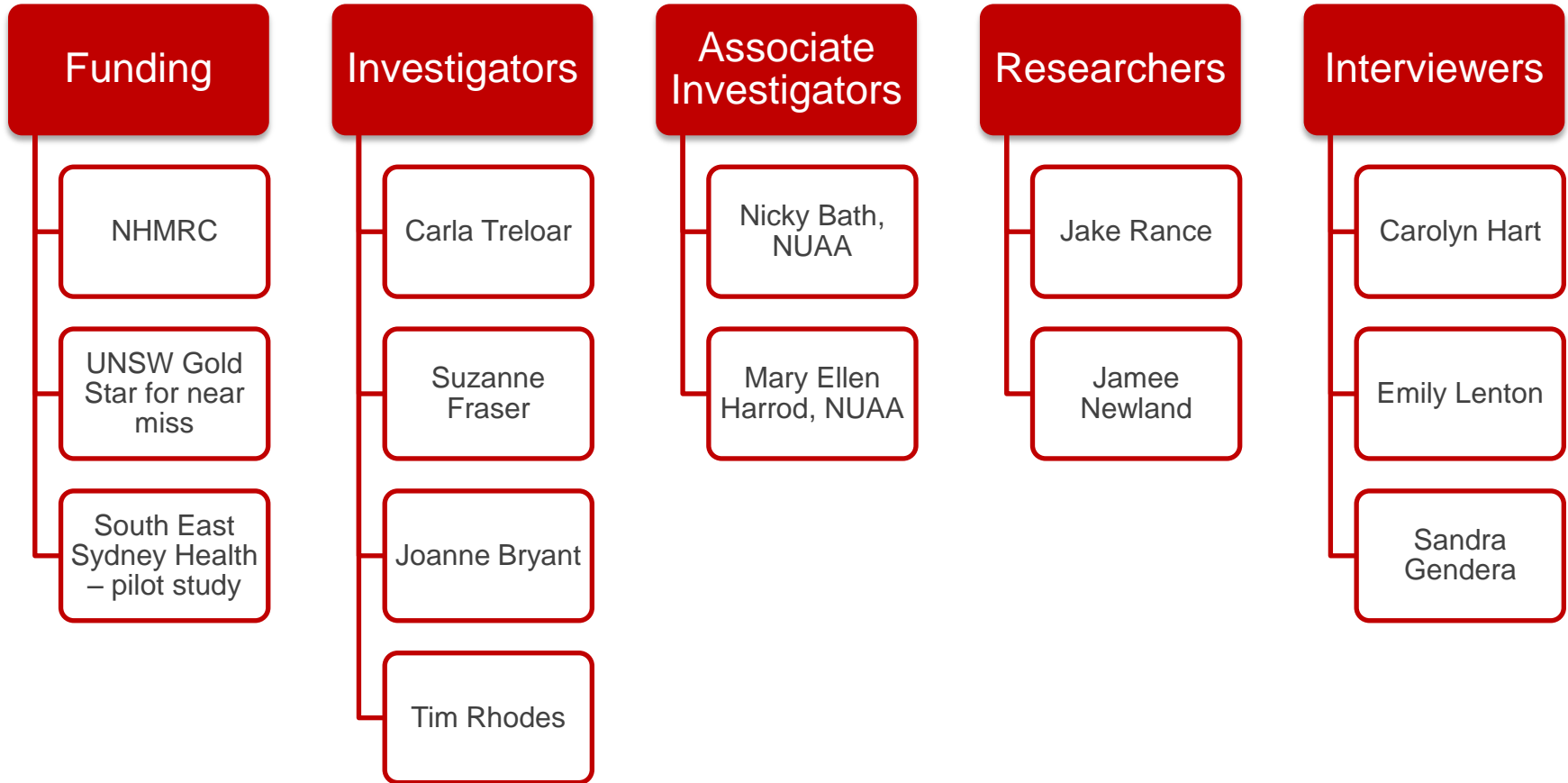


Understanding and preventing hepatitis C transmission within sexual partnerships



The Project



Rationale & Aims



Harm reduction

- Designed for atomised individuals
- Social aspects not understood; incorporated
- Social = silenced



Couples who inject drugs (CWID)

- Focus on heterosexual, gay and lesbian separate study
- Special features of this relationship
- Care, social protection of couple not recognised, but discounted



New harm reduction resources

- Provide some evidence
- Start the conversation about what's possible
- Inspire, aspire, propose “out of the box”

Rationale – Why couples?



Transmission of HCV

- Requires two or more people

Surveillance data

- Majority of people sharing – sexual partners
- 50-60% of sharing of N/S
- Similar, higher rates for ancillary equipment

Some research about women's patterns of drug use

- E.g. less likely to go first, be injected by partner

Useful, but not how / why sexual partners engage in practice

- Limitations of epidemiological focus, can reproduce stereotypes
- Sexual relationship not seen as unit of analysis
- Special qualities/features of sexual relationship – intimacy, trust

Rationale – Health promotion?



Health education most effective

- Targets defined segments of population
- People actively identify with messages

Review of >200 hep C health promotion materials

- What kinds of messages, assumptions?
- Address social context of HCV transmission?

Social context - couple as unit of action?

- 75% addressed individual
- Couples sometimes addressed in sexual transmission sections
- Only 2 materials specifically addressed couples

- Dwyer, Fraser, Treloar (2011)

Rationale – Health promotion?



What's missing in relation to couples?

- Love, trust, intimacy, commitment
- Routines, sharing enjoyable/mundane tasks
- Constructed meanings

- Dwyer, Fraser, Treloar (2011)

Rationale – Our starting point



Hep C prevention neglects the “social”

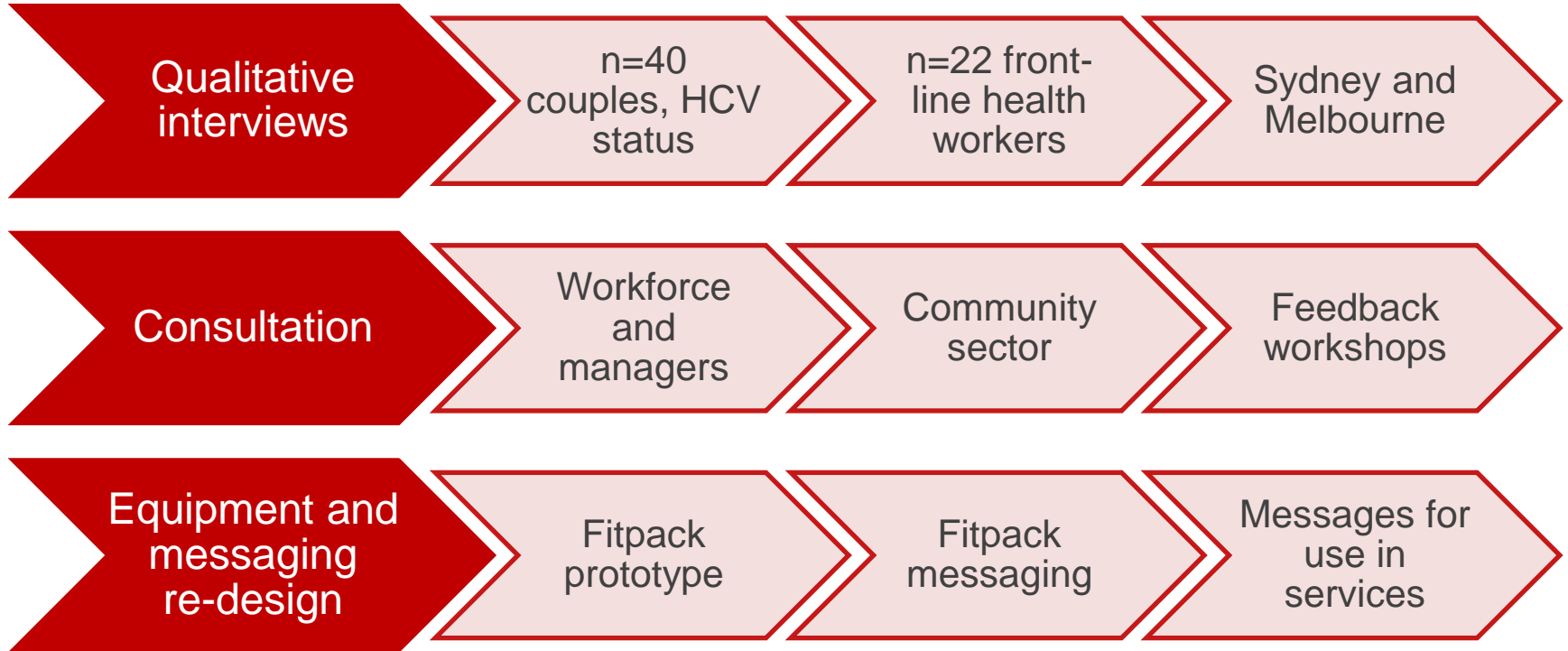
- Special features of couple
- Gender, relationship security
- Not individual choice, but complex array of social conventions

Prevention education is a social practice

- Shaped by unexamined social norms
- Homogenize readers
- Gender, individuality, risk, responsibility
- Inauthentic “drug” relationships

- Fraser, Treloar, Bryant, Rhodes (2013)

The Project - Method



The Project – Analysis



Shifting unit of analysis

- From individual to couple

Link couples data structurally

- Extended pseudonym and attributes
- Shelley, 34 years, HCV positive; Steve, 33 years, HCV negative following treatment

Read data “together”

- Difficult to keep focus
- Team work to keep focus on “couple”
- What do these data tell us about the couple?

Caveats



- Some couples will struggle with issues of power, violence
- Changing HCV prevention to include/acknowledge couples will not change structural factors such as poverty, dependency, housing etc.

In your groups

- Introductions
- How do couples figure in your work?
- Report back on:
 - One main similarity in the group
 - One main difference in the group



Main Areas of Findings (to-date)



Caring couples

- Social protection
- Multiple care

“Negotiated safety”

- Trust & intimacy
- Evolving

Everyday objects

- Convenience
- Meaning

Couples “work”

- Seen in risk frame
- Where is the love?



Caring couples



Care potential

- Social protection when partnerships/practices are marginalised

“Everything together” of care and protection

- “We’re two partners become one. We’re in it together” (Jim)
- Indispensable system of mutual care and support
- Product of the particularities – and difficulties – of the situation of drug use
- I haven’t used on my own in a long time and just having him there I know at least if I overdose I’ll be OK. I trust him completely, and just kind of, I think safety. Like I feel you know, just having somebody there, because we have been using a lot, we’ve kind of been very isolated, like don’t really see many people, lost kind of friendships, so it’s kind of like that’s why we kind of relied on each other for everything. (Jenn)

- Rhodes et al. (2017)

Caring couples



Co-dependency?

- I share everything with her. It might be a bit co-dependent in other people's eyes. I don't mind saying we help each other. I think that's *always a positive thing*. We're not lonely because we have each other to turn to, so I think that again is a *healthy thing*. It's a beautiful relationship. (Seth)
- It's like déjà vu, every day. It's like just the same in and out, day in day out. And it's an ugly routine. And you start to fall behind in life and bills, and just your friends are moving forward and I'm staying back. And it's the worst scary place to be, because it's quite lonely at the end of the day. Even now with my partner, we can't connect because of it. It's *always in the middle of us*, daily. We can be so much in love but at the end of the day if we've been together 8 years on drugs as soon as we stop and stay on scratch, so you're really not together, you are, but *the drug is in the middle*. (Fred)

• Rhodes et al. (2017)

Caring couples

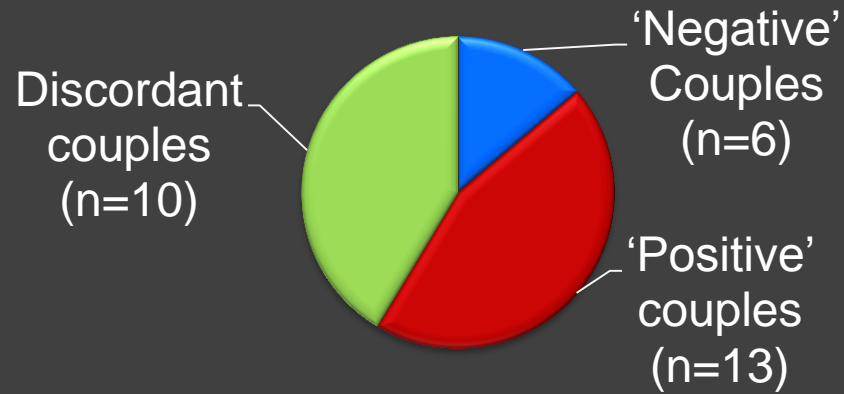


Social relations of relationship practices

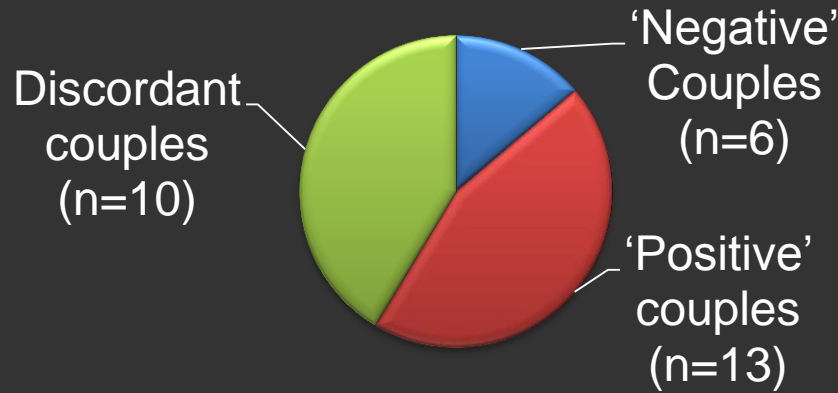
- Counter other representations of CWID as “less than”, destructive, dysfunctional, self-care/concern dominates genuine care for another
- Multiple meanings of “care”
 - Viral and risk management; drug use; dependency; intimacy and security; protection from stigma
- Care within the relationship
- Care external to the relationship
 - Understand partnerships as response to social environment
 - Intimacy insulates from harm, but does not change structure

• Rhodes et al. (2017)

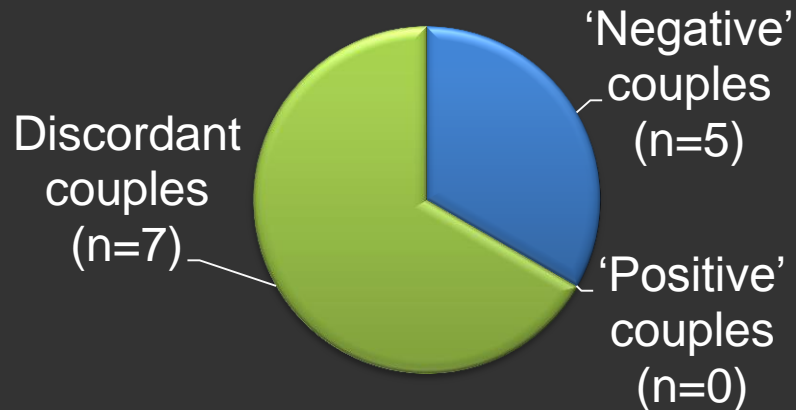
'Shared' in current relationship (29/41)



'Shared' in current relationship (29/41)



'Not shared' in current relationship (12/41)



Negotiated safety



From HIV MSM tradition

- When all UAI = risk regardless of context
- Deliberate prevention strategies
- Risk/safety = negotiated and fluid (vs fixed/determined)

Trust and partnership

- Reduce uncertainty, heighten security
- Relational boundary – inoculating partnership from outside risks (social, emotional, virological barrier)
- Belinda: [I]t's just a matter of trust, and I don't trust anyone but him ... I don't need those people. I have my partner to trust and to use with. (**Belinda, 36, HCV pos; Bob, 46, HCV pos**)
- Codes, rules - co-created sign of mutual trust, commitment
- [I]t's not only my life I got to worry about. Once I inject with them [others], I'm going to be bringing it on to her [Fran], so I have to take care of her too. (**Fred, 29, HCV pos; Fran, 29, HCV pos**)

- Rance et al. (in press)

Negotiated safety



Intimate knowledge and negotiation of safety

- Biomedical enactment re hep c status, genotype
- Co-created practice that reproduced togetherness, “we-ness”
- Pam: Every now and then when we have been stuck and we’ve only got one fit between us ... he’ll [Patrick] make sure that I use it ... then he’ll rinse it and use it ... Because he has it [HCV] and I don’t ... And he wants to keep it like that.
- Interviewer: *It sounds like on those occasions you’ve been very aware of Patrick’s hep C status?*
- Pam: Yeah.
- Interviewer: *And so you’ve gone first?*
- Pam: Yeah ... he just wouldn’t have it any other way. [Negotiating serostatus] isn’t really an issue for people like us that are partners and are faithful, and are loyal and stuff; I just think there’d be a lot of people out there that keep secrets. (**Pam, 50, HCV neg; Patrick, 52, HCV pos**)

• Rance et al. (in press)

Negotiated safety



Intimate knowledge and negotiation of safety

- Doing everything together, witnessing (medical check ups, histories)
- Evolve over time as intimacy grows (incl via witnessing)
- Emerging commitment to relationship
- Interviewer: *And so you guys didn't, you didn't try and distinguish your fits from [your partner's] fits sort of thing?*
- Seth: There were times earlier on in the piece, like if we just had one fit each, we're going to reuse them later. We'd wash them out, and one of us might burn an end or something, but as time wore on and we sort of realised that we were going to be spending quite a lengthy period of time together, not just a fling kind of thing, it'd develop more into something like 'ours'. **(Seth, 24, HCV pos; Suzie, 46, HCV pos)**
- Adapt practices with knowledge
- In the past when we both were hep C positive and we both had the same strand, and we knew that, we weren't too concerned ... If we didn't have clean syringes we would just use our old ones and I'm sure I used his and he used mine ... but we don't do that now [that Steve has begun HCV treatment]. **(Shelly, 34, HCV pos; Steve, 34 HCV neg following treatment)**

- Rance et al. (in press)

Negotiated safety



Intimate relationship = safe and trustworthy

- Selective sharing with partner – last resort – but prioritises safety of relationship
- Management of risks constitutes partnerships, deeply meaningful
- “Us” safe from “them”

Serodiscordant couples

- This contradicts normative/epi understanding of risk (risk within the home, rather than outside)

Re-fashioning negotiated safety

- Not just “risk calculus”
- Cannot divorce couples’ emotional lives from decision making
- Complex, confusing and sometimes contradictory
- Work with, rather than ignore, these dynamics

- Rance et al. (in press)

Changing status



14 couples

- 13 seroconversions (including two instances alternatively described as “clinical mistakes”)
 - 8 exposures-plus-spontaneous-clearances
 - 2 successful treatment outcomes.

 - negotiating new diagnoses and accommodating chronic infections
 - status confusion
 - pri-oritisation of partnership
- Rance et al. (2017)

Changing status



14 couples

- Keith40pos/Karen32neg (8 yrs.) 2 exposures + spontaneous clearance 1 seroconversion.
- Initially positive seroconcordant. Both claimed to have been HCV-positive twice.

Karen: “I had hep C and then it went away and come back and now it’s gone”;

Keith: “I’ve got rid of it and got it again . . . I feel stupid”.

Although unclear, it seems Keith’s latest infection was acquired during his relationship with Karen but not via her. Karen reported she had been exposed to the virus twice during the relationship (at least once via Keith) but is now HCV-negative. Keith, however, believes they are both still HCV-positive. Accounts suggest Karen began injecting drug use after the relationship began.

Rance et al. (2017)

Changing status



Prioritisation of the relationship

- “Don’t think I’m going to leave over it”
- Among people who are socially excluded, including many who inject drugs, meaningful intimate relationships may provide one of the few forms of social capital available to them.

- Rance et al. (2017)

Everyday objects



Analysis

- Treat PWID/CWID as consumers like any other
- Issues that shape decisions about goods and services
- Convenience (marketing)
- Meaning beyond convenience

Why share equipment?

- “Run out”
- Like mundane household items, bread and milk

• Fraser et al. (2016)

Everyday objects



“Run out”

- Use of new equipment is preferable where convenient
- Linked to hours of NSP operation
- Type of equipment
- Travel time
- Box of 100 – but altruistic distribution, practices of care
- Thorough disabling of equipment

Jim

- I think being really cautious and really careful can come back to bite you in the ass ... Because not only do I bin mine but I snap the end off and put the piece that could hurt anyone down the barrel and jam the barrel down there so it is never going to hurt anybody ... *(61, HCV pos; Janine, 48, HCV neg)*

- Fraser et al. (2016)

Everyday objects



Convenience
and meaning

- Equipment use demonstrates care
- On basis of HCV
- Chivalry

Pam

- Every now and then, when we have been stuck and we've only got sort of like one fit between us ... he'll [partner, Patrick] make sure that I use it ... then he'll rinse it and use it ... because he has it [HCV] and I don't. (50, HCV neg; Patrick, 52, HCV pos)

Tanya

- There have been a grand total of three or four times when we've had to share ... we've never shared a dirty one ... [but] we've shared a clean one. Both me and him [partner, Tim] agree that ... I would go first, he would go second ... Ladies first. (23, HCV pos; Tim 39, HCV neg)

• Fraser et al. (2016)

Everyday objects



Convenience

- Call for greater coverage of equipment
- But convenience means more than just coverage

Meaning - other insights

- Equipment – banal and deeply meaningful
- Challenge assumption that equipment is ‘blank’
- NSP within a marketplace of priorities and options
- Enhance meanings to interrupt “running out”

• Fraser et al. (2016)

Couples “work”



Literature: Some attention to “couples interventions”

- “Shift” required for staff to increase awareness and skill in couples-based approaches

Couples – not present, same as individuals

- Because I never see a couple together, so that’s harder as well, because you’re never having a couple discussion around risk factors, you’re always having individual discussions and you’re always...But yeah, its I guess its not frequent that we have conversations around avoiding transmission within a relationship. (Vic 9)

- Treloar et al. (2016)

Couples “work”



Couples – not present, same as individuals

- I would be talking about the same information that I would be talking about with anyone who is sharing, you know. Really, it is really key that they have their own stuff and as they are using stuff, they’re cleaning it up and continuing to, kind of, maintain, you know, that everyone’s blood is really contagious in any way. So, I mean, yes, great if you want to be injecting together. That’s actually an okay practice as long as you are keeping things separate. In fact, you know, quite legitimate to have your own, injecting it quickly than to be injecting each other but then just maintain that level of awareness that you’re not crossing over. (Vic 7)

- Treloar et al. (2016)

Couples “work”



Couples – not genuine

- For a lot of them you it’s like you don’t know which is the stronger partner relationship there, the relationship or the relationship with the drugs, or something else (NSW 3)
- Just drug buddies who are fucking (Vic 6)

Couples – risk dominates

- Couples grounded in epi categories of risk i.e. sex

Couples – impenetrable to messaging

- “Mantra” of high level of trust in partner; risk is outside of relationship

• Treloar et al. (2016)

Couples “work”



Couples – alternative framing

- There’s all sorts of rituals around using and its rituals about sharing and how they fit into the couple sense of connection, togetherness, you know and often that’s you know, while the message we might be giving is “you should always be considering your safeness as an individual yourself”. For many couples that isn’t their experience. Their experience is “we’re a unit, we’re safe within that unit, we won’t share out that unit, but within that ...” (NSW 5)

- Treloar et al. (2016)

Couples “work”



Couples – organisational and professional barriers

- Respond to client’s needs at that time
- Avoid imposing agenda
- Many other competing things

- Treloar et al. (2016)

In your groups

- What is your first response to these findings?
- What does it mean for you and your work?
- Please record what you want us to know...



Next Steps – Fitpack re-design



Status quo
for 20+
years



Why
designed
like this?



Whose
needs does
it serve?



How could
re-design
support
couples?

Fraser, IJDP, 2013

Our Approach



Using
same
dimensions

Two
chambers

Two
disposal
chambers

Perforated
join -
symbolic &
practical



We know you care for each other, and you want to look after each other's health, so this new fit pack was designed to help make that a little easier.

Couples in Sydney and Melbourne told us what was important to them, hopefully we came close.



Explaining Fitpack



Distributing responsibility

Engaging clients in prevention partnership

Enable clients to discuss with their partner

Labelling chambers “yours”, “mine”



*Some things are
best kept for
yourself*



our hit...your fit...my fit



*Some things aren't
meant to be shared*



our hit...your fit...my fit



Loving someone doesn't mean
you need to share everything



our hit... your fit... my fit



Share Life...Share Love



our hit... your fit... my fit



I think you're my type...but maybe not
my genotype



our hit...your fit...my fit



UNSW
SYDNEY



CSRH

Centre for Social Research in Health

NDRI

national drug research institute



Curtin University

Results



Affording love and care

Poster #6 and serodiscordant relationships:

“because I love you, I don’t want you to get my hep C. Because I love you, I’m careful when I inject. Because I love you, I’m careful about what I do with my blood ... That’s *your* perspective. My perspective is around, you know ... it’s like I trust you. Because I love you, I trust you to do that and I trust you to look after me in that way.”
(Jackie 50 HCV neg. Jacob 63 pos.)

- Fraser et al. (under review)

Results



Affording new responsibilities

- “So Jacob’s supposed to go in and get his own equipment. I’m supposed to go in and get my own equipment. Nobody ever addresses us like a community... or friendships and couples, and, you know, people in your house that might use, or even in the block, the same block of flats that might use, or the neighbourhood, or what of friends coming over, or whatever. Nobody ever addresses us like that because we’re not supposed to be passing gear on, legally. So yeah, you’re supposed to just be there for you. And I think it’s about time that people did, because it’s so central to the way we use and it’s central – it’s not just central to the way we actually inject – it’s central to the way we use. It’s central to whether we get on that day. We make those decisions as a couple.”
(Jackie 50 HCV neg. Jacob 63 pos.)

- Fraser et al. (under review)

Results



Affording new conversations

- Janine: “Because, if you weren’t aware, you’d go, ‘Loving someone doesn’t mean you need to share everything,’ [poster 6] and you’d think, ‘What don’t we need to share?’ And then you’ve got ‘your fit, my fit’. So it would bring on a conversation about [the assumption that] ‘if we had sex, we were going to get everything anyway.’ And, you know, it brings on that process of, of learning...”
- James: “I think it’s great. Like let me say it doesn’t mean that you need to share everything and I just reckon like it’s great.”

(Janine 54 HCV neg. James 50 HCV neg.)

- Fraser et al. (under review)

Results



Recommendations for improvements

- “But, as I said, to me it’s a lot of box. Like, I, I tend to prefer to just get a handful of fits rather than a box, like, you know, even a 10-pack box or something because I just, like I said before, the concern about the environment and stuff and just, you know, the amount of stuff you have to get rid of, you know.”

(Uma 46 HCV neg. Ulrich 36 HCV pos.)

- Fraser et al. (under review)

NSP & Harm Reduction Services



Draw attention

- Something that portrays couples

Enabling conversation

- Between client and staff

Explain to staff

- Not meant to provide complete messages
- Health absolutism



Accompanied by activity?

- Elaborated experience

Summary



Activate special features of couples

- Couple \neq individual x 2
- Couple frequently ignored, discounted, seen as site of harm
- Care and social protections of couple can be positively used
- Couple – fluid and dynamic

Use in sector, work with professional ethos

- Understand concerns and limitations

Re-think materials and objects

- Not neutral in meaning
- Re-design materials to enhance meanings for impact and create new worlds



our hit...your fit...my fit



UNSW
SYDNEY



CSRH

Centre for Social Research in Health

NDRI

national drug research institute



Curtin University

Recommendations



1. Develop and implement workforce capacity-building strategies for the BBV sector
2. Develop and implement harm reduction/HCV prevention materials tailored to couples who inject drugs
3. Consider other programs within the harm reduction, drug treatment and HCV care sectors that are amenable to including a focus on couples who inject drugs – naloxone, couples-oriented detox, OST, HCV care
4. Review programs in the broader social welfare field that do not acknowledge the resources of couples, or indeed exclude couples as clients, such as drug rehabilitation facilities, crisis accommodation, and other social services and welfare agencies
5. Consider more focused advocacy for reform of relevant laws and regulations around injecting equipment that impact couples

Recommendations



6. Recognise the importance of an enabling legal and policy environment (e.g. Ottawa Charter principles) for all people who inject drugs. This should include the participation of drug users in all processes that affect people who use drugs.
7. Recognise that many of the harms from injecting drug use result from the criminalisation of drug use. This includes acknowledging the impact that criminalisation continues to have on people's capacity to access healthcare and reduce harm.
8. Further research on same-sex couples is required

In your groups

- What would you do with these results?
- Meanings of objects/equipment – where else does this apply?
- How should HR work change as a result of these results?
- How should these results be further disseminated?



For the record...

- Thinking back over the day...
 - What do you want us to know?
 - What do you want us to do?
 - Will this day affect your work?



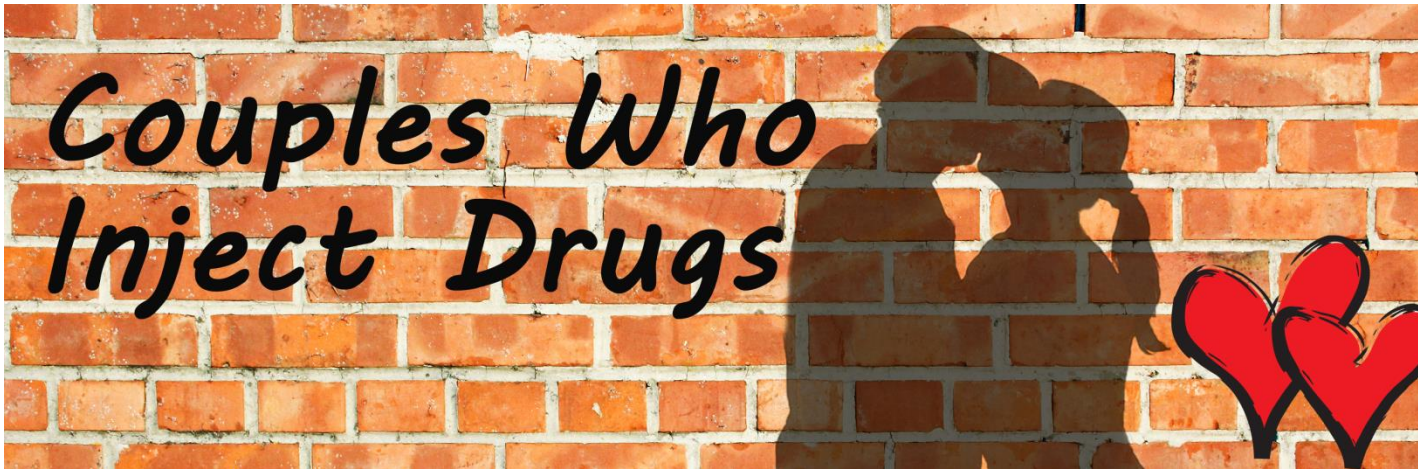
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Thank you



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