

# Empowering Persons with Stroke, Enriching Outcomes: Using Patient Centred Goals and Outcome Measures to Guide Care

Anne W. Hunt PhD OT Reg.(Ont.)

September 27, 2024

# PRESENTER DISCLOSURE

- **Presenter:** Anne W. Hunt PhD OT Reg. (Ont.)
- **Relationships with commercial interests:**
  - Speakers Bureau/Honoraria:
    - COPM Inc. committee on education & community outreach
    - Toronto Stroke Network

# MITIGATING POTENTIAL BIAS

- **Presenter:** Anne Hunt
- **Mitigation of conflict:** Use and choice of patient reported outcome measures (PROMs) are at the discretion of the user

# LEARNING OBJECTIVES

- 1) Explain the importance of cultivating a team culture where patient goals drive individualized care plans and decision-making processes.
- 2) Identify approaches and techniques for eliciting and establishing patient-centred goals in healthcare settings.
- 3) Understand the significance of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in evaluating outcomes.



# Land Acknowledgement

# Agenda

## Empowering Persons with Stroke, Enriching Outcomes: Using *Patient Centred Goals* and *Outcome Measures* to Guide Care

- Introduction
- Patient centred goals
- Team Culture
- PROMs & PREMs
- Questions

# Who is Anne Hunt?



## Who are you?



- Do you use patient goals in your practice? Why? Why not?
- If so, do you have a standard process to:
  - Set goals?
  - Measure/review progress?
  - Determine achievement?



# Think about...

## Identify issues that are:

- Problems for the patient?
- Important, meaningful & relevant?

## Ensure your practice is patient-centred & collaborative?

- How do you ensure that goals & interventions are important, meaningful and relevant?
- How do you ensure the patient is an active participant in their care?

## Measure outcomes

- What happens to the client's goals/care plan at discharge?
- How do you communicate goals/progress to the next point of care?
- How do you document progress? Outcomes?



# Goal setting in rehabilitation

- Goal setting is standard practice for many rehabilitation professionals <sup>1,2</sup>
- Provide focus for teams, framework for interventions <sup>3</sup>
- Use of patient-centred goals is associated with improved outcomes <sup>4-7</sup>

1. ACOTRO, ACOTUP, & CAOT. (2021). Competencies for Occupational Therapists in Canada/Référentiel de compétences pour les ergothérapeutes au Canada. Accessed (insert date) at [https://acotro-core.org/sites/default/files/uploads/ot\\_competency\\_document\\_en\\_web.pdf](https://acotro-core.org/sites/default/files/uploads/ot_competency_document_en_web.pdf)
2. <https://www.collegept.org/rules-and-resources/assessment-diagnosis-treatment-standard>
3. Siegert et al., 2004
4. Brock et al., 2009;
5. Dalton, et al., 2011;
6. Kus et al., 2011

# Goal-Setting Theory

1. Linear relationship between goal difficulty & performance
2. Specific, difficult goals lead to higher performance than no goals or vague goals 'do your best'



## New Developments in Goal Setting and Task Performance

Edited by  
Edwin A. Locke  
and Gary P. Latham



# Goal mechanisms

1. Goals direct attention
2. Goals sustain effort
3. Goals support persistence
4. Goals activate knowledge and skill

Moderators

Ability, feedback from others



## New Developments in Goal Setting and Task Performance

Edited by  
Edwin A. Locke  
and Gary P. Latham



# Goal setting & pursuit is hard!

- Goal setting and including the patient in this process is challenging! <sup>8-10</sup>
- Many professionals do not routinely include clients in goal setting. <sup>11</sup>
- Default is the organization's goal
  - 'the goal is discharge' <sup>12</sup>

8. Barnard et al., 2010


9. Schoeb, 2009

10. Kang et al 2022

11. Holliday et al., 2007

12. Hunt et al., 2015





## Why is patient-centred goal setting hard?

- Lack of time, process
- Conflicts in type goals (e.g., impairment vs occupation focused goals)
- The organization's goal is prioritized over the patient's goal

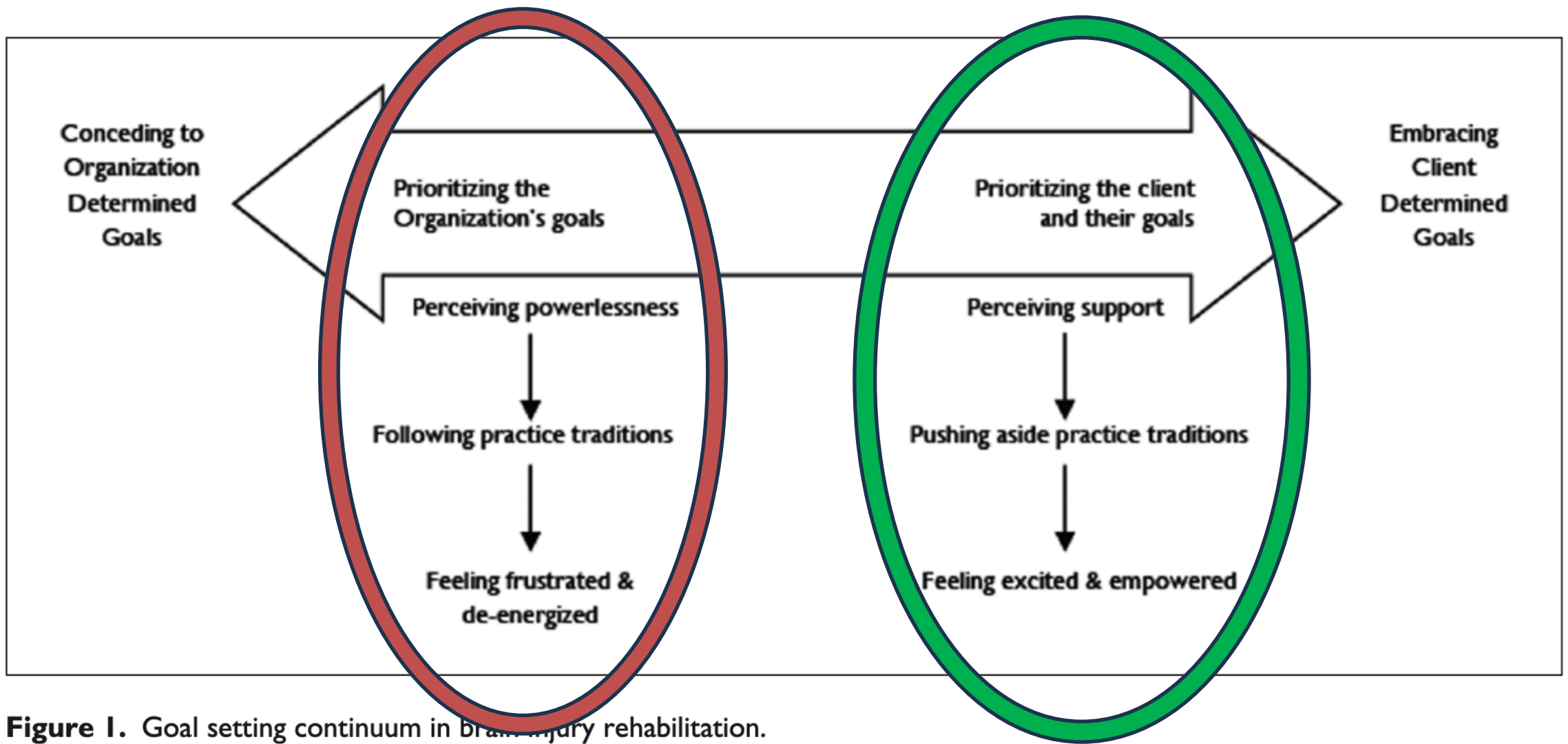
# Balancing patient-centeredness with organization priorities=conflicts & tensions

*“We wanted to be doing more client-based goal setting. But you are always fighting the system which is very medical based. When I’d bring up a client-based goal, I often hit a brick wall with certain people, some days I didn’t address client goals with the client because I didn’t want to deal with the hassle.”*

*Laurel, inpatient rehab*

*“ I don’t know how interested the institution is in supporting client goals. It’s really demotivating.”*

*Tamara, inpatient rehab*



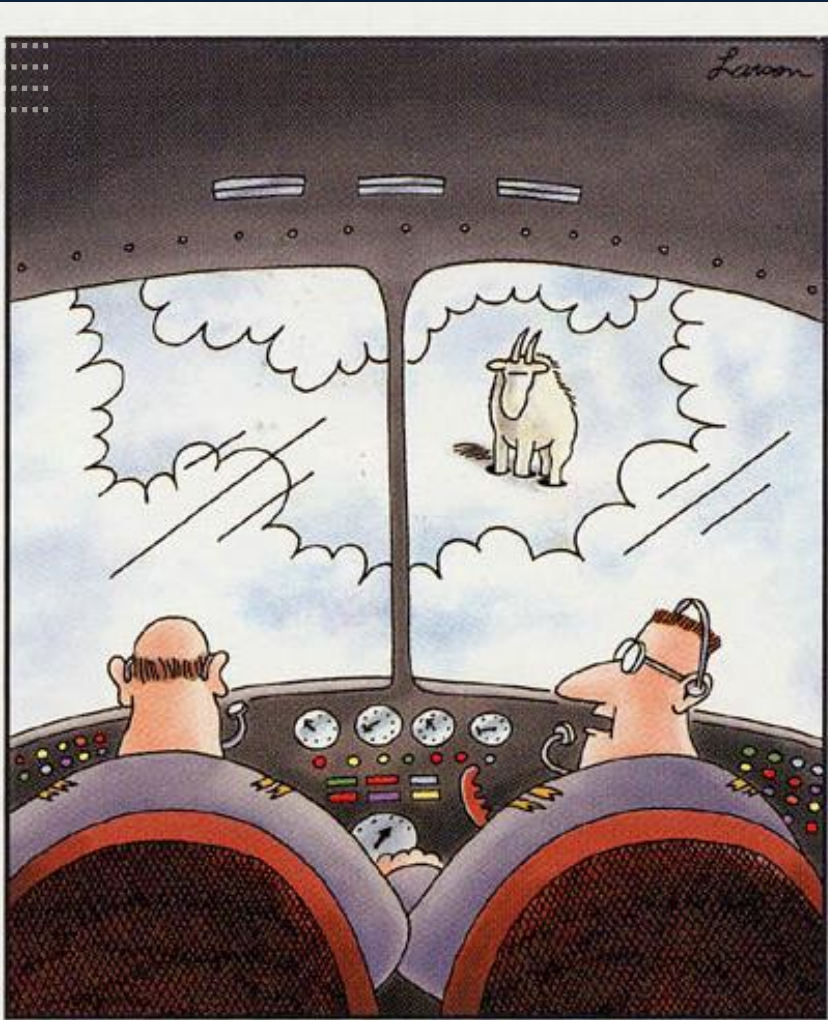
**Figure 1.** Goal setting continuum in brain injury rehabilitation.

(Hunt et al., J of Qual Health Research 2015)



# Clinical Implications

- **Who decides the goals is important.**
  - These are the goals that are prioritized.
- **Embracing patient goals aligns with patient-centred practice**
- **Using occupation-based goals was difficult for therapists in some settings; yet was integral to embracing client-centred goals.**
  - Consistent with previous rehabilitation research (Holliday et al., 2005, Bright et al., 2012).
  - Differences may reflect discomforts in talking about occupation in some environments (e.g., medical model).



"Say ... what's a mountain goat doing way up here in a cloud bank?"

# The importance of problem identification

- First step in goal setting!

# Facilitative techniques-Identification of problems

## **Be direct**

- What do you really need to do to be able to go home?

## **Ask for detail**

- If you could do that activity, what would it look like?

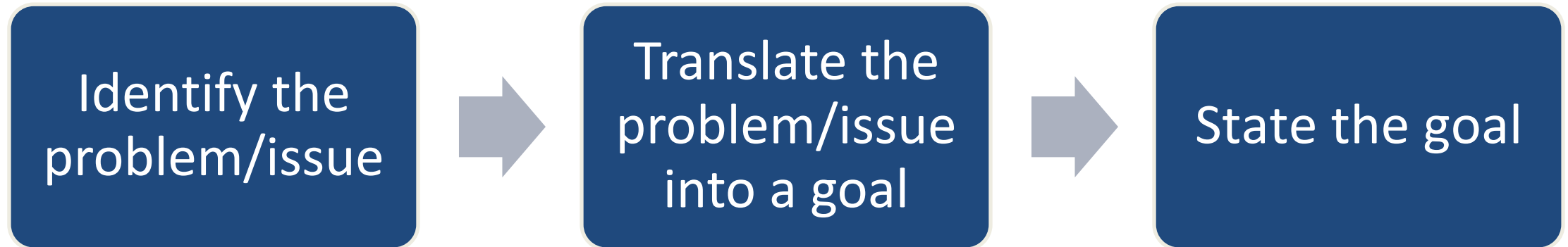
## **Ask open ended questions about specific tasks**

- How are you managing your grocery shopping? (NOT Are you having any problems with...)

## **Summarize**

- So I understand you are having difficulty with XXX... and YYY...Is there anything else you'd like me to know?

# Translating problems into goals



# Formulating goals from identified problems

- Avoid making judgements and assumptions about what is realistic for now
- Keep in mind that significant others may have different perspectives
- Use the patient's words
- Begin with "I will..."
- Consider SMART or other frameworks
- Include a statement about goal achievement-what will it look like?
- Understand that you may not be able to address all performance issues/problems
  - Share this with your patient & family!

# It takes time to set 'good' goals

## **Really listening to the client**

*“For me, its all about finding out who they were before they came to the hospital. I spend a lot of time getting a sense of that person...it’s important to really listen...”*

*Kimberley, acute care*

*“We need to hear the patient’s perspective, because so many times, we as a team just dismiss people’s wishes or goals...that’s just not fair until we really hear them out and understand them”*

*Elizabeth, acute care*

# Embracing patient-centred goal setting

Let the patient lead

Ask the client the 'right' questions

Focus on occupation, not impairment

Take the time needed

Support from the organization is key!

# Team Culture

An example of taking on the challenge of  
patient centred goals



# Assumptions

## **View the patient as capable**

*“I think we don’t assume that they are incapable. We assume that they are capable. We want to empower our patients with as much information and education as we can so that they can make an informed decision [about goals]”*

*Elizabeth, acute care*

## **Realism of goals may not be necessary**

*“It’s ok for them to have goals that are unrealistic. You need to let them set those goals because if you don’t you’re really limiting them...people make so many gains many years post-injury. Who really knows what they can achieve until you try it?”*

*Ava, community*

# Embracing Patient- Centred Goal Setting

- Recognize the importance of goal setting
- Assume the patient is capable of participation in their own care
- Provide foundational information.
  - What is goal setting? How will it be used to facilitate care?
- Emphasize occupation
  - Activities that are meaningful to the patient
- Advocate for the patient & their goals.
  - Within and beyond team!
- Use a consistent process
- Consider using a patient reported outcome measure (PROM)
- Take the time needed!

# Patient Reported Outcome Measures

“Patient-reported outcome measures (PROMs) are used to assess a patient’s health status at a particular point in time. **PROMs are standardized, validated survey tools that assess health outcomes reported by patients**, in areas such as general health and quality of life, or around specific symptoms, functional ability and physical, mental and social health...In some cases, using pre- and post-event PROMs can help measure the impact of an intervention.”



## Why use a PROM?


- Support a patient centred approach
- Informs care
  - Individual (micro)
  - Hospital/facility (meso)
  - Systems (macro)
- Supports evaluation of effectiveness/quality of care
- Can be linked to other data (e.g., PREMs) to inform individual and systems level decision making

# Why use a PROM/PREM?

I want to demonstrate that:

- My/my team practice is patient-centred
- My/my team service includes evidence-based practice
- I/my team measure outcomes
- I/my team am interested in quality of care
- My/our intervention/service makes a difference!



<b>PRO Category</b>	<b>Main Characteristics</b>	<b>Main Strengths</b>	<b>Main Limitations</b>
Health-related quality of life (HRQL)	<ul style="list-style-type: none"> <li>• Is multidimensional</li> <li>• Can be generic or condition-specific</li> </ul>	<ul style="list-style-type: none"> <li>• Yields a global summary of well-being</li> </ul>	<ul style="list-style-type: none"> <li>• May not be considered a sufficiently specific construct</li> </ul>
Functional status	<ul style="list-style-type: none"> <li>• Reflects ability to perform specific activities</li> </ul>	<ul style="list-style-type: none"> <li>• Can be used in addition to performance-based measures of function</li> </ul>	<ul style="list-style-type: none"> <li>• May reflect variations in self-reported capability and actual performance of activities</li> </ul>
Symptoms and symptom burden	<ul style="list-style-type: none"> <li>• Are specific to type of symptom of interest</li> <li>• May identify symptoms not otherwise captured by medical workup</li> </ul>	<ul style="list-style-type: none"> <li>• Are best assessed through self-report</li> </ul>	<ul style="list-style-type: none"> <li>• May fail to capture general, global aspects of well-being considered important to patients</li> </ul>
Health behaviors	<ul style="list-style-type: none"> <li>• Are specific to type of behavior</li> <li>• Typically measure frequency of behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Target specific behavior categories</li> </ul>	<ul style="list-style-type: none"> <li>• Validity may be affected by social desirability</li> <li>• May produce potential patient discomfort in reporting socially undesirable behaviors</li> </ul>
Patient experience 	<ul style="list-style-type: none"> <li>• Concerns satisfaction with health care delivery, treatment recommendations, and medications (or other therapies)</li> <li>• Reflects actual experiences with health care services</li> <li>• Fosters patient activation</li> </ul>	<ul style="list-style-type: none"> <li>• Is an essential component of patient-centered care</li> <li>• Is valued by patients, families, and policy makers</li> <li>• Relates to treatment adherence</li> <li>• Relates to health behaviors and health outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• May be a complex, multidimensional construct</li> <li>• Requires confidentiality to ensure patient comfort in disclosing negative experiences</li> <li>• Does not provide sufficient evidence that activation enhances health care</li> </ul>

# Patient Reported Experience Measure

“Patient-reported experience measures are instruments that capture a patient’s experience of receiving care, specifically the patient’s perception of what happened during their care encounter and how it happened”



# PROMs & PREMs

- O'Callaghan G, Fahy M, O'Meara S, Chawke M, Waldron E, Corry M, et al. Transitioning to home and beyond following stroke: a prospective cohort study of outcomes and needs. BMC Health Serv Res. 2024;24(1):449.
- O'Callaghan G, et al. Experiences and preferences of people with stroke and caregivers, around supports provided at the transition from hospital to home: a qualitative descriptive study BMC Neurology. 2024; 24:251



# Implementing a PROM or PREM

- Team decision
  - Use shared decision making!
- Pick the PROM/PREM
- Decide who/how it will be administered
- Determine how will results be used
- Establish documentation process
- Train the team
- Establish PROM champion
  - Responsibilities to ensure use, train new team members, liaison with administration
- Evaluate & Re-evaluate regularly

# Implementing PROMs & PREMs

**TIME IS NECESSARY!**



# What can the organization do?

## Create and maintain team cultures that support the use of PROMs/PREMs

- Allow clinicians' sufficient time to complete the measures
- Support a consistent process
- Provide education to all new team members & designate who is 'in charge' of training.
- Share the PROM if appropriate with next point of care between care settings.
- Include the PROM in your documentation
- Provide support for aggregation of data, evaluation, reporting
- Document findings to support need for service
- Check in regularly with the team

# Take Home Points

Patient-centred goals are important & lead to better outcomes

Time is needed to set patient-centred goals

PROMs & PREMs contribute to patient-centred care

Organizations have a responsibility to support individuals and teams to embrace patient-centred goal setting/PROM/PREM use



# Questions



