

# Community advocacy around new treatments

Expediting changes in policy and service delivery for people living with hepatitis C



## Introduction

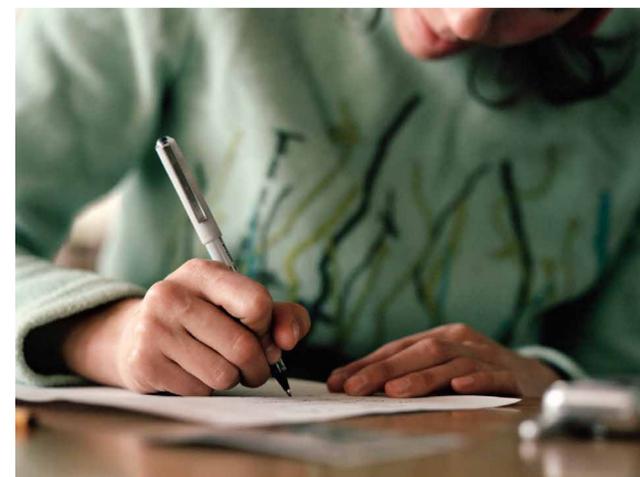
Community advocacy by people with hepatitis C has been limited by the absence of a cohesive community of the affected population.

- Hepatitis C faces significant challenges in attracting community support because of its association with injecting drug use
- Drug use is an illegal and highly stigmatized behavior
- People living with hepatitis C are often socially excluded or isolated because of stigma and discrimination.

## Background

Hepatitis NSW established the *C me* project in 2012. *C me* is a grass roots peer based project to engage and train a network of Community Advocates from across NSW to act as local campaigners and advocates:

- Lobbying local influencers and providing a voice for people affected by hepatitis C
- Use their lived experience, understanding and position of influence to help their peers advocate for change.



## Results

- Activities involving Community Advocates were successful in presenting the case for treatment approval to key political decision influencers
- The petition with over 1,024 signatures was delivered to the Federal Health Minister Tanya Plibersek on 28 September 2012 with a key letter outlining the case for funding boceprevir and telaprevir on the PBS
- 388 emails were sent during the campaign period
- One community Champion sent a hand written letter to every Liberal and Labor member in NSW outlining his own story of waiting for effective treatment for his hepatitis
- **C me** Community Advocates and staff from Hepatitis NSW met with 21 NSW-based federal and state parliamentarians or their staff
- A meeting was secured with the Health Minister in her constituency office
- The largest ever hep C advocacy campaign across NSW contributed to the PBS listing of boceprevir and telaprevir on April 1 2013

## Methods

### COMMUNITY ADVOCATES

We recruited 15 Community Advocates from the affected community to act as local advocates in each of the 15 Local Health Districts in NSW.

Training was provided to enable Community Advocates to be active in advocating for change and to put a human face to campaigning.

Training covered:

- How government works
- Working with politicians
- Planning an effective advocacy campaign around hepatitis C
- Speaking from experience: developing a public narrative
- Participating in a delegation
- Speaking to the media
- Who's who in the health sector

### Key results from training

- ▶ Knowledge, skills and ability to engage MPs increased from 21% to 45%
- ▶ Understanding of advocacy campaigning increased from 42.5% to 72%

### OUR FIRST ADVOCACY CAMPAIGN

In July 2012 boceprevir and telaprevir, two new hep C treatment drugs, had been recommended by the Pharmaceutical Benefits Advisory Committee (PBAC) for listing under the Pharmaceutical Benefits Scheme (PBS). If the PBS listed them, it would mean that the Australian Government would then subsidise them.

This gave HNSW and the *C me* Project an opportunity to develop a peer based advocacy campaign to support national advocacy to have these drugs approved for subsidy.

- Fast tracking PBS listing would provide a real tangible benefit for many thousands of people living with hepatitis C.
- Community Advocates could all identify with the need for this through lived experience.

Community Advocates chose the **campaign name** *Treat Us Better*.

### CAMPAIGN ACTIVITIES

- **Online tools:** a *C me* microsite was developed and a series of online tools were created including a petition for the Federal Health Minister and 'email your local MP' tool. Templates were developed and distributed through both organizational and peer networks. Factsheets around the issue were produced and placed on the website.
- **Face-to-face meetings:** Community Advocates contacted their local MPs and were supported to arrange visits to speak with them.
- **Media:** a social media plan was developed and used across Facebook and Twitter with shared hashtag #TreatUsBetter. Media releases were used across the campaign.
- **Champions:** A round table meeting with key advocates from the health sector and community Champions led to a set of recommendations around treatment access.

## Conclusions

Results from the *Treat Us Better* campaign demonstrate the importance of engaging in community advocacy campaigns.

Thanks to the *C me* Community Advocates without whom the project would not be possible.

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