Taking Charge After Stroke

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People who **achieve** amazing things **dream** of amazing things

Intrinsic motivation is a **necessary condition** for successful rehabilitation

What the person with stroke can **do for themselves**, is as much as anything clinicians can **do to them**

Take Charge puts the person with stroke in the driving seat – where they belong

Take Charge aims for transformation: from a stroke person to a person who happens to have had a stroke

Take Charge is effective

The first time an intervention has been shown to be effective (at the level of participation, independence, quality of life) in the community phase of stroke rehabilitation

Response: How can this be possible?

My job today:

1. Show how it is possible for Take Charge to be effective
2. Get you excited about using Take Charge (using it will convince you)
3. Remind us all to keep the person with stroke at the centre – person-centred care

- Some practical issues

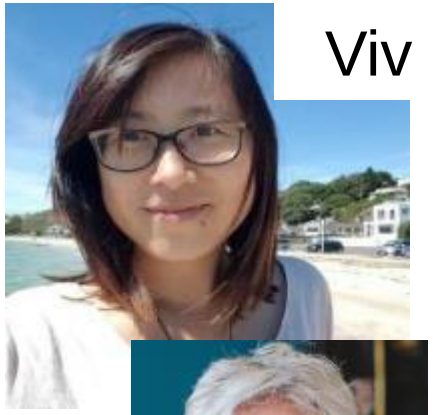
- Questions

The Take Charge team: 2005-2020


Matire


Anna R


Judith


Viv


Will

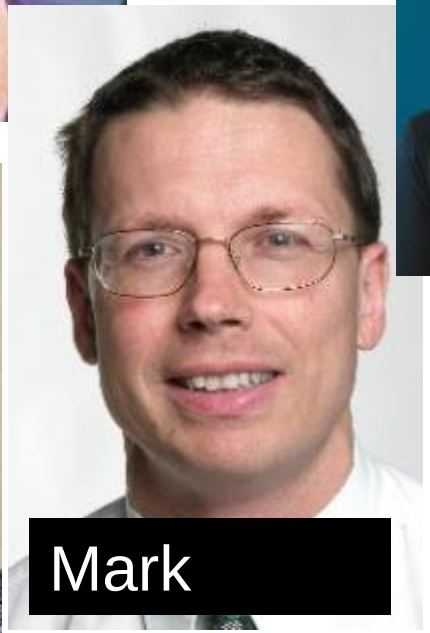

Kath


Anna M


Carl


Harry


Tom


Mark

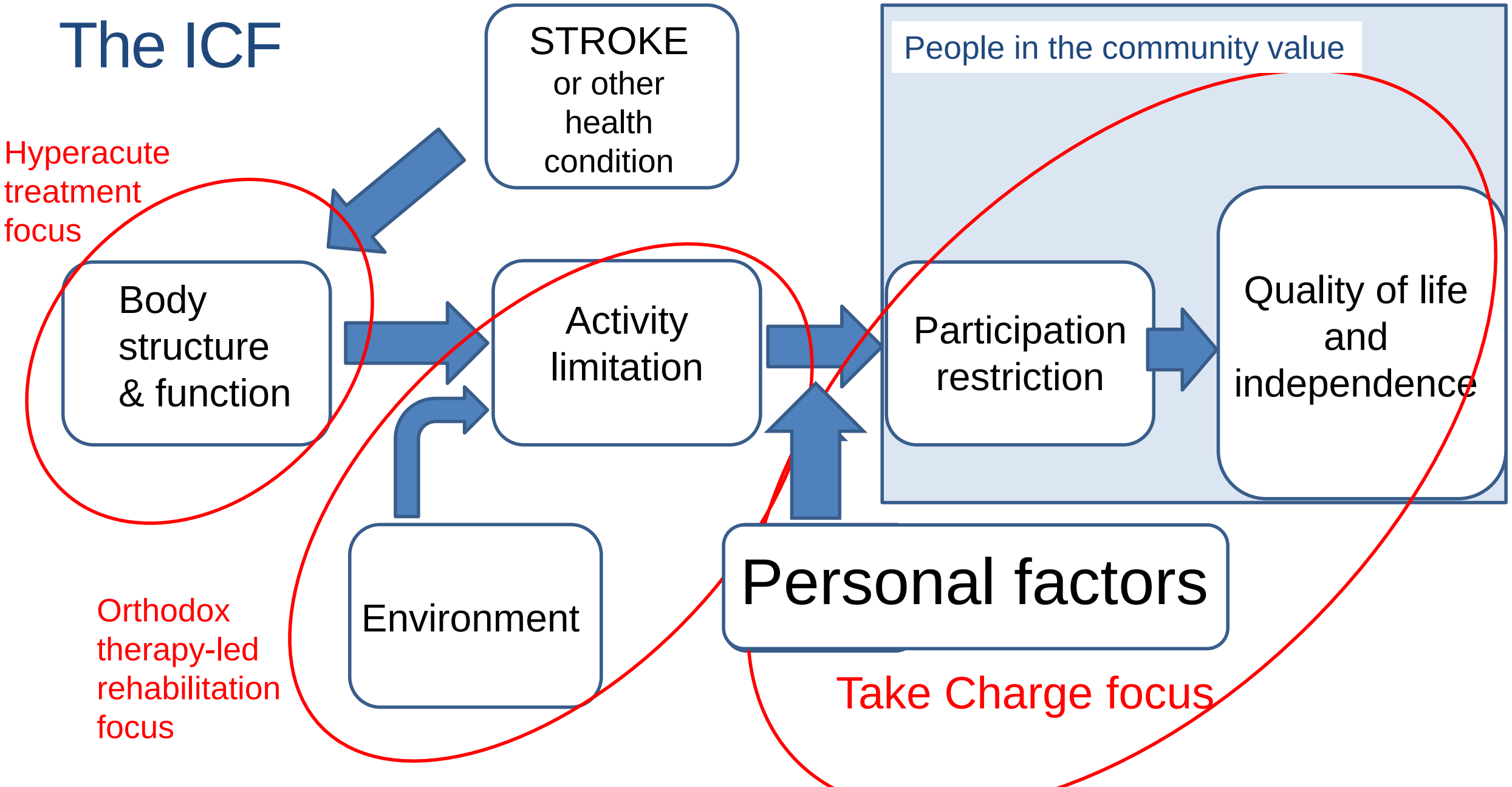
Geoff

Api

Alan


John

The ICF


STROKE
or other
health
condition
People in the community value
Hyperacute
treatment
focus
Body
structure
& function
Activity
limitation
Participation
restriction
Quality of life
and
independence
Environment
Personal factors
Orthodox
therapy-led
rehabilitation
focus
Take Charge focus

Personal factors

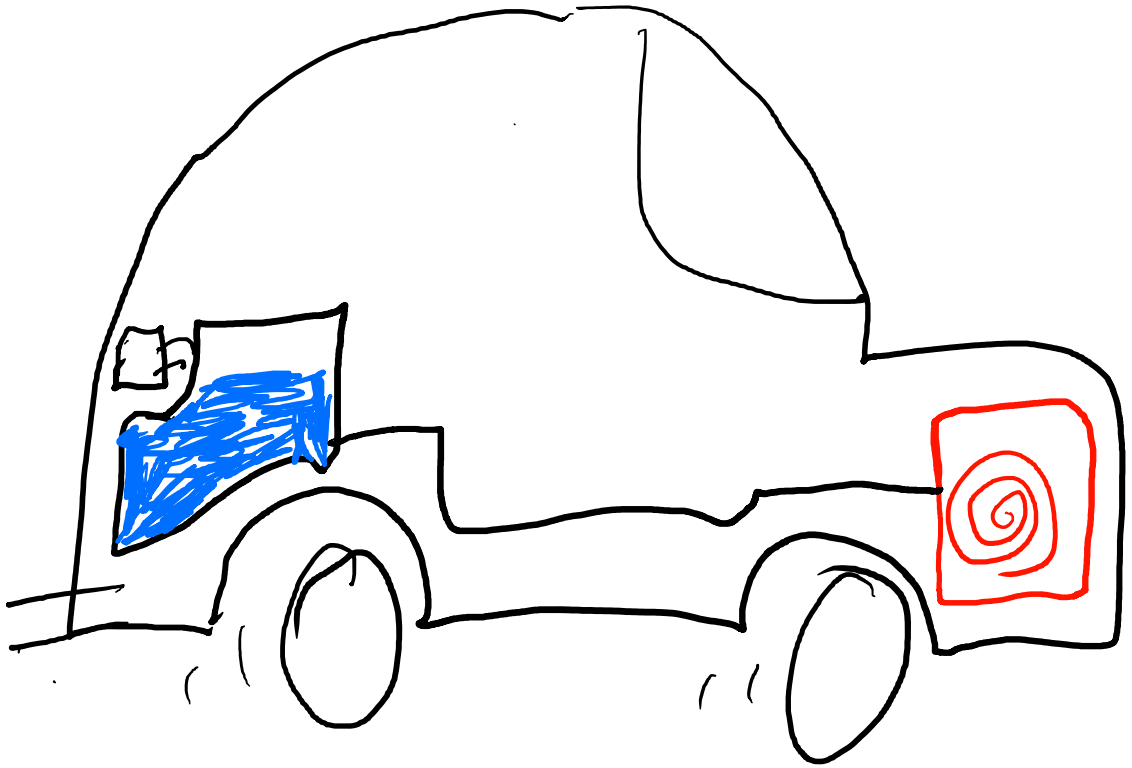
- gender, age
- social background, education, profession
- **past and current experience**
- **coping styles**
- **overall behaviour pattern**
- **character**
- ‘and other factors that influence how disability is experienced by the individual’

- Intrinsic motivation is a necessary condition for successful rehabilitation

The Other bits

The Fuel

= My Intrinsic motivation



The Engine

= My Sense of self

‘Who I really am as a person’

Fuel ingredients:

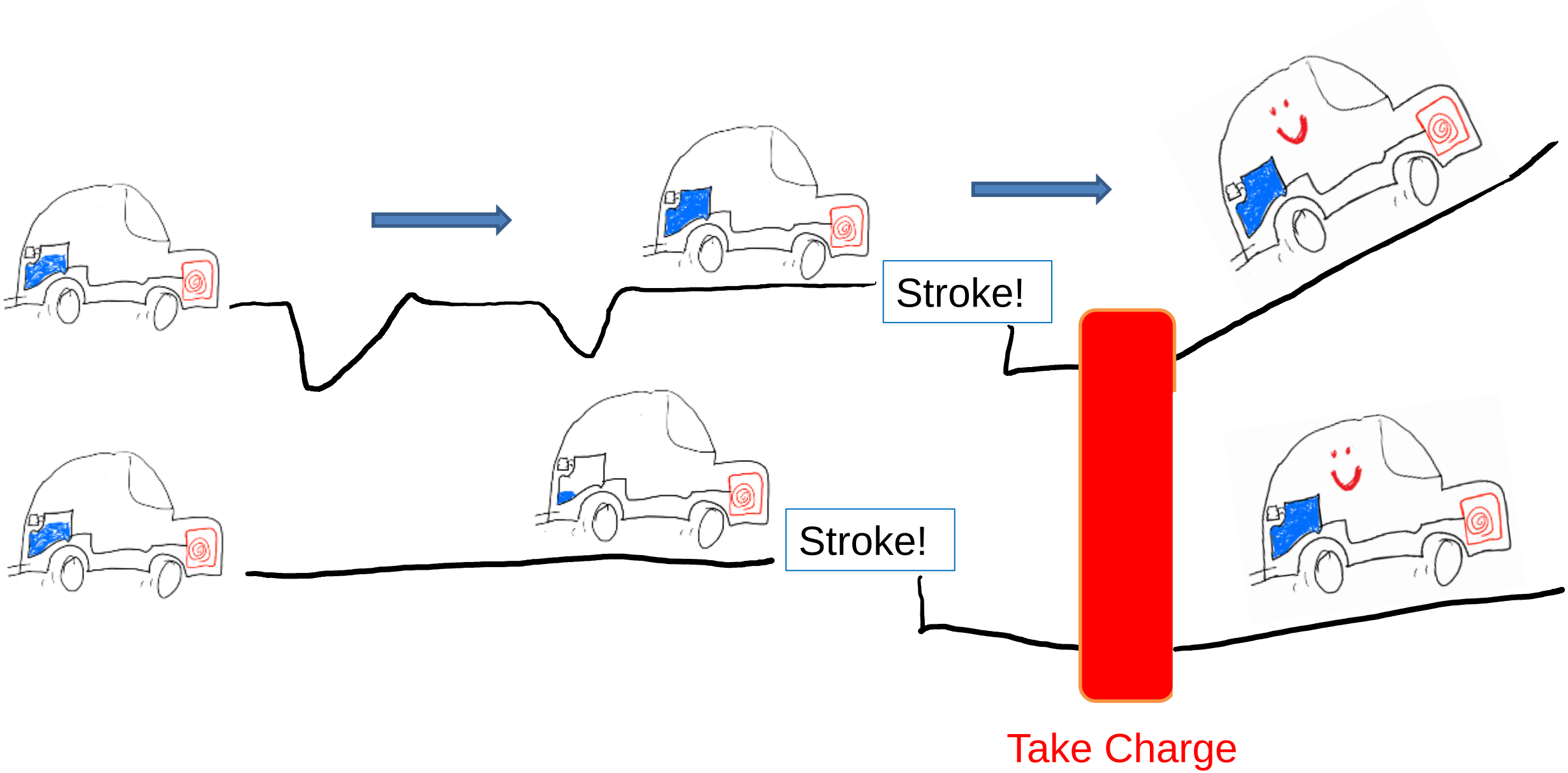
AMP-C

Autonomy – I have choices

Mastery – I can do this

Purpose – Where I want to go

Connectedness – My support crew


Stroke!
Stroke!
Take Charge

Intrinsic vs extrinsic motivation

- For full story: self-determination theory, Deci & Ryan (full references are in the IJS paper)

- Simple version
  - Intrinsic motivation – internal, personal, **your fuel**
  - Extrinsic motivation – external incentive (cash, praise, award)

someone else pushing your car

Julia

- 54 years old
- Successful businesswoman
- Husband and 2 teenage children

- Significant stroke with R hemiparesis and aphasia
- Thrombolysed @ 2.5 hours without significant change

- Transferred to rehab ward Day 7, needing 2 assistants to transfer safely

‘Rude’

‘Aggressive to staff’

‘Attempts unsafe mobilisation’

‘Husband gets in the way’

‘Dangerous’

‘Doesn’t listen to staff’

‘**Demanding**’

Julia was intrinsically motivated. She had:

1. A sense of **Purpose** focussed beyond the stroke itself

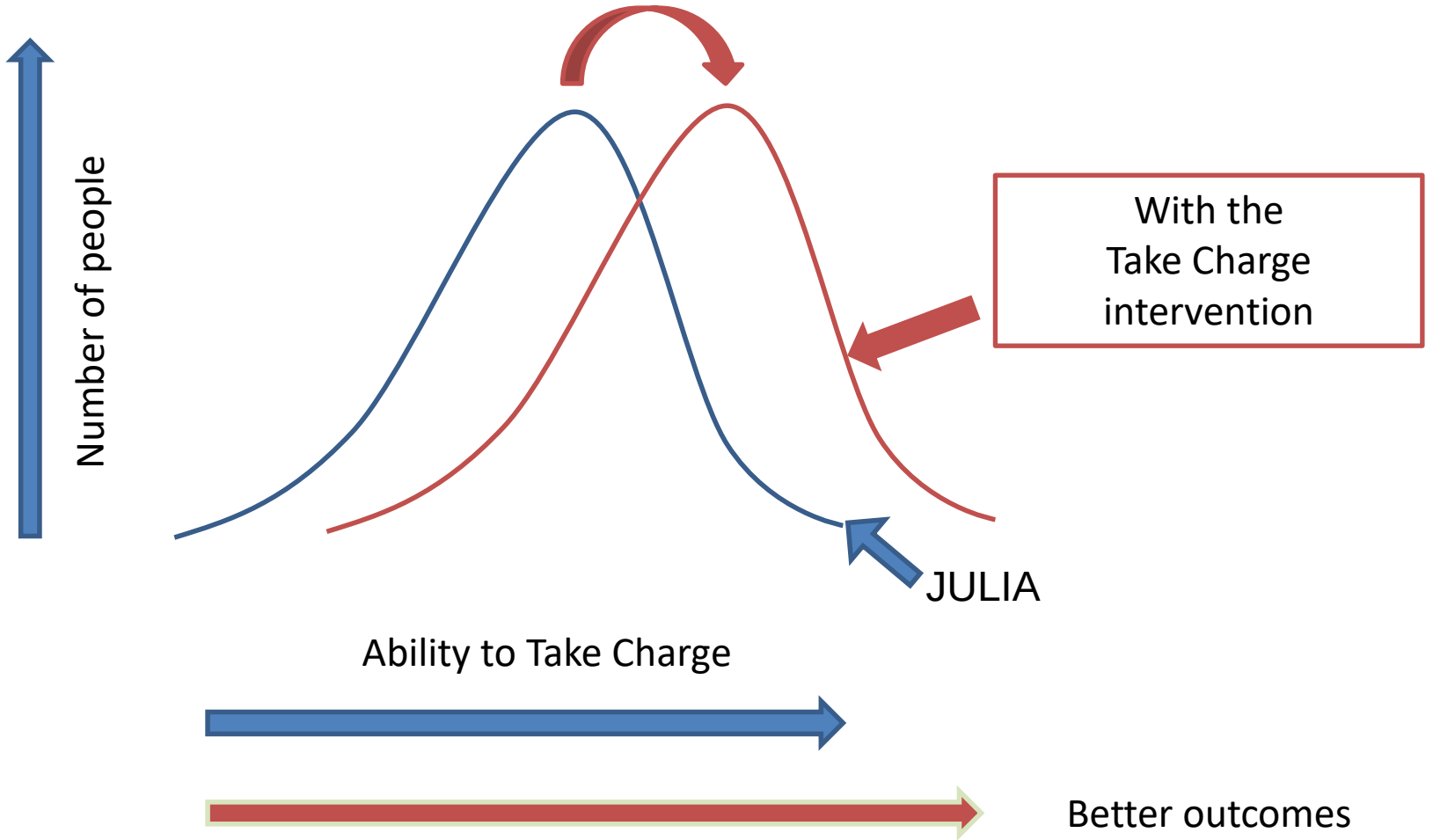
2. A very strong sense of **Autonomy**

3. A strong sense of competence/**Mastery**

4. **Connectedness**

The Take Charge intervention
tries to spark, or support, **intrinsic motivation**
for **all** people with stroke

Better ability to Take Charge = better outcomes?

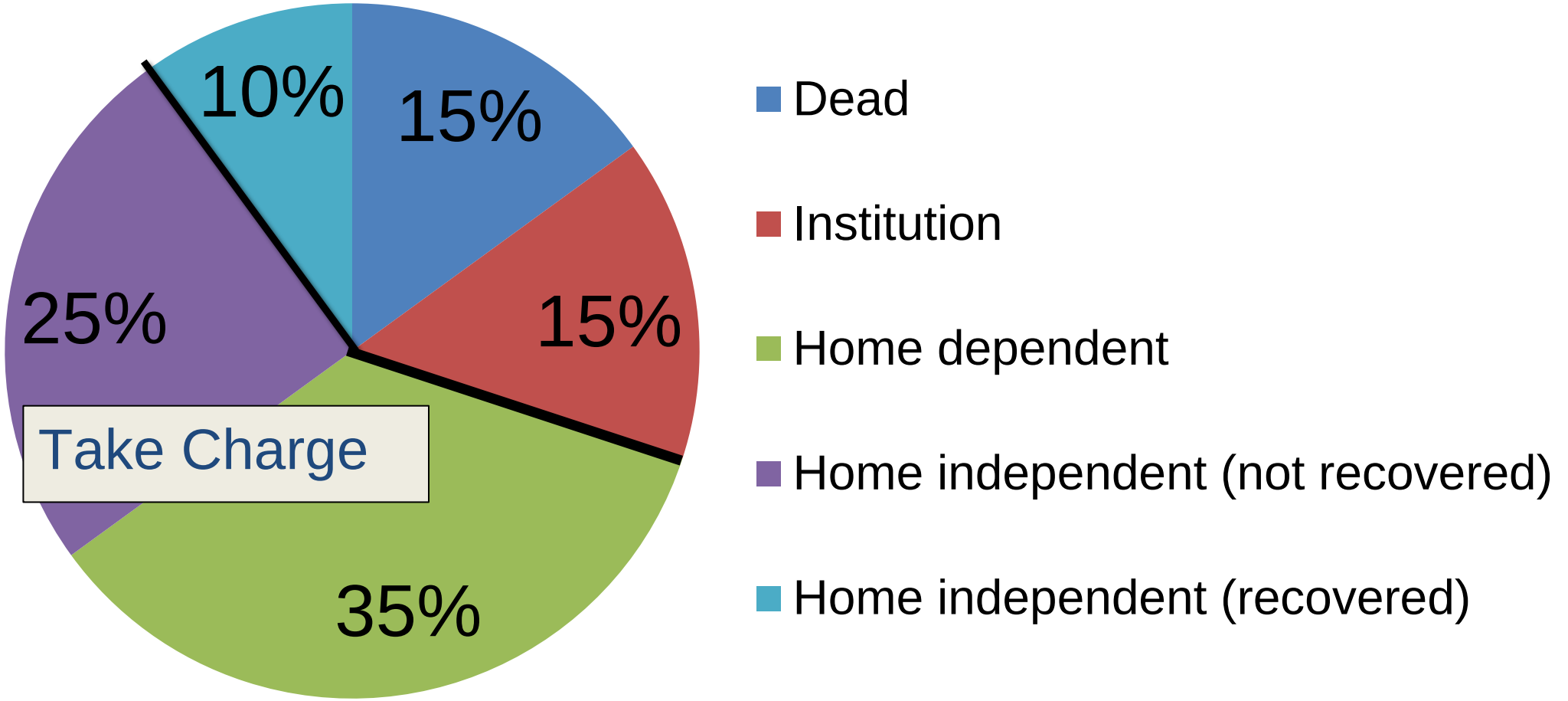


How Take Charge was delivered in the Taking Charge after Stroke (TaCAS) trial

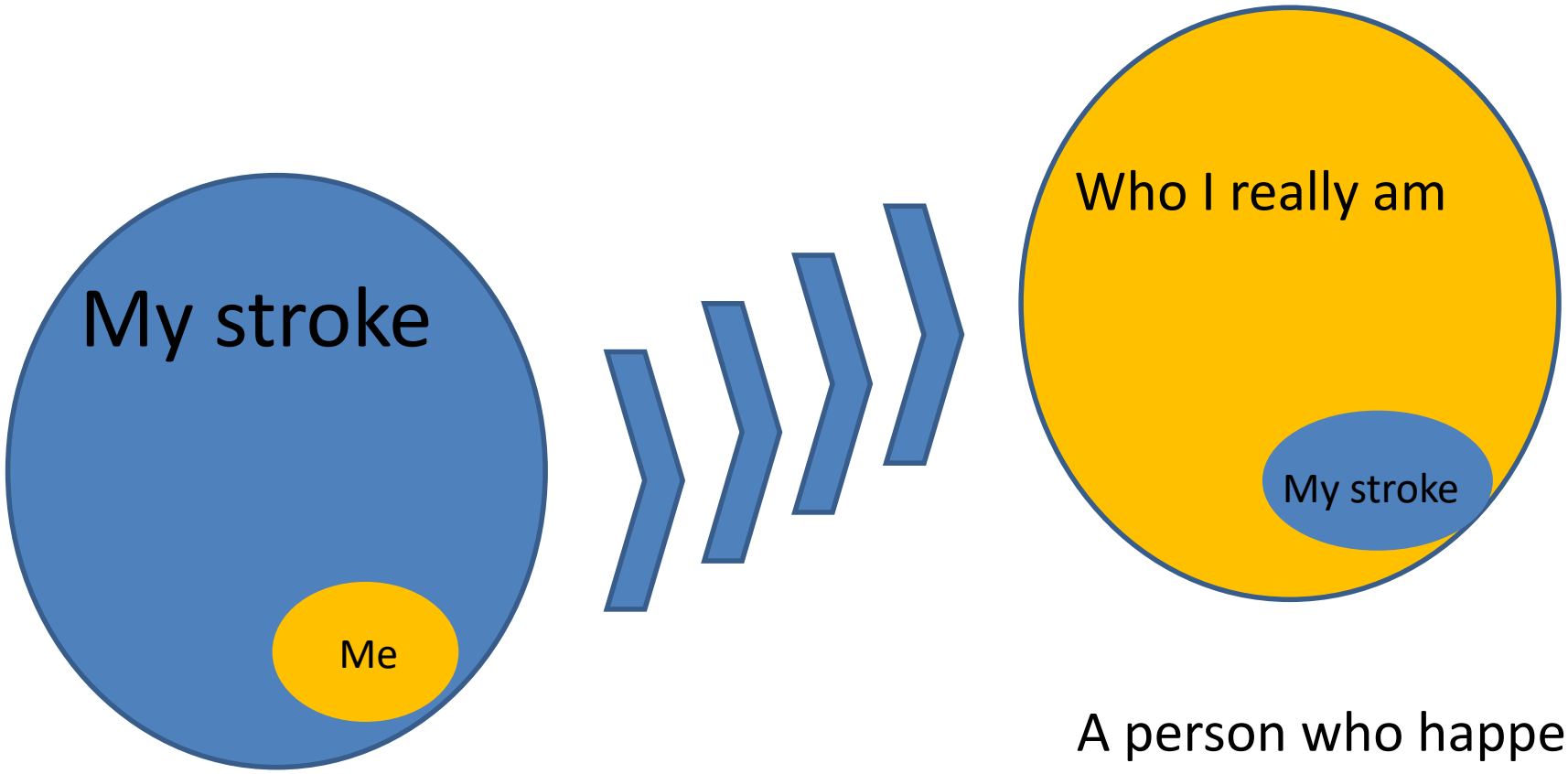
Looking beyond the stroke

- Intervention at around 3-16 weeks following stroke, community-living people (not institutional care)
- Either **one** or **two** sessions, 6 weeks apart, session ~ 60 mins
- Trained facilitator
  - Baseline assessment (ADL, IADL, QoL, independence, risk factors)
  - Make a **Connection**
  - **Listen**, don't speak
  - **Reflect**: All the ideas from person with stroke and family
  - Unlimited time – generally about 60 minutes
  - Independent from usual rehabilitation team

Delivering Take Charge: Up to 60% eligible



What Taking Charge is all about



A stroke person

A person who happens to have had a stroke

Taking charge

For example:
weak, hard to talk, hard to walk, feel funny, tired, can't concentrate, lonely, sad, can't work, need help



A stroke person





For example:
Mother, daughter, wife, choir member, helper, walker, gardener, grandma, teacher, friend, reader, joker, volunteer, strong, happy, energetic, warm, kind, gentle and lots more!



A person who happens to have had a stroke

Download from www.mrinz.ac.nz/programmes/stroke





Taking Charge after Stroke

Overall hopes, aims, aspirations for next 12 months

1.

2.

3.

4.



Main fears

1.

2.

3.

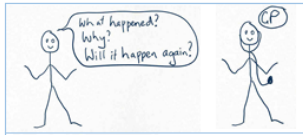
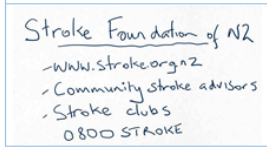


What would my ‘Best Day’ look like?



Draw a picture of your best day here. Friends and family may also want to draw something.

Information needs

	Date	Goals in own words	Specific objectives + time frame	How to achieve these
	*e.g.*	*Understand what happened and why*	*1. Understand what stroke is* *2. Understand why stroke occurred* *3. Understand rehabilitation*	*1. Talk to other people, including Stroke Foundation, doctor, internet (www.stroke.org.nz)*
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.

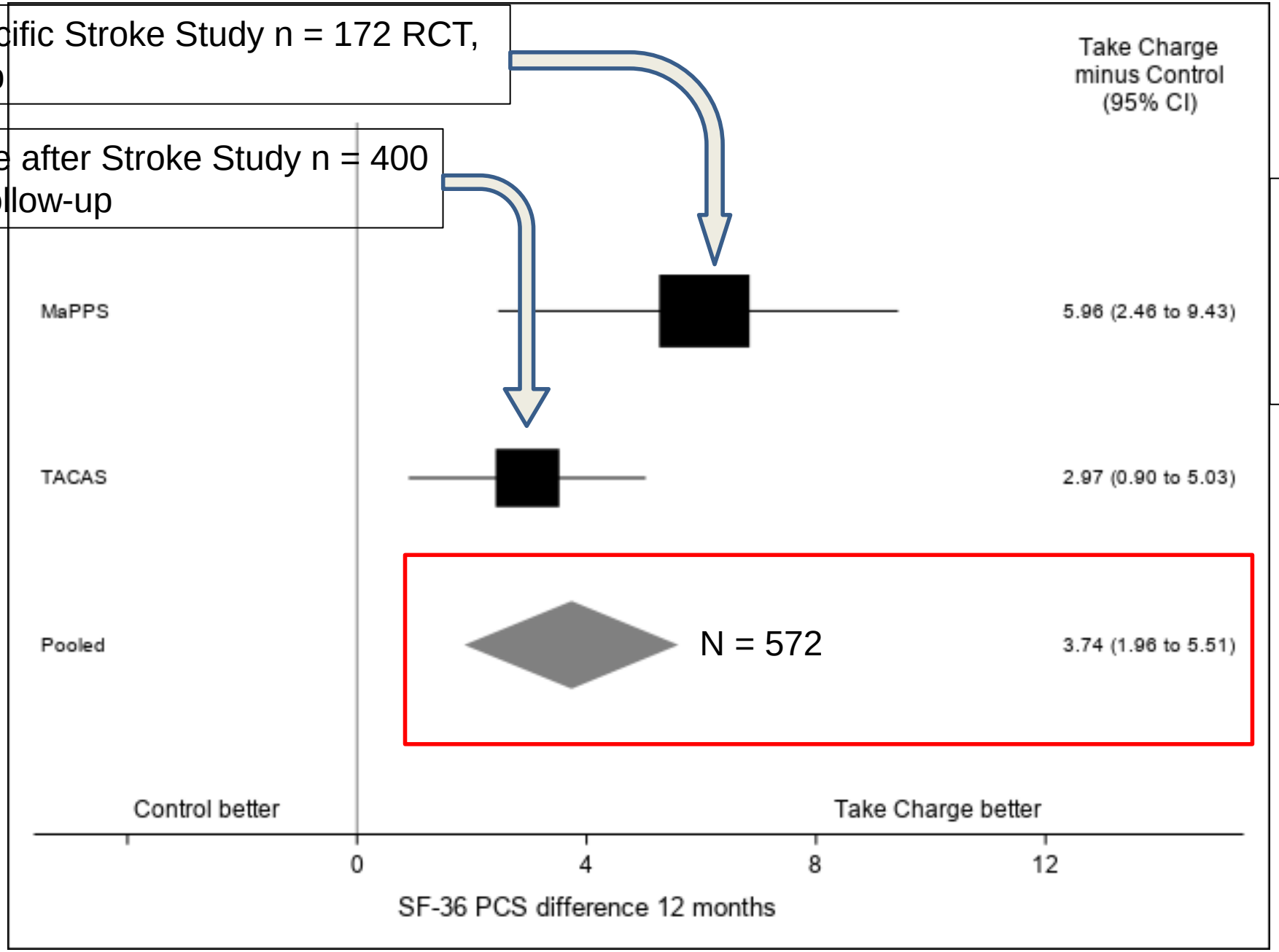
Financial issues like paying the bills, returning to work, using a budget, knowing about available supports

	Date	Goals in own words	Specific objectives + time frame	How to achieve these
	*e.g.*	*To reduce travel costs*	*1. Mobility car sticker* *2. Taxi chits and other supports* *3. Informed about WINZ support*	*1. GP to provide* *2. Stroke foundation, local providers* *3. WINZ information*
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.

Quality of life

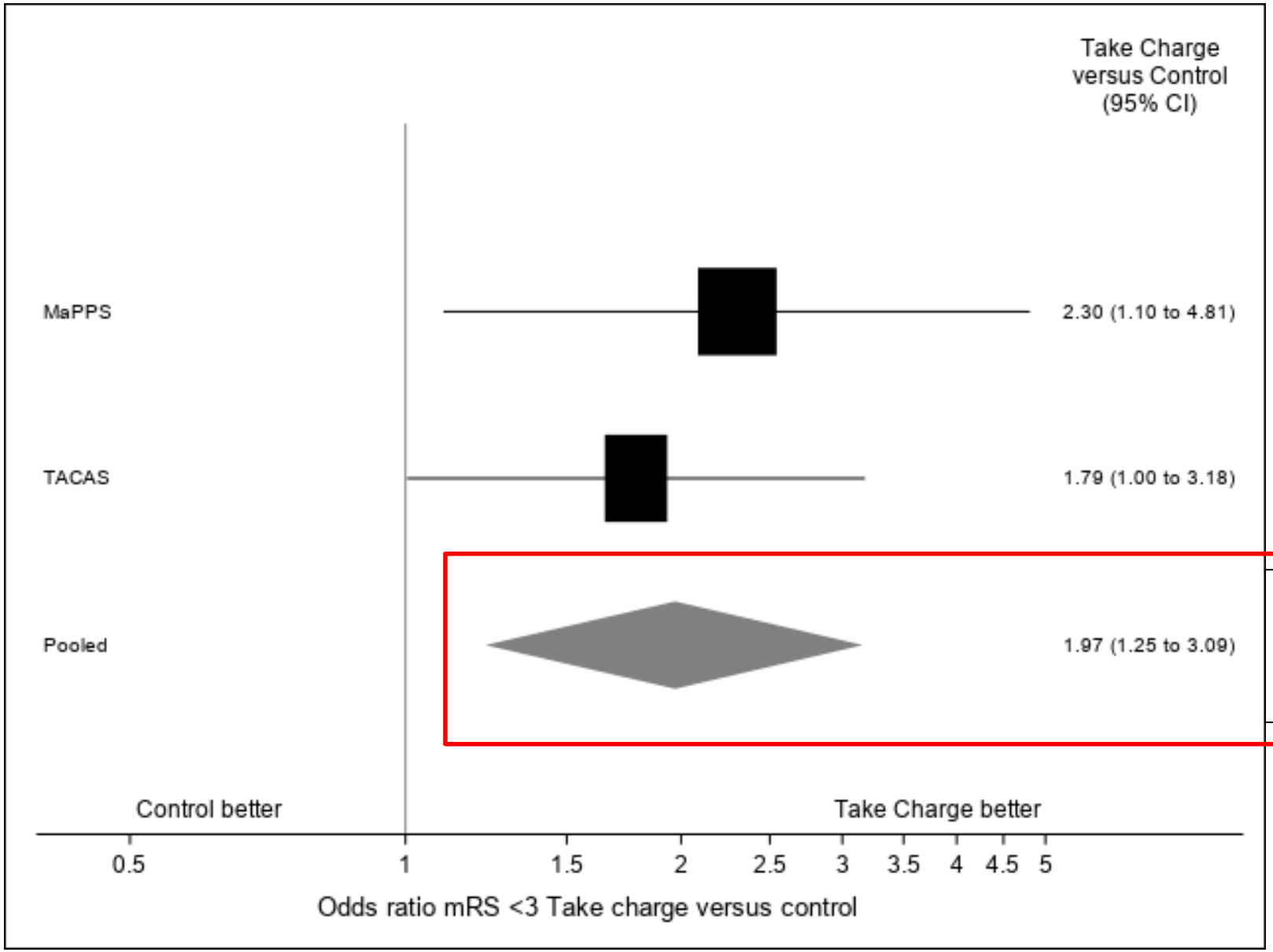
Maori and Pacific Stroke Study n = 172 RCT, 80% follow-up

Taking Charge after Stroke Study n = 400 RCT, >99% follow-up



SF36 measures health-related quality of life. MCID of the PCS in stroke = 2-3

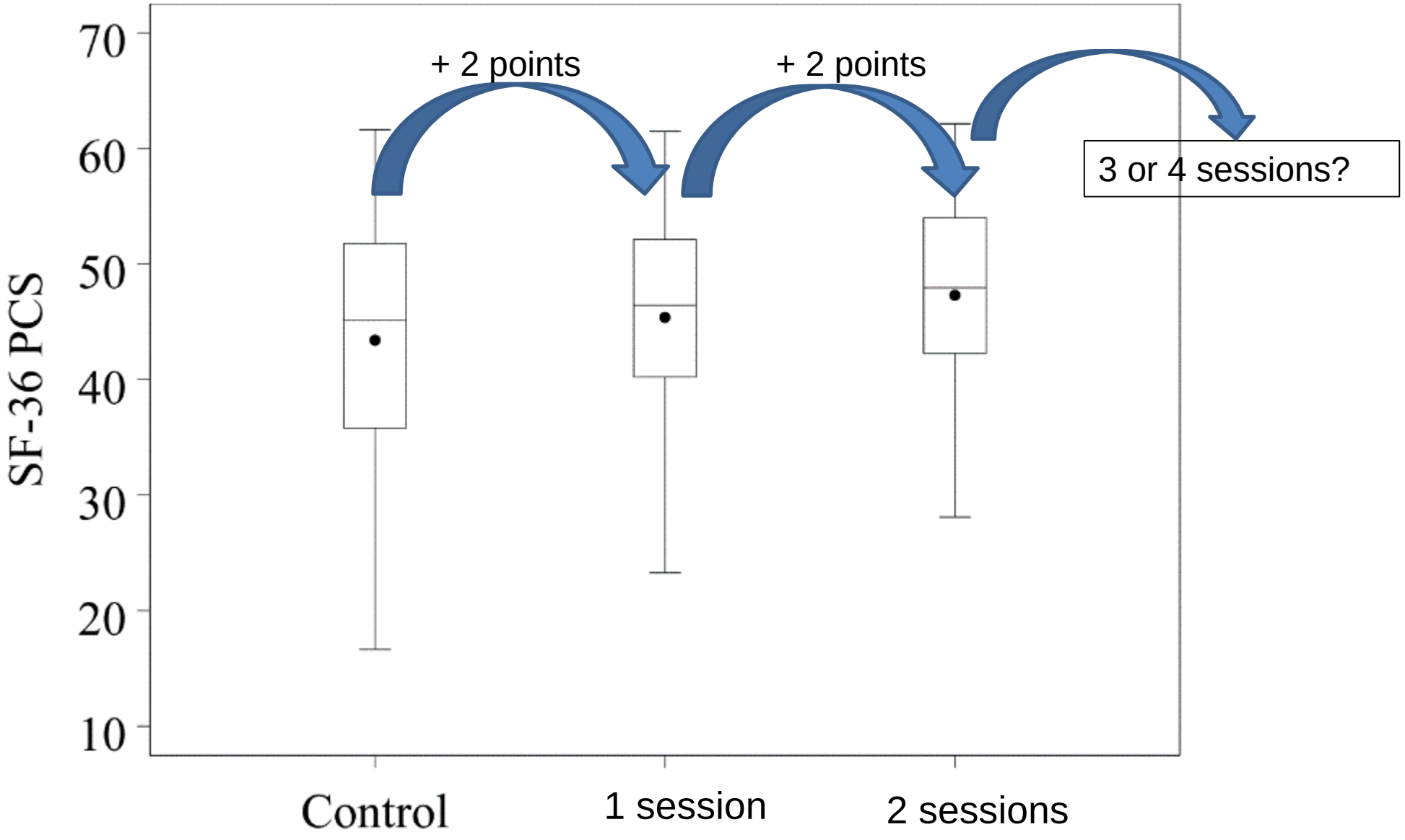
Independence



Modified Rankin Score (mRS) measures 'functional outcome'; scores 0-2 = independent; 3-5 increasing levels of dependence

NNT for 1 more person to be independent at 12 months = 7.9

2 sessions better than 1



“But we are doing this already”

- Probably not
- Review:
  - Rosewilliam S, Roskell C, Pandyan A. (2011). A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centered goal setting in stroke rehabilitation. Clin Rehabil, 2011;25,:501–14



The clipboard test

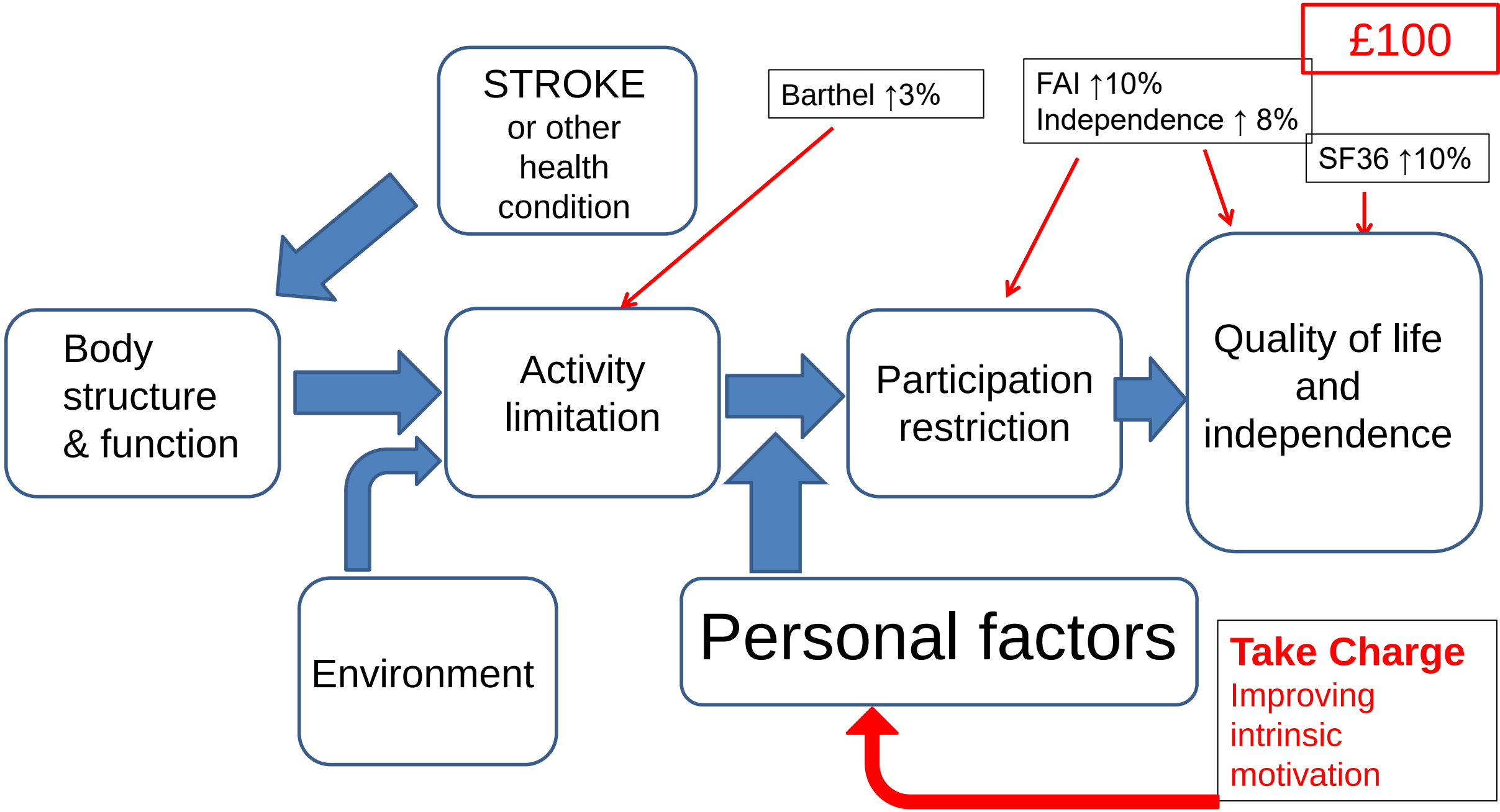
Traditional goal-setting vs Take Charge

Traditional Goal setting	Take Charge
Generic goals tailored to the individual	Completely personal
Structured	Loosely structured
Teacher/coach/counsellor	Reflecting the person's own thoughts
Clinician talking	Facilitator listening, not talking
Focus on what is do-able	Focus on what the person wants
Complete plan of future action	No written plan at the end of a session is OK
'SMART' (Specific/Measurable/Achievable/Realistic/Timed)	Anti-SMART
Time limited (often 45 min)	No time limit (often 45 – 90 minutes)

Take Charge is anti-SMART

- S - specific
- M - measurable
- A - achievable
- R - realistic (relevant)
- T - time-related




£100
STROKE
or other
health
condition
Barthel ↑3%
FAI ↑10%
Independence ↑ 8%
SF36 ↑10%
Body
structure
& function
Activity
limitation
Participation
restriction
Quality of life
and
independence
Environment
Personal factors
Take Charge
Improving
intrinsic
motivation

Number needed to treat (NNT) for death or independence

Stroke unit care	20	(mainly deaths prevented)
Aspirin acutely	100	
IV tPA within 3 hours	10	
Mechanical thrombectomy	5	
Take Charge	**8**	**(independence)**

Why stroke rehabilitation is so important

Your next 1000 people admitted to hospital with stroke: Benefit of treatments on death/dependence

Stroke unit care	50	(NNT = 20, 100% eligible)
Aspirin acutely	9	
IV tPA within 3 hours	12	
Mechanical thrombectomy	5	(current) – 15 (potential)
Hemicraniectomy for malignant MCA infarction	5	(mainly deaths avoided)
Take Charge	**62**	**(NNT = 8, 50-60% eligible)**

(in addition to best stroke rehab)

Sufficient evidence to change clinical practice?

Level 1a evidence of benefit for independence in stroke

- Benefit at 6 months, sustained at 12 months
- Dose effect
- Effective in both ethnic-minority and ethnic-majority populations
- No harm
- Cheap
- Training easy
- [Cost saving, not yet published]

Practical issues

- Which patients and how many sessions
- Integrate with current rehabilitation services or ‘add-on’?
- The facilitator
  - Good listener
  - Maybe not a rehabilitation clinician
  - Older person?
  - Training: this webinar + read the training manual is sufficient – email any questions. Skype or Zoom session for bigger groups? Get in touch.
- Training/ booklet modification if necessary
  - Materials all free on the website: www.mrinz.ac.nz/programmes/stroke
  - Send us any translations so that we can post these for others (German, Estonian, Russian underway)



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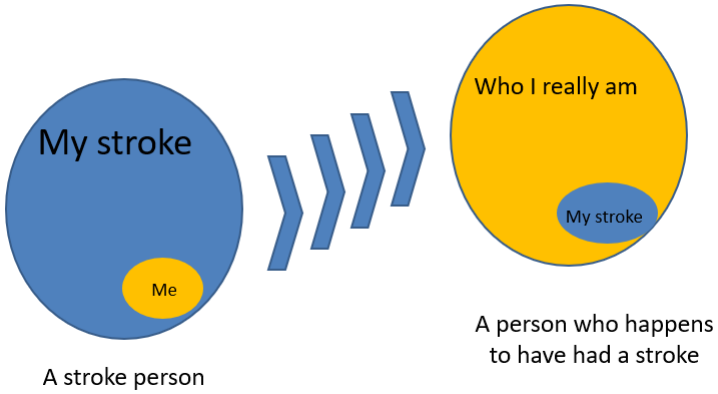
Experience Take Charge for yourself

- Materials free to download and modify
  - www.mrinz.ac.nz/programmes/stroke

- 3 different ways to think about using Take Charge to enhance stroke outcomes



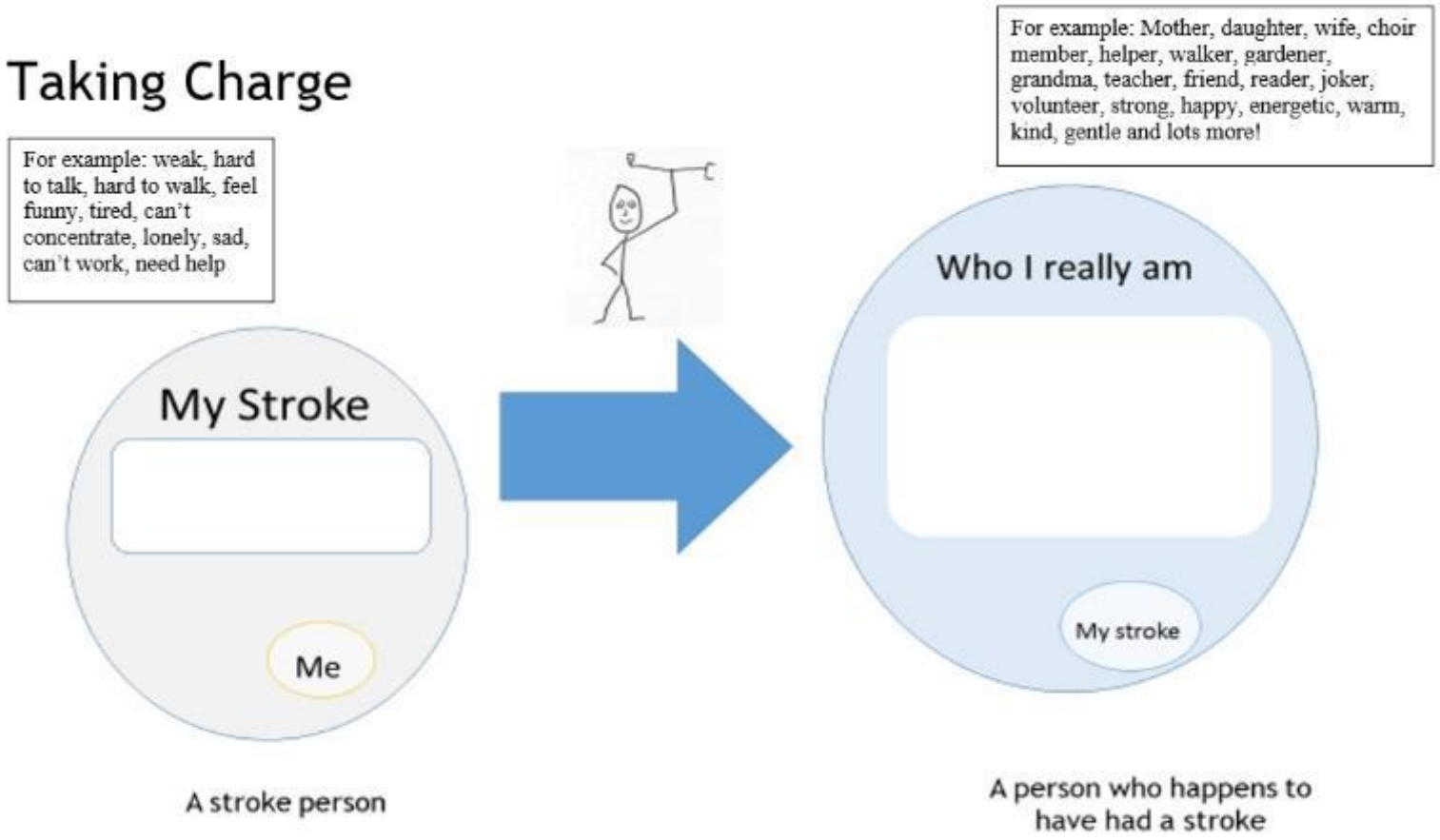
Julia



Research potential!

- Take Charge
  - More sessions?
  - Timing of first intervention?
  - Conditions other than stroke?
  - International study?
- Using Take Charge to enhance new therapy interventions
- Alternatives to Take Charge?
- Better measures of ‘intrinsic motivation’, outcome

Contacts and links



- Harry McNaughton
  - Stroke department, Royal Derby Hospital
  - Harry.mcnaughton@nhs.net
  - Harry.mcnaughton@mrinz.ac.nz
- Take Charge booklet and training manual
  - www.mrinz.ac.nz/programmes/stroke
- Main paper results: https://doi.org/10.1177/1747493020915144

“But what did they do after Take Charge?”

We don’t know for sure. So much unknown about the psychology of recovery from illness – likely to be very individual

- Not more face-to-face rehab
- (In my opinion) It’s not about ‘more therapy’ (compare what we know about elite athletes, musicians, students studying – more about motivation, focus, engagement)

Some insights from qualitative study (unpublished)

- Permission to do my own thing
  - Rebel against paternalistic doctors and therapists ‘one size fits all’, ‘scripted’
  - Therapists ‘obsessed with safety’ – I’m not allowed to take risks (compare Julia)
- Felt properly listened to for the first time
- Came to a better understanding of ‘who I really am’
- Better focussed on what is really important (to me)
- Working out a plan over time – booklet helped with ‘big ideas’ and simple structure to ‘get on’

- Alan's story

Permission to take risks and fail

Michael Jordan, the greatest basketballer to play the game

"I've missed more than 9,000 shots in my career. I've lost almost 300 games. Twenty-six times, I've been trusted to take the game winning shot and missed. I've **failed** over and over and over again in my life”

From the facilitators' perspective

- Judith's story 'I was going to say that …
  - Privilege to share the stories of people with stroke in their own homes

- Therapists turned facilitators
  - 'so hard not to say anything'
  - 'so wanted to 'help' but you told me not to!'
  - 'amazing to see the look on their face when they started to talk about what they really wanted'
  - 'They said 'no-one has ever asked me questions like this before'. How can that be possible?'
  - 'The first session was a wash out but the second was amazing'

What's in a phrase?

- Self-management (SM) vs self-directed rehab (SDR)
  - Depends on resources available
  - 'DIY' (SM) vs employing the top mechanical engineers for your car (SDR)
  - But some things always better done yourself (eg risk factor management?)
  - Who is driving the car?

- Take Charge vs intrinsic motivation
  - **Take Charge** is the name of the intervention
    - People with stroke can relate to it
    - The person with stroke is undoubtedly the subject not the object
    - You can't 'do' Take Charge 'to' someone, only 'with' someone
  - **Intrinsic** motivation describes the underlying principle
    - Possibly more confusing to use with people with stroke
    - Possible confusion with motivational interviewing

Take Charge for every day

- Inpatients – I say to all patients and families: ‘the 3 most important things for a better outcome are’
  - A **Dream** for the future - ‘know where you want to be going’ (= Purpose) + Belief (= Mastery)
  - An **Attitude** (= Autonomy)
    - Permission to misbehave (like ‘Julia’)
  - A **Person in your corner** (= Connectedness) – Paul Farmer’s ‘accompagnateur’

- Outpatients/GP: I ask:
  - ‘What do you dream about for the future?’
  - ‘What is your biggest fear?’

Take Charge: timing

- Stroke dogma: 95% of motor recovery complete by 12 weeks – ‘plateau’ effect
- So how can an intervention at 3-16 weeks improve outcomes at 12 months?

