

“The Mexican wave always stops with me”

*What matters most about the arm –
and do outcome measures capture this?*

Julie Duncan Millar¹, Frederike van Wijck²,
Alex Pollock¹, Myzoon Ali¹

¹Nursing Midwifery and Allied Health Professions Research Unit, Glasgow Caledonian University

² School of Health and Life Sciences, Glasgow Caledonian University

nmahp-ru
Nursing, Midwifery and Allied Health Professions Research Unit

Improving health through research  CHIEF SCIENTIST OFFICE

GCU
Glasgow Caledonian
University



Background:

Top stroke research priorities

1. To improve cognition after stroke
2. To help people come to terms with long term consequences of stroke
3. To help people recover from aphasia
4. Treatments for arm recovery and function
5. To treat visual problems after stroke

Background: Upper limb clinical trials



Duncan Millar (in preparation)

Background: Upper limb clinical trials



- 243 RCTs
- 146 different measures
- 79 used in only one RCT
- 0 used in every RCT

Duncan Millar (in preparation)

Background: Upper limb clinical trials



- 243 RCTs
- 146 different measures
in only one RCT
in every RCT



Duncan Millar (in preparation)

So what?



Inconsistent outcome measurement means:

- Difficult to share and compare data
- Difficult to pool and meta-analyse data
- **Difficult to draw conclusions about clinical effectiveness**

Aims

**Standardising
Measures in
Arm
Rehabilitation
Trials**



(SMART) Stroke Outcome Study

#SMARTstrokeoutcome

Research Question

What matters most
about the arm –
*and do outcome
measures capture this?*

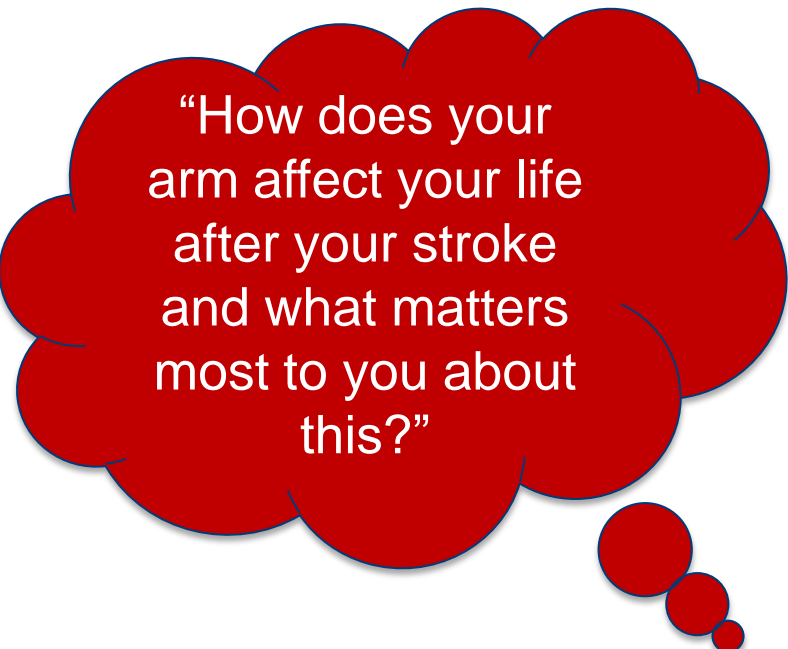
Methods: Identifying 'what matters'

- 1) **16 focus groups** using Nominal Group Technique (NGT)
 - stroke survivors with upper limb impairment AND family and friends
 - health professionals
- 2) **8 interviews** with stroke survivors and family/friends



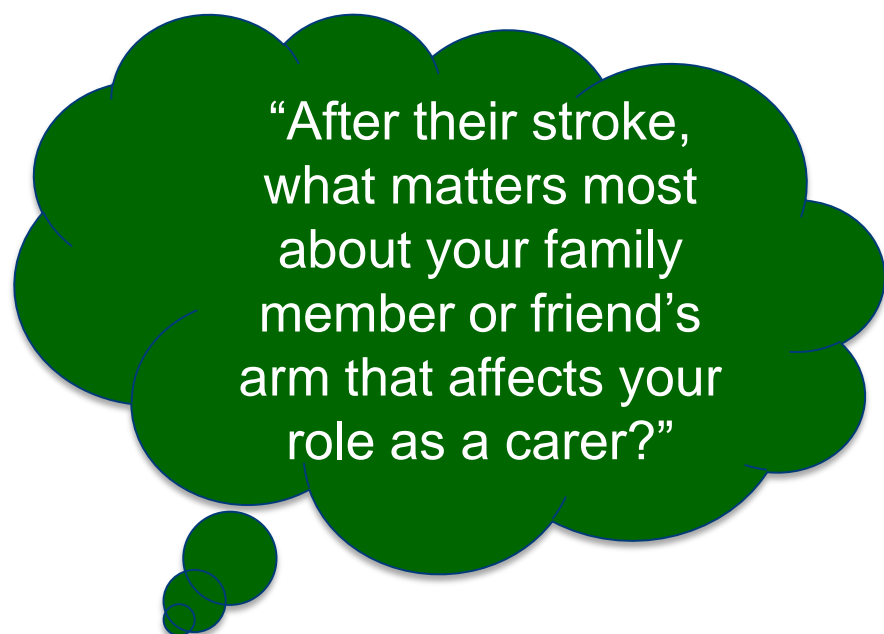
“How does your arm affect your life after your stroke and what matters most to you about this?”

Stroke survivor

A large red thought bubble with a white outline, containing white text. It is connected to a box below by three smaller red circles of decreasing size.

“How does your arm affect your life after your stroke and what matters most to you about this?”

Stroke survivor

A large green thought bubble with a white outline, containing white text. It is connected to a box below by three smaller green circles of decreasing size.

“After their stroke, what matters most about your family member or friend’s arm that affects your role as a carer?”

Family/ friends

“How does your arm affect your life after your stroke and what matters most to you about this?”

Stroke survivor

“After their stroke, what matters most about your family member or friend’s arm that affects your role as a carer?”

Family/ friends

Health professional

“When working with a stroke patient’s arm, which outcomes are most important to you?”

Participants: Stroke survivors and carers




Stroke Survivors	(n=43)
Age (years)	60 [55,67]
Sex	17 female
Time since stroke (years)	1.5 [0.6-4.0]
Modified Rankin Score	2 [2,3]

Family/ friends	(n=10)
Age (years)	63.5 [57.8, 71.5]
Sex	5F 5M
Length of Caring (years)	2.8 [0.9, 3.9]


Participants: Health Professionals



Health Professionals	(n=58)
Experience (years)	1/4- 30
Physiotherapists	23
Occupational Therapists	15
Nurses	7
Support workers	5
Consultants	5
Clinical neuropsychologist	1
Orthotist	1
Speech & language therapist	1



“How does your
arm affect your life
after your stroke
and what matters
most to you about
this?”



“How does your arm affect your life after your stroke and what matters most to you about this?”

“The Mexican wave always stops with me”

Analysis: Qualitative Content Analysis

Statement/ 'meaning unit'	Code	Outcome category
"I find it frustrating not being able to do things I could do before. E.g. putting a duvet cover on."	1. 'Frustration' 2. 'Things I could do before'	1. Frustration 2. Everyday tasks

Analysis: Qualitative Content Analysis

Statement/ 'meaning unit'	Code	Outcome category
<p data-bbox="98 682 755 1106">‘I find it frustrating not being able to do things I could do before. E.g.’</p>	<p data-bbox="755 682 1271 1106">1. ‘Frustration’ 2. ‘Things I could do before’</p>	<p data-bbox="1271 682 1825 1106">1. Frustration 2. Everyday tasks</p>

Results: Top 10 outcomes

Health Professionals

1. Pain
ADL & usual activity
3. Coping & self-management
4. Knowledge & understanding
5. Patient specific outcomes
6. Goal attainment
7. Avoid harm
8. Expectation
9. Tone & spasticity
10. Arm care, positioning & hygiene

Results: Top 10 outcomes

Health Professionals

1. Pain
ADL & usual activity
3. Coping & self-management
4. Knowledge & understanding
5. Patient specific outcomes
6. Goal attainment
7. Avoid harm
8. Expectation
9. Tone & spasticity
10. Arm care, positioning & hygiene

Stroke Survivors & Carers

1. Independence, freedom & autonomy
2. Difficulty (with routine actions)
3. Everyday tasks
4. Reliance on others
5. Ability to work
6. Ability to drive
7. Change & adjustment
8. Mealtime
9. Frustration
10. Personal care

Results: Top 10 outcomes

Health Professionals

1. Pain
ADL & usual activity
3. Coping & self-management
4. Knowledge & understanding
5. Patient specific outcomes
6. Goal attainment
7. Avoid harm
8. Expectation
9. Tone & spasticity
10. Arm care, positioning & hygiene

Stroke Survivors & Carers

1. Independence, freedom & autonomy
2. Difficulty (with routine actions)
3. Everyday tasks
4. Reliance on others
5. Ability to work
6. Ability to drive
7. Change & adjustment
8. Mealtime
9. Frustration
10. Personal care

Results: Top 10 outcomes

Health Professionals

1. Pain
- ADL & usual activity
3. Coping & self-management
4. Knowledge & understanding
5. Patient specific outcomes
6. Goal attainment
7. Avoid harm
8. Expectation
9. Tone & spasticity
10. Arm care, positioning & hygiene

Stroke Survivors & Carers

1. Independence, freedom & autonomy
2. Difficulty (with routine actions)
3. Everyday tasks
4. Reliance on others
5. Ability to work
6. Ability to drive
7. Change & adjustment
8. Mealtime
9. Frustration
10. Personal care



Results: Shared outcomes

Health Professionals		Stroke survivors family & friends
1=	Everyday tasks	3
1=	Pain	12
9	Muscle tone & spasticity	20=
10	Arm care & hygiene	40
14	Strength & power	27=
15	Motor function, coordination & stability	34
20	Fatigue	39
26=	Neglect&learned non-use	20=
30=	Sensation	29

Results: Shared outcomes

Health Professionals		Stroke survivors family & friends
1=	Everyday tasks	3
1=	Pain	12
9	Muscle tone & spasticity	20=
10	Arm care & hygiene	40
14	Strength & power	27=
15	Motor function, coordination & stability	34
20	Fatigue	39
26=	Neglect&learned non-use	20=
30=	Sensation	29

Outcome measure → Outcome ↓	Fugl Meyer Assessment Upper Extremity (33%)	Action Research Arm Test (23%)	Modified Ashworth Scale (22%)	Motor Activity Log (18%)	Functional Independence Measure (14%)
Independence, freedom and autonomy					
Difficulty (with routine actions)					
Relying on others					
Ability to work					
Everyday tasks					
Pain					
Coping and self-management					
Knowledge and understanding					

Outcome measure → Outcome ↓	Fugl Meyer Assessment Upper Extremity (33%)	Action Research Arm Test (23%)	Modified Ashworth Scale (22%)	Motor Activity Log (18%)	Functional Independence Measure (14%)
Independence, freedom and autonomy					
Difficulty (with routine actions)					
Relying on others					
Ability to work					
Everyday tasks					
Pain					
Coping and self-management					
Knowledge and understanding					

Outcome measure →	Fugl Meyer Assessment Upper Extremity	Action Research Arm Test	Modified Ashworth Scale	Motor Activity Log	Functional Independence Measure
Outcome ↓	(33%)	(23%)	(22%)	(18%)	(14%)
Independence, freedom and autonomy					
Difficulty (with routine actions)					
Relying on others					
Ability to work					
Everyday tasks					
Pain					
Coping and self-management					
Knowledge and understanding					

Outcome measure →	Fugl Meyer Assessment Upper Extremity	Action Research Arm Test	Modified Ashworth Scale	Motor Activity Log	Functional Independence Measure
Outcome ↓	(33%)	(23%)	(22%)	(18%)	(14%)
Independence, freedom and autonomy					
Difficulty (with routine actions)					
Relying on others					
Ability to work					
Everyday tasks					
Pain					
Coping and self-management					
Knowledge and understanding					

Outcome measure →	Fugl Meyer Assessment Upper Extremity (33%)	Action Research Arm Test (23%)	Modified Ashworth Scale (22%)	Motor Activity Log (18%)	Functional Independence Measure (14%)
Outcome ↓					
Independence, freedom and autonomy					
Difficulty (with routine actions)		√		√	
Relying on others					√
Ability to work					
Everyday tasks				√	√
Pain	√				
Coping and self-management					
Knowledge and understanding					

Outcome measure →	Fugl Meyer Assessment Upper Extremity (33%)	Action Research Arm Test (23%)	Modified Ashworth Scale (22%)	Motor Activity Log (18%)	Functional Independence Measure (14%)
Outcome ↓					
Independence, freedom and autonomy					
Difficulty (with routine actions)		√		√	
Relying on others					√
Ability to work					
Everyday tasks				√	√
Pain	√				
Coping and self-management					
Knowledge and understanding					

Conclusion:

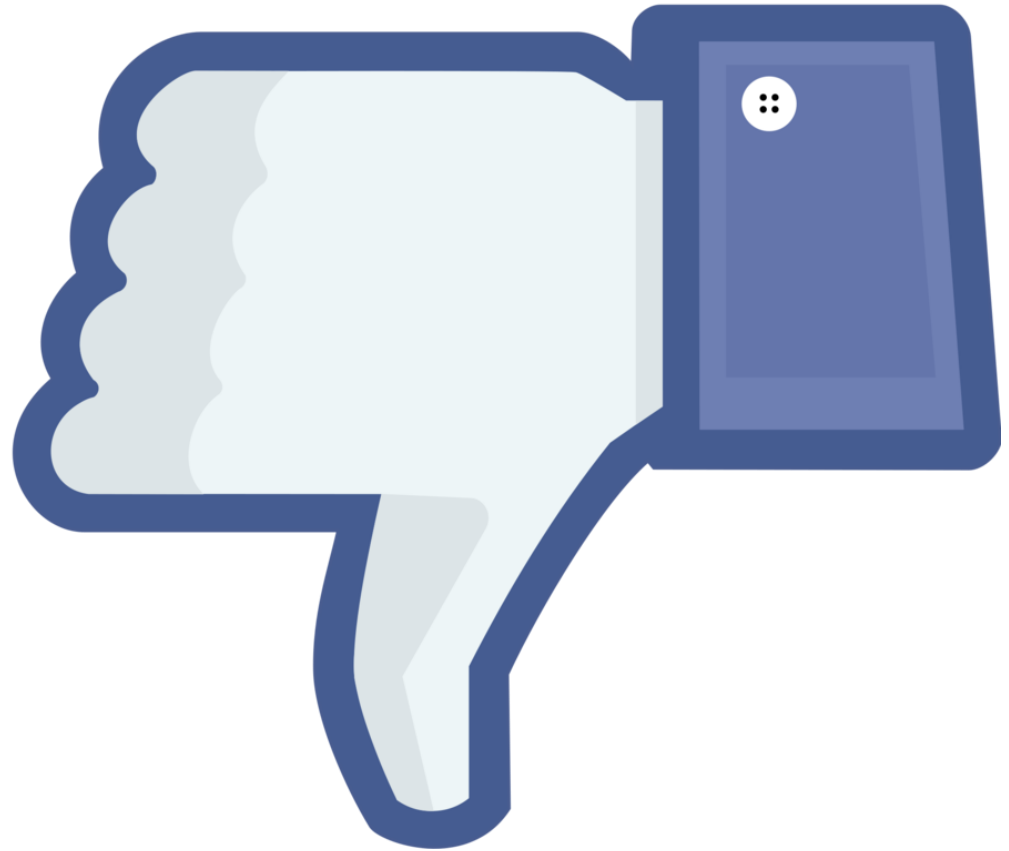
Do we measure what matters?

- Outcomes that are most important to stakeholders are **not** comprehensively captured by currently used outcome measures.

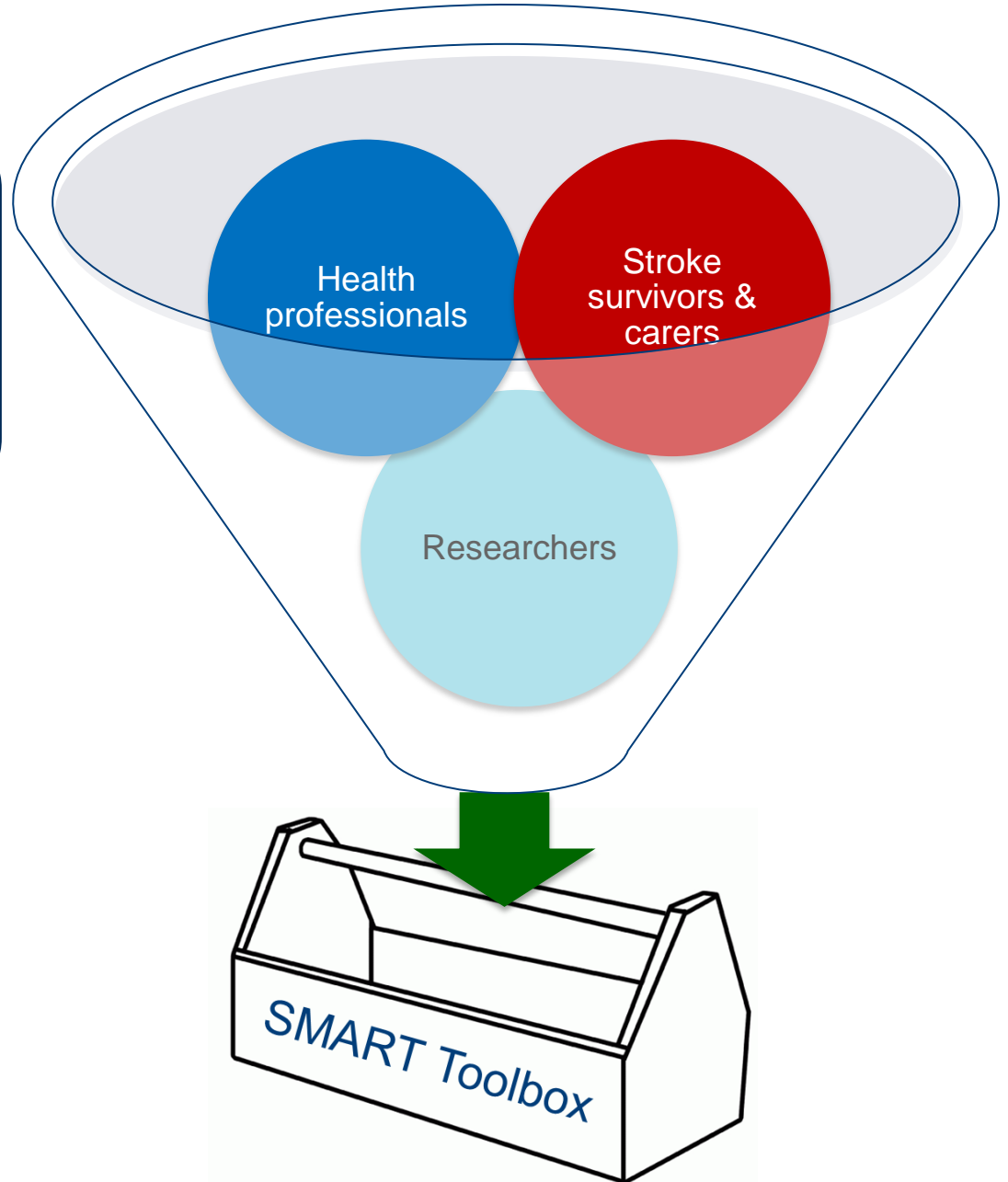
Conclusion:

Do we measure what matters?

- Outcomes that are most important to stakeholders are **not** comprehensively captured by currently used outcome measures.



Where to next?



By standardising outcome measures...



We will:

Obtain a larger pool of comparable outcomes



Strengthen the evidence base for interventions



Improve clinical decision making



Achieve more outcomes that matter

Acknowledgements



All Stroke Survivors, their Family and Friends, and Health Professionals who participated in this study

Chest Heart & Stroke Scotland for funding this study



Glasgow Caledonian University for funding Julie Duncan Millar's PhD studentship

Thank you @jduncanmillar #SMARTstrokeoutcome

