



Sarcoma Patients EuroNet

Together We Can Make A Difference For Those Affected By Sarcomas!



Patient Forum Miner

Many patients join internet discussion forums to share information, ask questions and support each other. Internet discussion forums contain a wealth of data on patients, their disease history, experienced quality of life, and side effects of treatments. Often, patients develop strategies to cope with side effects and share these strategies with other patients. The timeline of patient discussion forums contains a wealth of information, but often it takes a lot of time to search for the valuable information. In daily practice patients simply post a question, and one or more patients give answers. But it is likely that similar questions have been asked in the past, and it would be interesting to aggregate all the relevant information and present this to the patient.

The patient forum miner project aims at harvesting the valuable information from internet discussion forums using modern technology (objective). The techniques that are used are based on computational linguistics and machine learning. Advanced search algorithms detect interesting information, which is presented in a graphical interface in order to reveal relationships among various entities. Relevant discussion are summarised automatically to allow fast perusal.

The primary target group is sarcoma patients, but another important target group is medical professionals. It is expected that the method will provide a valuable resource of input for medical research.

The project is an initiative of Patientenplatform Sarcomen and a unique multi-disciplinary collaboration between patients, computer scientists, oncologists and other patient organisations. The project was started in 2015 and has been tested on patient forums in Dutch and English. The software is operational on a database of discussion threads of GIST patients, breast cancer patients and data from a general healthcare. It will be implemented on Dutch and international internet forums of sarcoma patients and most probably on forums for patients with breast cancer and lymphoma, for regular use by patients, in 2019 (results). More details on the timeline are given in the attachment. All software is open source and will be available to other patient organisations.

The objective for a next phase is to combine the data obtained from patient discussions with data in cancer registries.

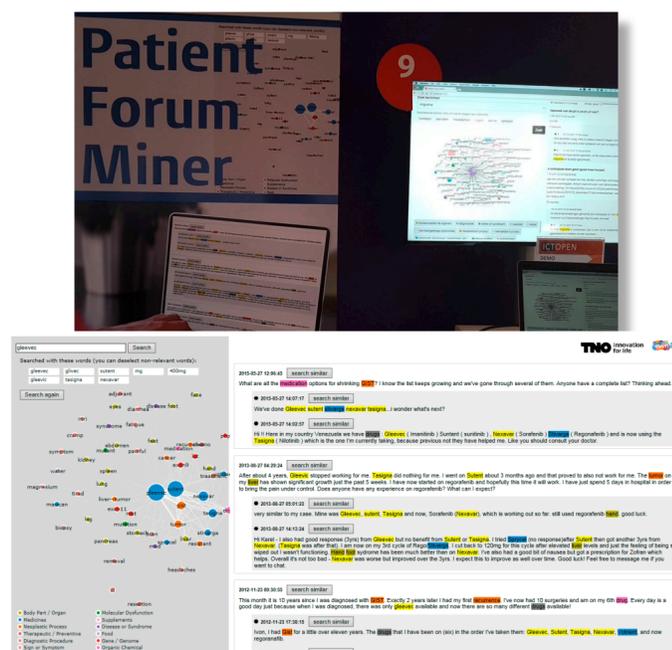
Resources until now: Expert patient volunteers, researchers in data science, artificial intelligence and computational linguistics. Total budget spent so far € 325,000, still available 200,000.-

The remaining budget is for implementation (2019) and for a PhD project at Leiden University aiming at determining the quality of results produced by the method, to be completed in 2021.

Additional value of your project for the sarcoma population

Sarcomas are rare and diverse. Cohorts of patients available for research are often too small for gathering enough data needed for reliable conclusions. The added value of this project is twofold:

- information can be gathered from patients all over the world
- On internet discussion forums patients share not only factual data on their disease and treatment, but also on the experienced outcome of the treatments as well as on quality of life in all its aspects.



Patientenplatform Sarcomen