Open Drug Discovery Teams: Sharing Data for Rare Diseases

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Introduction

There are over 7000 rare diseases and most of these do not have a treatment or a cure. The general public is barely aware that they exist unless a member of their family or a friend has the disease. We are already seeing pharmaceutical companies eyeing rare diseases as a potential money machine with some treatments costing >$300,000 per year/ per patient. We are increasingly seeing a shift to more companies, institutes and researchers openly sharing data on the internet. Alongside this there are increasing efforts by researchers to publish in open access journals and release data into open or free databases. Researchers working on these diseases are generally spread throughout the globe and in developing countries. Many of the rare diseases attract little funding and therefore less research, so how can we draw attention to them? How can we possibly connect all of this data and impact research?

We believe scientific mobile apps [1] may have a role to play in collaboration and aggregating the available data for different diseases. This lead us to develop a free app called Open Drug Discovery Teams (ODDT) for the sharing of scientific data initially focused on neglected and rare disease drug discovery. These tools could also be used as part of a drug repurposing [2, 3] or other strategy for rare or orphan disease research [4].

We have created a user interface via the ODDT app, for iOS-based devices (iPhone, iPod and iPad) that is "Flipboard or magazine-like". The user initially selects from a list of topics, and from there can flip through recently posted content. The app was launched April 12 2012 and is free for anyone to use, and provides content-consumption features as its primary purpose. We are capturing content on a server and make use of Twitter as the primary source (as a proof of concept), which is regularly polled and assimilated into the data collection. The service provides an API for accessing ODDT topics and content. As the project evolves, the server will be gradually augmented to recognize particular data sources and information streams, and provide value added functionality. Currently it is able to recognize chemical data such as molecular structures, reactions and datasheets. The project is open to participation from anyone and provides the ability for users to make annotations and assertions, thereby contributing to the collective value of the data to the engaged community.

Methods

Using the hashtags #huntingtons, #sanfilipposyndrome and #hhf4gan we capture Twitter feeds for Huntingtons Disease, Sanfilippo syndrome and Giant Axonal Neuropathy, respectively. We can also inject chemistry related and other content into the App.

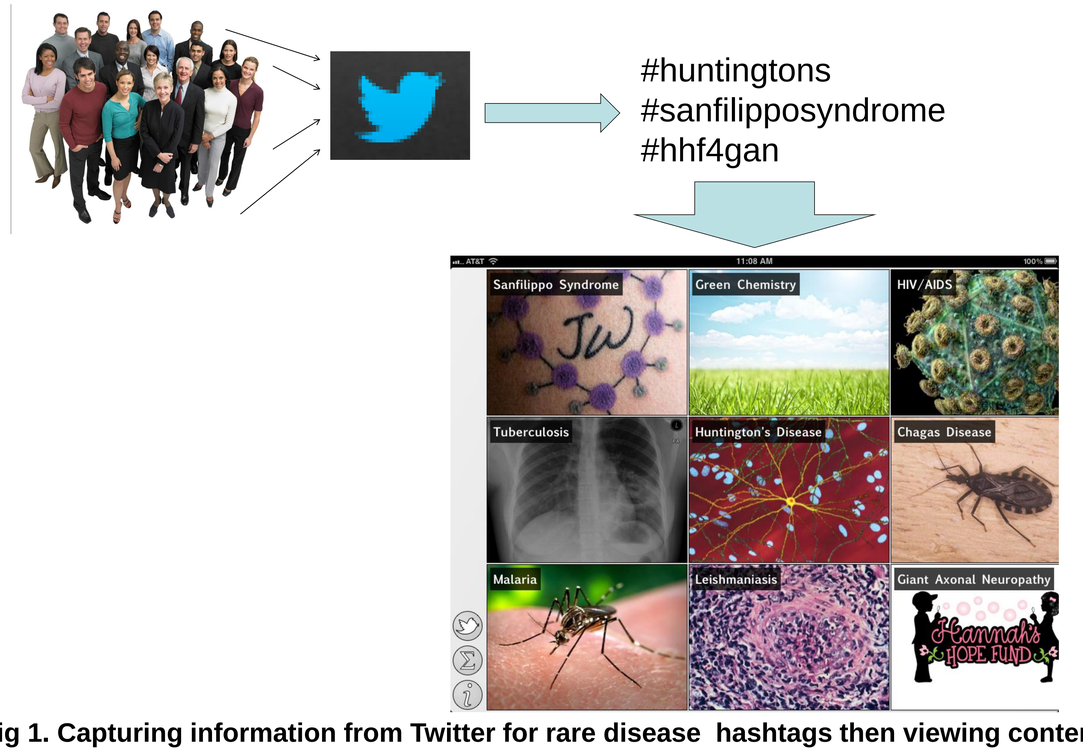

Fig 1. Capturing information from Twitter for rare disease hashtags then viewing content in ODDT app.

Results

We have defined a small number of rare orphan disease topics, corresponding to Twitter hashtags such as: #huntingtons, #sanfilipposyndrome and #hhf4gan. (Fig 1). We have also injected relevant chemistry related data into the app to illustrate how it could be used for sharing results from compound screening (e.g. structure activity relationships), tweeting important results from papers behind firewalls and increasing awareness of rare disease related news (Fig 2.).

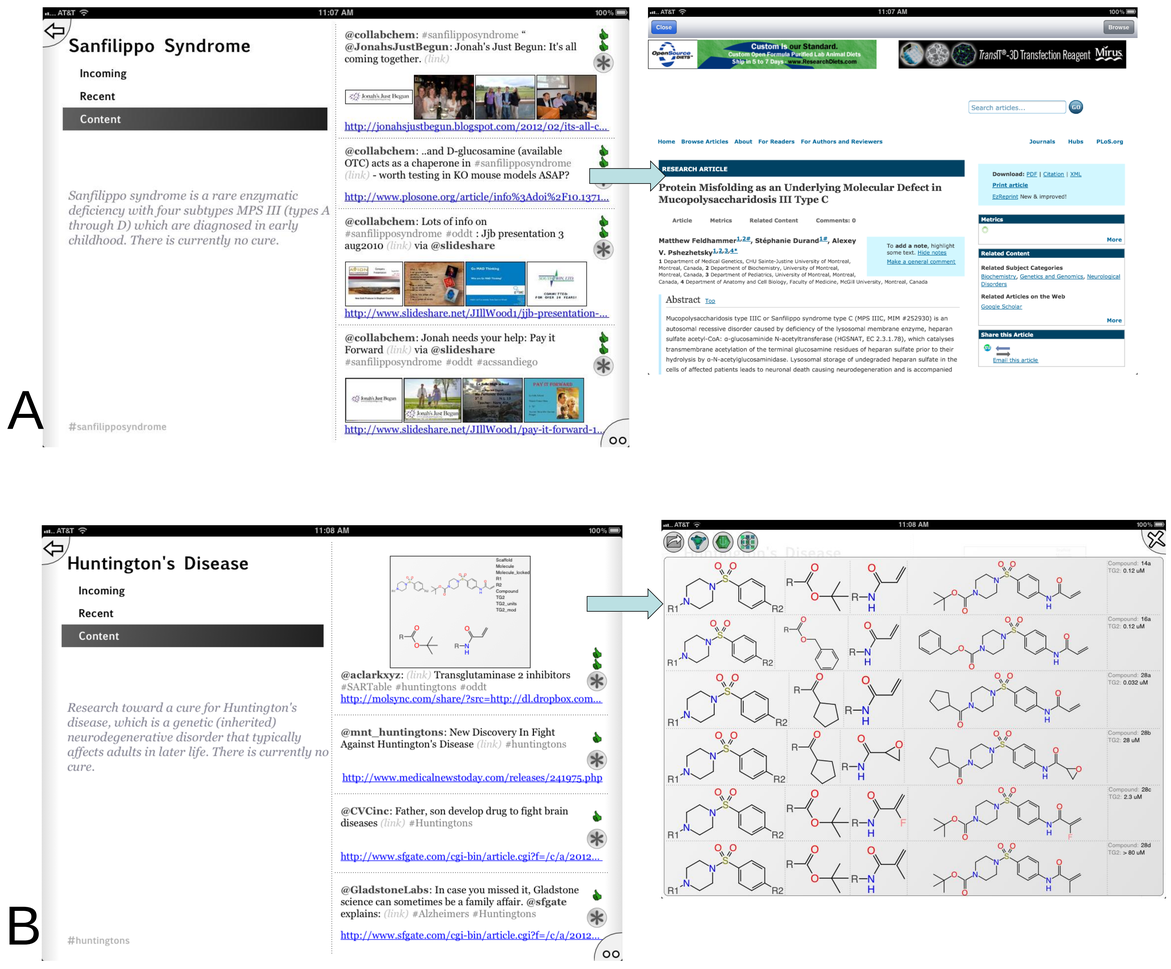

Fig 2. Links to A. scientific papers and B. Molecule Structure Activity Relationships from tweets captured in ODDT that are endorsed and saved in the content section of the App.

Discussion

In order to expand ODDT further we have launched an IndieGoGo crowdfunding campaign to fund support of the server for 3 years and increase the number of sources of data integrated (http://www.indiegogo.com/projects/122117). In return donors get to select additional diseases which we will add into the App. This will enable the community to decide which rare diseases can be followed in the same way as those currently (Fig 1).

References

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