



Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Project overview

Treatment for hepatitis C (HCV) has been revolutionised in recent years with the introduction of interferon-free direct-acting antiretroviral (DAA) medications that have far fewer side effects and much higher success rates than past treatments. With the advent of these new treatments, the Australian Government adopted the World Health Organisation's ambitious goal of eliminating HCV by 2030. Efforts to eradicate HCV depend upon consistently high rates of treatment uptake. While the eradication of HCV is an important public health goal, not enough is known about experiences of HCV, treatment and post-treatment life in this new age in which HCV elimination seems possible. This project will produce urgently needed detailed understandings of experiences of and meanings given to HCV for people affected by it, helping to identify impediments to treatment uptake, including the role of stigma. In addressing the challenges of HCV eradication in Australia, publicly accessible information and support resources can play a key role. This project will produce a public website to fill this gap. The website will present personal experiences of the new treatments, issues to consider in decision-making about treatment, and tips and suggestions to enhance life on treatment and after. The resulting website will speak directly to potential treatment users and their friends and family, while also informing health workers and other relevant professionals about the new treatments and the issues surrounding them. In doing so, it will also tackle the stigma associated with injecting drug use and HCV. This study received ethics approval from La Trobe University's Human Research Ethics Committee. Approval number: HEC20078

Project team

- Professor Suzanne Fraser, Australian Research Centre in Sex, Health and Society, La Trobe University
- Professor Carla Treloar, Centre for Social Research in Health, UNSW
- Professor David Moore, Australian Research Centre in Sex, Health and Society, La Trobe University
- Dr Michael Edwards, National Drug and Alcohol Research Centre, UNSW
- Elizabeth Birbilis, Department of Health and Human Services
- Dr Adrian Farrugia, Australian Research Centre in Sex, Health and Society, La Trobe University
- Dr Renae Fomiatti, Australian Research Centre in Sex, Health and Society, La Trobe University
- Emily Lenton, Australian Research Centre in Sex, Health and Society, La Trobe University

Aims

- Investigate the experiences of people affected by HCV in Australia and any impediments they identify to treatment uptake;
- Investigate the treatment experiences of people affected by HCV in Australia;
- Explore any health issues they identify post-treatment; and
- Explore the role of stigma in treatment access, if any, and the potential impact of stigma on post-treatment quality of life, including healthcare access.

Method

- Sixty in-depth qualitative interviews conducted in NSW and Victoria: recruit for variation between treatment knowledge, types of treatment used, gender, age, ethnicity, socioeconomic background and sexuality
- The interviews will form the basis for a website presenting hepatitis C and treatment experiences and related information. Linked to the established Livesofsubstance.org and Overdoselivesavers.org websites, the site will include key topics (experiences of hepatitis C, experiences of diagnosis, experiences of disclosure, experiences of stigma etc.) illustrated with anonymised text quotations, audio clips and video re-enactments to illustrate the key topics



Outcomes

- Innovative, theoretically informed analyses of experiences of hepatitis C, treatment and stigma to improve understandings of impediments to treatment uptake;
- New knowledge on how established forms of hepatitis C and drug use-related stigma shape treatment uptake in a time of new treatments; and
- An accessible Australian resource presenting lived experiences of hepatitis C, different forms of treatment, health after treatment, and stigma. The website will benefit people affected by hepatitis C, members of the public and associated health professionals and policymakers, aiming to support treatment uptake and completion.