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D2.2 Resources for registry operations and for import/export to EU Member States

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Periodic report: 1st 2nd 3rd 4th x

Period covered: from 01st January to 31st December 2021

Organisation: **World Marrow Donor Association**
(WMDA)

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1. Preface

This report, as part of the 2021 work programme of the World Marrow Donor Association (WMDA) for the EU Third Health Programme (2014-2020), outlines the online resources provided by WMDA for sharing information and guidance globally with registries that export stem cells to EU member states. It builds on Deliverable 3.1, 2019¹; Deliverable 3.4, 2019² and Deliverable 2.2, 2020³ by giving an update on the status and use of practical tools and resources that support the efficient import of stem cells by EU member registries and the export to other countries. Efficient import and export include details of EU safety and quality regulations and the rationale underpinning them.

The resources described in this report are all fully aligned with WMDA's mission to promote global collaboration and the sharing of best practices between its member for the benefit of stem cell donors and patients.

In this report, each chapter covers an update on the status and/or use of tools and resources that WMDA provides for members to share their data and to keep them informed on topics that affect import and export of hematopoietic stem cells. The graph below shows the total of imported and exported products by EU member states. Each number represents a patient waiting for a cure. For them and for the physicians treating them, it is of the essence that the data provided and shared by WMDA members, is accurate and actual.

The graph below, as well as specific details per EU member state, can be found in Deliverable D2.1, 2021⁴.

	BM	PBSC	CBU	DLI
National	263	2.704	68	394
Export to EU member states	394	2.931	88	329
Export to third countries	423	3.227	163	239
Import from EU member states	383	2.712	88	329
Import from third countries	102	965	76	102
Import-Export ratio	485:817	3.677:6.158	164:251	431:568
	37% import	37% import	40% import	43% import

Figure 1. Overview of total import and export for EU Member States in 2020

2. Maintaining Operational Information and Regulatory Survey

As described in Deliverable 3.4, 2019², WMDA provides public webpages with essential information on Stem Cell Donor Registries and Cord Blood Banks. All organisations that are facilitating stem cell donations or cord blood for international patients are obliged to update the information annually. WMDA sends reminders through the three-weekly newsletter, Stem Cell Matters (SCM) and by email to request members to check and update their information on the public webpages. These are the messages that were sent on this topic in 2021:

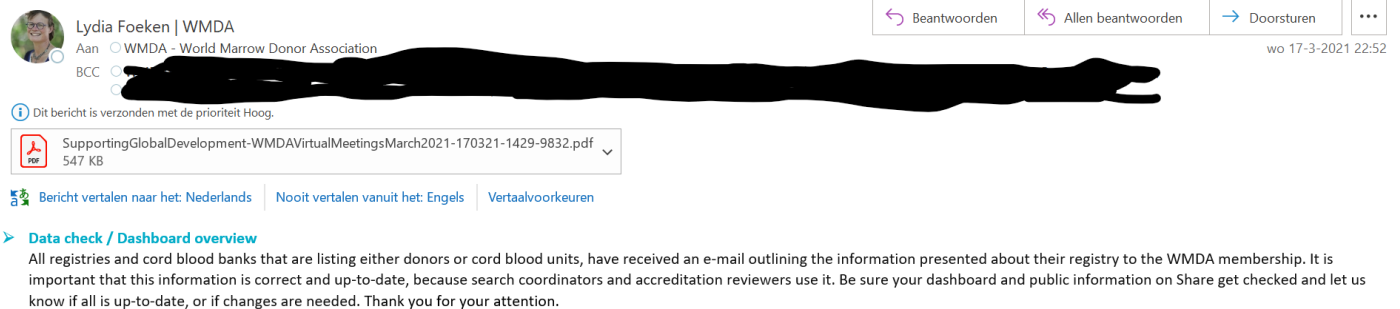
Data check / Dashboard overview

All registries and cord blood banks that are listing either donors or cord blood units, have received an e-mail outlining the information presented about their registry to the WMDA membership. This information is helpful for search coordinators to assist during the selection process and for the reviewers inspecting a registry to get WMDA accredited. Have a quick look and let us know if the information of your organisation is up-to-date.

→ [Contact the WMDA office](#)

Stem Cell Matters 73 - March 2021 ([link](#))

WMDA connecting to member organisations



Lydia Foeken | WMDA
Aan: WMDA - World Marrow Donor Association
BCC: [Redacted]

Beantwoorden | Allen beantwoorden | Doorsturen

wo 17-3-2021 22:52

Dit bericht is verzonden met de prioriteit Hoog.

SupportingGlobalDevelopment-WMDAVirtualMeetingsMarch2021-170321-1429-9832.pdf
547 KB

Bericht vertalen naar het: Nederlands | Nooit vertalen vanuit het: Engels | Vertaalvoorkeuren

Data check / Dashboard overview
All registries and cord blood banks that are listing either donors or cord blood units, have received an e-mail outlining the information presented about their registry to the WMDA membership. It is important that this information is correct and up-to-date, because search coordinators and accreditation reviewers use it. Be sure your dashboard and public information on Share get checked and let us know if all is up-to-date, or if changes are needed. Thank you for your attention.

Best regards,

Lydia Foeken
Executive director



CEO letter 17 March 2021

Appendix 1 gives an overview of the Cord Blood Banks, Donor Registries and Donor Centres in EU Member States that have submitted their information for the public pages. Dates have been added in black to show which organisations have followed up on WMDA's request to update their data. The dates in red indicate that data is available for these organisations, but that it hasn't been updated within the last year. Chapter 5 describes follow-up and actions WMDA will take to ensure all information on the public pages gets updated.

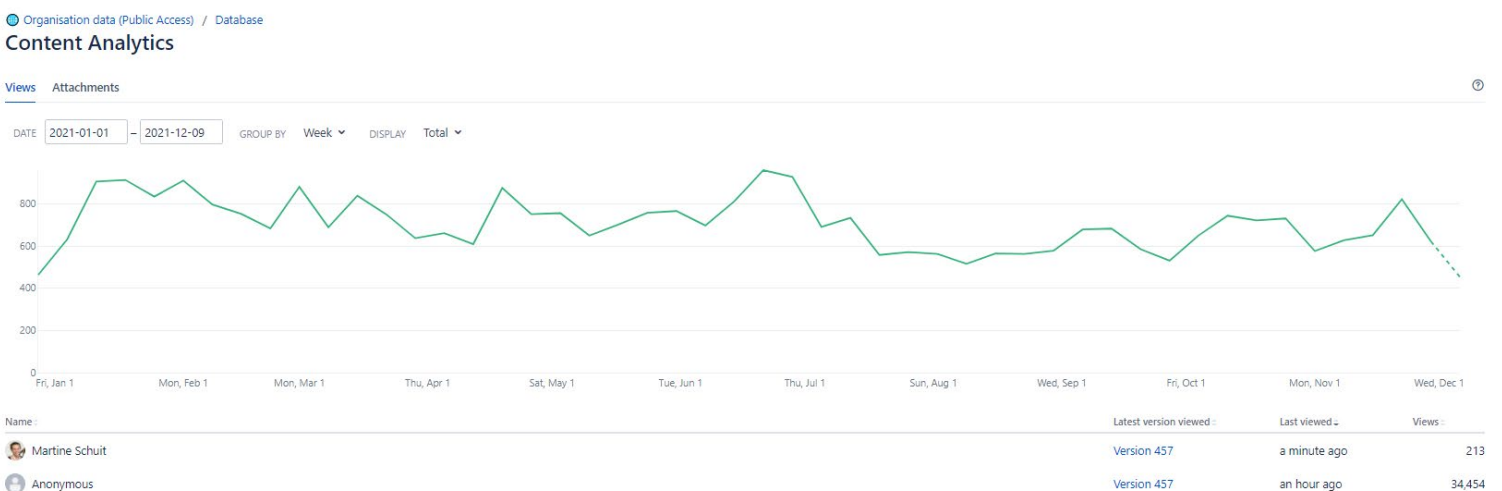
3. Use of Operational Information and Regulatory Survey

This chapter provides an overview of the amount of views the pages with operational information and regulatory surveys got throughout 2021, to show the importance of the pages.

Most people access the operational information and regulatory survey through the ‘Database’⁵; the overview of all the donor registries and cord blood banks that are known to WMDA and that are listed in WMDA’s Customer Relationship Management (CRM) system. This is a screenshot of the page:

Country	Type	ION	WSMS listed	Affiliation	Organisation	Accreditations	Member information	WO-number	Shortcode
Andorra									
Andorra	CBB		no		Cellab Andorra	AABB	WO-1955	WO-1955	AD-Cellab (C)
Argentina									
Argentina	CBB		via registry	ION-5117	Argentina National Cord Blood Bank	AABB	WO-1327	WO-1327	AR-INCUCAI (C)
Argentina	DR with CBU	5117	yes		Argentine HSC Donors Registry		ION-5117	WO-1009	AR-INCUCAI
Armenia									
Armenia	DR	5019	yes		Armenian Bone Marrow Donor Registry Charitable Trust		ION-5019	WO-1010	AM-ABMDR
Australia									
Australia	DR with CBU	7748	yes		Australian Bone Marrow Donor Registry	WMDA accredited (D/C) 2017	ION-7748	WO-1011	AU-ABMDR
Australia	CBB		via registry	ION-7748	Murdoch Childrens Research Institute - BMDI Cord Blood Bank	FACT	WO-1372	WO-1372	AU-BMDI
Australia	CBB		via registry	ION-7748	Queensland Cord Blood Bank Al The Mater	FACT	WO-1371	WO-1371	AU-Queensland
Australia	CBB		via registry	ION-7748	Sydney Cord Blood Bank	FACT	WO-1346	WO-1346	AU-Sydney
Austria									
Austria	DR with CBU	2614	yes		Austrian Bone Marrow Donor Registry	WMDA qualified (D) 2017	ION-2614	WO-1012	AT-ABMDR
Austria	CBB		via registry	ION-2614	Red Cross Blood Transfusion Service of Upper Austria		WO-1279	WO-1279	AT-RedCross (C)
Austria	DR	4961	via registry	ION-6939	Verein Geben für Leben		ION-4961	WO-1407	AT-GFL
Austria	CBB	8162	yes		Vita 34 Gesellschaft für Zelltransplantate mbH	FACT	ION-8162	WO-1014	AT-Vita34 (C)

The graph below shows that the total amount of anonymous views from 1 January to 9 December 2021 has been 34.454 and the last anonymous view was 1 hour before the screenshot was made. On average this page gets 700 views a week from both members who are users of the Share platform, as well as from anonymous viewers. The total amount of views is higher than shown below the figure.

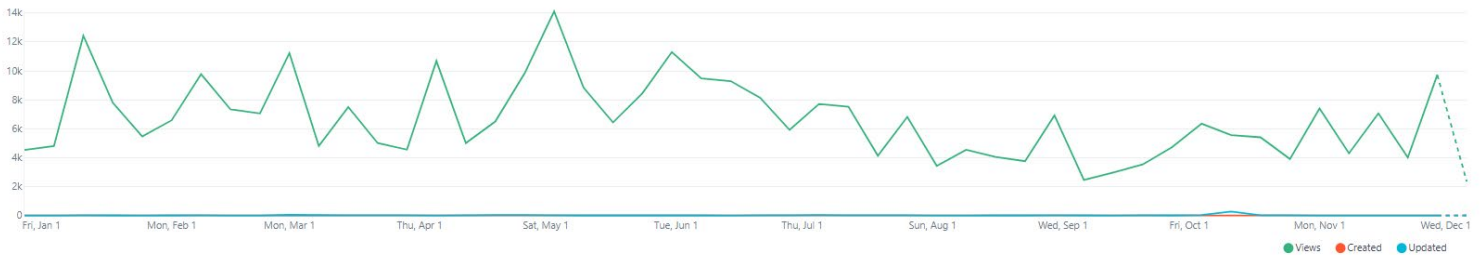


The graph below shows the total amount views of the ‘space’. This ‘space’ contains all the pages that fall under the database. It shows the top 5 of pages that have the most views. On average the pages of this space get 7.000 views a week. ION-7748 is the organisation that got the most views in 2021. This is the Australian Bone Marrow Donor Registry. ION-1033 is Gift of Life Registry, USA and ION-7414 is Fundacja DKMS, a registry in Poland.

Organisation data (Public Access)
Space Analytics

Overview Content Users

DATE 2021-01-01 - 2021-12-09 GROUP BY Week DISPLAY Total CONTENT All



MOST POPULAR CONTENT

Database	34,995 views
Organisation Information Public Access	5,510 views
ION-7748	1,986 views
ION-1033	1,897 views
ION-7414	1,601 views

MOST ACTIVE READERS



MOST ACTIVE CONTRIBUTORS



To give more insight specifically in the use of the Operational Information and the Regulatory Survey, the top three most viewed pages of organisations from EU member states have been analysed. The top three was selected, based on the overview below, that shows the full list of views per page for the space. Find screenshots for ION-7414, Fundacja DKMS – Poland; ION-1804, France Greffe de Moelle Registry – France and ION-2614 Austrian Bone Marrow Donor Registry – Austria on the next pages.

Organisation data (Public Access)
Space Analytics

Overview Content Users

DATE 2021-01-01 - 2021-12-09 CONTENT All

Title	Created	Last modified	Last viewed	Comment activity	Users viewed	Views
Database	6 years ago	a month ago	6 minutes ago	0	276	34,995
Organisation Information Public Access	6 years ago	5 months ago	6 hours ago	0	203	5,510
ION-7748	6 years ago	2 months ago	4 hours ago	0	39	1,986
ION-1033	6 years ago	2 months ago	36 minutes ago	0	17	1,897
ION-7414	6 years ago	2 months ago	2 days ago	0	26	1,601
ION-1804	6 years ago	a month ago	5 hours ago	0	32	1,539
ION-2614	6 years ago	2 months ago	6 hours ago	0	27	1,525
ION-3785	6 years ago	2 months ago	a day ago	0	38	1,487
ION-6939	6 years ago	2 months ago	6 hours ago	0	46	1,287
ION-4987	6 years ago	2 months ago	5 hours ago	0	24	1,265

The page with operational information for Fundacja DKMS⁶ was viewed 288 times anonymously between 1 January and 9 December 2021, mostly in the beginning of the year.

Organisation data (Public Access) / Operational Information ION-7414

Content Analytics

Views Attachments



ION-7414: Fundacja DKMS - Poland

The regulatory survey for ION-7414⁷ was viewed 241 times anonymously with a peak of 14 views in the week before World Marrow Donor Day, which could be related, but it might also have been a coincidence.

Organisation data (Public Access) / Regulatory Survey ION-7414

Content Analytics

Views Attachments



ION-7414: Fundacja DKMS - Poland

The page with operational information for France Greffe de Moelle Registry⁸ was viewed 295 times anonymously between 1 January and 9 December 2021.

Organisation data (Public Access) / Operational Information ION-1804

Content Analytics

Views Attachments

DATE 2021-01-01 - 2021-12-09 GROUP BY Week DISPLAY Total



Name	Latest version viewed	Last viewed	Views
Martine Schuit	Version 4	a few seconds ago	3
[Redacted]	Version 4	6 hours ago	1
Anonymous	Version 4	14 hours ago	295

ION-1804 France Greffe de Moelle Registry - France

The regulatory survey⁹ was viewed 203 times anonymously between 1 January and 9 December 2021. Combined with the operational information, that's 498. That's 31 views less than the total of anonymous views for the Polish registry, Fundacja DKMS (total = 288 + 241 = 529).

Organisation data (Public Access) / Regulatory Survey ION-1804

Content Analytics

Views Attachments

DATE 2021-01-01 - 2021-12-09 GROUP BY Week DISPLAY Total



Name	Latest version viewed	Last viewed	Views
Martine Schuit	Version 6	a few seconds ago	2
[Redacted]	Version 6	7 hours ago	1
Anonymous	Version 6	a day ago	203

ION-1804 France Greffe de Moelle Registry - France

The page with operational information for the Austrian Bone Marrow Donor Registry¹⁰ was viewed 267 times anonymously between 1 January and 9 December 2021. Not a week has gone by this year that the page wasn't viewed at least once.

Organisation data (Public Access) / Operational Information ION-2614

Content Analytics

Views Attachments

DATE 2021-01-01 - 2021-12-09 GROUP BY Week DISPLAY Total



Name	Latest version viewed	Last viewed	Views
 Martine Schuit	Version 17	a few seconds ago	3
 Anonymous	Version 17	a day ago	267

ION-2614 Austrian Bone Marrow Donor Registry - Austria

The regulatory survey for the Austrian registry¹¹ was viewed 204 times anonymously between 1 January and 9 December 2021.



Organisation data (Public Access) / Regulatory Survey ION-2614

Content Analytics

Views Attachments

DATE 2021-01-01 - 2021-12-09 GROUP BY Week DISPLAY Total



Name	Latest version viewed	Last viewed	Views
 Martine Schuit	Version 4	a few seconds ago	2
 Anonymous	Version 4	a day ago	204

ION-2614 Austrian Bone Marrow Donor Registry - Austria

Appendix 1 shows that many cord blood banks haven't added their banking and operational specifics yet. Chapter 5 will describe actions to improve this situation. To show that this information is valuable two cord blood banks have been selected to show the analytics of their banking and operational specifics: CYCORD PACCB, Cyprus, which was the first to update their pages in 2020, but hasn't updated since, and Banc de Sang i Teixits - Barcelona Cord Blood Bank, Spain, which has most recently done an update both pages in 2021.

The graphs below show that the Cord Blood Bank from Cyprus had 184 anonymous views for the page with banking specifics¹² and 172 for the operational specifics¹³.

Organisation data (Public Access) / CB banking specifics WO-1389

Content Analytics

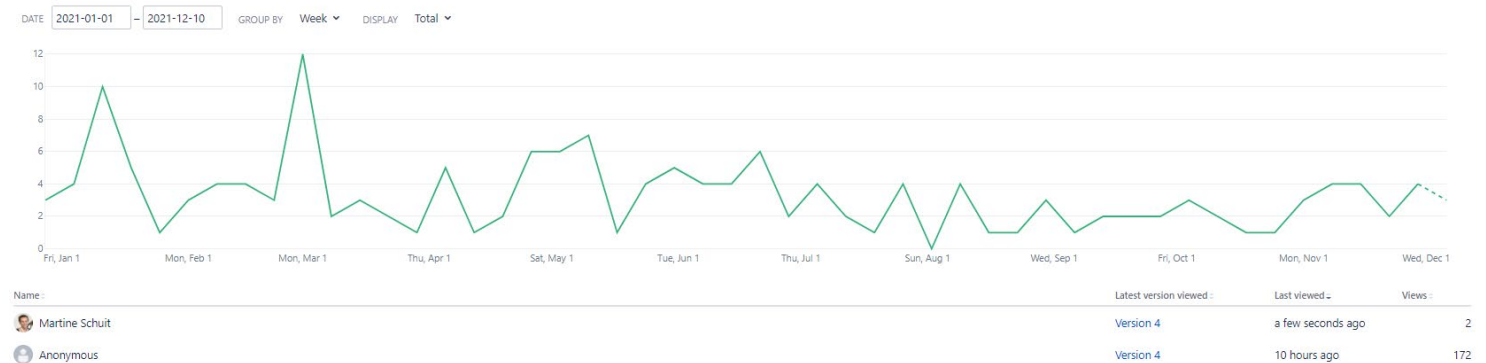
Views Attachments



Organisation data (Public Access) / CBB operational specifics WO-1389

Content Analytics

Views Attachments



The figures below show that the Spanish Cord Blood Bank in Barcelona had 406 anonymous view in total; 195 for the banking specifics and 211 for the operational specifics. A clear peak is visible in July, which was when the pages were updated.

Organisation data (Public Access) / CB banking specifics WO-1390

Content Analytics

Views Attachments



Organisation data (Public Access) / CBB operational specifics WO-1390

Content Analytics

Views Attachments



4. Digital Dashboards

For the first time, all WMDA members that have an International Organisation Number (ION) for listing their donors in the international Search and Match Service provided by WMDA, received a Digital Dashboard through email. The Dashboards give an overview of overall activity of the organisations in relation to WMDA. It also shows if operational and regulatory information has been provided and updated. Find the Dashboard that was sent to the Finnish Stem Cell Registry in Appendix 2 as an example.

The emails with dashboards were sent to the CEOs and the Organisation Profile Administrators of the organisations in the first week of March 2021. The Organisation Profile Administrators have the rights to access the operational and regulatory pages as editors to make changes and to update the information.

This is the email that was sent:

WMDA Dashboard for your organisation



The screenshot shows an email header from WMDA - World Marrow Donor Association. The recipient is redacted. The email contains two attachments: a PDF file named '20200806-WGQR-KPI.pdf' (1 MB) and a Word document named 'WMDA Dashboard 8118.docx' (113 KB). Below the attachments are translation options: 'Bericht vertalen naar het: Nederlands', 'Nooit vertalen vanuit het: Engels', and 'Vertaalvoorkeuren'. The email was received on 'wo 3-3-2021 16:55'. The interface includes buttons for 'Beantwoorden', 'Allen beantwoorden', 'Doorsturen', and a menu icon.

Dear [redacted]

I hope you are well.

The team of WMDA would like to connect with you to check the information for your organisation recorded in our system. Find attached a dashboard that we have prepared for you to review.

This is the first edition of the WMDA Dashboard in which you can see the overall activity of your registry in relation to WMDA. It also shows the data WMDA has in their CRM for your registry. Please note that the dashboard was generated in June of last year, so some information might not be accurate anymore.

We ask you to review all the data presented in this document and to inform us of any corrections. This way we keep your data accurate and up to date.

Please provide any feedback you might have to us, so that we can improve our future edition of the dashboard.

Explanation of the colors used in this document:

- A green box means that data has been provided to us and/or that your registry complies with WMDA defined common practices
- An orange box means that your registry needs to check data and/or is recommended to work on improvement
- A red box means that your registry needs to take action and/or provide missing data

For the KPI's and corresponding benchmarks for 2019, please refer to the second attachment with explanation.

We are happy to have a call with you in case you have any questions or would wish to discuss any content.

Thank you very much in advance for reading the dashboard.

Best regards, also on behalf of Lydia,

Martine Schuit
Project Coordinator:
Supporting Global Development

martine.schuit@wmda.info
+31 88 505 7902
Mon. Tue. Wed. Thu. Fri.



World Marrow Donor Association
Phone: +31 88 505 7900
Address: Schipholweg 57, 1st floor,
2316 ZL Leiden, The Netherlands

Not all registries that received the Dashboard took action to update their data on the public webpages on WMDA Share, as can be seen in Appendix 1. The next chapter will discuss follow-up actions to ensure outdated information gets reviewed and corrected if needed.

5. Follow-up actions

All registries and cord blood banks that haven't updated or submitted their data to the public pages on WMDA Share yet, will receive a personal email with detailed instruction how to add and change the information for their organisation. The email will be sent in January 2022 and it will explain the importance of ensuring their data is well-displayed, with statistics similar to the ones that have been added in chapter 3 of this report.

A clear deadline (1 March) will be stated. If the deadline is not met, a personal call in Zoom or Teams will be scheduled with the Organisation Profile Administrators to guide them one-on-one in the months March, April, May and June. By 1 July all data should be available and up to date.

In January 2022 an article will be shared in Stem Cell Matters on the importance of having actual and accurate organizational data on WMDA's public webpages. The article will also outline the steps and actions mentioned above.

Regarding the Dashboards, WMDA would like to have the information that was sent to registries by email in March 2021 available as digital dashboards online instead. This will allow for real-time data display from which both the WMDA members and the WMDA office staff will benefit. Members will have access to their dashboard at all times and it will save the WMDA office staff a lot of work gathering the data in a Word document and having to send that to each organisation separately. Organisations will be reminded to check their dashboards (once available) and update their data twice a year: once in June and once in December.

An annual check, done by WMDA, is needed to see if all members have updated their pages. This will be done yearly in December, with follow-up actions in Q1 and Q2 of the next year in case members haven't reviewed their data.

6. Conclusion

Chapter 3 of this report shows how often the public pages with operational information are consulted, thus proving their importance and the importance of displaying accurate and actual data. The overview in appendix 1 shows that not all members in EU member states comply with WMDA's standards to review and update information annually. Moreover, there are still many cord blood banks that haven't submitted their data yet.

One reason for this might be the SARS-CoV2 pandemic, partially because that's causing more urgent problems that get prioritised over updating the information on WMDA Share and also because some information might be temporarily different due to the pandemic.

Another reason for the cord blood banks specifically might also be that many of them are not a direct member of WMDA, because they list their cord blood units through a national registry. This makes them less familiar with WMDA and the public pages WMDA provides.

The actions described in chapter 5 should lead to improvement of the public data displayed on Share for member organisation. This will be assessed yearly in December and action will be taken towards organisations that haven't been able to maintain their data by offering support.

Appendix 1. Status of information submitted by WMDA members in EU Member States

EU Member State	Donor Registry	Operational Information	Sibling Typing*	Regulatory Survey
Austria	Austrian Bone Marrow Donor Registry	30-6-2021		24-9-2019
	Verein Geben für Leben	26-4-2016		24-9-2019
Belgium	Marrow Donor Program Registry Belgium	28-12-2020		21-10-2021
Bulgaria	Bulgarian Bone Marrow Donor Registry	11-3-2021		11-3-2021
Croatia	Croatian Bone Marrow Donor Registry	8-4-2020		24-9-2019
Cyprus	Cyprus Bone Marrow Donor Registry	29-8-2021		29-8-2021
	Cyprus Paraskevaïdio Bone Marrow Donor Registry	13-4-2016		24-9-2019
Czech Republic	Czech National Marrow Donor Registry Plzeň	16-3-2021		16-3-2021
	Czech Stem Cells Registry Prague (CSCR)	25-10-2021		4-3-2021
Denmark	Danish Stem Cell Donors - East (DSDE)	23-2-2021		19-11-2020
	Danish Stem Cell Donors - West	20-4-2021		1-10-2020
Estonia	No registry			
Finland	Finnish Stem Cell Registry	19-8-2020		5-2-2021
France	France Greffe de Moelle Registry - FGM	19-11-2021		26-11-2021
Germany	DKMS gemeinnützige GmbH	29-4-2021		26-4-2021
	DKMS Registry gGmbH	29-4-2021		25-10-2021
	Westdeutsche SpenderZentrale (WSZE)	** see below		
	ZKRD - Zentrales Knochenmarkspender-Register Deutschland	21-11-2021		15-5-2020
Greece	Centre of Bone Marrow Donor Volunteers - Save a life, University of Patras	**see below		
	EOM Hellenic Transplant Organization	28-7-2020		
	Orama Elpidas	**see below		
Hungary	Hungarian Stem Cell Donor Registry	3-5-2016		4-11-2019
Ireland	Irish Unrelated Bone Marrow Registry	26-6-2017		24-9-2019
Italy	Italian Bone Marrow Donor Registry	8-5-2021		8-5-2021
Latvia	No registry			
Lithuania	Lithuanian National Bone Marrow Donor Registry	23-5-2016		24-9-2019
Luxembourg	Luxembourg Marrow Donor Program (LMDP)			
Malta	No registry			
Netherlands	Matchis Foundation	30-7-2020		5-11-2019
Poland	Against Leukemia Foundation (ALF), Warsaw	7-5-2016		24-9-2019
	Fundacja DKMS	7-12-2020		24-8-2021
	Poltransplant	26-4-2016		24-9-2019
Portugal	CEDACE/Portuguese BMD Registry	1-9-2019		24-9-2019
Romania	National Registry of Hematopoietic Stem Cells Voluntary Donors	21-10-2021		1-11-2021
Slovakia	Slovak National BMD Registry	5-4-2018		5-11-2019
Slovenia	Slovenia Donor	19-9-2019		24-9-2019
Spain	Registro de Donantes de Médula Ósea (REDMO)	23-4-2021		21-4-2021
Sweden	Tobias Registry	7-5-2021		7-5-2021

*Sibling Typing is not a mandatory service and not all organisations provide this

**lists through parent organisation, same information applies

Caption: Information has been submitted

Information needs to be added

EU Member State	Cord Blood Bank	CB Banking Specifics	CBB Operational Specifics
Austria	Red Cross Blood Transfusion Service of Upper Austria	23-6-2020	23-6-2020
	Vita 34 Gesellschaft für Zelltransplantate mbH	12-4-2021	12-4-2021
Belgium	Banque de Sang de Cordon, Cliniques Universitaires Saint Luc	22-6-2020	5-10-2020
	CHU de Liège - Liege Cord Blood Bank (Sart Tilman)	5-8-2020	5-8-2020
	Cord Blood Bank UZ Leuven		
	Institut Jules Bordet - ULB Cord Blood Bank		
	UZ Gent Cord Blood Bank		
Bulgaria	Bulgarian Cord Blood Bank		
Croatia	Public CBB Ana Rukavina		
Cyprus	CYCORD PACBB	3-6-2020	3-6-2020
Czech Republic	Cord Blood Bank Czech Republic	29-5-2020	29-5-2020
Denmark	No Cord Blood Bank		
Estonia	No Cord Blood Bank		
Finland	Finnish Cord Blood Bank	3-3-2021	3-3-2021
France	Banque de Sang Placentaire du CHRU de Montpellier		
	Besancon Cord Blood Bank		
	Bordeaux Cord Blood Bank		
Germany	Bayerische Stammzellbank GmbH		
	Deutsche Stammzellspenderdatei Nabelschnurblut		
	DKMS Stem Cell Bank gGmbH		
	José Carreras Cord Blood Bank Düsseldorf-Universitätsklinikum Düsseldorf	4-5-2021	4-3-2021
	Norddeutsches Knochenmark- und Stammzellspender Register gGmbH		
	Universitaetsklinikum Erlangen Stammzellbank		
Greece	Hellenic Cord Blood Bank	12-8-2020	12-8-2020
	Public Cord Blood Bank Crete		
	Thessaloniki Public Cord Blood Bank	14-8-2020	
Hungary	No Cord Blood Bank		
Ireland	No Cord Blood Bank		
Italy	Banca Del Sangue Cordonale Di Cagliari (Cccb)		
	Banca del Sangue Cordonale di Treviso (Treviso Cord Blood Bank)		
	Banca Del Sangue Del Cordone Ombelicale Di Sciacca		
	Banca Del Sangue Di Cordone Ombelicale Di Verona		
	Banca Di Tessuti E Cellule Regione Toscana Pisa Cord Blood Bank	10-7-2021	1-6-2020
	Banca Sangue Placentare Regione Abruzzo Pech		
	Calabria Cord Blood Bank	9-6-2020	9-6-2020
	Campania Cord Blood Bank	19-7-2021	19-7-2021
	CBB Roma Azienda Policlinico Umberto I		16-7-2021
	Emilia Romagna Cord Blood Bank		
	Florence Cord Blood Bank		
	Liguria Cord Blood Bank		
	Milano Cord Blood Bank	20-8-2021	
	Padova Cord Blood Bank		
	Pavia Cord Blood Bank		
Puglia Cord Blood Bank			
Torino Cord Blood Bank			
Unicatt Cord Blood Bank		30-7-2020	
Latvia	No Cord Blood Bank		
Lithuania	No Cord Blood Bank		
Luxembourg	No Cord Blood Bank		
Malta	No Cord Blood Bank		
Netherlands	Sanquin		
Poland	Diagnostyka Bank Komórek Macierzystych		
	The Public Stem Cell Bank, Regional Science and Technology Center		
Portugal	No Cord Blood Bank		
Romania	No Cord Blood Bank		
Slovakia	Slovenský register placentárných krvotvorných buniek - Eurocord-Slovakia (SRPKB)		6-9-2016
Slovenia	ESPOK Cord Blood Bank Slovenia		
Spain	Andalucia Cord Blood Bank (Malaga)		
	Banc de Sang i Teixits - Barcelona Cord Blood Bank	23-7-2021	23-7-2021
	Basque Country Cord Blood Bank		
	Galicia Cord Blood Bank		
	Ivida Cord Blood Bank		
	Madrid Cord Blood Bank		
	Valencia Cord Blood Bank	26-10-2021	
Sweden	Swedish National Cord Blood Bank		
Caption:	Information has been submitted		
	Information needs to be added		

WMDA DASHBOARD

This is the first edition of the WMDA Dashboard in which you can see the overall activity of your registry in relation to WMDA. Our goal is to send out this dashboard annually to keep you updated and on track.

Please provide any feedback you might have to us, so that we can improve our second edition of the dashboard.

GENERAL INFORMATION:

ION: 9738

Membership: Regular

CEO: [REDACTED]

Voting member: [REDACTED]

PLEASE CHECK THE DATA ON THE WEBSITE BELOW

PRESENTATION ON WMDA SHARE, Organisation Information Public Access:

[ION-9738 - Organisation data \(WMDA Members access\) - Share](#)

PILLAR 1: SEARCH, MATCH & CONNECT

DATA USE AGREEMENT

WMDA has established two data use agreements for international collaboration. The first data use agreement is signed with WMDA. The second data use agreement can be used for collaboration with other registries. WMDA provides an overview of the signed data use agreements on WMDA Share: <https://share.wmda.info/x/HznkEw>

	SIGNED?	STATUS
Data Use Agreement with WMDA	18-06-2020	
Data Use Agreement with registries	18-06-2020	

In case there is a data breach at WMDA or at one of the WMDA member organisations, an alert will be sent out to all WMDA data protection officers. Your registered data protection officer is:

Data Protection Officer:	Privaon (outsourced)
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GRID:

On **December 15th**, all registries stopped using the donor-ID number in their communication and GRID will be the sole identifier to communicate with.

The registered GRID officer is:

GRID Contact Person	[REDACTED]
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	Percentage	Status
GRID in donor file	100%	

DATA UPLOAD:

WMDA is moving to real time data to facilitate the search coordinators in their daily job. Ideally, a registry submits its donor file daily or at least once a week to WMDA. A cord blood file is submitted at least once a month. On WMDA Share you can find the upload frequency of WMDA member organisation:

<https://share.wmda.info/x/TwfkEw>.

The number of donors and cord blood units listed, are presented on <https://statistics.wmda.info/>.

File Source	Last Upload Date	Status Frequency:
Donor File	02-03-2020	
Cord Blood File	04-01-2020	

Link to the WMDA Data Quality Report: https://statistics.wmda.info/reports/dq/report.php?id=ion-9738-p-9738-B-2020-06-14-068b4665320dbe75_0bda0a71cb083200&key=0002a0015e21512bcfd2859da31211e

CONTACT PERSONS REGISTERED AT WMDA:

Data uploader(s): [REDACTED]

Persons who have access to search for potential matches in Search & Match Service: [REDACTED]

INTERESTING WEBINARS TO SHARE:

Title	Weblink
Data Dictionary & Differential Uploads	https://youtu.be/c_i03V11Qvl
Search, Match & Connect	https://youtu.be/jCyWnm3X5vY

PILLAR 2: GLOBAL DEVELOPMENT:

EMERGENCY CONTACT DETAILS:

24 H Emergency Number	+ 358 50 327 3447
Primary Emergency Contact	
Secondary Emergency Contact	

DONOR CRITERIA:

WMDA has an online tool on the WMDA website for potential donors, that can guide them to the registries in their country. The donor criteria of all registries are visible on WMDA Share:

<https://share.wmda.info/x/x8KbEw>. These data were used for the virtual global donor drive on September 19, 2020.

For your registry, we have registered the following criteria:

Chronic diseases	Minimum Age	Maximum Age	BMI minimum	BMI maximum	Other
Yes	18	40	17	34,9	-

ORGANISATION CLOSURE AGENDA:

WMDA provides a google calendar on the website, presenting when each registry is closed due to national holidays.

Please check if all dates are correct for your organisation and let us know if additional days need to be added:

<https://wmda.info/professionals/optimising-search-match-connect/organisation-closure-agenda/>

GLOBAL TRENDS REPORT 2019:

WMDA has received the information from your registry. This information was used to prepare the 2021 membership invoice. The data for your registry are provided by:

WMDA Global Trends Report	
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2019 data	National	International
Bone Marrow	0	3
PBSC	21	12
Cord Blood	0	0

OPERATIONAL AND REGULATORY INFORMATION

WMDA Standard 1.04 requires that registries update their operational and regulatory information once a year. Your registry has registered [REDACTED] as organization profile administrator, who has access to these webpages and can update them.

	Link	Update	Status
Operational information	Share	10-05-2016	Red
Regulatory information	Share	10-03-2020	Green
Membership documents	Share	15-06-2020	Green

CORD BLOOD STATUS:

According to our records your registry is collaborating with 1 cord blood bank.

	Link	Update	Status
CB banking specifics	WO- 1348	-	
CB operational specifics	WO- 1348	-	

WORLD MARROW DONOR DAY

Join us on Saturday, September 18th 2021 for our virtual celebration of World Marrow Donor Day.

Contact person for World Marrow Donor Day	
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INTERESTING WEBINARS TO SHARE:

Title	Weblink
World Marrow Donor Day 2019 Prize Winners	https://youtu.be/UGGVMGPeMTA
Global Trends Report 2018	https://youtu.be/ctCDXgQUNUk
Donor Selection	https://youtu.be/kl2tIAqRgPU
World Cord Blood Day	https://youtu.be/4-1EwK2BLzE
COVID-19 webinars	https://share.wmda.info/x/Yj6OF

PILLAR 3: DONOR CARE

In case there is a rapid alert, the WMDA will send out a notification to all registered medical directors. Your registry's medical director is:

Medical director	
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The following persons are registered as SEAR reporters: Matti Korhonen

REPORTS SUBMITTED BY WMDA:

	Reports submitted to WMDA	Reports in draft
Number of reports in 2018/2019/2020	2	1

INTERESTING WEBINARS TO SHARE:

Title	Weblink
Serious Adverse Events and Examples	https://youtu.be/wLzWbcHYoCQ
WMDA S(P)EAR Educational Webinar	https://youtu.be/ctCDXgQUNUk

PILLAR 4: QUALITY

WMDA ACCREDITATION PROGRAMME:

WMDA is maintaining an accreditation programme for registries. Being either WMDA certified, qualified or accredited is evidence that your registry is compliant with the WMDA Standards and international practices.

The status of your registry is:

	WMDA	Source	Status
Status	Qualified	Donor/Cord Blood	

KEY PERFORMANCE INDICATORS (KPIs)

		KPI 2019
1	High resolution requests performed <14 days	15
2	Blood samples shipped for CT < 14 days	96
3	Donor availability at CT stage	85
4	Donor availability at WU stage	87
5	Participation in HLA discrepancy survey	yes

INTERESTING WEBINARS TO SHARE:

Title	Weblink
Accreditation Program-Reviewer Update	https://youtu.be/6KhjbWH5K9o
WMDA IT Standards 2020	https://youtu.be/kEIJUZSPqb8
WMDA Standards 2020	https://youtu.be/M290V9DT0B0
Weekly 15 minutes webinars	https://share.wmda.info/x/QwlgFQ

WMDA is striving to keep information accurate for all members, in order to facilitate the search coordinators in their daily job and to assist the reviewers with their reviews.

If data are not correct, feel free to contact the WMDA office. We can make an appointment with you correct the data together.



MAIL@WMDA.INFO



+ 31 88 505 7900

References

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- ¹ Pustjens E, Foeken L. D3.1 Public webpages with cord blood banking practices. 2019 SAVDON, WP3, Grant Agreement number 837354.
- ² Pustjens E, Foeken L. D3.4 Webpages with information for organisations importing hematopoietic stem cells to EU Member States. 2019 SAVDON, WP3, Grant Agreement number 837354.
- ³ Schuit M, Foeken L. D2.2 Resources for registry operations for import/export to EU Member States. 2020 SAVDON, WP1 Grant Agreement number 881553.
- ⁴ Foeken L. D2.1 Report on 2020 unrelated stem cell transplants. 2021 SAVDON, WP1 Grant Agreement number 881553.
- ⁵ Database on WMDA Share platform for online collaboration and communication:
<https://share.wmda.info/x/4gdcAQ>
- ⁶ Operational Information ION-7414: <https://share.wmda.info/x/CxRcAQ>
- ⁷ Regulatory Survey ION-7414: <https://share.wmda.info/x/dQeOF>
- ⁸ Operational Information ION-1804: <https://share.wmda.info/x/AxNcAQ>
- ⁹ Regulatory Survey ION-1804: <https://share.wmda.info/x/BweOF>
- ¹⁰ Operational Information ION-2614: <https://share.wmda.info/x/GxJcAQ>
- ¹¹ Regulatory Survey ION-2614: <https://share.wmda.info/x/EweOF>
- ¹² CB banking specifics WO-1389: <https://share.wmda.info/x/ZimOF>
- ¹³ CBB operational specifics WO-1389: <https://share.wmda.info/x/aCmOF>