

Oregon Health Authority
Quality and Health Outcomes Committee
AGENDA



MEETING ACCESSIBILITY

Everyone is welcome to the meetings. For questions about accessibility or to request an accommodation, please call 971-304-6236 or write OHA.qualityquestions@dhsosha.state.or.us.

Requests should be made at least 48 hours prior to the event. Documents can be provided upon request in an alternate format for individuals with disabilities or in a language other than English for people with limited English skills. To request a document in another format or language, please call 971-304-6236 or write OHA.qualityquestions@dhsosha.state.or.us

MEETING INFORMATION

Meeting Date/Time: January 10, 2022 / 10:00 a.m.– 12:00 p.m.

Location: Zoom

Call in information: 1-669-254-5252 / **Meeting ID:** 161 366 3644 / **Passcode:** 105585

Registration required: [Zoom Registration](#)

On meeting day, after registered, click the join link: [Zoom Join Link](#)

All meeting materials are posted on the [QHOC website](#)

Clinical Director Work Group
10:00 a.m. – 12:00 p.m.

TIME	TOPIC	OWNER	MATERIALS (page #)
10:00 a.m.	Welcome & Announcements	Jeanne Savage Lisa Bui	TC TA handout
10:10 a.m.	December follow up items	Lisa Bui	Presentation slides
10:20 a.m.	COVID update	Dawn Mautner Kristen Dillon	Presentation slides
11:00 a.m.	P&T update	Roger Citron	Presentation slides
11:15 a.m.	HERC update	Ariel Smits	Presentation slides
11:45 a.m.	Quality Performance Improvement (QPI) update	Laura Matola Lisa Bui	Presentation slides
12:00 p.m.	ADJOURN		

SPEAKER CONTACT SHEET
QHOC – January 10, 2022

AGENDA TOPIC	SPEAKER	CONTACT INFO
HERC Update	Ariel Smits, MD, MPH	ariel.smits@dhsoha.state.or.us
P&T Update	Roger Citron	roger.a.citron@dhaoha.state.or.us
QHOC Chairs		
Medical	Jeanne Savage	Jeanne.Savage@trilliumchp.com
Medical	Douglas Carr – Vice Chair	dcarr@umpquahealth.com
Behavioral Health	Jeremy Koehler	koehlerj@healthshareoregon.org
Oral Health	Laura McKeane	Laura.mckeane@allcarehealth.com
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Behavioral Health	TBD	
Oral Health	Kaz Rafia	kaz.rafia@dhsoha.state.or.us
Quality	Lisa Bui	LISA.T.BUI@dhsoha.state.or.us

QHOC Website:

<https://www.oregon.gov/oha/HPA/DSI/Pages/Quality-Health-Outcomes-Committee.aspx>

Questions:

OHA.qualityquestions@state.or.us or call Lisa Bui at 971-673-3397

OHA Transformation Center Technical Assistance for CCOs

TA index

Metrics TA	1
Social-emotional health	1
SBIRT (screening, brief intervention and referral to treatment)	2
Tobacco cessation.....	2
Non-metrics TA	2
Care coordination	2
Community advisory councils (CACs).....	3
Family Connects Oregon	3
Health-related services	4
SHARE (supporting health for all through reinvestment)	5
Transformation and quality strategy	5
Value-based payment (VBP)	5
Transformation Center technical assistance updates	6

Metrics TA

Social-emotional health

Webinar: System-level social-emotional health metric asset map

This webinar will demonstrate how to use and submit the fillable version of the asset map template, one component of the new system-level social emotional health metric. This will allow CCOs to fulfill this requirement and provide participants with practical strategies to address capacity issues within a CCO’s service area.

- **January 25, 11 a.m.-noon** (rescheduled from Jan. 13). Anyone already registered will be sent the new date. The registration link and connection details will remain the same.
- **Audience:** CCO staff and clinical partners who will be completing asset maps for CCOs
- **Register here:** <https://www.zoomgov.com/meeting/register/vJIsdOCggTMOHceoiQQairm97rHt3Axro-8>

Metric background: As of January 2022, CCOs have a new incentive measure to support health aspects of kindergarten readiness: system-level social-emotional health. This metric focuses on identifying and connecting young children with social emotional health needs to services. One component of this new measure is that CCOs must complete a map of local assets available to address the social-emotional health needs of young children. The first year of the asset mapping process will help CCOs identify behavioral health providers trained to provide behavioral health services to infants, and young children with their caregivers. The [measure specifications](#) include a template that CCOs can use, and OHA has created a fillable version of this template.

Contact: Bhagavati (Adrienne Mullock) (Adrienne.P.Mullock@dhsola.state.or.us)

SBIRT (screening, brief intervention and referral to treatment)

Free clinical technical assistance for clinics addressing the increasing prevalence of unhealthy alcohol (SBIRT)

The OHA Transformation Center is partnering with the Oregon Rural Practice-based Research Network (ORPRN) to support clinic technical assistance related to SBIRT for unhealthy alcohol and drug use. Within Oregon, SBIRT is an incentive benchmark for CCOs in 2022. This collaborative project, ANTECEDENT, can provide primary care clinics with 15 months of tailored support to implement changes to address unhealthy alcohol use at no-cost to the participating clinics.

- **See flier:** <https://www.oregon.gov/oha/HPA/dsi-tc/Documents/ANTECEDENT-flier.pdf>
- **When:** Recruiting through February 2022
- **Who:** Clinics across Oregon and neighboring states are invited to participate in this free technical assistance opportunity.
- **Contact:** Alissa Robbins (Alissa.Robbins@dhsoha.state.or.us) or contact the program directly at ANTECEDENT@ohsu.edu.

Tobacco cessation

Free, quick online tobacco cessation counseling training to address higher COVID-19 risk for cigarette smokers (with CME)

What: With cigarette smokers at higher risk for COVID-19, this short online course will improve your care team's ability to help patients quit tobacco. The course focuses on brief tobacco intervention and motivational interviewing techniques.

Who: All members of the care team committed to supporting their patients to quit tobacco.

When: The course is self-paced and takes approximately 45 minutes. The course can be started, paused and resumed later as needed.

CMEs: This training has been reviewed and is accepted for up to 1.0 prescribed credit from the American Academy of Family Physicians (AAFP). For other licensing boards that may not pre-approve continuing education credits (for example, the Board of Licensed Professional Counselors and Therapists), please submit the certificate of participation to your accrediting body.

Access the training (link updated 12/29/21): <https://learn.optum.com/redeem/or>

Non-metrics TA

Care coordination

Virtual learning collaborative: Care coordination and intensive care coordination (CC/ICC)

The Oregon Health Authority Transformation Center is hosting a monthly virtual learning collaborative to support CCOs and other organizations that provide care coordination services to Oregon Health Plan (OHP) members. The year-long learning collaborative will provide support toward understanding and meeting CCO 2.0 care coordination requirements and facilitate sharing of CC/ICC best practices.

Audience: This event series is for staff of CCOs, Kepro, and other organizations who are involved in planning or delivering CC/ICC to OHP members.

Participants will hear from subject matter experts and peers on key topics such as:

- CCO contract requirements and OARs related to CC/ICC
- Best practices for:
 - o Interdisciplinary care team (ICT) meetings

- o Sharing assessments and care plans
- o CC/ICC staffing models
- CC/ICC reporting requirements/template
- Face-to-face requirements in rural/urban areas
- Prioritized populations
- Using data to support CC/ICC activities and workflows
- In lieu of services (ILOS) and care coordination

When: This virtual collaborative will be held on the 3rd Thursday each month in 2022, noon–2 p.m.

To participate:

1. Please complete this brief questionnaire: <https://forms.office.com/r/pTsBLxhrq1>
2. Save the date(s): 3rd Thursday of each month, noon–2 p.m., starting January 20, 2022

Contact: Jackie.Wetzel@dhsosha.state.or.us

Community advisory councils (CACs)

CAC member learning series: The social determinants of health & equity

The Oregon Health Authority Transformation Center is hosting a learning series for CAC members on the social determinants of health & equity. All session will be held via Zoom. This learning series is being held in support of:

- OHA’s goal to eliminate health disparities across Oregon by 2030; and
- The contractual requirements for CACs in addressing the social determinants of health & equity.

Schedule

- **How CAC members can advance health equity**
 - o [View session recording](#)
- **Applying an equity lens when reviewing community spending requests**
 - o January 7, noon–1 p.m.
 - o [Register here](#)
- **Community health assessments (CHAs): Making sense of health disparities**
 - o January 31, 3–4:30 p.m.
 - o [Register here](#)
- **Community health improvement plans (CHPs): Evidence-based strategies to address the social determinants of health & equity**
 - o February 24, 11:30 a.m. –1 p.m.
 - o [Register here](#)

Consumer CAC members are eligible for a \$10 electronic gift card for each session they attend in the learning series. Electronic gift cards are available from Albertsons, Safeway and CVS.

At each session, closed captioning, ASL interpretation and Spanish interpretation will be provided.

[Click here](#) to view a learning series flier in English.

[Haga clic aquí](#) para ver un folleto de la serie de aprendizaje en español.

Family Connects Oregon

Rescheduled webinar: Family Connects Oregon

The OHA Transformation Center and OHA Public Health Division will be hosting a webinar on Oregon’s new nurse home visiting program. Family Connects Oregon builds on Oregon’s current home visiting programs and will offer home visiting

to all families with newborns. It is a voluntary, opt-in program. No families are required to participate. Please note that Family Connects is rolling out in stages across the state, and is not yet universal at this time.

In this session, maternal and child health staff will provide details on the new home visiting model, as well as requirements for CCOs.

- January 21, noon-1 p.m.
- Audience: CCO staff.
- Register here: <https://www.zoomgov.com/meeting/register/vJltc-murjkuHJi4F4iFILBwEcK6Q9OM6SM>

Contacts: Bobbie Bowman-Meza (Bobbie.Bowman-Meza@dhsoha.state.or.us) and Tom Cogswell (thomas.cogswell@dhsoha.state.or.us); please contact Tom Cogswell if you require any accommodations to fully participate in this learning session.

Health-related services

Webinar: Health information technology investments using HRS

This webinar will cover HRS health information technology (HIT) expenditure criteria and basics, and highlight successful CCO HIT strategies and investments. The webinar will also connect this work to statewide efforts and priorities. Presenters include staff from the OHA Transformation Center, the Office of Health Information Technology, and CCOs.

When: January 12, 11 a.m.–noon

Register in advance: <https://us02web.zoom.us/meeting/register/tZUrdO-qrT8pGtximduG3zvwOn4i3lPjU2gi>

CCO learning collaborative: SHARE and HRS community benefit

Please save the date for a monthly CCO learning collaborative focused on SHARE (Supporting Health for All through Reinvestment) and health-related services (HRS) community benefit, which will take place on the 4th Monday of each month through June 2022. These meetings will be facilitated by technical assistance consultants, and will be an informal way for CCO staff to share ideas around program strategy and implementation. The list of monthly topics is forthcoming, and will be created based on ideas from conversations with CCOs.

Who: All CCO staff working on SHARE or HRS are welcome to attend.

When: Next meeting January 24, 4–5 p.m. (4th Monday of each month through June 2022; not meeting in December)

Register here: <https://us02web.zoom.us/meeting/register/tZwvcuigrT8tE9ylvWs79L86TfxilqibPkQ3>

Contact: Nancy Goff (nancy055@gmail.com)

HRS office hours

CCO staff are invited to participate in general HRS office hours and staff may join the calls at any point during the scheduled times.

- **When:** Every three months through 2022
 - Next: January 11, 11–11:30 a.m.
 - Full schedule at <https://www.oregon.gov/oha/HPA/dsi-tc/Pages/Health-Related-Services.aspx>
- **Join on your computer or mobile app** (no registration required)
 - Or call in (audio only): +1 971-277-2343
 - Phone conference ID: 895 910 664#

SHARE (supporting health for all through reinvestment)

CCO learning collaborative: SHARE and HRS community benefit

A monthly CCO learning collaborative focused on SHARE (Supporting Health for All through Reinvestment) and health-related services (HRS) community benefit will take place on the 4th Monday of each month September 2021–June 2022. These meetings will be facilitated by technical assistance consultants, and will be an informal way for CCO staff to share ideas around program strategy and implementation. The list of monthly topics is forthcoming, and will be created based on ideas from conversations with CCOs.

Who: All CCO staff working on SHARE or HRS are welcome to attend.

When: Next meeting January 24, 4–5 p.m. (4th Monday of each month through June 2022)

Register here: <https://us02web.zoom.us/meeting/register/tZwvcuigrT8tE9ylvWs79L86TfxilqibPkQ3>

Contact: Nancy Goff (nancy055@gmail.com)

Transformation and quality strategy

2022 TQS guidance documents

The 2022 TQS template and guidance documents are posted to the Transformation Center website:

<https://www.oregon.gov/oha/HPA/dsi-tc/Pages/Transformation-Quality-Strategy-Tech-Assist.aspx>

This includes a template, guidance document, scoring criteria, example strategies, FAQ, project ID numbers, and a change log of major updates.

Technical assistance schedule for 2022 submissions

Webinar recordings are posted on the TQS TA page: <https://www.oregon.gov/oha/HPA/dsi-tc/Pages/Transformation-Quality-Strategy-Tech-Assist.aspx>

Office hours (first Thursdays, 11-11:30 a.m.)

- Feb. 3, March 3
- [Join on your computer or mobile app](#)
- Or call in (audio only): +1 971-277-2343,,394186822#
- Phone conference ID: 394 186 822#

Value-based payment (VBP)

VBP resource library

OHA's value-based payment (VBP) website now features a library of resources: <https://www.oregon.gov/oha/HPA/dsi-tc/Pages/VBP-Resource-Library.aspx>

The library covers a wide range VBP topics, including:

- Overviews
- Risk stratification
- Attribution
- Evidence-based care and workflows
- Performance measurement
- Promoting health equity
- Emerging trends

In addition, you'll find sections on each of the five care delivery areas required in CCO contract:

- Hospital
- Maternity
- Behavioral Health
- Oral Health
- Children’s Health

Audience: CCOs, other payers, and providers

Transformation Center technical assistance updates

For updates, [sign up for the Transformation Center's events, resources and learning opportunities distribution list](#).

MINUTES

Evidence-based Guidelines Subcommittee

Online meeting
December 2, 2021
2:00-5:00pm

Members Present: Devan Kansagara, MD, Chair; Alison Little, MD, MPH; Lynnea Lindsey, PhD; Leslie Sutton; Max Kaiser, DO; Leda Garside, RN, MBA; Lisa Kouzes, DC.

Members Absent: Michael Adler, MD; Abigail Khan, MD.

Staff Present: Ariel Smits, MD, MPH; Jason Gingerich; Liz Walker, PhD, MPH; Daphne Peck.

Also Attending: Val King MD, MPH and Shauna Durbin (OHSU Center for Evidence-based Policy); Dr. Aaron Trimble; Dr. Alison Christy; Dr. Paria Zarrinagar; Carrie Woodman; Cathy Daraee; Deborah Miller; Diana Pohlman; Diane Quiring (OHA); Dr. Earl Harley; Gary Hansen, Ph.D. (Phillips); Inga Deckert; Ivan Vejar; Christina Cronin-Vejar; Joey Razzano; Katie Warnock; Kelley Utterback; Kimberly Goddard; Kym McCornack; Madison Walters; Dr. Mike Daines; Molly Ryan Ochoa; Dr. Beth Latimer; Paul Ryan; Rachel E Morse; Representative Rachel Prusak; Sara Zeman; Sarah Lemley; Scott Graime; Taylor Sarman; Wendy Nawara.

1. Call to Order

Devan Kansagara called the meeting of the Evidence-based Guidelines Subcommittee (EbGS) to order at 2:00 pm. A quorum of members was present at the meeting.

2. Minutes Review

Minutes from the 9/9/2021 meeting were reviewed. Staff identified a few typos in the draft minutes in the meeting materials. The minutes were approved 7-0.

3. Staff Report

Gingerich reported that Drs. Saboe and Stecker are no longer EbGS members but Drs. Kouzes and Khan have been appointed to join the subcommittee. There may be some additional appointments between this meeting and the February 2022 meeting.

Gingerich also reminded current members that the annual Conflict of Interest survey is due December 3, 2021.

4. Review Public Comment Disposition: High-Frequency Chest Wall Oscillation Devices

Gingerich notified the committee that Dr. Aaron Trimble, the appointed expert for this topic, will be joining at 2:45 pm. He introduced the appointed expert by reading his biographical statement:

Dr. Aaron Trimble is Assistant Professor in Pulmonary and Critical Care Medicine at Oregon Health and Science University. He has expertise in pulmonology and conducts research in cystic fibrosis and mucociliary clearance. He prescribes high-frequency chest wall oscillation devices for patients with cystic fibrosis and bronchiectasis and is also part of the adult CF clinic at OHSU. He has received grant funding from the Cystic Fibrosis Foundation to study high-frequency chest wall oscillation devices. He has also received research funding and food/travel/beverages for his work on CF medications.

Smits reviewed the second public comment disposition. There were 3 formal comments submitted regarding evidence, patient preferences, and personal experience. Staff reviewed the proposed responses to each comment. Staff then presented the revised coverage guidance, including the modified box language. Changes were specifically made to the language regarding patients with non-cystic fibrosis bronchiectasis and patients with neuromuscular disease resulting in chronic lung disease.

Little asked if the revisions to the coverage guidance recommendations were made based solely from the formal public comment. Gingerich clarified that expert input also shaped the revised language. Kaiser said he is comfortable with the revisions in the draft report given that the service is equivocal to other interventions, and does not cause harm. Smits noted the dearth of evidence for very small, affected populations makes it necessary to rely on expert input, especially when there is no anticipated new research that will provide additional evidence in the future. Little asked if the expert was supportive of coverage for the non-cystic fibrosis population at the last meeting but agnostic in relation to the neuromuscular disease population. Kansagara said the subcommittee will clarify with Trimble once he joins the meeting later today. Sutton said that relying on expert testimony is reasonable when no new anticipated research is expected. Kansagara stated that strong patient preferences were also considered. Kouzes said that she feels comfortable with the proposed language as written. Kansagara noted the general agreement with the direction of these revisions. Garside agreed with the changes made in the revised draft report. The subcommittee paused before taking a vote to wait for the appointed expert to join and moved to the next topic in the interim. At 3:00 pm, the subcommittee returned to this topic to hear public testimony and confer with the appointed expert.

Public testimony

Gary Hansen, Director of Scientific Affairs for RespirTech (manufacturer of devices): Hansen thanked the subcommittee for their work on the revised report but has concerns about ambiguous language in Section D of the second paragraph of the revised draft report's box language, including use of the term "standard of care." He suggested alternative language of "failure" of chest physiotherapy and positive expiratory pressure devices (PEPs) to make the box language clearer.

Kansagara asked Trimble of his thoughts regarding Hansen's testimony. Trimble said he feels the language is reasonable as currently written. Gingerich asked for clarification of requiring both chest physiotherapy as well as PEPs to be considered first. Trimble said requiring both is reasonable. Little said that "standard of care" doesn't add anything to the box language and proposed striking it altogether. Kansagara agreed with Little. Smits revised all three sections of the box language in which "standard of care" appeared and struck through each instance. There was some discussion about what "adequately

provided” chest physiotherapy meant, with Trimble citing he often has concerns about the adequacy of the chest physiotherapy his patients receive. That clause was also struck after deliberation.

Little asked Trimble about his stance on adding coverage for patients with neuromuscular disease. Trimble responded he was initially agnostic about coverage but that the current wording of the draft report specifically refers to neuromuscular disease with “chronic lung disease as a result of chronic lung infection,” which limit coverage to patients who would benefit from this device therapy.

A motion was made to refer the draft coverage guidance as modified to the Health Evidence Review Commission for review. **Motion approved 6-1 (Nay: Little).**

DRAFT HERC Coverage Guidance

High-frequency chest wall oscillation devices are recommended for coverage for patients with cystic fibrosis (*weak recommendation*) when there is documentation of frequent exacerbations requiring antibiotics, frequent hospitalization, or rapidly declining lung function measured by spirometry, despite either:

- A) having received chest physiotherapy and positive expiratory pressure therapy, OR
- B) documentation that chest physiotherapy and positive expiratory pressure devices are not tolerated or not available (e.g., inability of a caregiver to perform chest physiotherapy).

High-frequency chest wall oscillation devices are recommended for coverage for patients with non-cystic fibrosis bronchiectasis (*weak recommendation*) when the 4 criteria below are met:

- A) The bronchiectasis is confirmed by computed tomography (CT) scan, AND
- B) There is evidence of chronic lung infection, AND
- C) The patient has experienced either:
 - 1) daily productive cough for at least 6 continuous months, OR
 - 2) frequent (> 2 times a year) exacerbations requiring antibiotic therapy, AND
- D) The patient has received chest physiotherapy and positive expiratory pressure therapy OR chest physiotherapy and positive expiratory pressure devices are not tolerated, contraindicated, or not available (e.g., inability of a caregiver to perform chest physiotherapy).

High-frequency chest wall oscillation devices are recommended for coverage for patients with neuromuscular disease resulting in chronic lung disease (*weak recommendation*) when there is evidence of chronic lung infection, despite either:

- A) having received chest physiotherapy and positive expiratory pressure therapy, OR
- B) documentation that chest physiotherapy and positive expiratory pressure devices are not tolerated, contraindicated, or not available (e.g., inability of a caregiver to perform chest physiotherapy).

High-frequency chest wall oscillation devices are not recommended for coverage for patients with chronic obstructive pulmonary disease (*weak recommendation*).

5. Review Draft Coverage Guidance: PANDAS/PANS

Gingerich read aloud the meeting orientation statement. Smits gave an overview of the revised draft coverage guidance. Based on previous public input and expert input at the last meeting, staff dropped interventions that were not subject to prior authorization controls, such as a single course of antibiotics, corticosteroids, SSRIs, or psychotherapy. Staff instead retained those interventions that had higher costs, risk of harms, and were subject to prior authorization criteria. Based on subcommittee direction from the September 9, 2021 meeting, staff also revised the draft report to exclude pediatric autoimmune encephalitis as a condition. Therefore, the revised draft only pertained to two conditions: PANDAS and PANS. Staff proposed two options of the draft box language. Option 1 identified a pathway to coverage of IVIG and therapeutic plasma exchange based on low-quality evidence, expert opinion, and public testimony. Option 2 was similar to the initial draft recommendation, which does not cover any of the interventions identified for PANDAS/PANS. Option 2 was based on the low-quality evidence and anticipation of future research. Smits asked the subcommittee as to which option was preferable.

Kansagara asked for a brief overview of the evidence for the retained interventions in the report. Smits walked through the GRADE tables for each intervention and summarized the evidence base. Kansagara asked the subcommittee members if there were any outstanding questions about the evidence review and which option seemed preferable. Kouzes said that in the last meeting minutes, public comment from Dritan Agalliu indicated to wait until clinical studies had completed before making a coverage decision, so she would like clarification of the timeline of making a coverage decision. She said her second concern was related to requiring two subspecialists to approve IVIG or plasmapheresis. Smits clarified that waiting for trials to be over would be a de facto adoption of Option 2. Sutton asked what it would look like if the subcommittee pursued Option 1 first. Smits said coverage could be added later based on trials indicating benefit. Once HERC adds coverage for a service, there is generally a higher bar to meet when trying to remove a service than when trying to add a service as a covered benefit. Kansagara noted the strong public involvement as impetus to make a decision now instead of waiting for trials to be over and then making a decision. However, there can always be a re-review in the future.

Once the subcommittee returned to this topic, Gingerich introduced the three appointed experts:

Dr. Alison Christy is the Clinical Director for Providence Pediatric Neurology at Providence St. Vincent Medical Center. She is a pediatric neuroimmunologist and her areas of expertise include neuroimmunological disorders, pediatric neurology and movement disorders. She has given multiple talks on the topic of PANDAS/PANS at professional conferences in Portland. She is director of the Doernbecher Immune Brain Disorders Clinic. Christy has no relevant conflicts of interest to disclose.

Dr. Michael Daines is Associate Professor and Division Chief of Pediatric Allergy, Immunology and Rheumatology at University of Arizona. He is also the Co-Director for the Children's Post Infectious Autoimmune Encephalitis Center of Excellence in Tucson, AZ. His specialties are pediatric allergy and immunology. Daines is the lead investigator of an FDA-approved phase 3 clinical trial for IVIG in the treatment of PANS. His division also oversees several active research projects related to PANDAS/PANS and has a registry for patients and family members. Dr. Daines has received industry funding from Octapharma for the design of the Phase 3 IVIG trial (paid to the university). He has also received travel reimbursements from the PACE Foundation, a PANDAS/PANS advocacy organization.

Dr. Paria Zarrinnegar is Assistant Professor of Psychiatry at OHSU, joining in 2018. She is a board-certified psychiatrist who specializes in biopsychosocial assessment among children and adolescents. Zarrinnegar has no relevant conflicts of interest to disclose.

Kansagara moved to hear public testimony, and limited the testimony to two minutes per person citing a large number of registrations.

Public testimony

Christina Cronin-Vejar: Ms. Cronin-Vejar ceded her time to Dr. Earl Harley.

Deborah Miller: Ms. Miller ceded her time to Dr. Harley.

Kym McCornack: Ms. McCornack ceded her time to Dr. Beth Latimer.

Ivan Vejar: Mr. Vejar ceded his time to Dr. Beth Latimer.

Diana Pohlman: Ms. Pohlman ceded her time to Dr. Harley.

Rachel Morse, parent: Ms. Morse began her testimony by thanking the subcommittee. She is the mother of two PANDAS/PANS patients. She said that these families have PTSD scores like combat veterans. She said the lack of data for this condition is because of the minor age of the patients. She warns that testing protocols can add to long wait times and prevent timely access to care. Morse asked for an emergency task force to be formed and a multidisciplinary clinic to be established. She said that long COVID is a form of PANS by definition.

Paul Ryan, PACE Foundation (PANDAS/PANS advocacy group): Mr. Ryan said his group is involved with clinics around the country, and his group includes IVIG as a standard of care. He said that Option 1 should be expanded to include infectious disease doctors and cited Dr. Daines as one such medical expert. He said his concern about requiring subspecialists and requiring pre- and post-testing is something that a mature multidisciplinary clinic is capable of but has concerns that Oregon will need educational programs to facilitate awareness of these conditions.

Sarah Lemley, Director of the Northwest PANDAS PANS Network: Ms. Lemley said she has no conflicts. She said she was concerned with requiring two subspecialists as outlined in Option 1. She said there is a lack of expertise and support for PANDAS/PANS within these specialties, and said that out of the two local children's hospitals that have such specialists, one will not see PANDAS/PANS patients due to the controversial nature of the disorders. Lemley identified other Oregon hospitals and departments that will not take OHP, diagnose or treat PANDAS/PANS patients, or which have a long wait time. She asked the subcommittee to remove the two-physician subspecialist requirement as it would only increase the burden of accessing care for vulnerable families.

Earl Harley, MD, Professor of Otolaryngology and Pediatrics at Georgetown University: Dr. Harley began his testimony by describing his 28-year practice and association with Dr. Beth Latimer in working on PANDAS/PANS research. He would like the subcommittee to consider tonsillectomy and adenoidectomy as treatment options of PANDAS/PANS. Tonsillectomy is very controversial in the world of PANDAS/PANS as well as the field of pediatrics. He cited a 2018 red book recommendation against tonsillectomy or any PANDAS/PANS treatments by the American Academy of Pediatrics. He has seen almost 300 PANDAS/PANS patients, half of whom received tonsillectomy, and has done CME conferences on the topic of these disorders. Harley said he has an ongoing trial funded by the PANDAS PANS Network that is looking at tonsil tissue samples and conducting various analyses. His theory is that strep infection is one of many triggers of the disorder, and that almost any bacteria can trigger this disorder, many of which are found in the tonsils and in the gut microbiome. He said he is continuing this

research in the current pilot study, and is conducting other retrospective analyses. He recommended tonsillectomy, treating the gut microbiome, and having access to IVIG as treatment options for PANDAS/PANS. He said tonsillectomies are safe and should be considered for select children.

Sarah Zeman, parent: Ms. Zeman introduced herself as a former disability attorney and parent of a child likely affected by PANS. She said she has no conflicts. Zeman said she supports increasing access to IVIG with only one physician consultation and recommendation, not two, as she said that places unnecessary burdens on families and currently treating providers. She said her family's trauma and burdens are exponential and echoed earlier testimony that her family has PTSD. Zeman attempted to secure care for her gravely ill child and said that Oregon is a doctor desert. Doctors in Oregon tend to lack awareness of PANS and refuse to treat PANS. She said while we wait for national treatment standards that access to care should not be made burdensome on overtaxed and traumatized families.

Beth Latimer, MD, d/b/a Latimer Neurology Center: Dr. Latimer began her testimony by describing her 20-year practice in pediatric neurology. She said she agrees that current published studies for PANDAS/PANS have not been done well, citing limitations of inherent bias, not enough differential between intervention and placebo groups, and not enough children enrolled in the studies. She said the American Academy of Apheresis approves of treating PANDAS/PANS. Latimer said that symptoms of OCD, depression, suicidality and sleep deprivation were outlined in two international studies as a result of low REM sleep in these affected children. She said the subcommittee's recommendation of two subspecialists agreeing on IVIG might be possible if these providers were in the same hospital but that it is too burdensome for families to make two separate consultations. She also expressed concern that requiring less-invasive therapies may exacerbate symptoms of suicidality, such as the use of SSRIs. Parents are desperate for a treatment option for their children. She said it is more cost effective to treat these children than treating their symptoms. Access to care is a financial burden. She said of the 25% of children that received IVIG in her clinic and showed no improvement; she would consider those children as candidates for tonsillectomy.

Oregon State House Representative Rachel Prusak: Representative Prusak began her testimony by thanking the subcommittee. She stated her concern of watching her community members not having access to care. She said she was a 20-year family nurse practitioner and that we need to improve access to care for the community to decrease suffering. Requiring two subspecialists may be harmful and other types of providers, such as nurse practitioners, should be considered. She said that her own adult patients face at least six month wait times to see a specialist, and assumes it is worse for the pediatric population. She understands requiring one subspecialist. She is working to strengthen Oregon's investments to solve these problems.

Kansagara thanked the members of the public and asked the three appointed experts for their comments. Daines said he supports immunomodulatory treatments in children with PANDAS/PANS and there is evidence to suggest a significant response. He is not a practitioner in Oregon and every place has unique challenges. In Arizona, there is a system in place such that requiring multiple providers to agree on a treatment plan is feasible, but does not think that is the case for Oregon. Christy said that if she's concerned enough about a child, that there is not a concern of getting timely care. She is working with Dr. Zarrinnegar to establish a multidisciplinary clinic and feels this is important. Christy also said that the two subspecialist requirement is important to provide protection against children receiving unnecessary care. Requiring two providers to agree will help make things better, not worse.

Sutton asked the experts about the lack of access to care. She said other types of providers as identified by Representative Prusak could be utilized, and wants experts to chime in on what kind of providers they would feel comfortable identifying for consultation. Christy said she disagrees that it is difficult to see a single subspecialist, with the exception of rheumatology, and that her own waitlist is two months out with an ability to get patients in earlier if needed. She suggested the subcommittee require one subspecialist in addition to a general pediatrician. Gingerich said the next step is a formal comment period, so the main objective of today is deciding on which option to pursue, and then getting it out for public comment to get feedback on specifics. Lindsay asked if a pediatric psychologist would be included in the provider list.

Kansagara polled the group about developing option 1 versus developing option 2. Little supported option 2 because of insufficient evidence, while the other members supported some version of option 1, which recommends coverage under limited circumstances. There was consensus that the evidence alone was not sufficient to support coverage, but several members expressed support for option 1 since it is limited and has safeguards to prevent overtreatment. Kaiser and Lindsey expressed support for the two-specialist requirement, and Kouzes expressed concern that, while some guardrails are needed, two consultations would be difficult to obtain for families experiencing this kind of crisis. Kouzes also disclosed she has a relative whose condition might fit under these diagnoses.

Garside asked about the current coverage landscape for these disorders. Gingerich clarified that there is no ICD-10-CM code for either PANDAS or PANS. There is an unspecified diagnosis with an index entry for PANDAS; this diagnosis is in the funded region of the List. IVIG is an FDA-regulated medication, so it is covered if prescribed for a funded condition supported by an FDA indication or by compendia, so there is some ambiguity in terms of medical necessity. There are no official diagnostic criteria specifically for PANDAS/PANS.

Kansagara acknowledged the need to expand access and educate providers is important but said that is not within the purview of HERC; the intent of this subcommittee is to create evidence-based coverage criteria. He asked the subcommittee to focus on identifying the types of providers that can diagnose and treat these disorders. He says that perhaps the two physician specialist requirement does not mean that an individual must independently travel to two physically separate appointments but that a family could see one specialist who could confer with another provider.

Garside and Sutton said that there must be consideration for access to care for rural patients. Sutton also asked about the requirement to try and fail two less-invasive therapies. She understands the need to try less invasive therapies first before proceeding to a more invasive therapy but wonders about the timeline for that. Christy said that for life-threatening conditions, a child would be hospitalized and treatments in the hospital setting are outside of the coverage purview of this draft report. Zarrinnegar said that by the time children are seeking very specialized care, they have already tried some other therapies such as SSRIs or psychotherapy to treat symptoms of anxiety or OCD, and SSRI treatment takes typically 2-3 months to observe the effects and titrate doses. As far as NSAIDs and steroids, these outpatient options can be utilized and it takes a week or two to determine whether there is a difference in symptom management.

Garside asked about the prevalence of this condition. Kansagara said there is no consensus, with estimates varying very widely. Some advocates say it could be 1 in 200, which supports the need for robust guardrails. Zarrinnegar said that OCD is a very common condition and that adds to the controversy for PANDAS/PANS. She said that half of OCD patients have treatment-resistant OCD, and up

to 20% of people who present with OCD may have an immune trigger of their OCD and/or tics. Daines said he agreed and added that there is not a lot of awareness of these disorders and children, especially those who are more economically vulnerable, may be misdiagnosed with behavior or psychiatric disorders.

Kansagara asked Dr. Latimer of her sense of the epidemiology of these disorders. Latimer responded that it is unknown and said the problem is when someone knows how to diagnose it, it becomes very common, citing a local psychiatric hospital in DC that performs a strep culture on every psychiatric intake. She said per her personal experience, she has treated 5 very ill children in her town of 30,000 who were bed-ridden and out of school.

Christy said she has seen children referred for PANS who were suffering from migraines or seizures, which emphasizes the need for gatekeeping with the subspecialists because the expertise is needed to know what is going on. Kansagara suggested that trying lesser invasive therapies could be done between a matter of weeks to months instead of years, citing Sutton's earlier concern. Sutton asked if that could be made clear in the box language so that criterion A of option 1 makes sure that parents of these children don't have to wait years to access care for their children. After discussion, the subcommittee added the word "limited" to the required trials of other therapies.

Latimer said that she would not give IVIG to a child who does not respond to steroids, as a trial of steroids predicts responsiveness to IVIG. Often, children respond to steroids and antibiotics and don't need anything else. She said it takes about 5 days to know whether a child is responding to steroids, though sometimes she will try IV steroids if oral agents fail. Daines said he agrees completely with Latimer and referenced Stanford data on nonsteroidals for PANDAS/PANS, noting the effect can be observed in a few days. Smits said SSRIs might require 6 weeks, steroids would take a few days, suggesting "limited course" as proposed wording. Smits said that while crafting the box language with the experts, staff learned that oftentimes by the time parents present with a PANDAS/PANS child, they already have tried accessible therapies.

Kansagara asked the subcommittee and the experts for their thoughts about the requirement for two subspecialists. He suggested that consultations could occur among providers in a clinic, or that provider-to-provider consultations or e-consultations might meet the requirement (so that the patient wouldn't have to be seen by two separate unaffiliated providers). After discussion, the subcommittee approved language to be posted for public comment, requiring two specialist consultations, one of which could be a provider-to-provider consultation or an e-consultation.

A motion was made to refer the draft coverage guidance as modified for a formal 30-day public comment period. **Motion approved 6-1 (Nay: Little).**

DRAFT HERC Coverage Guidance

Tonsillectomy, adenoidectomy, adenotonsillectomy, and prophylactic antibiotic therapy are not recommended for coverage to treat pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS) (*weak recommendation*).

Up to 3 monthly immunomodulatory courses of intravenous immunoglobulin (IVIG) therapy or therapeutic plasma exchange are recommended for coverage to treat PANDAS and PANS (*weak recommendation*) when both of the following are met:

- a) Two or more less-intensive therapies (e.g., appropriate [limited](#) course of nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids, selective serotonin reuptake inhibitors (SSRIs), behavioral therapy, short-course antibiotic therapy) have been tried and were not effective, AND
- b) A consultation with and recommendation by 2 pediatric subspecialists (e.g., pediatric neurologist, pediatric psychiatrist, neurodevelopmental pediatrician, pediatric rheumatologist). [One of these consultations may consist of a provider-to-provider consultation or e-consultation.](#)

A reevaluation at 3 months by both pediatric experts is required for continued therapy of IVIG or plasma exchange. This evaluation must include objective clinical testing, which must be performed pretreatment and posttreatment to demonstrate significant clinical improvement.

Note: Other treatments (corticosteroids, SSRIs, NSAIDs, short-course antibiotics, and behavioral therapies) were included in an initial version of this report. These therapies were determined to be beyond the scope of a HERC coverage guidance, as these therapies are commonly used for many indications and are not typically subject to utilization control. Only treatments subject to coverage criteria were retained for the final version of this report.

6. Adjournment

The meeting was adjourned at 5:15 pm. The next meeting is scheduled for February 3, 2022 from 2:00-5:00 pm in a virtual meeting format.