

Testing Minors for Huntington's Disease

Table 1

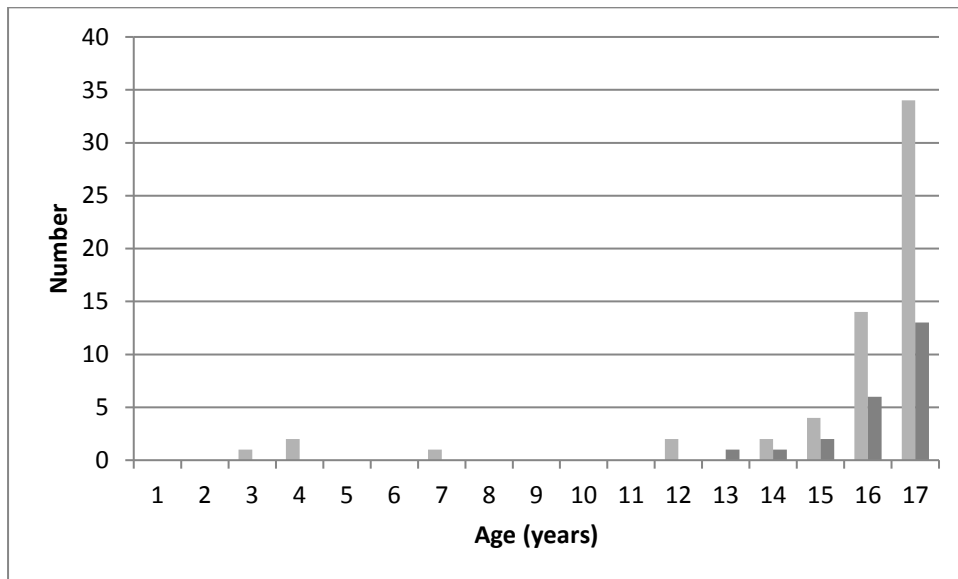
Reasons for testing	Number (UK and Dutch data combined)
Close to age 18 years	25
Pregnancy	6
Currently in care and more support available <18 years	4
Person never having the capacity to consent	2
Siblings in the family with young onset HD	3
Persistent requests age 15 and 16 years	4
Mother had an intermediate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

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Figure 1

Age structure of 60 predictive tests undertaken in the UK 1994-2015

and 23 in the Netherlands 1997-2016



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Legend to Figure 1

Light grey represents the UK predictive testing of minors

Dark grey represents The Netherlands testing of minors