



Belgian **Red Cross**

**Marrow Donor
Program Belgium
Registry**

GDPR
General Data Protection Regulation

Introduction

Flemish Red Cross

- Diversity in activities
- Great amount of personal data
- Sensitive, judicial and health data

Growing attention for privacy

- EU legislation
- Specific Belgian legislation: health data, judicial data,...
- Press and media attention
- Significant penalties

Approach of Belgian Red Cross Flanders

Project 'PJ-15016 Privacy policy' started in November 2015.

- Central register of personal data processing
- Database owner is responsible
- Data Privacy Impact Assessments
- Data Processing Agreements with our suppliers
- Data policy for each activity
- Independent advice and support is delivered by DPO

Approach: communication is essential

- Communication and awareness are essential
 - > To all personnel through info sessions and e-learning
 - > Yearly awareness campagne for personnel and volunteers
 - > SPOC for internal and external contacts: DPO@rodekruis.be

Iedereen 'Beschermer van persoonsgegevens'



Jij bent de **privacyheld** die Rode Kruis-Vlaanderen nodig heeft!

DOE DE TEST

Samen beschermen we al **30%** van de persoonsgegevens



Privacy for Marrow Donor Program Belgium



Privacy for Marrow Donor Program Belgium

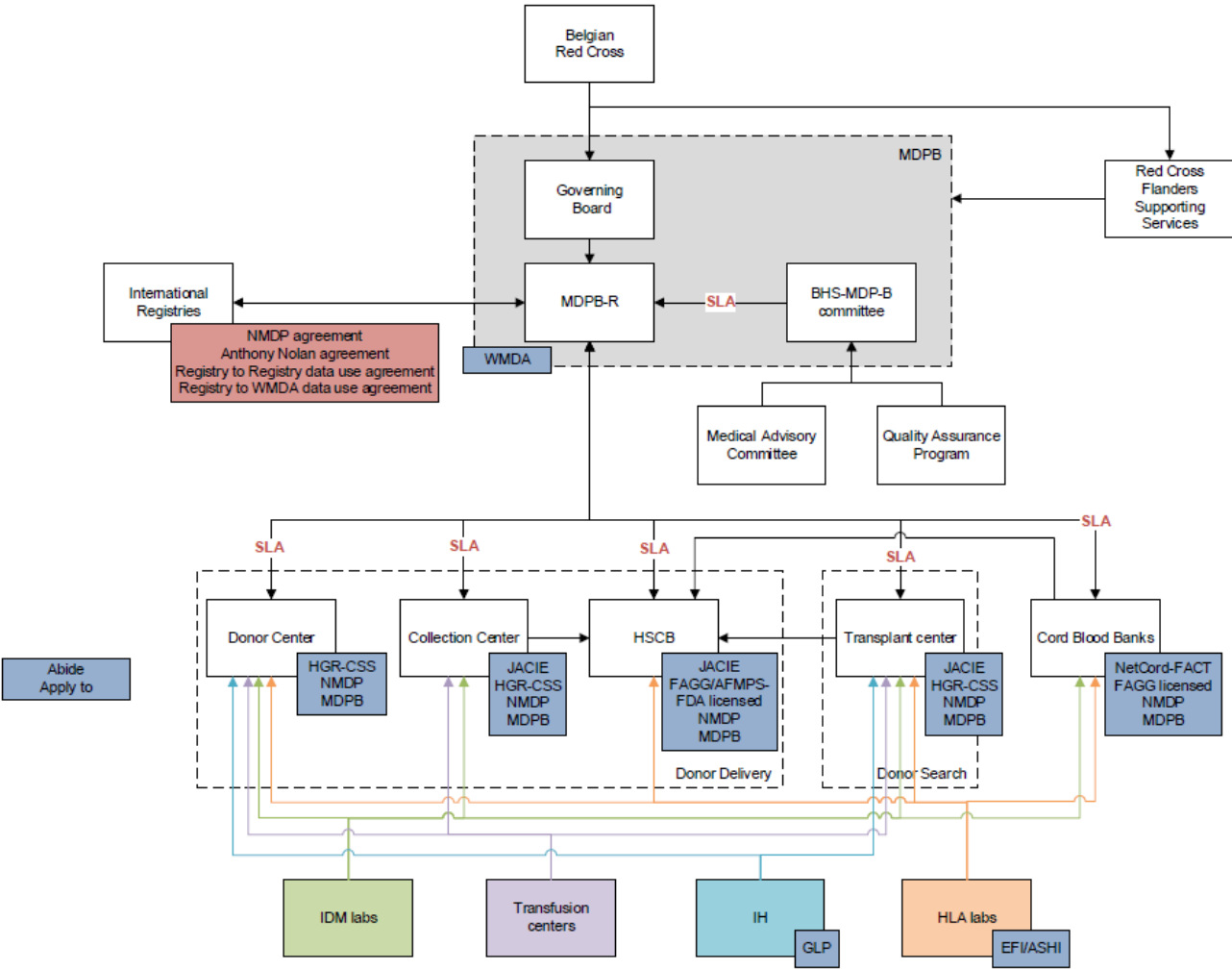
- MDPB Governance
 - > MDPB-Registry : operational exploitation
 - > BHS, MDPB-B : scientific and medical advisory function

- Complex Ecosystem

- Transfers of personal and health data between different parties worldwide:
 - > WMDA (World Marrow Donor Association)
 - > International registries and health providers worldwide
 - > Cooperative centers

- 2 main groups of data
 - > Donor information
 - > Patient information

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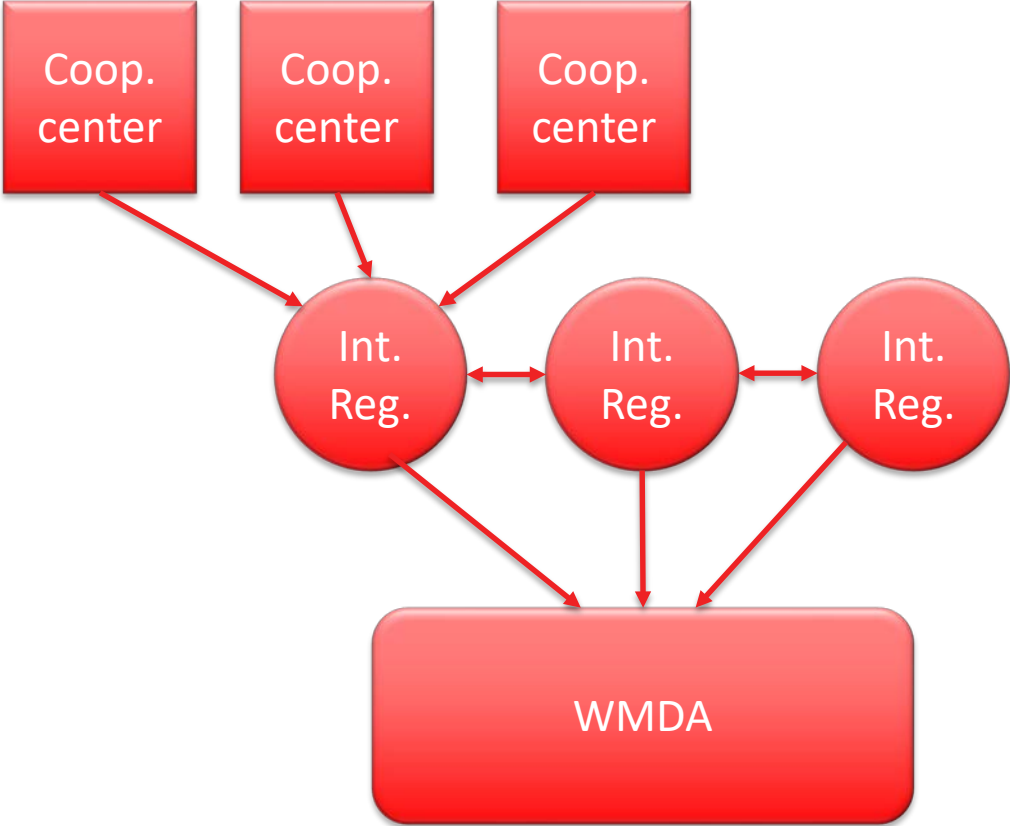
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Donor information

Privacy for MDPB: Donor information



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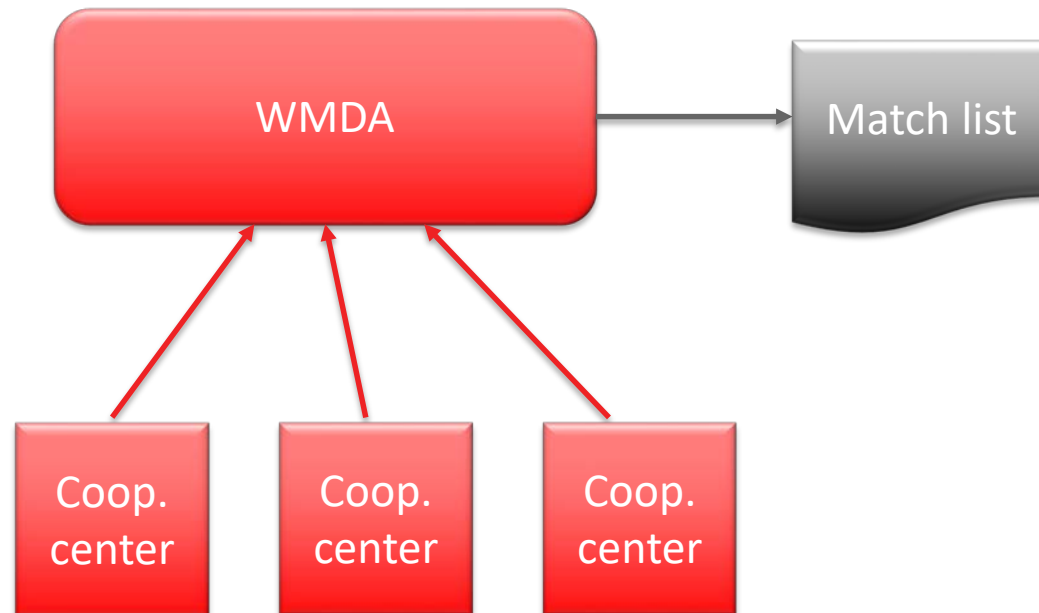
- GDPR within WMDA
 - > Exchange of personal data between registries and cooperative centers
 - > Exchange of personal data between registries and WMDA

- Global donor identifier (GRID) : uniquely identifies potential donors a global scale (fully implemented december 2020).
 - Identification based on date of birth (no international interchange of donor name).

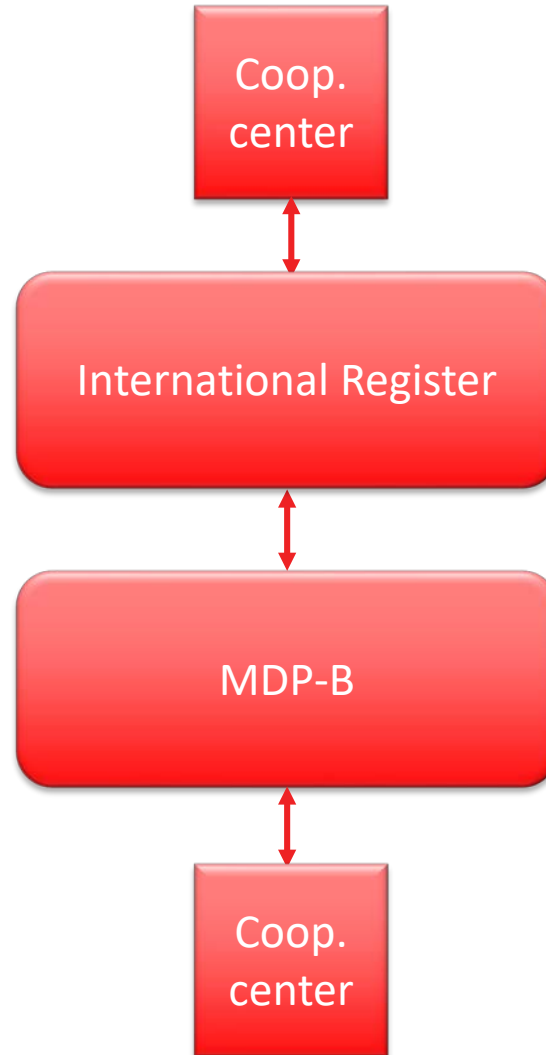


Patient information

Privacy for MDPB: Patient Information



Privacy for MDPB: Patient information



Privacy for MDPB: Patient information

- Data exchanges:
 - > Transplant center enters patient data into the WMDA Search & Match Service to find the most suitable stem cell source for their patient
 - > Exchange of patient data between transplant center and registry
 - > Exchange of patient data between registries
 - > Exchange of patient data between international registry and cooperative center

- To cover all relationships of MDPB:
 - > Agreement between WMDA and every registry
 - > Agreement between all WMDA-registries
 - > Agreement between MDPB and all participating cooperative centers
 - > Agreement between MDPB and its suppliers
 - > Agreement between MDPB and Stichting Kankerregister

Privacy for MDPB: formalising the ecosystem in agreements

- WMDA standard GDPR agreements
 - > 1 WMDA template for all registries, signed by MDPB-R
(Not all international registries have signed the template yet)

- Joint controllership between MDPB and cooperative centers
 - > few guidelines in GDPR
 - > joint approach is crucial

Privacy for MDPB: Patient information

- Different systems for patient-ID's in every transplant center
 - Identification based on name and date of birth
 - Patient name and date of birth on invoices

- Use of patient names in e-mail communication:
 - > no worldwide secured e-mail communication system available
 - > no unique patiënt ID system similar to GRID for patients
 - > Severe medical risks in case of mixing up identities
 - > WMDA must take actions on international level

Meanwhile: In principle, general outlook e-mailings are already encrypted (TLS encryption), except for the subject of the e-mail

General guideline: do not use patient names in subject of your email

Privacy for MDPB: formalising the ecosystem in agreements

To do:

- Joint data protection impact assessment

- Agreement between registry and all cooperative centra
 - > Replaces the current service agreement
 - > GDPR is part of "standard cooperation agreement"
 - > Joint controllership
 - > Applies both for donor and patient information

- Informed consent for donors
 - > Information letter templates will be updated by MDPB/BHS

- Informed consent for patients

GDPR Working group with delegation of 5 cooperative centers
(donor centers and transplant centers)

Privacy for MDPB: Patient information

Implementation and timing

- Revised policies and procedures to be implemented in the MDPB standards

- Approval by
 - the MDPB-R Governing Board
 - the BHS, MDP-B committee

- Implemented before the biennial WMDA qualification application of the MDPB-R in June 2020.