

Health care of persons without permanent residence permits

Ethical aspects of treatment requiring aftercare

Report by the Swedish Council on Medical Ethics

November 2020



Smer 2020:6

Smer 2020:6. Health care of persons without permanent residence permits.
Ethical aspects of treatment requiring aftercare.
(This is an unofficial translation of the report)
Original title: Vård av personer utan permanent uppehållstillstånd.
Etiska aspekter på behandling som kräver eftervård.
Please find the report on www.smer.se

The Swedish Council on Medical Ethics
Statens medicinsk-etiska råd (S 1985:A)
103 33 Stockholm
Phone 08-405 10 00

Stockholm 2020

Layout: Kommittéservice, Government Offices of Sweden

ISBN 978-91-986328-3-5
ISSN 1101-0398

Foreword

At present a large number of people without permanent residence permits are living in Sweden. Some of these individuals may need health and medical care interventions that require care of long duration or access to aftercare, such as organ transplants.

There is currently uncertainty in the profession as to when and in what circumstances persons without permanent residence permits should be offered treatment of this kind. Representatives of the medical profession have turned to the Swedish National Council on Medical Ethics, Smer, to obtain ethical and legal guidance concerning organ transplantation to persons without permanent residence permits. This question includes several difficult important issues of ethical principles that have broader implications for society. Many of these ethical issues also come up when decisions are made about offering other health and medical care interventions that require care of long duration or access to after care.

One of the most fundamental principle of medical ethics is that access to care should be equal for all and be governed solely by medical need. The right to health is regarded as one of the fundamental human rights; it was formulated as early as in 1946 in the Constitution of the World Health Organisation and was included, shortly thereafter, in the United Nations' Universal Declaration of Human Rights.

Following the above-mentioned request, Smer has produced this report on ethical aspects of health care for persons without permanent residence permits, taking organ transplantation as an example.

The Council is publishing this report to increase knowledge of the ethical complexity of the question and to provide support for decision-makers in health and medical services. Smer would also like to see the report being used as input for future measures and policies.

Smer also hopes that the report will stimulate debate about these issues in society.

This report has been prepared by a working group consisting of the experts Göran Collste, Mikael Sandlund and Titti Mattsson. Lotta Eriksson, secretary general, and Helena Teréus, research officer, (until 13 June 2020) have also participated in the group. Ulrika Axelsson Jonsson, research officer, (as of 15 June 2020) and Michael Lövtrup, research officer, have participated in work on finalising this report. Göran Collste has had a special commission regarding the ethical analysis, where he has assisted in the writing of the report.

Yana Litins'ka, Doctor of Laws in medical law, has made an independent review of the legal position as a commission from the Council.

Experts and representatives of public authorities and interest organisations have been heard as part of the project. See the list in Annex 1.

The decision to adopt this report has been taken by Kenneth Johansson (chair), Michael Anefur, Åsa Gyberg Karlsson, Ulrika Jörgensen, Dag Larsson, Sofia Nilsson, Lina Nordqvist and Malena Ranch, all members of the Council. Lilas Ali, Göran Collste, Titti Mattsson, Olle Olsson, Bengt Rönngren, Anna Singer, Marie Stéen, Nils-Eric Sahlin and Mikael Sandlund, all expert members of the Council, took part in the preparation of the report.

The report has been fact-checked by Bo-Göran Ericzon, Professor and Consultant, and Bengt von Zur-Mühlen, Docent and Consultant.

Stockholm,
November 2020

/Kenneth Johansson

Content

1	Introduction	7
2	Background	11
2.1	Persons without permanent residence permits in Sweden today.....	11
2.2	The asylum process and the profession’s desire for an advance ruling.....	12
2.3	The health care professions knowledge of “care that cannot be deferred”.....	13
2.4	Need for health care and health care available as drivers behind migration.....	14
2.5	Other examples of health care not provided.....	15
2.6	The right to health care, treatment and transplantation.....	16
3	Organ transplantation	19
3.1	Who can receive organs for transplantation in Sweden today?	20
3.2	Practice at the country’s transplantation units	21
3.3	View of the Swedish Transplantation Association	22
3.4	Scandiatransplant	24
3.5	The Istanbul Declaration.....	25
4	International outlook	27

5	Applicable law.....	33
5.1	Regions' responsibility to offer health care in Sweden	33
5.1.1	Health and medical services legislation in general.....	34
5.1.2	Responsibility to offer care under the Health and Medical Services Act	35
5.1.3	Special legislation on access to health care for asylum seekers and persons without documents	36
5.1.4	Economically vulnerable EU citizens and their children	37
5.1.5	Other people staying temporarily in Sweden.....	38
5.2	Fundamental principles in Swedish health and medical services	38
5.2.1	Guiding ethical principles in the Health and Medical Services Act	39
5.2.2	Requirement of science and proven experience	40
5.3	“Care that cannot be deferred” and care that requires aftercare.....	40
5.3.1	Legislative history and previous general advice from the Swedish National Board of Health and Welfare.....	41
5.3.2	Decisions by the Swedish Health and Social Care Inspectorate (IVO).....	45
5.4	International law.....	46
5.4.1	EU law	47
5.4.2	International conventions on human rights and migration	48
5.4.3	The right to health	48
5.4.4	The right to life and prohibition of torture.....	50
5.4.5	Expulsion of a seriously ill person may be contrary to the European Convention	53
5.4.6	How far does the responsibility of States extend regarding the right to life and health and the prohibition of torture?	54

5.5	Severe illness of importance for a residence permit and expulsion.....	55
5.5.1	Swedish law concerning residence permits and impediments to enforcement.....	55
5.5.2	Proposals from the Committee on Sweden's future migration policy	57
5.6	Assessment of whether care of some duration or a requirement of aftercare is covered by care that cannot be deferred.....	59
5.6.1	National law	60
5.6.2	International law and case law	62
5.6.3	Overall assessment	63
6	Theoretical starting points	65
6.1	Allocation of limited resources, such as access to organs for transplantation	66
6.2	Are there moral reasons to draw a dividing line between citizens and non-citizens?	68
7	Analysis.....	71
7.1	Transplantation for persons without permanent residence permits	71
7.1.1	The principles of human dignity principle, of needs and solidarity – ethical basis and starting point	71
7.1.2	Solidarity	72
7.1.3	Professional norms	73
7.1.4	Citizenship and permanent residence	73
7.1.5	Mutuality – giving and receiving organs	75
7.1.6	Uncertainty concerning aftercare.....	76
7.1.7	Best possible use of donated organs.....	77
7.1.8	Risk of harming the patient	78
7.1.9	Medical tourism.....	78
7.2	Overall assessment.....	79
8	Conclusions	83

9	Recommendations etc.....	85
9.1	Recommendations	86
9.1.1	Increased knowledge in the profession and among care providers	86
9.1.2	Guidance for the profession.....	86
9.1.3	Current picture of health care needs	86
9.1.4	Continued focus on organ donation and transplantation services.....	87
9.2	Exchange of information between the Swedish Migration Agency and health and medical services.....	87
 Appendix		
	Appendix 1 List of experts heard.....	89
	Appendix 2 References.....	93

1 Introduction

Smer has been notified, in several contexts, that there is a need for ethical and legal analysis of questions concerning access to organ transplantation and other health and medical care interventions that require a care of long duration or access to after care for persons without permanent residence permits in Sweden.

In a letter to Smer the Transplantation Process Group in Lund has pointed to the difficult deliberations they are faced with when decisions have to be made concerning whether or not to offer transplantation to persons without permanent residence permits, when there is a risk that the patient will not be able to receive aftercare in the event of a subsequent expulsion¹. In their letter, the group describes four recent cases, both children and adults, who needed heart or lung transplantation. In their assessment of these cases, the doctors have chosen to treat the children because children, with or without a residence permit, have full access to health care in Sweden. However, they have refrained from transplanting the adult patients, partly because these individuals ran the risk of being expelled in the near future.

Smer has also been contacted regarding a woman with a temporary residence permit, but with her husband and children in Sweden. She was refused the kidney transplantation she needed because she did not have a permanent residence permit in Sweden. The Council was also contacted by a doctor in spring 2020 regarding a patient without a permanent residence permit who was in need of a kidney; here the patient had not been put on the waiting list for kidney transplantation for the same reason.

The media have highlighted several patient cases in recent years. One example is the case of a stateless Palestinian from Lebanon, who was denied admission to the waiting list for transplantation because

¹ Reg. no Komm 2017/01672/S1985:A.

he had not been given a permanent residence permit in Sweden, and who later died of his disease².

In addition to transplantation services, some psychiatric treatments and orthodontics have been highlighted as examples of treatments where there is uncertainty about whether the treatment can be completed.

In the light of these examples, the conclusion can be drawn that it does happen that persons without permanent residence permits in Sweden are refused the care they need when there is uncertainty about the patient's future in the country. Under special legislation, the regions have a responsibility to offer certain care to these persons, called "care that cannot be deferred". However, the scope of this care is not specified clearly in the text of the law, its legislative history or via clarifications provided by any authority.

The question that the Council deals within this report is what importance the absence of a permanent residence permit has for access to organ transplantation and certain other health care interventions. What value conflicts come up in making these decisions? Can a health care provider refuse to provide a transplantation or other care for a patient who risks dying without the intervention and, if so, on what grounds?

In Sweden access to health care and the prioritisation of health care interventions have to be governed by three principles. They are the human dignity principle, the need and solidarity principle and the cost-effectiveness principle. The human dignity principle means that every human being has an equal right to health care and that, as a result, no prioritisation may take place on the basis of personal characteristics, age or position in society. Under the need and solidarity principle, need has to govern the allocation of health care resources. The patient in greatest need has to take precedence to the patient in less need. The principle assumes that those in lesser need will, out of solidarity, give up resources to those in greater need. According to the cost-effectiveness principle, health care resources have to be used as effectively as possible.³

This platform for prioritisation, as it is called, has broad support among decision-makers and the public and has formed the ethical basis for prioritisation decisions in health care since 1997. So, what

² Lindholm 2018. For another case, see Ekhem 2019.

³ Govt Bill. 1996/97:60.

relevance and importance does this platform have for the question of transplantations in persons without permanent residence permits? Representatives of the profession have sought guidance from Smer regarding the assessment of these questions. It has also emerged that views differ within the profession about how these situations should be dealt with, which may mean that individuals are offered different health care depending on where and by whom they are treated. Health care therefore risks not being equal for these patients. It is not likely that the number of people living in Sweden without permanent residence permits will decrease in the foreseeable future; on the contrary, the number can be expected to remain the same and possibly increase.⁴ The problems concerning access to health care for these groups will therefore remain. As far as Smer is aware, no other national actor is currently considering the questions dealt with in this report from an ethical perspective. Against this background, the Council has made the assessment that there is a need for an ethical analysis of the present issues.

Purpose and structure of the report

The purpose of the report is to present and analyse the ethical problems that arise in connection with health and medical care that requires a care of long duration or aftercare for persons without permanent residence permits, with organ transplantation as an example.

By publishing this report, the Council wants to increase knowledge of the ethical complexity of the question and to provide input for future measures and policy. The report is also intended to stimulate debate about these issues in society. The target groups for the report are the Swedish Parliament and the Government, decision-makers in health and medical services, the professions, the relevant authorities and organisations and the public.

Smer's analysis is restricted to analysing the case of organ transplantation for persons who do not have permanent residence permits. Ethical problems can, however, arise in other health care interventions that require care of long duration or aftercare.

⁴The cross-party Migration Policy Committee has proposed that temporary residence permits should be the main rule instead of permanent residence permits for people seeking asylum in Sweden. See SOU 2020:54.

In this report, Smer does not analyse the question of what is called ‘medical tourism’, a term that has been used to describe the situation in which a person makes their way to a country to either get access to subsidised health care or to buy these services.

Within the framework of the project Smer has had a dialogue with representatives of the profession, civil society, public authorities and researchers (see appendix 1). The Council has also had the assistance of the Government Offices library for literature and information searches regarding health care for persons without permanent residence permits and relevant cases regarding expulsion of seriously ill persons at the European Court of Human Rights and the Migration Court of Appeal. The Council has also made its own searches in the literature.

The report opens with a background to the report’s issue, followed by a description of practice regarding organ transplantation. Then comes a short international overview in which the Council describes how the question has been discussed in certain other countries. This is followed by a chapter on the applicable law, which gives a description of national legislation and certain relevant international agreements, as well as the Council’s assessment of the applicable legal position. In the subsequent chapter Smer deals with theoretical starting points for the question of the allocation of limited health care resources and, in particular, the question of who should be given access to transplantation. This is followed by the Council’s analysis, which looks at the question of transplantation for persons who do not have permanent residence permit. The Council’s conclusions and recommendations are set out at the end of the report.

The translation from Swedish has not been reviewed by the Council.

2 Background

2.1 Persons without permanent residence permits in Sweden today

Sweden is a multicultural society in the sense that people with different ethnic, cultural and geographical backgrounds stay and live here. A person without Swedish citizenship can be in Sweden on various legal grounds.¹ For example, an alien can stay here if they have a visa, a right of residence, some kind of residence permit or are seeking asylum.² Some persons are staying and living in Sweden without a legal right to do so. Persons without permanent residence permits are thus a heterogeneous group of people in widely different circumstances.

On 31 December 2019, 228 108 persons were registered in Sweden with temporary residence permits.³ According to information from the Swedish Migration Agency, there were 56 583 asylum seekers with temporary residence permits in Sweden on 1 October 2020.⁴ There are no official figures about how many people without documents there are in Sweden. They are estimated to be somewhere between 10 000 and 35 000 people.⁵

The regulations for offering health and medical care to aliens in Sweden differ regarding access to care and regarding who are offered subsidised health and medical care and who have to meet their own health care costs,⁶ see chapter 5 for more information.

¹ Aliens Act (2005:716) and EU legislation.

² Thorburn Stern 2020, pages 25–38 and Litins'ka 2020.

³ Information from Statistics Sweden by email, 8 September 2020.

⁴ Information from the Swedish Migration Agency by email, 1 October 2020.

⁵ Swedish Agency for Public Management 2016.

⁶ Swedish Association of Local Authorities and Regions 2016 and Swedish Migration Agency 2018.

Persons without permanent residence permits may need health care interventions that require care of long duration or access to aftercare; organ transplantation is an example of this.

2.2 The asylum process and the profession's desire for an advance ruling

Some doctors who have contacted Smer have asserted that they need information about the risk that a patient will be expelled to enable them to make well considered decisions about health care interventions. This is especially so in connection with health care interventions where access to aftercare is crucial if the patient is to benefit from the intervention, and ultimately to survive.⁷ Smer has been in contact with the Swedish Migration Agency to obtain information about how these processes are conducted. The Swedish Migration Agency has communicated that they neither can, nor should give an advance ruling in this type of case since it can endanger legal certainty.⁸

A person whose asylum application has been refused and who is receiving vital ongoing treatment and is therefore too ill to be expelled or refused entry, can apply for an impediment to enforcement, i.e. an impediment to implementing a refusal-of-entry or expulsion order. A refusal of an application for an impediment to enforcement can be appealed. In accordance with the applicable regulations and the international conventions that Sweden is committed to observing, the Swedish Migration Agency has to take account, ahead of any refusal of an application, of whether the person can receive vital care in the country to which they may be expelled.⁹

⁷ Internal hearing at Smer's regular meeting on 18 October 2019, round-table discussion on 31 January 2020 and letter to Smer from the Transplantation Process Group in Lund, 14 June 2019 (reg. no. Komm2017/01672/S1985:A).

⁸ Meeting with the Swedish Migration Agency in Malmö on 11 March 2020.

⁹ See chapter 5, Applicable law.

2.3 The health care professions knowledge of “care that cannot be deferred”

Adults who are asylum seekers or persons without documents are, under Swedish law, entitled to what is called “care that cannot be deferred” (for more information, see section 5.3). Within the framework of the Council’s preparation, it has emerged that many professionals in health and medical care feel that it is not clear what is included in care that cannot be deferred and that there is insufficient knowledge about the applicable regulatory framework.¹⁰ Several bodies have criticised the term care that cannot be deferred since it is considered unclear and difficult to apply in practice.¹¹

As a commission from the Government, the Swedish Agency for Public Management has examined how the Act on Health and Medical Services for Certain Aliens Staying in Sweden without the Necessary Permits (2013:407), often called the Act on Care for Persons without Documents, has been implemented and how it is applied. Its final report finds that even though most persons without documents are offered care in accordance with the provisions of the Act, there are still obstacles and deficiencies in health care. In the view of the Agency, the greatest risk for persons without documents not being offered health care is due to insufficient knowledge of the legislation among health care professionals.¹²

This picture is confirmed by experience and statistics from the care exchange operated by the Swedish Red Cross which shows that when persons without permanent residence permits are refused care, this largely happens because the health care professionals do not have knowledge and information about the legislation. According to Red Cross statistics, a lack of knowledge among staff of the regulations accounts for more than half of the obstacles encountered by patients in health care. The Act is said to be hard to understand and there is still great uncertainty about how to apply the term “care that cannot be deferred” in practice, as well as about how staff in health care are to assess who does not have documents.¹³ It is common that

¹⁰ Round-table discussion at Smer on 31 January 2020 and letters from the Transplantation Process Group in Lund in 2017 and 2019 (reg. no Komm 2017/01672/S1985:A).

¹¹ See, for example, National Board of Health and Welfare 2014, Swedish Association of Local Authorities and Regions 2016 and the Right to Care Initiative [Rätt till vårdinitiativet] 2014.

¹² Swedish Agency for Public Management 2016, p. 83.

¹³ Swedish Red Cross 2018.

staff registering a patient do not know who is counted as not having documents, which can result in a care provider demanding proof that a person does not have documents, even though there is no such proof. There are also instances where money has wrongly been demanded from patients for access to medical care.

This picture is confirmed by a recent questionnaire study of what health care asylum seekers and persons without documents have the right to. It was conducted among nursing students, medical students and doctors in the Region Västra Götaland.¹⁴ A large majority of the doctors responding (89 %) considered that they needed more knowledge of what health care persons without documents have the right to. A majority of the doctors (66 %) replied that they did not know who to contact if they have questions about what health care persons without documents have the right to. Only 7 % of the students replied that they had good or very good awareness of the legislation regarding what health care asylum seekers and persons without documents have the right to. A majority of the respondents were aware that persons without documents and asylum seekers have the right to emergency medical care, but there was a low level of knowledge that they also have to be offered care that cannot be deferred and what is included in that term. The author of the study stresses that more teaching is needed about the right to health and about what care persons without documents and asylum seekers have the right to under Swedish law; otherwise the risk is that these groups will be offered less care than they have the right to.

2.4 Need for health care and health care available as drivers behind migration

It has been asserted in the debate about health care for asylum seekers and persons without documents that access to health and medical services for these groups should be restricted since excessively generous accessibility can result in disturbances to regulated immigration and increase the number of persons staying in the country without permission.¹⁵

¹⁴ Lönnermark 2018.

¹⁵ See, for example, SOU 2011:48.

Medical reasons are not a ground for asylum in Sweden, and a residence permit in Sweden is not automatically granted, as a result of illness, either, even though this can constitute an impediment to expulsion (see section 5.5 for more information).

The reasons why people migrate or flee are complex and can be due to a number of factors, involving both “push” and “pull”¹⁶ effects. Dominant drivers making people migrate are to escape from war, political oppression and economic impoverishment. Several different factors determine what country a person migrates to; they include whether the person has relatives there and the possibilities of getting established and supporting themselves. Even though there are examples of people seeking asylum in Sweden in the hope of getting access to advanced health care, there is, however, no empirical support, as far as Smer can judge, for a generous offer of specific health care automatically leading to more asylum seekers in a country.

2.5 Other examples of health care not provided

The examples mentioned above, in which specific patients were refused care because they did not have a permanent residence permit or because there was uncertainty concerning access to aftercare, all applied to organ transplantation. Through discussions with representatives of the Swedish Association of Local Authorities and Regions (SALAR) and civil society, among others, and through an inquiry to the Swedish Health and Social Care Inspectorate (IVO), the Swedish Medical Council has identified other forms of health and medical care where persons without permanent residence permits are refused or risk being refused care that they are in need of because of uncertainty about how long they will remain in Sweden. Psychiatric treatment and certain forms of orthodontics are identified as areas where asylum seekers have been refused health care because it is unclear whether the treatment can be completed. Corresponding problems ought probably also arise concerning cancer treatment or care including various medical devices.

Smer has found two reports made to IVO about care providers, where patients have been refused health care against the background

¹⁶ Professor Everett Lee has developed an explanatory model of why people move from an area on account of negative circumstances, called “push factors”, and to another area because of positive circumstances, called “pull factors”.

of their status under migration law. One case was about an asylum-seeking patient where there were strong indications for treatment with an implantable cardioverter-defibrillator (ICD – “heart starter”). The patient died in Sweden shortly after the decision not to offer treatment (for more information, see section 5.3.2).¹⁷ In another case IVO has criticised a health care provider for not giving a patient without a permanent residence permit care for their diabetes in accordance with the national guidelines for diabetes care and because the management of the health centre mixed up the terms emergency care and care that cannot be deferred. The patient’s situation was assessed as coming under the term care that cannot be deferred since their health might deteriorate without care and delaying treatment could result in serious consequences for the patient’s health.¹⁸

2.6 The right to health care, treatment and transplantation

To arrive at a well-founded position on the question of which type of health care should be offered to persons without permanent residence permits, it is necessary to make some distinctions.

Whether the person is a child, or an adult, can be of importance, as can the probability that the person can get a permanent residence permit.

Another question concerns what type of care and treatment can be offered, ranging from simple to more advanced care in the sense that it requires care of long duration or aftercare.

Child or adult

On the basis of the applicable law, access to care and medical treatment can be affected by whether the person without a permanent residence permit, is an adult or a child. Under Article 24 of the UN Convention on the Rights of the Child, which became Swedish law on 1 January 2020, every child aged 0–18 years has the right to the highest attainable standard of health and to full access to health care services, a general right that is not enjoyed by every adult. The

¹⁷ IVO reg no.8.2-36521/2015-15.

¹⁸ IVO reg.no 8.2-35696/2013-26.

position taken on whether, and to what extent, patients who do not have permanent residence permits in Sweden should have access to health services, is therefore affected by whether the patient is an adult or a minor. As described in the chapter on the applicable law, adults with temporary residence permits who are registered in the population register in Sweden have to be offered health care on the same terms as the rest of the population. Adult asylum seekers and adults without documents have to be offered “care that cannot be deferred”. As set out in section 5.6, Smer makes the assessment that care of certain duration or requiring prolonged aftercare, such as organ transplantations, falls within the concept of “care that cannot be deferred” in cases where the assessment is that an even moderate delay of care and treatment may result in serious consequences for the patient.

So, it is of no importance whether the patient is a child or an adult in cases that involve “care that cannot be deferred” for the adult patient. However, decisions on access to care, including transplantation, can be determined by the patient’s possibilities of accessing aftercare or by whether the treatment can be completed.

Different types of treatment

Care and treatment offered by medical care varies in terms of how technically advanced it is, how much resources it requires, how prolonged it is and the length of the aftercare it requires.

3 Organ transplantation

Organ transplantations are a unique form of health care. In addition to being a type of highly specialised care that requires premises and equipment meeting a high standard, and health care professionals with specific skills, it is dependent, to be provided at all, on access to organs and it requires prolonged, sometimes lifelong, aftercare if its outcome is to be of lasting benefit to the patient.

There is a shortage of organs, both nationally and internationally. Waiting times are long and everyone who needs an organ and who has been assessed as capable of receiving a transplant does not receive a transplantation. In Sweden the total need for organs was 860 on 1 January 2020. The need was greatest for kidneys (693), followed by livers (52), hearts (49) and lungs (25). A person can be waiting for more than one organ. The number of organs on the waiting list increased by 50 compared with the same date in the previous year. In 2019, 37 persons were reported to have died while waiting for an organ transplantation, which is a slightly lower number of cases than in the two preceding years.¹

The number of donated organs from deceased persons has increased in Sweden in the past ten years on account of a greater focus on the question of donation and purposeful donation promotion work in health and medical services. The number of organ donors in 2019 was the highest so far recorded in Sweden, 191 persons, and the regional differences in donation frequency are continuing to decrease. In 2019 a total of 811 organs were transplanted, with 661 organs coming from deceased donors. Kidney transplantation was the most common type of organ transplantation, and a total of 476 kidney transplantations were performed in 2019. Kidneys transplanted from living donors made up a third of the total number transplanted.

¹ The information in this paragraph has been taken from National Board of Health and Welfare 2020, p. 12.

The number of kidney and liver transplantations increased compared with the previous year, while the number of hearts and lungs transplanted decreased slightly. Despite the positive development of the number of donors, the need for organs for transplantation is still greater than the supply.²

3.1 Who can receive organs for transplantation in Sweden today?

Before a patient is put on the waiting list to be considered for organ transplantation, a careful individual assessment is always made; it includes a medical risk assessment and a prognosis appraisal. To be considered for transplantation, the patient has to have a critical failure of one or more of the organs that can be transplanted. The patient must also be in good enough shape to be able to undergo the operation and the treatment required by a transplantation. If a potential recipient is too ill, the transplantation cannot be performed since the risks associated with the procedure are then judged to be too high. Alongside this, an appraisal is also made of the patient's possibilities and ability to complete the checks and the treatment required after an organ transplantation. Examples of obstacles to transplantation include active substance misuse and malignant tumours. The regulations regarding assessment for transplantation in brief:

- The provisions regulating the transplantation of organs in addition to those in general legislation on health and medical services, are set out in the Act on Transplantation etc. (1995:831), the Transplantation Act, and in the National Board of Health and Welfare's Regulations on the management of human organs intended for transplantation (SOSFS 2012:14).
- The Transplantation Act contains provisions on procedures to harvest organs or other biological material from a living or deceased human being for treatment of a disease or physical injury in another human being (transplantation) or for another medical purpose.

² National Board of Health and Welfare 2020, p. 7.

- The National Board of Health and Welfare's regulation contains supplementary provisions to the Transplantation Act and shall, according to the regulation, be applied in health and medical services in the management (donation, control, characterisation, harvesting, preservation, transport and transplantation) of human organs intended for transplantation.
- Since 2015 the Government has appointed two inquiries in order to amend the regulations concerning organ donation so as to promote the performance of organ donation and clarify the regulations for donation.³ On 24 September 2020 the Government decided to refer the proposal Organ Donation to the Council on Legislation.

3.2 Practice at the country's transplantation units

It has emerged in dialogue with representatives of the profession that there are unclear points concerning the interpretation of the applicable law and that persons without permanent residence permits are given organ transplantations in certain cases, while they are not in others. The reasons for transplanting and refraining from transplanting vary. The picture that has emerged is that different assessments are made and that there is no agreement in the profession about how to deal with these situations.

As part of the legal analysis commissioned by the Council, the lawyer Yana Litins'ka, Doctor of Laws in medical law, held interviews in early 2020 with doctors from the three units, at two centres, that perform heart and/or lung transplantations in Sweden today to obtain an overview of their decision-making regarding the patient group concerned. Her analysis shows that each of the units has only had a few patients without permanent residence permits and that they do not have any specific guidelines for decision-making in these situations. The interviewees expressed uncertainty about how the legislation should be interpreted in these cases. If aftercare could not be arranged, this was considered to be an absolute contraindication. One unit replied that it is difficult for adults without documents to obtain transplantations, but that it is not impossible for persons

³ SOU 2015:84 and SOU 2019:26.

without permanent residence permits to obtain this care. Having access to aftercare and following up at a competent medical centre carries a great deal of weight in this assessment. Two of the units indicated that they had discussed what steps should be taken when assessing whether a patient without a permanent residence permit can be put on a waiting list for transplantation.⁴

At the end of 2019 the Swedish Transplantation Association produced a document summarising the Association's interpretation of the applicable law regarding the possibility for a person who is applying for a residence permit in Sweden to obtain a transplantation. The transplantation units at Sahlgrenska University Hospital and Karolinska University Hospital stated in September 2020 that they are now following the Transplantation Association's document from 2019.

According to current information from the transplantation units in Sweden, the position is as follows: Uppsala University Hospital does not offer organ transplantation (kidney transplantation) to persons without permanent residence permits, but they are offered dialysis in their home region. Sahlgrenska University Hospital states that their transplantation centre follows the 2019 document from the Swedish Transplantation Association (see section 3.4). Karolinska University Hospital also states that they follow the Transplantation Association's document. The transplantation unit in Lund/Malmö report that they perform transplantations on children without permanent residence permits with reference to the UN Convention on the Rights of the Child (the CRC) and that children have to be offered care on equal terms to the rest of the population under the applicable law in Sweden. The unit has, for instance, performed heart transplantations on two children, one who did not have documents and one who was an asylum seeker. Both transplantations were successful and the children are now in good health.

3.3 View of the Swedish Transplantation Association

The Swedish Transplantation Association has recently summarised its interpretation of the regulatory framework concerning the possibility of offering transplantation to foreign nationals who are

⁴ Litins'ka 2020.

applying for or have been granted a residence permit in Sweden.⁵ The document deals with liver transplantation and kidney transplantation. A distinction is made here between organ transplantations from living donors (in these cases other patients on the waiting list for organs are not affected since the organ generally comes from a close relative in these cases) and transplantations using organs from deceased persons. The Association takes the view that patients with temporary residence permits should undergo the same individual assessment as other patients. The accepted assessment principles should be followed, i.e. a patient should only be accepted for transplantation if the referring unit has investigated and documented that it is very probable that future medication and monitoring can be guaranteed. If this cannot be guaranteed, the transplantation should not be performed? This is the same approach that applies to all patients, irrespective of whether or not they are Swedish nationals. If there is any remaining doubt about monitoring of the care that is based on the fact that the patient may be expelled from the country after a transplantation it is reasonable to base the position taken on humanitarian grounds and to acquit rather than convict, they assert.

The Association also makes the assessment that “foreign, non-EU, nationals who are applying for a residence permit in Sweden are covered by the main rule that they are only offered emergency medical care”.⁶ Patients with terminal kidney failure, i.e. whose kidney function has ceased, who are applying for residence permits in Sweden can therefore be given immediate treatment with dialysis, which is a lifesaving and life maintaining treatment that cannot be deferred. It is therefore given to everyone who presents this indication, even to asylum seekers without permanent residence permits. However, the Association considers that kidney transplantation for these patients can almost always be deferred since modern dialysis treatment is often a perfectly satisfactory alternative. But it ties the patient to the dialysis apparatus several times a week, in the view of the Association.

The Transplantation Association also writes in the document that “there can be reason to refrain from transplantation ..., if the

⁵ Regarding the possibility of transplantation with a deceased donor for persons who have applied for residence permits in Sweden, Swedish Transplantation Association 2019.

⁶ *Comment*: Emergency medical care is not the same as “care that cannot be deferred”. The latter is a broader term, see section 5.3. 7 SOU 2019:26, s. 46.

patient has come to Sweden solely in order to be given transplantation treatment”.

3.4 Scandiatransplant

The transplantation services in the Nordic region and, since 2017, also in Estonia cooperate through an organisation called Scandiatransplant.⁷ Agreement has been reached in this organisation about how to prioritise organ recipients. The transplantation services identify potential recipients according to the following order of priorities.

1. In their own catchment area, but taking account of the specially agreed prioritisation rules in Scandiatransplant;⁸
2. in other catchment areas in the same country;
3. in the Nordic region;
4. In the rest of Europe.

In a special guidance document⁹, Scandiatransplant has drafted guidelines for the cases where organ transplantation of individuals from a non-Scandiatransplant member country can be performed within Scandiatransplant. Under them, the main rule is that organ transplantation is not performed on nationals of countries that are not Scandiatransplant members in cases where such a care need arises during a temporary stay in a Scandiatransplant member country. However, the guidelines do permit special agreements on exemptions from them in certain circumstances. But the guidelines clearly state that national legislation in Scandiatransplant member countries have to be applied before the guidelines.

Scandiatransplant cooperates with other international transplantation organisations, such as Eurotransplant, which is a collaborative framework for organ donation consisting of numerous countries in Europe.

⁷ SOU 2019:26, s.46.

⁸ The term specially agreed prioritisation rules means for example, urgent transplantations, exchanges of organs in the event of special tissue types or for immunised patients. In such cases these patients are prioritised in Scandiatransplant ahead of patients in the service's own catchment area.

⁹ Scandiatransplant 2017.

3.5 The Istanbul Declaration

In 2008 a group of leading international medical experts met in Istanbul to draw up strategies to put an end to organ trafficking and transplant tourism. The outcome of that meeting was the Declaration of Istanbul.¹⁰ In brief, the Declaration states that all countries should also strive to achieve self-sufficiency in organ donation and transplantation; organ donation should be a financially neutral act; organs for transplantation should be allocated equitably guided by clinical criteria and ethical norms. Countries should also strive to prevent organ trafficking. The Declaration of Istanbul defines the term organ trafficking for the first time in an international instrument. However, what is said in the Declaration of Istanbul is not legally binding.

¹⁰ The Transplantation Society and the International Society of Nephrology 2018.

4 International outlook

The question of access to medical services, and organ transplantation in particular, for persons who are asylum seekers, or lack documents or have no permanent residence permits, is a controversial and debated question in many countries.¹ Migrants are not always given access to the health and medical services they need, and they run a higher risk of falling into exclusion and poverty.²

The number of migrants and refugees in the world has increased strongly in the past 20 years. In the period 2000–2017 the total number of migrants rose from 173 million to 258 million, an increase of 49 %.³ Access to health and medical services for the groups affected differs from country to country. The literature highlights psychiatry, preventive care and long-term care as priority areas that should be given greater attention.⁴

Several international organisations are working to improve access to health and medical services for the groups concerned. In one of many initiatives, the WHO has produced a framework of priorities and guiding principles to support member countries in promoting access to health care services for asylum seekers and migrants. The WHO calls on all countries to implement guidelines that give all migrants and refugees health and medical services irrespective of their legal status.⁵

There is also a great deal of literature highlighting ethical problems linked to health and medical services for asylum seekers and migrants.⁶

¹ Fortin and Greenberg 2016; Stevens 2010.

² Bradby et al. 2015 and Razum, Karrasch and Spallek 2016.

³ WHO 2019.

⁴ Lebano et al. 2020.

⁵ WHO 2019.

⁶ One example of an ethical analysis that highlights the problem of different regulatory systems and the importance of a common policy in questions concerning organ transplantation is Hermerén (in the press).

Migrants' access to health and medical services differs in the EU and Europe. A recently performed literature review from 2020⁷ charts migrants' access to, and obstacles to, access to health and medical services in Europe. It presents a highly heterogeneous picture in which there are great differences in access to health and medical services for these groups. The authors point out that better data is needed about migrants' health status, needs and access to health and medical services, to better secure access and be able to design medical services in line with the special needs of these groups. They also point out the need for studies that highlight migrants' experiences and what obstacles they themselves experience to obtaining access to medical services.⁸

Smer does not have any certain cross-country information about what access to organ donation, and practice in the care of these patients, is like. However, the existence of obstacles to organ transplantation for migrants and refugees is a question that has attracted attention at the European level.⁹ A questionnaire from 2012 that examined access to organ transplantation for non-nationals and non-residents in Council of Europe Member Countries found great differences in access to this care among the 29 responding countries.¹⁰ In France, for instance, aliens can, in special circumstances, be registered on the waiting list for kidney transplantation irrespective of whether or not they are residents.¹¹ In the UK aliens' access to organ transplantation has been investigated and discussed.¹² In the Nordic region the question has been up for discussion in *Scandiatransplant*. Through searches in various research databases we have found several articles that discuss various challenges and dilemmas in the health care of migrants and refugees concerning organ transplantation.¹³

A few examples are given below of how the question of health and medical services, focusing on organ transplantation, for the groups

⁷ Lebano et al. 2020.

⁸ Lebano et al. 2020; Cantrelle et al. 2006.

⁹ See, for example, EKHA (no date) p. 38 and Bhopal et al. 2019. According to information received, work is also being done in the Council of Europe's Ethics Committee (COMETH).

¹⁰ Carella et al. 2012.

¹¹ See, for example, the British Transplantation Society 2009 and Barrett 2013.

¹² *Scandiatransplant* 2015.

¹³ See, for example, Poulakou, Len and Akova 2019, Van Biesen et al. 2016 and Van Biesen et al 2018.

concerned is dealt with in Canada and the US, where there is an on-going discussion.

Canada

Canada, like Sweden, has publicly funded health and medical services and access to care is based on residence in the country. Status under migration law is of importance for what form of health and medical services with state public subsidy is offered.

Canada does not have any national guidelines concerning organ transplantation for aliens.¹⁴ At present, transplantation units must handle these decisions by themselves. Some units have a limited number of aliens on their transplantation waiting lists, while certain local organisations have produced their own guidelines and procedures.¹⁵

The organisation responsible for organ transplantations in the Province of Ontario has produced guidelines for transplantation for aliens and persons without permanent residence permits. Under these guidelines, aliens and refugees who meet certain requirements can be listed for transplantation. Only persons who are in need of life-saving treatment and do not have any other treatment alternatives can come into consideration. Decisions are to be made on the basis of an individual assessment and in accordance with the ethical principles of justice and utility. All patients must show that they have the ability to cope with the aftercare and have future access to immunosuppressants and treatment. The organisation's guidelines include the following¹⁶:

”According to the principle of utility, the exclusion of transplantation for non-Canadian residents who do not have access to post-transplant care is ethically justifiable. Medical professionals are responsible for calculating the risks using available knowledge, which includes acknowledging the reality of sub-optimal conditions that some foreign patients may be returning to.”

In Canada there has been a discussion about whether foreign nationals should be offered organ transplantation. An attitude survey from 2019 among health care professionals working in transplan-

¹⁴ Greenberg et al. 2019.

¹⁵ Fortin and Greenberg 2016.

¹⁶ Trillium Gift of Life Network 2016.

tation surgery examined practice regarding, and attitudes to, transplantation for aliens. Among its findings were that only a few centres had guidelines regarding organ transplantation for aliens and that views differed as to whether, and under what circumstances, these patients should be offered transplantation.¹⁷

There are discussions in the literature of questions concerning access to transplantation and, especially, whether children without residence permits should be offered transplantation. Several authors have highlighted the importance of putting a national policy in place and have put forward various proposals about how an offer of treatment for these patient groups could be designed.¹⁸ The description of the problem and the arguments for and against transplantation for children and adults without residence permits resemble those in Sweden (see chapter 7).

United States

Health and medical services in the United States are not publicly funded and many people do not have health insurance. There are estimated to be around 11.3 million immigrants without documents in the United States,¹⁹ which corresponds to around 3 % of the population. In many cases these groups have severely limited access to health and medical services as they often do not have access to health insurance and cannot pay out of their own pocket.

In the United States immigrants without documents donate organs to a greater extent than they receive organs. It has been estimated that around 3 % of all donations from deceased persons come from immigrants without documents, but that they only receive around 0.5 % of organs.²⁰ In a study from 2019 regarding liver transplantations among immigrants without documents in the United States in the period 2012–2018 it turned out that 0.4 % (166 out of 43 192) of liver transplantations had taken place in this population. The risk of the treatment failing is reported to be the same for

¹⁷ Greenberg et al. 2019.

¹⁸ Fortin and William-Jones 2013; Greenberg et al. 2019; Fortin and Greenberg 2016.

¹⁹ Gelatt and Zong (2018).

²⁰ See, for example Maier 2019, Pullen 2019, Gupta 2014, Baru et al. 2013 and Jawed 2020.

transplanted patients without residence permits as for patients with residence permits.²¹

It is the absence of health insurance that is identified as the main reason why patients without documents receive transplantations to a smaller extent than the rest of the population.²² There are, however, considerable inter-state differences. In California persons without document also have some cover in the health insurance system and can obtain a kidney transplant, while even getting access to dialysis is difficult in Texas.²³

The question of aliens' access to organ transplantation has been discussed in the United States in the light of different types of situations. One concerns what is called 'medical tourism', i.e. people making their way to the United States in order to buy highly specialised health and medical care.²⁴ The other is about people without documents who are resident in the United States and their limited possibilities of obtaining access to health and medical services, such as dialysis and organ transplantation, for example. Children without residence permits who are in need of organ transplantation often undergo transplantation financed by a charity organisation or through the federal Medicaid programme. However, the subsidised care ceases when the patient reaches adult age, and they then risk being unable to pay for the medicines and follow-up treatment required to be able to retain the organ. There is discussion in the literature of various possibilities of ensuring that transplanted patients in this group can be given assistance with vital care and treatment. The examples discussed illustrate dilemmas similar to those faced by the profession in Sweden when it has to make decisions as to whether a person's status under migration law should play a part when they make decisions on whether or not to transplant. There are those who oppose transplantation to these groups and those who advocate transplantation.²⁵

Against the background of the discussion in North America about transplantation for asylum seekers it has been pointed out that weighty reasons are required to refuse anyone a transplantation and that assumptions about the worst conceivable future scenario for a

²¹ Lee and Terrault 2020.

²² King et al. 2005.

²³ Pullen 2019.

²⁴ See, for example, Ahya 2017.

²⁵ See, for example, Wightman and Diekema 2015, Ackah, Sigireddi and Murthy 2019, Goldberg et al. 2007 and Gupta 2008.

particular person does not constitute such reasons. The future is uncertain – in various respects – for almost everyone on a waiting list for transplantation.²⁶

²⁶ Wightman and Diekema 2015.

5 Applicable law

This section describes the applicable law regarding access to health and medical services in Sweden for persons staying in Sweden without having a permanent residence permit.¹ The obligation of the regions to offer care to asylum seekers and persons without documents is described in the legislation using the expression “care that cannot be deferred”. The question is whether care of certain duration or requiring aftercare can be considered to be included in that kind of care when it comes to patients without permanent residence permits.

The presentation mainly covers national legislation, but it also deals with relevant international agreements in the area.

In the final section the Council sets out its assessment of the position under the applicable law as to whether health and medical care that requires aftercare, taking organ transplantation as an example, can be considered to fall within care that cannot be deferred and how far the obligation to offer that kind of care can be considered to be extended for persons without permanent residence permits.

5.1 Regions’ responsibility to offer health care in Sweden

Summary of section 5.1:² A person who is resident in Sweden is covered by the regions’ responsibility to offer health care. Foreign nationals who have permanent residence permits or a right of residence in Sweden can be registered in the population register and then have full access to subsidised care.

¹ The applicable law chapter is partly based on a legal investigation by Yana Litins’ka, a post-doctoral fellow at the Faculty of Law, Lund University, see Litins’ka 2020.

² In the applicable law chapter Smer has chosen to place summary boxes in certain sections as an aid to the reader.

Adults who are applying for asylum in Sweden or staying in Sweden without having the necessary permits (persons without documents) have limited access to health care and dental care. The regions' responsibility to offer care is limited to care that cannot be deferred and certain other care. Children of asylum seekers and persons without documents have the right to the same care as a person resident in the region.

Other people, for instance tourists and Swedish citizens living abroad who are visiting Sweden, have the right to be given immediate care, which, in principle, means emergency care.

5.1.1 Health and medical services legislation in general

The objectives of Swedish health and medical services are to offer people accessible and effective care of a good quality adapted to their needs. This is of crucial importance in enabling the public to feel confidence in health and medical services. The acts, government ordinances and agency regulations that regulate activities in health and medical services are intended to enable care to achieve these objectives.

The general provisions in the area of medical services refer to health and medical service activities in general and concern questions that can arise in all activities of this kind. For example, they cover general principles for the organisation of medical services and the prioritisation of these services between patients. The rules about patients' influence in health care or consent to specific care interventions are also included. The central provisions about the organisation of care and the responsibility of the regions to offer care are set out in the Health and Medical Services Act (2017:30), HMSA. The long-standing trend has been for the patient's self-determination and the interests expressed by the patient to be given greater weight in health and medical services. As part of these endeavours the Patients Act (2014:821) was introduced on 1 January 2015. The purpose of the Act is to strengthen and clarify the position of the patient and to promote the patient's integrity, self-determination and participation in activities in health and medical services. In addition to the Health and Medical Services Act and the Patients

Act, the Patient Safety Act (2010:659) is also of central importance for the questions considered in this report.

As a supplement to the more general legislation, there are also special rules regulating a particular situation or measure or a defined area in health and medical services. Some examples are the Act on health and medical care for asylum seekers and others (2008:344), the Act on health care for certain aliens staying in Sweden without the necessary permits (2013:407) and the Act on Transplantation etc. (1995:831).

5.1.2 Responsibility to offer care under the Health and Medical Services Act

The responsibility of the regions to offer health and medical services is defined in Chapter 8 of the HMSA. Chapter 8, Section 1 of the HMSA provides that the region shall offer good health and medical services to persons resident in the region. Thus, a person who is resident has full access to subsidised care. The legislative history of the Act states that population registration provides guidance as to whether a person is considered to be resident in the region. Aliens with a right of residence or either a temporary or a permanent residence permit may be registered in the population register under Section 4 of the Population Registration Act (1991:481). Hence, these aliens with temporary residence permits also have full access to subsidised care.

EU citizens who are not regarded as being resident in the region but who are covered by the provisions on benefits in kind under Regulation (EC) no 883/2004 of 29 April 2004 on the coordination of social security systems are also covered by the region's responsibility, see Chapter 8, Section 2 of the HMSA.

In addition to the responsibility to offer care that the regions have as described above, the regions shall also offer immediate health and medical services to a person who is staying in the region without being resident there and who needs immediate care, see Chapter 8, Section 4 of the HMSA. This applies, for example, to tourists visiting Sweden (see also section 5.1.4). As regards immediate care, the legislative history states that this care cannot be defined more precisely and has, instead, to be determined in each specific case by the attending doctor

or some other person responsible for the care. In principle, immediate care means emergency care, for example if someone is injured in a traffic accident or becomes acutely ill.³ Under this provision the regions are not obliged to provide subsidised care and have the right to request payment from the individual.⁴

5.1.3 Special legislation on access to health care for asylum seekers and persons without documents

The situation is different for aliens who cannot be registered in the population register. Adults seeking asylum or staying in Sweden without having the necessary permits (persons without documents) have limited access to health care and dental care. The group of persons without documents includes both persons in hiding to avoid enforcement of a refusal-of-entry or expulsion order under the Aliens Act (2005:716) and persons who are in Sweden without having applied for the permits necessary to stay in the country.⁵

The regions' responsibility to offer health care and dental care to these groups is regulated in special legislation. The provisions are set out in the Health and Medical Care for Asylum Seekers and Others Act (2008:344) and the Act on health care for certain aliens staying in Sweden without the necessary permits (2013:407). The responsibility to offer health care and dental care is designed in a similar way in both Acts, and under the provisions adult asylum seekers and persons without documents have to be given care that cannot be deferred (see section 5.3), obstetric maternity care, abortion care and advice on contraception. The Act on health care for certain aliens staying in Sweden without the necessary permits (2013:407) states explicitly that a region may offer aliens who have turned 18 years and who are covered by the Act on health care over and above what is stated in the Act (see Sections 7 and 8). The responsibility of the regions only covers aliens staying in that specific region.

³ Govt Bill 1981/82:97 p. 120 and Sahlin 2016.

⁴ Govt Bill 1981/82:97, p. 120 and Zillén 2019, p. 74. Some regions have decided to give asylum seekers and persons without documents full access to care.

⁵ Comment: A person living as a "person without documents" does not necessarily lack identity documents such as passport, ID card or the equivalent. The lack of documents refers to the absence of permits to stay in the country.

However, children of asylum seekers and persons without documents have the right to the same care as a person resident in the region. Children means persons who have not turned 18 years.

5.1.4 Economically vulnerable EU citizens and their children

When it comes to economically vulnerable EU citizens staying temporarily in Sweden, they often have difficulty meeting the residence requirement since they are living in homelessness and because they usually have difficulty meeting the requirements for a right of residence.⁶ If, moreover, they do not have an insurance in their country of origin that covers health care, or cannot prove that they are insured, they are not covered by Regulation (EC) No. 883/2004 and not by Chapter 8, Section 2 of the HMSA either. The care that then remains for this group is immediate care under Chapter 8, Section 4 of the HMSA. But the region has no obligation to offer that care at a subsidised cost. According to regional representatives the regions act differently regarding demands for payment in these cases.

The question is whether economically vulnerable EU citizens and their children could be regarded in some cases as persons without documents and therefore be covered by the care stipulated in the Act on health care for persons without documents. The Act applies to persons staying unlawfully in Sweden. That means that EU citizens who are in Sweden lawfully, i.e. during their first three months, or thereafter if they have a right of residence, are not covered by the Act. If, however, they have been in Sweden for longer than three months and do not have a right of residence they may possibly be regarded as persons without documents and be covered by the Act. The legislative history of the Act states that it is not impossible that the Act may come to be applicable regarding EU citizens in isolated cases.⁷ However, it is not clear whether and in what situations the Act can be applied to EU citizens and their children.⁸ According to Section 5, the Act does not apply to aliens staying temporarily in

⁶ Zillén 2019, p. 69.

⁷ Govt Bill 2012/13:109, p. 41.

⁸ Zillén 2019, p. 77.

Sweden either, which may perhaps rule out economically vulnerable EU citizens.⁹

So certain groups of EU citizens and their children risk being left without health care. This is at the same time as the Swedish legislature has worked so far to ensure that children who are in Sweden are given equal possibilities of care, irrespective of their legal status.¹⁰ It is also hard to see how this situation is compatible with the Convention on the Rights of the Child, which became Swedish law¹¹ in 2020 and whose provisions include the right of the child to the best attainable health and access to health care services, see Article 24.

5.1.5 Other people staying temporarily in Sweden

If a person who is staying in a region without being resident there needs immediate health and medical care/services, the region has to offer this care according to Chapter 8, Section 4 of the HMSA. The obligation for regions to offer this care covers both persons who belong to another region and persons who do not, e.g. aliens visiting the region temporarily. Examples that can be mentioned are tourists and Swedish nationals living abroad who are visiting Sweden. Swedish nationals who have moved abroad and have been de-registered from the population register in Sweden are not regarded as being resident in Sweden and are therefore not covered by Swedish health and medical services.

5.2 Fundamental principles in Swedish health and medical services

Summary of section 5.2: Prioritisation in Swedish health and medical services is based on three fundamental principles:

- the human dignity principle, i.e. all human beings have equal dignity and have the same right to medical care irrespective of their personal characteristics and function in society;

⁹ Govt Bill 2012/13:109, pages 37 ff and p. 58 and Zillén 2019, p. 77.

¹⁰ Read more in Zillén 2019, p. 153

¹¹ Act on the United Nations Convention on the Rights of the Child (2018:1197). 12 Govt Bill 1981/82:97, p. 120 and Govt Bill 2016/17:43 p. 138.

- the need and solidarity principle, i.e. resources should be allocated according to need;
- the cost-effectiveness principle, i.e. when choices are made between different activities or measures, a reasonable relation should be sought between cost and effect.

The human dignity principle is applied first, followed by the need and solidarity principle and then, finally, by the cost-effectiveness principle.

There is also a requirement that the care has to be given on the basis of science and proven experience.

5.2.1 Guiding ethical principles in the Health and Medical Services Act

The fundamental ethical principles that have to guide all health and medical services are set out in Chapter 3 of the HMSA. Chapter 3, Section 1 of the HMSA states that the overall objective of Swedish health and medical services is for the whole population to have good health and access to care services on equal terms. When needs exceed resources in health and medical care and a prioritisation must be made, the principles in the ‘ethical platform’ adopted by the Swedish Parliament in 1997 have to be applied.¹² These principles guide both everyday clinical practice and decision-makers at political and administrative levels. Since the principles have different purposes, their internal ranking is important in handling potential conflicts. The human dignity principle has to be applied first, followed by the need and solidarity principle and, finally, by the cost-effectiveness principle.

Human dignity principle

The human dignity principle means that all human beings have equal dignity and have the same right to care, irrespective of their personal characteristics and functions in society. The principle is expressed in the following way in Chapter 3, Section 1, second paragraph of the

¹² Govt Bill 1996/97:60.

HMSA: “Care shall be provided with respect for the equal dignity of all human beings and the dignity of the individual”.

Need and solidarity principle

The need and solidarity principle means that resources have to be allocated according to need. The principle is set out in Chapter 3, Section 1, second paragraph of the HMSA: “The person who has the greatest need of health and medical care shall be given priority for care.”

Cost-effectiveness principle

This principle means that when choices are made between different activities or measures, a reasonable relation should be sought between cost and effect, measured as better health and higher quality of life.¹³

5.2.2 Requirement of science and proven experience

The requirement that the care given has to be supported by science and proven experience is set out both in the Patient Safety Act (2010:659), PSA, and in the Patients Act (2014:821), PA. Under Chapter 6, Section 1 of the PSA, health care professionals have to perform their work in conformity with science and proven experience. Under Chapter 1, Section 7 of the PA, the patient has to be given expert and careful health and medical care that is of good quality and that is in conformity with science and proven experience.

5.3 “Care that cannot be deferred” and care that requires aftercare

“Care that cannot be deferred” is the expression that the legislature has chosen for the health care and dental care that the regions are obliged to offer asylum seekers and persons without documents. Neither the Act on health care for asylum seekers nor the Act on

¹³ Govt Bill 1996/97:60 p. 54 f and p. 103.

health care for persons without the necessary permits contains a clear definition of the term. This has led to many questions from health and medical services about what is included in that care. As regards persons without permanent residence permits, special questions can arise about how long the person can be expected to stay in Sweden, since some treatments need to continue for a long time or require access to aftercare to have the intended effect. To assess what the care that cannot be deferred covers, it is necessary to examine what is said in the legislative history and in the decisions made by the Health and Social Care Inspectorate (IVO). There are no agency regulations regarding care that cannot be deferred.

The following section gives a relatively detailed description of what is said about care that cannot be deferred in the legislative history of these Acts. In section 5.6 the Council gives its summary assessment of the scope of the term.

5.3.1 Legislative history and previous general advice from the Swedish National Board of Health and Welfare

Summary of section 5.3.1: According to the legislative history, the term care that cannot be deferred in the legislation includes:

- care and treatment of diseases and injuries where it is assessed that even a moderate delay could have serious consequences for the patient. This also includes follow-ups to this care and to psychiatric care.
- care to counter a more serious condition.
- care to avoid more extensive care and treatment.
- care to prevent serious acute conditions, where the interventions can reduce the use of resource-consuming emergency treatment interventions.

According to the legislative history, an assessment always has to be made in the specific case. Account also has to be taken of the fact that it is uncertain whether the alien will remain in Sweden, but no description is given of how to strike this balance.

The assessment of **The National Board of Health and Welfare** (2014) is that it is not possible to specify what conditions or measures constitute care that cannot be deferred and that this must, instead, be decided by the health care professionals in each specific case.

The term “care that cannot be deferred” was used for the first time in the legal text of the Act on health and medical care for asylum seekers and others (2008:344). The same term is used in the Act on health care for certain aliens staying in Sweden without the necessary permits (2013:407), and the legislative history of that Act refers to the government bill that formed the basis for the Act on health and medical care for asylum seekers.

Expansion of the care defined as immediate

The government bill (Govt Bill 2012/13:109) that formed the basis for the Act on health care for certain aliens staying in Sweden without the necessary permits described what is covered by the term “care that cannot be deferred” in the following way:

The term “care that cannot be deferred” was intended to be an expansion of the care defined as immediate. The term has come to use both in statutes and in agreements to define the scope of the health and medical care and dental care that can be offered to adult asylum seekers and others. According to the explanatory note to Section 6 of the Act on health and medical care for asylum seekers and others (Govt Bill 2007/08:165¹⁴), the term “care that cannot be deferred” includes care and treatment of diseases and injuries where it is assessed that even a moderate delay could have serious consequences for the patient.¹⁵

It also states the following:

This also includes follow-ups to this care and to psychiatric care. It should be possible to offer care at an early stage when this can counter the development of a more serious condition and a need of more extensive treatment arises. Early interventions can also be justified in

¹⁴ The reference in the Bill is incorrect. The right bill number is 2007/08:105.

¹⁵ Govt Bill 2012/13:109, page 42.

physical care when given to prevent the patient suffering serious acute conditions and the early interventions can therefore also reduce the use of more resource-consuming emergency treatment measures. One example is information and support for ‘self management’ of certain conditions, e.g. diabetes and asthma. In the case of a person who has special needs, such as a person who has been subjected to torture or other serious abuse or traumas, a particularly careful assessment should be made of what care cannot be deferred. Care that care cannot be deferred can also include an obligation to offer loans of assistive devices to persons with disabilities when that need cannot be met in some other way.¹⁶

Serious consequences for the patient

As regards care and treatment of diseases and injuries where it is assessed that even a moderate delay could have serious consequences for the patient, the legislative history does not define what types of situations can result in serious consequences of this kind for the patient. However, the legislative history of the Acts refers to the interpretation of the term “care that cannot be deferred” made by the National Board of Health and Welfare in the Board’s long since repealed general advice for persons seeking asylum.¹⁷ The following is said in Bill 2012/13:109:

According to the repealed general advice from 1995 the assessment has to take account of the patient’s possibilities of receiving care in the near future and of the fact that, unlike other patients, an asylum seeker cannot be referred to their home county council or country of origin for care if their need for care can be deferred for a few days or a week or so. The National Board of Health and Welfare considered that the asylum-seeking person’s need for care must be assessed from the perspective that several months may pass before they are able to receive care other than emergency care. The decisive factor in the assessment is whether a delay of the care interventions may lead to serious consequences for the patient. This can be a danger to the patient’s life on account of, for instance, a risk of suffocation or exsanguination. The fact that a treatment performed later leads to

¹⁶ Govt Bill 2012/13:109, pages 42f.

¹⁷ Govt Bill 2012/13:109 p. 19 and National Board of Health and Welfare 1995.

a much poorer prognosis or greater risks of complications must also be a weighty consideration in the assessment of whether care should be given or not.

Follow-up measures and period of stay

The explanatory note adds the following specification of what follow-up measures are covered by the term:

Follow-up measures can, for instance, be completion of a treatment for tuberculosis, an X-ray check of the healing of a fracture, the removal of plaster and sutures, a dental prosthesis if teeth are extracted on account of an indication entitled to compensation or a prosthetic leg in the case of amputation. It should be possible to offer care at an early stage when this can counter the development of a more serious condition and a need for more extensive treatment arises ... When assessing what care to give, account must be taken of the uncertainty about how long the alien will stay in the country.¹⁸

Uncertain whether the person can remain in Sweden – assessment of proportionality

The legislative history states that when assessing whether or not a treatment can be deferred, account must be taken of the uncertainty about whether the alien will stay in the country. An offer of treatment measures or assistive devices has to be reasonably proportionate with the fact that the person's stay is to be considered temporary.¹⁹ However, nothing is said about how to strike this balance. The above-mentioned repealed general advice from the National Board of Health and Welfare stated that care that requires long treatment periods and that is not of an emergency nature, should not be started if an interruption of the care may have negative consequences for a person seeking asylum who is not permitted to stay in Sweden. Examples mentioned are extensive operations or treatments in several stages when it is not certain they can be completed before the permit issue is decided.²⁰ As regards emergency operations of

¹⁸ Govt Bill 2012/13:109, p. 58f.

¹⁹ Govt Bill 2007/08 :105, p. 31 and Govt Bill 2012/13:109, p. 43

²⁰ See reference in Govt Bill 2012/13:109, p. 20.

patients with critical conditions that need prolonged treatment periods, there is still no guidance.

Regarding deliberations on a more detailed specification of the term

The legislature has intentionally refrained from defining the term “care that cannot be deferred” in more detail since the assessment made was that this might lead to a much too narrow an interpretation. Instead the Government considered that further clarification and guidelines concerning the application of the term would be given by the National Board of Health and Welfare.²¹ The Board gave its view of the term in its report *Care for persons without documents – care that cannot be deferred, documentation and identification in care of persons staying in the country without permits.*²² The Board expressed some criticism of the term, and its conclusion was that it was not possible or appropriate, either ethically or medically, to specify in lists what diagnoses, conditions or measures are covered by the term “care that cannot be deferred”, since it is not possible to cover every conceivable situation. Moreover, the same diagnosis can sometimes mean that care can be deferred and that, in other cases, it cannot be deferred. The Board therefore considered that what is care that cannot be deferred must be decided by the health care professionals in each specific case.²³

5.3.2 Decisions by the Swedish Health and Social Care Inspectorate (IVO)

The decisions by the Swedish Health and Social Care Inspectorate (IVO) regarding the term “care that cannot be deferred” are not precedents but are examples of how the Inspectorate views questions concerning what specific interventions can be covered.

One example is a decision concerning a patient with the diagnosis hypertrophic cardiomyopathy. The health care professionals made the assessment that the patient needed to have a defibrillator, a pro-

²¹ Govt Bill 2007/08:105 p. 30 f.

²² In Swedish: *Vård för papperslösa – vård som inte kan anstå, dokumentation och identifiering vid vård till personer som vistas i landet utan tillstånd*, Socialstyrelsen 2014.

²³ Govt Bill 2012/13:109 p. 19 and Govt Bill 2007/08:105, p. 31.

phylactic ICD. However, the medical director considered that the risk of severe complications carried more weight because the patient was an asylum seeker and there was a great risk of expulsion to a country where nearness to a medical care centre able to handle ICDs could not be guaranteed. The assessment made was that the risk of an adverse event, if the ICD was inserted, would be unacceptably high and therefore the treatment was not given. The patient died as a result of a sudden cardiac arrest.

IVO agreed that there were strong indications for ICD, partly because it was judged to be a great risk of sudden death. IVO also considered that it was reasonable of the care provider to take account of the risks associated with the treatment as well as the possibility of following up these risks where the patient would be located. However, IVO underlined that a decision cannot be based on assumptions but must be well-founded and justified in the patient's medical record. According to IVO's investigation there was no statement of the grounds on which the care provider had made its assumptions about when the patient would be expelled, or what possibility there was of obtaining care in the patient's country of origin. IVO criticised the care provider for not having investigated the circumstances sufficiently to be able to make a well-founded decision as to whether ICD treatment could be deferred.

5.4 International law

Summary of section 5.4: The right to health is regarded as one of the fundamental human rights and is included in several important conventions that Sweden has ratified and is therefore bound by. Like other human rights, the right to health applies to everyone staying in the geographical area of a country, irrespective of their nationality or status under migration law, for example.

Under the UN Covenant on Economic, Social and Cultural Rights everyone has the right to enjoy the best attainable physical and mental health, and under the UN Convention of the Rights of the Child every child has the right to enjoy the best attainable health and the right to medical care and rehabilitation. The European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) states that everyone has the

right to life and prohibits anyone being subjected to torture. Access to health and medical care has been considered to be a necessary precondition for ensuring the right to life and the prohibition of torture.

Expelling a gravely ill person can be contrary to the ban on torture in the ECHR if there are material reasons to fear that this risk leading to intensive suffering or a considerable reduction of their life expectancy.

Sweden is a contracting party to several international agreements with other countries. Sweden has both been a member of the European Union since 1995 and has also ratified a number of conventions that are binding under international law. So, the responsibility that Swedish health and medical services have to offer care to persons who do not have permanent residence permits must also be viewed in the light of Sweden's international commitments.²⁴

5.4.1 EU law

Membership of the European Union entails a number of obligations. Health and medical care is an area where Member States have national competence, but there are, nevertheless, a number of EU regulations and directives that affect national regulatory frameworks for health and medical care.

One directive of importance for the question in this report is Directive 2013/33/EU laying down standards for the reception of applicants for international protection.²⁵ For instance, the Directive requires Member States to ensure that asylum seekers receive the necessary health care, which shall include, at least, emergency care and essential treatment of illnesses and of serious mental disorders. Member States shall provide necessary medical or other assistance to applicants who have special reception needs, including appropriate mental health care where needed (Article 19). Moreover, the Directive states (Article 21) that Member States shall take into account the specific situation of vulnerable persons such as persons with serious illnesses in their national law. The minimum requirements

²⁴ Section 5.4 is based on Litins'ka 2020.

²⁵ Directive 2013/33/EU of the European Parliament and of the Council.

for health care for asylum seekers are therefore more extensive than emergency care and are considered to be met in Sweden since adult asylum seekers are offered care that cannot be deferred.

5.4.2 International conventions on human rights and migration

Conventions are binding on the states that have ratified them. In the Swedish legal system a convention must be incorporated into national legislation to be applicable in Sweden. If the domestic rules are unclear in an area, the regulatory system can be interpreted in the light of the relevant conventions that Sweden has acceded to. To know what care an alien who does not have a permanent residence permit has access to in Sweden is therefore important to be aware of the significance of these international legal acts and agreements.

5.4.3 The right to health

The right to health is regarded as one of the fundamental human rights; it was already formulated in 1946 in the Constitution of the World Health Organisation and was included, shortly afterwards, in the United Nations' Universal Declaration of Human Rights. Since then the right to health has been included in numerous important conventions, albeit in slightly different ways. Here are some of the more important documents:

- the UN International Covenant on Economic, Social and Cultural Rights (the ICESCR), Article 12;
- the UN Convention relating to the Status of Refugees (the Geneva Convention), Article 24;
- the United Nations Convention on the Rights of the Child (the CRC), Article 24;
- the UN Convention on the Rights of Persons with Disabilities, Article 25;

- the European Social Charter, Articles 11 and 13²⁶ and
- the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR).

Neither the UN's nor the Council of Europe's conventions define the concept of health. Instead it is the comments of the various competent bodies that are capable of providing guidance when it comes to interpreting the scope of the States' commitments.

Article 12 of the UN International Covenant on Economic, Social and Cultural Rights begins by stating that "the States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". To satisfy this right the States Parties have to take the steps necessary to achieve a number of goals, including "the creation of conditions which would assure to all medical service and medical attention in the event of sickness."²⁷

Article 24 of the CRC begins as follows: States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Sweden has ratified both these conventions, which means that under international law Sweden is bound by these documents. The Convention on the Rights of the Child is also Swedish law.²⁸

What do the Conventions mean in practice for the responsibilities of states and the rights of the individual?

The responsibilities of the State under the Conventions it has ratified normally apply in relation to every individual staying within the jurisdiction of the State, which is normally limited to the geographical area of the State. The right to health therefore applies irrespective of, for example, nationality or status under migration

²⁶ Article 11 of the European Social Charter (revised) is about the right to health, while Article 13 guarantees the right to social and medical assistance. The right to medical assistance can be regarded as part of the right to health.

²⁷ The United Nations Convention on the Rights of the Child (the CRC), adopted by the UN General Assembly on 20 November 1989.

²⁸ Act on the United Nations Convention on the Rights of the Child (2018:1197) entered into force on 1 January 2020.

law or whether a person is staying in the State with all the necessary permits.

The UN Committee on Economic, Social and Cultural Rights has stated that an individual's right to health must be assessed in relation to both the individual's biological and socioeconomic circumstances and the resources available to a State. According to the Committee, States have the obligation to strive to the maximum of their available resources to ensure the human rights under the ESC Convention at national level through what is called progressive realisation. This does not mean that demands are made that the States implement the objectives of the Convention right away, but States have to work in the direction of full compliance with the objectives and their obligations (Article 2). Greater demands for speedier implementation are made on richer countries that, with their greater resources, have the possibility of doing this.

5.4.4 The right to life and prohibition of torture

In certain cases, the right to health can be linked to other rights such as the right to life and the prohibition of torture. Both the European Court of Human Rights (European Court, ECtHR) and UN Committees have stated that access to health and medical care is a necessary condition for ensuring compliance with both the right to life and the prohibition of torture.²⁹ The absence of access to primary care and emergency care have been held to be situations where the right to life is threatened.³⁰

The right to life is laid down in, for instance, Article 6 of the UN International Covenant on Civil and Political Rights and in Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR). Sweden has ratified both these conventions. The ECHR has been Swedish law since 1995 and has been given elevated status through a provision in Chapter 2, Article 19 of the Instrument of Government that no act of law or other provision may be adopted that contravenes the Convention.

²⁹ ECtHR, Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania, para. 130; ECtHR, Cyprus v. Turkey, para. 219; ECtHR, Ashot Harutyunyan v. Armenia, paras 112 and 114–115; ECtHR, Tysiãc v. Poland, para. 124; UN Human Rights Committee 2018, para. 11.3.

³⁰ UN Committee on Economic, Social and Cultural Rights 2008, p 37. ³⁴ ECtHR, Paposhvili v. Belgium.

The prohibition of torture or other inhuman or degrading treatment or punishment is set out in the same Conventions, in Article 7 and Article 3 respectively.

Both negative and positive obligations are imposed on States in order to create conditions for individuals to enjoy their rights. One example of a negative obligation is that, under certain circumstances, a State must not expel a gravely ill person to a country where there is no suitable care or where there is deficient access to such care. One example of positive obligations is creating conditions to enable people to survive certain serious situations.

Case law of the ECtHR on the right to life and the prohibition of torture

In its case law the ECtHR has developed a method of examining whether a State has breached its positive obligations according to the right to life and the prohibition of torture in the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR). According to this method the ECtHR uses the following criteria:

1. whether the authorities knew, or ought to have known, that there was a risk to a person's life or integrity;
2. whether the risk to their life or integrity was real and immediate;
3. whether the authorities ought to have had the power to avoid the risk; and
4. whether the authorities took reasonable preventive measures that did not entail an impossible or disproportionate burden, and respected other rights and guarantees.³¹

The criteria can be used to assess how far the obligation of states to provide care extends on account of the right to life and the prohibition of torture.

³¹ ECtHR, *Osman v. the United Kingdom*, para 116; ECtHR, *Fernandes de Oliveira v. Portugal*, paras. 109–110 and 112, ECtHR, *Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania*, paras 130–131; ECtHR, *El-Masri v. the Former Yugoslav Republic of Macedonia*, para. 198 and ECtHR, *J.K. and others v. Sweden*, para. 87. See also Mowbray 2004, pages 15–17 and Harris et al. 2018, p. 209.

As regards the first criterion, it ought to be met as soon as health care professionals became aware that a patient has an extensive need of care.³²

The assessment under the second criterion depends on how extensive the need of care is in the specific case. However, the criterion has probably been met if the absence of an intervention entails a risk that the patient will die or be subjected to serious suffering and this risk must be seen as real and immediate.

The third criterion concerns the power of the authorities to eliminate the risk. If the Court were to find that the authorities did not have the necessary power to protect life or integrity, the Court would probably criticise the state for not having established a functioning regulatory framework, and therefore having neglected its positive obligations.³³ Neglect of this kind can, for instance, be that the State has refused medical treatment to certain persons in need of care or has regulated questions in such an unclear way that the health care professionals have refused to provide care in a specific situation because their obligations were unclear.³⁴

The fourth criterion is of particular interest. The European Court's discussion of what measures are reasonable regarding the obligation of states to provide care such as organ transplantation, is bound up with what alternatives are available in the specific state. The patient can only be given access to methods that are approved or are accepted in some other way in the state in question. The European Court has, for instance, considered that access to dialysis³⁵ treatment for AIDS³⁶, or chemotherapy and transplantation for lymphatic leukaemia³⁷ are an integrated part of the right to life and the prohibition of torture. As yet, however, the European Court has not made any decision about the right to receive lungs or hearts.

Questions concerning access to medical treatment as part of the right to life or the prohibition of torture (or other civil rights) in the UN International Covenant on Civil and Political Rights have also

³² ECtHR, *Tariyeva v. Russia*, para. 88; and ECtHR, *Ilbeyi Kemalöglu and Meriye Kemalöglu v. Turkey*, para. 41. See also Harris et al. 2018, pages 209–211.

³³ ECtHR, *Lopes de Sousa Fernandes v. Portugal*, paras 188–196.

³⁴ ECtHR, *Lopes de Sousa Fernandes v. Portugal*, paras 188–196 and ECtHR, *Arskaya v. Ukraine*, paras 84–86.

³⁵ ECtHR, *M.T. v. Sweden*, paras 7, 50–53.

³⁶ ECtHR, *D. v. United Kingdom*, paras 50–53.

³⁷ ECtHR, *Paposhvili v. Belgium*, paras 34–45, paras 205–206.

been discussed by the UN's monitoring bodies.³⁸ Their discussions correspond, in all essential respects, to the case law of the European Court of Human Rights.³⁹

5.4.5 Expulsion of a seriously ill person may be contrary to the European Convention

However, the fact that organ transplantation is held to be included in the right to health under the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) does not mean that every single patient has an unconditional right to transplantation. But it does mean that the person has a right to a medical assessment in the same way as applies to the population or people resident in the country.

As mentioned above, Article 3 of the ECHR provides that no one shall be subjected to torture or to inhuman or degrading treatment or punishment. The Convention applies as Swedish law. The European Court of Human Rights in Strasbourg checks the compliance of States Parties and has established in its case law that it can, in certain exceptional cases, be contrary to Article 3 to expel a seriously ill person. This presupposes that it has been shown that there are material reasons to believe, on account of the absence of suitable health care in the receiving country or deficient access to such health care, that the person would encounter real risks of a serious, rapid and irreversible deterioration of their state of health, resulting in intensive suffering or a considerable reduction of their life expectancy.⁴⁰

The standard of proof is high, it must have been shown that the person runs a real risk of being subjected to that treatment.⁴¹ It is the person who is applying for a residence permit who has to present proof that there is a risk of treatment contrary to Article 3. Under case law, however, the applicant cannot be required to present full proof. The Swedish Migration Agency also has an obligation to conduct an investigation that comes into play when the applicant cites evidence indicating that, on returning, they risk being subjected

³⁸ UN Human Rights Committee, 28 December 2016. para 9.4; UN Human Rights Committee, 2018. para 11.3. See also UN Human Rights Committee, 28 April 2016, CCPR/C/SWE/CO/7, para. 15.

³⁹ UN Human Rights Committee 2018. para. 11.3.

⁴⁰ ECtHR, *Paposhvili v. Belgium*.

⁴¹ ECtHR, *S.H.H. v. the United Kingdom and Paposhvili v. Belgium*.

to treatment contrary to Article 3. It is also important that their state of health is well documented through acceptable doctor's certificates.⁴² If there are still unclear points after an investigation, the State must request individual and sufficient guarantees in the specific case from the receiving State that suitable treatment will be available to the person concerned.⁴³

As regards the case law of the European Court in relation to sick children, there does not seem to be any difference in its reasoning compared with case law for adults.⁴⁴

5.4.6 How far does the responsibility of States extend regarding the right to life and health and the prohibition of torture?

As stated above, the term "care that cannot be deferred" has been considered to incorporate the requirements set by the EU Directive laying down standards for the reception of applicants for international protection⁴⁵ concerning what responsibility the regions have for offering care to asylum seekers.

The Court of Justice of the European Union (ECJ) has established that Member States shall ensure that the prohibition of inhuman and degrading treatment is guaranteed in relation to the medical care provided. What is to be regarded as inhuman and degrading treatment is to be understood in the light of the minimum standard guaranteed in the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR).⁴⁶ EU case law also states that what is to be regarded as necessary care for asylum seekers depends on what requirements are laid down in international conventions on human rights.

As regards the right to health and what measures a country is required to offer, this depends on a large number of factors, including the level of development of the specific country.⁴⁷ The UN Committee on Economic, Social and Cultural Rights has stated that

⁴² Migration Court of Appeal, MIG 2007:35 and MIG 2007:43.

⁴³ ECtHR, *Paposhvili v. Belgium*.

⁴⁴ Swedish Migration Agency 2018, p. 8.

⁴⁵ Directive 2013/33/EU of the European Parliament and of the Council.

⁴⁶ ECJ, *C. K. and others v. Republic of Slovenia*, paras 75–80.

⁴⁷ UN Committee on Economic, Social and Cultural Rights 2008, para 12(a).

states have an obligation to provide a number of different measures, ranging from preventive to treatment and rehabilitation measures.⁴⁸ This comment means that the spectrum of measures that states are obliged to provide is broad. What a state must be able to provide also depends on its level of development and economic resources.

The Council of Europe’s Committee for Social Rights (the European Committee of Social Rights) has declared that whether a person is entitled to emergency care under the European Social Charter (revised) must be assessed in the light of whether the individual’s needs are serious and urgent. Moreover, this criterion should not be given a narrow meaning.⁴⁹ To sum up, the Committee has concluded that, irrespective of their legal status, individuals have the right to medical measures that are necessary.

5.5 Severe illness of importance for a residence permit and expulsion

Summary of section 5.5: In cases of severe illness there are, at present, provisions providing some possibilities of impediments to enforcement of expulsion orders and of obtaining residence permits.

The Cross-party Committee of Inquiry on future Swedish migration policy has presented proposals that may be of importance for these provisions.

5.5.1 Swedish law concerning residence permits and impediments to enforcement

Under Swedish law a residence permit can be granted in view of an alien’s state of health, see Section 11 of the Act Temporarily Restricting the Possibility to Obtain Residence Permits in Sweden (2016:752) (the Temporary Restrictions Act) and Chapter 5, Section 6 of the Aliens Act (2005:716), (AIA).

⁴⁸ UN Committee on Economic, Social and Cultural Rights 2008, para 17.

⁴⁹ European Committee of Social Rights, CEC v. the Netherlands, para 105 and FEANTSA v. the Netherlands, p. 171.

Chapter 5, Section 6 of the Aliens Act states the following. If a residence permit cannot be awarded on other grounds, a permit may be granted to an alien if, in an overall assessment of the alien's situation, there are found to be exceptionally distressing circumstances that mean that they should be allowed to stay in Sweden. In making this assessment, particular attention shall be paid to the alien's state of health, their adaptation to Sweden and situation in their country of origin. For children a residence permit under the first paragraph may be granted if the circumstances are particularly distressing. In the period 20 July 2016–19 July 2021, the provisions applicable are the deviations from the first and second paragraphs set out in Sections 11 and 12 of the Act Temporarily Restricting the Possibility to Obtain Residence Permits in Sweden (2016:752).

The provision in Section 11 of the Temporary Restrictions Act comes under the heading "Residence permits on account of Sweden's international commitments" and according to that Section a residence permit may only be granted if it would be contrary to a Swedish commitment under a convention to refuse entry to or to expel the alien. This means that a residence permit can be granted if it follows from a Swedish commitment under a convention. Under Section 12 of the same Act, a residence permit granted under Chapter 5, Section 6 of the Aliens Act (2005:716) has to be temporary and apply for thirteen months. If a new residence permit is granted, the new permit also has to be temporary and has to apply for two years.

Furthermore, in a case concerning enforcement of expulsion or refusal of entry an impediment (impediment to enforcement) can arise that means the order cannot be carried out. One such impediment can be the alien's state of health, see Chapter 12, Section 18, first paragraph, point 3 of the Aliens Act and section 5.4.2 above. However, for it to be possible to establish an impediment to enforcement and grant a residence permit, new circumstances must have come to light in relation to what has already been examined. The assessment of a child's situation is less restrictive than for an adult, see Chapter 12, Section 18, third paragraph of the Temporary Restrictions Act.

These provisions require the Swedish Migration Agency to determine whether an expulsion is contrary to Article 3 of the ECHR and to base its assessment on the circumstances described above.

EU law can also give sick persons protection from expulsion in a corresponding way to the European Convention.⁵⁰

5.5.2 Proposals from the Committee on Sweden's future migration policy

In June 2019 the Government appointed a Cross-party Committee of Inquiry to investigate and make proposals for the shape of future Swedish migration policy. The Committee consisted of members of all the Swedish Parliament parties and of experts. The Committee reported on its remit on 15 September 2020 in its final report A long-term sustainable migration policy (SOU 2020:54)⁵¹.

The Committee is a result of the 'January Agreement' between the Social Democratic Party, the Green Party, the Centre Party and the Liberal Party. In the agreement the parties decided to extend the temporary act by two years at the same time as Sweden's future migration policy would be investigated by a cross-party committee of inquiry.

The Committee's main remit was to investigate Sweden's asylum policy. The terms of reference adopted for the Committee by the Government included consideration of the following issues:

- whether temporary or permanent residence permits should be the main rule for persons who are given asylum in Sweden;
- what the duration of these permits should be, and the conditions under which a person should be granted a temporary or permanent residence permit;
- whether it should be possible to grant residence permits on grounds additional to those that follow from EU law and Swedish convention commitments. In that context the Committee was

⁵⁰ See Article 19(2) of the Charter of Fundamental Rights of the European Union and Article 15(b) of Directive 2011/95/EU of the European Parliament and of the Council of 13 December 2011 on standards for the qualification of third-country nationals or stateless persons as beneficiaries of international protection, for a uniform status for refugees or for persons eligible for subsidiary protection, and for the content of the protection granted (reworked) and Article 5(c) of Directive 2008/115/EC of the European Parliament and of the Council of 16 December 2008 on common standards and procedures in Member States for returning illegally staying third-country nationals.

⁵¹ In Swedish: En långsiktigt hållbar migrationspolitik SOU 2020:54.

also to give special consideration to whether a new humanitarian ground for granting residence permits should be introduced.

In the terms of reference, the Government stressed that migration policy has to be humane, legally certain and effective and to have broad support in the Swedish Parliament. In its work, the Committee was to take account of regulatory frameworks that may be adopted by the EU, national rules in other EU countries and what measures may be needed to strengthen legal certainty in the asylum process.

The Committee's proposals of importance for this report

Temporary residence permits will be the main rule, in contrast to permanent residence permits that were the main rule under the previously applicable Aliens Act. It should still be possible to grant permanent residence permits, but only after three years and only if certain requirements are met. The requirements are that applicants have the ability to support themselves and good knowledge of the Swedish language and of civics. There will also be an examination of good character. The design of these requirements is being considered by an ongoing inquiry into requirements concerning language skills and knowledge of civics for citizenship.

The Committee proposes reintroducing a possibility of being granted a residence permit on humanitarian grounds. Under its proposal, residence permits can be granted if there are exceptionally distressing circumstances. One such circumstance (for adults) can be an exceptionally serious state of health. The Committee proposes that, as a rule, residence permits granted on these grounds should be temporary.⁵² The length of the permit granted on these grounds is 13 months, with the possibility of an extension for two years at a time and the possibility of a permanent residence permit, if those requirements are met. There should be some relaxation of the assessment of humanitarian grounds in the case of children.

⁵² SOU 2020:54, p. 301 f.

5.6 Assessment of whether care of some duration or a requirement of aftercare is covered by care that cannot be deferred

Summary of section 5.6: There is no support in the applicable law for excluding any form of medical care in advance from the term “care that cannot be deferred”. Organ transplantation ought to be that kind of care, especially when it is a matter of life-saving treatment.

There is no support in national or international law for making an assessment at group level. An individual assessment must always be made of every patient.

Nor is there support in the applicable law for refraining from giving care solely for the reason that the person’s future status under migration law is unclear.

There are different views in the profession about how to apply the provision and there is no guidance to the profession in these situations.

Under the applicable law it is possible to decide on impediments to enforcement and to grant residence permits for patients with critical conditions.

A review has been made in this chapter of the legal position in order to examine whether organ transplantation and other health and medical care interventions that require longer duration or access to aftercare come under the term “care that cannot be deferred” and the responsibility of the regions for offering care of this kind to persons who do not have permanent residence permits. Following a review of the legislation and its legislative history, it is unclear what is covered by the term “care that cannot be deferred”.

As has been shown, there are some guidelines in the legislative history of the legislation as to how to interpret the meaning of care that cannot be deferred. However, there are no regulations or other guidance from a government agency, and no case law. But when it comes to organ transplantation, there is a special regime in an act of law and regulations that is also applicable to decisions on care in those cases. A summary is presented below of the import of previous

sections and is followed by an overall assessment based on what has been presented.

As a supplement to the applicable national law, Smer has also studied international law and what commitments Sweden can be considered to have assumed by acceding to various international conventions.

5.6.1 National law

Legislative history of care that cannot be deferred

The legislative history of the legislation on care that cannot be deferred says that the term “care that cannot be deferred” is intended to be an expansion of the care defined as immediate. When making an assessment of whether a care intervention should be considered to be included in care that cannot be deferred the doctor has to assess whether delaying the intervention(s) may lead to serious consequences for the patient. What these serious consequences can be has not been defined in the legislative history, but that history refers to the National Board of Health and Welfare in the Board’s repealed general advice, which specified action including care interventions to counter the development of a more serious condition and a need for more extensive treatment arising. The decisive factor in the assessment of whether care cannot be deferred is whether a delay of the care interventions may lead to serious consequences for the patient, which may, for instance, apply to danger for the patient's life. The legislative history does not say anything explicitly about organ transplantation, but when it comes to that kind of treatment there are often no other treatment alternatives, and there is, instead, an imminent risk of the patient dying if no transplantation is performed. In the cases where the doctors treating a patient make the assessment that organ transplantation is required to save the patient’s life or to avoid serious consequences, Smer considers that a reasonable interpretation of the legislative history is that this care is included in care that cannot be deferred.

According to the legislative history, the patient also has the right to the follow-up measures required by the treatment and this means that there is no statement in the legislative history that contradicts the inclusion of organ transplantation in the term “care that cannot

be deferred”. The legislative history also says that the assessment of what care has to be given must take account of the uncertainty about how long the alien will stay in the country. However, particular difficulties are associated with that assessment, since the legislative history does not specify the way in which the time when the patient will be in Sweden should be given importance or how to weigh it against the patient’s condition.

Particular difficulties in care requiring lifelong aftercare

There are particular difficulties in cases where the doctor has to consider whether to carry out transplantation or other care requiring lifelong aftercare where there is uncertainty, on account of the patient’s status under migration law, about what possibilities the person will have of accessing that care in the future. Then the question is, first, what importance to give to the time when the patient can be expected to be in Sweden and, second, whether the person can obtain care in the country to which they are going to be expelled and, if so, what care.

One decision from IVO states that a decision (to give or refrain from giving care, see section 5.3.2) cannot be based on assumptions and must, instead, be well-founded and be justified in the patient’s medical record. In that decision, IVO stated that the care provider has an obligation to investigate the circumstances to a sufficient extent for it to be possible to consider that the decision is well-founded.

The problem is that often no information can be obtained about the future prognosis for these persons. Moreover, the legislative history is unclear about how to make the assessment of care in a situation that is life-threatening for the patient in cases where the care is of some duration or requires aftercare.

Impediments to enforcement and right to residence permit on account of illness

Under the Act Temporarily Restricting the Possibility to Obtain Residence Permits in Sweden (2016:752) and the Aliens Act (2005:716) a residence permit can be granted on account of the alien’s state of

health. These provisions require the Swedish Migration Agency to determine whether an expulsion is contrary to Article 3 of the European Convention for the Protection of Human Rights and Fundamental Freedoms and to base its assessment on the circumstances described above in Section 5.4.

In a case concerning enforcement of expulsion, an impediment (impediment to enforcement) may arise that means the order cannot be carried out. Under the Alien's Act one such impediment can be the alien's state of health. However, for it to be possible to establish an impediment to enforcement and grant a residence permit, new circumstances must have come to light in relation to what has already been examined.

The proposals recently presented by the Cross-party Committee of Inquiry on future Swedish migration policy will be processed in the Government Offices and a decision on new legislation is planned to be implemented in 2021. Two of the proposals will, if implemented, be of importance for health care and the subject of this report: first, making temporary residence permits the main rule, which is expected to result in more patients not having permanent residence permits and, second, making it possible to grant residence permits on humanitarian grounds.

5.6.2 International law and case law

Following a review of what importance international law and case law may have for the assessment of whether a person should be given care, it can be seen that states are obliged to give necessary health and medical care to persons with critical conditions who are staying in their territory. The right to health therefore applies irrespective of, for example, nationality or status under migration law or whether a person is staying in the country with all the necessary permits. In that case, it is also likely, against the background of the right to life and the prohibition of torture, that there is an obligation for states to also offer non-citizens organ transplantation, like other care, on the same terms as the state's own citizens. It is only when this can be considered to entail an unreasonable or disproportionate burden that a state can refuse to offer non-citizens organ transplantation.

In special cases a possible expulsion can be postponed if there is considered to be an impediment to enforcement on account of the illness.

5.6.3 Overall assessment

There is no support in the applicable law for excluding any form of care or treatment in advance from what is included in care that cannot be deferred. This must be considered to be particularly applicable to cases where the patient risks dying if the treatment is not provided. Nor is there any support in the applicable law for making an assessment at group level for persons who do not have permanent residence permits; every patient must instead be given an individual medical assessment on the basis of their specific situation.

Against the background of its review of national and international law, the Council considers that health care interventions that require care of long duration or access to aftercare, such as organ transplantations, fall within the term “care that cannot be deferred” in cases where even a moderate delay of care and treatment can result in serious consequences for the patient, such as danger to the patient’s life. Particular difficulties are associated with the assessment and decision in the cases where information is not available about the patient's future prognosis. The Council notes that there are different views in the profession about how to apply the provision and that there is no guidance to the profession about this.

The Council considers that there is support for the interpretation that an expulsion of a person with a life-threatening disease can be contrary to the European Convention for the Protection of Human Rights and Fundamental Freedoms.

The proposals presented by the Cross-party Committee of Inquiry on future Swedish migration policy may be of importance for the questions dealt with in this report.

6 Theoretical starting points

The purpose of normative ethical theories is to present fundamental justifications of why an act is right or wrong. They point to values or principles on which moral decisions or standpoints can be based. Even though ethical theories differ regarding ultimate values and principles, they can complement one another by pointing to aspects of relevance and importance for a moral decision or standpoint. In applied ethics it is therefore common to adopt a syncretic approach, which means starting from different ethical theories. One well-known example is the four ethical principles used by the philosophers Beauchamp and Childress – beneficence, non-maleficence, respect for autonomy and justice – that can be justified in terms of both consequential ethics and deontological ethics.¹

In this chapter Smer discusses the question of the distribution of limited health care resources – and, in particular, the question of who should have access to transplantation – in the light of some relevant ethical theories. The first section deals with the question of how limited health care resources, such as access to organs for transplantation, should be distributed and the second section deals with the question of whether there are reasons to draw a dividing line between citizens² and non-citizens regarding access to health care resources.

¹ Beauchamp and Childress 2019.

² Smer is aware that access to health care in Sweden is based not on citizenship but on residence (and EU membership), but the discussion in ethical theories that we describe in this section centres on the importance of that ground for access to health care.

6.1 Allocation of limited resources, such as access to organs for transplantation

Normative ethical theories can be divided into consequential ethics and deontological ethics.³ According to utilitarianism, which is a consequential theory, the act that contributes to the greatest happiness or utility is right. Utilitarianism's answer to who should be given access to limited organs for transplantation is that it is decided by maximising utility.⁴ In general, it can be said that a transplantation provides more utility for a younger person than an older person since the younger person probably has a longer life expectancy. It is also usually said that a transplantation for a person who is a parent provides more utility than for a person who is not a parent since the transplantation also leads to better conditions for the child and so on. On utilitarian grounds, a person who has great probability of getting access to the necessary aftercare after a transplantation should take precedence to a person who has lower probability of this. The person who has the greater possibility of receiving aftercare also has the greatest utility of the transplantation.

One alternative to consequential ethics is deontological ethics. One main approach in deontological ethics starts from the ethics of the philosopher Immanuel Kant and is therefore called Kantianism. Kantianism starts from two fundamental principles. The first says that it must be possible to elevate a moral position to a universal law. In a situation where you are faced with alternative courses of action, you should ask the question: which alternative do I want everyone to choose in a similar situation. The answer to that question is the alternative that I ought to choose. The second principle, the human dignity principle, emphasises that every person should be treated as an end in themselves. This means, for instance, that people should be treated with respect, should never be used as a means, and should be treated equally. When Kantianism is applied to the question of transplantation, the first point is that it is important that transplantation decisions follow well-considered rules that everyone can agree to. The rules are not legitimate if there are people who can assert with good reasons that there are alternative rules that would better

³ A common feature of different types of deontological ethics is that what is decisive in the moral assessment is not the consequences of the act but a characteristic of the act, for instance whether it is compatible or incompatible with certain rights, principles of justice or rules.

⁴ See, for example, Singer 2016.

satisfy every person's interest. So, this means that good reasons are not reasons that benefit self-interest, but reasons that everyone can agree to.⁵ Second, Kantianism asserts that no person may be discriminated regarding, for example, access to transplantation when needed. Here discrimination means treating people differently without having reasonable grounds.

Justice is a central concept in ethics. Medical care is a limited resource that can be distributed on the basis of different principles. So how can the question of access to care in general and transplantation in particular be assessed from a justice perspective? In reply to this question different theories of justice refer to different principles for distribution.

Our lives are governed both by factors that we cannot influence, such as family membership and social class, and by the choices we make ourselves.

People's possibilities of living valuable lives should not be governed by factors that they have not been able to influence themselves. This applies both to natural characteristics such as skin colour, genes and talent, and to social circumstances such as what social class they belong to or what country they happen to have been born in. These factors are the result of the lottery of nature and social circumstances.⁶ Health care is an important resource for a valuable life, and access to health care should therefore be decided by a justice principle under which the distribution of resources is steered solely by need.

There are also good reasons from an ethical perspective for giving priority to the interests of the worst off in distributions. This view can be justified both on the basis of John Rawls's theory of justice, with its difference principle saying that resources should be distributed equally unless an unequal distribution favours the worst off, as well as on the basis of utilitarianism's idea that the worst off have most benefit of a measure.⁷ The need principle leads to the worst off, i.e. those in greatest need, being given priority when health care resources are limited.

Applied to the question of transplantation, where the supply of organs is limited, this perspective means that need is the only factor

⁵ See, for example, Scanlon 2000.

⁶ See, for example, Tan 2012.

⁷ Rawls 1971, Parfit 1997, Arneson, 2000.

that should steer the distribution of organs. The person who has most need of a new organ should be first in the queue.

As is seen, the ethical theories dealt with in this section identify utility, respect for human dignity and justice according to the need principle as important values in moral decisions, such as the decision to distribute limited health care resources and health care interventions.

6.2 Are there moral reasons to draw a dividing line between citizens and non-citizens?

In ethics there has been an intensive discussion in recent years about global justice and the importance of national borders. Questions that have been discussed are what moral obligations follow from the idea of the equal dignity of all human beings and the idea of human rights, whether we have special obligations to citizens of our own country and whether the right to health care and other social values is based on a citizens' contract, etc. For the theory called moral cosmopolitanism, it is the individual who is the starting point for moral judgments. This theory starts from the equal dignity of all human beings, and factors such as social status, gender, age and nationality are of no relevance to moral judgments. The philosopher Simon Caney asks the question:

Given that it is an injustice that some face worse opportunities because of their class or their ethnicity, is it not an injustice that some face worse opportunities because of their nationality?⁸

Moral cosmopolitanism asserts that from a moral perspective all human beings are citizens of the world with the same and equal dignity.

So, is there any ethical theory that can justify citizenship being able to decide the question of who should have access to care? Yes, a standpoint like that can be justified on the basis of the idea of a communitarian/nationalist contract. Communitarianism asserts that membership of a community, such as being a citizen of a nation, gives members/citizens certain rights that non-members do not have. The philosopher Michael Walzer is an ethical communitarian.

He writes:

⁸ Caney 2005, p. 123.

Membership is important because of what its members of a political community owe to one another or to no one else, or to no one else in the same degree. And the first thing they owe is the communal provision of security and welfare.⁹

Health care is a welfare factor. In line with Walzer's view, the question of who should have access to what health care is decided by who is a member or isn't a member. The national contract between citizens of a nation also guarantees citizens access to welfare services, such as health care. This view could justify a sceptical attitude to why persons who do not have Swedish citizenship should be given access to transplantation.

Moral cosmopolitanism and moral nationalism are two alternative positions. It is, of course, possible to imagine different types of intermediate positions. It could, for instance, be asserted that citizenship justifies access to certain fundamental welfare values in the form of health and medical care and security, but that we also have moral and humanitarian obligations to persons who are not Swedish citizens.¹⁰ It has also been asserted that moral cosmopolitanism is an ideal theory, but that it is not realistic and feasible and that our moral obligations must, instead, be possible to overview and limited.

Both questions touched upon in this section, the question of how welfare should be distributed in a society and the question of what importance membership of a nation has for the right to welfare services, are under lively discussion in ethics. Here we have only referred to some theories without taking a closer look at arguments for and against them.¹¹

It should be stressed that ethical theories do not give clear-cut answers to the specific question of access to transplantation for persons without permanent residence permits. That question must be answered through a process of reflection and weighing of arguments. But the theories do provide important starting points for decisions on the distribution of limited health care resources and the importance of citizenship.

⁹ Walzer 1983, p. 64.

¹⁰ See Tan 2004 for a discussion of these questions.

¹¹ A more detailed presentation and discussion of normative ethical theories can be found in Collste 2019, Namli and Grenholm 2019 and Tännsjö 2012.

7 Analysis

The question that has been put to Smer concerns whether or not persons without permanent residence permits should be offered transplantation, when there is a risk that the patient will not be able to receive aftercare in the event of a possible expulsion. The care involved meets the legal conditions for care that cannot be deferred but requires long-term aftercare.

In this chapter Smer presents and analyses ethical aspects and reasons advanced for and against organ transplantation to persons who do not have permanent residence permits. Then the Council makes an overall appraisal of the various aspects and arguments.

7.1 Transplantation for persons without permanent residence permits

What reasons can be put forward in the discussion on transplantations or other health care for persons without permanent residence permits and are these reasons tenable?

7.1.1 The principles of human dignity principle, of needs and solidarity – ethical basis and starting point

As stated above, the human dignity principle, the needs and solidarity principle are the fundamental prioritisation principles in medical care in Sweden (see section 5.2.1). The background to these principles is the view that life and health are such fundamental values that every human being, irrespective of their characteristics, has the right to the best attainable health (see section 5.4). According to

such a view, it is the equal dignity of all human beings that grounds the right to care and treatment. Access to care and treatment is determined solely by need set in relation to access to care/the resource.¹ In contrast, citizenship or personal characteristics such as age, gender, disability or ethnicity must not be decisive considerations when it comes to access to care. Therefore, from a human dignity perspective, giving people different care depending on their status under migration law is problematic. Treating persons without documents and asylum seekers aged over and under 18 years differently can also be considered to be contrary to the principle.

In previous consultation responses on the right to care for persons staying in Sweden without permits, Smer has referred to the principle of equal human dignity.²

7.1.2 Solidarity

An argument, closely related to the human dignity principle, for giving persons without permanent residence permits access to advanced care, including transplantation, is that these persons are socially vulnerable and live an uncertain life. This vulnerability is a result of the lottery of nature or of social circumstances that they have not been able to influence themselves. For reasons of solidarity, these persons should be given access to the care resources that Swedish society can offer.³ The idea of solidarity is expressed in the Swedish platform for prioritisation through the need and solidarity principle (see section 5.2.1) part of which is that care shall give particular consideration to “... those who have less possibility than others of making their voice heard or being able to enjoy their rights.”⁴ This often applies to refugees and people without documents.

The objection can be made that Sweden does not have resources to show solidarity in this way with the vulnerable people of the world. In the long run, doing so could undermine publicly funded care. To prevent that from happening, the number of asylum seekers who can be considered for transplantation ought to be limited.

¹ The idea of equal human dignity and the need for care as decisive for access to care has been given various forms of support in ethical discussions, see Düwell et al. 2014, Collste 2002 and Smer 2012a.

² Smer 2012b.

³ For a corresponding discussion concerning Canada, see Bruni and Wright 2011.

⁴ SOU 2001:8, p. 34.

Eurotransplant has, for instance, previously limited the number of aliens who can be given access to liver, heart and lung transplants to 5 % of the total number of transplants.⁵ Having a quota system of that kind limits the cost. However, the problem of that kind of quota system is that it can lead to a “slippery slope” where other care interventions will also be rationed in a similar way. This type of quota system is also contrary to the principle that decisions about care should be taken after an individual assessment. This kind of trend is incompatible with the human dignity principle and the need principle as a basis for what care interventions to offer.

7.1.3 Professional norms

One of the most fundamental principles of medical ethics is that doctors and other health care professionals should treat all patients equally and should only pay heed to medical need. The Swedish Medical Association’s ethical rules state that medical need should be the sole governing principle for providing care.⁶ § 1 states “In their practice, the doctor shall always have the patient’s health as their foremost objective.” No distinction is made based on the patient’s nationality. Marie M. Budev, a doctor, writes:

It would be absolutely inappropriate and wrong to ask transplant physicians to become “de facto” immigration officials by requiring candidates to produce legal documents for evaluation for transplantation.⁷

So, discriminating against patients based on their status under migration law is contrary to medical ethics.⁸

7.1.4 Citizenship and permanent residence

An argument that can be made against transplantations for persons who do not have permanent residence permits is that access to certain advanced care falls outside what states can offer others than their own citizens and permanent residents in the country. Accor-

⁵ Bruni and Wright 2011.

⁶ See also WMA 2016, WMA 2017 and ICN 2012.

⁷ Budev 2017.

⁸ Budev 2017.

ding to this view, states have certain special obligations to their own citizens or persons who have the right to stay in the country. Moreover, advanced care often results in high costs for society that are met by taxpayers. The social contract between a state and its citizens thus points out where the dividing line runs between the state's obligations to its own citizens and to others. The standpoint that the social contract prevents individuals who are not citizens or who do not have permanent residence permits for being given access to transplantation can be justified theoretically by a communitarian theory (see chapter 6).

The following objections can be made to this argument. First, it can be asked what the grounds are on which the dividing line concerning access to care is to be drawn between citizens, permanent residents and persons who are here on a more temporary basis or do not have permits in Sweden. For instance, does this restriction apply to all subsidised care or only the most advanced or expensive care? In that case, what are the grounds on which this dividing line can be drawn? Citizenship, population registration, status under migration law? Then there is a risk of an A team and a B team arising when it comes to access to care in Sweden. This standpoint conflicts with the human dignity and need principles, which mean that human dignity and medical needs – and not citizenship or permanent residence permits – are the basis for prioritisation in health care.

The question of high costs for care has not been raised in the Swedish discussion specifically regarding asylum seekers, for example, and the question has been discussed as a general social problem instead. Putting forward cost in this way as a reason against transplantation means departing from the human dignity principle and the need principle as the basis for the prioritisation of care provision. Moreover, it can sometimes be more cost-effective to transplant. This applies, for instance, to kidney transplantation which is, on average, more cost-effective in the long run than dialysis.⁹

But it can be asserted, since persons without permanent residence permits have not contributed to the tax revenue that finances the advanced care, they should not be given access to this type of care provision either. However, the first objection that can be made here is that there are also many Swedish citizens who, for various reasons, do not contribute to tax revenue and who are nevertheless offered

⁹ Fortin and Williams-Jones 2014.

advanced care provision when needed.¹⁰ As a second objection, the argument implies, by extension, that persons without permanent residence permits should not have access to any care funded by tax revenue.

7.1.5 Mutuality – giving and receiving organs

Are organ donor services based on a mutuality principle? Perhaps organs for transplantation should only be given to the country's citizens? Perhaps the will to donate decreases if donated organs go to people other than the country's citizens? Ahya asserts that "... restrictions based on citizenship or residency is consistent with the social contract between a government and its citizens/residents", and refers to an American survey showing that 38 % of those polled would be doubtful about donating organs if they did not go to US citizens and people resident in the US.¹¹ However, here the alternative recipients were rich foreign citizens who were going to buy organs in the US (i.e. this was about transplantation tourism) and not persons resident in the US.

The mutuality principle can be given various interpretations. According to one interpretation, organs from Swedish donors should go to Swedish recipients. But that kind of view is hardly reasonable. It is in conflict with the human dignity principle, which means that every human being has the same dignity, irrespective of ethnic background and nationality. It also seems reasonable to assume that many donors in Sweden want their organ to go to the person who has the greatest need of the donated organ.

According to a second interpretation of the principle, a person who is prepared to donate their organs should also be able to receive organs when needed. Persons without permanent residence permits who are in Sweden can be organ donors themselves and their organs can therefore be used in Swedish transplantation services.¹² Since these persons contribute to the Swedish organ pool, they should, as a result, be able to be recipients of organs when needed.

¹⁰ Fortin and Williams-Jones 2014.

¹¹ Ahya 2017.

¹² For a corresponding discussion concerning the United States, see Ackah, Sigireddi and Murthy 2019.

According to a third interpretation of the mutuality principle, persons who have the right to receive an organ should also themselves be prepared to donate their organs. However, this is not the case in Sweden; even a person who has expressed a wish not to donate their organs can be given access to organs when needed.

7.1.6 Uncertainty concerning aftercare

One reason for not performing organ transplantations for persons who do not have permanent residence permits is that a transplantation normally requires lifelong aftercare and that it is uncertain whether the patient can receive that kind of aftercare if they are not able to settle permanently in Sweden.

Aftercare must be seen as an integrated part of the transplantation and is a precondition for the patient's survival in the long term. The obligation to investigate the patient's possibility of aftercare follows from the requirement of science and proven experience and is part of patient safety work. Several countries do not have medical care resources to give necessary aftercare, or the resources to do so are in place, but are not available to the whole of the population. If the patient does not have access to aftercare, the risk is that the treatment will be performed in vain.

Before a patient is put on a waiting list for organ transplantation, not only is an assessment made of the patient's medical prospects of coping with the procedure as such, but an appraisal is also made of the patient's prospects and ability to complete the controls and treatment required after an organ transplantation (see section 3.1). The factors assessed in transplantation candidates include psychosocial and mental factors, for example.¹³ The reason for this careful assessment is to achieve an adequate allocation of existing organs, in view of the limited supply of organs, and to ensure that the patient will not be subjected to an extensive and risky treatment that they have little prospect of coping with and therefore benefiting from. So, uncertainty concerning aftercare that is due to reasons other than

¹³ Sefastsson and Wahlström 2020. Weighing in requirements of social support for transplantation is contrary to the principle of justice for access to care since it has, in practice, the consequence that the most socially vulnerable persons are discriminated against, thus advantaging people with higher social status – see for example Berry, Daniels and Ladin 2019.

a risk of expulsion can be a reason to refuse a person an organ donation.

The argument that persons without permanent residence permits should not be given organ transplantation, since their access to aftercare is uncertain, presupposes that the probability is high that the person will be expelled to a country where they are not given lasting access to aftercare. If the probability of expulsion is not high, the tenability of the argument decreases to a corresponding degree. The tenability of the argument for not transplanting aliens because aftercare cannot be guaranteed is dependent both on the probability that the asylum seeker or person without documents will be expelled – and, if so, to what country, and what is the probability that the particular person will not have access to aftercare there. It is not unusual for asylum seekers whose applications are refused to end up not in their country of origin but in another country. In that country there may be access to necessary aftercare resources and those may be available to the person who has been expelled from Sweden.

This means that determining, at the time of the health care intervention, whether the person is going to be expelled at all, or is going to be expelled to a country that is not able to offer the necessary aftercare, and whether that particular person will not be given access to necessary care there is a difficult and very uncertain assessment in terms of both facts and probability.

7.1.7 Best possible use of donated organs

Another reason for not performing advanced transplantations on persons without permanent residence permits when there is uncertainty about their future access to aftercare is that there is a shortage of organs and the organ available could go to another person who has the possibility of being given the necessary aftercare. The transplanted organ could contribute to a longer life for another potential recipient. This argument presupposes that there is, at the time of a transplantation, another potential organ recipient who is a match for that particular organ (which is often the case). It also presupposes that the organ is taken from a general organ bank and not from a living donor such as a relative (which is possible regarding kidney transplantations, for instance). If the organ can be taken from a rela-

tive, the patient is not receiving the organ in competition with any other patient.¹⁴ However, it is not only organ transplantations that have an alternative cost. Given limited care resources, all care offered is a draw on limited resources and means, in practice, that some other care intervention is not provided.

7.1.8 Risk of harming the patient

A further reason given against organ transplantations for persons without permanent residence permits is that it is a dubious undertaking to subject a patient to an extensive operation involving risks and suffering if there is a risk, on account of deficient aftercare, that the operation will not be of lasting benefit. The alternative would be to give palliative care instead. However, this argument presupposes that the alien will be expelled to a country where they will not be given access to the necessary aftercare. But this is, as we have concluded, a difficult and uncertain assessment of probability. It can also be said that it should be up to the patient themselves to decide, after having been informed of the situation, whether they want to take this risk; if the choice is between a likely death soon and the possibility of surviving, many patients will probably choose transplantation.

7.1.9 Medical tourism

It can be asserted that if Sweden offers advanced care, such as transplantation to asylum seekers, this will lead to medical tourism or “transplantation tourism”.¹⁵ Sweden will become, it is assumed, an attractive destination for people with severe health problems, such as heart failure, for which they cannot be given treatment in their country of origin and, were that to happen, it would be a drain on limited Swedish medical resources. However, Smer has learned that there is no empirical support either for or against this claim.

It does happen that people seek asylum in Sweden in the hope of being given access to transplantation treatment or other health and

¹⁴ There are high requirements that the living donor is given the possibility of receiving lifelong aftercare.

¹⁵ Ahya 2017.

medical care. However, there is no reliable information about how common this is.¹⁶

7.2 Overall assessment

The question of whether care that requires certain duration or long aftercare, such as organ transplantation, should be offered to persons without permanent residence permits contains difficult balances between ethical considerations and uncertain assessments of facts and probabilities.

In certain situations, organ transplantation can be necessary if a person is to survive (in these cases the transplantation meets the legal requirement of care that cannot be deferred). The human dignity principle and the need principle form the basis for decisions on access to care in Sweden, according to the Swedish platform for prioritisation. Citizenship is certainly an important ground for rights in many contexts, but refusing a person who does not have Swedish citizenship or a permanent residence permit in Sweden, vital care such as organ transplantation solely on account of their status under migration law comes into conflict with the human dignity principle and therefore entails unjustified special treatment of these persons. The human dignity principle also rules out special treatment on the basis of age (or other personal characteristics). Making a distinction, as is done today, between children and adults regarding access to life-saving care such as organ transplantation is therefore contrary to that principle.

There may, however, be specific circumstances that prevent a person being given access to an organ transplantation. Under the Swedish platform for prioritisation care has to be distributed according to need. When an assessment is made of the need for a care intervention, including organ transplantation, account must be taken of the benefit of the intervention. A measure that is of no benefit to the patient is not needed either. So, a transplantation is not performed if the assessment made is that a person will not be able to cope with the procedure on account of failing health or if the person has another disease and is therefore judged to have a short time left to live. In

¹⁶ During the Council's consideration of this report it has emerged in dialogue with representatives of the profession that this does happen, but that it is not a frequent occurrence.

principle, an analogous assessment could be made regarding organ transplantation for a person without a permanent residence permit where there is high probability that the person will be expelled to a country that does not have the necessary resources for aftercare. The transplantation will not have the desired long-term positive health effects for the patient in that case either.

The probability that a patient will have access to aftercare depends on a number of different circumstances, such as the probability of being expelled, what care is available in the country that the patient ends up in after their expulsion and the patient's ability to pay for the necessary care themselves, and these circumstances vary from patient to patient. The patient may also be granted a permanent residence permit on humanitarian grounds. Smer takes the view that the sole fact that there is uncertainty about access to aftercare cannot, by itself, be a reason to refuse a person vital care. This would be contrary to the principles in the ethical platform that prohibit special treatment and lay down that care has to be distributed by need.

To not take account of the actual probability that the patient will be given access to aftercare would be contrary to the requirement for an optimal allocation of donated organs and the requirement that care decisions should be based on a reasonable balance between risk and benefit for the patient. If it was possible to make a certain assessment of the probability that the patient will have access to aftercare, that would change the situation. However, the fact that so many factors have an effect means that, in practice, there is always considerable uncertainty in such an assessment. According to Smer, it is difficult to see how decisions made on the basis of such assessments could live up to reasonable requirements for patient safety and legal certainty when decisions about life and death are involved. In such a situation, decisions should, according to the Council, be taken to the benefit of the patient, according to the principle of the benefit of the doubt.

Smer also wants to emphasize that this type of assessment differs from the assessment of the patient's prospects of completing the treatment which are currently made in connection with the investigation of transplantation candidates. The assessment of whether or not the patient can cope with an organ donation is a medical assessment that is made by medically qualified professionals. In contrast, assessing the possibility of obtaining aftercare in cases dependent on

decisions under migration law is a matter of uncertain assessments of probability in questions that are highly dependent on future circumstances and that are outside the area of medicine. Furthermore, this future is not independent of the decisions made today; a transplanted patient may be granted a residence permit on humanitarian grounds in the future, which would be in accordance with the international conventions that Sweden is committed to observe.

Smer also considers that it must be asked what broader consequences a policy that gives weight to “uncertainty around future aftercare that is not founded on a medical assessment” as a governing factor in assessing whether to perform a transplantation has for patients in need of organ transplantation. This also applies to other patient groups in a broader societal perspective. Is an assessment principle being introduced here which can have unpredictable consequences? Can it also be applied to refuse organ transplantation, and other life-saving treatments, for children who may pass the age limit of 18 in one or a few years? Can it be the case that a patient’s membership of a social group or personal characteristics will play a role?

Smer sees the risk of a “slippery slope” if doctors deviate from the human dignity principle in their assessment of treatment and start to take other considerations into account, such as the patient not having a permanent residence permit.

Under the current rules for organ donation, persons who do not have permanent residence permits can be organ donors. According to Smer, this also strengthens the reasons why these people should also have the possibility of being recipients of organs.

The conclusion that Smer arrives at, after having considered the arguments, is that persons who do not have permanent residence permits should also, when in need of care that cannot be deferred, be offered organ transplantation in Sweden on the same terms as the rest of the population. This conclusion is based on both the human dignity principle and the need and solidarity principle, which constitute the ethical platform for health and medical care in Sweden and are in accordance with the applicable law and the norms of professional ethics.

8 Conclusions

A need has emerged to clarify what principles should guide decisions about whether care like organ transplantation, which requires long-term aftercare, should be offered to persons without permanent residence permits. Based on the Council's assessment of the applicable law and the ethical analysis, Smer draws the following conclusions:

- Decisions on essential care interventions, including transplantation, should be based on a medical assessment of the individual patient's need for and prospects of benefiting from the treatment. This applies to patients registered in the population register in Sweden, who have full access to care, as well as to patients who do not have permanent residence permits. Consequently, persons who do not have permanent residence permits and who need essential care interventions, including organ transplantation, have the right to an individual medical assessment. In these cases, too, care decisions should be guided by the ethical platform that forms the basis for prioritisation in health care in Sweden. Taking account of other factors, such as status under migration law, before making decisions of this kind comes into conflict with the fundamental principle of equal human dignity.
- There should be a clear division of responsibility between the doctor who is responsible for care decisions and the Swedish Migration Agency, which is responsible for any decisions on expulsion, refusal of entry, impediments to enforcement and residence permits.
- In cases where a patient who has received a transplantation does not have grounds for asylum, in the assessment of Swedish Migration Agency, the applicable law requires the Agency to take account of whether the patient can be given access to essential aftercare in the country that the patient is going to be expelled

to. This assessment is made in consultation with medical expertise, in accordance with other expulsion cases of sick patients who must be guaranteed essential care. So, when making this assessment, account must be taken both of the general situation in the country and of the applicant's individual circumstances. This can be of importance in, for example, decisions about whether there are impediments to enforcement.

9 Recommendations etc.

Today the profession is faced with several dilemmas when they have to decide about transplantation for persons who do not have permanent residence permits. In addition to the uncertainty that is always present as to whether a transplantation will succeed, there is a further uncertainty concerning the patient's future because they do not have a permanent residence permit, which can influence the possibilities of aftercare. The profession can be faced with similar difficulties regarding other long treatments or treatments requiring aftercare.

Smer makes the assessment that the problems are partly rooted in uncertainty in health and medical services around the interpretation and application of the term "care that cannot be deferred", both in general and in specific situations where there is uncertainty about future access to aftercare. This uncertainty risks leading to an inequitable offer of care to persons who do not have permanent residence permits and to patients being refused life-saving treatment and other treatment they are in great need of without there being any medically, ethical and legally tenable ground to do so.

In this chapter, Smer makes a number of recommendations, which if implemented, can contribute to clearer supporting information for the profession and care providers concerning decisions on care interventions that require longer duration or access to aftercare for persons without permanent residence permits and thereby to more equal/equitable care for this group of patients.

9.1 Recommendations

9.1.1 Increased knowledge in the profession and among care providers

Health and medical care professions and other groups including administrative and political decision-makers, need further knowledge about the applicable law concerning access to care for persons who do not have permanent residence permits, especially considering that this group is expected to increase. A suitable authority should be given responsibility for ensuring that all care providers have correct and uniform information about the responsibility to offer health and medical care and dental care to persons without permanent residence permits.

9.1.2 Guidance for the profession

There is a great need for some form of guidance for the profession regarding offers of care interventions that require long duration or access to aftercare for persons without permanent residence permits. A guide should be produced in order to support the doctor treating patients, in particular, and other health care professions in making decisions on health care. The guide should have the purpose of ensuring equal care and equivalent offers of health and medical care to these patients in Sweden. It has been concluded on good grounds that guidance in the form of lists of diagnoses or conditions is inappropriate for several reasons. However, guidance can be designed on the basis of the scale of the patient's need for healthcare, for instance.

9.1.3 Current picture of health care needs

There is a need to enhance the knowledge available regarding health and medical care for persons without permanent residence permits in Sweden. A suitable authority should be commissioned to produce supporting information, in consultation with other relevant authorities and stakeholders, concerning the number of people staying in Sweden, what the need for care and access to treatment is like in the groups concerned and whether – and, if so, how many – persons make their way to Sweden to get access to health and medical care.

This supporting information is needed for other measures that may need to be taken in the future by the regions or by the Government and the Parliament.

9.1.4 Continued focus on organ donation and transplantation services

In this context, Smer also wants to take the opportunity to highlight how important it is that the Government and the regions continue to create conditions for stronger donation services in Sweden so that the number of organs for transplantation continues to increase in Sweden. The objective must be to work off the present queue to be a recipient of a new organ. In Smer's view, the National Donation Centre at the National Board of Health and Welfare, the Swedish Association of Local Authorities and Regions (SALAR), the regions, the special transplantation centres and interest organisations are important actors in this work.

9.2 Exchange of information between the Swedish Migration Agency and health and medical services

A model that has been raised for discussion is whether a special committee could be appointed consisting of representatives of the Swedish Migration Agency and the profession/care provider that would provide assistance in cases of severely ill patients who do not have permanent residence permits. However, there are problems in having that kind of arrangement. It presupposes, for instance, that the Swedish Migration Agency is able to assess a case before a decision has been made on expulsion and means that the doctor's responsibility for the care decision is undermined. A committee would probably not be in a position to establish the future patient's possibilities of obtaining access to medicines and treatment. So, with this model, there will also still be uncertainty about future outcomes in the event of expulsion.

Another model that has been discussed is to set up a fast track for the processing of asylum cases for persons who are severely ill and are in need of care so that vital care can be offered with less

uncertainty about the future benefit on account of factors outside the medical assessment. One problem with an arrangement of that kind is that in the cases where the patient is in need of care that requires duration and aftercare and is in an acute critical phase, there will probably seldom be time to make a prompt enough decision on the question of asylum to save the patient's life. Consequently, guidance for health and medical care would also be needed in cases of that kind.

List of experts heard

The following is a list of the persons that the Council has been in contact with while preparing this report, at the round-table discussion on 31 January 2020, the Council's meetings on 18 October and 13 December 2019 and individual meetings.

Linda Almqvist, Chief Legal Officer, the Swedish Health and Social Care Inspectorate

Tesi Aschan, Desk Officer and Legal Adviser, National Board of Health and Welfare

Henry Ascher, MD, Professor of Public Health, Associate professor in Child Medicine

Ludwig Beckman, Professor of Political Science, member of the Swedish Migration Agency's Ethical Council

Elis Enwall, consultant, former programme officer at the National Board of Health and Welfare, former Vice Chair of Swedish Doctors of the World

Bo-Göran Ericzon, MD, Professor, Karolinska Institutet/Karolinska University Hospital, Stockholm

Sara Fridlund, Adviser, Swedish Red Cross

Cristina Grenholm, Priest in Church of Sweden, author and professor of Systematic Theology and Studies in Worldviews, Ethics and Philosophy of Religion, Chair, Swedish Migration Agency's Ethical Council

Erik Gustavsson PhD, Senior Lecturer, Applied Ethics, Linköping University

Katarina Hanséus, MD, Associate professor, Children's Heart Centre, Lund

Agneta Holmström, Head of Unit, National Board of Health and Welfare, Department of Knowledge-Based Policy of Health Care National Donation Centre

Effi Iliou, Project Manager, Stadsmissionen, Stockholm

Ragnhild Karlsson, Vice Chair, Swedish Association of Health Professionals

Björn Kornhall, MD, Section for Heart Failure and Heart Valve Disease, Skåne University Hospital, Lund

Yana Litins'ka, Doctor of Laws in medical law, postdoctoral fellow in migration law, Lund University

Niels Lynöe, Emeritus Professor of Medical Ethics, MD, Department of Learning, Informatics, Management and Ethics (LIME), Karolinska Institutet (KI)

Johanna Lönn, Desk Officer, Swedish Red Cross

Torsten Mossberg, MD, Swedish Medical Association

Christian Munthe, Professor of Philosophy, Gothenburg University

Daniel Salehi, Process Specialist, Swedish Migration Agency, Malmö

Anne Sjögren, licensed nurse, Convener, Right to care initiative [Rätt till vård-initiativet]

Karin Tran Lundmark, MD, Associate professor, Children's Heart Centre, Skåne University Hospital, Lund

Inger Torpenberg, licensed nurse, Swedish Nurses' Association,
Right to care initiative [Rätt till vård-initiativet]

Kavot Zillén, Associate professor in Public Law, Stockholm University

Bengt von Zur-Mühlen, MD, Associate professor, nephrologist,
Consultant at Transplantation Surgery, Uppsala University Hospital,
Uppsala

Jonas Widell, Legal Specialist, National Board of Health and Welfare

Håkan Wåhländer, MD, Head of Section, Children's Heart Centre, Queen
Silvia Children's and Young People's Hospital, Gothenburg

References

- Ackah, RL., Sigireddi, RR. and Murthy, BVR. (2019). Is Organ Retransplantation Among Undocumented Immigrants in the United States Just? *AMA J Ethics*. 21:E17–25.
- Ahya, VN. (2017). Should US Centers Transplant Solid Organs Into International Recipients? No. *Chest*. 152:244–246.
- Arneson, R. (2000). Luck Egalitarianism and Prioritarianism. *Ethics*. 110:339–349.
- Barret, D. (2013, 3 July). Doctors condemn plan to ban foreigners from organ transplants on NHS. *The Telegraph*.
www.telegraph.co.uk/news/uknews/immigration/10158331/Doctors-condemn-plan-to-ban-foreigners-from-organ-transplants-on-NHS.html.
- Baru, JS. et al. (2013). Organ donation among undocumented hispanic immigrants: an assessment of knowledge and attitudes. *The Journal of clinical ethics*. 24:364–372.
- Beauchamp, TL. and Childress, JF. (2019). *Principles of Biomedical Ethics* (8 ed.). Oxford University Press.
- Berry, K., N. Daniels, and K. Ladin. 2019. Should lack of social support prevent access to organ transplantation? *The American Journal of Bioethics* 19: 13–24.
- Bhopal, A. et al. (2019, 23 September). Migrant and ethnic minority groups across Europe have a rising demand for organ transplantation, particularly renal transplants. *Tidsskr Nor Lægeforen*. <https://tidsskriftet.no/en/2019/09/debatt/organ-donationmigrants-and-ethnic-minorities>.

- Bradby, H. et al. (2015). Public Health Aspects of Migrant Health: A Review of the Evidence on Health Status for Refugees and Asylum Seekers in the European Region. *WHO Health Evidence Network Synthesis Reports 44*.
www.euro.who.int/__data/assets/pdf_file/0004/289246/WHO_HEN-Report-A5-2-Refugees_FINAL.pdf.
- Bruni, R. and Wright, K. (2011). Sharing organs with foreign nationals. *Progress in Transplantation*. 21:78–82.
- Budev, M. (2017). Should US Centers Transplant Solid Organs Into International Recipients? Yes. *Chest*. 152:242-243.
- Caney, S. (2005). *Justice beyond borders: A Global Political Theory*. Oxford. Oxford Scholarship Online.
DOI:10.1093/019829350X.001.0001.
- Cantrelle, C. et al. (2006). Access to kidney transplantation in France of non-French patients and French patients living in overseas territories. *Transplantation*. 81:1147–1152.
- Carella, C. et al. (2012). Transplantation of non-nationals and non-residents in the countries of the council of Europe: results of a survey conducted in the context of the initiatives of the European committee on organ transplantation. Italian National Transplant Centre (CNT), Rome, Italy *Newsletter Transplant*. 17:83–87.
- Collste, G. (2002). Is Human Life Special? *Religious and philosophical perspectives on the principle of human dignity*. Peter Lang.
- Collste, G. (2019). *Inledning till etiken*. Studentlitteratur.
- Düwell, M. et al. (2014). *The Cambridge Handbook of Human Dignity*. Cambridge University Press.
- EKHA (European Kidney Health Alliance). (n.d.). Joint statement. *Thematic network on improving organ donation and transplantation in the EU 2019*.
- Ekhem, S. (2018, 26th of April). Lungsjuka Saeideh fick inte den vård hon behövde – avled. *SVT*.
www.svt.se/nyheter/lokalt/skane/lungsjuka-saeidehsuppehallstillstand-drojde-dog-i-brist-pa-vard.
- Directive 2008/115/EC of the European Parliament and of the Council of 16 December 2008 on common standards and

- procedures in Member States for returning illegally staying third-country nationals. *Official Journal of the European Union*. L 348, 24th of December 2008:98–107.
<https://eur-lex.europa.eu/legalcontent/SV/TXT/PDF/?uri=CELEX:32008L0115&from=SV>.
- Directive 2013/33/EU of the European Parliament and of the Council of 26 June 2013 laying down standards for the reception of applicants for international protection (recast). *Official Journal of the European Union*. L 180, 29th of June 2013:96–116.
<https://eur-lex.europa.eu/legalcontent/SV/TXT/PDF/?uri=CELEX:32013L0033&from=LV>.
- Directive 2011/95/EU of the European Parliament and of the Council of 13 December 2011 on standards for the qualification of third-country nationals or stateless persons as beneficiaries of international protection, for a uniform status for refugees or for persons eligible for subsidiary protection, and for the content of the protection granted (recast). *Official Journal of the European Union*. L 337, 20th of December 2011:9–26.
<https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:337:0009:0026:sv:PDF>.
- European parliament. (2020, 1st of July). *Exploring migration causes – why people migrate*.
www.europarl.europa.eu/news/en/headlines/world/20200624STO81906/exploring-migration-causes-why-people-migrate.
- Charter of Fundamental Rights of the European Union (2012/C 326/02). *Official Journal of the European Union*. C 83, 30th of Mars 2010:389–403.
<https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:083:0389:0403:en:PDF>.
- Committee on Economic, Social and Cultural Rights (CESCR) (2008). *General comment No. 19. The right to social security (art. 9)*. www.refworld.org/docid/47b17b5b39c.html.
- Human Rights Committee. (2016a). *Views adopted by the Committee under article 5 (4) of the Optional Protocol*,

- concerning communication No. 2465/2014, Ndongala Nzo Mambu v. Democratic Republic of the Congo.*
- Human Rights Committee (2016b).
Concluding observations on the seventh periodic report of Sweden, CCPR/C/SWE/CO/7.
- Human Rights Committee. (2018). *Views adopted by the Committee under article 5 (4) of the Optional Protocol, concerning communication No. 2348/2014, Toussaint v Canada.*
- Fortin, M-C. and Williams-Jones, B. (2014). Should we perform kidney transplants on foreign nationals? *J Med Ethics*. 40:821–826.
- Fortin, M-C. and Greenberg, RA. (2016). Should Transplantation Be Offered to Pediatric Foreign Nationals? I Greenberg RA et al. (ed.). *Ethical Issues in Pediatric Organ Transplantation, International Library of Ethics, Law, and the New Medicine* 66. Springer.
- Gelatt, J. and Zong, J. (2018). Settling In: A Profile of the Unauthorized Immigrant Population in the United States. *Migration Policy Institute*.
www.migrationpolicy.org/research/profile-unauthorized-immigrant-population-united-states.
- Goldberg, AM., Simmerling, M. and Frader, JE. (2007). Why nondocumented residents should have access to kidney transplantation: arguments for lifting the federal ban on reimbursement. *Transplantation*. 83:17–20. DOI: 10.1097/01.tp.0000247795.41898.55
- Greenberg, RA. et al. (2019). Organ Transplantation for Foreign Nationals in Canada: A Survey of Transplant Professionals. *Can J Kidney Health Dis*. 6:2054358119859530.
- Gupta, C. (2008). Immigrants and Organ Sharing: A One-Way Street. *Medicine and Society. Virtual Mentor*. 10:229–234. DOI: 10.1001/virtualmentor.2008.10.4.msoc1-0804.
- Harris, D. et al. (2018). *Harris, O'Boyle, and Warbrick: Law of the European Convention on Human Rights*. (4 ed.). Oxford University Press.

- Hermerén, G. (forthcoming). A future for migrants with acute heart problems seeking asylum? *Cambridge Quarterly of Health Care Ethics*.
- ICN (International Council of Nurses). (2012). *ICN Code of Ethics for Nurses*.
www.icn.ch/sites/default/files/inline-files/2012_ICN_Codeofethicsfornurses_%20eng.pdf.
- Jawed, A. (2020). Transplantation for Undocumented Immigrants: Time to Change the Way the Story Ends. *Kidney News*. 12:18.
www.kidneynews.org/kidney-news/features/transplantationfor-undocumented-immigrants-time-to-change-the-way-the-story-ends.
- King, LP. et al. (2005). Health Insurance and Cardiac Transplantation: A Call for Reform. *J Am Coll Cardiol*. 45:1388–1391.
- Lebano, A. et al. (2020). Migrants' and refugees' health status and healthcare in Europe: a scoping literature review. *BMC Public Health*. 20:1039.
- Ledoux, C. et al. (2018). Migrants' access to healthcare services within the European Union: a content analysis of policy documents in Ireland, Portugal and Spain. *Global Health*. 14:57.
- Lee, BP. and Terrault, NA. (2020). Liver transplantation in unauthorized immigrants in the United States. *Hepatology*. 71:1802-1812.
- Lee, E. (1966) A Theory of Migration. *Demography* Vol. 3, No. 1: 47–57.
- Lindholm, A. (2018, 7th August). Ahmad dör om han inte får ett nytt hjärta – nekas transplantation. *Dagens Nyheter*.
www.dn.se/nyheter/sverige/ahmad-dor-om-han-inte-far-ettnytt-hjarta-nekas-transplantation/.
- Litins'ka, Y. (2020). *Hjärt- och/eller lungtransplantation för personer som saknar permanent uppehållstillstånd*. Underlag till Smer. Dnr 2020/00112/S1985:A
- Lönnermark, E. (2018). *Kunskap om rätten till vård för tillståndslösa och asylsökande personer. En enkätstudie bland sjuksköterskestudenter, läkarstudenter och läkare i Västra Götaland*. Göteborgs universitet, Västra Götalandsregionen.

- <https://alfresco.vgregion.se/alfresco/service/vgr/storage/node/content/workspace/SpacesStore/1c95e699-b619-4969-9f7261b762d0d902/Kunskap%20om%20r%c3%a4tten%20till%20v%c3%a5rd%20f%c3%b6r%20tillst%c3%a5ndsl%c3%b6sa%20och%20asyls%c3%b6kande%20personer.pdf?a=false&guest=true>.
- Maier, S. (2019, 20th of September). *Undocumented Immigrants' Transplant Survival Rates on Par with U.S. Citizens'*. University of California San Francisco.
- Migrationsverket. (2018). Handbok migrationsärenden. Hälso- och sjukvård. Updated 2018-10-29
- Mowbray, A. (2004). *The Development of Positive Obligations Under the European Convention on Human Rights by the European Court of Human Rights*. Hart Publishing.
- Namli, E. and Grenholm, CH. (2019). *Etiska teori*. Studentlitteratur.
- Parfit, D. (1997). Equality and Priority. *Ratio*. 10:202–221.
- Poulakou, G., Len, O. and Akova, M. (2019). Immigrants as donors and transplant recipients: specific considerations. *Intensive Care Med*. 45:401–403.
- Prop. 1981/82:97. om hälso- och sjukvårdslag, m.m.
- Prop. 1996/97:60. Prioriteringar inom hälso- och sjukvården.
- Prop. 2007/08:105. Lag om hälso- och sjukvård åt asylsökande m.fl.
- Prop. 2012/13:109. Hälso- och sjukvård till personer som vistas i Sverige utan tillstånd.
- Prop. 2016/17:43. En ny hälso- och sjukvårdslag.
- Pullen, LC. (2019). Transplantation and Undocumented Immigrants: A Tale of Two States. *Am J Transplant*. 19:2665–2667.
- Rawls, J. (1971). *A Theory of Justice*. Harvard University Press.
- Razum, O., Karrasch, L. and Spallek, J. (2016). Migration: A neglected dimension of inequalities in health? *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz*. 59:259–265.
- Rätt till vårdinitiativet. (2014). *Uttalande om begreppet Vård som inte kan anstå rörande vård till asylsökande och papperslösa*.

- www.vardforpapperslosa.se/files/vardforpapperslosa/UndertecknatAnsta140616.pdf.
- Sahlin, J. and Johnsson, L-Å. (2016). *Hälso- och sjukvårdslagen med kommentarer*. Wolters Kluwer.
- Scandiatransplant. (2015, 22th of September). *Minutes of Meeting. Meeting No: 20th meeting in the Nordic Transplant Committee*. www.scandiatransplant.org/members/ntc/MinutesNordicTransplantCommitteemeeting22.Sept.2015Copenhagen.PDF/view.
- Scandiatransplant. (2017). *Guidelines for Deceased organ transplantation of individuals from a Non-Scandiatransplant member country performed within Scandiatransplant and the use of organs from such countries for Scandiatransplant recipients*.
- Scanlon, TM. (2000). *What We Owe to Each Other*. Belknap.
- Sefastsson, Y. and Wahlström, L. (2020, 12th of February).
- Utredning av kandidater för transplantation varierar stort. *Läkartidningen*.
- Singer, P. (2016). Praktisk etik (3 ed.). *Thales*.
- SKL (Sveriges Kommuner och Landsting, numera Sveriges Kommuner och Regioner). (2016). *Vård av personer från andra länder* (7 ed.). ISBN-nummer:978-91-7585-401-4 <https://webbutik.skr.se/sv/artiklar/vard-av-personer-fran-andra-lander.html>.
- Smer (The Swedish National Council on Medical Ethics) (2012a). *Det svärfångade människovärdet – en debattskrift*. Etiska vägmarken 4. Fritzes. ISBN 978-91-38-32597-1. https://www.smer.se/wp-content/uploads/2012/08/Det-svärfångade-människovärdet_WEBB.pdf.
- Smer (The Swedish National Council on Medical Ethics) (2012b). *Remissvar avseende departementspromemorian Hälsa- och sjukvård till personer som vistas i Sverige utan tillstånd* (Ds 2012:36).
- Socialstyrelsen. (1995). *Allmänna råd om hälsovård för asylsökande och flyktingar* (1995:4).
- Socialstyrelsen. (2014). *Vård för papperslösa. Vård som inte kan anstå, dokumentation och identifiering vid vård till personer som vistas i landet utan tillstånd*.

- www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2014-2-28.pdf.
- Socialstyrelsen. (2020). *Organ- och vävnadsdonation i Sverige 2019*. Socialstyrelsen.
www.icuregswe.org/globalassets/artiklar/organ_och_vavnadsdonation_sverige-_2019.pdf.
- SOU 2001:8. Prioriteringar i vården Perspektiv för politiker, profession och medborgare.
www.regeringen.se/49b6c2/contentassets/05988c7faece4f5fbd778e5123d01866/prioriteringar-i-varden.
- SOU 2011:48. Vård efter behov på lika villkor – en mänsklig rättighet.
- SOU 2015:84 Organdonation En livsviktig verksamhet.
- SOU 2019:26. Organbevarande behandling för donation.
- SOU 2020:54. En långsiktigt hållbar migrationspolitik.
- Statskontoret. (2016). Vård till papperslösa – Slutrapport av uppdraget att följa upp lagen om vård till personer som vistas i Sverige utan tillstånd (2016:11). Statskontoret.
www.statskontoret.se/globalassets/publikationer/2016/201611.pdf.
- Stevens, D. (2010). Asylum seekers and the right to access health care. *N Ir Legal Q*. 61:363–390.
- Svenska Röda Korset. (2018). *Nedslag i Verkligheten – tillgång till vård för papperslösa. Röda Korsets nulägesbeskrivning av hinder till vård för papperslösa personer och dess humanitära konsekvenser*.
- Svensk Transplantationsförening. (2019). *Angående möjligheten till transplantation med avliden givare för personer som sökt uppehållstillstånd i Sverige*.
<https://svensktransplantationsforening.se/tx-och-uppehallstillstand/>.
- Tan, K-C. (2004). *Justice without borders*. Cambridge University Press.
<https://doi.org/10.1017/CBO9780511490385>

- Tan, K-C. (2012). *Justice, Institutions and Luck: The Site, Ground and Scope of Equality*. Oxford University Press.
DOI:10.1093/acprof:oso/9780199588855.001.0001
- The British Transplantation Society. (2009). *Allocation of Organs to Non UK EU Residents*.
<https://bts.org.uk/wp-content/uploads/2016/09/Buggins-Report-ALLOCATION-OF-ORGANS-TO-NON-UK-EU-RESIDENTS.pdf>.
- The Transplantation Society and the International Society of Nephrology. (2018). *The Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2018 Edition)*.
doi: 10.1097/TP.0000000000002540.
- Thorburn Stern, R. (2020). Migration. I Lerwall L (ed.) *Makt, myndighet, människa: en bok i speciell förvaltningsrätt* (4 ed.). Iustus Förlag.
- Trillium gift of life network. (2016). *Listing and Allocation of Organs for Transplantation to Non-Canadian Residents & Outof-Country Transplant Funding*.
- Tännsjö, T. (2012). *Grundbok i normativ etik*. Thales.
- Utlänningslag (2005:716). Justitiedepartementet.
www.riksdagen.se/sv/dokument-lagar/dokument/svenskforfattningssamling/utlanningslag-2005716_sfs-2005-716.
- Van Biesen, W. et al. (2016). Rental replacement therapy for refugees with end- of state kidney disease: an international survey of the nephrological community. *Dialysis for refugee patients. Kidney Int Suppl.* 6:35–41.
- Van Biesen, W. et al. (2018). Caring for Migrants and Refugees With End-Stage Kidney Disease in Europe. *Am J Kidney Dis.* 71:701– 709.
- Walzer, M. (1983). *Spheres of Justice. A Defense of Pluralism and Equality*. Basic Books.
- WHO (World Health Organization). (2019). *Promoting the health of refugees and migrants. Draft global action plan, 2019–2023. Report by the Director-General*. World Health Assembly, 72. A72/25 Rev. 1.
<https://apps.who.int/iris/handle/10665/328690>.

- Wightman A. and Diekema D. (2015). Should an Undocumented Immigrant Receive a Heart Transplant? *AMA J Ethics*. 17:909– 913.
- WMA (World Medical Association). (2016). *Resolution on Refugees and Migrants*.
www.wma.net/policies-post/wma-resolution-on-refugees-andmigrants/.
- WMA (World Medical Association). (2017). *Declaration of Geneva*.
www.wma.net/policies-post/wma-declaration-o-geneva/.
- Zillén, K. (2019). *Barn i välfärdsstatens utkant – om rätten till sjukvård för barn som är unionsmedborgare och som lever i ekonomisk utsatthet i Sverige*. Iustus förlag.