Tokenism in patient engagement: What we learned from a joint CCAG/PaCE workshop at NAPCRG 2015

David L Hahn, Amanda E Hoffmann, Maret Felzien, Joseph W LeMaster, Jinping Xu, Lyle J Fagnan

NAPCRG's Community Clinician Advisory Group (CCAG)

- **CCAG Mission:** to bring more voices from community practice to inform (1) the functions of the NAPCRG and PBRN annual meetings and (2) add community clinician perspectives to formulating the future primary care research agenda

- **CCAG Activities:**
  - Vetting NAPCRG "Pearls" (presentations at the NAPCRG annual meeting of most interest and relevance to practitioners)
  - Disseminating "Pearls" at local, regional and state/province-wide venues
  - Membership on other NAPCRG board committees at the discretion of the respective Chair
  - Facilitating greater clinician-researcher interactions via formal and informal participatory activities at the NAPCRG annual meeting (including panel discussions or other dialogues)

NAPCRG's Patient and Clinician Engagement (PaCE) Project

- Funded through a PCORI Eugene Washington Engagement Award

- PaCE Mission: to develop a robust community of patients and primary care providers with knowledge and understanding of the unique features of PCOR related to primary care in preparation for engagement in primary care research and advocacy

# NAPCRG's position on patient/community engagement

- 1998: NAPCRG adopted and endorsed a policy statement on responsible participatory research (PR) with communities

- 2009: Amendment to the 1998 Policy Statement endorsed the ongoing relevance of the Statement and presented recommendations for ongoing NAPCRG support for PR

> *"Fundamentally, PR improves the quality of the research enterprise and addresses social injustices inherent in non-participative research"*

- 2014-2017: **Fostering patient and clinician engagement as research partners** was added as a priority to NAPCRG's 3-year strategic plan

AIM: Explore the characteristics of token vs genuine engagement

- **Tokenism:** the practice of making only a perfunctory or symbolic effort to do a particular thing, especially by recruiting a small number of people from underrepresented groups in order to give the appearance of sexual or racial equality within a workforce (Encyclopedia.com)

- **Genuine:** actual, real or true; not false or fake (Merriam-Webster.com)
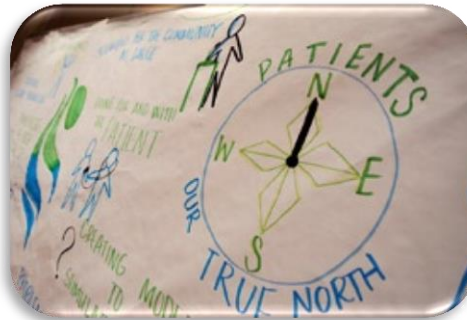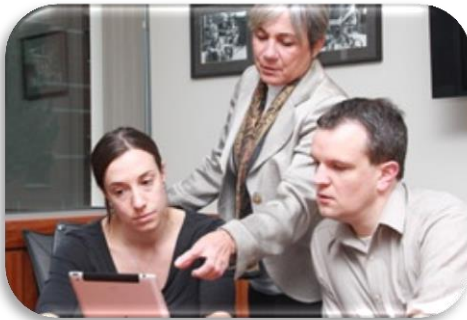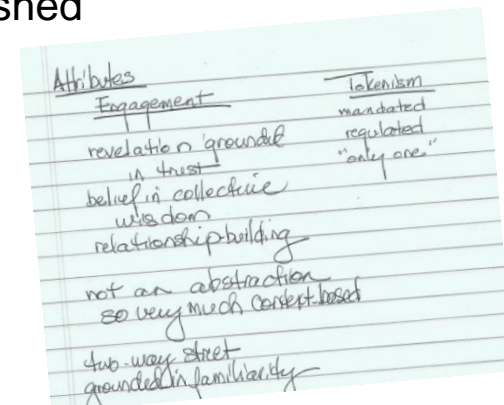
2015 NAPCRG Workshop: "How Do We Move beyond Tokenism in Patient Engagement?"

- **50 conference attendees:** 1/3 patients, 1/3 non-academic community clinicians, 1/3 academic researchers

- Methods:
  - Each participant completed a 1-page summary sharing examples of token vs genuine engagement
  - 6 discussion groups shared their examples and experiences
  - Summary group reports were documented
  - All documents were scanned, transcribed and categorized into themes using qualitative methodology
 - A manuscript was prepared, submitted, accepted and published

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OXFORD

Qualitative Research

Tokenism in patient engagement

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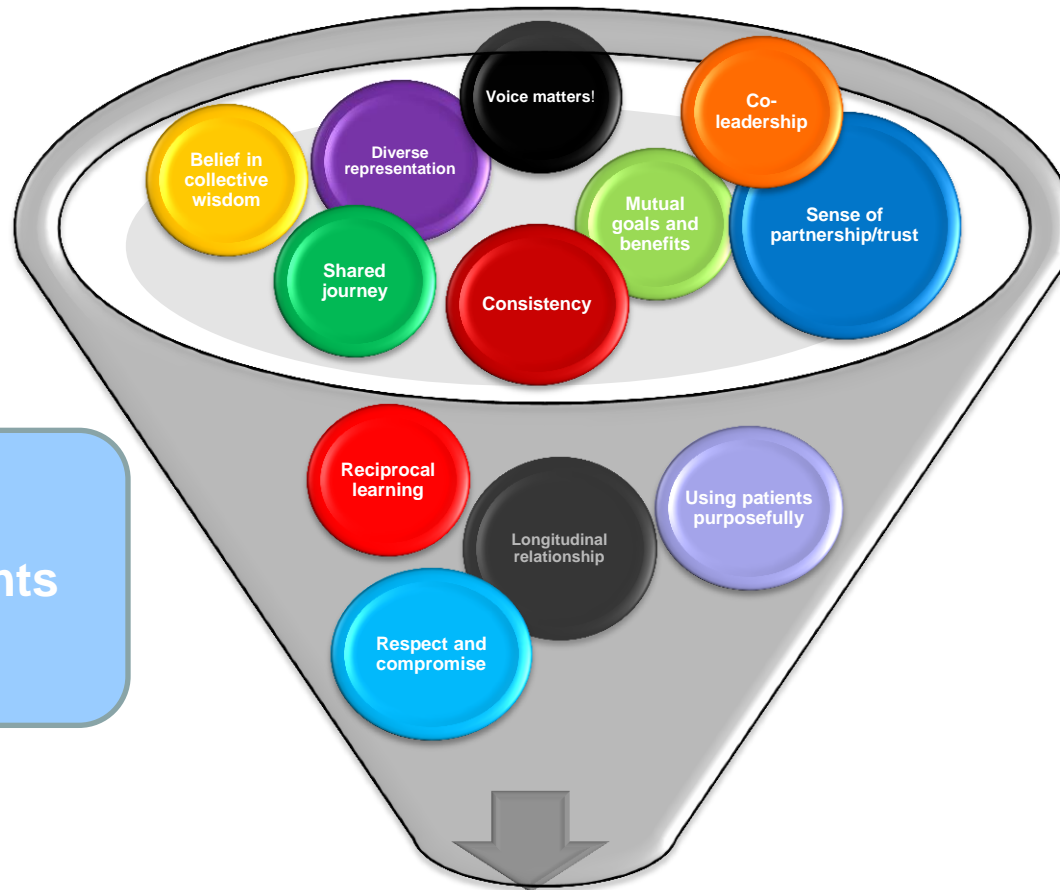
What we heard: Example quotes

- Tokenism: "I accepted an invitation to sit on a community advisory study panel; it never met."
  –primary care physician

- Genuine: "The reason I continued to participate was because I began seeing my suggestions appear in the results."
  –community citizen
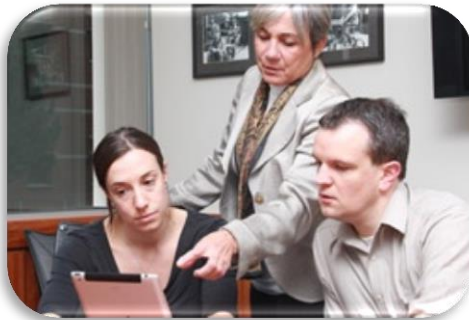
Domains

- **Methods/structure of engagement**
  - ➤ Group composition and management
  - ➤ Scheduling
  - ➤ Communication and feedback

- **Intent**

- **Relationship building**
  - ➤ Before project
  - ➤ During project
  - ➤ After project

Concannon's seven-item questionnaire

1. What types of stakeholders were engaged?

2. What were the a priori target number(s) for each type of stakeholder? Were targets met?

3. How was the balance of stakeholder perspectives considered and achieved?

4. What methods were used to identify, recruit and enrol stakeholders in research activities?

Concannon TW, Fuster M, Saunders T *et al.* A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research. *J Gen Intern Med* 2014; 29: 1692–701.

Concannon's seven-item questionnaire

5. Did engagement occur:

    a.   before?

    b.   during?

    c.   after?

6. What were the intensity, methods and modes of engagement?

7. What, if any, was the impact of stakeholder engagement on:

    a. relevance?

    b. transparency?

    c. adoption?

Concannon TW, Fuster M, Saunders T *et al*. A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research. *J Gen Intern Med* 2014; 29: 1692–701.

Nuggets and questions for future research

- **Reconciling structure & intent:** Can intent be inferred from structure? Some newer engagement activities may appear tokenistic as relationships evolve. Are "engagement checklists" useful? (see Table 2 in manuscript)

- **Patient experience:** Perceived levels of trust, that patients' voices were heard, and future willingness to remain engaged: can these be used to create patient reported outcome measures (PROMs) subject to validity testing?

- **Longitudinal engagement:** Relationships that transcend individual projects were viewed as very valuable and worthy of emulation.