



# British Aphasiology Society



# Today's session

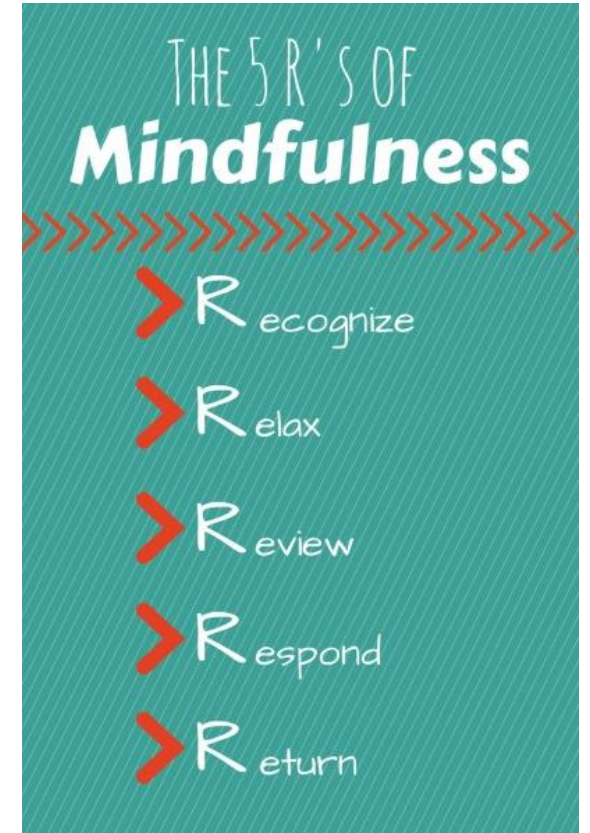
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- The importance of outcome measures and real-world data
- Background to the Therapy Outcome Measure (TOM)
- Overview of the RCSLT Online Outcome Tool (ROOT)
- Examples of ROOT data related to aphasia
- Q&A

# How can we improve our therapy?

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- 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'?

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- '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....
- identifies the **effectiveness of practices**....”

(Enderby, John & Petheram, 2006)

# Reviewing the Impact of Change

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- 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

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- 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

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- 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”

<https://www.nhsconfed.org/sites/default/files/2021-07/The-proposed-NHS-reforms-what-do-we-think-so-far.pdf>



# Team Working - Integrated Care Pathways

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## 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”.*

# Choosing the right metrics

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## 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?

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- 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

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- 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?

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- Impairment/disorder reduction
- Improved Function
- Psycho social gain
- Wellbeing

# Therapy Treatment Goals

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- 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.

# Therapy Outcome Measure

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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)

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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

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

# Activity, disability, functioning, independence

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

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

# Participation

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## Person within their social context

Advantage/disadvantage:

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

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

# Wellbeing

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

# Choosing an Outcome Measure

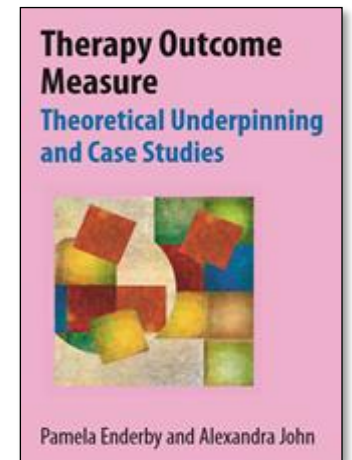
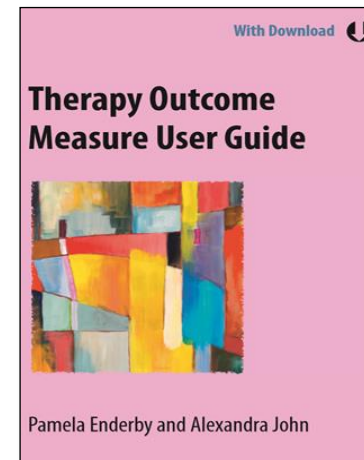
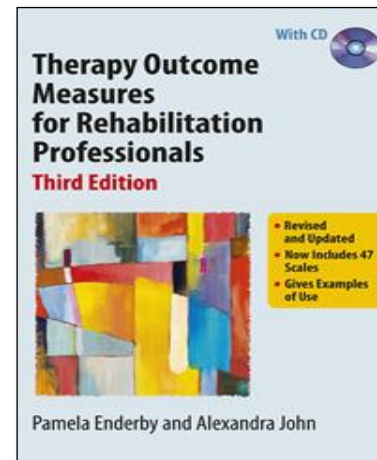
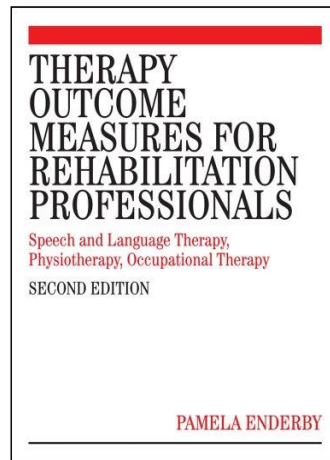
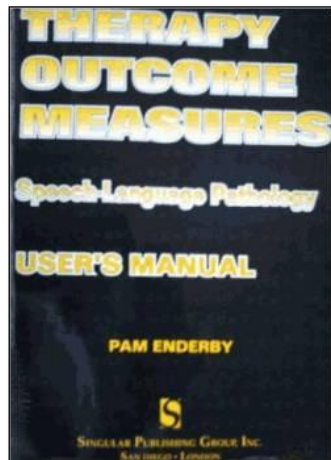
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- **Relevance**--considers the importance of the information for your research
- **Validity**--Validity refers to **how accurately** a method measures what it is intended to measure.
- **Reliability**--the extent to which a research instrument consistently 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



J&R publications



"So when do we do it?"



# The Sorting Hat

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Objectives:

1. improvement,
2. maintenance,
3. managed decline



# Discharge codes and why they are important

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- 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)

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- ICD 10
- Why is this useful?



# THERAPY OUTCOME MEASURE (TOM)

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

Profound		Severe		Severe/ moderate		Moderate		Mild		Normal limits
0	0.5	1.0	1.5	2.0	2.5	3.0	3.5	4.0	4.5	5.0

# Impairment TOM – dysphasia/aphasia

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**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

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**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

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**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

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**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

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- '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

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- **Internal Benchmarking:** Assess own performance
- **External Benchmarking:** Assess performance against benchmarking partners

# Stroke with dysphasia

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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.







# PROM TOM

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- In development
- Each domain—need support of healthcare professional
- Visual analogue scale
- Influence your rating?

# Real-world data and evidence

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## **Real-world data (RWD):**

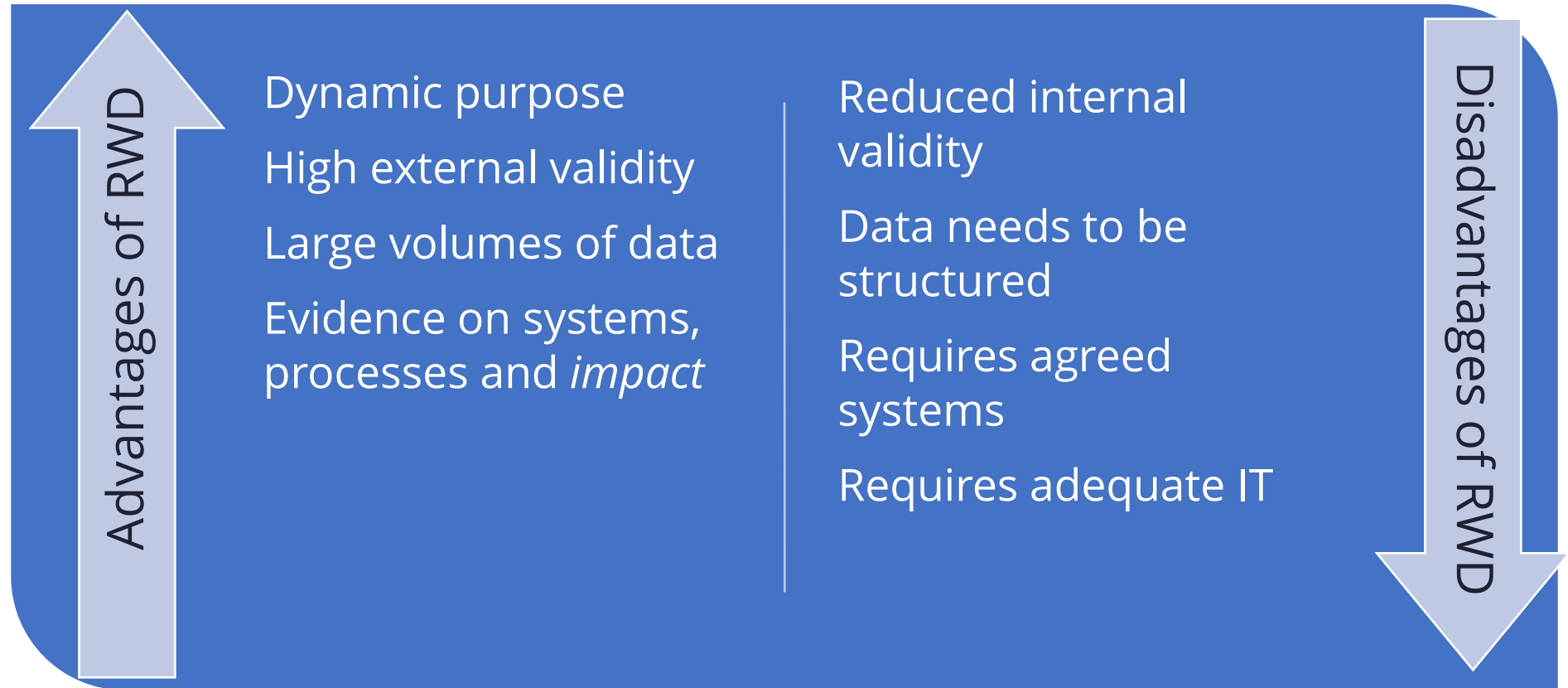
“Data relating to patient health or experience or care delivery collected outside the context of highly controlled clinical trials”

## **Real-world evidence (RWE):**

“evidence generated from the analysis of real-world data”

NICE (2022)

# Real world data – benefits and limitations





# RCSLT Vision

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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”**

<https://bit.ly/RCSLTVision>



# RCSLT Online Outcome Tool

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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

## WHAT IS ROOT?

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<https://bit.ly/ROOTintro>

# 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

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- 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

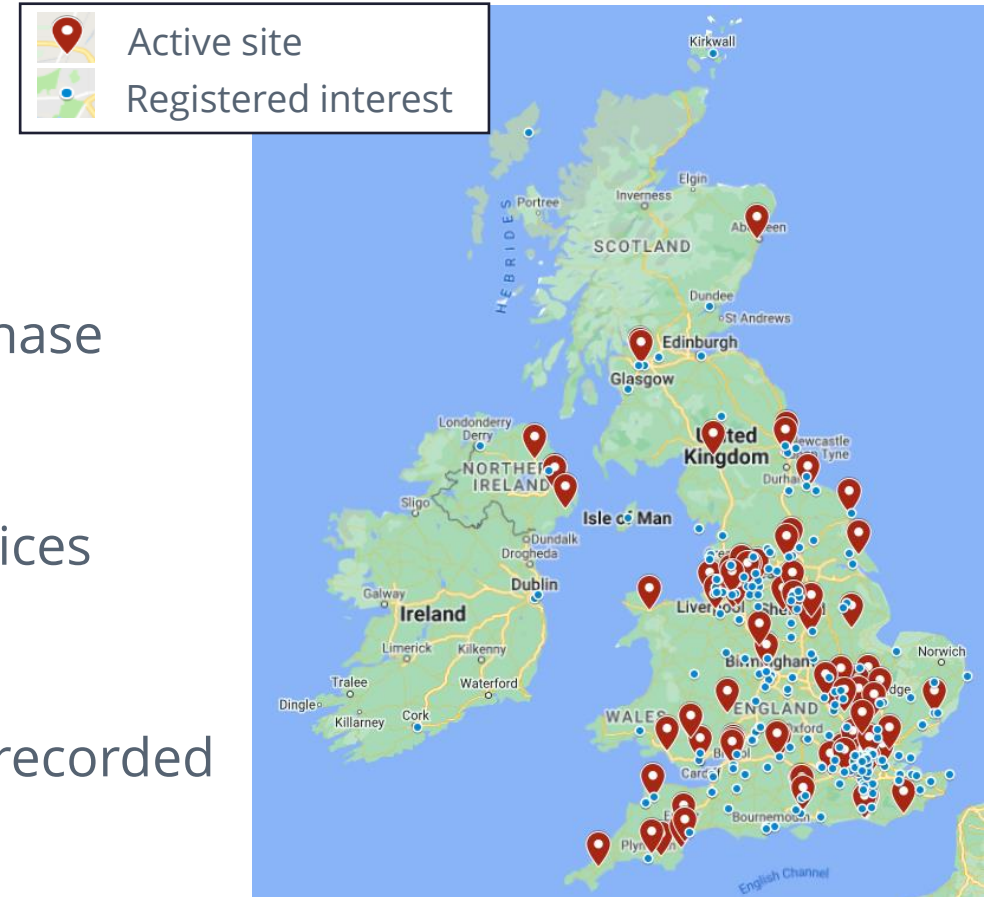
services in implementation phase

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

## USING ROOT TOMS WITHIN INPATIENT ADULT NEURO-REHAB

Amber Masterson  
Senior Speech and Language Therapist  
The Marbrook Centre  
Cambridgeshire



Watch on  
YouTube:  
[bit.ly/45mA333](https://bit.ly/45mA333)



# ROOT reports

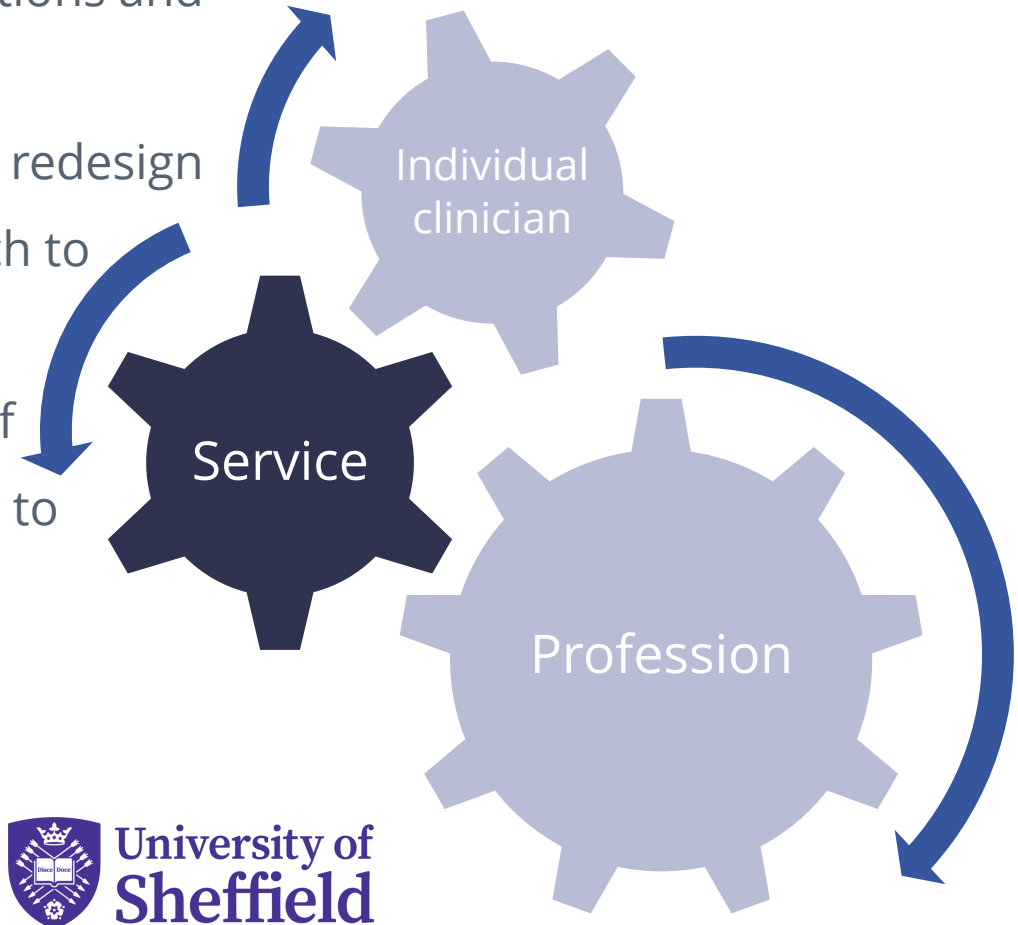
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*"I am always particularly interested in 'anomalies' ... This provides an opportunity to reflect on the reasons why the outcomes were either more or less positive than anticipated at the start of therapy, and consider what - if anything - to do differently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



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[REDACTED]

# ROOT reports

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*"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

## USING ROOT TOMS WITHIN INPATIENT ADULT NEURO-REHAB

Amber Masterson  
Senior Speech and Language Therapist  
The Marbrook Centre  
Cambridgeshire



Watch on YouTube:  
[bit.ly/45mA333](https://bit.ly/45mA333)

Request and secure funding from local CCG's for an extension of funding or equipment

Show improvements in impairment, activity, participation and wellbeing to CCGs, patient, family and MDT.

Identify those no longer benefitting from therapy input

Highlight need for additional funding, training or recruitment

Demonstrate impact of SLT on patient outcomes

# 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



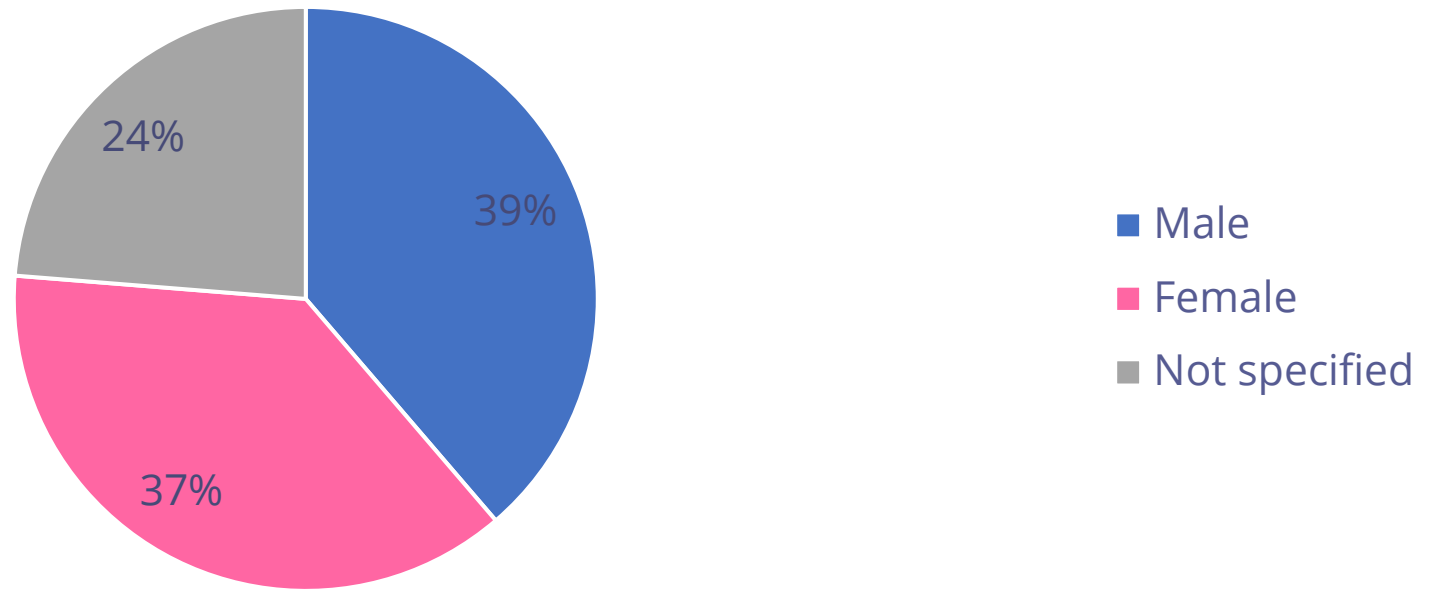
# ROOT: top 10 TOM scales

Primary TOM scale	Completed therapy episodes
Dysphagia	40860
Aphasia/Dysphasia	5755
Core Scale	5175
Dysarthria	4381
Dysphonia	4347
Developmental Language Disorder / Difficulties	3879
Augmentative and Alternative Communication	3270
Phonological Disorder	2565
Autism	2027
Learning Disability – Communication	1414

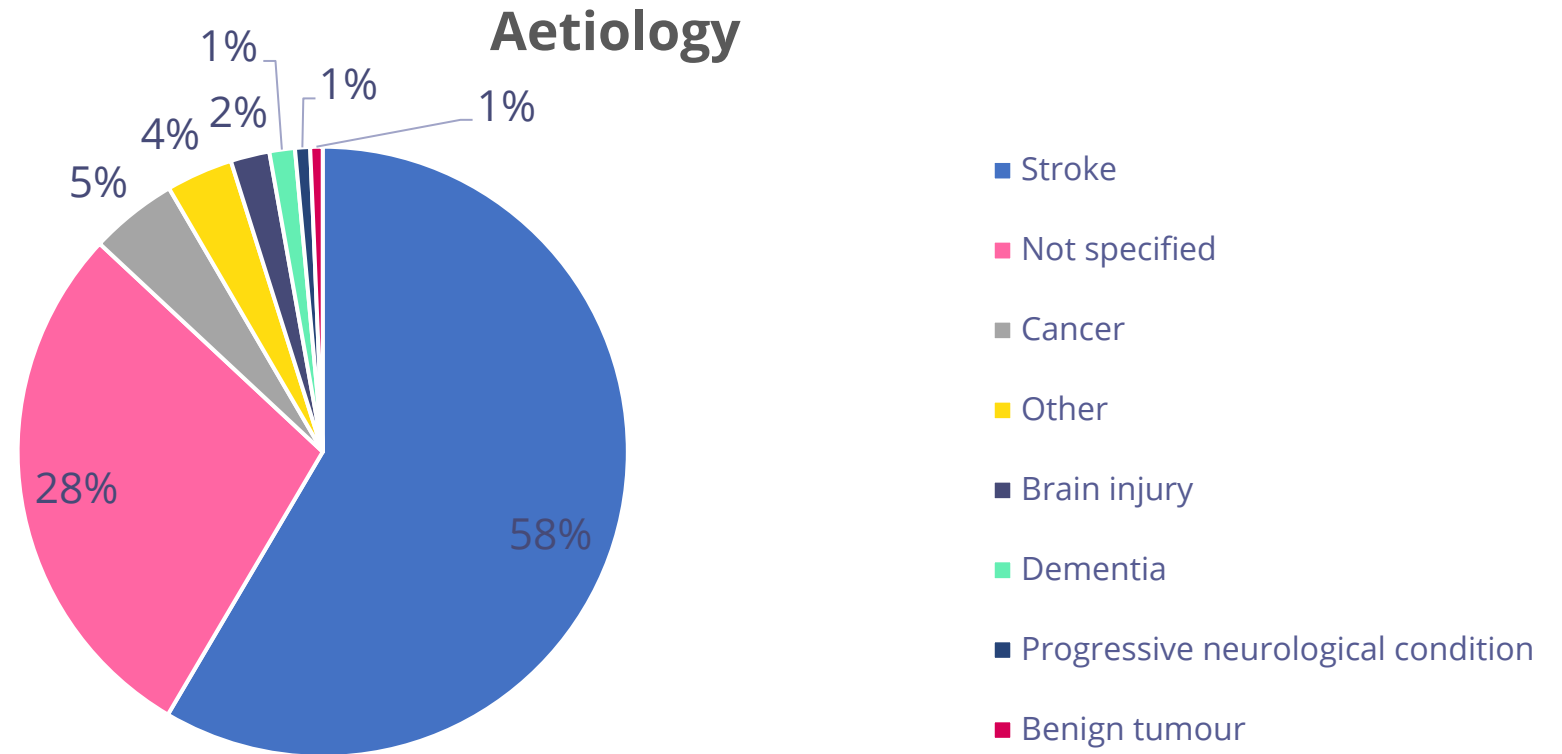
# ROOT data on aphasia - gender

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Gender

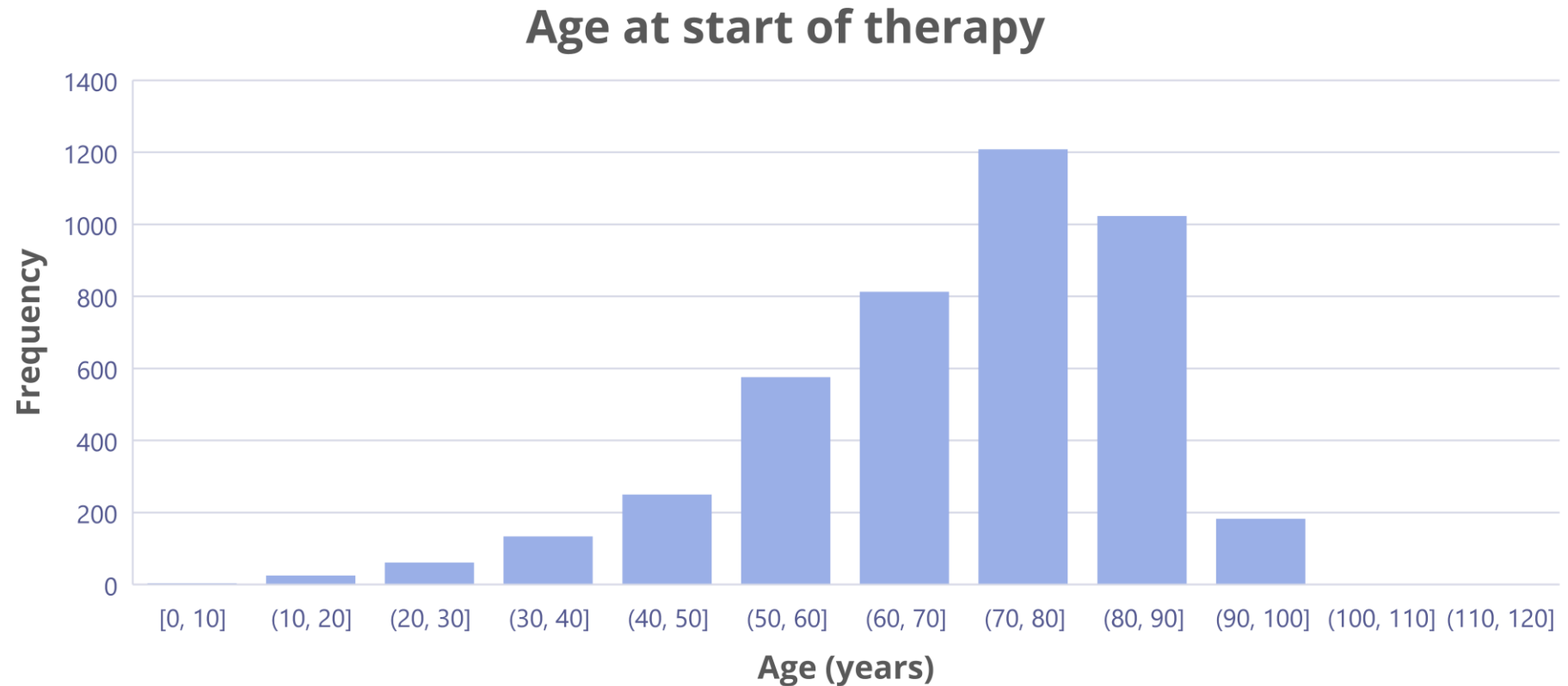


# ROOT data on aphasia – aetiology



# ROOT data on aphasia – age

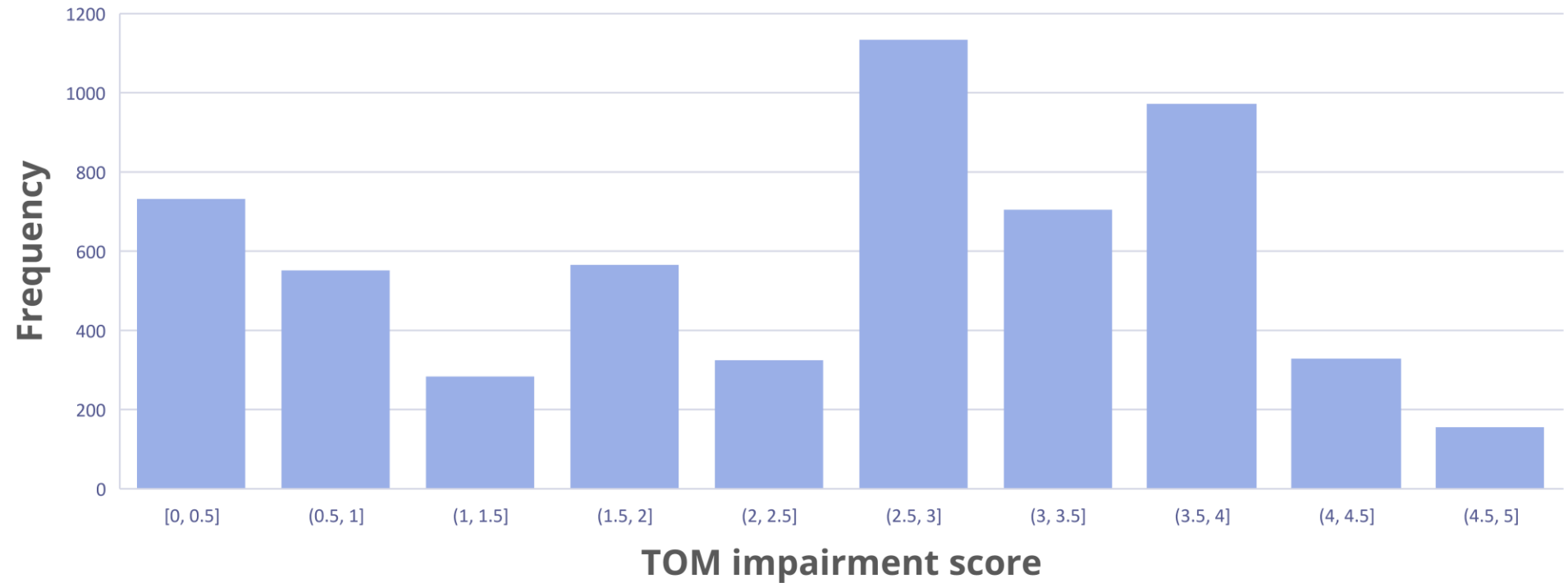
Average age: 70.1 years



# ROOT data on aphasia – impairment severity

Median: 3.0

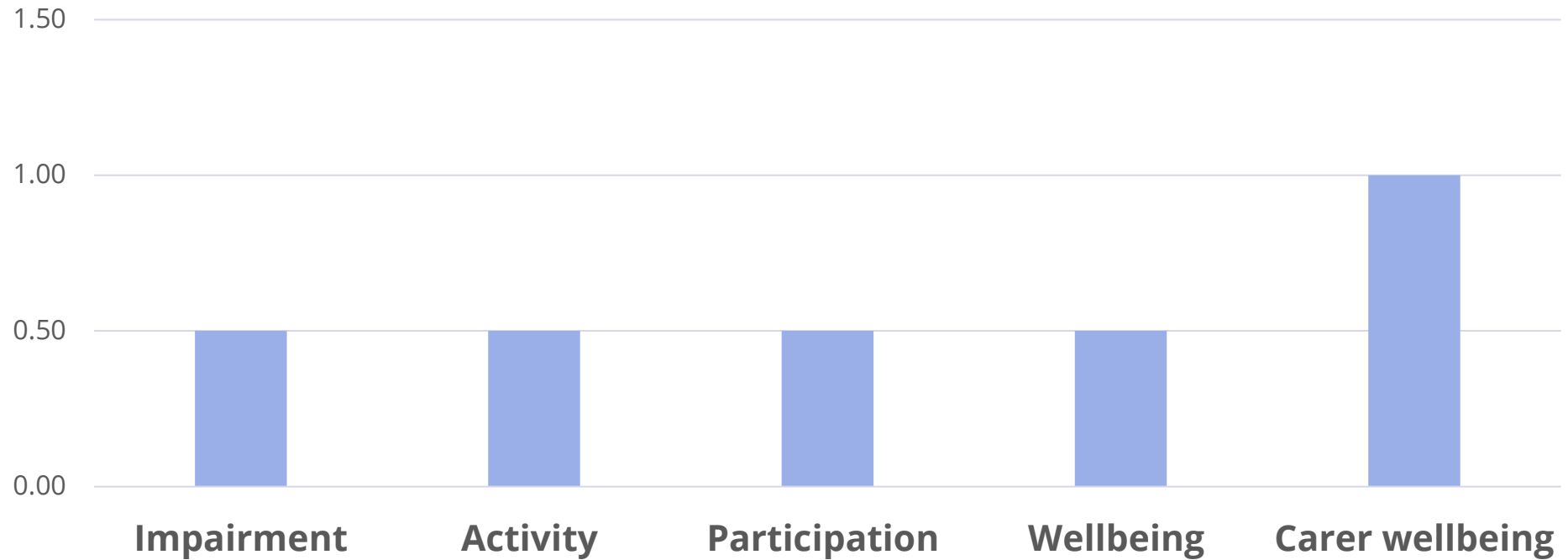
## Severity of impairment at start of therapy



# ROOT data on aphasia – outcomes

79.1% improve in  
at least one  
domain of the  
TOM

Average (median) change in the TOM





# Key takeaways

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- 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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We would like to acknowledge the extensive support of Mark Bedwell and Paddy Guest at Different Class Solutions Ltd for their work in developing the ROOT; all the RCSLT members contributing data to the ROOT; as well as Professor Pam Enderby and the members of the RCSLT Outcomes Programme Steering Group for their continued support in the project, including former project sponsor Kamini Gadhok.

For more information, please contact [root@rcslt.org](mailto:root@rcslt.org)



# References

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Thank you for listening





# Any questions?

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