

# Data and outcomes framework for moderate-severe TBI developed by a Collaborative

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Governance Group

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## Introduction

A Collaborative comprising funders, providers and consumer representatives was set up in Auckland in 2016

Its aim is to improve the client journey for people with moderate-severe traumatic brain injury (TBI)

This presentation briefly describes how an outcomes framework is being developed by the Collaborative as one of its key work streams

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## Data & outcomes work stream

**Aim:** to identify a framework, develop and test measures that can be used consistently by TBI providers at:

- An individual level to improve clinical care
- A service level to improve quality of care, and
- A health system level where aggregated information is used to measure system-wide process initiatives across the rehabilitation journey

The Institute of Medicine Six Domains of Health Quality (IOM6)<sup>1</sup> was selected and work commenced to agree measures

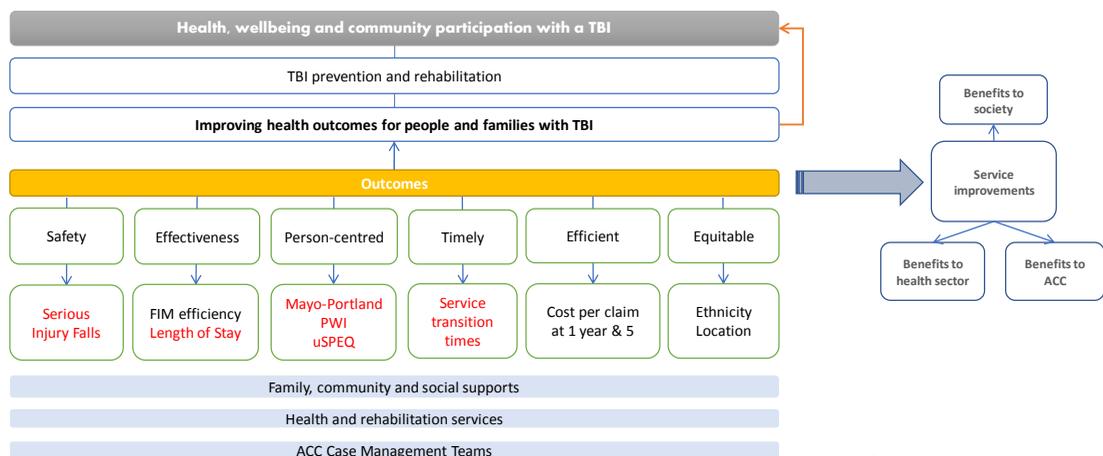
1 Institute of Medicine (US) Committee on Quality of Health Care in America (2001) *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington (DC): National Academies Press (US)

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## Identifying measures

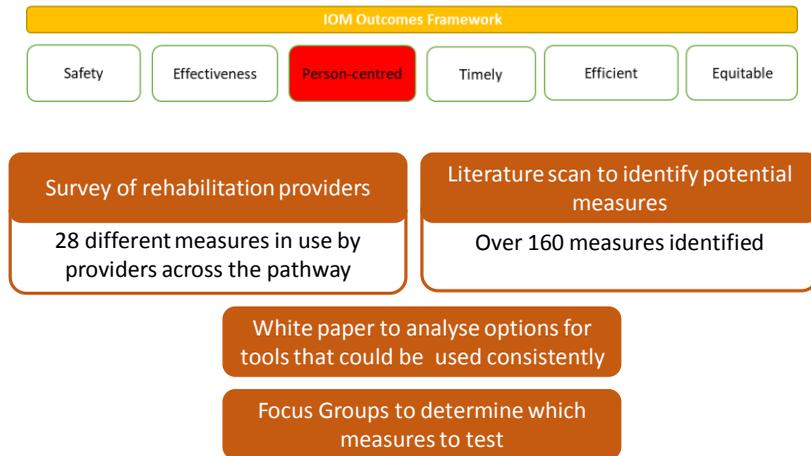


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# Determining person centered outcome measures

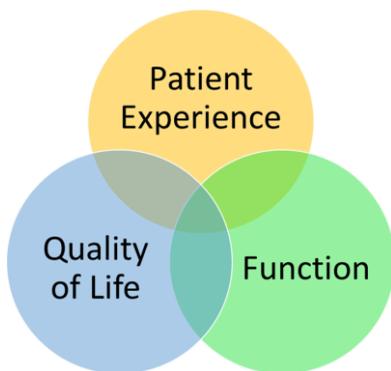


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# Determining Person Centered Outcomes Measures



Attribute	Criteria Decision
Measure	<ul style="list-style-type: none"> <li>Quality of Life</li> <li>Function</li> <li>Patient Experience</li> </ul>
Specificity	<ul style="list-style-type: none"> <li>Generic Across Presentations</li> </ul>
Ease of Administration	<ul style="list-style-type: none"> <li>Number of questions</li> <li>Complexity of questions</li> </ul>
Utility across a range of Presentations / Pathways	<ul style="list-style-type: none"> <li>Able to be utilised across different presentations, services and pathways</li> </ul>

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PROM	Description
<b>NeuroQoL</b>	Condition specific (acquired brain injury) quality of life tool Questions are negative, geared towards experience of symptoms
<b>WHODAS</b>	Generic instrument that assesses patient reported function
<b>EQ5D</b>	Generic tool assessing General Health Perceptions
<b>WHOQOL</b>	Generic tool assessing quality of life
<b>QOLIBRI</b>	Condition specific instrument specifically developed to assess health-related quality of life (HRQoL) of individuals after traumatic brain injury.
<b>PWI</b>	Multi-dimensional scale measuring satisfaction with life covering basic quality of life domains

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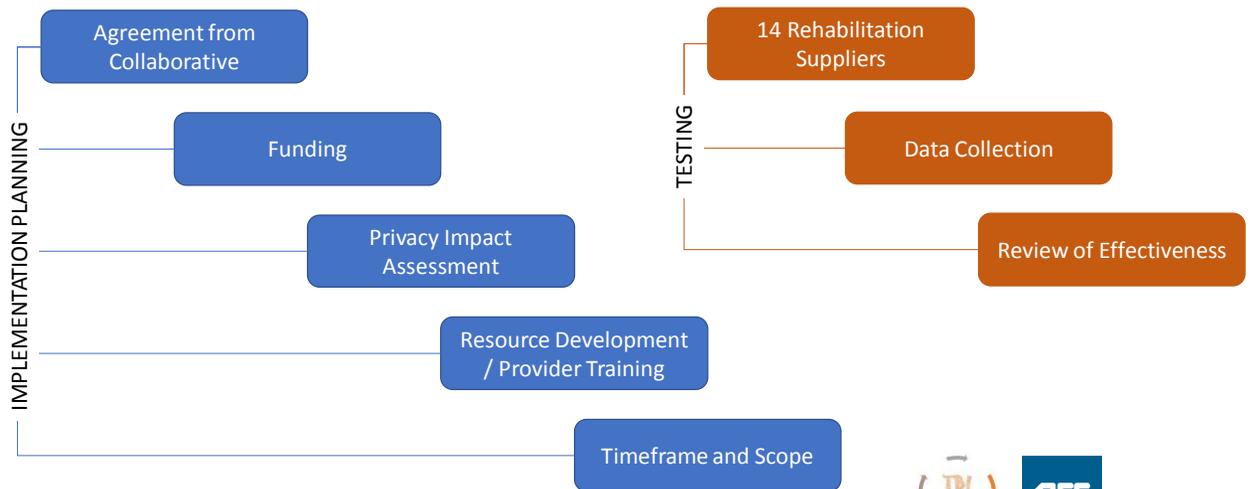
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PROM	Measures	Generic / Specific	Ease of Administration	Utility across services
<b>NeuroQoL</b>	Quality of Life ✓	Condition Specific	24 items (short form)	Brain injury specific
<b>WHODAS</b>	Functioning ✓	Generic ✓	12 Items (short form) ✓	Currently used in other ACC Programmes ✓ Applicable across presentations / services ✓
<b>EQ5D</b>	Health Perceptions	Generic ✓	15 items with yes/no answers	Applicable across presentations / services ✓
<b>WHOQOL</b>	Quality of Life ✓	Generic ✓	26 Items	Applicable across presentations / services ✓
<b>QOLIBRI</b>	Quality of Life ✓	Condition Specific	37 items (short form)	Brain injury specific
<b>PWI</b>	Quality of Life ✓	Generic ✓	8 items ✓	Currently used in other ACC Programmes ✓

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## Testing of the Tool – Personal Wellbeing Index



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## Results to date (Personal Wellbeing Index)

- 100 PWI's administered over a 4-month period
- 2nd PWI not administered in the majority of clients yet
- Survey of providers found:
  - Providers rate usefulness of PWI as 3.23 on a 5 point scale
  - Administration time varied (5 – 40 minutes)
  - "Spirituality" question improves engagement with some clients
  - Clear definitions of questions needed by some clients
  - Relevance of PWI to the client's recovery is not always obvious
  - More guidance in the relevance of PWI required

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## Conclusion

- The Collaborative provides a mechanism for decision making and governance over what to collect, its purpose, how it is stored and how information is shared
- Consumer participation in the Collaborative has been vital in choice of measures, cultural lens and provider training
- Providers are keen to have consistency collecting common measures but there is concern around “over-surveying” for some clients with the number of measures being tested – some rationalisation will be required
- Measures have the potential to inform future commissioning models

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