

CASE STUDY – DEVELOPING A PARTICIPATIVE STRATEGIC APPROACH TO HEPATITIS C WITHIN THE MID WESTERN REGION:



GOSHH

GOSHH stands for Gender, Orientation, Sexual Health and HIV. We are a charity working in the Mid Western Region of Ireland. Our offices are based in Limerick City and we cover counties Clare, Limerick and Tipperary. We have been known as GOSHH since 2013 after Red Ribbon Project (sexual health and HIV) amalgamated with Rainbow Support Service (gender and orientation). Since then we have developed a new vision and an integrated way of working with all these areas.



Context

GOSHH as an organisation has always supported people living with Hepatitis C (PLWHCV). We have provided support, information, advocacy, empowerment and free condoms. In 2003, in response to a request from a client, we provided extra support for self-advocacy with medical professionals. In 2005 we then supported him (Tony) to learn auricular acupuncture, reiki and support skills. Tony was recruited as our HCV specialist peer volunteer. In 2012, in response to an increase in PLWHCV callers to the helpline we started to improve service provision for PLWHCV. A new full-time support position, Community Support Project Worker, was created which covered sex work, PLWHCV and Rapid testing. We needed to develop a more cohesive service, informed by and designed by PLWHCV.

In 2014, the safety net clinics (Health Equity Partnership) began in Limerick. The Safety Net clinics provided free medical care to people who otherwise did not have access to a doctor. This care did not require a medical card and it was available to everyone. At the

same time we began to develop effective working relationships with drug, alcohol and homeless agencies in our area.

Through our discussions with workers in the field we discovered that many people diagnosed with HCV, were not attending for follow up medical care. People were spiralling into increased drug or alcohol use, and disappeared from medical services altogether. At the same time, it became clear that there were barriers to access that were not being addressed and that staff in agencies were unaware of the new treatment, (Direct Acting Anti Retroviral Therapy (DAART)).

Approach, Strategy and Tactics

Our initial plan was to find out what PLWHCV needed from our service, then to develop and promote those services. We wanted to ensure that PLWHCV were at the heart of the decision making process. Our aim was to increase the engagement with follow up medical care, in particular the PCR test, within the mid western region.



1992

STEADY WORK

Free condoms
Support
Information



2003

CLIENT CENTRED
RESPONSE

Advocacy
Free condoms
Support
Information



2005

DEVELOPING PEER
VOLUNTEERS

Peer Acupuncture
Reiki
Peer support
Advocacy
Free condoms
Support



2012

SUPPORT WORKER

Links with HCV networks
HCV included in GOSHH
strategic plan
Advocacy
Peer Support
Free condoms
Support
Information



We conducted a focus group of People Living with Hepatitis C (PLWHCV). This was step one to developing a trusting rapport with PLWHCV. The information was written up and used to begin a local conversation between service users and service providers. (As requested, agreed and decided by the focus group).

- How do you feel about your HCV diagnosis?
- How do you manage living with HCV?
- What do you think PLWHCV need?
- What would you like done differently?
- What would talking with someone LWHCV have done for you?

We learned that psychosocial support for PLWHCV was minimal and often PLWHCV had little or no information about HCV. We offered an opportunity for relevant agencies to discuss Hepatitis C, how it affects their staff and what their clients need. We decided to do this as part of our action around World Hepatitis Day.

Four agencies attended: - McGarry House, Ana Liffey Drug's Project (ALDP), Safety Net Clinic and Limerick Drug and Alcohol Service. This meeting was also attended by two people living with HCV (Tony and Susan). The findings from the HCV focus group were presented. The peer members spoke about the types of issues people living with Hep C experience. Agencies spoke about the issues they encountered supporting PLWHCV. This was the beginning of the Mid Western HCV Network and the HCV peer support group.

In June 2015, we were contacted by Community Response and asked if we would like to organise the placement of a 'Giant Green C' somewhere in Limerick for World Hepatitis Day (July 28th). A massive Big Green C (similar to the yellow 'C' in America and the big red 'C' in Scotland) made out of metal was placed in a busy pedestrian area in Limerick city and surrounded by activities and HCV information. It was family friendly and very visible. We had a marquee, face painting, circus tricks, a selfie competition and giant outdoor games all promoting our 'Giant Green C' in Bedford Row, Limerick. This was staffed by a host of volunteers all wearing Big C t-shirts and handing out promotional materials provided by Community Response. Social media promotion was busy with the tags #Cme #Cthis #HepC #WorldHepDay #WHD2017

Outcomes

Focus Group - Participants' confidence increased and they were eager to continue to discuss the issues they faced among their peers. Participants were supported to set up a Peer Support Network. Participants became politicised through the knowledge and analysis developed during focus groups and subsequent network meetings

Interagency Meeting - Mid Western HCV Regional Network was established. A plan was created for increasing professional knowledge and skill base. We agreed to research the possibility of providing HCV Rapid tests onsite. Peer support workers were linked in with service user support mechanisms.

Promotional Event - Over 500 HCV leaflets, keyrings and other merchandise, were distributed. We met 3 PLWHCV, 2 parents of PLWHCV and 1 parent whose child had died from HCV related illness. We made 2 appointments to the STI clinic and 7 other referrals for follow on medical care or screening.



2014

BUILDING NETWORKS

HCV focus groups
Advocacy
Peer Support
Free condoms
Support
Information



2015

WORLD HEPATITIS DAY

Participation in
World Hepatitis Day
(WHD) and
European HIV and
Hepatitis Testing Week
(ETW)
Peer supported HCV
awareness training
Peer led HCV
professional network
HCV peer support group
Advocacy
Peer Support
Free condoms
Support
Information



Rapid HCV testing - Interagency, Peer Supported Rapid HCV testing in Community Based Settings - Staff from agencies involved with the Mid Western Regional HCV Network and members of the Peer Support Network were trained to provide Rapid HCV test (10 minute results for HCV antibodies). Rapid tests were provided to 17 people in the pilot program.

Increased visibility with local radio, newspaper and agencies - With peer workers being supported to tell their stories we were able to promote HCV awareness in a very real way. Local community members responded by attending testing and asking for information and support. Four new agencies joined the Mid Western Regional HCV network. One of our peer workers bought a motion to Limerick City Council to demand better services in the mid-west. This motion was passed unanimously.

Service user informed campaign - The network was able to support the release of the focus group findings to national governmental bodies who were working on HCV strategy for Ireland and to local drugs and alcohol agencies.

Staff in relevant agencies receive training on HCV - A staff member from GOSHH, accompanied by a Peer Worker, visited relevant agencies in the area to talk to them during their staff meetings about HCV, how to work with it and how to support people who are diagnosed.

Development of a HCV training workshop for professionals - A staff member from GOSHH, accompanied by a peer worker, providing a structured workshop about HCV and how to support PLHCV, particularly a new diagnosis and engaging with follow on medical care.

Development of resources - The two groups (regional network and peer support) created three leaflets with plain language, which targets the relevant information in each case:

- What is Hepatitis C - explains HCV, prevention, transmission, progression and treatment.
- Living with Hepatitis C - designed for use at first diagnosis, contains everything the PLWHCV wished they had been told, plain language, short sentences, and information for further support.
- Hepatitis C – Services Provided - designed for service users and other agencies, this is about everything a person can access through GOSHH, including the Peer Support Network and the Mid Western Regional HCV Network.

Increase in testing for HCV - When accompanied by a peer worker, testing teams were very successful. The peer worker is able to relieve fears and offer immediate support. More people were now being tested for HCV through engaging with the safety net clinic, more people were now being diagnosed and HCV has gone from being something no-one encountered, to something more frequently encountered.

Increase in engagement with follow on medical care - It is slowly increasing and people are coming back to ask questions. We can now accompany people to doctors' appointments or hospital appointments to make it a little easier. We can also arrange for immediate support when a diagnosis for HCV is about to be provided.



2016

RAPID HCV TESTING
Peer and multi agency testing team trained
Community based Rapid HCV Testing
Rapid HCV testing during WHD and ETW Program
Peer developed HCV leaflets
Peer Support Advocacy
Free condoms Support Information



Increase in information about DAART cure - People are being to share the information that there is a cure for HCV and people who have been living with HCV for a long time are now coming forward to talk about their options.

Challenges

Care pathways for people diagnosed with HCV in the mid-west are not clear. This is in part due to the individual nature of HCV progression, but also because we have no HCV treatment facility in the mid-west. Our service users are travelling to Dublin, Cork or Galway to see consultants. Many do not have the health and well being levels to be able to travel, and so do not attend.

The experiences of our service users are consistently discriminatory. People are forced to wait until the last appointment in the day, even though their scheduled appointment was earlier; are being told by medical professionals to “go away and get your Hep sorted out” and told by the HCV consultants that “you are not sick enough to need treatment”. When people complained about the way they are treated or spoken to by HSE staff, these complaints are dealt with badly by the HSE, causing despondency, and mistrust of the services as well lowering their mental resilience for LWHCV. These types of experiences left us with a challenge in developing trust.

Having no access to treatment, no information about options and no clear care plan in place whilst living with severe symptoms or medical conditions is mentally and emotionally taxing. This can cause severe mental and emotional health issues. Talking about needs, can be traumatic and trigger terrible feelings, amongst PLWHCV there are often already high levels of trauma present. We needed to make sure it was fun but also validate emotions.

We were an unknown organisation amongst the general public as well as target groups. We had very little trust built up within the affected community. Having peer workers included was essential yet, peer workers are unpaid, as our finances were limited, and so we were left with little options but to be strategic about peer engagement.

Learning

All agencies involved saw the need for this work to be developed immediately. It was something many had been thinking of but not spoken about until we started the conversation.

The model of service user engagement at decision making level works brilliantly. Service user experience is the key information we need whilst gathering local evidence. We need to continue to share our knowledge and resources.

Next Steps

In 2016 Tony died. The peer network needs careful support and constant renewal if it is to succeed in becoming fully autonomous.

Plans are being developed to pilot Rapid HCV testing in NEX pharmacies and other community based settings throughout the Mid West.

DAART is not as available as it needs to be. Political pressure is required to promote community based treatment facilities.



2017

SHARING KNOWLEDGE

Presentation at European Community Hep C Summit and Irish Street Medicine Symposium
Funding secured from Mid Western Regional Drug and Alcohol Forum (MWRDAF) for roll out of community based Rapid HCV Testing
Pharmacy Rapid HCV Testing
Peer support group in Clare
Advocacy
Peer support
Free condoms
Support
Information