care, many participants had a limited understanding of how their personal health information could be shared with third parties such as different levels of government, academics and private companies such as insurance or pharmaceutical companies.

Among those who are more knowledgeable about how health information may be used, they recognized the need to reimburse provincial health plans, track health trends and develop new drugs. These same participants were more likely to be sceptical about how private corporations access and use personal health information and felt that companies could primarily be motivated by monetary/profit considerations.

"Private firms might use the information for statistical research to track our health and develop health plans"

"Government needs health information for future planning, OHIP, health trends and research"

"Drugs firms want our personal information for direct marketing"

Comfort with Disclosure of Personal Health Information

When asked, participants are the most comfortable with those involved in primary health care and within the circle of care having access to their personal health information. Comfort with this type of access is tied to their trust in their personal physician as well as their sense that it only makes sense to share their personal information within the circle of care (specialists, MRI clinics, OHIP).

"It is okay as long as it is for your benefit"

"OHIP – well it is automatic"

"Those involved in primary care – like other doctors"

Participants also tended to feel comfortable with those involved in research intended for the common good (tracking health trends, health planning and the development of new medications). These organizations included government agencies, academics and pharmaceutical firms. However, comfort with this process is directly tied to the requirement that their personal identifiers must be stripped from their health data.

"It's okay [access to personal health information] - as long as it is used for statistics for research"

Participants were clearly less comfortable with private companies such as insurance or pharmaceutical firms having access to their personal information. Participant discomfort is linked to their concern that the insurance companies could deny coverage to individuals or raise insurance rates based on their health record, or that pharmaceutical companies could direct market to vulnerable members of our society (the elderly or the chronically or terminally ill). These companies were regarded as profit driven and not concerned about patient care.

"Pharmaceutical firms [access]? No, it's just for profit"

CONSENT

Need to Know and Control Access to Personal Health Information

When asked, participants said that it is important that they "know and control" how their personal health information is disclosed. However some participants demonstrated low awareness regarding how much they are entitled to access or control. This may be a possible consequence of heavy patient reliance on their personal physician for the management of their personal health information, or their deference to physicians in general.

"It is very important"

" I hadn't thought about it until now – I don't know who I would ask"

"I have confidence in my doctor"

Some participants were less trusting of those outside the circle of care such as government agencies, researchers or private corporations. Unlike personal physicians and other care providers, participants demonstrated less trust in these organizations and questioned whether they would handle personal health information as responsibility as health care providers.

"Are they [outside firms] responsible enough to take care of my health information?"

Need for Consent

Participant perceptions on the need for consent were influenced by who wishes to access personal health information and the intended purpose of access.

Participants felt that at least initially physicians should discuss how the patient's personal health information might be shared within the context of care and treatment. Subsequently, most participants felt that consent may be considered as implied or "taken for granted" within the context of treatment.

"The first time we should be asked for consent"

"I only want to be asked the first time – afterwards, you are granting the doctor consent by seeking treatment"

Aside from primary care or provincial health plans, participants said that they want to be consulted about any disclosure of their personal health information to those outside the circle of care. Also, they felt that personal identifiers should not be included with data sent on to others for research purposes such as tracking health trends. Again, they do not want end users of personal health data to have the ability to track back patient identity.

"It is okay for statistics – as long as it is anonymously done"

"It depends on the type of information being asked for and by whom"

"I want to be asked [sometimes] when it would involve disclosure of my personal information for a study"

"I always want to be asked or at least advised when it going outside the circle of care"

Most participants felt that regardless of the issue of consent or of who the personal health information might be released to, that only information relevant to the request (e.g. health condition) and not the entire medical record should be released. This condition pertains to specialists, physiotherapists and pharmacists as well as government agencies, studies and insurance companies.

"Patients should discuss the level of disclosure with their physician"

Implied Consent

Many participants had problems with the term "implied consent " and felt that as a term it is too vague and ambiguous. Others felt that implied consent was linked to the assumption that physicians must communicate and exchange information with each other as part of the treatment process. Some questioned how "implied consent" could be defined, limited or controlled. There was support for written consent among the participants, rather than implied or verbal consent. Participants felt that these later two forms of consent could be difficult to verify at a later date.

"Implied consent is a grey area"

"Is it general consent? Then everyone could know everything"

"C'est trop vague, c'est dangereux"

"Il y a pas vraiment des consentements implicites"

However, on further discussion of how and when consent should be sought, participants felt that it is reasonable to expect that consent may be implied after a patient seeks treatment from a physician and as part of the treatment process where other health care professionals are involved.

"If you trust the doctor and understand that information should be accessed"

"If you are consent to see a specialist – then you are consent is implied"

PARTICIPANT DESIGNED MATERIALS

Participants felt that materials intended to inform Canadians on how their personal health information is treated by physicians should include the following:

- Definition of personal health information;
- Information on who has access to personal health information;
- Information on how personal health information is stored, protected and used by end users; and,
- Security of centralized health information data banks.

Participants felt that the federal government and provincial governments are responsible for informing Canadians on how their personal health information is treated. The provincial government is regarded as having a "closer to the ground" relationship with health care providers, while the federal government, particularly Health Canada is seen as having a responsibility for developing and overseeing national standards for protecting personal health information.

ASSESSMENT OF PROPOSED BROCHURE

Overview

Overall, while participants felt that the brochure needed some additional work, they felt that it met their expectations of materials designed inform Canadians on how their personal health information is treated by health care professionals. Participants regarded the brochure as an appropriate and worthwhile initiative.

"It is reasonable and very clear"

"It is well written and informative"

"It is meant to increase our understanding of how our health information is disclosed"

"It is on the right track, but needs some clarification"

"L'intention est de rendre confiance aux gens au niveau de la santé."

"L'idée est bonne... tout le monde la ramasserait."

The majority of participants gave the current draft of the brochure a "yellow light"[2] and felt that the brochure is on the right track and that it required some work to fine tune some aspects of the terminology and the amount of information provided to the readers.

A good proportion of participants gave it a "green light" and felt that the brochure is well written, informative and user friendly. Only 3 of the 30 participants gave it a "red light".

"Concise, clear, but there is some awkward terminology"

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[2] Participants were asked to rate the readiness of the brochure for release by assigning the brochure a green, yellow or red light. A green light indicates that the brochure is ready for release; yellow indicates the brochure is good, but some additional work is required, while red means that the brochure would require have to be redone.

"There are a couple of things I didn't like. - It needs contact information"

While English participants liked the conciseness, clarity and level of language used in the brochure, the French language participants felt that brochure contained too much information making the information difficult for readers to understand and digest.

"C'est clair, mais c'est trop lourd"

"On n'a pas de temps pour lire tout ça"

Overall, most participants tended to rate the brochure favourably across the attributes of believability, appropriateness, relevance and interest. Yet, they were less likely to rate the brochure as highly as an effective communications vehicle, or whether it has enough information to help them understand how their personal health information may be used, or whether it increased their confidence in how their personal health information is being treated.

"It is contains believable information"

"It is easy to read and understand"

"It isn't clear on how I can be assured [about how my information is protected]"

"There are not big words - it is simple"

" *Une brochure n'est pas suffisante, sujet trop délicat - met plus d'argent que juste une brochure"*

Concern about how effective the brochure is as a communications vehicle or the amount of brochure information is directly related to the difficulties associated with the issue of the privacy and confidentiality of personal health information. Specifically, the collection, control, disclosure and usage of personal health information. These difficulties include:

- patient sensitivity to privacy, confidentiality and security;
- heavy patient reliance on their personal physician to guard their personal health information; and,

- requirements of end users (Medical research, tracking health trends, the development of new drugs vs. direct marketing) vs. privacy of personal health information.

In many ways, it would be difficult for a brochure to address and alleviate all concerns that Canadians have about this sensitive issue.

"Ca a soulevé plus de questions que de réponses."

Participants felt that to a certain extent that patient anxiety or uncertainty on this issue could be alleviated by additional contact information such as a 1-800 number or web site information. They felt that readers should be directed to the 1-800 number or a web site for additional information on their personal rights regarding how their personal information is accessed and used. This added feature would also serve to provide additional information on how and where to complain about the accuracy of their health record or how their personal health information is managed by their health care professional.

Assessment of Draft Brochure

Participants took part in an exercise where they were asked to highlight areas of the brochures that they liked or understood in *green* and those that they found to be less clear or understandable in *red*. The table below sets out areas in which participants had the highest incidences of green or red marker. Participant concerns about the highlighted areas follow the table below.

Section	Green	Red
Front Page		Nothing highlighted
Left-hand panel on inside	What is my personal health information	Density of paragraphs within "What is my personal health information section"
		Knowing what is in your health record and understanding how your personal health information is used.
Middle Panel	"Making informed decisions regarding disclosure to others.	Section on implied consent **(Most problematic section)**
		Section on how your personal information will not be disclosed to anyone not directly involved in your care and treatment...social workers, physiotherapists, nutritionists and other health care professionals.
Right-hand panel on side of brochure	"What are your rights?	Some of your personal information may be released without your consent.... where it is required or authorized by law.
		Information on how health information is stored electronically.
Back panel	Entire section	Minimum fee

Section	Green	Red
		Bullets involving assurances on how your personal health information is safeguarded and protected.
		Accuracy – how information can be amended.
		Complaint section. No information on where and how to complain.

Front Cover

Some participants felt that the front cover of the brochure was appealing: good title and strong front page. However, several felt that the colour could be boosted and suggested moving toward a green-based colour scheme. Also, some felt that the brochure lacked polish and a strong link to the health sector.

"It has a good title and a strong front page"

"It needs to be linked to the health sector"

"The font isn't professional"

"Boring – the look is boring"

"This blue – suggest "Tory" blue – I don't think the government wants to do that"

Inside Left Panel

Participants generally approved of the information contained on the inside left panel of the brochure detailing "What Is My Personal Information?" Some participants suggested breaking that information into bullets to increase the amount of white space, visual appeal and readability of the section.

"This section needs more white space – there is a lot of text and the information should be itemized and broken into bullets"

Inside Middle Panel

Within the inside middle panel of the brochure, participants approved of the section further detailing the benefits of knowing what is contained in personal health records (accuracy and understanding for who has access to personal health information) and informed decisions about disclosures to others. By far, the most problematic section of the brochure involved "implied consent". Few participants approved or entirely understood the term "implied consent".

"The paragraphs on consent are contradictory – permission vs. no permission?"

"Trop de répétition, une contradiction"

"Je ne veux pas que mes informations soient divulguées sans mon consentement."

"Je veux être capable de dire oui ou non et dire quelle information je donne."

Some participants also expressed discomfort with the disclosure of their personal health information to the broad range of "others" involved in primary care as detailed in this section. In some ways, it was almost too much information for some participants.

Right Inside Panel

On the right inside panel, participants expressed concern about how their personal health information could be released without their consent to others (e.g.: Ministries of Health). Participants felt that including an example of these circumstances could alleviate patient concern about this provision.

"Need to explain why the information is being disclosed"

"Presque excellente, très clair la seule chose - qu'elle situation la loi l'autorise?"

Some participants felt that the information contained in the bullets covering consent and disclosure of personal health information were contradictory (consent implied, consent required or no consent required in some circumstances?) Also some participants felt the brochure lacked information on the consequences of refusing to consent to the disclosure of their personal health information.

Outside Left Panel

On the left outside panel, participants felt that the bullets involving assurances on the protection of personal health information (regardless of format) and access should include an explanation of how these assurances could be met. Participants also questioned how patients could ascertain the accuracy of their personal health information and how they could complain about their health record to their personal physician. Many felt that patients should be provided with information on how to complain to a third party authority. Also, some participants were not happy about the minimum fee charged for copies of personal health records.

Participant Suggestions

The following section details how participants suggested the brochure could be improved.

Content:

- State the purpose of the brochure within the context of the new legislation effective as of Jan 1 2004. Rationale will reassure participants that this is a positive and proactive initiative and not a cover up on the part of the government.
- Clearly state that this information targets all Canadians (including landed immigrants).
- Explain why information may be disclosed to others (e.g.: Ministries of Health and others, where required by law) – offer specific examples or circumstances – epilepsy or medical condition induced fainting.
- Be more specific about assurances offered on last panel on the back of the brochure – participants question how these assurances can be offered or met.
- Boost information about how personal health records may be amended.
- Include more specific information on how a patient may complain. Participants said that it would be difficult to complain to your health care provider about personal health records in their care.
- (French Language Groups) Shorten the amount of information within the brochure.
- Include 1-800 number and web site address.
- Direct readers to 1-800 number or web site for detailed information on how their information is collected, stored, accessed and disclosed.

Boost visual appeal:

- Add additional polish (font type and colour).
- Change colour – moving away from "Tory" blue toward a green based colour scheme.
- Change font of title (brighter and more professional font).

- Break dense text in bullets to increase readability and interest of reader.
- Include picture of physician and patient in consultation on front page (see third bullet below).

Credibility and Stronger Link to Health Sector:

- Include Health Canada and Government of Canada logo/word mark.
- Include logos for health stakeholders' organizations (e.g.: Medical Associations).
- Include picture of physician and patient in consultation to suggest a shared partnership, responsibility and decision-making process.

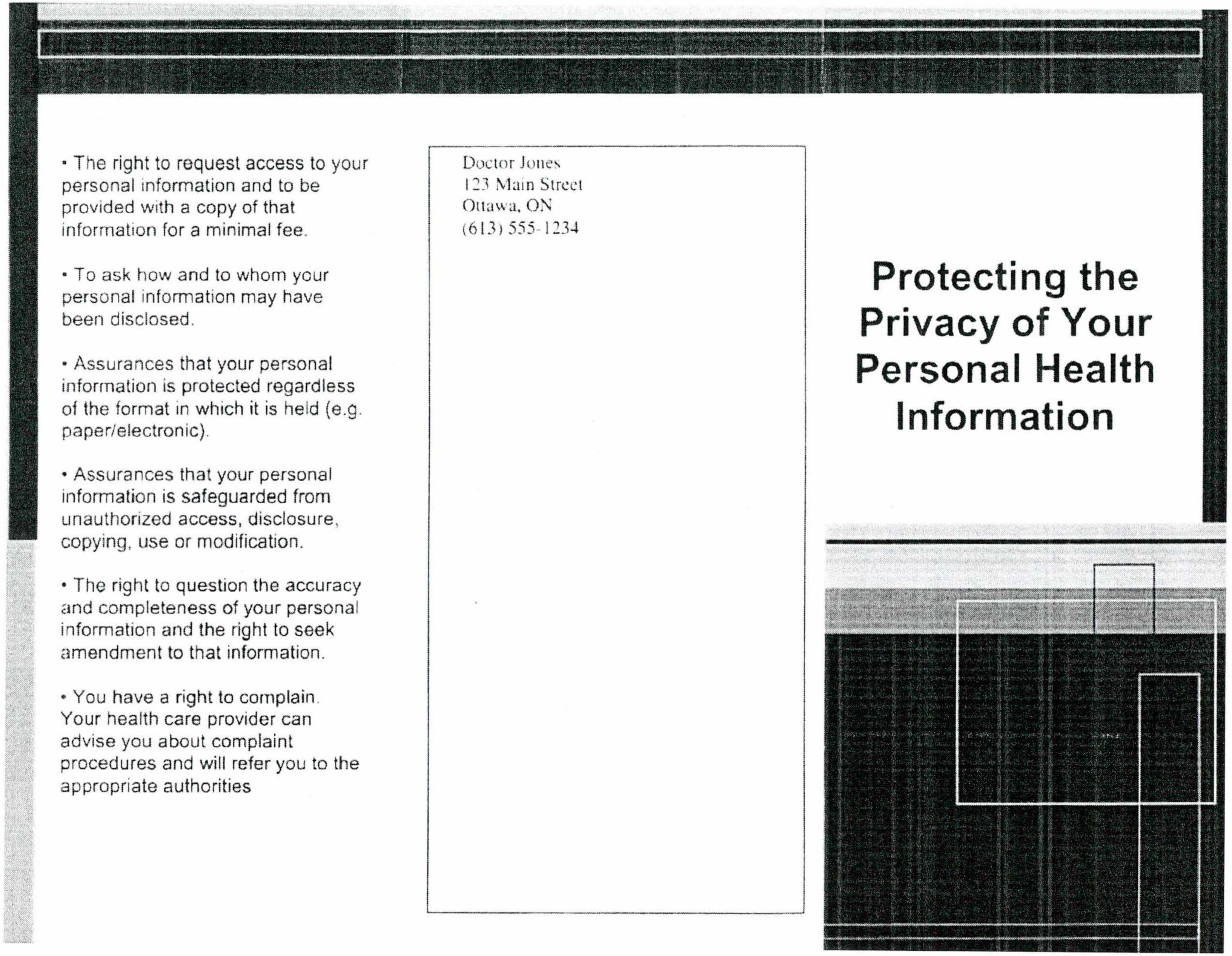
Suggestions for Distribution:

- Through physicians - directly or indirectly (Placed in physician waiting rooms and offices);
- Pharmacies;
- Emergency rooms;
- Law courts'
- Any health care providers/clinics; and,
- Direct mail along with government information or health private insurance companies (e.g.: Great West Life).

Assessment of Proposed Poster

Participants were shown one poster, which contained an outline of the information contained in the brochure. Overall, the poster was well received by the participants and was regarded as a good companion/introductory piece for the brochure. Participants indicated that it was visually appealing and that it contained the right amount of information. Most said that they would read it and suggested that it be placed in physician waiting rooms and offices along with the brochure. Participants felt that readers should be directed to additional information via a 1-800 number and web site. Like the brochure, participants felt that a stronger link to the health sector should be made and that credibility should be increased through the inclusion of logos as suggested in the brochure section of this report.

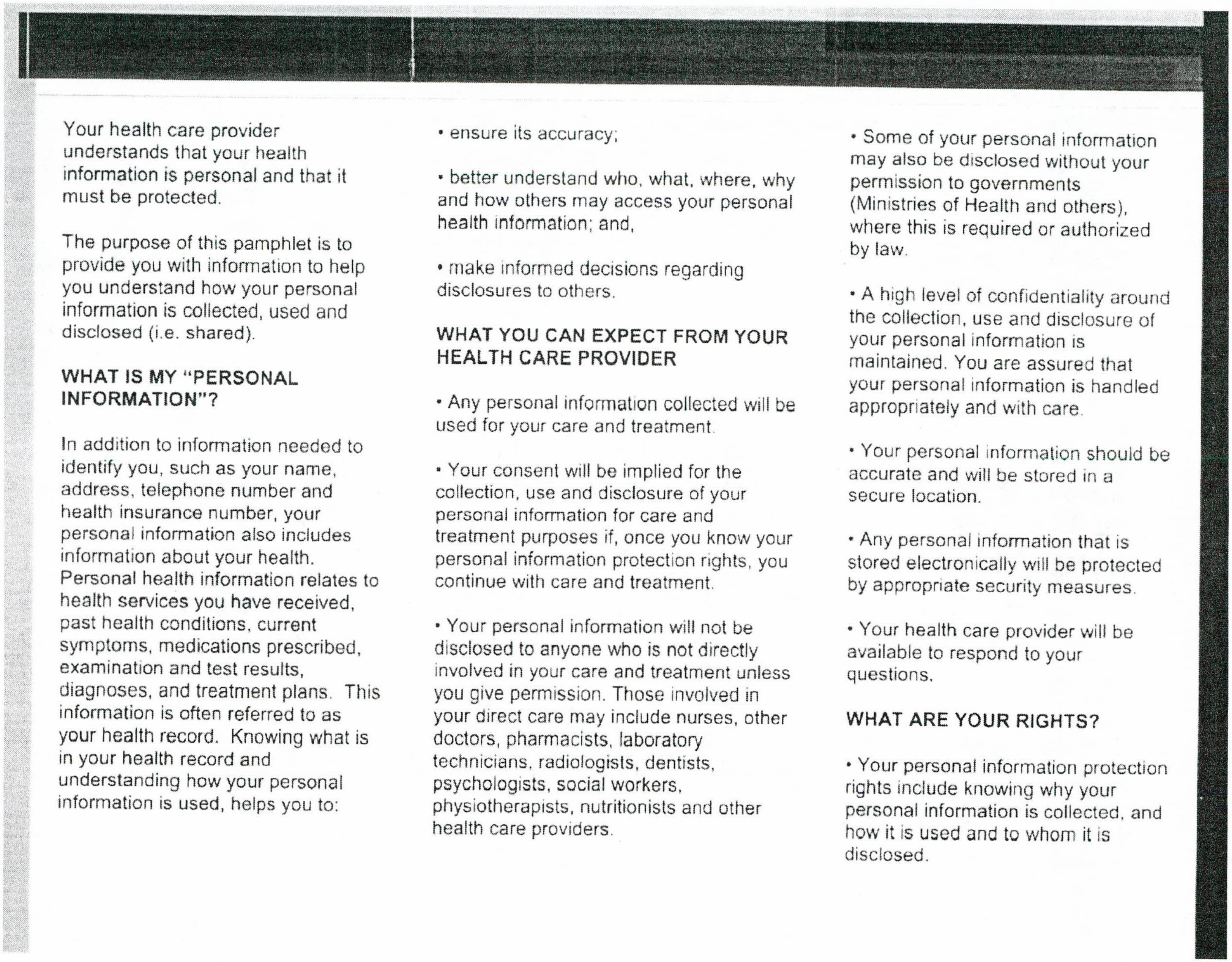
APPENDIX I – POTENTIAL PRINT MATERIALS



- The right to request access to your personal information and to be provided with a copy of that information for a minimal fee.
- To ask how and to whom your personal information may have been disclosed.
- Assurances that your personal information is protected regardless of the format in which it is held (e.g. paper/electronic).
- Assurances that your personal information is safeguarded from unauthorized access, disclosure, copying, use or modification.
- The right to question the accuracy and completeness of your personal information and the right to seek amendment to that information.
- You have a right to complain. Your health care provider can advise you about complaint procedures and will refer you to the appropriate authorities

Doctor Jones
123 Main Street
Ottawa, ON
(613) 555-1234

Protecting the Privacy of Your Personal Health Information



Your health care provider understands that your health information is personal and that it must be protected.

The purpose of this pamphlet is to provide you with information to help you understand how your personal information is collected, used and disclosed (i.e. shared).

WHAT IS MY "PERSONAL INFORMATION"?

In addition to information needed to identify you, such as your name, address, telephone number and health insurance number, your personal information also includes information about your health. Personal health information relates to health services you have received, past health conditions, current symptoms, medications prescribed, examination and test results, diagnoses, and treatment plans. This information is often referred to as your health record. Knowing what is in your health record and understanding how your personal information is used, helps you to:

- ensure its accuracy;
- better understand who, what, where, why and how others may access your personal health information; and,
- make informed decisions regarding disclosures to others.

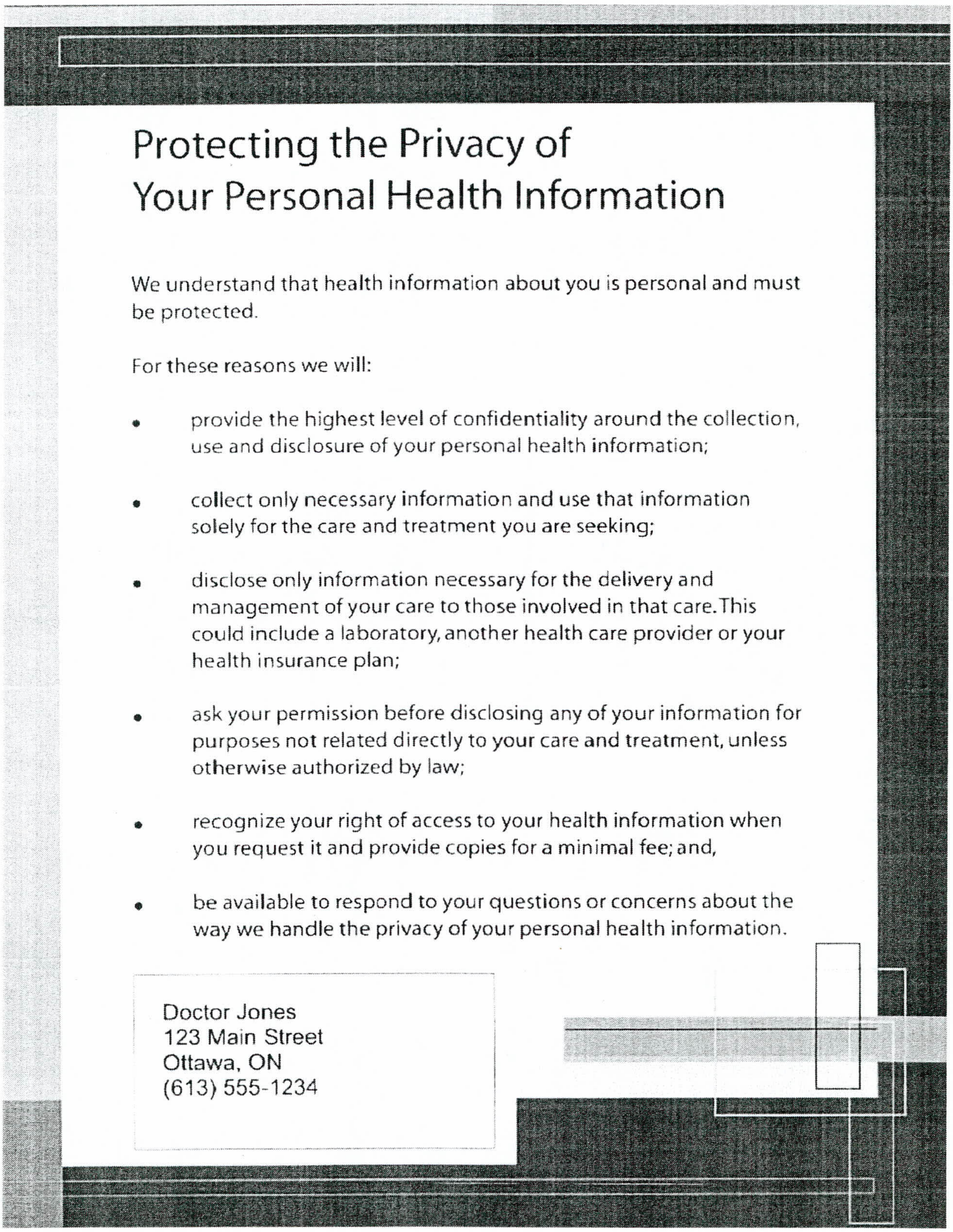
WHAT YOU CAN EXPECT FROM YOUR HEALTH CARE PROVIDER

- Any personal information collected will be used for your care and treatment.
- Your consent will be implied for the collection, use and disclosure of your personal information for care and treatment purposes if, once you know your personal information protection rights, you continue with care and treatment.
- Your personal information will not be disclosed to anyone who is not directly involved in your care and treatment unless you give permission. Those involved in your direct care may include nurses, other doctors, pharmacists, laboratory technicians, radiologists, dentists, psychologists, social workers, physiotherapists, nutritionists and other health care providers.
- Some of your personal information may also be disclosed without your permission to governments (Ministries of Health and others), where this is required or authorized by law.
- A high level of confidentiality around the collection, use and disclosure of your personal information is maintained. You are assured that your personal information is handled appropriately and with care.
- Your personal information should be accurate and will be stored in a secure location.
- Any personal information that is stored electronically will be protected by appropriate security measures.
- Your health care provider will be available to respond to your questions.

WHAT ARE YOUR RIGHTS?

- Your personal information protection rights include knowing why your personal information is collected, and how it is used and to whom it is disclosed.

Poster



Protecting the Privacy of Your Personal Health Information

We understand that health information about you is personal and must be protected.

For these reasons we will:

- provide the highest level of confidentiality around the collection, use and disclosure of your personal health information;
- collect only necessary information and use that information solely for the care and treatment you are seeking;
- disclose only information necessary for the delivery and management of your care to those involved in that care. This could include a laboratory, another health care provider or your health insurance plan;
- ask your permission before disclosing any of your information for purposes not related directly to your care and treatment, unless otherwise authorized by law;
- recognize your right of access to your health information when you request it and provide copies for a minimal fee; and,
- be available to respond to your questions or concerns about the way we handle the privacy of your personal health information.

Doctor Jones
123 Main Street
Ottawa, ON
(613) 555-1234

APPENDIX II - MODERATOR'S GUIDE

INTRODUCTION (5 MINUTES)

- Explain to participants:
- introduction to Ipsos-Reid
- the length of session (1.5 hours)
- taping of the discussion
- some colleagues viewing but they will not be taking part in the discussions
- results are confidential and reported in aggregate/individuals are not identified/participation is voluntary
- this group is being sponsored by Health Canada. .
- the role of moderator is to ask questions, timekeeper, objective/no vested interest
- role of participants: no need to reach consensus, speak openly and frankly about opinions, no right/wrong answers

WARM- UP – 20 minutes

Note to Moderators: Definitions for some terms used within group are included on the last page of the guide

1abc
- What do you consider to be personal information? 1a [Information that is most likely to 1b be regarded as somewhat private]? Probe: privacy, confidentiality and security. 1c + definitions 1d. 1e 1f. end. P3A

2ab.
- How important is it to you, that the personal information you provide your physician is kept confidential? 2a Is this something you are concerned about? 2b

3ab.
- As far as you know, who would your personal physician share your health information with? – 3a [PROBE: Other health care professionals, governments for health planning, private companies such as pharmaceutical companies or insurance companies] – 3b

4a→[illegible]
- Why would other organizations (people) need access to your personal health information – 4a [PROBE: PURPOSE – Medical treatment, provincial health plan, insurance companies, health statistics - academics or pharmaceutical companies – 4b research for medical research, development of new drugs or marketing]?
  - Which of these organizations or purposes are you the **most comfortable** with? 4c The **least comfortable** with? [PROBE: those involved in delivery of primary care, compared to governments 4d or companies – research 4e compared to marketing] Why? 4f

  - How important is it for you to know and control how your health information is disclosed (i.e. shared with others)? 4g
  - Thinking about consent, before releasing personal information to someone outside their medical practice, how often do you think health care professionals should <u>ask their patients for consent?</u> (Initially, only as required or always) 4h

8

5 - Does it depend on whom it will be released to?
6 - On the type or the extent of information requested? 7a
7ab - What does the term implied consent mean for you? [We will need a definition to probe their views on this after the initial prompt] *<u>Issue of always asking for consent interfering with provision of service?</u>* 7b
8a→d - Have you seen, read or heard anything lately 8a regarding steps taken to protect Canadians personal **health** information? Where did you (see, read or hear) about steps taken to protect personal **health** information? 8b What have you heard? 8c Are you reassured by this, or is a bit of overkill? 8d

<u>INTRODUCTION TO EVALUATION OF MATERIALS</u>

Participant Designed Information Materials – 10 minutes

- Currently, the federal government and other key health care stakeholders are developing materials to assist health care providers to inform Canadians about how their personal health information will be treated by physicians.
- Tonight we are going to examine some possible materials that are designed to provide Canadians with this information.
- 9a→d Before we do that, I would like to know if you were in charge of developing such materials what would they look like? 9a
  - What type of information should they include? 9b Anything else? 9c
  - Who is responsible for providing Canadians with information on how their personal health information is treated? 9d

Brochure Testing "Protecting the Privacy of Your Health Information" - 35 minutes

- Now, I am going to hand out a draft of a brochure and I would like to get your views on it. I will give you a few minutes to read through it and to fill out a short questionnaire.
- Also, I would like each of you to use a green marker to highlight the parts that you like or agree with, or that are clear and easy to understand, and use a red marker to highlight any sections or any parts that you do not like or do not agree with or that are not as clear and easy to understand.

- Please feel free to write additional comments on the brochure.

General Probes

10a→c ③
- Before we go through the brochure, I would like you to think about when we talked about what your materials would look like. Tell me does this meet your expectations? 10a Why? 10b Why not? 10c

11a→c ③
- What are your views overall? 11a Likes? 11b Dislikes? 11c

12a→g ⑦
- How did you answer the questionnaire? (Overall design, 12b Believable? 12c Appropriate? 12d Relevant? 12e Informative? 12f Interesting?) 12a 12g

13
- Would you read it?

14ab ②
- Thinking about the terms, confidential, privacy and security? Has your perception of 14a these terms changed after reading this material? How so? 14b

15a→e ⑤
- What would be the best way for physicians to distribute this brochure to patients? 15a
  - Would you call the 1-800 number for more information? 15b If so, what information would you ask about? 15c
  - Would you visit the web site for more information? 15d If so, what information would you look for? 15e

16a→c ③
- Is there anything you would like to see added to the brochure? 16a Any information? 16b Any creative suggestions? 16c

17
- Green/yellow/red light?

Poster – 10 minutes

- Health Canada is considering using a poster to inform Canadians about how their personal health information is used. [SHOW POSTER]

③ 18abc
- What do you think about the poster? 18a Would it catch your attention or just part of 18b the blur in the doctor's office? Likes/dislikes? 18c

19
- Informative? 19

20a→d ④
- What about the tag line [READ TAGLINE]. 20a What do you think when you read this 20b tag line? Catchy? 20c Effective? 20d
- **Suggestions?**

21
  - Green/yellow/red light?

CONCLUSION (10 MINUTES)

22 - As a result of this exercise, has your opinion changed on how your personal health information should be released and to whom?
23 - Why do you say that?
24 - Do you have any other comments on the issues we discussed this evening?

Thank you

Definitions

1d. Privacy: The fundamental right to control the collection, use, and disclosure of information about ourselves.

1e Confidentiality: The obligation of a custodian to protect personal information and not misuse or wrongfully disclose it.

1f Security: The process of assessing threats and risks to information and taking steps to protect it.