

#	Forum Type	Source Document	From	Date	Review point	Comments/Input (some may be paraphrased)	Organ / Tissue	Category (using new list - Integration Discussion for Organs only; Tissue may differ slightly)
1	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Consistent application of agreed upon allocation principles with accountability for practices so net exporters of organs are not disadvantaged	Organ	Allocation
2	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Adequate funding will be a key success factor to meet the resource requirements to implement improvements for a national OTDT system	Both	Funding
3	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Ongoing consultation is expected; it is important for those being consulted to hear back about how their input was received and considered.	Both	Policy development
4	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Address issue of diabetes, including First Nations leadership at federal government level discussions	Organ	Policy development
5	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Acute care lines linking intensivists in the city with rural physicians has potential to support identification and transfer of potential donors	Both	Donation
6	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	A barrier to donation is that there may be donation costs that fall to donor families (e.g. ambulance trips)	Organ	Funding
7	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	National standards and guidelines are helpful; with accountability for consistent implementation across the country	Both	Safety and quality
8	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Coordinating body for unbiased advice and leadership would be welcomed	Both	Principles
9	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Public awareness and education to increase donation. Models suggested for consideration included MADD and Breast Cancer marketing	Both	Public and Professional Awareness and Intent to Donate
10	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Donation opportunities are being lost in emergency departments and medical wards	Tissue	Donation
11	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	National tissue databank needed, can learn from jurisdictions that have proceeded with this work	Tissue	Information management, measurement and reporting
12	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Professional and public education and awareness is key to increasing tissue donation	Tissue	Public and Professional Awareness and Intent to Donate
13	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Participants were interested in the Spanish model and elements that may be appropriate for Canada	Both	Policy development
14	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Important to include neurosurgeons, ophthalmologists and orthopedic surgeons in consultation for national system design	Both	Policy development
15	Expert	Summary Report	Saskatoon Multi-Disciplinary Event	2009-12-11	OTDT National Plan	Consider opportunity to discuss national system design at a table of CEOs, e.g. a "virtual" round table if there is such an opportunity	Both	Principles
16	Expert	Detailed Notes	Saskatoon Multi-Disciplinary Event	2009-12-12	OTDT National Plan	Challenge on workload issues with hospital staff to accommodate/address transplants	Both	Processing and Distribution
17	Expert	Detailed Notes	Saskatoon Multi-Disciplinary Event	2009-12-13	OTDT National Plan	Challenge on availability of transplant surgeons balanced with number of transplant procedures	Both	Processing and Distribution
18	Expert	Detailed Notes	Saskatoon Multi-Disciplinary Event	2009-12-14	OTDT National Plan	In general, the challenge of hospital capacity with respect to OR time: (a) availability and (b) prioritization over other procedures, e.g., bariatric surgery	Both	Processing and Distribution
19	Expert	Detailed Notes	Saskatoon Multi-Disciplinary Event	2009-12-14	OTDT National Plan	Opportunity to engage and leverage NGOs	Both	Principles
20	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Quality System:</p> <ul style="list-style-type: none"> Quality includes safety, as well as continuous improvement and customer satisfaction. Regulatory agencies only consider whether the manufacturer meets its claims and whether products are safe. They are not responsible for looking at customer satisfaction and continuous improvement. The national system will need to define the appropriate level of standardization/ customization. It was noted that the more centralized an organization is, the easier it is to standardize. Audit was only one tool in determining whether quality requirements are met. System wide quality indicators are built into the Canadian Blood Services' Balanced Scorecard and are reviewed quarterly. Economies of scale (staff for example) can be achieved to a certain extent with centralization; however, a base level is still required to conduct quality activities. Reporting requirements for cells, tissue and organs are complicated and unclear, there are many relationships with many organizations to manage, and there are multiple points of contact even with Health Canada. Reporting is a small part of surveillance. Canadian Blood Services has additional activities, such as monitoring emerging pathogen, to support this. 	Tissue	Safety and quality

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21	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Identification and Referral:</p> <ul style="list-style-type: none"> The most viable tissue donors are external to the intensive care unit environment. Donor identification and referral initiatives should reflect this. Tissue donors should be identified and referred both from hospitals and from medical examiner/coroner offices outside the hospital, to increase the pool of potential tissue donors. Support is needed for medical examiners and coroners, to help them become part of the tissue donation system. Front-line hospital staff can play a key role in identifying potential donors. Referrals should be made to a central call centre. All provinces should have mandatory donor referral legislation. There should be nationally standardized practices. 	Tissue	Donation
22	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Consent:</p> <ul style="list-style-type: none"> Professional, trained requestors who use proven processes/best practices should be used to obtain family consent for donation. Front-line health care workers who may be in contact with families often have little time or training or are uncomfortable about making the donation request. A separate requestor also counteracts any perception of conflict of interest. Trained, dedicated requestors should be available 24/7 to support donation. This can be achieved by providing the service by telephone, which has been shown to be as effective as in-person requesting. Phone requesting also allows for efficient initial screening and eligibility, and allows better targeting of who should be approached. Trained, dedicated requestors should also provide bereavement support to donor families and follow-up support. Trained, dedicated requestors who provide support for organ donation can also provide services for tissue donation and this synergy should be supported when possible. 	Tissue	Donation
23	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Consent:</p> <ul style="list-style-type: none"> Intent/consent registries for potential donors should also be considered, in order to improve consent rates. The information regarding the donor's wishes on the registry should be available to the requestor. 	Tissue	Public and Professional Awareness and Intent to Donate
24	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Tissue Recovery:</p> <ul style="list-style-type: none"> Tissue recovery should be done by trained recovery teams, focused geographically, and multiple tissues should be recovered. These recovery teams could include physicians. 	Tissue	Processing and Distribution
25	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Tissue Recovery:</p> <ul style="list-style-type: none"> A standard Canadian training program should be developed for tissue recovery and processing. Currently, there is only in-house training which differs from tissue bank to tissue bank. While there is training through the AATB in the US, this is only classroom training and does not include hands-on training. EEAB does have a hands-on component, but this addresses only eye tissue. 	Tissue	Processing and Distribution
26	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Tissue Recovery:</p> <ul style="list-style-type: none"> Tissue procurement must be linked to demand and must be efficient. Not all locations in Canada will have tissue recovery and some areas may be tissue specific (e.g. ocular tissue). Location and logistics will determine whether the donor is moved to a central recovery site, or whether recovery takes place in a hospital OR. 	Tissue	Processing and Distribution
27	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Canadian Production of Tissue Allografts</p> <p>Surgical bone</p> <ul style="list-style-type: none"> It is expected that bone products based on new technologies (strips, pastes, injectables) as well as increased cadaver yields will gradually replace surgical bone as the product of choice for surgeons, and that surgical bone banking will phase out over time. The national strategic plan should not focus on surgical bone banking. However, it was noted that where banks continue to exist, they will need to meet the required standards and regulations. One TEC member expressed the view that surgical bone is considered safer than deceased donor bone, however there was no consensus on this issue. 	Tissue	Processing and Distribution
28	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Skin Tissue:</p> <ul style="list-style-type: none"> As with surgical bone, it is expected that products based on new technology will gradually replace use of skin. However, Canadian tissue banks should recover and process as much skin as surgeons demand. Fresh skin is considered the "gold standard" by surgeons, but requires coordination of recovery and surgery. A supply of skin should be kept in inventory as emergency stock, in case of a natural disaster or other catastrophe. We should also consider sending skin to the US for processing into advanced products, according to supply and demand. 	Tissue	Processing and Distribution
29	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Canadian Production of Tissue Allografts</p> <p>Ocular Tissue:</p> <ul style="list-style-type: none"> The current funding model is a barrier to sharing tissue inventory across provinces. Benchmark wait times need to be established for cornea transplant patients. Canada needs to build ocular processing capacity to support the increasing demand for advanced corneal grafts; specifically partial thickness grafts. Processing centres should be centralized to ensure competence and efficiencies. The number of sites needs to be determined based on the shelf-life for corneas and the need to ship within short time frames. Canada needs to increase cornea donation, especially in areas with low donation rates. Investigation is needed into how to improve accessibility to hospital ORs, where this is a limiting factor for performing cornea transplants. 	Tissue	Processing and Distribution

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30	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Canadian Production of Tissue Allografts Cardiac Tissue:</p> <ul style="list-style-type: none"> The number of Canadian cardiac processing facilities (n=4) exceeds the US cardiac processing facilities (n=3). It is estimated that the 3 programs external to Quebec produce small volumes totalling less than 100 grafts annually. Depending on the exact number, consideration should be given to consolidating production, sending to the US for processing or eliminating collection and processing altogether. A significant portion of recovered valves go unutilized as the majority of demand is for the smallest valves (paediatric population). Awareness initiatives and procurement should be targeted to increase the recovery of smaller valves. 	Tissue	Processing and Distribution
31	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Canadian Production of Tissue Allografts Musculoskeletal Tissue:</p> <ul style="list-style-type: none"> Recovery and capacity for basic processing of MSK tissue should be expanded. A cost-benefit analysis should be conducted to determine whether advanced processing of MSK tissue should be performed in Canada. Centralization of processing of MSK tissue should be considered, to take advantage of potential economies of scale, with a national distribution system for MSK (and all tissue) Processing of MSK tissue would best be supported in a facility outside the hospital environment. 	Tissue	Processing and Distribution
32	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Canadian Production of Tissue Allografts Tendons and Soft Tissue:</p> <ul style="list-style-type: none"> Canada needs to increase recovery and production of tendons and soft tissues. These products are expensive for Canadian hospitals to import and they are often in short supply. Increased Canadian supply will allow patient need to be met, as well as allowing for clinical outcome studies and structural investigations to assess what practices and products work best. There is a need to increase processing capacity in Canada; however, depending on the amount of tissue recovered, processing some of this tissue in US should be considered. <p>Demineralized Bone Matrix and Machined Graft Products:</p> <ul style="list-style-type: none"> DBM and machined grafts products could be produced in Canada, though a business case is needed to determine whether it is feasible from a financial point of view. 	Tissue	Processing and Distribution
33	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Canadian Production of Tissue Allografts General Comments:</p> <ul style="list-style-type: none"> There is a need to address issues of access to surgeons and hospital ORs where this is a limiting factor for transplantation. Centralized processing is needed, if cost-efficiency is to be achieved. Good Manufacturing Practices are best supported outside of the hospital healthcare delivery environment. Processing of some tissues by US processors is likely to be an ongoing requirement if advanced products are to be made from Canadian tissue. 	Tissue	Processing and Distribution
34	Expert	OTDT TEC Meeting	Toronto Multi-Disciplinary Event	2010-01-13		<p>Costing and Data Gaps</p> <p>A costing project was undertaken by Canadian Blood Services in order to understand current OTDT costs and funding. The project was needed to identify critical gaps in costing data, as well as to assist in the development of budgets for implementation of the strategic plan. While data was provided for tissue donation and cornea transplantation, limitations of the data were reviewed. Discussion then took place on the data and potential next steps for the project. Discussion and suggestions followed on what can be done to fill information gaps:</p> <ul style="list-style-type: none"> Canadian Blood Services will hire a market research company to investigate and estimate amount of tissue imports. Surgeons will be surveyed on skin and cardiac usage and importation. Skin and soft tissue for dental are small volumes and won't be a priority for investigation. It was suggested that current or recent unit costing data be obtained from comprehensive tissue banks, if they were willing to share the data. R&D costs should be investigated. It was suggested that infrastructure costs could be calculated as a percentage of operating costs. <p>Work on costing</p>	Tissue	Funding
35	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Are we missing any critical elements in the case for change?</p> <ul style="list-style-type: none"> Establishment of system to enable identification and referral of donors. Need to differentiate between provinces that have a Medical Examiner's system versus a Coroner system. (Common challenge...For tissue...chief coroner comments) Pathologist... challenges --- lack of standardization in dealing with coroner's cases...need development of SOP's. Coroner's Act prohibits recovery before coroner approves of action. As the coroner is not a medical doctor they rely heavily on pathologists. There needs to be a team effort to define which tissues can be donated or who could be a donor. Need for professional education and national practice standards around this issue. 	Tissue	Donation
36	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>What is the most important element that needs to be fixed for Organs?</p> <ul style="list-style-type: none"> Long wait times for patient assessment – need objective measures and benchmarks 	Organ	Donation
37	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>What is the most important element that needs to be fixed for Organs?</p> <ul style="list-style-type: none"> Need to start by developing common national definitions around consent rate, conversion rate, etc. Need to develop national benchmarks and standards (It was noted that a national coordinating body could assist / facilitate the development of benchmarks and standard; how they would be administered would need to be determined) 	Organ	Information management, measurement and reporting
38	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>What is the most important element that needs to be fixed for Tissues?</p> <ul style="list-style-type: none"> Funding models need to be addressed - nationally for processing and recovery. 	Tissue	Funding

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39	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>What is the most important element that needs to be fixed for Tissues?</p> <ul style="list-style-type: none"> • Need for increased public awareness around tissue donation. Tissue donation consent is more of a challenge than organ donation as there is a lack of public awareness. • Need to address professional education... (e.g., US model, GIVE model in NB) 	Tissue	Public and Professional Awareness and Intent to Donate
40	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>What is the most important element that needs to be fixed for Tissues?</p> <ul style="list-style-type: none"> • Questions around safety. Health Canada regulations will help, but also need other systems like accountability, monitoring, outcomes monitoring, traceability. • Canada has a safe supply of tissue; however we need to guarantee that our imported tissue is safe. We need to ensure that safety expands beyond what is produced in Canada and identify who is responsible for ensuring safety? • Who owns the responsibility for tissue traceability as everyone thinks it is someone else. 	Tissue	Safety and quality
41	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • Required / mandatory referral legislation. Are referral rates higher in provinces that have mandatory referral? If so should this be standardized? In NB, viewed as on only effective in concert with other initiatives. • Important to investigate why mandatory referral is working so that efforts can be focused in the right areas to focus on for future • For tissue donation the system needs to extend beyond hospital; best donors are usually identified outside of a hospital setting • Professional education and awareness required and should include opportunity for health professionals to meet donor families and understand how valuable the donation opportunity is. 	Organ	Donation
42	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • Criteria for listing by organ and processes for allocation need to be consistent 	Organ	Allocation
43	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • Strong support for development of a national, electronic tracking system for donors and recipients. 	Organ	Information management, measurement and reporting
44	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • Is presumed consent going to be considered --- (Response experience of some countries has been that introduction of presumed consent legislation has increased donation, but the legislation has been introduced with an investment in donation resources.) Area on consent has been an area of under investment in Canada. Will consider opt in and opt out • Is there a strategy to increase living donation? (Response: Strategy will consider opportunities to increase living donation and could include need for additional resourcing to support living donation.) • Is there ethics board involved? Yes, CBS is planning to consult with ethics experts as national strategic plan is development. 	Organ	Public and Professional Awareness and Intent to Donate
45	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<ul style="list-style-type: none"> • Traceability and safety: build on experiences and learning from CBS. e.g., detailed policies and procedures such as accountability for ensuring the refrigerator maintains the correct temperature. 	Tissue	Safety and quality
46	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<ul style="list-style-type: none"> • Look at experience of CBS related plasma protein products and the economies of scale around bulk purchasing. • CBS --- very effective at getting right product to right place at right time. 	Tissue	Processing and Distribution
47	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <ul style="list-style-type: none"> • Confirming positive direction of organization bringing together specialists in field to administer those changes • Confirm that discussion is premature regarding the national system governance role 	Both	Policy development
48	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <ul style="list-style-type: none"> • Need to consider ownership of (accountability for) ordering, monitoring and tracing tissue - Who is responsible for these areas? Reaction was it should be a tissue bank - but need resources and mechanisms to support this function --- need to reflect this in system principles • Need to address the issue of informing patients that they are receiving tissue, as many receive tissue and are not made aware. 	Tissue	Audit and accountability
49	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <p>Discussion if organs/tissues are a local, regional, provincial or national resource:</p> <ul style="list-style-type: none"> • View that families may change their decision about consent if they know that the donor organs are going out of the province. Question about whether status on wait list affects this view. • Need to consider whether the province / region has a transplant program • For tissues: all corneas go to Halifax for distribution; families don't seem to mind that tissue leaves the region • Different perspective: retaining kidneys in region (Atlantic Canada) and sharing other organs more widely has never been an issue 	Both	Allocation
50	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<ul style="list-style-type: none"> • Fearful that NB donor kidneys will be distributed across Canada... and those regions with lower donation rates will be "suck" organs from NB and provinces with high donation rates. Concern voiced that we need to advocate for our patients as a national system may make our provincial wait time increase and to ensure this doesn't occur need a strong provincial representation in place. • System performance needs to be as strong a concern as allocation • Need access to data to support understanding of where organs are distributed and how they are used. This will enable analysis of relative to performance and donation potential --- need network of experts to support data analysis • Questions about outcomes .and willingness to share organs with programs whose outcomes are poor - is this a good use of a scarce resource 	Both	Allocation

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51	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Current NB state issues / opportunities:</p> <ul style="list-style-type: none"> • Organ Donor Resource Nurses – 4 new hires as of Feb 4/10 (0.7 FTE each) • New NB provincial health care structure, • Consent to donate registry attached to health care card...build underway...target by 2012 • Current organ donation rate: 14 - 16 dpmp • Additional information about the reimbursement of hospitals for donation cases: 1600 referral annually; 131 donors; 261 corneal donation • Commencing the development of new educational (school based program) donation materials • Public awareness initiatives need to be increased for organ and tissue donation and transplantation • Cornea retrieval nurse (from OR perspective) only allowed to retrieve corneas after hours. Also are challenged by OR nurses having the option to decide whether they want to take call for donation (based on their views on donation). Need to elevate importance of donation. System needs to be resourced adequately (human, OR, etc.) to support donation opportunities. 	Both	Public and Professional Awareness and Intent to Donate
52	Expert	Summary Report	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Other options:</p> <ul style="list-style-type: none"> • Socially in NB its important for people to be donors – a culture that ability to donate is a right and a privilege...also noted that the public doesn't distinguish between organ and tissue • Health professional education aspect; education should include information on the beneficiaries of organ and tissue donation and need for cultural change • It was emphasized that the need for professional education and policies be established determining death and who is a donor. In Canada two systems co-exist the coroners system and the medical examiners / pathologists. 	Both	Public and Professional Awareness and Intent to Donate
53	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Within NB the tissue program is funded via the province but is only loosely affiliated with the provincial program and is managed separately.	Tissue	Funding
54	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		A NB initiative – G.I.V.E. – which essentially is a branding /educational tool to enhance awareness of the diagnosis of brain death within critical care environments has recently been adopted by Australia.	Tissue	Public and Professional Awareness and Intent to Donate
55	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Need for ethics review of the system principles.	Tissue	Principles
56	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Some of the statements within the case for change are fairly broad – ie appropriate assessment times – definitions and benchmarks need to be established.	Tissue	Audit and accountability
57	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Allocation was a key concern within the organ group and specifically the risk that smaller programs would be significantly disadvantaged by a national allocation system.	Tissue	Allocation
58	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		They have had examples where donor families ask where the organs will be used – the families are OK with them being used regionally (Atlantic Canada) but sometimes are challenged when broader allocation. Families seem to understand the distribution to high status and are reassured when told the kidneys are always used locally.	Organ	Allocation
59	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		No concerns within the tissue community re allocation indicating it had not come up in conversations with donor families.	Tissue	Allocation
60	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Discussion of whether or not mandatory referral actually increases donor numbers. Suggestion that analysis be undertaken of provinces with mandatory referral to understand this issue.	Tissue	Donation
61	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Public awareness for tissue is lacking. Challenges in getting consent for tissue due to lack of public knowledge.	Tissue	Public and Professional Awareness and Intent to Donate
62	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Professional awareness is highly lacking in tissue. There is a culture where some health professionals will not support tissue – ie they have a list of which nurses they can call in for tissue donors – some nurses refuse to participate. This is due to a lack of understanding and a lack of exposure to the recipients and donor families who benefit from tissue donation.	Tissue	Public and Professional Awareness and Intent to Donate
63	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		There are distinct cultural and operational differences in provinces with Medical Examiners vs Coroners. Coroners are not doctors and not pathologists. They really heavily on the legal documentation in the coroners act and in direction from pathologists. Sometimes a barrier to donation. Relationship development is required for both the coroners and their associated pathologists.	Tissue	Donation
64	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		There was great concern that there are no processes in place to audit hospital practice in relation to the management and safety of the tissue they import, store and use.	Tissue	Safety and quality
65	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Discussion about the great alignment of tissue with plasma products at CBS and the opportunities for using the CBS model for tissue. Specifically stated the advantages of the purchasing power of CBS re plasma products. It was stated that "Canadian Blood Services is very good and getting the right product to the right person at the right time" and that they could do this for tissue to.	Tissue	Processing and Distribution
66	Expert	J. Mohr notes	Fredericton Multi-Disciplinary Event	2010-02-03		Within NB they have created legislation and a culture where donation is viewed as a right and a privilege. The idea that tissue donation may not be maximized – i.e. adjusting supply to meet demand presented significant challenges to them.	Tissue	Policy development

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67	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<ul style="list-style-type: none"> • Donation rate currently low; commitment to donation could be better (Drop in donation rate in part due to decrease in medicine, increased medical intervention with improved outcomes, limited trauma) • Less contribution to identification of donors by neurosurgeons – in part due to bed limitation (not a province wide service) • Positive / supportive of the move to hospital based donor coordinators • Sees opportunity to improve donor identification and referral processes for organs and tissues 	Both	Donation
68	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<ul style="list-style-type: none"> • Good processes and involvement of neurosurgeons • Have been challenged by lack of structure and leadership (provincially and within NB Health) 	Both	Policy development
69	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<ul style="list-style-type: none"> • Build on current interprovincial collaboration (among Atlantic provinces), including monthly neurosurgical teleconference 	Both	Principles
70	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<ul style="list-style-type: none"> • Established culture / practice of transferring donors from community hospitals to Moncton; commitment to accepting all potential donors, regardless of limited space in ICU 	Both	Donation
71	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<ul style="list-style-type: none"> • Annual neurosciences conference (neurology and neurosurgery) – There was advise against presenting to this group as neurology represents higher proportion of participants and they are less interested / involved in donation – neuro rounds may be a better target group with broader attendance. 	Both	Donation
72	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<p>Level of support for national system design</p> <ul style="list-style-type: none"> • Wants to see governance structure • NB needs some voice / representation in governance of national system (not NS representing Atlantic Canada); all provinces should have representation 	Both	Audit and accountability
73	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<ul style="list-style-type: none"> • Need accountability mechanism; transplant physicians cannot "police" themselves 	Both	Audit and accountability
74	Expert	Detailed Notes	NB One on one meeting	2010-02-03		<p>Principles:</p> <ul style="list-style-type: none"> • Need to protect against inequity; • System and allocation principles should be fair and reasonably equitable (different from equal) • Supports need for balance among principles, e.g., equity, utility, medical need • Transparency is important but "not always our strong suit" 	Both	Allocation
75	Expert	Summary of Feed back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Organs Case for Change should...</p> <ul style="list-style-type: none"> • Ensure that there is clarity on the goal for the number of donations. How do we know how many are missed? As an administrator I need a target to work toward. • Include need for better working relationship with tissue program • Auditing process to identify what is currently done well and where improvement is needed. This would provide valuable information to guide future strategies • Data collection that is standardized nationally 	Organ	Audit and accountability
76	Expert	Summary of Feed back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Organs Case for Change should...</p> <ul style="list-style-type: none"> • Include funding issues surrounding live donor work up, wait list management (keeping current testing) and recipient work ups prior to listing 	Organ	Funding
77	Expert	Summary of Feed back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Organs Case for Change should...</p> <ul style="list-style-type: none"> • Improve public education to support informed decision making • Link to a web site that provides information on organ and tissue donation (including what tissue donation entails as well as uses of tissue and that tissue donation does not affect funeral processes) --- applies to organs and tissues cases for change • A good beginning • Electronic tracking system • Electronic information system • Comparative data on rates of donation of other countries to prove we can do better • OK as is 	Organ	Information management, measurement and reporting
78	Expert	Summary of Feed back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Tissues Case for Change should...</p> <ul style="list-style-type: none"> • Make it mandatory for hospitals/surgeons to inform surgical patients when they have been recipients of human tissue of any kind (e.g., tendons, bone, putty, dental surgeries) – much the same as patients who receive a written record when they receive blood transfusion • If public knew how much human tissue is used it would elevate the perceived importance of tissue donation, increase awareness and increase donors • Address regulation and use of products given that patients are not always aware that they are receiving tissue and programs not always aware of source • OK as is 	Tissue	Transplantation
79	Expert	Summary of Feed back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-03		<p>Tissues Case for Change should...</p> <ul style="list-style-type: none"> • Comparative data on rates of donation of other countries to prove we can do better • Electronic information system 	Tissue	Information management, measurement and reporting
80	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		<p>Current state issues / opportunities:</p> <ul style="list-style-type: none"> • Limited human resources: 3 resource nurses / donor coordinators – based in St. John's – responsible for on-call, education, policies, procedures, chart audits, tissue (cornea) retrieval • Obtaining family consent currently a challenge • ICU Capacity issues – but never say no to a donor – this can result in cancellation of elective surgery 	Both	Donation

#	Forum Type	Source Document	From	Date	Review point	Comments/Input (some may be paraphrased)	Organ / Tissue	Category (using new list - Integration Discussion for Organs only; Tissue may differ slightly)
81	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Current state issues / opportunities: <ul style="list-style-type: none"> Lack of data – huge issue – particularly around tissue donors Challenging to develop business case for additional resources given small OTDT volumes and lack of data 	Both	Information management, measurement and reporting
82	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Current state issues / opportunities: <ul style="list-style-type: none"> Need for national coordination and ongoing focus on OTDT (OTDT is a small portion of Eastern Health's business; the region doesn't have resources to devote to national coordination/consistency) 	Both	Funding
83	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Current state issues / opportunities: <ul style="list-style-type: none"> Re transplant waiting times / wait list – no outcry from public 	Both	Transplantation
84	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Level of support for national system design / options <ul style="list-style-type: none"> Support for national approach Support CBS mandate Need to address efficiency, effectiveness (both from financial and non-financial perspectives, e.g., quality adjusted life years gained) Need for development of national Standards of Practice Recommend looking at linkages / partnerships with national NGOs such as CF and Kidney Foundation Support national data repository and national registries 	Both	Policy development
85	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Level of support for national system design / options <ul style="list-style-type: none"> Need to address efficiency, effectiveness (both from financial and non-financial perspectives, e.g., quality adjusted life years gained) 	Both	Processing and Distribution
86	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Level of support for national system design / options <ul style="list-style-type: none"> Business case needs to speak to opportunity to redirect funding from dialysis to kidney transplantation 	Both	Funding
87	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Level of support for national system design / options <ul style="list-style-type: none"> Recommend looking at linkages / partnerships with national NGOs such as CF and Kidney Foundation Support national data repository and national registries 	Both	Principles
88	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Level of support for national system design / options <ul style="list-style-type: none"> Support national data repository and national registries 	Both	Information management, measurement and reporting
89	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Level of support for national system design / options <ul style="list-style-type: none"> Understand and support need for data for benchmarking, accountability – this presents huge challenge Support for transparency of waiting times / waiting listing criteria for the public 	Both	Audit and accountability
90	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Tissue specific comments <ul style="list-style-type: none"> Supportive of looking at options for consolidating tissue processing Lack of data – huge issue – particularly around tissue donors 	Tissue	Processing and Distribution
91	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Tissue specific comments <ul style="list-style-type: none"> Challenged by ensuring that patients are informed that they have had a blood transfusion; this challenge is even greater for informing (gaining consent from) tissue recipients 	Tissue	Transplantation

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92	Expert	Detailed Notes	St. John's Meeting with OPEN	2010-02-04		Other comments: <ul style="list-style-type: none"> • Work in partnership with NB and NS • Attempting to working with other RHAs in NL to increase awareness about potential for donation and create OTDT presence 	Both	Public and Professional Awareness and Intent to Donate
93	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • Case for change misses addressing the referral process for donation. We need to make the system more streamlined for neurosurgeons, intensivists, etc. • Need to shift thinking /mind set to one where donation is part of patient care. 	Both	Donation
94	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • Need to include donation as part of curriculum in professional education i.e. post grad, during medical school and residency. 	Both	Public and Professional Awareness and Intent to Donate
95	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • An OR nurse commented on impact of tissue retrieval on elective OR time, i.e., cancellation of elective OR slates due to donation makes garnering support for donation challenging. Need to consider in resourcing options to minimize such cancellations. 	Both	Funding
96	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		What is the most important element that needs to be fixed? <ul style="list-style-type: none"> • The competition for scarce resources (OR time). The current situation of penalizing surgeons (losing their OR time) needs to be addressed. (It was stated that if retrieval occurs outside of booked OR time, the time dedicated to retrieval in some instance will be considered part of the surgeon's booked /elective OR time.) • Need to address barriers of neurosurgeons referring donors that result in cancellation of their OR slates cancelled to referring a donor...and the resultant transplant surgeons. 	Both	Funding
97	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Are there other options we should consider as part of system design? <ul style="list-style-type: none"> • Consider a national allocation centre to guide what organs are offered • Related to accountability in allocation: need to understand and track reasons why offered organs are rejected • Information about why organs are accepted/ rejected is needed to support understanding of utilization and how practices change; we need to measure utilization • Part of transparency is reporting back to donor programs; need to close loop related to assessment of potential organ donors • Need to address the effort / resources devoted to support allocation and offer management process; suggestion that an offer management system be developed 	Both	Allocation
98	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Are there other options we should consider as part of system design? <ul style="list-style-type: none"> • Support for national standards and national policies 	Both	Policy development
99	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Are there other options we should consider as part of system design? <ul style="list-style-type: none"> • Consent and other types of registries need to be interoperable to avoid silos among registries --- need to address privacy issues. Recommend national model to support inter-operability and capacity to input data locally. • Support recommendation to for electronic consent to donate registry that is accessible to OTDT program staff. 	Both	Public and Professional Awareness and Intent to Donate
100	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Specific feedback on Case for Change (Tissue or Organ) <ul style="list-style-type: none"> • Development of information systems and national approaches for donation should apply to tissue as well as organs. Recommendation to avoid silos between tissues and organs that create challenges. • Addressing traceability is critical. St John's has an established manual system for traceability of tissues. By using this paper document system, backed by disk, they have successfully traced product to the recipient but the system needs to be automated. 	Both	Information management, measurement and reporting
101	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Specific feedback on Case for Change (Tissue or Organ) <ul style="list-style-type: none"> • Recommendation to seek out all potential tissue donors and to share tissue nationally and internationally (from social perspective). Would be cost-effective if cost recovery were pursued. 	Tissue	Processing and Distribution
102	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Other discussion topics arising <p>Question about whether organs are a local, regional, provincial or national resource</p> <ul style="list-style-type: none"> • How much coloration between registries and provincial EHRs? ...response...consultation with Canada Health Infoway --- need to address interoperability up front... • Is there a role for lead provinces to develop systems, guidelines, etc. --- head nodding about building on existing models and initiatives...and extend them nationally rather than rebuilding a national approach.... e.g., the ON consent to donate registry 	Both	Policy development
103	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Other discussion topics arising <p>Model needs to be developed that takes into consideration ICU capacity. ICU must have donation care as part of model.</p>	Organ	Donation
104	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		Other discussion topics arising <p>Would love to see a future where there is a possible collaboration between CBS and provincial records - electronic health system records. Donors would be identified once and the information shared nationally.</p>	Both	Information management, measurement and reporting

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105	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Need to enforce legal consent to donate in practice...need to recognize donor cards are legal...approach to families needs to be to inform rather than an ask...needs a public awareness.don't see driver's or health care cards...intensivists would hugely benefit from online access at point of care to enable clinicians to understand patients' wishes Problem...with enforcing consent without talking to the family is the need for social history Support for access at bedside to consent registry Public education...CBS adds on radio generated discussion about O&T donation...important role for CBS --- support for continued role of CBS in public awareness and advertising Advocate a public awareness system with strong messaging like "live life and love life" 	Both	Public and Professional Awareness and Intent to Donate
106	Expert	Summary Report	St. John's Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other information 3 donor coordinators (2 x 0.5 FTE, 1 FTE) serve the entire province Have had to turn down cornea donors because of access to OR for retrieval OPEN coordinators fly out to the donor on occasion and transmit diagnostics via PACs 	Both	Funding
107	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Governance options should include representation from all provinces – large and small Need to ensure options recognize unique features of a smaller program with population scattered over a large area and no transplant program 	Both	Policy development
108	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Use health care card (and renewal process) as affirmative consent to donate registry as health care number provides unique life long identifier; add characters to the ULI to indicate type of donor, e.g. 123456B for bone donor; 234567S for skin donor, etc 	Both	Public and Professional Awareness and Intent to Donate
109	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Need more discussion about funding for transplant follow-up (in light of having no formal transplant program), organ and tissue retrieval, education, etc. Because the later are add on activities they fall lower on priority list. 	Both	Transplantation
110	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Accountability for development of programs by province Availability of standards and compliance to standards, including who has responsibility for ensuring / monitoring compliance Uniform coroner arrangements across Canada 	Both	Audit and accountability
111	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Education of public and health care professionals is critical Address public awareness of OTDT 	Both	Public and Professional Awareness and Intent to Donate
112	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Address funding models 	Both	Funding
113	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Options presented that are not supported... Organs and tissues being shared nationally National system for organ distribution (x 2) – organs should be offered in donor's home province first 	Both	Allocation
114	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Options presented that are not supported... More support (funding/resource allocation) for tissue donation. Untapped potential, however need the resources in place to begin 	Both	Funding
115	Expert	Summary of Feed-back/Event Evaluation	Fredericton Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other comments: There seems to be a big divide between tissue and organ in NB (so big I didn't dare talk about it) 	Both	Policy development
116	Expert	Summary of Feed-back/Event Evaluation	St. John's Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Organs Case for Change should...involvement of neurosurgeons/neurologists in donor recruitment efforts Streamline system for identification and referral of potential donors from centres outside of urban / academic settings Identify and address the road blocks to advancing organ donation 	Organ	Donation
117	Expert	Summary of Feed-back/Event Evaluation	St. John's Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Tissues Case for Change should... Identify and address the lack of traceability Improve standardization, safety and quality of tissue 	Tissue	Safety and quality
118	Expert	Summary of Feed-back/Event Evaluation	St. John's Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> Other options to consider... Use health care card as a mechanism to register individual wishes to be an organ donor – given that it expires every few years – registration of consent to donate could be part of the renewal process 	Both	Public and Professional Awareness and Intent to Donate
119	Expert	Summary of Feed-back/Event Evaluation	St. John's Multi-Disciplinary Event	2010-02-04		<ul style="list-style-type: none"> General comments: Makes sense to have a national strategy (x 2) 	Both	Policy development

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120	Expert	Summary Report	Halifax Opportunities in the Medical Examiner Service	2010-02-05		<p>Current state opportunities, issues, challenges 8,000 deaths per year in NS with 4,800 going through the medical examiner with 1000 autopsies. Currently 50% of the Regional Tissue Banks donors go through the medical examiner office. The NS Medical Examiner office is considering a process where ALL deaths in the province would go through their office. This would support consistency, integrity and comprehensiveness in mortality data. It would also provide a ready opportunity for the identification and referral of tissue donors.</p> <p>NS is considering (this has not been shared publicly) developing a proposal where the Medical Examiner Service would take a leadership in the identification, referral and recovery of tissue donors. They are considering the inclusion of a recovery suite in their new facility. They indicated they believe their proposal would demonstrate more consistency and cost efficiency than the current hospital based recovery model.</p> <p>The medical examiner service reports through Department of Justice. Medical examiner and coroner services are provincially based with policy linked to provincial legislation. There are no national policies for medical examiner and coroner services.</p>	Tissue	Donation
121	Expert	Summary Report	Halifax Opportunities in the Medical Examiner Service	2010-02-05		<p>What options we should consider as part of system design? The potential for medical examiner and coroner services to take a more active and operational role in both the identification and recovery of tissue donors.</p>	Tissue	Donation
122	Expert	Summary Report	Halifax Opportunities in the Medical Examiner Service	2010-02-05		<p>What options we should consider as part of system design? The inclusion of medical examiners and coroners in system design discussions. There is a meeting of medical examiners and coroners in Whitehorse in June. It was indicated that there was an opportunity for CBS to engage this group at that meeting; also indicated the willingness to facilitate a teleconference of colleagues prior to that meeting to help inform system design.</p>	Tissue	Donation
123	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>Current state opportunities, issues, challenges There is a culture of protectionism within the tissue community with programs not sharing information. This impacts quality as well as the ability to service our patients. We need to get beyond protectionism and start system thinking.</p>	Tissue	Safety and quality
124	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>Current state opportunities, issues, challenges Their customer service model seems distinct. This model includes education of end users including the provision of advice as to product utilization. It is focused not just on filling an order but on relationship development and ensuring the maximum utilization of the gift.</p>	Tissue	Transplantation
125	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>Current state opportunities, issues, challenges There is no professional identity. The field of tissue banking has no professional profile or recognition. This needs to be addressed to recruit and retain staff. Perhaps affiliations with college programs who could provide academic training while technical training is provided by tissue banks. Suggestions included job fairs or educational sessions with lab, nursing, science programs.</p>	Tissue	Processing and Distribution
126	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>Current state opportunities, issues, challenges The provision of a multi-province broad geographical recovery service is becoming challenging. The costs of transportation as well as the ability to staff. The RTB is currently turning down donors due to lack of recovery capability (staff). This lack of recovery capacity conflicts with the Legacy of Life professional awareness campaign to increase referrals (as these donors are declined due to recovery capacity hospitals are less likely to refer future donors)</p>	Tissue	Funding
127	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>Current state opportunities, issues, challenges The RTB is developing a Web Based training program which could be expanded beyond its program.</p>	Tissue	Information management, measurement and reporting
128	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>Views on elements of Case for Change (if discussed) Indicated that the challenge of misalignment of a manufacturing model located within the hospital service delivery model. This is common in tissue banking – is there a connection to the organization – is tissue banking a service the organization wishes to provide? Their administration is trying to work to improve the misalignment and better support the work of the RTB. Partnerships are a key strategy their administration is pursuing.</p>	Tissue	Processing and Distribution
129	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>What are the most important elements that need to be fixed in national system design? You must increase and control the supply of donor tissue.</p>	Tissue	Processing and Distribution
130	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>What options we should consider as part of system design? Principle – Right tissue to the right patient at the right time. Principle – Good stewards of the gift (donor tissue). Maximize the donor gift. Principle – Good stewards of the public purse</p>	Tissue	Policy development
131	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>What options we should consider as part of system design? End user engagement – education and customer service must be a key focus</p>	Tissue	Transplantation
132	Expert	Summary Report	Halifax Multi-Disciplinary Event	2010-02-05		<p>What options we should consider as part of system design? Partnerships HR Strategy – create a professional identity to recruit and retain the staff needed to support a national tissue service</p>	Tissue	Processing and Distribution

#	Forum Type	Source Document	From	Date	Review point	Comments/Input (some may be paraphrased)	Organ / Tissue	Category (using new list - Integration Discussion for Organs only; Tissue may differ slightly)
133	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Current state opportunities, issues, challenges Tissue Bank is a recovery organization which has developed processing contracts with two US processors MTF and Regeneration Technologies. With MTF they provide donor tissue and receive processed product back for distribution. With Reg Tech they provide donor tissue and receive recovery fees. They receive funding from the WRHA, recover tissue from the Winnipeg area, they forward tissue to MTF and Reg Tech and redistributed MTF processed tissue to the WRHA surgeons. For tissue distributed external to WRHA they cost recover. Note: Reg Tech has recently asked them to reduce their supply of tissue due to the current surplus of donor tissue in the US. Their model allows them to provide a full range of tissue products to the end users – they function at a cost neutral basis for the WRHA. Tissues classified as medical devices are outside the scope of their contractual relationships and the WRHA still purchases these directly from MTF and other organizations. There HTGA identifies 3 distinct donation org – Transplant Manitoba, the Eye Bank and the Tissue Bank.</p>	Tissue	Processing and Distribution
134	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Current state opportunities, issues, challenges They have required referral which is directed or managed through their admitting departments (who are promptly notified of all deaths).</p>	Tissue	Donation
135	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Level of support for development of a national OTDT system Support for centralization and streamlining to support quality and specialization.</p>	Tissue	Safety and quality
136	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Level of support for development of a national OTDT system Support for the call centre approach.</p>	Tissue	Donation
137	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Views on elements of Case for Change Identified the need for an ethical component or assessment of system design.</p>	Tissue	Principles
138	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Views on elements of Case for Change Contract processing could be a cost effective component of system design.</p>	Tissue	Processing and Distribution
139	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>What are the most important elements that need to be fixed in national system design? Donor supply – required referral and the implementation of social marketing strategies to increase donation.</p>	Tissue	Public and Professional Awareness and Intent to Donate
140	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Success factors Development of a solid business case was key to the successful implementation of their recovery organization / US processor partnership model. At first their executive was challenged by the fiscal and business realities of tissue banking but their business case sold it.</p>	Tissue	Funding
141	Expert	Summary Report	MB - Tissue Bank Manitoba Staff	2010-02-05		<p>Other topics discussion They utilize 4 persons for a recovery team. They distribute both frozen and freeze dried MTF products.</p>	Tissue	Processing and Distribution
142	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Organs Case for Change should...</p> <ul style="list-style-type: none"> • Focus on donation – without improvement in this area it will be difficult to address allocation • Limit family right to over ride donors' wishes • Ongoing measurement of the true potential for organ donation • "there is enough on your plate" 	Organ	Public and Professional Awareness and Intent to Donate
143	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Tissues Case for Change should...</p> <ul style="list-style-type: none"> • Address funding; as tissue donors increase so does the need for resources; increased donors means increased processing needs and increased funds to do the job. Without an increase in donors there will always be insufficient allografts across Canada to meet the demand 	Tissue	Funding
144	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Tissues Case for Change should...</p> <ul style="list-style-type: none"> • Education of physicians/end users on tissue types and importance of tracking events, reactions, etc. 	Tissue	Safety and quality
145	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Other options to consider...</p> <ul style="list-style-type: none"> • Mandatory registry of death with screening questions posed to identify donors • Encourage medical staff to approach families for donation 	Both	Donation
146	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Other options to consider...</p> <ul style="list-style-type: none"> • Ensure that hospitals are accountable • Physician support for work 	Both	Audit and accountability
147	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Other options to consider...</p> <ul style="list-style-type: none"> • Address organ and tissue tracking from donor to recipient, just like CBS – vein to vein 	Both	Safety and quality
148	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		<p>Other options to consider...</p> <ul style="list-style-type: none"> • Strong business case given understanding that there are no new funds for Health • Cost benefit needs to be clear; effectiveness needs to be quantified; strong business case required 	Both	Funding

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149	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		Options presented that are not supported... • Having difficulty with national quality system - how does CBS approach this?	Both	Safety and quality
150	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		Options presented that are not supported... • Incentive payments particularly for physicians	Both	Funding
151	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		Options presented that are not supported... • Execution plan to support strategy	Both	Policy development
152	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		Options presented that are not supported... • See a role for CBS in registries and procurement, unclear about how CBS / CCDT could or should be involved in tabulation outcome results, evaluation of medical utilization, etc. This seems to be the role of provinces/territories – not CBS	Both	Processing and Distribution
153	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		Options presented that are not supported... • Having difficulty with national quality system - how does CBS approach this?	Both	Safety and quality
154	Expert	Summary of Feed back/Event Evaluation	Halifax Multi-Disciplinary Event	2010-02-05		Other comments: • Wonder how rural areas will fit in – or will they be phased out to focus more funding on major centres • It is hard to really discuss OTDT when we have not been privy to the current state of OTDT – establishing what exists in the current system must not be underestimated; the perceptions are disparate among stakeholders	Both	Funding
155	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		Are we missing any critical elements in the case for change? • Need national policy leadership to increase donation. o National principle created with equity to be a donor	Both	Public and Professional Awareness and Intent to Donate
156	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		Are we missing any critical elements in the case for change? • Agree from principle perspective that there is a need to address allocation, but view that we need to first focus on donation	Both	Allocation
157	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		Are we missing any critical elements in the case for change? • Priority is donation...need national policy leadership to increase o The equitable treatment of potential organ donors the same as other patients	Both	Policy development
158	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		Are we missing any critical elements in the case for change? • Need to consider geography --- need commitment and resources to address geographic challenges...need to differentiate Canada from international models due to geographic differences. • Need to have a strong business case...cost advantage Need ability to build a business case for a successful federal case optimizing living donation • Accountability for hospitals / units ... around donor potential and expectations ...should be addressed...need to understand why...need system of incentives and penalties to support sustained donation...look to US model for funding donation activity	Both	Funding
159	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		What is the most important element that needs to be fixed? • Highest priority is to increase donation as there is a fundamental is the shortage of organs. • Donor identified away from a trauma centre...How do you transport donors to major centres for donation to proceed? What do other centres do? o Principle established that all should have right to donate...different logistical challenges and priorities and procedures in each province...models vary...experts go to donor; donor transported to major centre...Could CBS bring standardization to this...geography and family views are important considerations. Body can travel to organ procurement area. o Atlantic system works well...regular review of lists and allocation algorithms...focus on organ donation and supply first...very strongly...	Both	Donation
160	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		What is the most important element that needs to be fixed? • Need to focus on and resource donation as a priority. Lack of resources – currently and in future...therefore need to concentrate resources in areas that will make the most difference...that is donation...	Both	Funding
161	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		What is the most important element that needs to be fixed? Allocation will be difficult to standardize...NS does it for 4 provinces o Differences in values across the provinces...this impacts allocation for kidneys...life sustaining organs are a different case.	Both	Allocation
162	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		What is the most important element that needs to be fixed? o Why can't other regions (NB, NL) retrieve DCD organs, opportunity to for expanded or extended criteria donors	Organ	Donation
163	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		What is the most important element that needs to be fixed? o Need to educate public and need physician champions then backed with cash.	Both	Public and Professional Awareness and Intent to Donate

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164	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<ul style="list-style-type: none"> Priority are medical champions. What do you need to get physicians on board? --- need paid physician champions that are held accountable for their jobs--- adequate resource for performance of organ donation roles....recognizing that these are important roles --- ORs need to be recognized....(for organ donation living and deceased and tissue donation) Donation should be existing practice. 	Both	Donation
165	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<ul style="list-style-type: none"> Recommendations and options established need to have interprovincial business case to optimize donation 	Both	Funding
166	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<ul style="list-style-type: none"> Founding premise...Potential organ donors must be considered high priority patient...if this principle was endorsed, resourcing prioritization etc. would follow. 	Both	Donation
167	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<ul style="list-style-type: none"> Strong support for transparency... Measurement to support decision making....need to drive measurement and consistent, system wide improvement. 	Both	Information management, measurement and reporting
168	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>What needs to be fixed</p> <ul style="list-style-type: none"> Need data...1/3 show of hands on utilization of data... need comparability...need to ensure consistent data collection and cleansing...and who is going to pay for entry, -- need national system that is reliable and resourced --- Data is only as good as input: quality in quality out 	Both	Information management, measurement and reporting
169	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>What needs to be fixed</p> <ul style="list-style-type: none"> Very good recommendations on donation side. Funding will be critical along with education. If separate funding is flowed to support donation, it removes the competition for elective resources... <ul style="list-style-type: none"> Need to be careful to avoid the view that organs are being bought Need to understand costs of donation Want to be careful that funding is a reason why people can become donors....need adequate resources to fund donation teams and ICUs --- tissue 	Both	Funding
170	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<ul style="list-style-type: none"> Need to shift the paradigm...donation needs to be provided at the same opportunity level as other services...whether transplantation or other health services. Need national principle of equity for donation and transplantation. Kidney Foundation of Canada....has spent \$\$ but not effective...need to consider societal aspects of donation 	Both	Donation
171	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<ul style="list-style-type: none"> 11 donors in 9 weeks...in Cape Breton...recently...success due to investment in professional education...investment in and recruitment of champions medical and nursing, structure / process to accept donors. Discussion occurred of potential that hospital funding be tied with donation 	Both	Funding
172	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		Build onto the success within the medical community / presumed consent to donate.	Both	Donation
173	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> Principles...dismayed to see privacy at top of list...it's a factored to be considered and addressed...but it shouldn't be a barrier to access...doesn't belong at list of emphasize need that privacy is not a barrier 	Both	Principles
174	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>Are there other options we should consider as part of system design?</p> <p>Discussion: In Florida...corneas are collected in the morgue...where view is when you die you are a donor --- is that type of option on the table?</p>	Both	Donation
175	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> Principles...dismayed to see privacy at top of list...it's a factored to be considered and addressed...but it shouldn't be a barrier to access...doesn't belong at list of emphasize need that privacy is not a barrier....reword 	Both	Principles
176	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <ul style="list-style-type: none"> Committees have done a good job identifying the case for change --- Next important step.... address the lack of measurement, tracking, traceability and measurement to support decision making....need to drive measurement and consistent, system wide improvement 	Both	Information management, measurement and reporting
177	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <ul style="list-style-type: none"> Believes that donation rate will drop off if organs exported out of province...to detriment of a region. 	Both	Allocation
178	Expert	Summary	Halifax Multi-Disciplinary Event	2010-02-05		<p>Other comments</p> <ul style="list-style-type: none"> In Atlantic Canada health budgets are 50-60% of total provincial budgets... so additional \$\$ are extremely unlikely Need to be aware that not everyone supports transplantation....some view that \$\$ are wasted on transplantation. 	Both	Funding
179	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Are we missing any critical elements in the case for change?</p> <ul style="list-style-type: none"> We did an extensive community consultation with CCDT- Aboriginal, Indo-Canadian and Asian-Chinese community. I have worries about ideas talked about in the past, especially about community development, which have not received the appropriate community development model solution. One thing that gets diminished in the Spanish model -- they are working with a less diverse model. Overall, the case for change sounds like a fabulous plan -- needs more focus and attention on community development. 	Both	Public and Professional Awareness and Intent to Donate

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180	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> • Availability of donor organs (quoted statistics on % of donors from deceased/living. Living donation is increasing and we need to go more to living donors.) • St. Paul's Hosp has done only 3 DCD donors shortly after the DCD was in place and none since. Source of anxiety - lack of deceased donors. 	Organ	Public and Professional Awareness and Intent to Donate
181	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> • National lack of understanding regarding if we are performing worse or better than other parts of the country. Can we improve our deceased donor opportunities? Should organs be a national resource rather than a regional resource? 	Both	Information management, measurement and reporting
182	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> • The OPOs are doing a good job. The ICUs are the gatekeepers of the system. It is hard for me to push ICU to say why you aren't getting more donors – when that is their business. But that is what controls # of donors. 	Organ	Audit and accountability
183	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<ul style="list-style-type: none"> • I think that BC has done a good job keeping our head above water through innovation of care in chronic conditions. We are not recognized for keeping the chronic liver patient alive. Our work isn't adequately resourced – throughout the entire programmatic level. Struggling to do what we can -- living donor struggling for resources and to manage patients that are very complex. 	Organ	Funding
184	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<ul style="list-style-type: none"> • Critical care is reviewing data from one site – there are not too many opportunities for donation. Low donor rates are not due to missed opportunities. Need discussion at all levels – including at community level. Have a lot to do in terms of public education – and professional education. • Need to educate. If supported by public – leaders in hospitals in ICU, Emerg, and Administration – opportunity to bring it forward. We (transplant physicians) are seen as having a vested interest so we can't approach our colleagues. The public needs to prompt this and get the message to ICUs and Emerg. Need a "religious fervor" – to get this process moving which will require a lot of effort and has some financial implications. Here there are colleagues with negative comments re: use of ORs for donors, etc as they do not see the patients on the waiting lists. 	Organ	Public and Professional Awareness and Intent to Donate
185	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • Donation – more than semantics. System needs to provide for patients who have indicated willingness to donate organs. Needs community based education – high schools, signing cards, etc. Much is driven by families. Could make it the system job to make it the right of every patient to donate. • Informed consent – we have struggled with this in the community. Signing the card or registry – most people do not understand this. Even more difficult to get informed consent with DCD. We are not dealing with informed consent issue very well. • What about Presumed consent? (PN) --- I am a bit nervous to do this at this time. Would require significant education. We could, in fact, lose some organ donors. Without relevant public/professional education there is a risk, especially given our heterogeneous population. • Informed consent is important for person signing it. What is more important - Dad sits at the table with all family and has the discussion. Need to get the word out and get high schools involved. Aboriginal communities may not be involved – lacking in trust. Try to change culture through young people – work through schools. • Efficacy issue. Transplant tourism - speaks to resources of educating patients about options. 	Organ	Public and Professional Awareness and Intent to Donate
186	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • The solutions may need to be flexible – one size may not fit all. • Major underpinning – going to cost many dollars in personnel 	Both	Funding
187	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Are there other options we should consider as part of system design?</p> <ul style="list-style-type: none"> • Efficacy issue. Transplant tourism - speaks to resources of educating patients about options. Speaks to need to penetrate earlier in the chronic disease process. Transplant tourism is a symptom of ineffective donation rate. 	Both	Transplantation
188	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>A key part of this work (to standardize processes, develop policy) is the resourcing side. The biggest hurdle to overcome is financial at the provincial level. As someone engaging the bureaucracy in BC – they do not have an issue of low volume and high cost. They want it done well. The challenge may be to say "I could make it better if ...". Needs to be a clear funding strategy. Can't do all this work and just get a public advertising campaign. There needs to be a grinding at the DM table – must have great business cases. First satisfy the financial preoccupation. Patient safety, quality of care – quality of life – these appeal to the public. There is no simple answer. So many competing issues. Need to be sure transplantation gets connected to broader continuum of care without losing focus. Look for connections – Chronic Kidney Disease and quality of care – healthier population.</p>	Both	Funding
189	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Any other areas that Ministry and Finance people are interested in? For example, patient safety, transparency?</p>	Both	Safety and quality
190	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Cost benefit to include utility and equity - it was done initially for heart patients (many years ago). The population has changed. We now transplant older people and people who may die within 3 years. Harder to make the argument – can't use the example of the 45 year old as it is now 65 year old who is getting the Tx.</p>	Both	Allocation
191	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>We have good actuarial tables re: liver transplants. Need to have 50% 5 year survival to get a transplant. Model – preserving life years over the disease process. Need to show quality of life is superior. Also showed 60% of liver transplant patient's return to pre-morbid activities (jobs). How do you cost this?</p>	Organ	Transplantation

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192	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <ul style="list-style-type: none"> Should organ and tissues be married to help drive the entire enterprise? For example, going to the public. Tying organs and tissues together – may have strength Canada has a great opportunity. We learned from Krever – we had to reinvent ourselves. Now is time to develop a whole new national concept for organs and tissues. We can do it. Think of Canadian blood system compared to the American now. 	Both	Policy development
193	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Specific feedback on Case for Change (Tissue or Organ)</p> <ul style="list-style-type: none"> No question that there are business cases for tissue (revenue neutral or revenue generating). More kidney transplants – can save significantly on health care burden. Costs need to be modeled. Orthopedic Surgeon – we have looked at as high cost – low volume for transplants. Currently, we get tissue from US and it costs a lot of money from private sources. Bundle instruments with tissue/ ligaments. Huge business case to be made for tissues. In some cases the Cdn tissue banks are more expensive than US banks. US tissue is sterile – much preferred. Need to set up as cost neutral or beneficial. 	Both	Funding
194	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Other discussion topics arising</p> <ul style="list-style-type: none"> Donor rates - Cdn Liver Tx group has tackled these problems across the country. We don't know why organ donor rates differ so dramatically. For a period of time Calgary was very high and now they are very low. There is significant range and fluctuation across the country. PN – where is the data to capture it to address questions? With multicultural community. Patients who require transplants but their culture does not believe in donation. What is CBS doing with this? 	Both	Public and Professional Awareness and Intent to Donate
195	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Other discussion topics arising</p> <ul style="list-style-type: none"> Is Quebec involved as well? PN – Quebec did not join the other provinces to sign on for CBS to develop registries. Federal dollars are available to include Quebec in various initiatives. We are seeing Quebec wanting to join in on national initiatives. Do they not have paid physician positions whose responsibility it is to ensure they are delivering? Not currently happening in Quebec Coordination is a foreign concept. Currently regions in BC are funded on regional budget; transplantation takes patients out of their regions. 	Both	Funding
196	Expert	Summary Report	Vancouver Multi-Disciplinary Event	2010-02-08		<p>Other discussion topics arising</p> <ul style="list-style-type: none"> The current liver pay back system is not working well.. Payback – many logistical and equitable issues. Improved standardization of listing. We view it in a different way - makes people more uniform. Need to start with standardization. Top down approach – using Accreditation Canada (AC) standards and metrics. AC is a good start. Not insisting that hospitals show number of potential, converted donors, etc. AC will help globally but won't show all the metrics. Nobody tracks it. We need donor metrics and they need to be used in accountability. AC is one of the few organizations that can mandate data reporting on specific dimensions. AC will be reasonable for hospitals. Hospitals like to be transplant hospitals. To be a donation hospital – is more of a slog (funds, resources). Accreditation may be a stick to make people do what they should be doing. How can we create incentives for this donation specialty? Some hospitals in Canada wave the banner of transplant – we have not noted that transplant will attract business, etc. Some regions identify a donor hospital – one in Quebec City (SS) – which does not do transplants. Some hospitals embed it in their mission – work with hospital administrators. 	Both	Audit and accountability
197	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		<p>Current state opportunities, issues, challenges</p> <p>Timing is very good to consult– people are ready. From OEC – feel very positive sense that we are going in the right direction. The background conversations – “let’s get on with it”.</p>	Both	Policy development
198	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		<p>Level of support for development of a national OTDT system</p> <p>Doesn't see any resistance from the physician side. Western Canada docs – there is interest to move forward. Branding is a big issue. Tissue/organ clinicians are not even sure why they are going to a “blood” meeting. Why does Canadian Blood Services want to meet with us? This is part of the purpose of this engagement.</p>	Both	Audit and accountability
199	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		<p>Views on elements of Case for Change (if discussed)</p> <p>Biggest concern going forward is not the physicians – they generally want the same thing. Concern – how do you get diverse OPO's to move together?</p>	Both	Policy development
200	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		<p>Views on elements of Case for Change (if discussed)</p> <p>Question – how do you moderate threat that regions with good donor rates may be disadvantaged? If there are standardized protocols that people follow – then the regional discrepancies will be shown to relate to the region and not the system. It may turn out that regions do more than they expect – or less. Very hard to predict how a national system of allocation would unfold.</p>	Both	Allocation
201	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		<p>What are the most important elements that need to be fixed in national system design?</p> <p>Standardized procurement activities</p>	Both	Processing and Distribution
202	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		<p>What are the most important elements that need to be fixed in national system design?</p> <p>High urgency patients are easy to agree from the patient perspective. Trust is a big issue.</p>	Both	Allocation

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203	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		What options we should consider as part of system design? We need to look at outcomes of the patient and also outcomes of the organ. Information Systems – this can be positioned as a benefit to CBS involvement.	Both	Information management, measurement and reporting
204	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		What options we should consider as part of system design? Would like to see national allocation.	Both	Allocation
205	Expert	Summary Report	Vancouver Local connection of OEC and community	2010-02-08		Other topics discussion BC Transplant - in transition and some uncertainty. May be an opportune time to align them with a national approach. There is likely going to be some realignment in BC health system - The level of complexity is so great – perfection will be the enemy of good.	Both	Policy development
206	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		The Organs Case for Change should also include..... <ul style="list-style-type: none"> • Gap analysis • Ethical framework • Situating donation as part of the transplantation continuum of care (instead of separate silos for donation and transplantation and situating transplantation in the chronic disease continuum of care) 	Organ	Policy development
207	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		The Organs Case for Change should also include..... <ul style="list-style-type: none"> • Algorithms and times (wait times?) • National metrics (standardized and explicit) with respect to donation 	Organ	Information management, measurement and reporting
208	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		The Tissues Case for Change should also include..... <ul style="list-style-type: none"> • cost analysis • recognition that tissue procurement should not be seen as a “cash cow” to fund solid organ transplant • some preliminary data on cost benefit/research of import vs home grown tissue • Some reflection on end users/tissue usage and a realistic look at the current status in Canada 	Tissue	Processing and Distribution
209	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		The Tissues Case for Change should also include..... <ul style="list-style-type: none"> • 99% of Canadians likely have no idea about the breadth of tissue donation and transplantation in this country. [I think] it is imperative that the system inform Canadians that some of their “minor” surgeries are in fact tissue transplants. 	Tissue	Transplantation
210	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		Other options that should be considered as part of national system design are..... <ul style="list-style-type: none"> • cost benefit of evolving tissue transplantation techniques such as osteochondrial grafts, etc. 	Both	Transplantation
211	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		Other options that should be considered as part of national system design are..... <ul style="list-style-type: none"> • Should provincial entities identify a network OPO site (s) to enable CBS vision? • Public education and professional education as a critical piece of this. And with education in place would be supportive of presumed consent • Introduction of organ donation issues into the school curriculum • Multicultural issues/plans and public education strategies 	Organ	Public and Professional Awareness and Intent to Donate
212	Expert	Summary of Feed-back/Event Evaluation	Vancouver Multi-disciplinary event	2010-02-08		Other options that should be considered as part of national system design are..... <ul style="list-style-type: none"> • Clear funding strategy • Costing and funding details • Cost analysis supporting transplantation. It is not always cost effective – we must also focus on quality of years/life preserved. 	Both	Funding
213	Expert	Meeting Notes	Calgary - Roundtable	2010-02-12		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • Organ utilization a big black area in Canada – have crude measures of organs utilized per donor – good date on that but it’s really unmonitored and not talked about. Very clearly substantial variation across the country. AB a primary exporter of organs so very apparent in our program. Is there discussion of making this a focus and in particular with respect to principles related to allocation – why shouldn’t we have nationally based principles of equity on the utilization of organs. Should we not have some system of oversight such that good organs that should be placed are placed? 	Organ	Audit and accountability
214	Expert	Summary Report	CST Meeting	2010-02-12		Current state opportunities, issues, challenges Overall system – pitfalls to avoid: Don’t think too small. This is a one-shot deal and the “ask” has to be big to start with. Registries, labs up to spec – discreet jobs and tasks. The whole system needs to be fixed. If we go at it task by task – DMs will say – we’ve heard about this again and again – haven’t you guys fixed this yet? (We as a community has failed to speak as one voice. CST, OPOs, provinces, etc.) One way of attaining would be to partner with CST – develop an effective policy generation – framework into how do we say what CST thinks about something. What does the CST as an organization think about CBS role in pan Canadian system. If we say this is what transplantation in Canada needs, then who are the OPOs versus the professional society. (Professional society endorsement – critical element. Society also has to make political movement demanding solution with provinces. CST must come out strongly in absence of that voice – one major pillar needed. The other pillar is the public voice coming out. To what extent can CST generate public groundswell too? i.e. in local environments? Kidney Foundation has	Both	Policy development

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215	Expert	Summary Report	CST Meeting	2010-02-12		CST didn't know where this was coming from. Concern in this forum that there will only be one solution brought forward and that it will be CORR. Integrated data management system would be best linked to the registries, outcomes of donors and recipients, wait listing, with a research basis so that enough meaningful data accessible to everyone. Would have same consideration for open access to researchers to access data base even if it was housed at CST. Confused – why now, why this and why not in a more integrated fashion? Concern with risk of duplication. Have heard for years that output from CORR unreliable, incomplete, post humous. There have been attempts to fix it, but no dedicated funding for data entry, analysis, etc. It won't allow us to determine who's not waitlisted; who's dying on the wait list; and it won't capture huge mortality that occurs before someone's transplanted. Not convinced it's an open system that anyone can access. Do we take something that's broken for decades (although it's fulfilled a function and is the only data we have right now) and seriously flawed to move it to something that's better or look at building something from the ground up that can be excellent to start. (current focus – post-tx outcomes)	Both	Information management, measurement and reporting
216	Expert	Summary Report	CST Meeting	2010-02-12		Level of support for development of a national OTDT system: Very supportive of this initiative. CST is the professional voice for transplantation. Would have liked CBS to have approached CST to ask who we would like to sit on our expert committees – we don't want CBS to tell us who the rep will be. Problem – CST feels they weren't recognized as the professional society to partner with. Other thing is that the members chosen to be the experts feel no obligation to feedback through the CST and build on our strength as CST because they believe they've been chosen as individuals. Is there a process for turning over Craig's position? There is a point to be made for continuity and inefficiency. Want CBS to be involved in our governance change. Want to be more responsive to our membership and can deliver policies and procedures as we've been unable to do. Want to have much better integration with organ and special interest groups. Once achieved, we'll be more useful to CBS and a better partner to CBS. Our current structure not amenable to me putting out a call and ask members what they think. Hopefully will have within next year. Lock step with	Both	Policy development
217	Expert	Summary Report	CST Meeting	2010-02-12		CST will get into professional accreditation. Have been discussions with College – recently met in Toronto. Two options – 1) full accreditation for tx as a subspecialty 2) special certificate of competency. Seems to be split on what would be better option. Full accreditation is a huge job – full time for many people. Not one that many want to take on as volunteers at this time. Special certificate would at least bring community together to develop guidelines and curricula on the training side. College keen to move it forward and tx identified as potentially one area that would move forward on that stream. Don't have consensus so will have to discuss with general membership. Moving forward and looking to contribute on work with accreditation of transplant programs – would be interested to partner with CBS. (5 sets of accreditation standards being developed by Accreditation Canada – have been piloted, etc. Key things in each set of standards will be mandated and tracked (metrics). CST could partner with AC to contribute accreditors with expertise to go out with the teams.)	Both	Audit and accountability
218	Expert	Summary Report	CST Meeting	2010-02-12		What options we should consider as part of system design? CST would love to partner with CBS on all aspects. Would love to put forward something on research for the government in the fall. CST has done survey on \$ being invested in research so know where we're at. (Should have another phone call to follow up – will arrange for that.) Would like to see the research element go forward in lock-step with everything else. Can research this initiative and publish – i.e. what's wrong, implement interventions and publish how this was accomplished and what the outcomes were. Small research piece but could give us something tangible.	Both	Research and development
219	Expert	Summary of Feed-back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		The Organs Case for Change should also include..... • Research funding • Funding on a per organ basis – back to the ICU, transplant centre	Organ	Funding
220	Expert	Summary of Feed-back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		The Organs Case for Change should also include..... • Media attention • Staff education • Pamphlets out • Consideration of how to change public perception / misconceptions re: donation (i.e. cultural issues, belief systems, etc.) • Improve / increase public awareness • Utilize various communication tools to get the message out there	Organ	Public and Professional Awareness and Intent to Donate
221	Expert	Summary of Feed-back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		The Organs Case for Change should also include..... • Whether or not Quebec has an independent system, it will need to participate fully in data sharing, organ movement in a Canadian system. • Consistency in organ utilization, i.e. criteria for organ function • Consistency in allocation approach – common criteria – data collection	Organ	Allocation
222	Expert	Summary of Feed-back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		The Tissues Case for Change should also include..... • Centralized banking registry to address supply and demand issues	Tissue	Information management, measurement and reporting

#	Forum Type	Source Document	From	Date	Review point	Comments/Input (some may be paraphrased)	Organ / Tissue	Category (using new list - Integration Discussion for Organs only; Tissue may differ slightly)
223	Expert	Summary of Feed back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		Other options that should be considered as part of national system design are..... <ul style="list-style-type: none"> • Include utilization of tissue – especially in ocular tissue world • Utilization of organs / tissues. 	Both	Processing and Distribution
224	Expert	Summary of Feed back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		Other options that should be considered as part of national system design are..... <ul style="list-style-type: none"> • Resources (human) for awareness and education • Compensation for living donors (resource support to address accommodating donors needs) • Assume mandatory donation with an "opt out" process on driver's licenses/provincial health cards 	Both	Funding
225	Expert	Summary of Feed back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		Other options that should be considered as part of national system design are..... <ul style="list-style-type: none"> • Assume mandatory donation with an "opt out" process on driver's licenses/provincial health cards 	Both	Donation
226	Expert	Summary of Feed back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		Options presented that I do not support are..... <ul style="list-style-type: none"> • Do not get reps provincially. Even within cities transplant programs/OPOs may not have agreement. In Alberta, there is some disagreement between North and South. Allowing only North representation will reduce buy in in Calgary. 	Both	Policy development
227	Expert	Summary of Feed back/Event Evaluation	Calgary Multi-Disciplinary Event	2010-02-12		Options presented that I do not support are..... <ul style="list-style-type: none"> • Allocation of funds based on utilization / performance / outcomes. Don't want this to foster a climate of competition across programs / regions. 	Both	Funding
228	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • Lack of ability to motivate Canadians to donate organs. Approval rate high in general yet we only motivate less than half to sign donor card or register, etc. We've not been able to convince people to act. Involves social marketing and I don't see that in your overall plan. Without helping to change people's opinion and motivate them to act, you won't be able to do all the good things you're talking about. We've spent a lot of time and effort and have not been able to develop a social marketing strategy for Canadians. • (We're using term public and professional awareness – this is a good example of something that benefits from economies of scale and that social marketing / awareness campaign best done nationally. Concern we're also hearing is to be careful that we create the downstream capacity in the system to handle potential increased donation. This is something CBS could do – can leverage the expertise they have on the blood side. Need for social marketing has been commonly expressed across Canada) • Daunting question – where do we start. The answer is everywhere. But danger of putting off public if we increase donation and system can't respond. • In Wpg inherent distrust in health care system which plays out in organ donation. The compass 	Both	Public and Professional Awareness and Intent to Donate
229	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • Donation hasn't been professionalized.. In critical care community, we say best place for these patients is in the ICU but not really, competing with the living. Teams are divided on this. So the idea that it's all part of our work is great if you're trying to set up a volunteer organization, so think it is time to professionalize this. Although US does better than we do, they are squeamish compared to the Europeans. When you talk about DCD, North America does controlled DCD, Spain does uncontrolled DCD. As neurosurgeons get better at craniotomies?? (not the right term) there will be a lot less control. Number of patients who cone and become neurologically dead is plummeting because surgeons now have figured out how to take the skull cap off and have patient survive. So if we're not emulating what other countries do, we won't get rates up. Reason the rates have stayed low is because care has improved. There is a lot more opportunity for donation in emergency than in ICUs. 	Organ	Donation
230	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		Are we missing any critical elements in the case for change? <ul style="list-style-type: none"> • Speaking to public trust in system theme – concept of equal access is generally agreed to. As kidney tx physician – wait times different across country. Public's loyalty is local – to ship kidneys before organ utilized locally should be avoided. (payback system in liver – forced them to look at listing practices and outcomes across jurisdictions. Has been accountability mechanisms to hold each jurisdiction accountable to play by the rules as there has been no national agency) are organs a local or national resource. Is payback a good or bad thing? If not, what are solutions vis a vis being net exporter of organs. 	Organ	Allocation

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231	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>Are we missing any critical elements in the case for change?</p> <ul style="list-style-type: none"> Equity – have been talking about jurisdictional and geographic but there are segments of society who cannot participate (e.g. African Americans in the US) so we need to be sensitive to this. Need to consider ethnocultural mix in our society. Not about payback but comment (pediatric nephrologist) – health care professionalism idea –important to roll this out to peripheral and community hospitals. Imagine this is an untapped resource that should be recognized. (Our experts are tertiary, most of these audiences are tertiary.) Don't have specific answer to payback question but made me think about when we went through period this fall when we were short of flu vaccine and came up with criteria about who should get it, who should come to clinics, etc. Significant segments of public disregarded this because at the end of the day they believed they had a right, despite criteria. But provinces responded differently, some turned blind eye, some got confrontational, some really sorted people out and there were some ugly scenes. We all say everything should be equal, but when 	Both	Allocation
232	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>Are we missing any critical elements in the case for change?</p> <ul style="list-style-type: none"> National resource – CCTN – most patients have no clue what's happening in provinces with no transplant centres. We were listing patients across country with no payback system in place. As a whole, the transplant centres have come up with listing criteria. Cases reviewed in national forum once a year to justify high status listing. Improvements to be made in terms of reviewing individual cases but we have overall consensus for listing status patients. Working on a payback system, if you have a patient from MB listed in your centre, you will receive a heart from MB as a payback. I think payback is appropriate. 	Both	Allocation
233	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>Are we missing any critical elements in the case for change?</p> <p>Advocate for national list – for one, we're not a cardiac Tx centre. Hard to advocate for Ontario – they think all organs should be there because they have the tx centres and aren't keen about sharing their organs. Have to know your own back yard very well and show you're doing due diligence to improve donation in your province. Just did audit of potential missed donors (2007?) – majority of them were cared for in ICU, not emergency room. You need to know where your donors are presenting in terms of donor management care. Potentially 23 hearts were missed so reviewing processes to improve donor heart identification in MB. 15 potential DCD candidates during that time too. Lots of room for improvement so to advocate for national list have to make improvements locally before we ask for national changes.</p>	Both	Transplantation
234	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>Are we missing any critical elements in the case for change?</p> <ul style="list-style-type: none"> Real time death audits for 4 sites, SBGH, HSC, Grace, 7 Oaks. ICU data base audit as well to validate ability to provide accurate data. Use these against each other to assure audit criteria accurate. Criteria come from notification document. Multiple reasons for organs not being identified, including consent. (some will consent other organs, but not heart – ethnocultural issues may be organ specific) Broader question – accountability is the larger issue to be addressed. The cardiac issue is peer pressure, no carrot, no stick. Has to be real accountability – once we decide route to follow, what are the consequences if we don't follow. Have to put a line where bad behaviour not acceptable and there have to be consequences. (Big discussion – but what are the mechanisms, e.g. legislative framework?) Every level has to be involved. In ON a number of years ago, for hospitals to get accredited, needed mandatory request for donation as part of post mortem packages. Have to start where institutional accreditation at stake for example so desired behaviours become normalized. (Yes, 	Both	Audit and accountability
235	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<ul style="list-style-type: none"> As part of kidney transplant review, reviewing organ allocation and have been strategizing and developing series of codes based on UNOS as to why a particular kidney was not allocated according to local algorithm. Wonder if a series of codes could be developed nationally as part of who is an eligible donor and if this would help to entrench accountability. 	Organ	Allocation
236	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<ul style="list-style-type: none"> Awareness point – get impression that public not really engaged in this like they are in blood. We all say it's important but these other things have to be in place before we can promote. Challenge this notion – don't think we should be afraid of raising public awareness and getting them engaged. That will create its own driver to the system and bring in new ideas and might help to forge directions for the system. I think it's the key element in this thing and should not wait until other ducks in a row. 	Both	Public and Professional Awareness and Intent to Donate
237	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<ul style="list-style-type: none"> Good point – push strategy can work well. A key success factor is the need for coordination because other capacities will quickly be seen to be huge gaps. Capacity in each local area needs to be determined and prioritize the elements so you don't get into a mess. Need to coordinate things like living donor reimbursement, etc. 	Both	Processing and Distribution
238	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> Opportunities – but issues related to native donation, range of services that we're trying to build and strengthen from that perspective but more to do re donation needs. Not a good public understanding of donation. 3 things come to mind. These are issues that have been around for 20 years. The whole Tx field needs to evolve. One thing that needs to happen is to professionalize the donation side. Seen in other jurisdictions, e.g. Spain. Key aspect, including public perception, donors in intensive care unit – at the same time, those who are care givers now become donation experts – it doesn't pass the "smell test" – that needs to change. Discrepancy needs to be addressed from perspective to local disincentives, public education, etc. In London ON, quite advanced in Tx field, and source of public pride in terms of what they did. Their organ donation rate was as high as anywhere in Canada. The two biggest jurisdictions in Canada have lowest rates so huge public education piece. Disincentives in hospitals are key – not enough beds, ICU always under pressure – to spend extra 24 hrs to process donor not acceptable. So professional education also important. One of biggest factors is the insidious disincentive to organ donation which is 	Both	Public and Professional Awareness and Intent to Donate

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239	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> Tissue bank – lots of opportunities in tissue bank. Have come a long way in few years. Different from organ side in terms of number of donations. Relatively well off – not short of tissue – have inventory that’s enough to export to other areas. But opportunities to expand further to get more tissue donors, currently concentrating only on hospitals in WRHA, not to any other regions so huge potential for more tissue donors in MB which would create more tissue to be available throughout the country. We have unique relationships with processors in the US, which other tissue banks don’t have so in that regard, there are opportunities for other areas of the country to see how tissue banking can work and meet needs for Canadians and further field. 	Tissue	Donation
240	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> Eye bank – biggest challenge is getting other RHAs on board. Since new tissue gift act in 2004 it was mandated that only WRHA and Brandon hospital. In the last week got the Assiniboine region on board. It’s all about money. The other RHAs have to contribute to the funding of the program. We have a small budget and cannot support all the RHAs so it’s a challenge to get them to provide money for the educators whom we train to get tissue donation in outlying communities. 	Tissue	Funding
241	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> Wait list for corneas – about 100 at any given time. Last year did most we did in 20 years – 260 eyes and about 156 surgeries out of that, not including other tissue from the eye. We could do better. Other big challenge is getting families to consent for tissue. Heart program – recently did an audit of last few years of organ donors. Noted that there were hearts that weren’t consented so that process is a concern. Would advocate for donor management physician team to be initiated in MB to have more consistent management of potential donors. Massive challenge in terms of not having heart transplant locally. At present patients are listed at other centres across the country. We’re focusing on 1-2 centres only but challenge advocating for these patients in different provinces. Recent situation – patient on ventricular device while waiting for transplant – asked to be switched to another province because he heard wait list in province he was waiting was too long. Massive discrepancy of wait time across provinces – not fair. Makes me lean toward national list for that reason, particularly for this particular organ group. 	Both	Donation
242	Expert	Summary Report	Winnipeg Multi-Disciplinary Event	2010-02-25		<p>What is the most important element that needs to be fixed?</p> <ul style="list-style-type: none"> Other big challenge is getting families to consent for tissue. 	Tissue	Donation
243	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<p>Current state opportunities, issues, challenges</p> <ul style="list-style-type: none"> We need to maximize opportunity for NDD donors, start DCD program. Referral potential is what’s key – if you don’t have referrals you don’t have donors. Audit shows they’re not being referred and that we’re missing donors. Our program focused on Wpg, we try to maximize services here before we branch out. Are making telehealth sessions to the regional health authorities and have gotten 1 donor. With that, looking at global system, putting resources in to include rural. Also, rural Ontario such as Thunder Bay. What would it look like – someone that travels through rural MB and does audits, education. Need to set up teams at the sites working for you, like Collaborative teams in Winnipeg. Huge untapped resource. Smaller groups of physicians – may get better buy in, you become part of their community, change the way they think. They may not have capacity to do diagnostics but have gotten referrals – may be easier to get them on board because staff more static. Personal touch is important – telehealth is fine but need personal interaction, networking, develop clinical triggers, etc. gives them a reason to call you, etc. Central registry – legislation may need to change with respect to when there’s no written directive. Only includes very narrow group of people who can consent. Even when donor card signed, potential that family over rides. Need more clarity on what first person consent means and need to educate the public on that. 	Both	Donation
244	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> Point needs to be made that we’re not getting out to outlying hospitals. Used to get out there to do professional education, etc. but there’s a catchment that’s still sitting. When potential, I know they do stabilize and bring them in so we’re not likely missing a lot. Physicians in outlying areas – their people are on our waiting list so those communities should try and give back by giving potential donors. No one’s been around do outlying hospitals with ICU beds – may not be an issue. May become an issue if DCD. If someone has a CAT scan, I wonder how many of those patients are being discontinued on, that we might be able to do DCD on. We have a provincial imaging network now so we don’t hear about those cases – scope yet undetermined so is something we need to pay attention to in the future. Physician to physician communication is more powerful. Dedicated physician – missed donor – not sure that all these cases were actually missed donors. You don’t know whether recoverable, if treated aggressively, damage may be reversible. Having a dedicated ICU physician would be good. At night, you have resident with you, physician 	Both	Donation
245	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> Families may want to stop earlier if the wait is too long. Non-therapeutic ventilation is a huge issue (when they’ve done chart audits). Patients discontinued on when prognosis grim – don’t feel comfortable calling ICU for non-therapeutic intervention. Physicians afraid of this because of the case in Winnipeg last year. Physicians won’t go there unless a very clear brain death. 	Both	Donation
246	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> Donor assessment process – organ allocation algorithm is a huge bone of contention amongst transplant community – paediatric heart, adult heart, lung, liver, all have different allocation guidelines. As donor coordinator, have to figure out which algorithm to follow for which organ – they can’t be exactly the same but could be a little more standardized. If this was taken out of our hands, i.e. have an external agency settle this to say we will all do it this way, it will improve delivery. 	Both	Allocation

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247	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> In terms of living donors, some money from kidney foundation partially funded by government, etc. to match reimbursement for donors. Don't think donors should be out of pocket for anything, including pre-op work up, (day care, hotel, parking, meals, etc.) We look at post op and fund based on certain criteria. There needs to be a system where you submit receipts and are reimbursed because in the long run you're saving the health system hundreds of thousands of dollars per year per donor. We like to tell the public that transplantation is accessible to all but it really isn't. If you're a single mom in The Pas and you want to be a living donor to someone in Winnipeg, you can't. Not against paired exchange, but personally I'd think about the cost. A lot of donors are working poor. Particularly the travel. 	Both	Funding
248	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> Sometimes recipients pay the donor which could be misconstrued as unethical – happens a lot. We have become an urban type of service – we used to go to rural MB on regular basis for public and professional education. There is a willing community out there. Get a lot of questions from rural MB, rural media, etc. When someone transplanted, it's always a story in the community. But they're not phoning us for stats, backup material, info on how do you become a donor, etc. so we are missing an opportunity. Missed donors – It's not so much a missed donors - I think it's a missed opportunity. If family hasn't consented to heart donation, you don't have a heart donor. Or, if consented, we can offer a heart to all programs and UNOS, but there may not be a suitable recipient. Other areas of missed opportunity – it goes back to infrastructure. When we did audits, we would do education. They don't even have ventilators in some of these little hospitals. Public education addresses public misperceptions – saying yes we'll donate but not acting. There are issues we've been talking about for years and they haven't been addressed. Have developed lots of strategies but there aren't the resources to implement them nationwide. Lots of background work has been 	Both	Donation
249	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> Tapping into northern communities for DCD potential – an issue might become resources and funding. To have patient transferred down is very expensive – if time too long and have to send body back – that's expensive – needs different container, etc. 	Organ	Funding
250	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> What about organ and tissue donation being separate? As long as regulated by separate bodies will be separate. Currently have an organization very hospital based and another out-of-hospital entity that has a business model (for-profit). Good to separate organ and tissue – with legislation changed 	Both	Policy development
251	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> What about organ and tissue donation being separate? Tissue uses a call centre. Good thing - it has expanded what's collected (e.g. heart valves, skin, etc.) Tissue now being stored, didn't used to store anything. Separation allows each organization to focus. If together – how do you make sure you optimize each side of things. 	Both	Processing and Distribution
252	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> What about organ and tissue donation being separate? Tissue bank has an equal amount to do with public education as we do. You mention skin or muscle, people cringe – it "creeps people out". Eyes not so much. Tissue awareness is low (did a combined survey 5-6 years ago) – people don't think about tissue donation and don't know a lot about it. 	Both	Public and Professional Awareness and Intent to Donate
253	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> What about organ and tissue donation being separate? We are not losing tissue donors by being separate. We used to offer tissues as part of our consents. We still offer option of tissue donation and can have tissue bank specialist call them to obtain consent. 	Both	Donation
254	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> Not surprised to hear we're importing more tissue. Why not focusing on our own processing here – why are we farming things out all the time? Lets' retain and distribute more effectively in Canada so we can ensure security and safety of supply. 	Tissue	Processing and Distribution
255	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<p>What are the most important elements that need to be fixed in national system design?</p> <ul style="list-style-type: none"> Need a central donor database. There is a lot of time spent on phone and on faxing and re-faxing the same information. Need system where there's a central secure database where you enter all your donor information, including serology, x-rays, eco reports, etc so other OPOs would have access to it. The donor info would be on the website that they could log in to. 	Both	Allocation
256	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<p>What are the most important elements that need to be fixed in national system design?</p> <ul style="list-style-type: none"> Coordination today takes twice as long as it used to. Have to send every piece of information before they'll consider your offer. Waiting for them to receive document, look them over, determine suitability, etc. Used to be done over the phone. Have agreed amongst coordinators to give them an hour but usually it goes beyond that time. Or you go on the backburner because there are other cases going on. 	Organ	Allocation
257	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<p>What are the most important elements that need to be fixed in national system design?</p> <ul style="list-style-type: none"> Professionalizing our image to the general public but also to our professional colleagues. We're this big disjointed group of people across the country. Prior to 2007 didn't have a regulatory framework and all did what we saw fit. Health Canada standardized and is now auditing. That's the first step. Second step is figuring out our own Canadian UNOS group to manage organ allocation for the country. Perhaps this is what CBS role needs to be. The UNOS model is where we want to go with all of this if you want to improve everything. Standardize and centralize, have accountability. Central organization to manage it all. Because of all this we're failing to reach our donor potential. 	Organ	Audit and accountability

#	Forum Type	Source Document	From	Date	Review point	Comments/Input (some may be paraphrased)	Organ / Tissue	Category (using new list - Integration Discussion for Organs only; Tissue may differ slightly)
258	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> • Social marketing – not a shot in the dark or onetime thing. Has to be a thoughtful, ongoing process – takes a long time to change social attitude and behaviour. In order for that to happen, there has to be a national commitment. • Public's awareness level needs to be brought up. In the US it's more "in your face" – TV commercials, billboards, it's so much a part of our culture – not taboo to talk about, not a foreign topic. For professionals, all nurses had to attend seminars in the ICU, OPO always present in the hospital. This would happen at least quarterly. Every death or pending death had to be called in to hospital administrator – it was up to them to contact LifeBank. (this was from a staff member who has just joined the organization from the US) 	Both	Public and Professional Awareness and Intent to Donate
259	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<p>Education is a huge piece – public education. For professional education – we develop a plan for educating physicians, who's going to do it – the coordinators? If so, how does that get balanced with our day to day work. We all want more people to come to the end result of transplant so what kind of support do we get for that. Working on audit, standardizing operating procedures, developing patient materials, we don't have the resources for nice materials. Need this to be consistent across Canada – user friendly, attractive, something people want to read it. For post transplant compliance issues – if we can look at the education we're giving to people, if someone on the waiting list for a long time – can we maintain an education process so they know what they need to do as a potential recipient. Education on recipient side, potential donor education, living donor education, public and professional education. Would be good to have a cohesive way of doing this.</p>	Both	Public and Professional Awareness and Intent to Donate
260	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> • On the side of standardization – HC regulation – everyone interpreting it a little differently. Developing their own questionnaires, etc. It would be nice to have one questionnaire across the country, the same labelling and packaging requirements, etc. Would be good to have a central organization that would develop this so all the programs can use it. 	Both	Safety and quality
261	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> • LDPE, sharing of donors with recipients across country – there are guidelines on how patients assessed but everyone doing things differently. Not necessarily minimum requirements so our program will still take a look at them based on our criteria to see if we will transplant them. Need minimum requirements that are standard across Canada. 	Both	Allocation
262	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> • Metrics – what we lack is that everyone has their own idea of what a potential donor is and what they think the metric should be. So you're not dealing with apples and apples. Data is a key element when you're going to stakeholders. 	Both	Information management, measurement and reporting
263	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> • Transparency may enhance public trust and in that we may see a rise in donation. Not that there's a reason to have distrust in distribution of organs but if you're coming open it might say a lot. Recognition for services is a very big thing. Those involved in donor process, people give us what we want from recipient to donor side people step up to the plate. 	Both	Audit and accountability
264	Expert	Summary Report	Transplant Manitoba, Gift of Life	2010-02-25		<ul style="list-style-type: none"> • Payback of organs and tissues – can go either way – families donate regionally or at least they think we do. The program tells them that the donations are for Canadians. We're a net exporter so for us, payback is a good thing. • Our program at a disadvantage – look at Edmonton being fed from US and SK – they get all the offers. MB has to depend on Wpg population to supply our need so it's so much less. Might be hard to payback. Believe in it but don't think we can produce. 	Both	Allocation
265	Expert	Summary of Feed back/Event Evaluation	Winnipeg Multi-disciplinary event	2010-02-25		<p>The Organs Case for Change should also include.....</p> <ul style="list-style-type: none"> • A public relations component to help engage the general public • Dedicated professionalization and dedicated resources • PR campaign to raise awareness and need of organ donation • It is important to standardize criteria between programs (donation and transplant) • I see education of professionals and public as most important in the key elements for change • Roll out into community hospitals to maximize the health care professionalism of organ donation 	Organ	Public and Professional Awareness and Intent to Donate
266	Expert	Summary of Feed back/Event Evaluation	Winnipeg Multi-disciplinary event	2010-02-25		<p>The Tissues Case for Change should also include.....</p> <ul style="list-style-type: none"> • PR campaign to raise awareness and need of tissue donation 	Tissue	Public and Professional Awareness and Intent to Donate
267	Expert	Summary of Feed back/Event Evaluation	Winnipeg Multi-disciplinary event	2010-02-25		<p>The Tissues Case for Change should also include.....</p> <ul style="list-style-type: none"> • Rural outreach • How and who will be implementing changes – workload • Roll out into community hospitals to maximize the health care professionalism of tissue donation 	Tissue	Policy development
268	Expert	Summary of Feed back/Event Evaluation	Winnipeg Multi-disciplinary event	2010-02-25		<p>Other options that should be considered as part of national system design are.....</p> <ul style="list-style-type: none"> • Development of a Canadian version of UNOS! (United Network for Organs Sharing) • Public reporting of comparisons of provincial data • Assigning costs to procurement and delivery that are charged to the centre using the tissue • Accountability codes for eligible potential donors, e.g. family refused organ donation due to personal preference, cultural reasons, etc., family approached / not approached. 	Both	Allocation
269	Expert	Summary of Feed back/Event Evaluation	Winnipeg Multi-disciplinary event	2010-02-25		<p>Other comments:</p> <ul style="list-style-type: none"> • As a transplant physician not often hearing discussions on tissue donation, I was uncomfortable with the repeated use of terms such as "product", "business", and "production". When tying discussions of organ donation in with tissue, we need to be sensitive to the fact that such terminology may be viewed as cold and distasteful to the professionals and particularly the public. 	Both	Processing and Distribution

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270	Expert	Meeting Notes	London Multi-disciplinary Event	2010-02-17		Feedback from Initial Discussion -Funding for transplantations will be a challenge. They are working with older funding models. Funding needs to address technology etc	Both	Funding
271	Expert	Meeting Notes	London Multi-disciplinary Event	2010-02-17		Feedback from Initial Discussion -What they have done well: Successful donation arms. Historically they have partnered with community and critical care community. This is has resulted in the shortest wait times.	Both	Public and Professional Awareness and Intent to Donate
272	Expert	Meeting Notes	London Multi-disciplinary Event	2010-02-17		Feedback from Initial Discussion There could be some angst if wait times were the same. (I think this was referring to if London organs were shared to low performers...) - Critical fear- If the have a good deceased donation program they should not be penalized as good performers. Need to define what works for donation and bring people up to standards...not penalize good performers.-It is not necessarily an opportunity to bring programs up to a certain level... we just need to teach the public and have good public education.	Both	Allocation
273	Expert	Meeting Notes	London Multi-disciplinary Event	2010-02-17	OTDT	Business model - different funding mechanisms. Re examine cost of actually doing OTDT. Overall ...long term. Systems view of cost - "The system is surprisingly unregulated" There is no data on how many donors, organs allocation, survival.	Both	Funding
274	Public		OTDT website	2009-10-27	OTDT	As a lawyer I would say that would be smart to talk to lawyers who do wills to discuss organ donation with clients - it could be a natural part of their conversation with clients.	Organ	Public and Professional Awareness and Intent to Donate
275	Public		OTDT website	2009-11-01	OTDT	[encouragement to become organ donors]	Organ	Public and Professional Awareness and Intent to Donate
276	Public		OTDT website	2009-11-01	OTDT	[thanks to the donor - 3]	Organ	Donation
277	Public		OTDT website	2009-11-02	OTDT	[encouragement to register as a donor, with CBS registry too]	Organ	Public and Professional Awareness and Intent to Donate
278	Public		OTDT website	2009-11-15	OTDT	[receiving transplants must be equitable, no preferred process for the well-to-do]	Organ	Allocation
279	Public		OTDT website	2009-12-02	OTDT	[we should study Iran, which has no waiting list for transplants]	Organ	Policy development
280	Public		OTDT website	2009-12-13	OTDT	[put organ donor cards in the yellow pages]	Organ	Public and Professional Awareness and Intent to Donate
281	Public		OTDT website	2010-01-13	OTDT	[encouragement to those awaiting transplant]	Organ	Transplantation
282	Public		OTDT website	2010-01-17	OTDT	[transplant system needs to help the patient, need support group]	Organ	Transplantation
283	Public		OTDT website	2010-01-21	OTDT	[health system needs to be better at diagnosis of organ failure]	Organ	Transplantation
284	Public		OTDT website	2010-01-21	OTDT	[wait list rules should be the same in all provinces]	Organ	Transplantation
285	Public		OTDT website	2010-01-28	OTDT	[encouragement to consider donation]	Organ	Public and Professional Awareness and Intent to Donate
286	Public		OTDT website	2010-01-29	OTDT	[high cost and consequences of being on kidney wait list for 9 years]	Organ	Funding
287	Public		OTDT website	2010-02-04	OTDT	[national co-ordinated system in the UK contributed to the success of my kidney transplant]	Organ	Audit and accountability
288	Public		OTDT website	2010-02-13	OTDT	[encouragement to support organ donation and transplantation]	Organ	Public and Professional Awareness and Intent to Donate
289	Public		OTDT website	2010-02-22	OTDT	[educate people on organ donation, no one should die]	Organ	Public and Professional Awareness and Intent to Donate
290	Public		OTDT website	2010-03-06	OTDT	[support for donation from a living donor]	Organ	Public and Professional Awareness and Intent to Donate
291	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	Consistent pan-Canadian system: eliminate provincial fragmentation; focus resources	Both	Principles
292	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	Raise awareness; provide consistent information and education programs.	Both	Public and Professional Awareness and Intent to Donate
293	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	System integrity and effectiveness: system works and can be trusted.	Both	Safety and quality
294	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	Accountability: transparent, feasible and makes responsible use of tax-payers' dollars.	Both	Audit and accountability
295	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	Fair and equitable: universal access, independent of where you live or your circumstances.	Both	Allocation
296	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	Open and transparent: process discloses all information.	Both	Audit and accountability
297	Public	Summary	London Public Dialogue	2009-10-24	Guiding Principles	Safe and reliable: public needs to be able to trust the system.	Both	Principles
298	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Emphasis on educating the general public on the importance of donation and issues relating to consent, using clear and consistent information, delivered through diverse channels (e.g., education system, medical professionals, pastoral care, government, employers)	Organ	Public and Professional Awareness and Intent to Donate
299	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Single, electronic pan-Canadian registry for organ donors and coordination of organ distribution, including standardized criteria for evaluating donors and recipients.	Organ	Allocation
300	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Prompt identification, testing and declaration of donors	Organ	Donation
301	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Prompt diagnosis, testing and referral for transplant recipients.	Organ	Transplantation
302	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Change system for donor consent to make it easier to express consent/harder for families to counter wishes of donor.	Organ	Donation
303	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Create a program for national traceability.	Tissue	Safety and quality
304	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Learn from best practices in other jurisdictions.	Tissue	Research and development
305	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Set national standards and enforce greater compliance with existing regulations.	Tissue	Safety and quality
306	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Banks need to assume full responsibility for the quality of end products.	Tissue	Audit and accountability

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307	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Educate the public on the importance of donating tissues as well as organs, and the current lack of standards - tissue-specific challenges are largely unknown or misunderstood.	Tissue	Public and Professional Awareness and Intent to Donate
308	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Reduce the number of tissue banks.	Tissue	Policy development
309	Public	Summary	London Public Dialogue	2009-10-24	Key Actions	Legislate with the view to enabling tissue (skin) to be taken without requiring permission from the family of the deceased	Tissue	Policy development
310	Public	Summary	London Public Dialogue	2009-10-24	Testimonials	Raise awareness in my family, talk about what they would want in regards to donation and let them know what I would want them to do for me.	Both	Public and Professional Awareness and Intent to Donate
311	Public	Summary	London Public Dialogue	2009-10-24	Testimonials	I will increase tissue donation on the floors by educating residents yearly.	Tissue	Public and Professional Awareness and Intent to Donate
312	Public	Summary	London Public Dialogue	2009-10-24	Testimonials	I will continue to speak to any individual or group about transplantation and organ and tissue donation. I would like more information and speaking points on tissue donation as I am ill-informed on this subject.	Both	Public and Professional Awareness and Intent to Donate
313	Public	Summary	Vancouver Public Dialogue	2009-11-14	Guiding Principles	Transparent and accountable; promotes awareness of and education on OTDT; integrated with-end-of-life; increases potential and clarifies criteria for donation and recipients; increases confidence in the system; develops policies.	Both	Audit and accountability
314	Public	Summary	Vancouver Public Dialogue	2009-11-14	Guiding Principles	Equitable access for all Canadians; reduces barriers to access; equal opportunity for donors and recipients; non-discriminatory; fair allocation of resources.	Both	Policy development
315	Public	Summary	Vancouver Public Dialogue	2009-11-14	Guiding Principles	Equitable access for all Canadians; reduces barriers to access; equal opportunity for donors and recipients; non-discriminatory; fair allocation of resources.	Both	Allocation
316	Public	Summary	Vancouver Public Dialogue	2009-11-14	Guiding Principles	One national system: not-for-profit; consistent; Canada Health Act supports national system.	Both	Principles
317	Public	Summary	Vancouver Public Dialogue	2009-11-14	Guiding Principles	Opt-out system: moral imperative to give back; opting-in tends to be less effective; requires public education; family or others can't influence individuals' right to decide for themselves.	Both	Public and Professional Awareness and Intent to Donate
318	Public	Summary	Vancouver Public Dialogue	2009-11-14	Guiding Principles	Safe and trustworthy system: system safe for donors and recipients; imperative of trust for Canadians; consistent and compatible processes and standards across the country; full disclosure.	Both	Principles
319	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	National system/registry/wait list/standards for donors and recipients.	Organ	Information management, measurement and reporting
320	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Funding for national education programs for general public, health professionals.	Organ	Public and Professional Awareness and Intent to Donate
321	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Improve and accelerate evaluation of donors and recipients through standardized processes and protocols; effective use of technology; health professional training.	Organ	Donation
322	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Quantify current donation potential in different regions.	Organ	Information management, measurement and reporting
323	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Raise awareness through public education; mobilization of volunteers.	Organ	Public and Professional Awareness and Intent to Donate
324	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Change donor consent system (e.g., Opt-out).	Organ	Public and Professional Awareness and Intent to Donate
325	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Set and enforce national standards; strict guidelines and evidence requirements to ensure safety of all tissue donations.	Tissue	Safety and quality
326	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Streamline processing and distribution (e.g. federally-mandated and licensed facilities).	Tissue	Processing and Distribution
327	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Create a National Inventory system to maximize available Canadian product; ensure reliable procurement by getting tissue locally.	Tissue	Processing and Distribution
328	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Increase donation capability for tissues.	Tissue	Donation
329	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Educate health professionals to educate the public on tissue vs. organ donation.	Tissue	Public and Professional Awareness and Intent to Donate
330	Public	Summary	Vancouver Public Dialogue	2009-11-14	Key Actions	Assess costs of importing vs. local procurement for tissues.	Tissue	Processing and Distribution
331	Expert	Letter	Canadian Cardiac Transplant Network	2009-11-23	OTDT National Plan	It is imperative that we have a national waiting list for patients awaiting organ transplantation, both for pediatric and adults patients. Waiting list must be computerized and real time.	Organ	Information management, measurement and reporting
332	Expert	Letter	Canadian Cardiac Transplant Network	2009-11-23	OTDT National Plan	The current system's delayed inputting leads to delays in allocation, confusion as to the appropriate recipient for a donor, and compromise the collegiality between transplant programs and colleagues, all of whom are advocating for their individual patients.	Organ	Information management, measurement and reporting
333	Expert	Letter	Canadian Cardiac Transplant Network	2009-11-23	OTDT National Plan	We feel strongly that there should be national oversight of Canadian organ procurement organizations. In whatever form this takes, there must be shared policies, open communication, and transparency across all provinces and territories.	Organ	Audit and accountability
334	Expert	Letter	Canadian Cardiac Transplant Network	2009-11-23	OTDT National Plan	The CCTN has, over the last decade, developed and implemented policies around priority listing status, organ allocation, and organ sharing across the country. It has been difficult to communicate these policies effectively within the current system of separate organ procurement organizations, leading to misinformation, confusion, and frustration on the part of the CCTN and the OPO's.	Organ	Allocation
335	Expert	Letter	Canadian Cardiac Transplant Network	2009-11-23	OTDT National Plan	In order to facilitate the most appropriate utilization of donor organs across Canada, and optimize equity and transparency within the system, the new national system of organ procurement organization(s) must have the authority to enforce policies and compliance with practice standards, which would include imposing penalties and sanctions if required.	Organ	Safety and quality
336	Expert	Presentation	Canadian Cystic Fibrosis Foundation	2009-12-03	OTDT National Plan	We strongly encourage Canadian Blood Services to provide solutions in their recommendation to the heavy financial burden placed on individuals who undergo transplant, especially when they must relocate to specialized transplant centres.	Organ	Funding

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337	Expert	Presentation	Canadian Cystic Fibrosis Foundation	2009-12-03	OTDT National Plan	In Canada, the personal financial costs associated with transplant should not deter a person with CF, or any Canadian, from receiving this life-saving treatment.	Organ	Funding
338	Expert	Letter	University Health Network - Toronto	2010-01-08	Oct 2009 Minutes, System Principles	In the OTDT System Principles: where it states "Evidence-based, Outcomes driven, Ethically pursued". "Ethically pursued" refers only to the process and not to standards (of selection, allocation etc) which might be met by "Ethical in procedure and substance". I suspect you plan to be ethical on both counts, so why not say so?!	Both	Policy development
339	Expert	Letter	University Health Network - Toronto	2010-01-08	Oct 2009 Minutes, Page 6, Point 4.6	The statement calls for equal access for transplant from both LDs and DDs. This is a very laudable goal, but it would require a fundamental change to our LD system to disallow LDs from directing their organs to whomever they wish. A policy to encourage Living non-directed donation would increase the opportunity for people to access LD organs, but it still would not achieve equity if directed donation were still permitted.	Organ	Allocation
340	Expert	Letter	University Health Network - Toronto	2010-01-08	Oct 2009 Minutes, Page 6, Point 4.6	A comment re balancing Equity, Utility and Medical Need: there are times when they cannot be balanced and a choice has to be made. This requires some agreement re prioritizing the principles. Also, they may not be the same for all organs. Your inclusion of Transparency is an excellent addition to address disagreement re the prioritization.	Organ	Policy development
341	Expert	Letter	University Health Network - Toronto	2010-01-08	Oct 2009 Minutes, Page 6, Point 4.6	A comment re balancing Equity, Utility and Medical Need: Mechanisms for review and appeals would be helpful also.	Organ	Audit and accountability
342	Expert	Letter	University Health Network - Toronto	2010-01-08	Oct 2009 Minutes, Page 14 last line	A policy of whether people should have the right to direct their organs after death would impact the pursuit of equal access for recipients of DD organs. It seems counter to the goal of equal access. Such a policy is defensible if it increases overall donation, but it would challenge the statement about equal access.	Organ	Allocation
343	Expert	Summary Report	Canadian Organ Replacement Register (CORR)	2010-02-08		Current state opportunities, issues, challenges CORR is planning a national forum on End Stage Organ Failure in May and will include CBS representatives. Many key players to be involved including Health Canada, Public Health Agency of Canada, CIHI, CIHR, CST, OPOs, BC Renal Agency, pharmaceutical companies, etc. Focus on information needs for real time patient needs related to clinical patient management, research, regulatory and policy. The Kidney Foundation is providing the Secretariat. Posed that CBS role not be a sponsor as it could be seen as vested interest. Future State – need to examine the current limitations of current CORR register; issues with resourcing, ability to innovate. There is much CORR data that is not utilized. CORR should develop a registry (for ??) with annual data reporting.	Both	Information management, measurement and reporting
344	Expert	Summary Report	Canadian Organ Replacement Register (CORR)	2010-02-08		Level of support for development of a national OTDT system Real time data - should be championed by CBS. Data acquisition is key – CBS could facilitate registries. Possibly need an independent analytical arm to work with the data. Need to link end organ failure to predict transplant needs (connect to dialysis data base)	Both	Information management, measurement and reporting
345	Expert	Summary Report	Canadian Organ Replacement Register (CORR)	2010-02-08		What are the most important elements that need to be fixed in national system design? <i>Mandatory data reporting</i> <i>Monitoring performance - CORR is limited in putting out flags on low performers.</i> <i>Focus on variability across Canada – a safety issue.</i> <i>Outcomes – increase access to Tx and improve patient care</i>	Both	Information management, measurement and reporting
346	Expert	Summary Report	Canadian Organ Replacement Register (CORR)	2010-02-08		What options we should consider as part of system design? Moving away from CIHI ?? Dialysis registry group would want to know what the plan to ensure registry survives/thrives is. Provinces fund CIHI – would potentially prefer to strengthen/improve CIHI as opposed to starting a new group. Need a national data allocation system, with an accountability stream. Clinicians want outcome data	Both	Information management, measurement and reporting
347	Expert	Summary Report	Canadian Organ Replacement Register (CORR)	2010-02-08		Need a national data allocation system, with an accountability stream.	Both	Allocation
348	Expert	Summary Report	Canadian Organ Replacement Register (CORR)	2010-02-08		Other topics Is CST 100% behind us? From John's viewpoint – CBS's strength is as a conduit to policy makers	Both	Policy development
349	Expert	Summary of Feed back/Event Evaluation	London Multi-disciplinary Event	2010-02-17		How do you see the financial modelling? Global budget? How would it work? Carrots and sticks for \$. If money is just provided to institutions (e.g. TGLNI) money will disappear.	Both	Funding
350	Expert	Summary of Feed back/Event Evaluation	London Multi-disciplinary Event	2010-02-17		Accountability -tacked on to funding -continued funding. Leverage funding.	Both	Audit and accountability
351	Expert	Summary of Feed back/Event Evaluation	London Multi-disciplinary Event	2010-02-17		The system must have the trust of programs. No one wants to be managed but we want the system to be equitable. Highlight funding issues...	Both	Allocation
352	Expert	Summary of Feed back/Event Evaluation	London Multi-disciplinary Event	2010-02-17		(Finance representative from surgery) "I hear the same issue in every venue. Ideas are great. But where is the value proposition? There needs to be more understanding of added value" There are 2 value propositions. 1. long term outcomes/benefits and 2. national service delivery advantages (over regional provision)	Both	Policy development

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353	Expert	Summary of Feed-back/Event Evaluation	London Multi-disciplinary Event	2010-02-17		Some discussion re: funding ensued.... "It would be good if the money came with patients (money followed patients through the systemmore activity based.) The question was asked to the finance representative whether this could work in the current system. Her answer "No- we do not have sophisticated systems to apply \$ to patients throughout the system at this point."	Both	Funding
354	Expert	Summary of Feed-back/Event Evaluation	London Multi-disciplinary Event	2010-02-17		The finance person was very interested in tissue component and mentioned that there was no funding for the bone bank in London but that they end up buying tissue at high costs.	Tissue	Processing and Distribution
355	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		Education is important. There is a difference between education and awareness (education enabling action)	Both	Public and Professional Awareness and Intent to Donate
356	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		The London program has the support of the community. From the beginning the public and the press have been engaged and have supported the program. As a result, families will often bring up donation.	Both	Public and Professional Awareness and Intent to Donate
357	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		Intent to Donate registries are simply a tool that can help in the consent process.	Both	Public and Professional Awareness and Intent to Donate
358	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		Some discussion re: federal and provincial jurisdictions. It was noted that there is no national governance and no monitoring or audit function. Could be national standards of practice.	Both	Audit and accountability
359	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		CBS could be an advocate for the patient. (I think this was tied in with the provincial/TGLN issues they discussed.)	Both	Public and Professional Awareness and Intent to Donate
360	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		There is major opportunity to increase tissue donation .	Tissue	Donation
361	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		There is also a challenge with tissue where nurses are required to provide medical history information which can take up to an hour in addition to their routine work. Given the resource issues, nurses it is easier for nurses if their patients were not tissue donors.	Tissue	Donation
362	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		They have had challenges working with the TGLN model and the use of the call centre.	Organ	Donation
363	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		National allocation could be considered.	Organ	Allocation
364	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		Meeting the needs of regions, provinces and country	Both	Policy development
365	Expert	Meeting Notes with Organ Coordinators	London - Meeting of Organ Coordinators	2010-02-17		National marketing-common voice and common message would be helpful	Both	Public and Professional Awareness and Intent to Donate
366	Expert	Detailed Notes	London One on one meeting	2010-02-17		Access to transplantation is an issue. We have patients who need transplants but aren't getting them or aren't getting them in a timely manner. The reasons include resources, organ supply, OR beds – this is our "care gap". We need to close the care gap for patients needing transplants.	Organ	Transplantation
367	Expert	Detailed Notes	London One on one meeting	2010-02-17		Living donor reimbursement is an issue.	Organ	Funding
368	Expert	Detailed Notes	London One on one meeting	2010-02-17		We also need to better follow living donors and monitor outcomes.	Organ	Transplantation
369	Expert	Detailed Notes	London One on one meeting	2010-02-17		Data handling, leverage existing resources effectively. Developing standards and processes for organ sharing and amalgamating data.	Organ	Policy development
370	Expert	Detailed Notes	London One on one meeting	2010-02-17		Organ sharing does not have to be 100% - there could be local consideration.	Organ	Allocation
371	Expert	Detailed Notes	London One on one meeting	2010-02-17		There is value in a national network and coordination. Sharing best practices is important and a national body could help with that. Strategic planning and policy development could be managed nationally.	Organ	Principles
372	Expert	Detailed Notes	London One on one meeting	2010-02-17		Health policy interventions for example, presumed consent.	Organ	Policy development
373	Expert	Detailed Notes	London One on one meeting	2010-02-17		Early engagement of opinion leaders and minimizing barriers would help with increasing donation Social marketing would help increase awareness	Organ	Public and Professional Awareness and Intent to Donate
374	Expert	Detailed Notes	London One on one meeting	2010-02-17		Research is an important opportunity – there should be research opportunities with the new system	Organ	Research and development
375	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Accountability- look individually at donor and recipient; establish a well-researched and evidence-based system, focus on monitoring and measuring the results of anything put into place; responsible management of costs	Both	Audit and accountability

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376	Expert	Detailed Notes	London One on one meeting	2010-02-17		Knowledge transfer is key	Organ	Principles
377	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Efficiency and cost-effectiveness- develop cost per case indicators and standardize data collection criteria	Both	Information management, measurement and reporting
378	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Develop business case at local, provincial and national levels; make sure costs can be managed by savings in other parts of the system	Both	Funding
379	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Maximize utility for resources and allocation, as well as donor gifts	Both	Processing and Distribution
380	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Transparency- build public confidence and public trust in the system Safety-focus on recipient safety (i.e. traceability of organs/tissues, quality systems for tracking and infection); improve public trust and confidence in donation	Both	Safety and quality
381	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Equitable and fair- establish national standards and guidelines to ensure consistency; balance regional considerations with the integrity of a national allocation system	Both	Allocation
382	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Ethical considerations- base system on ethical concerns (e.g. handling of remains and tissues, opt-in vs. opt-out systems considerations)	Both	Principles
383	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Top Guiding Principles for a Pan-Canadian OTDT System Education- issue should be integrated into school curriculum early on; ensure that people have sufficient information to have a dialogue	Both	Public and Professional Awareness and Intent to Donate
384	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Educate the general public and health professionals on the importance of donation and issues relating to consent, using clear and consistent information, delivered through diverse channels (including a social marketing strategy)	Organ	Public and Professional Awareness and Intent to Donate
385	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Establish a national, integrated IT registry system to coordinate organ distribution and improve the capacity for information sharing	Organ	Information management, measurement and reporting
386	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Develop clear, standardized criteria for evaluating donors and recipients	Organ	Safety and quality
387	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Promote fair allocation standards at the national level to ensure equal opportunity for everyone, regardless of region	Organ	Allocation
388	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Centralize and enhance the capabilities of tissue processing facilities	Tissue	Processing and Distribution
389	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Create a national quality control system which supports standardization, training and accreditation to ensure consistent and quality tissue products	Tissue	Safety and quality
390	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Emphasize academic and R&D investment within Canada to improve the technology and infrastructure needed to boost the production of tissue products domestically (thereby reducing dependence on U.S. imports)	Tissue	Research and development
391	Public	Preliminary Report	Halifax Public Dialogue	2010-02-06		Apply business and health human resource (HHR) principles, which include increased collaboration between hospitals and having the CBS adopt economies of scale that could make the delivery of services more effective, efficient and sustainable over the long-term	Tissue	Processing and Distribution
392	Expert		Vancouver one to one meeting	2010-03-12		Ensure that we are accurately and comprehensively measuring the number of eligible donors in each jurisdiction (province).	Organ	Information management, measurement and reporting
393	Expert		Vancouver one to one meeting	2010-03-12		Ensure that these data are freely shared with interested parties within each jurisdiction and among jurisdictions.	Organ	Information management, measurement and reporting
394	Expert		Vancouver one to one meeting	2010-03-12		Express the donation rate per eligible donors, not per population.	Organ	Information management, measurement and reporting
395	Expert		Vancouver one to one meeting	2010-03-12		As UNOS has done, calculate where the largest gaps are in the flow from eligible donor to successful transplant (ie. identification of eligible donor by neurologic determination of death), consent requested, consent obtained, donor maintained, organs transplanted).	Organ	Donation
396	Expert		Vancouver one to one meeting	2010-03-12		Address the largest gaps as first priority. In the US, obtaining consent is the biggest opportunity for improvement. It may also be a big opportunity in Canada.	Organ	Donation
397	Expert	Event Notes	Winnipeg one to one meeting	2010-02-25		Current state opportunities, issues, challenges • Fragmented eye-banking community is a problem. Tissue supply is a barrier –enough in Toronto but not in MB. Cornea transplants are scheduled "every Wednesday" in Toronto, "we scramble to do one on a weekend in MB when a cornea is available". Corneas outdate in some regions.	Tissue	Processing and Distribution
398	Expert	Event Notes	Winnipeg one to one meeting	2010-02-26		Current state opportunities, issues, challenges • Funding of eye banks by Lions is "a problem". • Funding, or more specifically cost recovery practices, is a prevalent issue in the ocular community and to date has not been resolved.	Tissue	Funding
399	Expert	Event Notes	Winnipeg one to one meeting	2010-02-27		Current state opportunities, issues, challenges • Eye Banks had sought COS support for developing a Canadian accreditation model. Put on hold pending outcome of national system design. May cost less and be more responsive to Canadian environment than EBAA accreditation (US).	Tissue	Audit and accountability
400	Expert	Event Notes	Winnipeg one to one meeting	2010-02-28		Level of support for development of a national OTDT system • Not explicitly discussed, but strong support for dialogue and further opportunities for discussion at AGM, Board meeting, special meeting of cornea transplanters.	Tissue	Policy development
401	Expert	Event Notes	Winnipeg one to one meeting	2010-03-01		What are the most important elements that need to be fixed in national system design? • Unequal and inadequate supply of cornea across Canada.	Tissue	Donation
402	Expert	Event Notes	Winnipeg one to one meeting	2010-03-02		What are the most important elements that need to be fixed in national system design? • Disparities in wait times from Province to Province.	Tissue	Donation

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403	Expert	Event Notes	Winnipeg one to one meeting	2010-03-03		What are the most important elements that need to be fixed in national system design? • Turnaround time for TD testing, especially on long weekends results in wastage of tissue (takes too long)	Tissue	Donation
404	Expert	Event Notes	Winnipeg one to one meeting	2010-03-04		What options we should consider as part of system design? • Centralizing cornea processing may be an issue if corneas cannot be made available quickly (fresh tissue). • Pre-cutting corneas would be best for surgeons. Currently the cutting is done in the OR. • Use of endothelial transplants vs whole cornea will increase the demand for cornea – lower risk, less invasive procedure so more usage likely.	Tissue	Processing and Distribution
405	Expert	Event Notes	Winnipeg one to one meeting	2010-03-05		Other topics discussion • Wait Time Alliance issues wait time report cards for a range of medical procedures, including cornea transplantation. DMs actually call to ask when the next report card is due (issued every 6 months).	Tissue	Donation
406	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Comprehensive national system: efficient, effective, practical, common standards; mandatory participation from all levels of government as well as the Health Care System	Both	Safety and quality
407	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Fair, equitable and consistent access for all Canadians: equitable access to sufficient supply to meet the needs of all Canadians; consistent quality and equal treatment across the country	Both	Allocation
408	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Safe and trustworthy system: standardized national safety and quality to build public confidence and trust, and help donors and recipients make informed decisions	Both	Safety and quality
409	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Transparency: builds trust in the system and process; ensures the system is working and enhances support	Both	Audit and accountability
410	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Informed and engaged public/stakeholders: universal education and awareness regarding organ and tissue donation; dispel misconceptions among public and healthcare professionals	Both	Public and Professional Awareness and Intent to Donate
411	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Accountable and sustainable system: accountability defines expectations and drives performance; sustainable, consistent performance over time; avoid false starts; money to support donors and recipients.	Both	Audit and accountability
412	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		A National Education Program to raise awareness, dispel fears and ignorance and provide accurate and consistent information through school curriculum, faith communities, cultural organizations, etc.	Organ	Public and Professional Awareness and Intent to Donate
413	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		A national body at arm's length from government to oversee a national recipient waiting list/sharing system, standardized criteria for transplantation eligibility across the country and a national donor registry	Organ	Transplantation
414	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Lobby the provincial/territorial and federal governments to enforce standardized, integrated donor consent processes and infrastructure	Organ	Donation
415	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Design, develop and implement a comprehensive, user-friendly, accessible, highly reliable national data management system for OTDT	Organ	Information management, measurement and reporting
416	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Establish national standards for tissue retrieval, processing, storage, traceability, and adverse effects	Tissue	Safety and quality
417	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Create a National Tissue Registry using one central tissue ordering point; increase number of comprehensive tissue banks; establish criteria for safe storage, distribution, and expiry dates and use of transplanted tissue	Tissue	Processing and Distribution
418	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Consolidate processing and distribution locations to achieve efficiency of tracking movement and resources required to support these processes (inventory management)	Tissue	Processing and Distribution
419	Public	Summary Report	Edmonton Public Dialogue	2010-01-16		Legislative reform (policies and procedures): mandate a national system that involves federal/provincial/territorial jurisdictions and compels them to participate	Tissue	Policy development