

# Organ Expert Committee Meeting

*June 22<sup>nd</sup>, 2009*

Sheraton Gateway Hotel, Toronto

## The Organ Expert Committee

### Members:

- ❖ Dr. Peter Nickerson (Chair)
- ❖ Dr. Ian Alwayn
- ❖ Dr. Stephen Beed
- ❖ Dr. Michel Carrier
- ❖ Dr. Noel Gibney
- ❖ Dr. David Grant
- ❖ Dr. Greg Grant
- ❖ Dr. Tom Blydt-Hansen
- ❖ Dr. Debra Isaac
- ❖ Dr. Anthony Jevnikar
- ❖ Dr. Shaf Keshavjee
- ❖ Dr. Norman Kneteman
- ❖ Dr. Greg Knoll
- ❖ Dr. Adeera Levin
- ❖ Dr. Robert Levy
- ❖ Dr. Frank Markel
- ❖ Ms. Raylene Matlock
- ❖ Mr. Scott McIntaggart
- ❖ Dr. Joe Pagliarello
- ❖ Ms. Deanna Paulson
- ❖ Dr. Sam Shemie
- ❖ Dr. John Tallon

### CBS Observers:

- ❖ Dr. Graham Sher (Steering Committee Chair)
- ❖ Ms. Sophie de Villers
- ❖ Ms. Kimberly Young
- ❖ Ms. Sylvia Torrance
- ❖ Ms. Lorna Tessier

## Meeting Objectives

- Understand the process and decide how we will accomplish our goals
- Develop a compelling case demonstrating the priority of OTDT system change
- Identify the key topics for which the committee must advance recommendations and/or consensus
- The OTDT overview documents will **not** be reviewed; however, we welcome any feedback or corrections to make the description of the current state as accurate as possible

## Organ Expert Committee Agenda

Agenda Item	Time
Welcome and Administrative Items	9:30 – 10:15
Review of 2008 National Consultation Results	10:15 – 10:45
<i>----- Break -----</i>	
Introduction to Canadian Blood Services	11:00 – 11:15
Review of Methodology to Design National System	11:15 – 11:30
Introduction to the Draft Case for Change	11:30 – 11:45
<i>----- Lunch -----</i>	
Discuss the Draft Case for Change	12:15 – 2:45
<i>----- Break -----</i>	
Discuss Solution Design Topics	3:00 – 4:00
Wrap Up and Next Steps	4:00 – 4:30

## Administrative Items

- Approve the minutes from the Committee's last meeting on May 20<sup>th</sup>, 2009.
- Develop ground rules for working as a committee
- Approve the Terms of Reference

## CBS Commitment to Committee Support

CBS will support the committees through the process in part by making the following commitments to the Organ Expert Committee:

- Schedule key milestone meetings at least three months in advance
- Schedule additional meetings a minimum of one month in advance
- Distribute meeting material two weeks prior to the meeting date
- Distribute meeting minutes no longer than three weeks after the meeting
- Maintain an open channel of communication to receive feedback from any member of the committee

## Organ Expert Committee Principles and Ground Rules

In order to enable the Committee to work as effectively together as possible, principles and ground rules will be established to guide our interactions.

Topics to consider in developing ground rules include:

- Attendance
- Communication
- Confidentiality
- Meeting Conclusion

## Administrative Items

- ✓ Approve the minutes from the Committee's last meeting on May 20<sup>th</sup>, 2009.
- ✓ Develop ground rules for working as a committee
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## Review of 2008 National Consultation Results

# The Organ Donation and Transplantation Process

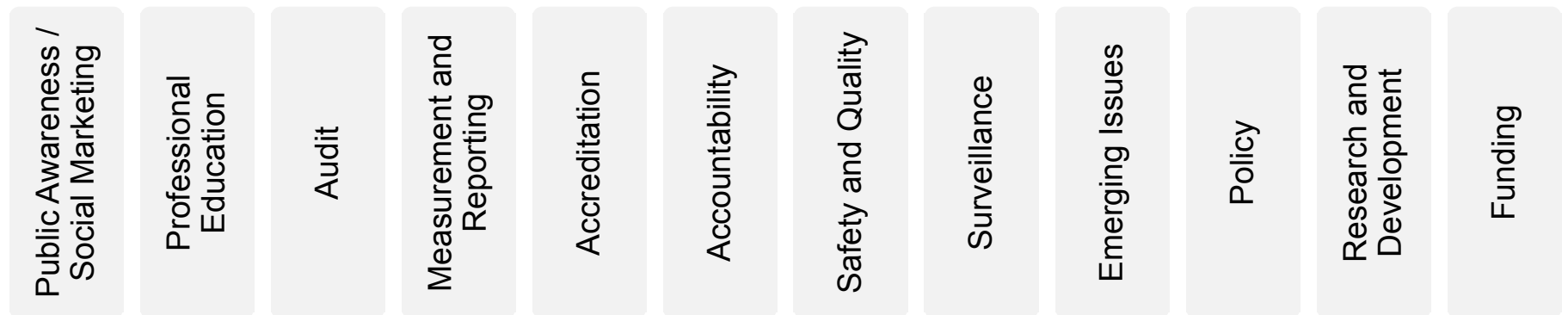
## Donation Process



## Transplant Process



## Governance

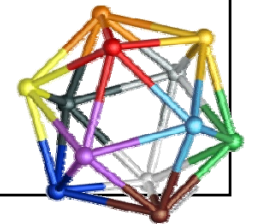
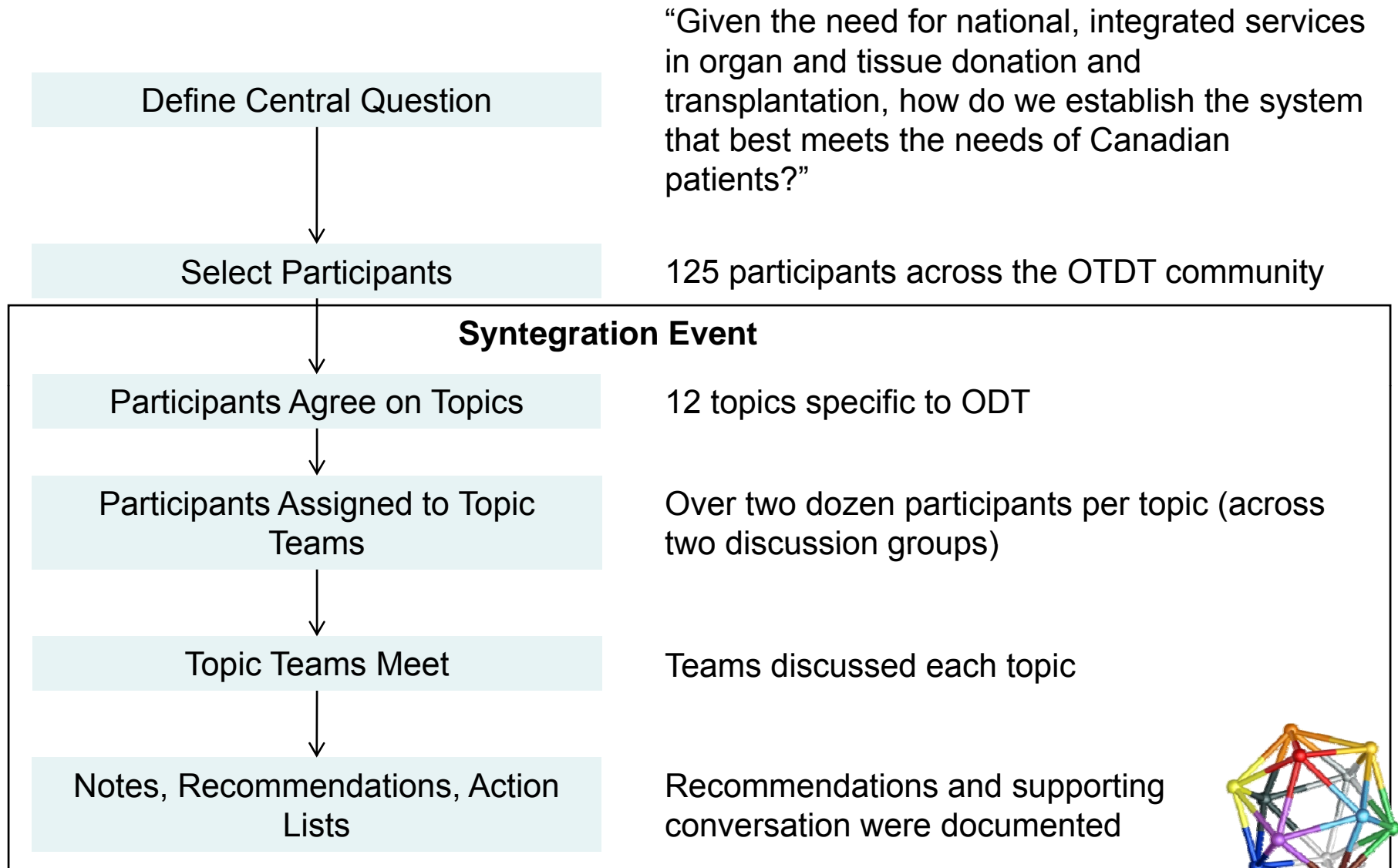


## Why a National Consultation was Convened

After receiving a mandate in August of 2008 from FPT Deputy Ministers of Health, CBS organized a national consultation to be convened in September that would engage and solicit the expertise of OTDT stakeholders for several reasons:

- To **listen** to expert opinions, ideas, aspirations, and frustrations regarding the system
- To explore and start to **define** problems, challenges, and risks regarding organ and tissue donation and transplantation in Canada
- To find areas of common understanding and **shared perspective** for a **national vision** and system model
- To identify areas of **informed disagreement** among participants
- To inform the **development of the process** used to create a plan for a national OTDT system

## How the National Consultation Worked



# Topics Determined and Addressed by Organ Participants

## Topics

Critical Care/Hospital Donation Practices

Live Organ Donation

Allocation & Utilization

Governance and Structure

Federal, Provincial and Local Roles

System-Wide Barriers and Opportunities

System Funding

Measuring Outcomes

Research

Information Systems

Awareness and Public Education

Mandate of National Agency

## Scope of Each Topic (1/4)

### Topics

Critical Care/Hospital Donation Practices

Live Organ Donation

Allocation & Utilization

Governance and Structure

Federal, Provincial and Local Roles

System-Wide Barriers and Opportunities

System Funding

Measuring Outcomes

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Mandate of National Agency

### Scope

- Culture
- Donation
- Donor management
- Funding (cost recovery)
- Intent / consent registry
- OPO / hospital relationship
- Referral practices

- Awareness
- Governance
- Hospital commitment
- Insurance
- LDPE
- Reimbursement

- Allocation
- Audit and compliance
- Listing
- Legislation
- Principles
- Standards
- Utilization

## Scope of Each Topic (2/4)

### Topics

Critical Care/Hospital Donation Practices

Live Organ Donation

Allocation & Utilization

Governance and Structure

Federal, Provincial and Local Roles

System-Wide Barriers and Opportunities

System Funding

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Mandate of National Agency

### Scope

- Agency composition
- Culture
- Governance function autonomy
- Oversight structure

- International models
- Local roles
- National agency roles
- OPO roles
- Province roles

- Best practice sharing
- Measurement and accountability
- Public engagement
- Stakeholder engagement

## Scope of Each Topic (3/4)

### Topics

Critical Care/Hospital Donation Practices

Live Organ Donation

Allocation & Utilization

Governance and Structure

Federal, Provincial and Local Roles

System-Wide Barriers and Opportunities

System Funding

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### Scope

- Funding channels
- Funding models (performance-based)
- Funding priorities

- Accreditation and auditing
- Measures
- Oversight roles
- Participation
- Public trust / transparency
- Standardization

- Funding
- Governance
- System's research role

## Scope of Each Topic (4/4)

### Topics

Critical Care/Hospital Donation Practices

Live Organ Donation

Allocation & Utilization

Governance and Structure

Federal, Provincial and Local Roles

System-Wide Barriers and Opportunities

System Funding

Measuring Outcomes

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### Scope

- Infrastructure implementation
- Oversight
- Participation
- Principles
- Purpose in OTDT
- Resources

- Messages
- Past experience
- Principles
- Roles
- Target audiences

- Governance roles
- Mechanisms available
- Regional variation
- System objectives
- System values

## Moving Forward...

### What we learned from the National Consultation:

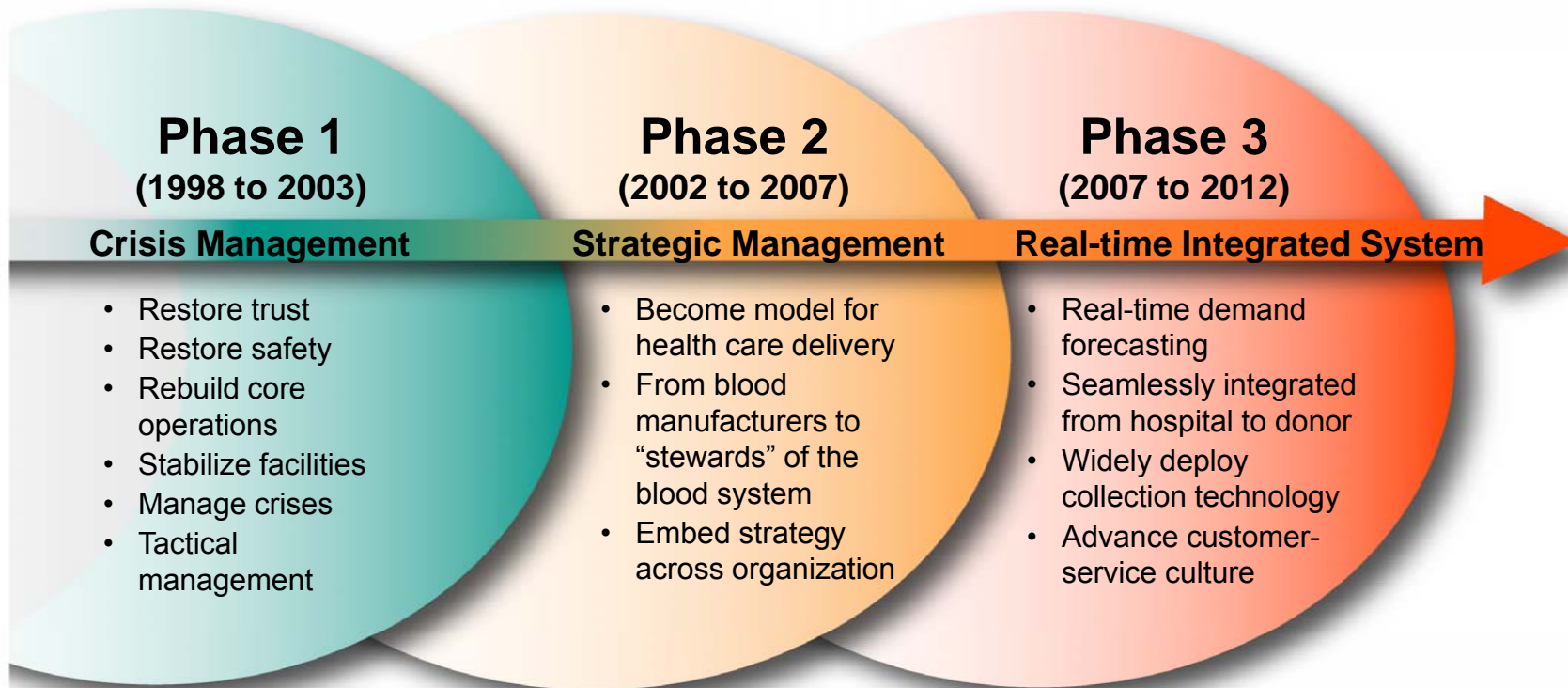
- Proposed directions for some of the most pressing organ donation and transplantation challenges
- Common ground in the organ community on a wide variety of topics
- Gaps in the community's knowledge and understanding of the current state
- Divergent perspectives in the community about the best way to design a national system

### How the results have and will be used:

- Results were an input to the draft Case for Change
- Recommendations have been used to shape the proposal for Solution Design Topics
- Development of materials for the fall meetings will use overall Consultation results as a starting place for the development of solution options

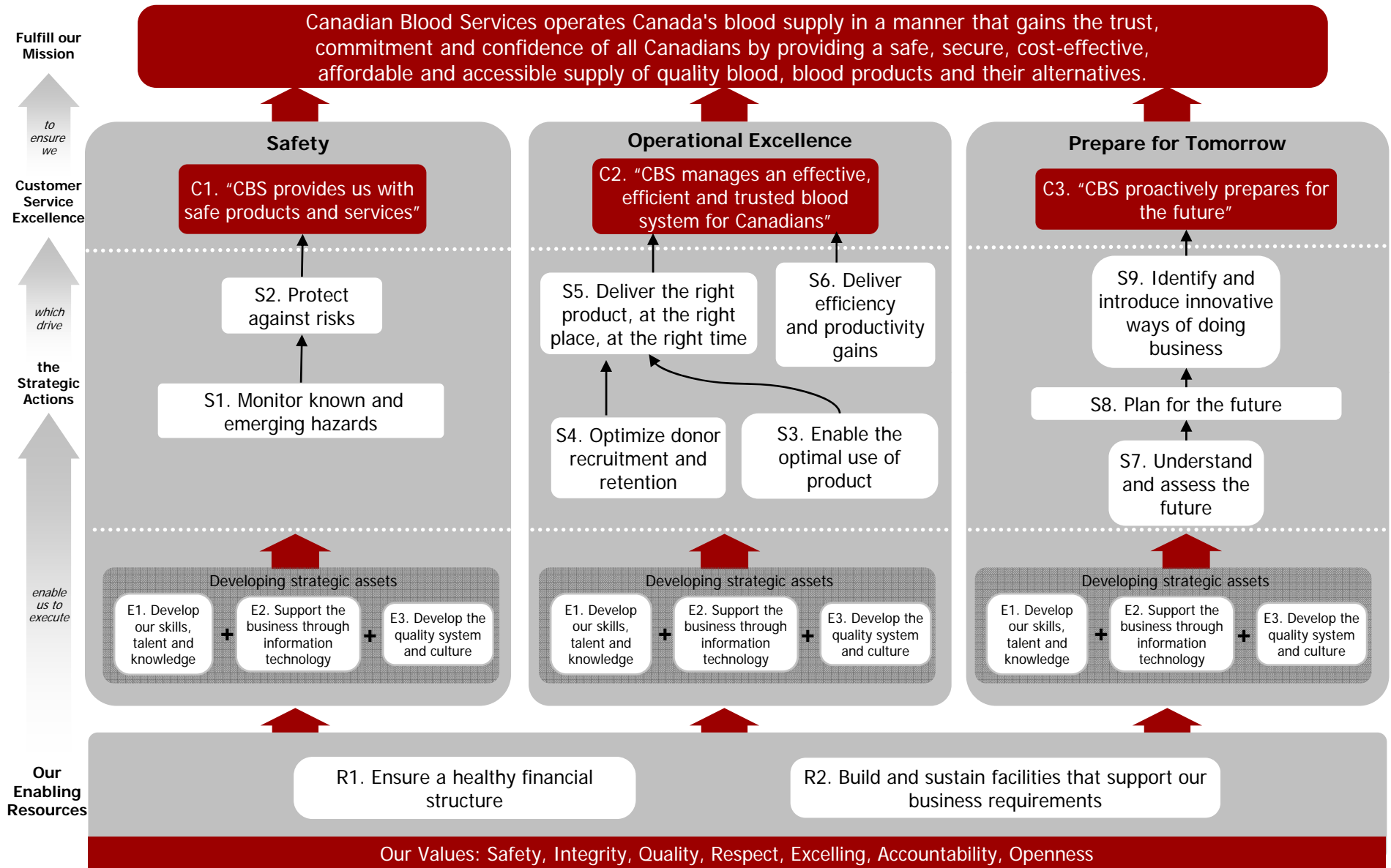
## Introduction to Canadian Blood Services

# History of Canadian Blood Services



- Canadian Blood Services founded in 1998 as the successor organization to the Canadian Red Cross, as a result of the tainted blood scandal
- Canadian Blood Services has transformed the legacy operations of the Canadian Red Cross into a national integrated service-delivery organization focused on quality and service excellence

# The First CBS Corporate Strategy Map



## Restoring Public Trust



*“I trust Canadian Blood Services to act in the best interests of the public.”*

**Stakeholders: 97%**

**Donors: 92%**

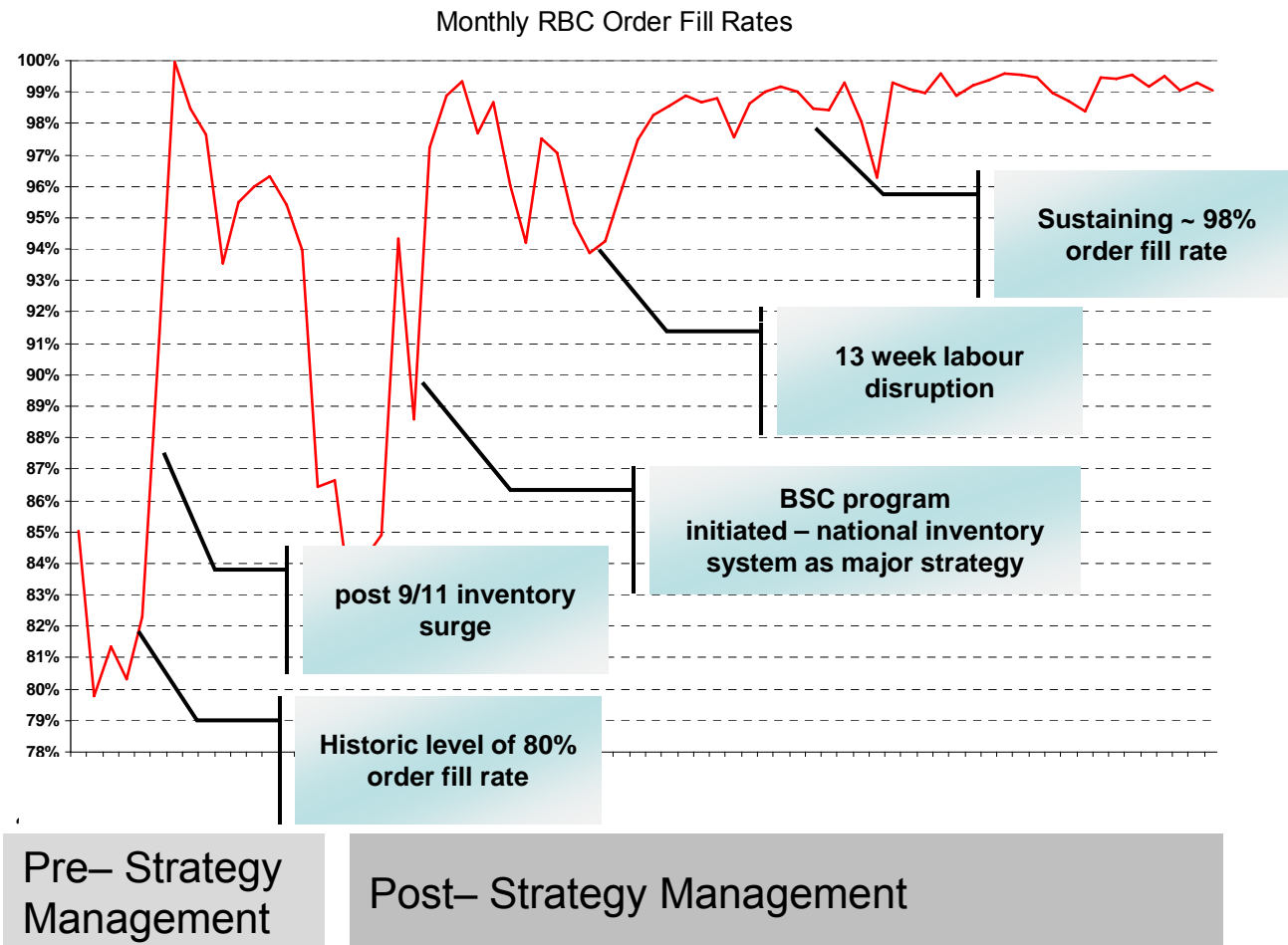
**Public: 75%**

IPSOS-Reid public opinion survey, Winter 2008

Public trust in the scandal ridden blood system measured < 50%

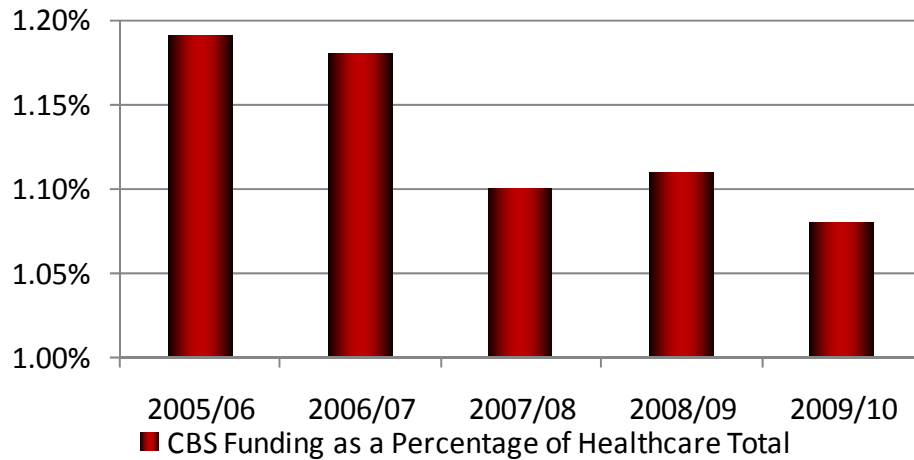
# Becoming a Trusted Partner

## Monthly hospital order fill rates



## Results Amid Change: The New Model in Action

**CBS Funding as a Percent of Provincial Healthcare (excl PQ) Total Spending**



- Year-over-year increases in core funding have declined for CBS below the general Health Care rate yet CBS has delivered increased value to Canadians
- CBS has increased operational effectiveness. Collections have grown more than 30% since 1998
  - Whole Blood (27%)
  - Plasmapheresis (40%)
  - Plateletpheresis (180%)

## Today, More Than Blood Collection ...

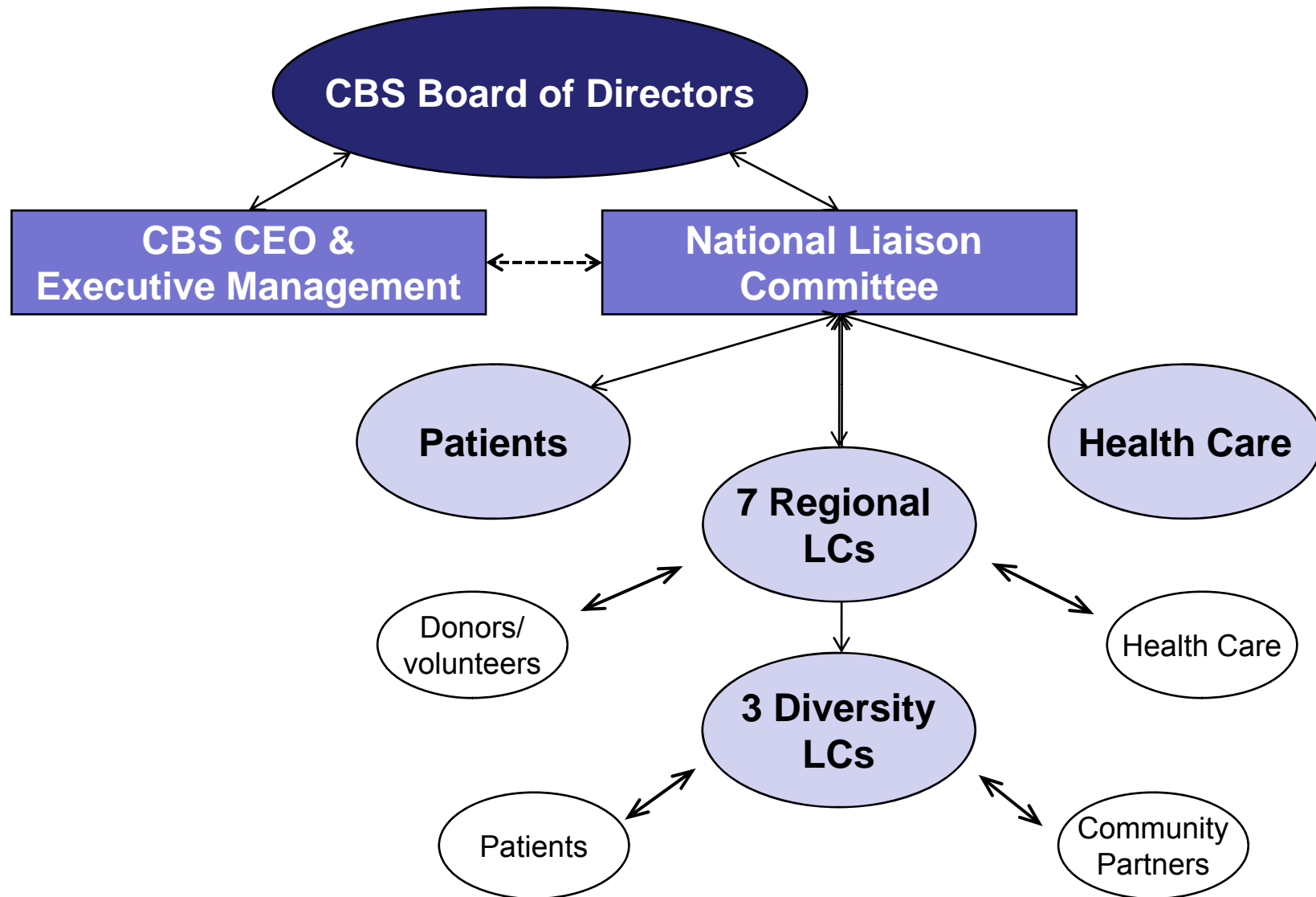
### WHAT WE DO:

- **Blood Operations:** Recruit donors, collect, process, test, distribute blood components
- **Plasma Program:** Collect plasma, custom fractionation, purchase and distribute plasma protein products
- **Related Programs:** Education, R&D, clinical consultation
- **OneMatch Marrow and Stem Cell Network:** Linked to 51 other registries worldwide, emerging umbilical cord blood bank
- **Diagnostic Laboratories**
- **Insurance Captive:** Wholly owned subsidiary
- **CBS Foundation:** To support and extend the mission of CBS

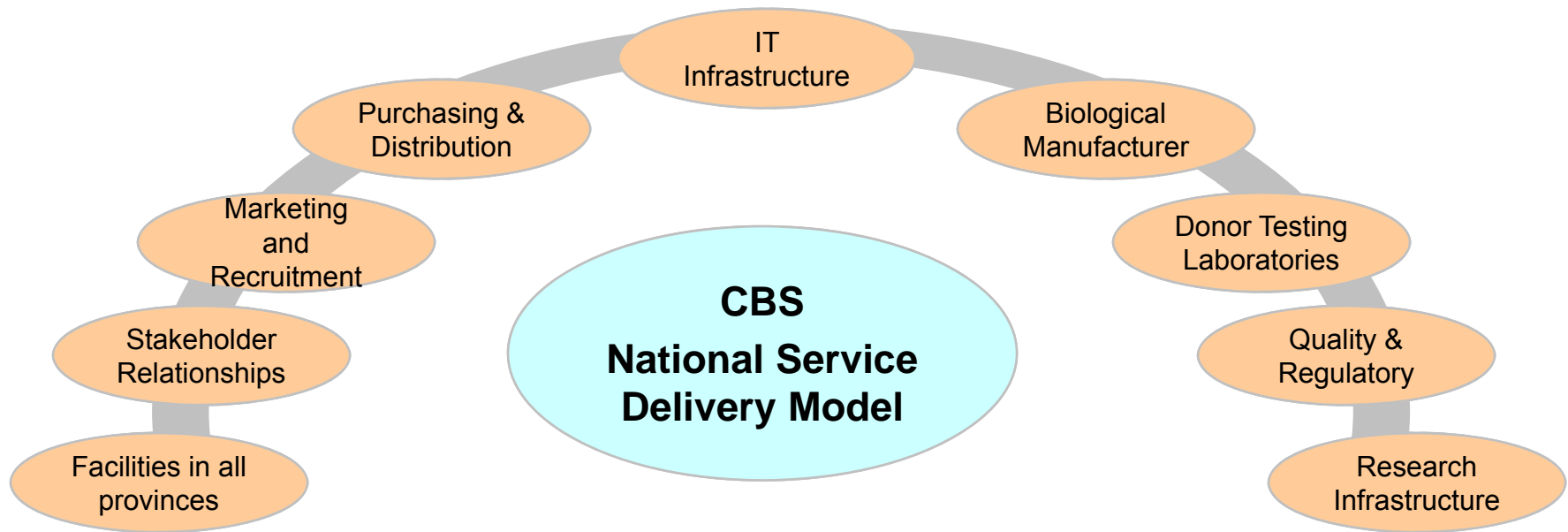
### HOW WE DO IT:

- **890,000 Whole Blood Donors**
- **52,000 Plasma Donors**
- **32,000 Platelet Donors**
- **450,000 Active Donors**
- **220,500 OneMatch Registrants**
- **732 Health Care Facilities Served**
- **4,500 Employees**
- **19,600 Volunteers**
- **\$890 Million Annual Budget**

# Liaison Committee Structure



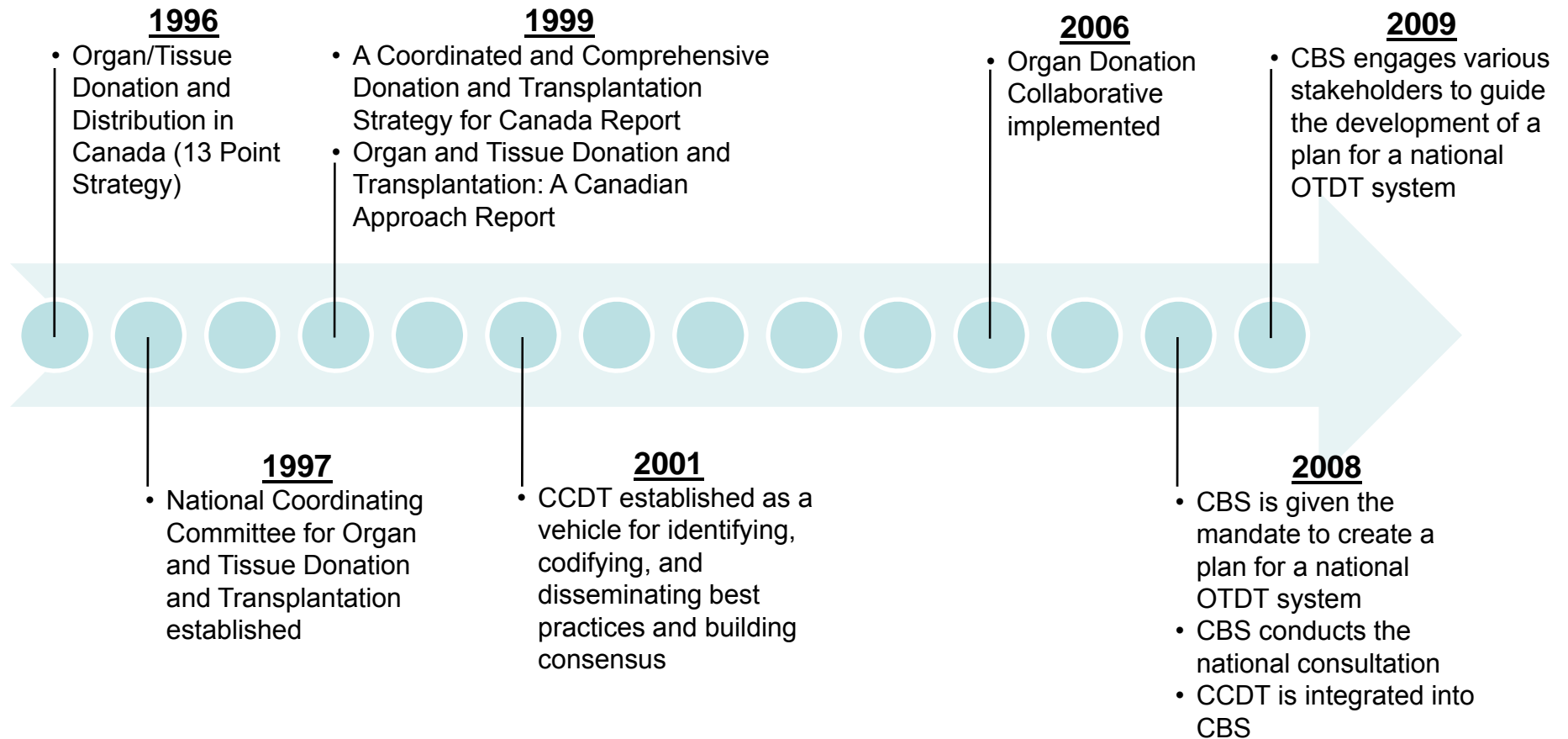
## CBS has a unique and distinctive national operating model.



- national, not-for-profit corporation with independent Board of Directors
  - accountable, transparent, with public participation
  - subject to Federal regulations (under Food and Drugs Act)
- P/T Ministers of Health are Members (shareholders) of the corporation
- two wholly owned insurance subsidiaries provide \$1 billion coverage
  - extensive risk management programs embedded

## Review of Methodology to Design National System

## How did we get here?



## The CBS Mandate

Aug 2008 – Canadian Blood Services given a mandate by FPT Deputy Ministers of Health (except Québec) for organ and tissue donation and transplantation:

- Continue work developing policies and knowledge translation for: leading practices, guideline developments, performance measurement, accreditation, public engagement and awareness
- Develop national registries for living donor paired exchanges, urgent status patients and highly sensitized patients
- Design a system for OTDT in Canada in collaboration with the OTDT community

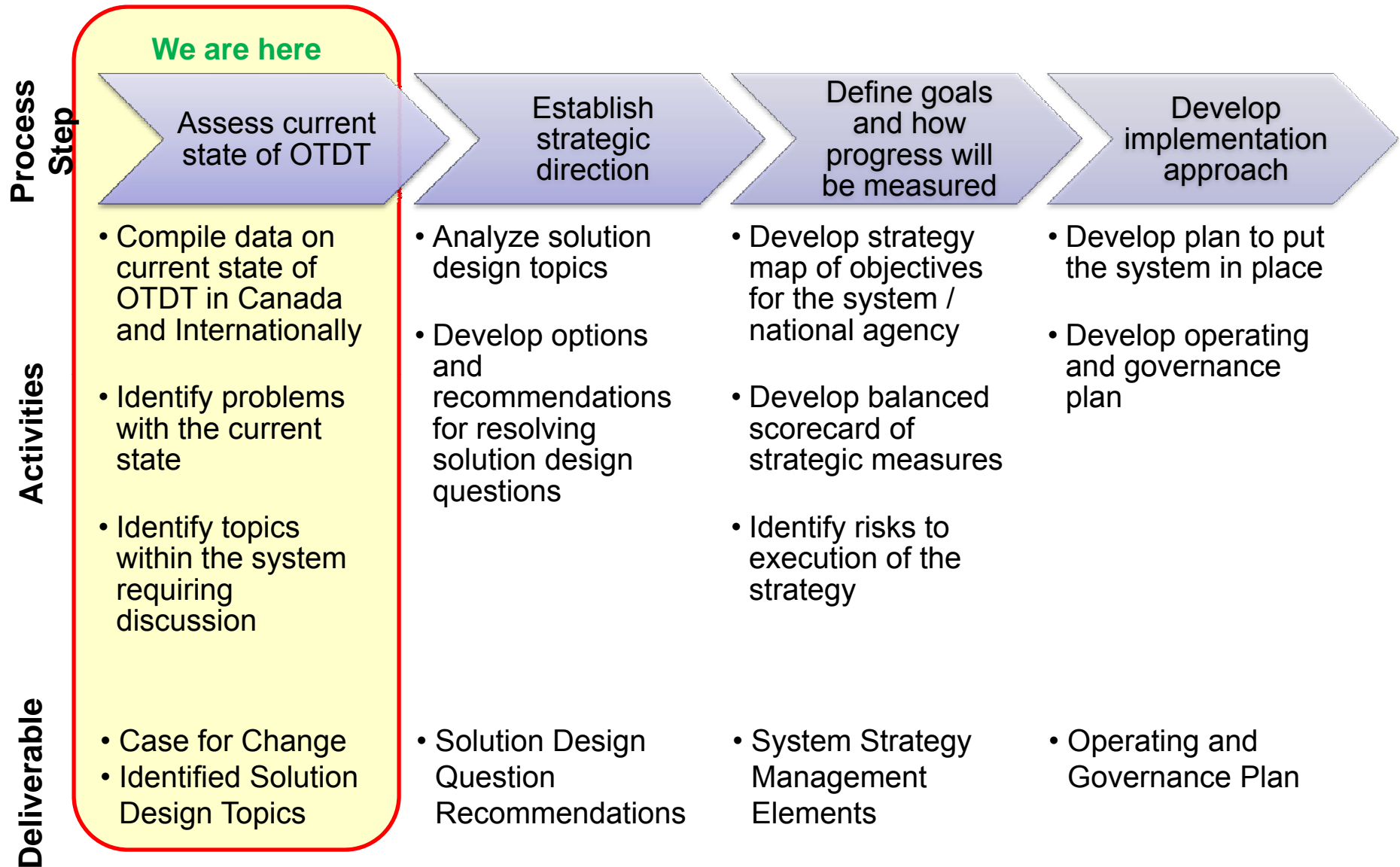
## What has CBS done in regards to the mandate to develop an OTDT plan?

- The National Consultation
- Detailed international consultation with:
  - UK Blood and Transplant
  - Australian experts (ARCBS, Jeremy Chapman)
  - United Network for Organ Sharing (UNOS)
- Discussions with the Health Resources and Services Administration (United States)
- Review of documents and research on the current state of the Canadian system
- Meetings with the Assistant Deputy Ministers Transition Team

## The process should be designed to...

- Be consultative, engaging as many stakeholders as possible to generate buy-in
- Be transparent, all activities and outputs demonstrable
- Acknowledge successful elements of the current system, and previous work done
- Be deliberate, logical and drive towards evidence-based conclusions
- Be respectful of the time we request from contributors
- Be completed within a reasonable time

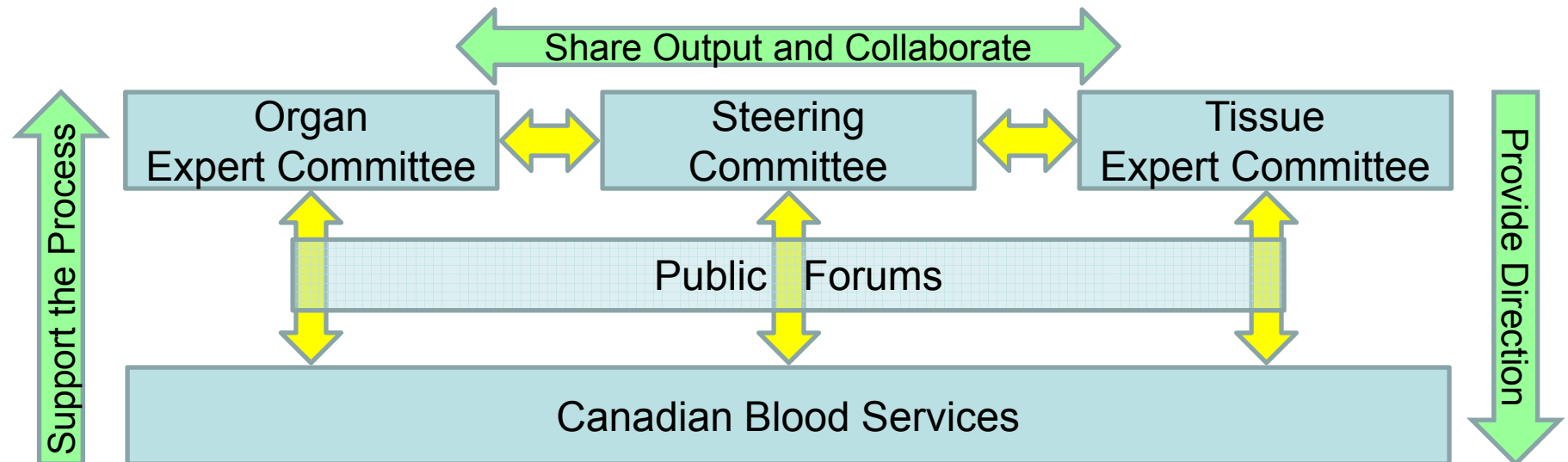
# Process Overview



## Roles and Responsibilities

### The Committees:

- The primary role is providing expert guidance on the content of the plan
- Each committee has a focus that is different from the others
- Committees have equal standing and share output openly
  - The Expert Committee Chairs will attend the Steering Committee as observers
  - The Steering Committee Chair will attend the Expert Committees as an observer



### Canadian Blood Services:

- The primary roles are to guide the plan development process and draft related and supporting content

## The Public Forums

### What:

- 4 – 6 geographically-distributed sessions open to the public to provide thoughts and opinions on OTDT topics
- An electronic forum to make a communication channel available for engaged Canadians who cannot attend a forum in person

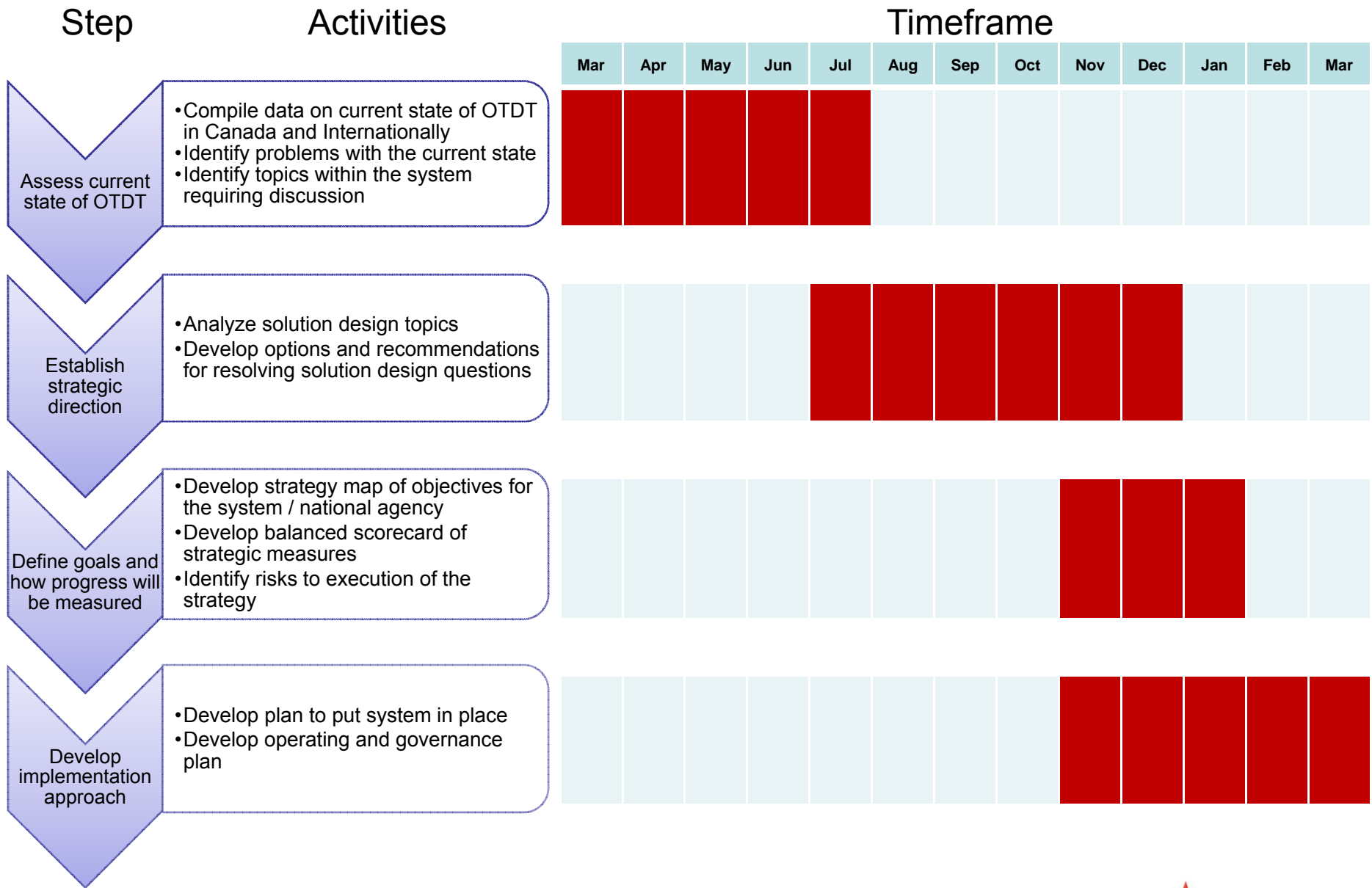
### Why:

- The public represents a key process stakeholder
- The public has interacted with the system and has opinions to share that are relevant input to the solution design process
- Gaining the support of the ministers is more likely if the public is insistent on OTDT being a priority

### When:

- The public will be engaged during the “Establish Strategic Direction” phase

# Process Timeline



## Discuss the Draft Case for Change

## What is the purpose of a “Case for Change”

- To achieve a shared understanding of the elements of ODT most in need of improvement
- To identify the elements of ODT that must be emphasized in the final business plan
- To develop common ground we can turn to when developing recommendations to address system challenges
- To create a basis for measuring the success of the national system

## Structure of the Case for Change

- The Case for Change document has been structured to facilitate a discussion of what most needs to be addressed by the OTDT strategic plan
- Identified weaknesses were grouped into major “problem headlines”; each problem headline is supported by more detailed problem statements, a brief discussion and references to supporting data
- The draft problem statements cover much of the ODT system
  - Donation
  - Transplantation
  - Infrastructure and Technology
  - Measurement and Accountability

# The Organ Donation and Transplantation Process

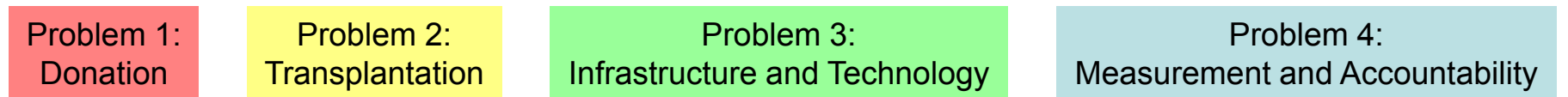
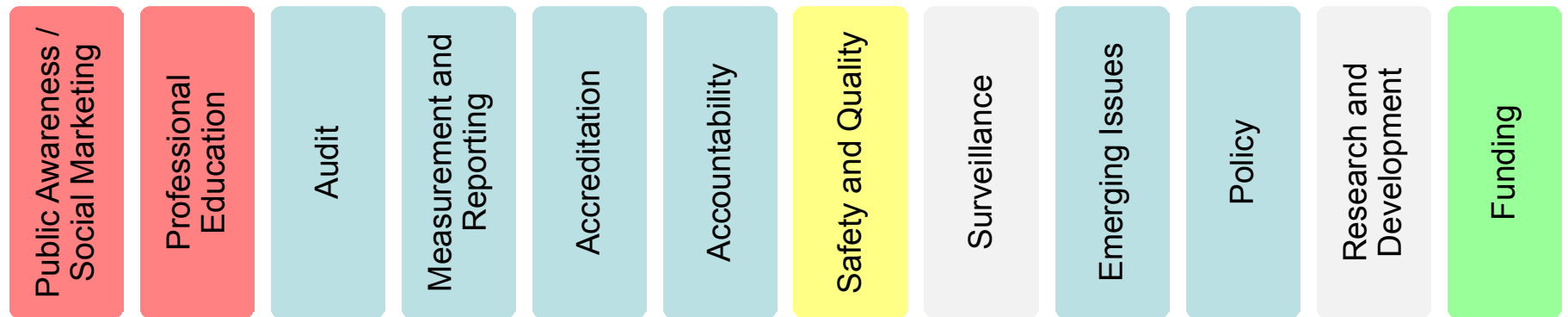
## Donation Process



## Transplant Process



## Governance



## ODT – Problem Statement 1

### Problem 1: Canada is failing to realize its potential for organ donation

- Strong public support for ODT does not ultimately translate into commensurate rates of registered intent/consent and family approval
- Registered intent/consent of potential donors is not regarded as binding despite its legally-binding nature
- Donor identification and referral remain a professional option, rather than an obligation; best practices in identification, referral, and consent are adopted inconsistently
- Donation by Living Donors and Donation after Cardiac Death, practices with potential for increasing organ donation, are under-utilized
- Financial disincentives to accommodate organ donation impair donation performance

## ODT – Problem Statement 2

### Problem 2: Patients with end-stage organ failure are an under-serviced population

- Patient assessment and waitlist referral practices vary by province and practitioner, leaving some patients with a lower likelihood of transplant
- Referral and allocation practices are not transparent and patients do not have visibility into their waitlist status
- Likelihood of receiving a transplant varies widely based on a patient's province of residence
- Highly-sensitized patients receive a disproportionately small share of the available organs

## ODT – Problem Statement 3

Problem 3: The quality and efficiency of allocation, utilization, and transplantation of donated organs are constrained by resource and technology limitations

- There is limited capacity in hospitals to optimally maintain potential donors
- Constraints on recovery facilities, transportation and on recovery and transplantation team availability negatively impact donation quantity and organ quality
- Limited automation in matching and offer management is inefficient and can result in sub-optimal matching or lost transplantation opportunities

## ODT – Problem Statement 4

Problem 4: The current ODT system lacks the measurement and accountability mechanisms to drive consistent, system-wide performance improvement

- Inconsistent data capture and quality and the lack of centralized reporting and analysis diminish the system's ability to make evidence-based improvements in practice or policy
- Uncoordinated policy development and implementation limit the system's ability to respond to emerging issues and safety incidents
- Best practices and national guidelines and policy are not adopted quickly and consistently
- Unclear and uncoordinated audit and accountability diminishes both incentives and mechanisms for effecting improvement

## Breakout Sessions

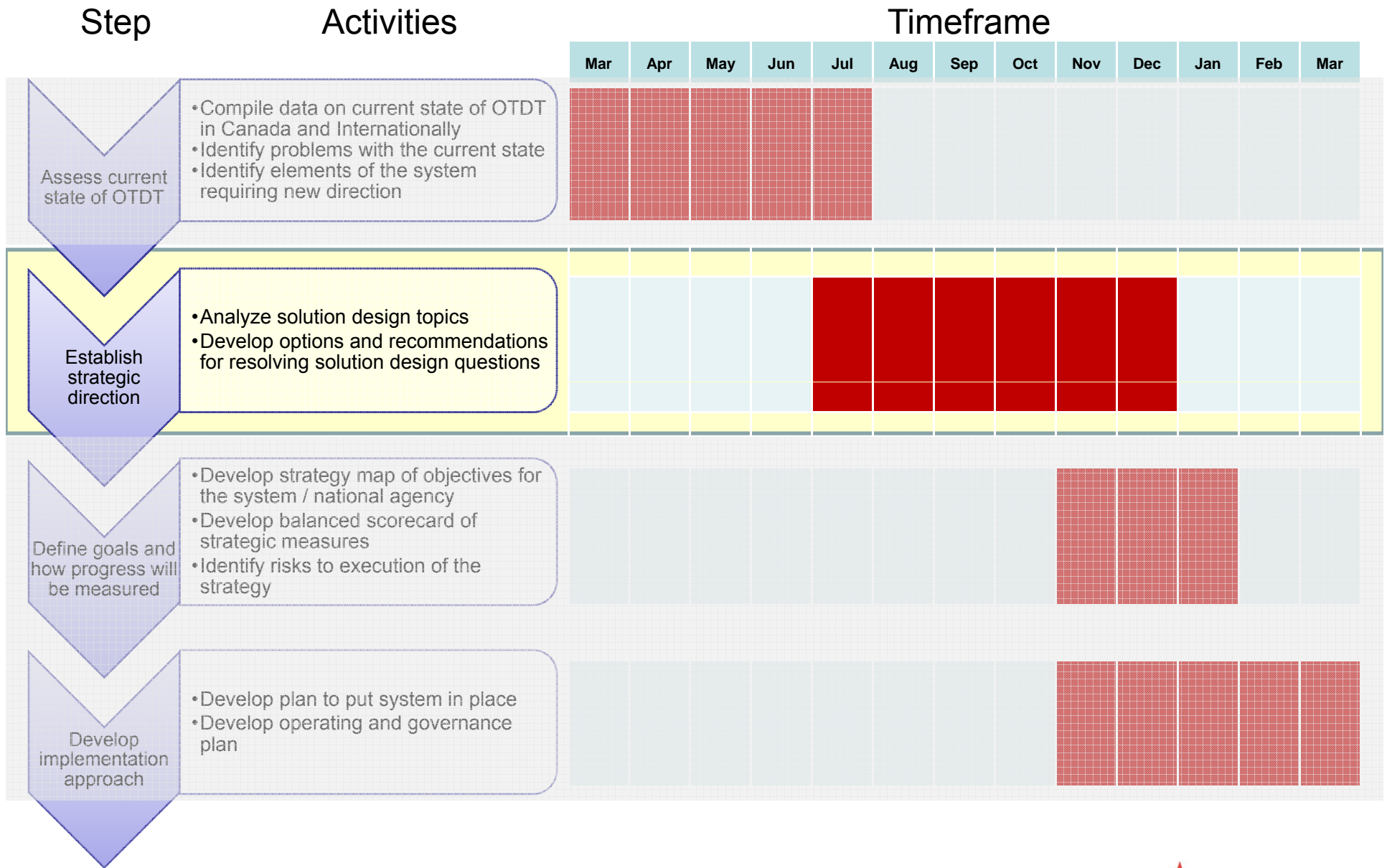
- Over the next hour we will conduct a breakout exercise to discuss the draft case for change in greater detail
- For the first 30 minutes choose a problem to discuss:
  - Problem 1 (Donation) – main meeting room
  - Problem 2 (Transplantation) – breakout room
- For the second 30 minutes choose a problem to discuss:
  - Problem 3 (Infrastructure and Technology) – main meeting room
  - Problem 4 (Measurement and Accountability) – breakout room
- Each of the four breakout sections will seek to answer the following questions in regards to the problem statement and description
  - To what extent does the problem statement and supporting bullets capture the nature and scope of the system's short-comings?
  - Among the short-comings identified, which one do you feel is most critical to solve?
  - What data, evidence, or information is required to substantiate or prove the scope or extent of the problem?
- After one hour we will reconvene in the main meeting room

## ODT - All Problem Headlines

- Problem 1: Canada is failing to realize its potential for organ donation
- Problem 2: Patients with end-stage organ failure are an under-serviced population
- Problem 3: The quality and efficiency of allocation, utilization, and transplantation of donated organs are constrained by resource and technology limitations
- Problem 4: The current ODT system lacks the measurement and accountability mechanisms to drive consistent, system-wide performance improvement

## Discuss Solution Design Topics

# Process Timeline



## The Committees' Roles During the Next Phase

- Develop solution options and recommendations to be integrated into the OTDT strategic plan, based on inputs such as:
  - Analysis of data, research and other empirical evidence
  - The accumulated experience of provincial efforts
  - The examples of other international ODT systems

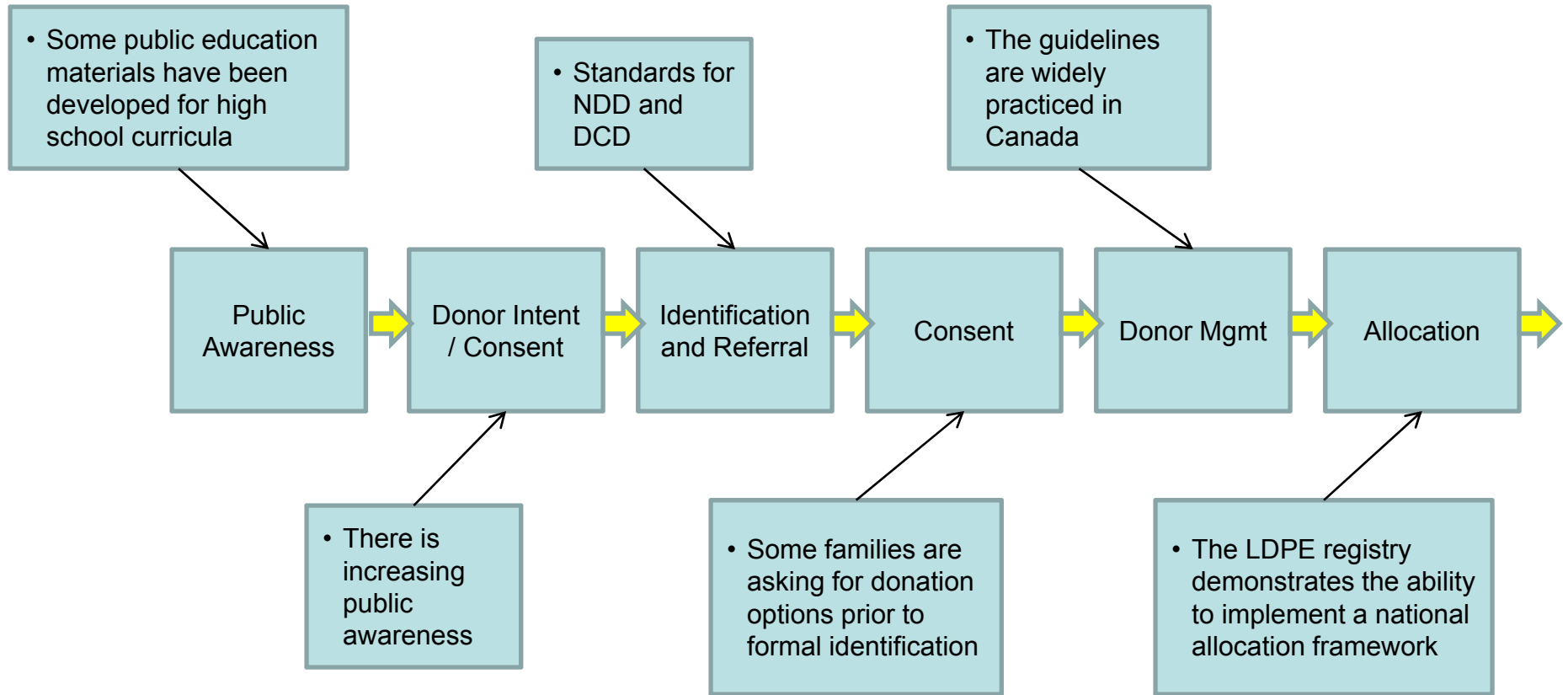
### The Organ and Tissue Expert Committees:

- The Organ and Tissue Expert Committees will provide advice that guides the design of the ODT and TDT systems respectively

### The Steering Committee:

- The Steering Committee will provide guidance on how the OTDT system needs to be structured to function effectively in the context of Canada's overall healthcare system

# Recommendations are based on fixing problems and leveraging strengths.



(illustrative)

## Objective for Today

- In order to properly plan and prepare for the fall meetings and begin work on the right elements of solution design, we must determine
  - Topics for which the committees will provide analysis, options and recommendations
  - An approach to analyzing and providing recommendations for each topic
- The selection of topics should be driven by the need to:
  - Address open questions that are critical to resolve for our OTDT strategy to be clear
  - Advance the consensus of the OTDT community beyond the current level
- The committee may consider several potential approaches for each topic area
  - Approach 1: A **small group** from the committee will discuss the topic and will **present the options and recommendations** to the committee for **review**
  - Approach 2: The **committee** will review information and options as a group and will together **decide on recommendations**
  - Approach 3: The **committee will engage additional experts** from the community to assist in the discussion of the topic and the **determination of recommendations**

## Today's Exercise

- Four draft topic areas have been proposed for possible assignment to this committee
- For each topic, a set of draft “open questions” suggest focus areas for analysis and recommendations
- For each topic, the group will answer the following:
  - Do the suggested questions represent the right focus for our design efforts?
  - How will we work together to analyze these topics and develop recommendations for the plan?
- **After today's meeting,**
  - CBS will coordinate and support the analysis and resolution process for each topic regardless of the approach
  - CBS will work with a point person for each topic to clarify the intent of the group and to ensure an effective work process for each topic

## Draft Solution Design Topics

Topic	Open Questions (draft)
Donation	<ul style="list-style-type: none"> <li>•How can we better enable and empower Canadians to translate support for donation into action?</li> <li>•What mechanisms (e.g., measurement, technology, regulatory, accountability) should be used to ensure that registered intent/consent is available and respected?</li> <li>•What mechanisms (e.g., measurement, technology, regulatory, accountability) should be used to ensure that identification and referral are made a standard of care?</li> <li>•How can we improve resource availability to accommodate organ donation and recovery?</li> </ul>
Transplantation	<ul style="list-style-type: none"> <li>•What mechanisms (e.g., measurement, technology, regulatory, accountability) should be used to ensure consistent practices in patient assessment and waitlist referral?</li> <li>•What mechanisms (e.g., measurement, technology, regulatory, accountability) should be used to ensure system transparency for patients, the public and funders?</li> <li>•How can we ensure that resource constraints do not unduly limit access to transplantation?</li> </ul>
Allocation	<ul style="list-style-type: none"> <li>•What are the principles of a successful allocation system for organs (e.g., provincial vs. national)?</li> <li>•What mechanisms (e.g., measurement, technology, regulatory, accountability) should be used to ensure consistent application of the allocation principles across the system?</li> <li>•How should we increase the likelihood of transplant for urgent status and Highly Sensitized Patients?</li> <li>•How do we overcome resource constraints in offer management?</li> </ul>
Governance	<ul style="list-style-type: none"> <li>•What should the overall measurement and reporting regime look like?</li> <li>•What does a successful national audit regime look like?</li> <li>•What should the national policy development apparatus be?</li> <li>•What are the right accountability principles necessary to determine roles and responsibilities?</li> </ul>

## Wrap Up and Next Steps

## Next Steps

- Minutes from this meeting will be distributed no later than July 13<sup>th</sup>
- CBS will be reaching out to relevant committee members for further solution design topic clarification
- The next Organ Expert Committee meeting is scheduled for October 19<sup>th</sup>
- Future committee dates are being scheduled