



# Understanding Patient and Provider Experience of Shared Decision-Making in Community Rehabilitation: Steps to Realizing Patient-Centred Care

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## Background

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The refrain "no decision about me without me" reflects a growing trend in provincial, national, and provincial healthcare systems towards greater patient-centred care and patient engagement.<sup>1-6</sup>

- Alberta Health Services (AHS) is a learning health system.
- In April 2017, AHS released a new Model of Care for Community Rehabilitation sites to redesign and standardize how care is delivered.
- 18 sites voluntarily pilot tested the new Model during a 1year implementation process beginning April 2017. The Model will spread to all 140 AHS sites over four years.
- One facet of the new Model is to enhance the practice of patient-centred care across the province.<sup>7</sup>

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Study Tool	Description	Completed						
Alberta Shared decision- maKing Measurement Instrument (ASK-MI)	<ul> <li>1-page</li> <li>Dyadic instrument</li> <li>Measures experience of SDM</li> </ul>	Patient and provider T0 and T1						
Patient Health Engagement (PHE) Tool	<ul> <li>1-page</li> <li>Measures patient activation and engagement in care</li> </ul>	Patient T0 and T1						
EQ-5D-5L	<ul> <li>2-page</li> <li>Measures quality of life to understand patient-reported outcomes</li> </ul>	Patient T0 and T1						
WatLX <sup>™</sup>	<ul> <li>2-page</li> <li>Captures patient's perceptions at the end of their care in rehabilitation</li> </ul>	Patient T1						
Table 1.   Survey Tools								
Results								
Site	Providers F	Patients						
Recruitment	n=10 r	e=24						
Demographic Information	80% Caucasian860% Female6Average age = 37.4 years6Average work experience =512 years40% Physiotherapists	87.5% Caucasian 66.7% Female Average age = 48.3 years 60% Employed						

### Results

**Time** "Time is a really difficult challenge, [...] because I feel that even when people are talking about their health 75 minutes goes by so fast. [...] [I] just need to give them more time [...] for them to gain that trust to feel they want to come back." – Female provider (non-early adopter).

"I think it's just with [...] time and experience, just telling them up front, that's how I clarify with my uncertainty." – Female provider (non-early adopter)

Buy-in"When [appointments] go well the [...] patients usually pretty involved. [...] They'remotivated to get better and [...] they want it. They show an interest in knowing what'sgoing on." – Female provider (non-early adopter)

"We need to get that motivation. We need to get why you're not doing [the exercises]. What's happening and trying to reinforce the importance of doing it, and why." – Female provider (early adopter)

"I feel it hasn't gone well [...] when you can kind of tell that the patient is very skeptical

- Shared decision-making (SDM) is a key component of patient-centred care.<sup>6</sup>
- An interdependent decision-making process between patients and their providers in which patients share their personal values and preferences, and providers share best clinical evidence, so that both parties work together to reach medical decisions.<sup>8</sup>
- Evidence demonstrates that SDM increases patient knowledge, lessens anxiety, improves patient health outcomes, increases adherence to treatment, and decreases inappropriate service usage.<sup>8,9-11</sup>
- SDM is neither routinely practiced or taught in healthcare.<sup>11-16</sup>

#### Gaps in Knowledge

- 1. There is a lack of understanding of how SDM is practiced in community rehabilitation settings.<sup>17</sup>
- 2. AHS is interested in understanding how best to support the implementation of the new Model.

## Phase 1 Objectives

- 1. What are the best methods to study SDM and patient-centred care in community rehabilitation?
- 2. What is the best way to support the implementation of the new Model? We were particularly interested in the best recruitment strategies for sites, providers, and patients, as well as the appropriateness of our interview question guide and study tools.

#### Table 2. Summary of Data Collected

#### **Recruitment Challenges**

- 1. Sites' and providers' concern regarding the burden research participation would add to their already busy caseloads.
- 2. Low feasibility and low completion rate for patients' T1 surveys when appointmentbased as few patients had 6-week (or near) appointments booked.
- 3. Small patient populations.
- 4. Low turnover in patients.

- from the get go. [...] Often I feel like [...] your early patient attitude [...] will influence whether or not that that interaction will go well and often whether they continue to pursue care or if they if they go elsewhere." – Male provider (non-early adopter)
- **Goal-setting** "I'll generally give patients options, but I found that when I was more democratic in offering different options patients would actually think a little bit less of me. [. . .] They want an expert that's going to tell them what's best. [. . .] Not that I don't give them options, I do, but I always say what's best and what I want to do and they 99% of the time go with that." – Male provider (non-early adopter)

"Ultimately it is the patient's decision. [. . .] You might think the patient's decision is not the appropriate one, but that's [. . .] the autonomy and it's their right [. . .] it's their human right it's [. . .] their right to do and still get care." – Male provider (early adopter)

#### Table 3. Exemplar Transcript Quotes Regarding Key Themes

## Conclusions

- Based on our internal consistency calculations, previously published calculations, and participants apparent ease completing the questionnaires, we believe that the study tools are appropriate for Phase 2.
- Based on the quantity and quality of discussion generated during interviews, we believe our question guide is appropriate for Phase 2.
- Phase 2 will be split into two studies (Figure 3) to address the recruitment challenges encountered in Phase 1 (Figure 2).

Separate research questions for SDM experience in community rehabilitation and for the new	TO surveys Inded out by site recruiter	No provider exclusion criteria	T1 surveys handed out at 3-months Draw for Fitbit	Include rural, urban, and metropolitan sites
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### Methods

#### **Participant Population**

- Inclusion criteria for patients: ≥ 18 years of age, able to consent without proxy, and able to understand and speak English.
- There were no patient exclusion criteria.
- Inclusion criteria for providers: professionally-licensed in Alberta, and employed in community rehabilitation setting where recruitment is taking place for at least 6 months.
- Exclusion criteria for providers: working less than 0.3 FTE.

### Focused Ethnography

- 2 community rehabilitation sites in urban-metropolitan city in Alberta: one early adopter site and one non-early adopter site.
- Our culture of interest was patients, providers, and managers at musculoskeletalfocused community rehabilitation sites.



5. Variant conditions between community rehabilitation sites including: group versus individual-based care; treatment in an open exercise area versus a private room; and public versus privately financed.

#### **Qualitative Results**

- Only reached saturation for provider interviews (n=10). We did not reach saturation with patient interviews (n=3).
- Two main themes emerged: time and buy-in (Table 3).
- In community rehabilitation, providers do not use the language of SDM, but rather goal-setting.
- Time and buy-in directly influenced what goals were set, how goals were set, and whether goals were reached (Table 3).

#### **Quantitative Results**

- From our preliminary results, we begin to see the presence of variability in our quantitative data, which will become more apparent in a larger, more diverse sample.
- Internal consistency was calculated for the ASK-MI and EQ-5D-5L using Cronbach's Alphas and for the PHE using an Ordinal Alpha via Empirical Copula.
- Because only four patients completed the T1 follow-up that included the WatLX<sup>™</sup>, our ability to draw conclusions on its internal consistency is very limited.



Figure 2. Phase 2 Changes

#### Limitations

- 1. Small site and sample size.
- 2. Both community rehabilitation sites were from the same geographical area.
- 3. Small patient voice (did not reach saturation).



References

- Coulter A. Making shared decision making a reality: no decision about me without me. Londong; 2011
- Health D of. Liberating the NHS: No decision about me without me [Internet]. London; 2010. Available from: https://www.gov.uk/government/uploads/attachment\_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf
- Pope TM. Certified Patient Decision Aids : Solving Persistent Problems with Informed Consent Law. J Law Med Ethics. 2017;45:12–40.
- Canada's Strategy for Patient- Oriented Research (SPOR) The SPOR Rewarding Success Initiative.
- Alberta Innovates. The Alberta SPOR Support Unit. 2017. Advisory Panel on Healthcare Innovation. Unleashing Innovation: Excellent Healthcare for Canada [Internet].,2015. 164 p. Available from: http://www.health-system-systeme-sante/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins/alt/report-healthcare-innovation-rapport-soins/eng.pdf
- Alberta Health Services. Community Rehabilitation Model of Care Guide for Year 1. Edmonton, AB; 2017
- O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR, et al. Toward the "tipping point": Decision aids and informed patient choice. Health Aff. 2007;26(3):716–25.
- Stacey D, Légaré F, Nf C, Cl B, Mj B, Kb E, et al. Decision aids for people facing health treatment or screening decisions (Review ) Decision aids for people facing health treatment or screening decisions. 2014;(1).
- Légaré F, Stacey D, Turcotte S, Mj C, Kryworuchko J, Id G, et al. Interventions for improving the adoption of shared decision making by healthcare professionals (Review ) SUMMARY OF FINDINGS FOR THE MAIN COMPARISON. Cochrane Database Syst Rev. 2014;15(9):CD006732
- Elwyn G, Scholl I, Tietbohl C, Mann M, Edwards AGK, Clay C, et al. " Many miles to go ... ": a systematic review of the implementation of patient decision support interventions into routine clinical practice. BMC Med Inform Decis Mak [Internet]. 2013 [cited 2017 Oct 12];13 Suppl 2(Suppl 2):S14. Available from: http://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/1472-6947-13-S2-S14
- Godolphin W. Shared decision-making. Healthc Q. 2009;12:e186–90.



Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Educ Couns [Internet]. 2014;94(3):291–309. Available from: http://dx.doi.org/10.1016/j.pec.2013.10.031
 Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. Patient Educ Couns. 2008;73(3):526–35.
 Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D, Macphail S, et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. Bmj [Internet]. 2017;1744:j1744. Available from: http://www.bmj.com/lookup/doi/10.1136/bmj.j1744
 Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. Implement Sci [Internet]. 2015;11(1):114. Available from: http://implementationscience.biomedcentral.com/articles/10.1186/s13012-016-0480-9
 Rose A, Rosewilliam S, Soundy A. Shared decision making within goal setting in rehabilitation settings: A systematic review. Patient Educ Couns [Internet]. 2017;100(1):65–75. Available from: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=prem&NEWS=N&AN=27486052





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