



Barriers to screening and assessment of HCV from a patient perspective: A review of the qualitative literature

Never Stand Still

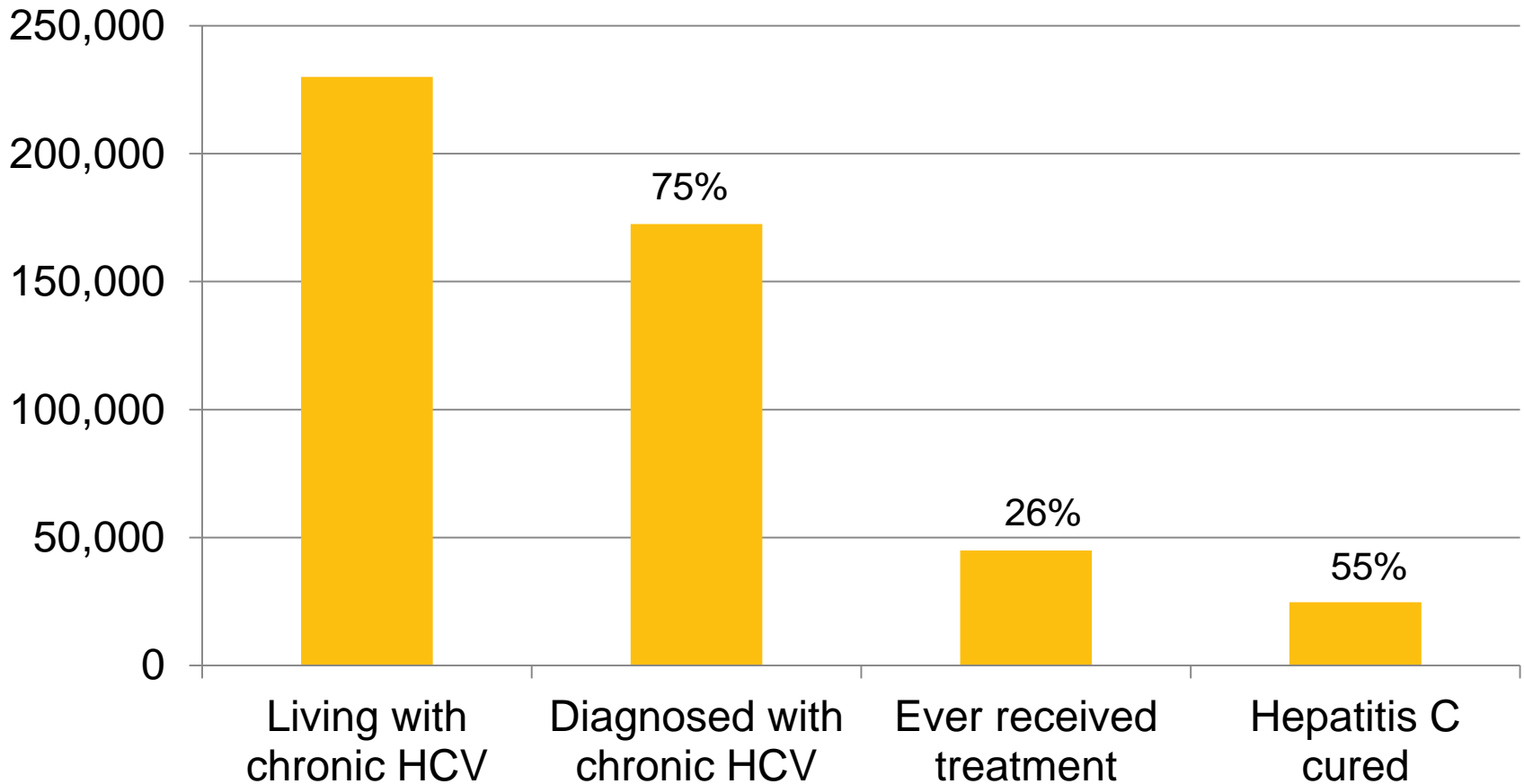
Arts & Social Sciences

Centre for Social Research in Health

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Centre for Social Research in Health

2014 HCV cascade - Australia



Barriers

Patient level

- limited awareness about HCV and its treatment
- asymptomatic nature of HCV
- treatment fears including of side effects and of non-response
- difficulties adhering to physician recommendations
- economic or social pressures
- psychiatric disease
- injection drug use

Provider level

- lack of knowledge and awareness by practitioners
- limited specialist availability, lack of referral & communication issues

Systems level

- lack of treatment promotion
- insufficient funding
- limited accessibility of testing
- results and treatment
- long waiting lists for treatment
- lack of insurance coverage
- high out-of-pocket expenses
- excessive paperwork
- poorly developed surveillance systems
- inadequate educational initiatives
- fragmented viral hepatitis services

Possible response



Patient

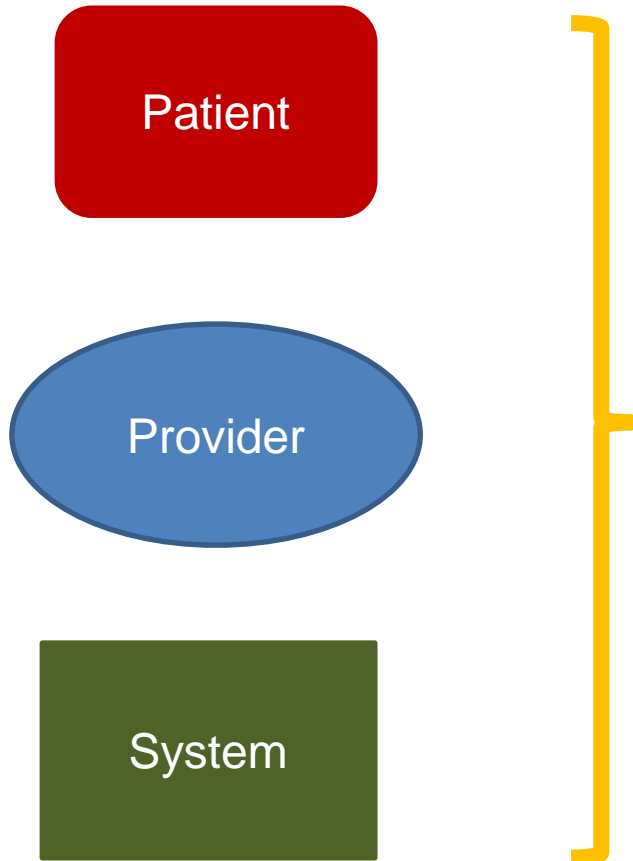


Provider



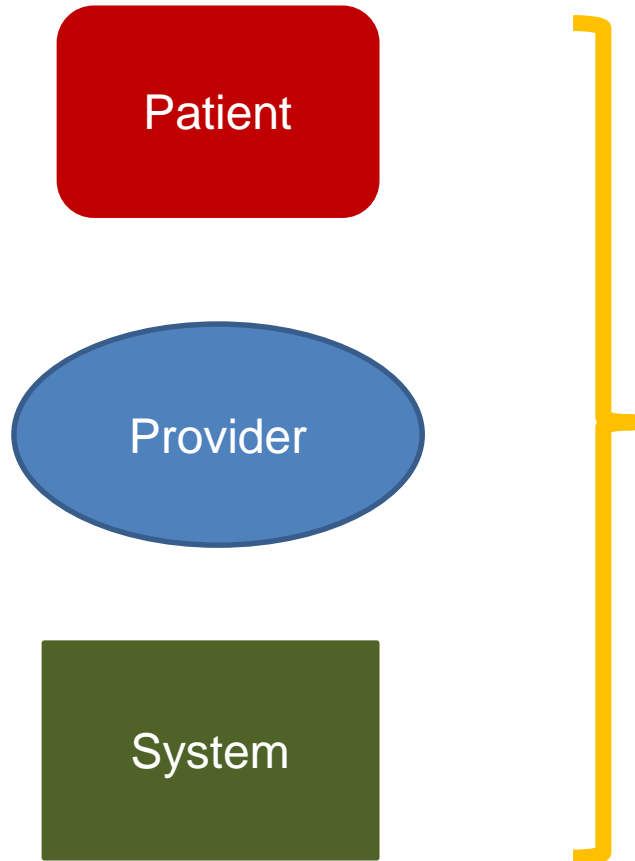
System

Possible response



Something that wraps up barriers into a more coherent whole:

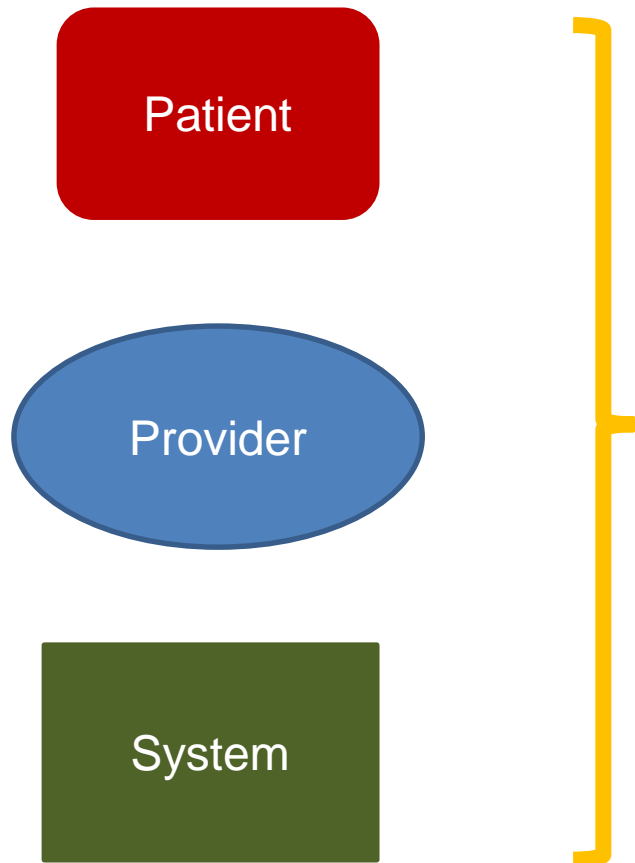
Possible response



Something that wraps up barriers into a more coherent whole:

that considers the factors that creates the system, shapes the expectations and behaviours of individuals;

Possible response

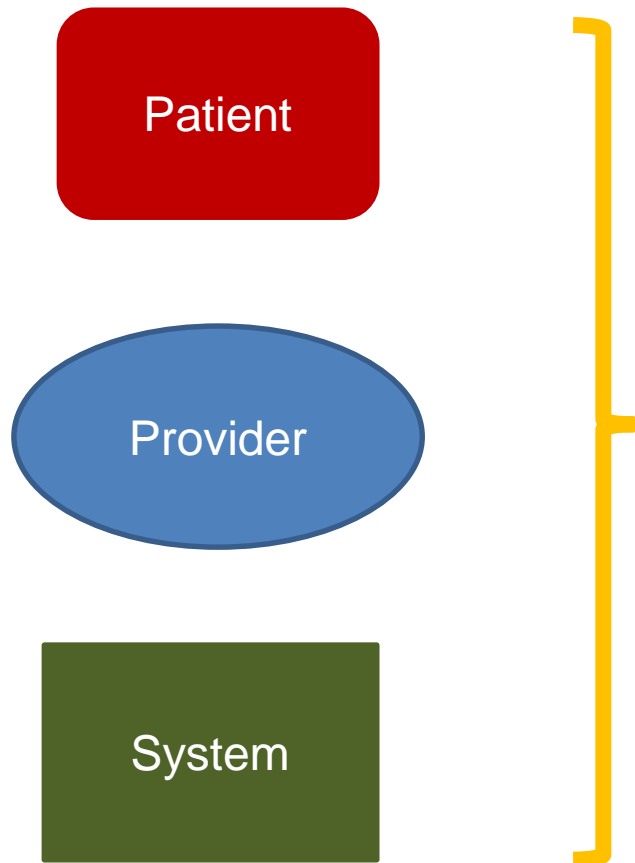


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that doesn't blame individuals for limitations of the system that work within or seek care from?

Possible response



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Healthy citizen

Healthy Citizen?



Healthy Citizen?



Healthy Citizen?



“HEALTHY CITIZENS
are the greatest asset any country can have.”

- Winston Churchill



Health Citizenship

- Overlap of health, politics and society
- “Neoliberalism” – greater focus on choices and responsibility of individual
- Everyone called upon to play their part in advancing the public’s health
 - Lifestyle, healthy eating, exercise, preventive testing/screening etc.

Health Citizenship

- Live life like an “enterprise”
 - Align our own desires/aspirations to those of “authority”
 - Act responsibly - vigilant, prudent
 - Imperative to pursue one’s best interests
 - But within bounds of collective good

Petersen, Davis, Fraser, & Lindsay, 2010

Health Citizenship

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 - “Failed citizens”

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- Moral judgements esp those whose illness is linked to behaviour and “lifestyle” Davis, Rhodes, & Martin, 2004
 - “Failed citizens”
- Injecting drug use directly at odds with healthy citizens
 - Illegal, “irresponsible” (not prudent)
 - Fails to align with health “imperative” & common good
 - Seen to take up resources of those “more worthy”, “better used”

How does the idea of healthy citizen help?

A critical view acknowledges:

- Underlying assumptions of how we should “do” health
- Breeds judgements (“less worthy”)
- Focus on individual (“failed citizens”), not systems

HCV care cascades

HCV prevention



HCV Ab diagnosed



HCV RNA diagnosed



HCV assessed



Liver disease assessed



On-going monitoring



HCV treatment



HCV cure



What does a healthy citizen look like; how is that reflected in care experience?



Prevention

NSPs - recognising clients' contribution to health protection

- **Interviewer:** And you're coming here cause you're looking after your health...

Yeah! That's right, you know? So I shouldn't be judged... not praised, I'm not saying praised but I shouldn't be looked down on. I'm trying to keep myself safe and the community safe, you know? And I think there... a lot should be said for that. (Kat, female, 35)



HCV diagnosis

Lack of information/referral

Oh the doctor didn't say anything just that, except that I have hep C. And they didn't explain to me anything about it or anything really. I didn't get given anything. I asked, "Do I need to change my diet or anything?" and I was told, "No, nothing I could do." (Andrew, 38)

Treloar, Newland, Harris, Deacon, & Maher, 2010



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- Comparison to extensive HIV knowledge
- Few encouraged to ongoing care - disengagement from care

Jordan et al., 2013



Referral for assessment/treatment

Anticipating disinterest (not engaged, enterprising citizens)

In theory it sounds great but in practice the client group that we work with aren't necessarily that highly motivated or interested in the treatment. And I even find that when I'm talking to clients ... So I really would need some help around how to try to change peoples' level of motivation and interest in the program. That's the main thing because the pathway and them accessing ... there's no restriction anymore for them to access the services. (Clinical manager)

Treloar, Newland, Rance, & Hopwood, 2010



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I'm sure he would've said something to me a lot ... if I need treatment or, my liver, or whatever, my hep C was not going too good. I'm sure he would've said something ... but, no, he didn't (Male, 38)

Treloar, Newland, Rance, & Hopwood, 2010



HCV care/monitoring

10 years at Hospital A

- No treatment, limited treatment literacy, felt little investment by clinician

[The HCV doctor] was literally saying 'Look, you're never ever going to be treated here'. ... I wasn't a productive member of society. That's what I felt. I wasn't someone who was going to make a difference to society, you know. He had more important patients than me, that's what I felt, you know.



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Interpretation: failed to make it as a patient/citizen, did not count enough, deservedness of treatment is doubted



HCV care/monitoring

“Perform” treatment worthiness, navigate eligibility

Rhodes et al., 2013



HCV care/monitoring

“Perform” treatment worthiness, navigate eligibility

Rhodes et al., 2013

Now when he looked at me ... he thought that I was just going to be one of them people that didn't care even though the medication was very expensive. But I showed him that I did care for my health. ... he goes “are you sure you want to do this? Because we don't want to waste all this medication and stuff if it isn't going to work out for you”. I proved to him that I could literally do it. I've been doing this for two consecutive years. ... I'm still clean, haven't smoked, haven't done nothing.

Clark & Gifford, 2014



During treatment

Omitting selected information: “secret nurses’ business”

There are certainly people who have got through this treatment and have used heroin through it, and that’s okay. But what I would say to them is “Down-play that stuff when you talk to the doctor. Talk about it openly when you talk to us”. And that’s because, I don’t think that that needs to be written in their hospital notes, unless it’s impacting on their treatment. (HP 6)

Hopwood & Treloar, 2007

28



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“sanitising people in order that they become acceptable patients for specialist physicians sustains a culture of ignorance among specialists and the clinical research literature”

Hopwood & Treloar, 2007



As a result of treatment

Non-virological benefits – facilitating inclusion, identity transformation

I like to think of it as the hep C treatment turned me around a little bit. The whole issue of the hep C, addressing it, that's how I like to think of it. Saving my ass, in plain English, saving my life, you know...So, coming into the hepatitis treatment really was a big turnaround.

Batchelder, Peyser, Nahvi, Arnsten, & Litwin, 2015



As a result of treatment

Non-virological benefits – facilitating inclusion, identity transformation

I hadn't realised . . . how transforming it can be for some people . . . You can often have a great help to their lives by just, you know, having someone keep an eye on them, get their teeth done, offer them services . . . give them some hope . . . I've been surprised by the expectation and the need, and how . . . effective we've been . . . (Bea, staff).



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*It was nice to know that somebody actually looked out for Tracy, not just 'Methadone Tracy' . . . They took the time out to realize that there was something more than me just coming to get methadone. I had other issues.
(Tracy, client)*

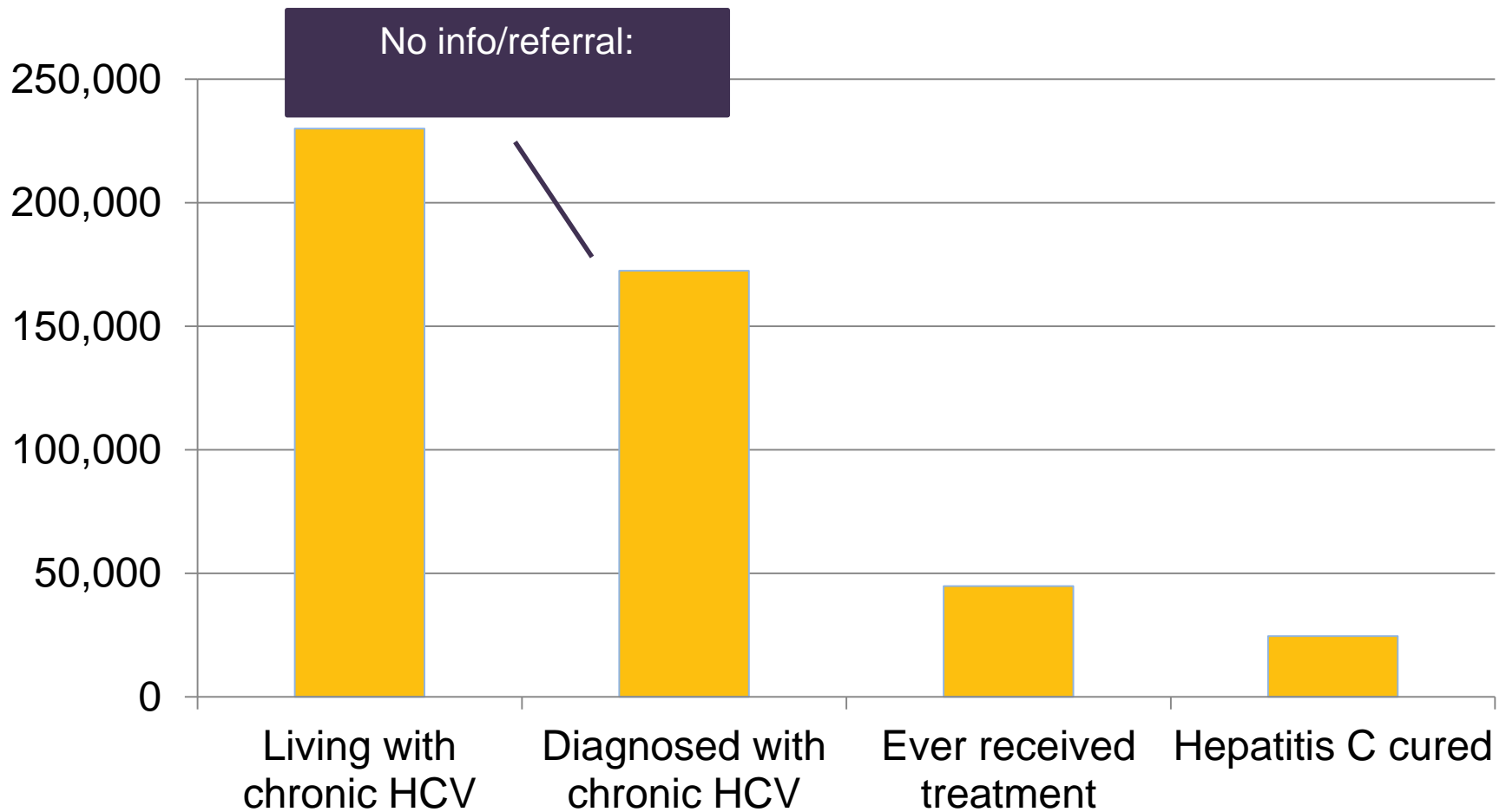
Rance & Treloar, 2013 32

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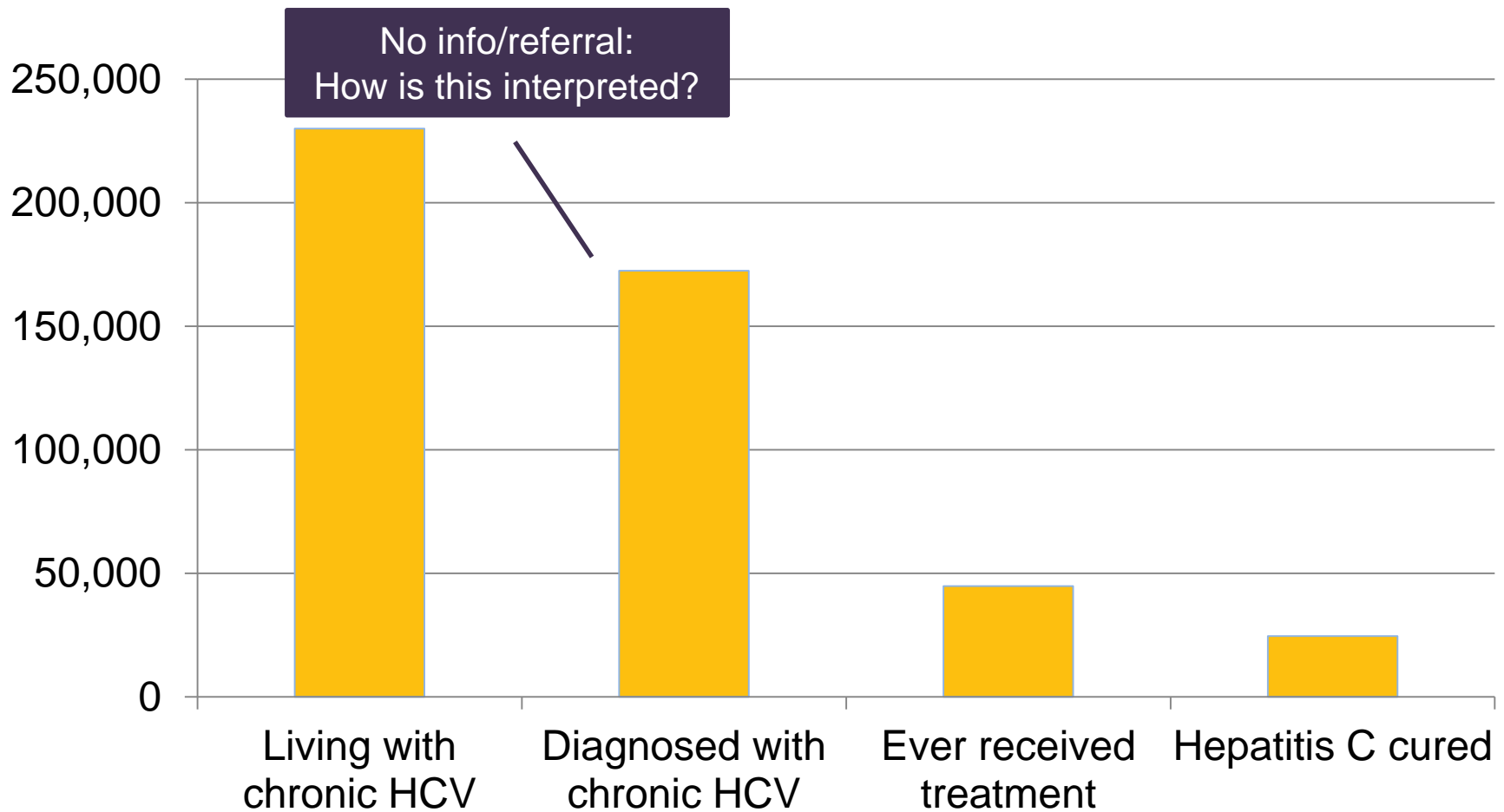
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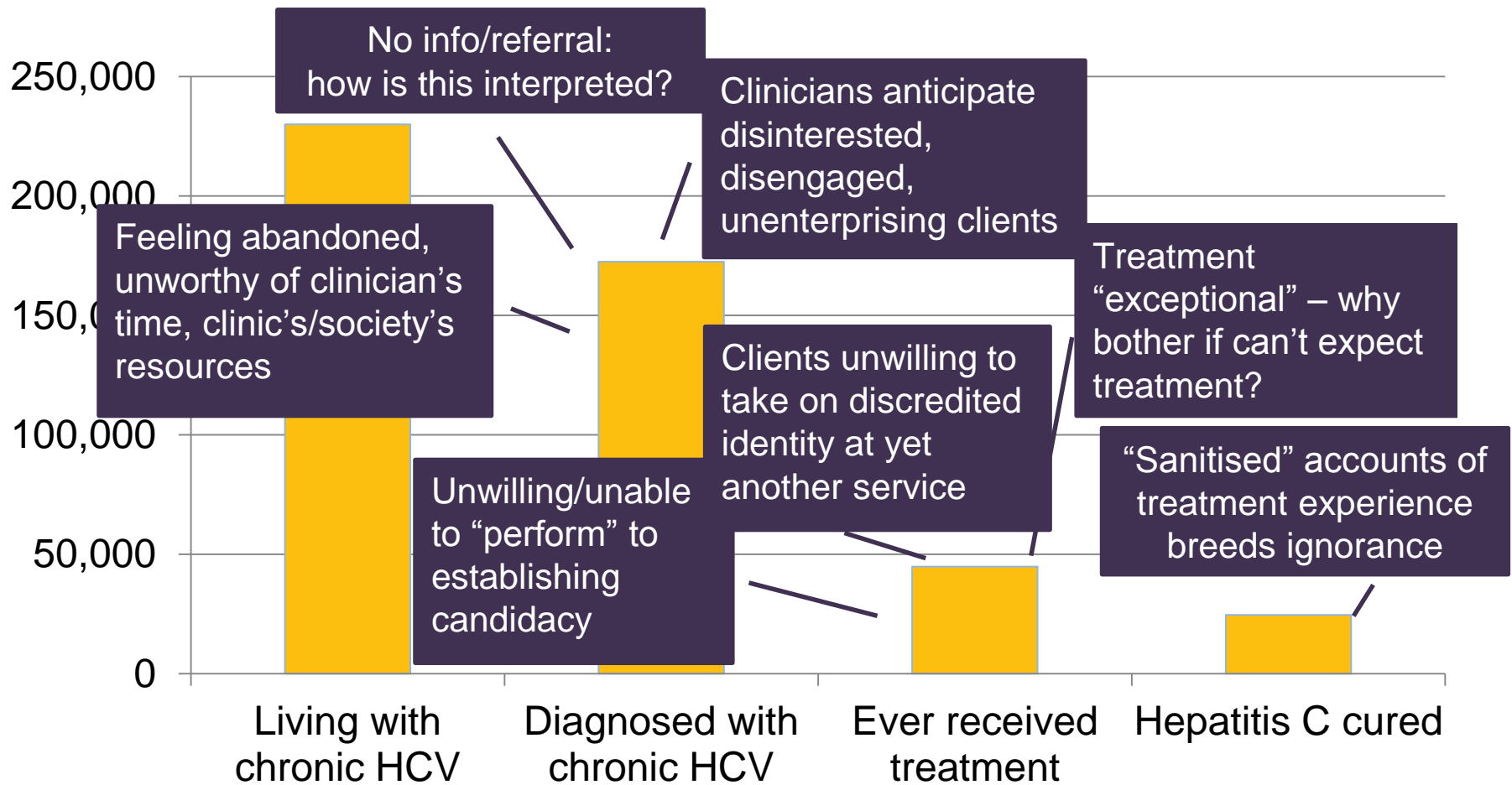
HCV cascade – citizenship analysis



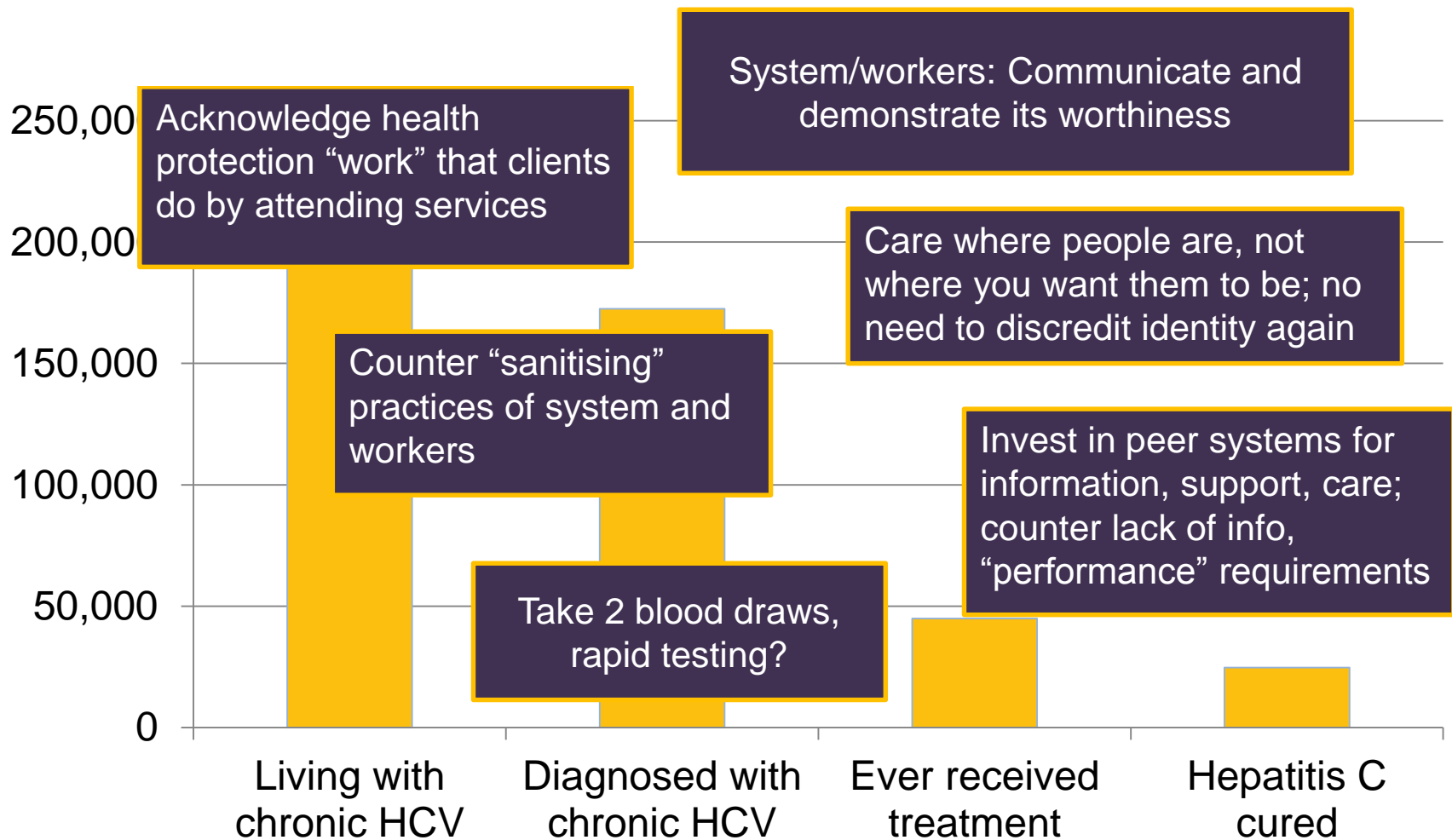
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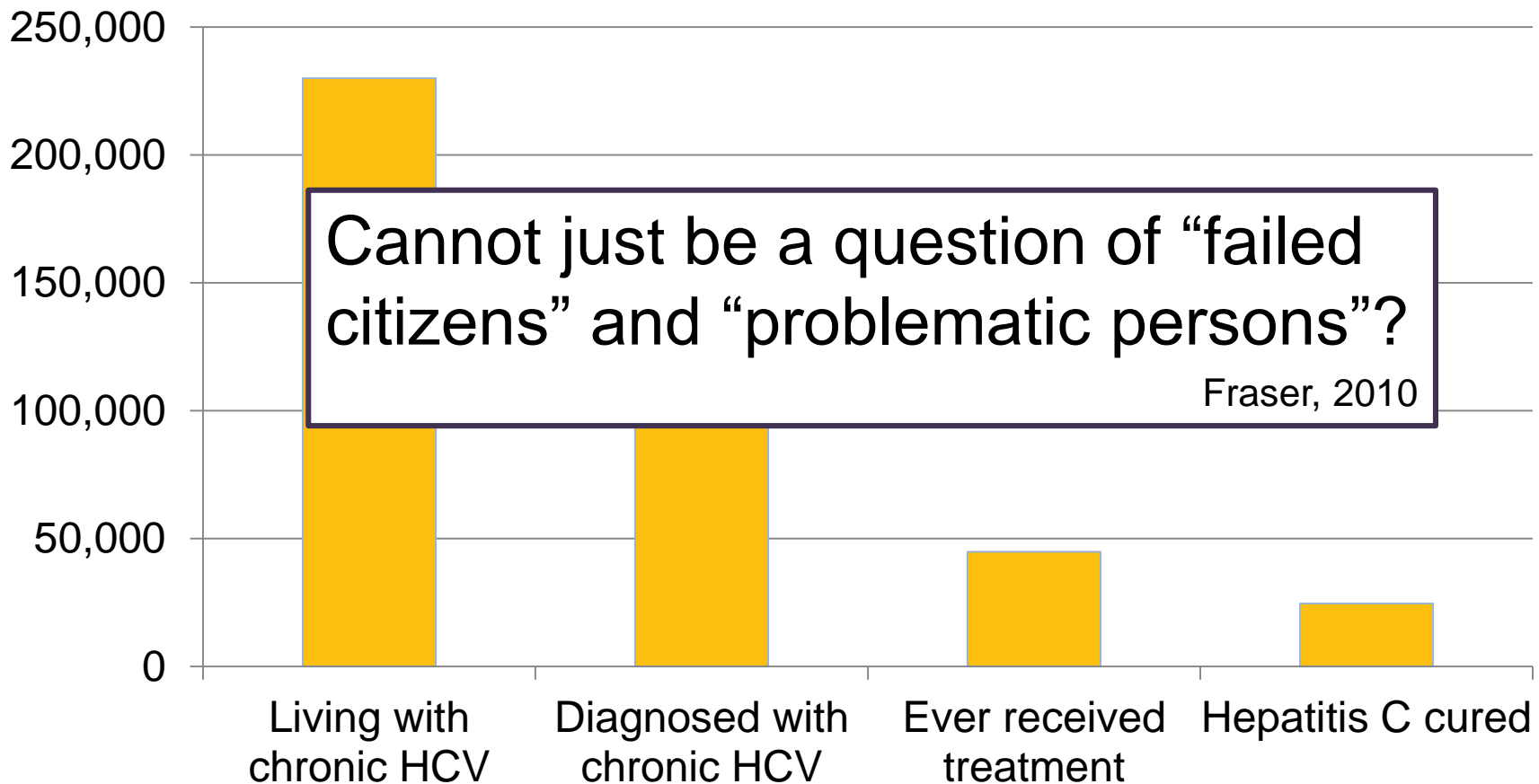
HCV cascade – citizenship analysis



HCV cascade – citizenship responses



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