Email introduction:

Dear _____,

I am part of a Learning Collaborative co-sponsored by the National Academy for State Health Policy (NASHP) and the Patient Centered Outcomes Research Institute (PCORI). We are reaching out to invite you to participate in two activities.

The first activity is a brief survey. We are interested in talking with you for about an hour in early May to learn about formal and informal ways that your agency may already use Clinical Effectiveness Research (CER)/Patient Centered Outcomes Research (PCOR). The second activity is a half-day workshop this summer where experts in CER/PCOR will provide us with technical assistance on topics identified through our survey.

Learning collaborative members in Massachusetts are from the Department of Public Health, Department of Mental Health, the Executive Office of Elder Affairs, and UMass Medical School. The goal of the Collaborative is to assess two areas: (1) how Massachusetts state agencies use CER/PCOR; and (2) how state agencies seek input from consumer, families and advocacy groups to participate in health policy decisions.

Would you let me know if you or someone from your organization would be interested in a brief conversation in early May and the workshop this summer?

Thank you, in advance, for your consideration.

Sincerely,
INTRODUCTION

We are participating in a learning collaborative co-sponsored by the National Academy for State Health Policy (NASHP) and the Patient Centered Outcomes Research Institute (PCORI).

The goal is to assess how state agencies utilize Clinical Effectiveness Research (CER)/Patient Centered Outcomes Research (PCOR) to inform health policy and how state agencies seek input from consumer, families and advocacy groups to participate in the review of CER/PCOR and to inform health policy.

Clinical Effectiveness Research (CER) refers to research designed to compare the effectiveness of different interventions, examining the risks and benefits of several treatment interventions, supporting consistent and rational decision making, and improving the delivery of care.\(^1\)

Patient-Centered Outcomes Research (PCOR) refers to research that assesses the benefits and harms of different interventions while also including an individual’s preferences and needs, focusing on those outcomes of most value to the patient.\(^2\)

We are interested in formal and informal ways that state agencies use CER/PCOR.

For the purposes of this survey, we are limiting our definition of stakeholders as including: consumers, family members, advocacy groups receiving services from state agencies.

SURVEY QUESTIONS

Stakeholder involvement

1. What formal structures exist for soliciting input from stakeholders in determining policy and programming? Such as the following:
   a. Health Planning Council?
   b. Consumer Advisory Councils?
   c. IRB?
   d. Other, please specify

2. If a stakeholder or advisory group exists,
   a. is there formal or informal authorization (statute or regulation)
   b. what is its scope and function and
   c. how do decisions of this group influence the decision-making process?
   d. Do decisions apply state-wide, locally, regionally or other?


\(^2\)www.pcori.org/research-results/research-we-support
3. How is stakeholder input shared with delivery system staff?

4. What other avenues are available to stakeholders for involvement in affecting agency culture, priorities, and initiatives?

5. What examples are there of stakeholder involvement in research and policymaking?

For each group we’ve discussed so far, here are some follow up questions:

6. What is the composition of the group? How is diversity of constituency and perspective ensured?
   a. What agencies are part of this?
   b. What advocacy groups?

7. How are people recruited
8. What, if any, are the regulations that govern this?

9. What is the on-boarding process for new members?

10. How often does this group meet?

11. Are consumer stakeholders compensated for their participation or other costs, e.g. transportation?

12. Are accommodations such as interpreters, large print documents, and call-in options inquired about and offered?

13. Are there opportunities for training on topics relevant to the group? On CER/PCOR?

14. What are some initiatives the group has been part of?

15. What roles do consumers play in this group? Leadership? Co-facilitators?

16. What resources do you have to support consumer engagement?

17. How do you manage lead-time to engage consumers meaningfully?

18. How do you cultivate relationships to engage/sustain involvement of consumers?
Evidence-based Practices (EBP)

Evidence-based Practice refers to integrating individual clinical expertise with the best available external clinical evidence from systematic research.³

1. Are there examples of EBPs that you use or promote in providing services? What are the ways that you utilize EBPs?

2. What led to the decision to utilize those EBPs (e.g., grants, lawsuits, legislation)?

3. How did you select those EBPs?

4. Do you have the resources to utilize CER/PCOR to help you in your decision making?
   a. Access to library and research resources?
   b. Time to conduct literature reviews?
   c. Data infrastructure including an evaluation plan?
   d. System for collecting feedback?

5. What is your process for assessing fidelity to EBPs in an ongoing way?

6. What data is available to you to assess EBP efficacy?

7. How will you utilize data to engage consumers in evaluating efficacy of chosen EBPs? Is there a process for sharing the data with the governing board?

8. How does your IRB operate?

9. Do you evaluate how inclusive (how did it feel to them) the role of stakeholders in formulating research questions/plans? If so, how?

10. Can you give an example of when input of stakeholders changed the direction of the initiative?

In closing,

11. Is there anyone else we should talk to about things going on in your agency?

12. The workshop can cover a few topics – we would like to include what you are most interested in. Do you have a preference for a topic? Are any/all of the following seem responsive to your areas of interest? (If not, what would you like to learn more about?)⁴

³ http://guides.mclibrary.duke.edu/c.php?g=158201&p=1036021
⁴ Examples from attachments to Jennifer Reck’s Feb 12 email to us for Feb. 16 MA Team Call
1. What is evidence-informed health policy?

2. Organizational self-assessment - Applying evidence to policy decisions: Where are you? What do you need next?

3. Defining questions so research can help: “Why don’t those academics ever do a study that helps answer my question?”


5. Grading evidence: Is all evidence created equal? (Evidence hierarchy, study designs, and grading the evidence)
   - Randomized controlled trial (RCT) example "When can a study be trusted?"
   - Systematic Review example: "How can I make sense of all those studies?"

6. Moving from evidence to policy by integrating:
   - Quality of Evidence
   - Balance between benefits and harms
   - Values, preferences, politics
   - Resource allocation (costs)

7. What to do with insufficient evidence: Assessing observational and evaluation studies: "How do I know if my new program worked?"

8. Implementation: Applying evidence to policy decisions