Translational Products for Systematic Reviews: A Stakeholder Workshop Meeting Summary

November 2016

Overview

On October 14, 2016, PCORI convened a workshop to solicit stakeholder input about how to effectively translate and disseminate findings from systematic reviews of scientific literature in order to help people and organizations make evidence-based health decisions. Stakeholders were asked to provide input on the content and format of the final information product that would be most useful for their decision making. They also provided their preferences for sourcing this information. PCORI intends to use this feedback to help guide development of information products that will be useful and meaningful to a range of healthcare decision makers.

Workshop participants included patients and consumers as well as clinicians, representatives from public and private insurers, purchaser representatives, and representatives from life sciences industry groups. The meeting was open to the public via webinar for the plenary sessions and via teleconference for the breakout sessions.

The morning plenary session consisted of key PCORI staff discussing the need for evidence in decision making, the role of systematic reviews, and the elements of information products such as the format and content. Attendees then participated in interactive breakout sessions organized by stakeholder type to provide feedback about the information products and related sources they currently use as well as opportunities for improvement. A representative from each group reported out high-level findings from each breakout group to the larger group in the afternoon plenary session. This was followed by a panel discussion highlighting differences and similarities across the various stakeholder groups.

Related Information

- Agenda
- Presentation Slides
- Participants List
- Participants List (Breakout Sessions)

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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Introduction

As part of its mission to produce and promote high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community, PCORI convened the Translational Products for Systematic Reviews Workshop. The purpose of the workshop was to gain stakeholder feedback on how best to translate and disseminate findings so that they are informative and actionable by healthcare decision makers.

The Workshop began with brief overview presentations by Dr. Joe Selby, PCORI Executive Director, and Ms. Jean Slutsky, Chief Engagement and Dissemination Officer and Program Director of Communication and Dissemination Research at PCORI. Dr. Selby welcomed the workshop participants, described the purpose of the workshop, and summarized the process that would be used for organizing the discussion over the course of the workshop. In her presentation, Ms. Slutsky emphasized the importance of evidence in decision making in the context of health care, providing examples of what healthcare decision makers want to know and the consequences of not having access to the best available evidence.

Senior Program Officer Dr. Jennifer Croswell, Office of the Chief Science Officer, explained the role of systematic evidence reviews in decision making. By definition, a systematic evidence review is an objective, transparent way to locate, critically appraise, and summarize all evidence relevant to a particular question. Such reviews are comprehensive, rigorous, and reproducible. In doing systematic evidence reviews, we gain power and precision from combining the results of multiple studies addressing the same active treatments and comparisons and obtain a summary of "what we know" and "how surely we know it." Systematic reviews also explain differences in findings across similarly designed active treatment-comparison studies and can be used to set research agendas by highlighting gaps in evidence. Systematic reviews are the most reliable way to identify benefits and harms associated with various treatment options and are essential for all stakeholders in health care.

Senior Program Officer Dr. Bill Lawrence, Communication and Dissemination Research, presented a framework intended to describe the critical elements influencing effective dissemination of information products, which PCORI identified through a literature review and environmental scan. Examples of format-related elements known to influence uptake of information by decision makers include: brevity; comprehensiveness; use of graphics and tables; use of plain language; addressing nuance as necessary to help stakeholders make decisions; and being explicit about the "bottom line" findings. Typical content-related elements of evidence syntheses include: background information; research findings on benefits and harms; current recommendations; information about strength of evidence and research gaps; comparative information about treatment risks; personal preference prioritization tools, information summarizing other patient considerations when deciding upon treatment; patient testimonials and narratives; and action steps patients may follow when considering treatment options.

Dr. Lawrence ended his presentation by explaining PCORI's charge to workshop participants. He asked stakeholder participants to share their perspectives regarding:

- What works well
- What does not work well
- What is most valuable with respect to the content and format elements of information products

He also asked stakeholders to share their sources for information products that summarize healthcare evidence for decision making and whether they find these sources valuable.

Breakout Sessions

The purpose of the breakout sessions was to obtain feedback from six different groups of stakeholders about their preferences for the content, format and sources of information products. Small groups were used to generate a broad range of responses, encourage a diversity of perspectives, and gain an understanding of the underlying reasons for each perspective. The six stakeholder groups were comprised of: two groups representing patients/consumers, and one group each representing clinicians, purchasers, insurers, and industry. Facilitators used the nominal group technique to solicit stakeholder feedback. The process began with each facilitator posing the following questions to stakeholders:

- What do you find most valuable about the *content* of information products, and what needs improvement?
- What do you find most valuable about the *format* of information products, and what needs improvement?
- What *sources* do you use for information products, and why do you find them valuable?

Facilitators next asked stakeholders to silently write responses on post-it notes and affix the notes to separate pages labeled with the appropriate category (e.g., *Content*/*Format*/*Source*). Facilitators then read from the notes, posing open-ended questions about the responses written on them to the group and encouraged feedback from all participants. During the last few minutes of the breakout sessions, facilitators worked with the group to distill feedback to report back to the larger group. A volunteer from each small group served as a representative to present this feedback at the afternoon session. A summary of the stakeholder perspectives is provided below.

Patients: Because there was strong alignment in the comments received from the two patient groups, their feedback is combined throughout this summary. Patients reported that they most value the following information about the content of healthcare evidence to help make an informed decision: (1) healthcare evidence that is personalized or tailored to better reflect the patient population, taking into account race/ethnicity, literacy and education level, "where they are at," and co-morbidities; (2) research findings on the benefits and harms; (3) research gaps, specifically what is not known; (4) the strength of the evidence, noting that insufficient evidence does not necessarily mean that the treatment is ineffective; and (5) current recommendations and action steps.

> *"Healthcare evidence needs to be presented in a way that is person-centric, not treatment-centric."*

With respect to how to present healthcare evidence, patients emphasized the importance of summarizing the information but also allowing them to "dig deeper" if desired. Patients also noted that products should clearly indicate where and how consumers can access additional information. Patients emphasized the need for strength of evidence to be presented in a more understandable and consistent manner across organizations and conditions. For example, patients suggested using a 5-star rating system to communicate strength of evidence because many consumers are familiar with and understand this rating system. Patients expressed a strong need for healthcare evidence regarding patient-centered outcomes—meaning that they want information to be presented in the context of

patients' goals, including nonmedical goals related to quality of life. Patients felt strongly that products should use testimonials appropriately and carefully, noting that some may place more weight on testimonials than data. Finally, patients want clear, comprehensive graphics that include accompanying succinct and understandable explanatory text.

Patients reported that they often seek healthcare evidence from healthcare providers, patient advocacy groups, and online sources. When seeking healthcare evidence, patients want to know that the information is from a credible, trusted source and up-to-date. Patients also seek information from family and friends and other patients that have experience with the disease and/or treatment.

Clinicians use evidence in multiple ways but do not have much time to review studies. They need synthesized information from trusted sources that can be readily accessed at the point of care. Ideally, the evidence should be layered so that they can review a concise report and then drill down for more detail, as needed. The evidence should inform clinicians' decisions and be presented in such a way that they can translate the information to the patient and family and consider it with them. Reports that say "insufficient evidence" are not helpful.

> *"I think about how to take the information and make it so that you're not making the learner drink out of a firehose. You're able to break it down into bite size pieces that you can get supported and nourished by."*

The context in which the research was developed is important because it may or may not be relevant to the situation in which clinicians work. For example, are the recommendations replicable in a Federally Qualified Health Center with a large portion of low-income or uninsured patients, where the majority of visits require an interpreter? The cultural context is also important. Cultural context should inform how physicians understand and apply the research and not be presented exclusively through the lens of Westernized medicine.

Aside from the organizational context, the evidence report should be applicable to different clinical situations and lay out diagnostic and treatment alternatives, making clear whether and how the evidence applies to those alternatives. The value of treatments is also an important consideration; for example, this information is important to oncologists who may prescribe a particular costly chemotherapy agent only rarely.

Purchasers are interested in outcomes that are not always included in systematic reviews. These include factors that affect productivity such as whether employees come to work on time, absenteeism, whether employees go on disability, and whether they leave the labor force. Employers need information that links healthcare evidence to these outcomes of interest. They also need information in a variety of formats, given the heterogeneity of groups under the label "purchaser/employer." Many purchasers will get this information from other companies. For example, if Company X shows that a new benefit improves productivity, then they are often willing to try it. Insurers often look to other companies' coverage decisions on new benefits to guide their own.

> *"I got an email from AHRQ about Omega 3s and maternity care. The first few screens I just wanted to know if there was something that I needed to know. If they could say "we didn't find anything new", then just say it. Should I be including this under our maternity care benefit?"*

Additionally, typical evidence reports *"that go through 30 pages of text and at the end say that 'the evidence is inconclusive in terms of recommendation as a covered benefit'"* are not useful. Information should put the answer first, then include key facts, risks, and finally more information for those who want to read further. Lastly, employers primarily go to trusted third-party entities like Consumer Reports and Choosing Wisely—resources that help consumers and employers decide how to avoid wasteful or unnecessary medical tests—to get their information.

Payers: The overarching takeaway from the payer group was that when it comes to understanding and applying the results of research findings, the most important overarching element to consider is **context.** Contextual details such as the target population, the condition context, comparison to existing treatments, relative cost/benefit in the context of existing treatments, inclusion/exclusion specifics, and so forth are critical to their determination of whether or not the findings are something they need to pay attention to and address with and for their members. Payers were very concerned with the kind of information their constituents—their members—are concerned about, and therefore, to a large degree what is important to members is important to them.

Key questions that payers want answered are:

- *Why should I care about this?*
- *Why is it worth my time to review this information?*

The discussion also emphasized that information should be succinct and presented in an easily absorbed and understood manner, and the most critical information should be front and center and very clear. Simple charts and graphics that display information and results are valued, as long as they are understandable and the information presented demonstrates the key findings in a straightforward manner. Finally, cost information and cost relative to benefit and in comparison to existing therapies is critical but generally missing, or it is missing the important contextual details needed to properly evaluate the true value of the research findings.

Industry: Members of the life sciences industry use evidence throughout research, development, and commercialization to identify targets for discovery; understand and prioritize areas of unmet medical need; and communicate the value of drugs, biologics, and devices to payers and policy makers. From a content perspective, industry representatives emphasized that the strength of the evidence is most valuable, particularly as they are accustomed to developing high-quality evidence suitable for use by regulatory bodies. However, they are also concerned with how payers and professional societies view evidence and determine value and stressed the importance of considering a wider range of study designs when conducting systematic reviews, including observational studies. Participants also emphasized the need for greater heterogeneity with respect to the types of patients studied and study endpoints, including treatment response, outcomes prioritized by patients, and longer term outcomes. This will require more attention to the methods used in evidence development as well as a greater understanding of patient perspectives regarding disease experience using techniques such as patient journeys. Although research gaps are routinely identified in systematic reviews, what is typically missing is stakeholder input regarding whether and how to address

"There is an opportunity which is consistent with PCORI's mission which looks at all forms of decision making to bring patient-centeredness into tools for population-level decision making."

the gaps. This is where PCORI could play a major role given its engagement with a broad set of stakeholders.

Participants emphasized the need to make evidence electronically available in interactive evidence tables that could support subgroup analyses by a range of users throughout research and development. Effective use of executive summaries that include only the key conclusions is also critical, but developers of information products must be cognizant of the unintended consequence of misinterpretation of the evidence due to oversimplification. A novel suggestion by participants was to recommend greater inclusion of evidence in electronic health records, clinical decision support systems, and related work flows that promote clinical integration of evidence into practice. Finally, participants discussed how formats that support population-level decision making will need to be different from formats that support decision making at the individual level where patient-centeredness is emphasized. Although no solutions were identified other than suggesting that tools will need to be customized to specific applications, participants suggested that PCORI could play a role in facilitating this type of discussion, leading to audience-specific formats.

Tables 1–3 provide a high-level summary of the feedback gathered during the breakout sessions. **Table 1** summarizes stakeholder feedback on the *content* of evidence products—what content is most valuable and what needs improvement. **Table 2** summarizes stakeholder feedback on the *format* of evidence products—what format is most valuable and what needs improvement. **Table 3** summarizes stakeholder feedback on the *source* for information products—where stakeholders look for information products and what makes those sources valuable.

Table 1. Stakeholder feedback on content

Stakeholder Group	Content Most Valuable	Content Needs Improvement
Patients/Consumers	• Personalization of product to patients' cultural backgrounds, literacy levels, stage of disease • Provides balance between benefits, harms, evidence strength (and its importance) • Provides balance between evidence from randomized controlled trials and evidence that is applicable to individual patients' co-morbidities, family histories, etc. • Transparency regarding study funder, study source, study population • Strength of evidence • Research gaps; specifically, what is not known about the study • Culturally competent • Can it translate into policy? Is it actionable and definitive?	• Should provide information that facilitates conversation between the patient and physician and covers patients' current goals and lifestyle activities (make it person-centric, not treatment-centric) • Should encourage open conversations between clinicians and patients to dig into the information before making final treatment decisions; important for physicians to be open to new research • Should be understandable to patients but also be scientifically thorough and accurate • Should have more consideration of personal risks and benefits, which can be difficult with evidence based on large populations • Testimonials: Division within group. Some said PCORI should not use testimonials; others said they could be helpful and if used, should be about more than one patient's story, should be thoughtful, and should not be used as advertisements.
Payers	• Provides actionable results • Takes into account the research context (payer, population studied) • Provides clarity and guidance in comparing discrepant or differing ranges of evidence and results, and contextualizes that for different patients and their individual circumstances • Provides information on how evidence is different from evidence from previous studies	• Need cost analysis information • Need information about extent to which evidence can be generalized and who specifically the results apply to • Need clarity about limitations of study scope and data collected • Need consistency in measures used/format for reporting across studies • Need more studies that connect clinical outcomes to outcomes that are meaningful to employers (e.g., absence from work, disability).
Purchasers	• New information that will change current practice	• Should add financial consequences of different options for cost/quality

Stakeholder Group	Content Most Valuable	Content Needs Improvement
	• Outcomes that are important to employers (e.g., absence from work, productivity) • Focus on where the evidence is conclusive or not so that employers can choose to implement based on demographics of employees • Clear comparisons with options, risks, and outcomes • Cost evidence	• Should add plan design implications. • Should partner with other organizations that can help with next steps either with cost or plan design
Clinicians	• Content that is dynamic, fluid, and transparent • Included outcomes must be important to patients for them to be important to clinicians • Content tailored depending on whether audience needs individual-level or population-level evidence • Personalization of product to patients • Information is easy to explain to patients and healthcare professionals • Appropriate identification of uncertainty • Wide-ranging—not limited to just one field or area • Grading system with common application used by other recognized sources • Areas of clinical uncertainty defined	• Need unbiased synthesis • Should provide adequate background on the context of the evidence • Should translate evidence to the office, home, or care facility • Should include related patient tools • Should describe how to do things that require several steps (e.g. exercise, checking BP) and are actionable • Should consider diversity and complexity of patients today and is culturally competent • Should list all available alternatives even if not addressed by synthesis and clarifies which parts are evidence based • Should address benefits and harms over time • Should consider cost and value
Life Sciences	• Strength of evidence is critical (include data from RCTs as well as other sources, such as observational studies) • Background section includes what is known and highlights research gaps/unmet medical needs • Methodology is consistent so that evidence from systematic reviews can be compared • Methodology accommodates heterogeneity of patients and treatment effects as well as new treatments with limited evidence • Includes patient perspective/patient tolerance for low strength of evidence, especially for diseases with few treatment options	• Need better understanding of individual patient journeys, experiences, and needs for more relevant study outcomes and disease diagnosis • Need for systematic review methods to be consistent to avoid conflicting conclusions • Should focus on longer term outcomes • Should focus on outcomes that matter most to patients • Should prioritize the research gaps that matter most to patients

Table 2. Stakeholder feedback on format

Stakeholder Group	Format Most Valuable	Format Needs Improvement
Patients/Consumers	• Credibility of source • Clear where patients can go to get additional information • Patient testimonials with balanced perspective on research, used for education and advocacy • Behind the testimonial, opportunity to dig deeper • Structured as shared decision-making tools—but need to be equally relevant to clinicians and patients • Social media as carefully used dissemination tool; must separate evidence-based social media presentations from those that are not evidence based • Graphic displays that are understandable, fit the evidence to one page • Parameters specified for all elements of the data (e.g., study dates, sources of data, populations included)	• Should use clear graphics • Should use plain language; ensure products are understandable for consumers • Need star ratings for strength of evidence; need to streamline across organizations • Personalization: should ensure products are relevant and important to individual patients, their medical histories, medical co-morbidities, etc. • Within context of Precision Medicine Initiative, evidence products must be balanced to needs of individuals for decision making as well as needs for population-based decision making (e.g., similar to FDA initiative, inclusion of race/ethnicity data). If PCORI could supplement evidence with other sources of clinical data, it could go a long way toward precision medicine. • Should ensure presentation of evidence is relevant to a patient's needs for information about what is coming next for them
Payers	• Use of visual charts, graphics, tables • Clear up front statement (1–3 sentences) summarizing study question, conclusions, and relevance: *"Why should I care about this?"*	• Should move away from long, dense narratives • Need evidence that can be quickly absorbed • Should create consistent standards and scales of evidence • Should present the evidence with clear information about tradeoffs and without value judgments and let users decide (e.g., *"Do you prefer a car that is cheap or a car that has good gas mileage?")*

Stakeholder Group	Format Most Valuable	Format Needs Improvement
Purchasers	• Includes key bullets up front (e.g., what's the issue, why should we care, what we can do about it) • Short, simple, easy to understand • Research findings in plain language • Video vignettes of 90 seconds or less	• Should not be too clinical; just need key information and will read more if interested • Should not be 300 pages with a statement that evidence is inconclusive at the end
Clinicians	• Concise, clear, flows in logical format • Displayed so physician can share with patients; printable • Uses diagrams and other pictorials • Links to additional detail	• Should be accessible to both patients and providers in multiple formats that are searchable and drillable (e.g., app; website; integrated with electronic health record [EHR]) • Need a single source of information for evidence-based recommendations that includes recommendations from various sources (USPSTF, professional societies) and why recommendations may not be consistent
Life Sciences	• Uses evidence tables (include data from subgroups; electronic format so users can analyze data) • Contains short executive summary with key findings; all data in appendices • Supports population level decision making while recognizing individual differences and preferences (will require tools customized for users)	• Tools should fit into clinical workflow: should be placed into EHRs to aid in clinical decision making • Need to avoid oversimplification (unintended consequence is misinterpretation of the evidence) • Should tailor evidence products to different stakeholders

Table 3. Stakeholder feedback on source for information product

Stakeholder Group	Source for Information Product	Why Valuable
Patients/Consumers	• In the past, second opinions from physicians • YouTube videos—utilize this platform to put up content that is valuable and credible • Professional organizations • Governmental organizations: AHRQ, NIH, PCORI • Peer-reviewed literature • Patients also access direct consumer advertising, peers support programs (potentially different than evidence-based recommendations)	• Accessible, understandable, concise, and culturally competent • Credible and up-to-date with the latest information • Includes decision support for both patients and clinicians, such as a portal solution that directs patients toward jargon-free information and clinicians toward clinical information • Ensures the data is complete, with information about demographics and subgroups—*"How relevant is it to patients like me?"* • Data source and funder is transparent; and is a trusted person, organization, or group that physicians trust as well
Payers	• Peer-reviewed literature • Professional organizations • Cochrane reviews • Governmental organizations: NIH, CDC, AHRQ • Other employers: if another large employer implements program, tracks transparency, achieves good outcomes, then others follow	• Results from expert consensus • Provides an objective analysis • Results from rigorous research
Purchasers	• Consumer Reports/Choosing Wisely • National associations • Governmental organizations: AHRQ, PCORI	• From trusted independent sources • Relevant to employer population • Presents new information
Clinicians	• Professional associations • PubMed, Cochrane, AHRQ • USPSTF	• Provides unbiased synthesis • Provides executive summaries with links to more detail • Free to end user, easy to access • Includes patient-facing content

Stakeholder Group	Source for Information Product	Why Valuable
Life Sciences	• Peer-reviewed literature (e.g., Cochrane) • Independent, credible data sources • Inclusion of manufacturer-sponsored studies to add to body of evidence • Industry often sponsors its own systematic reviews because it finds current reviews lacking	• Results from crowdsourcing (e.g., PatientsLikeMe) • Expands access by being open source (small companies may not have access to all published sources)

Afternoon Plenary Session

A representative from each stakeholder group presented the topline conclusions from their breakout sessions as part of a panel discussion. The session was moderated by Kristin Carman from American Institutes for Research® (AIR). After each stakeholder representative presented their conclusions, Ms. Carman asked the group a series of questions concerning similarities and differences across the groups and emphasized areas of improvement that PCORI is uniquely qualified to address. The following themes represent areas of importance for all stakeholders; however, each content area will vary significantly in the strategic and tactical implementation of solutions for different decision makers.

Cross-Cutting Themes Across Stakeholder Groups

Recurrent themes emerged from the stakeholder presentations and panel discussion related to the content, format, and sources of evidence they would need to inform their decision making. Taking into account that stakeholder groups are not monolithic in their information needs, areas of common focus for workshop participants included the importance of the strength of the evidence in evidence products, the need for tailoring of evidence products, the importance of placing evidence into context, the need for ensuring transparency and trustworthiness of both sources of evidence and methods for synthesis, and the desire to emphasize "bottom line" conclusions from the review.

Content: The "What" of Information Products

Stakeholders considered the various content-related elements of information products, agreeing on some and debating others (see table 1). However, across all stakeholders, two recurrent ideas permeated their feedback: strength of evidence, and the importance of including the context for findings in information products.

Strength of Evidence

Understanding the strength and direction of the evidence is important to all stakeholders. A majority of stakeholder groups suggested that it is helpful to have translational products that clearly spell out what is known and unknown about the body of research, the results of the research, and their limitations. Stakeholders agreed that instead of focusing on the merits of one study methodology over another (*"my evidence is better than your evidence"),* information products should clearly state the study or systematic review's tradeoffs and accompanying uncertainties. Some panelists stated that it was important to consider a broader range of studies than randomized controlled trials, such as observational studies. There was recognition across stakeholder groups that the methods for synthesizing evidence were not standardized and sometimes lead to conflicting conclusions.

> *"Lack of evidence is not a statement about whether it could or should be done, so it's important to communicate that just because there's insufficient evidence, that does not mean lack of effectiveness, but just means that we don't know or can't document in the way of how we typically do these things whether there is an effectiveness."*
>
> – Consumer

Many stakeholders suggested that summary information about the strength of evidence be provided up front in information products; for example, if the strength of the evidence is weak, then payer stakeholders would like to know that before having to read to the end of the product. Patient stakeholders

suggested that strength of evidence scales be standardized across reviews and explained for ease of comprehension. One panelist referenced the existing US Preventive Services Task Force (USPSTF) evidence grading system as a potential model while another suggested the development of a "star" rating system that would be used to indicate the overall quality of the evidence.

Most stakeholders recognize that patients and other consumers access direct-to-consumer advertising and patient testimonials as sources of information. However, some patient representatives in particular actively discouraged use of these sources in evidence products. The concern was the lack of balance that could be attributed to evidence communicated in testimonials versus the more labor-intensive process of generating robust evidence syntheses. Testimonials might have an appropriate role in the dissemination of practice guidelines. However, stakeholders emphasized that it is important to continue to brainstorm how to evolve research methodologies and processes so that systematic reviews and clinical guidelines stay ahead of clinical practice, the media, and testimonials.

Discussions of the strength of the evidence were often difficult to disentangle from comments about how the evidence should be generated in the first place (i.e., how studies or systematic reviews should ideally be conducted). For example, although randomized controlled trials are typically preferred in the hierarchy of evidence, there was a discussion about whether there should be different levels of evidence for different conditions; for example, a rare disease without any known treatment is a situation where a lower level of evidence may be appropriate. Panelists representing patients, industry, and clinicians suggested the need for evidence from other types of studies that advance personalized medicine, using both phenotypic and biomarker data to individualize care. These stakeholders wanted evidence that accounts for the heterogeneity of both patient experience and treatment effects and is relevant and important to individual patients and their caregivers.

Purchasers expressed their interests in broadening the current clinical focus of information products to include outcomes that matter to employers—absenteeism, workplace productivity, and healthcare costs. Payers, purchasers, clinicians, and industry stakeholders all indicated an interest in obtaining information about the costs and cost offsets associated with use of a particular intervention. A patient advocate remarked that groups had specifically lobbied Congress to mandate constraints on the types of data PCORI could include in research and wanted comparative effectiveness research to focus on clinical data exclusively.

Context for Decisions and Evidence

Participants emphasized the importance of presenting the specific context of the review in order to facilitate their understanding of the findings—the conditions and details of the study populations and methods are critical framing contexts for determining the relevance of the review to different stakeholder groups. For example, purchasers may be trying to make a business decision about where to invest in health care, a payer may be trying to make a regional coverage decision, and a clinician and patient may be trying to make a shared decision about a particular medical therapy in the context of an individual's particular clinical and personal circumstances. In each case, the context drives (or at least significantly influences) both the content and

> *"What is really needed is the relevant information at that point in time applicable to that decision, whether you are a payer making medical policy or a patient making clinical decisions or a consumer deciding what benefit you are going to sign up for."*
>
> – Payer

format of the optimal information product. Panelists also emphasized the importance of presenting research findings within the context of other results from the same area of research and discussing how the findings advance or change current comparative effectiveness conclusions.

Every stakeholder group agreed it would be helpful to have translational information products that provide timely information. A major limitation of current systematic reviews is that the evidence is not available at the time a decision needs to be made or the results are not updated when new information becomes available. For example, payers suggested it would be helpful to have a resource that connected various payer organizations' medical policies and guidelines to relevant research syntheses. Similarly, patient stakeholders may want an evidence product relevant to whatever clinical decision they may be making at a certain point in time. Both the life sciences and patient stakeholder groups stated the importance of including patients' medical *and* nonmedical end goals in clinician-patient conversations regarding medical treatment and providing culturally competent tools to facilitate the use of evidence in these conversations.

Format: The "How" of Information Products

Given the volume and complexity of information included in most evidence reviews, one of the format-related themes that all stakeholder groups emphasized was the importance of including the "bottom line," *not* at the bottom of information products, but at the top. Another theme was that all stakeholders want to see information that is both relevant and tailored to their specific constituencies, which may have overlapping implications for the content of evidence reviews. For example, the ability to provide information about specific patient subgroups may require different types of studies as well as novel approaches to formatting (See table 2 for more detailed recommendations).

The "Bottom Line" Conclusions

All stakeholders alluded to the problem of information overload, and most stakeholders agreed that they preferred to see bullet points or other summary statements describing key findings at the front of evidence documents. Stakeholders also suggested including a brief, up front statement that clearly states what the study was about, who it is intended to impact and how, and why they should pay attention to or care about a particular study or systematic review. Stakeholders indicated that it is also important to know about negative findings; if a particular treatment or intervention has been shown not to be helpful to patients, then that is a very important finding to communicate.

Stakeholders also stated that it would be helpful to understand whether the evidence is reporting new findings and whether it could change current practice. Purchasers, for example, care whether the results will be something they can immediately implement and whether the evidence will connect clinical outcomes to nonmedical outcomes such as whether people come to work and perform at work. Payers and clinicians care about whether the evidence produced actionable results.

> *"Don't talk to me for half an hour and tell me the program isn't working. I have an alert I'm working on—what's the issue, why should you care, what should you do. You can dive into it, but the critical issues come first."* – Purchaser

Tailoring Information Products

Participants agreed that stakeholders use data differently in their decision-making processes, depending on the types of decisions that must be made (e.g., administrators making policy decisions, professional organizations creating clinical practice guidelines or clinicians treating patients). There may be markedly different decisions even within any one stakeholder group. For example, clinicians have widely varying information needs because their practice setting is evolving, their patient base is increasingly diverse, and they must customize their professional recommendations to individual patient needs and expectations. To illustrate this point, the physician panelist shared her perspective that the information needs of a family physician in regards to a particular cancer will clearly be different from the needs of an oncologist. However, both physicians should be able to go to the same place to obtain the information they need, and it should be consistent. What is required is the ability to "drill down" on the information and obtain the information in whatever format is most accessible and useful to both the patient and the physician. Most stakeholders recommended that information products report results in multiple formats, tailored to the outcomes most relevant to their interests. Access to raw data in a searchable format is critical for several groups such as clinicians, payers, and the industry as they anticipate conducting their own analyses. It is important to link the evidence to actions that are clear, feasible, and presented in a culturally competent manner. Payers, patients, and clinicians all agreed that the evidence must be relevant and important to individual patients in their particular circumstances for it to be helpful to them.

> *"The content must be tailored to provide information at a high level for the population as a whole while enabling drill down to the details of the individual clinician or patient. It is a big broad thing to ask for but if we were being idealistic, that is what we would like to have."*
>
> – Clinician

Although many stakeholders expressed interest in customized information products, they agreed that information products tailored to different stakeholder groups may look different but should encourage rather than obstruct conversations between different stakeholders, and suggested it is most important to have information products featuring strong, credible, and transparent evidence that facilitates shared decision making.

Sources of Information Products

All stakeholders mentioned traditional sources of evidence reviews such as peer-reviewed literature as well as professional and governmental organizations that conduct systematic reviews. Other sources tended to vary by stakeholder type and included online sources such as YouTube videos as well as manufacturer-sponsored studies (see table 3). However, regardless of which sources stakeholders utilized for information, all were emphatic that the evidence provided must be *transparent* and *trustworthy*.

> *"Transparency is not just about sharing the data but it is also about where it came from/how it came to be so that you can really know whether it applies and have cultural relevance to the group you are working with today. What you study might be relevant today but might not be relevant tomorrow."*
>
> – Clinician

Transparency and Trustworthiness of Evidence

To promote trust, stakeholders emphasized the importance of ensuring transparency regarding how studies and systematic reviews are funded and the quality of both evidence and methods used to

develop the reviews. Stakeholders tend to evaluate studies based on whether they are peer reviewed and whether the reviews were conducted by a reputable agency or organization that uses unbiased methods. All stakeholder groups agreed that it is important that evidence products be transparent in their sources of information and utilize trustworthy sources for that information. Examples of trusted sources of systematic review information include the Agency for Healthcare Research and Quality (AHRQ), USPSTF, and the Choosing Wisely Campaign. Patient stakeholders especially emphasized that it was important to be able to trust the source of information and to know their physicians trusted the source of information.

Opportunities

There were a few suggestions for what PCORI might be uniquely positioned to do moving forward. Some of these included:

- Form strategic partnerships with multiple organizations (e.g., Choosing Wisely, AHRQ) to compile evidence from multiple sources into a uniform format that enables easy comparison of treatment options or other interventions.
- Convene stakeholders to develop common approaches to conducting systematic reviews. Currently, different groups analyze the same evidence and come to different conclusions—this causes confusion among decision makers and wastes resources.
- Use patient-powered research networks to develop an understanding of endpoints and diagnosis of disease in a manner that is more meaningful to patients. This is missing from the literature and could influence study design.
- Support the development of tools to inform application of evidence syntheses from both a patient-centered and a population-centered approach in order to help decision makers understand the trade-offs.
- Develop a standardized “star” rating system that provides an agreed-upon evaluation of quality of evidence.
- Lead the development of methods to tailor the translation and dissemination of evidence for various stakeholder groups.

The meeting ended with concluding remarks by PCORI’s Chief Engagement and Dissemination Officer, Ms. Slutsky and PCORI’s Executive Director, Dr. Selby who emphasized similar themes from the meeting. Meeting attendees were reminded that this was just the beginning of PCORI’s discussions regarding evidence synthesis, and they were encouraged to remain engaged and to continue to provide ideas.