

PEER SUPPORT FOR THE HUNTINGTON'S COMMUNITY ...BY THE HUNTINGTON'S COMMUNITY

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BACKGROUND:

The complexity of Huntington's disease (HD) has a significant psychosocial impact on the individual diagnosed as well as the family unit. Peer support groups is a way of community members can attempt to understand the stressors associated with living with HD. However there a number of barriers to accessing in person peer support namely location, issues with anonymity and limited access to information resources. In response Huntington's Victoria in collaboration with the Victorian HD community partnered with key stakeholder groups to develop 'Huntington's community connect' a sustainable online peer support group for the Huntington's community... by the Huntington's community.

OBJECTIVE:

To develop a national peer-lead model of capacity building for people impacted by HD through implementation of the peer support web-based interface, "Huntington's community connect (HCC)". To provide a mechanism to deliver up to date, high quality information for people impacted by HD.

RESULTS:

The outcomes of the rapid evidence review and the gap analysis informed the development of the HCC with respect to the following:

- Numbers of potential users of the HCC
- Identifying specific information themes relevant for HCC users
- Access to shared lived experiences normalise the impacts of HD

Since the HCC forum's launch in May, we have had 16 registrations per month across Australia. The Peer Leaders who are representatives of the HD community facilitate discussions with people on the forum by sharing their personal experiences. In addition, the Huntington's Victoria team, in collaboration with the Peer Leaders oversee a yearly calendar of information topics utilising different mediums such as video, information sheets, webinars that address gaps identified by the community. Users of the forum also have access to information about local supports through access to up coming events.

CONCLUSION:

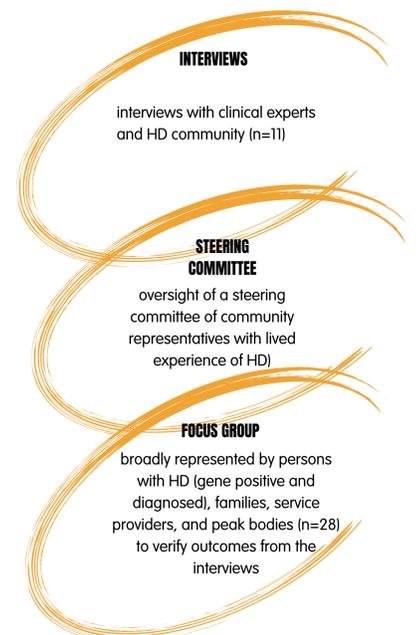
The HCC was officially launched in May 2022 to overcome barriers to engagement for the HD community. For the first time in Australia the HCC has enabled nation-wide access to peer support and mentoring in addition to providing a mechanism to deliver up to date, high quality information for people impacted by HD to exercise choice and control

METHODS:

1. Undertake a rapid evidence review to clarify national prevalence of HD



2. Conduct a gap analysis on information needs and access to specific peer support



3. Launch and Evaluation of the of HCC

Upcoming Events

SEP 8	September 1 @ 8:00 am - September 30 @ 5:00 pm September Information Topic: Services available for the HD community
OCT 1	October 1 @ 8:00 am - October 31 @ 5:00 pm October Information Topic: Basics of Huntington's Disease
OCT 29	10:00 am - 4:00 pm The Huntington's Victoria 2022 Community Conference
NOV 1	November 1 @ 8:00 am - November 30 @ 5:00 pm November Information Topic: Relationships and Communication
DEC 1	December 1 @ 8:00 am - December 31 @ 5:00 pm December Information Topic: Health and Wellbeing

[View Calendar](#)