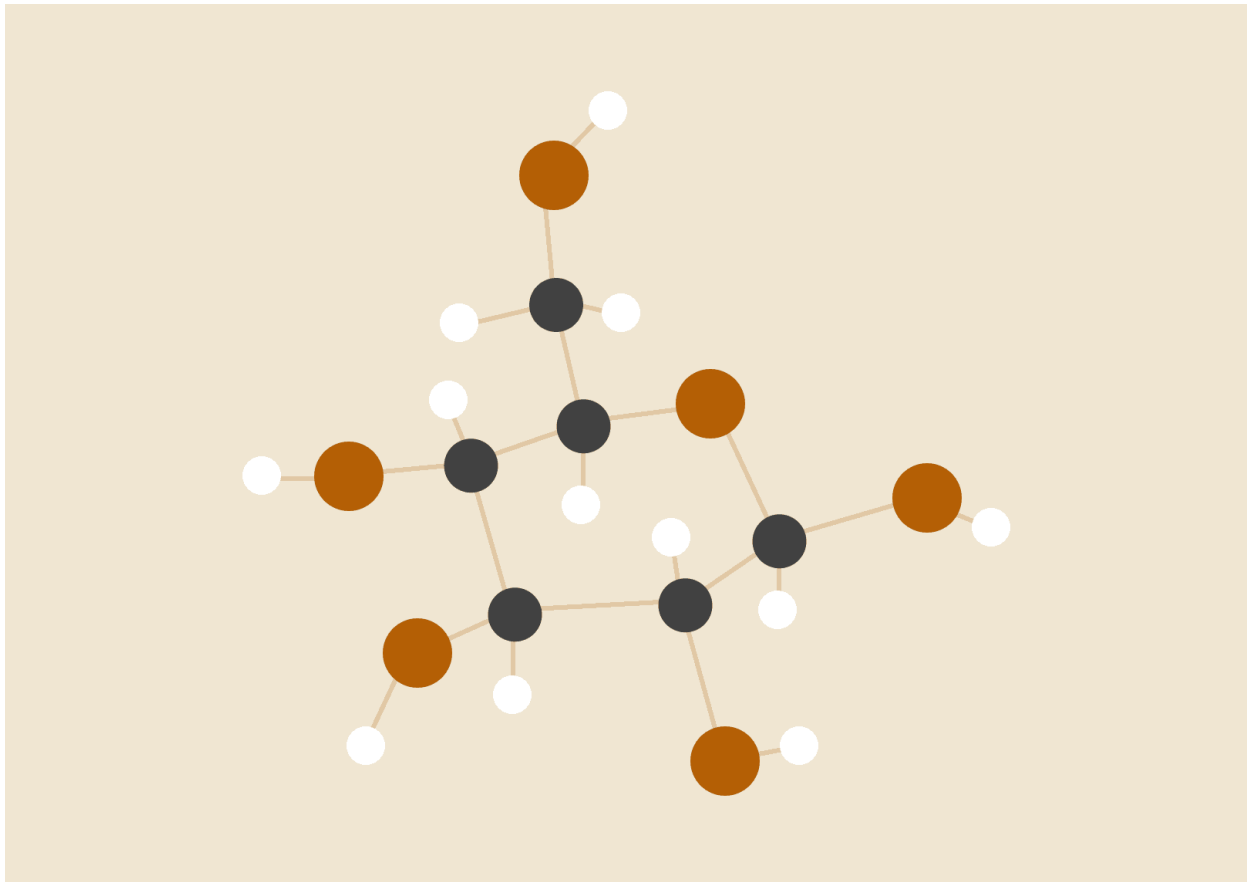


SCI-Powered Network

SCI Seal of Approval

Specifications Document



FINAL

04.07.2025

INTRODUCTION

Today, people living with SCI are inundated with information, some of which is helpful or accurate while others can be misleading or harmful. From a one-year series of roundtable discussions with SCI advocacy and resource organizations, NASCIC uncovered this real-world experience as well as the need to harmonize information across groups to identify what can be trusted quickly and efficiently. NASCIC also uncovered that, despite the breadth of resources currently available, people living with SCI still feel information-deprived and have difficulty finding trustworthy, credible, practical, and accessible information.

The goal of the SCI Powered Network is to build a community-driven framework of credible and trustworthy spinal cord injury information through exchange and dissemination in an inclusive and engaged manner to serve stakeholders inside and outside the SCI community. There are two objectives and three deliverables for this group:

Objective 1: Identification of high-priority information needs and daily challenges of living with spinal cord injury gathered through a needs assessment designed and conducted with diversity and under-served individuals in mind.

Objective 2: Conduct a landscape search to identify common characteristics of inclusive and trustworthy information and resources.

Deliverable A: Provide a gap analysis between the high priority needs of spinal cord injury and the identified information and resources.

Deliverable B: Development of metrics of SCI information and resources to create the SCI Powered Network seal of approval.

Deliverable C: Create a design criteria report consisting of solutions definition, system characteristics, and key attributes needed for a community-driven structure for information identification, exchange, and dissemination.

Created through feedback from the SCI lived experience community, NASCIC formed the SCI-Powered Network to begin the first stages of addressing the information gap. There are 3 elements to this overall effort:

1. Information Needs SCI Community Survey
2. SCI Seal of Approval
3. Design Criteria Report - Information tools for SCI Artificial Intelligence (AI)/LLM learning attributes

This report highlights element two, the SCI Seal of Approval. This exercise builds the criteria,

attributes, and framework around the SCI Seal of Approval. This specifications document outlines the aims of this project, the methodology, and the recommended specifications to implement an SCI Seal of Approval for SCI-specific health information.

PROJECT AIMS

The aims of this element are to 1) identify a ranking system of SCI health information, similar to a “good housekeeping” symbol for the SCI community, and 2) propose a framework to implement such a system. The final outcome provides guidance on key elements, ranking criteria, review process, and identification for developing information dissemination tools for the SCI community.

METHODOLOGY

The efforts for this project were conducted with a diverse Working Group of representatives across the SCI community in the US and Canada. The final Working Group consisted of 20 members representing a wide range of advocacy and information resource organizations specifically for SCI. The Working Group members:

Name		Organization
Reveca	Torres	BackBones
Kim	Anderson	NASCIC
Spring	Hawes	Praxis Institute
Lindsay	Perlman	Paralyzed Veterans of America
Kim	Beer	Christopher & Dana Reeve Foundation
Sarah	Skeels	SCI-Coaches
Peter	Athanasopoulos	SCI-Ontario
Matthew	Queree	SCIRE
Jake	Beckstrom	United 2 Fight Paralysis
Matthew	Castellucio	United Spinal Association
Jose	Hernandez	United Spinal NYC
Bill	Fertig	United Spinal Virginia
Kimberley	Monden	University of Minnesota
Angela Brian	Denny Rodriguez	South Carolina SCI
Ian	Burkhart	Co-Chair
Jennifer	French	Co-Chair

The exercise for the SCI Seal of Approval was conducted through a literature review of health information attributes and criteria. These attributes were revised and refined through a series of e-Delphi surveys via our established community Working Group. Coupled with follow-up group discussions, we derived a consensus document for the formation and framework for the SCI Seal of Approval.

The literature review was to help inform how health information is categorized to help inform patient populations. The following references were used to inform the Working Group of health information attributes and criteria. These included:

- Sbaffi, Laura, and Jennifer Rowley. "Trust and Credibility in Web-Based Health Information: A Review

and Agenda for Future Research.” *Journal of medical Internet research* vol. 19,6 e218. 19 Jun. 2017, doi:10.2196/jmir.7579

- Sun, Yalin et al. “Consumer Evaluation of the Quality of Online Health Information: Systematic Literature Review of Relevant Criteria and Indicators.” *Journal of medical Internet research* vol. 21,5 e12522. 2 May. 2019, doi:10.2196/12522
- Kington, Raynard S et al. “Identifying Credible Sources of Health Information in Social Media: Principles and Attributes.” *NAM perspectives* vol. 2021 10.31478/202107a. 16 Jul. 2021, doi:10.31478/202107a

From the literature review, we then conducted four e-Delphi surveys. Each survey was followed by a group discussion to inform the next round of surveys until a consensus was formed. The first survey was conducted using an artificial intelligence interview and evaluation tool. The next three surveys were conducted via a simple online survey tool. The following describes each round of survey and discussion results.

E-Delphi Survey One: Attributes and Considerations

This Delphi round asked about the general attributes and considerations we should account for while designing the criteria and framework for the SCI Seal of Approval. The survey asked two basic open-ended questions:

- Do you think Credible, Trustworthy, Reliable, Quality, and Accessibility should be attributes for the SCI seal of approval? and Why?
- What other attributes should we consider, such as transparency or currency/recency?

The suggestions included:

- The participants generally agree that Credible, Trustworthy, Reliable, Quality, and Accessibility should be attributes for the SCI seal of approval.
- They believe these attributes are important because they help define the value of the seal and distinguish it from unreliable information.
- Additional Suggestions:
 - a. Grouping Credible, Trustworthy, and Reliable together as they represent similar concepts.
 - b. The importance of defining these attributes clearly to ensure they stand apart.
 - c. There might be challenges in rating these attributes consistently.

Additional attributes for discussion were currency/recency, reality/realistic, and transparency. The next step was to refine the attributes and definitions.

The group discussion was also centered around scoring. To this point, we referenced the methodology of the Good Housekeeping Seal. The summary was that the elements of the Seal are based on product categories, defined evaluation and rating criteria, category scores are summed for an overall score, and the seal is standard for two years. From the discussion, the Working Group

agreed to the following scoring methods:

- a. Define the criteria and attributes.
- b. Define a Likert scale scoring system.
- c. Explore the use of attribute weighting.
- d. Create a system with a minimum score and an overall score.

These discussions informed the second e-Delphi survey.

E-Delphi Survey Two: Attributes and Considerations

This Delphi round asked about the:

- a. Attributes and definitions,
- b. Scoring process and evaluation method, and
- c. SCI specialists

These attributes should all be considered while designing the criteria and framework for the SCI Seal of Approval. For the attributes, we proposed these original definitions:

- CREDIBLE, TRUSTWORTHY & RELIABLE:
 - This is a source from an authority or expert in the field of SCI information that it is reporting, and
 - Information provided by this source is consistently relied upon as honest or truthful.
- PRACTICAL & USEFUL:
 - This information may be readily applied by or for a person with a spinal cord injury , and
 - The information is provided at an appropriate level to be used by a person with a spinal cord injury.
- ACCESSIBLE:
 - A person with a spinal cord injury is able to acquire information, read and understand the information, and
 - The information is provided in a manner that is accessible using assistive technology.
- CURRENCY & RECENCY:
 - The source of information is up to date, and
 - The information is relative to spinal cord injury with what we know today.

The final definitions from the survey and discussions are provided in the RESULTS section.

We also asked about the scoring process with the following questions:

- Should we score attributes differently for each category of information? For example, information may be categorized as Physical Health, Mental Health, Sports & Recreation, etc
- Should we have a minimum score per attribute, a minimum score overall, or something else for evaluating an information source?
- Should there be a minimum threshold for each attribute?

- What type of scale should we use for scoring?
- Should we have a panel of reviewers to do the scoring?
- If we do have a panel, what is the balance of SCI lived experience to professionals?
- Should the information reviewers rotate on and off periodically?

The consensus was that the categories should not be scored differently but there will be topic experts for the major categories. The majority preferred having both a minimum score per attribute and a minimum score overall, as well as providing an overall score and showing the score for each individual attribute. The Seal will be based on the overall score, and each attribute score will be visible to the user. Consider how Amazon provides scoring, there is an overall score and the user can view the score for each attribute to make a decision if they want to consider using that information. The team agreed on the idea of a 5-point rating.

The group agreed that the reviewer panel should ideally be composed of both individuals with lived experience (LE) and professionals, with a suggested balance of 50%. However, the exact percentages were not finalized, and the team acknowledged that the balance might vary depending on the technicality of the issues at hand. We should consider that some technical topics do need a good balance of LE with professionals. There needs to be some flexibility in managing this based on the need for expertise. The goal was to ensure that all perspectives were represented to avoid an imbalance of power.

We also asked:

What specialties should be included in a review panel? (Choose all that apply.)

The consensus was to always include Rehabilitation Clinicians, SCI Resource Specialists, and Peer Mentors. The other panel members will rotate depending on the topic area, ie. physical health, mental health, recreation, etc.

E-Delphi Survey Three: Review Panel and Topic Areas with Resource Queries

This round of questions focused on the following:

1. Refine the evaluation process of information, including scoring and the review panel,
2. Identification of secondary conditions of SCI,
3. Tags for categorization of information and for the process of experts, and
4. Gather frequently asked questions by new injuries.

Some of these topics relate to Part III - Design Criteria Report; however, items 1 & 3 above are applicable for the Seal of Approval.

Building upon the discussions from the previous e-Delphi survey, we asked further questions about the scoring process. These included:

- What should the minimum score be for each attribute based on a 5-point scale with 1 being very poor and 5 being very good?
- What should the overall score be based on?
- What should be the minimum overall score? There are 4 attributes based on a 5-point scale. On that 5-point scale, 1 is very poor and 5 is very good

The responses and discussions lead to consensus for a site or source of information to receive a Seal of Approval. These are:

- **Each attribute must have a minimum score of 3, that is, at least an adequate rating.**
- **The overall score for a site or source of information is the sum of the total scores from all four attributes. To receive a Seal of Approval, a minimum overall score of 12 is required.**

There was also an important discussion about the transparency of the scores. Working Group members expressed a need to provide not only an overall score but also the score for each attribute. The analogies provided were Amazon or Google reviews, as well as Consumer Reports. The consensus was to be fully transparent and provide all attribute scores to allow the user to make individual decisions.

There were also questions to refine the Review Panel. Here we asked the following questions:

- Select the qualities that a lived experience panelist should have. Select all that apply. Peer Mentor, Leadership in an advocacy organization, Forum discussion leader, Social media influencer, Other.
- Are there other specific qualities or experiences that should be included for people with lived experience who will serve on the review panel?
- Should the panel always include a rehabilitation clinician?
- Should the panel always include a SCI resource specialist?
- Should the panel always include a Category or Special topic expert?
- What other suggestions do you have for the composition of the review panel?
- How often should the review panel members rotate on and off the panel? Note: it will be on a staggered basis.

The team discussed the qualities they wanted the panelists with SCI lived experience to possess, with an emphasis on being peer mentors, forum discussion leaders, or being in leadership or advocacy organizations. Concerns were raised about the potential influence of social media, with a consensus that it should be used in conjunction with other qualifications. The team agreed on the importance of considering factors such as time since injury, knowledge of resources, and topic areas

when selecting panelists. They also expressed the need for a variety of those with tetraplegia, paraplegia, and care partners/family members with direct contact.

The team discussed the composition of a review panel. They agreed that the panel should include a rehabilitation clinician, a category or special topic expert, and a specialist from a resource center. However, they encountered difficulties in defining the role of a resource specialist, as they are often highly busy and taxed. The team decided to keep the definition broad and to allow for flexibility in the panel's composition. They also agreed that panelists should serve for a two-year term to ensure continuity and avoid overtaxing individuals.

Also related to the Seal of Approval, we asked about the categorization of resources. An initial list (below) was provided to the group:

- Physical Health: Mobility
- Physical Health: Chronic conditions
- Mental Health
- Autonomic Health
- Lifestyle
- Sports, Recreation & Fitness
- Tools & Technology
- Home Modifications & Adaptive Equipment
- Health Journey
- Advocacy
- Caregiver
- Finances/Employment
- Relationships
- Mobility Equipment
- Nutrition & Wellness
- Pediatrics
- Women
- Travel
- Support Network
- Resources

The concept of tagging resources was created for easier filtering and access. There was much discussion around sub-categories for physical health as well as parenting, the definition of health journey, and support networks. There was also discussion to amend "Resources" to "Miscellaneous". As we learn more, then there may be additions of further new categories. The team also debated the categorization of 'accessibility' and 'environmental accessibility', with suggestions to integrate it under 'advocacy', 'travel', and 'home modifications'. The final decision on whether to create a new tag or subsume it under existing categories remained undecided and was refined in the next round

of e-delphi surveys.

E-Delphi Survey Four: SCI Resource Specialists and Topic Areas with Resource Queries

In the final round of e-Delphi surveys, we asked about the following topic areas:

- definition of a SCI Resource Specialist
- refining the secondary conditions of SCI,
- finalizing tags for the categorization of information and for the process of experts,
- common general questions about SCI
- general types of "useful products", and
- areas of treatments.

Related to the SCI Seal of Approval, we will focus here on the definition of the SCI Specialist and the finalizing of the categorizations.

The proposed definition of a SCI Specialist is:

A SCI Resource Specialist may have one or more of the following qualities:

- Works or volunteers at a SCI resource center at a medical facility or advocacy organization.
- Has 2+ years of experience gathering or aggregating SCI information and sharing it with others.
- Leads a peer resource group/forum either in-person or online.
- Completed training and/or certification for providing SCI resources to others.

There was wide consensus on this definition, plus an addition to add flexibility in the recruitment since these individuals are in high demand.

The Working Group was also asked about the refined list of categorizations from the previous discussions. The following list was presented to them:

- Physical Health: Mobility
- Physical Health: Autonomic Health
- Physical Health: Pediatrics
- Physical Health: Women
- Physical Health: Other
- Mental Health
- Lifestyle
- Sports, Recreation & Fitness
- Tools & Technology
- Home Modifications & Adaptive Equipment

- Life with SCI (replaced Health Journey)
- Advocacy
- Caregiver
- Finances/Employment
- Relationships
- Mobility Equipment
- Nutrition & Wellness
- Adaptive Driving
- Travel
- Support Network
- Alternative Rehabilitation Services
- Parenting with SCI
- Social, Cultural, and Environmental Barriers (social determinants of health)
- Miscellaneous (replaced Resources)

The suggested additions were Aging and Sexual Health.

RESULTS

Attributes

CREDIBLE, TRUSTWORTHY & RELIABLE:

This is a source from an authority or expert in the field of SCI and the information provided by this source can be consistently relied upon as honest and truthful.

PRACTICAL & USEFUL:

The information provided is appropriate and actionable by or for a person with a spinal cord injury and/or caregiver.

ACCESSIBLE:

The information is provided in a manner that is accessible to people with and without assistive technology so that they can acquire, read, or listen to the content.

CURRENT & RECENT:

The information is relevant to spinal cord injury with what we know today.

Scoring Evaluations

Scoring shall be the same across all health information categories. The scoring is based on a 5-point Likert scale. On this scale, the points will be defined as follows:

- 1 = very poor
- 2 = poor
- 3 = neutral
- 4 = good

- 5 = very good

Attribute Score

Each resource will receive a separate score for each of the four attributes: Credible, Trustworthy, & Reliable; Practical & Useful; Accessible; Current & Recent. A minimum score for any attribute to receive a SCI Seal of Approval is a 3.

Overall Score

An overall score for an information resource will be the sum of the scores from the 4 attributes. For a resource to receive the Seal of Approval, there must be no individual attribute score below a 3 and an overall score of 12 or above.

Scoring Transparency

The Seal will be based on the overall score, and each attribute score is visible if the user would like to view those scores. Attribute scores may be displayed in a variety of ways; however, they should be based on a rating system similar to popular sites like Amazon or Google. This will allow for ease of communication and understanding by the user.

Review Panel

This review panel will consist of at least 50% people with lived experience with the remainder being composed of SCI professionals in clinical care, research, or a specific topic area. The distribution is flexible depending on the technicality of the topic area; however, potential power imbalances must be accommodated, and the voice of lived experience must be within the panel.

For panelists with lived experience of SCI, the qualities should emphasize peer mentorship, forum discussion leadership, and membership in leadership or advocacy organizations. Other factors include a diversity of time since injury, injury level and severity, knowledge of resources, representation from care partners/family members, and topic areas when selecting panelists.

The Review Panel should include a rehabilitation clinician (PM&R, PT, OT, RN, etc), a specialist from a resource center, and a category or special topic expert. The Review Panel should also consult various specialists of conditions related to spinal cord injuries. The listing is provided below. The top 5 consisted of Rehabilitation Physicians, Occupational Therapists, Urologists, Physical Therapists, Wound Care specialists. The experts consulted will be dependent on the topic area.

- Physical Therapists
- Occupational Therapists

- Rehabilitation Physicians or Physiatrists
- Registered Nurse
- Personal Care Attendants
- Neurologists
- Neurosurgeons
- Orthopedic surgeon
- Urologists
- Gastroenterologist
- Pain Management Specialists
- Registered Respiratory Therapists
- Speech Language Pathologist
- Psychologists/ Psychiatrist
- Case Managers
- Dietitians/ Nutritionists
- Vocational Rehabilitation Counselor
- Assistive Technology Specialist
- Social worker
- Recreation Therapists
- Clinical Pharmacists
- Sexual Health Specialists
- Wound Care Specialists
- Endocrinologists

The definition of a SCI Resource Specialist may have one or more of the following qualities:

- Works or volunteers at a SCI resource center at a medical facility or advocacy organization.
- Has 2+ years of experience gathering or aggregating SCI information and sharing it with others.
- Leads a peer resource group/forum either in-person or online
- Completed training and/or certification for providing SCI resources to others.

The review panelist members rotate every 2 years in a staggered manner. The goal is to ensure people do not remain on panels for extended periods. In addition, there should be some training for each new review panelist regardless of education and area of expertise. Therefore, an orientation is necessary.

Categorizations

There also needs to be a means of categorizing the variety of information. The following is the recommended list from the Working Group, which was refined from surveys and discussions.

- Physical Health: Mobility
- Physical Health: Autonomic Health
- Physical Health: Pediatrics
- Physical Health: Women
- Physical Health: Other
- Mental Health
- Lifestyle
- Sports, Recreation & Fitness
- Tools & Technology
- Home Modifications & Adaptive Equipment
- Life with SCI (replaced Health Journey)
- Advocacy
- Aging
- Caregiver
- Finances/Employment
- Relationships
- Mobility Equipment
- Nutrition & Wellness
- Adaptive Driving
- Travel
- Support Network
- Alternative Rehabilitation Services
- Parenting with SCI
- Sexual Health
- Social, Cultural, and Environmental Barriers (social determinants of health)
- Miscellaneous (replaced Resources)

It is key to note that information may appear in more than one category.

CONCLUSION

The SCI Seal of Approval is a means to help people living with SCI, their families, and care partners to easily identify health information that they can trust. The efforts by the SCI Powered Network Working Group were a collective and iterative process. The outputs provided in this document will help to guide the execution and framework for building a system directly for the SCI community, while including the voice of those from the SCI community. The Working Group suggests next steps as a pilot program to further test the execution of a program such as this with SCI community input.

OVERALL SCI-POWERED NETWORK EFFORT

SCI-Powered Network was created through feedback from the SCI lived experience community. This first effort focused on listening to members of the community and gaining feedback for a framework to improve SCI information dissemination. A Working Group of representatives from the SCI lived experience community and community organizations was formed and drove the development and input for the results. There are 3 elements to this overall effort. These are listed below with a brief description.

- Part I - Information Needs SCI Community Survey: This is a survey created by representatives from the SCI community. The survey focused on how people find SCI information, their challenges and suggestions, and impressions of information. Data collection took place from February-June 2024 with 448 qualified responses. Insights from the survey results can help us understand the information needs of people living with SCI.
- Part II - SCI Seal of Approval: This effort is to find a way to help people evaluate information. Here we developed guidance on the framework, ranking criteria, review process, and identification for developing information dissemination tools for the SCI community. A future goal is to create an easily identifiable mark to signal which resources are best for people living with SCI.
- Part III - Information Tools for SCI Artificial Intelligence/LLM Learning: This information was directed by the premise that we can no longer use static databases; the combination of artificial intelligence with human involvement is the tool for the future. Provided in this effort are categories and tools to use to train AI tools and harness human input collaboratively to ensure the right resources are available to the right person at the right time.

All of these elements of the initial effort are interconnected and should be used together.

POSSIBLE ACTIONS

- Explore opportunities for co-branding or partnerships between these organizations to improve access.
- Create methods for access to information sources when and where it is needed.
- Advocate for Telehealth to remain an available option for people living with SCI.
- Build an identifier, like the SCI Seal of Approval, can help people with SCI decipher trusted information.
- Execute a framework for building a system directly for the SCI community should be implemented while including the voice of those from the SCI community.
- Train AI tools with concerted and continuous input from members of the SCI community.

- Combine AI/LLM tools with human assessment to provide a comprehensive resource tool.
- Officer information resource tools should include a combination of key trusted sources for people living with SCI: medical professionals, SCI organizations and SCI peers.
- Address trust-building and community adoption as critical factors, requiring collaboration among organizations and consideration of diverse SCI experiences.
- Implement strategies to focus on usability and leveraging existing trust relationships within the SCI community.

REFERENCES

1. May Discussion Slides:
https://docs.google.com/presentation/d/1O4IIQsPIGjI6R_HrEX2c-88Cb0a6nsK6/edit#slide=id.g2de05ac5876_1_8
2. June Summary Notes:
https://docs.google.com/document/d/16aMN7MzS8Rr1XvsedCE0LC8T70zGCHk7/edit?usp=share_link&ouid=114323796969939703931&rtpof=true&sd=true
3. June Discussion Slides:
https://docs.google.com/presentation/d/1OwD8NAt8Yd8iQtxnw3lmAdevitaxCWq6/edit?usp=share_link&ouid=114323796969939703931&rtpof=true&sd=true
4. July Summary Notes:
https://docs.google.com/document/d/1wXsZLwi8PuONHuwMTV9DdcxxRVIWdidn/edit?usp=share_link&ouid=114323796969939703931&rtpof=true&sd=true
5. July Discussion Slides:
https://drive.google.com/file/d/1j55m69EsUmHBNU6X0UZm0U17_1Ei0Eql/view?usp=share_link
6. August Summary Notes:
https://docs.google.com/document/d/1PvBLp007VnMKshEM2GBsHfD5zMvSZuPO/edit?usp=share_link&ouid=114323796969939703931&rtpof=true&sd=true
7. August Discussion Slides:
https://drive.google.com/file/d/1-BV1rQ06dOKnOvzAdYCeyUnHtLZKjMrg/view?usp=share_link