

# Patient reported Experience and Outcome of Hepatitis C treatment in people who inject drugs or receive opiate substitution therapy.

## A peer initiated survey in Denmark.

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### Background

There is limited knowledge on how people with recent injecting drug use or on opiate substitution therapy(OST) experience access to and process of Hepatitis C treatment with direct acting antivirals(DAA).

In addition, only a few studies have reported on the patient related outcomes of hepatitis C treatment in people who inject drugs.

Investigating the patient perspective and their experience with treatment might help identify potential barriers to treatment.

### Method

Peer initiated survey by the peer organization "Brugernes Akademi" – "The Users Academy" an activist organization for people who use drugs.



Target population: People on OST or with recent injecting drug use treated with DAA(past 24 months). Target n=200



The questionnaires included

- Patient Reported Experiences(PREM).
- Patient Reported Outcomes(PROM).
- Questions on treatment and provider.

The PREM and PROM were developed for, and with people who inject drugs by Centre for Social Research in Health, University of New South Wales<sup>1</sup>. The instruments were translated and adapted to Danish according to WHO guidelines.

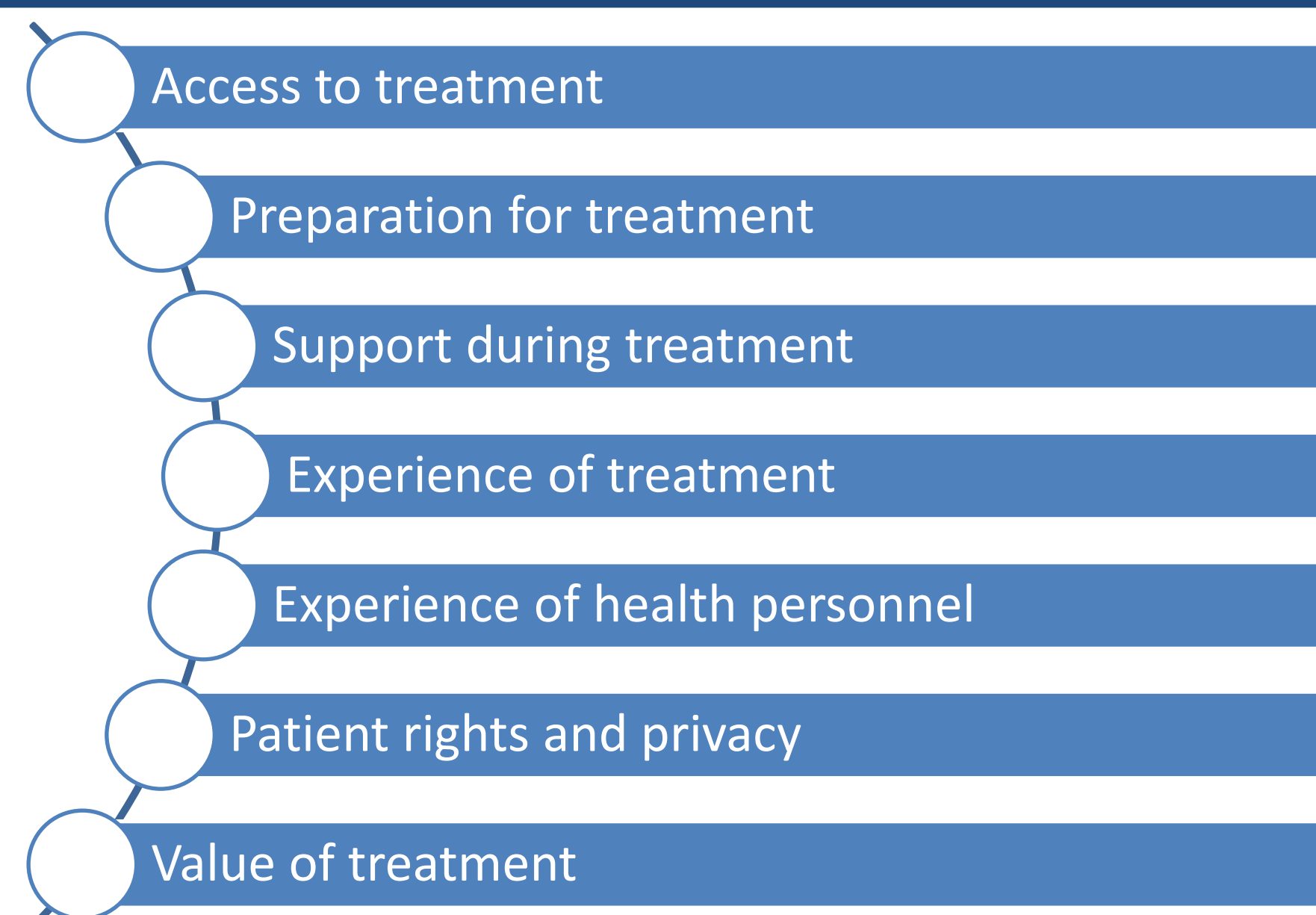


Survey could be accessed online by link from social media or on an I-pad with assistance from a peer or staff at hepatitis C follow-up visits.

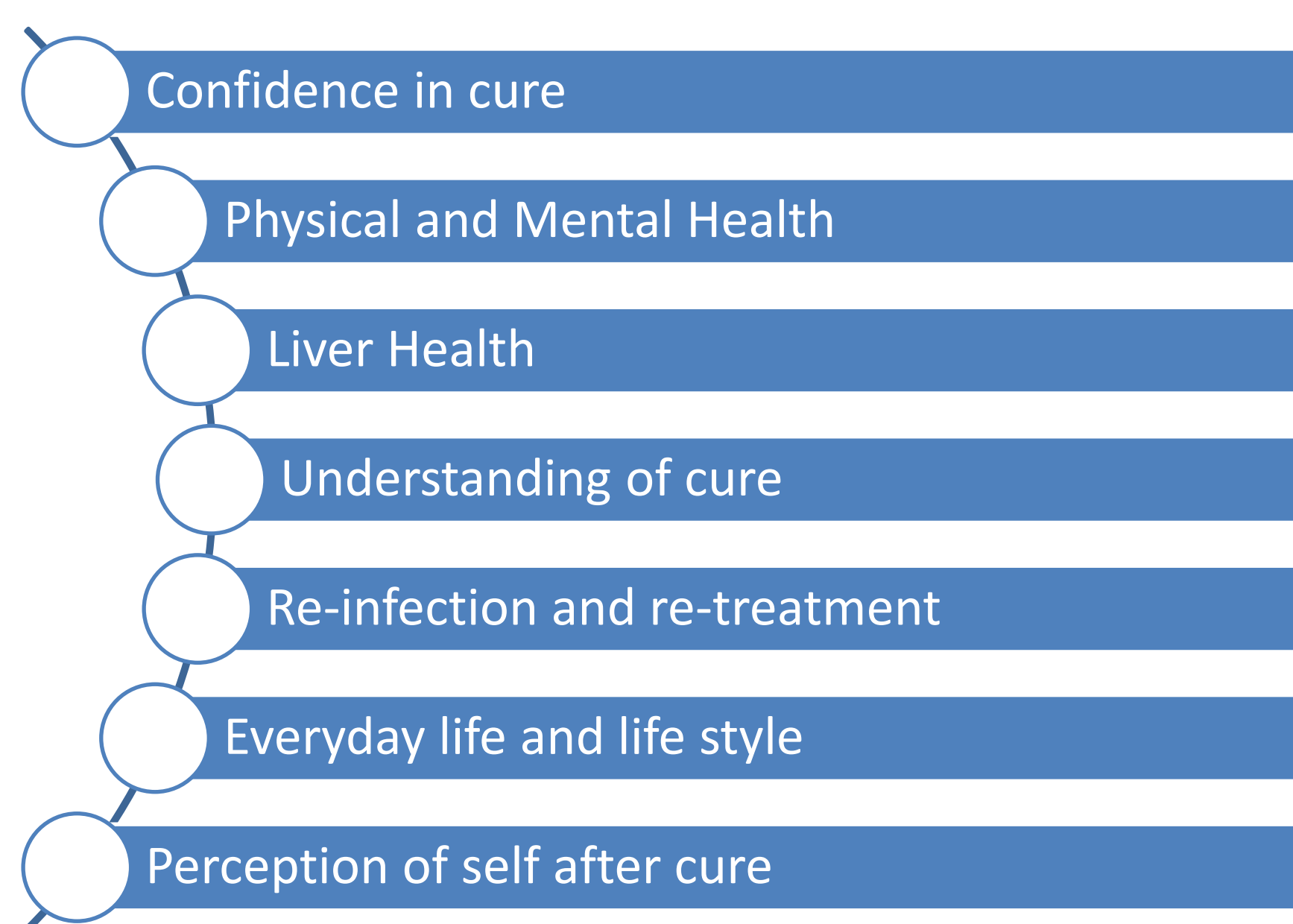
Data were collected in a REDCap database

Questions were answered on a Likert scale (Five options on level of agreement).

### Patient reported Experience Domains



### Patient reported outcomes Domains



### Results

From November 2018 to June 2019, a total of 54 persons accessed the survey. Survey is ongoing. Preliminary results.

Characteristics	Number	(% of respondents)
(Number answering each question)		
<b>Gender (self reported) Female</b> (48)	17	(35.4)
<b>Year of birth</b> (31)	1964	
Median (range)	(1947-1985)	
<b>Self declared Hepatitis C cure</b> (44)	Yes	38(84.4)
	No	1(2.2)
	Uncertain	6(13.3)
<b>Treatment provider</b> (44)	Hospital	30 (68.2)
	OST center	11 (25.0)
	Self purchased	3 (6.8)
<b>Opiate Substitution therapy</b> (45)	Yes	29(64.4)
	No	16(35.6)
<b>History of injecting</b> (34)	Never	2(5.9)
	Not in past 12 months	16(47.1)
	Within 1-12 months	6(17.6)
	Within past week	10(29.4)
<b>Year of first injection</b> (38)	1992	
	Median(Range)	(1973-2018)

Table 1: Cohort

### Patient Reported Experience

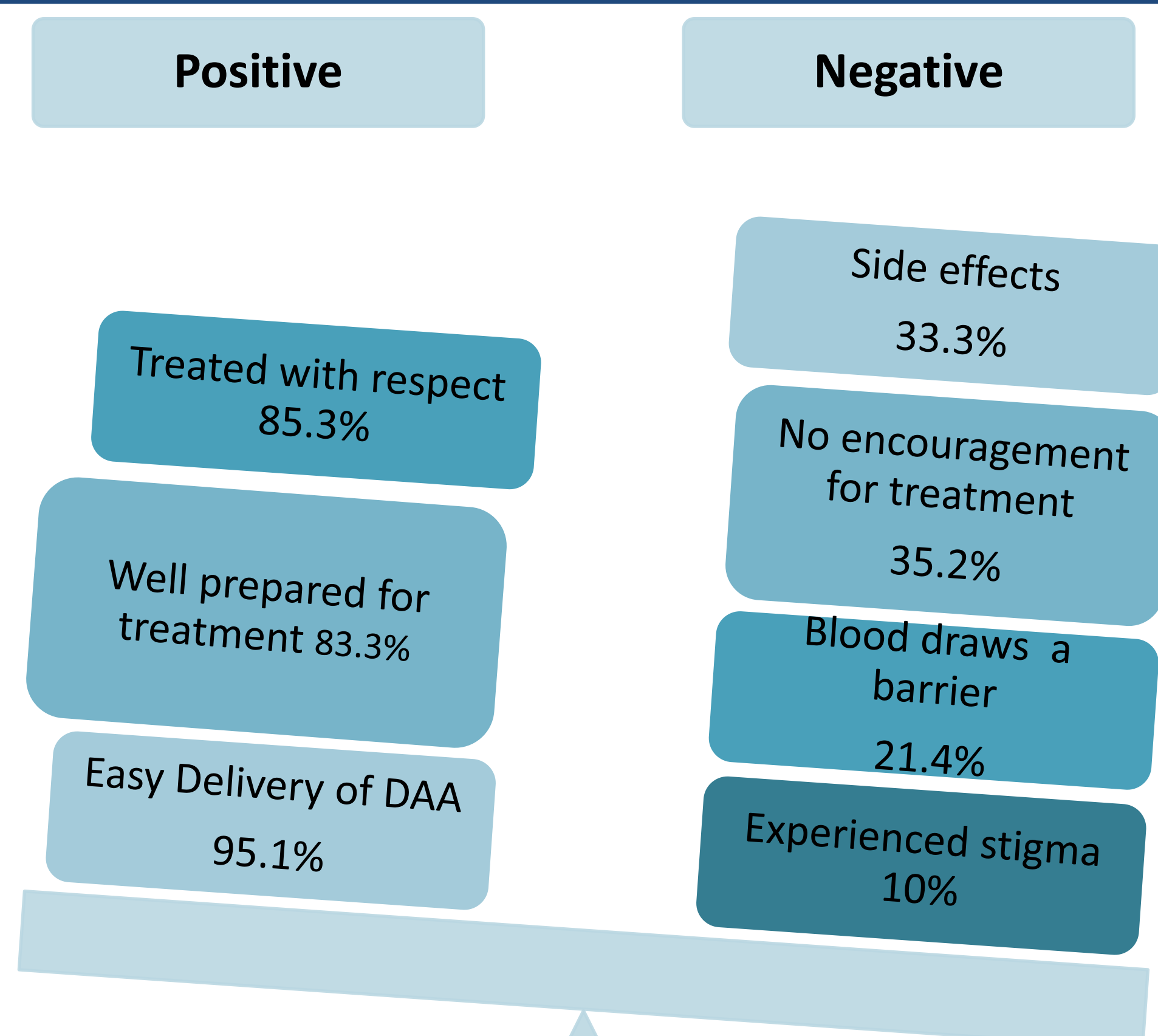


Figure 2. Selected PREM results % of respondents that strongly agree or agree to question

### Patient reported outcomes

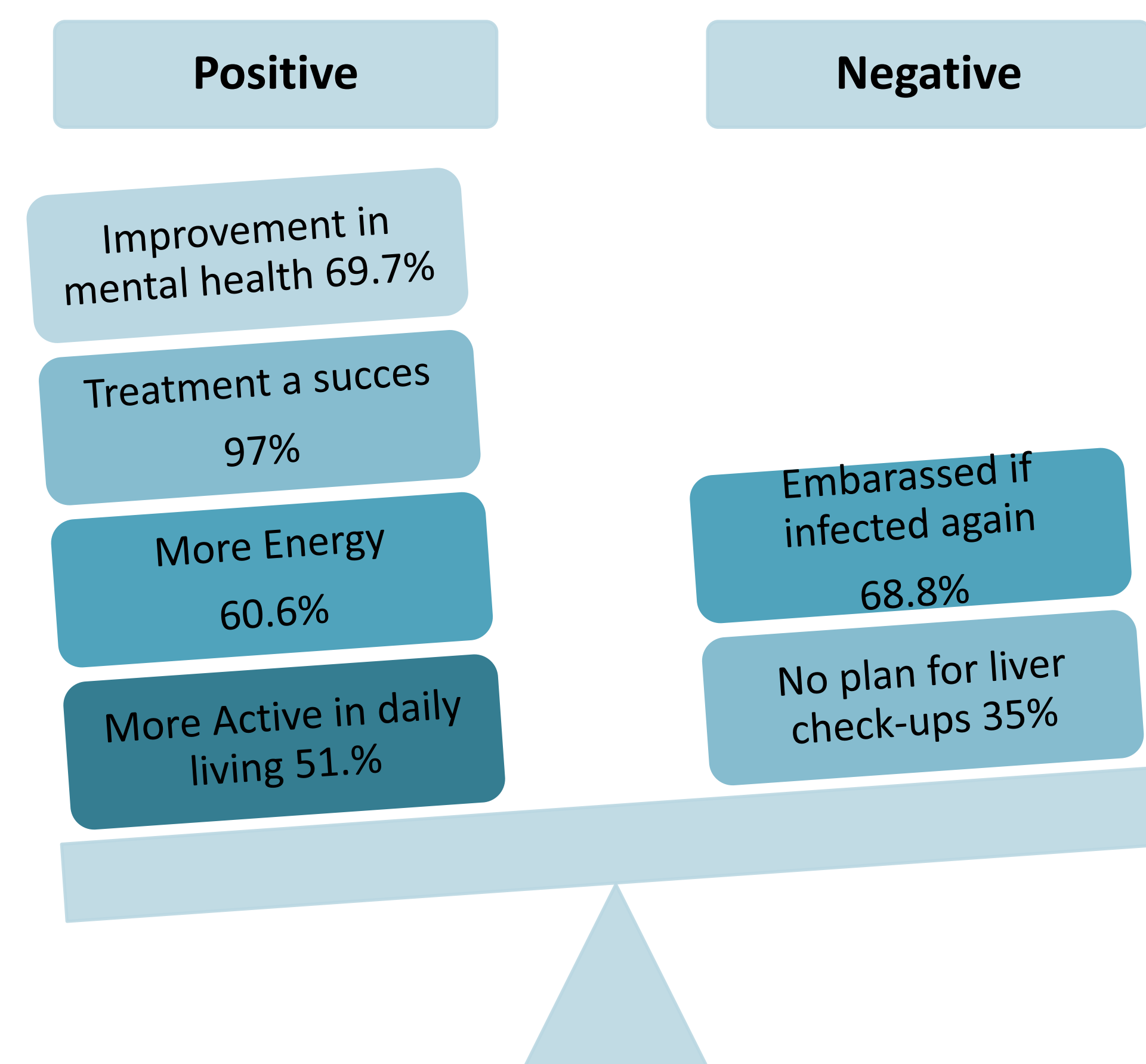
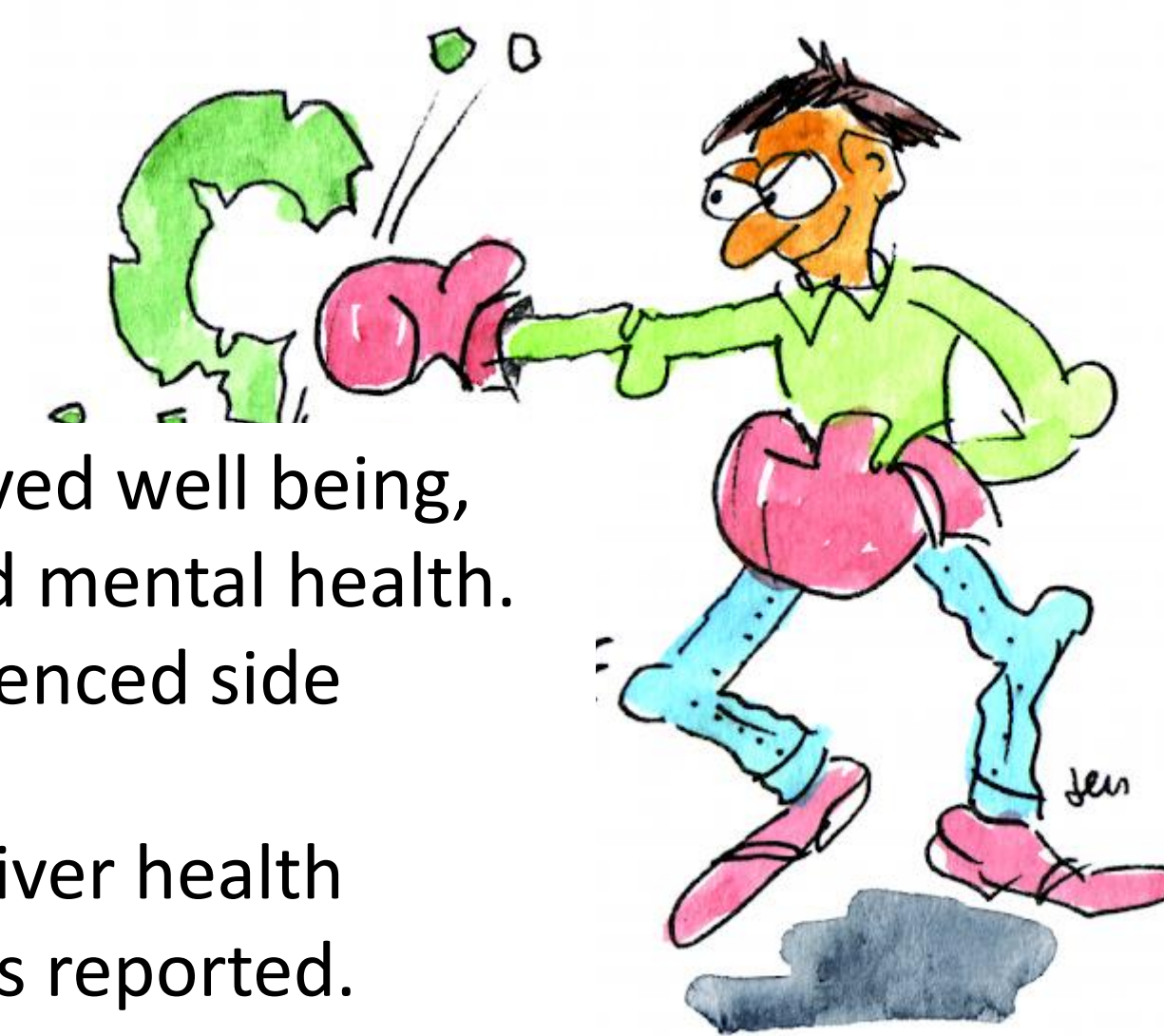


Figure 2. Selected PROM results % of respondents that strongly agree or agree to question

### Main findings

- Stigma and respect still an issue for a minority
- Majority felt improved well being, energy, physical and mental health.
- One in three experienced side effects.
- Uncertainty about liver health and re-infection was reported.



### Conclusion

Although very preliminary results, these patient reported measurements shows potential in documenting the experience and outcome of DAA treatment. There are unresolved issues that needs to be addressed.

We found a very positive effect of hepatitis C treatment across outcome domains, but post treatment uncertainty about liver health and re-infection might need further emphasis.



#### Disclosures

Nothing to disclose for this presentation

#### References

1 Madden A, Hopwood M, Neale J, Treloar C. Patient. 2019 Apr;12(2):259-265. doi: 10.1007/s40271-018-0332-6

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