

CART-wheel Centre for Analysis of Rare Tumours

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INTRODUCTION

The study of rare tumours, similarly to other rare diseases, has been hindered by small numbers of cases available for research. Backed by a Victorian Cancer Agency (VCA) Consumer Grant, BioGrid Australia has developed a website dedicated to rare tumour research serving consumers, researchers and clinicians alike: the CART-wheel database. The vision is to attract international participation to aggregate as high numbers as possible of real cases of rare tumour types. The website offers clinically vetted information about research into rare tumours and a support forum for patients. It also hosts a questionnaire to collect data about the patients' clinical episodes, tissue samples and background information. The patient chooses whether to give permission for clinicians/researchers to contact them in case their tumour is of interest for a lab-based study or a clinical trial. Participating in the questionnaire enables the patient to view reports based on the aggregated data from within the CART-wheel database. Interested researchers can apply to BioGrid for permission to search the database for potential subjects and to contact relevant patients (if they have consented) for participation in an ethically approved study.

THE DIFFICULTIES OF BEING RARE

Although numbers of each type of rare tumour are small, all rare cancers combined account for up to 20 percent of cancers diagnosed each year and 31 percent of cancer-related deaths, with increasing associated morbidity and mortality [1]. There are more than 500 types of rare tumours. A significant cohort of any one type will not exist at any single institution. This leads to limited basic research and infrequent and often uninformative clinical trials of tailored pharmaceuticals to treat patients with these tumours. It is clear to see the unfortunate situation of 20 percent of cancer patients with minimal research into the mechanisms of rare tumour development and effective treatments for their disease. In addition, as we increasingly recognise the importance of treating all cancer patients with treatments designed to target their cancers at a molecular level, the need to identify rare subtypes of more common cancer is becoming essential and these patients will also be included in CART-wheel. As rare subtypes of cancer are included in clinical trials of new targeted drugs, patients can be linked to clinical trials more quickly.

ETHICALLY APPROVED REGISTRY

More than 10 years ago, Cynthia Pollak, the parent of a patient with hemangioidenothelioma, began her own registry of patients with similar cancers in response to the lack of information available to her. However, it has grown into a task that is too large for one person to carry on so she turned to the cancer research community for help. Clinicians could see the value in this because Cynthia was able to gather data from over 200 voluntary international participants over the duration of her work to date. However, the researchers recognised that Human Ethics Approval was required if they were going to take over a project of this type, and use the data collected for research. Dr. Clare Scott obtained the ethics approval, including a consent form for the participants that they allow their data to be viewed and allow researchers to contact them in case a relevant research study is designed for which they are an appropriate participant.

DESIGN OF THE CART-WHEEL WEBSITE

Information

There are pages on the CART-wheel web site with information for the patients and clinicians. These include brief explanations about the importance of and opportunities for research, links to other informational web sites, explanations about the purpose of this web site and a link to BioGrid Australia's web site. As time progresses there will be some aggregated reports from the rare tumour data itself.

Questionnaire (data collection)

A detailed questionnaire is the main application of the web site. This questionnaire collects information about the patient, their tumour, symptoms, treatments, biopsies, outcomes and more. The patient has the opportunity to return to the questionnaire multiple times. They can also enter new information at a later date. Once they have entered their data, the patient can download and/or print out a report of their medical history. This application is written in Microsoft .NET Framework with a Microsoft SQL Server backend. It is hosted at Melbourne Health, in Melbourne, Victoria, Australia.

Support

There is a link to a (cancer services) consumer designed and moderated forum. This is the platform for CART-wheel users to offer and seek personal support for each other.

POTENTIAL FOR SUPPORT

One of the most difficult aspects for patients with rare tumours is the lack of local support. A patient may have to travel hundreds of kilometres or even internationally to attend a clinician with experience in their tumour. Furthermore, they might never meet anyone else facing the same problem.

The section above notes how CART-wheel provides a reliable source of information for patients about their rare tumour. It also provides a moderated forum for the patients to exchange their personal experiences, successes and frustrations. It is hoped that the availability of the information and personal support will have a multiplier effect to bring more activity to the site from the international community of patients and clinicians. In this way, the information and the support will grow.

POTENTIAL FOR RESEARCH

The ultimate goal for CART-wheel is to gather enough entries over time to be able to service a clinical trial for different types of rare tumours. However, before then, a variety of research may be able to be done with the consent of the CART-wheel participants. BioGrid Australia provides the infrastructure to make the CART-wheel data available to researchers.

Anonymise

The research data in the CART-wheel database will be anonymised before it is made available in aggregated reports and federated. Some reports will be made directly available on the CART-wheel website for all to view. More will be reserved for registered members.

Federate

The data in CART-wheel of research interest will be ingested into BioGrid using data warehousing and the IBM Federation Server technology. The BioGrid infrastructure enables the structuring and classifying of the data so it can be searched and analysed by researchers.

Propose Research Study/Apply for Access

BioGrid provides an Access Request System by which researchers can apply for access to specific databases. They must describe the basis of their proposed usage of the data and agree to the terms and conditions of use of BioGrid. Sometimes additional ethics approval is required. Through this system, the data owners approve access to their data and a Scientific Advisory Committee assesses the proposed investigation.

Search CART-wheel database using BioGrid analysis tools

BioGrid provides data analysis tools over the Internet such as SAS, STATA and SPSS. The successful applicant will be able to select CART-wheel data and analyse it for content relevant to their study. Through BioGrid the investigator might also have designed a study linking more than one database, as BioGrid enables study across multiple databases federated into its infrastructure.

Contact CART-wheel participants to form a cohort if applicable

A researcher who has obtained approval from a recognised Human Research Ethics Committee or equivalent, nationally or internationally, is able to apply to Biogrid to determine how many patients who fit the required description have entered their data into CART-wheel and provided written consent to allow contact by Biogrid for a possible research study or clinical trial. Upon receipt of such a request, Biogrid will assess the quality of data, providing an estimate of the number of patients who appear to have a complete dataset and appropriate contact details for pathology specimens. Following approval of the new project by the Biogrid project approval process, patients will be sent an ethically-approved letter by Biogrid, inviting them to take part in the relevant research study and facilitating contact between the patient and the relevant study investigator for potential involvement in the study. The researcher closes the loop by informing Biogrid of the outcome of each patient contact.

CONCLUSION

As the form and content of the CART-wheel website unfolded, the utility of collection of data and consent to use it in the same application became very clear. At the time of writing, data collection has just begun. However, we expect that the presence of CART-wheel will increase the likelihood of efficient research in the area of Rare Tumours, making possible studies which could otherwise not be contemplated. Our clinical researchers are working on robust international linkages. We look forward to the consolidation of CART-wheel as an effective foundation for ongoing research and discovery in the field of Rare Tumour etiology and treatment.

REFERENCES

1. AIHW (Australian Institute of Health and Welfare) & AACR (Australasian Association of Cancer Registries) 2008. *Cancer in Australia: an overview*, 2008. Cancer series no. 46. Cat. no. CAN 42. Canberra: AIHW.