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Travel for Transplantation – Identifying the good, the bad and the ugly

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What are National Focal Points?

- Council of Europe

- Human rights organisation that includes 46 member states, 27 of which are members of the European Union

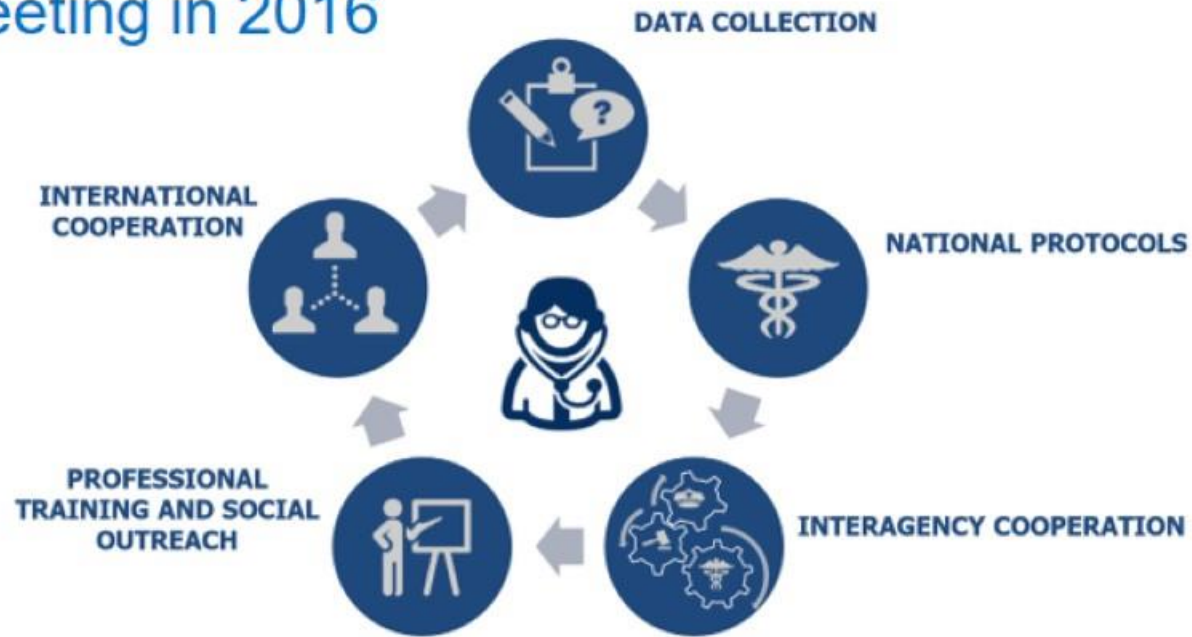
- Resolution CM/Res (2013)55 on establishing procedures for the collection and dissemination of data on transplantation activities outside a domestic transplant system

- designate a contact person in charge of data collection on illicit transplantation activities. This contact person should be based at the existing national transplantation body or, alternatively, at the ministry of health in those member States where a national transplantation body does not exist or is not in charge of following-up on transplantation activities;



What are National Focal Points?

- First meeting in 2016
- Role*



- Audit data collection - Registry of International Travel for Transplantation Activity (RITTA), Council of Europe

- The data collected will be used by our national authorities to analyse the phenomenon of travel for transplantation and to design appropriate measures and policies.

*Marta Lopez Fraga, Technical Meeting for NFPs 2019

National Focal Point Representation

2 representatives with delegated responsibility

- Lisa Burnapp, Associate Medical Director- Living Donation and Transplantation
 - Clinical and HTA liaison
- Matthew Robb, Principal Statistician, Statistics and Clinical Research
 - Data collection and analysis

Types of Travel for Transplant

- TTA – Patients who travelled for transplantation abroad and returned to their country after the transplantation procedure
- NRP – **Non-resident recipients** who received an organ transplant from a non-resident living donor
- NRD – **Resident recipients** who received an organ transplant from a non-resident living donor
- NRR – **Non-resident recipients** who received an organ transplant from a resident living donor
- KEP – Transnational living kidney exchange programmes where donors and/or recipient travels to your country

How are Transplants Identified?

- Transplants reported to RITTA are 2 years in arrears
- Transplants are identified by searching for transplants on the National Transplant Database where either:
 - Transplant took place outside UK
 - Transplant involved a non-resident donor/recipient
- Complexities related to time of collection and information held

How is Data Collected?



(Click here to insert logo of national authority)

Centre-specific survey on transplant procedures having taken place in your country and involving:

- i. A NON-RESIDENT RECIPIENT and a NON-RESIDENT LIVING DONOR
- ii. A NON-RESIDENT RECIPIENT and a RESIDENT LIVING DONOR
- iii. A RESIDENT RECIPIENT and a NON-RESIDENT LIVING DONOR

Since 2017, the Council of Europe network of National Focal Points (NFP) on Travel for Transplantation is collecting information about all patients who travelled abroad to receive an organ transplant, in a dedicated international database. The international exchange of information about these patients would help to better understand and analyse the phenomenon of travel for transplantation, to assess its dimension, and to identify possible hotspots of transplant tourism that deserve careful investigation by the concerned countries. In addition, it would help gain better knowledge of the profile of donors and recipients, the quality in the transfer of recipient care and its impact on post-transplant outcomes.

FORM ON TRANSPLANT PROCEDURES HAVING TAKEN PLACE IN YOUR COUNTRY AND INVOLVING:

- i. A NON-RESIDENT RECIPIENT and a NON-RESIDENT LIVING DONOR
- ii. A NON-RESIDENT RECIPIENT and a RESIDENT LIVING DONOR
- iii. A RESIDENT RECIPIENT and a NON-RESIDENT LIVING DONOR

(please complete 1 form per case)

This form is about a transplant procedure having taken place in your country and involving:

A non-resident recipient who received an organ transplant from a non-resident living donor

[Go to questionnaire I](#)

A non-resident recipient who received an organ transplant from a resident living donor

[Go to questionnaire II](#)

A resident recipient who received an organ transplant from a non-resident living donor

[Go to questionnaire III](#)

What is Reported?

- Anonymised information provided
- Details related to the transplant from the questionnaire

13.	Was the RECIPIENT referred for transplantation abroad by a team/centre or relevant government body in their country of residency? <i>Referral <u>should be understood</u> as the establishment of a direct contact between the treating team/centre or relevant government body in the country of origin and the team/centre where the transplantation procedure would take place in</i>	<input type="checkbox"/> yes <input type="checkbox"/> no <i>if 'yes' please complete question 13a</i> <i>if 'no' please complete question 13b</i>
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17.	How was the DONOR-RECIPIENT relationship verified? <i>Choose as many as apply</i>	<input type="checkbox"/> Legal verification process involving authorities to include documentation +/- donor and recipient interviews <input type="checkbox"/> Personal documentation (e.g. birth certificates or marriage certificates) <input type="checkbox"/> Personal interview in the transplant centre <input type="checkbox"/> HLA tests <input type="checkbox"/> It was not verified
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What is Reported?

- Anonymised information provided
- Details related to the transplant from the questionnaire
- Summarised data is shared