Power for the People and Of the People

25 YEARS OF EMPOWERMENT


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Levels of Collaboration

- Client engagement in health care requires two levels of engagement:
  - Individual care choice
  - Systems level decision-making

Empowering Collaborative Care for Individuals

- Client and Care Providers understand Informed Consent
- Capable Client is in charge of own care
- Develop shared understanding of person's life.
- Form a menu of options for addressing difficulties and goals
- If there are team meetings: Agree on the team and the roles . Record all meetings, record to be approved by client. Client has option of having support person/advocate present who is not on care team

Perspectives on patient involvement can be conceptualized in terms of a continuum from consumerism (patients as customers who deserve to be satisfied) to participatory democracy (patients as citizens with rights to participate). *Gauvin (2010)*

An informed patient voice is necessary for effective and meaningful patient involvement. *Knutilla (2007)*

In practice this can range from meeting the requirements of informed consent on an **individual** level, working toward client identified goals,
to **system** level participation which ensures client representatives are connected to a client group - to bring a broad perspective and avoid co-optation.

Tokenism vs. Meaningful Involvement

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Qualitative Research

Tokenism in patient engagement

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Abstract

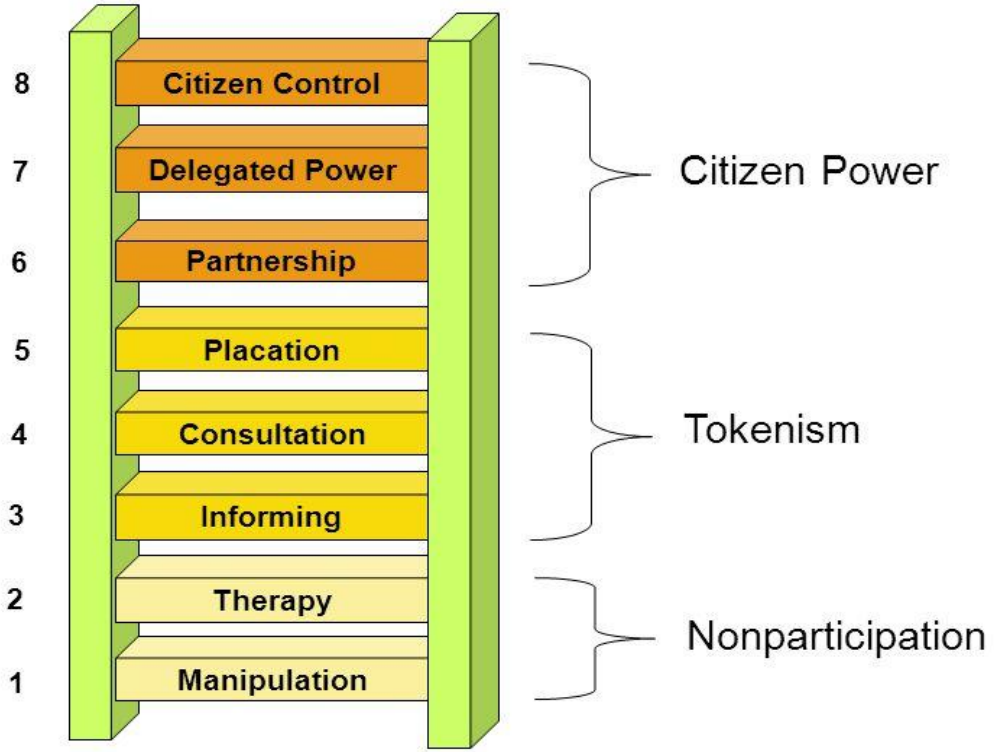
Background. Patient engagement throughout research is a way to generate more relevant patient-important research questions, methods and results with the ultimate aim of facilitating translation of research into practice. Tokenism is defined as the practice of making perfunctory or symbolic efforts to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

The Ladder of Citizen Participation (Arnstein)



Conditions for Meaningful Participation:

individually and systemically

- Sharing of power, trust and respect

There is a shift of decision-making power from providers to clients .

Clients are heard and action results (without negative repercussions).

- Connection to other clients and independent advocacy

"If participation processes are about sharing power and partnership, then it is difficult to see how a sole consumer representative could achieve such equity of influence." (Coney)

Consumers prefer the model of partnership. (Kelson, Duff et al, Anderson et al, NZ)

A service user run organization is engaged as a partner to ensure broad based representation, accountability to the group represented, to avoid conflict of interest and co-potation and to provide support for the people acting as representatives.

- Availability of choices

Genuine alternative courses of action are available (based on an holistic view of clients as people).

Client self-identified needs are the foundation of planning of individual care and systemic change.

- Structures and Processes

There is an established role for clients in decision-making:

from individual care plans, to policy, to resource allocation.

Barriers to Meaningful Participation

- *Health professional attitudes (often described as keeping people "in their place") can prevent real engagement in decision making by clients. Practices such as presenting decisions as good as made, preventing clients from expressing themselves, being unresponsive to client raised issues (Gagliardi et al 2008).* The valuing of "compliance".
- Poor access to information and coercive care *(Kidd et al).*
- Attempting to stand up for one's self on one's own is difficult – lack of connection to a client organization/independent peer advocacy.
- Lack of effective engagement strategies.
- Overemphasis on a biomedical perspective can invalidate client as expert on self, and be dismissive of the importance of experience(s)

How to Empower the Client Voice on an Organizational Level:

1. Resources – food and transportation, honouraria , facilitation by peer
2. Ask an existing peer run organization to advise and assist in development
3. Reach out to clients of your organization through posters, outreach, invitations…
4. Peer(s) facilitate large client only group who identify client needs, and elect representatives to meet regularly and report back to larger group
5. Ideally, provide funding so this group can hire staff who report to them
6. Most empowering if group can become their own organization

What an Empowered Client Voice Can Do

- ADVOCATE

  Identification of people's needs, how they can be addressed, to right people

- EDUCATION AND RESEARCH

  Educate about client eye view e.g. of what is quality care

- ENGAGEMENT/CONSULTATION

  Outreach and organize relevant client groups for consultations, evaluations, etc

Better outcomes

Consumers' perceptions that their needs were met were related to better state of mind and quality of life outcomes. In addition, consumers' perceptions that they had some say in service-related decisions had an indirect effect on mental health outcomes by increasing the likelihood that needs were met. Service amount was unrelated to mental health outcomes.

Roth & Crane-Ross (2002)

One of the most common themes is that patient voice representation provides a necessary "reality check".

Knutilla (2007)

CAMH BILL OF CLIENT RIGHTS

Process:

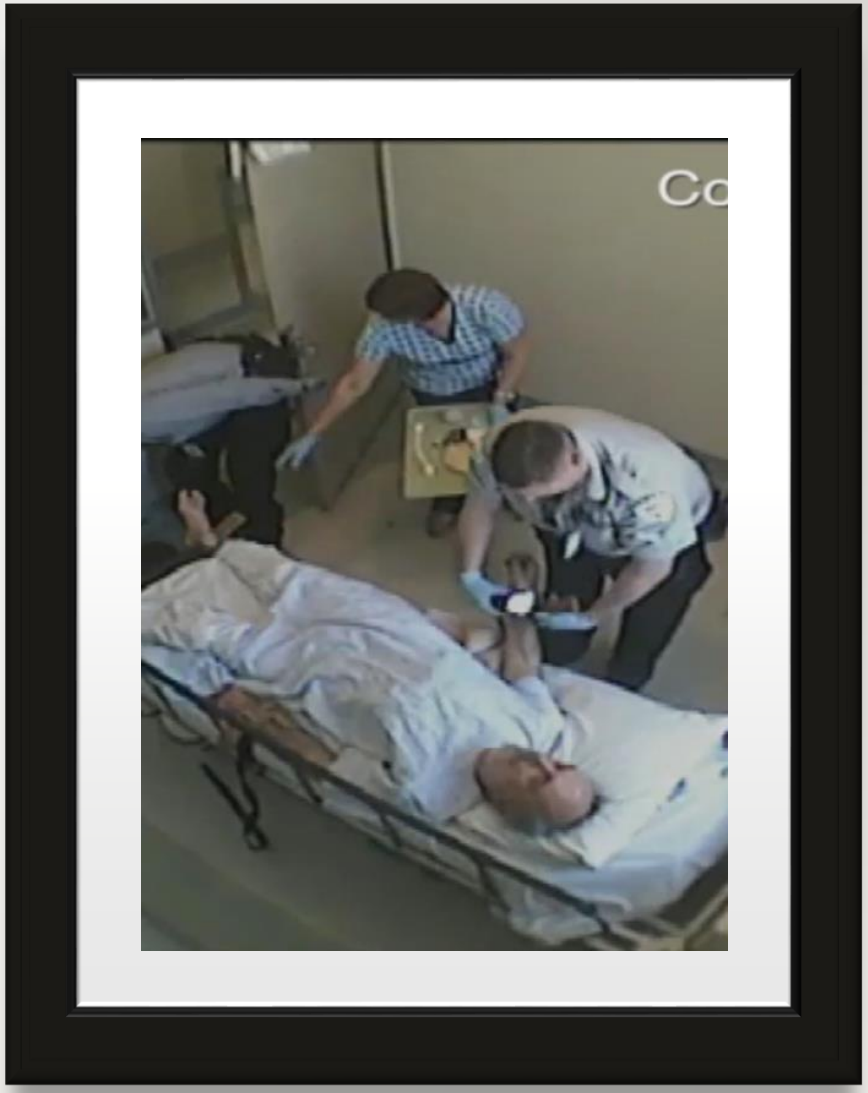
- Meet clients for initial list
- First committee of clients and staff draft versions
- Then direct meetings of client reps and management
- Versions back to clients for consultation, redraft, new request/offer
- Reword, return, repeat

Result:

- Powerful list of detailed rights
- Empowers clients to self advocate
- Guides policy and practice

RESTRAINTS

When the patient voice is not allowed to be effective, results can be fatal.



Restraints and Inquests

EMPOWERMENT COUNCIL had standing at two inquests: James and Mpelos

Drafted most of the recommendations that were adopted by juries at both inquests

Negotiated with CAMH for joint recommendations, which they honoured, and which formed basis of RNAO guidelines. Ongoing practice of all restraints at CAMH ongoing advocacy issue.

St Joseph's in Toronto less aligned with recommendations - no meaningful voice for clients at facility (patient advisory unaware of death or inquest)

Examples of Ongoing Collaborative Accomplishments: EC and CAMH

- EC reviews and revises CAMH clinical policy
- EC and CAMH co-draft or mutually inform public policy positions
- EC on Clinical Quality Committee brings client experience, concerns, questions to programs and Board
- EC organized forensic client voice for vision of future services
- EC consultations with relevant client groups identified in CAMH Equity strategy
- EC co-creates and revises CAMH curriculum: Trauma Informed De-scalation for Safety; Online courses

And because the lives of CAMH Clients don't stop at the doors of CAMH…

EC Advocates:

Government

Police

Courts

Successes:

- Influenced Legislation *e.g Unfit*
- Changed Charter case law at SCC

  e.g. leg must comply with Rights
- Toronto Police Service

  Changed polices, practices, training…
- Recommendations at Inquests

  Police, prison, hospital changes

Other accomplishments:

- EC staff one of authors on at least 13 publications
- Organization and staff recipients of a few awards
- Teach U of Toronto psychiatric residents and York U nursing students
- Regularly on news: paper, TV, radio, magazines, online

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