Guardians experience of collecting dried blood spots from children with epilepsy-preliminary results from a survey

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Background
Dried blood spots (DBS) is a possible alternative matrix in therapeutic drug monitoring (TDM) and has the advantage to be utilized for home sampling. Good quality DBS home sampling for TDM use requires correct information and training. To standardize and facilitate the sampling procedure we produced an instruction video, reached via YouTube. The aim of this study was to describe how guardians experienced the situation of collecting a blood sample and what information they needed to perform it correctly.

Methods
The study was performed on guardians to children with epilepsy and concomitant diagnoses who were willing to sample their children. Guardians were told to study the instruction video at home, and at the time of sample collection at the clinic the parents could ask questions. After collection of a DBS sample from their child they filled in a referral and answered a questionnaire about information, the sampling instructions and experiences of the DBS collection.

Results
57 DBS samples were collected on filter paper by guardians making finger pricks on their children. 10.7 % were rejected based on sample quality criteria, mainly because of too small drop volumes. Guardians in all cases managed to fill in the referrals.
All participants filled in the questionnaire and 92 % of the respondents were satisfied with the combination of the instruction video and the practical information from the nurse. 72 % found it easy to perform the sampling, 5 % that it was problematic and 23 % were neutral or did not answer this question. 84 % wanted to have the possibility of home sampling in the future and 3.5 % would not choose this alternative (12.5 % were neutral).

Conclusions
The preliminary result from this study concludes that a majority of guardians can collect DBS samples with good quality from their children with epilepsy and concomitant diagnosis. The instruction video in combination with practical training at the clinic is a good way of educating guardians. Most guardians are positive to use this alternative way of sampling since it was relatively easy, saves them time and reduces work-leave for these families.