Ontario Degenerative Cervical Myelopathy Summit Report

For additional information on the Ontario Degenerative Cervical Myelopathy Summit, please contact:

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Executive Summary
Degenerative cervical myelopathy (DCM) refers to age-related osteoarthritic and congenital spinal column disorders that cause progressive narrowing of the spinal canal and compression of the cervical spinal cord, resulting in functional impairment (Badiwala, et al., 2020). DCM is the leading cause of spinal cord impairment in adults worldwide.

Summit Purpose
Develop an Ontario-based plan for DCM in a white paper to inform healthcare challenges, advocate for better care, advance an Ontario-based DCM strategy, and create a plan for future DCM knowledge translation activities.

Summit Scope
Build an Ontario approach to DCM that aligns with research, evidence, and consensus work on the topic in other jurisdictions.

Summit Findings
Our work – alignment with the AO Spine RECODE-DCM Consensus – will focus on the following priorities

- **Raising Awareness** - Three presentations conducted in each of primary care, spine surgery, orthopedic surgery, and community
- **Diagnostic Criteria** - We will have identified gaps in our understanding of diagnostic tools and clinical signs. We will have a list of DCM red flags warranting further assessment. For mild to moderate, what can we accomplish with just an x-ray?
- **Assessment and Monitoring** - Literature review and an Initial clinical tool
- **Rehabilitation** - Ontario Consensus Guidelines for the Treatment and Management of DCM - divide into parts, only one part in Year 01

Summit Next Steps
The information from the Summit will inform the development of the following.

- Create a set of Working Groups to work on research towards identified priorities and/or help oversee or facilitate research projects towards DCM priorities.
- Establish a 2021 follow-up event to continue working on an Ontario DCM strategy and the Steering Committee and Working Groups results.
- Publish the ODCM work in the form of an Editorial to further advance the importance of DCM in Ontario.
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What is Degenerative Cervical Myelopathy (DCM)

DCM is the leading cause of spinal cord dysfunction in adults worldwide. DCM encompasses various acquired (age-related) - and congenital pathologies related to degeneration of the cervical spinal column, including hypertrophy and/ or calcification of the ligaments, intervertebral discs and osseous tissues. The pathologies narrow the spinal canal, leading to chronic spinal cord compression and disability (Badiwala, et al., 2020). The following key points provided additional information about DCM by Badiwala et al.

- Degenerative cervical myelopathy (DCM) develops when age-related osteoarthritic or genetically based changes to the spinal column cause progressive compression of the cervical spinal cord, resulting in functional impairment.
- DCM is the most common cause of spinal cord impairment, and the resultant burden of disability on our society is expected to grow owing to the ageing global population.
- The pathophysiology of DCM involves static and dynamic factors that lead to chronic spinal cord compression and resultant ischemia, inflammation and apoptosis of neurons and oligodendrocytes.
- Diagnosis of DCM requires a careful history and physical examination to identify signs and symptoms of myelopathy and to rule out alternative diagnoses; clinical findings should be correlated with MRI findings.
- The natural history of DCM can include a period of stable neurological status in some patients; however, a substantial number of individuals experience progressive, stepwise decline in function.
- Current clinical practice guidelines recommend surgical decompression for patients with severe or moderate DCM and either surgery or a supervised trial of structured rehabilitation in patients with mild DCM.

Why is DCM Important to Address?

DCM is important, given it is a diagnosis that can be missed or delayed. The natural course of DCM presents as a stepwise decline, with symptoms ranging from muscle weakness to complete paralysis. DCM is the most common cause of spinal cord dysfunction in adults. (Milligan, Ryan, Fehlings, & Bauman, 2019). The following experiences from a patient and clinician provide insights into DCM.

“I had on again off again symptoms for a while before my symptoms became persistent and I was diagnosed with DCM. Based on my own experience, I think early awareness is very important for individuals at risk for DCM. If my symptoms had been recognized earlier, I could have avoided some of the activities that potentially exacerbated my condition and altered my lifestyle accordingly.” - Liang Zhang, Patient
“Family physicians receive little training about this important condition and therefore the risk of delayed or misdiagnosis is increased. As our population ages and this condition becomes more prevalent, we need increased awareness and appropriate tools to diagnose and treat it early” - Dr. Upe Mehan, Family Physician

Global Top 10 Priorities for DCM


1. **Raising awareness** - What strategies can increase awareness and understanding of DCM amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?

2. **Natural history** - What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?

3. **Diagnostic criteria** - What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the Assessment of DCM?

4. **Assessment and monitoring** - What Assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?

5. **Pathophysiology** - What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?

6. **Rehabilitation** - What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?

7. **Novel therapies** - Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?

8. **Socio-economic impact** - What is the socio-economic impact of DCM? (The financial impact of living with DCM to the individual, their supporters, and society as a whole).
9. **Imaging techniques** - What is the role of dynamic or novel imaging techniques and neurophysiology in the Assessment of DCM?

10. **Individualizing surgery** - Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?

The priorities\(^1\) informed the conversation for the Summit.

**Ontario DCM Planning Focus**

The focus for DCM planning includes the following considerations.

- Increasing public, clinician and ministry of health awareness
- Deciding on a common nomenclature
- Improving access to timely diagnosis (imaging and referral)
- Improving communication between sectors (primary care – surgery - rehab-community)
- Improving access to acute care management
- Improving access to rehab
- Improving community living
- Management of secondary complications

The deliverable for Ontario through the work of the Summit will include:

- Ontario-based plan for DCM in the form of a white paper to inform healthcare challenges and advocate for better care
- The development of an Ontario-based DCM strategy
- A plan for future DCM knowledge translation activities

**Ontario Degenerative Cervical Myelopathy Summit**

**About the Summit**

The Summit brought together individuals with lived experience, surgeons, primary care providers, specialists, allied health professionals, researchers, advocacy agencies and ministry representatives with the goals of:

- Reviewing the current knowledge and research in DCM
- Understanding DCM in the Ontario Context
- Informing future objectives and research in DCM

\(^1\) An additional sixteen priorities can be found on the AO Spine website under “Additional Research Priorities.”
ODCM Summit Results

Dr. Michael Fehlings and Dr. James Milligan served as hosts for the Virtual Summit.

Appendix 01 is a copy of the Summit Invitation.

Appendix 02 is a copy of the Summit Agenda.

Event Supporters

Our thanks to our event supporters.

Ontario Neurotrauma Foundation

Through research, knowledge mobilization and implementation initiatives we aim to prevent neurotrauma injuries and improve the lives of Ontarians with acquired brain injury and spinal cord injury.

Mobility Clinic

The goal of the Mobility Clinic is to help persons with mobility issues and their primary care providers with health care needs that may be difficult to manage, given existing physical and system barriers to care.

University of Toronto Spine Program

The University of Toronto Spine Program is a unique collaborative program of clinical expertise, research, and education. The Program implements frameworks for innovation and excellence in the delivery of spine care and the translation of research.

The Krembil Research Institute

The Krembil Research Institute is the research arm of Toronto Western Hospital. Research within Krembil is directed at the development of diagnostics, treatments and management strategies in i) brain and spine disorders, bone and joint disorders, and iii eye disorders.

Summit Participants

Special thanks to the Summit participants for the insights, ideas and support for an Ontario DCM Strategy.

Appendix 03 contains a list of the summit participants.

Summit Events

Day one of the Summit consists of the following seven presentations about the topic of DCM.
• Dr. Fehlings shared an overview of the clinical issues and research around the subject of DCM and implications for practice in Ontario.
• Dr. Milligan provided a Family Medicine perspective on the challenges and opportunities related to DCM and primary care.
• Dr. Liang Zhang shared his journey regarding DCM, including insights, reflections and lessons learned about the DCM journey.
• Dr. Eldon Loh shifted the conversation and provided insight about DCM from a rehabilitation perspective exploring prevention and non-operative insights.
• Dr. Melanie Jeffery brought a focus to the challenges and inequities faced by indigenous persons related to DCM.
• Dr. Susan Jaglal shared the challenges and opportunities related to administrative data to support DCM care in Ontario.
• Dr. Ben Davis shared his insights from a global perspective on DCM research (AO Spine RECODE-DCM project), activities, and opportunities.

Appendix 04 has a link to the full set of presentations and materials from Day 1.

The session ended with a group conversation and a vote to identify which of the ten priorities should be the foundation of the Ontario DCM Strategy. Summit participants identified the following four priority areas of focus for DCM research from the top 10 DCM Priorities previously outlined by the AO Spine RECODE-DCM project (AO Spine, 2019).

• **Raising Awareness** - What strategies can increase awareness and understanding of DCM amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?

• **Diagnostic Criteria** - What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the Assessment of DCM?

• **Assessment and Monitoring** - What Assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?

• **Rehabilitation** - What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?

**Figure 1** is a copy of the Survey Results.
Day two was a working session for the participants. Each of the identified four priorities (e.g., Raising Awareness) had a small working group complete the following work.

- **Brainstorming** – “What could we achieve in the next three to five years in Ontario for our assigned topic?” e.g., Raising Awareness
- **Prioritize** – Using the Brainstorming list, “what could we achieve in year one?”
- **Short Term Planning** – What are the major steps to achieve our year one priority?
- **Long Term Planning** – What are the results we should achieve in years 2 – 5?

The day ended with the four groups sharing their first year and year two through five goals with the larger group. A copy of the initial thinking and proposed goals is in the Summit Participant Report (ODCM Steering Committee, 2021).
DCM Short Term Priorities

The working groups identified the following set of results for the first year of an Ontario DCM Strategy.

- **Raising Awareness** - Three presentations conducted in each of primary care, spine surgery, non-surgical medical and allied health disciplines (e.g., neurology, rheumatology, physiotherapy, chiropractic, rehabilitation medicine) orthopedic and neurological surgery, and community.
- **Diagnostic Criteria** - We will have identified gaps in our understanding of diagnostic tools and clinical signs. We will have a list of DCM red flags warranting further assessment. For mild to moderate, what can we accomplish with just an x-ray?
- **Assessment and Monitoring** - Literature review and an Initial clinical tool.
- **Rehabilitation** - Ontario Consensus Guidelines for the Treatment and Management of DCM - divide into parts, only one part in Year 01.
Next Steps
The information from the Summit will inform the development of the following.

- Create a set of Working Groups to review the Summit results, identify resource needs and work together to find resources to support the year one results.

- Establish a 2021 follow-up event to continue working on an Ontario DCM strategy and the Steering Committee and Working Groups results.

- Publish the ODCM work in the form of an Editorial to further advance the importance of DCM in Ontario.
Appendix 01 – Summit Invitation

The following is a copy of the Summit Flyer.

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**Ontario Degenerative Cervical Myelopathy Virtual Summit 2020**

**ODCM Summit 2020**

**2 Virtual Sessions**
**2 Consecutive Mondays**

@11am -1pm (EST)

Mon, Nov 23rd
Mon, Nov 30th

Bringing together individuals with lived experience, surgeons, primary care providers, specialists, allied health professionals, researchers, advocacy agencies, ministry representatives with the goals of:
- Reviewing the current knowledge and research in DCM
- Understanding DCM in the Ontario context
- Informing future objectives and research in DCM

Co-Host
Michael G. Fehlings, MD, PhD, FRCSC, FACS, FCAHS
University of Toronto & Toronto Western Hospital

Co-Host
James Milligan, MD, CCFP
Mobility Clinic

Meeting By Invitation

Register here!

For questions contact: Lindsay Beuermann at <lindsay.beuermann@family-medicine.ca>

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*Ontario Neurotrauma Foundation*
*Fondation ontarienne de neurotraumatologie*

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Mobility Clinic
Appendix 02 – Meeting Agenda
The following is a copy of the agenda for the two-day virtual Summit

Welcome to the Ontario Degenerative Cervical Myelopathy Virtual Summit 2020!

In this package, you will find the agenda for Day 1 as well as recommended reading materials. If you have any technical difficulties during the summit, please contact lindsay.beuermann@family-medicine.ca

Day ONE Agenda – Monday November 23rd, 11:00 am – 1:00 pm EST

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>11:00-11:10</td>
<td>Welcome and introduction to the day</td>
<td>Tara Jeji</td>
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<tr>
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<td>Jerry Mings</td>
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<tr>
<td>11:10-11:25</td>
<td>DCM background and overview of work done to date</td>
<td>Michael Fehlings</td>
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<tr>
<td>11:25-11:40</td>
<td>DCM and primary care</td>
<td>James Milligan</td>
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<tr>
<td>11:40-11:55</td>
<td>Lived experience perspective</td>
<td>Liang Zhang</td>
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<tr>
<td>11:55-12:10</td>
<td>Rehabilitation, prevention and non-operative perspective</td>
<td>Eldon Loh</td>
</tr>
<tr>
<td>12:10-12:15</td>
<td>Indigenous challenges</td>
<td>Melanie Jeffrey</td>
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<tr>
<td>12:15-12:25</td>
<td>Administrative data</td>
<td>Susan Jaglal</td>
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<tr>
<td>12:25-12:40</td>
<td>RECODE Project</td>
<td>Ben Davies</td>
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<tr>
<td>12:40-1:00</td>
<td>Facilitated discussion about future of DCM care in Ontario</td>
<td>Michael Fehlings</td>
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<td>James Milligan</td>
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Recommended Reading

AO Spine Top 10 Research Priorities for DCM

Available at https://aospine.aofoundation.org/research/recode-dcm/research-priorities
1. **Raising awareness**
   What strategies can increase awareness and understanding of DMC amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?

2. **Natural history**
   What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?

3. **Diagnostic criteria**
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   What assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?

5. **Pathophysiology**
   What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?

6. **Rehabilitation**
   What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?

7. **Novel therapies**
   Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?

8. **Socio-economic impact**
   What is the socio-economic impact of DCM? (The financial impact of living with DCM to the individual, their supporters, and society as a whole).

9. **Imaging techniques**
   What is the role of dynamic or novel imaging techniques and neurophysiology in the assessment of DCM?

10. **Individualizing surgery**
    Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?
Welcome to the Ontario Degenerative Cervical Myelopathy Virtual Summit 2020!

In this package, you will find the agenda for Day 2 as well as recommended reading materials. If you have any technical difficulties during the summit, please contact lindsay.beuermann@family-medicine.ca

Day ONE Agenda – Monday November 30th, 11:00 am – 1:00 pm EST

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<tr>
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<td>Jerry Mings</td>
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<tr>
<td>11:10-11:20</td>
<td>Review of the Ontario DCM opportunities</td>
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<tr>
<td>11:22-11:45</td>
<td>Working Session – Identify the results we wish to achieve in Ontario at the end of one year.</td>
<td>All</td>
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<tr>
<td>11:45-11:55</td>
<td>Full Group Check</td>
<td>All</td>
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<tr>
<td>11:55-12:15</td>
<td>Working Session - Preparing for Group Presentation</td>
<td>All</td>
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<td>Share your result and the steps to achieve it in year 1</td>
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<td>12:15-12:35</td>
<td>Presentations- Group Presentation</td>
<td>Groups</td>
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<td>12:35-12:50</td>
<td>Next Steps for DCM</td>
<td>Michael Fehlings</td>
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<td>James Milligan</td>
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<td>12:50-1:</td>
<td>Closing Remarks and Thanks</td>
<td>Tara Jeji</td>
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## Appendix 03 – Summit Participants

### Day 1

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Joy Lehmann</td>
<td>Centre for Family Medicine Mobility Clinic</td>
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<tr>
<td>Jay Varghese</td>
<td>University of Cambridge, UK</td>
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<tr>
<td>Mark Kotter</td>
<td>Centre for Family Medicine Mobility Clinic</td>
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<tr>
<td>Craig Bauman</td>
<td>Centre for Indigenous Studies, University of Toronto</td>
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<tr>
<td>Melanie Jeffery</td>
<td>University Health Network</td>
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<tr>
<td>Julio Furlan</td>
<td>Person With Lived Experience</td>
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<tr>
<td>Liang Zhang</td>
<td>Hamilton Health Sciences</td>
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<td>Jennifer Duley</td>
<td>University Health Network</td>
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<td>Jefferson Wilson</td>
<td>The Ottawa Hospital</td>
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<tr>
<td>Ruchi Parikh</td>
<td>DCM Planning Committee</td>
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<td>Patricia Nistor</td>
<td>DCM Planning Committee</td>
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<td>Upender Mehan</td>
<td>Centre for Family Medicine Family Health Team</td>
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<td>Joseph Lee</td>
<td>Centre for Family Medicine Mobility Clinic</td>
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<tr>
<td>Paul Miki</td>
<td>Person With Lived Experience</td>
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<tr>
<td>Eve Tsai</td>
<td>Ottawa Hospital Research Institute</td>
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<td>Athina Hall</td>
<td>Queens University</td>
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<tr>
<td>Karen Smith</td>
<td>Toronto Rehabilitation Institute</td>
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<tr>
<td>Brian Chan</td>
<td>Co-Chair DCM Planning Committee/Centre for Family Medicine Mobility Clinic</td>
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<td>Harrison Mair</td>
<td>Lawson Health Research Institute</td>
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<td>Tim Worden</td>
<td>Co-Chair, DCM Planning Committee/University Health Network</td>
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<td>Swati Mehta</td>
<td>The Ottawa Hospital</td>
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<td>Ontario Neurotrauma Foundation</td>
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<td>Peter Anthanasopoulos</td>
<td>Spinal Cord Injury Ontario</td>
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Day 2

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Appendix 04 – Day 1 Presentations
The following is a link to a YouTube recording from Day 1 of the Summit.

Link the YouTube Video
https://youtu.be/xa5PRdGYIzQ
References


