



# How does the public want to be involved in healthcare and health research policy?

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# Rise of public engagement

- Many purposes
  - Fit for purpose → Recognize rights
- Many 'publics'
  - Patients → Providers → Lay publics
- Many degrees of engagement
  - Inform → Consult → Partner → Control
- Many domains
  - Health research (health services, medical)
  - Health care (health technology assessment, health care programs)

# Public opinion on public involvement

- **Public:** those who have not gone through training or socialization into a particular medical profession (e.g., medicine or nursing) and are assumed to have “ordinary” norms and values of society (Hogg & Williamson, 2001)
- In general, lay public expresses interest in being involved in decision making around health care (Wiseman et al., 2003; Bowling et al., 1993; Richardson et al., 1992; Dolnan et al., 1999)
- *How* do they want to be involved?
  - Consulting role vs. decision making role
  - General preference for consulting role (Abelson et al., 1995; Litva et al., 2002; Shrimpton et al., 2008; Litva et al., 2009; Castle & Culver, 2006)
- Less is known about the public’s desired role in health research decision making

# Objective

- We sought to explore preferences among the ‘lay public’ in Canada for involvement in health policy decisions
  - Comparing across contexts:
    - Medical research
    - Health care programs
  - By degree of involvement:
    - Taking more account → Having decision authority  
(consulting) (decision making)

# Methods

- In 2013, administered bilingual Internet survey to a representative sample of Canadians, recruited through an Internet panel
- Ran two generalized ordered logistic regressions to examine factors associated with expectations for public involvement
- **Dependent variables** – constructed from 2 items:
  1. To direct [HC programs/medical research] in the right way, it would be better to take more account of what the public thinks
  2. Decisions about [HC programs/medical research] should be based primarily...
    - On the advice of experts OR on the general public's views
- 3-part ordered categorical variable (status quo input without decision authority; more input without decision authority; more input with decision authority)
  - 4<sup>th</sup> residual category, not included in regressions

# Methods

- **Key independent variables:**
  - Type of evidence (scientific vs. moral; forced choice)
  - Trust in the government's stewardship of health care (3 items)
  - Trust in medical research (3 items)
  - Beliefs about the importance of access to the most advanced medical tests and treatments (1 item)

# Results

- Response rate
  - 94% participation rate – proportion of visitors to invitation page who started the survey: n=2,345.
  - 47% completion rate – proportion who started of those who completed, meeting strict quality criteria: n=1,102

# Results

- Taking more account
  - 80% agreed that “it would be better to take more account of what the public thinks” in directing **healthcare programs**
  - 65% agreed to the need to take more account of public views for **medical research**
- Decision authority
  - 74% preferred to rely on expert advice for **healthcare programs**
  - 80% preferred to rely on expert advice to make decisions about **medical research**



# Expectations for degree of public involvement

Healthcare programs	
<b>Highest</b> involvement: More input with decision authority	23%
<b>Intermediate</b> involvement: More input w/out decision authority	57%
<b>Least</b> involvement: Status quo input w/out decision authority	17%
Residual category: Status quo input with decision authority	3%
Medical Research	
<b>Highest</b> involvement: More input with decision authority	18%
<b>Intermediate</b> involvement: More input w/out decision authority	47%
<b>Least</b> involvement: Status quo input w/out decision authority	33%
Residual category: Status quo input with decision authority	2%

## Factors associated with expectations of more public involvement in **HC programs** – ordered relationships

(Status quo input without decision authority) vs. (More input without decision authority OR More input with decision authority)

(Status quo input without decision authority OR More input without decision authority) vs. (More input with decision authority)

Those with higher **trust in the government's stewardship of health care** and those who preferred that **decisions about health care programs be based primarily on scientific evidence** were more likely to want *less* public involvement

**Women** and those with **less education** were significantly more likely to want *more* public involvement

## Factors associated with expectations of more public involvement in **HC programs** – non-ordered relationships

(Status quo input without decision authority) vs. (More input without decision authority OR More input with decision authority)

(Status quo input without decision authority OR More input without decision authority) vs. (More input with decision authority)

**Trust in medical research** was associated with *more* input without decision authority

Belief in the importance of **access to the most advanced medicines** was associated with a preference for *more* input, with or without decision authority

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

## Factors associated with expectations of more public involvement in **medical research** – ordered relationships

(Status quo input without decision authority) vs. (More input without decision authority OR More input with decision authority)

(Status quo input without decision authority OR More input without decision authority) vs. (More input with decision authority)

Those who preferred that **decisions about medical research be based primarily on scientific evidence** were more likely to want *less* public involvement  
  
likely to want *more* public involvement

## Factors associated with expectations of more public involvement in **medical research** – non-ordered relationships

(Status quo input without decision authority) vs. (More input without decision authority OR More input with decision authority)

(Status quo input without decision authority OR More input without decision authority) vs. (More input with decision authority)

Being more trusting is associated with wanting *less* than the highest level of public involvement

Belief in the importance of **access to the most advanced medicines** was significantly associated with a preference for *more* input, with or without decision authority

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

# Conclusion 1.

- Strong public belief in need to **take more account** of what the public thinks
- But does not extend to belief that decisions **should be based primarily** on these views
- Overall preference for **'intermediate'** involvement
  - More input w/out decision authority
- Aligns with previous research (Abelson et al., 1995; Litva et al., 2002; Shrimpton et al., 2008; Litva et al., 2009; Castle & Culver, 2006)

## Conclusion 2.

- Public expectations for involvement reduced for medical research relative to healthcare
- Reduced sense of public 'ownership' of the medical research enterprise relative to the health care enterprise?
  - Health care in Canada a visible public enterprise, and consistently a top policy priority for members of the public
- Lack of awareness of possibility for, or value of, public engagement in health research?
  - Less attention to role of public in health research policy in Canada – See 2011 CIHR International Review Panel report
- Need for further research and policy development?

## Conclusion 3.

- Factors associated with expectations for **less** public involvement
  - Men/ higher education → less involvement
  - More trust in science and various governing arrangements → less involvement
- Similar factors broadly associated with **increased** political efficacy in recent studies of the public's role in governance of science
  - Belief that one “can make demands of governing systems and get adequate responses from these systems” (Knight & Barnett, 2010)
- Need for further consideration in future research



# Limitations & Strengths

- Limitations:
  - Terms not explicitly defined
    - ‘Health care programs’
    - ‘Medical research’
  - Contexts
    - Can’t generalize to all health policy contexts (e.g., health technology assessment, health services research)
- Strengths:
  - Novel comparison
  - Assessment of factors associated with expectations of more public involvement

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