

COUNCIL OF EUROPE
COMMITTEE OF MINISTERS

**Recommendation Rec(2001)5
of the Committee of Ministers to member states
on the management of organ transplant waiting lists
and waiting times**

*(Adopted by the Committee of Ministers
on 7 March 2001
at the 744th meeting of the Ministers' Deputies)*

The Committee of Ministers, under the terms of Article 15.b of the Statute of the Council of Europe,

Considering that the aim of the Council of Europe is to achieve greater unity between its members and that this aim may be pursued, *inter alia*, by the adoption of common action in the public health field;

Bearing in mind Article 11 of the European Social Charter on the right to the protection of health;

Recalling that Article 3 of the Convention on Human Rights and Biomedicine requires that Contracting Parties provide “equitable access to health care of appropriate quality”;

Taking into account Resolution (78) 29 on the harmonisation of legislations of member states relating to removal, grafting and transplantation of human substances, the final text of the 3rd Conference of European Health Ministers (Paris, 16-17 November 1987) and Articles 19 and 20 of the Convention on Human Rights and Biomedicine;

Having regard to Recommendation No. R (99) 21 on criteria for the management of waiting lists and waiting times in health care;

Considering that the collection of medical data raises special concerns with regard to data protection, especially where the data are to be collected or used for purposes other than immediate health benefits to the individual;

Having regard to the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108) and to Recommendation No. R (97) 5 on the protection of medical data;

Aware that waiting lists and waiting times may appear when the demand for organs exceeds availability;

Taking account of World Health Organisation Resolution WHA 42.5 condemning the purchase and sale of organs of human origin;

Considering that organ transplantation is severely restricted by the availability of organs for transplantation and that a properly managed waiting list is essential to ensure equality of access to organ transplantation, Recommends that governments of member states conform to the following rules:

1. Member states should guarantee that a system exists to provide equitable access to

transplantation services for patients which ensures that organs and tissues are allocated in conformity with transparent and duly justifiable rules according to medical criteria.

2. There should be a mechanism, enforceable by law or regulations, for establishing and managing an officially recognised regional, national or international waiting list for each of the main types of organ transplantation.

3. Cadaveric organs should only be allocated to patients registered on the official waiting list.

Patients receiving organs from a living donor should also be registered if there is any possibility that they might need an organ from a deceased person.

4. Patients may only be registered on one official transplant waiting list be it regional, national or international. Individual transplant units may have their own local waiting list but only as a subset of the official waiting list.

5. Criteria for registration on the waiting list should be established by a process of consensus based on medical criteria. Registration should include the data essential to identify patients individually, their location and the criteria for their inclusion on the waiting list. The criteria for inclusion should ensure there is no discrimination on the grounds of race, religion, disability or any other non-medical factor. Priority on the waiting list such as “urgent” or “very-urgent” categories should be based solely on medical factors relating to the severity of risk for the individual patient. If patients are registered who do not normally reside in the area covered by the official waiting list, then those managing the waiting list should make all reasonable efforts to check with other transplant organisations that the patient is only on one waiting list.

6. Only transplant units recognised by the official waiting list should be able to register patients in their charge on the waiting list and should do so directly with the organisation managing the official waiting list. Patients should be informed that they are on the waiting list and notified if for any reason they are subsequently suspended or removed.

7. There should be a nationally recognised organisation responsible for the management of the waiting list and the allocation of organs. Organs should be allocated on behalf of the transplant units on the basis of objective rules. The allocation rules should be agreed by all the relevant transplant organisations within the geographical area covered by the waiting list.

8. The waiting list should be regularly updated in conjunction with the transplant units. In particular, the situation of suspended patients or those who have been on the list for a long time should be reviewed to make sure they still meet the registration criteria.

9. Allocation rules should ensure that, as far as possible, no group of patients waits longer than another group waiting for the same type of organ. Waiting times should be analysed regularly to ensure that no patient group is disadvantaged. The allocation rules should be changed when necessary to ensure similar waiting times for all groups of similar patients on the waiting list.

10. The organisation responsible for managing the waiting list should provide information, on at least an annual basis, for health professionals and the public. Information should include:

- i. the criteria for registration, the allocation rules and any changes thereto;

ii. the numbers and flows of patients registered;

iii. the waiting times on the various transplant lists including:

- a. the actual waiting time for patients who have been transplanted;
- b. the time patients still on the list have waited; and the average time patients in any group on any organ transplant list can expect to wait.

11. All organisations managing transplant waiting lists should exchange information with comparable organisations to help improve practice. Research should be promoted to analyse and improve the quality of organ transplant waiting lists and waiting time management.

12. Member states should guarantee that a system is put in place for implementing, monitoring and supervising the rules set out in this recommendation.