

Monica Busse 1, Joyce Kenkre 2, Premanand Govindan 2, Anne Rosser 3

1. Department of Physiotherapy, School of Healthcare Studies, Cardiff University, Cardiff, CF14 4XN, United Kingdom  
2. Faculty of Health, Sport and Science, University of Glamorgan Pontypridd, CF37 1DL, United Kingdom  
3. Schools of Medicine and Biosciences, Cardiff University, Cardiff, CF14 4XN, United Kingdom

### Introduction

The Client Service Receipt Inventory (CSRI) is designed to collect information about use of health and social care services and is routinely collected as part of the European Huntington's Disease Network (EHDN) Registry study.

This study utilised CSRI data to evaluate physiotherapy input and assistive devices for aspects of Activities of Daily Living (ADL) in HD according to the Total Functional Capacity Scores (TFC).

### Method

Data from 1395 Registry visits for 793 participants (up to 5 separate visits between the years 2004 and 2008) in participating Registry countries was available for analysis.

Descriptive data of demographics, scores for Unified Huntington's Disease Rating Scale (UHDRS) motor and Total Functional Capacity (TFC) scores, physiotherapy input, assistive devices and adaptations was obtained. Cross-tabulations according to TFC scores were undertaken.

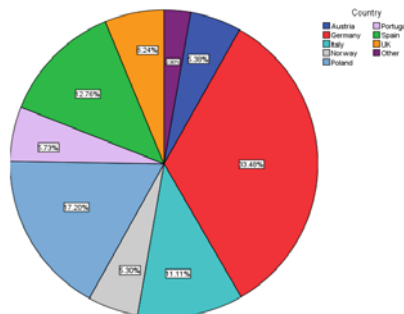
### Results

Countries represented were Austria, Germany, Italy, Norway, Poland, Portugal, Spain, United Kingdom, Czech, Finland, Switzerland and Sweden (see Figure 1).

### Results

CSRI data from 385 males and 408 females at their first registry visit was considered. Mean (SD) age was 49.5 (13.3) years. Median (range) UHDRS motor and TFC scores were 54 (0-106) and 8 (0-13) respectively).

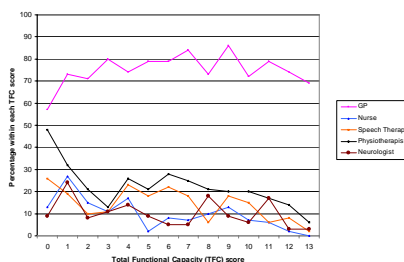
Figure 1: Distribution (%) of countries providing CSRI data\*



\* Categories containing less than 5% collapsed

Only 19% of participants had received physiotherapy input of which 24% was in the home environment. There was a trend to more provision of physiotherapy with lower TFC scores (see Figure 2) with little indication of early physical interventions.

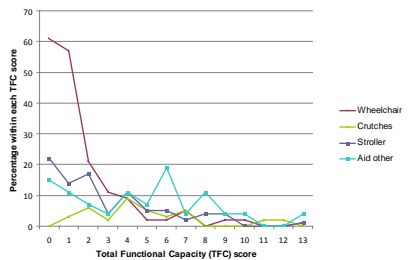
Figure 2: Utilisation of services within TFC scores



### Results continued

Occupational therapy (OT) input was not routinely coded in the CSRI data; 4.4% of respondents reported seeing an OT (other category). There was clear utilisation of assistive devices; more adaptations and home care support associated with decreasing TFC scores (see Figure 3).

Figure 3: Utilisation of walking aids within TFC scores



### Conclusion

Initial data analysis suggests an underutilisation of physiotherapy services and limited occupational therapy input, particularly in the home environment. The CSRI is not designed for in-depth evaluation of service provision and a more targeted, systematic data collection approach to evaluate rehabilitation services is required. Potential bias in terms of proportional representation of services received in countries represented in this data should be considered.

### Acknowledgements

We would like to acknowledge the EHDN study site investigators, raters and coordinators for contributing the data presented here.