# Perceptions, motivators and barriers to the acceptance of wearable trackers in people with Huntington's disease

P. Morgan-Jones<sup>1,2</sup>, A. Jones<sup>3</sup>, L. Mills<sup>2</sup>, P. Pallmann<sup>2</sup>, C. Drew<sup>2</sup>, A. Arnesen<sup>4</sup>, M. Busse<sup>2</sup> and F. Wood<sup>5</sup> on behalf of the DOMINO-HD Consortium.



(1) School of Engineering, Cardiff University (CU), UK; (2) Centre For Trials Research, CU, UK; (3) School of Medicine, CU, UK; (4) European Huntington Association (5) Division of Population Medicine and PRIME Centre Wales, CU, UK; (correspondence email: dominohd@cardiff.ac.uk)



#### Background

Environmental factors such as lifestyle behaviours have emerged as

Table 1. The percentage of median positive, neutral, and negative responses along with the total number of responders for each questionnaire section. Key: IQR = Interquartile range.

Questionnaire Section	Positive	Neutral	Negative	Cohort Response	Total Number of
Domain	Responses (%)	Responses (%)	Responses (%)	(Median [IQR])	Responders (n)

potential moderators of Huntington's disease (HD) onset and progression<sup>1,2</sup>. Wearable activity trackers (WATs) offer an exciting opportunity to further investigate the role of lifestyle in disease modification but are reliant on end user acceptance and long-term adoption.

Aim: To explore views across the HD community on using WATs to monitor lifestyle behaviour.

## Methods

Recruitment took place at the 2019 Annual European HD Association meeting (Bucharest, Romania) and 3 regional UK meetings, where individuals with HD and family members/carers were invited to take part in the following:

#### **User Acceptance Questionnaire**

- Adapted from Wu et al<sup>3</sup>.
- Available in English, German, Polish and Spanish.
- Consisted of 2 demographic items and 35 items across 8 domains:
- The average response for each domain was recorded as positive (score >2.5), negative (score <1.5) or neutral (score 1.5-2.5) opinion.
- Kruskal-Wallis and Wilcoxon Rank-sum tests were used to explore

Relative Advantage	94.17	1.94	3.88	3.6 [3.0 – 4.0]	103
Ease of Use	89.32	4.85	5.83	3.4 [2.8 – 4.0]	103
Compatibility	78.43	8.82	12.75	3.3 [2.3 – 4.0]	102
Results Demonstrability	86.27	7.84	5.88	3.0 [2.8 – 4.0]	102
Enjoyment	66.67	12.12	21.21	3.0 [2.0 – 4.0]	99
Social Influence	66.67	16.67	16.67	2.6 [2.0 – 4.0]	102
Attitude	85.15	2.97	11.88	3.2 [2.5 – 4.0]	101
Behavioral Intention	89.32	4.85	5.83	3.7 [3.0 – 4.0]	103

### Focus Group Results

- 15 participants took part in three focus groups.
- 5 key emerging themes were identified (Figure 1).

Influenced by appearance and design, battery life, cost, ease of use and compatibility of a given device.

The potential for activity

trackers to influence

personal relationships

(self/friends/family) and

medical professionals.

Accessibility

*I'm only going to pay a lot of money if it's* accurate, if it's comfortable, it's battery life, it's easy to use and this that and the other "



Relationships

Accuracy

*If the individual feels that by doing this* they're taking more control of their situation that's got to be good for the outlook and the interaction with people around them "

differences due to (1) Age and (2) whether they had HD or were a family member/carer.

#### **Focus Group Discussions**

- Conducted in English in groups of 4-6.
- 3 focussing exercises were employed:
  - 1. An adapted semi-structured topic guide exploring attitudes towards wearable devices<sup>4</sup>.
  - 2. A vignette-scenario around using wearable technologies.
  - 3. A 10 item ranking task (relating to comfort, appearance, accuracy, ease of use, battery life, cost, the location of the tracker on the body, data security and smartwatch functionality).
- Conversations were audio recorded, transcribed and thematically analysed.

### Questionnaire Results



How accurate activity trackers need to be in order to be useful and meaningful when used clinically.

Implications of how activity tracker data is used and how safe the data needs to Data security *It gives data that is continuous, so now you have* a sense over time, all the time, not just when the person goes to hospital or goes to clinic "

Let's face it, I mean if it's not accurate it's a complete waste of time ""

*Keeping your data safe and secure* though would be very important for some people I'd imagine "

be.

- 105 completed questionnaires were analysed (47 HD; 58 family members/carers).
- All sections of the questionnaire produced median scores greater

Figure 1. Key emerging themes and illustrative quotes from focus group participants.

# **Discussion / Conclusion**

than 2.5, representing a tendency for positive opinions towards WATs (being advantageous, easy and enjoyable to use, compatible with lifestyle, able to understand the information from a WAT and having a willingness to wear (Table 1).

- HD participants reported a more positive attitude to WATs than family members/carers (Test Statistic = 3.073, adjusted p value = 0.017).
- Whilst WATs were broadly recognised as acceptable for both monitoring and management, aspects of device design/functionality must be considered to promote acceptance in this clinical cohort. These include, how accessible and compatible the device is to people with HD, how it could influence relationships and how it can be used for self-management. The accuracy and security of data from a given device must also be considered.



Acknowledgements: This research is part of the Multi-Domain lifestyles Targets for Improving Prognosis in Huntington's Disease (DOMINO-HD) Consortium with partners in Cardiff University, University College Dublin, Ulm University, University Hospital Zurich, Hospital Universitario Burgos, the Institute of Psychiatry and Neurology, Warsaw and RAND Corporation. DOMINO-HD is funded though the EU joint program for Neurodegenerative Disease Research as part of the JPND funding call in to Health and Social Care (2019) with funding from Alzheimer's Society, Secretary of State for Health and Social Care, Health and Care Research Wales, Public Health Agency Northern Ireland, Jacques and Gloria Gossweiler Foundation, Bundesministerium für Bildung und Forschung, Narodowe Centrum Badań i Rozwoju, Swiss National Science Foundation (SNF), 32ND30\_185548 and Health Research Board (JPND-HSC-2018-003).

References: [1] Mo et al. (2015). Neurosci Biobehav Rev. 52:178-92. doi:10.1016/j.neubiorev.2015.03.003. [2] Fritz et al. (2017). J Huntingtons Dis. 6(3):217-235. doi:10.3233/JHD-170260. [3] Wu et al. (2016). Comput / DOM NOH D Human Behav. 64:383-392. doi:10.1016/j.chb.2016.07.005. [4] Papi et al. (2016). BMJ Open. 6:e009544. doi:10.1136/bmjopen-2015-009544.