

my health, our family: documenting stories of family life in the context of HIV, hepatitis B or hepatitis C

*Summary report from the project:
Critical perspectives on serodiscordance in family life*

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Further information:

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<https://www.arts.unsw.edu.au/csrh/our-projects/my-health-our-family>

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How can we strengthen the role of families in the response to blood borne viruses?

- Recognise the role of the family in clinical care, health promotion, research design, and policy formulation
- Feature the stories of families with mixed viral status in social marketing and clinical education campaigns
- Avoid a one-size-fits-all approach to supporting affected families, given their diversity in experiences
- Work in a family-inclusive way with sensitivity to the diverse systems of meaning across families
- Look beyond education about transmission risk to emphasise the ways that families support each other
- Recognise that the families of people living with blood borne viruses can have support needs also

The clinical management of blood borne viruses has changed rapidly in recent years. Yet social stigma remains a persistent issue. Families which include people with mixed viral status (also known as 'serodiscordance') play a critical role in supporting those who have been diagnosed with HIV, hepatitis B and/or hepatitis C. However, little is known about the role and experiences of families in the prevention, management and treatment of these viruses.

We conducted the first qualitative interview study to describe the experiences of families in Australia affected by HIV, hepatitis B or hepatitis C. 61 people shared with us their stories of living with a blood borne virus or supporting a diagnosed family member. We also interviewed 20 key informants working in the health and social policy, care and advocacy sectors.

We published a number of papers which describe what we learned from these interviews, and more are on the way. But some key findings include:

- Stories of disclosure to family included experiences of shock, blame and rejection, as well as families rallying to provide emotional, practical or financial support.
- Some families felt compelled to reach out and educate friends and acquaintances to try and destigmatise these blood borne viruses, while others kept the diagnosis strictly secret.
- Family support was both desired and often expected when facing a crisis, so when support was not forthcoming, it was seen as hurtful and unforgivable.
- Some families spoke openly about the diagnosis and took an interest in finding out more about living with blood borne viruses, while others emphasised the importance of carrying on as 'normal' and not giving the diagnosis undue attention.
- Despite the unlikely probability of transmission in casual, everyday interactions, fears about 'contagion' surfaced in some of our interviews. This occurred across cultural backgrounds and across all three viruses.

- In contrast, in many interviews, transmission risk was dismissed as a consideration and narratives of love, solidarity and science were instead prioritised and mobilised to counter traditional notions of risk.
- Key informants shared many heartening stories of families they had encountered through their work who provided genuine support, care and love to a diagnosed family member.
- They also emphasised that family relationships can be complicated by the lack of mainstream knowledge about blood borne viruses, by different cultural or religious beliefs, and by a critical lack of services and support for family members themselves.
- Many key informants struggled with the disconnect between viewing families as essential 'health brokers', and recognising they did not have the time, resource, funding or policy frameworks to meaningfully engage them.
- Key informants argued for the need for more widely accessible and culturally resonant education about the contemporary biomedical realities of blood borne viruses, such as Direct-Acting Antivirals (DAAs) for HCV and an undetectable viral load for HIV.

For more information, visit:

<https://www.arts.unsw.edu.au/csrh/our-projects/my-health-our-family>

Why did we conduct this research?

The clinical management of blood borne viruses has changed rapidly in recent years. Today's effective treatments mean that many people living with HIV can live long and healthy lives. Treatments also prevent sexual transmission of HIV when a person's viral load is undetectable, or when taken as a pre-exposure prophylaxis (PrEP) by people who don't have HIV. Hepatitis B can be prevented through use of a vaccine and managed through lifelong monitoring and treatment where indicated. Hepatitis C can be cured through predominantly tolerable treatments, such that it has been reframed as a curable disease with potential for elimination as a public health threat. There is significant commitment to the development of curable treatments for both HIV and hepatitis B. Yet social stigma remains a persistent issue (see Table 1).

Families that include people living with a blood borne virus as well as those who are not (also known as serodiscordance, that is, mixed viral status) play a critical role in supporting those who have been diagnosed and responding to the health and social implications of these viruses. And yet both research and policy responses to blood borne viruses have remained largely focused on the individual, with far less known about the role and experiences of families in the prevention, management and treatment of these viruses. Throughout this period of biomedical transformation, an understanding of the forms and meanings of 'family' have also changed, as have the ways families provide care and support to loved ones facing health challenges. And yet few studies have brought together the sociology of family life with social research on the changing landscape of blood borne virus prevention and care.

There are essential questions to be asked about how families respond to these often-stigmatised blood borne viruses, and how these viruses affect family life and relationships. How, for example, does the stigma associated with blood borne viruses figure in family relationships today, and how does it continue to shape experiences of communication, care, and belonging? How do people who are not themselves living with blood borne viruses support family members who are? And how can we learn from and build on the contributions of families to enhance the prevention, management and treatment of HIV, hepatitis B and hepatitis C?

Table 1. Summary of transmission, treatment and social impacts of blood borne viruses in Australia

HIV	Hepatitis B	Hepatitis C
Mostly sexually transmitted, majority through sex between men, but increasingly heterosexual people, and people born overseas	Mostly transmitted from mother to child, acquired overseas and affecting specific migrant communities	Mostly transmitted through the sharing of drug injecting equipment, can be sexually transmitted if blood is present
No cure or vaccine, but can be managed with early and lifelong (daily) treatment, bringing risk of sexual transmission to negligible	Can be prevented with a vaccine, but no cure. Treatment starts after evidence of damaging the liver	Can be cured through treatment, especially 'DAAs' which have high success rates and few side effects. No vaccine
Persistent social stigma linked to fears/beliefs about contagion, and associations with homosexuality, sex outside marriage, drug use and sex work	Persistent social stigma linked to fears/beliefs about contagion, experiences of marginalisation in some countries of origin, racism experienced in Australia	Persistent social stigma linked to fears/beliefs about contagion, and associations with criminalised practices including injecting drug use and sex work

What did we do?

Researchers at the Centre for Social Research in Health (UNSW Sydney), in collaboration with the Social Policy Research Centre (UNSW Sydney) and The Burnet Institute, received funding from the Australian Research Council to conduct a three-year qualitative Discovery Project (DP160100134) to document – for the first time – firsthand accounts of what serodiscordance means in the context of everyday family life.

This funding supported us to bring together researchers with expertise in the social aspects of blood borne viruses (Christy Newman, Asha Persson, Joanne Bryant, Jack Wallace) and expertise in the social impacts of chronic illness on families and carers (kylie valentine, Myra Hamilton). We were also guided by an Advisory Committee (see Acknowledgements) representing a range of professional perspectives on the prevention and treatment of blood borne viruses, and on supporting the wellbeing of families, carers and intimate relationships.

In this study, we set out to:

- Describe the experiences of families in Australia affected by HIV, hepatitis B and/or hepatitis C.
- Understand how differences in family forms and contexts intersect with understandings of and approaches to the prevention, management and treatment of these viruses in family life.
- Build a theory of serodiscordance which is informed by the lived experiences of affected families and extends beyond a biomedical focus on individual health and risk.

Our research activities included a critical examination of the literature on families and caregivers affected by HIV, hepatitis B or hepatitis C (Hamilton et al., 2018; Persson et al., 2017), along with in-depth interviews with:

- People with a primary lived experience of being diagnosed with one or more blood borne virus (HIV, hepatitis B or hepatitis C) ('primary participants').
- People with a family member who has been diagnosed with one or more blood borne virus (HIV, hepatitis B, and/or hepatitis C) ('family participants').
- Key informants working in the health and social policy, care and advocacy sectors, with particular expertise in blood borne viruses, families, and their intersections.

Our aim in capturing these different perspectives was to understand: what families mean in the context of stigmatised infectious diseases; what these viruses mean in the context of everyday family life and how they can shape relationships; and how to meaningfully recognise, engage and support families in the prevention, management and treatment of these viruses.

What did we observe in the literature on families with mixed viral status?

We published two literature reviews in the initial stage of the project. The first reviewed the literature on families affected by HIV, hepatitis B and hepatitis C, building a case for extending the concept of 'serodiscordance' beyond its current use in the literature on (HIV) mixed-status relationships involving sexual or injecting practices. The analysis found that the focus of the literature on serodiscordance is on transmission risk in couples or injecting networks, and the literature on families and blood borne viruses is limited to resource poor settings and the pre/early treatment era (in research on HIV), and non-sexual transmission, prevention, and stigma (in research on hepatitis B and hepatitis C). There is almost no sociological analysis of how serodiscordance figures and is managed within families.

As we argued in the paper: 'Lifting our gaze from the preoccupation with 'risk' in relation to these blood borne viruses is vital to understanding how today's era of effective treatment options might shape the 'family life' of viral infections' (p.2). In building our case for extending the concept of serodiscordance to also include families, we argued:

Mixed-status families can be entangled in myriad relational processes, such as social stigma, social isolation, treatment decisions, access to support, disclosure to friends, extended family, and community, cultural health beliefs, gender dynamics, and care responsibilities, all of which are grounded in and negotiated through the politics and practices of serodiscordance [...] However, we still lack a concept for understanding blood borne viruses in the wider family contexts in which they are often situated and experienced. There is no reason why the concept of serodiscordance could not be extended to mixed-status families (and beyond) given it simply means differing (discordant) blood (sero). Making serodiscordance more inclusive [...] is an important step in recognising and drawing much needed attention to the diverse ways families' everyday lives, relationships, and futures can be entangled with these viral infections.

Families living with blood borne viruses: the case for extending the concept of 'serodiscordance': <https://doi.org/10.1155/2017/4352783>

The second paper was a scoping review of the literature on the needs of family members providing care and support to people diagnosed with a blood borne virus. Although we searched for literature across all three blood borne viruses, there was very little on viral hepatitis so we limited the analysis to the literature on informal care in the context of HIV in high-resource settings in which effective treatment is available and accessible. This review found that despite significant advances in treatment, many people living with HIV still needed and benefited from a range of forms of informal care and support, including emotional support, practical help, assistance with arranging and attending health service appointments, and remaining adherent

to medications. The people who provided these forms of care were largely unrecognised, however, meaning that the support needs of those carers were largely overlooked in health and social policy, despite the continued importance of their contribution to the health of people living with HIV. Stigma and discrimination can complicate support seeking and service engagement among carers, as can the perception that there are no support needs for people living with HIV in an era of effective treatment.

Many people with HIV in economically developed countries still have care needs [which] go largely unrecognised [and yet] the experience and fear of stigma in health and social services, schools, and even personal relationships may prevent carers from seeking and receiving needed support. This review also suggests that the service environment plays an important role in the 'visibility' (or invisibility) of this group of carers, contributing to their hidden nature and creating inequalities in access to resources. The lack of recognition of HIV carers by services, practitioners and policymakers, and a subsequent lack of services and support available to these carers, indicates a considerable gap in meeting the needs of carers of people with HIV. [p544]

Hidden carers? A scoping review of the needs of carers of people with HIV in the contemporary treatment era: <https://doi.org/10.1332/239788218X15411705099442>

How did we conduct and analyse the interviews?

All of the materials used for recruiting and conducting the interviews were developed in collaboration with our advisory committee, as representatives of organisations who work with and on behalf of affected families.

We recruited people living with blood borne viruses (primary participants) and family members of people living with blood borne viruses (family participants), through our partner organisations who promoted the study through their email lists, newsletters and social media platforms, posted posters and flyers in clinic waiting rooms, and in some cases asked clients if they were interested in taking part.

Data collection focused on the Sydney metropolitan area and surrounding regions in the state of New South Wales (NSW), which has the largest population of people living with HIV in Australia, as well as a significant prevalence of hepatitis B and hepatitis C (Kirby Institute, 2020). However, as the study generated interest outside of NSW, we also included participants from other parts of Australia if they had heard about us through word of mouth.

Prospective participants contacted us directly to volunteer to take part, and we then confirmed their eligibility before scheduling an interview. In addition to fulfilling the criteria for age (10 years or older for primary participants, 16 years or older for family participants), we had made the decision to focus on recruiting participants whose family (however defined) had some degree of involvement in their health. We primarily conducted interviews in English, although translators were engaged to support the interview process in a few cases. Adults could self-consent, but children aged 10-15 years required parental consent. Interviews were conducted either in person or by phone/video-apps depending on preference. Participants were provided with a \$40 gift card in recognition of their time and any expenses incurred in taking part in the interview.

Importantly, family was defined by participants. We had stated on the study materials that we were using the term broadly to include partners, parents, children, siblings and extended family, as well as families of choice, affinity, or intimate connection, but participants were given the opportunity to tell us who counted as family in their lives. Primary participants – that is, those participants who had themselves been diagnosed with one or more of the blood borne viruses – were asked at the start of their interview to visually map those who represented family, indicating the relative sense of closeness and distance they felt to each of the people they named on the map (see Drysdale et al, 2020). After taking part in an interview, some participants then invited family members to contact the researchers about taking part in the study. Family members were also able to contact the research team directly, without being referred through a family member. Although we noted which participants were related if we were aware of those connections, our aim was not to analyse linked accounts, but rather to capture as broad a range of perspectives as possible.

We used a semi-structured question guide during interviews to explore how participants described the personal and relational impacts of diagnosis and disclosure, how they made sense of and responded to stigma and secrecy, and how they negotiated any unfolding responsibilities associated with care and treatment. After each primary/family interview, the interviewer recorded observational notes about the interview, including key 'characters', physical environment, verbal and non-verbal interactions, cultural and other aspects of the interview, as well as any notable themes, issues or insights for the research team to consider.

Key informants were invited to take part in the study through emails from the lead researcher, drawing on existing networks to identify professionals with relevant expertise in the fields of infectious disease and family wellbeing. While some of these professionals were located in different parts of Australia, the majority were based in NSW.

All interviews were audio recorded, then transcribed and deidentified in order to protect participant anonymity. Pseudonyms were given to primary/family participants, taking care to not link these to original names. Data was imported into NVivo, a qualitative data analysis tool, and coded to identify broad thematic categories in the data to support more in-depth analyses by the broader research team.

Coding categories for the primary/family interview data included family relationships, diagnosis, disclosure, understandings and awareness, treatment and monitoring, formal services, informal care and support, institutional systems, identity, and advice. Two additional codes were developed through analysing the key informant interview data: similarities and differences across the blood borne viruses, and career trajectories through the blood borne virus sector. We also produced summaries describing each interview in the form of a case study, with example quotes, to support the analytic process.

Who took part in our study?

61 people generously shared their stories of living with a blood borne virus or supporting a diagnosed family member, or both (Table 2). 20 professionals took part in key informant interviews (Table 5).

Table 2. Number of primary/family participants by perspective

	HIV	HIV & HCV	HCV	HCV & HBV	HBV	Totals
Primary perspective	12	4	10	1	4	31
Family perspective	10	0	4	0	1	15
Primary AND family perspectives	7	3	3	2	0	15
Totals	29	7	17	3	5	61

Around 50% of our participants had experiences related to HIV (n=36/61), 44% to HCV (n=27/61) and 13% to HBV (n=8/61). Although we had hoped to recruit more participants who could speak about the family life of viral hepatitis, particularly hepatitis B, we nonetheless were able to access a sufficiently broad range of perspectives overall to result in a rich analysis of diverse experiences and views.

As outlined in Table 3, year of diagnosis also varied widely among our primary participants (note: participants have been double counted in this table if diagnosed with more than one blood borne virus). Although our total numbers are relatively small, there is value in considering the mean and median years of diagnosis among these groups also, given this provides some additional context for understanding the experiences being described by our participants. Notably, many participants believed they had lived with their blood borne virus for many years before their diagnosis.

Table 3. Year of diagnosis of primary participants

Year of diagnosis	Range	Mean	Median
HIV	1984–2017	2002	2003
Hepatitis C	1979 to 2013*	1997	1995
Hepatitis B	1970 to 2008	1984	1992

* People diagnosed prior to 1989 were initially diagnosed with hepatitis (non-A/non-B) and later learned of their hepatitis C status. The hepatitis C virus wasn't 'discovered' until 1989.

Our participants reported diverse demographic profiles (see Table 4), particularly in terms of age, gender and sexual identity. The majority of participants (62%) were born in Australia (although there were no participants who identified as an Aboriginal or Torres Strait Islander person), and 38% were born overseas. Participants were mainly English speaking, but some spoke a language other than English at home. Although our location clearly reflected our focus on New South Wales, there was some diversity in the location of participants, spanning four states in total, and with 36% of the sample based in regional areas of Australia.

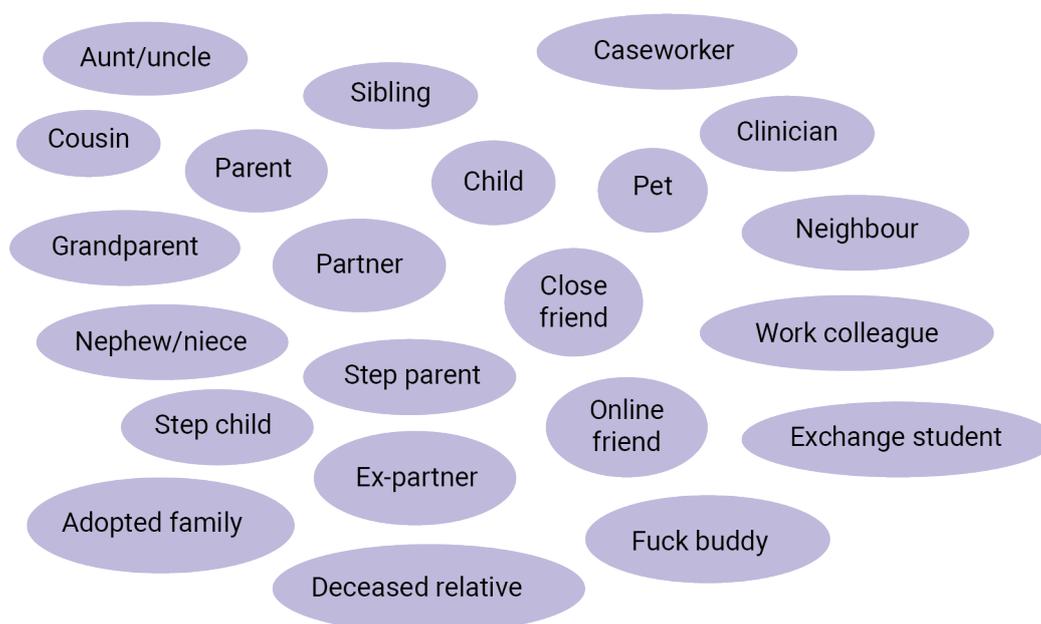
Family roles and relationships were also diverse. A selection of the ways in which families were defined and mapped in the primary interviews is captured in Figure 1. Among the family participants, their role in relationship to the person diagnosed with one or more blood borne viruses in their families was described as: mother (4), sister (4), male same-sex partner (4), male heterosexual partner (4), female heterosexual partner (4), daughter (4), father (1), step mother (1), step father (1), son (1), brother (1), and close friend (1).

Table 4. Demographic profile of primary/family participants

	Number	% of total (n=61)
Mode of interview		
Face to face	27	44%
Remote (phone/computer)	34	56%
Age (Range = 15–89)		
Teens	5	8%
20s	4	6%
30s	7	11%
40s	9	15%
50s	18	30%
60s	12	20%
70+	6	10%
Currently living		
Metropolitan New South Wales	27	44%
Regional New South Wales	15	25%
Metropolitan Queensland	4	6%
Regional Queensland	4	6%
Metropolitan Victoria	7	12%
Metropolitan South Australia	1	2%
Regional South Australia	2	3%
Regional Western Australia	1	2%
Gender identity		
Woman (including two trans women)	34	52%
Man	27	45%
Sexual identity (with gender, to make clear the range)		
Heterosexual woman	27	44%
Heterosexual man	15	25%
Gay man	10	16%
Lesbian/queer woman	2	3%
Bisexual man	2	3%
Bisexual woman	2	3%
'Trans' [note: although this is not a sexual identity, this was the term used by these participants when asked]	2	3%
Not provided	1	2%

Region of birth		
Australia	38	62%
Africa	7	12%
Other English-speaking nation	5	8%
Asia	5	8%
Europe	3	5%
Not provided	3	5%
Languages spoken		
English only (English-speaking background)	38	62%
1-3 other languages (Non-English-speaking background)	14	23%
1-3 other languages (English-speaking background)	9	15%

Figure 1. Relationships participants defined as 'family'



Key informants were recruited for their expertise and experience. Most were English-speaking and Australian born, but there was some diversity in cultural and language background, as well as age, and sexual diversity. Two thirds were women, and three quarters were based in New South Wales. Professional perspectives were fairly evenly distributed among sectors with more counselling/social work professionals than policy/research, health promotion/communication and medical/nursing professionals. There were equal numbers of government and non-government organisations represented, and although there was a slight weighting towards HIV as an area of expertise, all of the blood borne viruses were well represented.

Table 5. Demographic and professional profile of key informant participants

	Number	% of total (n=20)
Mode of interview		
Face to face	2	10%
Remote (phone/computer)	18	90%
Age (Range = 31–63)		
30s	5	25%
40s	3	15%
50s	8	40%
60s	3	15%
Not provided	1	5%
Organisation type		
Government health service	7	35%
NGO community/family service	6	30%
NGO health promotion organisation	4	20%
Government health promotion organisation	3	15%
Blood borne virus scope of expertise		
All blood borne viruses	6	30%
HIV only and/or HIV and sexual health	8	40%
HIV and HCV	2	10%
HCV and HBV	1	5%
HIV and HBV	1	5%
HBV only	1	5%
Chronic health	1	5%
Professional role		
Counselling/social work	8	40%
Policy/research/administration	5	25%
Health promotion/communications	4	20%
Medical/nursing	3	15%
Professional jurisdiction		
New South Wales	15	75%
South Australia	3	15%
Victoria	1	5%
National	1	5%
Gender identity		
Woman	13	65%
Man	7	35%
Sexual identity		
Heterosexual	9	45%
Gay man	4	20%
Lesbian/ gay woman	3	15%
Queer	3	15%
Not provided	1	5%
Cultural identity		
Anglo/English/Irish-Australian	14	70%
European/Middle Eastern/Indian	4	20%
Aboriginal	1	5%
Not provided	1	5%
Highest qualification		
Postgraduate	10	50%
Graduate	7	35%
Diploma	2	10%
High school	1	5%

What kinds of stories were told about families with mixed viral status?

In this report, we describe just a small selection of the stories we were told about how HIV, hepatitis B and hepatitis C figure in the everyday lives of affected Australian families, but we provide more in-depth analyses in our published papers. Please visit the study website for ongoing updates on our publications and presentations: <https://www.arts.unsw.edu.au/our-projects/my-health-our-family>

The participants in our study described a wide range of meanings and impacts of serodiscordance in family life. One of the most striking findings was the diversity of family approaches to managing and living with mixed viral status. Contrary to stereotypical representations and often stigmatising assumptions about transmissible viral infections, families responded to the diagnosis in a range of ways. We review some of the key themes in these stories here.

Disclosure to family

There were stories of shock, blame and rejection of the diagnosed family member, but also many stories of families rallying to provide emotional, practical or financial support and to find ways to get through the experience together.

Sarah (50s) was diagnosed with HIV in the 1990s, after acquiring the virus from a partner who was unaware that he was HIV positive. After her relationship ended, she decided she needed to tell her large and close-knit family:

I [told my parents] over the phone and I was sobbing, and I just said, “I need to tell you something and it’s not good news. I’ve been diagnosed with HIV.” [...] within I think 24 hours, every sibling knew and had called me. My little brother said, “I’ve been on the Internet all night [...] And it’s okay. You’re on medication and that’ll keep you well” ... And so they were all incredibly supportive and just saying, “We’re all gonna chip in. And we’ll pay for the removalist to get you [here].”

Sarah’s HIV status was not a closely guarded secret; most of her extended family knew and she let her family disclose to others, because she felt they might need someone to talk to. The only rule was that they needed to tell her who knew. She used her HIV status as an educational tool to talk about safe sex with her many nephews and nieces.

Some families felt compelled to reach out and educate friends and acquaintances to try and destigmatise these viruses, while others circled the wagons and kept the diagnosis strictly secret, which sometimes had long term effects across multiple generations.

Layla (30s), for example, was diagnosed with hepatitis B as a child, after being brought to Australia from overseas for adoption. She was taught by her adoptive parents that her hepatitis B diagnosis had to remain a secret. This reinforced her strong sense of stigma, and she has remained fearful of disclosure throughout her life. She didn't want anyone else to know she had hepatitis B, because she didn't want this to define her:

[A]s a little kid they'd say, "You're not allowed to tell anybody. It's a really big secret." And that's kind of carried on to now [...] it took me years to tell my boyfriend. I know it sounds terrible but, yeah, I just can't. I can't. The stigma, I guess. It's really bad.

At the time of interview, Layla was struggling with her recent decision to disclose her hepatitis B to her daughter, who had been immunised as a child (and was therefore not at risk of acquiring hepatitis B), but who had never been told about her mother's diagnosis. The quote also highlights a fear and vigilance around the potential failure of prevention interventions and risk of ongoing transmission within families:

I would have left it 'til she was 18. But that was [my boyfriend's] influence and I respect what he says. [...] He worries that if something has gone wrong, 'cause nothing's guaranteed, that she's putting other people in danger as well as herself [...] "She has a right to know about you and care about you [and] she's getting boyfriends! It's the responsible thing to do."

Significance of family in the context of blood borne viruses

There was a general sense among both primary participants and family members that family had a 'right to know' about the diagnosis, that sharing this information was a 'given', not because of concerns about transmission risk, but because the diagnosis was regarded as family business: the welfare of one member being a matter for the whole family.

Family support was both desired and often expected when facing a crisis, so when support was not forthcoming, it was seen as hurtful and unforgivable. Disclosure did not always translate into family support, and we heard some heart-breaking stories of rejection, indifference, and betrayal. But we also heard many moving stories told by both diagnosed participants and family members of unquestioned, heartfelt support. These stories often included a 'we' voice, casting the diagnosis as a shared experience within the family, as something affecting everyone.

Christopher (50s) felt a strong sense that his HIV diagnosis was something he ought to share with all the people in his blended family. While some in the family were unsupportive, many key people in his family extended their care and support without question. He was surprised about that more positive response, because their reaction to his past disclosure that he was gay had been 'horrendous':

So I was a bit nervous about this, that particular day, coming out to them, and they were amazing. My [father] then immediately remembered when he'd been very ill when he was young and he'd been sent off by his parents to a sanatorium to recover. And so his reaction was, "Do we need to send you to a sanatorium?" Which is probably the nicest thing he could have said, in terms of, "Okay, what do we do to fix

this?" And my step-mother then took it upon herself to find out as much as she could about the tests and the treatments ... And we actually had a number of years where we were, we became very close. So it was nice, yeah.

Barbara (70s) said she was heartbroken when her son initially told her of his HIV diagnosis. She thought it meant that he would not live long. She then took the initiative to contact some HIV organisations and they sent her information about HIV, which put her mind at ease. At the time of interview, she said it didn't worry her at all. Her main priority was to love and support her son.

I thought it was a death sentence 'til I got more information about it and read-up on it all. Yeah ... [His siblings] they're frightened of catching it and stuff like that. They didn't want to use the utensils or stuff like that that he used ... It's not worried me any. I just get on with life. 'Cause I'm his mother. It's just I love my kids. I mean it's a mother's way of coping with this ... Just to love them and let them know you love them, and be there if they need you.

Linda (50s) told her family not long after her dual diagnosis with hepatitis C and HIV. She then regretted it because the response she received was cold and uncaring. She felt very unsupported by her family, except for her sister whom she felt only gave a little bit of support. She explained that her family never talked about HIV or asked her anything about it or her health. She said that she could not turn to or rely on her family for any kind of support, and even though she considered herself very independent, she still felt quite hurt by that.

I didn't feel that I had any support from the family. And I'll never forgive them 'til the day I die ... To me, if I'd had a kid back in that time and they were in a state, I would have walked across the desert, got them and said like, "You've got a year to live. Come home," you know. "We'll take you to the appointments. What does all this mean? We'll find out together," you know.

Impact on family relationships

Some families spoke openly about the diagnosis and took an interest in information, while others emphasised the importance of carrying on as 'normal' and not giving the diagnosis undue attention.

Daniel (teens) was born with HIV and diagnosed when his family migrated to Australia. He is very close to his mother who also lives with HIV and to his older brother who does not. Daniel's brother was originally very worried his mother and brother would become ill and die, but once he was reassured that HIV could be managed, their family relationships became focused on living life as normally as possible.

And then my mum sat down with him and like explained to him that it's not actually the end. There's like treatment and stuff out there [...] Like now we're like pretty much like closer than ever. He knows but he doesn't treat me like I'm sick or anything. Just he's like a normal brother. Like kind of, yeah, we still make fun of each other and that kind of stuff. So it's kind of good that he knew as well, yeah. [...] It's just normal. It's like part of everyday life now..

Some families approached the diagnosis as a 'family affair', as a shared experience and joint responsibility, while others took a backseat and respected the privacy or self-care ability of their diagnosed family member.

Helen (50s) had been diagnosed with hepatitis C in the 1990s, when it was still relatively unknown in the community and treatment options were limited. But she was very unwell when diagnosed and so she decided to tell everyone she knew, including her whole family, as she felt they needed to understand what was happening.

My parents, I guess they were concerned about it but they really didn't say much [...] I'm sure they were worried but they didn't relay that worry to me [...] Being very sick is, it's a really lonely thing to go through. You know, being really quite sick. And sort of, that process of actually facing your own mortality, because that's what I did [...] to know that my family were in the corner like fighting for me was really important [...] I have talked to enough people who have disclosed about it, who have had a really terrible experience. And, you know, they have had their family and friends kind of walk away from them. And that's an awful thing to have to live with.

While these responses were often shaped by existing family relationships and communication styles, the diagnosis also had the capacity to change previous family dynamics by bringing some families together in a new way, or even repair broken family connections.

Sebastien (50s) acquired hepatitis C through sharing injecting equipment when he was young, but he chose to avoid monitoring his liver function because he had given up drug use and was living a healthy, active life. He had disclosed his status to everyone except for his parents, because he was both concerned about transmitting the virus to others inadvertently, but also ashamed about what his middle-class parents would feel about his drug use history. However, when his health started to deteriorate, he felt he needed to tell his parents.

[I was] happy to tell people that, usually through the term of 'misspent youth', I'd contracted the disease [but] I really hated the thought of [my parents] finding out [...] There was a shame to that [...] right up to the point where I had to sit my mother down and tell her that I had health issues. [But she] was very caring, and mothering, and didn't fall apart at all, and just said, you know, "Why did you keep this from me?" So it was a very, very, very difficult time for both of us [...] And she asked who have I told, and she then had to cope with the answer, "Everyone except you." [...] Nobody likes things being public knowledge and not knowing about it. I explained that I was deeply ashamed of the lack of care I had taken in the body that she had given birth to and nurtured [...] It was very, very sad but very bonding at the same time. And the honesty of it was, then allowed, you know, much better communication [... And now] Mum loves being involved [...] she loved being brought in from the cold, I suppose.

Nhu (30s) told her parents when she was diagnosed with hepatitis B a few years after she had migrated to Australia. She said her Mum felt really guilty because she realised she had transmitted hepatitis B, but vaccinations were not available in Vietnam when Nuh was little. She believed that people didn't know much about hepatitis B back then.

I think [my Mum] blamed herself really badly because she knew that she had hep B. But I think she didn't think of ... I don't know. She may not have been sure about the transmission from mother to child and so, when I was at primary school, so hepatitis vaccine was not, was not available when I was little ... By that time I didn't even know that she also has hep B. We never had that conversation in the family about it. [L]ike sometimes there are people like pretend to be expert by saying that like, "Oh, you know, your mum has hep B and then you must, you must have like, have it from your mum." I don't like it. That's really bad. I know there may be some possibility that I got that from my mum, but that's not the thing that I want people to discuss about. And even if it's for sure that I got that from my mum, I still don't want people to talk about that, because it's just like make her feel really bad. And that doesn't help ... [I] just don't like my mum to feel bad.

Perceptions of risk

Despite significant advances in the treatment of blood borne viruses and the unlikely probability of transmission in casual, everyday interactions, fears about 'contagion' surfaced in some of our interviews. This occurred across cultural backgrounds and across all three viruses, and had a marked effect on diagnosed participants' sense of family belonging.

A few family members that had clung to outdated ideas around 'infectiousness' demonstrated their fear by suddenly treating their diagnosed family member in a new way, with wariness or, in some cases, with outright hostility. Such reactions did not always pivot on perceptions of transmission risk, but on being perceived as 'the sort of person' who engages in socially stigmatised practices that can lead to acquisition of a blood borne virus.

In contrast, in many interviews, transmission risk was not raised as a family concern and was even sometimes dismissed as a valid consideration when making sense of their experiences of mixed viral status. They responded to news about the diagnosis with empathy rather than fears about risk. Their overwhelming concern was the health and survival of their diagnosed family member, not their own potential exposure to acquisition. Narratives of love, solidarity and science were prioritised and mobilised to counter notions of risk.

Lauren (20s) encountered both responses. When she was diagnosed with HIV two years ago, she disclosed her status to her family. She received 'amazing' support from her grandmother, but her older brother reacted very differently.

His reaction to it was to tell me I'm a slut. And to tell me not to share food with my niece and nephew, because he doesn't want me to give [HIV] to my niece and nephew ... He had no clue. He just assumed any kind of bodily fluid, including saliva [was infectious]. When I tried to explain it, he just got narky [irritated] with me and didn't speak to me for nearly three months ... Even now I only speak to him kind of very occasional ... And he's never apologised for what he said, and that's what causes the biggest issue. But he never admitted he was wrong.

When **Hannah** (40s) disclosed her hep C diagnosis to her family, they were very accepting and loving, which was not what she had expected. Though they raised some questions about transmission risk (which were quickly put to rest), they never treated her any differently. They provided emotional and practical support while she was on treatment (previous treatments available pre 2016), especially her Dad, but made no fuss about it.

And they were just wonderful ... I guess people can have dramatic reactions when they, well, I'm assuming, I suppose when they feel that they may have been exposed or when they're fearful and don't understand what the transmission risks might be. So, in particular, I was concerned about talking with my brother-in-law, who I thought would have reacted strongly about possibly exposing his two kids to hep C, because I hadn't told them before. But he was just wonderful ... And he said, "Oh Hannah, I'm really sorry to hear that." He said, "Well, as a family, we'll get through everything together." Was just the best [...] Like all of that stuff of being infectious is so internalised. It goes a long way when family members don't take on that infectious kind of, I guess, propaganda that's out there.

Jessica (50s) said that when her sister was diagnosed with HIV, the family set about informing themselves. Although the family were devastated, their main concern was the health and well-being of their loved one.

Oh, it was just, it was an education for all of us in understanding, you know, sort of what it meant to all of us, you know, understanding the disease, you know, how it can be contracted and, you know, that, you know, it's not possible for, if, you know, you're touching somebody. You can still hug them. You can still kiss them and, you know, still be okay" [...] It doesn't faze any of us. We treat [Sarah] the same way that we treat everybody. It's no different. None at all.

Migration could complicate the issue of risk and create separate risk contexts across family networks in different parts of the world. The risk of transmitting hepatitis B was not an issue for **Aisha** (20s) and her family in Australia. Her husband had cleared hepatitis B and was now immune, and her two children had been vaccinated. So even though they were a family with mixed viral status, prevention strategies were not needed. But things were different in relation to Aisha's family (biological mother and siblings) back in her country of origin, where health services access, including for people with hepatitis B, are limited:

Like I worry about going back home because I don't know what that would mean where the majority of people are not vaccinated. So then I'm scared or if something happens I'm gonna pass it onto them. What does it mean? ... So I haven't seen my mum and my family for 16 years. It's fucked-up, yep.

Key informant perspectives

The key informants we interviewed had a broad view of what constitutes 'family', a view that was generally shared by the organisations or services they worked for. Family, from their perspective, should always be self-defined: "Whatever a person regards as their family, is their family" (KI 13). This perception was largely informed by their extensive experiences of working with diverse populations in the fields of blood borne viruses.

The concept of family is such a broad term ... [It] could include partners, siblings or it could also include extended family, especially for families who have strong connections to other cultural backgrounds where family is not just the nuclear family in relation to an Anglo-Saxon cultural sense. The family can include grandparents and cousins, and aunts and uncles ... The concept of family [is] around who is around you to support you and who you feel connected with and your sense of belonging ... It could also mean family in the sense of family that you've come to live with, or [who] have taken over your care for other reasons ... There's lots of definitions and layers of families (KI 2).

There was broad consensus among key informants that relationships and a sense of belonging matter deeply to all humans. Families were seen as especially significant in terms of people's experiences of being diagnosed with a blood borne virus and how well they live with that blood borne virus: "Family support can make or break a person in their journey coming to terms with their blood borne virus" (KI 3).

These participants shared many heartening stories of families they had encountered through their work who provided genuine support, care and love to a diagnosed family member: "It's always a really powerful thing when you see it" (KI 19). But they also emphasised that family relationships can be complicated by the lack of mainstream knowledge, or different cultural or religious beliefs, about blood borne viruses, or about sex and drugs, and by a critical lack of services and support for family members themselves.

We know as professionals ... that 99.9 per cent of the cases now, with all three of the viruses, are gonna live long-term and be well-controlled, or cured if it's hepatitis C. But families don't understand that. The message isn't out there. Nobody ever talks about it. You never see this in magazines. You don't see it on billboards ... Even if they're in a really loving family, they still don't feel they can trust their family not to judge them. You know, it's incredibly, incredibly sad, that it can instantly change relationships. And it can do that, a diagnosis. So, there are many problems for families around that [...] It's that fear around a diagnosis. It's that belief in a whole load of myths and legends around, you know, how it is transmitted. So, what causes the problem is the lack of knowledge. And because we're not allowed to talk about all of this stuff, you know, because it involves either sex or drugs, it's just so hard (KI 8).

I think for a lot of people from other cultures, if you lose your family, you really are alone within your community ... They just go into exile from their communities and their families in order to avoid their HIV status ever being found out. So, it's a massive loss, often in a way that is hard to really understand sometimes (KI 13).

Many key informants struggled with the disconnect between two realities. On the one hand, key informants saw the importance of families as 'health brokers' (KI 4). On the other hand, key informants explained that they did not have the time, resources, funding or policy framework to include family members in their work, to build family's capacity and resilience, or to equip diagnosed people to navigate family dynamics and have helpful conversations: "I wish we could do it more" (KI 1).

I think, you know, there's not a lot of support. That's one of the things that comes out, that family members say to us. You know, they sometimes feel like they need support, but there's not really [any] specific services for [them], where they feel like they can go and where someone is knowledgeable about [blood borne viruses], but can also support. 'Cause there's no specific services for families or for partners (KI 9).

I would agree that the support needs of family members are not adequately resourced or addressed ... I do think some of the services we already have would be perfectly adequate for that purpose. They're not currently doing that work and there's not really any movement towards enabling them to do that work (KI 5).

Those who worked in services or organisations that had the ability to include families in some way emphasised the importance and benefits of family involvement.

It's really important to try and keep that family unit together. It's really important to the person living with [a blood borne virus], but it's just as important to the person who isn't living with a blood borne virus. And to try to feel that we've helped them to understand what the virus is about, what it's like for the person living with [it], and to reduce their fear and their panic around that means that they will be better mentors to other family members potentially, to provide better support and care for that person living with [the blood borne virus] (KI 8).

Participants were also keenly aware of the complexities of family relationships in the context of blood borne viruses, especially if the diagnosis is compounded by existing challenges or stigmatised dynamics in the family, such as incarceration, sexuality, drug use, mental health issues, domestic violence, housing instability, migration, and intergenerational trauma.

There is a real opportunity there, from a resourcing perspective, for families. Like, you know, the [blood borne virus] is gonna be managed. It's the other stuff they're gonna need help with, if it's someone diagnosed today ... I mean, [a blood borne virus] is just one of the issues they're trying to deal with ... there's usually a whole burden of stuff that then becomes issues for them to deal with as well, at the same time, which for many families, I think, is just simply overwhelming. There's no resource of health promotion or, you know, material that can prepare you to deal with that stuff (KI 15).

A common theme among the key informants was the need for more widely accessible and culturally resonant education about the contemporary biomedical realities of blood borne viruses, such as DAAs for hepatitis C and undetectable viral load for HIV: "Certainly, in the broader community, I think the information hasn't caught up with the reality" (KI 3).

This is just a brief snapshot of some of the most salient themes that emerged in the key informant interviews. We cover these and other important issues and perspectives in more detail in forthcoming publications.

What have we learned about the experience of serodiscordance in family life?

A range of in-depth analyses are in development, exploring such topics as: disclosure, communication agreements, advice for other families of mixed viral status, intersections between family mobility, migration and blood borne viruses, and professional perspectives on families affected by blood borne viruses, including on issues of confidentiality, stigma, cultural diversity and migration, and perceived similarities and differences across the three viruses.

We have also published articles on the following key findings, each of which is summarised briefly here:

Serodiscordance becomes embodied and embedded within family relationships

Even though people living with HIV and viral hepatitis are in mixed-status relationships not just with intimate partners, but with other family members too, the existing literature includes little about the wider world of significant relationships in the lives of those with blood borne viruses.

In medical science, HIV and viral hepatitis are conceptualised as pathogens confined within individual bodies, until transmitted to other bodies. The body's connection to other bodies only becomes relevant in relation to risk, real or imagined. In this article we provide an alternative perspective to these individualising tendencies in medical science, and a more inclusive analysis of serodiscordance than the literature's focus on transmission risk in couples.

Today's biomedical treatments mean that people living with hepatitis C can now clear the virus, while people living with hepatitis B and HIV can live relatively normal lives, and keep their status private, if that is what they prefer. And yet our study clearly shows that these infections continue to be experienced and negotiated through embodied connections to significant others, made meaningful through culturally situated understandings and expectations regarding kinship, affinity, love, shared history and family obligations.

We illustrate how this relationality is manifested in multiple ways, focusing on several prominent themes: disclosure of diagnosis to family; illness as a 'family affair'; 'being a body for other bodies'; the impact of a diagnosis on families in social, emotional, financial and generational ways; and the capacity of a diagnosis to create divisions and distance within families, but also to bring families together and strengthen their connection. Families could play a powerful role in social marketing campaigns to de-stigmatise blood borne viruses by highlighting that these viruses are located and lived within everyday relational contexts.

Even in the current biomedical era, viral infections are experienced and lived through webs of affective relations; the very fabric that constitutes and animates our embodied existence [...] [To] “flesh out” this larger world of connections and their significance in the context of serodiscordance, we invoke the phenomenological concepts of embodiment and intercorporeality [which] provide us with a critical tool to extract viral infections from their solitary molecular habitat in science, as well as from the risk paradigm in public health, and to re-locate and reembody them within the relational worlds that infuse these infections with meaning and shape the lives of those affected. In doing so, we seek to “normalise” stigmatised blood borne viruses, in the sense of emphasising their embeddedness in everyday relationships and lifeworlds, but also to draw much needed attention to the impacts on family members and their potential support needs. [pp1–2]

The embodied relationality of blood borne viruses: How families matter in the context of a stigmatised viral infection: <https://doi.org/10.1016/j.socscimed.2019.112620>

Families with mixed viral status can be mapped through both spoken and visual methods

We explored how visual methodologies can contribute to our understanding of mixed viral status as this is experienced in families, especially for those affected by blood borne viruses that have long been characterised by cultural fears and social shame. Mapping ‘family’ at the start of interviews with people living with one or more blood borne viruses was a technique that enabled participants to visually represent the social practices and relationships that enact families, and in doing so, revealed to us how the meanings around ‘family’ itself are negotiated through the stories told about them.

As the interviews unfolded, the depiction of family was delineated, negotiated and justified by the specific conditions of each research encounter, and this process often continued throughout the duration of the interview as research participants added people on the diagram in response to the unfolding narrative they were producing. The benefits of a mapping exercise were in the co-construction, rather than static representation, of family.

We found that this exercise also provided the space for exploring other familial themes that were related to the broader implications of mixed viral status, such as the perception or experiences of stigma, the movement of family corresponding to states of knowledge about the diagnosis, and explanations of giving or receiving support. Therefore, serodiscordance becomes a part of the stories people tell about their family, including how they manage the experience of having a different blood borne virus status amid their more everyday interactions.

Paying attention to how stories of living with mixed blood borne viral status are told is equally important, especially through the spatialising metaphors of closeness and distance. The use of visual tactics for representing families works to reveal how the meanings rely upon particular representational codes, and require the engagement of particular audiences, in order to make the specific configurations of family legible.

In the context of stigmatized transmissible infections, family relations can represent “the strange spatiality of intimacy” (Maclaren, 2014) that moves between proximity and distance, support or disengagement, even extending to claims of family or not-family, as they navigate the emotional, practical, and geographical terrain of living with mixed infection status [...] What counts as family oscillates as people negotiate and re-negotiate relationality in response to changing circumstances of living with serodiscordance. The intertwining of narratives of family life with their spatializing representations demonstrates that while serodiscordance can be felt as intensely personal at times, it is always necessarily relational. [pp 802–3]

Mapping experiences of serodiscordance: using visual methodologies to construct relationality in families living with or affected by stigmatised infectious disease: <https://doi.org/10.1177/1049732319890304>

Experiences of serodiscordance in families is shaped by social stigma as well as sociocultural understandings of risk

Notwithstanding their differences, blood borne infections also share important characteristics that set them apart socially from many other health conditions. Foremost are their transmissibility and potential for acquisition and, crucially, the social stigmatisation of those who are diagnosed with them. It is these shared aspects that frame our exploratory study and our analysis in this article, with the aim of generating new insights into the relational dynamics of ‘risk’ in families with mixed viral status.

Anthropologist Mary Douglas argued that perceptions of risk are shaped by deep-rooted cultural and existential ideas around disease and danger, pollution and contagion, which are mobilised to contain perceived threats by creating boundaries against ‘outsiders’, by marking out their ‘difference’ and by assigning blame. In short, the concept of risk performs a powerful social role.

Throughout the history of HIV and viral hepatitis, ‘risk’ has been at the core of both expert and popular perceptions of these blood borne viruses. Expert understandings of risk have changed considerably over time as medical science and treatments have advanced, but mainstream understandings continue to lag behind.

Our study found that families responded to a diagnosis in a variety of ways. They made sense of their situation by drawing from an array of cultural systems of meaning, expert knowledge, norms and values, as well as personal experiences, emotions and priorities. Responses by some migrant families were also shaped by the cultural understandings of blood borne viruses that they had brought with them from their countries of origin.

Despite significant advances in the treatment of blood borne viruses and the negligible risk of transmission in casual, everyday interactions, a few family members clung to outmoded ideas around ‘infectiousness’ and risk, and expressed their fear by treating their diagnosed family member in a different way. However, many families were completely unconcerned about risk,

either because they understood the science, or because they prioritised love, support and solidarity, or both.

Perceptions of risk in relation to HIV and viral hepatitis are understood through persistent conditions of stigma [...] But not predictably so; the potential risk of these viruses—including their stigma—is assessed and navigated through relational histories, love and loyalty, medical science, and other cultural and emotional meaning systems that help families make sense of the virus in their midst and manage its impact on their lifeworld and connection. We have shown how the ‘doing’ of risk within families could be constitutive of difference, unsettling the family connection or deepening existing fault lines. Conversely, and more commonly, the ‘undoing’ of risk enabled the preservation of the family bond by rejecting difference and reframing risk as an external threat to the family in the form of stigma.

Understanding ‘risk’ in families living with mixed blood borne viral infection status: The doing and undoing of ‘difference’: <https://doi.org/10.1177/1363459320946469>

Families with mixed viral status reveal both the value and the risk of telling your story openly

It is important for some families to tell their stories, and many benefit from doing so.

Better information on the experiences of families could change the unsupportive social, policy and legal environment for people affected by blood borne viruses if these stories could be shared openly, but there remain many risks to the safety and wellbeing of those who share biographical narratives openly.

The ‘lived experience’ of families is increasingly visible in policy and political documents, but this doesn’t always happen in the interests of families. In many instances, family stories are used in the service of government agencies or service providers.

Our ongoing responsibilities as researchers are to represent the stories of our participants as they choose to tell them, and to frame their stories with analysis that contextualizes their accounts and deepens our understanding. One of our concerns is that these responsibilities are not shared by others who tell the stories of vulnerable people in public forums. Research is always imperfect and incomplete, but it affords certain protections, not least through its constraints: Researchers are always limited in the claims that they can make, especially when it comes to the “real lives” of research participants. The use of biographical narratives in policy is generally not framed by the same constraints. [p13]

Experience as evidence: the prospects for biographical narratives in drug policy: <https://doi.org/10.1177/0091450920916244>

How can we strengthen the role of families in the response to blood borne viruses?

A range of implications for strengthening the role of families in the policy and practice response to blood borne viruses are suggested by these and forthcoming analyses of the data from this study.

- People live with and experience their blood borne virus through relationships with other people, including family. Recognising that a web of social connections surrounds the individual may help to achieve more meaningful and effective outcomes in clinical care, health promotion, research design, and policy formulation.
- It is critical that the role of families is recognized when providing support to people living with a blood borne virus, given the unique contribution of family relationships to health and well-being.
- The diversity of families, including chosen families, needs to be recognised and accommodated if initiatives to strengthen the contribution of these relationships are to be effective.
- Social marketing and clinical education campaigns could feature families to foreground how stigmatised viruses are located and lived within everyday relational contexts, throughout the community.
- Stigma remains a problem in the community. Much could be achieved by incorporating narratives related to families in stigma reduction strategies within health and social service organisations.
- When working in a family-inclusive way, healthcare workers and the blood borne virus workforce are well-placed to sensitively interpret the diverse systems of meaning across families and to build their capacity, knowledge and resilience around blood borne viruses.
- Achieving a more family-inclusive approach to the design and delivery of prevention, care and support services requires recognition that the diversity of people living with a blood borne virus may require quite different strategies of response and support.
- Given there is much diversity in the way that blood borne viruses are understood and addressed, it is essential that a culturally appropriate and sensitive approach is implemented when designing strategies to support affected families.
- The diversity of perspectives among families should be utilised to inform the development of tools and resources to assist those caring for and supporting a family member diagnosed with a blood borne virus, including information on how to provide support and access support for themselves.

- There is much potential for peer support models to be developed and delivered by community-based organisations which aim to engage, support and build on the strengths of families with mixed viral status, although confidentiality remains an essential priority in working beyond the individual client.
- Dedicated funding is required for developing support services for families with mixed viral status, and must not compete with or compromise funding for individuals who are directly affected.
- Family-inclusive messages in health promotion resources should prioritise education about transmission risk and emphasise the ways that families can and do support each other by embracing and overcoming difference.
- There is a pressing need to recognise that family members of all kinds have a role to play in providing forms of 'informal care' to people living with blood borne viruses, and to also recognise that these family members may also need support.
- There is much potential for the families of people with blood borne viruses to be better recognised within contemporary social care and policy frameworks, and more research on their needs would assist in informing this process.
- More research is needed in order to understand the role of families in the experiences of people living with hepatitis B and hepatitis C, given these experiences remain even less well understood and recognised than those of people living with HIV.

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