Improving the quality of services for people with aphasia; practical implementation of TOMs and the ROOT

British Aphasiology Society
Today’s session

- The importance of outcome measures and real-world data
- Background to the Therapy Outcome Measure (TOM)
- Overview of the RCSLT Online Outcome Tool (ROOT)
- Examples of ROOT data related to aphasia
- Q&A
How can we improve our therapy?

- Learning from research
- Learning from others
- Learning from experience
- Knowing what we are doing now
- Data collection
- Measuring the impact of changes
- Reflection
So what is an ‘Outcome’?

- ‘address the effects, not the process, of particular interventions’
  
  (Hesketh & Sage, 1999)

- “results or visible effects of interventions…. forms part of the quality cycle….. provides information on the impact of interventions…."
  
  (Enderby, John & Petheram, 2006)
Reviewing the Impact of Change

- How do patients/clients benefit from your service?
- How do patients/clients benefit from service change?
- How are patients/clients disadvantaged by service change?
Reviewing the Impact of Change

- How do patients/clients benefit from your service?
- How do patients/clients benefit from service change?
- How are patients/clients disadvantaged by service change? 
  e.g. COVID-19
  - Possible benefits--- video conferencing/tele-health
  - Possible disadvantage-- delay in access to services
  - ? reduced intervention
Why has outcome measurement got to the top of the agenda?

- Increasing demands on the health service
- Knowledge of variation in provision
- Financial constraints
- Demonstrating benefits of investment
- Need to focus on quality
The NHS reforms: Priorities

- Improving population health and healthcare
- Tackling unequal outcomes and access
- Enhancing productivity and value for money
- Helping the NHS to support broader social and economic development
- “While integrated care systems have some statutory responsibilities, they are primarily partnership collaborators”

Team Working - Integrated Care Pathways

Teams have changed

“We now expect that place-based partnerships are consistently recognised as key to the coordination and improvement of service planning and delivery, and as a forum to allow partners to collectively address wider determinants of health”.

RCSLT

University of Sheffield
Choosing the right metrics

Robust metrics are often:

- **comparative**: so you can compare over time or between user groups or services
- **understandable**: if your team does not understand what a metric is measuring, it will be harder to use as it will not feel meaningful or helpful,
- **easy to quantify**: numerical information is easier to compare and monitor over time. It tells you by ‘how much’.
- **able to influence decisions or behaviours**: you should be able to answer the question ‘what will I do differently based on the measure?’ If you cannot, the metric may not be useful.
How can outcome measurement help you?

- Examine change over time
- Investigate particular issues (e.g. intensity of therapy)
- Identifying areas of strength
- Identifying areas of weakness
- Communicate with the client, other professionals and funders
Rehabilitation, Habilitation, Enablement

- The process of trying to help people who have suffered some injury/disease or developmental delay to maximise psychological well being, functional ability and social integration (Wade, 1992)

- An often complex process which enables individuals after impairment by illness, developmental delay or injury to regain as far as possible control over their own lives (King’s Fund, 1999)
What is Therapy Aiming at?

- Impairment/disorder reduction
- Improved Function
- Psycho social gain
- Wellbeing
Therapy Treatment Goals

- to identify and reduce the disorder/ dysfunction
- to improve or maintain the function and ability
- to assist to achieve potential or integration
- and to alleviate anxiety or frustration.
The Therapy Outcome Measures for Rehabilitation Professionals (TOM) (Enderby, John & Petheram 1999, 2006, Enderby and John 2015, 2019, 2021) was designed to be a simple, reliable, cross-disciplinary and cross-client group method of gathering psychometrically robust information.
International classification of functioning (ICF)

ICF is the World Health Organisation (WHO) framework for measuring health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States on 22 May 2001 (resolution WHA 54.21) as the international standard to describe and measure health and disability.
Impairment

- Underlying physical, physiological, mental condition
- Integrity of the body system
- Reflects the disease/medical disorder
Activity, disability, functioning, independence

- What the person can do independently
- Level of dependence
- Limitation on action

*Compared with someone of the same age gender and culture.*
Participation

Person within their social context

Advantage/disadvantage:

- reflecting social participation,
- integration,
- interaction,
- Autonomy

Compared with someone of the same age gender and culture.
Wellbeing

- Emotions, feelings, burden of upset, anxiety, frustration
- Not covered by WHO- ICF
- 2 constructs:
  - severity
  - constancy
Choosing an Outcome Measure

- **Relevance**—considers the importance of the information for your research.

- **Validity**—Validity refers to how accurately a method measures what it is intended to measure.

- **Reliability**—the extent to which a research instrument consistently has the same results if it is used in the same situation on repeated occasions.

**Other considerations**

- Ease of use
- Communication
The Therapy Outcome Measure
“So when do we do it?”

- Referral /case history/ assessment
- Aim/Goal
- Intervention
- End of episode of care
The Sorting Hat

Objectives:
1. improvement,
2. maintenance,
3. managed decline
Discharge codes and why they are important

- Therapy complete (TC)
- Transferred to Other Service (TO)
- Did Not Attend (DNA)
- Died (RIP)
- Moved Out Of Area (M0A)
- Intervening Illness (II)
- Different Intervention Required (DIR)
- Unknown (UK)
International Classification of Diseases (ICD)

- ICD 10

- Why is this useful?
THERAPY OUTCOME MEASURE (TOM)

- Based on: WHO Classification – ICF.
- 11-point ordinal scale with 6 defined points

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<th>Profound</th>
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Impairment TOM – dysphasia/aphasia

0 Profound. Aphasia affecting all modalities, auditory and reading comprehension inconsistent even at one keyword. No meaningful expression.

1 Severe dysphasia/aphasia: Auditory and/or reading comprehension is consistent at one keyword level. Occasionally understands and expresses limited amount within context.

2 Severe/moderate dysphasia/aphasia: Auditory and/or reading comprehension consistent at a minimum of two or three keyword level. Some limited verbal and/or written expression used appropriately and purposefully.

3 Moderate dysphasia/aphasia: Constant auditory and/or reading comprehension for simple sentences or structures. Inconsistent with complex commands and structures. Consistently reduced verbal and/or written language structure and vocabulary. May have a specific, more severe difficulty in one modality.

4 Mild dysphasia/aphasia: Occasional difficulties present in auditory and/or reading comprehension and in verbal and/or written expression particularly in more complex environments.

5 No dysphasia/aphasia.
Activity TOM – dysphasia/aphasia

0 Unable to communicate in any way. No effective communication. No interaction.

1 Occasionally able to make basic needs known with familiar persons or trained listeners in familiar contexts. Minimal communication with maximal assistance.

2 Limited functional communication. Consistently able to make basic needs/conversation understood but is heavily dependent on cues and context. Communicates better with trained listener or family members or in familiar settings. Frequent repetition required. Maintains meaningful interaction related to here and now.

3 Consistently able to make needs known but can sometimes convey more information than this. Some inconsistency in unfamiliar settings. Is less dependent for intelligibility on cues and context. Occasional repetition required. Communicates beyond here/now with familiar persons; needs cues and prompting.

4 Can be understood most of the time by any listener despite communication irregularities. Holds conversation; requires occasional prompts particularly with a wider range of people.

5 Communicates effectively in all situations.
Participation TOM – dysphasia/aphasia

0 Unable to fulfil any social/educational/family role. Not involved in decision making/no autonomy/no control over environment; no social integration.

1 Low self-confidence/poor self-esteem/limited social integration/socially isolated/contributes to some basic and limited decisions. Cannot achieve potential in any situation.

2 Some self-confidence/some social integration/makes some decisions and influences control in familiar situations.

3 Some self-confidence; autonomy emerging. Makes decisions and has control of some aspects of life. Able to achieve some limited social integration/educational activities. Diffident over control over life. Needs encouragement to achieve potential.

4 Mostly confident; occasional difficulties integrating or in fulfilling social/role activity. Participating in all appropriate decisions. May have difficulty in achieving potential in some situations occasionally.

5 Achieving potential. Autonomous and unrestricted. Able to fulfil social, educational and family role.
Wellbeing TOM – dysphasia/aphasia

0 Severe constant: High and constant levels of distress/upset/concern/frustration/anger/embarrassment/withdrawal/severe depression/apathy. Unable to express or control emotions appropriately.

1 Frequently severe: Moderate distress/upset/concern/frustration/anger/embarrassment/withdrawal/severe depression/apathy. Becomes concerned easily, requires constant reassurance/support, needs clear/tight limits and structure, loses emotional control easily.

2 Moderate consistent: Distress/upset/concern/frustration/anger/embarrassment/withdrawal/severe depression/apathy in unfamiliar situations. Frequent emotional encouragement and support required.

3 Moderate frequent: Distress/upset/concern/frustration/anger/embarrassment/withdrawal/severe depression/apathy. Controls emotions with assistance, emotionally dependent on some occasions, vulnerable to change in routine, etc., spontaneously uses methods to assist emotional control.

4 Mild occasional: Distress/upset/concern/frustration/anger/embarrassment/withdrawal/severe depression/apathy. Able to control feelings in most situations, generally well adjusted/stable (most of the time/most situations), occasional emotional support/encouragement needed.

5 Not inappropriate: Distress/upset/concern/frustration/anger/embarrassment/withdrawal/severe depression/apathy. Well adjusted, stable and able to cope emotionally with most situations, good insight, accepts and understands own limitations.
Why do we need adapted scales?

Importance of Reliability

- A valid measurement should be reliable.
- If a test produces accurate results, they should be reproducible.
Clinically Significant Change TOM = 0.5

- 'The practical importance of the treatment effect-- where it has a real genuine noticeable effect on daily life'
- Involves clinical, personal, and statistical consideration.
- What is the smallest difference in the domain of interest which is perceived as beneficial
- A threshold for outcome scores
Conducting a Benchmarking Study

- **Internal Benchmarking**: Assess own performance

- **External Benchmarking**: Assess performance against benchmarking partners
Stroke with dysphasia

Ken, 75 years old, had a stroke 5 weeks ago, he is dysphasic and frequently becomes extremely distressed. He understands simple sentences related to the here and now but becomes easily confused with longer conversation. He uses gesture effectively, and can write down the 1st letter of words that he wishes to communicate. He is able to make his needs known at most times of the day and particularly when he is relaxed and with people he knows. He is very embarrassed by his situation. Ken withdraws from all social situations. He leaves it up to his wife to take on decisions and all social roles.
Practice
Practice
Practice
PROM TOM

- In development
- Each domain—need support of healthcare professional
- Visual analogue scale
- Influence your rating?
Real-world data and evidence

Real-world data (RWD):
“Data relating to patient health or experience or care delivery collected outside the context of highly controlled clinical trials”

Real-world evidence (RWE):
“evidence generated from the analysis of real-world data”

NICE (2022)
Real world data – benefits and limitations

Advantages of RWD
- Dynamic purpose
- High external validity
- Large volumes of data
- Evidence on systems, processes and *impact*

Disadvantages of RWD
- Reduced internal validity
- Data needs to be structured
- Requires agreed systems
- Requires adequate IT
It looks like our business is in trouble. Quick! Let's quibble endlessly about the quality of the data and how it's sourced.
RCSLT Vision

Royal College of Speech and Language Therapists (RCSLT) is the professional body for SLTs in the UK.

The RCSLT strategic vision (2022 – 2027):
“Evidence-based practice firmly established in the profession and outcomes measured routinely”

The RCSLT Online Outcome Tool (ROOT) supports speech and language therapy services with:

- Collecting and collating Therapy Outcome Measures (TOMs) data
- Evaluating and reporting outcomes

Data collection

Direct data entry: Data about service users is entered directly into the ROOT.

Data upload: SLT services that are currently able to collect and collate TOMs data effectively within their local electronic system(s) can export data and upload to the ROOT.
Data collected via the ROOT

- Therapy Outcome Measures
- Patient demographics
- Nature and severity of the speech and language therapy needs (e.g. dysphagia, aphasia, speech sound disorder)
- Relevant medical diagnoses (e.g. stroke, Motor Neurone Disease, cerebral palsy)
- Duration of therapy episode
- Status at the end of the therapy episode (e.g. therapy complete (discharged), transfer to another service, died)
- Optional fields (e.g. total amount of therapy time, objectives of the intervention etc.)
ROOT – a source of real-world data

- 82 services contributing data
- 99 services in implementation phase
- 10 years of data from some services
- 81,000 episodes of care recorded
How can outcomes data be used to support the delivery of quality speech and language therapy?
How can outcomes data be used to support the delivery of quality care?

- Showing and sharing progress for individual clients, families and other professionals
- Informing clinical decision making and facilitating goal setting
- Answering clinical questions
- Supporting reflective practice, evidence-based practice and CPD
ROOT reports

Watch on YouTube: bit.ly/45mA333

Using ROOT TOMS within Inpatient Adult Neuro-Rehab
Amber Masterson
Senior Speech and Language Therapist
The Martock Centre
Cambridgeshire

Start of Episode - Jan 2022
End of Episode - May 2022

RCSLT
University of Sheffield
"I am always particularly interested in ‘anomalies’ ... This provides an opportunity to reflect on the reasons why the outcomes were either more or less positive than anticipated at the start of therapy, and consider what - if anything - to do differently in future."

Nikky Steiner - Principle Speech & Language Therapist, Central London Community Healthcare NHS Trust
How can outcomes data be used to support the delivery of quality services?

- Evaluating the effectiveness of interventions and areas for improvement
- Supporting improvement, planning and redesign of services, using a data-driven approach to change
- Showcasing and celebrating the value of services, and providing this information to clients, other professionals, funders/commissioners, the public
"It equips us with a means of highlighting the areas where we have effected positive change."

Geri Napier - Speech & Language Therapist, South Eastern Health and Social Care Trust
ROOT reports

Watch on YouTube: bit.ly/45mA333
How can outcomes data be used to support the speech and language therapy profession?

- The production of evidence for the wider profession, to complement the existing evidence base
- Demonstrating the value of speech and language therapy to the public, policy-makers, funders and commissioners to raise the profile of the profession
- Supporting our lobbying and influencing work on behalf of the profession and service users
## ROOT: top 10 TOM scales

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<th>Primary TOM scale</th>
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<td>Learning Disability – Communication</td>
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ROOT data on aphasia - gender

- Male: 39%
- Female: 37%
- Not specified: 24%
ROOT data on aphasia – aetiology

- Stroke: 58%
- Not specified: 28%
- Cancer: 5%
- Other: 4%
- Brain injury: 2%
- Dementia: 1%
- Progressive neurological condition: 1%
- Benign tumour: 1%
ROOT data on aphasia – age

Average age: 70.1 years

Age at start of therapy

Frequency

Age (years)

[0, 10]  (10, 20]  (20, 30]  (30, 40]  (40, 50]  (50, 60]  (60, 70]  (70, 80]  (80, 90]  (90, 100]  (100, 110]  (110, 120]

[0]  [1, 1]  [2, 2]  [3, 3]  [4, 4]  [5, 5]  [6, 6]  [7, 7]  [8, 8]  [9, 9]  [10, 10]  [11, 11]  [12, 12]
ROOT data on aphasia – impairment severity

Severity of impairment at start of therapy

Median: 3.0
Root data on aphasia – outcomes

Average (median) change in the TOM

79.1% improve in at least one domain of the TOM
Key takeaways

- Importance of real-world data
  - providing quality services
  - communicating with others
  - learning from across the profession – ‘big data’
  - stimulating questions and reflections
Acknowledgements

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For more information, please contact root@rcslt.org
References


Thank you for listening
Any questions?

Pam Enderby: p.m.enderby@sheffield.ac.uk

Kathryn Moyse: kathryn.moyse@rcslt.org