MINI-COURSE M 14

PATIENT VOICE IN QUALITY: BEYOND ADVISORY COUNCILS
SESSION OBJECTIVES

› Develop confidence to propose and implement plans for appropriate engagement for any project in their organizations

› Demonstrate skills to move their organizations beyond advisory councils and become leaders in patient engagement
DISCLOSURE AND INTRODUCTIONS

› Connie Davis has nothing to disclose*
› April Lawrence has nothing to disclose*
› Richard Scholtz has nothing to disclose*

* All faculty must disclose a serious passion for the topic. This could lead to hand talking, excessive sincerity and going on a bit.
LEARNING NEW WAYS OF LISTENING

Poem creation

Please use the index cards on your table to capture turns of phrase or words that stand out to you today

They will be turned into a poem!
HOUSEKEEPING AND OTHER ISSUES
GROUND RULES

Confidentiality

Monitoring progress

Take care of yourself!

If it’s not working, speak up!

?
CREATING COMMON LANGUAGE

› Patient
  › Anyone experiencing the delivery of health care
  › Family, friends, community, constituency
  › Civilians

› Provider
  › Anyone experiencing delivering or coordinating care
  › Administration, practitioners, government
  › The System
INTRODUCING
YOUR NEIGHBOURS

› Name
› Place you work
› Role
› Your most inspiring story of outside influence changing an organization
› Table will report out favorite
WHAT YOU ARE HOPING FOR FROM TODAY

› To be filled out with survey responses from pre-work
THE GROUPS YOU ARE PLANNING TO ENGAGE

› To be filled out with survey responses from pre-work
ENGAGEMENT SIMULATION – WHAT WOULD YOU TELL THE TSA?
BREAK
LISTENING EXERCISE
ENGAGEMENT OR BEING ENGAGED CAN MEAN TWO TOTALLY DIFFERENT THINGS...

First...

A personal state of being (adjective).

- The engaged employee
- The engaged patient
- At the moment of clinical care
Secondly…

At least two people in a conversation about a question that needs to be answered (noun).

- An interview
- A focus group
- Quality Improvement
- Program changes
ENGAGEMENT (THE NOUN KIND)
DEFINITION

› Engagement is including stakeholders (people affected) in aspects of:
  › identifying problems and opportunities,
  › developing alternatives and
  › making decisions.

› NOT the PR definition of “engagement”
  › Liking you on Facebook
  › Tweeting when no one is listening
THE PROCESS OF ENGAGEMENT

› Establish your purpose
› Contact your chosen community
› Pick a date at least a month out, piggyback something if you need it to be sooner
› Pick a venue, ask the community if they have a preference
› Set up catering and supports (babysitting? opening prayer? clinical support?), ask the community what they need
› Share any advance materials well in advance
› Have your day
› Follow up in any way you said you would
› Write your report
› Share results with community as previously agreed
SHHH... DON’T TELL ANYONE, BUT...

75% = Thinking clearly about it

25% = Skilled facilitation, event planning

Today we are looking at the 75%
TIPS FOR THE 25%

› Use a neutral facilitator
  › No skin in the game
  › Willing to hear anything
  › Willing to say anything to your Leadership
  › Versed in engagement techniques
  › Able to create a safe space
  › Talking to them won’t threaten future care
  › Can help you plan
IDEALLY, ENGAGE EARLY, ENGAGE OFTEN, BUT...

- Time Limits
- Political Limits
- Limits to Influence
- Budgetary Limits
SOMETIMES YOU JUST DON’T ENGAGE

› When your purpose isn’t clear…
› When you have run out of time…
› When the level of influence offered is totally disproportionate to the level of disclosure you are asking for…
› When you don’t have leadership willingness to hear what they have to say…
› When you have no budget for coffee and snacks…
HOW YOU SEE ENGAGEMENT CHANGES WHAT YOU OFFER PEOPLE

› An Opportunity!
  › Lend your Voice
  › Make a Difference
  › Influence the Outcome

› A Favour!
  › We can’t do this without you
  › We are legislated to include you
  › Help us
Complete the first two statements

- We are engaging to...
  - You may have more than one objective
- The benefit to our organization will be...
  - You may have more than one benefit

Be prepared to share the statements with the group

Be prepared to refine based on what you hear
PLANNING AN ENGAGEMENT HAS 2 SIDES

› Your organization’s needs:
  › What information are we looking for
  › What question are we asking
  › How much power can we share
  › What resources do we have
  › How can we get the information effectively

› The needs of those you are asking to have this conversation
YOUR ORGANIZATIONS NEEDS

› Your Draft Questions – Remembering to Listen
  › Exchange them with the person next to you
  › Read the other person’s from a ‘naïve’ perspective (5 min)
    • decide what they are asking and
    • what their assumptions are
  › Share this information with each other (5 min each)
    • Do not defend!
    • Listen quietly,
    • Ask one or two clarification questions only
    • Say “Thank you”
  › Re-draft questions (10 min)
  › Repeat (5 min each, TOTAL TIME 35 MIN)
LUNCH
LISTENING AND REPORTING EXERCISE
SCOPING YOUR ENGAGEMENT

› How much power are you sharing?
› What is on the table and what is off?
› How big is the engagement itself?
THREE WAYS TO DO HEALTH CARE IMPROVEMENT

1) Don’t listen very much to patients and we do the designing for them.

2) Listen to our patients then go off and do the designing for them.

3) Listen to our patients and then go off with them to do the designing together.

Paul Bate, 2007
IDEALLY MORE INFLUENCE IS TRANSFERRED...

› When the impact on the patient experience is greater
  › Who touches me
  › Who knows my information

› When a community is needed to deeply inform the process
  › Serving Native or Aboriginal populations

› When the issue starts or ends outside your walls
  › Advanced Care Planning
  › Readmissions of people with housing issues
BUT BE HONEST!

› The community can decide if what you are offering is good enough to be worth coming

› If you exaggerate you will never talk to them again
The ‘Ladder of Engagement and Participation’

There are many different ways in which people might participate in health depending upon their personal circumstances and interest. The ‘Ladder of Engagement and Participation’ is a widely recognised model for understanding different forms and degrees of patient and public involvement, (based on the work of Sherry Arnstein\(^7\)). Patient and public voice activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

<table>
<thead>
<tr>
<th>Devolving</th>
<th>Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborating</td>
<td>Working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.</td>
</tr>
<tr>
<td>Involving</td>
<td>Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered. For example, partnership boards, reference groups and service users participating in policy groups.</td>
</tr>
<tr>
<td>Consulting</td>
<td>Obtaining community and individual feedback on analysis, alternatives and / or decisions. For example, surveys, door knocking, citizens’ panels and focus groups.</td>
</tr>
<tr>
<td>Informing</td>
<td>Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.</td>
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</tbody>
</table>
ANOTHER WAY TO LOOK AT THE NHS LADDER

› Full control: service user control decision making at the highest level

› Sharing power: service users share decisions and responsibility, influencing and determining outcomes

› Participation: service users can make suggestions and influence outcomes

› Consultation: service users are asked what they think but have limited influence

› Information: Service users are told what is happening but have no influence

› No control: service users are passive consumers

http://www.serviceuserinvolvement.co.uk/whatisit_laderOfP.asp
WORKSHEET

Scope

› Position on the Ladder
› Topics on the table
› Topics that are off the table but which will come up
› Any clarification you need from Leadership
THINKING ABOUT YOUR PATIENTS/FAMILIES AND COMMUNITIES NEEDS

› Safety, now and later
› Accessibility
› Respect
› Support
What is an “Accessible” Engagement?
WHEN PLANNING ENGAGEMENTS FOR DIFFERENT GROUPS...

› Urban, Rural, Aboriginal, Marginalized, Senior Citizens, Caregivers, Parents of Pediatric Patients...

› ...it is always the same questions and always totally different results when thinking about the needs of the group being engaged.
IT’S ALWAYS THE SAME QUESTIONS

- What time would be best for the community (not you)?
- What location would be easiest and most comfortable?
- Is there someone who should be there to increase a feeling of support or lend legitimacy? Case manager, Elder, advocacy organization rep, head of a department?
- Is there a special consideration or support? Baby sitting, diet, ground floor? Cultural norms to follow? Food?
- Are there literacy or language concerns?
- Is the playing field level?
And if you have any doubt about a need of a group you should...
WORKSHEET

› Make a list of everything those you wish to engage may need to ensure a successful engagement.

› Write them down even if you don’t think you can provide them

› Don’t worry about order or editing

› 10 minutes
WORKSHEET

› Exchange lists with a person next to you
› Ensure they know the basic details of who you are engaging – 1 or 2 minutes (do not talk about your organization at all)
› 3 minutes to read, 3 minutes each to add anything missing
› Again, just listen and say thank you
› 3 minutes to refine the list
› 15 minute total
SECONDARY STAKEHOLDERS? WORKSHEET

› Internal or External
› People who you don’t want to find out about the engagement accidentally

› Write them all down (5 minutes)
  › Other departments
  › Other communities
  › Staff
HARD TO REACH or HARDLY REACHED?

The department of psychiatry wants to know more about the in-patient experience. Their strategic planning phase is starting. Hearing from patients may expand or shift the focus. They would like someone who has experienced involuntary commitment to come and speak at psychiatry grand rounds at 6:45 in the morning on a Thursday at the hospital.

They are disappointed that no one agrees and decided that this population is, like everyone says, hard to reach.
HARD TO REACH OR HARDLY REACHED?

Illusion of “Hard to Reach” demographics is often created by:

› Designing engagements that are for the system’s convenience and comfort
› Ignoring power imbalances
REDESIGN THAT PREVIOUS SCENARIO

- What time would be best for the community (not you)?
- What location would be easiest and most comfortable?
- Is there someone who should be there to increase a feeling of support or lend legitimacy? Case manager, Elder, advocacy organization rep, head of a department?
- Is there a special consideration or support? Baby sitting, diet, ground floor? Cultural norms to follow? Food?
- Are there literacy or language concerns?
- Is the playing field level?
The Department of Psychiatry needs to update their privacy policy. They want to hear how people feel about communication with families. They know they can make significant changes.

With advance permission, they bring cookies, bagels and coffee to the local Mental Health Association Clubhouse. People have been told they are coming and why. They have a listening circle for 90 minutes but then hang around for another 3 hours to let people chat informally or privately. A staff person stays with them.
QUESTION TO PONDER AT BREAK

› Who in the community that surrounds you organization is already working on or thinking about your issue?

› What might already be known?
BREAK
LISTENING EXERCISE
FEEDBACK: PREVENTING TOKENISM

› Have a plan for sharing before you start
› “Listening” is not an outcome
› Prevents tokenism by
   › Keeping your organization accountable
   › Managing expectations
› What influence did you promise they would have?
› What happened as a result?
BRAINSTORM

But what if it is going to take years to see the final results of this consultation? Then what?
WORKSHEET

› Draft a plan for feedback (15 minutes)

› How will the feedback come?
  · Suitable format for the community?
  · Public or private?

› When will feedback come?
  · All at once?
  · At intervals?
  · Stages of a project?
BRAINSTORM/TABLE TALK

› Who is likely already working on or thinking about an issue being faced by your institution?*
› What might they already know?

› Are you or your non-profit or foundation being an askhole? Non-Profit with Balls (blog, ) Jan 25, 2015

*Hint: if your issue impacts or involves a group that can self-identify, they are already talking about it
REAL BARRIERS TO ENGAGEMENT

› Poor Planning or Running out of Time
  › Running out of time reduces the level of engagement
  › It also prevents process conversations

› Money
REAL BARRIERS TO ENGAGEMENT

› Provider (Un)Willingness
  › This trumps everything
  › Resistance is real and common
  › Sometimes reducing the level of engagement until providers are comfortable is the best option
REAL BARRIERS TO ENGAGEMENT

› Apathy in Over-studied, Over-promised Communities

› Process conversations are the best counter to this
WORKING WITH SUSPICIOUS OR RESISTANT COMMUNITIES

› Devote time to process conversations and co-design
  › How would you like to be listened to?
› Have an answer to the question “Why will this time be different?”
› Listen to their list of priorities too
› Have resources
› Go for wins
WORKSHEET

› Questions you can’t answer
› Concerns about your organization’s willingness to hear results
Feedback/Evaluation
FOR MORE INFORMATION, CONTACT INFO@CENTRECMI.CA