


Advisory Council on Health Infostructure



*Workshop on Citizen
Engagement and Accessibility
in Relation to a National
Health Infostructure*

Workshop on Citizen Engagement and Accessibility in Relation to a National Health Infostructure

Toronto, Ontario

Report of Proceedings

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NOTA

This document was prepared for the Working Group on Health Information for the General Public, of the Advisory Council on Health Infostructure.

The opinions expressed in this document are those of the participants of the Workshop and do not necessarily reflect the official views of Health Canada or of the Advisory Council on Health Infostructure.

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INTRODUCTION

The Advisory Council on Health Infostructure invited a wide selection of key informants in the health field to participate in a workshop whose purpose was to support the work of the Council and enlighten its deliberations. The workshop was organized by the Office of Health and the Information Highway of Health Canada and was held in Toronto on October 8, 1998.

The Advisory Council on Health Infostructure was established in August 1997 to contribute to the development of a national strategy for an integrated Canadian health infostructure by providing recommendations and strategic advice to the Federal Minister of Health. The Council is expected to present its final report to the Minister early in 1999. Information about the Council can be found at Internet URL: <http://www.hc-sc.gc.ca/ohih-bis/>

The Advisory Council is addressing a wide range of issues related to all aspects of a health infostructure; but among the critical topics are those dealing with *health information for health consumers and the general public*. Specifically, Council was looking for input on empowering the health consumer and the public, on fostering citizen engagement and participation in the health process and on improving the quality and accessibility of consumer health information. Participants at the workshop were afforded the opportunity to provide expert advice on these issues. The turnout was impressive and the discussions both stimulating and informative.

WORKSHOP GOAL

The objective of the workshop was to provide advice and recommendations to the Advisory Council on mechanisms, processes and structures for empowering the health consumer and the public by fostering citizen engagement and participation in the health process and by improving the quality and accessibility of consumer health information.

BREAKOUT GROUP SESSIONS

GROUP 1. ACCESSIBILITY ISSUES AND HEALTH INFORMATION

Issue: What are the unmet needs, barriers and opportunities regarding health information for health consumers and the general public?

Key themes and issues identified by the group

- what is the values framework which informs the health system?
- support for health intermediaries is essential;
- the Infostructure should be consumer driven not market driven;
- important to support consumer groups who produce health information;
- importance of international networks (the global village);
- need for a variety of modalities of access;
- need to focus on health and not on health care;
- the power of information alone cannot change health situations;
- acknowledge the existing diversity in Canadian society and support it into the future;
- build on work being done at all levels of government, and internationally.

Recommendations to the Advisory Council

1. The Infostructure must support the individual health consumer to make informed decisions on health.
2. The Infostructure must ensure that the needs of citizens and health consumers always take priority.

3. New partnership models need to be developed that include ongoing policy and process involvement of consumers in the development of the integrated Canadian Health Infostructure.
4. Intermediaries should be defined as anyone helping the health consumer to get information to make decisions about his/her health.
5. Funding should be increased to ensure the sustainability and capacity of community organizations and public institutions to provide consumer health information.
6. A vision for an emerging “system” fostered through the Health Infostructure should be supported whereby the Infostructure can lead to informed, empowered consumers.

GROUP 2. CITIZEN ENGAGEMENT AND STAKEHOLDER INPUT

Issue: How to facilitate the participation of health consumers and the general public in the development of the health infostructure, in broad health policy debate, in the provision of input on health policy, planning and delivery of health care services and in the use of health information to inform personal health care choices.

Key themes and issues identified by the group

- health information will allow citizens to be engaged in, and make informed decisions about personal health and public policy; determinants of health; a broad range of factors -social, physical, environmental and economic which influence health;
- all aspects of the determinants of health are linked to the health infostructure;
- important to unbundle the determinants of health and bring them to the level that the public can understand them while avoid fragmentation;
- citizen engagement will allow the public to meaningfully influence public policy and to collaborate on issues of mutual concern;
- build on work being done at all levels of government and internationally;

- the role of the intermediary is missing, or not acknowledged properly: these are the links, the bridges, the navigators to help people get access to health information; include libraries, information centres, family resource groups, not for profit organizations, voluntary organizations and NGO's (including professional groups). These organizations already have in place governance and accountability structures and transparency of information sources.

Recommendations to the Advisory Council

1. Fund organizations in the not for profit sector to participate in the development of content and governance of the health infostructure in their key role as intermediaries.
2. The health infostructure must include the entire continuum of care, not just hospital and physician information; people must have information on home care and other services.
3. A publicly-funded network of community-based health organizations should be developed to provide information and to link individuals with reliable health information.
4. A publicly-funded mechanism for independent verification of health data on the information highway.
5. Develop a public policy “watchdog” organization to make sure that health information is unbiased and available to the public. The organization should have a mandate to report to the public on the health system, engage in public interest research, engage in public health advocacy.
6. Develop strategies to ensure that the public have timely and broad access to information.

Recommendations by the full plenary

The full plenary met to comment on the above recommendations and had the following additional recommendations and comments:

1. The text of the Advisory Council final report needs to be humanized and written in plain language.

2. It is important to accept the notion of a public health information system which is independently vetted to ensure an open approach and the consideration of such areas as: who is the exact source of specific health information; who is funding its development and dissemination; who has validated and published it; who ensures its integrity.
3. There is a need for independence of research, and, therefore, for clear, open, transparent funding for research directed towards health consumer interests.

CONCLUSION

The recommendations produced by the workshop will be submitted to the Advisory Council for consideration. Recommendations which are retained may either be actioned as separate items or integrated into similar recommendations or areas under review by the Council.

APPENDICES

WORKSHOP PROCEEDINGS

N.B. Based on transcription from tapes of the *plenary* session only; the breakout sessions were not taped.

OPENING REMARKS BY DR. MARY-ELLEN JEANS, CO-CHAIR OF THE WORKSHOP.

N.B. The views expressed below by Dr. Jeans are her own personal views and do not necessarily reflect the views of Health Canada.

Mary Ellen Jeans welcomed the key informant workshop participants on behalf of the Advisory Council on Health Infostructure and introduced her co-chair, Madeline Boscoe, and noted that other members of the Advisory Council were also present. She introduced Lin Grist and Jody Orr as co-facilitators of the workshop.

“Madeline and I are members of the federal Minister of Health’s Advisory Council on Health Infostructure; we co-chair the *Health Information for the General Public Working Group* of the Council. The working group has been focusing its deliberations on the needs of the general public and the health consumer as opposed to those of the other stakeholders of Canada’s health system. The group has been leading council’s work in very critical areas of concern to the public: participation/engagement in the health process, accessibility and quality health information. The Advisory Council as a whole will develop, over the next few months a strategy for an integrated national health infostructure to be presented to Minister Allen Rock early in 1999.

While there are many of issues of interest, we need to focus on two key issues today. It has been made clear to Council that Canadians want to be involved in the development of the infostructure and health policy formulation generally; that was clear from the National Conference on Health Infostructure held in Edmonton in February, 1998.

The question now is: by what processes can involvement and engagement be facilitated? What processes can be developed and lead to real and meaningful engagement? How do we put in place mechanisms, policies and processes to ensure that all citizens have involvement and access to information when they need it, in the way they need it, and where they need it?

The Canadian Health Infrastructure can be many things - and especially to the general public. It can afford opportunities for improving our knowledge, help us make informed decisions about health promotion, health care options, treatment choices and so on, but it can also empower public participation in overall health policy and health care system decisions and discussions. These benefits will be timely since they occur at a time when Canadians are being called upon to take increasing responsibility for their own health and that of their families and also at a time when, I believe, Canadians are very concerned about the future of health care and the health care system in Canada. They want to be a part of discussions and decisions being made about the nature of that health care system - its characteristics, its parameters and so on. As we devolve more and more decision-making around health care there are more and more citizens sitting on regional boards, health care institution boards and so on and the knowledge and information that they need in order to make responsible and accountable decisions is a continuing source of pressure for them. But the benefits of health information and the health infrastructure won't happen unless people can be meaningfully engaged and have real access to the info-structure and are able to directly participate in its development and its administration. How that can be accomplished is the objective of this workshop.

Finally I'd like you to bear in mind in today's discussions that you weren't invited here as spokespersons for any particular organization, although all of you belong to some organization or group. You were asked as individuals and professionals who have particular expertise and experience that we think will benefit Council in terms of generating recommendations for the final report. You have knowledge and you have thoughts about some of the issues that we feel are extremely important to incorporate into the work of Council and to the recommendations. We are not seeking solutions which are a product of any specific organization, but we are seeking advice and we are seeking recommendations at a broader level if you like.

In addition, I want you to be assured that you will receive feedback from our work here today by way of a report of what we discuss and generate and I want to assure you that Council will take this advice into serious consideration as we continue our work in gearing up to a final report. Also at the end of today we will distribute copies of Council's interim report which was released on September 30. We would encourage you to read that report in light of some of the issues that we discuss here today and in light of your own experience and knowledge and please provide feedback on the report, it tells you in the report how you can do that - but I think its very important that we have feedback from a variety of people as we move to the next stage. I really encourage people to read the report and provide guidance, feedback and

critique of what's in there and what's not. It is particularly important that you let us know what you think needs to be addressed for the final report.

The Advisory Council on Health Infostructure was formed following the report of National Forum on Health. The report contained recommendations about Canada establishing an integrated health infostructure and the Minister of Health established a Council about a year and a half ago with a mandate to provide recommendations to the Minister on strategies and processes that need to be put in place if Canada is to achieve some sort of integrated health infostructure across the country. There are three working groups of Council, ours is a working group on the health information needs of the general public, there is a key policy issues working group and a working group on technology and applications. They are all looking at various aspects of the challenges that face us in trying to move ahead on this and while there is some overlap on the thinking of the three working groups we come together in plenary and hammer those things out on a fairly regular meeting schedule. We will be going into a four day retreat in November where the Council will be discussing the feedback on the interim report, taking input from meetings such as this one and beginning to crystalize some of the recommendations that we feel the Minister of Health and others - we'll have to specify who needs to take responsibility for what recommendations - but which we hope will inform government and Canadians how on how we need to move forward.

Thank you for agreeing to share your time and your valuable knowledge with us today. I would ask that participants introduce yourselves to each other; you will have all received an agenda and some short discussion papers to help us with our work today.”

Lin Grist provided participants with an overview of the day - participants were pre-assigned to the two break-out groups - Citizen Participation and Accessibility - in order that a broad spectrum of sectors and ideas were represented in each group. Break-out rooms were on the third floor. The workshop has been designed to give the participants an opportunity to discuss the gaps, barriers and other issues in the morning session. A short working lunch organized in the plenary room and the same groups to re-assemble for the afternoon break-out sessions to begin to focus on a “menu of potential solutions and recommendations to the Advisory Council on the issues. One member of each group will be asked to report back to the plenary - with a synopsis of the discussion of the gaps and barriers and recommendations and the group as whole will begin to work towards a consensus around the potential solutions and the recommendations to be forwarded to the Advisory Council.

REMARKS BY ANDREW CLEMENT, CONSULTANT TO THE ADVISORY COUNCIL

N.B. The views expressed below by Mr. Clement are his own personal views and not necessarily those of the Advisory Council or of Health Canada.

“My background is as a computer scientist with particular interest in accessibility of technology. My previous experience, in the early 1970's was experimenting with on-line data base and community memory and making it accessible to the community - a forerunner of community bulletin boards and other more recent forms of on-line public access.

More recently involved with a series of workshops on universal access to develop a national access strategy for the development of Canada's Information Communication Info-Structure, work being supported by Industry Canada and Heritage. The culmination of that work has been a report called *Key Elements of the National Access Strategy: A Public Interest Proposal*. This has been developed as an alternative to the federal government's promotion of the notion of *Connecting Canadians* which we believe is a rather limited view which we think emphasizes too much the wires and the bandwidth and that sort of thing.

At the OECD summit on electronic commerce which took place yesterday, we presented a report which is referred to as the *National Access Strategy* (summary brochures were provided to participants). The report is an attempt by people involved in the information policy and advocacy area to provide a broad framework that the Canadian government and others should adopt as a way of guaranteeing this principle of universal access. Health was not the specific focus of this work, but I have appreciated the opportunity to contribute and be involved in the development of the health infostructure and I would appreciate hearing the advice of participants on the specific issues related to health.

The discussion about health infostructure implies that is just now being created, that we didn't talk about this until we had electronic means, but in fact if we look at it, much of this was already being built and put in place with other means. Any proposals for the health infostructure have to take into account the vast array of information resources, trained personnel, publications and organizations and individuals and the patterns of communications amongst people themselves and that has to be the starting ground. Electronic networking capabilities, while they may be the focus of attention now can only be seen as an addition to that, not as a replacement for or something that gets created de novo.

Particularly in the information highway discussions I see as a continuing theme an emphasis on high bandwidth, technology-intensive solutions to problems that have been around for some time and the difficulties of meeting those problems have not been adequately addressed. As a computer scientist I am constantly struck by the ways in which other computer scientists promote solutions before they have identified the problems. We have the answer, the answer is a computer system of some kind, we'll worry about the problem later. There is very much a technology push in this field and I think that it needs to be countered in some way if we are going to put the attention where it belongs - which is identifying the very particular needs and information gaps that people experience in their lives.

So in this view of the health infostructure and the questions of access to it, I see an array of existing players and one in particular that has been under-rated, and that is the role of health information intermediary. In the Arlington Group's conceptual report they identify the stakeholders in the health infostructure. Health information intermediaries, people whose principal role it is to link individuals and groups to health information and health providers is left out of that formulation and it's a critical one. If we are going to develop this facility, this health space, this Canadian health network, which has already been developed - that is playing an intermediary role, its playing a role of linking people to other resources and the skills and expertise has been developed around addressing that needs to be central in the planning and design of anything future in terms of development of the health infostructure. It is left out of the discussion in part because it is not directly in the health field, also because it is more recent and it lacks resources compared to other aspects. I think it is essential and unless we build it in from the beginning, we will be building elaborate technical networks on a very poor foundation. The first point is the key role of health information intermediaries.

In terms of access, much of the discussion about access gaps is related to the characteristics of the population and the variety of groupings and the various populations having different needs and differential resources and access. People with language, age, geography and income barriers - these present obstacles in the sense of getting to the existing info-structure, they will be even more magnified if we talk about an electronic info-structure, at least to begin with. All of the studies on who has access to the Internet and so on, show the re-emergence of the classic forms of inaccessibility and differential access. So if you are poor, single, remote or non-English - all correlate extremely highly with Internet access. So any technical solutions that are being proposed have to counteract those enduring patterns of disadvantage.

Getting people into the Internet, which is the central idea of the Connecting Canadians agenda - getting people on line and plugged in and overcoming all kinds of access difficulties, also misses the point that information needs are not the general and abstract ones, they are always situated in the particular experiences of the given moment. It's late at night, your kid is crying, do I need to do something now and call an emergency service or can I wait until the morning? That's when a vital recognized information need arises, it's not a general one about the emergency services, it's what do I do now, given this situation? Many of the proposals around the info-structure do not address that. There are kiosks in shopping malls and home terminals and they do not account for how these people are going to have to work this into their lives. This is again where the role of health information intermediaries come in the people that help navigate people through those contingencies at the time. So the idea of 1-800 numbers for instance is more likely to be much more useful to people than needing to fire up their web browser and hunt around on the web to find something. So even though electronic resources can play a vital role in making that information available in a common pool, we are going to continue to need a wide range of ways into that pool in order to serve us in our immediate situations. That's one side of the problems I see in access, the variety and the differential of locations of the public and their situated health needs, and rooted in their daily lives.

The other side, which doesn't get talked about so much, is the institutional barriers that exist in this existing array of health information providers and health providers. We have an infra-structure which is highly elaborate and extremely fragmented and very confusing. It is rife with jurisdictional, professional and disciplinary barriers and formats; There are enormous inconsistencies and if we are going to overcome that, there has to be a lot of pressure on these other organizations to open up, However, at the same time, it has to be relatively easy and attractive for them to be forthcoming, so they need to get something out of making information available in formats that are inter-operable, ones that work across the various institutional boundaries.

As we are developing electronic information-based services the first step is for each organization to present information about themselves according to the ways in which they have organized their own internal activities. So if you looked at many government web sites, what they are, what they reflect, is the current way in which that particular department or government has organized its own internal operations, so that each body, each entity can present itself to the world. But of course, that is not how we, the public, view things, and it is not a particularly useful way when we are trying to deal with situated health needs. So there needs to be a some kind of strong incentives for these various actors out in the in health information provision side to coordinate.

The broad conceptual idea here that I would like to explore is what I have called the Canada Health Space which would be a public commons on health information and communication. The general principle would be if you have health related communications needs, that is the first place for you to go to, that is the principle place that would come to mind. I have a problem with my child, I have a product on my shelf, what are the health effects of this, what is that factory over there producing? We want to be able to go to into a common pool that everybody is oriented to and if it can achieve that kind of preferred place to look it will develop a synergy of other people looking there as well and then that will also be the place where people will find an incentive to make their information available. If you want to play in the health game then you should be in that place because that is where everyone else is going to be. I believe its only when you can achieve that kind of synergistic effect, creating a network effect - as you add a further element, the benefit to all the other players increases This is when you can create something that is new and viable.

Now that rather grand vision of one place for everything presents all kinds of severe contradictions. If is going to be that comprehensive, then it is going to be chaotic, then you are going to have a hard time finding things, therefore its going to be unrewarding to look, and after the first time, you are likely to say I am not going to go there as it wastes my time and it will die. There are, however, various design ideas that can support and create a good balance between comprehensiveness on the one hand and ease of access on the other.

In a nutshell, that's the Health Space, many other names could be used - this was chosen in part because it is inspired by the Canada Health Act and the Canada Health Space would ring nicely with that. Related to that, developing such a project is obviously a long term project, we are not going to be able to create that in the next few years, but I think at this point we can lay some foundational principles that will guide that development and encourage and stimulate further growth on the part of the related actors that would build that over time. That Health space needs to combine as a repository of authoritative, non-controversial information that people with find useful, plus links to all others and its in the links to all others that we can involve anyone who wants to put up their own information and present it in their own way. It will be a directory and a guide. At the same time people need to have some guidance and assistance to determine the validity, value and authenticity of what they are going to find there. Combined with this we need to develop some rich ways of rating that information. One new major element that needs to be developed further, and there are precedents for this, are rating services that will apply a variety of well publicized and stable criteria for evaluating information sources of various kinds. This will be both an interesting and controversial discussion. The virtue of this, is that these decisions

can be made as you go, if there is not agreement, then you are linked, but not directly in it, but you do not have to make a priori decisions that something doesn't belong there.

I want to alert you to two things. One is in the brochure that has been distributed; included in that is the *Access Rainbow* which we have used in our policy formulation work as a useful way of talking about the various measures and layers of access. Access is a very complex concept and it is widely used to mean all sorts of things, and what we want to do here is to be able to use access in a comprehensive way, but to distinguish its elements because different people refer to different parts. We see this as a multi-layered phenomenon starting at the inner layer which refers to carriage facilities - that is the wires and the band width and that is what much of the information highway is about,- it's about plugging-in and getting the wires. Devices and software tools are other elements and where they are located and whether or not the tools are inter-operable and so on comes up.

Another issue around access is content and services, in the health field that is where I see much of the emphasis having to be. The carriage facilities are already in place, we don't need higher band width connections at this point to provide an enormous amount of useful information, it is not required, except in certain trunk line areas. In addition access also implies the organizations that support people in getting access. Much of our access to the Internet at this point is through work -places and we also rely on others to configure our systems to help us over the difficulties. We need literacy abilities to read and interpret and to navigate search and find - those are also important aspects of access.

Finally access to the governance process that enables us as citizens to regulate the overall development of this infra-structure belongs there as well. We see this multi-layered, embracing concept as something to keep in mind in the design of information and communications services for universal accessibility.

I have given some ideas and starting points for recommendations in the material that was sent to you - but I am hear to listen today."

REMARKS BY CAROL KUSHNER, CONSULTANT TO THE ADVISORY COUNCIL

N.B. The views expressed below by Mrs. Kushner are her own personal views and not necessarily those of the Advisory Council or of Health Canada.

“I am exploring citizen engagement in the info-structure and the ways in which the public can participate using this technology to inform itself, but also to engage more actively in public consultations around health policy development. There are three major areas I am exploring: first, how can we maximize the public’s opportunity to say what it would like the health infostructure to be; secondly to clarify its role in the provision of health information to meet the public’s need for health information, and finally what the public needs in order for the public to participate in policy development processes. In doing a pragmatic review of the recent literature in this area and having worked with of consumer groups over a number of years, I think there are a few things that need to be said off the batt about what I have found out. I have in addition completed a number of key informant interviews.

The first is that there are an awful lot of assumptions on what the public information needs really are and I am not sure that those assumptions have ever been tested. There is therefore a great deal of content out there which in fact does not satisfy the public’s need or even a small subset of the public’s need because of its format, its language - it may be inaccessible, it may also be that the information was produced more to promote the producer than to respond to the needs of the people who are presumably being targeted with this information.

The second is that it would lovely and a lot easier for the policy people if the general public was a homogenous group, but of course, we are as varied as the different types of apples that Canada used to produce, but now we’ve homogenized them and we are pretty much down to Spy, Mac and Granny Smiths - but there used to be literally hundreds of different types. Certainly, in the area of consumer information we have a need to recognize that for most people, the very broadest definition of the general public, the interest in health - period - is very diffuse and health information seeking behaviour for that very broadest definition of the general public will tend to be very specific and quite sporadic over time. On the other hand, if you have a chronic condition your interest in health information is likely to become quite concentrated, although it will change over time when you are willing, able and interested in getting that information and it varies not only over time but for the individual. So we are dealing with extraordinary complexity here. People, for example, with a new diagnosis of a life threatening disease. It can overwhelm you so much that you cannot take in any more information than the fact that you are terribly sick. A week later, a

day later, who knows, that same individual will not be able to satisfy their thirst for more information and could easily, then again, find themselves overwhelmed with information that they cannot process. When Andrew made the point about intermediaries, I think it is extremely important to note that in the health care field (even though its also possible for people to do all sorts of independent looking around for information), at the end of the day access to the system is through professionals, except for those elements of self-care that people can manage for themselves. Access is largely through professionals and they are probably the first set of intermediaries through whom we all interact in order to access the care that we need. The decision making part in health care which everyone likes to portray as a shared decision making process, is in fact very largely influenced by professional knowledge and recommendation and it is the very brave consumer who simply rejects all professional advice and goes their own way - it occurs - but it is unusual, for a lot of reasons.

There is, in addition, another group that has concentrated interest that has nothing to do with a health condition and that is if you are a board member in an agency that delivers health services you have a very concentrated interest, not because of personal health reasons, although you may be there because you have the condition in question, but a broader interest in health system and health policy issues particularly as it relates to the prudent functioning of your organization.

We are also dealing with different capacities, information asymmetry is legion in health care, it probably is in most fields, but it could consume a busy practitioner's time just to keep up to date and one of the fascinating things about the increased access for those privileged people who can in fact do searches on the Internet, is that they can come into a doctor's office armed with reams of information which they may not be able to interpret, but which they would sure like the doctor to give them more information about,.. and have you read this.. and do you think this might help? Over time we are beginning to see a change in the relationship between patient and practitioners that might actually approach a partnership, but it is also creating some stresses and strains as well. So there is a social fall-out to this technology.

The other point I wanted to make is that the different groups - this notion of a population falling into different categories shifts over time. We are all at one time going to get sick. Interestingly as we get older, there is a relationship between aging and health and concerns about health do tend to manifest often in older people. One of the ironies is that the more concentrated your interest often the less your capacity to participate because you are sick. I am not suggesting for a moment that every older

person is sick, only that there is a genuine potential to maximize participation through citizen groups by focusing on those sub-populations that are likely to have a concentrated interest in health.

Finally, there is enormous potential for this technology, not just danger signs. The ability to connect people with a rare condition is enormous; imagine being told that you have something and that the doctor has never seen a case like yours and doesn't know anyone who has. This happens rarely, but for example, with certain types of brain cancers there has been a way to connect people around the world with these conditions that has produced at least reassurance for the patients involved and the opportunity to connect with others. In fact that is perhaps is, the great strength.

In talking to people about over-arching issues, we heard and read that privacy was an over-arching concern and of course it is, but frankly whose privacy? I mention that not all the information available electronically is desired or wanted or needed by consumers but by the same token there is lots of stuff they would like to have that they cannot get. So whose privacy are we protecting here? There are for example proprietary rights about information, for example a new drug that is approved in Canada, we the public do not get review all of the data that is used in the decision to approve or not approve of the drug. This, by the way, is very different from the process in place in the United States where a more open process exists. There are also questions about provider, one of the brief little statements in the interim report deals with the issue of "consumers will be able to make more informed choices, not just about their health care but about where they go to get health care". Well, will they? First I am not sure that the evidence about providing this information is very clear, for example in the United States they publish data about the mortality rates - by institution - naming the hospitals. You can imagine how popular that was. There were problems with the data, raw data can be extremely threatening to people because when you analyse you need to risk -rate, as a sicker population in a specific institution will give a worse rating. Never-the-less, between 1992 and 1996 when this information was publicly available they wanted to see did this actually change where consumers went to get their health care. And the answer was, not very much. There was one fewer discharge per week for those hospitals whose mortality rates were twice as high as the best rated hospitals. That is not a very significant change. On the hand a single death reported in the media publicly produced a 9% drop. I think what we are talking about is the diffusion technique and public perception will be swayed by a high profile, gripping story. We still learn by stories, not by data, so it's unclear actually what the impact will be. It's also unclear whether practitioners will cede to the desires of consumers to know what their individual or specific complication rate is, or more positively what their success rate is. Clearly consumers would love the

opportunity, particularly those with a known health problem to say - there is a way that I can be helped with my problem by going to this practitioner because that person already has a track record of dealing with people like me.

Secrecy versus transparency; in an earlier in an earlier project dealing with information and consumers the comment was made, “ Either the information you want is not available or what is available is not what you want, but the bottom line is when you finally find the perfect piece of information you need, it’s either a secret or it costs a fortune” . This is, I suppose trampling on the access turf, but there are overlaps and the question is, to what extent is government generated information, generated for the public purpose, going to be free, or going to cost us money? It is a very fundamental issue and it comes up time and time again when you speak with consumer groups.

Another, issue, and this relates directly to the value of this notion of public space, public ownership, the kind of collective social responsibility as expressed in the programme criteria of the Canada Health Act, which people have said they would love to see in the governance and in the operating principles for the info-structure. How do you create standards and structures for authoritative, valid, and reliable information. Well the truth of the matter is that these are values too. My authoritative source of information may not be yours and beliefs profoundly affect how people value information. One of the terrors for those who are firmly convinced that evidence-based health care needs to prevail if we are to spend dollars wisely, is that we already know that the compelling story has a more profound affect on beliefs than good information and scientifically based data. How do we reconcile this? In other words, could the info-structure contribute to a more costly, less efficient system? I think its wonderful to look at the positives and there are many positives, but these cautions I think are important, because we have not necessarily inculcated within our society a valuing of science. I don’t know if you read your paper this morning, but it turns out that chiropractic isn’t useful for asthma. Now many of you may never have thought it was, but believe me within the chiropractic community this was an on-going debate. Many chiropractors in their individual practices firmly believed that they were helping patients, particularly children, with asthma because they were reporting improvement. However a systematic, carefully controlled study demonstrated that no, it does not appear to make any difference at all. To the credit of the chiropractors, they funded the study, they pursued it, they published it, they are saying that they are disappointed but they are living with the results. I think that this is a very big step forward, but can we expect the same thing from every aspect of the alternative medicine community whose access to research dollars, lets face it, has been very poor.

Speaking of access to dollars, the Internet appears to be largely about, or the info-structure appears to be largely about helping the public to connect with each other as much as it is about helping them connect with information they might need to make personal health decisions. In connecting with each other, there is an assumption that this is all that is necessary to maximize public participation. The truth of the matter is that we are dealing with an enormous power imbalance, not just in information asymmetry - providers tend to know a lot more than we do - but also a tremendous power balance in resources and in the capacity to participate.

It was affirming and wonderful to read a lot of emphasis placed in the interim report on consumer and citizen engagement, but the fact of the matter is that citizen engagement processes have been systematically undermined for a least a decade in this country. Consumer organizations are less able than ever to participate, tokenism is rampant - a single consumer invited to represent not just their group, but all consumers. So we have extraordinarily big challenges.

In terms of solutions, I can share with you the ones I have heard and if you agree with them, please repeat them in your sessions. One of them is, that citizen focus definitely needs parity with the health system management focus and the research policy focus. If we are putting citizen and consumer engagement first, let us make that real. Broad based, on-going, iterative and inter-active processes are needed if you really want to tap into what consumers want, you cannot just ask them once. It is to the credit of the Advisory Council that they are prepared to offer feedback in response to input received.

Transparency is another really important issue, people really want to know the source of the information, particularly if it is analysis. Its one thing to say this is how much the system costs and this is where our resource dollar went, that might be a source of fairly uncontroversial information, although its just as likely that someone will come up and say, I don't like those categories - the piece I want is in "other" - what is contained in "other" and I want it dis-aggregated.

Ownership is a big issue, intellectual property - as an author I see chunks of my work spread out over the Internet and I don't get a dime for it, but then publishing is not, at least for the author a particularly lucrative portion of the income generating spectrum. What we are seeing though, is proprietary rights sometimes interfering with public access and that needs to be clarified. Certainly people want to be able to distinguish information from advertising, they don't want info-mmercials, unless they are described as info-mmercials. Who wants to be given advice about a chronic illness from a single company producing a single product, because that company is never

going to mention the alternative product which could well be as good, even better or cheaper and unbiased sources of information are hard to come by, because of course, there is no funder for them.

Skill enhancement potential has been raised by a number of people and I had never thought of this before, but of course the Internet was initially promoted as a wonderful teaching tool. What is it that consumers could learn on the Internet, could they learn for example, "appraisal skills", could you do a self taught, self help course in some of the rules of scientific evidence, so that you can weed out stuff, and reduce your reliance on intermediaries by gaining some new skills yourself. Clearly self-care opportunities abound, also there is a certain amount of commonality that could be offered in a course on the Internet around the policy process. Does that mean that the Internet is going to compete with our universities and institutions of higher learning? Whose toes do we step on how?

Finally we do need to test the assumptions of the impact on decision-making, I think that whatever proposals come forward, I would love to see them in the form of, "this is our hypothesis, were we right" and be prepared to accept failure with good grace and move on, because we end up getting vested in solutions that don't seem to work very well and you can spend a lot of time and money that way and break people's hearts.

Two more points - there would seem to be an absolutely prerequisite for strengthening the citizen capacity to participate by restoring the foundational base of their very existence. - that is - we need to rethink core funding. That is what they are telling us and frankly the alternative to public support for consumer participation is private co-option. The private sector, particularly the pharmaceutical sector has very deep pockets and they are more than willing and are currently funding many, many consumer activities. But we have seen again and again, even though the strings-free arrangement may exist for years, the threat of withdrawal of those resources makes a group very vulnerable in terms of what it can and cannot speak out on, particularly when there is a conflict between private and public interest and there often is.

These are my points, they are not necessarily framed as suggestions yet, and I am particularly looking forward to your hearing discussions and recommendations to the Council so that the final report is even better than the interim one."

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