CASE STUDY



Connecting people living with hepatitis B to online support and research opportunities

Associate Professor Thomas TuWestmead Institute for Medical Research

The research and its impact

Associate Professor Thomas Tu is the Chief Investigator A (CIA) on an NHMRC-funded Ideas Grant, where he is testing new treatments that could lead to a cure for hepatitis B. Thomas also lives with chronic hepatitis B. He brings the perspective of a researcher, patient, and community advocate to his research.



2300 global users of HepBcommunity



More than **60** sector partnerships through **Hepatitis B Voices Australia**

To both support the community and understand the impacts of the condition on people's lives, Thomas established **HepBcommunity.org**, an online support network for people living with hepatitis B. This network connects the affected community with peer support, educational resources, and medical and scientific experts. Through this network, Thomas has built a global community of more than 2300 people. He coordinates a yearly research showcase, where hepatitis B researchers share their research and its findings with people living with hepatitis B.

Thomas is also the co-founder of Hepatitis B Voices Australia, the first Australian community group led by people living with hepatitis B. Hepatitis B Voices Australia has partnered with the research, clinical, and policy sectors on over 60 projects. People living with hepatitis B have been involved in research project design, study recruitment, and public speaking. Through national and international partnerships through Hepatitis B Voices Australia, Thomas recently published an article on best practices when engaging with affected communities, with people living with chronic hepatitis B as a case study.¹

What is Hepatitis B?



Hepatitis B is a common liver infection caused by the hepatitis B virus (HBV). It is transmitted through bodily fluid exchange, most commonly during birth or in early childhood. Many people who get hepatitis B clear it within 6 months. But when exposed as newborns or infants, the infection often lasts longer and becomes life-long. People with chronic hepatitis B are at greater risk of developing liver cancer, liver failure, and cirrhosis (scarring of the liver). Globally, diagnosis and treatment rates are low, leading to preventable deaths. Stigma, education, awareness, and advocacy are significant factors that must be addressed to improve health outcomes for people who live with chronic hepatitis B.



A/Prof Tu has played key roles in developing novel approaches to engage the affected community in research, clinical implementation, and decisions in health policy.

Professor Jacob George University of Sydney



¹Best practices for engaging with affected communities: chronic hepatitis B as a case study.