Report

Annual Membership Meeting

Consumers United for Evidence-based Healthcare (CUE)

U. S. Cochrane Center

3 September 2009

Location Host:
The National Partnership for Women and Families
18 75 Connecticut Avenue, NW, Suite 650
Washington, D.C.
Minutes, CUE Annual Membership Meeting, 3 September 2009 (cont’d)

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(i) Abbreviations used

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<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
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<td>Comparative Effectiveness Research</td>
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<td>Consumers United for Evidence-based Healthcare</td>
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<td>EBHC</td>
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<td>HAI</td>
<td>Hospital-acquired Infections</td>
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<td>National Breast Cancer Coalition</td>
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<td>USCC</td>
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1. Overview

The 2009 Annual Membership Meeting for Consumers United for Evidence-Based Healthcare (CUE), hosted by the US Cochrane Center (USCC), was held on September 3 in Washington, D.C. The National Partnership for Women and Families hosted the meeting in their conference room at 1875 Connecticut Avenue, NW. The meeting objectives were (1) to provide education and training on research and methodology that promotes the inclusion of consumer advocates in scientific research, (2) to address administrative matters pertaining to CUE, and (3) to strengthen the infrastructure of CUE.

We invited outside speakers to provide insights into topical issues, for example, a key Senate staffer gave a legislative update on healthcare reform, the Director of the Center for Outcomes and Evidence at the Agency for Healthcare Research and Quality (AHRQ) highlighted the consumer role in comparative effectiveness research (CER), and a representative from the Foundation for Informed Medical Decision Making spoke about the latest developments in shared decision-making. CUE members shared their lobbying efforts (1) to include sexual orientation and gender identity in health statistics, (2) to increase application of childbirth-related quality measures to Medicaid recipients, and (3) to ensure that women’s concerns are part of health reform. CUE members also provided updates on emerging issues in healthcare, care delivered in retail store clinics, and surveillance and prevention of hospital-acquired infections. Members also learned about the Wellstone Action program and The Cochrane Library.

Continuing challenges facing CUE include finding ways to increase CUE’s visibility in the consumer, legislative, and health professional communities, to increase consumer awareness and use of evidence in making healthcare decisions, and to increase consumer understanding of what CER is and is not. Finding financial support to expand CUE’s work will be critical to the group having maximal impact (see Appendix A, CUE Annual Membership Meeting agenda, and Appendix B, CUE Annual Membership Meeting Speakers).

2. CUE Annual Membership Meeting agenda

Kay Dickersin welcomed CUE members and guests, thanking them for their support and contributions to CUE, including covering their own travel expenses. She thanked the National Partnership for Women and Families for hosting the meeting, Sallie Bernard for providing breakfast, and Childbirth Connection for providing lunch.

2.1 Recognition of the life work of Carolina Hinestrosa

Dr. Dickersin asked for a moment of silence to recognize the life work of the late Carolina Hinestrosa, Executive Vice President of the National Breast Cancer Coalition (NBCC).
and founder of Nueva Vida. After being diagnosed with breast cancer, Carolina searched for the evidence on the effectiveness of available breast cancer treatments, completed NBCC’s Project LEAD, and ultimately obtained a Master of Public Health degree. Carolina’s passing is an incredible loss for the NBCC, CUE, and the advocacy community as a whole.

2.2 Introduction of CUE member organizations - Barbara Warren, Co-Chair, CUE Steering Committee

Barbara Warren welcomed CUE members and remarked that now is the ideal time for CUE to engage its constituency, and to empower and educate consumers in healthcare decision-making. She asked each member to introduce him/herself and tell us how his/her organization is involved in evidence-based healthcare (EBHC) and CER.

2.3 CUE annual report - Sallie Bernard, Co-Chair, CUE Steering Committee

Sallie Bernard welcomed meeting participants and highlighted CUE’s accomplishments over the past year in membership, grants, consumer education and training, dissemination, policy, and decision-making (see Appendix C, “CUE Accomplishments 2008-2009” – PowerPoint presentation). She noted that CUE’s AHRQ large conference grant proposal may yet be funded, and that the USCC had received funding from the Blue Shield of California Foundation to enhance the online course “Understanding Evidence-based Healthcare: A Foundation for Action” for use by doctors. As of July 10, 2009, more than 2,000 people have enrolled in the online course. CUE dissemination activities have included our annual meeting, workshops, posters, oral presentations, and the premiere of the CCNet video, produced by CUE members Barbara Warren and Richard Davis, at the 16th Cochrane Colloquium in Freiburg, Germany, October 6, 2008.

Ms. Bernard highlighted CUE’s involvement in policy, noting submission of letters to the editor, to President Obama’s administration, and to the Institute of Medicine on priority topics for CER. She thanked CUE members for their active participation on guideline committees, advisory boards, and for serving as peer reviewers for Cochrane reviews.

Ms. Bernard urged CUE members to look at Cochrane reviews in their advocacy area, links to which are now posted quarterly on their organization’s page on the USCC website, www.cochrane.us. Members were asked to regularly report their education, policy, translation and dissemination activities to the USCC, as these accomplishments are the backbone of our grant proposals.
2.4 What consumer advocates need to know about healthcare reform

2.4.1 What to expect when Congress returns - Mona Shah, Health Legislative Assistant, Senator Barbara Mikulski (Democrat - Maryland)

Ms. Shah updated participants on current and expected healthcare reform bills in the Senate and House. She noted that the House tri-committee bill, entitled America’s Affordable Health Choices Act (HR 3200), was introduced on July 14, 2009, just before the summer recess. On the Senate side, the Health, Education, Labor and Pensions Committee (HELP), which shares jurisdiction on healthcare reform with the Finance Committee, passed the Affordable Health Choices Act on July 15, 2009. The Finance Committee, led by Max Baucus (Democrat - Montana), is also currently working on a healthcare reform bill.

The Senate HELP bill, in addition to addressing healthcare coverage, calls for a government-based Institute for Comparative Effectiveness Research; identifies the need for patient safety checklists, better drug information and dissemination of evidence-based healthcare practice; and strengthens the Health and Human Services (HHS) Office on Women’s Health. The bill also includes new mandatory funding reserved solely for public health and prevention programs.

CUE members made several points regarding CER; they asked that a strong role for consumer advocates be part of any legislation and noted that currently there are inadequate resources for consumer advocate participation. Members questioned whether cost considerations would be included as part of CER. Ms. Shah stated that the bill does not mandate that cost information be used for coverage decisions; however, cost can be assessed and this information can be disseminated.

It was noted that the lesbian, gay, bisexual and transgender (LGBT) communities are concerned that special populations are too often overlooked in research studies. Ms. Shah noted the Senate Affordable Health Choices Act ensures that consideration is given to health disparities and minority populations when developing quality measures, and recommends that current gaps be addressed, where measures are not in place and health disparities exist. The bill states that data collected must include a breakdown by subpopulations; however, the language does not specify required subgroups. Ms. Shah commented that the language is intended to be inclusive.

CUE members asked about inclusion of oral health coverage in the bill and about malpractice reform. Ms. Shah noted that HELP will not mandate coverage; however, within the public health provisions, oral health may be included. Malpractice reform, which is under the jurisdiction of the Judiciary Committee, will likely be raised if the bill goes to the Senate floor for a vote.
A final question was raised about protections to ensure that the consumers “at the table” are truly representing consumer groups and are not representing industry interests. Ms. Shah noted that this kind of language could be included in the Senate Affordable Health Choices Act.

2.5 How to get your priorities into legislation

2.5.1 Being counted - Rebecca Fox, Executive Director, National Coalition for LGBT Health

Ms. Fox used her experience lobbying on behalf of the LGBT community to demonstrate the steps in effective legislative advocacy. She noted that for her coalition of 65 LGBT organizations it is important that health statistics include sexual orientation and gender identity. For the LGBT Coalition, an early lobbying step in this regard was to get sexual orientation and gender identity questions on the National Health and Nutrition Examination Survey. The LGBT Coalition identified potential support in Congress by reaching out to LGBT staffers on the Appropriations Committee. Ms. Fox noted that finding partners in Congress who care about your issue is critical to success.

The Coalition engaged members in three different ways: First, because staffers respond to constituents, the Coalition sponsored a lobby day. Second, they issued email action alerts -- a way to inform members about actions to take. In this case, the message was “Make sure we’re counted” at every level of data collection -- local, state, and national. Third, the LGBT Coalition sponsored virtual lobby and call-in days by partnering with Healthcare for America Now, which has a toll free number to reach members of Congress. Ms. Fox advised CUE members to start off with small and discrete activities to achieve a few “good wins,” and build from there.

2.5.2 Medicaid quality improvement - Maureen Corry, Executive Director, Childbirth Connection

Ms. Corry highlighted Childbirth Connection’s involvement in Medicaid quality improvement. She noted that after conducting a national survey about women’s birthing experiences, Childbirth Connection identified major differences between women’s experiences, and practices supported by the evidence. This led to a collaborative project between Childbirth Connection and the Reforming States Group, with support from the Milbank Memorial Fund, and a published report: “Evidence-Based Maternity Care: What It Is and What It Can Achieve.”

Following release of the report, Childbirth Connection initiated a campaign to implement the report’s recommendations. Echoing Ms. Fox’s advice to find a Congressional partner who cares about your issue, Ms. Corry noted that Capitol Hill staffers who had recently given birth proved to be good supporters. To improve maternal care during delivery and to lower costs, Childbirth Connection advocated for extension of the Children’s Health Insurance Program
Reauthorization Act (“CHIPRA”) to Medicaid populations. As 43% of U.S. births are covered by Medicaid this expansion would have a significant impact. Ultimately, Childbirth Connection’s proposal won the support of Congressman Eliot Engel (Democrat -17th Congressional District of New York), who sponsored an amendment to HR 3200 Quality Measures for Maternity and Adult Health Services under Medicaid and Children’s Health Insurance Program. Childbirth Connection is now waiting to see if the provision will be included in the Senate healthcare reform bill.

Ms. Corry emphasized lessons learned: First, Childbirth Connection approached Congress as advocates armed with evidence. Second, advocating for regulations on an agency or departmental level is useful. For example, there is a lack of specificity regarding adult health measures in HR 3200 Quality Measures for Maternity and Adult Health Services under Medicaid and Children’s Health Insurance Program. This means that if this bill becomes law, the Health and Human Services Secretary will convene an expert panel to identify specific quality measures. This is an entry point for Childbirth Connection and other advocates to make evidence-based recommendations. Ms. Corry suggested that CUE members consider agency level advocacy (see Appendix D, “Medicaid Quality Improvement,” – PowerPoint presentation).

2.6 Evidence in practice

2.6.1 What is the evidence on care delivered in retail clinics? - Rebecca Burkholder, Vice President, Health Policy, National Consumers League

Ms. Burkholder reported that in 2008 the National Consumers League convened a forum on retail clinics to address quality, staffing and implications for the consumer/health care provider relationship. She noted a dramatic expansion of retail clinics, i.e., healthcare clinics based in retail stores, such as Walmart. Four years ago there were about 100 such clinics and there are approximately 1,000 today. Ms. Burkholder remarked that state regulations differ as to whether retail clinics must be overseen by a practicing physician. According to a Wall Street Journal/ Harris Poll, although retail clinic consumers are satisfied with convenience and cost, 65% of respondents were concerned about retail clinic staff qualifications and that serious health problems might not be diagnosed.

Ms. Burkholder provided data indicating that retail clinics may serve a different function than a traditional primary care setting. She noted that a RAND study found that the top ten reasons for retail clinic visits comprise only 18% of the reasons for a primary care visit to a traditional care site. She indicated that 60% of people using retail clinic services do not have a primary care physician. Surprisingly, most retail clinics are located in affluent areas. She argued that while retail clinics may have the potential to increase health care options for the uninsured, to date they have not improved health care access for medically under-served populations. While
retail clinics score well on some quality care metrics (limiting use of antibiotics, methods of diagnosis) it will be important to monitor new models, collect data on quality of care, and better understand the impact on consumers’ health.

Ms. Burkholder closed by posing several questions. Will retail clinics lead to fragmented care? Will patients at retail clinics be referred to community healthcare providers for ongoing care? How will patient privacy be protected? Will clinic clients be subject to retail marketing tactics to increase in-store sales? Will attracting sick individuals to retail environments lead to increased disease transmission? (See Appendix E, “What is the Evidence on Care Delivered in Retail Clinics?” – PowerPoint presentation).

2.6.2 The evidence for making hospitals safer - John Santa, Director, Consumer Reports Health Ratings Center

John Santa described the Safe Patient Project, organized to eliminate medical harm, improve FDA oversight of prescription drugs, and promote disclosure laws about health, safety, and quality. Dr. Santa reported that in 2002 “the number of hospital-acquired infections (HAIs) exceeded the number of cases of any currently notifiable disease, and deaths associated with HAIs in hospitals exceeded the number attributable to several of the top ten leading causes of death according to U.S. vital statistics.” While 26 states require public reporting of HAIs, only seven states have actually produced detailed reports on these infections. When interviewed, 93% of consumers stated that information on rates of HAIs at hospitals would influence their medical decision-making.

The Center for Disease Control and Prevention National Healthcare Safety Network is emerging as a leader in setting standards for HAI reporting. In addition, New York and Pennsylvania are emerging as national models for HAI control programs. Dr. Santa noted that the number of evidence-based measures to prevent HAIs is growing. He closed by calling for advocacy for expansion of state reporting of HAIs and increased implementation of effective control programs (see Appendix F, “The Evidence for Making Hospitals Safer,” – PowerPoint presentation).

2.6.3 Lunch tele-conversation: What consumers can learn from new models for building advocacy and leadership in the 21st century - David Wellstone, Board Co-Chair, Wellstone Action

Mr. Wellstone highlighted a signature program of Wellstone Action, Camp Wellstone, a series of training camps to prepare participants to either run for office, run a campaign, or do grassroots advocacy and organizing. He described what a customized advocacy camp for CUE might look like. He shared lessons learned about successful advocacy on the legislative front,
mentioning tenacity, and being strategic about who champions and sponsors your bill. He recommended that CUE members be vocal, get loud, and make connections in Congress. He noted that both obtaining funding and increasing visibility are challenges facing CUE.

2.7 Current hot issues and developments in healthcare

2.7.1 Where is the consumer in comparative effectiveness research? - Jean Slutsky, Director, Center for Outcomes and Evidence, AHRQ

Jean Slutsky suggested that we are at an important juncture in US healthcare, with the expansion of CER and the legislative healthcare reform debate underway. She noted that AHRQ’s Effective Health Care Program sponsors health technology assessments for Medicare and Medicaid; promotes, funds and translates comparative effectiveness findings; and funds training grants focused on comparative effectiveness.

Ms. Slutsky reported that the 2009 American Recovery and Reinvestment Act provided $1.1 billion ($300 million to AHRQ) to advance CER (see www.hhs.gov/recovery for more information). AHRQ’s plan to use these funds includes obtaining stakeholder input and involvement, horizon scanning, evidence synthesis and generation, and research training and career development. In addition, AHRQ plans to form a citizen’s forum on effective health care to formally engage grassroots consumers in all aspects of the Effective Health Care Program. She closed by noting that consumers are part of all AHRQ programs; they serve on stakeholder and technical expert panels, participate in testing of translation products, and suggest research questions for systematic reviews and new research (see Appendix G, “Where is the Consumer in Comparative Effectiveness Research?” – PowerPoint presentation).

2.7.2 Shared decision-making: how to make it work for you - Lyn Paget, Director of Communications, Foundation for Informed Decision Making

Lyn Paget noted that the current system of delegating decision-making solely to health care providers leads to sub-optimal care for patients. Research findings show that providers often do not ask about patients’ opinions and values and, in addition, do a poor job of predicting patient preferences. She emphasized that patients often do not have adequate knowledge about their medical conditions and the recommended treatments. Patient decision aids assist health care providers in communicating with their patients about both the risks and benefits involved in treatment, thus enabling shared decision-making. A recent Cochrane review of decision aids shows that their use leads to greater patient knowledge, more accurate risk perceptions, increased comfort with decisions, increased participation in decision-making, fewer undecided patients, and fewer patients choosing major surgery. Ms. Paget mentioned that two pieces of federal legislation, the Empowering Patient Choices Pilot Act, and the Affordable Health Choices Act”
promote the development and implementation of shared decision-making techniques.

A CUE member asked whether promotion of shared decision-making tools was changing how physicians deliver care. It was noted that reimbursement policies must change before physicians will spend the time necessary for shared decision-making. A CUE member remarked that the unique needs of sub-populations must be considered in the development of decision aids. (see Appendix H, “Shared decision-making: how to make it work for you,” – PowerPoint presentation).

2.8  Advocacy in action

2.8.1 Raising Women’s Voices for the healthcare we need - Cindy Pearson, Executive Director, National Women’s Health Network

Ms. Pearson described the “Raising Women’s Voices” campaign as one of many efforts to promote health reform that meets women’s needs. The campaign calls for a system that recognizes all of us, regardless of our sexual, racial, or ethnic orientation, and that ensures that all individuals are treated with dignity. She echoed a point made by previous speakers, that working at the agency level is an important role for advocates. She noted that a priority for Raising Women’s Voices, is to have an impact on what is included in the essential benefits package of the Senate bill. Ms. Pearson cautioned that educated consumers must be involved in nominating members of any independent board that will make medical coverage recommendations to the Secretary of the U.S. HHS. A CUE member pointed out that we need a nationwide conversation that challenges the common view that more medicine means better healthcare and better outcomes.

2.9  Finding the evidence: Demonstration of The Cochrane Library - Kay Dickersin, Director, the US Cochrane Center

Kay Dickersin provided a quick “walk through” of The Cochrane Library website. Janie Gordon reminded participants that each CUE member organization has been given a free subscription to The Cochrane Library which provides access to full Cochrane reviews. Each CUE member organization also has a webpage on the USCC site, where the USCC posts Cochrane reviews on the organization’s topic areas. These are updated with each new issue of The Library. Ms. Gordon urged each organization to link directly from their home page to their organization’s page on the USCC website.

2.10  CUE projects: Updates and future directions

Several CUE members proposed ideas to build CUE’s strength and presence in evidence-
based health advocacy. We discussed the pros and cons of hiring a grant writer. Kay Dickersin noted that previous grant applications had been criticized for not demonstrating convincingly that of EBHC is well-disseminated to CUE organization members. Member organizations were urged to keep the USCC abreast of their EBHC accomplishments.

Members discussed current methods used by decision-makers to identify consumers for their committees. Decision-makers frequently question whether CUE members are “too sophisticated” or are not “real people.” CUE members were concerned that policymakers or scientists are able to choose who does and does not qualify as a “consumer” and what the “correct” consumer viewpoint should be. It was also noted that a single consumer representative on a regulatory agency board or committee cannot carry the burden of effectively representing consumers, rather there must be more than one consumer representative at the table. The need to reach out to attract low literacy, minority, and hard to reach populations to our CUE organizations was stressed. We must increase efforts to expand minority membership.

Reaching medical students was deemed a strategy that could pay high dividends. Program ideas included developing a course in shared decision-making, and a grand rounds program that the American Medical Students Association might fund. CUE could also promote its online course “Understanding Evidence-based Healthcare: A Foundation for Action,” which is currently being adapted for healthcare providers, to this audience.

Members decided to form the following CUE committees: Membership, Fundraising, Advocacy Policy, and 2010 Colorado Cochrane Colloquium. Volunteers were requested for each committee.

2.11 Steering Committee election

A motion was introduced to change the CUE bylaws from requiring the Steering Committee to be composed of seven members, to “seven to nine members.” CUE members voted and all were in favor. Terrie Cowley from TMJ and John Santa from Consumers Union were voted in as new members of the CUE Steering Committee. Sallie Bernard and Barbara Warren will continue to serve as Co-Chairs for six months, and will then ask other Steering Committee members to replace them in this role.

2.12 Summary of CUE member evaluations

Twenty-five people attended the 2009 CUE Annual Membership Meeting, coordinated by the USCC. Participants were asked to complete a detailed evaluation form (See Appendix I, Evaluation Survey Instrument).
Eighteen respondents returned the evaluation, although not all questions were answered by all respondents. Respondents were positive (scoring excellent or very good) regarding the meeting’s presenters, content, and organization. Of the 15 respondents who answered the question, 100% (15/15) noted the CUE meeting met their expectations. Suggestions primarily focused on improving time management of the meeting and allocating more time for discussion.

2.13 Focus group participation with University of California, San Francisco researchers

Steering committee members and USCC staff participated in a 2-hour focus group immediately following the membership meeting. The focus group was part of a pilot project to identify how consumer advocates seek out the scientific information which they then disseminate to their constituents. The University of California researchers are conducting several focus groups with their Stewart Trust Cancer Research Award. Upon completion, the research results will be shared with CUE.
Appendix A - Meeting Agenda

Consumers United for Evidence-based Healthcare (CUE)
2009 Annual Membership Meeting
September 3, 2009; 8:30 am - 5:00 pm
Washington, D.C.
National Partnership for Women and Families Office

Program Agenda

8:00 am - 8:30 am  Registration and continental breakfast

8:30 am - 8:35 am  Recognition of life’s work of Carolina Hinestrosa, Executive Vice President, National Breast Cancer Coalition
Kay Dickersin, Director, US Cochrane Center

8:35 am - 8:40 am  Welcoming remarks
Sally Bernard and Barbara Warren, Co-chairs, CUE
Kay Dickersin and Janie Gordon, US Cochrane Center

8:40 am - 9:00 am  Introduction of member organizations
Barbara Warren

We ask all members to introduce themselves and their organization’s mission.

9:00 am - 9:30 am  CUE 2008/2009 report and discussion
Sally Bernard

What consumer advocates need to know about health care reform

9:30 am - 9:50 am  Legislative update: What to expect when Congress returns
Mona Shah, Health Legislative Assistant, Senator Barbara Mikulski (Md)

9:50 am - 10:15 am  Discussion

10:15 am - 10:30 am  Break
How to get your priorities into legislation

10:30 am - 10:45 am  **Being counted**  
Rebecca Fox, Executive Director, National Coalition for LGBT Health

10:45 am - 11:00 am  **Medicaid quality improvement**  
Maureen Corry, Executive Director, Childbirth Connection

11:00 am - 11:15 am  **Discussion**

Evidence in practice

11:15 am - 11:30 am  **What is the evidence on care delivered in retail clinics?**  
Rebecca Burkholder, Vice President, Health Policy, National Consumers League

11:30 am - 11:45 am  **The evidence for making hospitals safer**  
John Santa, Director of the Health Ratings Center, Consumer Reports

11:45 am - 12:00 pm  **Discussion**

12:00 pm - 1:00 pm  **Lunch**  
Call - in lunch discussion: What consumers can learn from new models for building advocacy and leadership in the 21st century - Back to the grassroots!  
David Wellstone, Board Co-chair, Wellstone Action

Current hot issues and developments in healthcare

1:00 pm - 1:20 pm  **Where is the consumer in comparative effectiveness research?**  
Jean Slutsky, Director, Center for Outcomes and Evidence, AHRQ

1:20 pm - 1:40 pm  **Shared decision making: How to make it work for you**  
Lyn Paget, Director of Communications, Foundation for Informed Decision Making

1:40 pm - 2:00 pm  **Discussion**
2:00 pm - 2:15 pm  Advocacy in action
Raising Women’s Voices for the health care we need
Cindy Pearson, Executive Director, National Women’s Health Network

2:15 pm - 2:30 pm  Discussion

2:30 pm - 2:45 pm  Break

2:45 pm - 3:00 pm  Finding the evidence: Demonstration of The Cochrane Library, other sources
Kay Dickersin and Janie Gordon

3:00 pm - 4:00 pm  CUE projects: updates & future directions
• Building membership - ideas and priorities for expansion
• CUE online course update
• Playing a key role in health care policy
• Dissemination
• Looking ahead: Goals for upcoming year
• Future directions

4:00 pm - 4:15 pm  Steering Committee election

4:15 pm - 4:30 pm  Wrap-up and evaluation
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<tbody>
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