

# Organ Expert Committee

April 27, 2010



## Objectives for Today's Meeting

- Review progress to date and understand the next steps in the process
- Review and discuss the ODT system strategy
- Review and discuss the first draft of system design options



# Agenda

Welcome and Follow-Up on Action Items	8:30 -8:45
LDPE, HSP and Urgent Status Registries Update	8:45- 9:30
Activity to Date	9:30 - 10:00
Break	10:00 - 10:15
System Strategy	10:15 - 11:30
Introduction to System Design	11:30 - 11:45
Lunch	11:45 - 12:15
Draft System Design Options	12:15 - 4:15
Wrap-up and Next Steps	4:15 - 4:30

## Follow-up on Action Items

- Approval of previous meeting minutes
- Public Case for Change
- Letter re: Istanbul Declaration
- Public Opinion Poll
- Disclosure Forms



## ***LDPE, HSP and Urgent Status Registries Update***



## CBS Mandate re Registries

The development of the following national patient registries for organ transplantations:

- (i) Living Paired Donor Exchange,*
- (ii) Urgent Status Patients, and*
- (iii) Highly Sensitized Patients*

and related databases for such things as performance measurement.

From Letter of Intent, March 31, 2008

# Quick Guide to the 'Registries'

## Highly Sensitized Patient (HSP) Registry

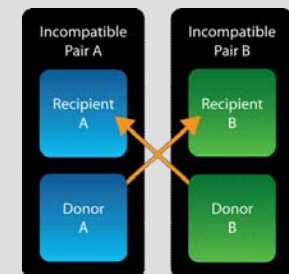
- Highly Sensitized patients\* comprise ~ 20% of provincial waitlists, but historically receive <1% of available donor organs.
- No inter-provincial sharing today for highly sensitized kidney patients. Sharing agreed in principal. Registry required to make it happen.

## National Organ Waitlist (NOW)

- Current national listing of heart, lung, liver, pancreas, small bowel, and multi-organ patients is maintained by the London Health Sciences Centre.
- Opportunity to improve access (on-line), timeliness (real-time), updates, security, privacy, data standardization.

## Living Donor Paired Exchange (LDPE)

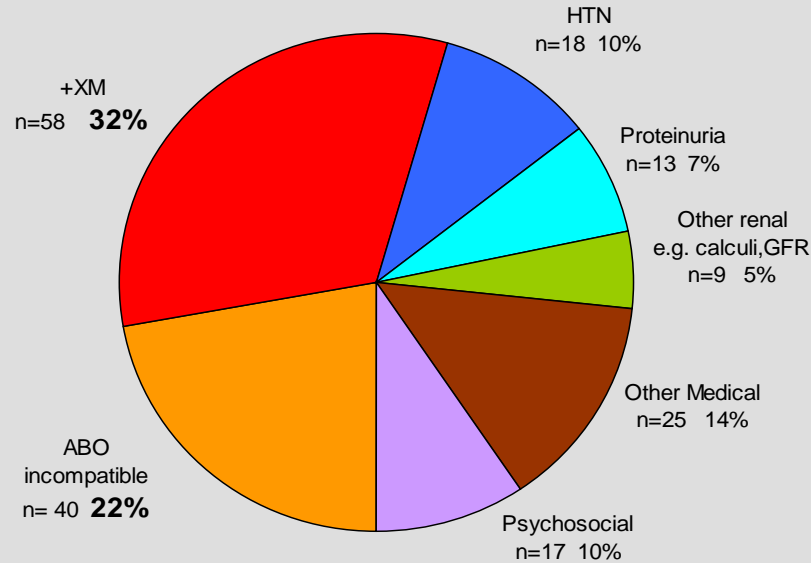
- Living Donor Paired Exchange creates transplant opportunities for recipients who have a willing living donor who cannot donate due to blood type or tissue typing incompatibilities.



# Living Donor Paired Exchange (LDPE)

# Reasons for Living Donor Exclusion

Reasons for LD  
exclusion  
(n=180)



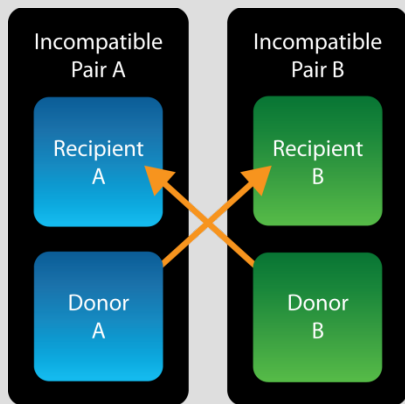
Martin Karpinski, Leroy Storsley, Greg Knoll, Adam Kohn, Robert Yang, Jennifer Cross, Amit Garg

## Options for Patients with Incompatible Living Donors

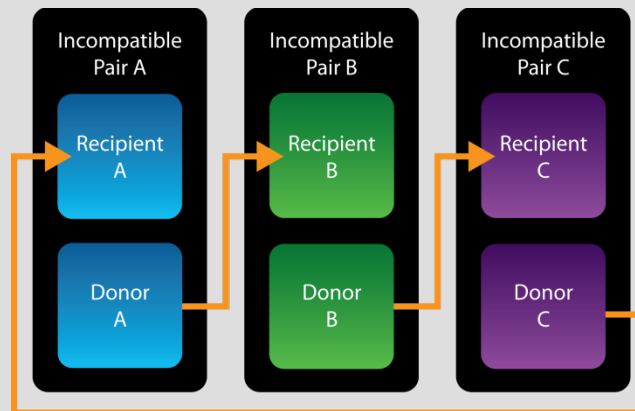
- Go on Deceased Donor List
- Desensitization
- Purchase a kidney in the developing world
- Living Donor Paired Exchange

# LDPE Transplants

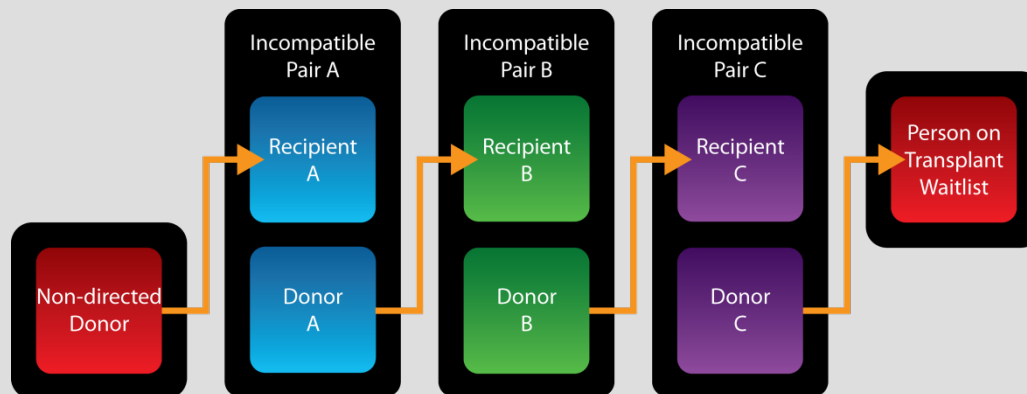
Paired Exchange



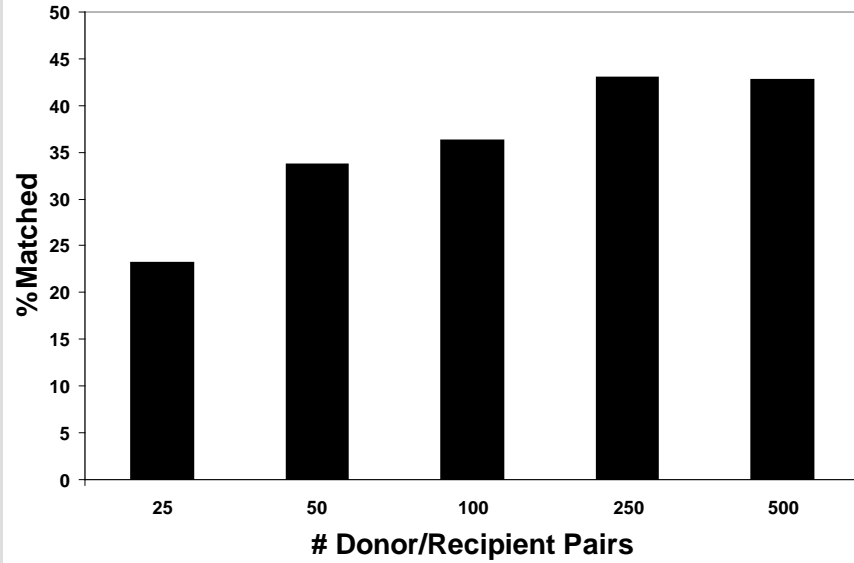
N-Way Exchange



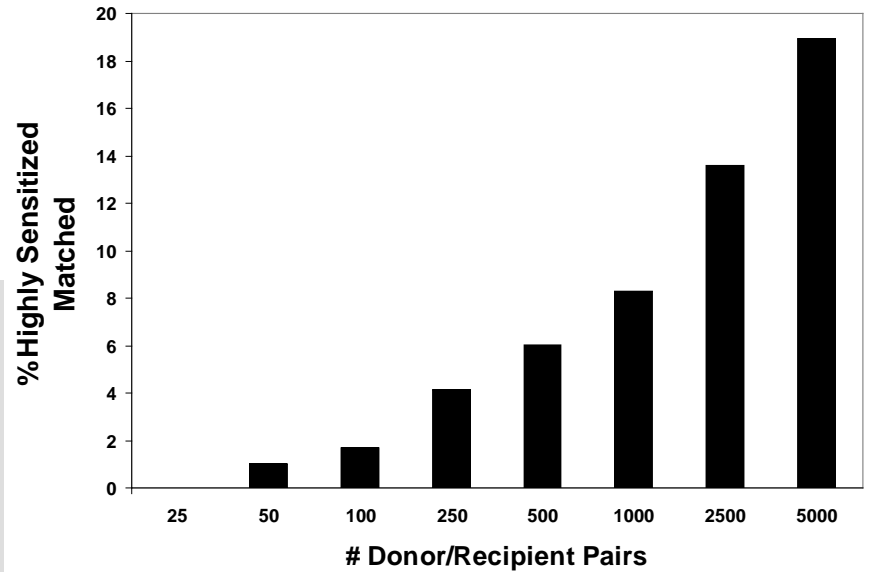
Domino/Chain



# More Pairs, More Matches



Segev et al, 2005 JAMA



## Enabling & Enhancing LDPE

Established and partnered with:

- National Kidney Registries Advisory Committee
- National Organ Registries HLA Advisory Committee
- National LDPE User Group

Originally restricted to **Paired Exchange** for the pilot, the LDPE program responded quickly to introduce **Domino/Chain** transplant functionality

Developed Canadian **Matching & Allocation** software

Introduced **Modelling & Simulation** capability

Revised algorithm, including bonus points, to optimize transplants and align with National Kidney Allocation Guidelines (CCDT)

**5** match runs

**78** pairs registered; **21** in first run; **45** in most recent  
**0** anonymous donors in first run; **12** over next 4 runs

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**50** transplants proposed; **25** completed; **15** scheduled; **10** cancelled

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**5** highly sensitized patients (PRA >80%) transplanted/scheduled

**8** PRA 20-79% patients

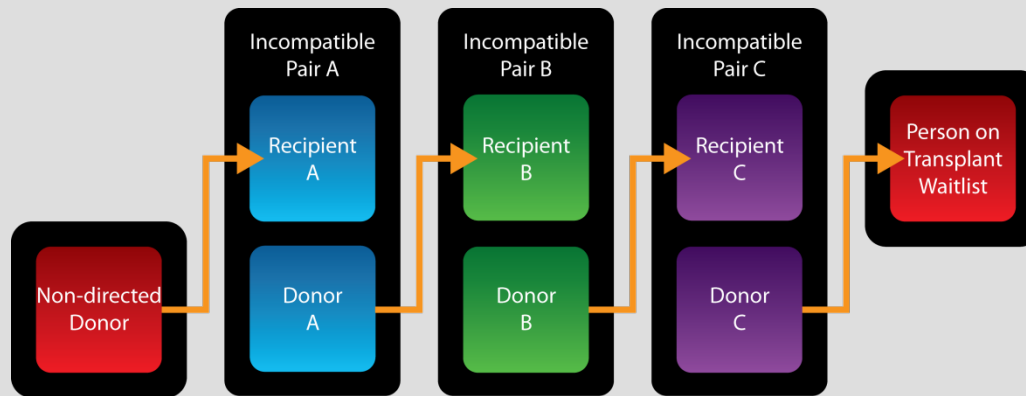
**10** Blood Group O recipients; **17** A; **7** B; **1** AB

Note: there are 5 waitlist patients (blood group unknown) yet to be transplanted

# Power of the Domino

Of the **50**  
transplants  
proposed  
so far

**6** from Paired Exchanges  
**44** from Dominos/Chains



## LDPE Rollout

- 2009 Pilot included BC, AB and ON
- NS and Calgary participated in February, 2010 match run
- Privacy reviews completed for SK, MB, NB, NL
- Next match run on May 3, 2010.
- Draft agreement under review with QC for participation in LDPE

- Manage increased number and complexity of transplant logistics
- On-going review and modelling to enhance allocation policy, e.g., Time in Registry, Bridged Dominos, Optimizing Anonymous Donors
- Implement international HLA nomenclature standards
- Assessment of shipped kidneys under LDPE program
- Continue to address Donor Reimbursement inconsistencies
- Introduce Business Intelligence (reporting, analytics)
- Develop Canadian PRA Calculator (currently use UNOS)

# Registry Concepts

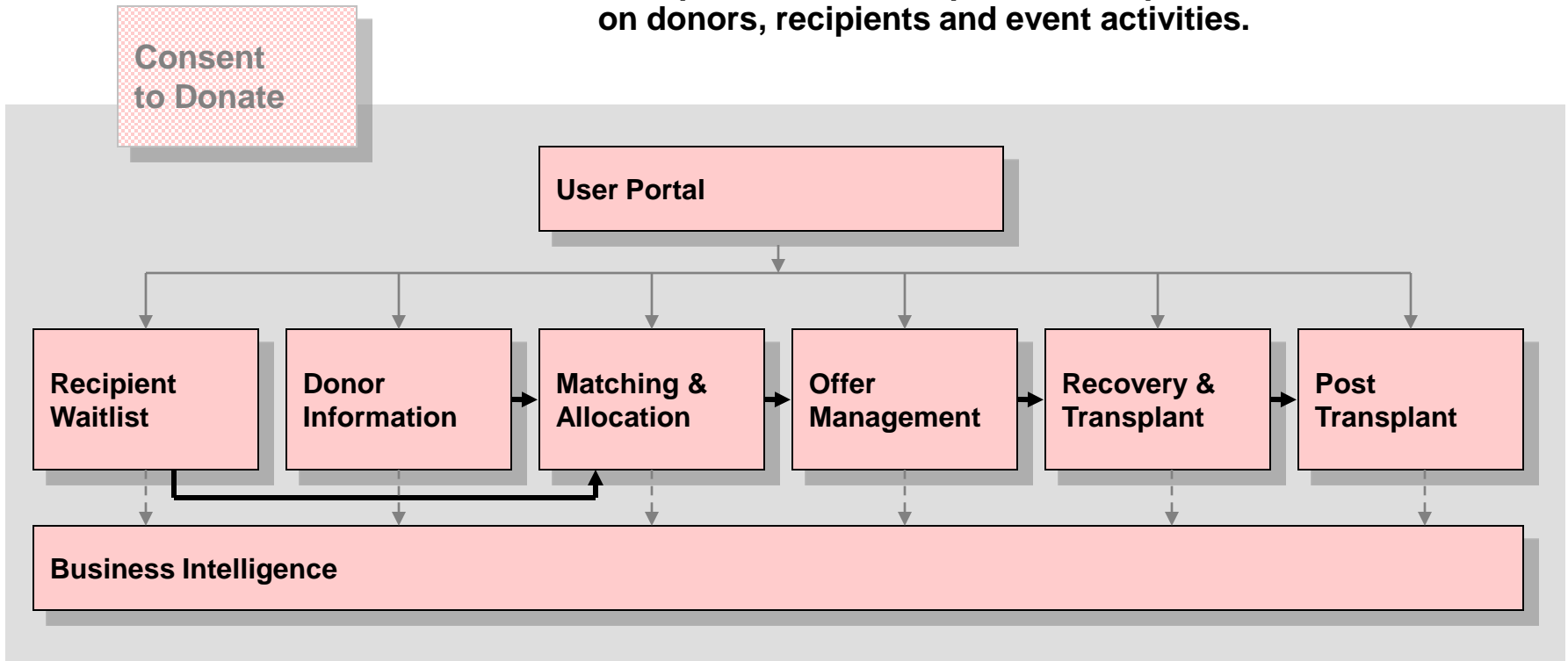
### Meetings with UNOS, EuroTransplant, OPO's, Transplant Programs, CST Committees, CORR and other stakeholders.

What we heard ... facts, ideas, comments, advice, requests from stakeholders:

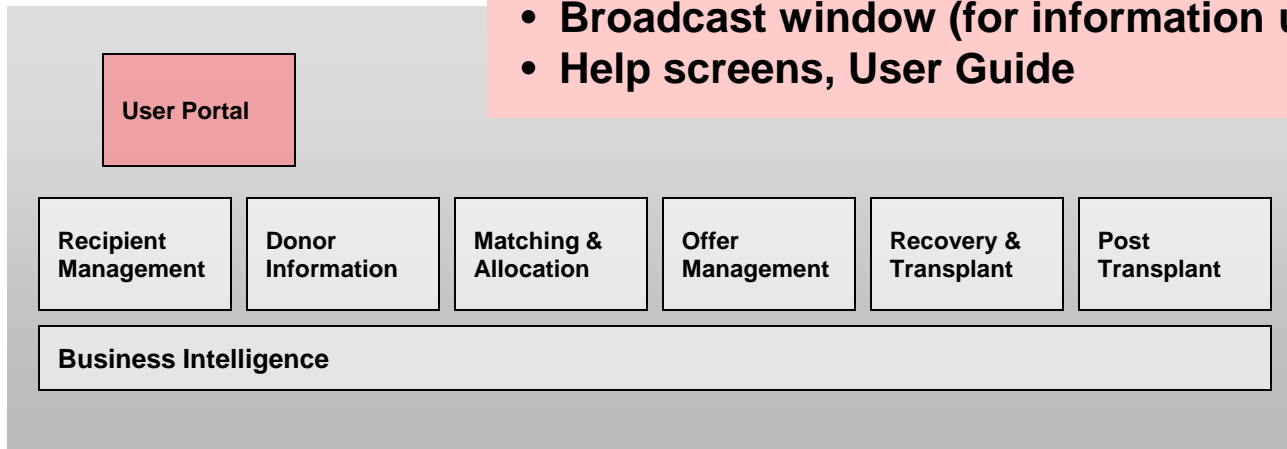
- Strong support for national registries.
- Awareness of UNOS integrated national registry model ... why not Canada ?
- Interest in local use of listings/registries by many provinces, especially those with less-than-robust technology solutions.
- Coordinators looking for improvements in managing communications and information exchange. **100-200 phone calls by donor coordinator managing single event.**
- Need for some sort of inter-provincial sharing monitoring & reporting.
- Need for comprehensive Canadian data on donation and transplantation;
- CORR interested in working with us to share data; rationalize data sourcing; clarify roles.
- Some concern re potential data entry workload and/or integration with existing systems.
- Transparency and auditability key requirements for registries.

# Organ Registries - Conceptual Design

The design outlined below is conceptual and describes the key modules of a fully integrated organ registry system to support the complete supply chain of organ donation and transplantation and to provide comprehensive information on donors, recipients and event activities.



- **Single portal to access all registries**
- **System administration and security (role based access and views)**
- **User profiles including contact info**
- **User schedule/availability, i.e., on-call**
- **Broadcast window (for information updates)**
- **Help screens, User Guide**



# Candidate Waitlists

- All organs (heart, lung, liver, kidney, pancreas, combinations)
- All status
- All required patient attributes including HLA
- On-line, real-time
- Regional/Provincial/Program views
- Enhanced filtering, sorting, display

User Portal

Recipient  
Management

Donor  
Information

Matching &  
Allocation

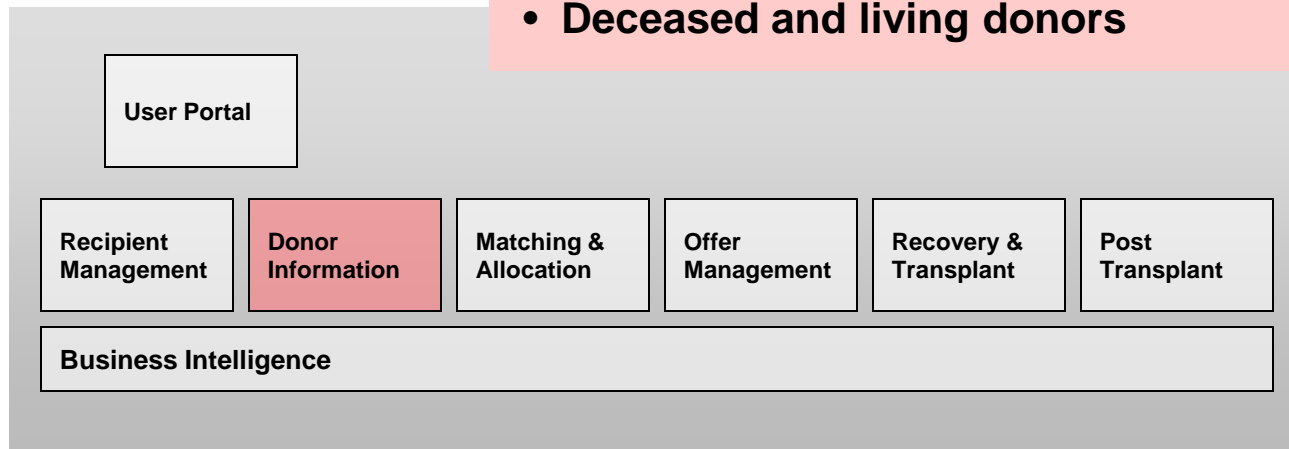
Offer  
Management

Recovery &  
Transplant

Post  
Transplant

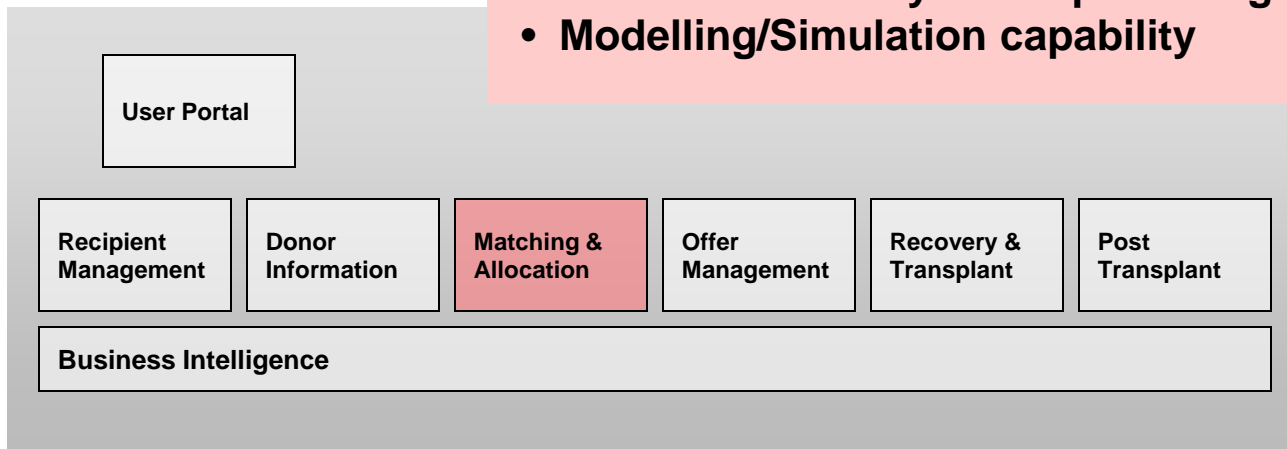
Business Intelligence

- Necessary demographic and medical information to support allocation and offer management
- Other information (e.g., consent, exceptional release, diagnostic images, forms)
- Deceased and living donors



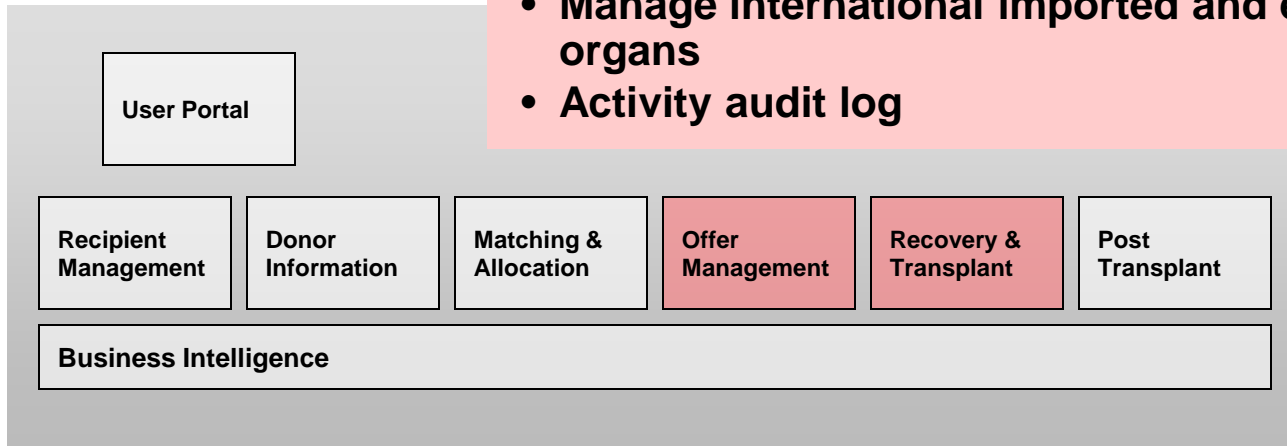
# Matching & Allocation

- **Matching & Allocation criteria and algorithms for each organ including Virtual Crossmatch**
- **National and regional/provincial/program allocation rules**
- **Canadian PRA Calculator**
- **Organ specific points systems**
- **Build for flexibility and rapid change**
- **Modelling/Simulation capability**



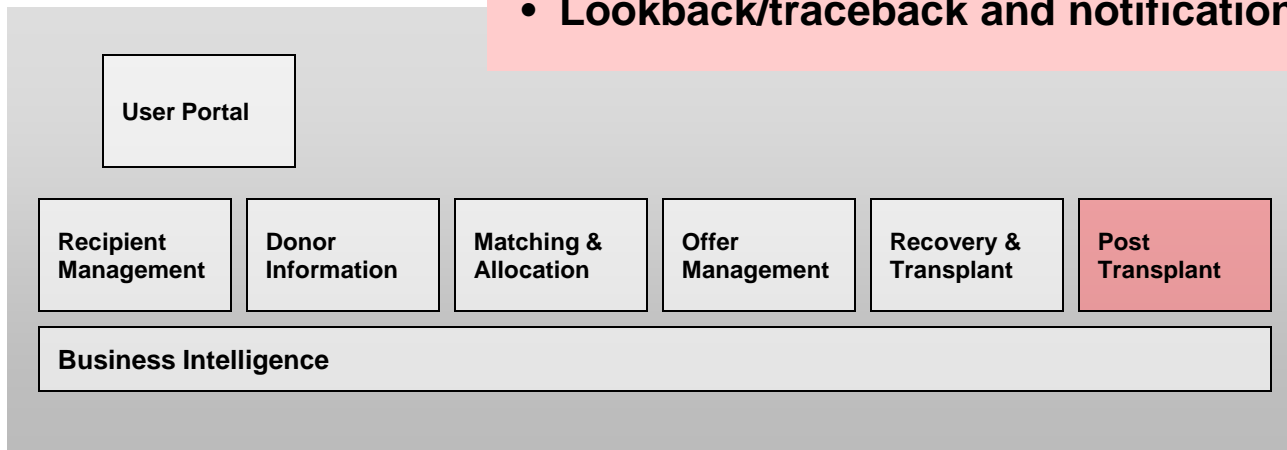
# Offer Management, Recovery & Transplant

- **Sequential vs. simultaneous offers**
- **Accept / decline / provisional accept**
- **Event dashboard, e.g., offers, time, status**
- **Logistics support**
- **Standardize forms, labels, checklists**
- **Mobile devices, Instant Messaging**
- **Manage international imported and exported organs**
- **Activity audit log**



# Post Transplant

- Capture agreed-upon transplant and post-transplant recipient and donor information
- Include living donors
- Scheduled reminders for updates
- Lookback/traceback and notification



- Complete information re donors, recipients, wait times, allocation, events, outcomes
- Business Intelligence tools to support reporting, research, ad hoc inquiries, performance measures
- Automated interface to CORR, Accreditation Canada, etc.
- Interprovincial organ exchange tracking

User Portal

Recipient  
Management

Donor  
Information

Matching &  
Allocation

Offer  
Management

Recovery &  
Transplant

Post  
Transplant

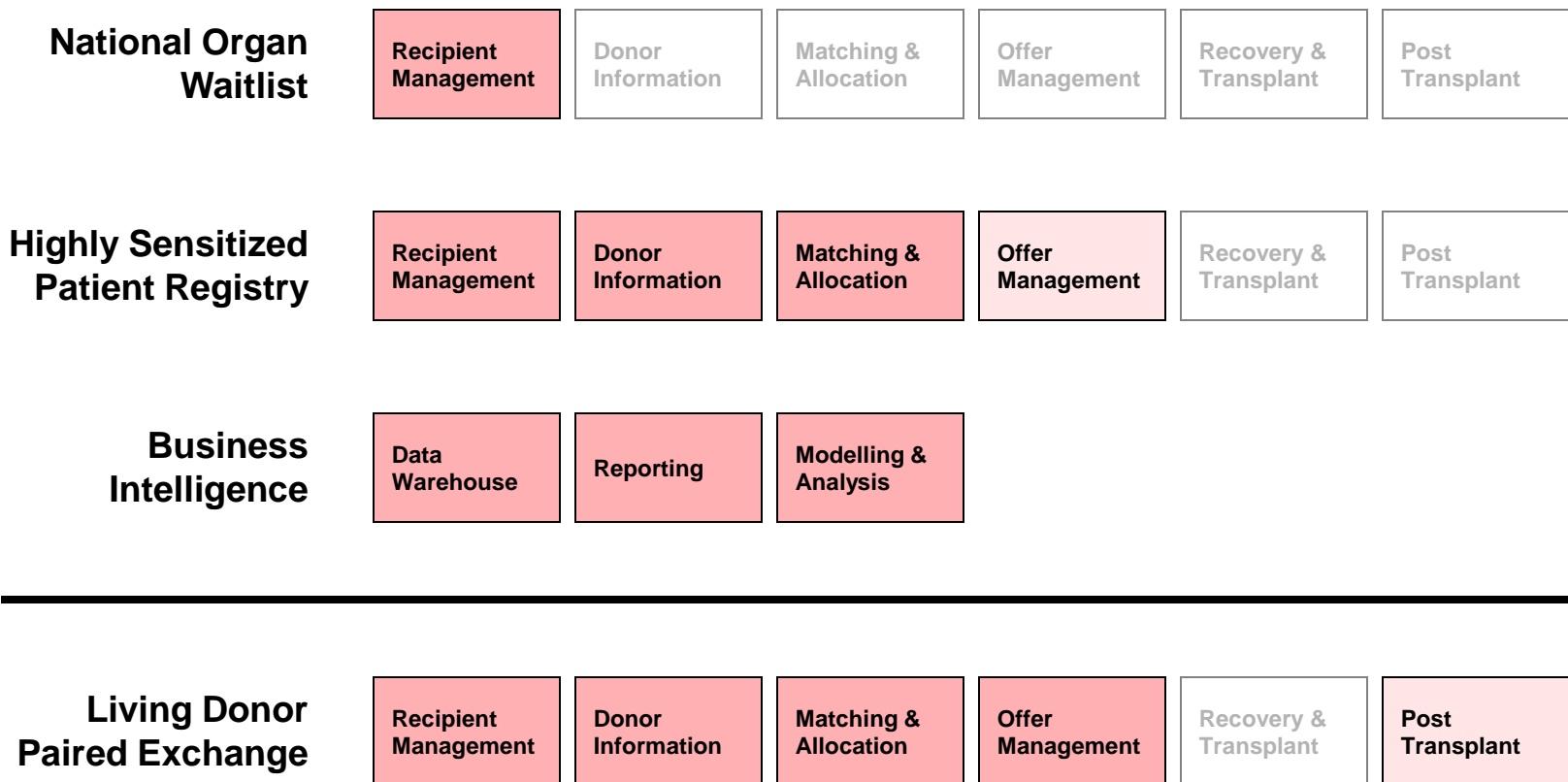
Business Intelligence

### Key Benefits of an integrated national registry management system:

1. Comprehensive, accurate, consistent, timely national data re donors, recipients and event activities
2. Transparent and Auditable
3. Single Information System serving national and regional/provincial/program needs
4. Efficiencies and enhanced communications for front-line staff in OPO's and transplant programs
5. Standardized nomenclature, forms, processes, data
6. Virtual Crossmatch and Canadian PRA Calculator
7. Shared costs



# Project Scope



## Key Issues Moving Ahead

- Finalizing scope and requirements to meet needs/expectations of a diverse client community
- Assessing, and responding to, impacts on OPO's and Transplant Programs (people, processes, systems, \$'s)
- Determining patient PRA % for inclusion in Highly Sensitized Patient Registry
- Developing implementation strategies (timing, training, data conversion, support)
- Privacy ....



# Privacy

LDPE Privacy Impact Assessment sent to non-pilot provinces in **March, 2009**. Non-pilot provinces to join Registry in **May, 2010**.

## Issue

- Multiple reviews (ministry, regional authority, hospital)

## Concern

- Impact on HSP and NOW registry timelines



# Highly Sensitized Patient (HSP) Registry National Organ Waitlist (NOW)

Current target for implementation is **July, 2011**

***Activity to Date***

**In June of 2009 we agreed on the Case for Change.**

**Canada is failing to realize  
its potential for organ donation**

**The Canadian organ donation and transplantation  
system is not equitable nor transparent.**

**There are system inefficiencies associated with  
patient assessment and organ allocation that can  
impact patient wait times and health**

**Lack of measurement and accountability to drive  
consistent, system-wide improvements**

## In October of 2009 and January of 2010 we agreed on preferred solutions for several solution design questions.

- How can the system best enable the public to turn support for organ donation into action?
- Should the system support a method for registration of first-person consent?
- How can the system improve and increase identification and referral of potential donors?
- To what extent should practices in patient referral and waitlist management be consistent? What are the best mechanisms for achieving this?
- What principles should guide an improved approach to organ allocation?
- What resourcing model(s) best accommodate organ donation services?
- What operating and resource models best accommodate organ transplantation?



# Strategic Planning Engagement

## Public Dialogues

- Inform the public about OTDT
- Receive feedback and learn what the public values

## Expert Engagement

- Inform experts regarding the planning process
- Receive feedback on content drafted to date

## Partnership Building

- Enhance and build partnerships with other organizations in support of the OTDT cause

## Government Engagement

- Inform government regarding the state of OTDT and the progress of the planning process

# Strategic Planning Engagement – Recent Developments

## Public Dialogues

- Recently completed Edmonton, Halifax, Winnipeg, Regina, St. John's
- Upcoming events in Moncton and Toronto

## Expert Engagement

- Recent activity in BC, AB, MB, ON, NS, NB, NFLD
- Recently speaking with many professional associations and societies

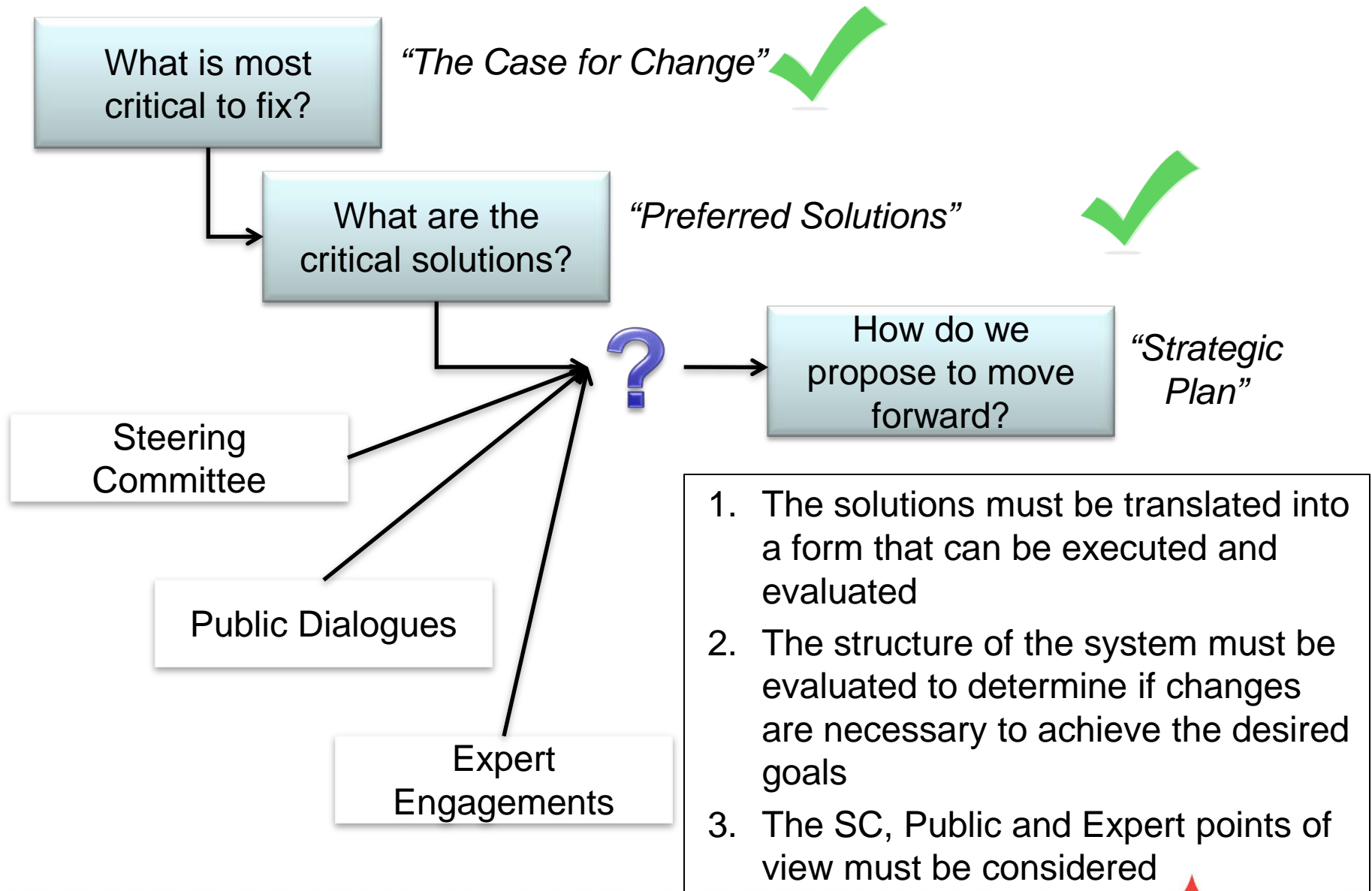
## Partnership Building

- Partnership Roundtable

## Government Engagement

- Meetings with PT blood contacts for updates on OTDT
- Upcoming June 7th meeting with DMs

## How do we transition into the next phase of the process?



## What are the next steps?

### System Strategy

- Translate committee direction into actionable form
- Describe the ultimate goals and the changes needed to achieve them
- Integrate the public and expert feedback

### System Design

- Describe the changes in system structure necessary to execute the strategy
- Describe roles and responsibilities
- Describe how major activities are coordinated and how accountability is achieved

## System Principles

## A critical foundation for both the performance strategy and system design are the system principles

- The Steering Committee, with feedback from both Expert Committees and various stakeholder groups has drafted a set of principles for the ODT and TDT systems
- These principles build on those implied by the Canada Health Act and align with those prescribed by the World Health Organization

**Collaboration and Integration**

**Fairness**

**Self-Sufficiency (Organs)**

**Security of Supply (Tissues)**

**Population-Based System**

**Safety**

**Accountability**

**Cost-Effectiveness**

**Privacy**

**Ethical Practices**

## ***ODT System Strategy***

## Purpose of this Discussion

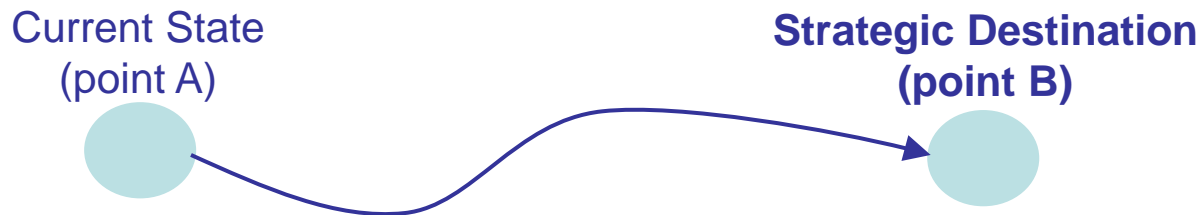
- To introduce the strategy management tools we will use to translate and communicate the ODT system strategy
- To review a draft strategic destination and draft strategy map



## The tool we will use to articulate the performance strategy is the Kaplan-Norton Balanced Scorecard.

- Although there are different frameworks for describing and managing a performance strategy, we have chosen the Kaplan-Norton Balanced Scorecard
  - Canadian Blood Services credits this framework for their success in strategic management
- There are several key components to a Kaplan-Norton Balanced Scorecard:
  - Strategic destination
  - Strategy map
  - Objective descriptions
  - Measures
  - Initiatives
- Ultimately the Balanced Scorecard is designed to describe the strategy in such a way that it can be successfully communicated, executed, measured, and managed

## Translating recommendations into strategy begins by identifying the ultimate outcomes we want the system to achieve



A **Strategic Destination** uses three components to answer the question: *Where are we going?*

1. Quantify the ultimate indicator of success

*“Double patient satisfaction...”*

2. Define the scope of where success will be attained

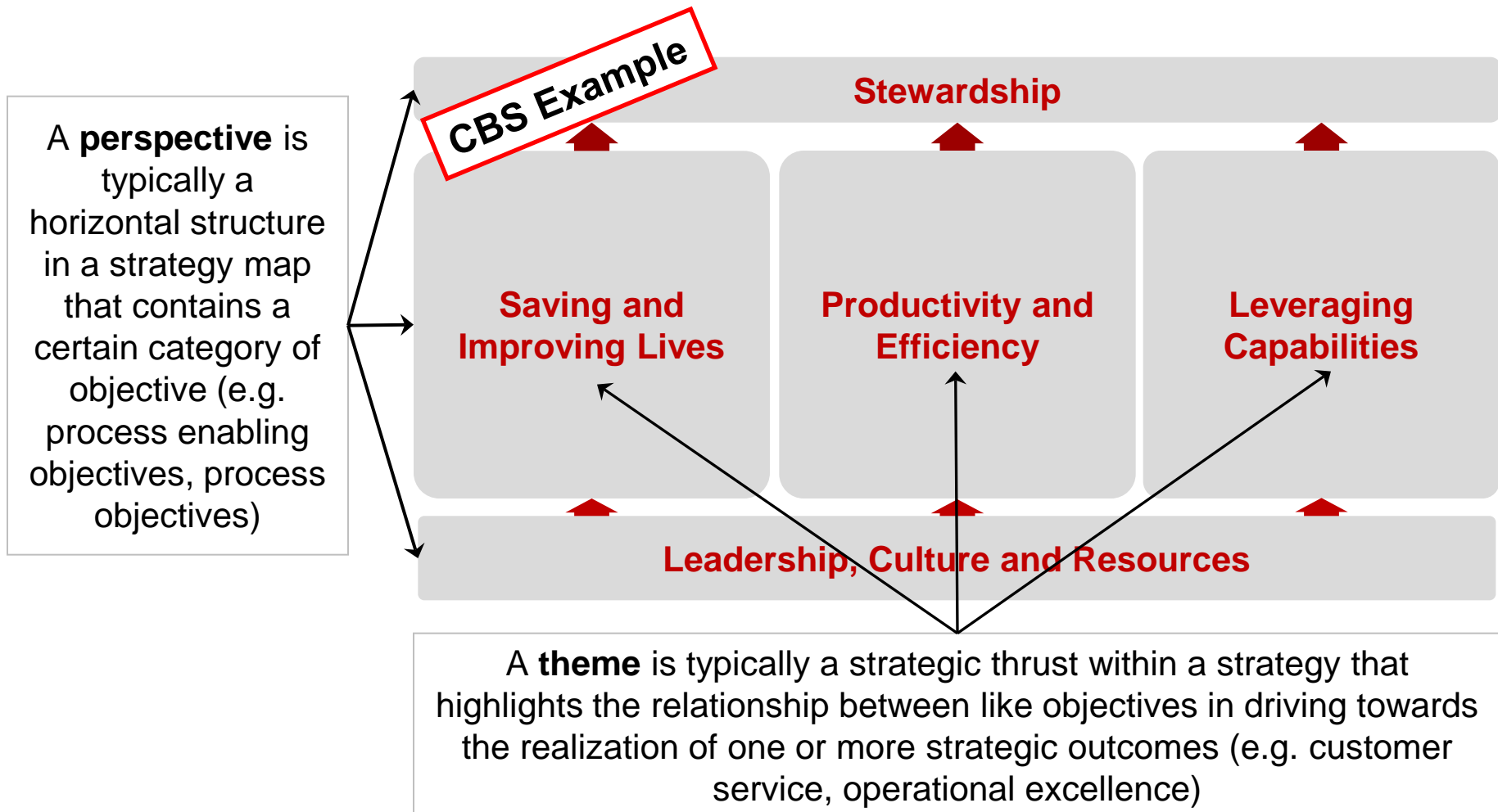
*“For patients with XYZ condition...”*

3. Identify the timeline for execution

*“In the next three years”*

**While the strategic destination describes the ultimate goal, the strategy map describes how the goal will be achieved.**

A **strategy map** is a one-page visual representation of an organization's strategy that depicts both desired outcomes and critical drivers across multiple perspectives and themes

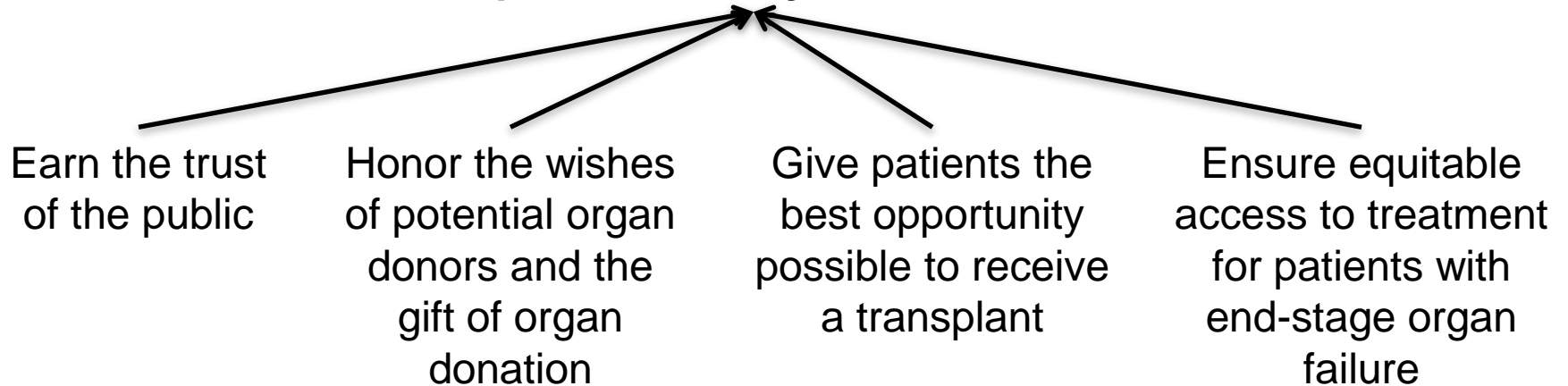


## There are many functions of a clear and thoughtful strategy map.

- A strategy map...
  - Communicates the ultimate outcomes the system should achieve and the path to achieving them in an easily-consumed format
  - Articulates the strategic hypotheses such that they can be tested and adapted over time
  - Supports system governance by creating a context for measurement and accountability

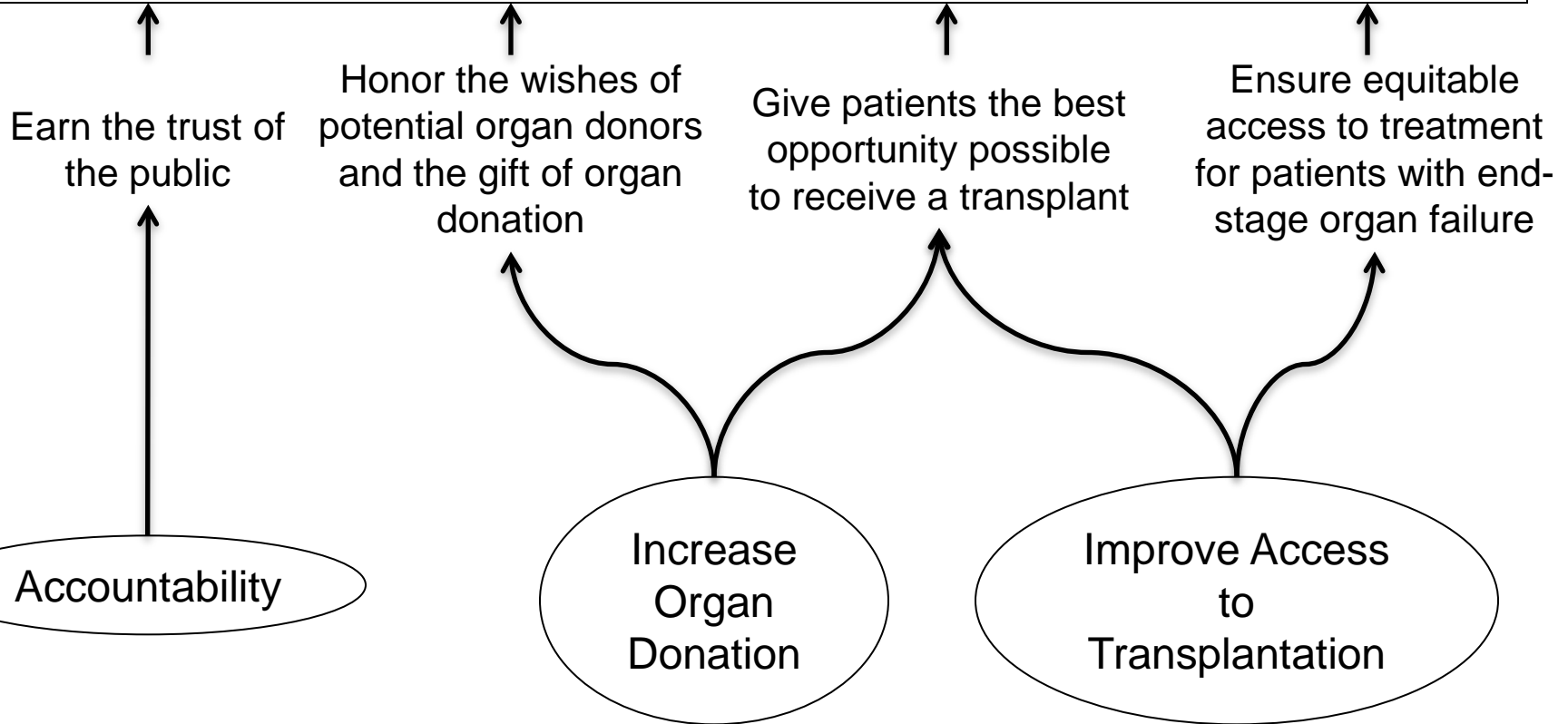


*“A trusted and self-sufficient system for Canadian patients by 2016”*



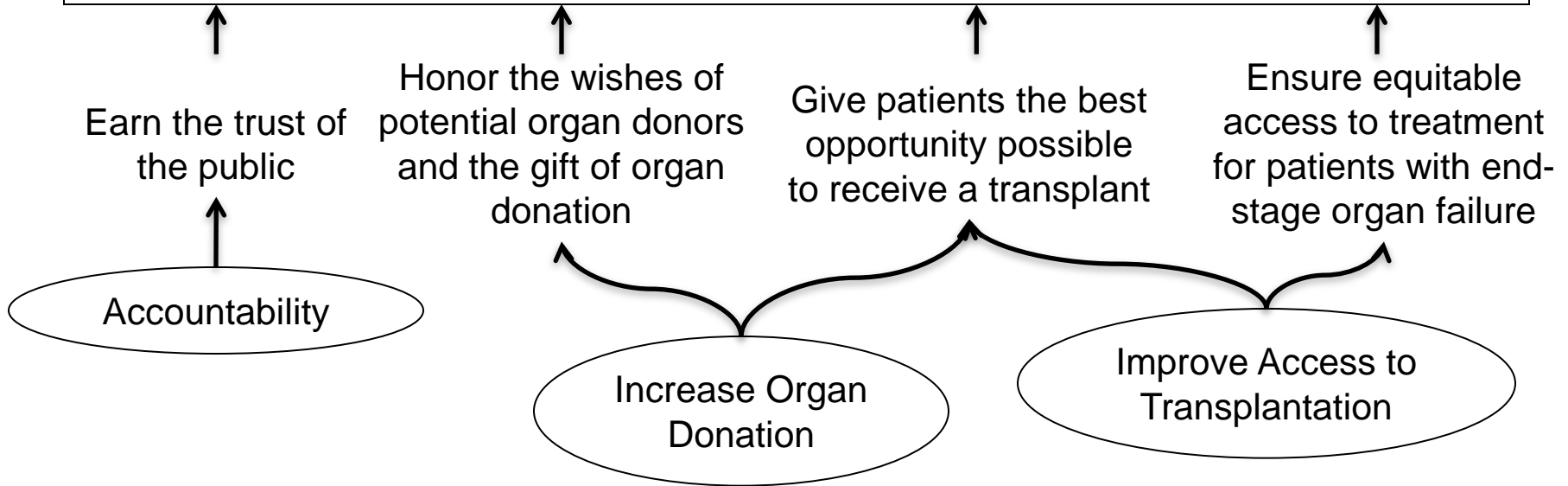
# What are the key system improvements that will achieve this destination?

*“A trusted and self-sufficient system for Canadian patients by 2016”*

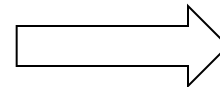


## Where do these improvements occur and who makes them happen?

*“A trusted and self-sufficient system for Canadian patients by 2016”*

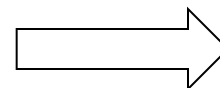


- Transplant Programs, OPOs, Hospitals, Regulators, Governments, etc.



Collaboration

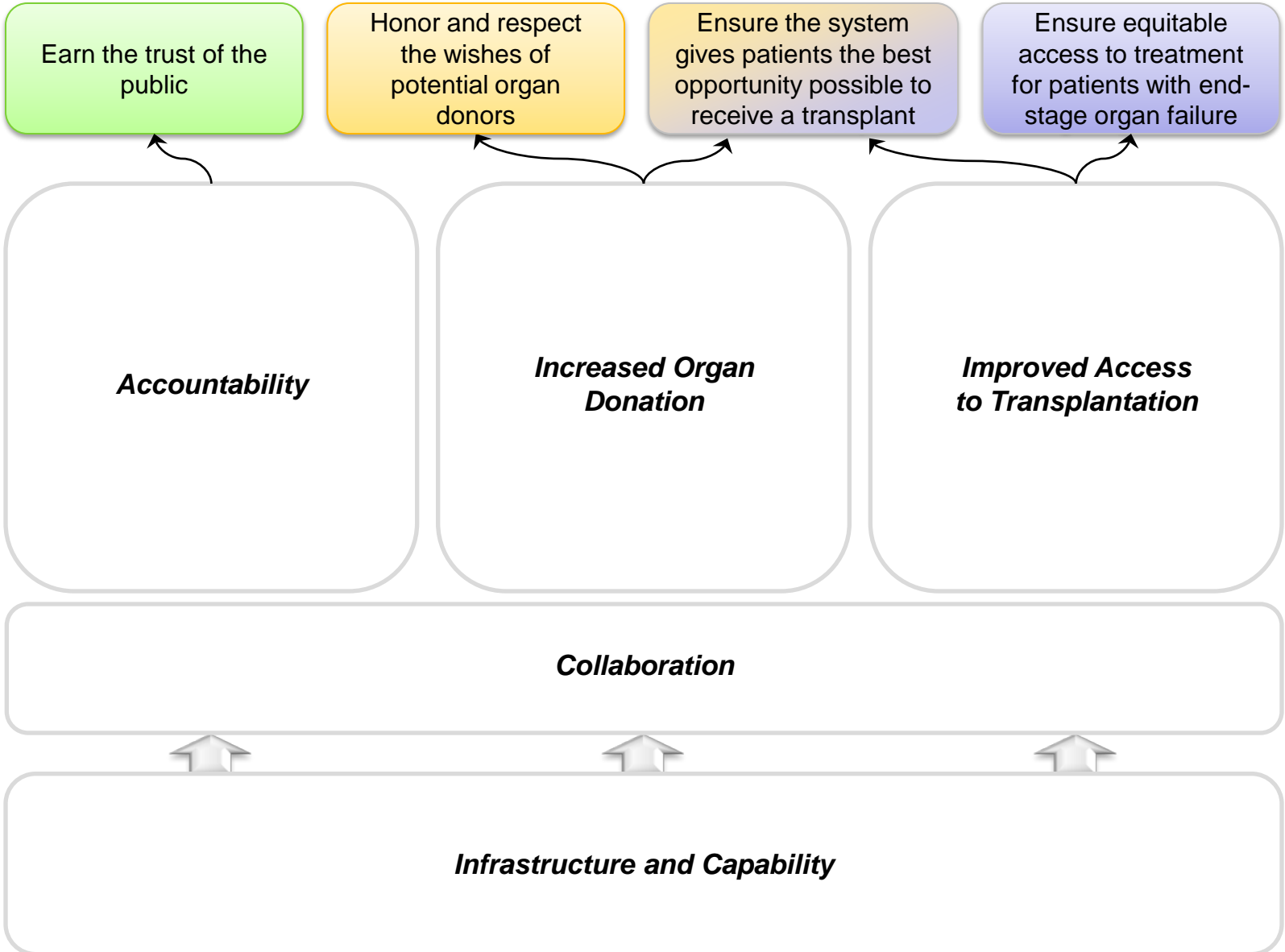
- Systems, Policies, Facilities, Resources, etc.



Infrastructure  
& Capabilities

# DRAFT - Organ Donation and Transplantation Strategy Map

***A trusted and self-sufficient system for Canadian patients by 2016***



Desired Outcomes

*to drive*

System Processes

*that enables*

Infrastructure and Capability

Earn the trust of the public

Honor and respect the wishes of potential organ donors

Ensure the system gives patients the best opportunity possible to receive a transplant

Ensure equitable access to treatment for patients with end-stage organ failure

***Accountability***

***Increased Organ Donation***

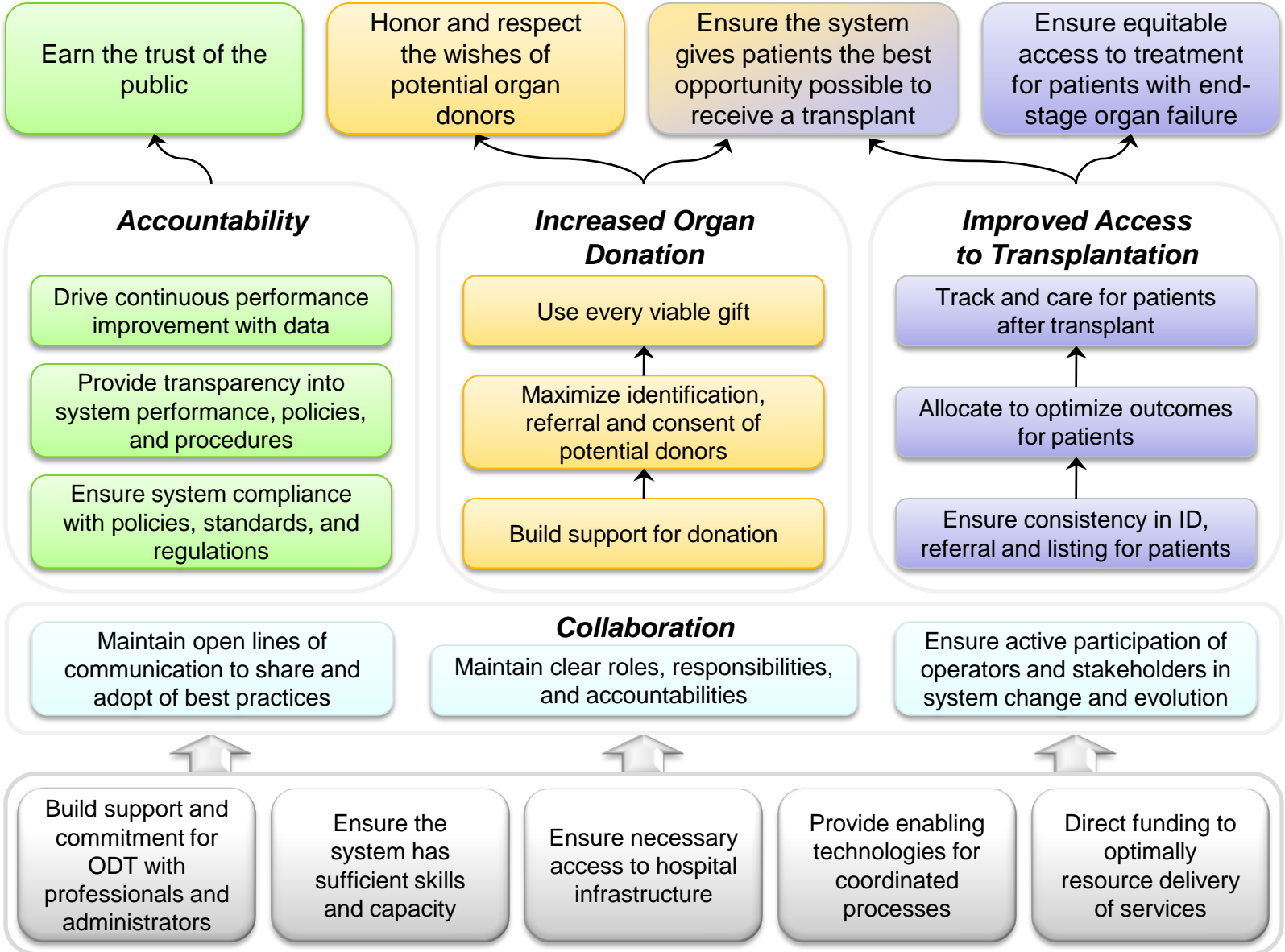
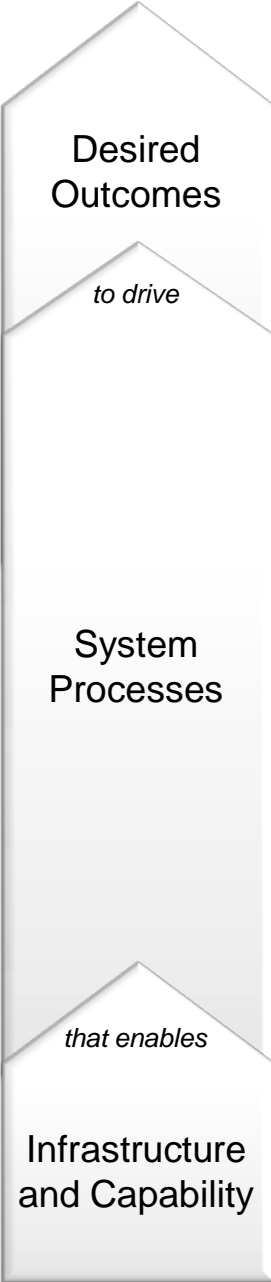
***Improved Access to Transplantation***

***Collaboration***

***Infrastructure and Capability***

# DRAFT - Organ Donation and Transplantation Strategy Map

## A trusted and self-sufficient system for Canadian patients by 2016



# The Balanced Scorecard is more than just objectives.

Desired Outcomes

Ensure the system gives patients the best opportunity possible to receive a transplant

System Processes

## Increased Organ Donation

### Utilize every viable gift

Maximize identification, referral and consent of potential donors

Build support for donation

Infrastructure & Capabilities

Workforce

Data

Infrastructure

Funding

# ILLUSTRATIVE

How we will evaluate progress and drive the desired behaviors

## Measures

- Organs per donor
  - X (SCD)
  - Y (ECD)

The desired level of performance

## Targets

- 2015 targets:
  - X+A (SCD)
  - Y+B (ECD)

Key projects required to achieve the objective

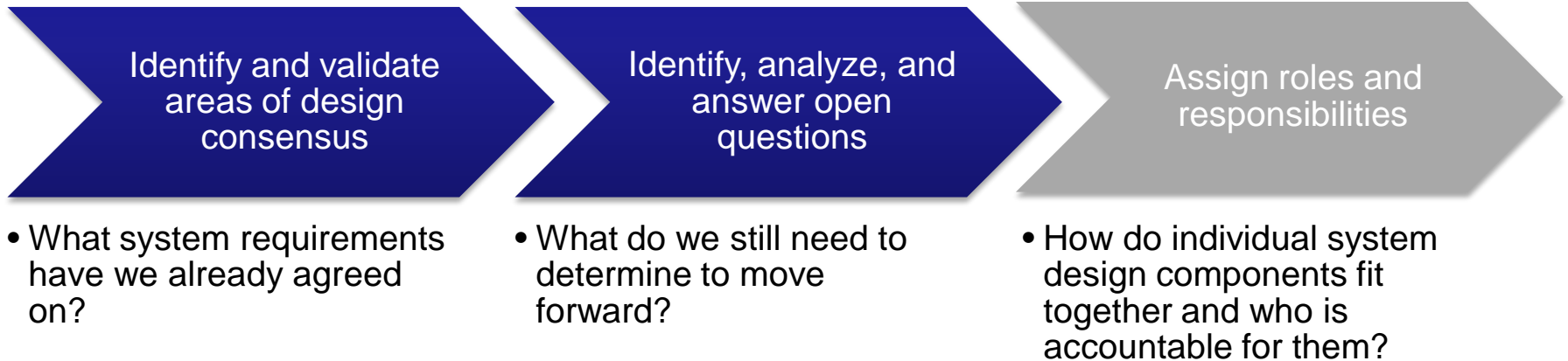
## Initiatives

- Automated matching system

## ***ODT System Design***

# Process for and Purpose of this Discussion

## Process:



## Purpose of Today's Discussion:

- To understand the process for proposing ODT system design
- To validate the draft system design requirements and begin to answer the most critical open questions that remain

# System Design begins with the direction established by the OEC

***“What did we recommend?”***

***“How must the system function?”***

***“What structures must the system have?”***

Preferred Solutions  
(Patient Referral)

- Donor registries to better inform and measure public awareness, improve access to ICU and provide info for family consent conversations

System Requirements

- Develop, implement and maintain donor registries

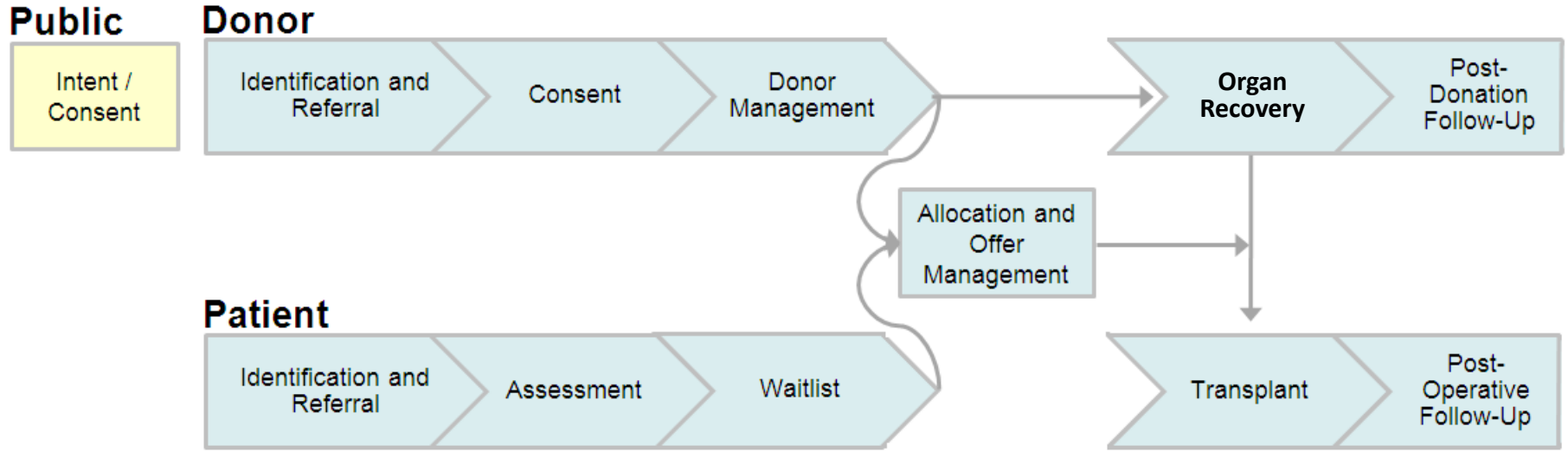
System Design and Open Questions

- SYSTEM COMPONENTS
  - Donor Registry
- ***What approach to donor registries should we recommend?***

**EXAMPLE**

***In this meeting, we will validate the requirements and discuss critical questions that remain open***

# Today's conversation will be organized around components of the ODT system



## Governance



## Today's breakout sessions will be organized around the following open questions

- What approach to donor registries should we recommend?
- Should allocation rules be consistent across provinces and programs?
- How should a central system support allocation (beyond LDPE, urgent status and HSP)?
- What additional mechanisms will ensure that ODT service delivery organizations will be accountable for agreed-to standards, policies and performance?



## Public and Professional Awareness, Donor Consent

### OEC Preferred Solutions

- Develop a national approach to increase public and professional awareness, supported by research, taking advantage of technology, measuring outcomes
- Use donor registries to better inform and measure public awareness efforts, improve access to ICU, and to provide info for family consent conversations

### Public Feedback

- Educate the public through diverse channels
- Support for donor registries
- Standardize processes for donor consent and make it easier for donors to express consent
- Presumed consent (opt-out model) should be considered

### Expert Feedback

- Increase donation through public awareness and improved understanding of consent
- Educate different demographic and cultural groups about this (i.e., social marketing)
- Presumed consent (opt-out model) should be considered
- Support for donor registries

# Public and Professional Awareness, Donor Consent

## System Requirements



- Design, implement and manage national social marketing efforts
- Design, implement and manage local social marketing efforts
- Coordinate national and local efforts to ensure consistency of messaging and take advantage of economies of scale where possible
- Develop, implement and maintain donor intent / consent registries

## System Design and Open Questions

### SYSTEM COMPONENTS

- National ODT Public/Professional Awareness
- Local ODT Public/Professional Awareness
- Intent / Consent Registry(ies)

### OPEN QUESTION:

**What approach to donor registries should we recommend?**

## Donor Registries:

### What approach donor registries should we recommend?

Description	Independent provincial registries	Linked provincial registries	One multi-provincial registry, linked to existing provincial registries	One central registry, access to all provinces
<p><b>Alignment with strategy and principles</b></p>	<ul style="list-style-type: none"> <li>• Integrated/ aligned with provincial data systems (i.e. health card, driver's license)</li> </ul>	<ul style="list-style-type: none"> <li>• OTDT Health workers have access to info on all registered Canadians</li> </ul>	<ul style="list-style-type: none"> <li>• OTDT Health workers have access to info on all registered Canadians</li> <li>• Provides registry for those provinces without one</li> </ul>	<ul style="list-style-type: none"> <li>• OTDT Health workers have access to info on all registered Canadians</li> <li>• Consistent messaging and registration process across Canada</li> <li>• Most efficient IT solution</li> <li>• Supports donor mobility</li> </ul>
<p><b>Conflict with strategy and principles</b></p>	<ul style="list-style-type: none"> <li>• No access to registries outside of province</li> <li>• Inconsistent capabilities</li> <li>• Many separate registries more costly than one registry</li> </ul>	<ul style="list-style-type: none"> <li>• Inefficient, complex and costly solution</li> <li>• Inconsistent capabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Inconsistent capabilities</li> <li>• More difficult to link to other provincial data systems (health card, driver's license)</li> </ul>	<ul style="list-style-type: none"> <li>• More difficult to link to other provincial data systems (health card, driver's license)</li> </ul>

# Donation (Identification, Referral, Consent, Donor Management)

## OEC Preferred Solutions

- Dedicated, funded staff to focus on donation process at hospitals, and accountable for implementation of national policy/best practices for donation:
  - Donor coordinators
  - Physician organ donation specialists
- Legislation for mandatory referral of potential donors to OPOs
- Standard triggers for referral of donors
- Continue best practice development and sharing (e.g., the Collaborative), linked to accreditation and international practices
- Training programs for health care professional involved in the donation process
- At least one centre in each region available for donation 24/7
- Increased funding for DCD and living donor programs

## Public Feedback

- Ensure sustainable funding

## Expert Feedback

- Need professional education
- Streamline system for identification and referral of potential donors
- Need to make donor identification a routine part of end-of-life care
- System design needs to address ICU capacity
- Increase donation through DCD and extended criteria donors
- Support outlying hospitals to identify and refer potential donors
- Include funding for living donor assessment and reimbursement of expenses
- Adequate funding for hospitals, ORs and ICUs to implement system improvements

# Donation

## System Requirements



- Develop national policies and best practices for donation process
- Monitor / ensure compliance with policies and best practices
- Manage donation locally, and implement national policies, best practices
- Develop training programs / materials for health professionals associated with organ donation
  - Work with professional colleges and associations to integrate organ donation into curricula

## System Design and Open Questions

### SYSTEM COMPONENTS

- Donation Policy and Best Practice Development
- Donor Identification and Management
- Monitoring for Compliance with Donation Policies and Best Practices
- Donation Training Development and Liaison with Royal College



## OEC Preferred Solutions

- Allocation Principles
  - Evidence-based, transparency, accountability, fairness, utility, medical need
  - Public input into allocation principles
- Formal structure for the development of allocation rules
- Standardized allocation processes for transplant programs and OPOs
- National oversight with audit function and consequences for non-compliance
- Transition phase with balancing to ensure that high-performers are not penalized

### Public Feedback

- Promote fair allocation standards at the national level
- Establish a national, integrated IT registry system to coordinate organ distribution
- Allocation practices should be fair and reasonably equitable

### Expert Feedback

- There should be equal access to transplantation
- Consistent national application of agreed upon allocation principles with accountability for practices, so net exporters of organs are not disadvantaged
- Need to determine whether organs are a local, regional or national resource
- Allocation practices should be fair and reasonably equitable
- Consider a national allocation and offer management centre
- Need a real-time central donor database to facilitate organ allocation
- Transparency and reasonable rationale in allocation decisions is important, and information needs to be shared
- Need a “payback” system for exporters of organs to other provinces

# Allocation Priorities Framework

## Allocation Principles:

Evidence-based,  
Transparency,  
Accountability,  
Fairness,  
Utility,  
Medical Need

### Mandatory Inter-Provincial Sharing:

- Urgent Status (non-renal)
- Highly Sensitized (kidneys)

### Sharing within province

Province

Province

Province

Province

### Non-Mandatory Inter-Provincial Sharing:

- Offers to avoid wastage of organs

Offers to the US to avoid wastage of organs

Matching, Offer  
and Balancing  
Rules

Agreements for  
Provinces  
without  
transplant  
programs

## Allocation

### System Requirements

- Develop and maintain allocation policies and algorithms (both overall and organ-specific) in accordance with allocation principles
- Monitor compliance with allocation policies and algorithms
- Communicate and educate on allocation policies and algorithms
- Collect allocation data, including transactional data on offer management, for purposes of transparency and ongoing evaluation and evolution of allocation policies and algorithms
- Allocate organs locally and nationally, as per allocation rules and algorithms



### System Design and Open Questions

#### SYSTEM COMPONENTS

- Allocation Policy (and Algorithm) Management/ Education
- Allocation of Organs
- Allocation Data Management
- Allocation Monitoring / Compliance
- IT System for Organ Allocation and Data Collection

#### **OPEN QUESTIONS:**

- Should allocation rules be consistent across provinces and programs?**
- How should a central system support allocation (beyond LDPE, urgent status and HSP)?**



## Allocation: Should allocation rules be consistent across provinces and programs?

Description	National standards and definitions; local discretion in application	Single national framework with explicitly identified exceptions for local discretion	Single framework, single set of rules
<p><b>Alignment with strategy and principles</b></p>	<ul style="list-style-type: none"> <li>• Takes into account reality of different donation rates</li> <li>• Acknowledges provincial issues and priorities</li> </ul>	<ul style="list-style-type: none"> <li>• Patients have same expectations across all provinces</li> <li>• Takes into account reality of different donation rates</li> <li>• Aligns with principle of evidence-base – exceptions are explained</li> </ul>	<ul style="list-style-type: none"> <li>• Patients have same expectations across all provinces</li> <li>• Clarity of application</li> </ul>
<p><b>Conflict with strategy and principles</b></p>	<ul style="list-style-type: none"> <li>• Conflicts with feedback looking for consistency across the country</li> <li>• May conflict with principle of equity/fairness</li> </ul>	<ul style="list-style-type: none"> <li>• May be difficult to manage, i.e., justification, consensus</li> </ul>	<ul style="list-style-type: none"> <li>• May not allow for unique provincial/regional needs</li> </ul>

## Allocation: How should a central system support allocation (beyond LDPE, urgent status and HSP)?

Description	Central recipient waitlist only	Central system to provide allocation functionality	Central system to provide allocation and offer management functionality
<p><b>Alignment with strategy and principles</b></p>		<ul style="list-style-type: none"> <li>• Single system supports both provincial and national allocation</li> <li>• Supports transparency and accountability</li> <li>• Cost sharing</li> <li>• Enhanced national data on donation and transplantation to support policy decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Standardization of forms, data, processes</li> <li>• Efficiencies for coordinators</li> <li>• Transparency of all offers and accepts/declines</li> <li>• Enhanced national data to support policy decisions</li> </ul>
<p><b>Conflict with strategy and principles</b></p>	<ul style="list-style-type: none"> <li>• Missed opportunity for standardization, virtual cross-match, cost sharing, data collection, efficiencies</li> </ul>	<ul style="list-style-type: none"> <li>• Missed opportunity for improving efficiencies for offer management</li> </ul>	

## OEC Preferred Solutions

- National organ-specific standard criteria for patient referral
  - Support for implementation through communication, education
- Single central waitlist for all patients (all organs, all status-codes)
  - Auditing for compliance to listing rules
  - Support for data entry into system

## Public Feedback

- Standardized criteria for transplantation eligibility across the country
- Need support group for transplant patients
- Need for financial support for patients who incur personal costs for transplantation

## Expert Feedback

- Advocate for a national wait list
- Need an integrated data management system linked to registries, outcomes of donors and recipients wait listing

# Patient Referral, Assessment, Waitlist, Transplant

## System Requirements



## System Design and Open Questions

- Develop national organ-specific standards for patient referral, listing for transplant and waitlist management
- Monitor and ensure compliance with standards
- Collect and manage data from these processes

### SYSTEM COMPONENTS

- Physician Referral to Transplant Program
- Transplant Program-based Assessment, Listing and Transplant
- Referral and Listing Standards Management
- Referral and Listing Compliance Monitoring
- Referral and Listing Data Management

## System Accountability

- What is accountability?
  - The principle that individuals or organizations are responsible for the results of their actions against agreed-upon standards or commitments, and that they are obliged to explain those results to their stakeholders.
- To whom are OTDT service delivery organizations accountable?
  - Patients
  - Donors and donor families
  - Staff and volunteers
  - Tax-payers/public/governments
  - Each other
- Why does the current system structure not support accountability?
  - Decentralized, with many independent organizations and programs involved in the process
  - Alternative approaches in service delivery among programs and provinces
  - Multiple types of funding structures and arrangements
  - Non-hierarchical relationships among service providers: partnerships, networks, informal agreements
  - Provincial and federal jurisdiction boundaries

## OEC Preferred Solutions

- Accountability includes the need to monitor and audit processes, actions and outcomes to enable policy improvement and to ensure compliance with allocation and utilization policies.
- There should be accountability for allocation and utilization decisions.
- Compliance with standards must be monitored and there must be accountability and transparency (Patient Referral)
- Support for national measures to monitor performance linked to collaborative score card and international measures
- Organ donation specialists need to be accountable for performance – clear accountability to national policies
- Central data collection, reporting and analysis

## Public Feedback

- Need open, transparent and accountable system and process which disclose all information

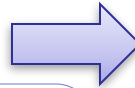
## Expert Feedback

- Auditing process to identify what is currently done well and where improvement is needed
- National oversight of OPOs
- Need accountability mechanisms in the ODT system
- Use accreditation to ensure compliance with standards and metrics
- Ensure monitoring and compliance to standards
- Create electronic information systems for performance data to allow comparisons, to stimulate donation rate improvements and to support accountability
- Need national metrics with respect to donation, freely shared among jurisdictions
- Need to drive measurement to support decision making and system-wide improvement
- Need real-time data repository that is available nationally
- Need resources to support accurate data collection, input, analysis and reporting
- Need tracking and traceability, and ability to report and share data between jurisdictions
- Need an integrated data management system linked to registries, outcomes of donors and recipients wait listing

# Accountability

## System Requirements

- Accountability for compliance with national policies, standards and processes, including reporting requirements
- Accountability for performance
- Accountability for public funds



## System Design and Open Questions

### SYSTEM COMPONENTS

- Boards
- Governments
- Regulators
- National collection of performance and compliance data
- Data review and analysis

### OPEN QUESTION:

**What additional mechanisms will ensure that ODT service delivery organizations will be accountable for agreed-to standards, policies and performance?**



## Accountability: What additional mechanisms will ensure that ODT service delivery organizations will be accountable for agreed-to standards, policies and performance?

### Accountability Mechanisms

- Transparent, mandatory, consistent reporting of performance
- Auditing and reporting of compliance
- Accreditation (Accreditation Canada or other organization)
- Membership arrangement (i.e. UNOS)
- Contract or reporting to a national oversight organization or coordinating body
- Fully integrated central registry covering supply chain (to enforce certain aspects of compliance and to support transparent, consistent reporting)

## *Wrap-Up and Next Steps*



## Next Steps in System Design

- We will update the strategy map
- We will draft measures for your review in June
- We will integrate all system design requirements into a holistic view for your review in June
- The Committee will meet again on Monday June 7, 2010

