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Using notification data to increase access to the hepatitis C cure: key stakeholder perspectives

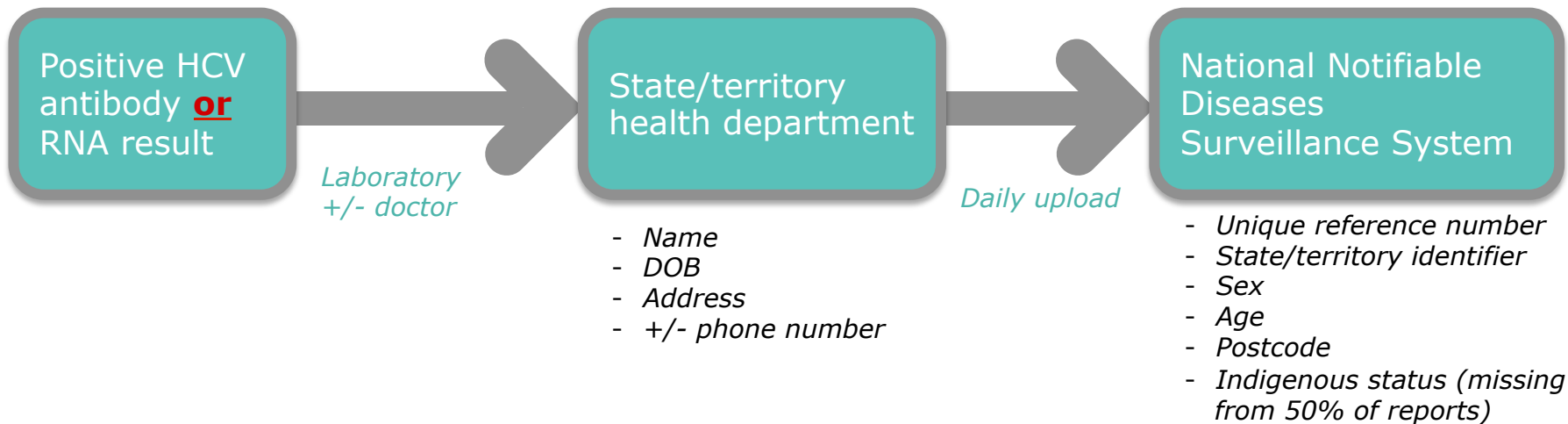
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Disclosure of Interest

- The Burnet Institute acknowledges funding received from the Paul Ramsay Foundation.

Background: Hepatitis C notification in Australia

- Hepatitis C has been a notifiable condition in most states and territories since 1991 (1993 in WA; 1995 in SA and TAS)



Background: Hepatitis C notification in Australia

- Two case definitions: **newly acquired** (acquired within 2 years of diagnosis) or **unspecified** (any positive HCV antibody *or* RNA result)
- ~350k notifications* of unspecified hepatitis C between 1991 – 2019 in Australia
- ~9k notifications each year

*not unique individuals

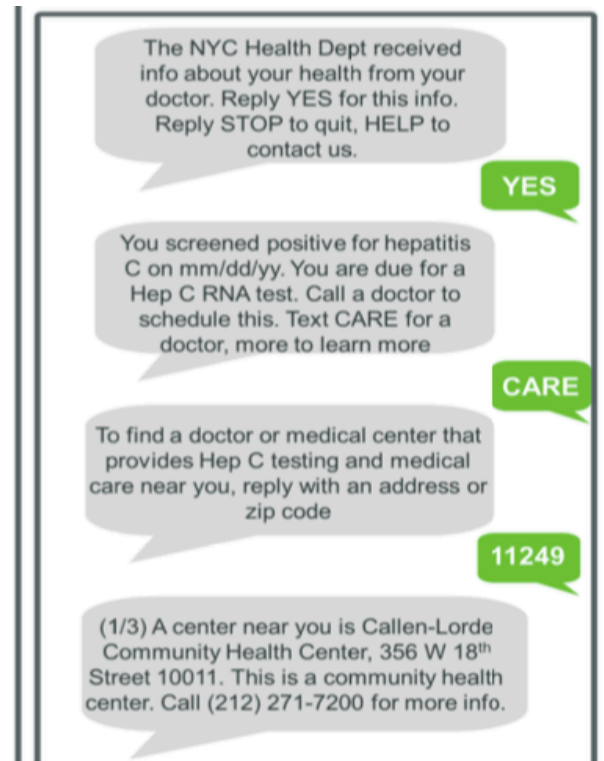
Australia's notifiable diseases status: Annual reports of the National Notifiable Diseases Surveillance System, 2000 – 2015 + NNDSS Disease Summary Tables

Current use of notification data for linkage to care

1. Pilot projects in Western Australia (Great Southern Public Health Unit) and South Australia (SA Health)
2. Public Health England patient re-engagement exercise
3. New York City Dept. of Health & Mental Hygiene (routine use of letters, pilot study of SMS)

Limited evidence on implementation and feasibility.

No studies of the acceptability of these approaches from the perspective of people living with or at risk of hepatitis C (including people who inject drugs).



Methods

2 x focus groups with people people with lived experience (n=27)



Key informant interviews (n=20)



- Injecting drug use and/or hepatitis C
- Harm Reduction Victoria (n=15)
- Hepatitis South Australia (n=12)
- All participants reimbursed \$40

- Govt health depts (n=12)
- Clinical practice/academia (n=3)
- Consumer orgs (n=5)
- NSW, Qld, SA, Tas, Vic, WA

- Separate deductive thematic analyses of focus group and key informant interviews guided by the Theoretical Framework of Acceptability (Sekhon et al.)
- Inductive content analysis to combine the above two data sets

Theme 1: *'The more benefit we get from the data the better!'*

"The more health benefit we can get from the data the better – it should be a dynamic, interactive thing rather than just data coming in and nothing being done with it."

Key informant

"It's not only a matter of like saving your life ... what's it's saving you from is potentially years of really horrible health."

Focus group participant

Theme 2: 'What the f..k! People know I've got hep C!'

Theme 3: 'Stigma and discrimination and all that!'

"Yeah, if GPs had access to the database, I'd feel a lot more comfortable ... the GP could see that you have hep C and then they could talk to you about it, instead of having some random person from the government calling you."

"There [was] no way I'd tell [my GP] I had hep C, because ... they'd discriminate against me ... But if it came from the government, I'd think, 'Okay, so the government isn't telling GPs about me, it's just them', so I can still go to my GP and keep my privacy"

Focus group participants

Who makes contact?

- A local health department?
- A general practitioner?
- Clinician that ordered original test?
- A peer worker?

Theme 2: "What the f..k! People know I've got hep C!"

Theme 3: "Stigma and discrimination and all that!"

How is the contact made?



- Voice calls were preferred to letters or SMS to reduce likelihood of sensitive information reaching an unintended recipient
- Health department key informants highlighted that most existing notification data does not include phone numbers (especially for data older than five years)

Theme 4: Data linkage – advantages and drawbacks

ADVANTAGES

- Obtain current contact details incl. phone
- Prevent inappropriate follow-up (e.g. by excluding people that have already been treated)

“There’s a strong ethical argument to use data linkage in order to reduce the number of people that are unnecessarily contacted.”

Key informant

DISADVANTAGES

- Intrusive and may be unacceptable
- Resource-intensive

“People who’ve had bad experiences with government agencies or been in trouble with the law, or on the other hand have led a squeaky-clean life for the last 20 years but have a hidden secret from when they were younger, I think both those populations would freak out about data matching. I understand that’s the most practical way to get contact details [but] that’s why we have reservations.”

Key informant

Acknowledgements

- Focus group participants
- Key informants
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- Hepatitis South Australia
- Paul Ramsay Foundation



Research paper

“It’s time!”: A qualitative exploration of the acceptability of hepatitis C notification systems to help eliminate hepatitis C



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