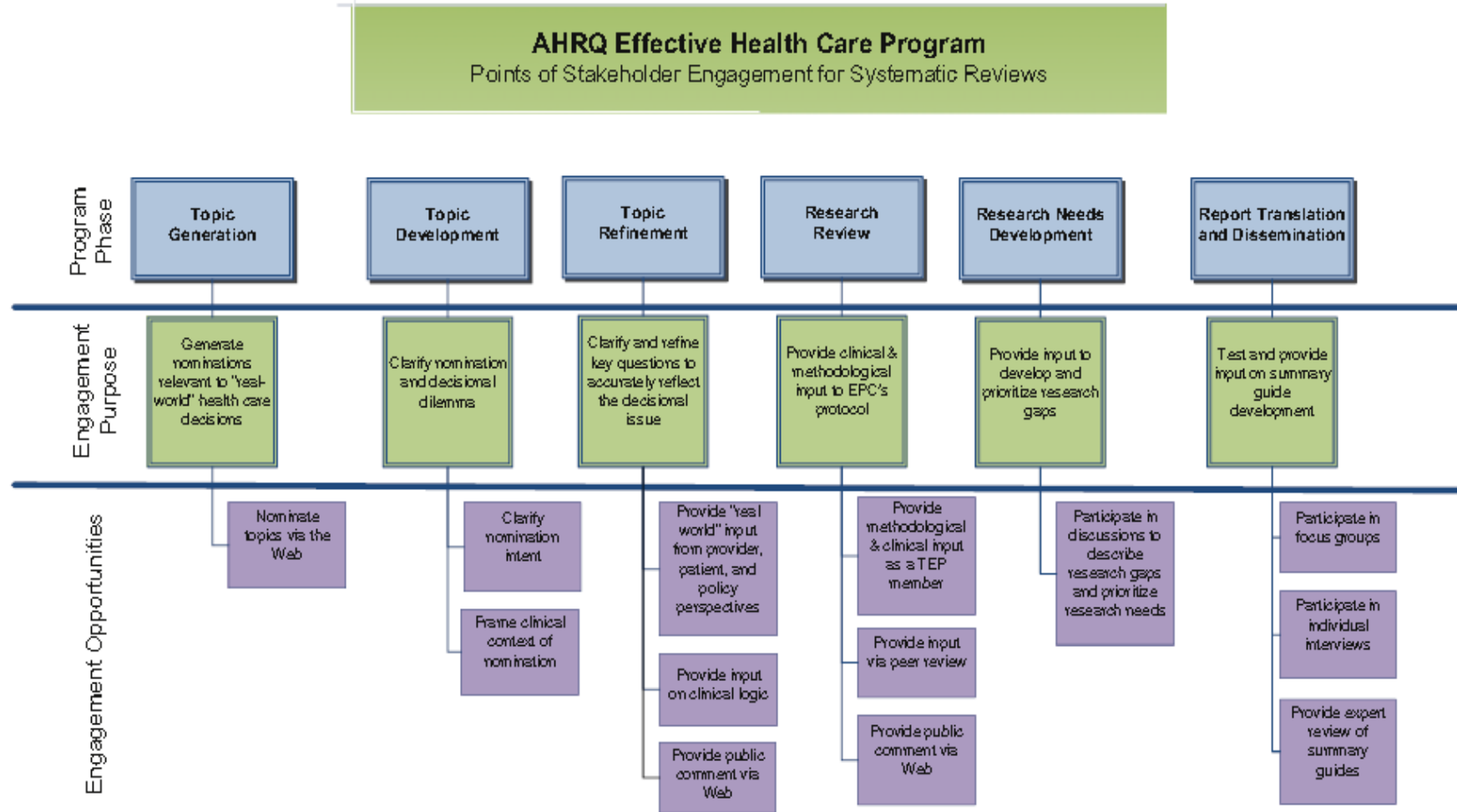


Are we doing enough to  
disseminate if we don't engage  
in the hard questions?

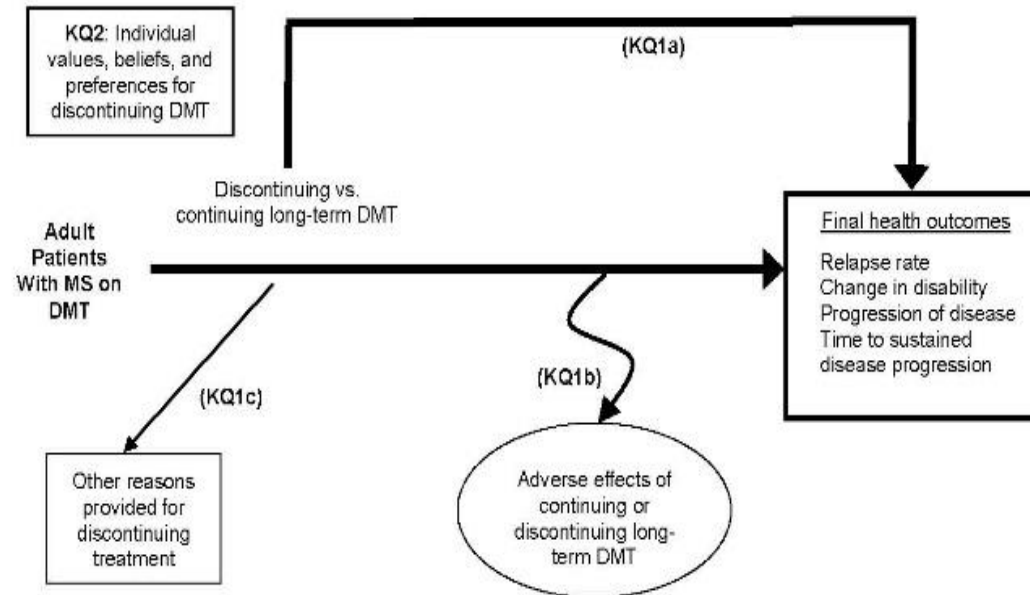
Mary Butler  
University of Minnesota

# AHRQ Evidence-based Practice Program Process

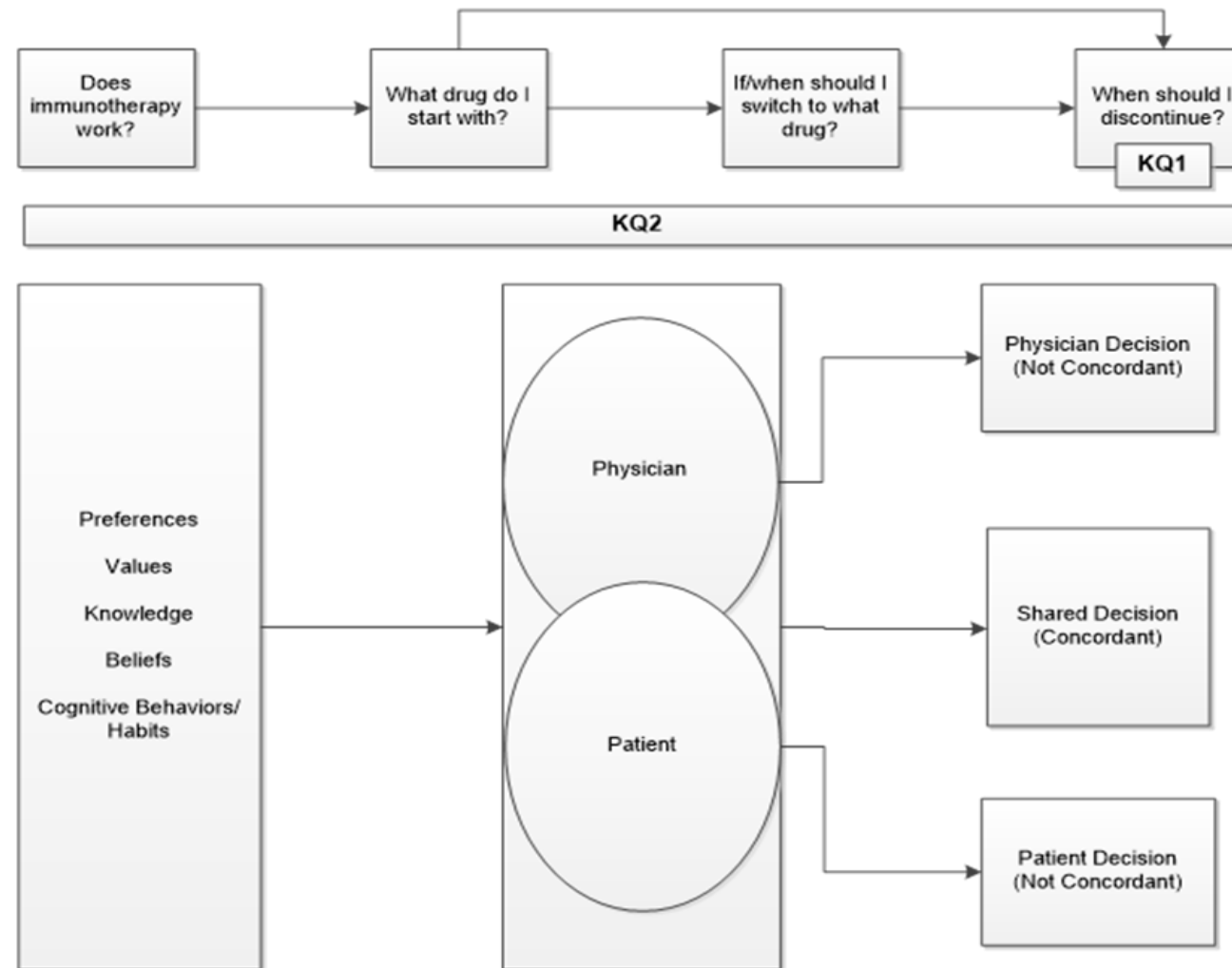


# Decisional Dilemmas in Discontinuing Prolonged Disease-Modifying Treatment for MS

## Analytic Framework for KQ1



# Logic model for KQ2



# Key Informants

- 3 Neurologists
- 1 Physical therapist
- 1 MS specialist RN
- 1 Patient
- 4 Researcher
- 2 Funder
- 1 Neurology association
- 1 MS Clinics consortium
- 1 MS patient advocacy group

# Peer Review / Public Comments

- **Bottom-line Finding:** essentially nothing to support decisions regarding discontinuing drug treatment
- Organized letter writing campaign to AHRQ to not release the report
- Full report – 51 pages
- Responses to each individual peer and public comment – 89 pages (and only because of consolidation)

# My personal favorites

- Drug companies strongly disagreed that treatment might not be life-long.
- “Please provide the list of authorsstudents[sic] of this draft. I would like to see if anyone above an 8th grade reading level contributed to this draft.”
- “We think that everyone might benefit if the most radical protagonists of evidence based medicine organised and participated in a double blind randomised placebo controlled crossover trial of the parachute.”
- “This draft should go no further should not be amended should not be published. The entire premise is false.”

# Epilogue to Report – 2 years later

RCT enrolling select relapsing-remitting MS older patients to test effects of discontinuing disease modifying treatment. PCORI Funded Research (\$6.7 M)

“We know little about when, if ever, to consider discontinuing DMTs for a trial period. A few studies suggest older patients with no recent new inflammation may discontinue DMT and not suffer return of new relapses or brain MRI lesions. **The possibility of discontinuation of MS DMTs has been the focus of a recent Agency for Healthcare Research and Quality comparative effectiveness review (No. 150). The main conclusion from this evaluation is, “MS patients and providers have little information to guide decisions to discontinue DMT.”**”



## 2 Types of Hard Questions

- Questions that examine stopping (vs not starting) are much less commonly asked.
  - Pushback can be intense
- How do we engage in the difficult conversations about the fears that underlie the responses?
  - What are appropriate venues?
  - What skill sets are needed?

Choosing Wisely – good resources and good work

The challenge:

Responding to emotional issues with reason and facts often doesn't work well.  
The on-going US political turmoil is an excellent example.

# Idea Sources

- On Being Certain: Believing You Are Right Even When You're Not (Robert Burton)
  - Neuroscience of ontology
  - "Knowing" is a mental sensation
- Mistakes Were Made (But Not By Me): Why We Justify Foolish Beliefs (Carol Travis & Elliot Aronson)
  - Social Psychology
  - Cognitive dissonance and defensive cognitive processes to maintain self-identity

- The Challenge of False Beliefs: Understanding and countering misperceptions in politics and health care (Brendan Nyhan)
  - Open research questions
    - What role does anxiety play in acceptance of corrective information
    - Can affirming people's self-worth make them more open-minded

Other Ideas?