



Introducing the Metastatic Breast Cancer Project: a novel patient-partnered initiative to accelerate understanding of MBC

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In this podcast, Marina Parry, ESMO Open Digital Editor, speaks to Elana Anastasio, Partnership Outreach Manager, and Brett Tomson, Scientific Outreach Manager, both from the Metastatic Breast Cancer (MBC) Project team at the Broad Institute of MIT and Harvard in Cambridge, Massachusetts, USA.

The MBCproject is a novel model of a patient-partnered initiative whose aim is to accelerate the understanding of metastatic breast cancer by generating a massive open database of deidentified genomic information from patients' tumour samples, alongside abstracted clinical information, and patient-reported data. Although research has increased the understanding of MBC, no cure exists and more work needs to be done. As 85% of US patients with cancer are treated in community settings where tumour samples are not often included in academic research projects; much of the diversity of this disease and other cancers has not yet been captured. However, by engaging patients directly regardless of where they live, the MBCproject is in a unique position to be able to help generate a data set to further decipher the complex biology behind disease progression and answer important research questions, such as why some therapies work in certain patients while others do not. The data generated by the MBC project has already been, and will continue to be, widely and openly shared with the global community.

Started in October 2015 by Nikhil Wagle (Assistant Professor of Medicine at Harvard Medical School, Medical Oncologist at Dana-Farber Cancer Institute, and Associate Member of the Broad Institute) and

Corrie Painter (Associate Director of Operations and Scientific Outreach in the Cancer Programme of the Broad Institute), the MBCproject has had over 4620 participants register at the time of recording (June 2018).

In the podcast, we discuss the challenges faced by the team, the enthusiasm they were met with from patients, the logistical and operational hurdles they have overcome, the importance of finding a common language and building trust between participants and researchers, the role of social media and patient advocates, as well as the other patient-partnered projects this team has since initiated, including in angiosarcoma (launched March 2017, >200 patients registered as of June 2018) and metastatic prostate cancer (launched January 2018, 450 patients registered as of June 2018), with a gastro-oesophageal cancer project starting in the coming months.

The MBCproject continues to grow, and a first batch of data has already been released, which organisers hope, and want, to be used by researchers worldwide. New directions for this project are discussed, as well as additional follow-up surveys that will be used to glean even more information from patient participants, thus building an incredibly rich database for use by the research community.

The MBCproject is an exceptional example of a scientifically focused project that is also a testament to human empowerment and which demonstrates a changed landscape of research where many people want to take an active role in the understanding of their disease, as well as being involved themselves in further accelerating scientific discoveries.

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Finally, the MBCproject organisers want to hear back from scientists and researchers about ideas or questions they have on how to use the existing data or new data you think would be good to try and generate. They encourage listeners to get in touch! Their website is <https://www.mbcproject.org>.

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