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Initial findings from the Stigma Indicators Monitoring Project

Acknowledgements

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Background

- Stigma originally “*an attribute that is deeply discrediting*” (Goffman, 1963).
- Stigma - social process of exclusion of an individual, who may possess an attribute devalued by the broader social group.
- Social isolation, psychological distress, poor QoL, poor physical outcomes.
- Communicable diseases (e.g. HIV) - transmission to others; negative attitudes re transmission pathways (e.g. unsafe sex, injecting practices).
- Double/layered stigma - possess multiple, co-occurring stigmatised attributes e.g. infectiousness + perceived mode of transmission.

“*Stigma remains the single most important barrier to public action*”

United Nations General Secretary

17th International AIDS Conference in Mexico City in August 2008

- There are five national strategies that address HIV, viral hepatitis and sexually transmissible infections.
- The strategies represent a coordinated national response to reduce the transmission, morbidity and mortality associated with these infections.
- Each contain a set of objectives and targets, with progress measured using a set of indicators via which progress in monitored.

Example:

Objective	Indicator
Reduce the incidence of HIV	Incidence of recent HIV infection among HIV diagnoses Estimated incidence of HIV

- Each strategy contains a clear objective to “eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people’s health”.

FOURTH National Hepatitis C Strategy	Objective	Indicator
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health	

SECOND National Hepatitis B Strategy	Objective	Indicator
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health	

SEVENTH National HIV Strategy	Objective	Indicator
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health	

THIRD National Sexually Transmissible Infections Strategy	Objective	Indicator
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health	

FOURTH National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy	Objective	Sub-objective	Indicator
	Eliminate the negative impact of stigma, discrimination and human rights issues on Aboriginal and Torres Strait Islander health	Actively engage with the Aboriginal and Torres Strait Islander community	

The Stigma Indicators Project

In 2015, CSRH contracted by AGDOH to develop an indicator of stigma among the priority groups identified by the national strategies.

Brief indicator of stigma to be used across the following priority groups:

- Gay and other men who have sex with men;
- People who inject drugs;
- People living with HIV;
- People living with viral hepatitis (B and C); and
- People who engage in sex work;

Related indicator for health care professionals and the general population - measure the expression of stigma, such as discriminatory or negative treatment of patients or clients by health care professionals.

Considerations

- Stigma is a complex construct, which can include anticipation, perception and actual experience of being treated differently to others.
- Range of relationships and settings: interpersonal (family, friends, sexual partners), health care (e.g. GP, dentist), criminal justice, housing, etc.
- Social and political institutions can serve to legitimise exclusion e.g. negative portrayal by the media.
- Enacted stigma (i.e. discrimination): avoidance, excessive pity, blame, shame, verbal abuse, physical abuse, social exclusion, sexual exclusion, among others.
- For people living with BBVs/STIs - multiple layers of stigma.

The indicator

In the last 12 months, to what extent have you experienced stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse or bullying) in relation to your:

	Never	Rarely	Sometimes	Often	Always	Not applicable
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Use of drugs for injecting	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
HIV status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis B status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis C status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Sex work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Other (please specify): _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

Additional items

In the last 12 months, to what extent do you agree that the following occurred?

	Never	Rarely	Sometimes	Often	Always	Not applicable
Health workers treated me negatively or differently to other people	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
People didn't want to have sex or an intimate relationship with me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

Mirrored indicator - HCW

We may judge or regard people negatively at times because of differing cultural background, lifestyle or health issues. The following question asks about whether you have ever done this to others, and we understand that it may be difficult for you to answer. Please be honest in your responses, they will be kept anonymous and confidential.

In the last 12 months, do you feel that you may have discriminated against patients/clients because of their:

	Never	Rarely	Sometimes	Often	Always	Not applicable
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Use of drugs for injecting	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
HIV status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis B status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis C status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Sex work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Other (please specify): _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

In the last 12 months, have you felt stigmatised because of the area you work in?

Never	Rarely	Sometimes	Often	Always
1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Methods

New and existing surveys:

- People living with HIV – new, online survey
- Men who have sex with men (Telling) – online survey via Kirby Institute
- People living with hepatitis C and people who inject drugs – new, online survey
- People who inject drugs – via ANSPS, Kirby Institute
- Health workers – new, ASHM contact list
- General Public – Australian Survey of Social Attitudes (Stigma 2)

New surveys:

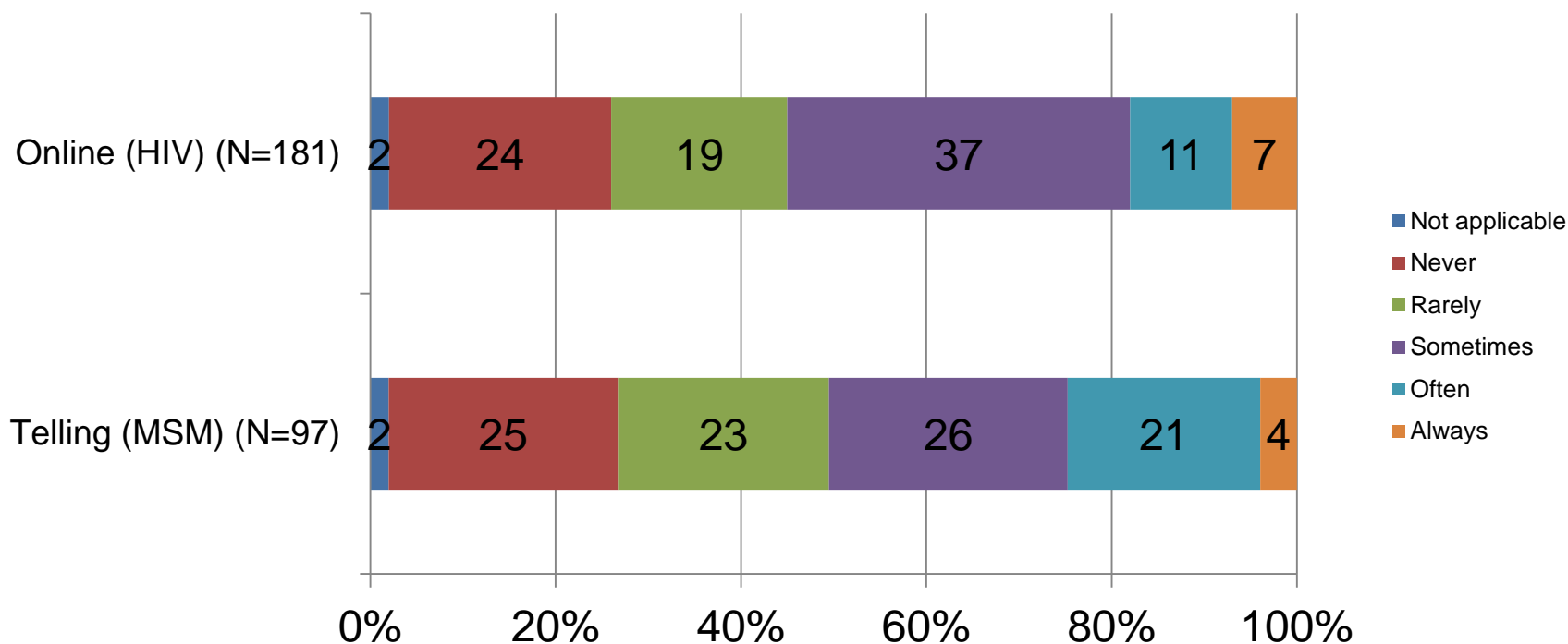
- examine covariates, including disclosure, treatment, substance use, social support and mental health (psychological distress).
- additional stigma measures, such as internalised and vicarious stigma.

Samples

	Online survey of people living with HIV (N=181)	<i>Telling</i> survey of men who have sex with men (N=339)
Mean age	50 years	39 years
Location	NSW 39%; Vic 18%; Qld 16%	NSW 36%; Vic 28%; Qld 17%
Male	88%	99%
Gay	71%	81%
Cultural background	72% born in Australia	72% Anglo-Celtic
HIV positive	100%	19%
Mean time living with HIV	16 years	14 years
Lifetime mental health	61%	-
On ART	99%	96%
UDVL	94%	95%
HIV/treatment symptoms	27%	-

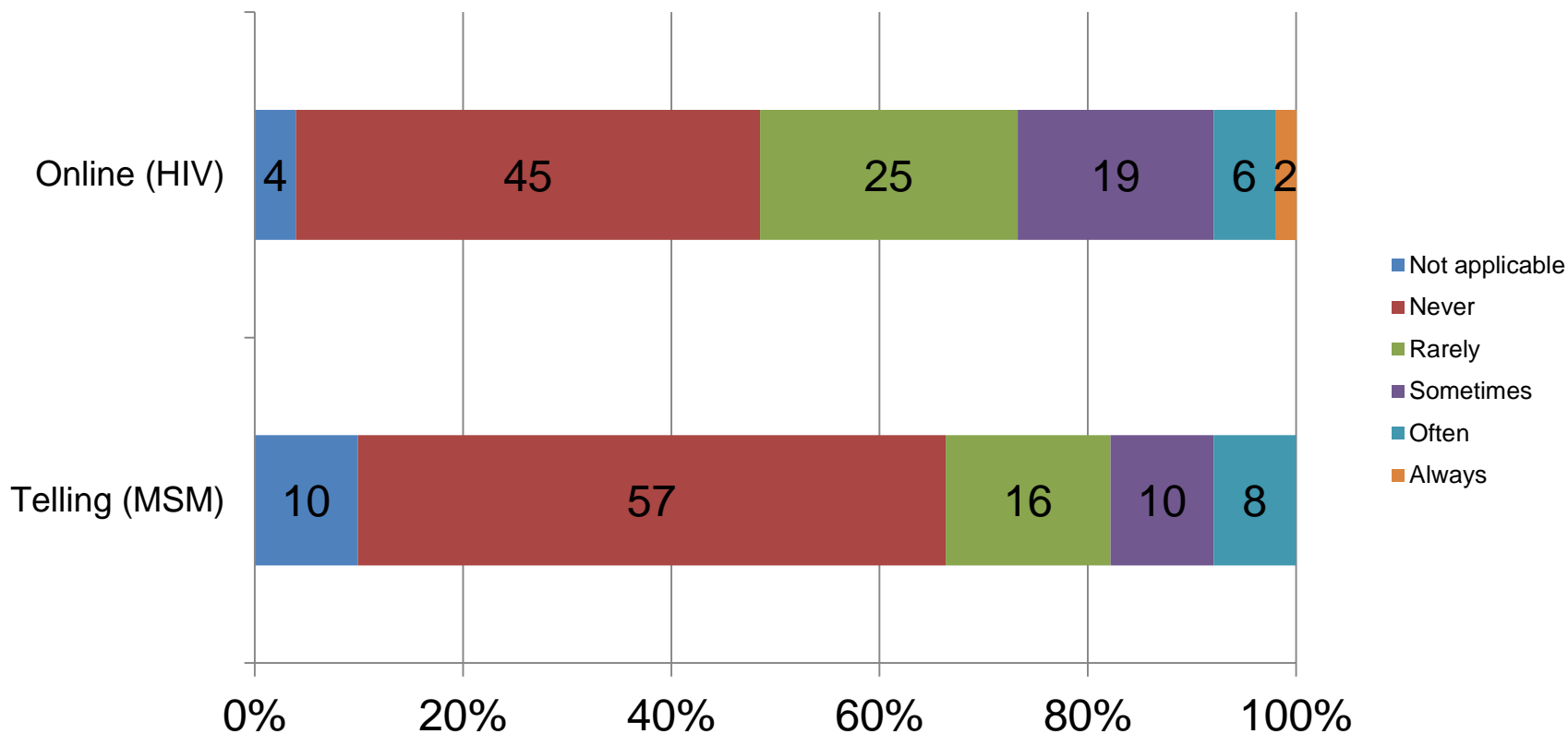
Indicator – HIV (positive participants)

In the last 12 months, have you experienced any stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse, bullying) in relation to your HIV?



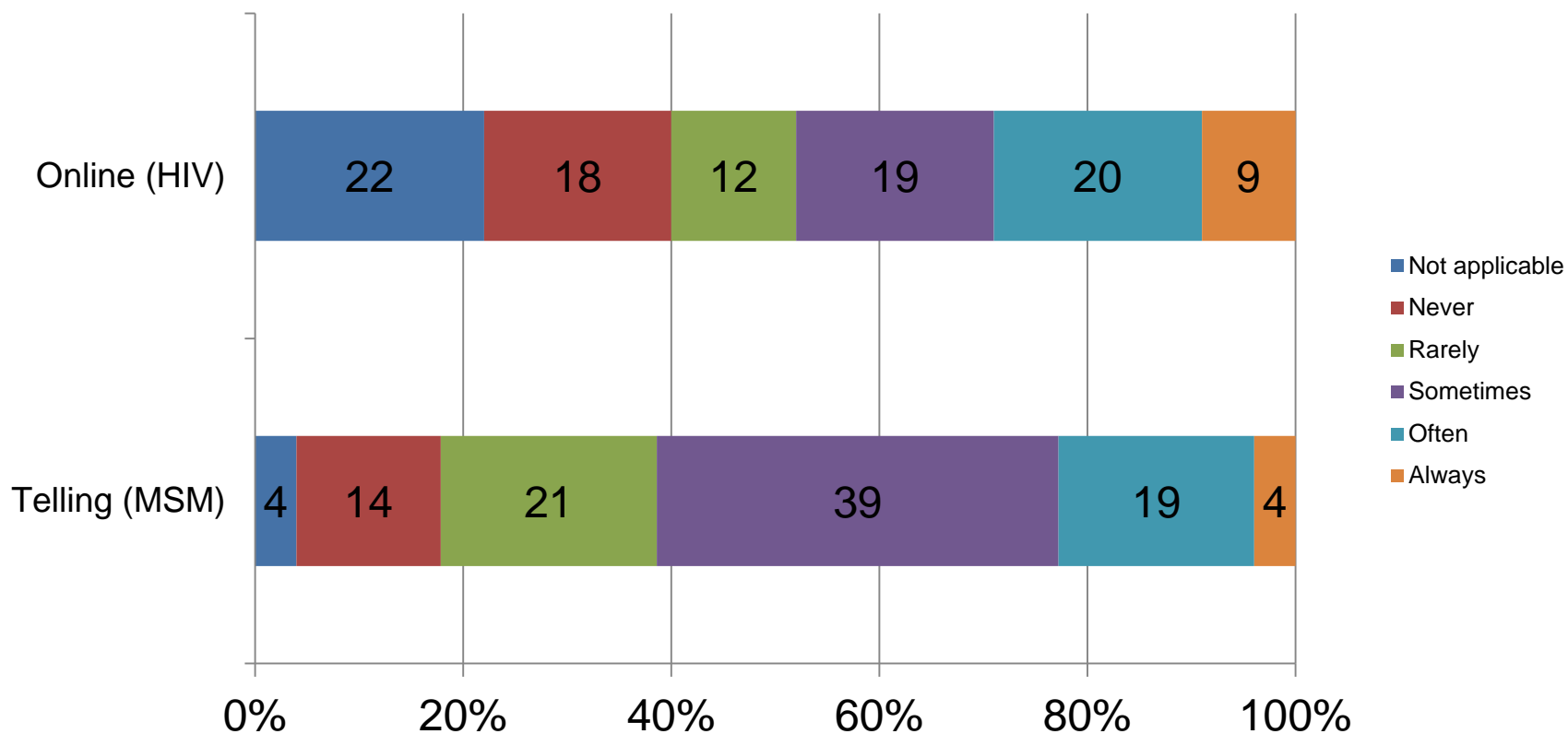
Additional indicator – People living with HIV

Health workers treated me negatively or different to other people



Additional indicator – People living with HIV

People didn't want to have sex or an intimate relationship with me



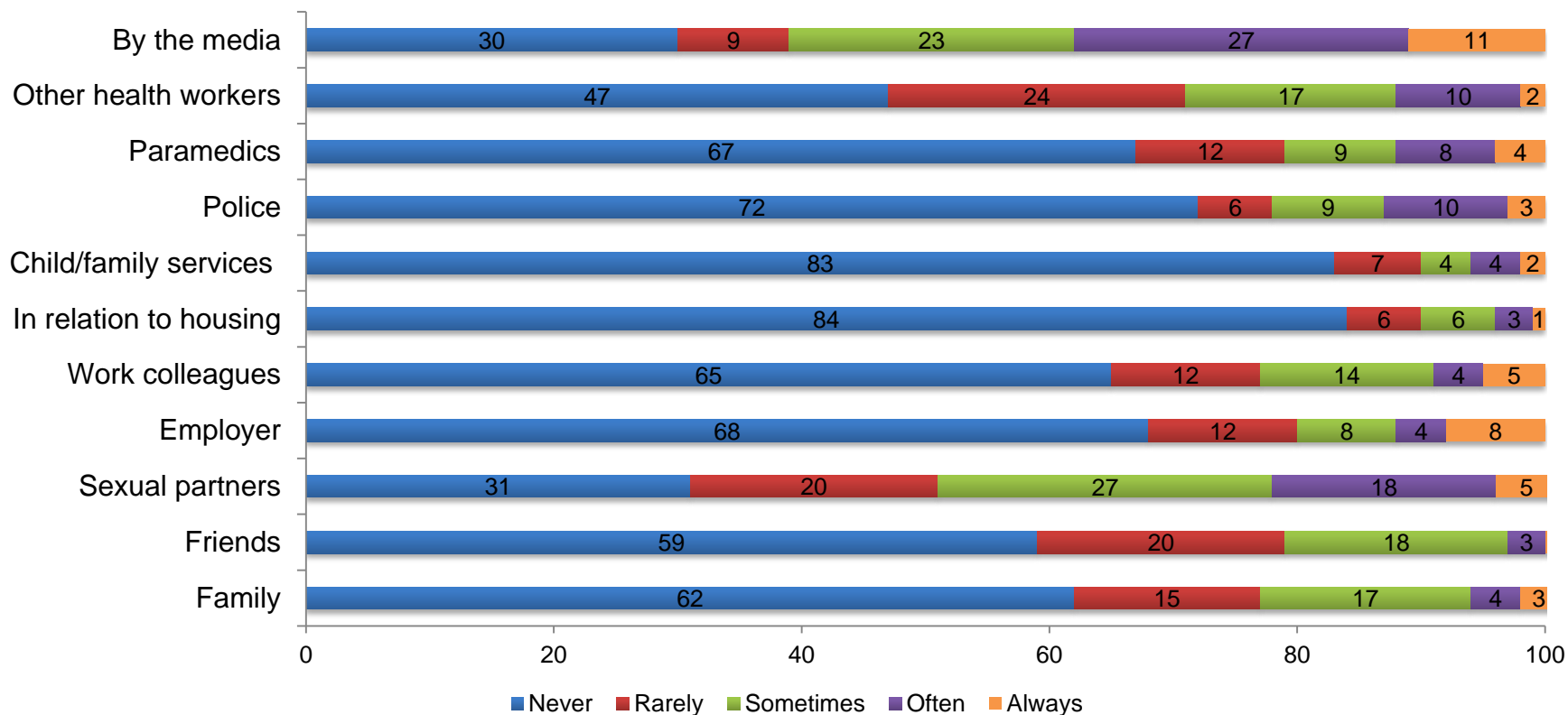
HIV Indicator and other measures

Indicator re HIV status – significantly correlated with:

- HIV-treatment related stigma
 - HIV experiences of discrimination
 - HIV vicarious stigma
 - HIV internalised stigma
 - Indicator – sexual orientation
-
- Greater psychological distress
 - Lower personal wellbeing
 - Reduced social support

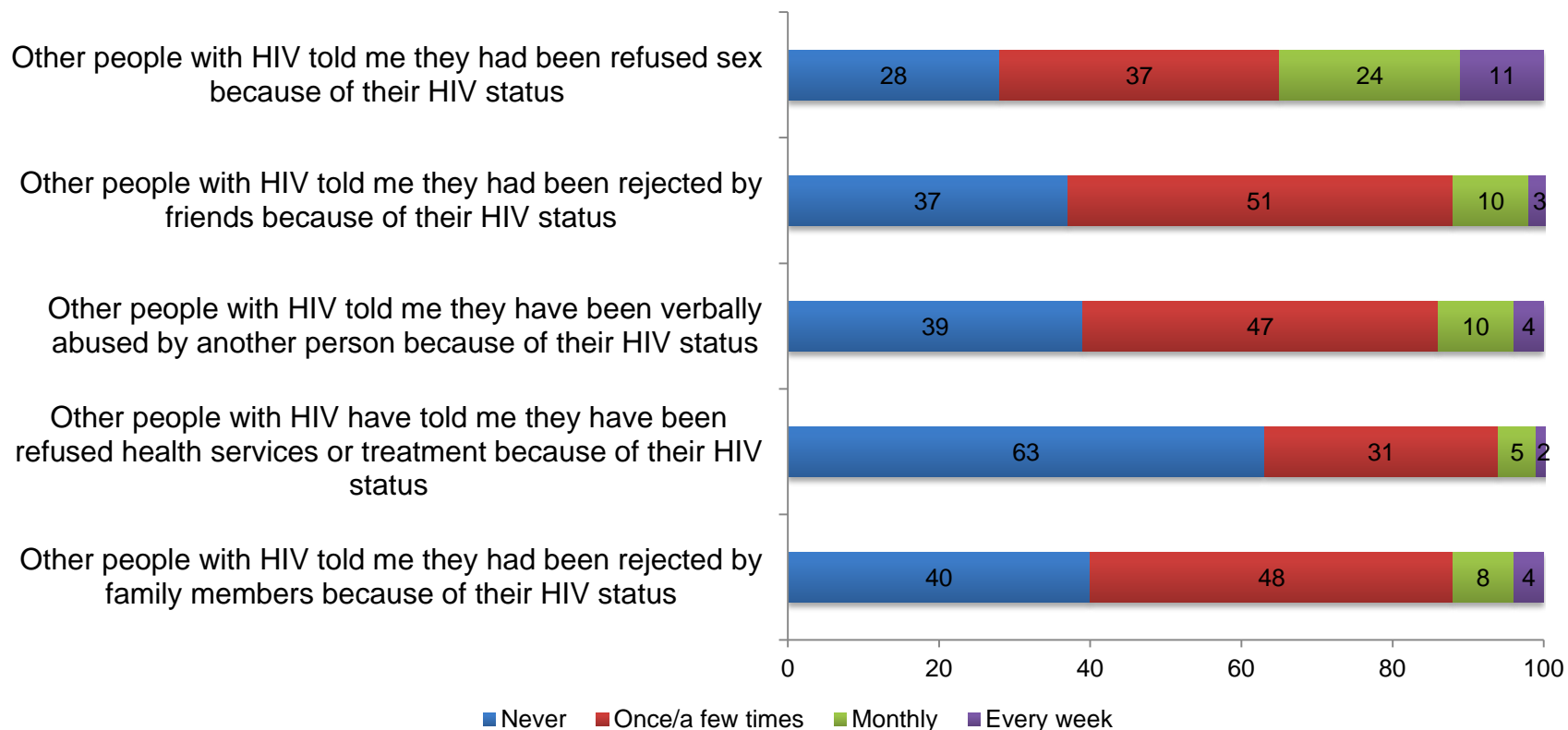
12 month discrimination - source

Past 12 month HIV discrimination by... (%)



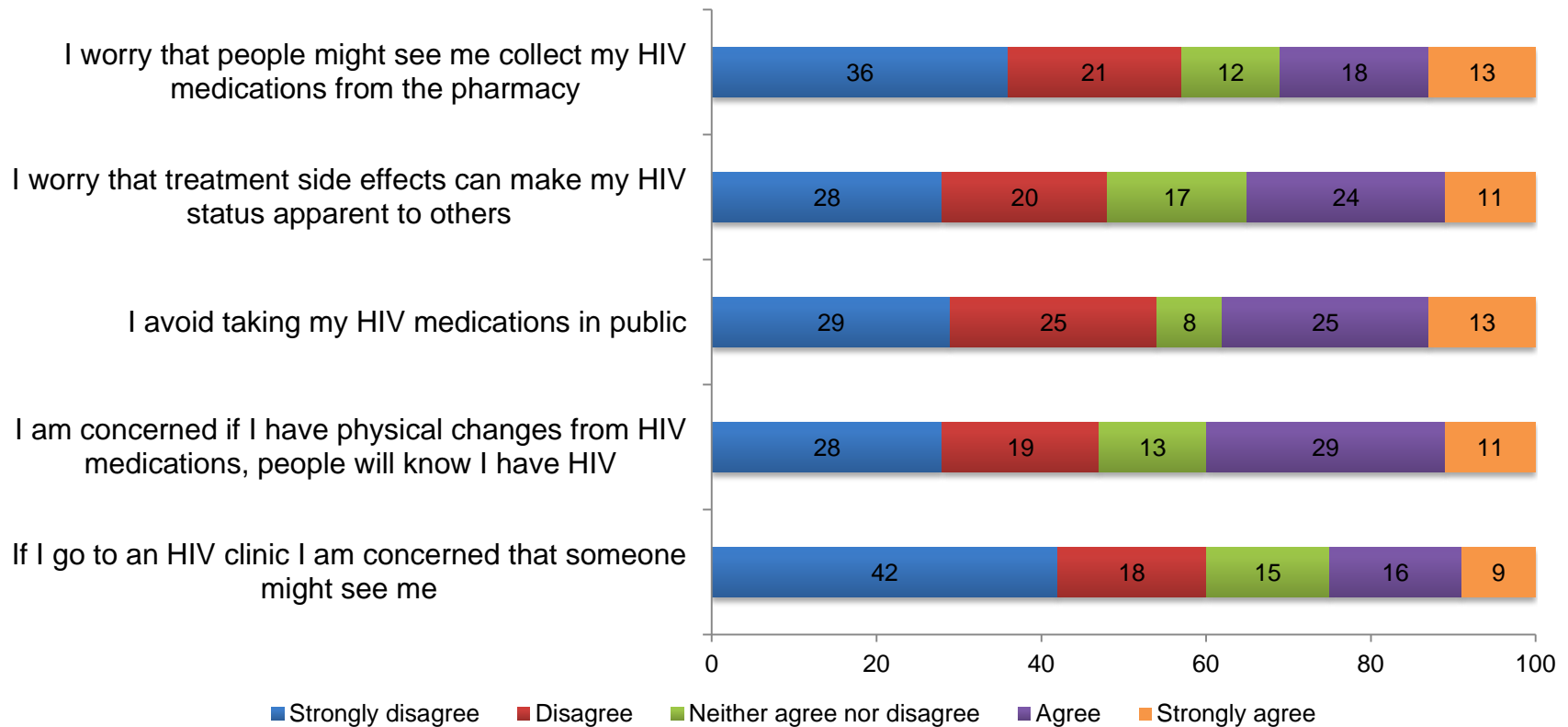
HIV vicarious stigma

Past 12 month HIV vicarious stigma (%)



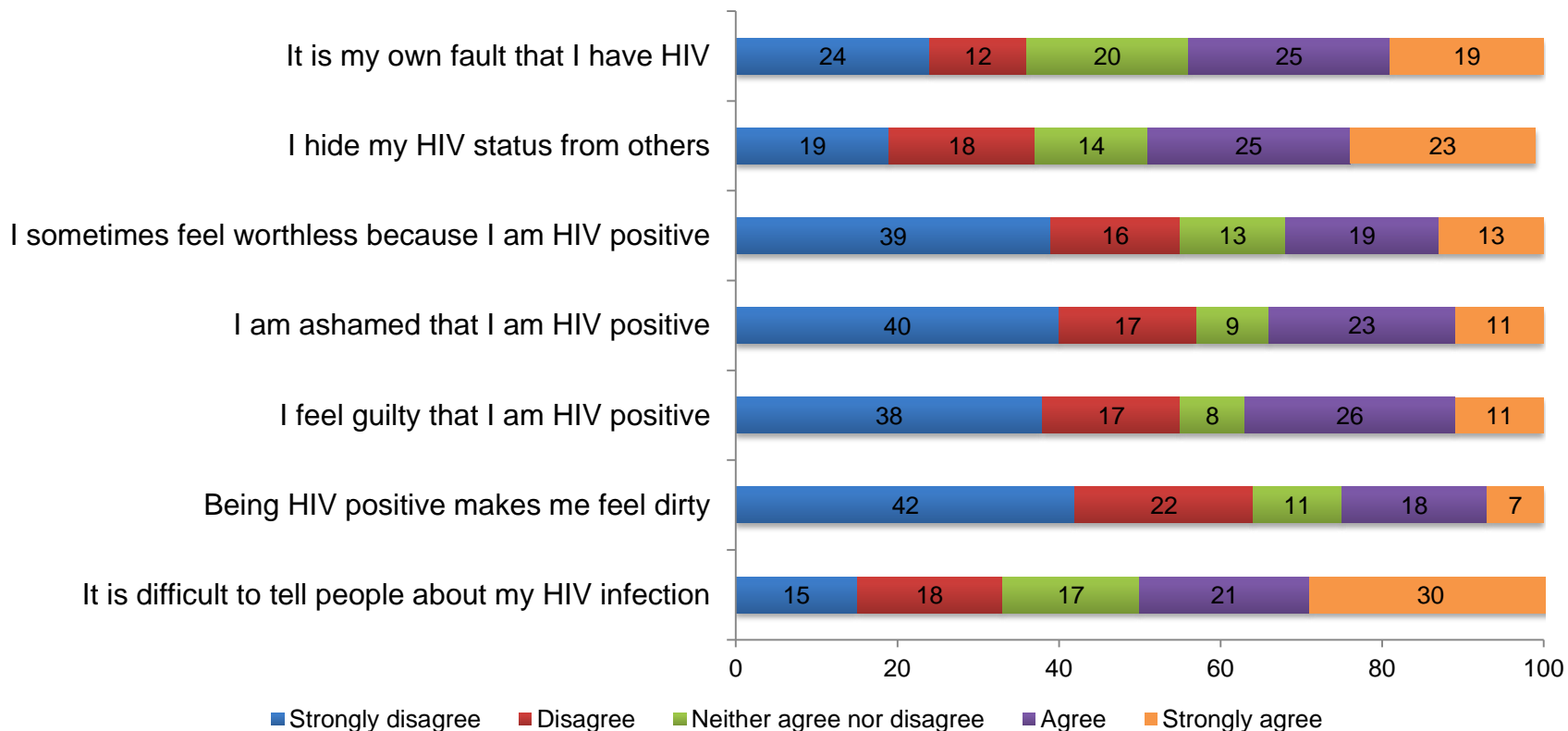
HIV treatment-related stigma

HIV treatment-related stigma (%)



Internalised HIV stigma

Internalised HIV stigma (%)



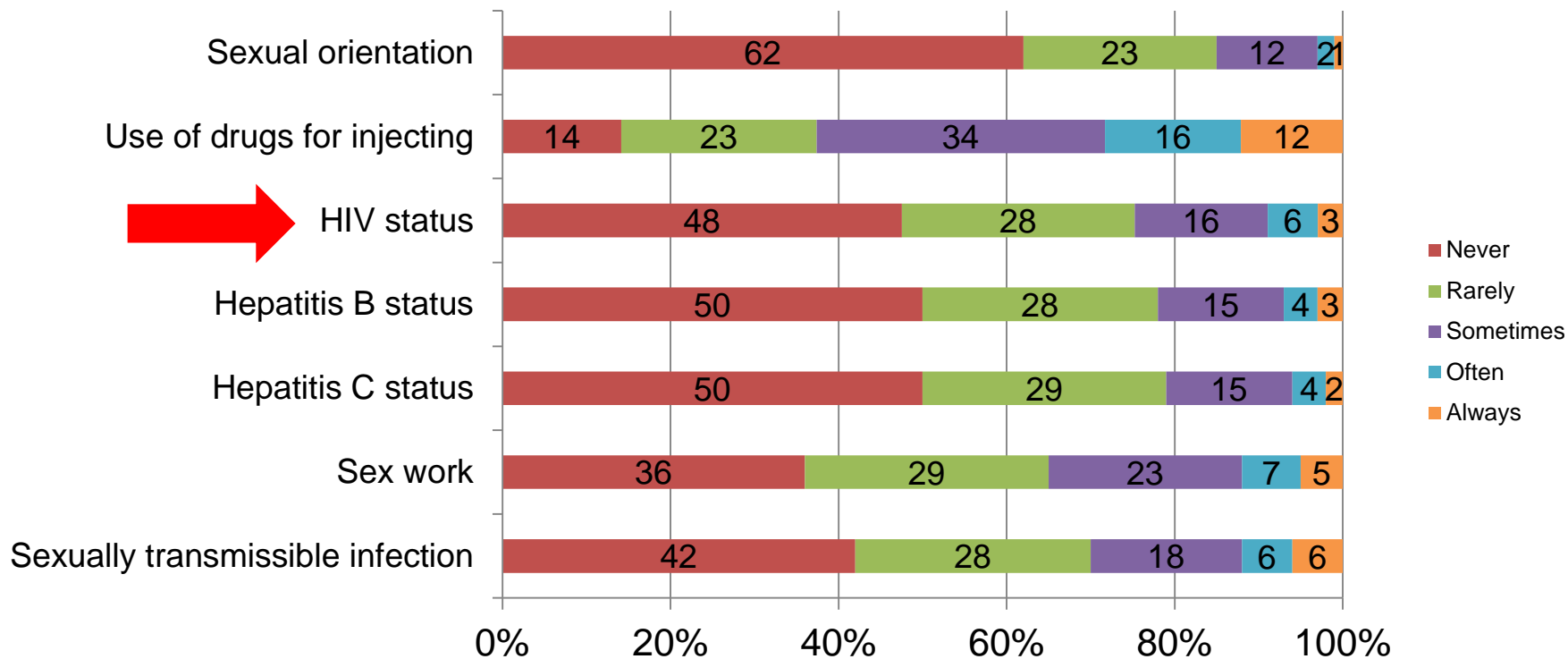
General Population – Stigma 2

N=1001		N (%)
Gender	Male	427 (44)
	Female	554 (57)
Age – Mean (SD)		54.34 (17.09)
ATSI		23 (2)
Completed Year 12		592 (61)
Completed university		329 (33)
Employed		566 (59)
Live in	Big city	592 (61)
	Town/small city	233 (24)
	Country	141 (15)

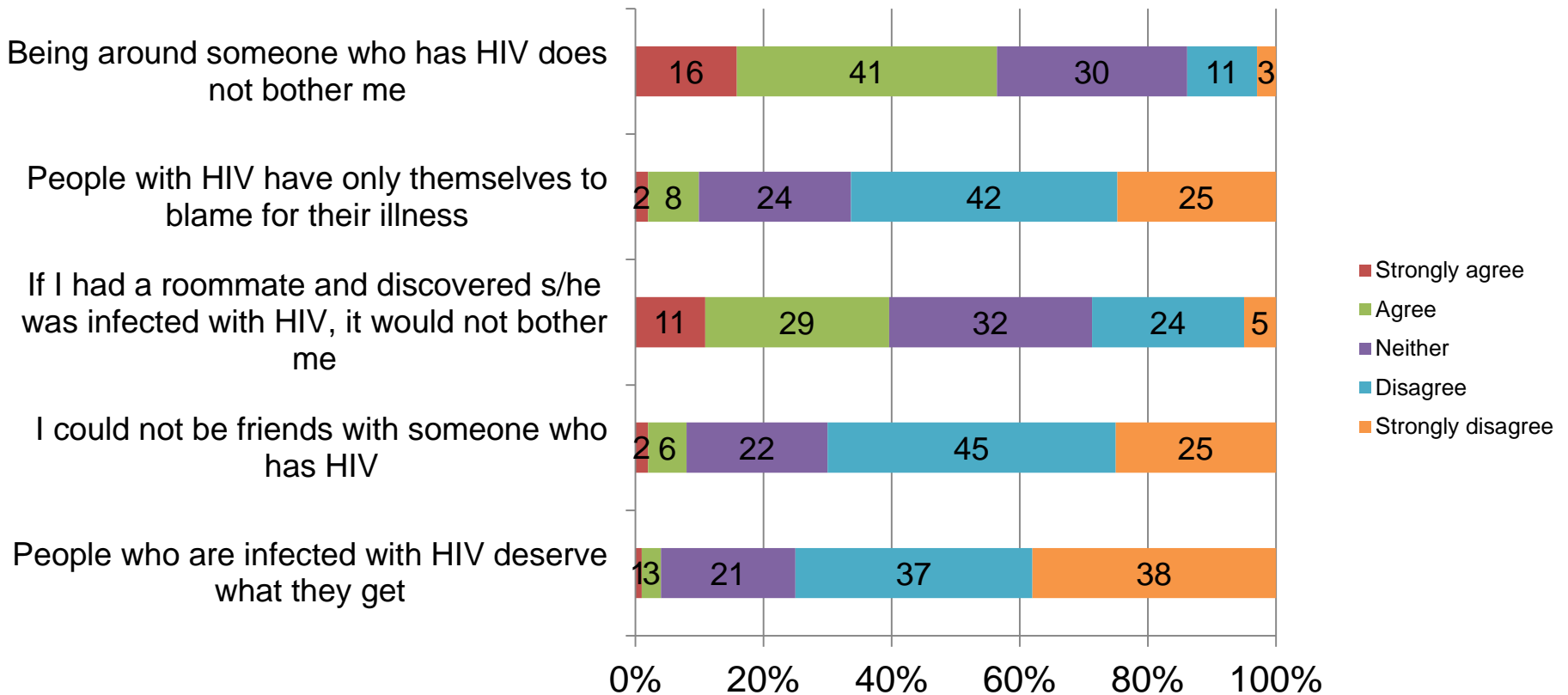
N.B. % reflects percentage of valid responses and does not include missing data

GenPop: Stigma Indicator

Would you behave negatively towards other people because of their:



GenPop: HIV stigma



Conclusion

- Complexities of sample and measures
 - Develop data management pathways, reduce data “messiness”
 - Ask if person lives with each attribute, then ask indicator (remove N/A)
- Stigma 2 – monitor over time:
 - People living with hepatitis B – qualitative work
 - Extend sex worker research, following qual research via Scarlet Alliance
 - STIs – expressed stigma in general population
 - Work to extend hep C, injecting drug use samples
- National strategies aim to eliminate stigma
 - Measure and monitor experiences of stigma is required