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Co-design of a Physical activity Volunteer Training e-kitbag for Huntington's Disease with stakeholders (PIVOT-HD)

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Background: Physical activity buddies within and external to the Huntington's Disease (HD) community who support each other to be active could positively impact physical activity engagement (the benefits of which are supported by research evidence in exercise trials in HD) and social interaction, raise awareness and reduce stigma. This project aims to co-design, create and evaluate a digital training resource for physical activity buddies to support people with HD to be physically active in their local communities.

Method: A co-design workshop was held with people gene positive for, or who have early-stage HD, participants from the volunteer community, the HD Association of England and Wales (HDA) and digital technology experts (9th June 2022). The content and resource will be created and evaluated by piloting the resource with six volunteers who will share their experiences and perceptions of usability in an online focus group. The resource may then be refined.

Results: The co-design workshop findings suggest stakeholders would prefer a 'fun', 'interactive' that includes a mix of podcasts, filmed video clips, written information and links to other existing resources about HD accessible on a smart phone or tablet. The PI will work with the digital technology experts, HD community to create the content and resource by November 2022.

Conclusion: The resource will be complete by November 2022, (dissemination event December 2022). The resource will be incorporated into HDA resources, Disability Sport Wales Inclusive training for volunteers and into an 'Active MotiMates' mobile application (follow-on project to support PIVOT-HD sustainability).