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Estimated Prevalence of Severe Paralysis With Loss of Communication in The Netherlands.

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Introduction: Brain computer interfaces (BCI) can be used to replace, improve, restore, enhance and study brain functions. One of the main topics in the *replacement* field is communication. The target population for this kind of BCI is commonly referred to as locked-in syndrome (LIS) patients [1]. According to BCI-researchers this population encompasses all patients with severe communication impairment due to severe paralysis regardless of the etiology. Medical professionals, on the other hand, define LIS as lesions in the ventral pons, and not by the level of functioning [2, 3]. This results in an underestimation of the number of people that benefit from the same kind of care and therefore poses an impediment for stakeholders such as developers of communication BCIs, caregivers and policy makers. These stakeholders stand to benefit from a more inclusive definition of the patient population for care, information and assistive technology development.

In the current study we argue that the target population for communication BCIs can therefore be best described and quantified using the more inclusive definition that includes all patients that *function* on the level of LIS (fLIS), disregarding etiology. Quantification of LIS has been done before, but these studies used the more constrained definition or only a subset of the population [4, 5].

Method: In the Netherlands all people are obliged to have a general practitioner (GP). Within 1 year we sent out 2 letters to all, 8865 GPs, covering the Dutch population (16.829.289; Statistics Netherlands, 2014) and asked them to report any patients with severe paralysis and communication problems. The GPs who responded affirmative where subsequently approached by telephone and asked to complete a questionnaire consisting of 22 items on the level of functioning of the patient, the cause of paralysis and the type of care and assistive technology used. After completion of the questionnaires two independent raters labelled the patients with LIS, incomplete LIS (iLIS) or not LIS according to the criteria stated in Snoeys et.al. [5]. In addition, as a result of recruitment efforts and media publicity for the Utrecht Neural Prosthesis project (UNP) another subset of patients was brought to our attention, not among the patients reported by the GPs. These patients were also given the questionnaire.

Results: 51 GPs were contacted by telephone and asked to fill out the questionnaire. 41 GPs cooperated. After screening by the two raters this resulted in 19 LIS, 7 iLIS and 16 neither LIS nor iLIS. Of the 53 patients brought to our attention through other channels 16 were rated with LIS or iLIS, leading to 42 patients in total confirmed. Extrapolation of the 26 patients, found among the GPs that replied to one of the two letters (22.3%), to the whole population results in a number of 117 patients in the Netherlands. The number of patients with fLIS living in the Netherlands can thus be estimated between 42 and 117, which gives a prevalence in the Netherlands between 0,00025% and 0,0007%. Furthermore, the questionnaire showed that the cause of fLIS is very diverse, for example, cardiovascular accidents account for 26% and amyotrophic lateral sclerosis 33%.

Discussion: The current research shows that there is a significant population in the Netherlands that functions on the level of LIS. However many of them are not labelled locked-in. This leaves a big number of people outside the scope of researchers and assistive technology developers. We hope that classifying people on the basis of level of functioning will prevent this in the future.

Significance: This research has quantified the target population for communication BCI in the Netherlands. Also it poses a new way of classifying people with paralysis.

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