INVESTIGATION OF BEHAVIOUR BY DOGS PRIOR TO HUMAN EPILEPTIC SEIZURES AND POTENTIAL UNDERLYING MECHANISMS: EXPERIMENTAL PROTOCOL.

WP1 International inventory of seizure alert dogs:

1. Introduction

Despite the interest of the general public, the size and composition of the population of seizure alerting dogs is still widely unknown, particularly the population of non-trained presumably alerting dogs. Previously published studies have focused on anecdotal reports (Strong and Brown, 2000), single case studies (Di Vito et al., 2010; Ortiz and Liporace, 2005) or small samples of the population (Strong et al., 2002). Some studies do not make a clear distinction between response and alert dogs (Dalziel et al., 2003) and/or include only one type of alerting dogs, i.e., pet dogs (Kirton et al., 2004). From the point of view of the owners, some of the studies failed to exclude patients who experienced non epileptic seizures (Krauss et al., 2007; Ortiz and Liporace, 2005) and/or some have focused on a particular demographic group of epileptic patients, i.e., children (Kirton et al., 2004).

The objective of this work package is to create an international alerting dogs database including trained Seizure Alert Dogs (SADs), spontaneously alerting Seizure Response Dogs (SRDs) and spontaneously alerting pet dogs. This information will be used to select a representative sample of the population for subsequent work packages and to perform a descriptive analysis of the population of presumably alerting dogs across the world.

2. Methods

A systematic online search has been performed to identify all Seizure Response Dogs and Seizure Alert Dogs training organisations across the world. These organisations will be contacted via email and telephone and be asked to distribute information about the study and an invitation to participate between their clients. The invitation will contain a link to the website of the project. In the website, the people interested can find information about the study, a link to the informed consents, the survey, contact information etc. We won’t be contacting epileptic patients directly to ask them to participate.
For the international distribution of the questionnaire, we will establish collaborations with national epilepsy research centres that can potentially assist us with local ethical review processes.

To reach epileptic owners of non-trained dogs that presumably alert, we will contact:
- Epilepsy support organizations.
- Medical non-profit organisations such as the Red Cross.
- Social media groups and forums.

We will ask those associations to distribute information about our project in their websites, forums, etc. by contacting the websites’ administrators. The advert will also include a link to the website of the project. We also aim to recruit epileptic owners of dogs that do not alert (control group) using the same recruitment methods.

Parents or guardians of epileptic children younger than 18 years old will be given the opportunity to fill in the survey for their children, as well as legal representatives of intellectually disabled people with epilepsy. We need to include these groups in our study as we aim to obtain information as representative of the real population of epileptic patients as possible.

Trainer Questionnaire

Survey Monkey will be used to create a short questionnaire that will be sent to SAD and SDR trainers. This questionnaire will request the following information:

- Number of active working dogs.
- Dog demographic information and selection criteria.
- Patient inclusion criteria: number of seizures, what type(s) of seizures, Psychogenic non Epileptic Seizure (PNES) patients excluded or not.
- Training methods used.
- For SRD that spontaneously started anticipating seizures, information about further training that may have been provided.

Dog owner questionnaire

A second questionnaire directed to epilepsy patients with dogs will be created using Survey Monkey. The following information will be collected:

- Demographic information: Age, gender, nationality, family status, etc.
- Epilepsy diagnosis: Seizure type and duration, age when first seizure occurred.
- Presence of auras and/or prodromi (and time of occurrence before the seizure onset)
- Type of dog: SAD or spontaneously alerting SRD or pet dog
- Time when the dog started “alerting”, if it’s an untrained dog.
- Demographic information about the dog.
- Type of alert behaviour.
- Time of anticipation (Time between “alert” and seizure onset).
- A questionnaire based on the Monash Dog-Owner Relationship Scale (MDORS) (Dwyer et al., 2006) to study the perceived bond between the patient and the dog. It consists of 28 (or 19) items with a score ranging from 1 to 5 that characterizes the emotional closeness, the dog-owner interaction and the perceive costs of dog ownership.
3. **Data management and informed consent**


The questionnaires will be available online and designed using SurveyMonkey (US-EU Safe-Harbor/Privacy Shield certificated) then exported and stored only using the UGent central IT environment managed by the Department of Information and Communication Technology. The data will be processed only via the Athena platform and will never be stored or processed locally.

The data will be anonymized for analysis, and the database of patients will be pseudonymised and stored also in the UGent central IT environment. Only the people responsible for the project (A. Martos, V. de Herdt and C. Moons) will be able to track the information back to their original source. The answers from the trainers questionnaires will also be anonymized for analysis.

The patients will be clearly informed of the use of the data and will be allowed to inquire about the state of their data and modify or remove themselves from the database at any point. All personal information will be destroyed at the end of the study.

An electronic informed consent for the participation and treatment of the data will be presented at the beginning of the survey. It will also be possible to download the informed consent through the website of the project.

In addition, for children between 12 and 18 years old, an adapted informed consent will be presented for the minors to sign at the beginning of the survey. It would not be possible to participate in the survey without signing the informed consent.

We will also enquire about their willingness to participate in subsequent work packages.

4. **Milestones**

- International database of alerting dogs (SAD and spontaneously alerting SRD and pet dogs) to be used in subsequent work packages.
- Descriptive analysis of the population of alerting dogs and their owners.
- A description of the human-dog relationship between epileptic patients and their alerting dogs.

5. **Bibliography**


