

HEADS: UP Aphasia: co-creating a Mindfulness-Based Stress Reduction self-management intervention for people with post-stroke aphasia

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Background & Aim

Aphasia affects 1:3 stroke survivors and although **anxiety** and **depression** are extremely common after post-stroke aphasia¹, emotional support for the affected individuals and their families is inadequate².

HEADS: UP Aphasia, *Helping Ease Anxiety & Depression following post-stroke aphasia*, aims to co-create an aphasia-friendly version of HEADS: UP³, a stroke-specific adaptation of Kabat-Zinn's **Mindfulness-based Stress Reduction** course to promote **self-management of mood disorders** for people with post-stroke aphasia and their family.



HEADS: UP Aphasia Advisory Group

Advisory Group:
Ongoing collaboration and consultation work

Pwa & family:
-co-creation meetings
-feedback meetings



HEADS: UP Aphasia Co-creation Group 1

Health professionals:
-questionnaire
-co-creation meetings
-feedback meetings

External peer review:
-feedback email on co-created manual

Level of involvement for each PPI group

Design & Methods

HEADS: UP Aphasia co-creation work implemented a **participatory approach** based on a **Patient and Public Involvement and Engagement** collaboration.

An **Advisory group** formed by n=4 stroke survivors with direct or indirect experience of aphasia supported the researcher throughout the project, assisting with:

ethics application, recruitment, co-creation procedures and strategies, data analysis and dissemination.

Two **groups of stakeholders** were recruited as co-creators:

- People with aphasia (pwa, n=12) and family members (n=1)
- Health Professionals (HPs, n=28)

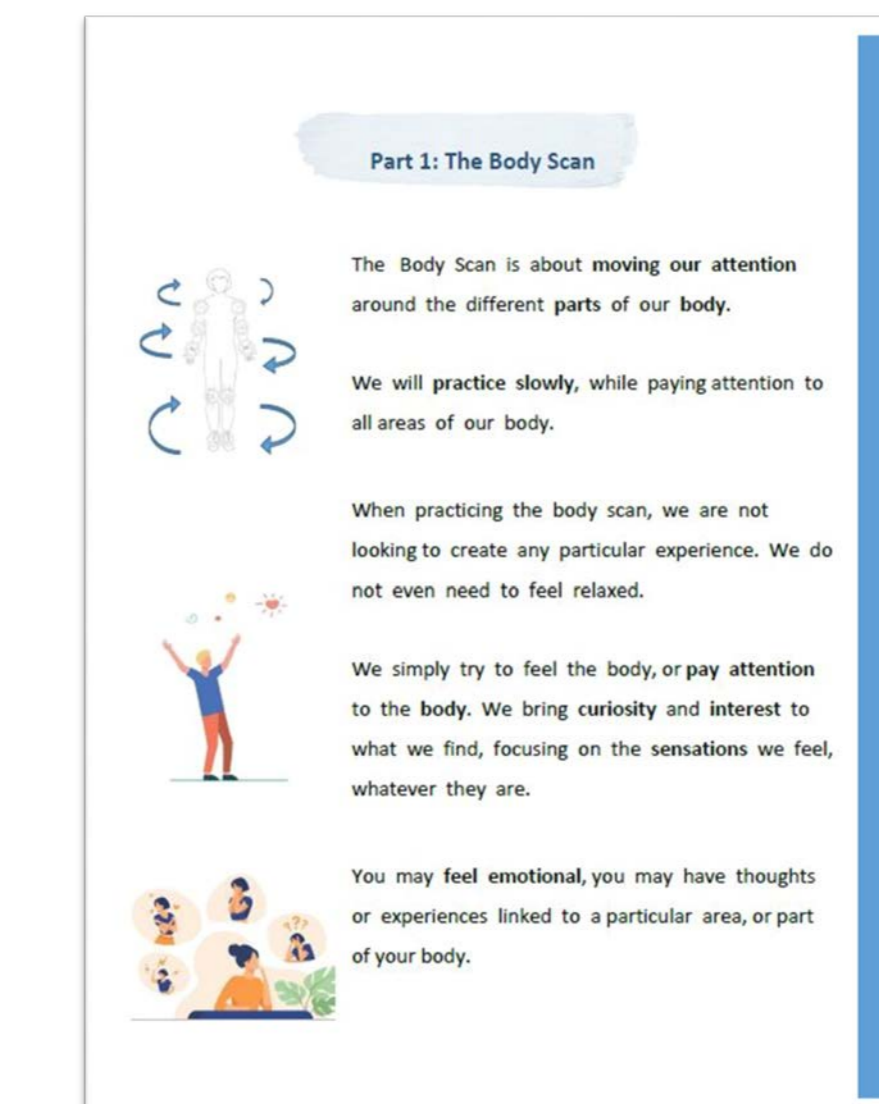
The research was an iterative process conducted online

- **Step 1: systematic review** to identify existing mind-body and creative arts interventions to promote pwa's well-being
- **Step 2: questionnaire** for HPs to define discussion topics for co-creation meetings
- **Step 3: co-creation online meetings** with key stakeholder groups to discuss course adaptations (Pwa, n=11 x10 meetings; HPs, n=8 x2 meetings)
- **Step 4: evidence framework** to guide course-related decision-making
- **Step 5: course outline** and materials adaptation
- **Step 6: consultation feedback** from stakeholder groups (Pwa, n=8 x6 meetings; HPs, n=4 x2 meetings) & external peer review work from pwa
- **Step 7: additional changes and final version** of the course

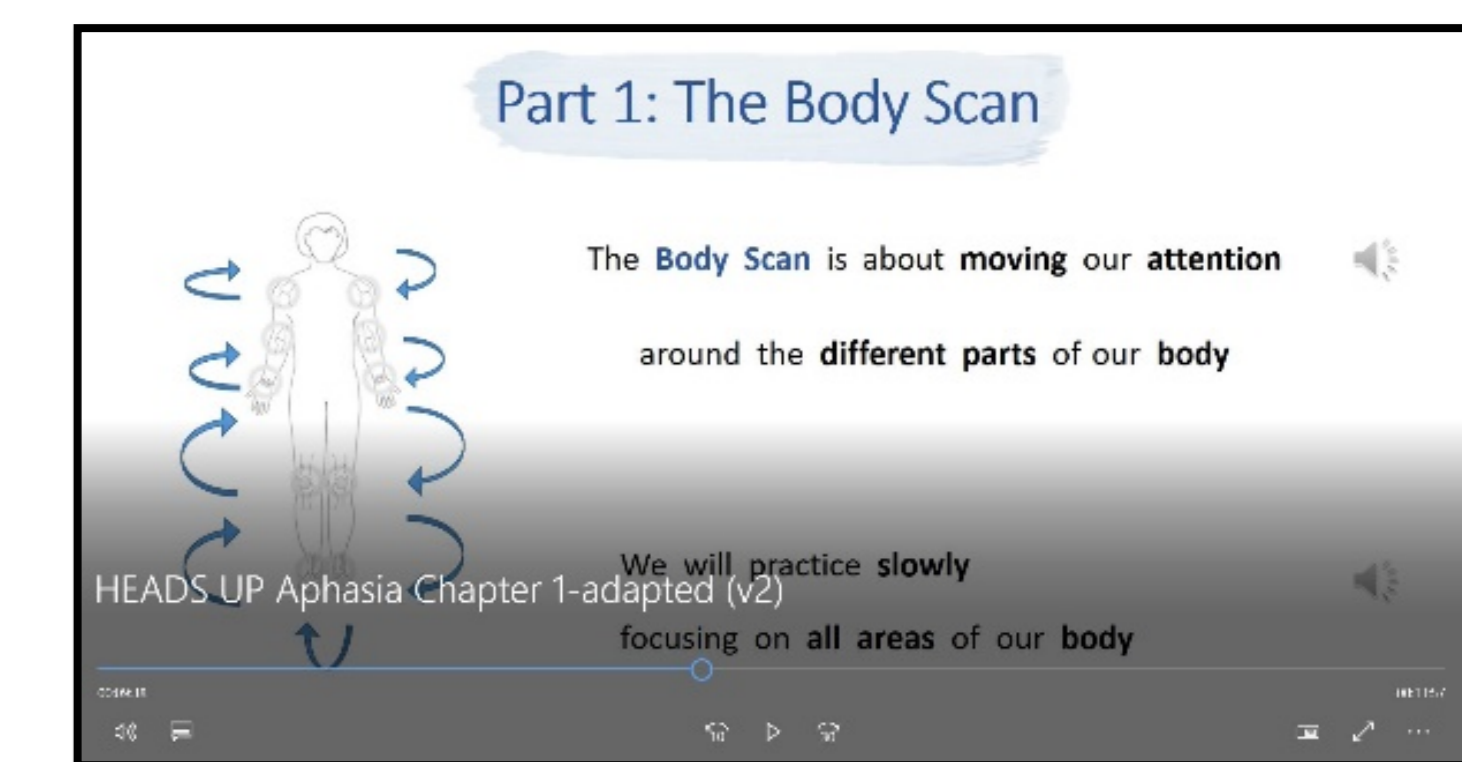
Outcomes

Study outputs include:

- Aphasia-friendly manual and videos
- HEADS: UP Aphasia YouTube channel
- Diary with visual support
- Animations to support engagement with practice instruction
- Shorter session length



Aphasia-friendly chapter and video



Conclusion

Co-creation methods with key stakeholders were an effective means of identifying and addressing pwa's needs and preferences in the context of a Mindfulness-based intervention.

References

1. Manning et al., 2019. DOI: <https://doi.org/10.1371/journal.pone.0214200>
2. Dickinson et al., 2017. DOI: <https://doi.org/10.1080/02687038.2016.1234582>
3. HEADS: UP: <https://www.gcu.ac.uk/hls/research/researchgroups/livingwithstroke/headsup/>