

# New search engine finds rare diagnoses

May 21 2013

---

Doctors are trained to think "common disease" when they meet patients in their practices, and as they rarely or never meet a rare disease, it often takes many years to reach the right diagnosis. A new search tool called FindZebra developed at the Technical University of Denmark can dramatically reduce this time in many cases.

If you hear the sound of galloping hooves behind you, your immediate reaction is, 'here comes a horse'. But in very rare cases it is actually a zebra approaching. Doctors are trained to think 'horse' or 'common disease' when they meet patients in their practices, and as they rarely or never meet a 'zebra', in the form of a rare disease, it often takes many years to reach the right [diagnosis](#). A new [search tool](#) called FindZebra can dramatically reduce this time in many cases.

Ole Winther is Associate Professor at DTU Compute, where he works with algorithms and other [mathematical tools](#) that can make the Internet more 'intelligent'. Three years ago, he was set on the path to develop FindZebra which has now become known around the world via various journals, websites and blogs.

## Targeted search

There is a wealth of articles on the Internet describing rare diseases and their symptoms—some of which are high quality and very thorough, while others are more haphazard and undocumented. Doctors often use the PubMed biomedical article database, which also has a search function. However, searching on individual symptoms is usually not

enough—doctors ideally need to know the name of an article's author or the like in order to get useful results.

If you search on [Google](#) you may be fortunate enough to find articles on rare diseases, but Google's (secret) algorithms are optimized based on how many clicks search results receive. Common searches are therefore continually improved, while specialized searches, for example for rare diseases, do not necessarily benefit from Google's ongoing development.

"When I became aware of the problem of finding the right diagnosis using normal Google searches, I thought to myself: 'There must be a better way!'," says Ole Winther.

He put together a small team to develop a search engine with a special focus on rare diseases. Two undergraduates were initially assigned to the project, and they were later joined by two MSc thesis students, Radu Dragusin and Paula Petcu.

The project team gathered material from the 6-8,000 known and documented rare diseases from 10 different Internet sites. All sources have been selected in cooperation with Henrik L. Jørgensen, Consultant at the Clinical Biochemical Department at Bispebjerg Hospital.

FindZebra searches over 31,000 articles in total. This is a limited amount compared to Google's breadth, but they are all potentially relevant to doctors seeking diagnoses for rare diseases.

## **State of the art**

A major element of the work on FindZebra has been to thoroughly test the search engine, and Henrik L. Jørgensen has also been a great help in this area by finding good test cases, i.e rare cases of illness where a diagnosis has been made.

"Rare diseases are defined as occurring in less than 1 in 1500 people, so they are not something doctors normally encounter. When you have a patient for whom all the more [common diseases](#) have been ruled out, FindZebra has been of great assistance," says Henrik L. Jørgensen.

"The search engine cannot make a final diagnosis, but a search on symptoms and any genetic information returns 20 possible diagnoses in priority order, giving the doctor input into new alternatives which can be investigated."

During the test phase researchers compared results from Google searches – both covering the entire web and limited to relevant material—and searches in FindZebra, and the result was surprisingly good: In 56 searches, Google found the correct answer in 32 per cent of the cases, while FindZebra produced twice as many useful results.

## **Overwhelming interest**

FindZebra has become known around the world via various journals, websites and blogs, and 30,000 people have already visited [findzebra.com](http://findzebra.com), where it has been possible for anyone to perform searches in the new lexicon of [rare diseases](#) since mid-March.

Ole Winther is very pleased with the overwhelming interest in the search engine, the more than 500 daily visits to the website, and several invitations to talk about the project at conferences around the world.

The plan for the moment is for FindZebra to continue to be an open and freely available resource. The database will be updated every three months to ensure that all available and relevant material is included at all times.

However, Ole Winther also conceives that the [search engine](#) could

achieve even greater value by becoming part of a forum for doctors where they enter new data each time they encounter a patient with a rare disease.

"In this way the engine could 'learn' from the many cases and become even more useful. But we will have to wait and see how things develop. Our primary goal is for [doctors](#) around the world to become aware of FindZebra," says Ole Winther.

Provided by Technical University of Denmark

Citation: New search engine finds rare diagnoses (2013, May 21) retrieved 19 April 2024 from <https://medicalxpress.com/news/2013-05-rare.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.