Final Report of the

**Task Force on Public Participation**

to the
Board of Directors
of
Canadian Blood Services

**Submitted by:**

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REPORT OF THE
TASK FORCE ON PUBLIC PARTICIPATION
TO THE BOARD OF DIRECTORS OF
CANADIAN BLOOD SERVICES

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Section 1:

Introduction

Establishment of the Public Participation Task Force.

On March 10, 2000 the Board of Directors of the Canadian Blood Services (CBS) announced the establishment of a three-member Public Participation Task Force. In doing so, then-Chairman Ken Fyke stressed the Board’s commitment to “operating in an open and accessible manner and to ensure public participation in decision-making.”

Our mandate was to advise the Board on “how to ensure effective public participation in the work of the CBS.” More specifically, we were invited to consider various practices and models of public participation, to review the kinds of decisions taken by CBS, and make recommendations on the nature and degree of public participation in such decisions. We were also asked to comment on “how the criteria by which achieving a satisfactory public participation will be assessed.”

Task Force Activities and Consultations

The Task Force sought to meet with any and all interested groups who might have views relative to public participation issues. We invited groups who expressed concerns in the past, or whose relationships to the blood system could help broaden the task force’s understanding of the issues at hand, to meet with us or to make submissions. As well, in order to ensure that any citizen with interests in the blood system, or in the participatory

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1 The Press Release, Members, and Terms of Reference (Appendix A, item 4) are on the CBS web site (http://www.bloodservices.ca).
processes that should prevail, felt welcome to come forward or to express views in any way, newspapers advertisements were taken out on a national basis across the country. Our terms of reference were also posted on the CBS web site and notices related to the work of the Task Force were distributed at blood collection clinics across the country. The Task Force held meetings with senior Ottawa-based staff of Canadian Blood Services on several occasions. Task Force Members met with the CBS Board of Directors on August 15, and the Task Force Chair consulted with the Director General of Héma-Québec.

Of particular value as well were our meetings with a series of clients of the blood system who had specific concerns or a particular perspective on participatory issues:

1. June 14, Ottawa: Consumer Advisory Committee of CBS;
2. July 7, Toronto: Tina Morgan, President, Canadian Immunodeficiencies Patient Organization;
3. July 7, Toronto: Steve Apps, Hepatitis C Society of Canada;
4. July 12, Ottawa, Durhane Wong-Rieger, President, Anemia Institute for Research and Education;
5. July 13, Montréal: Erma Chapman, President, Daniel Lapointe, Executive Director, and David Page, Canadian Hemophilia Society;
6. July 14, Toronto: Josephine Sirna and five members of the Canadian Thalassemia Foundation of Canada.

The Task Force also held sessions with others whose particular experience or expertise could be of value to our deliberations – specifically, the staff of the Toronto Blood Centre and representatives of hospital blood banking and transfusion practices, in Toronto on July 13;

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3 Rolf Calhoun, Canadian Association of Retired Persons (Chair); Jim Davies, Arthritis Society of Canada; Brian Huskins, Canadian AIDS Society of Calgary; Josephine Sirna, Thalassemia Foundation of Canada; and Eleanor Pask, Candlelighters Childhood Cancer Foundation.
Mr. Justice Horace Krever on July 14 in Toronto; and Greg Paoli of Decisionanalysis Risk Consultants, on July 12 in Ottawa.

Task Force members were able to meet with every group which indicated an interest in doing so. We encouraged our interlocutors to speak frankly about their aspirations and concerns on the issue of public participation, and we were pleased by the candour and cordiality of our exchanges. We wish to express our appreciation to the individuals who took the time out of their busy lives to provide us with the benefit of their views, particularly those private citizens and representatives of user groups who made the effort to do so. We likewise wish to thank the staff of CBS both in Ottawa and elsewhere for their substantive support, and for their efficient assistance in handling our logistical arrangements.4

In the course of its work the Task Force became acutely aware of the extreme sensitivity among the public about anything that reflects on the safety of the blood supply. One of the consequences of this fact is that CBS is constantly exposed to some risk of “collateral damage” from public statements about blood safety made by other parties. We had this in mind when designing some of our recommendations, because we hope very much that, if a robust new set of structures could be put in place at CBS for public participation in its decision-making activities, and relatively quickly, this risk may be more effectively dealt with.

4 We also reviewed a very large body of documentation that is pertinent to our mandate, including published books and papers, unpublished CBS documents, and other materials (see Appendix B).
Section 2:

Context and Findings

The Aftermath of the Blood Tragedy

Our consultations both within and outside CBS have led us to the conclusion that the commissioning of a review of public participation issues by Board of Directors was wise and timely. CBS came into existence in the midst of a most painful episode in the public health history of Canada which has become known as the “tainted blood tragedy.” Starting in the 1970s, and through into the 1980s, two viruses found their way into the national blood supply, “one causing a newly emerging disease [AIDS], the other causing a disease [hepatitis C] that had existed for many years but had not previously been identified precisely.”5 By the late 1980s, well over a thousand Canadians had died as a result of the use of infected blood or blood-related products. Hundreds of others learned that they had acquired infections that would shorten their lives in ways that would only be revealed with the passage of time. Children and adults alike were implicated. The sense of public betrayal and outrage was palpable as more and more families and individuals discovered that, as a consequence of their dependence on reputable public institutions, their own lives, or the lives of their loved ones, were to be abbreviated, sometimes lasting only a few months or less after a blood transfusion.

The feeling of betrayal was heightened by the slowness of response from all governments. Although the process of infection was well under way by the early 1980s, and Canadians were dying, it was almost a decade before the issue began to attain public
recognition: “Despite the enormity of the tragedy, tainted blood did not become front-page news in Canada until late 1992.”

A Parliamentary Committee, in a remarkable understatement, concluded in 1993 that the blood system “did not respond to the HIV/AIDS challenge as quickly as it might have.”

A commission of inquiry was established under the leadership of Mr. Justice Horace Krever in the same year, and his report was issued in 1997.

The blood system, if indeed it could be called a “system,” brings together a large and complex set of institutions. At the centre of that system, until 1998, was the Canadian Red Cross, which collected blood from thousands of donors across the country, tested it, and distributed blood and blood products such as plasma and other derivatives. These products continue to be used by more than 800 hospitals across Canada, which are thus also part of the system. The blood system also comprises the doctors who prescribe the use of blood products, the scientists who research them, commercial organizations which manufacture them, the associations which play a role in setting relevant professional standards, and the provincial and federal governments which share responsibility for the regulation of all these institutions.

What became obvious as soon as the scrutiny of the system began was that the lines of accountability for the administration of this “system” were extremely complex and confused. It was difficult if not impossible to determine who was in charge, or where accountability lay. As a consequence, when the viruses struck, the “system” failed to

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6 Picard, page 1.

7 Krever Report, page 5. Trebilcock et al. (page 1479) reviewed developments in seven countries, including Canada, and concluded: “In every country studied, denials by the institutions centrally involved in the blood collection, distribution and manufacturing process of risks of HIV-
respond with the speed and efficiency necessary to avert disaster. And thus, as one of the journalists who studied the tragedy wrote in 1995, “[a] dangerous new virus has infected the country’s blood system: mistrust.” One of the outcomes of this mistrust was the removal of responsibility for blood from the Canadian Red Cross, and, in due course, the replacement of the Red Cross by a new publicly funded agency, Canadian Blood Services. CBS began operations in September 1998; our report is being delivered as its second anniversary is being observed.

In our deliberations, we felt an imperative to remind ourselves of the context within which CBS began. Although a new organization, it had to cope with the legacy of mistrust. This mistrust is particularly keen among groups, such as some of those with whom we met, whose members, unlike most Canadians, have an ongoing dependency on the blood system, and who are therefore especially at risk if a virus is introduced into the blood supply. The rebuilding of trust is perhaps the greatest challenge faced by the various “players” in Canada’s post-Krever, reconstituted blood system, and, as discussed in more detail in the next section of our report, we believe public participation plays a key role in this process.

**Findings**

It is clear that CBS, while making progress, continues to face a major challenge in its relationship with the consumers of blood products. A difficulty which has faced CBS from the outset has been the fact that the blood operator it replaced, while having an admirable relationship with donors of blood, did not have a reputation for openness or transparency in the conduct of its operations. This reputation was further tarnished through the previous contamination of the blood system persisted well beyond the point in time at which scientific evidence conclusively demonstrated the existence of such a risk.”

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blood operator’s failure with respect to tainted blood. Canadians are looking for a new kind of relationship with CBS, characterized by the very values cited by the Chairman of the CBS Board in announcing our Task Force: openness and transparency.

So far as these values are concerned, some of those with whom we met told us that they did not discern, at least not yet, a significant change between the former blood operator and the new CBS – although some also recognize a genuine desire and effort on the part of CBS to be different. This is perhaps not surprising, since, as the literature on organizational change emphasizes, it takes years to change a corporate culture. However, this finding tells us that, despite the many positive initiatives we have noted, CBS still has a large area of opportunity in which to make further significant progress.

Problems with the Existing CBS Structure.

An issue brought to our attention early in our mandate was the inadequacy of two structural arrangements instituted at CBS, the purpose of which is to provide channels for public input into the decision-making processes of the agency. The first such arrangement is the requirement under CBS by-laws for two Directors on the Board to be “elected from the general public on the basis of their relevant knowledge or experience with organizations representing persons consuming blood and blood products” (CBS by-law 16(a)(3)). One of these “consumer” or “public” director positions has been vacant for many months. The process employed by CBS Corporate Members for filling vacancies, that is, through the services of an executive search firm, appears to us to be unnecessarily costly and ponderous; moreover, in our considered opinion, these processes have not led to outcomes consistent with the spirit of the by-law. And it is the viewpoint of many of the organizations with
whom we spoke, that existing arrangements for representation on the Board level are not seen to be providing an effective voice for users of blood products at the decision-making table.

It is possible that many citizens who are not directly involved with the blood system would regard such matters as relatively unimportant and wonder why so much attention is devoted to them. It is only the background context which provides an explanation, and we repeat it here: That context is defined by the slowly-evolving tragedy of those who suffered, and still suffer, injury and death from the contamination of Canada’s blood supply in the 1980s by the viruses causing AIDS and Hepatitis-C. The fullest documentation of that tragedy is to be found in the three volumes of the Krever Commission final report, and it is no exaggeration to say that, for many of the most directly involved stakeholders in the blood system today, that report provided the most definitive and authoritative statement of what such stakeholders should reasonably expect in the future, as to both the safety of the blood supply and their entitlement to effective participation in the Canadian blood system. The existing state of affairs is perceived, by many of the most directly involved stakeholders in the blood system today, as not in conformity with either the spirit or the letter of the Krever Report, so far as meaningful participation in CBS activities is concerned.

This context thus also explains the protracted dispute over the other structure intended to promote public input into decision-making, namely, the Consumer Advisory Committee of CBS. The establishment of a committee along these lines was one of the principal recommendations of the Krever Report, which proposed that a “liaison committee” should be set up as one of three reporting to the Board of Directors of the new national blood service. Krever’s view was stated as follows:
A liaison committee, consisting of representatives of community and consumer organizations [should be created]. This committee should ensure that special interests are brought to the attention of the board and that there is adequate communication between the national blood service and any pertinent external organizations, including community and national organizations for recipients, public health organizations, and national and international health and blood-banking organizations. It should also advise the board about the development of educational material for donors and consumers.8

Although the Letters Patent of CBS were granted in 1998, after the release of the Krever Report, the drafters of the CBS by-laws chose not to follow the Krever recommendations and instead established a somewhat different kind of committee structure. Specifically, they created a “Consumer Advisory Committee” at CBS as an Advisory Committee reporting to the Chief Executive Officer (CEO), not to the Board.9 This reporting arrangement has been a thorn in the side of user organizations who cannot understand why the reporting relation for “their” committee was “downgraded” from what Krever had proposed, and who perceive, rightly or wrongly, that having a reporting relationship at this level constrains their ability to communicate with the Board of Directors. In another context, this situation might not occasion serious concern, but in the raw environment that succeeds the tainted blood tragedy, it is not surprising that this arrangement is a source of skepticism for user groups.

Moreover, relationships between the CBS administration, on the one hand, and the members of the Consumer Advisory Committee as presently constituted on the other, can only be described as less than constructive, despite a measure of effort on both sides. This is


9 The same arrangements were instituted with respect to two other CBS committees, one on Research and Development and a Scientific Advisory Committee, both of which report to the CEO. The Krever report had recommended two Board-level committees with somewhat different mandates, one on Safety and the other a Scientific and Technical Committee (Recommendation 14).
illustrated by the protracted dispute between the members of CAC and CBS concerning the committee’s terms of reference: The fact that this dispute is unresolved after almost two years of discussion is itself a sufficient indicator that something is seriously wrong.10

Furthermore, in our view the Committee itself is having difficulty functioning, in part, because there appears to be uncertainty among its members as to whether their role is to act as a kind of arm’s-length watchdog or auditor of CBS, on the one hand, or whether they should work with the CBS Board and management to facilitate communication with user groups, on the other. This uncertainty complicates the establishment of a mutually agreeable and comfortable relationship with CBS. For all these reasons, the CAC is far from achieving the objectives contemplated for such a body in the Krever Report, and CBS is not benefiting as fully as it might from the kind of advice from such a committee that would support it in its effort to rebuild relationships with users and donors.

Turning the Corner

Despite these problems, we were encouraged by a number of factors. Perhaps most important, we sense among many of the user groups with whom we met a desire to “turn the corner.” During the 1980s and early 90s, because of their justifiable suspicion of existing institutions of the blood system, most if not all these groups felt that the only road open to them was advocacy – often, militant and even confrontational advocacy vis-à-vis the government and the Red Cross. This kind of relationship was both understandable and

10 It is our understanding that the “Terms of Reference” dated November 6, 1998 (Appendix B, item 13) are still the subject of disagreement. The dispute about the reporting relationship is a continuing source of bitterness and public complaint; see, for example, CBS Briefing Book No. 1 (Appendix B, item 2), Tabs 17 & 19 and CBS Briefing Book No. 2 (Appendix B, item 3), Tabs 1-6. The documentation makes it clear that this ongoing dispute was one of the main reasons for the appointment of the Public Participation Task Force.
necessary during the years of apparent political and institutional indifference to tainted blood. However, we found in most of our interviews, including that with CAC members, evidence of a disposition to move toward a new kind of collaborative relationship between users and CBS. Although there are a few salient exceptions, there appears to be a willingness among most individuals and groups in the “blood community” to start looking ahead rather than dwelling on the events of the past, about which little can now be done. This willingness provides fertile soil within which CBS can start to nurture a new set of relationships.

**Progress at CBS**

We were also encouraged by attitudes among the staff within CBS. In our meeting in Toronto with the Blood Centre, for example, we were impressed with the concern expressed to strengthen relations with the local community and their intention to reestablish some type of consumer liaison group to replace one that had fallen into disuse. Another indication of this attitude is the inclination of CBS to use the “Consensus Conference” model developed by the National Institutes of Health in the U.S., which appears to serve as an effective vehicle for securing both expert and public input on difficult policy issues. We were likewise encouraged by the apparent attention to consultation issues manifested in a briefing we received from CBS on their strategy for the future, which anticipates some strategic changes in the way the agency operates and its internal systems.

We also note that the challenge of public consultation facing CBS is a complex and difficult one. As one senior official from CBS put it, the agency was established amid expectations of “mega-change,” expectations upon which they could not reasonably be expected to deliver while trying to rebuild, from the remains of the Red Cross, a fractured
organization whose morale had been severely damaged in the wake of the blood tragedy. We are aware that the constituencies with whom CBS has to deal have differing objectives and often do not speak with a united voice. It is not easy to achieve a “satisfactory” measure of public participation under these circumstances.

We were also impressed with the fact that, as an organization which inherited its mandate under difficult circumstances, Canadian Blood Services has been preoccupied with issues about openness, transparency, and availability of information for the public throughout its brief existence. A number of significant and constructive steps along these lines have been taken, including: holding some open Board meetings, regional consultation sessions, and public forums; maintaining a large, interactive web site with detailed information about issues and activities; issuing a public report on its performance and a quarterly newsletter; preparing a policy on access to information; holding numerous meetings with its Consumer Advisory Committee; soliciting and analyzing feedback from the public in a variety of ways; publishing newspaper advertisements on critical decisions, such as donor deferral; hiring professional consultants in an effort to improve its internal and external organizational communications; maintaining a 1-800 line; and many others. We think that CBS deserves to be recognized and applauded for these steps, which go far beyond the practices of its predecessor.

Another important point relating to these initiatives must be noted, namely, that CBS has had to seek to transform its organizational culture and practices in midstream, so to speak. In other words, there could be no interruption in the supply of blood and blood products while these other matters were being attended to. Moreover, there are few, if any,
other organizations in Canada which must go about their business in a climate of such extreme sensitivity, where any mistake can have catastrophic results.

*Access to Information Policy.*

During the period when the Public Participation Task Force was conducting its activities, the CBS Board of Directors approved a new Board policy, “Freedom of Information and Protection of Personal Information Policy.”\(^{11}\) Obviously the subject of this policy is closely related to our own mandate, since adequate and timely access to information is one of the fundamental pillars of public participation; therefore it is necessary for us to make some observations on this policy at the outset.

The approval of this policy follows closely upon receipt by the Board of a paper commissioned by them from Dr. David H. Flaherty, submitted on May 1, 2000 and entitled “A Policy on Access to Records held by the Canadian Blood Services (CBS).” In his report Dr. Flaherty states that “CBS has to strike a balance somewhere between full disclosure and non-disclosure of records” and that “the standard for disclosure needs to be on the high end of the openness scale,…“\(^{12}\) He acknowledges that every organization is entitled to have some form of what he calls a “zone of confidentiality” around the process of its decision-making as exercised both by senior management and the board of directors. He also states that, on the other hand, he is in full agreement with the view “that the zone of confidentiality at CBS should be a very ‘thin’ one in light of the recent history of the blood system.”

\(^{11}\) Approved September 14, 2000, to become effective April 1, 2001.

\(^{12}\) David Flaherty is a leading authority in the field of privacy and was the first Information and Privacy Commissioner for the Province of British Columbia, serving in that post from 1993 to 1999. The quotations in the text are from pages 19 and 20, respectively, of his paper (Appendix B, item 15).
A comparison of the new CBS Board policy with the Flaherty paper shows that the Board generally followed the paper’s recommendations on how to structure an access to information policy. The CBS policy states that “CBS shall … give the public a right of access to information” except where specific exemptions, specified in the policy, apply. There will also be a designated CBS Information Officer “to address questions and concerns in the context of this policy,” as well as an “independent dispute resolution mechanism” to adjudicate disagreements. We cannot do a thorough review of the exceptions, but almost certainly disagreements will to some extent be focussed on the following sections of the policy:

4. CBS shall not be required to release any of the following information:

   4.1 The substance of deliberations of the Board of Directors or any of its committees, including any advice, recommendations or policy considerations submitted to the Board or any of its committees;

   4.2 Advice, information or recommendations developed by or for CBS in respect of or in the course of policy formulation;…

The provisions do fall in the “zone of confidentiality” articulated by Flaherty; however, in our view everything depends on how CBS management and Board interpret and apply them. One of our recommendations in Section 4 deals with this point.13

13 Further guidance is supplied by Flaherty himself in the concluding section of his paper (page 27): “It is obvious to me that the Canadian Blood Services has to adopt a very strong and strict openness policy with all of the positive qualities of the best provincial and territorial freedom of information acts. I can hardly think of another national organization that has a more compelling obligation to disclose information and records on a matter of such fundamental importance to the public, the safety of the blood supply…. [E]specially in the case of the Canadian Blood Services, the imperatives demanding extensive public scrutiny are overwhelming.”
Section 3:

Public Participation: Principles and Practice

The terms of reference of our task force ask us to comment on what constitutes “effective public participation” (our emphasis) as well as what “degree of public participation” would be desirable for CBS, which we interpret to mean, how much is satisfactory? We are also asked to comment on the “criteria by which achieving a satisfactory degree of public participation will be assessed.” This section examines these important questions.

In considering what type of participation is appropriate for any organization, it is useful to start by asking why such participation is necessary. We therefore begin by looking at the relationship between participation and public trust, and do so through a series of propositions related to trust in organizations. We then turn to citizen participation. Again through a set of propositions, we examine its various shades of meaning, the different methods of securing participation and the question of who should participate. We conclude this section with a discussion of implications for CBS: What might “effectiveness” and “satisfactory” mean in its circumstances?

Trust

1. The corporation’s most important asset: trust.

For any corporation, public or private – as for any individual – trust is its most important asset. With trust goes confidence and reputation, and all else hinges upon this, as
poets and sages have long recognized.\textsuperscript{14} The private corporation which loses market confidence goes bankrupt; the public corporation loses its mandate, as the Red Cross discovered.

2. \textbf{Trust is fragile and difficult to rebuild.}

   Trust – a firm belief in reliability, honesty, or veracity - may be damaged in many ways: by a series of poor decisions over time, leading to a long-term decline in performance; by a failure to keep abreast of contemporary developments; through corruption, inadvertence, misinformation, or association; or simply through an unanticipated development for which a corporation is unprepared. Whatever the reason, once trust is damaged, the bar goes up. That is, the standards required of the corporation seeking to rebuild trust tend to be higher.

   In rebuilding trust, actions speak louder than intentions, and decisions speak louder than corporate procedures and structures, although the latter are not unimportant.

   There are multiple pathways to rebuilding trust, a process that usually takes years. Citizen participation is one such pathway, as discussed below.

3. \textbf{Trust prevails when certain values are prevalent.}

   Trust in a corporation rests upon a complex tapestry of considerations: the kinds of decisions it takes, the quality of its services or products, the reputation of its senior officials, its governance arrangements, history, methods of treating staff, and community relations.

   The source of trust, however, is the values which are reflected in the way in which the corporation conducts its affairs. Many of these are the values conventionally associated with good governance or with service quality: honesty, probity, transparency, accountability,

\textsuperscript{14} “The purest treasure mortal times afford/ Is spotless reputation; that away, / Men are but gilded loam or painted clay.” William Shakespeare, \textit{King Richard II}, I, i.

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openness, fairness, responsiveness, accessibility. How a corporation behaves in its relationships may be just as important as what it does.

A corporation may seek to represent itself as trustworthy through cosmetic or surface initiatives, but over time, if appropriate values do not prevail, their absence will begin to manifest themselves in some aspect or other of the corporation's dealings. Confidence will start to erode.

4. Trust is a function of both particular and general relationships.

Most corporations must maintain relationships with groups of stakeholders of varying levels of importance. Different stakeholders may harbour different or even conflicting perceptions of the reliability of the corporation. The relative importance of different stakeholders’ views may vary over time – for example, sometimes a business may be particularly concerned about customer confidence; at other times, investor confidence may be the prevalent consideration; at still other times, employee or government confidence may be particularly important. Maintaining trust is the art of tending the perceptions of each of these stakeholders and keeping them in some degree of balance.

Beyond the views of individual groups of stakeholders lies the concept of general public confidence. This is a consideration for CBS just as it is for private corporations. The views of the public or of citizens at large may not be simply an amalgam of the interests of particular stakeholder groups. Where these interests diverge, strategies for retaining general public confidence have to go beyond those required for dealing with individual stakeholders.
Citizen Participation

1. **Purpose: better decisions, greater legitimacy, greater trust.**

For some individuals, citizen participation is at best a fad and at worst an unfortunate but necessary impediment to the efficient conduct of business. A limited view of citizen participation, therefore, seeks the minimum level required to maintain a measure of corporate respectability. Participation is orchestrated in ways that provide evidence of involvement without seriously affecting the manner in which decisions are taken or power is exercised: For example, through corporate newsletters designed to inform citizens and related communications initiatives where the essential flow of information is one-way, or through structures and procedures designed to accommodate a limited measure of citizen input.

An alternative, broader, and in our view, more informed view of citizen participation sees it as an important ingredient in the battle to regain and strengthen public confidence in organizations. Many surveys chart evidence of the disaffection of Canadians with institutions which only a few decades ago enjoyed widespread legitimacy and deference. The causes of this disaffection are the object of some controversy, but most observers believe at least part of the cause rests in a sense of lack of ownership or engagement by the public in the decision-making processes of these organizations.

According to the broader view of participation, the substantive involvement of interested stakeholders in the affairs of the corporation improves the information available for decision-taking, increases the likelihood that those stakeholders’ interests will be taken into account, and ultimately, enhances the legitimacy of the corporation and the confidence of the public in it. This school of thought sees citizen participation not as a set of procedures or structures but a way of doing business, a philosophy of both management and governance.
This philosophy, underpinned by a set of values, is reflected in the culture of the corporation (defined as “the way we do things here”) and in its day to day relationships with citizens, clients or stakeholders. These relationships may take many forms: service encounters, citizens acting as volunteers, consultative meetings, requests for information, complaints about problems or participation in committee work.

This approach to participation is not, however, an abrogation of leadership. Decisions still rest with those ultimately accountable. But the decisions are more informed, and they enjoy greater legitimacy because they have been the object of citizen input.

2. **Organizations and citizens: different realities, different expectations.**

Most organizations behave in a predictable way in relation to citizen participation; and unfortunately how they behave is often seriously at odds with the expectations of citizens. Many corporations are benignly unaware of this gap.

For example, most organizations perceive that if there’s a blemish or fault line in public trust, it arises from a failure of communication, an inability to “get our story out”. This viewpoint is often allied to a somewhat condescending belief that one of the main reasons for this distrust is that the public is poorly educated (“if they were better informed they’d understand us”). Such organizations define citizen participation as, us telling you our intentions, us seeking your views on what we expect to do (with little expectation that plans could be modified), or us providing you with lots of information.

Citizens operate from a different set of premises. They think of participation as meaningful involvement, be it in discussion or in activities. Contrary to the preconceptions of many corporations, both experience and surveys of citizens tend to show that most citizens do not expect all their views to be implemented. They recognize that other viewpoints may
have to be taken into account, and that this responsibility lies with the corporation’s executives and board of directors. However, they do expect to be listened to. They also expect to be informed as to what is done with their input and why (a common courtesy most corporations forget to observe, and one that nourishes citizens’ cynicism about the value of consultative processes). Also contrary to the perceptions of many corporate officials, citizens have an extraordinarily keen nose for manipulation, and can smell a process that is cosmetic rather than substantive a mile away.

In gauging the success of a corporation’s efforts in securing participation, citizens use their own metric. Corporations ask, was our process sound? Are our structures appropriate? Success is often defined in terms comfortable to the corporation, such as, as having a defensible set arrangements that let citizens get their noses a short distance into the tent, while allowing the corporation to maintain firm control of the agenda.

Citizens ask, are these people open to outside views? Does anything important ever change as a result of our involvement – and if not, do we know why? While they may focus from time to time on their dissatisfaction with some specific element of participation, such as their role in a process or their involvement in a committee, their views on specific matters are informed by their more general confidence in the organization. This in turn rests on the sum of their own experiences with the organization and the results achieved in their different interactions, as well as what they hear about the experiences of others. The more the values associated with trust-building are reflected in their interactions with the corporation, the higher are their levels of confidence.
3. No one best way.

Citizen participation, ultimately, is about building relationships, not implementing processes. However, there are times when specific initiatives need to be mounted to secure input on an issue. There is no magic formula, no single “best practice”. The “Consensus Conferences” employed by CBS are useful for some purposes, not for others. Corporations have to make difficult judgements on two questions in deciding how to deal with the need for public participation. First, what kind of interaction are we looking for in this instance: are we communicating? seeking limited input? entering into a dialogue? sharing decision-making? building a partnership? Different kinds of interactions require different skills and serve different purposes.

Second, they must ask, whom do we wish to involve – and why? Again, there is a spectrum of possibilities, ranging from clients to stakeholders to citizens at large. A perennial challenge is how and when to talk to citizens at large – given that not all citizens can be involved, who can legitimately speak on their behalf? What are the most cost effective ways of securing this kind of input? This type of question is particularly germane to CBS, which in its blood-collecting role, deals with thousands of donors. These donors are vital to the success of CBS but they have no unifying organization or voice. Ensuring their involvement in CBS decision-making thus presents a special challenge.

In determining the answers to such questions, it is advisable to bear in mind certain principles. Among these are:

- be clear about your objectives. This is often the most difficult decision to be taken.

Make sure you know what purpose the information you collect will serve.
- specify what is on the table – what can be changed - and what is not, at the outset. Do not consult if there is no willingness to change, as this merely builds cynicism.
- be authentic, respectful, and courteous.
- the most important kinds of consultations, and the ones where the views of citizens will be most useful, are those where difficult choices related to values have to be made. The more complex and value-based the issue, the more the process should be designed to generate dialogue.
- in planning and in implementing a consultation, make sure the skills you bring to bear are appropriate to the objectives you wish to achieve. The skills required for dialogue, for example, are different from those required for outward communication.
- make sure the process is well defined and clearly understood by the participants, yet be prepared, within reasonable limits, to adapt your process in light of citizen input.
- respect the agendas and priorities of those whose opinions you wish to secure. Remember they may need to consult within their own constituencies to provide you with informed input, and this may take time.
- share relevant information openly.
- provide feedback on what happened.
- advocacy is not consultation. It has an important and legitimate place in the public policy process. However, if a particular interest group or its representative is only prepared to act as an advocate, it may not be able to participate constructively in efforts to reach consensus on difficult issues where different viewpoints need to be accommodated. Consultation imposes certain obligations on citizens and stakeholders just as it does on corporations.
Section 4:

Towards Effective Public Participation at CBS

CBS should strive to build a framework of open and collaborative relationships with both donors and users of blood and blood products, as well as other stakeholders in the organization. If this is done effectively, the corporation will build a reputation for responsiveness, honesty, accessibility and transparency. As these and related values are entrenched in the operations of the corporation, public trust in CBS will be enhanced. We see this as the ultimate goal. Furthermore, such relationships will provide a platform for the conduct of effective public participation activities.

The Board of Directors has a central role to play in ensuring that these values are reflected in all major decisions related to CBS policies and operations. The Board should be supported in this respect by the executive and management team at CBS.

Public participation in the decision-making at CBS should take place in two basic ways: first, through standing structural arrangements that extend from the front lines of CBS work up to the level of the Board of Directors, and second, through periodic consultative initiatives that are custom designed for discrete purposes. In this section of the report, we discuss each of these aspects of the CBS, beginning with a review of the governance structure of the corporation and the composition of the Board. We conclude with a more general discussion of the need for a “Blood Ombudsman” who could examine and report on problems from a perspective on the blood system as a whole which, in our view, continues to lack the single point of contact on administrative matters that most citizens would wish for if they encountered problems with blood administration.
Structural Issues

The CBS Governance Structure

To develop our recommendations, we found it necessary to take stock of the existing governance arrangements at the Canadian Blood Services. We review them briefly here.

As constituted as present, CBS is a national not-for-profit corporation, incorporated in 1998 under federal legislation, under the terms of Letters Patent granted by the Minister of Industry. The “Members” of this Corporation – the functional equivalent of controlling shareholders in a for-profit corporation – are the Ministers of Health (or other ministers as so designated) of all the provinces and territories of Canada except the Province of Québec. The Members elect the CBS Board of Directors, and this Board has full decision-making authority for the corporation. The Board composition is specified in By-law 16, and includes a Chair; four nominees of the Members, representing the provinces and territories; up to six Directors with experience in “business, scientific, medical, technical or public health matters”; and

… two Directors [who] shall be elected from the general public on the basis of their relevant knowledge or experience with organizations representing persons consuming blood and blood products [hereafter referred to as the “public directors”].

The Chief Executive Officer of CBS, who is ex officio a (non-voting) Director, has the following mandate under By-law 32:

The Chief Executive Officer of the Corporation shall be responsible for all aspects of the management of the affairs of the Corporation. He or she shall see that all orders and resolutions of the Board are carried into effect.

Our terms of reference ask us to frame our recommendations “within the existing governance model of CBS,” although we are also requested to “make recommendations on
any modification [we] may see as required to [the] CBS governance model.” We are therefore obliged to state at the outset what we think is meant by the phrase, “the CBS governance model.” We think that this “model” is straightforward: Decision-making authority rests with the Board of Directors, and the CEO is charged with ensuring that the management of the Corporation is carried out in accordance with the Board’s decisions.

However, the Board’s authority itself is derived from the Corporation’s Letters Patent and from the by-laws as approved by the Members; the Board may initiate amendments to the by-laws, but any such proposed amendments require ratification by the Members. The Board is not self-perpetuating, in that the current directors cannot chose their own successors, nor does the Board elect its own Chair. We therefore see the governance model of CBS as one where the Members are the ultimate authority for decision-making at CBS, and where the Board of Directors acts (ultimately) as agents for the Members.

On the other hand, the CBS Board is entitled to be regarded as having a clear “moral authority” derived from its standing as de facto guardians and trustees of the safety of the blood supply in Canada. Although not independent in the strict sense, the Board remains autonomous in the exercise of its judgement as to how best its special mission (safety) should be discharged. And if there is one dominant theme in the aftermath of the blood tragedy, it is that full transparency and public participation in decision-making is the bedrock on which the edifice of safety must be constructed.

As noted previously, the core of our mandate is to evaluate, and make recommendations on, the means of securing “effective” public participation in the decision-making processes at Canadian Blood Services. Our terms of reference further ask us to make recommendations on “the most appropriate processes and structures to involve stakeholders
(inside and outside) and the general public in CBS decision making.” With regard specifically to the effectiveness of public participation in the context of the CBS corporate governance model, this is then a matter of structure, that is, the set of entitlements (of some kind) to membership in the governance body of the organization (i.e., representation). In response we have formulated some recommendations that pay particular attention to improving the quality of public participation within the general framework of the established CBS governance model, but which do also require some changes to its existing by-laws.

Our recommendations are crafted in full knowledge of the fact that the Board of Canadian Blood Services cannot amend its corporate by-laws on its own authority, but must seek the approval of its Members for any such actions. We are firmly of the view, however, that seeking such amendments, along the lines we propose below, is essential if CBS is to significantly improve the involvement of the public in its decision-making. Therefore we urge the Board to adopt our recommendations, to draft the appropriate amendments and changes in wording to its by-laws, and to ask the Corporate Members of CBS to approve those changes and amendments.

CBS’ External Stakeholders

Our recommendations are also framed on the basis of our understanding that CBS’ most important relationships related to its service role are with two groups: donors and users or consumers. Its connections with donors are more intimate than those with users, since donors provide blood in CBS operated facilities, whereas most users meet their blood-related needs in or through hospitals, over which CBS has no jurisdiction. Users themselves fall into two basic categories: those who have an ongoing dependence on blood and blood products
(e.g. hemophiliacs, thalassemia victims), and those who have a periodic or episodic need (e.g. surgery patients, accident and burn victims). Paradoxically, the best organized and most articulate users of blood products are the former group, and these, while extremely important because of their high dependency, constitute a relatively small portion of the overall user population. As for donors, as noted previously, this group is generally unorganized and therefore there is a tendency for them to be less visible than other stakeholders in discussions related to blood issues. Yet all of these groups have a legitimate right to be consulted in decisions related to the collection or use of blood and blood products. Many of the decisions related to CBS’ relationships with donors are taken at or near local collection centres. For this and other reasons we believe it is important for CBS to establish a strong network of consultative committees at the “field” level, and our recommendations begin at here.

Recommendation 1:

At each Local Blood Centre, CBS should establish a User, Donor and Volunteer Local Liaison Committee (LLC).

(a) Each such committee should be convened on a periodic and regular basis to provide input on decisions of interest to local users, donors and volunteers; to assist CBS in communicating with local stakeholder groups, whether organized or not; and generally to facilitate liaison with citizens on all issues related to the collection and distribution of blood products.

(b) Membership in LLCs should be drawn from among:
   ♦ locally-based donors;
   ♦ citizens representing the principal local users of blood products;
   ♦ hospital blood bank and transfusion specialists;
   ♦ local CBS volunteers.

CBS should provide modest operating costs and administrative support to foster the operation of an effective committee at each local site. Such committees should meet at least twice each year.
Rationale.

We are firmly of the view that there is a need at CBS for a strong voice representing the broad range of persons and organizations who are active in the blood system at the local level, and that the blood centres are the appropriate focal point for bringing this into being.\(^\text{15}\) Whereas regular users of blood and blood products have organizations which represent them and their interests, donors – the base on which the entire blood system rests – do not. CBS should initiate appropriate processes so that there emerges an organizational means for the interests and concerns of donors to be articulated. The same should be done for volunteers.

Recommendation 2:

The Consumer Advisory Committee (CAC) as currently constituted is not serving a constructive purpose and should be permanently discontinued.

Rationale.

We wish to emphasize here, in the strongest possible terms, our view that the individuals who currently serve on this Committee, as well as the groups they represent, both directly and indirectly, have made many valuable contributions over the years to the improvement of the blood system in Canada. Under no circumstances should this recommendation be interpreted as a criticism or derogation of their efforts. Rather, it reflects our concern with building effective structures for public participation at CBS. As presently constituted, the CAC is based on far too narrow a range of public interests in the blood system. We believe that the new liaison committee structure will correct this flaw, and that the recommendation which follows below will give the new structure the profile it deserves.

\(^{15}\) There is much useful guidance for identifying specific stakeholder interests, and for responding to specific user and donor interests, in three of the CBS documents we reviewed (Appendix B, items 6, 11, and 19).
Recommendation 3.

The Board of CBS should recommend to its Members that By-Law 41 be amended, discontinuing the CAC and establishing in its place a new National Liaison Committee (NLC), with a terms of reference consistent with the role contemplated by the Krever Report.16

(a) This Committee should report to the Board of Directors of CBS.

(b) This Committee should include: (i) one member from each of the LLCs, selected for service on the national body by a suitable method; (ii) individuals drawn from a representative cross-section of national user groups; (iii) representatives of any other pertinent external organizations, domestic or international, as appropriate.

(c) The Chair of this Committee should be selected by its members.

(d) CBS should use this Committee as a sounding board to secure advance input on issues coming before the Board of Directors in which Committee members are likely to have an interest.

Establishing a Board-level reporting relationship of any new committee would, we realize, alter the symmetry of the reporting relationships of the three Advisory Committees provided for in the CBS by-laws. Nonetheless, the issue of the reporting relationship of the committee has become a focal point for the dissatisfaction of user groups with whom we met, and we therefore believe that in creating a new committee for purposes of external liaison, CBS would be well advised to return to the concept espoused by Mr. Justice Krever. We note, furthermore, that the approach favoured by Mr. Krever was adopted almost word-for-word by the Province of Québec in the establishment of Héma-Québec, and unlike the model crafted by the architects of the CBS by-laws, this approach appears to be working well.

16 "This committee should ensure that special interests are brought to the attention of the board and that there is adequate communication between the national blood service and any pertinent external organizations, including community and national organizations for recipients, public health organizations, and national and international health and blood-banking organizations. It should also advise the board about the development of educational material for donors and consumers." Krever Report, page 1055.
CBS may wish to consider adjusting the reporting relationships of the other two Advisory Committees, provided for in by-laws 42 and 43, to establish consistency with the foregoing recommendation; we leave this to the discretion of the Board. The Board may also wish to consider the advisability of seconding one or two members of the National Liaison Committee to the Research and Development Advisory Committee and the Scientific Advisory Committee.

Recommendation 4:

An annual meeting sponsored by CBS should be held in Ottawa to discuss issues related to the blood system in Canada.

(a) Participants should include representatives from each local LLC as well as representatives from national user group organizations, hospitals, and other organizations or associations with an interest in the blood system.

(b) The primary purpose of this meeting should be to provide a forum in which informed dialogue around issues of concern to stakeholders and citizens can take place.

(c) The agenda of this meeting should be developed collaboratively by a task force of NLC members and CBS staff. The task force should be chaired by an individual who is not a member of CBS staff.

(d) At each such meeting, CBS should present an overview report on the state of the blood system and any issues of concern related to the safety and operation of the system.

CBS should provide a reasonable budget and administrative support to facilitate the planning and implementation of this conference.

Recommendation 5:

CBS should assign a high priority to completing its work on formulating and publishing a credible risk management framework for decision-making on blood safety, including engaging all of its advisory committees on this important endeavour as well as undertaking a process of public consultation.
Rationale.

Safety of the blood supply is the matter of highest public concern and, therefore, the most important matter on which CBS can engage the broad public in an ongoing dialogue. To be sure, for the most important risk issue in Canada’s blood system during the last few years – the possibility that nvCJD is transmissible by blood –, CBS engaged in extensive public consultation, explanation, and discussion. Again, it is necessary to recognize that this approach is a tremendous improvement over what happened in the past.

What is still required and as yet unfulfilled is a response to the public need for a comprehensive CBS risk management framework to form the basis of its further participation in that dialogue. In other words, CBS needs to set out its general approach to detecting, understanding, and controlling various threats to the safety of the blood supply, in language accessible to the general public, and to explain how this framework ensures that this mission will be discharged. The explanation of the framework should cover the terminology of risk-based decision making, including the concept of acceptable risk.

Recommendation 6:

The wording of by-law 16(a)(3) should be interpreted in such a way that both of the “public directors” will be drawn from the ranks of a specific community, namely, persons who are recognized by their peers as having performed valuable service, (1) with organizations representing persons consuming blood and blood products and (2) on behalf of the donor community.

(a) One of the public directors should be appointed to each of the existing Committees of the Board (Executive Committee, Finance and Audit Committee, Human Resources Committee, and the Safety, Science and Ethics Committee).

(b) CBS should adopt a simpler process for filling vacancies in the “public director” slots, as specified below.
Rationale.

The most substantial part of governance is, of course, representation, which may be defined simply as the entitlement to a seat at the table, on equal terms with all others there, where the decisions that give authoritative direction to an organization are taken by voting. On boards of directors for incorporated entities, the articles of incorporation (or letters patent) and by-laws often structure representation by categories, and this is indeed the case for CBS, as detailed above: one category for representatives of the Members, one for a broad range of professionals, and a third category. We repeat the text of by-law 16(a)(3):

… two Directors [who] shall be elected from the general public on the basis of their relevant knowledge or experience with organizations representing persons consuming blood and blood products.

At the time of writing one of these positions has been vacant for some time, although the Members have been engaged in the process of re-filling it.

Before we comment on the category of “public directors” at CBS, we think it is useful to provide a comparison with the Board of Directors of Héma-Québec, which is, after all, the only other comparable entity in Canada. The Héma-Québec board is also one that is structured according to representation by categories, which include hospitals, medical specialists, universities, the public health sector, and business, as well as the following:¹⁷

1. one person selected from among the persons proposed by associations representing recipients of blood components or blood products;

2. one person selected from among the persons proposed by blood or plasma donors and volunteer blood donor clinic organizers;

Ignoring for the moment the role assigned to organizations in proposing such candidates, we would like to focus on the element of comparability between these provisions and that of

CBS by-law 16(a)(3), with its reference to “organizations representing persons consuming blood and blood products.” The underlying intent in both cases seems similar, although they also differ in that, in Héma-Québec’s case, donors are named.

Qualifications of the Public Directors.

Notwithstanding this difference, we think that the underlying intent is quite evident, namely, to include on the Board persons with a close connection to organizations representing the regular users of blood products. We do not wish to get mired in agonizing textual analysis, however. Rather, we maintain that the text of 16(a)(3) should be interpreted in what we have called the “spirit of Krever,” which in our view encompasses the strong presumption that both of the two public directors should be persons having “[direct] experience with organizations representing persons consuming blood and blood products.” We have added and italicized the word “direct” because we think that, in a way, this is implicit in any fair reading of the intent of the word “experience.” In other words, those persons should have had, as a qualification of office for the role of public directors at CBS, active involvement over some period of time in the affairs of the types of organizations so named.

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18 An immediate objection might be that the text of CBS By-law 16(a)(3) refers to two quite different criteria for selection, that is, “relevant knowledge or [our italics] experience with organizations representing persons consuming blood and blood products.” And, if this is read literally as a disjunctive construction (either/or), one might argue that the category, “persons with relevant knowledge,” permits of a broad interpretation that could encompass, say, any type of public-service role, for example, service on boards of not-for-profit agencies in the voluntary sector generally. On the other hand, 16(a)(3) could be read as stipulating “knowledge [of] or experience with…,” in which case it is not disjunctive, but discretionary.
To recapitulate: First, there is no more important, meaningful, or “effective” type of public participation in the decision-making processes of any organization, including Canadian Blood Services, than guaranteed representation as an equal voting member on its senior decision-making body. This proposition seems self-evident to us. Second, although by-law 16(a)(3) can be read as having two separate and equally-valid criteria for qualification for the role of public director, the “spirit of Krever” commands us to give special weight to the second of the two.

Read in this light, by-law 16(a)(3) gives rise to a reasonable expectation, on the part of external stakeholders, that both of the public directors will be drawn from the ranks of a specific community, namely, persons who are recognized by their peers as having performed valuable service with “organizations representing persons consuming blood and blood products.”

There is another option as well. If the Board were to amend slightly the wording of by-law 16(a)(3), and encourage its Members to ratify the amendment, the new wording could parallel the provisions of the Act which established Héma-Québec and include the donor community within the category of “public directors.” The wording could read, for example, “organizations representing persons regularly donating and using blood and blood products,” providing one director “slot” for each of these two sub-categories. In terms of appropriate qualifications for these positions, the same stipulation as made above applies, namely, that the donor representative should be drawn from the ranks of the community of persons well-
regarded by their peers as having performed valuable and long-term services on behalf of blood donors. We leave this suggestion to the discretion of the Board.19

**Method of Selecting the Public Directors.**

By-law 16(a)(3) stipulates that the two public directors shall be “elected [by the Members] from the general public,” and certainly the type of persons specified above fall into that category. Neither by-law 16(a)(3), nor any other by-law, specifies the mode of election or selection further. As mentioned earlier, the CBS Corporate Members have developed the practice of employing an executive search firm to screen potential candidates for this role, advertising nation-wide for expressions of interest and presenting a slate of candidates to the Members. We think that this mode of selection for the “public directors” is unnecessarily cumbersome.20 Many of the most suitable candidates for those slots are more or less on CBS’ door-step, so to speak, and their capacities and reputations are well-known to CBS. It does not require a costly national search to identify the names of credible and capable persons who can fill these places.

We urge the Board of Directors of CBS to recommend to the Corporate Members that they adopt a different procedure for the screening and selection of the public directors. There is nothing in the existing governance model of CBS, so far as we can ascertain, that constitutes an obstacle to it. The steps in this suggested new procedure could be as follows:

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19 There is a strong emphasis on the better recognition of donors, and the importance of donor satisfaction, in the current CBS strategic forward planning document (Appendix B, item 11), which would be quite consistent with the suggestion made in this paragraph.

20 The text of the national advertisement for nominations for board directors, placed by an executive search firm on behalf of CBS Corporate Members, is generic in nature and does not use the language of by-law 16(a)(3).
1. The Board shall establish a list of (a) “organizations representing persons consuming blood and blood products,” and (b) groups which may have knowledge about persons who are recognized by their peers as having performed valuable service on behalf of the donor community.

2. The Board shall solicit multiple nominations from those groups to fill vacancies, as they occur.

3. The Board shall screen these nominations according to generally-recognized criteria for service on non-profit boards (e.g., depth of knowledge, length of service in relevant organizations, fair-mindedness, willingness to work cooperatively with one’s peers, etc.).

4. The Board shall forward two or more names to the Corporate Members for their decision.

These new procedures should be implemented as soon as possible.

Recommendation 7:

The CBS Board should develop a structure and policy for governance issues.

(a) The CBS Board should establish a Nominating & Governance Committee to review and update governance policies, and also to recommend renewals and changes in Board membership to the Board, as appropriate, for its consideration and for reference to the Members of CBS. One of the “public directors” should be a member of this Committee.

(b) Based on the advice of this Committee, the CBS Board should adopt a set of governance policies. These policies should inter alia address CBS expectations of Board members and criteria for the assessment of Board performance.

(c) CBS articles of incorporation and bylaws should be reviewed independently every five years to ensure their appropriateness, and the results of that review should be tabled in the legislatures of each of the Members.

Rationale.

There are two reasons why we make this set of recommendations. First, we are in a period of changing public expectations about the governance of corporate institutions, both
for-profit and not-for-profit, and it is advisable for the Board of a high-profile organization such as CBS to test periodically its structure and procedures against the changing external environment. Second, and more important and as mentioned several times previously, CBS has a special profile in Canada, and a special set of expectations associated with its performance. In this context of heightened scrutiny, the Board would benefit from periodic self-examination on matters of governance, as well as from commissioning periodic external reviews by qualified experts in these areas.

**Recommendation 8:**

CBS should increase the number of Board meetings which are open to the public, perhaps beginning with quarterly open meetings.

(a) CBS should explore whether CPAC would broadcast its open Board meetings, or alternatively, whether these meetings could be transmitted over the CBS web site.

(b) We recognize that issues of personnel, procurement, policy formulation, and perhaps other specific matters, require a closed session.

**Rationale.**

The members of the Public Participation Task Force, as well as another authority consulted by the Board, Dr. David Flaherty, all believe that CBS should commit itself to the highest standard of transparency and openness. Regular and easy public access to decision-making at the board of directors level is surely one of the best forms of accountability and openness that can be achieved. Happily, the Board already has had some generally positive

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21 Dr. Flaherty commissioned a report from Dr. Ernie Keenes, “Boards and Governance: Openness and Issues,” which was submitted to the CBS Board on April 27, 2000 (Appendix B, item 17); there are sections in this report that are pertinent here.
experience in this regard.\textsuperscript{22} We acknowledge that, if holding more frequent open Board meetings were to be made a routine practice, the Board may occasionally experience some practical difficulties. However, we believe that, if the Board were willing to make an honest and determined effort in this regard, the positive aspects would outweigh the negatives by a substantial margin.

**Recommendation 9:**

In implementing Sections 4.1 and 4.2 of its “Freedom of Information” policy, the CBS Board should, as a general matter, make available for release all documents relating to advice, information, or recommendations on policy considerations, developed by or for CBS or submitted to the Board or its committees, in a timely fashion, except in cases where other prohibitions against release in the policy may apply.

**Rationale.**

We refer back to our previous discussion, where we quoted David Flaherty’s view that, for CBS, “the standard of disclosure needs to be on the high end of the openness scale” and that “the zone of confidentiality at CBS should be a very ‘thin’ one in light of the recent history of the blood system.” We respect the need for confidentiality during the time when policy is being formulated, including the period when policy options, analysis and advice are being prepared by staff and consultants – and when both management and the Board are actively deliberating over policy choices, times which may (and probably should) feature vigorous debates, “straw-man” arguments, scenario development, and the like. However, there also comes a time when this process is brought to a conclusion and policy is adopted. When that point is reached, the need for confidentiality diminishes and (in most cases) the rationale for exclusion from access disappears, at least where most documentation is

\textsuperscript{22} Dr. Flaherty comments on this point at page 7, footnote 14 of his paper.
concerned. Thereafter, it seems to us, access should be allowed, subject only to over-riding considerations of confidentiality based on the other, more specific sections of the policy.

**Participatory Processes**

CBS staff presented to us in mid-June an internal draft document entitled, “Working Document on Public Participation Techniques” (Appendix B, item 12). We reviewed this document and find it to be a useful compilation of several dozen ways in which agencies can facilitate participation by both the general public and stakeholder groups. An evaluation scheme is included, where the strengths and weaknesses of each option is assessed against two general criteria (“possibility to develop an informed discourse” and “representativeness of the process”). This scheme shows a good understanding of participatory processes.

We have no specific recommendation to make concerning which processes CBS should use in future, since, as discussed previously, we believe each process needs to be tailored to particular circumstances and there is no “one best way” to be used in all instances. We encourage CBS to take steps to remain current with new ideas and developments related to citizen participation processes, and we suggest that this responsibility should rest with the office of the Corporate Secretary. Further, we encourage CBS to experiment with a wide range of consultative techniques in future. The document presented to our Task Force, updated from time to time, should be a helpful resource in choosing approaches to participation for specific circumstances.
The Need for a Blood System Ombudsman

Recommendation 10:

CBS should appoint a Blood System Ombudsman, and the Office of the Blood System Ombudsman should become a part of the independent dispute resolution mechanism authorized by the CBS Board in September 2000 (Section 1.4 of the “Freedom of Information and Protection of Personal Information Policy”).

Rationale.

The by-laws of Canadian Blood Services, the role of the National Blood Safety Council that advises the federal Minister of Health, the relationship between the Board of CBS and the provincial members, all speak to a genuine desire to address the governance and structure of the large “macro-system” that gathers, tests, distributes and oversees the blood supply in Canada. For the general public, however – and this is the case with almost all aspects of the health care system – the actual relationship between individual Canadians and the “system” never occurs at this “macro” level. While public health assessments reflect aggregate numbers of healthy births, incidence of disease, mortality and morbidity rates, the legitimacy of the system, as perceived by individuals among the general public, is not anchored in such aggregate outcome numbers. Rather, public legitimacy is well-anchored when individuals feel they have genuine and rapid access to a mechanism that can move quickly to cut through the systemic clutter that often muffles or slows response to pressing concerns.
The Complexity Factor

Part of the core issues that impact public participation, public consultations and public legitimacy is the sheer complexity of the technical questions CBS must address, relative to decisions and policies which need to be formulated.

There are a series of buffers between CBS and the individuals who come into contact with the blood system. Whether they are regular product users, donors, or occasional users of blood products (cancer patients, etc.), the range of buffers between them and CBS are significant. These buffers are neither intentional nor the result of any specifically-designed structure. Rather, they are a reflection of the fact that the blood system as a whole is a series of agencies, from hematology departments in hospitals, to local hospital blood banks and local blood centres, on up to the various federal and provincially established bodies, all of which appear to operate independently. From the point of view of the patient, the patient’s family, or of individual physicians or blood system professionals, these various agencies, as well as the hierarchy of an organization with the broad mandate of Canadian Blood Services, can – despite the best of faith and intentions – appear as an ominous and impenetrable bureaucracy.

Moreover, the issues of urgency that regular users of the blood supply or blood products may confront – such as allocation of limited supplies, local blood bank decisions about availability and procedures, concerns about procurement decisions, anxiety about how quickly the system will respond to various concerns – can, when left unaddressed, produce very high levels of public distrust and anxiety. In many cases these are more matters of process, or perception of process, than of specific events.
In addition, the seamless link between the Board of CBS and the members (namely, the provinces and provincial ministers of health) does not, in and of itself, promote open discussion of issues of controversy and public concern. Overwhelming and unavoidable concerns about potential litigation, appropriate roles for professional disciplines, and classic Canadian anxieties about “jurisdiction,” will serve over time to encourage the forces of inertia or official disengagement, because there is always some other agency in the system that can be referred to as a possible source of response.

This complexity, while unavoidable in this area of regulatory and administrative responsibility, easily lends itself to fear-mongering, exaggeration, and, on the side of government, anodyne assurances, well-intentioned and undoubtedly expressed in good faith. Moreover, the understandable desire of governments, agencies, and technical agencies to always appear to be firmly “in control” of difficult issues, while perhaps moderated by evidence-based analysis such as that of the Krever Commission, is still an unavoidable and real part of any relationship with the public.

The presence of a single, authoritative, and well-respected individual, occupying the Office of the Blood System Ombudsman, and capable of responding quickly to the urgent entreaties of concerned individuals, arguably could cut through that complexity and resolve many of those concerns expeditiously.

Ombudsman Functions.

The Office of the Blood System Ombudsman should have the following terms of reference:

1) to report quarterly on complaints and anxieties expressed about the system that have not been appropriately addressed in other ways;
2) to interact as necessary with the client and frequent user community to address matters of urgency relative to the blood supply, and individual patient access to the system;

3) to respond to specific complaints from citizens;

4) to raise issues about relevant matters where appropriate or necessary;

5) to advocate on behalf of citizens where bureaucratic inertia or overlap makes a timely response difficult to deliver;

6) to make recommendations on an ongoing annual basis about improving transparency and public access.

Implementation:

The Office of the Blood System Ombudsman should become a part of the independent dispute resolution mechanism that was authorized by the CBS Board in September 2000 (Section 1.4 of the “Freedom of Information and Protection of Personal Information Policy”). The Ombudsman would operate on the basis of “moral authority,” rather than having any statutory basis for compelling the co-operation of officials, at CBS or elsewhere, in the pursuit of his or her inquiries. On the other hand, the CBS Board should guarantee that all reports from the Ombudsman would be issued verbatim and expeditiously by CBS, by being posted on its web-site and publicized through a news release.

After a trial period of three years, CBS should commission an independent evaluation of the need for, and the effectiveness of, the Office of the Blood System Ombudsman. It is possible that experience may validate the need for this Office, but also demonstrate that the structure (part of the dispute resolution mechanism) itself is ineffective, due to the lack of a statutory basis for the Ombudsman’s authority. In this case the CBS Board may wish to
initiate discussions with the various governments of Canada, with a view to establishing the Ombudsman’s authority by statute.

In this case the Office of the Ombudsman should be established independently by federal statute. The costs of the Ombudsman operation should be born by the federal and provincial governments; candidates for the Blood Service Ombudsman should be solicited in a professional way. Its independent operation should be guaranteed by a one time federal/provincial endowment that will, as a principle, generate the yield necessary to properly fund an Ombudsman’s operation that has the staff and scope to channel complaints and concerns in an orderly, energetic, professional and thoughtful way.

Concluding Note.

It is the understanding of the Task Force that the CBS Board will release this Report on December 18, 2000.

Submitted to Canadian Blood Services by The Public Participation Task Force:

William Leiss, Chair
Tim Plumptre
Hugh Segal
Appendix A:

List of Task Force Recommendations

Recommendation 1:
At each local Blood Centre, CBS should establish a User, Donor and Volunteer Local Liaison Committee (LLC).

(a) Each such committee should be convened on a periodic and regular basis to provide input on decisions of interest to local users, donors and volunteers; to assist CBS in communicating with local stakeholder groups, whether organized or not; and generally to facilitate liaison with citizens on all issues related to the collection and distribution of blood products.

(b) Membership in LLCs should be drawn from among:
   ♦ locally-based donors;
   ♦ citizens representing the principal local users of blood products;
   ♦ hospital blood bank and transfusion specialists;
   ♦ local CBS volunteers.

Recommendation 2:
The Consumer Advisory Committee (CAC) as currently constituted is not serving a constructive purpose and should be permanently discontinued.

Recommendation 3:
The Board of CBS should recommend to its Members that By-Law 41 be amended, discontinuing the CAC and establishing in its place a new National Liaison Committee (NLC), with a terms of reference consistent with the role contemplated by the Krever Report.

(a) This Committee should report to the Board of Directors of CBS.
(b) This Committee should include: (i) one member from each of the LLCs, selected for service on the national body by a suitable method; (ii) individuals drawn from a representative cross-section of national user groups; (iii) representatives of any other pertinent external organizations, domestic or international, as appropriate.

(c) The Chair of this Committee should be selected by its members.
(d) CBS should use this Committee as a sounding board to secure advance input on issues coming before the Board of Directors in which Committee members are likely to have an interest.
Recommendation 4:
An annual meeting sponsored by CBS should be held in Ottawa to discuss issues related to the blood system in Canada.

(a) Participants should include representatives from each local LLC as well as representatives from national user group organizations, hospitals, and other organizations or associations with an interest in the blood system.
(b) The primary purpose of this meeting should be to provide a forum in which informed dialogue around issues of concern to stakeholders and citizens can take place.
(c) The agenda of this meeting should be developed collaboratively by a task force of NLC members and CBS staff. The task force should be chaired by an individual who is not a member of CBS staff.
(d) At each such meeting, CBS should present an overview report on the state of the blood system and any issues of concern related to the safety and operation of the system.

Recommendation 5:
CBS should assign a high priority to completing its work on formulating and publishing a credible risk management framework for decision-making on blood safety, including engaging all of its advisory committees on this important endeavour as well as undertaking a process of public consultation.

Recommendation 6:
The wording of by-law 16(a)(3) should be interpreted in such a way that both of the “public directors” will be drawn from the ranks of a specific community, namely, persons who are recognized by their peers as having performed valuable service, (1) with organizations representing persons consuming blood and blood products and (2) on behalf of the donor community.

(a) One of the public directors should be appointed to each of the existing Committees of the Board (Executive Committee, Finance and Audit Committee, Human Resources Committee, and the Safety, Science and Ethics Committee).
(b) CBS should adopt a simpler process for filling vacancies in the “public director” slots, as detailed in the main body of this Report.

Recommendation 7:
The CBS Board should develop a structure and policy for governance issues.
(a) The CBS Board should establish a Nominating & Governance Committee to review and update governance policies, and also to recommend renewals and changes in Board membership to the Board, as appropriate, for its consideration and for reference to the Members of CBS. One of the “public directors” should be a member of this Committee.
(b) Based on the advice of this Committee, the CBS Board should adopt a set of governance policies. These policies should inter alia address CBS expectations of Board members and criteria for the assessment of Board performance.
(c) CBS articles of incorporation and bylaws should be reviewed independently every five years to ensure their appropriateness, and the results of that review should be tabled in the legislatures of each of the Members.

Recommendation 8:

CBS should increase the number of Board meetings which are open to the public, perhaps beginning with quarterly open meetings.

(a) CBS should explore whether CPAC would broadcast its open Board meetings, or alternatively, whether these meetings could be transmitted over the CBS web site.

(b) We recognize that issues of personnel, procurement, policy formulation, and perhaps other specific matters, require a closed session.

Recommendation 9:

In implementing Sections 4.1 and 4.2 of its “Freedom of Information” policy, the CBS Board should, as a general matter, make available for release all documents relating to advice, information, or recommendations on policy considerations, developed by or for CBS or submitted to the Board or its committees, in a timely fashion, except in cases where other prohibitions against release in the policy may apply.

Recommendation 10:

CBS should appoint a Blood System Ombudsman, and the Office of the Blood System Ombudsman should become a part of the independent dispute resolution mechanism authorized by the CBS Board in September 2000 (Section 1.4 of the “Freedom of Information and Protection of Personal Information Policy”).
Appendix B:

Documentation and Literature Reviewed


4. Canadian Blood Services, “Call for Nominations for Board Directors.”


25. Thalassemia Foundation of Canada, documents.
