

Finding the undiagnosed: A collaborative project

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Background

- ~9 million living with HCV in Europe yet:
 - Only 10-40% of cases diagnosed
 - Over 100,000 undiagnosed in the UK
- Current treatment innovations will have limited population impact if case finding not improved
- Late presentation impacts on transmission potentials, disease progression, treatment success and trust

The study

- HCV treatment journey study (2012-2016)
 - Late presentation evident in data collection (40% sample)
- Collaboration with Hepatitis C Trust (2014)
 - 3 focus groups, 1 interview: 17 participants
 - Explore context of testing delay, diagnosis & awareness
 - To inform effective testing and awareness interventions
 - Development of survey instrument

Participants

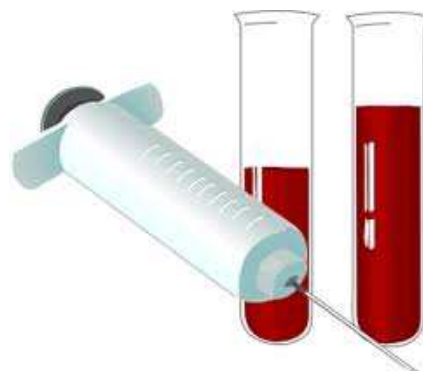
- N= 25 (Interviews: 9, FG: 16)
- 16 Male, 9 Female, 30 – 67 years old (av 53 yrs)
- Diagnosis: 2009 - 2014, Transmission: 1970 - 1994
- Transmission to diagnosis gap: 18-42 yrs (av 28yrs)
- Mode of transmission:
 - Drug injecting (10), blood transfusion (7), don't know (5), SEA origin (2), unsterile blood donation (1)
- Ever on OST or in touch with D&A services: 1
- Cirrhosis when diagnosed: 9

Findings

- Testing delay



- Testing context



- Awareness campaigns



Testing delay

- Limited awareness
- Felt wellness
- Perception tested
- GP inaction
- Test expense
- Stigma / compartmentalisation of prior life



Limited awareness / relevance

- Majority not heard of HCV / not relevant
- A 'generic' illness
- Presumption of prior testing / vaccination

I thought hepatitis was a generic illness and I remember saying to him [GP] "But I can't have that I've been vaccinated against it," from having travelled, I assume I'd had a hep vaccine. (Helen)

Felt wellness

- Felt wellness = limited awareness impact

*I'd heard of Anita Roddick ... there was no connection and **I was so well ... I was totally disinterested**, I just didn't think I was ill. (Helen)*

*I've spent the last 30 years of my life full of people with hep C and addiction problems. **But I was fit and well ... The idea that if you have no symptoms you can't be ill is quite a powerful notion.** (Sam)*

- Health + lack of visibility as an ex-user = hidden

GP inaction / expense

- Elevated LFTs attributed to alcohol
- Symptoms attributed to 'women's problems'

*I was only diagnosed last June, but I had **been backwards and forwards to the GP for many years just unwell ...** they did loads of tests, even gave me a hysterectomy, had the lot out ... so **I don't know if that was necessary** or not. (Jane)*

- GP reluctance to test as 'expensive'

***If I hadn't insisted** I wouldn't have got the second test ... I know it's a bit like PCR and that is **a lot more expensive. It's about 300 quid isn't it?** (Anton)*

Stigma & the compartmentalised self

- Screening questions rare
- Few would disclose prior injecting if asked or request test

I was ashamed of it, I didn't want people to know. Plus being a nurse I couldn't admit to being that other person that I had been. (Moir)

- Desire / need for GPs to take initiative

I don't know whether I'd want to know. The shame of it...what I'd put my family through ... I didn't want to go back to it being so long ago.

So is there anything that would have spoken to you?

I don't think so, I think it's just if they'd screened me and then I have to face it which is what I've done. (Jane)

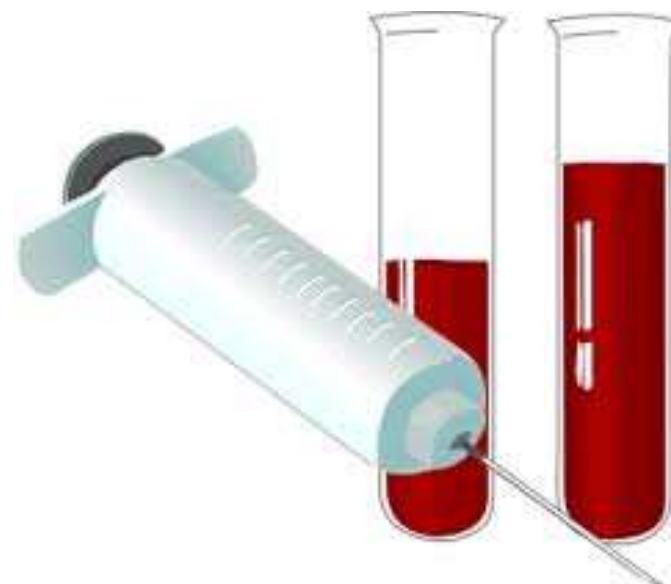
Testing context

Change of doctor

Illness onset / intervention

Other's experience

Chance



The new doctor

- Change of GP context of test for many
- New GP invariably younger, previous GP 'old'

She was clued up, she was young ... I think I was so lucky to have her rather than one of the older GPs who perhaps wasn't so aware. (Nikki)

If my doctor had retired sooner and I got my new doctor sooner I'm quite sure I would have been diagnosed sooner (Rosie)

HCV awareness



SAFE?

AT RISK?

VIRAL HEPATITIS CAN BE AVOIDED. KNOW THE RISKS.

HEPATITIS: THINK AGAIN
#thinkhepatitis

 **World Hepatitis Alliance**
This is hepatitis...

WORLD HEPATITIS DAY: JULY 28

She shows all the signs of hepatitis C

Hepatitis C can cause fatal liver disease with no obvious symptoms.

**Get tested.
Get treated.**



hepctrust.org.uk
0845 223 4424

The Hepatitis C Trust is a registered charity UK 1104279 Scotland SC038914



**DON'T LEAVE IT
TOO LATE....**



World Hepatitis Day

Approximately 1 million people worldwide die every year from chronic viral hepatitis B or C. Yet the majority of those infected are unaware. If left untreated, these cancer-causing viruses can kill.

Don't leave it too late to find out if you are at risk. Visit www.aminumber12.org

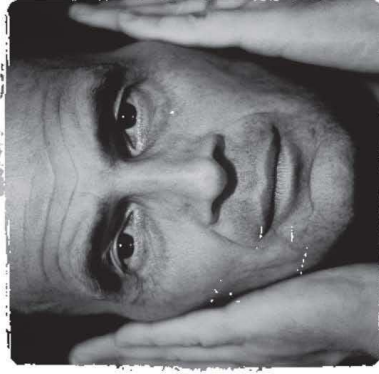


World Hepatitis Day: 28 July
hepctrust.org.uk/vhd2013

The Hepatitis C Trust is a registered charity UK: 1146273 Scotland: SC038914

HepHIV **2014**
5-7 OCTOBER BARCELONA

**Know it.
Confront it.**



**Hepatitis C is curable.
Get tested.**



0845 223 4424

Generously supported by
Clear Channel

Have you ever...

- a** Pranged your mate's car?
- b** Pulled a sickie after a night out on the lash?
- c** Injected drugs at a party?

Hepatitis **C** Get tested. Get treated.

Have you ever...

- a** Haggled a bargain in a Moroccan market?
- b** Ordered a grasshopper starter in Thailand?
- c** Got a piercing or a tattoo after a sleepless night in Goa?

Hepatitis **C** Get tested. Get treated.

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IF HEP C WAS ATTACKING
YOUR FACE INSTEAD OF
YOUR LIVER, YOU'D DO
SOMETHING ABOUT IT.

READY TO FIGHT BACK?

HepCFight.com

Campaign impact

- Limited relevance
- Confusing
- Generic
- Desire for risk & symptom information

*They're basically saying anyone might have this. **There's nothing that says it's especially to do with me.** (Anton)*

***it's very generic** ... people will think 'So do you catch it by sneezing on someone, like is it airborne (Sarah)*

***There's no link to symptoms** no link to my symptoms that would have made me [get a test]. (Rosie)*



Can you say **yes?**

I've injected drugs

I got a tattoo or body piercing using unsterile equipment

I had medical attention overseas

I had a blood transfusion prior to 1992

I've been in prison

Hepatitis C often has no symptoms but can cause liver cancer and liver failure. Get tested. It can be treated.

**Talk to your doctor or get a free test from The Hepatitis Foundation of New Zealand.
Call 0800 33 20 10 or visit www.hepatitisfoundation.org.nz. Hepatitis C. Know it. Test it. Treat it.**

World Hepatitis Day - 28 July 2014. Individuals pictured are models and are used for illustrative purposes only.



She shows all the signs of hepatitis C



Hepatitis C can remain silent until it is too late.

It is transmitted through blood.

This could have happened through:

Blood transfusions (prior to 1992)

Injecting drugs, even once, even a long time ago

Unsterile tattoos or piercings

Medical or dental procedures abroad

Other blood to blood contact

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WorldHepatitis
Alliance
This is **hepatitis...**
JULY 28



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Awareness → Action?

- Felt wellness = limited motivation to act
- Assumption of prior screening
- Compartmentalisation of prior life / stigma
- Desire for GPs to instigate testing

Well if the doctors were better informed would you need a poster outside? Isn't it up to the doctors to ask these questions? (Rosie)

For me personally that speaks to me more than the other ones. ... Would it have made me trot off to the doctors and ask for a test? No, 'cos I don't and I didn't feel ill. (Helen)

In summary

- Many undiagnosed will not identify as drug users or be in touch with D&A programs: the real 'hidden population'?
- Need for a multi-pronged approach
 - De-stigmatisation
 - Screening
 - Informative awareness materials (incl symptoms)
 - GP awareness
- Intractability of some testing barriers
 - Felt wellness & compartmentalised self
- G.P role key
 - Utility of screening questions?

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