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University College London Hospitals NHS
NHS Foundation Trust

Investigating changes in quality of life after high-dose, high intensity upper limb rehabilitation in people later after stroke

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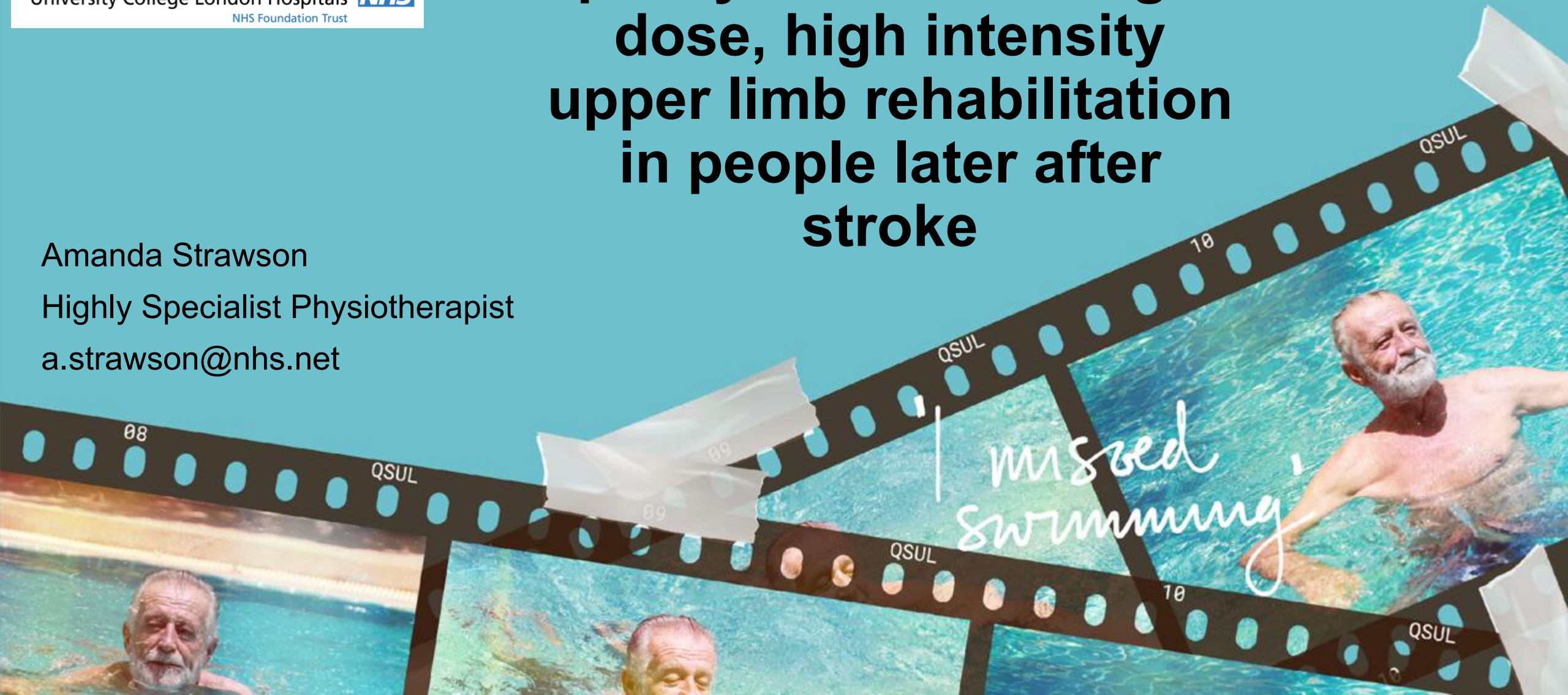

Disclosure statement

There are no conflicts of interest to declare.

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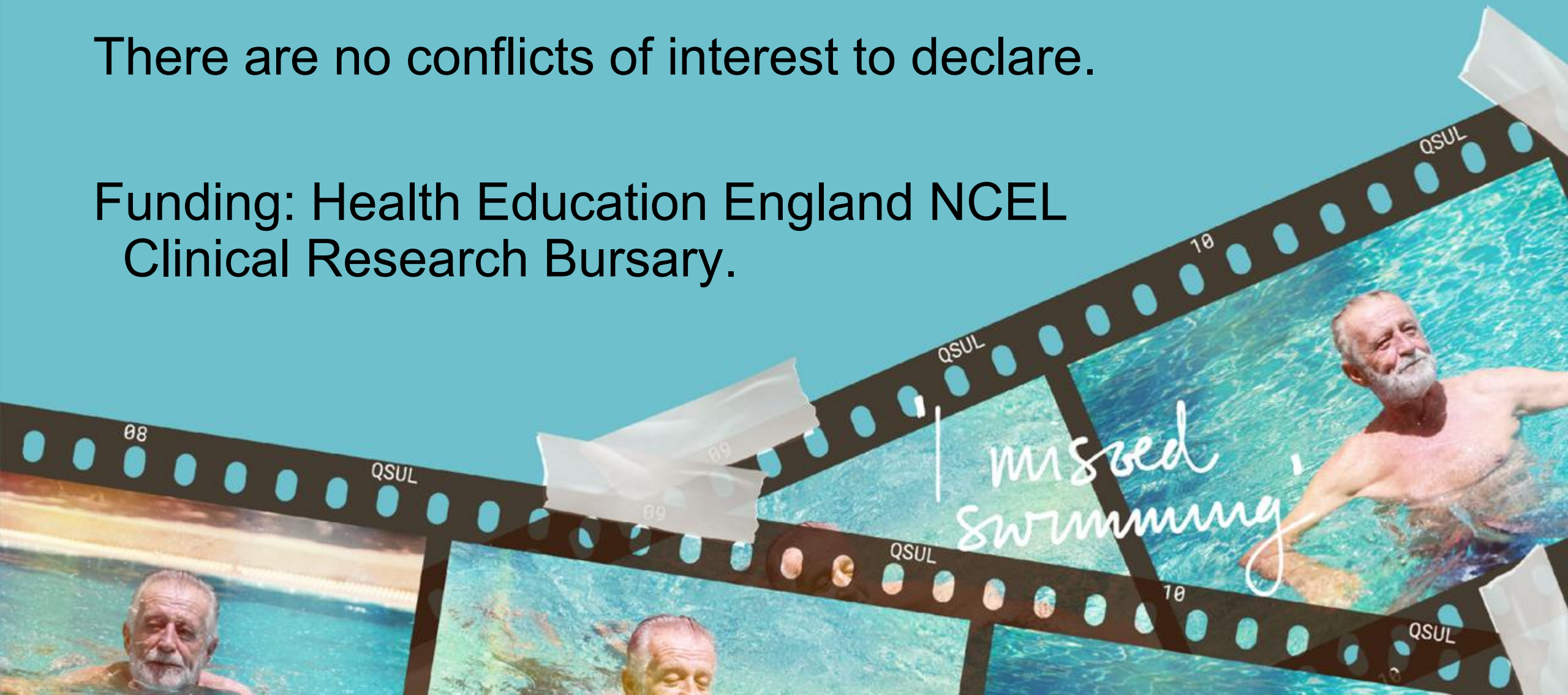
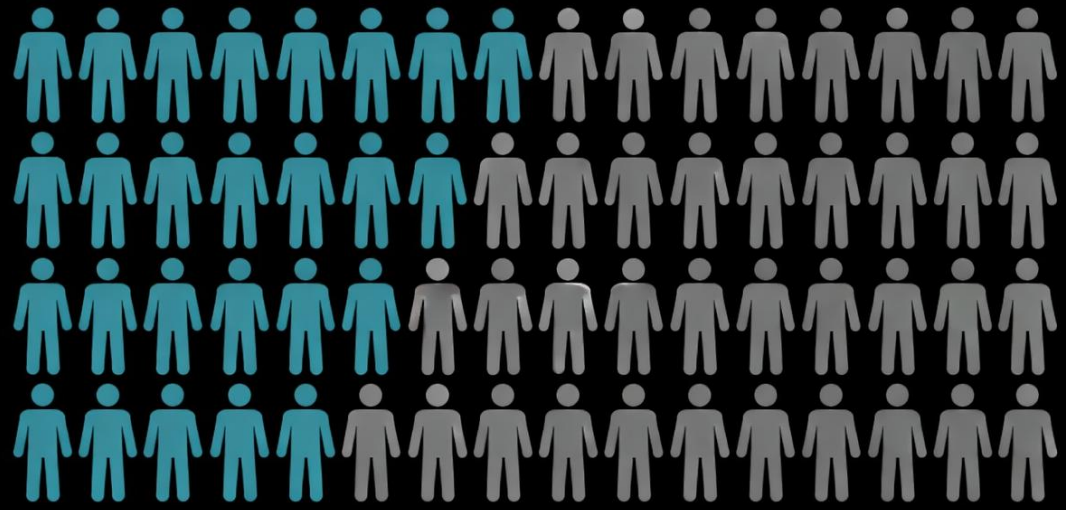


‘’They have saved his life and brought him back from the brink and then left him there, in effect giving up on him. As though he should be grateful to just be alive with no quality of life.’’



45%

of ALL STROKE SURVIVORS

Feel Abandoned When They Leave Hospital

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Immediately after stroke:

70-80% of stroke survivors have some degree of upper limb (arm/hand) deficit

At 3-6 months:

40-60% still have persistent upper limb impairment

At 6 months or longer:

30-50% have moderate to severe ongoing arm/hand dysfunction

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Intensive upper limb neurorehabilitation in chronic stroke: outcomes from the Queen Square programme, *Nick S Ward, Fran Brander, Kate Kelly*

Journal of
Neurology, Neurosurgery
& Psychiatry

Ward et al. 2019;90:498-506 – free to access

RESEARCH PAPER

Intensive upper limb neurorehabilitation in chronic stroke: outcomes from the Queen Square programme

Nick S Ward,[1,2,3] Fran Brander,[2,3] Kate Kelly[2,3]

ArmA (b)

CAHAI-13

Mod

n = 224

Fugl-Meyer (Upper Limb)

Median FM-UL 26 pts 34 pts 35 pts 37 pts

n = 224

ArmA-B

CAHAI

Admission Discharge 6 weeks 6 months

Individual Change in ArmA (b)

Individual change in CAHAI-13

'MCID' ΔArmA-A = -6 pts

ArmA-B change

Adm - Dis Adm - 6 weeks Adm - 6 months

Median ΔFM-UL 6 pts 7 pts 9 pts

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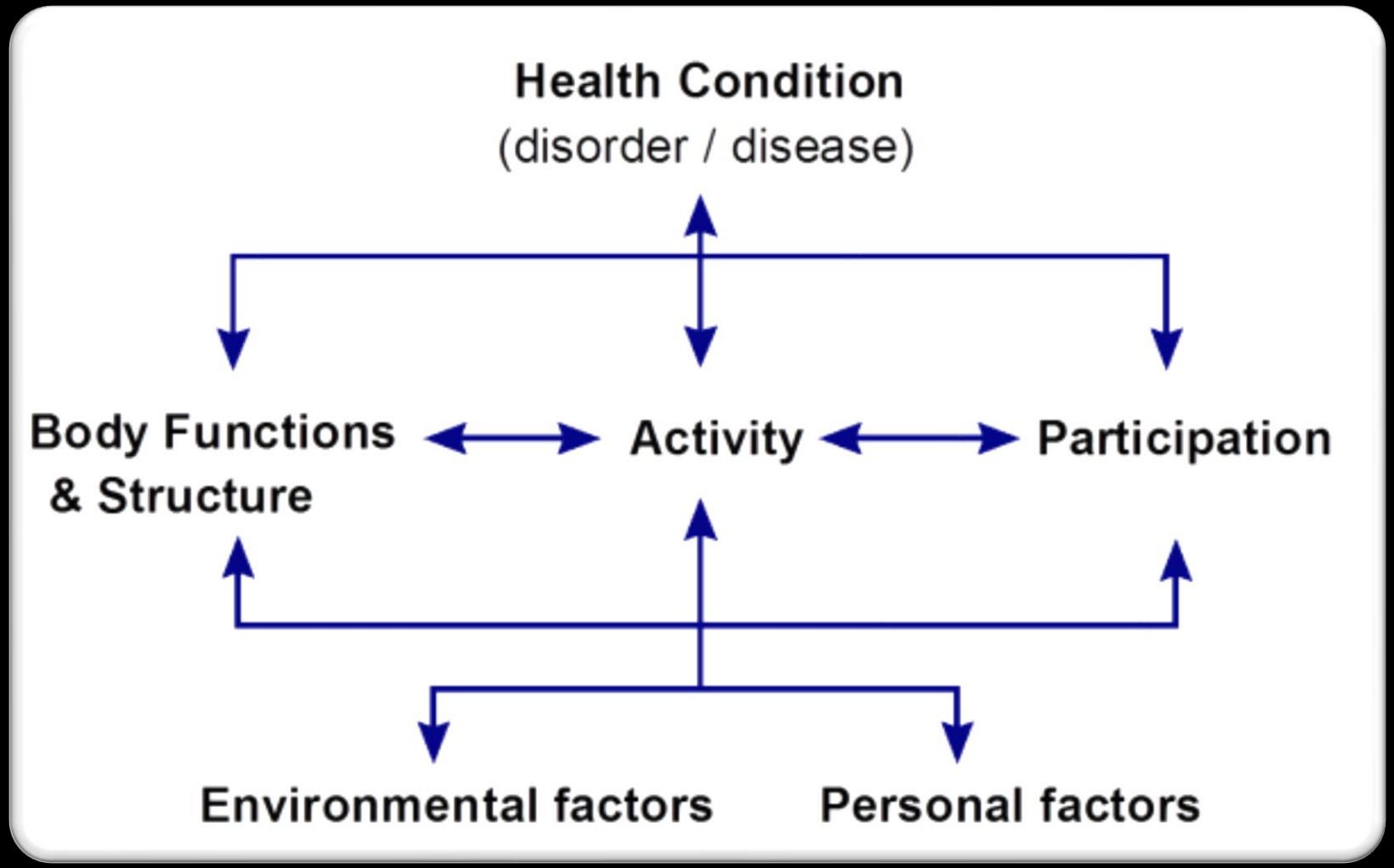

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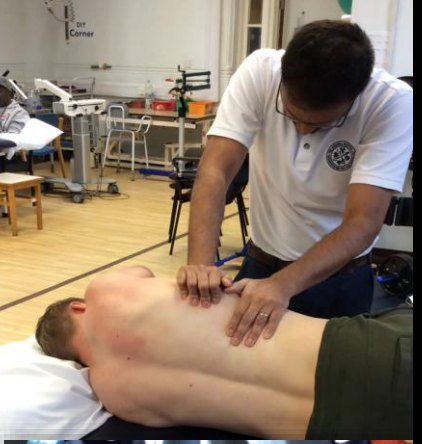

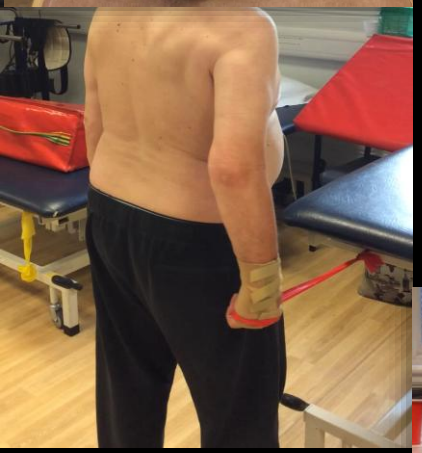

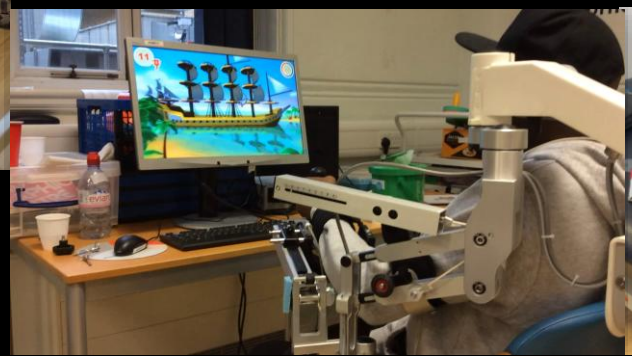

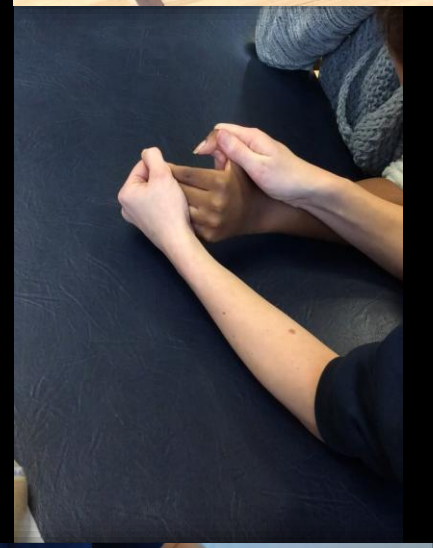

Original research article

CLINICAL REHABILITATION

Clinical Rehabilitation
1–16

DOI: 10.1177/02692155251363439
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Investigating changes in quality-of-life after high-dose high-intensity upper limb rehabilitation in chronic stroke survivors: A mixed-methods analysis of the Queen Square Programme

Amanda Strawson[1], Jill J Francis[2,3], Fran Brander[1], Kate Kelly[1], Mark Haddad[2] and Nick S Ward[1,4]

Letter to the editor

CLINICAL REHABILITATION

Clinical Rehabilitation
2025, Vol. 39(12) 1684–1686

DOI: 10.1177/02692155251380853
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Sage

Response to letter to the editor regarding 'Investigating changes in quality-of-life after high-dose high-intensity upper limb rehabilitation in chronic stroke survivors: A mixed-methods analysis of the Queen Square Programme'

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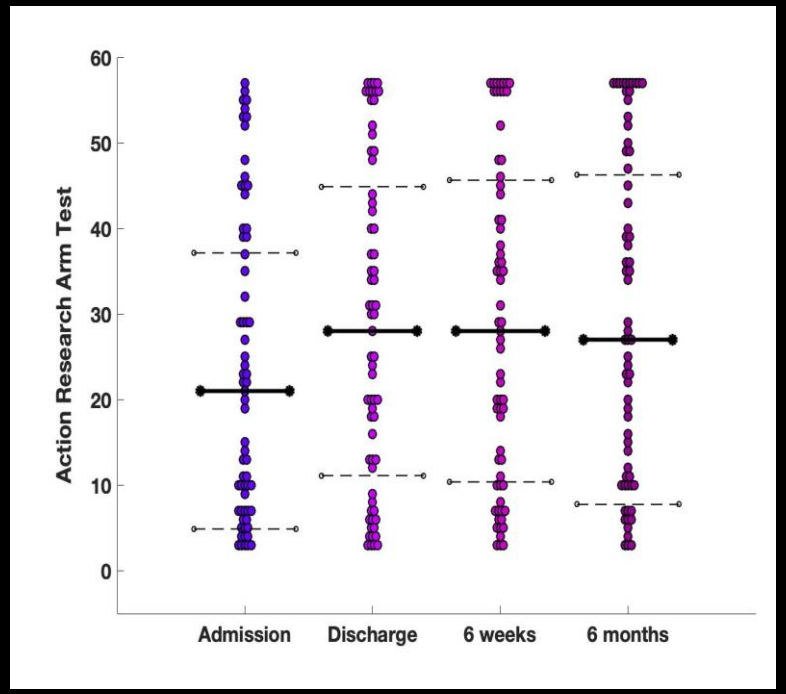
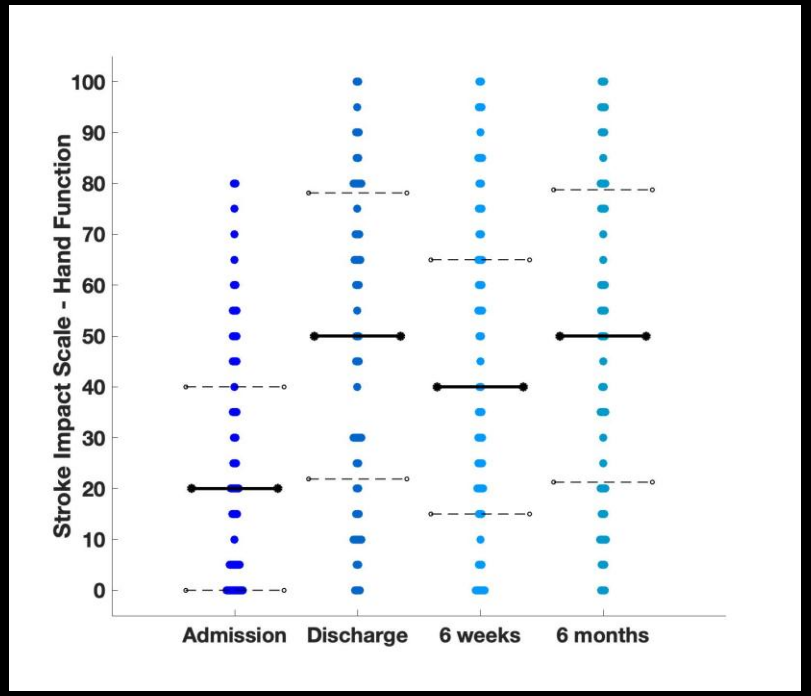
ACTIVITY - ARAT



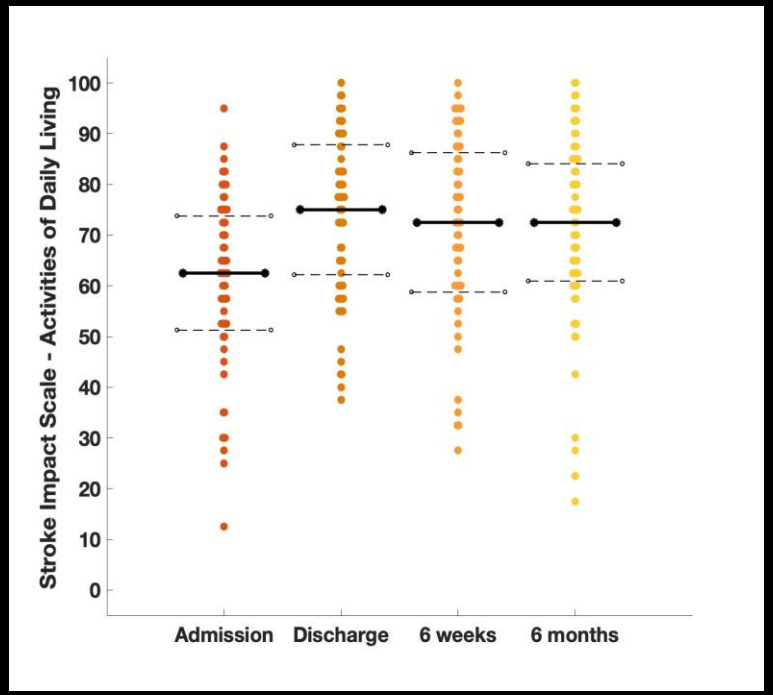
MCID ΔARAT = 6 pts

HAND FUNCTION



MCID ΔSIS-hand function = 17.8 pts

ACTIVITIES OF DAILY LIVING



MCID ΔSIS-ADL's = 5.9 pts

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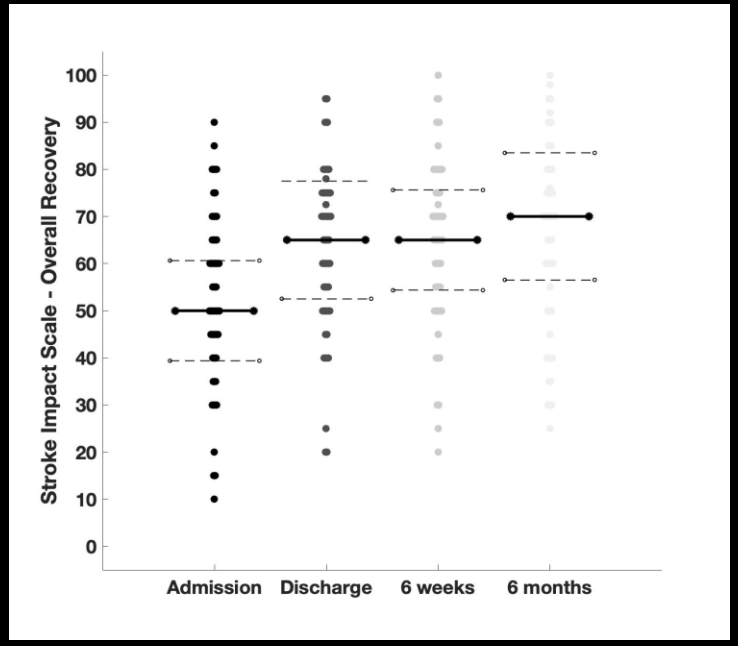
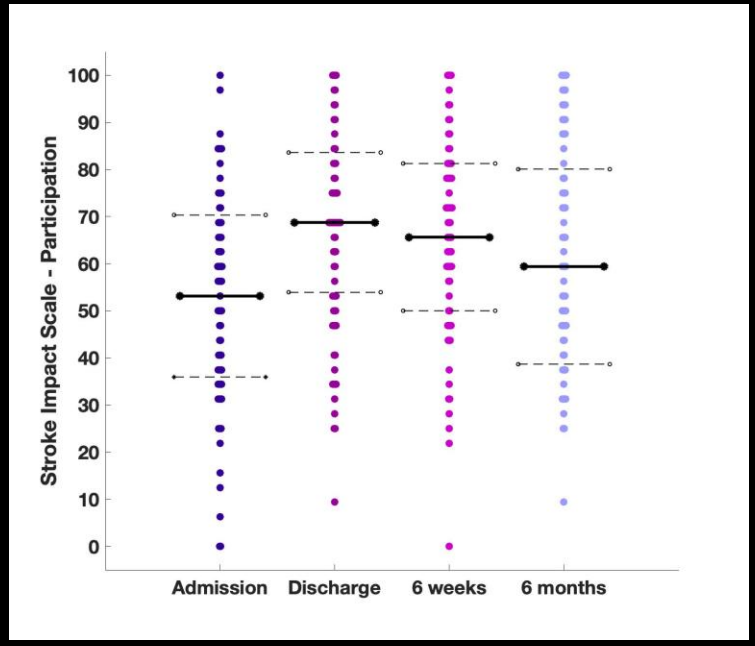
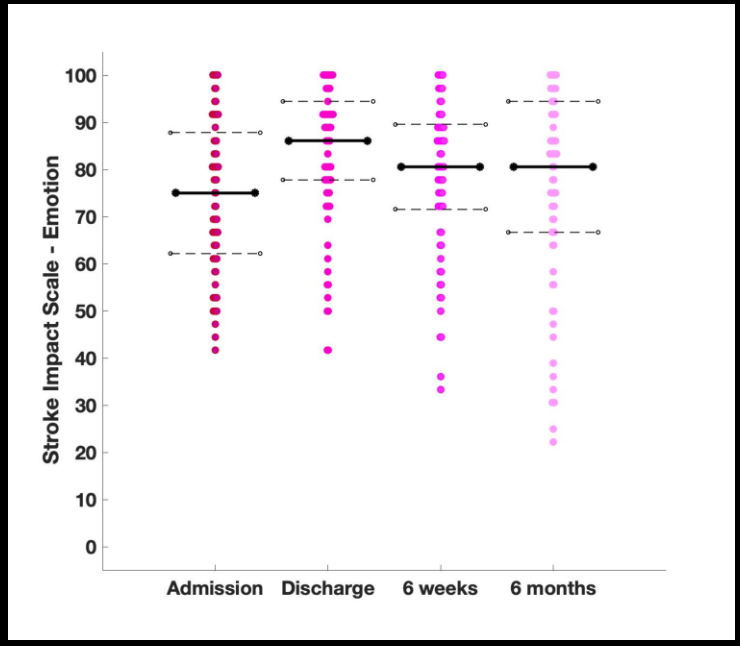
OVERALL RECOVERY



SOCIAL PARTICIPATION



EMOTION



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''Yes, your **mind has to think you can** – even thought you don't know, you really don't know. You have to **think you can recover**.''

''I'm still very **upset** about it, I still don't **cope** with it very well.''

''It just makes you realise that there are **more important things** too, than money and looking good.''

''I feel that I'm so **dependent** on my husband, and friends and family. They don't seem to mind, **but I mind.''**

SHARED THEMES

''To be honest, **I just get on with it,** I don't think about whether I can do it or not. **I just know what I can do and I get on.''**

''**I don't feel like me.** I was quite an outgoing person, and always on the go and everything, and it **sort of stopped me in my tracks**.''

''I **have a lot of things I think I want to do**…I would like to go and see my daughter in Ireland and maybe do it on my own, that' another **big thing for me.''**

''I know that I could if I worked really hard at it**, but I also know that I've got other stuff going on,** and I don't really have the **time** to do that.''

’You know it’s more like. It’s easier for me to forget the life I had before my stroke and **consider the stroke as a starting point**.’’

GROUP 1 & GROUP 2 INDIVIDUAL THEMES

Group 1

Getting on with life

Participants focused on adjusting to their abilities and moving forward, emphasizing recovery and social participation.

Group 2

Hidden Negative Effects

Participants dealt with pain, fatigue, depression, and uncertainty about managing these “invisible” struggles.

Loneliness

Participants described boredom, loneliness, and social isolation

‘’I also have.. short-term memory loss… I think that’s a massive problem with people who’ve had strokes, is because it’s a **hidden effect is the fatigue, and also depression and anxiety.’’**

‘’I haven’t got **much of a life** really.’’

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Intensive upper limb rehabilitation (QSUL) **improves upper limb activity and quality of life** in people later after stroke.

At **6-month follow-up**, improvements in quality of life were **sustained in several domains**, though not universally.

Benefits extended **beyond physical function**, influencing broader aspects of health and wellbeing.

For some individuals, **mental health and psychosocial factors strongly shaped quality of life and participation.**

Intensive neurorehabilitation programmes should **consider multiple outcome domains** to ensure a truly **holistic approach**.

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