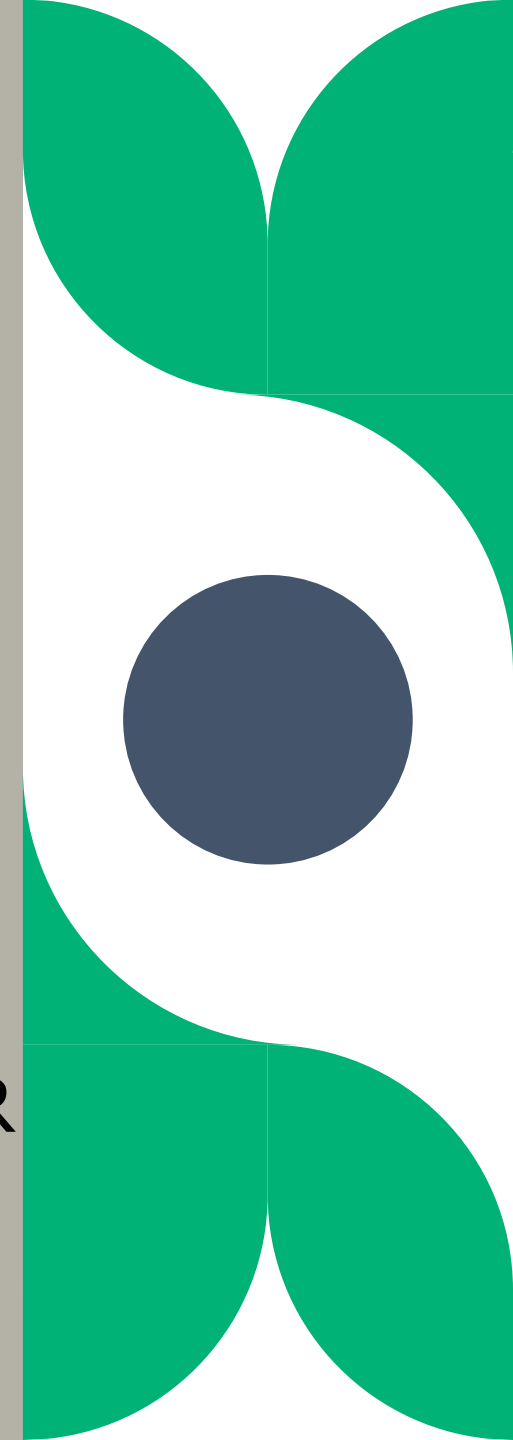


Measuring outcomes: three keys to success!

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Paragon Mobility, Brisbane, Australia

ATSA Independent Living Expo 2024

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Disclosures

- I work part time for *Paragon Mobility*, an Australian importer and distributor of wheeled mobility and seating AT
- This workshop is based on:
 - Published peer-reviewed evidence
 - Clinical consensus
 - Personal experience and opinions based on 20+ years in the AT industry



Slide deck and resources

- *2024 ATSA Measuring Outcomes: 3 keys to success!* slide deck
- *Measuring Outcomes* Handout



Outline

- Outcomes: What are they?
- Developing, reviewing, locating outcome measurement instruments
- Barriers, challenges, and facilitators to measuring outcomes
- Outcome measures for wheeled mobility and seating
- Practical considerations



Outcomes: What are they?

In the broadest terms, measuring outcomes asks:

What happened?

Three conceptualisations

- *Process*
 - The way in which a program / service / intervention is delivered or received
- *Output*
 - How much program / service / intervention is delivered or received?
- *(clinical) Outcome*
 - What happened for the client, person as a result of the service or intervention?
 - What are the broader results achieved through provision of goods and services (e.g. population health, economics)

Measuring the *Process*

- *How is the service / intervention provided?*
 - **E.g. Assess the clinical practice of clinicians**
- *Does the service meet required [clinical, operational] standards outlined in policies, procedures, clinical pathways?*
 - **E.g. How does 'usual clinical practice' compare with current best practice, E.g. CPGs, literature, other services (benchmarks)?**
- *What is the person's journey through the service?*
 - **Patient journey mapping – referral, intake, triage, allocate case to HCP, discharge, referral, procedures for *Did Not Attend***

Measuring the *Outputs*

- *Occasions of service:*
- *Time spent:* **per service, intervention, person, HCP**
- *Cost:* **per service, intervention, person, HCP**
- *Disciplines involved in service provision:* **HCPs, Technical, administration, management**
- *Quality indicators:* **e.g. Speed of response**

(clinical) Outcomes in AT

- *Who's perspective?*
 - AT user, caregiver, clinician or practitioner, supplier, funder ...
- *What is measured?*
 - AT device specifications, features, characteristics
 - AT device performance
 - Impact of AT use on activities, participation, productivity
 - Psychosocial impact of AT, satisfaction, QoL, Usability
- *How is it measured?*
 - Self report (person, circle of support), Objective measurement, Observations

Impact of AT on your life?

comfort⁽²⁾ active⁽¹⁾
Community engagement⁽¹⁹⁾
confidence⁽⁵⁾ easier⁽¹³⁾ excited⁽¹⁾ helpful⁽¹⁾
independence less pain⁽²⁾ freedom⁽¹⁰⁾
liberating⁽⁶⁾ q of l⁽¹⁾ less fatigue⁽⁴⁾ long term⁽¹⁾
wellbeing⁽¹⁾ peace of mind⁽¹⁾ mobile⁽¹⁾ safer⁽⁹⁾
social engagement⁽⁴⁾

UX, Usability, HROoL

UX vs. Usability

Usability

Effectiveness
Efficiency
Learnability
Error prevention
Memorability



USABILITY

User Experience

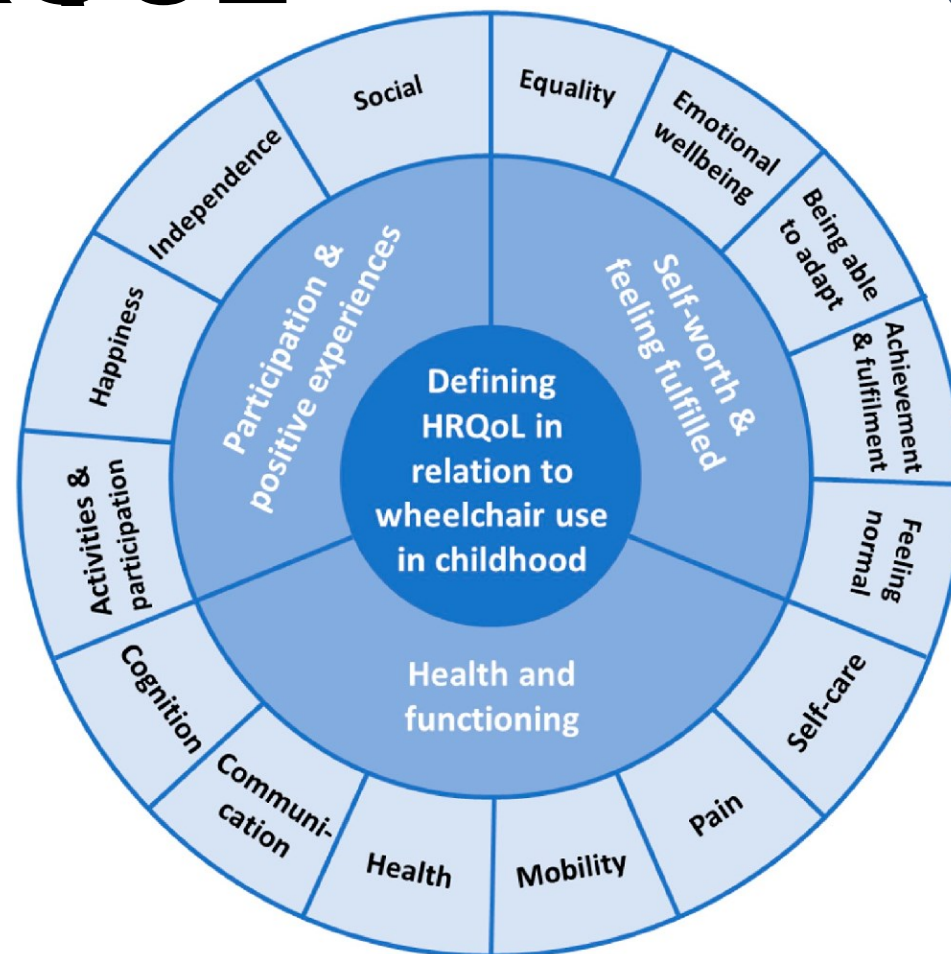
Satisfaction
Enjoyment
Pleasure
Fun
Value



USER
EXPERIENCE

Where usability is narrow and focused,
UX is broad and holistic.

@tristaljing. (2018, 2 January). *The Ultimate Guide — Difference Between Usability and User Experience*. HackerNoon. Retrieved 09 November 2023 from <https://hackernoon.com/the-ultimate-guide-difference-between-usability-and-user-experience-e926c11eac7a>

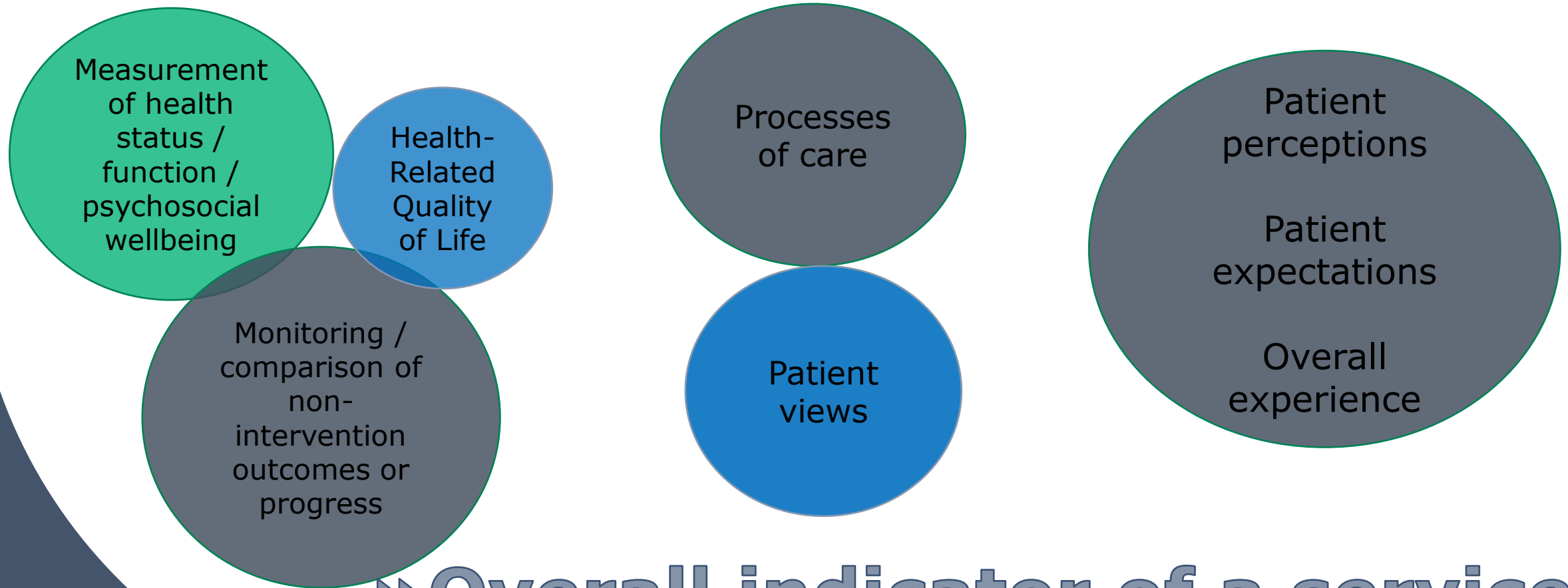


Tuersley, L., Bray, N., & Edwards, R. T. (2018). Development of the Wheelchair outcomes Assessment Tool for Children (WATCH): A patient-centred outcome measure for young wheelchair users. *PLoS ONE*, 13(12), e0209380. <https://doi.org/10.1371/journal.pone.0209380>

Measures used in healthcare

- *Patient-Reported Outcome Measures (PROMs)*
 - Assess status (of health, function, psychosocial wellbeing) as perceived by the patient, obtained by directly asking the patient to self-report.
- *Patient-Reported Experience Measures (PREMs)*
 - Assess patient experience with **PROCESS** of care
 - Aim to remove the subjectivity of “satisfaction”
- *(patient-reported) Satisfaction measures*
 - Patient’s subjective perception of services against their expectations.

PROMs + PREMs + Satisfaction



» Overall indicator of a service's performance and quality

P I C O model

- **P** *Population, Person, Problem* – describe the issue of interest
- **I** *Intervention or exposure*
 - *New practice, Current (usual) practice*
- **C** *Control / comparison to intervention – i.e. alternative*
 - *Could be a comparison with no intervention*
 - *Person as own control, e.g. case-control, cross-over, repeated measures*
 - *Sometimes not used!*
- **O** *Outcome – what does it accomplish, measure, improve, effect?*
- **M / T / T / T** – *Methodology, Type of study, Theoretical framework, Timeframe for data collection*

Different perspectives

- *"[Research / evaluation] has different purposes that are best served by different research methods..."*
 - Academic research, practitioner research, service evaluation
 - Fox, Martin & Green, 2010 – "Doing Practitioner Research"
- *There may be many ways of studying or evaluating the same thing*
- *Differences in **theoretical frameworks** & **research philosophies** e.g. from different clinical disciplines*

Steps to measure outcomes

1. Decide on outcomes of interest
Process, output, outcome? Who's perspective?
2. Define outcomes of interest
Which process, output, (clinical, person, patient) outcome?
3. Identify possible indicators of change
What could be measured to show change has occurred?
4. Decide how indicators can be measured
Data collection instruments, approaches for analysis
5. Decide how results will be reported and disseminated
Publications, reports, presentations, etc.;

Steps to measure outcomes

1. Decide on outcomes of interest
Process, output, outcome? Who's perspective?
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Which process, output, (clinical, person, patient) outcome?
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What could be measured to show change has occurred?
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Data collection instruments, approaches for analysis
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Publications, reports, presentations, etc.

What have others done?

- *Locate and review literature*
 - Peer-reviewed , grey, other e.g. clinical consensus, processes, procedures
- *Focus on*
 - Methods, methodology
 - Participants
 - Data instruments / outcome measures (see handout)
 - Limitations
 - Conclusions
- *Replicate an approach in your setting? New method?*

Outcome measures for wheeled mobility and seating

- *Wheelchair Outcome Measure (WhOM)*
- *Functioning Everyday with a Wheelchair (FEW)*
- *Psychosocial Impact of Assistive Devices Scale (PIADS)*
- *Quebec User Evaluation of Satisfaction with assistive Technology (QUEST)*
- *Goal Attainment Scale (GAS)*

Kenny, S., & Gowran, R. J. (2014). Outcome Measures for Wheelchair and Seating Provision: A Critical Appraisal. *British Journal of Occupational Therapy*, 77(2), 67-77.
[doi: 10.4276/030802214x13916969447119](https://doi.org/10.4276/030802214x13916969447119)

Outcome measures for AT

General Outcomes

- FIM – global measure of independence does not acknowledge value of AT
- ICF checklist – performance across activities and participation
- COPM – client centered measure of functional goals

AT – specific outcomes

- IPPA / EATS – service effectiveness
- MPT – global application of technology
- PIADS – impact of AT on quality of life and wellbeing
- SCAI – SIVA – cost analysis instrument

Borgnis, F., Desideri, L., Converti, R. M., & Salatino, C. (2023). A Systematic Review of Available Assistive Technology Outcome Measures. *JMIR Rehabilitation and Assistive Technologies*. [doi: 10.2196/51124](https://doi.org/10.2196/51124)

De Jonge, D., & Stevens, W. (2016). Capturing the True Value of Assistive Technologies to Consumers in Routine Outcome Measurement. *Technologies*, 4(4), 35. <https://www.mdpi.com/2227-7080/4/4/35>

Measuring Outcomes HANDOUT

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Questions for existing data collection & outcomes measurement instruments

These questions were originally devised by Jenny Knight and Vana Webster at University of New South Wales Centre for Primary Health Care and Equity (CPHCE) and the Centre for Health Equity Training Research and Evaluation (CHETRE).

What instrument am I using?

Identify the full name and version of the instrument; its original authors; and owners or holders of copyright for the instrument. Even if the instrument is published (e.g., in an open access publication), they may require approvals or licenses for use in different settings.

Why did I choose this particular instrument?

The justifications could be based on the target populations, methods of dissemination (e.g., electronic, internet, paper, telephone), current use in practice, availability (including costs for acquiring and using the instrument), and training required for those administering the instrument.

Has it undergone any psychometric testing? Is it valid? Is it reliable?

Read any studies that explore the validity and/or reliability of the instrument. Look at the populations and settings in which it was tested. Are they similar to your study population and clinical setting?

Who else has used it and with what success?

Look at previous studies where the instrument was used, and what they found. This could be reported in journal articles, conference papers and abstracts, or other documents. Check for any problems or issues in administration, scoring, defining missing values, or interpreting the results.

What are its strengths?

For example, is it widely used? Short or easy to administer? Easy to score and interpret? Available in many languages? Validated with participants and/or settings similar to yours?

Administration manuals for data collection & measurement instruments

This summary is adapted from:

Friesen, E. L. (2019). Developing an administration manual for *the electronic Mobile shower commode Assessment Tool (eMAST): A case study. Technology and Disability, 31*(S1), S174.
https://aaate2019.eu/wp-content/uploads/sites/24/2019/08/AAATE2019_Proceedings.pdf

Administrative and acquisition details of the instrument:

- Full name and version number,
- Authors and their affiliations and contact details,
- Copyright status, authorized distributors,
- Costs or fees for licensing and use,
- Requirements for training or accreditation of administrators prior to use,
- Reporting and disclosure requirements, and
- Recommended attribution for citations in publications.

Psychometric properties:

- Background information including underpinning theoretical framework, development history and summary of key development phases,
- Psychometric evaluation and testing, with statistical analysis of reliability and validity (especially published in peer-reviewed papers) and data on populations used for validation, and
- Potential limitations or threats to validity.

Administration and procedural data:

- Instructions for use and guidance on administering the instrument,
- Recommended delivery format/s and availability of templates or formatted instruments (i.e., electronic, online, paper),
- Recommended timing for administration (e.g., immediately after using the AT or after a week of use),
- Scoring of the instrument (e.g., Likert scale, word anchors, numerical scale), and
- Interpretation of sub- and total- scores
- Response burden for participants
- Administrative burden (time taken to administer, calculate results, and interpret results)

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Resources

Databases and repositories for outcomes measures

<https://www.sralab.org/rehabilitation-measures>

https://www.physio-pedia.com/Category:Outcome_Measures

<https://scireproject.com/outcome-measures/>

Books

Dahlberg, L., & McCaig, C. (2010). *Practical Research and Evaluation: A Start-to-Finish Guide for Practitioners*. London: SAGE Publications.

Fox, M., Martin, P., & Green, G. (2007). *Doing Practitioner Research*. London: SAGE Publications.

Kara, H. (2017). *Research and Evaluation for Busy Practitioners: A Time-Saving Guide*. Bristol, UK: The Policy Press. <https://helenkara.com/writing/books/>

Sheikhattari, P., Wright, M. T., Silver, G. B., van der Donk, C., & von Lanen, B. (2022). *Practitioner Research for Social Work, Nursing and the Health Professions*. Johns Hopkins University Press.

Peer-reviewed publications

Borgnis, F., Desideri, L., Converti, R. M., & Salatino, C. (2023). A Systematic Review of Available Assistive Technology Outcome Measures. *JMIR rehabilitation and assistive technologies*. <https://doi.org/10.2196/51124>

De Jonge, D., & Stevens, W. (2016). Capturing the True Value of Assistive Technologies to Consumers in Routine Outcome Measurement. *Technologies*, 4(4), 35. <https://www.mdpi.com/2227-7080/4/4/35>

Demers, L., Weiss-Lambrou, R., & Ska, B. (2002). The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0): an overview and recent progress. *Technology and Disability*, 14(3), 101-105.

Friesen, E.L. (2019). Developing an administration manual for the electronic Mobile shower commode Assessment Tool (eMAST): A case study. *Technology and Disability* 30(Supplement 1), s174. https://aaate2019.eu/wp-content/uploads/sites/24/2019/08/AAATE2019_Proceedings.pdf

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Accessing scholarly literature

Sources of scholarly literature

- Academic databases (e.g., Ovid, Scopus, PubMed)
- The Cochrane Library, Evidently Cochrane <http://www.evidentlycochrane.net/>
- PEDRo (Physiotherapy Evidence Database) <https://www.pedro.org.au/>
- OT Seeker <http://www.otseeker.com/>
- The Joanna Briggs Institute <http://joannabriggs.org/>
- ClinicalTrials.gov; Australian Clinical Trials
- Professional Associations (e.g., conference proceedings)
- Research centres, institutes and governments (e.g., research reports)
- Academic libraries (e.g., health services, universities, technical colleges)

Sources of scholarly literature - when you can't access to an academic library

This list is adapted from a blog post (and associated comments) by Helen Kara:
<https://helenkara.com/2016/01/06/ten-ways-to-get-hold-of-academic-literature/>

- Is there a way you can get access to a library?
 - Through your employer or professional association?
 - Reward for reviewing?
- If not Can you access a version of the literature – published version, “as accepted” version through:
 - Colleague / co-author with access to library
 - Google Scholar - click the “all x versions” link
 - Medline / PubMed – this picks up Open Access versions in indexed journals
 - Authors’ repository e.g., institutional or university repository, personal website
 - Write to the corresponding author (or any author!) and ask for a copy!
 - Research Gate, Academia.edu, other online repositories
- Purchase it

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Developing new data collection & outcomes measurement instruments

This information is adapted from:

Portney, Leslie Gross, & Watkins, Mary P. (2009). Surveys and questionnaires. In L. G. Portney & M. P. Watkins (Eds.), *Foundations of clinical research: applications to practice*. Upper Saddle River, N.J.: Pearson/Prentice Hall.

1. What construct/s do I want to measure? What are the indicators for the construct? What is the theoretical framework?

You may need to review literature on the construct you want to measure with your population. Different theoretical frameworks & underpinning philosophies (e.g., from clinical different clinical disciplines) will measure different things in different ways.

2. Review existing instruments (if they exist)

A literature review will help you identify instruments that already exist. It is usually easier to use an existing instrument, or adapt an instrument to meet your needs, than to develop a new instrument. However, adapting an instrument may affect validity and reliability.

3. Develop an item bank for the construct of interest

Develop an item bank using one or more of the following activities:

- *Review of research*: Behaviours that have been most frequently studied by others are used to define the construct of interest.
- *Content analysis*: open-ended questions are posed to subjects about the construct of interest. Their responses are sorted into topical categories, and analysed using content analysis.
- *Critical incidents*: A lists of behaviours that characterises extremes of the performance continuum for the construct of interest is developed.
- *Direct observation*: The test developer identifies the behaviours by direct observation.
- *Expert judgement*: The test developer obtains input from one or more individuals who have first-hand experience with the construct. Written questionnaires or personal interviews are used to collect information.

[*Developing data collection instruments, cont.*](#)

- *Instructional objectives*: Experts in a subject are asked to review instructional materials and develop a set of instructional objectives when an achievement test is being developed. An instructional objective specifies an observable behaviour that students should be able to exhibit after completion of a course of instruction.

From: Crocker, L. and Algina, J. (1986) *Introduction to Classical and Modern Test Theory*. Harcourt, New York, 67-68.

4. Develop possible questions and responses

Consider the type and wording of the questions for your instrument. You will also need to consider the type of responses – Likert scale? Yes/No? Visual Analogue Scale? Qualitative comments? Sometimes these can be dictated by the method of administration (e.g., online, paper, telephone).

5. Draft the preliminary questionnaire and instructions

Develop a draft of the questionnaire, and also instructions for using the questionnaire.

6. Establish content validity with Subject Matter Experts

Ask experts in the content area to review the instrument and associated resources. Is the content appropriate? Does the wording need to be changed? Revise based on feedback.

7. Pilot test (validity, reliability)

Test the instrument with a small sample of participants, preferably against a validated instrument that measures the same or similar domains. Is the instrument valid (does it measure what it says it measures)? Is the instrument reliable (does it measure consistently across time and/or administration methods)?

8. Revise

Revise the instrument based on results of the pilot testing.

9. Field testing (validity, reliability)

Test the instrument with a larger sample of participants.

Barriers

- Impractical
 - takes too long, limited ability or training to complete, volume of caseload, number of measures
- Client issues
 - reading level, language barrier, ethnic/cultural sensitivity, potentially disheartening if view progress as slow
- Perceived value
 - considered irrelevant to area of practice
 - potential cost
- “Punitive” use by management

Duncan, E. A., & Murray, J. (2012). The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC Health Services Research*, 12(96). [doi: 10.1186/1472-6963-12-96](https://doi.org/10.1186/1472-6963-12-96)

Friesen, E. L., & Comino, E. J. (2017). Research culture and capacity in community health services: results of a structured survey of staff. *Aust J Prim Health*, 23(2), 123-131. [doi: 10.1071/PY15131](https://doi.org/10.1071/PY15131)

Challenges

- Wrong tools used to measure AT outcomes
- Reliability, validity, and administrative burden (Salter et al. 2005)
- Difficulties in separating specific contribution of AT
- Diverse range of AT devices
- Application of AT devices used across tasks and environments
- Diverse goals and user expectations
- Needs (user, circle of support, carers) change over time
- Numerous stakeholders with range of interests
- Outcomes also dependent on good service delivery
- Resistance to evaluation of service delivery
- Constellation of AT services – limited tracking of outcomes

Facilitators

- Practical for clinician and client
 - **Appropriate and available**
 - **Easy, not too time consuming**
 - **No or low cost**
- Suitable for area of practice, good fit
- Cooperation of colleagues and management
- Specialised area of practice for
 - **Practitioner researchers**
 - **Embedded workplace researchers**
 - **Graduate student researchers**

Duncan, E. A., & Murray, J. (2012). The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC Health Services Research*, 12(96). [doi: 10.1186/1472-6963-12-96](https://doi.org/10.1186/1472-6963-12-96)

Friesen, E. L., & Comino, E. J. (2017). Research culture and capacity in community health services: results of a structured survey of staff. *Aust J Prim Health*, 23(2), 123-131. [doi: 10.1071/PY15131](https://doi.org/10.1071/PY15131)

Clinical & ethical governance

- Using (or piloting) a new data collection instrument may impact “usual care”
- Clarify your organisation’s requirements & policies on
 - Research governance (research and Quality Improvement)
 - Health data protection, privacy, consent
- Possible levels of clinical & ethical governance
 - Line manager
 - Senior management of your department or organisation
 - Research supervision and support services
 - Local gatekeepers for access to participants
 - Local Research & Development, research support services
 - Human Research Ethics Committees (HRECs)
- Clarify publishers’ requirements if you intend to present or publish in peer reviewed journals, conferences – HREC approvals, consent, etc

Practical considerations

- It takes time to embed outcomes measures into routine service delivery and clinical practice
 - **Consider additional time needed to administer, analyse results within usual service delivery and clinical practice**
- Plan time for
 - **Practitioner research support and training**
 - **Engaging and training data collectors**
 - **Review and evaluation of the project**
- ***Be realistic! Pick ONE outcome to measure and implement it well...***

Measuring Outcomes HANDOUT

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Measuring AT outcomes: Two case studies

MSCC usability

1. Outcomes of interest
(clinical) outcome for AT user (Adult with SCI)
2. Define outcomes of interest
AT impact » AT user (adult with SCI) » AT device Usability (MSCC).
3. Indicators of change
Change in self-reported satisfaction and usability scores.
4. Measuring the indicators
 - Self-report satisfaction and usability questionnaires.
 - Locate an existing usability questionnaire from AT literature.
5. Decide how results will be reported and disseminated
Report to AT funder, conference proceedings, journal articles.

Friesen, E. L., Theodoros, D., & Russell, T. G. (2017). Usability of mobile shower commodes for adults with spinal cord injury. *British Journal of Occupational Therapy*, 80(2), 63-72. doi:10.1177/0308022616676817

Accessing an AT consultation service

1. Outcomes of interest
(clinical) Outcome for AT user (people who access AT service)
2. Define outcomes of interest
Satisfaction; Was AT acquired?, User-centered goals.
3. Indicators of change
Change in self-reported satisfaction, goals, autonomy.
4. Measuring the indicators
 - Nature of problems/goals; importance, degree of difficulty (pre/post), and whether AT met expectations - IPPA
 - Changes in autonomy pre/post (overall and in mobility, self-care, usual activities, pain/discomfort, anxiety/depression and relationships - EATS 6D).
5. Decide how results will be reported and disseminated
Report to AT funder, conference proceedings, journal articles.

De Jonge, D., & Stevens, W. (2016). Capturing the True Value of Assistive Technologies to Consumers in Routine Outcome Measurement. *Technologies*, 4(4), 35. <https://www.mdpi.com/2227-7086/4/4/35>

What questions do you have?



Thank you

