

# Scientific research concerning asylum seekers and related ethical challenges

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The term asylum seeker refers to a person of foreign nationality who seeks protection and residence permit in another state. Refugee status is granted to an asylum seeker who is given asylum. Around 1.3 million asylum seekers during years 2015 and 2016 arrived in Europe.<sup>1</sup> Asylum seekers are a highly heterogeneous group in terms of cultural backgrounds, religion, education and language skills. In their countries of origin, asylum seekers have faced oppression, possibly even violence, which may cause them to be suspicious of other people, especially the authorities, also in the country where they are seeking asylum. Due to the aforementioned factors, asylum seekers are a vulnerable group from the perspective of research.<sup>2</sup>

An increasing amount of research is conducted globally in different fields of science among asylum seekers, also in the field of diabetes research.<sup>3–6</sup> It has been shown that asylum-seekers carry a high risk of developing diabetes, and the prevalence of diabetes among them has been shown to be higher as compared with the reference population, already six months after arrival.<sup>5</sup> Post-traumatic stress disorder, which is common among refugees, may be related to high levels of Type 2 diabetes among them. Clinicians, scientists and policymakers need to take several issues into account when assessing and treating diabetes among vulnerable immigrants.<sup>3,5,6</sup> Recently, a need for research among asylum seekers has been recognised, but on the other hand, the discussion has emerged on the ethical acceptability of research in this population. There are several ethical issues to be a need for identification of Issues under discussion include what should be taken into account and which ethical questions emerge in particular? The research process consists of versatile steps connected to interpersonal interactions. The professional ethics of the researcher plays a key role. Its central elements include respect for human dignity, confidentiality, honesty and fairness.

The fundamental question is whether it is generally ethically acceptable to ask a person seeking asylum to participate in a scientific study. Indeed, opinions against such research have been expressed.<sup>7</sup> However, many experts agree that research in asylum seekers can be carried out as long as the principles of research ethics with special considerations are taken into consideration.<sup>8,9</sup> Research concerning asylum seekers requires careful planning and consideration of the

justifications for the study as well as ethically sustainable ways conduct research. Leaning<sup>8</sup> has described the pre-conditions for ethically acceptable research conducted among asylum seekers. As a starting point, she argues that, as with other vulnerable groups, research may only be conducted when it is necessary or urgent for the health and well-being of the research subjects and only if the study cannot be implemented with a different population.

Respect for autonomy, which is closely connected to the voluntary nature of research and the informed consent process, is the most crucial ethical principle of research in human subjects. Voluntariness implies that consent for participation in research is given by a subject without any kind of coercion, and that the research subject has a proper competence to understand what the research entails. Furthermore, the subject must be capable to express his/her decision.<sup>10</sup> Informed consent is culturally bound and it might thus have a different meaning to asylum seekers compared to a researcher. In some cultures, the role of relatives plays a particularly important role in decision-making,<sup>11</sup> and the researcher might thus end up discussing the matter with a head of community/household. However, it must be noted that the consent given by this person does not supersede the consent of refusal given by the individual asked to participate in the study.<sup>8,11</sup> Further challenges emerge in connection with language; indeed, data collection often requires a professional interpreter who understands both elements related to consent as well as the nature of research. However, there are several issues researchers must take into account in relation to using an interpreter: (1) competence, which involves the interpreter's linguistic skills and understanding of research, (2) the role of the interpreter, which may be either passive or active and affects the reliability of the research material and (3) cultural factors, which may cause a conflict between the interpreter and the research subject, e.g. regarding factors related to gender.<sup>4</sup> In some situations related to asking for consent and collecting research data, the research subject may only be approached by a researcher who is of the same gender as the research subject.<sup>12</sup> It must also be considered that some concerns related to the protection of privacy may arise if the researcher or interpreter belongs to the same ethnic group as the research subject.<sup>13</sup>

The importance of interactive skills is emphasised in the informed consent process in research with asylum seekers. Giving consent is a process where good dialogue between the researcher and research subject is necessary to guarantee understanding, satisfaction and consent throughout the whole research process. The researcher may need to use more specific questions to find out whether the research subject has understood the purpose of the study. In addition to written information leaflets and discussions, methods such as videos or images, may also be applied in helping the person understand the purpose of the research.<sup>14</sup>

Voluntariness and privacy may be compromised if research subjects are recruited at a reception centre or other official facility. The researcher must consider if there is a risk that participation in the study could cause stigma to the research subject in his or her family of group, especially if the study is concerned with a sensitive topic such as psychological symptoms.<sup>8</sup> Furthermore, if the study is concerned with the reasons for displacement, the researcher must avoid causing any additional psychological trauma to the research subjects.<sup>12</sup>

It is vital that the research protocol presents justifications for the study from the viewpoints of the participants as well as the society.<sup>15</sup> The welfare, dignity and autonomy of the research participants must be respected and promoted at every research phase.<sup>8</sup> The potential benefits and risks of the study must be carefully evaluated. The research must benefit the research subjects or those belonging to the same group. In addition, research may only pose a minimal risk to the research population, and the subjects must be selected on exclusively scientific grounds. The risks of each study intervention of the study must be separately assessed.

Asylum seekers may have unrealistic expectations for the benefits provided by the study, and the researcher must discuss these issues in great detail. Research subjects may also think that participating in the study is compulsory, or that participation will have a positive impact on their asylum application process, particularly in cases where the authorities are involved in the study or help researchers in the recruitment process.<sup>7,16</sup>

Research in asylum seekers raises challenges also in the ethics committee assessment because there are no specific guidelines for evaluation of such studies.<sup>8</sup> Furthermore, ethical assessment of research differs in different fields of research. For medical research, principles of ethical review are well described in, e.g. the Declaration of Helsinki s,<sup>17</sup> the guidelines by the Council for International Organizations of Medical Sciences (CIOMS,<sup>18</sup>) and National legislations e.g. in Finland, the Medical Research Act 488/1999.<sup>19</sup> Asylum seekers are considered a vulnerable group, and evaluations of a proposed research project in this population require careful consideration of the justifications for research, possible benefits and risks to the research subjects.

While there are many, at times difficult, ethical questions related to research concerning asylum seekers, excluding this population from the research could prevent or at least delay building a better future for them.<sup>2</sup> Although guidelines and legislation lay a foundation for the ethics of research, conducting research relies on the personal ethical thinking and actions of individual researchers, research groups and recruiters such as nurses. Open dialogue with the research group and all stakeholders, including an interpreter, on the principles of research ethics, is of utmost importance. Cooperation with different actors and the transparency of research processes form a basis for the protection of the research subjects as well as for high-quality research.<sup>20,21</sup> Lastly, it is important to recognise that several different research projects targeted on one group at the same time may cause exhaustion and distrust, thus decreasing potential subjects' willingness to participate in research.<sup>13</sup>

In conclusion, research in the field of diabetes is important among asylum seekers. Ethical conduct of the research is responsibility of all stakeholders. Nurses play an important role in clinical care but also in recruiting patients and they need to be aware ethical issues of the research process in order to protect our patients. Collaboration with other professionals and mutual respect is also nurses' responsibility.<sup>20</sup>

## References

1. Eurostat. [http://ec.europa.eu/eurostat/statistics-explained/index.php/Asylum\\_statistics](http://ec.europa.eu/eurostat/statistics-explained/index.php/Asylum_statistics) (accessed 7 Dec 2017).
2. Sieber JE. All refugee research is the same. *J Empir Res Hum Res Ethics*. 2009;4:35–36.
3. Bozorgmehr K. The health of asylum seekers in Germany: surveillance, monitoring and research-driven approaches. *Eur J Public Health*. 2017;27. doi:10.1093/eurpub/ckx187.536
4. Eklöf N, Hupli M, Leino-Kilpi H. Planning focus group interviews with asylum seekers: factors related to the researcher, interpreter and asylum seekers. *Nurs Inq*. 2017;24:e12192. doi:10.1111/nin.12192
5. Goosen S, Middelkoop B, Stronks K, Agyemang C, Kunst AE. High diabetes risk among asylum seekers in the Netherlands. *Diabetic Medicine*. 2014; 31:1532–1541.
6. Agyemang C, Goosen S, Anujoo K, Ogedegbe G. Relationship between post-traumatic stress disorder and diabetes among 105 180 asylum seekers in the Netherlands. *Eur J Public Health*. 2011;22:662–6
7. Zion D, Briskman L, Loff B. Returning to history: the ethics of researching asylum seeker health in Australia. *Am J Bioeth*. 2010;10:48–56.
8. Leaning J. Ethics of research in refugee populations. *Lancet*. 2001; 357:1432–33.
9. Strous RD, Jotkowitz A. Ethics and research in the service of asylum seekers. *Am J Bioeth*. 2010;10:63–65.
10. Beauchamp T, Childress J. *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press; 2009.
11. Halkoaho A, Pietilä A-M, Ebbesen M, Karki S, Kangasniemi M. Cultural aspects related to informed consent in health research: A systematic review. *Nurs Ethics*. 2016;23:698–712. doi:10.1177/0969733015579312
12. Siriwardhana C, Adikari A, Jayaweera K, Sumathipala A. Ethical challenges in mental health research among internally displaced people: ethical theory and research implementation. *BMC Med Ethics*. 2013;14:1432.
13. Weiste-Paakkanen A, Jokela S, Kytö S, Koponen P, Castaneda A, Larja L, et al. Ulkomaalaistaustaisen väestön terveys- ja hyvinvointitutkimukset – Ulkomaalaistaustaisen kenttähenkilöstön kokemuksia. 2017. *J Social Medicine*. 2017;54:226–37. in Finnish
14. Halkoaho A, Pietilä A-M. Tutkimus monikulttuurisessa ympäristössä. Eettiset periaatteet kliinisen tutkimuksen toteutumisessa monikulttuurisessa toimintaympäristössä. In: Keränen T, Pasternack A, editors. *Kliinisen*

- tutkimuksen etiikka: opas tutkijoille ja eettisille toimikunnille. Helsinki: Duodecim; 2015. p. 118–20, in Finnish
15. Rid A, Wendler D. A framework for risk-based evaluations in biomedical research. *Kennedy Inst Ethics J.* 2011;21:146–79.
  16. Gillam L. Ethical consideration in refugee research: what guidelines do forman research ethics documents offer? In: Bloc K, Riggs E, Haslam N., editors. *Values and vulnerabilities: the ethics of research with refugees and asylum seekers.* Toowong, QLD: Australian Academic Press; 2013, p. 21–39.
  17. The Declaration of Helsinki. <https://www.laakariliitto.fi/liitto/etiikka/helsingin-julistus/> (accessed 13 Nov 2017)
  18. CIOMS. International ethical guidelines for health-related research involving humans.. Available from: <https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf> (accessed 13 Nov 2017).
  19. Medical Research Act (488/1999). Available from: <http://www.finlex.fi/fi/laki/ajantasa/1999/19990488> (accessed 5 Nov 2017)
  20. Nurmi S-M, Halkoaho A, Kangasniemi M, Pietilä A-M. Collaborative partnership and the social value of clinical research: a qualitative secondary analysis. *BMC Med Ethics.* 2017;18:123.
  21. Halkoaho A, Keränen T. Turvapaikanhakijoihin kohdistuva tutkimus ja sen eettisen haasteet. *J Social Medicine.* 2017;4:265–268. in Finnish.