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

Take care of yourself!

Monitoring progress

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
› The most inspiring story you know of outside influence changing an organization
› Table will report out favorite
WHAT YOU ARE HOPING FOR FROM TODAY

› Learning ways to empower patients to participate in the patient focus groups and have their voice heard.
› Inspiration, best practices, tools
› Integrate patients into hospital decision making
› Involve patients who aren’t as educated
› Re-invigorate an existing patient engagement plan
› Engage parents of NICU babies to improve outcomes
› Go beyond surface conversations
› Engage community in hospital strategic initiatives
› Improve transparency in patient engagement
› Bring patients into the practice for advisory or other vehicles

ENGAGEMENT SIMULATION – WHAT WOULD YOU TELL THE TSA?
THE QUESTION IS, THEN...

Why don’t hierarchical organizations full of highly-trained, well-educated people ask others about the impact of what they are doing?

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 together (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
WHAT ENGAGEMENT IS NOT...

› As we are discussing it, engagement is not a product in itself (that is the PR definition)

› It is an intentional process for the explicit purpose of answering together a question that your organization cannot or should not answer alone.

SHHH... DON’T TELL ANYONE, BUT...

75% = Thinking clearly about it

25% = Skilled facilitation, event planning

Today we are looking at the 75%
THE PROCESS OF ENGAGEMENT

› Establish your purpose (the 75% always)
› Contact your chosen community (the 75% often)
› 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

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
  › And, if they are good, they can help with the 75% too
BREAK

LISTENING EXERCISE
IDEALLY, ENGAGE EARLY, ENGAGE OFTEN, BUT...

› Time Limits
› Political Limits
› Limits to Influence
› Budgetary Limits
› Good, Collaborative, Fast... Pick 2. Just 2.

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...
IF YOU TAKE AWAY ONE THING...

Good, Collaborative, Fast... Pick 2.

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
**WORKSHEET**

› Complete the first two statements
  › We are engaging to...
    • You may have more than one objective
      • Seek opinions or data
      • Generate new ideas
      • Fulfill policy or regulatory requirements
  › The benefit to our organization will be...
    • You may have more than one benefit
  › Be prepared to share the statements
  › 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
GOOD QUESTIONS MATTER

› They matter because if they are poor they waste time, resource and good will.
› Your organization’s needs live here
› They honor (or not) the knowledge of the community you are engaging
› They are hard because
  › Jargon
  › Assumptions
  › Language

CONSTRUCTION OF A QUESTION

EXAMPLE: We have to shut one of these three rural hospitals for budgetary reasons. This decision is not open for debate.

› Which hospital should we shut? (Theirs! No, Yours!)
› What should we do instead of have three hospitals? (Can we have a clinic? An urgent care centre? A nurse practitioner?)
› How can we best serve all of the communities? (Who is most central to everyone? Which is the worst drive in winter? Where can helicopters land?)
ASKING GOOD QUESTIONS

› Are you asking questions people can answer?
  › “Was your care well coordinated?”
  › “Were you given the same information about your care by everyone?”

› Are you asking questions that produce information you can use?
  › “Were the staff well trained?”
  › “Did everyone introduce themselves?”

QUESTIONS HAVE ASSUMPTIONS INSIDE

› “What color should we paint the waiting room?” versus “We have $500 to spend on the waiting room. What should we do?”

› “What is the key to improving working relationships with the lab?” versus “How do we accomplish our shared goals?”

› “What went wrong and who is responsible?” versus “What can we learn and what is possible?”
YOUR ORGANIZATIONS NEEDS

› Your Draft Questions – Remembering to Listen
  › Exchange them with the person next to you
  › Read the other person’s from a ‘naive’ perspective (5 min)
    • What, exactly, are they asking and
    • What are their assumptions?
  › Share this information with each other (5 min each)
    • Do not defend!
    • Listen quietly,
    • Ask one clarification questions only (no statements!)
    • Say “Thank you”
  › Re-draft questions on worksheet (10 min)
  › Repeat (5 min each, TOTAL TIME 35 MIN)

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

IDEOALLY 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
› Native populations, LGBTQ, immigrant youth

› 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 more power you share, the more resources you need to support the process

POWER SHARING

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!). 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>Collaborating</th>
<th>Involving</th>
<th>Consulting</th>
<th>Informing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.</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>
<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>
<td>Obtaining community and individual feedback on analysis, alternatives and/or decisions. For example, surveys, door-knocking, citizens' panels and focus groups.</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>
</tr>
</tbody>
</table>
ANOTHER LOOK AT POWER SHARING

- 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
  - Power being shared
  - Topics on the table
  - Topics that are off the table but which will come up
  - Any clarification you need from Leadership
LUNCH

LISTENING AND REPORTING EXERCISE
THINKING ABOUT YOUR PATIENTS/FAMILIES AND COMMUNITIES NEEDS

› Safety, now and later
› Accessibility
› Respect
› Support

BRAINSTORM

› What groups could you engage?
› What demographics?
› What communities?
› What program’s clients or patients?
BRAINSTORM

What makes an “Accessible” Engagement?

WHEN PLANNING ENGAGEMENTS FOR DIFFERENT GROUPS...

› Urban, Rural, 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...
A “QUOTE” ON DIALOGUE

Don’t tell them what it is to be listened to...
Ask them what it is to be heard.

- Unknown

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
› 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 offer 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
REMEMBER THE QUESTIONS... 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?

HARDLY REACHED

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 Drop-in. 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?
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?

SOME OF OUR IDEAS

› Media stories
› Thank you letters
› Testimonial of impact
› Updates
› Reports including their input as published
› Bulletin board (and tell them about it)
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
  › This can be reduced by building engagement planning into organizational processes

› Money or resources

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?”
  › Better yet, let them tell you what “different” would look like
  › Listen to their list of priorities too
  › Have resources
  › Go for wins
A “QUOTE” ON DIALOGUE

Don’t tell them what it is to be listened to...
Ask them what it is to be heard.

- Unknown

AND AFTER ALL OF THAT, ENGAGEMENT IS LIKE

➤ A well orchestrated military campaign
➤ Dancing...
➤ ...with Donald Rumsfeld
WORKSHEET

› Questions you can’t answer (your known unknowns!)

› Concerns about your organization’s willingness to hear results and how to mitigate them

THE POEM!
BRAINSTORM

What are the limits of Advisory Groups, anyway?

Feedback/Evaluation
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