

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

Background

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.

We have always supported people living with Hepatitis C (HCV), even though we did not promote it anywhere in our literature. We also worked with sex workers in the same way. We provided support, information, advocacy, empowerment and free condoms.

We had a peer support volunteer in our project called Tony Rose. We worked with him to understand the medical language being used by doctors around his care, to advocate for his fair treatment in situations where he was being discriminated against, to empower him to access other supports like attending HEP Cats in Dublin, to support him to learn Auricular Acupuncture and Reiki. Tony became our (volunteer) HCV specialist and we left much of the work to him. When Tony began to get too sick to work, we answered a helpline call from a woman who had been diagnosed with HCV and wanted to know how long does it take for the results to come back. Our answers to her were vague and we realised the impact of all of our learning and expertise residing within Tony. We decided we needed to take responsibility for this work ourselves.

The woman who called our helpline got back in contact with us. We were able to put her in contact with Tony and we started to discuss the needs of people living with HCV. At a similar time, the safety net clinics (Health Equity Partnership) had started in Limerick, and through this we developed effective working relationships with drug, alcohol and homelessness agencies in our area.

In 2012, when we knew our projects were joining, we created a new support position which covered Sex Workers, PLWHCV and Rapid Testing. This was the Community Support Project Worker and was a full time post. We needed to develop a more cohesive service, informed by and designed by PLWHCV, for PLWHCV and the timing seemed right.

Many people diagnosed through Dr Patrick O' Donnell (safety net clinic), were not attending for follow up tests. Explaining to people that the first test only gave an indication that at some point in your life you have been in contact with HCV, was not adequate to manage their fear about dying. Many people spiralled into increased drug or alcohol use, and disappeared from medical services altogether. This meant that they did not get the second confirmation test for HCV presence (PCR test).

Our Initial Aims Were:

1. Find out what PLWHCV need from our service
2. Promote our HCV support services so people know they exist
3. Have PLWHCV at the heart of the decision making process within GOSHH and the Mid Western Region
4. Increase engagement with follow up medical care, in particular the PCR testing
- 5.

Approach, Strategy and Tactics

In June 2015, we were contacted by Community Response and asked if we would like to join in with their national campaign for International Hepatitis Day (July 28th), and if so, could we organise the placement of a 'Giant Green C' somewhere in Limerick. We decided to say yes and also find out what other things we could do but first we needed input from PLWHCV.

1) Focus Group with PLWHCV

We conducted a focus group of People Living with Hep C (PLWHCV). Even though the numbers in attendance were too small to allow for significant findings, 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).

We asked these questions which grew from the discussion:

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

2) Interagency Meeting on July 28th 2015

Following the guidance from the focus group we invited relevant agencies to an interagency meeting on HCV for World Hepatitis Day.

3) Big Green C in Limerick on July 29th 2015

A massive Big Green C made out of metal was placed in a busy pedestrian area in Limerick city and surrounded by activity and information. It was family friendly and very visible.

Outcomes

1) Focus Group

We began the creation of a Peer Support Network and discovered that our PLWHCV were actively wishing to be involved in political campaign for change.

2) Interagency Meeting

The invitation was sent out to as many agencies as possible and four replied: - 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) who had attended a focus group I facilitated, two weeks prior to the network meeting. At the Network meeting, the findings from the HCV focus group were presented. The peer members spoke about the types of issues people living with Hep C experience. Agency needs were identified. The Mid Western Regional HCV Network was established and a HCV Peer Support Group was established. It was also decided we would research the possibility of Rapid HCV testing in community based settings, which we then went onto establish for World Hep Day 2016.

3) Big Green C

An event management student on placement with GOSHH was delighted to be asked to run with the idea. 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. As well as having contact with over 500 people, we also had two people living with HCV introduce themselves to us and one mother of a man living with HCV received support. There were various appointments made for screening and follow up medical care.

4) 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. GOSHH now provides Rapid HCV Testing on an ongoing basis alongside its Rapid HIV testing program.

5) 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. We also bought a motion to the Limerick Council, which passed, about the need for treatment in the Mid Western Region.

6) 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.

7) 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.

8) Development of a HCV training workshop for professionals

Much the same as the agency staff meeting chat. This is a more structured version and also includes a staff member from GOSHH and a Peer Worker.

9) Development of resources

The two groups 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.

10) 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.

11) 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.

12) 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. Some of these are joining our group and some are re-engaging in medical care.

Challenges

No-one knows the care pathways for people diagnosed with HCV. This was in part due to the individual nature of HCV progression, but also because we had no HCV treatment facility in the Mid West. At the time there was a Hep Clinic at the local Infectious Diseases Clinic (IDC), but this was only once a month and could not prescribe treatment, it could only provide information and follow on referral. Our service users were travelling to Dublin, Cork or Galway to see consultants. Many did not have the health to be able to travel and so did not attend.

The experiences of our service users are consistently discriminatory. People are forced to wait until last in the day, even though their appointment was earlier. People are being shut out of rooms, because they do not have a blue card. People are being told that their symptoms were in no way related to HCV, even though these symptoms were consistent throughout our peer group members.

People are being prepped for surgeries and refused the surgery when the surgeon read HCV on their chart. People 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", leaving them in a vicious cycle of having nothing treated and being forced to live with severe symptoms or medical conditions that they had no hope of ever being able to recover from, with no hope of ever getting it treated.

When people complain about the way they are treated or spoken to by HSE staff, these complaints are dealt with so badly that PLWHCV get quite despondent, and this impacts on their trust in the services as well as their mental resilience for LWHCV. The overwhelming reason for people being treated badly by HSE staff is the assumption of active addiction.

Learning

All agencies involved saw the need for this 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.

Peer support group helps people to overcome their fears and provide them with actual examples of non-dead individuals, who can explain how HCV sounds much scarier than it is; who could talk about their own journeys towards managing their own health and well-being.

Moving Forward

- The Peer Workers have asked for training in other areas, which will be sourced or provided.
- HCV Rapid testing will be rolled out in more venues across the Mid West.
- The Network meetings need to move venue to accommodate people in all three counties.
- Service need to expand to include people who are living in isolated areas.
- Peer workers need to be found who can provide more than telephone support to people living in counties Clare and Tipperary.
- The broader medical rights of PLWHCV need to be advocated for. This may involved bringing cases through the equality legislation in Ireland on the grounds of discrimination of ability based on the presence of a virus within the body.