OpenSeizureDetector

Data Sharing

Graham Jones, January 2022
graham@openseizuredetector.org.uk
https://openseizuredetector.org.uk

OpenSeizureDetector: Data Sharing

- The OpenSeizureDetector algorithm has been unchanged since we published the system in 2016.
- The idea had always been to develop it to improve detection reliability and reduce false alarm rates.
- The main thing preventing this (apart from time!) is lack of data.
- Many users have offered to share their data if it will be useful, but we have not had the facility to store it and make use of it.
- The next version of OpenSeizureDetector will introduce a ‘Data Sharing’ facility to allow this to happen.

OpenSeizureDetector: Data Sharing - Why?

- The OpenSeizureDetector algorithm was **created by judgement** based on published information on seizure movement frequency and limited observations of real tonic-clonic seizures.
- We know that **it will detect large tonic-clonic seizures** (as long as the arm wearing the watch is able to move), but do not have any data on detection reliability or false alarm rates.
- **False alarms are an issue** for some users, who have stopped using the system because of it.
- The goal is to **improve the detection algorithm** so that we maintain or improve the detection reliability, and reduce the rate of false alarms.
- To do this we **need real world data** on activities that cause false alarms, and most importantly real seizures.
- This update is to **allow users to contribute** to this development work by sharing their data anonymously with developers and researchers to allow improved detection algorithms to be determined.

OpenSeizureDetector: Data Sharing - What?

- It has been over a year since we released an update to OpenSeizureDetector
- A new version of the OpenSeizureDetector App is being developed which will:
  - Record data on the phone
  - Connect to a remote database (on a server in London) where we will collect users' data.
  - Identify 'Events' in the data (Alarms, Warnings or manually generated seizure reports)
  - Upload the data to the remote database (for each event a period of 5 minutes centred on the event is uploaded).
  - Prompt the user to check the uploaded event and say whether it was a genuine seizure or a false alarm.
- Developers and researchers will be given access to the anonymised(*) data so that they can:
  - Look for patterns in real seizures that are not present in the false alarm data.
  - Train Neural Networks or other 'Artificial Intelligence' systems to distinguish between real seizures and normal activities.
  - Feed this knowledge back into future improved versions of OpenSeizureDetector.

(*) The system administrator (Graham Jones, graham@openseizuredetector.org.uk) will have access to the users' names and email addresses - we may use that to get in touch with users if they upload some particularly 'interesting' data and we need to understand what happened. Users' contact details will not be shared with other researchers.

OpenSeizureDetector: Data Sharing - How? [1]

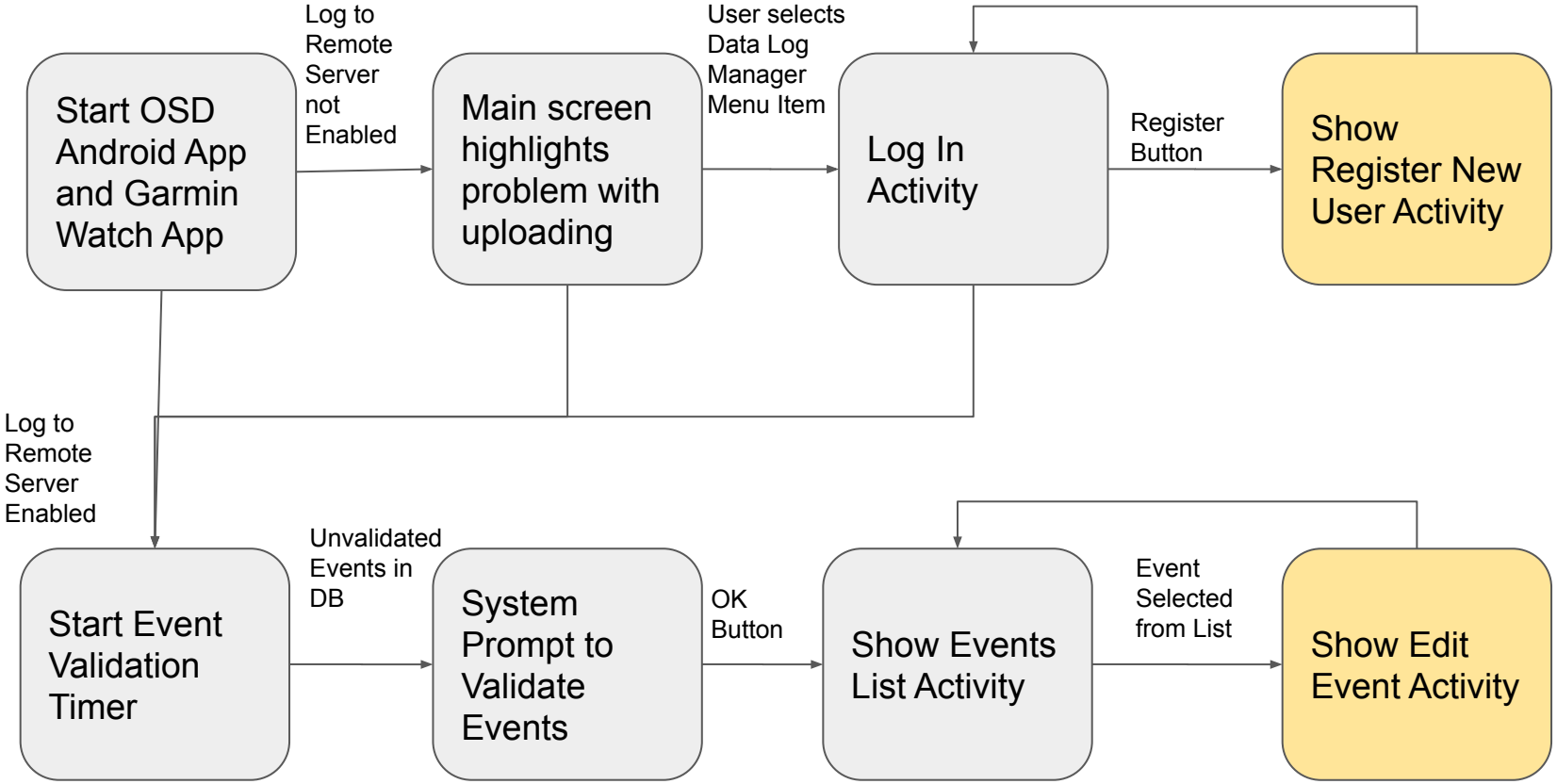
- The new version of OpenSeizureDetector will work in the same way as the current published version in terms of its detection algorithm and settings, and how it generates alarms. It remains (and will remain) free of any charges to use it - ‘no detriment’ to users.
- The option to share data will be enabled by default, but it will not work until you create an account - you can disable data sharing if you want to.
- The app provides the function to create an account on the data sharing database - the database will send an email with a link to verify that you do want to create an account and
- Once the new account has been verified, you use the OpenSeizureDetctor App to log into the data sharing database.
- Sharing of data will then happen automatically

OpenSeizureDetector: Data Sharing - How? [2]

- When an Event (ALARM, WARNING, FALL, or Manual Alarm) is created on the phone, the data will be uploaded to the data sharing database.
- The app checks the database to see if any Events have been created, but the user has not yet confirmed if they are genuine seizures or false alarms.
    - If there are, the app prompts the user to check the Event data by showing an extra notification with a (?) in front of the OpenSeizureDetector logo.
- Clicking on the ‘Confirm Event’ notification will open a Data Log Manager screen that will show all the events that are in the database.
- Clicking on an event shows a screen that will allow the user to say if the event is a genuine seizure or a false alarm - and if it was a false alarm, what was happening. There is also a ‘notes’ field where you can type any information that you think will be useful.

OpenSeizureDetector: What to Expect

- Initially you will not see much change as a result of sharing your data, sorry!
- We will need to work out how to analyse it and look for patterns.
- We may well need to change the watch app to send extra data to help with this.
- The first outcome is likely to be a system that will have a first go at determining what activity is taking place during the event - a researcher is working on such a system that we will integrate into OpenSeizureDetector to help with the false alarm reason identification.
- If we are successful in producing an alternative detection algorithm we are likely to produce a new version of OpenSeizureDetector that will use both algorithms and share the data from both methods. The user will be able to select which algorithm to use to generate alarms.



Should we provide an option to inhibit the nagging to configure uploading to database?