Health Canada Santé Canada

Health Canada's
Office of Consumer and Public Involvement

and

Best Medicines Coalition (BMC)

Consultation Workshop Report on Patient Involvement Strategy

December 13, 2002
Ramada Hotel and Suites
Ottawa, Ontario

INTERSOL

Canada

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EXECUTIVE SUMMARY

Health Canada's Office of Consumer and Public Involvement recently convened a workshop involving Health Products and Food Branch (HPFB) staff and the Best Medicines Coalition (BMC). Health Canada was consulting the Best Medicines Coalition on options for involving the patient communities in the Therapies Review System and the development of HPFB policies.

The workshop produced several key recommendations to HPFB from BMC participants including:

1. Use BMC as an umbrella group in its patient consultation strategy. BMC would not be an *exclusive* source of patient advice, but does represent a wide cross-section of key patient groups.
2. Health Canada should consult with patients suffering from acute and short-term illnesses, as well as healthy people trying to prevent illness.

In addition, HC and BMC participants agreed on several overarching principles that could serve as criteria for selecting consultation *mechanisms* or *options* to engage patients.

These principles included:

1. Meaningful participation
2. Targeted consultation
3. Build trust
4. Commitment to action
5. Transparency
6. Innovation
7. Evaluation / Accountability
8. Dealing with constraints
9. Mutual respect
10. Patience
11. Appropriate communications
12. Sustainability

All participants at the workshop felt the dialogue had been worthwhile, and that significant progress had been made on the workshop objective. Much goodwill was expressed on both sides and a "next steps" path forward was developed. Discussions will continue and a follow-up meeting is planned for Spring/Summer 03.

INTRODUCTION / OVERVIEW

The Best Medicines Coalition Consultation Workshop was held in Ottawa on Friday, December 13, 2002 to review consultation options for involving the patient community (ies) in *relation* to the Therapies Review System and Health Products and Food Branch (HPFP) *policies*.

The delegates from the Best Medicines Coalition and patients were:

- Kathy Kovacs Burns — Canadian Diabetes Association, co-chair of the Coalition
- Denis Morrice — The Arthritis Society, co-chair of the Coalition
- Deanna Groetzinger — Multiple Sclerosis Society of Canada
- Cheryl Koehn — Arthritis Consumer Experts
- Lynn Macdonald — Breast Cancer Advocate
- Jean Légaré — Canadian Arthritis Patient Alliance
- Rolph Calhoun — Canadian Association for the Fifty-Plus
- Patrick McIntyre — Canadian AIDS Society
- Jane Hamilton — Best Medicines Coalition
- Shawna Krebs — HepCURE
- Susan Jones — Canadian Arthritis Patient Alliance

The delegates from Health Canada were:

- Roger Farley — Director General, Office of Consumer and Public Involvement
- Sylvie Cantin — Director, Public Involvement and Outreach – OCAPI
- Jacinthe Guindon — A/Outreach Coordinator – OCAPI
- Mary Raphael — Project Manager, Policy Bureau, Therapeutic Products Directorate
- Linda Searson — A/Project Manager, Center for Policy and Regulatory Affairs, Biologics and Genetic Therapies Directorate
- Bill Leslie — Senior Advisor, Marketed Health Products Directorate
- Tilak Gunawardhane — Outreach Officer – OCAPI

Dr. Janet King, Senior Director General, Health Products and Food Branch, welcomed delegates on behalf of Health Canada.

The session was facilitated by Warren Wilson, Intersol Consulting Associates Ltd.

This report summarizes the discussions held at the workshop, the processes followed and outcomes achieved, and lists the action steps identified to ensure that the outcomes of the workshop are leveraged effectively within the Office of Consumer and Public Involvement (OCAPI).

GETTING STARTED

Opening Comments

Dr. Janet King, Sr. D.G. HPFB, opened the workshop and welcomed participants. Dr. King spoke to the workshop purpose and noted that Branch leadership was committed to developing more optimal approaches for consulting with Canadian patients. Dr. King welcomed the opportunity to develop a relationship with BMC.

Denis Morrice and Kathy Kovacs Burns welcomed participants on behalf of BMC. Both also welcomed the opportunity to work with HPFB/HC toward developing a model or strategy that will appropriately engage the patient community. BMC had just met with Health Minister and praised the partnership developed with OCAPI.

Context/Boundaries

Roger Farley, D.G. OCAPI, made a more formal opening presentation aimed at setting the context for discussions. Roger reviewed HPFB's mandate, role in HC, organizational architecture and challenges. A copy of Rogers' presentation was provided to participants and is included in Appendix A.

HPFB ISSUES REQUIRING PATIENT INVOLVEMENT

The group reviewed a current list of HPFB issues or initiatives. This list, which is included as Appendix B, represents broad, current areas of focus for the Branch. Following clarification of the list, participants were asked if there were any issues missing – additional areas where patient involvement might be advantageous?

The following issues were identified:

- Coverage/access to over-the-counter drugs and herbal products such as Sunrider natural products.
- Research in all the categories – consent and ethical process for evidence-based decisions, qualitative and quantitative.
- Process for practice-based research – gathering of qualitative evidence.
- Encouraging and facilitating knowledge transfer among practitioners – doctors, nurses, health providers (This is linked to point 14, communicating drug safety information to the public).
- Under number 11:
    1. Information on product monographs that go to physicians – making sure that is given to patients; reporting on adverse reactions to products; marketed health products directorate.
    2. Important to build in a patient information section.
- Prescription process between physicians and patients: teaching patients and physicians how to interact better. There is another Branch in Health Canada that leads the work with practitioners, the Health Policy and Communications Branch, and would be better positioned to address this issue. The suggestion was made that OCAPI take the lead on dealing with issues like this one that cross over jurisdictions, because the public really doesn't care who it belongs to, they want their issues addressed.
- Design of clinical trials (linked to # 8, but separate), including accessing clinical trials by patients, ethical considerations, and liability issues.
- Communicating with patients about consultation – must communicate in a way that reaches them. Use real, plain language, not jargon.
- Information on the role of the Branch in the various areas of regulation, policy and inspection.

The question of prioritization of issues was then explored. The following points were raised:

- Some initiatives are one-offs, others are ongoing. The one-offs require shorter, more intense involvement, possibly followed by communication to inform patients on the outcomes of the consultation.
- The relative importance of the initiatives depends on the individual – each individual will attach importance differently based on his/her issues or concerns and advocacy group. There are some initiatives that would probably be identified as cross-cutting because they are of concern to many individuals and groups.
- OCAPI could use BMC as a sort of review body or clearing house, so that as each issue comes up, you have a body that can say – Who and how to consult the patient community.

This is an emerging recommendation from the group: use BMC as an umbrella group in its patient consultation strategy – not the exclusive source of advice.

- Consultations that have worked in the past are those where target groups were brought in at the beginning to help shape the consultation, as opposed to back-end consultation with no involvement. Input to the consultation process should also be meaningful. Question: Who gets to determine the lesser and the greater degree of consultation? If BMC is not a part of that determination, can it be?
- Another suggestion to prioritize the list was analogous to Maslow's hierarchy of needs. The most *basic* issues are linked to patient safety and access to medicine. Next in the hierarchy are *proactive* actions to prevent increasing problems with a disease and finally *research*. Initiatives 1-26 appear to link well and belong in the basic level.

Participants were also asked to individually prioritize the list of issues as additional information for HPFB to help them in identifying high priority issues for consultation. The idea behind lists and prioritization is to try to deal with "consultation fatigue", and talk to the right people at the right time.

Once the list of initiatives is prioritized, additional dialogue may be required to identify specific issues or processes, which will be of particular interest for BMC.

WHO IN THE PATIENT COMMUNITY DO WE NEED TO CONSULT WITH?

The group next dealt with the question of *Who* in the patient community (ies) HPFB would need to consult with on the issues identified. A partial list of so-called "umbrella" organizations was identified as follows. This partial list includes organizations currently being invited by OCAPI:

- Consumers Association of Canada.
- Canadian Council on Multicultural Health / Canadian Ethno-cultural Council .
- Consumers Council of Canada.
- Option Consommateurs in Québec.
- Women and Health Protection, linked to Centers of Excellence for Women.
- YouCan.
- Fédération des communautés francophones et acadiennes.
- Québec Community Group Network.

This led to a discussion on the definition of *patient:*

- Chronic Patients - "Individuals who are trying to access best medicines in terms of treating chronic illnesses or conditions". Chronic in this context is *long term*, incurable illness, i.e. years in duration, in many cases life-long. The BMC is "Committed to people-centered access to the best medicines" and focussing on chronic patients.
- *Acute* patients - Patients with illnesses that are of some duration (medium term – months/years), but who generally have illnesses that are more curable than chronic patients. eg. Cardio vascular patients.
- People with *short* term illness – curable illness eg. The flu.
- Healthy people trying to prevent illness (by taking medicine/health products i.e. to reduce blood pressure or lower cholesterol).

Participant's advice to Health Canada is to consult with people from all of these patient groups to get the best perspective.

Who speaks for whom can be contentious. Each group has a mission. Since no single group represents the broader patient population, it is difficult to consult with them.

BMC's vision and mission is specific to the patient consultation topic, and this may make BMC more appropriate to represent the Canadian patient population. There are differing points of view, however, as to whether BMC could / should represent all of the groups described above.

BMC can represent chronic and acute patients, and a sub-set of the short term and even healthy patient groups, but its members may have a different view from people who are not dealing with chronic or acute illness.

- Patients with chronic illness often have to take the same medicines as patients who only deal with acute illness. They may, however, have a different perspective – there appears to be a philosophical split in the general population in terms of risk tolerance, with chronic patients tending to tolerate higher levels of risk because of their condition.
- An example where patients of chronic illness might differ from the general population is in the introduction of new drugs sometimes labelled "Me-too" drugs – drugs that fit in the same category as other drugs because they treat the same illness: the general public might want to genericize them or resist the introduction of a new drug, but patients dealing with chronic illness would want the new drug because they have had experience where one drug works with one patient but not another and vice-versa.

- What do we define as risk? Side effects? If defined in specific ways, it might be easier to differentiate. *Trade-offs* may be a better term than *risks*. People with chronic illness have to weigh everything. Some days they may not feel ready to take a risk either – their risk tolerance can vary over time.

BMC has a stake in many of the issues HPFB is dealing with, whereas the general consumer would have a stake in a smaller number of issues. Some of the points made in this respect include:

- One example of an issue that would interest the general public as well as BMC would be Direct to Consumer Advertising.
- There are drugs that are breakthrough, leading edge, versus others that are taken by the general public. This might be another criteria for differentiating consultation. Almost like therapeutic classes; general population, then disease-specific.
- Biologics and genetic therapies, therapeutic products, natural health products and marketed health products appear to be of particular interest to BMC.
- BMC represents 10-15 million chronically ill patients in Canada.

With regards to consulting the broader public, a participant asked why Health Canada would consult people on something that they are not using, not directly concerned with. The people who care about medication for chronic illness are those living with the illness. In these cases, Health Canada should not concern itself with the others nearly as much. To manage resources and get meaningful input, they should talk to groups that are affected by the specific drug or product, people who have a direct stake in the policy or product.

The point was made, however, that part of consultation is an education process, and there is a value in working with the “healthy” group to get their perspective and get information out to them, even on issues where they might not appear to have a direct and immediate stake.

HOW SHOULD WE CONSULT?

Sylvie Cantin, Director – Public involvement and Outreach – OCAPI, made a presentation that informed on how to involve patients. Sylvie's presentation outlined *the HC Public Involvement Continuum* and presented several consultation mechanisms or options for patients. Sylvie's presentation was provided to participants and is attached as Appendix C.

Following Sylvie's presentation, the group identified the following Consultation *Principles*. There was a high degree of consensus around the principles. They were viewed as guiding elements that could be/should be used in selecting consultation options.

Principles for Consultation

1. **Meaningful participation**
   If the strategy is engagement, there needs to be meaningful participation in the process from beginning to end: stakeholders are integrally involved in developing the process, have a say and their vote gets counted, are listened to and have an opportunity to influence, and something happens as a result.
2. **Targeted consultation**
   Clear purpose, clear goals.
3. **Build Trust**
   We need to build trust, define mutual expectations. This is particularly necessary for the engagement level. You need time and resources to build trust.
4. **Commitment to action**
   Where the goal is to effective implementation of policy, there should be more engagement of stakeholders. There should also be a commitment on the implementation by Health Canada before engaging the public. An engagement strategy can help ensure effective implementation.
5. **Transparency**
   Those being consulted have to be able to trust that they are being told the truth.
6. **Innovation**
   We have to get out of the idea that there's only one way to consult, investigate hybrid models and be innovative on solutions.
7. **Evaluation / Accountability**
   Decisions should be examined down the road to make sure they are still appropriate.
8. **Dealing with constraints**
   We need to recognize that they exist, where necessary, BMC should try to influence – we can play a role in helping to lift some constraints.
9. **Mutual respect**:
   For the consultation process, and for the people at the table and the expertise they bring. We can agree to disagree without discounting the other person.
10. **Patience**
    Consultation takes time and energy, and you have to let it unfold.
11. **Appropriate communications**:
    Ensure that participants are well equipped to participate effectively; sometimes the amount and complexity of information provided can be overwhelming and impedes meaningful participation. There is a shared responsibility to ensure participants are well prepared to participate in consultations.
12. **Sustainability**
    When consultation is initiated, resources have to be allocated at the right level so that time and cost constraints do not interrupt the process along the way.

For BMC, meaningful consultation will mean that they are consulted on the issues on which they will be most impacted, taking into account HPFB resource constraints.

It is also important for HPFB to state clearly which initiatives will not be opened to active engagement by BMC, either because they are too far along in the process, or for any other reason.

If there is an issue that deserves an engagement type of consultation, but resources will only allow for feedback, it may be better to put the initiative on hold until the right resources can be allocated to ensure the proper level of consultation.

One of the roles of OCAPI is to ensure that public consultation is taken seriously within the Health Products and Food Branch and is given proper weight in addition to other input such as expert advice in the departmental decision-making process.

Challenges / Obstacles to Effective Consultation

The following are real challenges, perceived or otherwise, to achieving a successful level of consultation.

- **Time**
- **Cost**
- **Culture**
  (There may be resistance in some government circles to implement meaningful consultation. There may be an opportunity to educate about the consequences of not consulting effectively.)
- **Legal Issues**

Potential Patient Involvement Approaches

The presentation on a mechanism for involving patients produced the following suggestions from participants to guide Health Products and Food Branch in its selection of consultation approaches and mechanisms.

- Make sure there are appropriate bi-laterals between Directorates and BMC on issues that are important to patients. If OCAPI has a partnership with BMC, this would result in regular discussions about specific topics to determine the best consultation approach on different topics, before they become issues and before the broader consultation begins. Direct to Consumer Advertising (DTCA) and Canadian Coordinating Office of Health Technology (CCOHTA) are examples of issues on which BMC would have important insights to contribute.
- All the options identified could be appropriate.
- Use option 3 to gather information from different groups, and use option 1 for ongoing consultation.
- When these options are to be implemented, there should be a plan; it may be that a consultative committee is established or already exists which could assist with developing or recommending a plan for the specific consultation. Each of the options will provide very different outcomes.
- Would patient advocates like to have separate patient approaches or mechanisms, or would they like to only participate in mixed groups? It would be easy to add BMC members in existing standing committees, and this would allow for addressing patient consultation on a broader base, but BMC has specific expertise on some of the issues identified earlier for which they should be consulted separately.
- BMC could be one of the HPFB standing committees, operating at a very high level of engagement. It could be an incredible vehicle for building capacity within the patient community, since it has flexible membership, can solicit additional members, and is very articulate.
- Participants agreed that a mechanism should be found to consult BMC on a regular basis on the consultation process.
- On another note, OCAPI will provide a list of standing committees to BMC to help them determine which ones are of interest to them, and conversations can proceed from there to see what is feasible.

WHERE TO FROM HERE / NEXT STEPS

The following action steps were identified to follow up on the workshop:

Action	Who	When
1. Present the idea of BMC playing a "standing committee" role to the executive committee of the Branch.	Roger Farley	Ongoing
2. Review list of standing committees and let HPFB know which standing committees are of interest.	BMC	End of January
3. Prioritize HPFB initiatives based on degree of interest in being involved and communicate priorities to HPFB.	BMC	December
4. Develop a strategy for BMC to assist Roger in advancing the idea of ongoing involvement of BMC with the Branch.	Kathy & Denis with input from Roger	Ongoing
5. Organize a follow-up meeting to further the agenda.	HPFB to lead	May/June 2003
6. Pursue opportunities for bilateral conversations on specific issues.	Kathy & Denis & HPFB	Immediately & ongoing
7. Develop and provide draft of the workshop report to HPFB and Kathy.	Intersol	December 20
8. Provide feedback on the first draft of the report.	Kathy and HPFB	Early January
9. Finalize report.	Intersol	Mid-January

Santé Canada Health Canada

APPENDIX A

Boundaries

Presentation to
The HPFB and Best Medicine Coalition
Consultation Workshop

by Roger Farley
Director General
Office of Consumer and Public Involvement (OCAPI)
December 13, 2002

Health Products and Food Branch

Canada

OUTLINE

- What's in and out
- HPFB's mandate
- What we do
- Organizational chart
- One of our challenges

What's in and out?

What's in? HPFB

What's out?
Other Branches

HPFB Mandate…

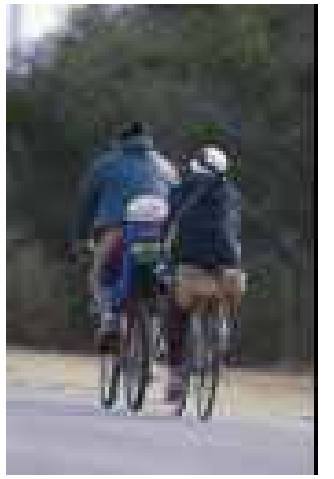
HPFB's mandate is to take an integrated approach to the management of the risks and benefits to health related to health products and food by:

Minimizing health risk factors to Canadians while maximizing safety provided by the regulatory system for health products and food; and,

Promoting conditions that enable Canadians to make healthy choices and providing information so that they can make informed decisions about their health.

Who we are…

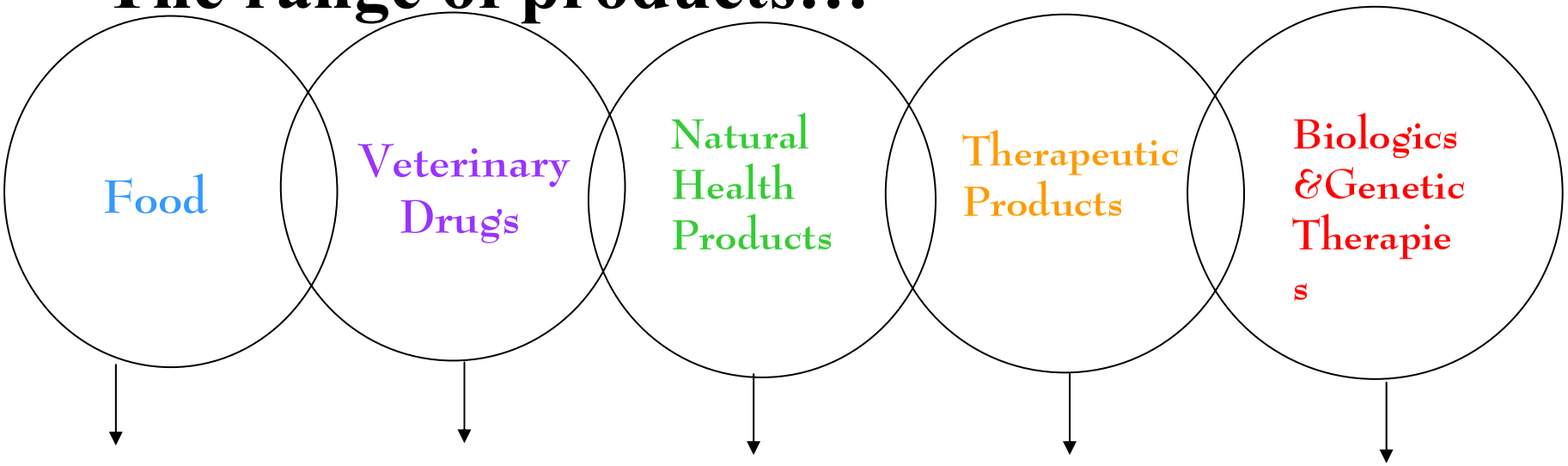
- **A regulator**
- **A policy maker**
- **A science-based, multi-disciplinary branch**



Our work affects the daily lives of Canadians

What we do…

The range of products…



Biomicrobial and chemical safety of foods, nutritional evaluation

Veterinary drugs, safety of foods from animals treated with drugs, Eg. milk, meat, eggs, fish and honey.

Vitamins, herbs, minerals, etc.

Drugs, medical devices, and other therapeutic products.

Blood and blood products, viral and bacterial vaccines, genetic therapeutic products, tissues, organs and xenografts.

What we do…

A large volume and wide scope of work:

- 22,000 human drug products
- 1,450 veterinary drug products
- 40,000 medical devices
- 400 biologics products
- 28 categories of food and more than 400 food additives
- An average of 8000 Adverse Drug Reaction reports received every year

Our Challenges…

Finding the Balance

Fast Access ⟷ **Safety**

Innovation ⟷ **Stewardship**

Sovereign Interests ⟷ **Globalization**

Western biomedical ⟷ **Alternative medicines**

Economic Interests ⟷ **Social Interests**

Organizational Chart

See attached document org. chart:

- 1st level = 5 product categories
- 2nd level = mainly horizontal directorates (OCAPI)
- 3rd level = 5 regional offices

Our Challenges…

If we, in Health Canada, are champions of public health, then we need to clearly understand and focus on public expectations and concerns with respect to health.

APPENDIX B

For each issue below, please indicate your organization's level of interest in being part of future consultations by checking the appropriate boxes:

A	Very interested
B	Moderately interested
C	Not interested

	Pharmaceutical drugs, Medical Devices, Biologics and Genetic Therapies	**A**	**B**	**C**
I.	Approval procedures for prescription and over-the-counter drugs	❑	❑	❑
II.	Recovery of costs for drug reviews.	❑	❑	❑
III.	Harmonization of drug approvals with other countries.	❑	❑	❑
IV.	Access to safe and effective drugs and therapies.	❑	❑	❑
V.	Issues related to making drugs available for compassionate reasons.	❑	❑	❑
VI.	Testing and regulations for medical devices (e.g. contraceptive devices, breast implants, pacemakers, medical equipment and instruments).	❑	❑	❑
VII.	Concerns related to low-risk products such as sun screens, antiperspirants, toothpaste.	❑	❑	❑
VIII.	Ethical issues in clinical trials (e.g., drug research in humans).	❑	❑	❑
IX.	Organ and tissue donation in Canada.	❑	❑	❑
X.	The safety of Canada's blood supply.	❑	❑	❑
XI.	Revisions to Product Monograph Guidelines.	❑	❑	❑

		A	B	C
XII.	Issues related to direct advertising of prescription drugs.	❑	❑	❑

Marketed Health Products

XIII.	Reporting on adverse reactions to products.	❑	❑	❑
XIV.	Communicating drug safety information to the public.	❑	❑	❑

Natural Health Products

XV.	Interactions between drugs and natural health products.	❑	❑	❑
XVI.	Labeling of natural health products.	❑	❑	❑
XVII.	How to ensure the safety and efficacy of natural health products.	❑	❑	❑
XVIII.	Good manufacturing practices - what they are and how to maintain them.	❑	❑	❑
XIX.	Ensuring consumers have the information they need to make informed choices.	❑	❑	❑
XX.	Current and emerging research areas related to natural health products	❑	❑	❑

Nutrition

XXI.	Nutrition and healthy eating.	❑	❑	❑
XXII.	Nutrition in pregnancy.	❑	❑	❑
XXIII.	The role of nutrition in diabetes prevention and management.	❑	❑	❑
XXIV.	Guidelines on healthy weights.	❑	❑	❑
XXV.	Progress on dietary reference intakes.	❑	❑	❑
XXVI.	Initiatives related to Vitality (program addressing healthy eating,active living and positive self-esteem).	❑	❑	❑

Food		**A**	**B**	**C**
XXVII.	Regulations on food labeling.	❑	❑	❑
XXVIII.	Recent initiatives on food-borne illness.	❑	❑	❑
XXIX.	Genetically-modified food.	❑	❑	❑
XXX.	Nutritional quality and safety.	❑	❑	❑
XXXI.	The health impact of food allergens.	❑	❑	❑
XXXII.	Identifying and reducing chemical contaminants in food.	❑	❑	❑
XXXIII.	Protecting Canadians from Mad Cow Disease.	❑	❑	❑
XXXIV.	Food irradiation.	❑	❑	❑
XXXV.	Issues related to seafood toxins.	❑	❑	❑
XXXVI.	New findings on food additives.	❑	❑	❑
XXXVII. **XXXVIII.**	The role of food packaging materials in food safety	❑	❑	❑

Veterinary Drugs				
XXXIX.	Approval procedures for veterinary drugs used to treat food-producing animals.	❑	❑	❑
XL.	Research on resistance to drugs that fight bacteria and disease.	❑	❑	❑
XLI.	Farm management practices and their input on the environment.	❑	❑	❑
XLII.	Testing and regulation of veterinary drug residues in food and meat	❑	❑	❑

Regulatory and International Issues	**A**	**B**	**C**
XLIII. The impact of chemicals in cosmetics, pharmaceuticals and other personal care products on the environment.	❑	❑	❑
XLIV. The importance of Canada considering other international regulations when developing its own regulations.	❑	❑	❑
XLV. Appropriate Dispute Resolution mechanisms	❑	❑	❑

Biotechnology

XLVI. Communicating to Canadians Health Canada's programs to increase public confidence in biotechnology products.	❑	❑	❑

APPENDIX C

Public Involvement

Office of Consumer and Public Involvement

Presentation to the Best Medicine Coalition

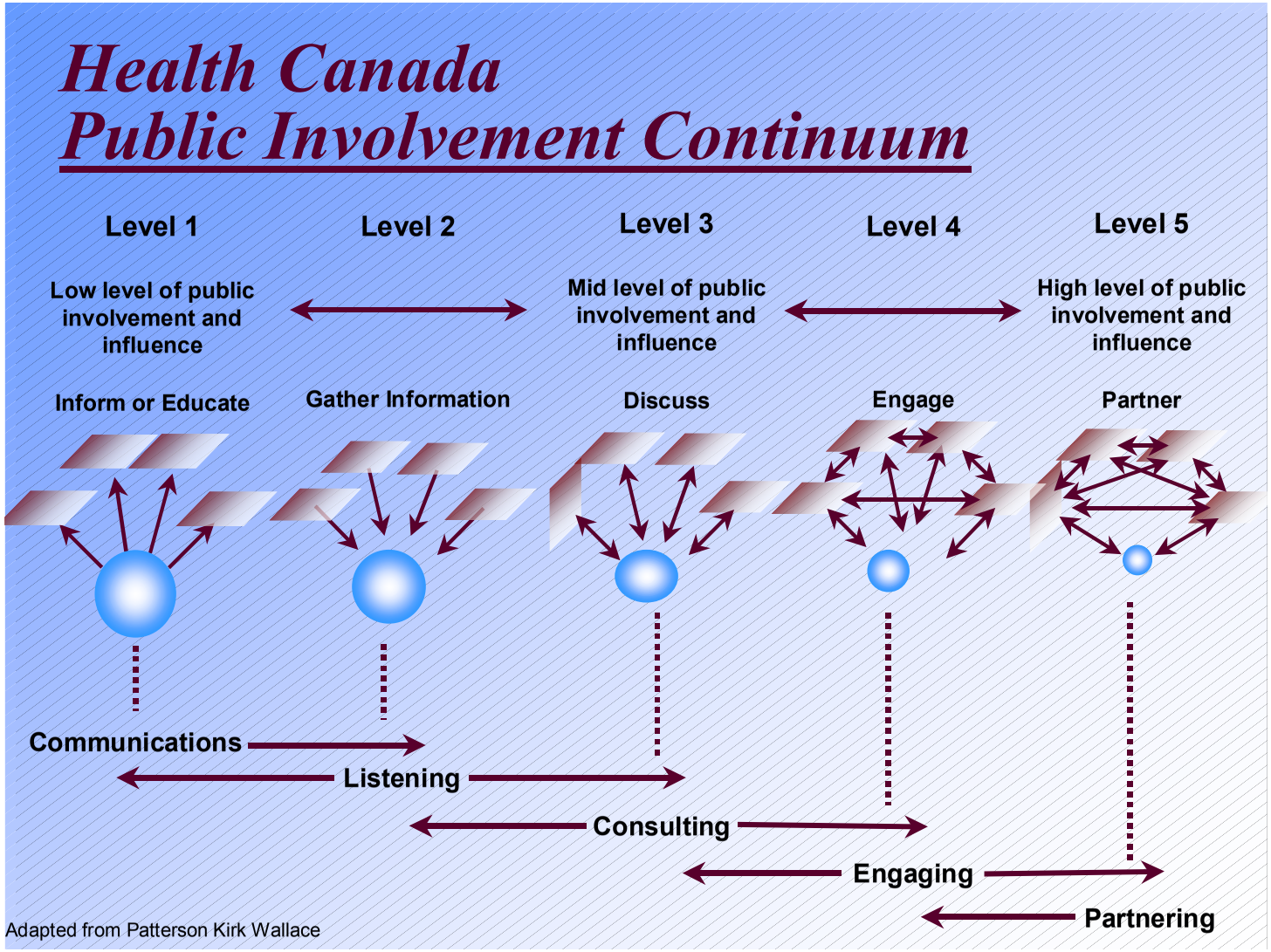
December 13, 2002

Outline

- Goal of public involvement
- Public involvement continuum
- Key Questions & Considerations
- Potential Patient Involvement Approaches

GOAL of Public Involvement

- To improve the quality of policy and decision-making.
- Effective and meaningful public involvement is essential to enable Health Canada to fulfill its mandate and build public trust.


Health Canada
Public Involvement Continuum
Level 1
Level 2
Level 3
Level 4
Level 5
Low level of public involvement and influence
Mid level of public involvement and influence
High level of public involvement and influence
Inform or Educate
Gather Information
Discuss
Engage
Partner
Communications
Listening
Consulting
Engaging
Partnering
Adapted from Patterson Kirk Wallace

Level 1: Inform / Educate

- Factual information is needed to describe a policy or issue or prepare for involvement
- A decision is already made
- The public needs to know the results
- There isn't an opportunity to influence the final outcome
- An emergency requires immediate action

LEVEL 2: Gather Information

- The purpose is to listen and gather information
- Policy decisions are still being shaped There may not be a firm commitment to do anything with the views collected

Level 3: Discuss or Involve

- A two-way information exchange
- Individuals & groups have an interest in the issue and will likely be affected by the outcome
- An opportunity exists to influence the final outcome
- We wish to encourage a discussion among and with stakeholders

Level 4: Engage

- Regarding complex, value-laden issues
- An opportunity exists for citizens to shape policies and decisions
- There is opportunity for shared agenda-setting and open time frames for deliberation on issues

Level 5: Partner

- When we want to empower citizens and groups to manage the process
- Citizens and groups have accepted the challenge of developing solutions themselves
- We are ready to assume the role of enabler

Potential Patient Involvement Approaches - Options

- Option 1: Consultative Committee for Patients
- Option 2: Conference on Patient Involvement Issues
- Option 3: Patient Roundtables
- Option 4: Regional Citizen Forums
- Option 5: Patient Representation on Advisory Committees

Option 1: Consultative Committee for Patients *Level - 3*

- Selected representatives from patient advocacy organizations to focus on specific issues and outcomes for each meeting.

Pros:

- Pressure to engage the group in achieving consensus
- Could be aligned with other public involvement activities
- Positive group dynamic would facilitate future meetings

Cons:

- Building consensus may be difficult
- Group may expect HPFB to adopt recommendations
- Resources needed to support the committee

Option 2: Conference on Patient Issues
Levels 1 & 2

- To inform groups and to engage participation on specific issues. Working groups could be created.

Pros:

- Broader participation of patient groups and public
- Variety of groups: larger umbrella organization and smaller community / grassroots groups

Cons:

- Lower level on the continuum
- More resources than Option 1 needed

Option 3: Patient Roundtables
Level 4

- Stand alone activity with clear objectives and outcomes opened to a range of patient groups which would vary depending on the topics

Pros:

- Pressure on groups to reach consensus
- Broader range of groups and individuals
- Variety of groups: larger umbrella organizations and smaller community / grassroots groups.

Cons:

- Building consensus may be difficult
- More resources than Option 1 needed

Option 4: Regional Citizen Forums
Level 5

- Pool of selected 30 to 50 citizens interested in Branch activities and representing the population and targeted groups such as patients

Pros:

- Not expensive
- Patients as individuals will be represented

Cons:

- Few patient participants and no advocacy groups

Option 5: Patient Representation on Advisory Committees

Level 3

- Increase in number of patients on the actual advisory committees and core of patient representatives in upcoming ones

Pros:

- No need to create additional mechanisms
- No additional resources required

Cons:

- Hard to increase number in actual committees
- Patients would be competing with consumers for limited number of positions
- Patients would not have separate mechanism