Search & Match Service Public Access

Search & Match Service provides a fast preliminary search facility to find the best suitable stem cell source in the world for a patient in need of a hematopoietic stem cell transplant.

Benefits of Search & Match Service:

- 'Search & Match Service' is the primary source of all hematopoietic stem cell donors and cord blood units globally
- 'Search & Match Service' holds over 40 million donors and over 800,000 cord blood units from 136 registries and cord blood banks from 55 countries
- 'Search & Match Service' helps the community find a donor as quickly as possible by providing:
  - **User friendly** interface and functionalities
  - **Probability matching** for each donor/cord
  - **Additional information** on each donor and cord blood unit (if provided by organisation)

Future directions of Search & Match Service - Search, Match & Connect

The WMDA has published a Vision and Operational plan on milestones that WMDA would like to achieve in the next years. You can download here the vision document outlining how to make the search process less administrative for search coordinators. Based on the feedback of the community, find here the most frequently asked questions and their response:

Does Search, Match & Connect mean that WMDA is becoming an IT company?	Not at all. WMDA does not have the desire nor the capacity or skills to create and sell software. The primary objective of the vision of Search, Match & Connect is to democratize access to global donor information by making communication easier, safer and better functioning between registries. WMDA is an association with a duty to facilitate the best and most open ways for its members to match donors to patients. Part of WMDA's role is to seek to identify gaps and capture demand for how the global search and match process may be optimised, including through the use of modern technologies. This also includes translating ideas into how such technologies can be developed as practical solution options. WMDA works on specific projects with a range of specialist software developers that have the knowledge and expertise to create solutions that may benefit to members should they choose to adopt them. We believe that the capabilities that will be offered by Search, Match & Connect will be attractive to many organisations and there is no mandate or compulsion for registries to use them. Furthermore, registries will be responsible for implementing the Connect solution into their own systems if they would like to take advantage of the benefits. WMDA will organise educational webinars for IT specialists to explain how they can implement the APIs into their registry management systems. As has been the case with many WMDA initiatives – for example, the implementation of the XML file format – we will provide basic support to all member organisations as needed.
Will EMDIS become obsolete?	No. The vision of Search, Match & Connect intends to help keep EMDIS relevant and to support the EMDIS community to be able to reach **more** organisations quickly and with less overhead on set-up and maintenance. Far from representing a competing solution, the vision of Search, Match & Connect will help to reduce the barrier to new registries joining the existing EMDIS network: instead of setting up peer-to-peer connections to every existing registry only a single WMDA connection would be needed. In the long term, Search, Match & Connect will help to provide a 'translation' layer between different versions of the EMDIS specification to help them move towards EMDIS 4.0 and to preserve backward compatibility. **By better integration of Search, Match & Connect and EMDIS capabilities we aim to get the best of both worlds and to create a sustainable solution for all registries.** Whilst the vast majority of Search, Match & Connect project team members are active EMDIS users we recognise that strengthening communication with the EMDIS community can only be beneficial. The Search, Match & Connect Board Committee has now increased representative EMDIS participation by inviting the Vice-Chair of the EMDIS User Group to join the Chairs of the EMDIS User Group and EMDIS Technical Group on the Board Committee and by establishing a liaison between EMDIS and the Search, Match & Connect project team.

Useful pages

Search & Match Service User Guide

Upload data - data schemes

Search &Match Service release notes

Connect

Meeting notes (only for WMDA Members)

How will registries integrate to Search, Match & Connect and what will be the implications?	As the project progresses, we aim to work closely with a small number of representative registries (e.g. a large EMDIS registry; a small EMDIS registry; a non-EMDIS registry and a new member registry) to help ensure a rounded set of solution options. We will build user cases from each of these perspectives and provide support materials suited to each to support integration to Search, Match & Connect. Because of the diversity of local systems and processes currently in use across the membership, it is very difficult to accurately forecast the effort that will be required for each organisation to adopt Search, Match & Connect. WMDA aims to deliver the API options with minimal disruption and with no forced timelines for implementation meaning that registries can plan according to their priorities and resource availability. • EMDIS registries will have to set up one single connection with the EMDIS proxy. Apart from this change, there will be a minor impact on current registry operations and the designated person will be authorised to decide on the business relationships. • Non-EMIDS registries will have to set up an API connection to Connect, which requires careful mapping of data definitions to be sure that they are aligned with the EMDIS data dictionary. WMDA will assist them with a step-by-step plan and connect them with software vendors that can help them. Our working assumption – based on member feedback - is that most organisations will wish to connect to Search, Match & Connect directly from their registry management solution. If demand dictates, WMDA will provide both basic functionality on the WMDA Search & Match web-site and invest in basic connectors (for example to MS-Excel) for those that do not have any in-house capability. We will also continue to work with Steiner Ltd. (and any other relevant software vendors) to help small and new entrant organisations to build their IT capability. **An EMDIS registry planning to upgrade its internal registry software should take into account the new developments as part of the architectural design of its registry software.** WMDA aims to make available the capability to request confirmatory typing/ extended typing via Search, Match & Connect by the end of 2020. The journey will start in 2020 to define work up definitions, which can be made available in 2021.
Will the role of registries be undermined by the developments of Search, Match & Connect?	Some registries are worried that they will become redundant and that transplant centres will become fully self-service through access to Search, Match & Connect. The Connect solution will address this by mandating that potentially interested transplant centres will have to work through an ‘assigned broker’. The transplant centre can search in Search & Match and transfer their data with a simple click to the registry which will then provide specialist value-added services to progress through the donor provision process.
How will I keep control of my registry’s relationships with other organisations?	Search, Match & Connect will ensure that registries get improved responsibility for keeping control over their connections to other business partners. A user-friendly ‘dashboard’ will be implemented to allow designated registry users to define and control communication settings. For example, if registry A is consistently not paying their invoices, registry B can stop their business connection with a simple click. Besides, a communication matrix will be visible to members on the WMDA Share site in which all registries can see how communication protocols are set across all members.

The technical details proposed are quite broad and not specified in detail.	The WMDA Search, Match & Connect Vision and Operational Plan sets the overall direction rather than attempting to define all the details. Refining the detailed specifications and plans will continue to be the responsibility of the project delivery team and will be subject to approval by the governance groups at the appropriate points in the project life-cycle. WMDA is keen to include perspectives so please do volunteer if you feel you can contribute to the development of the technical requirements. To date, the WMDA has gone through a long journey to explore solution options that pose minimal risk to members. Some elements of the proposed high-level solution have been tested and are already operational and compliant with EMDIS in a large registry. This means that major aspects of the development work are complete and proven. The next step is to adjust the solution to the WMDA needs, which will require about six months of development work. We will use the 2020 EU Grant funding for this project. Search, Match & Connect is predicated on registries being able to rely upon as a 'single source of truth' which means that data quality is of key importance. Benefits will be created for organisations that upload their data regularly. The Search & Match Service will provide information about when the last update has been received. Besides, the NMDP will use a copy of the Search & Match Service for their upfront search soon. This means that registries only have to exchange their donor data with a single connection to be visible in all searches globally. Bi-lateral exchange of data or special data hubs will continue to serve a purpose for some organisations but will not be a pre-requisite for the global search process.
Can you explain more about the EU Grant funding and what this will pay for?	The EU Operational Grant covers work across WMDA. The WMDA will use the grant to speed up projects that usually take longer. For example, the development of the new SEAR/SPEAR system and the certification of our accreditation programme. A part of the funding will be used for the development of Search, Match & Connect. The relevant milestones defined for the grant are as follows: • 2018: the implementation of the XML file format • 2019: the implementation of GRID and the development of the vision • 2020: the realization of Connect: Confirmatory typing/ extended typing request • 2021: the realization of Connect: Work up request One of the conditions of the grant for 2019 is for the WMDA to seek membership input and consultation for the plans to be developed in 2020 and 2021. We are confident that the **development costs of the Search, Match & Connect capabilities will be fully met by the EU grant.**
How will Search, Match & Connect be supported and maintained in the long-term? Should members expect their fees to rise?	The maintenance costs are an important consideration in how we are working with technical experts to design the project. The design principles will help ensure that the costs of hosting and maintenance of the APIs are kept as low as possible. The messaging system, which is needed to facilitate the AMQP (Advanced Message Queuing Protocol) messages between organisations, will require 1 IT full-time equivalent (FTE) support post. This post will be provided directly within the WMDA office team. Please note that the 1 FTE cost is already currently covered in the membership fees. The hosting and support arrangements should **not** lead to increased member fees but this will be partly dependent on the levels of service and support that the membership at large request (e.g. immediate service fail-over versus recovery in x hours). Options for the detailed service support levels are currently being developed under the guidance of the Project Steering Group and will be published for member consultation soon. **WMDA does not expect membership fees to increase as a result of Search, Match & Connect for at least 3 years ending 2022** (besides inflation correction).

Do you anticipate any issues with GDPR or data security?	The move to a single source of truth for donor searches gives more control and assurance to registries from a GDPR standpoint. WMDA is exploring the practice of operating its services from the Microsoft Azure cloud environment, based in Europe. Migration to the cloud offers several benefits to WMDA and its members. These include the following: • Standardisation and consolidation of hosting will lower the costs compared to a continuation of dedicated infrastructure in local data centres; • Cloud service providers are making significant investments in cyber-security that is generally not feasible for 'on-premises' systems. Gartner predicts that through 2020, services on public cloud infrastructure will suffer at least 60% fewer security incidents than those in traditional data centres; • Cloud providers achieve very high levels of redundancy in their environments and provide a wide array of options to improve system resilience and can address data sovereignty issues. By choosing a good mix of service options (what is an acceptable downtime, disaster recovery plan, security risks, data loss and leakage prevention), WMDA can work towards a robust solution within the current budget limits. This may also help the AMQP messaging solution of EMDIS. In contract negotiations, the WMDA will strive that the accountability of data security will be on the side of the cloud provider.
I don't feel that the WMDA is being transparent in the running of Search, Match & Connect: how do I know my interests are represented and how do I hear feedback?	The initial thoughts and plans for Search, Match & Connect were presented and debated in WMDA forums dating back to 2017 (including, for example, at the WMDA Open Meetings in Marseille, Minneapolis, Munich and Noordwijk) with regular updates and calls for participation in Stem Cell Matters and member surveys. More recently, a short newsletter called Connect has been launched by WMDA that focusses exclusively on Search, Match & Connect. The **Search, Match & Connect Board Committee** has had this project on the agenda of its monthly meeting for some 18 months. Moving forward, the status of the project and issues for escalation will be raised formally at each monthly meeting. Senior registry personnel representing all relevant working groups and committees sit on the Search, Match & Connect Board Committee and have a direct influence on decision making. The **Search, Match & Connect Board Committee** is made up as follows:

Committee Co-Chair	Mike McCullough	NMDP
Committee Co-Chair & EMDIS representative	Matti Korhonen	Finnish BMDR
Executive Director WMDA	Lydia Foeken	WMDA
Bioinformatics	Hans-Peter Eberhard	ZKRD
Data Dictionary Group	Ying Li	BBMR
Security & Privacy W/G	Virgilio Cervantes	Anthony Nolan
Project support	Alicia Venter	WMDA
Match-Connect Steering Committee	Julia Pingel	DKMS

Each of the Board Committee members have an equal say in steering the direction of the project and are expected to bring the views and feedback of their constituent group to the table. Likewise, committee members are to be assumed to present relevant feedback to their groups. The notes of each Committee meeting are open to all members on the WMDA Share site (https://share.wmda.info/x/XwcjF). If you can't find what you're looking for or don't feel you are getting the updates from your relevant Board Committee member(s), then please do not hesitate to contact the project team direct via the WMDA office as they'll be delighted to discuss things in detail.

Technical assurance and approval of the technical designs for Match-Connect is now the remit of the **Match-Connect Steering Committee**.
This group is comprised of experienced members who represent the interests of technical staff and users. They are as follows:

Committee Chair	Julia Pingel	DKMS
Committee Chair-elect	Hans-Peter Eberhard	ZKRD
Technical	Luke Neal	Anthony Nolan

Technical	Bertjan Nijhuis	Matchis
User	Simona Pollichieni	Italian BMDR
User	Deepa Mallapareddy	NMDP
Consultant	Albert Mustafin	Steiner Ltd.
Product Owner	Mark Melchers	WMDA
Pillar Coordinator and admin support	Alicia Venter	WMDA

How will the impact of Search, Match & Connect be determined and what measures will be used?	Establishing relevant KPIs to evaluate the success of Search, Match & Connect is currently in progress. It is envisaged that KPIs should, where possible, be aligned to the existing WMDA KPIs. They also need to capture less quantifiable benefits. As soon as the proposed KPIs have been identified and approved by the Board Committee, we will benchmark current performance and establish a plan on how to track progress over time. A periodic user satisfaction survey may be useful to track users' experiences.