



# Ethical considerations in the planning and implementation of a study on infectious diseases among people experiencing homelessness in Berlin, Germany

Sarma N<sup>1</sup>, Steffen G<sup>1</sup>, Cawley C<sup>1</sup>, Leicht A<sup>2</sup>, Weber C<sup>3,4</sup>, Heidrich S<sup>1</sup>, Kajikhina K<sup>1</sup>, Hövener C<sup>1</sup>, Jansen K<sup>1</sup>, Kröger S<sup>1</sup>, Zimmermann R<sup>1</sup>, Bremer V<sup>1</sup>

<sup>1</sup>Robert Koch Institute, <sup>2</sup>Fixpunkt e. V., <sup>3</sup>BeSog Berliner Sozialprojekte gGmbH, <sup>4</sup>Checkpoint BLN

## Background

- Homelessness in Germany, as in most European countries, is increasing<sup>1,2</sup>
- Poor access to harm reduction and safer sex measures, imprisonment and origin from high prevalence countries can increase the risk for HIV, Hepatitis B (HBV) and Hepatitis C (HCV) among PEH
- Valid data as basis for targeted prevention and care in Germany is scarce → POINT study was piloted in Berlin in 2021 (see Poster 353)
- Reliable research is essential to understand and improve health BUT it also has the potential to cause harm to already stigmatised and marginalised populations such as PEH and drug users
- Formal requirements of ethics in terms of the review by ethics committee were fulfilled by the POINT study, but this paper presents the approach taken in the POINT study to address ethical issues *beyond* the formal requirements

## Questions concerning ethical considerations

- How can we plan and implement POINT in a responsible and ethical way?
- How can we ensure that neither planning, nor the data collection or results harm the community?

## Methodological approach concerning ethical considerations

<p><b>1. Having the relevant stakeholders on board</b></p> <p>Multidisciplinary study team: addiction and homelessness services, epidemiological research and infectiology</p> <ul style="list-style-type: none"> <li>• Ownership</li> <li>• Dissemination of the results in relevant contexts and disciplines</li> <li>• Direct transfer of results into practice and policy</li> </ul> <p>Multilingual study team and material</p> <p>Close cooperation with low-threshold services for PEH and IVD</p> <ul style="list-style-type: none"> <li>• Consideration of complex needs</li> </ul> <p>Data collection in drop-in centres that are frequented and accepted by PEH</p> <ul style="list-style-type: none"> <li>• Participation in a known environment</li> </ul> <p>Network with institutions and projects that provide therapy or clearing of health insurance</p>	<p><b>2. Direct benefit for the study population</b></p> <p>Incentives for study participants (10 Euros)</p> <p>For some people, the [test] offer was enough, but 10 Euros was also a good reason to participate because people on the street don't have so much money</p> <p>Point-of-care test offer</p> <p>It gave me a "positive kick" because everything was negative</p> <p>I want to see if the infection has returned</p> <p>Physical examination</p> <p>Referral offer in diagnostics and specialised medical care in case of positive test result</p>	<p><b>3. Involvement of the perspective of PEH</b></p> <p>Evaluation of acceptance and feasibility of the study design with study participants</p> <ul style="list-style-type: none"> <li>• 2 Focus Group Discussions with Polish, Russian and German language mediation (→ see statements in the speech bubbles)</li> </ul> <p>Participants could leave written comments for us:</p> <p>Joint conference presentation</p> <ul style="list-style-type: none"> <li>• Presentation by two study participants, and persons from the national federation for homelessness, Robert Koch Institute and Charité (June 11th 2021, Digitaler Aktionskongress gegen Armut - Der Paritätische)</li> <li>• Study participants received financial compensation for their presentation</li> </ul>
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## Lessons Learned

- ✓ PEH could be reached by providing participation in a known and respectful setting
- ✓ Test – and physical examination offer in a respectful setting proved to be, besides the 10 Euros, an important benefit for the study participants
- ✓ POINT helped to raise awareness among partners and motivated them to improve access to diagnostic and care of infectious diseases
- ✓ Remaining project funds could be used for a hepatitis B vaccination programme because relevant partners were on board
- ✓ Our network enabled us to support the study participants in their next steps concerning diagnostics and treatment
- ✓ „Queues were too long“ → Processes need to be optimized
- ✓ “After the first study day, the information spread quickly on the street” → PEH could be active partners in the recruitment process

## Remaining challenges and open questions

- Treatment for (uninsured) PEH remains a challenge
  - In POINT, we “delegated” this "ethical responsibility" to other institutions and projects.
  - Is an ethical responsibility of research to guarantee treatment when testing for infectious diseases?
  - How to deal with other issues that might come up during the data collection such as the need for housing, legal or psychological assistance, detoxification and follow-up rehab?
- Involvement of PEH was only partially fulfilled, how can we improve that?
- What else can be done to ensure that scientific data collection is carried out in a respectful and non-discriminatory way?

<sup>1</sup>Foundation Abbé Pierre and FEANTSA: Fifth Overview of Housing Exclusion and Homelessness in Europe 2020

<sup>2</sup>European Commission: Fighting homelessness and housing exclusion in Europe 2019

Contact: [point@rki.de](mailto:point@rki.de)