ART use or non-use by PLHIV in Australia

UNSW AUSTRALIA

Never Stand Still | Arts & Social Sciences | Centre for Social Research in Health

Limin Mao,

Christy Newman, John de Wit

Limin.mao@unsw.edu.au

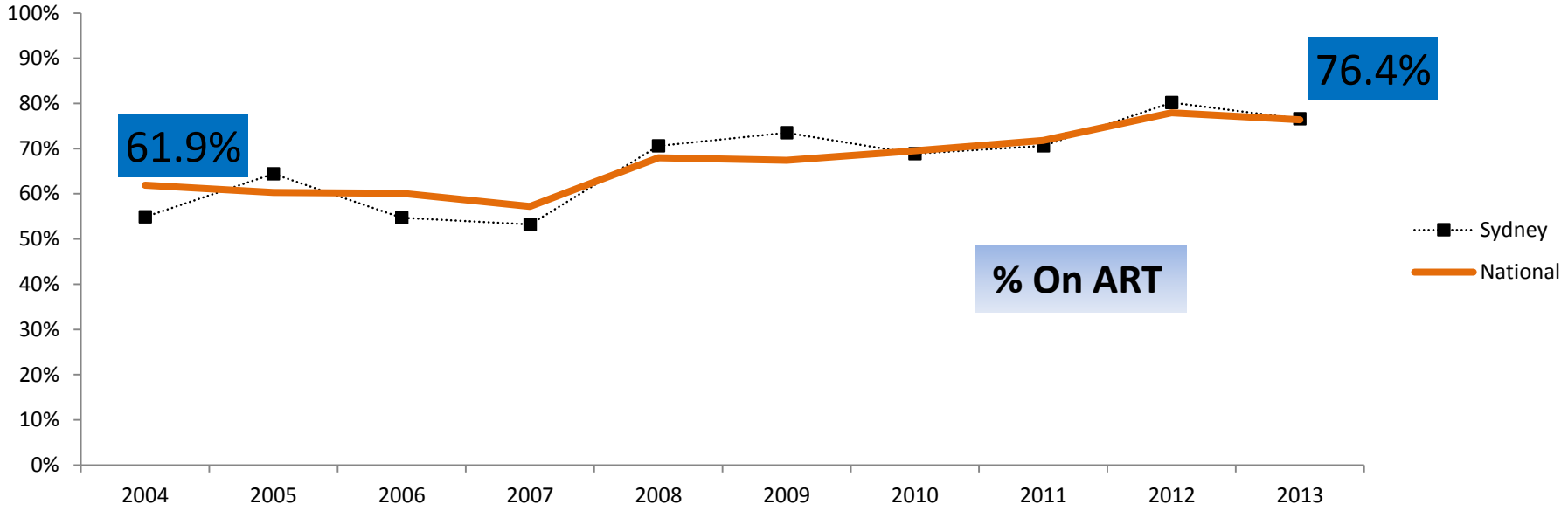
A successful HIV response depends on an increasing range of behaviours – not only of affected people but also of service providers and other stakeholders

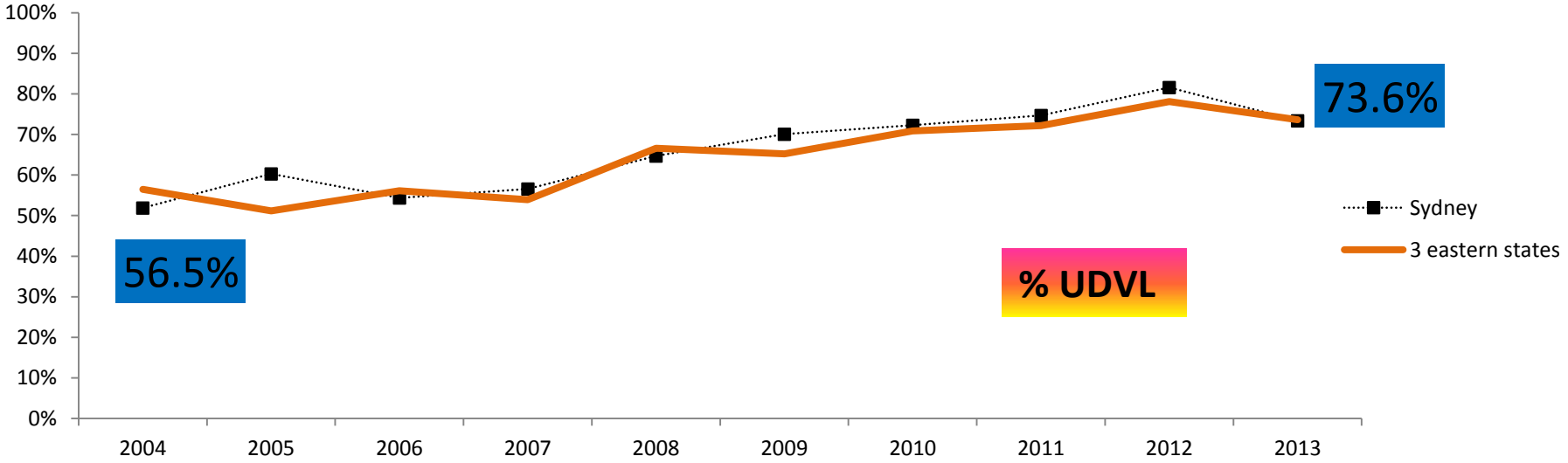
Latest country comparison in the HIV cascade

	Living with HIV	Dx	Linked to care	In care	On ART	Adhere	VL<50
Aus	27,674	86%	78%	76%	66%		62%
DMK	6,500	85%	81%	75%	62%		59%
UK	98,400	n/a	79%	70%	67%		58%
NLD	25,000	n/a	73%	68%	59%		53%
FRA	149,000	81%	n/a	74%		60%	52%
CND(BC)	72,000	71%	67%	57%	51%	44%	35%
USA	1,148,000	82%	66%	37%	33%		25%

Source: Raymond et al., 2014 J Int AIDS Soc

More on better ART: HIV+ GCPS participants





NHMRC-funded ART Uptake project

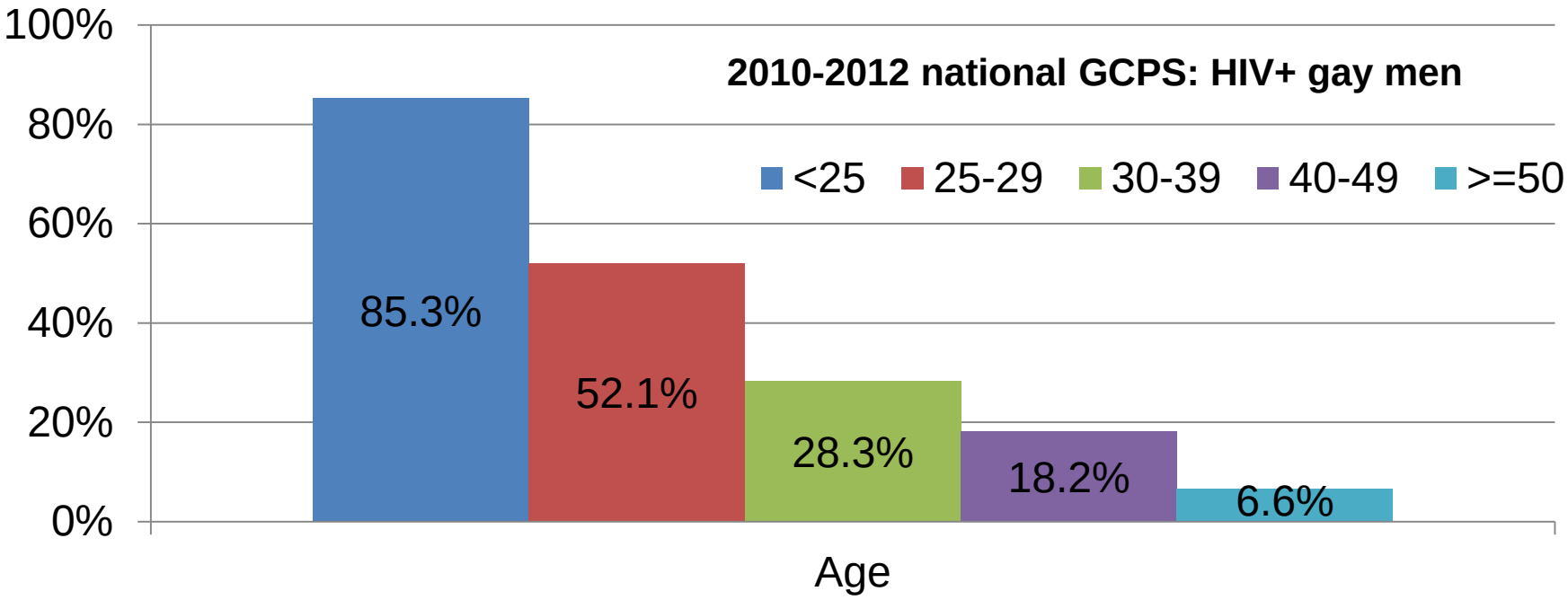
- Lack of robust estimates of ART coverage
  - How much improvement can be achieved?
- Understanding current non-use
  - Range of perspectives reflecting various concerns
- Offering support while respecting choice
  - Acknowledging and addressing subjective perspective
- Understanding prescribing practices
  - Increasing prescriber support for early ART initiation
- Attitudes and practices follow evidence and guidelines?
  - Process of gradual diffusion and behaviour change

Understanding ART use or non-use

- Clinical, personal, social and structural barriers to ART uptake and reasons for non-use in PLHIV

- Attitudes and practices of ART prescribers in terms of recommendations for ART initiation

ART non-use by age group: under 30s



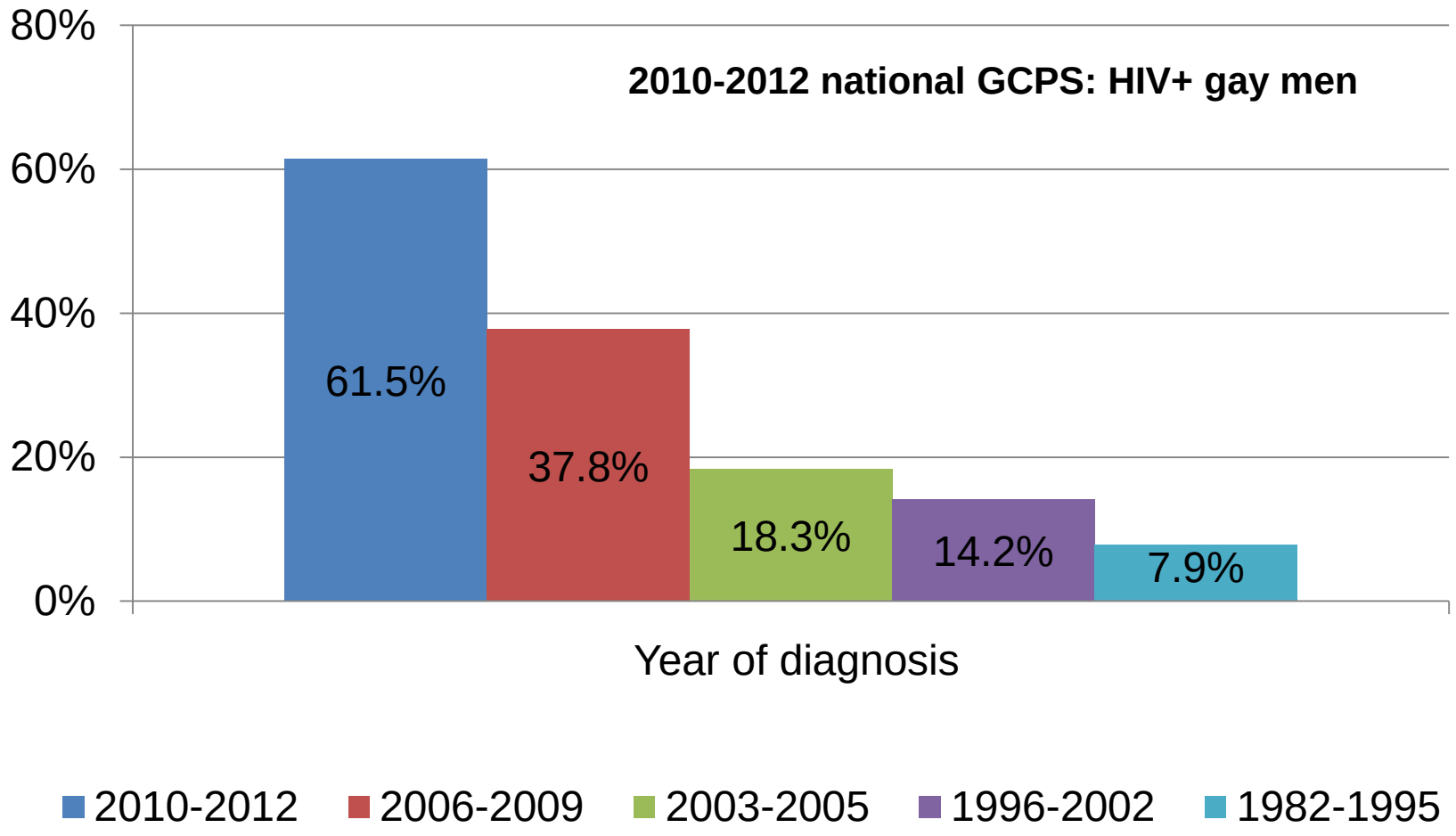
Mao, et al., 2015 *HIV Medicine*

TABLE 1. A Significant Difference by Age (in years) in CD4⁺ T-Cell Counts at HIV Diagnosis

	15–19	20–24	25–29	30–34	35–39	40–44	45–49	50–54	55–59	60–64	65–69	70–74	75+	*P*
MSM PHI														
CD4⁺ T cells/mm³	547	578	561	584	588	565	550	553	438	380	418	422	312	0.003
n	22	194	348	365	329	235	150	75	42	17	8	2	1	
All MSM														
CD4⁺ T cells/mm³	527	543	513*	493*	477*	438*	421*	365*	327*	309	291	253	251	<0.0001
n	107	840	1571	1850	1657	1287	826	543	355	177	109	39	17	

Source: Murray J. 2013 *JAIDS*, Australian HIV Registry 1980-2010

ART non-use by year of diagnosis: <=3 years



Mao, et al., 2015 *HIV Medicine*

Younger age, recent HIV diagnosis, no welfare support, and no annual sexually transmissible infection screening are associated with non-use of ART mong HIV-positive gay men in Australia

Table 2 Factors independently associated with ART non-use among HIV-positive men in the GCPS 2010-2012 (N=1,911)

	AOR*	95%CI	p
Earlier survey round	1.40	1.20-1.65	<.001
Younger age group	1.66	1.45-1.92	<.001
Shorter duration of HIV diagnosis	1.78	1.59-1.98	<.001
No testing for STIs in the 12 months prior to survey**	1.55	1.03-2.34	0.03
Not receiving social welfare payments	2.20	1.05-2.54	0.04

Current ART coverage among HIV-positive gay men in Australia is reasonably high. To further increase ART coverage and promote early ART initiation in this population, better clinical care and sustained structural support are needed for HIV management throughout their life course. (Mao et al., 2015 *HIV Medicine*)

Centrality of subjective experience

- Acceptance, adjustment and coping
- Perceptions, beliefs and attitudes
- Social norms and experiences of others

- Balance of perceived necessity and concerns
  - Horne et al. J Acquir Immune Defic Syndr 2007;45:334-41
  - Beliefs about ART were associated with uptake of and adherence to treatment at 12 month follow-up

Participant profile

- 27 in-depth interviews with PLHIV across Australia who were not currently taking ART (Aug 2012 – Jan 2014)
- 23 men and 4 women: aged 20-68 years
- 19 gay men; others heterosexual (3M, 4F), bisexual (1M)
- 8 born overseas (4 in English speaking countries)
- Diagnosed in different eras, and had been living with HIV for 0-4 years (11), 5-14 years (9) or 15-27 years (7)
- Almost half ART naïve (12), others minimal/intermittent
- Recent CD4: unknown (2), <350 (4), 350-500 (6), >500 (14)
- All engaged with medical care, treatment decisions known

Thematic analysis of reasons for not using ART

Why not now: understanding reasons for treatment non-use

- Following doctor's orders-not yet needing medication
- Questioning biomedicine
- Protecting wellbeing
- Protecting way of life
- Protecting sense of self

Thematic analysis of reasons for not using ART

Following doctor's orders

[The doctor] said I don't need to take antiretrovirals yet … He says, 'Your viral load is low and it's, everything's okay at the moment, within normal range.

Andrew: heterosexual man, 60s, born in Australia, dx 2009, no ART use, CD4+ count>500 cells/mm3

Questioning biomedicine

I feel like when I am starting the 'official' treatment… I [will] bring more chemicals to the body that I don't believe should be there … I always grew up in a house [where] vitamins and supplements [were] the priority [over] conventional medicine. And that's why I'm trying to prevent starting on medication as long as I can.

Caleb: gay man, 30s, born in overseas non-English speaking country, dx 2008, no ART use, CD4+ count 350-500 cells/mm3

Thematic analysis of reasons for not using ART

Protecting wellbeing

It's really just the side effect problem, the impacts of medication on the body. And also then how that impacts on my capacity to work … on just my alertness and those sort of things.

Tom: gay man, 30s, born in Australia, dx 2012, ART use for post-exposure prophylaxis only, CD4+ count 350-500 cells/mm3

Protecting way of life

I know what I'm like from past experience … I worry that … I'll just not be able to take it every single day for the rest of my life … And like, yeah … if I end up like staying out at the last minute … but [then remember], "Crap, I need to go back and take these tablets!"

Eddy: gay man, 30s, born in overseas English-speaking country, dx 2012, only ART use was for PEP, CD4+ count>500 cells/mm3

Thematic analysis of reasons for not using ART

Protecting sense of self

Well, there [are] a lot [of benefits to delaying initiation] because I don't have to worry about adherence to a particular drug. I don't have to worry about taking it for life. I don't have to worry about my liver or anything, problems or anything. I don't really have to worry. I'm just okay, so far I'm fine.

Sam: gay man, 50s, born in Australia, dx 2000, <1 month ART use, CD4+ count>500 cells/mm3

I don't want it to define me. I don't want treatment to define who I am. And I don't let the virus define me either.

Dominic: gay man, 30s, born in Australia, dx 2012, no ART use, CD4+ count>500 cells/mm3

Narrative analysis of frames to explain ART non-use

Where I'm at: appreciating underlying views on HIV treatment

- Treatment acceptance
- Treatment deferral
- Treatment refusal
- Treatment as low priority

Narrative analysis of frames to explain ART non-use

Treatment acceptance: **'It's just a waiting game'**

> The general impression I'm getting is, "Just hold and see, don't just jump straight into it if you don't have to." [And] my partner has said that, "Don't rush into it..." Wait and see if it's a consistent result and a pattern develops … [And the doctors] themselves, they think I should wait and see how it all plays out.
>
> *Tom: gay man, 30s, born in Australia, dx 2012, ART use for post-exposure prophylaxis only, CD4+ count 350-500 cells/mm3*

Treatment deferral: **'I'm trying to avoid it for as long as possible'**

> Look, I think that time will come, but for me it's obviously taking a very long time! … it's almost like for me a real stubbornness. It's like, "No! Not until I'm absolutely half-dead and have to."
>
> *Matt: gay man, 40s, born in Australia, dx 2005, few weeks ART use, CD4+ count>500 cells/mm3*

Narrative analysis of frames to explain ART non-use

Treatment refusal: **'It will never be worth the risk'**

> When I die, I'm still going to have [HIV] and then I [will have] gone through all these side effects … for nothing. For them to experiment to see which one might work. Well, it's not good enough … I wouldn't have the time to play with my daughter … to spend with my partner … My social life would be ruined … No, thanks. The side effects are just too great. Mate, if it said, "Oh, it might make you sick," okay. Not, "You might feel impending doom, like you're going to die, but you might be all right." … There's too many ifs.
>
> *Rachel: heterosexual woman, 40s, born in Australia, dx2011, no ART use, CD4+ count<350 cells/mm3*

Narrative analysis of frames to explain ART non-use

Treatment as low priority: **'I'm dealing with other things right now'**

> I am in a new country, I need money. I do cleaning … I stay awake all through the night and I have to do a lot of scrubbing and a lot of sweeping … Now you can imagine if I have to combine all that with taking drugs, it's going to be really, really huge. But I need to survive in Australia.
>
> *Adam: gay man, 20s, born overseas in non-English speaking country, dx 2010, no ART use, CD4>500 cells/mm3*

Views on initiating ART for prevention benefits

1. High levels of awareness: Only 4 had never heard of TasP

2. High levels of understanding: Of those who had heard of TasP, almost all were able to clearly articulate that this involved early initiation of ART for the purpose of reducing onward transmission

3. Small minority in support: Only 4 of the participants who were aware of TasP expressed views which were fully in support

4. Mostly concerned or critical: The remaining participants (n=19) articulated either uncertain or strongly critical views of TasP

Critical views on treatment as prevention

- Tensions regarding who will benefit
- Tension regarding risk reduction (alternative RR strategies already in place)
- Tension regarding treatment norms (shifting towards everybody should be on treatment)

Critical views on treatment as prevention

There are statements made like … ‘Starting treatment early has benefits’… I completely understand the public health imperative, that there is a chance here to reduce further, HIV transmissions. But I guess from a selfish perspective, I don’t really understand what that statement means to me, as someone who’s just contracted HIV … What is the balance of research at the moment? … Is there any benefit of really early commencement of treatment? … I have to rely on the experts that I deal with in terms of getting what they think and their advice. So … when I hear that, I think, well, “Maybe you could … get the clinicians more on side before starting those campaigns and getting the message uniform at least?”

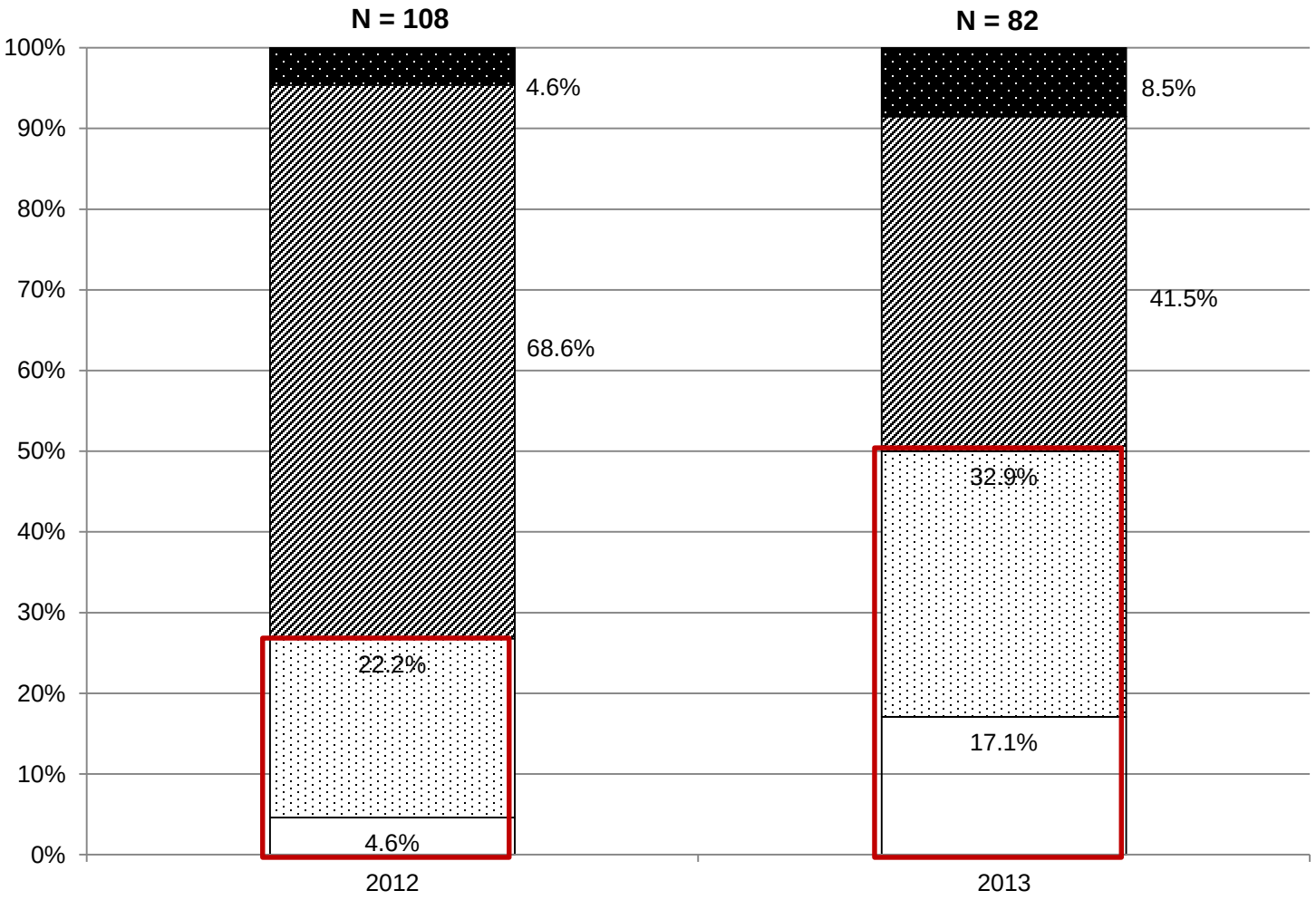
Gerard: gay man, 50s, born in Australia, dx 2012, no ART use, CD4+ count>500 cells/mm3

Critical importance of clinical settings

- Offering HIV testing
- Discussing risk reduction
- Providing treatment and care
- Linkage to other services
- Prophylactic use of cART

- More than operational issues
- Working effectively with clients
- Understanding behaviours

Recommended start of ART by prescribers



Mao, et al., 2015 *MJA*

Early ART as treatment-Yes, supported

- 50% of the prescribers in 2013 would most strongly recommend early ART initiation (CD4+ above 500 cells/mm^3 or ASAP regardless of CD4+) *vs.* 27% in 2012
- Over 80% of the prescribers believed that there had been sufficient evidence to support early ART initiation either at CD4+>500 cells/mm^3 (52%) or ASAP (30%)
- If the patient had a CD4+ 350-500 cells/mm^3 , were asymptomatic and willing to start: over 70% of the prescribers in 2013 reported that they would routinely recommend ART

Early ART primarily as prevention-Not really

- Prescribers' primary concern: individual patient health (over 90%) vs population benefit (less than one-third)
- Out of the average 10 patients each prescriber had initiated to ART annually, 1.4 patients had started predominantly for population benefits.
- High HIV caseload prescribers were more likely to initiate patients primarily to prevent onward transmission

Prescribers' perceptions on patient characteristics in relation to ART initiation

- Hypothetical patient: ART naïve, asymptomatic, CD4-cell count 350-500 cells/mm^3
- Willing to recommend starting ART if…

History of on-adherence	41.5%
History of missed appoint.	43.9%
Unstable housing	63.2%
Problematic alcohol/drug use	64.6%
Ineligibility for Medicare rebate	64.6%
No Medicare card	65.9%
Current mental illness	68.3%
HIV diagnosis < 6 months	73.2%
Using CAM	75.6%
History of imprisonment	82.9%
Younger than 25 years	84.1%
Frequent drug injection	85.4%
Unemployed / on welfare	89.0%
Living in non-metro area	90.2%
Being female	90.2%
Gay man or MSM	90.2%
CVD or diabetes	91.5%
Hepatitis C co-infection	91.5%
Hepatitis B co-infection	92.7%
Selling sex	96.3%
UAI with non-HIV-pos. partn.	97.6%
Non/discordant regular partn.	100%

Acknowledgement of organisational support

- NAPWHA
- ASHM
- AFAO
- Pozhet
- Positive Life NSW
- ACON
- QPP
- VAC
- Living Positive VIC
- Positive Life SA
- NTAHC
- ACT AIDS Action Council
- WAAC
- TASCAHRD
- The Albion Centre
- St Vincent IBAC
- BGF
- TIM

CSRH

ART USE OR NONUSE

SHARE YOUR VIEWS ON HIV TREATMENT

ART use and non-use: an anonymous online survey

Experienced researchers from the Centre for Social Research in Health (CSRH), UNSW, Australia would like to invite people living with HIV (PLHIV) to participate an online survey. The survey is anonymous and will take about 30-45 minutes to self-complete.

Funded by the Australian National Health and Medical Research Council, we want to have a better understanding of ART use and non-use among PLHIV. We will explore people's experiences with ART and measure a number of clinical, personal, social and structural factors of ART use and non-use.

If you are aged 18 years or above, living with HIV in Australia, we would like your help! Participation is voluntary. If you wish to take part in the survey, please click the following link artuse.csrh.org , which will direct you to the study webpage.

This study has obtained ethics approval from UNSW (HC14183), ACON (2014/18) & Victorian AIDS Council (VAC/RE&P 14/008). The National Association of People with HIV Australia (NAPWHA) and Australian Federation of AIDS Organisations (AFAO) are our key research collaborators.

UNSW AUSTRALIA