

The Value of Model Systems Research in the Policy-Making Process

Researchers are the most qualified and trusted spokespersons for science. You do not need to be a veteran researcher or policy guru to inform policy makers on the state of the science or your work. What you need is a willingness to spend time building relationships with policy makers and an understanding of how your research can inform policy to improve care for patients. Unfortunately, science reports cannot speak for themselves, and scientific writing is too often misinterpreted or misrepresented by the media and the general public. Researchers can make the link between data and policy making concrete ([Keune & Hall, 2013](#)). Strong rehabilitation policy requires the active engagement of researchers like you to help ensure that policy makers understand the science and that they use the research to make good rehabilitation-related policy decisions (see Figure 1).

Figure 1. Health Policy and Policy Makers

Health Policy



Health policy (as defined by the World Health Organization, or WHO) refers to decisions, plans, and actions undertaken to achieve specific health care goals within a society. For the government (whether federal, state, or local), the central purpose of health policy is to enhance health or facilitate its pursuit.

Policy Makers



Policy makers generally means individuals elected or appointed to office at some level of government, as well as chiefs of staff and other staff who play a major role in the policy process. Policy makers need information about health care costs, patient outcomes, and clinical effectiveness to make good policy decisions in a challenging fiscal and political climate.

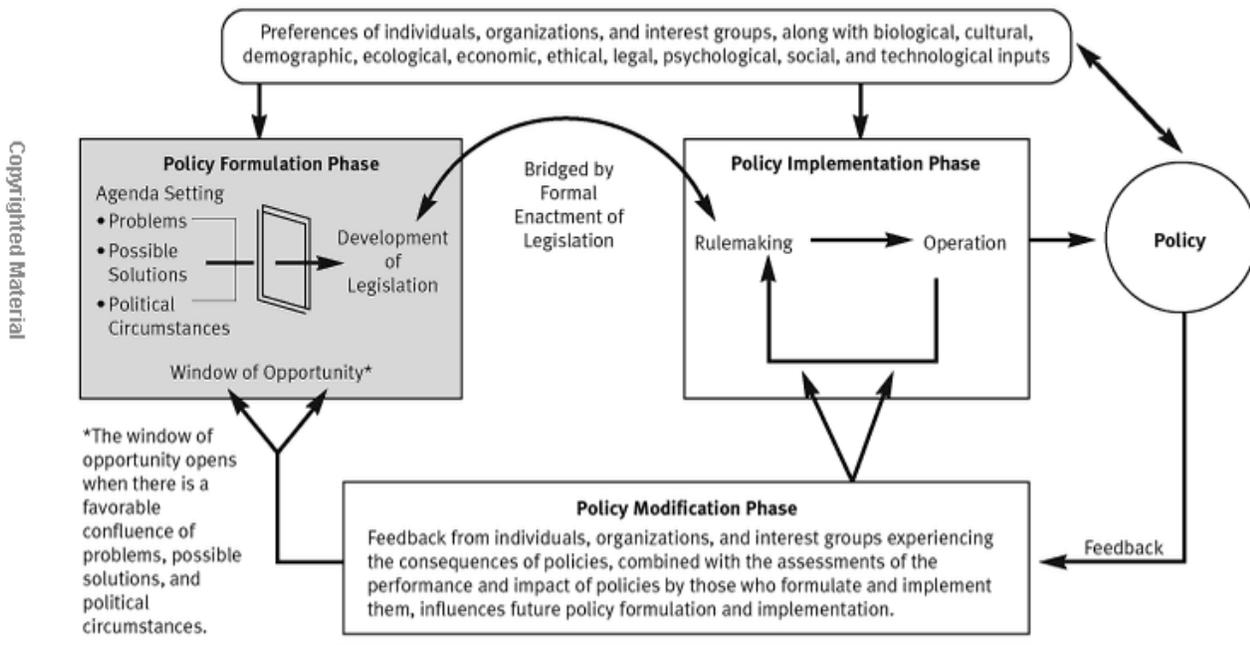
Policy Making and Knowledge Translation

Researchers play a critical role in the interchange between data and policy, but researchers also need to be aware of policy makers' concerns and the windows of opportunity to change policy ([Brownson, Royer, Ewing, & McBride, 2006](#)). Interactions between researchers and knowledge users (e.g., policy makers) are part of a dynamic and iterative process that the Canadian Institutes of Health Research calls *knowledge translation* ([CIHR, 2015](#)). A major goal of knowledge translation is to increase the likelihood that research evidence will be used in policy and practice decisions. Ideally, the development, implementation, and evaluation of public policies should be viewed as a shared responsibility among researchers, elected officials, advocates, and citizens ([Brownson et al., 2006](#)).

The Policy-Making Process

The policy-making process is a continuous cycle with three phases in which all decisions are subject to change (see [Figure 2](#)). Rehabilitation policies can take the form of laws, rules or regulations, operational decisions, or judicial decisions. By becoming familiar with the policy-making process, you can determine when and where to engage with policy makers.

Figure 2: A Model of the Public Policy-Making Process in the United States



Original source: Longest, Jr., B. B. (2010). *Health policymaking in the United States* (5th ed.). Segal. Printed with permission of the author.

Phase 1, policy formulation, involves agenda setting and the development of legislation. This phase results in new public laws or changes to existing laws. Not every problem that receives policy maker attention will necessarily result in the development of legislation. Model Systems researchers may engage policy makers in this phase to ensure that policy is supported by current science. In the absence of researcher involvement at this stage, policy makers are more likely to rely on vested interests (e.g., industry advocacy groups) or nonscientists for information.

Phase 2, policy implementation, involves rulemaking and operational decisions that come after the passage of new legislation. Rulemaking establishes formal regulations (in this context, *regulations* is used interchangeably with *rules*) and is necessary to carry out the intent of public laws. At the national level, proposed rules are published in the *Federal Register*, and interested parties—including Model Systems researchers—can submit comments before the regulations are finalized. The operation stage involves the actual running of the programs created by new legislation. Usually, appointees and civil servants are responsible for operational activities.

Phase 3, policy modification, occurs when the consequences of existing policies result in further policy making. Even policy decisions that are correct when made must adjust to accommodate changing circumstances. As the feedback loop in the model shows, policy modification can occur anywhere in the process. Individuals, organizations, or interest groups who benefit from a policy may seek modifications that increase or maintain these benefits over time. The flip side is also true: Those who are negatively affected will seek to minimize these effects. Model Systems researchers may reach out to policy makers to provide research that supports legislation or that indicates that changes are needed for legislation.

Tips To Engage With Policy Makers

One of the most important facilitators of moving research into policy is personal contact between researchers and policy makers (Innvaer, Vist, Trommald, & Oxman, 2002). Model Systems researchers must be prepared to invest the time and resources needed to reach their goal. Follow the tips below to establish and maintain your relationships with policy makers.

Tips for Getting Started

- TIP!** Educate yourself and others about the policy-making process. Resources provided in this document will help you think about the process that policy makers go through to create or modify policy.
- TIP!** Stay up to date on issues concerning your area of research or affecting your professional identity. One option is to join a professional organization and participate in any policy-oriented committees. For example, American Congress of Rehabilitation Medicine (ACRM) has a Policy & Legislation Committee. Pay attention to these action alerts!
- TIP!** Prepare your “elevator speech”: who you are, what you do, and why your listener should care. Also prepare three sentences explaining how your research can save money and saves or improves lives. Your elevator speech should provide enough information about you to grab your listener’s attention, and your three sentences will be handy when you respond to additional questions about your research.
- TIP!** Use the media to build community support. For example, you could write a letter to the editor of your local newspaper that cites your research and informs a policy issue. Also, introduce your community to research by giving tours, mentoring students, or giving talks at various community events.

Tips to Engage

- TIP!** Learn about your members of Congress and members from key health committees and subcommittees and find out where they stand on the issues you care about. Build on a policy maker’s known interest areas on the basis of his or her personal history or circumstances. Also, your credibility must remain politically neutral because you will need to work with members of both political parties.
- TIP!** Meet with a member of Congress or his or her staff and ask for something tangible: Sign on to introduced legislation, add his or her name to a congressional sign-on letter, support funding for a particular program, or even sponsor new legislation. In this way, you not only build relationships with specific policy makers, you also begin to build champions of health research in Congress.
- TIP!** Make yourself available: Volunteer to become a science advisor to your policy maker or candidate. Over time, your credibility as a reliable, accessible resource will add value to your relationships. Policy makers often need information quickly, so be that go-to person for the policy staff.

Tips to Convey Your Message

- TIP!** First, frame the health policy question: What is the problem and what is the solution? Then, identify the Model Systems’ research and other research that support that solution. Remember to be clear and careful about sharing evidence-based information in an objective manner. That is, show the research but do not overstate the evidence.
- TIP!** Translate research into policy, preferably in a brief, jargon-free format, to aid policy makers. Prepare succinct and compelling materials (e.g., fact sheets, policy briefs, and talking points). Keep this information up to date and within easy reach of your audience.
- TIP!** Include personal stories about patients whenever possible; these stories are qualitative in nature, but they give policy makers a personal connection to the consumer and help them to understand the impact of the policy they are considering. You can ask patients for permission to share their stories with legislators or encourage them to do so personally.
- TIP!** Borrow Research!America’s [Then, Now, Imagine](#) messaging framework: When explaining your research, remind people of the state of a condition or disease years ago (then), how research has improved the situation (now), and what further research might bring in the future (imagine). Example: HIV was once a death sentence; now it is a manageable chronic disease—imagine if we discovered a vaccine.

Tips to Overcome Barriers to Engagement

- TIP!** Be prepared for barriers that may include lack of interest, competing policy priorities, and budget constraints. Be aware that some policy proposals may be politically unfeasible.

TIP! Research your audience and offer tailored resources, including data, outcome measures, and your expertise. If a policy maker asks a question and you do not immediately have an answer, saying “I don’t know” is fine. Tell the policy maker that you will look into it and email or call back.

TIP! Be patient and persistent as you network and build relationships with policy makers.

Recommended Resources

Congress

Acquaint yourself with roles of the congressional staff: <http://www.congressfoundation.org/component/content/article/85/136-job-descriptions-house-office-sample>

Congressional candidates’ positions on medical research: http://askyourcandidates.org/results_state.php
Engaging Policymakers: A Self-Paced Course—Contact MSKTC@air.org to access this free resource:
<http://airlearning.org/course/view.php?id=61>

Meaningful civic engagement between citizens and Congress: <http://www.congressfoundation.org/citizen-engagement/partnership-more-perfect-union>

Meeting with a member of Congress regarding how-to’s (Porter’s Principles):

<http://www.researchamerica.org/uploads/PortersPrinciplesAdvocacyMessagesFINAL.pdf>

This webinar will help you craft an elevator speech and more: [*Communicating Your Science to the Non-Expert*](#).

Federal Budget

This link provides an 11-page overview about the federal budget: *A Citizen’s Guide to the Federal Budget*.

<http://olc.region10.org/21/wp-content/uploads/2013/06/Handout-1-Understanding-the-Federal-Budget.pdf>

Knowledge Translation

Healthcare Policy, a Canadian journal for health services and policy researchers, is a key knowledge translation vehicle to stimulate communication and cross-fertilization between researchers and health care decision makers:

<http://www.longwoods.com/publications/healthcare-policy>

Public Policy

A Public Policy Primer: How to Get Off the Sidelines and Into the Game (David C. Hollister):

<http://files.eric.ed.gov/fulltext/ED510117.pdf>

Rulemaking Process

This link provides an 11-page overview of the rulemaking process: *A Guide to the Rulemaking Process*.

https://www.federalregister.gov/uploads/2011/01/the_rulemaking_process.pdf

State Health Policy

To learn more about state health policy, go to the Kaiser Family Foundation website: <http://kff.org/statedata/>

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