

Qualitative Research

Tokenism in patient engagement

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Abstract

Background. Patient engagement throughout research is a way to generate more relevant patient-important research questions, methods and results with the ultimate aim of facilitating translation of research into practice. Tokenism is defined as the practice of making perfunctory or symbolic efforts to engage communities or patients.

Objective. We wanted to explore how tokenism might influence engaging patients in research to help researchers work towards more genuine engagement.

Methods. The Community Clinician Advisory Group and Patient and Clinician Engagement program held a workshop at the 2015 North American Primary Care Research Group meeting titled ‘How Do We Move beyond Tokenism in Patient Engagement?’ Patients, clinicians and academic researchers contributed examples of genuine and token engagement characteristics based on personal experience and knowledge. Data were iteratively collated and categorized into domains and items.

Results. Examples of genuine and token engagement were categorized into three domains: Methods/Structure of engagement, Intent and Relationship building. Members with experience in patient-engaged research projects felt that longitudinal engagement was a key element to effectively translating research into local community and practice.

Conclusions. The group (i) highly valued genuine intent and relationship building as elements to combat tokenism; (ii) noted that early genuine attempts at engagement may superficially resemble tokenism as researchers build enduring and trusting relationships with patient/community partners and (iii) emphasized the importance of seeking and utilizing patient experiences throughout research. These observations may contribute to more formal methods to help researchers (and reviewers) evaluate where engagement processes sit along the ‘genuine–token’ continuum.

Key words: Culture and disease/cross-cultural issues, doctor–patient relationship, faculty development, health literacy, primary care.

Introduction

QUOTE: ‘I accepted an invitation to sit on a community advisory study panel; it never met.’ –primary care physician
‘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 (1).

QUOTE: ‘The reason I continued to participate was because I began seeing my suggestions appear in the results.’ –community citizen
‘Genuine’: Actual, real or true; not false or fake (2).

The term ‘tokenism,’ defined as the ‘difference between...the empty ritual of participation and having the real power needed to affect the outcome,’ appeared at least as early as 1960s in the context of community housing initiatives (3). Arnstein (3) has described a typology of tokenism involving citizen participation in housing and urban development and suggested that similar constructs of tokenism might usefully be applied to other disciplines including the church, colleges and universities, public schools, city halls and police departments. Although ‘big businesses’ were included in the mix, health care was not specifically mentioned. About 50 years later, it is appropriate to consider the degree to which tokenism pervades current initiatives to involve patients in health care and health research. We acknowledge a growing consumer movement accelerating the shift from medical paternalism, in which the ‘doctor always knows best’ towards a partnership, where patients are engaged as stakeholders in their own care. We suggest that medical paternalism is also a characteristic of medical research, in which patients are seen as ‘subjects’ rather than as ‘partners.’

Community-based participatory research (CBPR), advocated for some decades, is defined as research that actively involves the community being studied (4). In 1998, the North American Primary Care Research Group (NAPCRG) adopted a detailed policy statement endorsing CBPR principles titled, ‘Responsible Research with Communities: Participatory Research in Primary Care’ (5). Recently, the concept of engaging communities in medical research has been extended beyond defined geographical communities to include patients and patient advocates in the research process. By ‘engagement’ in research, we are referring to partnerships with non-medically trained individuals—community members or patients, depending on the context—not only just as research subjects but also as partners in creating the research question, contributing to methods (particularly outcomes), conduct, interpretation and dissemination of research findings. Increasing genuine stakeholder engagement in health research leads to better participation and more relevant outcomes for patients (6). A recent narrative review described significant barriers that promote tokenism rather than genuine stakeholder empowerment when health researchers attempt to engage patients and the public (7). We address tokenism in the process of engaging stakeholders in medical research by asking the question, ‘Are there characteristics by which tokenism can be recognized, documented and thereby hopefully ameliorated?’ Researchers may unwittingly engage in token engagement because they are unaware of engagement’s deeper meanings.

We met at a 2015 NAPCRG workshop to discuss our personal experiences with genuine and token engagement from a variety of perspectives: as researchers, clinicians, and patients and community members with previous experiences engaging with clinicians and/or researchers. Our focus overlaps with, but is not identical to, that of CBPR because our group included patients and community members with two types of experiences: as members of community-based (i.e. CBPR) projects and/or as members of clinician–patient dyads (i.e. not the classical focus of CBPR). This study aims to explore the perspectives of participants in these experiences to contribute to building an emerging taxonomy describing the ‘genuine–token’ continuum to help researchers work towards more genuine engagement with patients and community members.

Methods

The Community Clinician Advisory Group (CCAG) and the Patient and Clinician Engagement (PaCE) program sponsored by the

NAPCRG held a joint workshop at the 2015 NAPCRG meeting in Cancun, Mexico titled, ‘How Do We Move beyond Tokenism in Patient Engagement?’ About 50 attendees, approximately one-third patients, one-third non-academic community clinicians and one-third academic researchers heard brief presentations from several clinician–patient dyad members of the PaCE program. Attendees then broke into smaller groups to discuss and document their experiences with token and genuine engagement throughout the research process. Each group then reported back on the main themes they discussed. These thematic summaries and individual documentation from each attendee were collected and compiled. Two of the authors (AEH and DLH) iteratively summarized and categorized the comments. Preliminary categorizations were circulated among the attendees who were invited to contribute comments and feedback. This process resulted in the domains presented in Table 1. The writing group consisted of workshop participants who contributed to writing and revising the manuscript, and one non-participant (AEH) with expertise in qualitative methods. All attendees who furnished an e-mail address were also given the opportunity to comment on the manuscript (see Acknowledgements for list).

Results

As a group, we struggled with the definition of ‘engagement’ in medical research, largely because the term can apply equally to deep and lifelong relationships (e.g. engaged to be married) and to ‘one off’ encounters (e.g. an engagement to go to the theatre). It is therefore useful to acknowledge a hierarchy of interactions between authorities (e.g. health system decision-makers) and the public that involve increasing amounts of commitment and power sharing (8) (Fig. 1a). This generic ‘level of engagement’ taxonomy has been applied to health research (9) (Fig. 1b). We asked ourselves whether tokenism could occur at only one level, or at some or all of the levels illustrated in Figure 1b. We concluded that each of the levels could be undertaken as a token gesture. We also concluded that (i) each level had its own value; (ii) the goals and objectives needed to be clearly defined and (iii) the level of engagement needed to be consistent with the project goals.

Table 1 presents a summary of the groups’ examples along the ‘genuine–token’ engagement continuum based on the personal experiences and general knowledge of the participants. We placed our examples under three broad domains (Methods/Structure of Research, Intent and Relationship Building). Some members of the group emphasized that tokenism was ‘all about the intent’ and this is reflected in the fact that the majority of examples from Table 1 involve the latter two categories, Intent and Relationship Building, with less emphasis placed on Structure. Most importantly, ‘the intent to engage needs to be genuine’. Genuineness of intent is not something that is stated but rather demonstrated all along the course of a project by collaboration in important decisions, e.g. who decides how the project budget will be spent, or if changes need to be made, who decides?

Conclusions

Our experiences along the ‘genuine–token’ engagement continuum in medical research are those of a single writing group; we invite others to continue the conversation. Group composition, appropriate scheduling, communication and feedback were noted to be essential to nurture genuine engagement (Table 1). These characteristics may be described as the ‘nuts and bolts’ of the process (structure).

Table 1. Domains from the 2015 Community Clinician Advisory Group workshop with examples along the 'genuine–token' engagement continuum

Domain	More 'genuine'	More 'token'
I. Methods/structure of engagement		
Group composition and management	Adequate stakeholder diversity	Low stakeholder diversity, e.g. one committee member in group of academics; inviting 'any' patient just to have a patient
	Co-leadership with patients; power sharing	Power imbalance; lack of ownership/leadership
Scheduling	Adequate time for accomplishing project tasks/goals	Poor scheduling, timeframe and format
	Discussion and questions fully fleshed out	Not leaving room for discussion or questions
Communication and feedback	Appropriate location and time that are convenient for all stakeholders Open-line of communication that everyone can understand	Inappropriate location Use of medical jargon; patient at table listening to high-level summary of research
	Showing results; showing patients where their work/input went and what it was for	Lack of showing data to patients; work and input goes into a void; patients are unable to see where work goes/what it accomplishes
	Proper education and preparation Responsibilities/duties for each person are well defined Upfront about project expectations	Lack of appropriate training Lack of role definition Not clear about project expectations
II. Intent		
	Involving stakeholders in determining patient/family/community priorities, goals and outcomes/objectives	Pre-determined goals, outcomes and agenda; taking final product for a patient/family 'rubberstamp'
	Not knowing answers to questions before asking/say you don't know all the answers and 'we will learn together'	Patients invited to participate as an afterthought; asking for a representative after a project starts
	Collectively identifying root problem/issue with patients	Requesting review of a proposal form/etc. after it has been developed
	Partnership in which the patients' priorities/needs are directing the process	Researcher pushing the themes; researchers' personal agendas different than patient groups
	Reciprocal learning Equal voices from researchers, clinicians and patients/belief in collective wisdom; shared power structure, decision process, goals, successes and challenges	One-directional benefit Decision-making process not explicit; not enough time to develop authentic partnerships, e.g. hearing each voice/clearing the air—especially if there are pre-existing tensions; fear of loss of control by researcher
III. Relationship building		
	Sense of trust; developing an atmosphere patients feel comfortable in; valued and respectful relationship Making research purposeful—customize to patient needs having full disclosure between all parties Mutual benefits Delving deep into roots of perspectives, cultures, beliefs, myths, needs and ensuring they are addressed	Lack of trust/feeling from patient of 'what I say doesn't matter' Not having full disclosure
Before project	Active dialogue prior to starting/developing research question/project; developing research question together with community/patient and what matters to them	Benefit is not mutual Patients are a means to an end
During project	Partnerships are promoted and nurtured	No active or pre-existing relationship with patients
After project	Sense of partnership that is sustained beyond specific grant or project; longitudinal ongoing partnership/relationship building	No attempt to create a partnership Relationship ends at the end of the project

Notably, the majority of issues identified by our group involved less tangible interactions in the Intent and Relationship Building domains (Table 1).

A key question we asked ourselves was: Can intent and relationship building towards genuine engagement be inferred from objective

metrics such as group composition, time management and communication? Put more simply, can intent be inferred from structure? We believe not necessarily; it is conceivable that sophisticated structures that appear designed to engage stakeholders could be employed with no intent to share power or use information (e.g. see first quote in

IAP2'S PUBLIC PARTICIPATION SPECTRUM



The IAP2 Federation has developed the Spectrum to help groups define the public's role in any public participation process. The IAP2 Spectrum is quickly becoming an international standard.

		INCREASING IMPACT ON THE DECISION				
		INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL		To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
	PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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Framework for Stakeholder Engagement

Engagement Levels	INFORM & EDUCATE	LISTEN & GATHER	DISCUSS	INVOLVE	PARTNER
Direction & Strength of Engagement	From Health System to Stakeholders 	From Stakeholders to Health System 	Bidirectional 	Bidirectional and ongoing 	Joint venture
Definition	Stakeholders benefit from information and education	Stakeholders give voice to experiences	Stakeholders provide valuable input and receive feedback	Stakeholders are ongoing advisors	Stakeholders are full participants
Methods	Websites, social media, newsletters	Surveys, cycle time, suggestion boxes, gathering narratives/stories	One-time focus group, town-hall style meetings, community gatherings, interactive interviews	Ongoing feedback panels, advisory boards	Voting members of governance boards, members of QI/research teams

- Continuum
- All valuable: Mix and match
- Different levels meet different needs
- Discernment necessary:
 - Whose voices do we need?
 - What kind of input?

• Davis, S. & Gaines, M. Patient Engagement in Redesigning Care Toolkit. 2014. Available at: <http://hipxchange.org/PatientEngagement>

• Davis, S., Berkson, S., Gaines, M. E., Prajapati, P., Schwab, W., Pandhi, N., & Edgman-Levitan, S. (2016). Implementation Science Workshop: Engaging Patients in Team-Based Practice Redesign—Critical Reflections on Program Design. *Journal of general internal medicine*, 1-8.

• Caplan, W., Davis, S., Kraft, S., Berkson, S., Gaines, M., Schwab, W., and Pandhi, N. "Engaging patients at the front lines of primary care redesign: Operational lessons for an effective program." *Joint Commission Journal on Quality and Patient Safety* 2014;40(12).

Figure 1. (a) Different levels of engagement with the public, with permission from the International Association of Public Participation (IAP2), www.iap2.org (8). (b) Framework for stakeholder engagement applied to health research, with permission from Davis *et al.* (9).

the Introduction section). The converse may also hold: members of our group noted that the developmental process of forming partnerships may include elements that first appear on the 'tokenism' end of the spectrum, i.e. beginning partnerships may start out with many

of the characteristics of true engagement being under-developed, but (as in any relationship) over time they develop and mature (e.g. see second quote in the Introduction section). Some of this is captured in the Addendum to the NAPCRG document 'Responsible Research in

Communities', called 'Engaging with Communities, Engaging with Patients: Amendment to the NAPCRG 1998 Policy Statement on Ethical Research with Communities' (10). Young partnerships may have some characteristics that suggest tokenism, but in fact genuine engagement has started—the relationships are just still so new that everyone is still learning to trust each other and 'figuring out' how to work together. We therefore concluded that intent and structure are orthogonal domains; statistically speaking they exist on axes perpendicular to one another and may be positively or negatively correlated depending on the context. Thus, we believe that inferring intent from objective activities must take context into account.

We grappled with the question of how to reconcile the structure (objective) with the intent (subjective) by asking participants to describe their experiences with what they perceived as genuine and token engagement. We then distilled their reports in an attempt to discover distinguishing characteristics that could be used to assess intent. Although this study did not purport to create a complete taxonomy, further research should explore accurate assessment of genuine versus token intent. Exploring the guidelines proposed by Macaulay *et al.* (5) that appear in the NAPCRG policy statement on participatory research might be a useful approach. These guidelines include a total of 25 questions in 6 domains [(i) Participants and the nature of their involvement; (ii) Origin of the research question; (iii) Purpose of the research; (iv) Process and context-methodological implications; (v) Opportunities to address the issue of interest and (vi) Nature of the research outcomes]. As not all research aims at deeply involving patients and communities, it also seems important to us to ask whether the researcher's intent is well matched to the research methods (e.g. Fig. 1b) and whether the researcher's intent is explicitly spelled out in the research plan and communicated to research partners/subjects. By requiring researchers to think explicitly about these issues, we hope they will examine their own willingness to share power and explore how best to match their intentions with their methods.

Pending the results of further research, we feel that assessing intent currently remains mainly a heuristic activity, guided more by human judgment than by science. For example, Concannon *et al.* (11) have proposed a seven-item checklist to describe the extent of stakeholder engagement in research based mainly on structure. Their checklist describes specific engagement activities, but does not include an 'intent' evaluation component (i.e. to what extent were the described activities genuine or token?). A rating of 'genuine versus token' could be applied to each checklist item. Table 2 presents the previously published checklist by Concannon *et al.* (11) in column 1 along with very preliminary criteria for judging where the activity lies along the 'genuine–token' engagement continuum in columns 2 and 3. We believe this requires revision and additional research to validate the rating scale. The guidelines proposed by Macaulay *et al.* (5) described above might be used to inform more robust assessments related to that effort.

Community members of our group also reminded us that it is important to take the patient experience into account (e.g. whether patient/community members feel safe to share their experience/story, or have fears that their treatment might be negatively impacted by voicing concerns or disagreeing with an authority figure). Evaluations that take 'patient experience' into account whenever possible might be useful adjuncts in evaluating potential tokenism. Reports including patients' currently lived or past experiences, perceived levels of trust, that their voices are/were heard and incorporated into results and their future willingness to remain involved, could be used to produce patient-reported outcome measures (PROMs) that could also be subjected to validity testing.

The Patient-Centered Outcomes Research Institute (PCORI) (12) requires patient engagement in all its funded projects, preferably at all levels of the research process from conception (creating the research question), birth (methodology, conduct, analysis and interpretation) and throughout the life cycle (implementation and dissemination). Other federal funding agencies, including the Agency for Health

Table 2. Identifying ways to report on stakeholder engagement in research using Concannon's (11) seven-item questionnaire

Seven-item questionnaire ^a	Examples of stakeholder engagement in research	
	Genuine	Token
1. What types of stakeholders were engaged?	All relevant stakeholders were engaged	Only selected stakeholder groups were engaged
2. What were the a priori target number(s) for each type of stakeholder? Were targets met?	Target numbers were adequate to allow meaningful contributions from all groups	Target numbers were small in relation to the numbers of researchers and/or other stakeholders
3. How was the balance of stakeholder perspectives considered and achieved?	Careful consideration was given to a variety of relevant factors	Perfunctory considerations determined the allocation
4. What methods were used to identify, recruit and enrol stakeholders in research activities?	Care was taken to include stakeholders capable of seeing 'the big picture'	No consideration for the ability to think beyond one's own situation was made
5. Did engagement occur: a. before? b. during? c. after?	Engagement occurred throughout the research process (before, during and after)	Engagement did not occur at one or more stages of the research process
6. What were the intensity, methods and modes of engagement?	Engagement was deep, extensive and long-lasting	Engagement was shallow, limited and short
7. What, if any, was the impact of stakeholder engagement on: a. relevance? b. transparency? c. adoption?	Engagement resulted in more relevant research questions, transparency and adoption	Engagement was insufficient to affect relevance, transparency and/or adoption

^aFrom Concannon *et al.* (11) with permission from the publisher.

Research and Quality (AHRQ) and the National Institutes of Health (NIH) are also promoting increased patient engagement in various aspects of the medical research projects they fund. Checklists evaluating genuine engagement might be useful to grant reviewers and to grant writers to produce improved research protocols.

Lastly, most current research engagement strategies remain project specific. Members of our workshop have had positive experiences with ‘longitudinal engagement’ that both ‘preceded’ and ‘continued after’ individual research projects (13). Engagement that transcends individual projects allows for richer interactions and more opportunities to discover community needs, and facilitates stakeholder contribution to design the research question(s). Longitudinal engagement may also be a key element in effectively translating research into practice.

In conclusion, one important difference between tokenism and genuine engagement comes from the intention to be truly engaged. Real engagement—to be involved in shared dialog and responsibilities, to build strong and lasting relationships between researchers and community/patient partners and to develop a research relationship that encourages this type of partnership—will move the needle towards the goal of what ‘genuine’ engagement really means. This depth and breadth of engagement, this shared belief that the outcomes and the research will be better because of it, is rare, but represents an aspirational goal we will strive to attain. And only then will the partnership be ‘genuine: actual, real and true.’

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References

1. Encyclopedia.com. Tokenism – Encyclopedia of Race and Racism. 2016. <http://www.encyclopedia.com/article-1G2-2831200372/tokenism.html> (accessed on 9 February 2016).
2. Merriam-webster.com. Definition of Genuine. 2016. <http://www.merriam-webster.com/dictionary/genuine> (accessed on 3 March 2016).
3. Arnstein S. A ladder of citizen participation. *J Am Inst Plan* 1969; 35: 216–24.
4. Agency for Healthcare Research and Quality. The Role of Community-Based Participatory Research, Creating Partnerships, Improving Health. <http://archive.ahrq.gov/research/cbprrole.htm> (accessed on 31 May 2016).
5. Macaulay AC, Commanda LE, Freeman WL *et al*. Responsible Research with Communities: Participatory Research in Primary Care. <http://www.napcr.org/Portals/51/Documents/1999PR.pdf> (accessed on 5 June 2016).
6. Jagosh J, Macaulay A, Pluye P *et al*. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012; 90: 311–46.
7. Odo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf* 2016. doi:10.1136/bmjqs-2015-004839.
8. International Association for Public Participation. IAP2’s Public Participation Spectrum. 2014. http://c.yimcdn.com/sites/www.iap2.org/resource/resmgr/Foundations_Course/IAP2_P2_Spectrum.pdf (accessed on 22 March 2016).
9. Davis S, Berkson S, Gaines M *et al*. Implementation science workshop: engaging patients in team-based practice redesign—critical reflections on program design. *J Gen Intern Med* 2016; 31: 688–95.
10. Engaging With Communities. Engaging with Patients: Amendment to the NAPCRG 1998 Policy Statement on Ethical Research with Communities. <http://www.napcr.org/Portals/51/Documents/2014PR.pdf> (accessed on 22 March 2016).
11. 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.
12. Pcori.org. Why PCORI Was Created. 2016. <http://www.pcori.org/about-us/why-pcori-was-created> (accessed on 29 March 2016).
13. Felzien M, Zittleman L, Westfall JM. Farming, ranching, research: patient engagement on the high plains. *J Gen Intern Med* 2016; 31: 3–4.