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Article:

Quarrell, O.W., Clarke, A.J., Compton, C. et al. (14 more authors) (2018) Predictive testing of minors for Huntington's disease: The UK and Netherlands experiences. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 177 (1). pp. 35-39. ISSN 1552-4841

<https://doi.org/10.1002/ajmg.b.32582>

This is the peer reviewed version of the following article: Quarrell OW, Clarke AJ, Compton C, et al. Predictive testing of minors for Huntington's disease: The UK and Netherlands experiences. *Am J Med Genet Part B*. 2017; 1–5., which has been published in final form at <https://doi.org/10.1002/ajmg.b.32582>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving

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Table 1

Summary of reasons for testing minors in the UK 1994 - 2015 and the Netherlands 1997- 2016

Reasons for testing	Number UK n=36	Number the Netherlands n=22	Number UK and Netherlands combined
Close to age 18 years	13	12	25
Pregnancy	5	1	6
Currently in care and more support available <18 years	4	0	4
Person never having the capacity to consent	2	0	2
Siblings in the family with young onset HD	3	0	3
Persistent requests age 15 and 16 years	2	2	4
Mother had an intermediate result	1	1	2
? Psychiatric symptoms	1	2	3
Confirm a prenatal test result based on linkage analysis	1	0	1
Estranged father with HD, mother had mental health problems and the young person had been told he/she would die young	1	0	1
Tested posthumously because mother wanted to make sense of the death which was due to another illness	1	0	1
Tested at the same time as mother	1	0	1
Diagnostic test but result was normal	1	0	1
Tested together with siblings >18 years (family wanted to go through the process as one)	0	3	3
Testing procedure not according to protocol (persistent request from minor was granted by the child neurologist, results given by clinical geneticist)	0	1	1