Advocacy in the Era of Evidence: An International Summit for Consumer Advocates

Consumers United for Evidence-based Healthcare (CUE)

Report Describing the 2010 Advocacy Summit

17 October 2010

Keystone, Colorado

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1. Overview

On October 17, 2010 the US Cochrane Center (USCC) and Consumers United for Evidence-based Healthcare (CUE) hosted "Advocacy in the Era of Evidence: An International Summit for Consumer Advocates" in Keystone, Colorado (see Appendix 1 for Summit Agenda). The meeting was open to consumers, consumer advocates, their science and policy partners, and others interested in working together to include the public in evidence-based health decision-making. To maximize impact for the attendees, the Summit was held in conjunction with the Joint Colloquium of the Cochrane and Campbell Collaborations which began on October 18, 2010 in the same location. The Summit received funding support from Agency for Healthcare Research and Quality (AHRQ), Blue Cross Blue Shield Association, and Wellpoint, Inc.

The one-day Summit included keynote presentations, plenary sessions, and workshops designed to provide practical training for consumer advocates and others on how to access and apply evidence-based healthcare to their advocacy and educational efforts. "Advocacy in the Era of Evidence" was chosen as the title of the summit to reflect the Planning Committee's meeting objectives, which were to:

- Strengthen and enhance the effectiveness of CUE as a leader in evidence-based consumer advocacy;
- Maximize international and US exchange about best practices and experiences in evidence-based consumer advocacy; and
- Increase US consumer participation in The Cochrane Collaboration.

Of 88 Summit registrants, we classified 54 as consumers (61%), 27 as from educational or research institutions (31%), 4 from the private sector (5%), and 3 from funding agencies (3%). Participants were from 15 states, the District of Columbia, and 10 countries outside of the United States.

Speakers' topics included methods being used and tested to educate consumers and consumer advocates about evidence-based healthcare (EBHC), consumer understanding of EBHC, and ways in which evidence is developed, interpreted, and applied. Recurring themes included the individual's need to get involved in healthcare decision-making issues, the move to EBHC by policymakers, what EBHC means for consumer advocates, and the many opportunities for consumer advocates to have a voice in the ongoing programs.

2. Keynote addresses

There were two keynote addresses, one at the conference opening and one as part of a working lunch.

2.1. How do we fight to get the consumer voice front and center in healthcare decision making: The vision ahead.

Cornelius Baker, *National Black Gay Men's Advocacy Coalition and AED Center on AIDS and Community Health*

Mr. Baker began by reviewing the path that had led him to become a consumer advocate, starting in 1981 with the beginning of the AIDS pandemic. He was shocked at the lack of swift and effective movement on the part of policy makers concerning AIDS, especially with the millions of lives at stake worldwide. He joined with many AIDS patients, along with their family and friends, fighting to provide input on how to prevent and treat the condition. As AIDS research groups were being formed, he noticed that only professionals and scientists sat on the boards of these groups.

Mr. Baker suggested that the audience become familiar with three of the Denver Principles, put forth by AIDS activists in 1983: (1) Form caucuses and choose representatives, to deal with the media, to choose an agenda, and to plan strategies; (2) be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations; (3) be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

Mr. Baker expressed concern that the consumer health movement has big challenges ahead. Although he noted that a uniformity of opinion is not desirable, he was concerned that the current election-related advertisements are not telling the truth to the American people. Evidence-based healthcare is being attacked as rationing; as removing control; and as a threat to economic viability and affordability of healthcare. Ultimately, the key to advocacy is unity among the diverse groups. Rather than fighting each other for funding, groups must realize that there are many resources that can be utilized for the benefit of all. Finally, consumers must be aware of who is serving on the committees that will be implementing evidence-based healthcare and be vocal if improper decisions are made.

2.2. Communicating evidence: Lessons learned from USPSTF's recommendations on screening young women for breast cancer.

Ned Calonge, MD *Chair, U.S. Preventive Services Task Force*

Dr. Calonge outlined the process that led to the USPSTF's (US Preventive Services Task Force) recommendation, updated in December 2009, that "the decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take patient context into account, including the patient's values regarding specific benefits and harms." He detailed the sequence of events that led to the public firestorm of reaction to the recommendation and lessons learned from the experience.

He began by pointing out that by focusing on a single premise for screening (ie, early detection improves outcomes), we often overlook potential harms. For example, when the condition is infrequent in a population (such as breast cancer in women under 50), a higher proportion of tests result in "false positives," which require some type of action including needless interventions and possible harm. There are not many deaths to be averted in younger women and so false positives and harm become a greater concern.

Lessons learned from the 2009 breast cancer screening recommendations mainly revolve around political, as opposed to scientific, issues. For example, the recommendation was originally released in July 2009, coincident with the national debate about legislation on healthcare reform. The recommendation was interpreted by some as supporting the "rationing" of health care and may have harmed citizens' receptivity to EBHC provisions in the health reform legislation. Dr. Calonge emphasized that cost is never a factor in the USPSTF recommendations. In a further example of a lesson learned, the USPSTF initially recommended "against routine screening mammography in women aged 40 to 49 years," but this phrasing caused misunderstandings. Consequently, this sentence was removed from the recommendation in December 2009. Dr. Calonge's presentation was followed by a lively question and answer session.

3. Panel discussions

3.1. Consumer engagement and partnerships

3.1.1. How can citizens and consumer advocates join with scientists to create a better future? The Agency for Healthcare Research and Quality (AHRQ) Community Forum.

Jean Slutsky, Director, Center For Outcomes and Evidence, AHRQ

Ms. Slutsky began by noting that one of the greatest problems facing the health care system today is that the focus of much research has little relevance to actual needs in society. Ultimately, the patient is the focus of any health care system, and she or he must be actively engaged in that system. Consumer engagement must be present at all levels, and there must be respect on both sides. This is needed in order to help reduce obstacles and to produce research that is relevant to the needs of the consumer.

As a result, the Comparative Effectiveness Research (CER) program at AHRQ centers around engaging the public. In fact, they rarely fund a topic for CER unless it has first been nominated by a potential user of that research. Ms. Slutsky displayed the system on the AHRQ website that encourages review and comment by consumers of proposed research topics.

In response to an initiative to expand and systematize citizen and stakeholder engagement in the AHRQ Effective Healthcare Program, the Community Forum was created. The purpose of the Community Forum is to develop and demonstrate deliberative methods and tools for obtaining informed public opinion concerning decisions related to the conduct of CER, as well as the application of research results in policy and practice. The lessons learned in the creation of the Forum are that consumers need to be involved at each stage of research, that both researchers and consumers need training on how to do this, that trust is essential and that this consumer/researcher partnership is an ongoing endeavor.

Ms. Slutsky concluded that public engagement in the Effective Health Care Program produces relevancy of research to users and helps to dispel myths and fears through the mutual understanding of issues and values of patients and providers.

3.1.2. Understanding enough about statistics to ask the right questions.

Steve Goodman, Johns Hopkins Medical Institutions

Dr. Goodman began by suggesting that consumers need a general knowledge of how studies are conducted and analyzed if they are to be actively engaged in providing input into research and policy. Conclusions from studies are almost never completely true or false. Rather, conclusions drawn are affected by the quality of the study design, the study's execution, the strength of its findings, as well as biological evidence and findings from other studies. Understanding the design, what or who is missing, the assumptions, the overall effect, and

uncertainty, is essential for consumers to gain a proper understanding of the research and therefore to be able to ask relevant questions.

Consumers should know whether the study was observational or experimental (including randomized or non-randomized) and whether this was the appropriate design for the research question being asked. In addition, use of what appear to be very clear and concise models may at the same time obscure important facts and conclusions, and lead to incorrect results. This can happen when certain statistical assumptions are being made. Consumers should actively check what assumptions are being made in analyses and whether they are valid. Consumers should always inquire about what is missing from each study, be it citations to results and findings from similar studies, excluded participants, or missing/strange data.

Perhaps most important for consumers to understand is interpretation of statistics. Relative risks are usually preferred by scientists, while absolute risks are usually preferred by the general public. Consumers should know how to convert between the two as well as how to interpret confidence intervals and p-values. It should be noted that a finding of "no evidence of effect" should not necessarily be interpreted as "no effect". It could mean that the findings were inconclusive.

Dr. Goodman concluded that the largest obstacle for consumer engagement with researchers is consumers' fear of numbers. Therefore, it is essential that a consumer be familiar with the basic workings and nature of statistical analysis. Also, one should never be afraid to ask for an explanation. Often, the ability of a researcher to explain a complicated model to a lay person demonstrates the researcher's own solid understanding of the subject matter.

3.1.3. Consumer Involvement in Guidelines International Network (G-I-N).

Richard Rosenfeld, Chairperson, Guideline Development Task Force, American Academy of Otolaryngology - Head and Neck Surgery

Dr. Rosenfeld began by explaining that clinical practice guidelines present evidence and make it actionable. Guideline development adds context, values and nuance to the evidence, resulting in statements about how to implement evidence and make it work in specific settings. Consumers are integral to this process and G-I-N is focused on their involvement. Guidelines benefit healthcare providers and consumers most when consumers contribute to guideline preparation. G-I-N strives to accomplish active consumer participation in guideline development by providing a platform for idea exchange between consumers and professionals.

G-I-N comprises 100 organizational members and has a guideline library of over 7100 guidelines. Dr. Rosenfeld explained that G-I-N is to guideline development what the Cochrane Collaboration is to systematic reviews, indicating high-quality, reliable output. As a way to maintain this quality and improve the process of guideline development, G-I-N has created the G-I-N Public Working Group to promote ways to inform and involve the public in clinical

guideline activity around the world. G-I-N Public offers a forum of exchange between patient and public organizations, clinical practice guidelines developers and researchers. This is primarily accomplished through their wiki website, and by holding workshops and presentations at conferences such as the G-I-N annual meeting.

Dr. Rosenfeld noted that great synergy exists between guideline development and the use and drafting of systematic reviews in uniting people for the implementation of evidence. Presently, the state of guideline development in the US leaves much to be desired. It has been done by many diverse groups in the past with varying quality. In response, G-I-N has formed a G-I-N North American Community which attracted 100 individuals to an exploratory session in 2010. This group has been mandated to conduct a pilot project establishing regional G-I-N communities.

3.2. Global Consumer Action

3.2.1. CCNET: Consumer action in the Cochrane Collaboration.

Janet Wale, Cochrane Consumer Network, Australia

Ms. Wale explained that the need for consumer action in healthcare is underscored by the fact that few consumers actually understand terms such as "medical evidence" or "quality." They often assume that more care, whatever that care is, results in a higher quality of care. Individual patients vary greatly from person to person. Differences in opinions and experiences can be the reason why EBHC is still unconvincing to consumers, media, and policy makers. The goal of the Cochrane Collaboration's Consumer Network (CCNet) is to increase awareness about EBHC, create an informed consumer voice, achieve a critical mass of informed consumers and global consumer action. This will assist the Cochrane Collaboration with its aim to help people make well-informed decisions by preparing, maintaining, and promoting the accessibility of systematic reviews.

The Cochrane Collaboration consists of a secretariat and editorial groups, review groups, methods groups, groups responsible for field/network implementation, and centers with their regional branches. All of these are guided by an international steering group. The product of the Collaboration's work is *The Cochrane Library*, and it includes plain language summaries of systematic reviews that are designed to be accessible to all people. The Cochrane Collaboration created CCNet as a way of engaging consumers in the development of systematic reviews and as a vehicle to raise awareness among consumers, recruit consumer members, commission plain language summaries, and recruit co-authors for reviews. New ideas to promote consumer involvement, such as videos, learning materials, evaluations, and the utilization of social networks such as Facebook have been recently implemented. Ultimately, consumers want accessible information that is up-to-date; they want to feel empowered with confidence to contribute to EBHC. CCNet aspires to contribute to providing these.

3.2.2. Demand for Information.

Hilda Bastian, Institute for Quality and Efficiency in Health Care, IQWiG, Germany

Ms. Bastian gave an account of the development of the Institute for Quality and Efficiency in Health Care (IQWiG) and its mandate to strengthen the autonomy of citizens through the availability of current scientific knowledge about healthcare. IQWiG, a non-governmental and non-profit agency, was created to evaluate effectiveness and patient information. The organization is funded by the German health system. A major goal is to ensure stakeholder input and editorial independence while keeping the organization relevant, objective, and independent, focusing on evidence-based medicine. Activities within the organization include evidence assessment, clinical, communication, and qualitative research.

IQWiG developed a tool called the "evidence tree" to describe to readers how they obtain information. They scan evidence in depth, assess qualitative research, consult stakeholders on all drafts, and get feedback from consumer focus groups. Post-publication criticism is vital, as is keeping information up-to-date.

The focus is on evidence-based patient information, which is developed to minimize bias and maintain neutrality while addressing uncertainties, and on analyzing risks and benefits of interventions. The evidence itself should be up-to-date and non-directive. A genuine interest and respect for the patient's opinions, desires, concerns, and confidence is vital.

Finally, the organization utilizes published surveys, studies, and data from professional organizations, as well as the internet, to assess public interest and demand. A website for IQWiG has been set up, and its name and purpose must become popular among patients. Therefore, IQWiG is paying attention to providing good quality translations of the evidence and to ensuring that the organization is devoted to questions in medicine as a whole, rather than to specific patient requests. IQWiG believes this approach is key to increasing the popularity of the website and the organization itself.

3.2.3. Raising Women's Voices for the Healthcare We Need.

Cynthia Pearson, Executive Director, National Women's Health Network

Ms. Pearson explained that the need for policymakers, both local and national, to listen and heed the experiences, questions, and concerns of women has dated as far back as the 1970s. Many procedures then and even some today, were not based on EBHC. Over three decades later, the fight continues to ensure that the health care needs of women across the nation, however diverse, are heard. Simple issues such as patient rights to written information on drugs, decision making, and treatment have already been reformed drastically. However, a collaborative effort is necessary to ensure all needs and concerns are met.

In 2007, many advocacy groups came together to establish this collaborative effort. Emphasis was placed on the voices of women who were disenfranchised from medical care. Initial funding and support were low due to the fear that this collaborative effort would also drag the issue of abortion into the picture. Nevertheless, a national conference was held to launch the effort, much like a typical social grassroots movement. The results of the launch were widely apparent. Ordinary citizens and policymakers started to listen. Even with the emergence and wide availability of the internet, the strong and time-tested operations of advocacy groups, dating back decades, still proved to be viable and essential today. Overall, the last two years have shown that when the power of voices with a unified demand are combined with old school advocacy tactics in an effort to reform health care, so that evidence overrides politics, the needs of women across the nation are met efficiently and promptly.

3.2.4. Results of survey of consumer involvement in systematic reviews: Challenges and opportunities.

Julia Kreis, Harkness/Bosch Fellow

Ms. Kreis presented the results of a project that explored the question "How are consumers currently involved in systematic reviews?" She reported that consumers are actively involved in all stages of systematic reviews not only in this country but also worldwide. Ms. Kries surveyed 17 organizations that either conduct or commission systematic reviews. Key informants from many professional societies, federal research institutions, international organizations, and payer/provider organizations were interviewed on consumer involvement in their systematic reviews. Of the 17, seven were found to regularly include consumers in their processes. Her presentation focused on the survey results of those seven organizations.

While there was a general consensus that consumers play a vital part in the validity of systematic reviews, they found that there was considerable variation across organizations concerning the approach used. Recruitment methods vary widely and include recommendations from patient organizations, individual patients via clinics and physicians, as well as the utilization of existing consumer networks and mailing lists. How transparent should this recruitment process be? The Cochrane Collaboration trains consumers in methods while AHRQ trains researchers in stakeholder engagement. This led to the question, "Who should be trained?"

Ms. Kreis concluded that several standards for consumer involvement in systematic reviews may be suggested as a result of this survey:

- Standards for compensating consumers for their time and expenses;
- Clear policies on the disclosure of potential conflicts of interest; and
- Consistent evaluation of the impact of consumer involvement in systematic reviews.

4. Workshops

Seven workshops were offered to conference attendees. A pre-conference workshop aimed to provide a basic introduction to CUE for those individuals with no or little experience with the coalition. Two sessions of six simultaneous workshops each were offered in the morning and afternoon to provide practical training on how to apply EBHC to advocacy efforts.

4.1. Pre-conference Workshop

4.1.1. Orientation to CUE Advocacy Summit

Maureen Corry, Exectuive Director, Childbirth Connection, Co-Chair, CUE Steering Committee,

John Santa, Director, Health Ratings Center, Consumers Union, Co-Chair, CUE Steering Committee

John Santa welcomed participants to the Summit and provided an overview of the session. He explained what CUE is and described its staff, The Steering Committee, and members.

Kay Dickersin presented a history of CUE, beginning with the AHRQ funding in 2003. She explained that the original idea for CUE was to assemble a coalition of consumer advocacy groups that would network with one another, and to provide a focus for consumer groups to obtain the education in EBHC they sought. Although the assembled groups have different foci (e.g., childbirth, cancer, autism), all have a desire for consumers to become engaged in EBHC. Kay outlined the mission and objectives of CUE, and explained that the USCC provides resources that support this coalition of consumer groups. CUE member organizations themselves drive the agenda. Projects that CUE has undertaken include:

- Development of the web-based course "Understanding Evidence-based Health Care";
- Dissemination of EBHC information to member organizations;
- Annual workshops;
- Videos describing the Cochrane Collaboration, CUE, and CCNet;
- Contributions to Cochrane reviews;
- Serving as a clearinghouse of consumer representative for advisory groups;
- Providing letters of support on EBHC issues.

John Santa continued with a brief synopsis of the activities of each of the 28 member organizations, highlighting their purpose and activities.

Maureen Corry addressed the future of CUE and emphasized that CUE is well-positioned as a coalition to take advantage of all the opportunities ahead.

4.2. Simultaneous workshops

4.2.1. Critical appraisal of the evidence: How to ask an answerable question.

Mark Helfand, Oregon Health and Sciences University
Cathy Gordon, Oregon Health and Sciences University

Two sessions of this workshop were conducted, with a total of 19 participants. The goal of the workshop was to learn how to critically appraise research questions for their relevance to the outcomes that are important to decision-makers. This was achieved by addressing 3 objectives:

- Understand the components of medical decision-making, including the role of evidence;
- Describe the process of scoping a systematic review, using analytic frameworks; and,
- Identify outcomes of interest to decision-makers and research questions that appropriately address them.

After the welcome and introductions, various models of decision-making were presented and discussed. Participants considered the components of making a medical decision by recalling a recent health decision from their own experience. Evidence is one important component of medical decision-making but other factors also impact choices. Analytic frameworks and logic models from various comparative effectiveness reviews were then reviewed in order to determine how researchers and others determine outcomes of importance to decision-makers. This process of starting at the end, so to speak, with outcomes that are important to patients and consumers in particular, is one element in ensuring that comparative effectiveness reviews or other systematic reviews are relevant to end-users. Questions that guide research need to address the concerns of importance to decision makers.

4.2.2. Critical appraisal of the evidence: What do the statistics tell us about the truth?

Steve Goodman, Johns Hopkins Medical Institutions
Cynthia Pearson, National Women's Health Network

The aim of this workshop was to critically appraise the presentation and interpretation of statistical evidence. Workshop participants were particularly interested in how to identify "good" studies and how to translate statistics into plain language. A concern raised was the ethics of randomized controlled trials (RCTs) and whether or not consumers should have a choice about their treatment. Also noted was that often the studies appearing in the media are those that are not well-conducted or reported.

Dr. Goodman and Ms. Pearson explained the importance of understanding the study design, characteristics of the participants and the appropriateness of the outcome measures. Moreover, conclusions about a treatment should not be based on a single study, but rather the synthesis of all available good evidence.

Specifically, one should consider:

- Study design: Is it an RCT or not?
- Sample size: This determines how certain one can be about the data. Evaluate the range of uncertainty by examining the confidence intervals. Confidence intervals are more useful than p-values;
- Recruitment: Where did the participants come from? Who is missing? For example, often pregnant women are excluded and only those who are otherwise healthy and wealthy are included. This affects whether or not the results are generalizable, i.e., applicable to the broader population. Meta-analysis can be problematic where studies have considerably different eligibility criteria and hence study populations;
- Publication bias: Studies with positive results are differentially published compared to studies with null or negative results;
- Journals do not guarantee the truth, but should guarantee transparency and the methods used in a study; and
- The current study in context with a clear and complete description of previous studies.

Articles were offered as case studies to highlight these important statistical and methodological considerations. The group worked through the article, "Chest compression-only CPR by lay rescuers and survival from out-of-hospital cardiac arrest," (Bobrow et al., *JAMA* 2010; 304: 1447-54). This was a prospective observational study to investigate the survival of patients with out-of-hospital cardiac arrest using compression-only CPR compared with conventional CPR. Dr. Goodman pointed out the importance of critically examining information and tables describing the characteristics of the study participants. Also, one should consider the impact of the intervention *after* adjustment for other important factors. The magnitude of the effect might be quite different. Another case study, "Insufficient sleep undermines dietary efforts to reduce adiposity," (Nedeltcheva et al., *Ann Intern Med* 2010;153:435-441), illustrated a well-conducted randomized cross over trial. However, a sample size of just 10 raised issues of generalizability.

The workshop aimed to be practical and helpful in assessing study design and statistical evidence, and encouraged discussion among the attending leaders and participants from diverse areas in the field.

4.2.3. Critical appraisal of the evidence: A technology assessment case study.

Naomi Aronson, Blue Cross Blue Shield Technology Evaluation Center
Vicki Tosher, Colorado Breast Cancer Coalition

Dr. Aronson gave an overview of the Accelerated Partial Breast Irradiation Case Study. Ms. Tosher provided a summary of "Tools for Advocates in Conducting a Critical Review."

Each of the two workshops had a different focus and set of priorities, leading to quite different discussions.

Workshop 1: Five attended the session. Four of the five came from outside the USA; three were researchers, one worked in a health center, one ran a consumer website and monitors research journals (one of the researchers is also a consumer advocate).

The Workshop aimed to use the "Tools for Advocates" as an outline to analyze the Case Study, starting with the question, "What journal is the article published in?", it became clear that for consumers in non-English-speaking nations, the point is irrelevant: almost all research of merit is published in English-language journals. As for systematic reviews, they are in English-only journals. Those attending stated they have neither time nor the skills to translate research. There was strong agreement that Cochrane's Plain Language Summaries must be available in many languages in order for consumers around the world to have access to Cochrane review information.

Workshop 2: Six people attended the session; interestingly, five of the six had attended the same workshop session earlier in the day. While not all of them were from the USA, all were from English-speaking countries. This group included researchers, a physician, and highly trained consumer advocates. There was a robust discussion on disagreements and terminology errors in conjunction with the Case Study. From the consumer perspective, it is important that the synthesis of science be summarized and disseminated broadly. For example, scientific study sections at NIH should understand the need for a systematic review before embarking on new research.

4.2.4. Clinical practice guidelines: Do they contribute to good quality care?

Marguerite Koster, Kaiser Permanente Southern California
John Santa, Consumers Union

Ms. Koster began by briefly describing clinical practice guidelines (CPG) and asked the question, "Do CPGs improve patient care?" She pointed out that implementation of recommendations is critical if guidelines are to improve patient care, and focused the remainder of her talk on the implementation strategies used by Kaiser Permanente for a recently developed guideline recommending Pap smear and HPV screening every 3 years for women 30-65 years, and Pap smear screening every 3 years for women under 30 years.

Kaiser Permanente, comprising 3.3 million members, 13 hospitals and 148 medical groups, develops guidelines using a team approach. This team is also responsible for developing a strategic implementation plan. For the Pap smear guidelines, the team used a combination of "active" and "passive" implementation strategies. Passive strategic approaches included continuing medical education presentations, site visits by regional implementation managers, and printed materials, including a 4-page printed booklet mailed to healthcare providers, quality

improvement staff, and executive/operational staff. Information on the Kaiser Permanente intranet and point-of-care posters were developed for more immediate access. Member education materials were developed in English, Spanish, Chinese, and Armenian. Active approaches include "KP Healthconnect", an electronic health system with automatic reminders for healthcare providers at the time of a patient encounter, and "Proactive Office Encounter". This latter feature reminds medical assistants to ask the patient about screening, including follow-up reminders if required. Screening reminders were also posted on patients' personal Kaiser Permanente websites. To demonstrate the effectiveness of this implementation strategy, Ms. Koster showed evidence for an increase in screening rates following implementation of the guidelines, and indicated that cancer rates would be monitored in the future.

Dr. Santa reinforced the role of monitoring performance following guideline development. Following the production of a systematic review showing that many nosocomial infections can be prevented through appropriate care of i.v. lines, his group issued a report on infection rates in various hospitals. This report led to extensive media coverage and support by the Centers for Disease Control and Prevention for public reporting. He believed that reporting, carried out fairly, would result in improved rates by each hospital; this will be tested in the next report.

Following assembly into small groups, Dr. Santa then led the groups through an exercise on self-monitoring of blood glucose. He provided background information on self-monitoring, and systematic review results showing no significant improvement in glycemic control, a mild increase in hypoglycemic events, and significant costs associated with self-monitoring. The goal of each group was to develop an implementation plan based on these findings. Interestingly, different groups developed different recommendations with the same evidence, but also concluded that strategies other than simply providing information to the clinicians was necessary for successful implementation of guidelines.

4.2.5. Who is a consumer and who gets to decide?

Barbara Warren, National coalition for LGBT Health
Janet Wale, CCNET

The definitions of a patient representative and advocate are important to differentiate when involving consumers, patients, and caregivers in research. The 26 workshop participants (total attendees for both sessions) were principally consumer advocates and engaged public. Other participants included clinical researchers, insurers and representatives from a health technology assessment agency.

It is apparent from the workshop that there is a continuum between patients and consumer advocates, and that the role of the advocate is to ensure that the consumer voice is articulated well and is heard. Consumer advocates gain a depth of experiential knowledge that they are able to apply, often in situations where they are a minority, and where they may not be considered as

partners in improving the effectiveness and safety of health care. The findings of the workshops were discussed, particularly in relationship to what it means to be a consumer, patient or client and a consumer advocate – what consumer authenticity entails; considerations in order to help consumers gain traction in highly professionalised environments; the support that consumer representatives can be given to function in their assigned roles; ethical dilemmas that might arise; and factors that can energize consumers as leaders in evidence-based healthcare.

4.2.6. Levels of evidence, benefits of each and when and how to use different kinds of evidence.

Prathap Tharyan, South Asian Cochrane Network and Centre
Sallie Bernard, SafeMinds

The session provided an overview of the steps in the evidence evaluation process (Asking, Acquiring, Appraising, Applying, Assessing), the different types of clinical studies (experimental, analytic, descriptive, laboratory), and the criteria on which studies can be evaluated. Particular attention was given to the GRADE system (www.gradeworkinggroup.org) as an objective means of evaluating a body of evidence. Concepts covered included risk of bias, narrative reviews vs. systematic reviews, magnitude of effect, precision, consistency, confounding, and the circumstances when one type of study is more appropriate than another. The goal was for participants to be able to categorize studies by type, to determine the strengths and limitations of each (including risk of bias as a marker of quality), and finally, to be able to synthesize the relevant evidence so as to make a healthcare treatment decision, whether on a population basis for guidelines or for an individual decision.

The workshop included two exercises, one on the drug Avandia (rosiglitazone) as a treatment for diabetes and one on selective serotonin reuptake inhibitors (SSRIs) for the treatment of autism. For Avandia, Dr. Tharyan provided the evidence in the manner that the manufacturer's marketing representatives presented it, and then demonstrated how the findings had been manipulated to show positive results and to ignore adverse effects. The demonstration highlighted several learning points, including possible limitations over use of surrogate markers instead of patient-important outcomes, use of marketing statements instead of science, and indications of safety problems that can be seen in the data and that could lead to a more accurate risk/benefit assessment.

For SSRIs, Ms. Bernard summarized the relevant evidence on autism and SSRIs which included a variety of study types, from a patient history and an anecdotal report to an open label study and a Cochrane systematic review. Participants were asked to assume they were the parent of a child with autism and to use the evidence presented to make a decision on whether or not they would use an SSRI for their child. The exercise illustrated how high quality evidence and systematic review might be integrated with patient-level information to make individual decisions.

5. Summary of participant evaluations

The conference contributed to building a strong and sustainable network of informed consumer advocates who would not otherwise have had reason or funding to come together for in-person meetings. The Summit evaluations and post-Summit communication with participants provided support for our conclusion that the knowledge and experience gained at the Summit contributed to consumer leadership in EBHC advocacy.

Eighty-eight individuals attended the 2010 CUE Summit for Consumer Advocates. Participants were encouraged to provide a written evaluation of the meeting and were given a survey instrument (see Appendix 2) that largely consisted of questions measured on a five-point Likert scale. Open-ended comments were also solicited. The evaluation scores and comments show that respondents were overwhelmingly supportive of the meeting's presenters, content, and organization. Forty-eight participants returned the evaluation, and not all questions were answered by all respondents. Most respondents (85%; 35/41) reported that the program met their expectations.

The largest number of comments focused on a desire for more time to cover the many topics, and for networking. Some respondents would have liked to have had printouts of the speaker's presentations and would have liked direction on possible next steps following the meeting. These suggestions will be taken into account when planning future meetings.