WHA/ECDC hepatitis stigma survey: lessons learned and next steps

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Global targets related to stigma and viral hepatitis

<10%

of people living […] hepatitis […] and key populations experience stigma

>90%

reduction of new chronic infections

>65%

reduction of attributable mortality

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Sources: Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030. Geneva: World Health Organization; 2022.

The impact of stigma



The only thing I knew about hepatitis at the time [of my diagnosis] was that it was a liver disease, as hepatitis in Vietnamese translates to 'liver inflammation'. My grandmother passed away due to liver cancer when I was a child, and I thought I would die too.

Lien Tran, 2021

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The impact of stigma



Education helps to reduce stigma and helps people understand that it is not your fault if you have hepatitis C.

Shabana Begum, 2023

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Methodological approach of pilot study

Initial steps to set up pilot:

- Advisory Committee established
- Pilot countries selected

Development of questionnaire:

- Use of validated questions
- Tested with people with lived experiences
- Translated to local languages

Survey dissemination:

- First few months of 2024
- Local civil societies and community organisations, clinical societies, public health contacts, dating apps

Pilot countries:



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Results from the pilot survey

Total responses:

2,104

ECDC/WHA, preliminary analysis, 2024

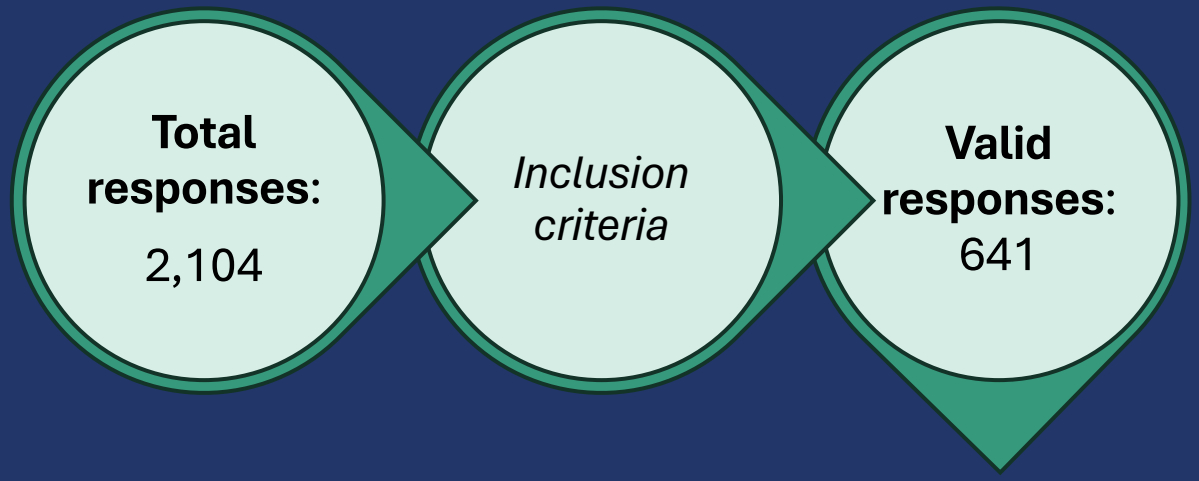
Results from the pilot survey



- ≥18 years old
- Live in a pilot country
- Provide informed consent
- Infected with hepatitis B and/or C

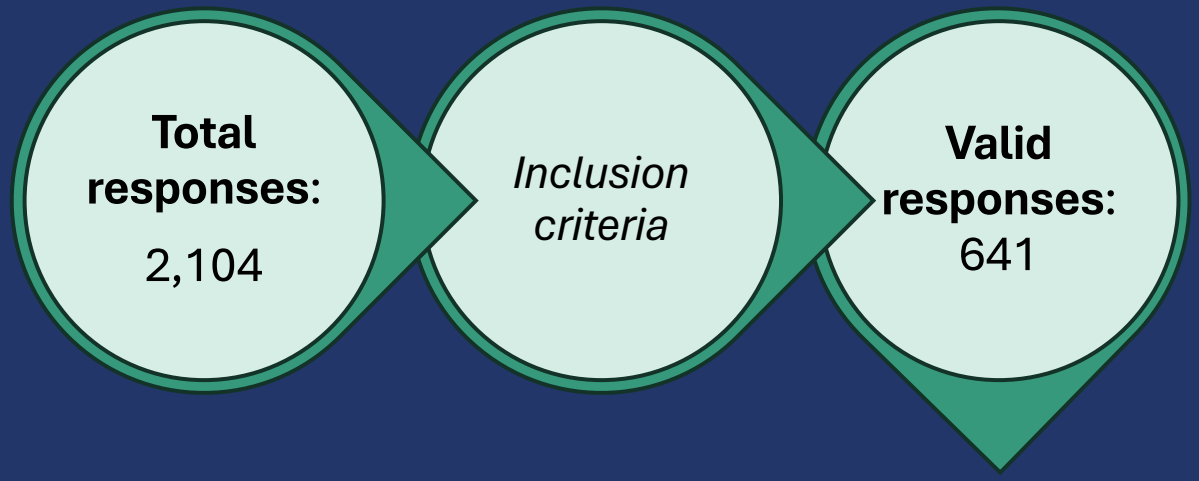
ECDC/WHA, preliminary analysis, 2024

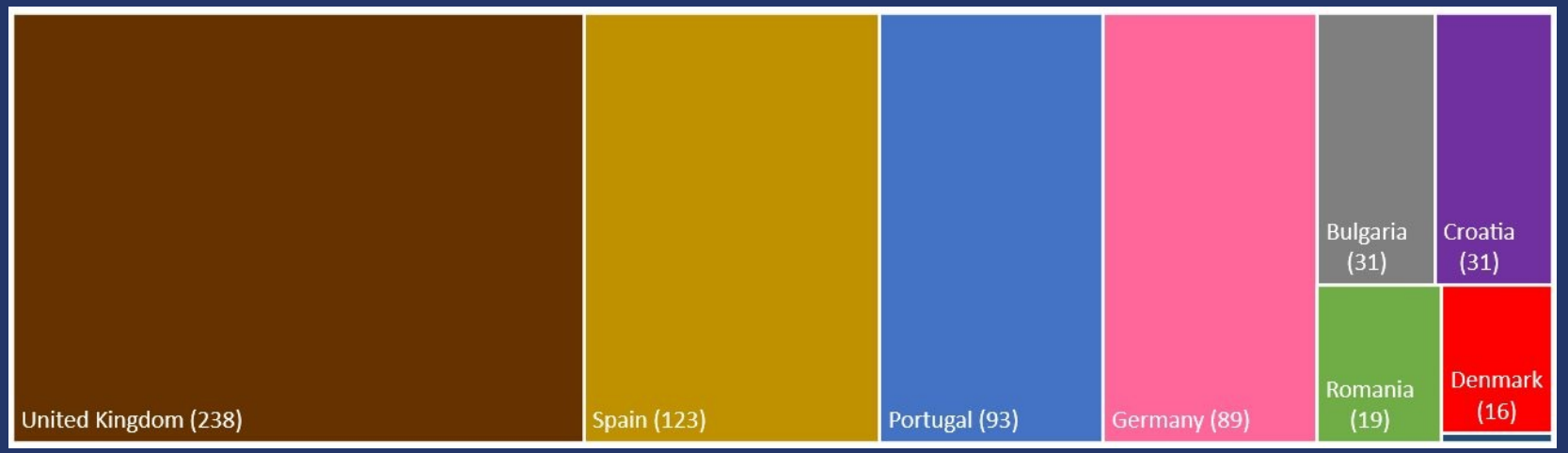
Results from the pilot survey



ECDC/WHA, preliminary analysis, 2024

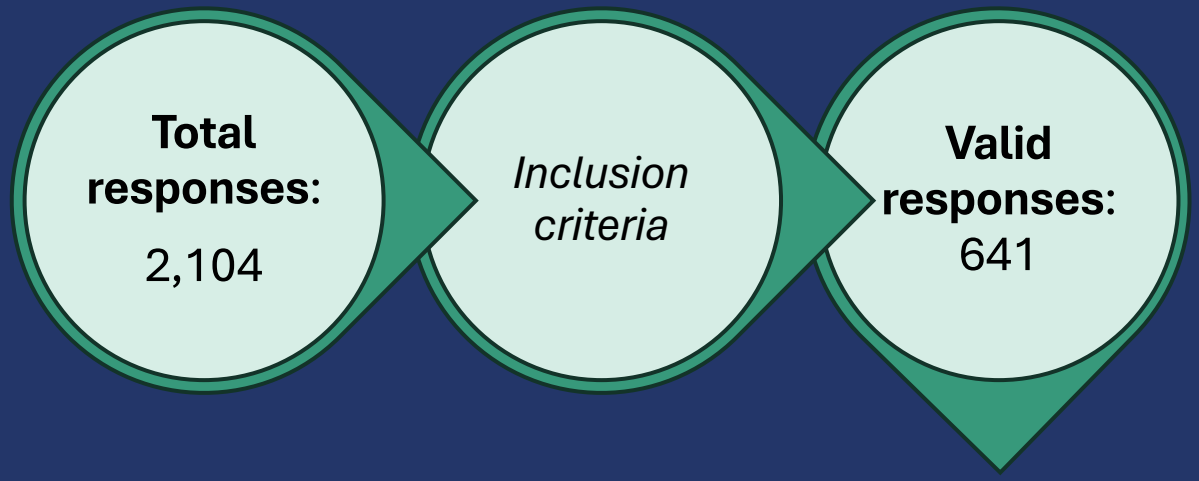
Results from the pilot survey





ECDC/WHA, preliminary analysis, 2024

Results from the pilot survey





ECDC/WHA, preliminary analysis, 2024

Limitations of the study

- Study restricted to a selection of European countries.
- Limited sample size in half of the countries.
- Small sample sizes restricted initial analyses of the data (e.g. by population groups such as MSM, migrant populations, PWID)

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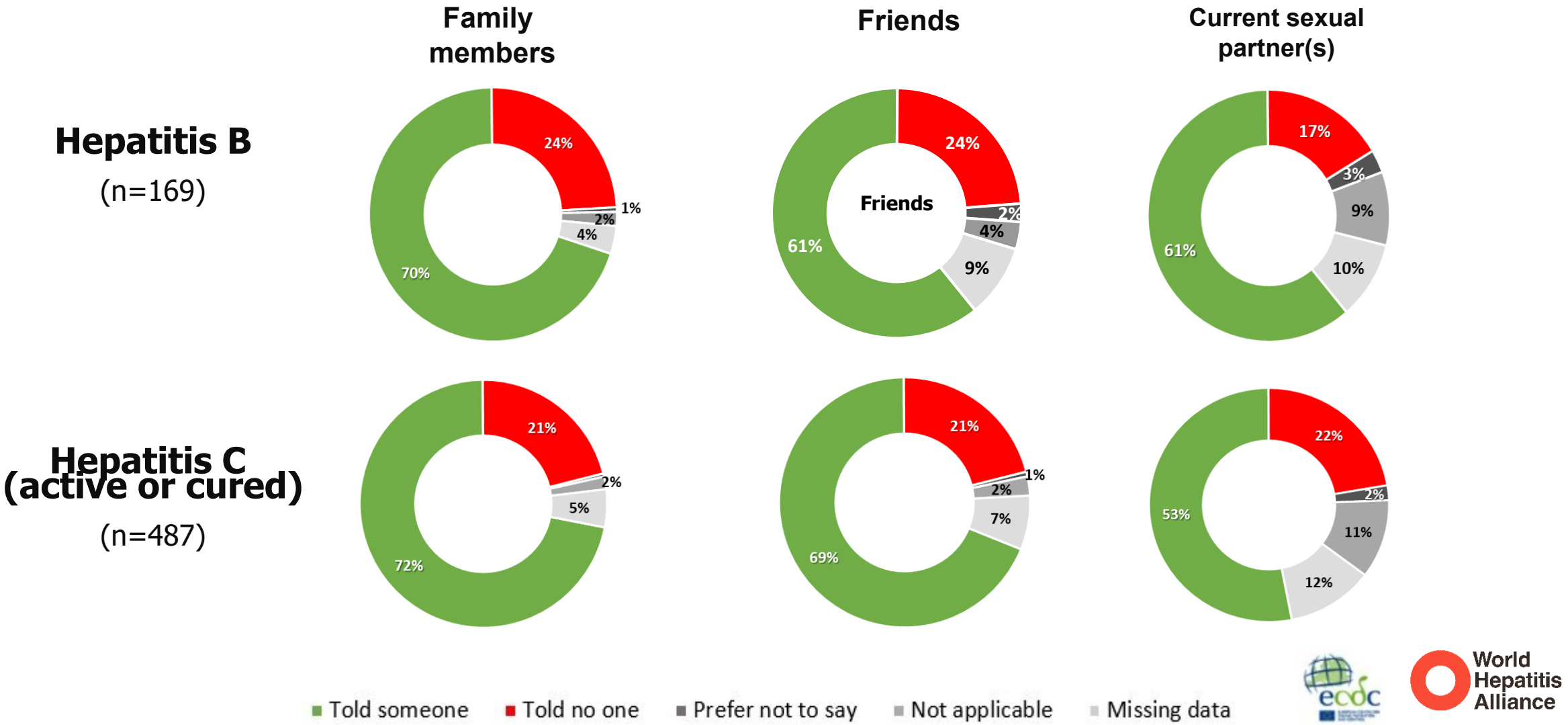
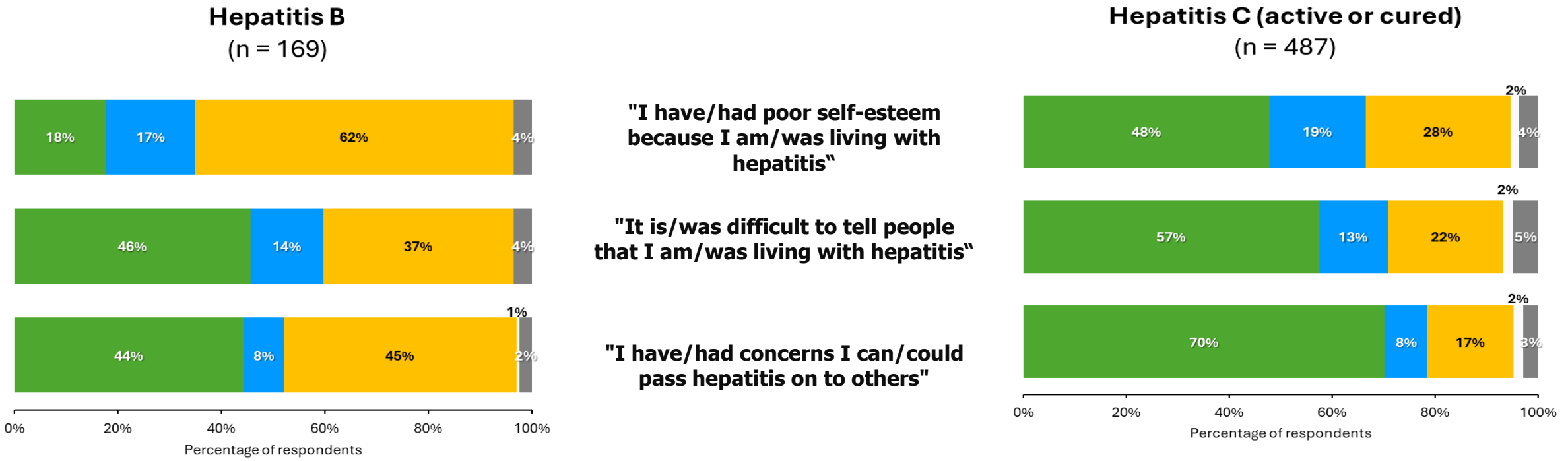
Who have you told you are/were living with hepatitis?



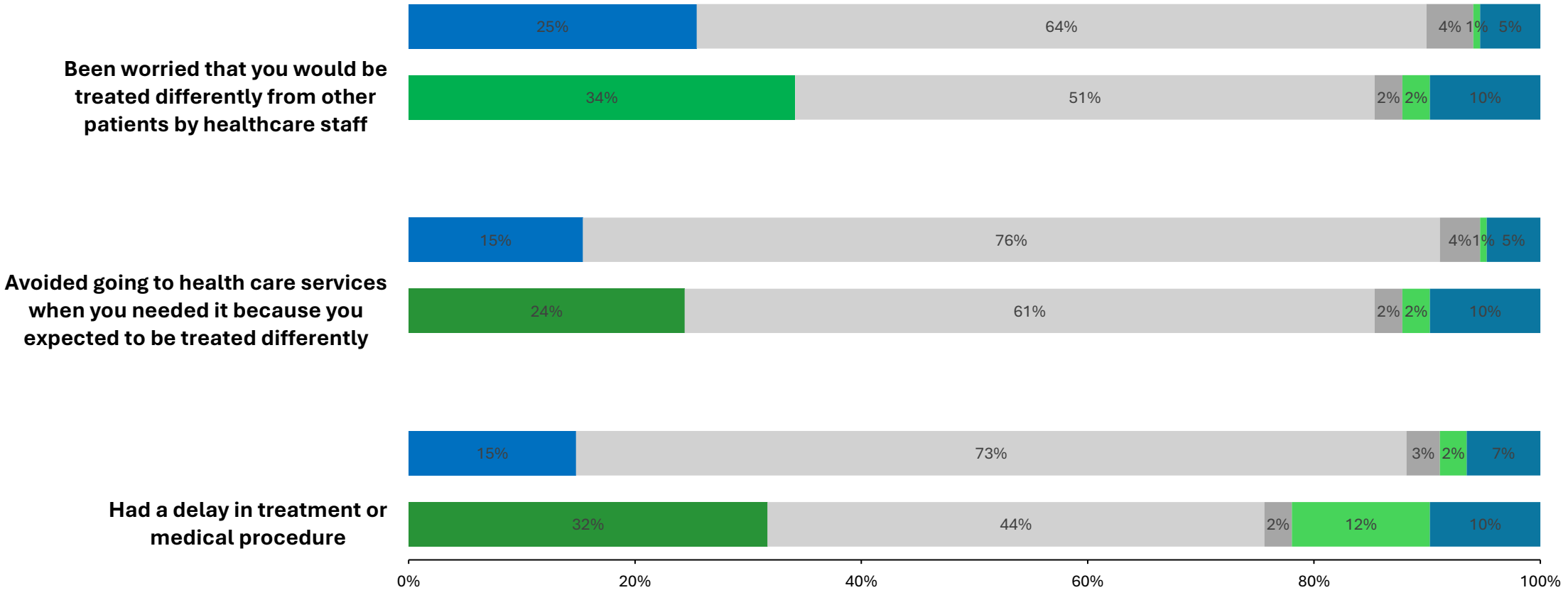
ECDC/WHA, preliminary analysis, 2024

How does/did living with hepatitis make you feel?



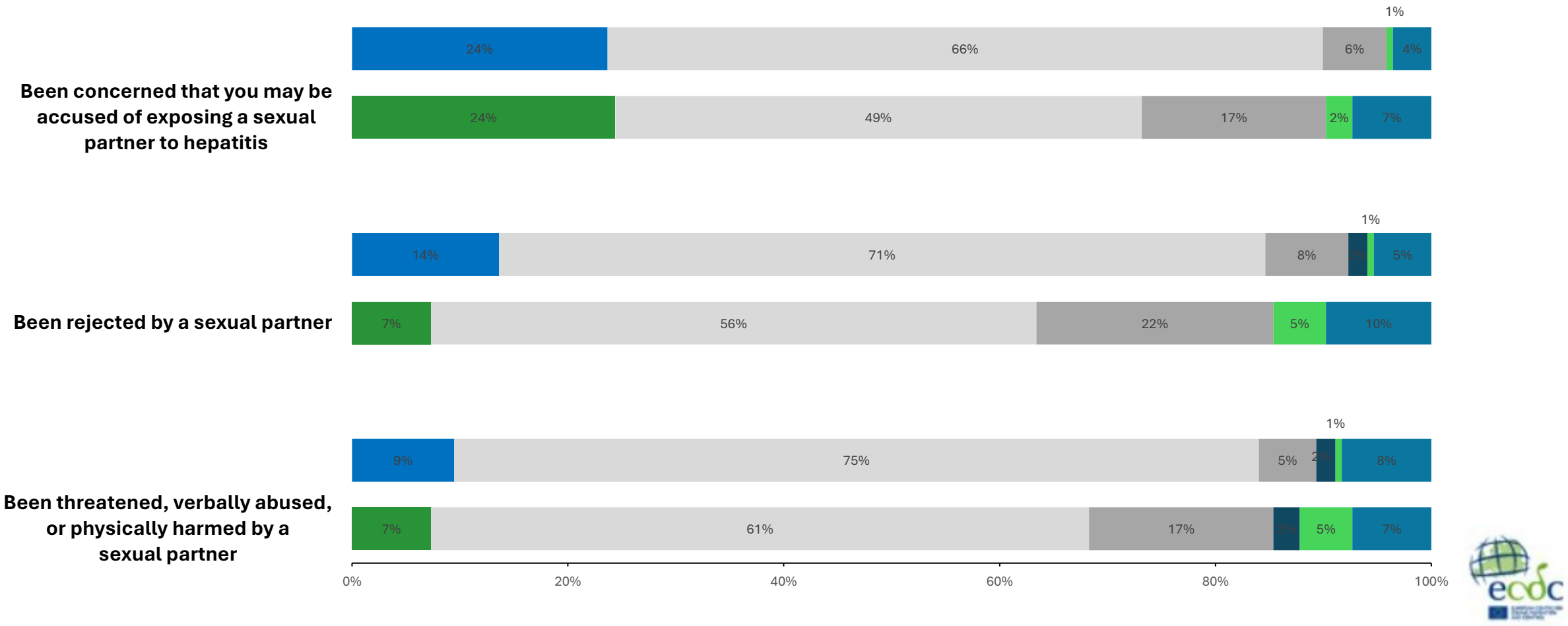
ECDC/WHA, preliminary analysis, 2024

Experiences of stigma at healthcare settings



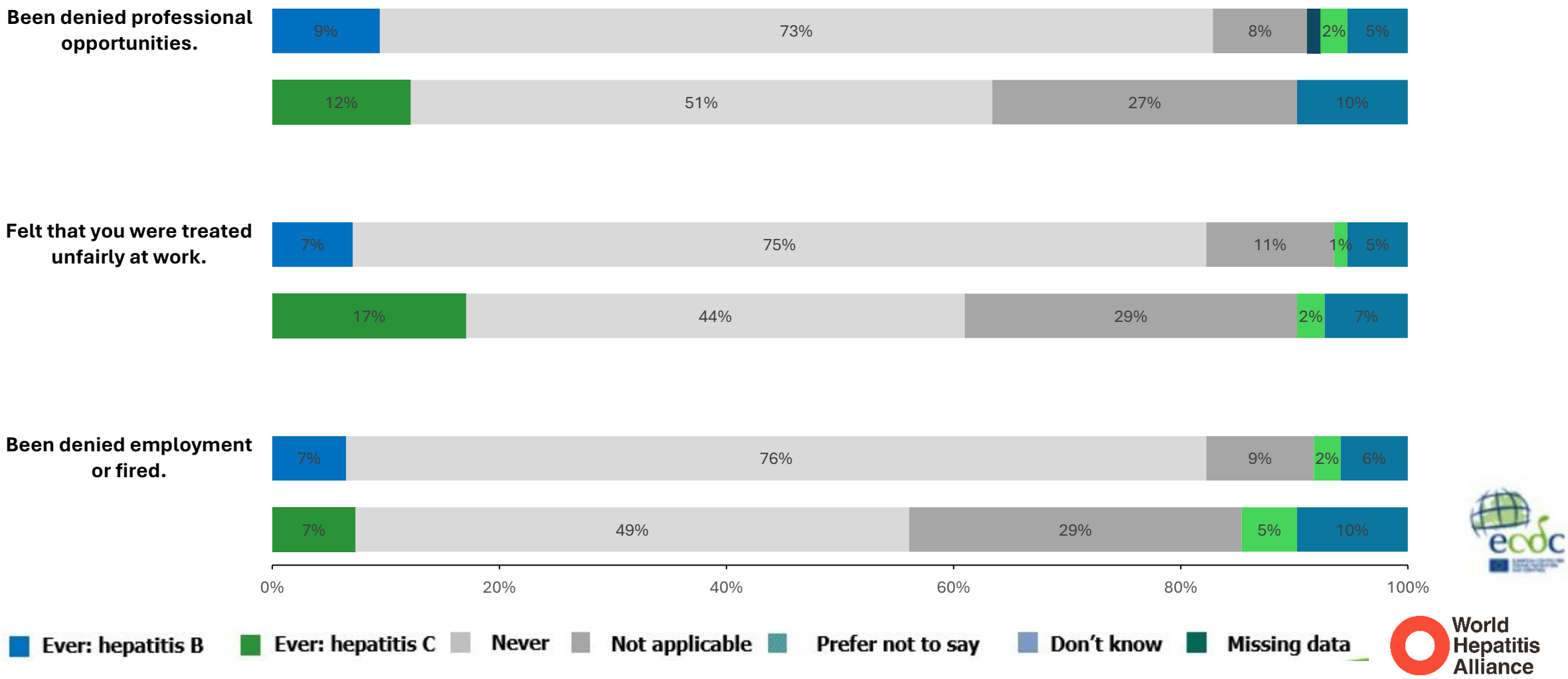
ECDC/WHA, preliminary analysis, 2024

Experiences of stigma in sexual relationships



ECDC/WHA, preliminary analysis, 2024

Experiences of stigma in professional life



ECDC/WHA, preliminary analysis, 2024

WHA's recommendations

1. Healthcare settings must do more to provide a stigma-free service for people living with hepatitis.

2. More efforts are needed to address mental health issues to improve the quality of life of those living with hepatitis.

3. More support must be given to people living with hepatitis who face discrimination in employment and other social settings.

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Lessons learned

- Importance of future studies ensuring a longer time period for rollout of the survey tool
- Stronger engagement with a range of civil society organisations representing people living with hepatitis, particularly key and vulnerable populations
- Using a broader range of communications to reach study participants
- Community involvement is key!

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Next steps

- Data sharing agreement with MOBHOPE to conduct the stigma survey in Croatia, Portugal and Spain
- WHA is seeking support to implement the survey in more countries globally
- Establishment of an online platform for the data

Email projects@worldhepatitisalliance.org

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Acknowledgements

All people living with hepatitis who took time to fill out the survey

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European Liver Patients' Association (ELPA)
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Thank you!

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