

# Mapping Huntington's disease services in the UK – a partnership approach

Wendy Kane<sup>1</sup>, Alistair Haw<sup>2</sup>, Hugh Rickards<sup>3</sup>, Anne Rosser<sup>4</sup>, Cath Stanley<sup>5</sup>

- (1) Roche Products Ltd, Welwyn Garden City, England, UK;
- (2) Scottish Huntington's Association, Paisley, Scotland, UK;
- (3) Birmingham and Solihull Mental Health NHS Foundation Trust, Birmingham, England, UK;
- (4) Cardiff University, Cardiff, Wales, UK;
- (5) Huntington's Disease Association, Liverpool, England, UK.



scottish  
huntington's  
association

UKHDN

## What does this study mean for the Huntington's disease community?

The UK Huntington's Disease Network (UKHDN), Huntington's Disease Association (HDA), Scottish Huntington's Association (SHA) and Roche Products Ltd are collaborating to map how HD services in the UK are delivered and resourced at a local and national level. This will provide evidence to support dialogue with decision makers to help secure healthcare resourcing and funding where needed.

## Conclusion

This new data will provide a local and national picture of current Huntington's disease services in the UK and act as evidence to support dialogue with payers/decision makers to help secure resourcing for current and future Huntington's disease service needs.

## BACKGROUND

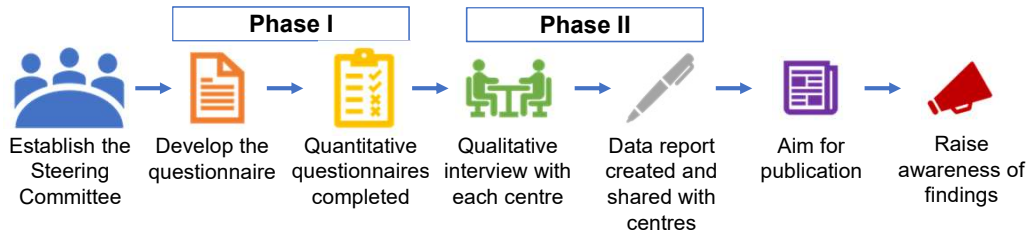
- Across the UK, Huntington's disease (HD) services have organically grown across different healthcare specialities: psychiatry, neurology, neuropsychology and genetics.<sup>1-4</sup>
- Currently, a comprehensive UK-wide picture of services does not exist. We do not know how HD services are delivered, funded or staffed at a local level or how many patients are treated in each service.
- This project intends to capture the current services so that we may quantify and understand any differences in the services across the four UK nations and in individual services.

**Objective:** To undertake a survey of UK Huntington's disease services to map the current organisation, funding of resources and explore future resource needs.

## METHODS AND PROJECT DESIGN

- This project has been initiated, designed and will be delivered through a partnership between the UK Huntington's Disease Network (UKHDN), the Huntington's Disease Association (HDA), the Scottish Huntington's Association (SHA) and Roche Products Ltd.
- All Huntington's disease centres in England, Scotland, Wales and Northern Ireland will be invited to participate in this initiative.
- The data will be gathered from each centre through a quantitative questionnaire in Phase I and a 1-hour qualitative interview in Phase II (**Figure 1**).

**Figure 1. Proposed project flow and activities**

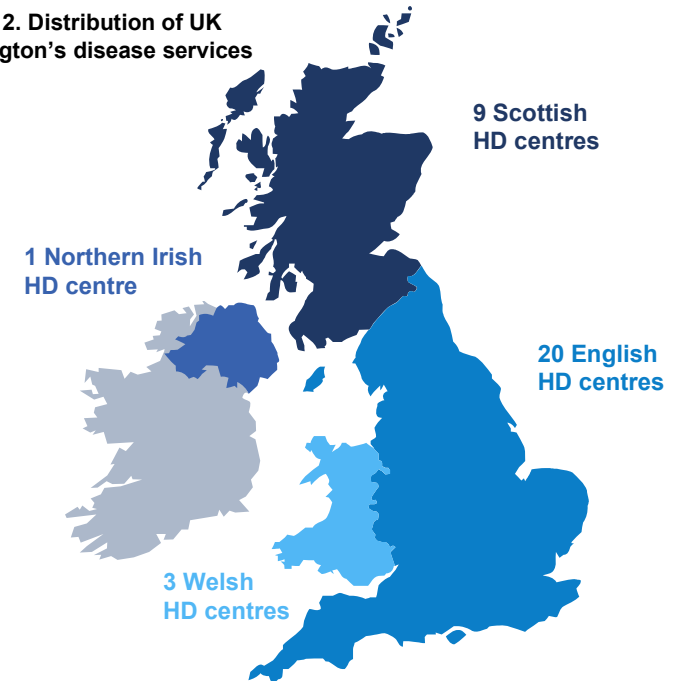


- In Phase I, the topics in the quantitative questionnaire distributed by the UKHDN will include: current service provision, patient pathways, multidisciplinary team resource, funding and support for patients.
- In Phase II, the qualitative interviews with each centre will be organised and led by the HDA or SHA, as appropriate.
- Results will be made publicly available through a report, accessible to the UK Huntington's disease community at a local and national level.
- This project is being funded solely by Roche Products Ltd.

## DISTRIBUTION OF UK HD SERVICES

- There are a total of 33 UK Huntington's disease services across the UK (**Figure 2**).

**Figure 2. Distribution of UK Huntington's disease services**



## Acknowledgements

This project is being funded solely by Roche Products Ltd. We would like to thank Rosa Willock, and her team from HCD Economics, for their contribution to this publication. The authors thank Kiran Verma, of Meditech Media (UK), for providing editorial support for this poster, which was funded by F. Hoffmann-La Roche Ltd in accordance with Good Publication Practice (GPP3) guidelines (<http://www.ismpp.org/gpp3>).

## Abbreviations

HD, Huntington's disease; HDA, Huntington's Disease Association; SHA, Scottish Huntington's Association; UKHDN, UK Huntington's Disease Network.

## References

1. <https://www.hda.org.uk/getting-help/shda-service> (Accessed August 2021);
2. Patch C and Middleton A. *British Medical Bulletin*. 2018; 126:27–36;
3. <https://ptc.bps.org.uk/> (Accessed August 2021);
4. <https://www.rhn.org.uk/what-makes-us-special/services/huntingtons-disease-service/> (Accessed August 2021).



Please scan using your QR reader application to access this poster on your mobile device. NB: there may be associated costs for downloading data. These costs may be high if you are using your smartphone abroad. Please check your mobile data tariff or contact your service provider for more details. Alternatively this can be accessed at: <https://bit.ly/3inde9E>