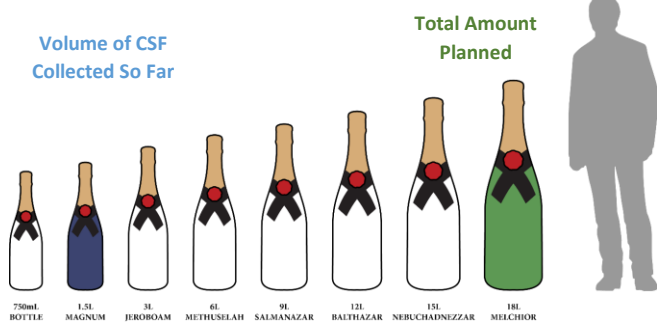


# HDClarity

## Newsletter

August 2017 Issue 5



Dear HDClarity Teams!

Thank you to all sites for your continued hard work.

### ! REMINDER

You must check all participant genetic reports against the criteria in the protocol prior to inviting a participant to screening. If the exact repeat lengths are not given or if there is no local report available, then please contact CC immediately.

All participants (except community and family controls) MUST have a local CAG report available and you should be checking these as part of the recruitment process.

To ensure participants meet the CAG eligibility requirements please notify HDClarity CC immediately of planned screening visits for the following:

- Any participant who does not have the exact repeat length specified on their CAG report
- Genotype negative controls with allele repeat lengths  $\geq 34$  repeats
- Premanifest participants with allele repeat lengths  $\leq 41$  repeats

Group	CAG Repeat
Control	$< 36$
Early Premanifest	$\geq 40$
Late Premanifest	$\geq 40$
Early Manifest	$\geq 36$
Moderate Manifest	$\geq 36$
Advanced Manifest	$\geq 36$

### ! IMPORTANT

#### Participant Classification in HDClarity

Participants can be categorised as manifest HD in Enroll-HD but premanifest in HDClarity. This is due to the fact that the Enroll-HD criteria for manifest is based on any or all of the persons behavioural, psychiatric, cognitive and/or motor symptoms. Whereas HDClarity will only class someone as manifest HD if they have motor symptoms with a DCL 4.

The implications of this are that you may have a participant that has been clinically diagnosed and you class as manifest HD but if their DCL is  $< 4$  then for the purposes of HDClarity you would need to consider them as premanifest.

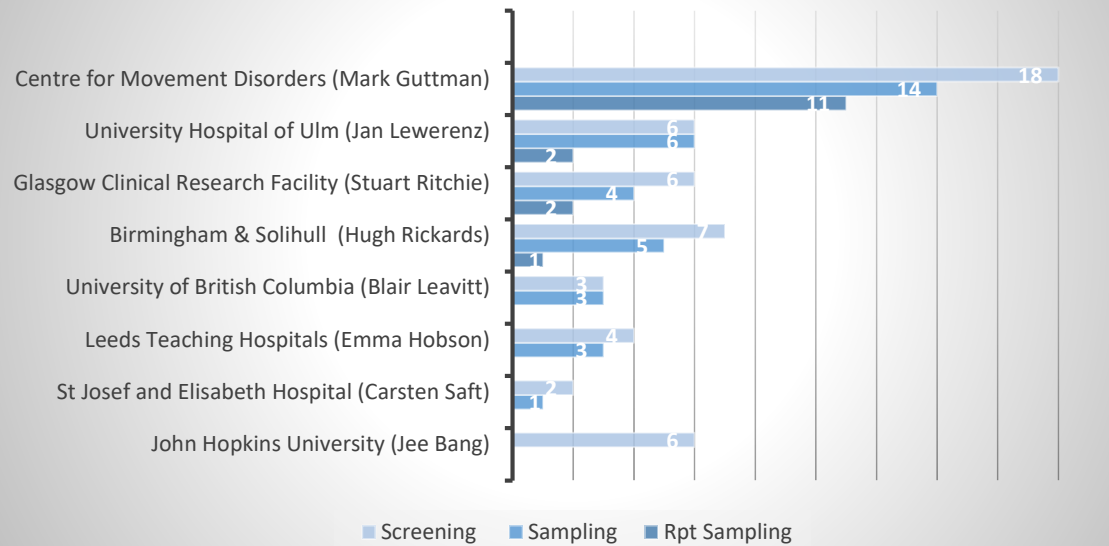
The EDC will not currently 'accept' this! We are working to find a solution and can hopefully update it soon but in the meantime can we ask you to please let us know of any cases you have like this so that we can make a note of their HDID and tell IT.

If this applies to any of your participants, then you will also need to make sure they meet the HDClarity premanifest inclusion criteria; CAG  $\geq 40$ .



# HDClarity

## HDClarity Site Recruitment



\*The chart reflects recruitment data of initiated sites extracted from the HDClarity EDC to date. Any data not yet entered on the EDC will not be shown here.

Please contact UCL Central Coordination if you have any questions [hdclarity-cc@enroll-hd.org](mailto:hdclarity-cc@enroll-hd.org)

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