



**EB Research Network's
Terms of Reference (ToR)**

December 2021

Content

1.	About EB Resnet	2
2.	EB Resnet Strategy (separate strategy paper available).....	2
2.1.	Our mission	2
2.2.	Strategic aims	3
2.3.	Activity plan	3
3.	EB Resnet's Funding Schemes	4
3.1.	Project scope 'Research grants'	4
3.2.	Project scope 'Ad-hoc grants'	4
3.3.	Project scope 'Industry co-funding'	4
4.	Grant management	5
4.1.	Grant Tracker	5
4.2.	Planning & Timing	5
4.3.	Reviewing Process & Decision making.....	6
4.4.	Terms & conditions (T&C) EB Resnet member	7
4.5.	Contracting.....	7
4.6.	Reporting.....	8
5.	Knowledge-sharing platform	8
6.	Translational research	8
7.	Members & Partners	8
7.1.	Funding Member	8
7.2.	Ordinary member	8
7.3.	Partner	9
7.4.	Strategic partner	9
7.5.	Membership & Partnership	9
7.6.	Funding commitments from members/ partners.....	9
8.	Managing team & structure	10
8.1.	Managing team.....	10
8.2.	EB Resnet meetings.....	11
8.3.	Finances.....	11
8.4.	Annual reviews	11
8.5.	Workstreams	11
9.	EB Resnet Website www.eb-researchnetwork.org	12

1. About EB Resnet

EB Resnet is a network of EB patient organisations actively funding EB research and partnering to drive its translation to clinical benefit. It has no legal status as an organisation – DEBRA Austria initiated the network in 2019.

The idea was to provide a platform for various EB patient groups, not only DEBRA groups, to cooperate and collaborate on supporting research, exchange knowledge, display EB research projects worldwide, and discuss the current EB research situation and challenges. The network focuses on EB research and addresses related topics that impact research and its clinical translation.

EB Resnet provides three funding schemes ranging from basic research to clinical trials in phase 1/2. The network is resourced through its member organisations and partners.

The main advantages of being part of this network are:

- ✧ It is open to all EB research-active organisations
- ✧ It provides a single hub for peer-reviewed EB research via its funding schemes
- ✧ High-quality reactive and proactive processes to support excellent EB research to address unmet needs
- ✧ The clarity for researchers & partners – EB Resnet is focussing on EB research
- ✧ Combine resources to fund larger-scale clinical development
- ✧ Collaboration with industry partners
- ✧ Coordinated access to patient organisation funding resources
- ✧ ,One-stop shop‘ for patient perspectives, disease information (due to network partners like DI, EB Clinet, etc.)
- ✧ Multiple funding models (for researchers, for industry, for clinicians, and consortia)
- ✧ Communication channel: EB Resnet website: www.eb-researchnetwork.org

2. EB Resnet Strategy (separate strategy paper available)

2.1. Our mission

Translating successful research for patient benefit.

EB Resnet’s mission focuses on supporting and promoting EB research and working together with like-minded organisations and individuals to drive research outcomes into clinical application for patient benefit. The ultimate goal is to ensure that research will benefit the estimated 500,000 people living with EB worldwide.

EB Resnet’s strategic aims are determined primarily by the unmet needs of patients, identified by both clinicians and people with EB. The feasibility of addressing these unmet needs through research, and the likelihood of translating research outputs into affordable treatments, also guide prioritisation of the support of particular research areas.

2.2. Strategic aims

The three key aims of EB Resnet's strategy are:

- ✧ Prioritise and support patient-centered research to develop effective and safe treatments
- ✧ Work in partnership to expand research capacity
- ✧ Drive clinical translation and adoption of treatments internationally

2.3. Activity plan

EB Resnet members are providing funding for excellent peer-reviewed research

- ✧ EB Resnet offers three different funding schemes:
 - Research grants: up to two research calls annually – either All Priorities (across all EB Resnet research priorities) or Special Call (focused on priority unmet need)
 - Ad-hoc grants, to respond to specific opportunities not met by annual calls
 - Co-funding for industry collaboration
- ✧ EB Resnet offers funding for basic research into disease mechanisms and clinical consequences, through to preclinical research and clinical trials up to phase 1/2
- ✧ EB Resnet funds researchers, clinicians worldwide, and collaborations with industry partners, and academic-industry consortia that meet funding-scheme requirements and priorities.
- ✧ EB Resnet provides information on relevant third-party funding opportunities for EB research.

EB Resnet provides an overview of what EB research has been funded and what is currently in the pipeline

- ✧ Research communications have a high priority. EB Resnet aims to convey the current status of EB research and give an overview of the most critical challenges & opportunities.
- ✧ EB Resnet provides a growing database of EB research projects (funded by EB Resnet members and others); completed and ongoing projects are included.
- ✧ Opportunities to exchange knowledge and clinical experience internationally with EB experts: research conferences and Expert-Panel workshops on unmet clinical and research needs

Approach industry partners/ academic partners for translational research

- ✧ Sharing know-how with industry to enhance research-study and clinical-trial design- information on EB and its clinical consequences, patient perspectives, and facilitating patient access to trials.
- ✧ Consultations or workshops (online or in-person) with an industry panel to identify priorities and actions
- ✧ Search for strategic partners for joint initiatives
- ✧ Provide expertise and co-funding for potential industry collaborations

3. EB Resnet's Funding Schemes

EB Resnet coordinates research funding on behalf of its member patient organisations and partners.

EB Resnet welcomes proposals for innovative research and clinical development of treatments or diagnostics. All submissions are evaluated for scientific excellence, feasibility, and value for money, and whether they address the priority needs of people with EB.

We undertake peer review to ensure that only the best research is funded (see Grant management).

Its member organisations and partners resource EB Resnet.

Each funding member, ordinary member, and partner will be asked for funding capacities for at least the following 12 months to plan the budget for research grant calls. There is also the opportunity to bring in funds after completing a funding round for recommended projects. Ad-hoc and co-funding schemes are resourced on a case-by-case approach.

3.1. Project scope 'Research grants'

- ✧ Fundamental to preclinical research and clinical trials projects in EB
- ✧ Research projects must fall into the scope of a current research call, either an 'All priorities call or a 'Special call,' i.g. Chronic inflammation and fibrosis
- ✧ Lead applicant: researchers and/ or clinicians (cooperation with industry welcome and possible)
- ✧ Project duration: 6 to 36 months
- ✧ Funding: up to EUR 90.000,00 p.a.

3.2. Project scope 'Ad-hoc grants'

- ✧ Fundamental to clinical research projects in EB
- ✧ Quick funding/ co-funding to respond to an arising opportunity in fundamental to preclinical research or proof of concept project in EB.
- ✧ Lead applicant: researchers, clinicians, and/ or industry partners (cooperation with industry welcome and possible)
- ✧ Project duration: up to 12 months
- ✧ Funding: up to EUR 100.000,00 p.a.
- ✧ Only open if no Research grant round is available or timeline of co-funding opportunity differs

3.3. Project scope 'Industry co-funding'

- ✧ Translational research and treatment development for EB
- ✧ The project is at the stage of late preclinical research to clinical
- ✧ Lead applicant: industry partners
- ✧ Project duration: no limitations
- ✧ Funding: up to EUR 250.000,00

4. Grant management

4.1. Grant Tracker

DEBRA Austria contracted with CC Technology (providing the online tool ,Grant Tracker‘), an online grant management software tool. It facilitates the whole grant management process, from receiving the initial research proposal, through peer-review, to financial and progress management for the duration of the grant and follow-up of outcomes following grant completion. All research proposals must be submitted via this system provided via the EB Resnet website.

EB Resnet and its members are responsible for the grant management: at present, individual grants are made by a single grant-awarding member, which is then responsible for issuing a research-grant contract, and assuming all responsibility for managing the research grant and its outcomes. Currently, only Funding Members can have access to Grant Tracker (GT). If a funding member can assist in grant management, a separate access to the Grant management system may be negotiated with the EB Resnet management team and DEBRA Austria.

All funding schemes require that funding applications are made via the GT-Grant Management system. For research grants, the application process starts directly via Grant Tracker in the 'Research grants' section as soon as a research grant call is open. For Ad-hoc and Industry co-funding projects applicants should first contact EB Resnet by sending a general enquiry (letter of interest to office@eb-researchnetwork.org): further clarification or details of the proposal may be sought by EB Resnet, before an invitation to submit a full proposal is issued, at which point the applicant will be provided with a Grant Tracker registration link.

The applicant will be informed whether the submitted research proposal is eligible under one of the three available funding schemes. If so, we provide a link to our Grant Management online application form.

EB Resnet is planning and managing the grant rounds and decides with the funding members whether calls will be ,All Priorities Call‘ or a ,Special Call‘. If a Special Call is organised, the international community will be approached to seek advice. Special calls already were implemented, i.e. Chronic inflammation and fibrosis (CIF call).

The online application process and subsequent peer-review are subject to strict conditions of confidentiality. Following final approval of funding and the issue of contracts, limited details of funded projects will be published on the EB Resnet website and may be published in EB community newsletters; unsuccessful applications remain confidential.

4.2. Planning & Timing

Research grant calls are launched on the EB Resnet website – ideally communicated on all member websites and newsletter systems.

As far as the grant management process is concerned, some timelines should be acknowledged:

Usually, up to two research grant rounds are scheduled each year.

Spring call: opens in December/January, closes in March/April, and expert panel meeting is held in June

Autumn call: opens in June/July, closes in September, and expert panel meeting is held in November/December

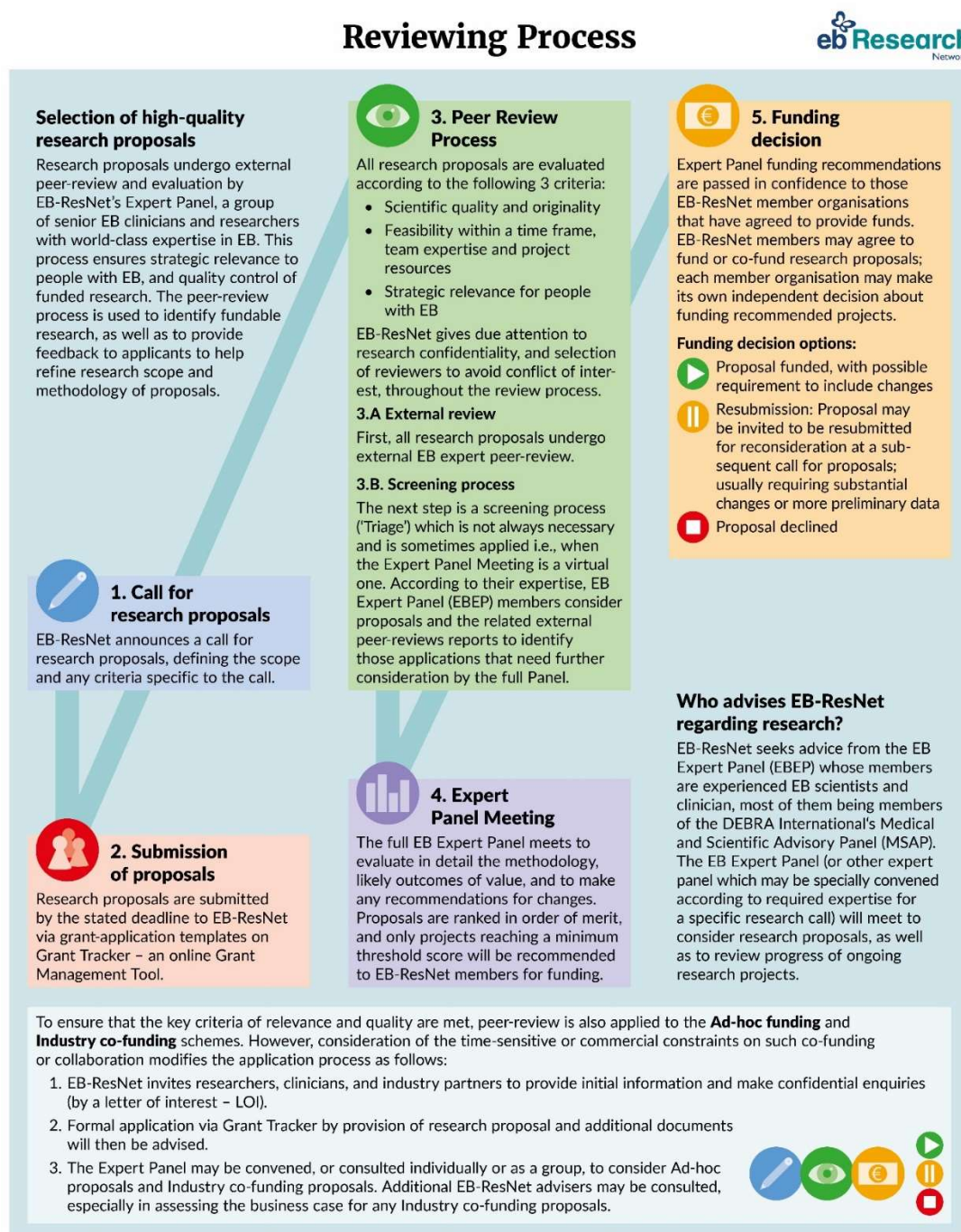
Reviewing takes a lot of time. We anticipate needing at least two months to find enough reviewers for all applications. Meeting places usually are either in London or in Vienna. In 2020 and 2021, the MSAP meetings took place as an online meeting due to Covid-19 Pandemic.

Contracting should not be finalised longer than three months after the funding decision was made.

4.3. Reviewing Process & Decision making

Members of the well established DEBRA International MSAP (Medical and Scientific Advisory Board) are crucial during the whole peer-reviewing process and form the so-called EB Expert Panel

See graphic explaining the reviewing process in detail:



4.4. Terms & conditions (T&C) EB Resnet member

All EB Resnet members are expected to adhere to the underlying principles and the general terms & conditions (T&C) for EB Resnet member grants they wish to cofund/ fund research projects. The T&C are an essential part of the funding agreement with the grant holder.

The [T&C](#) are provided by EB Resnet. Suppose minor amendments are needed owing to national regulations or charity statutes. In that case, this may be possible and is subject to negotiation with EB Resnet (and, where relevant, among co-funders) members. Currently, a major revision is done in cooperation with our strategic partner LifeArc.

The fundamental principles for this new document were:

- Achieve an appropriate revenue share of funded research;
- further consolidating our IP position as a funder;
- accelerating a path to clinical implementation

These T&C are only legally binding as soon as a funding member is contracting with an institution which happens only if the funding member is willing to take over at least 51% of the project budget. If so, this member is also responsible for the whole contracting process. See contracting.

General aspects:

- ✦ For applications from research consortia involving industry but led by an academic partner, additional side-agreements may be required.
- ✦ No funding of any overhead/ admin costs is eligible.
- ✦ The lead applicant must have a fixed contract at least for the project period - no salaries of PIs paid.
- ✦ Research has to be hypothesis-driven and meets at least one of the EB Resnet research priorities.
- ✦ We do not support service provision (i.e. clinical testing).

[Current version \(2021\) of Research Grants T&C](#)

4.5. Contracting

Decision making after funding recommendation provided by EBEP/ MSAP

All participating members taking part in a research call are encouraged to quick decision making after the reviewing process comes up with funding recommendations.

Ideally, applicants receive their approval/rejection information within three months after the MSAP, or Jury meeting was held.

Shared funding of peer-review projects

Shared funding is allowed but is not the preferred model of funding research projects. As far as research grants (call for proposals) are concerned, EB Resnet follows the idea to fund as many recommended (by EBEP/MSAP) projects as possible within the financial scope potential. A side agreement is reasonable and necessary if co-funding is needed to support one of the approved applications. One party must hold at least 51% of the funding to contract with the applicant.

Total funding is the preferred option.

Opt-out possibility if all recommended projects do not fit in the national strategy of a potential funding member organisation. This leads to a decline of high-ranked projects, which should not be favoured.

4.6. Reporting

Applicants will contract with the funding organisation. Only the contracting party will receive a reporting. If there is a side agreement for co-funding reporting will be shared with all funding bodies.

More about contracting can be found in the current T&C document which is available on the EB Resnet Website.

5. Knowledge-sharing platform

EB Resnet provides an overview of EB research projects worldwide and the challenges and difficulties being involved in doing EB research.

[EB research projects database \(Link\)](#)

Fundamental research into the biology of EB from the 1980s onwards has formed the basis for emerging diagnostics and concepts for therapy. Subsequent expansion of national EB patient organisations, including >50 DEBRAs worldwide, has created research support to create a depth and breadth of knowledge available for clinical translation.

EB Resnet continues to support excellent research worldwide, increase understanding of the causes and consequences of EB, and develop the evidence base for the development of better clinical care, diagnostics, and disease-modifying therapies for those with EB.

6. Translational research

- ✿ Sharing know-how with industry to enhance research-study and clinical-trial design-information on EB and its clinical consequences, patient perspectives, and facilitating patient access to trials.
- ✿ Consultations or workshops (online or in-person) with an industry panel to identify priorities and actions
- ✿ Search for strategic partners for joint initiatives
- ✿ Provide expertise and co-funding for potential industry collaborations

7. Members & Partners

Different types of membership/ partnership:

7.1. Funding Member

Funding members assist EB Resnet in managing and funding the grant schemes (at least 50,000.00 Euro funding contribution per call). Funding member status will be active for at least three years as soon as the funding member has contributed EUR 50,000 to fund at least three grant rounds. Suppose a funding member cannot contribute this minimum sum in the subsequent three years. In that case, their status becomes ,Ordinary Member‘ until such time as they are again able to contribute such funds.

Funding members are primarily EB patient groups active in EB research to support themselves, finding synergies and using EB Resnet for the benefits it provides in research-funding management, coordination, and communication with like-minded groups.

7.2. Ordinary member

Ordinary members are mainly EB patient groups active in promoting EB research, but which cannot contribute funding at the minimum level required of a funding member. They may promote their national research projects (should they fund such), and contribute small-scale research funding either annually or intermittently as resources allow to EB Resnet funding schemes.

7.3. Partner

Our partners are invited to push knowledge exchange in EB research (for researchers and industry). They share their research knowledge about EB, their current and completed EB projects and/ or EB patient access.

7.4. Strategic partner

Strategic partners help to drive research outcomes into clinical application for patient benefit. They provide expertise to help EB Resnet develop its strategy and activities and reach its goals. They support EB Resnet in framing interactions with other stakeholders, including regulatory authorities, healthcare providers, and manufacturers of devices, diagnostics, and therapeutics. Strategic partners assist in evaluating the existing portfolio of funded research for exploitable outputs and identify industry partners for development.

Partners and strategic partners may also appear as funding parties of EB Resnet funding channels.

7.5. Membership & Partnership

Membership is open to all EB support groups/ EB patient organisations that are legally constituted under the laws of their own country.

There is no membership fee. The partnership is open to all companies/entities legally constituted under the law of their own country having a relation to EB research.

Applications for EB Resnet membership/partnership has to be sent either via email to office@eb-researchnetwork.org or to

DEBRA Austria / EB Resnet

Am Heumarkt 27/1

1030 Vienne

Austria

Contacts: office@eb-researchnetwork.org

7.6. Funding commitments from members/ partners

Each member/ partner ideally states how much and if funding is available for the following 12 months (information has to reach EB Resnet office address by the end of September each year).

All members are allowed to indicate a preference for supporting particular research areas (e.g. cancer, or a specific type of EB) from their funding commitment but are discouraged from doing so. EB Resnet encourages all members to support research across all four identified EB Resnet research priorities, not solely their national priorities.

Members that provide support for any individual call for research proposals commit to funding the highest scoring research proposals (meeting the ,international‘ standard threshold) in order of highest score first, in preference to lower-scoring proposals (meeting the ,national‘ standard threshold). In addition, they agree not to fund proposals failing to meet the threshold scores for funding to meet the standards for scientific quality, value for money, and relevance to people with EB. (Further information on scoring of proposals: [MSAP/ EBEP Terms of Reference](#))

For Ad-hoc and industry co-funding, individual requests to national member groups will be sent out by EB Resnet management team.

The same research-priority criteria apply to ordinary members/partners/strategic partners if contributing funds.

8. Managing team & structure

Currently, EB Resnet is managed by the DEBRA Austria Research Team, which has initiated the network with the Head of Research for DEBRA International.

DEBRA Austria and DEBRA UK manage the Grant Tracker Software, while DEBRA Austria is the contracting party with Grant Tracker, and DEBRA UK is using the system by paying an annual fee.

8.1. Managing team

EB Resnet Research Management Committee (RMC) (suggestion – not active yet): Heads of research from all funding members form the research manager committee. Currently, DEBRA Austria’s and DEBRA UK’s and DEBRA Ireland’s heads of research would form part of this committee.

Currently, only DEBRA Austria is funding any research call, the Head of Research from DEBRA Austria is holding this position.

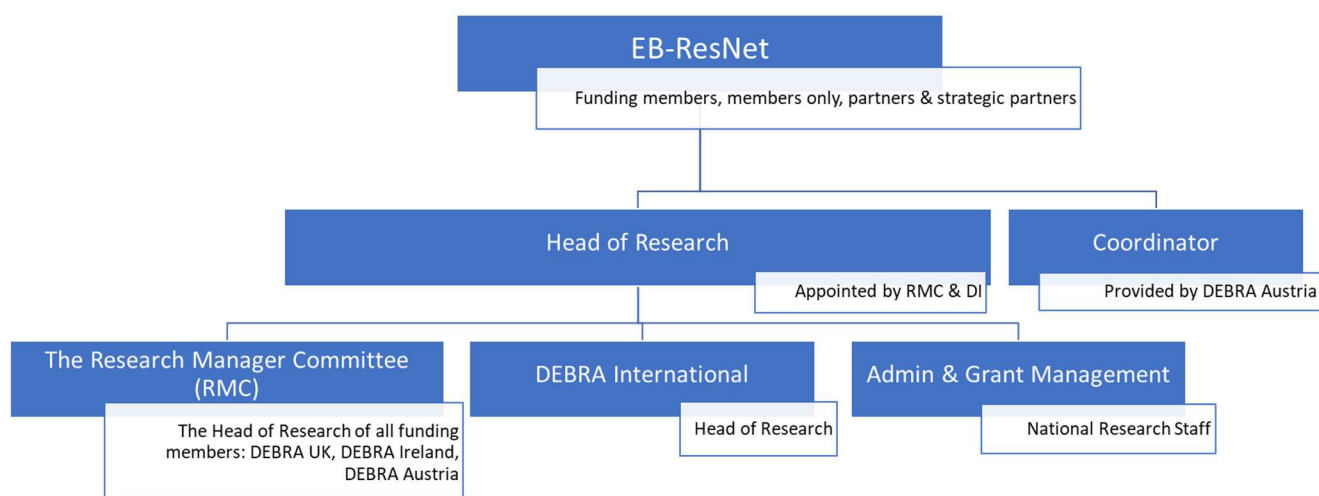
Those member groups taking part in the RMC are responsible for the research management and reviewing process and the development of the whole network.

Outlook: In the future, the RMC and DEBRA International Head of Research could appoint the Head of Research EB Resnet.

EB Resnet Coordination & Communication: the EB Resnet coordinator is responsible for coordination work for EB Resnet: Membership, partnerships, content management and development of the EB Resnet Website and Network.

DEBRA Austria is currently hosting and managing the EB Resnet website and is responsible for EB Resnet’s coordination and communication.

EB Resnet Research Administration & Grant Management: Those groups forming the research manager committee also have to commit a certain amount of resources for research administration and grant management by their local research staff.



8.2. EB Resnet meetings

As EB Resnet itself has no legal status as an organisation, general meetings are not mandatory. However, meetings, either online or, eventually, in person, for EB Resnet members/ partners on a regular basis are proposed.

8.3. Finances

Financial planning is crucial to ensure that sufficient funds are available for the three funding schemes. Where funds are restricted, 'All-Priority' calls will be prioritised. The EB Resnet Coordinator together with the EB Resnet Research Management Committee and the DI Head of Research is responsible for planning grant rounds and coordinating funding opportunities.

8.4. Annual reviews

EB Resnet anticipates the introduction of annual review of its activities at the appropriate time.

8.5. Workstreams

- ✦ Develop strategy and strategic aims (every 5 years)
 - RMC (Research Management Committee)
 - EBEP/MSAP
 - Strategic partners
 - DI Head of Research
- ✦ Funding schemes & grant rounds
 - Coordinator
 - RMC
 - DI Head of Research
 - Administration
- ✦ Reviewing process incl. Jury / MSAP meeting

- RMC
- Administration
- EBEP/MSAP
- DI Head of Research
- ✦ Grant Tracker: all application documents, reporting, stored there
 - RMC
 - Administration
- ✦ Managing & coordinating EBEP/MSAP
 - RMC & DI Head of Research
- ✦ Terms & Conditions for funding: Revision regularly
 - Coordinator
 - RMC
 - Life Arc (strategic partner)
- ✦ General admin & accounting: like award & rejection letters
 - Administration of the contracting party
 - Ideally, EB Resnet templates are used
- ✦ Membership
 - Coordinator
- ✦ EB Resnet communications
 - Coordinator

9. EB Resnet Website www.eb-researchnetwork.org

DEBRA Austria hosts and manages the EB Resnet Website.

All funding members have the right to be displayed on the EB Resnet website:

- Quick link on top of the pages
- Link in footer under 'DEBRA websites' – for DEBRA groups only
- Under Network & partners

Funding members, ordinary members, partners, and strategic partners are mentioned under Network & Partners and can provide a logo.

All members/partners are invited to share project details to be included on the EB Resnet Research project database. A 'project description' template is available via office@eb-researchnetwork.org.

EB Resnet is happy to share on its website relevant news articles of wider interest relating to EB research or clinical development that has been published on a national or international level. Please also contact office@eb-researchnetwork.org.

APPENDIX 1

Application form for EB Resnet membership/partnership

NAME OF NATIONAL GROUP/COMPANY

REGISTERED AS A NOT-FOR-PROFIT ORGANISATION UNDER NATIONAL LAW?

Yes

No

CONTACT DETAILS OF THE ORGANISATION

Address

Country

Telephone (landline)

Mobile phone

E-Mail

Website

NOMINATED REPRESENTATIVE (CEO, President, Chairman/woman, Research Manager)

Title (Mr / Ms / Mrs / Prof. / Dr.)

Surname

Forename(s)

MEMBERSHIP/PARTNERSHIP

Funding member	0
Ordinary member	0
Partner	0
Strategic partner	0

,Funding members‘ are willing to contribute to EB Resnet funding schemes by making substantial funding commitments of at least 50,000. Euro per call. The status as ,Funding member‘ is valid for at least three years after contributing once.

,Ordinary members‘ are invited to share their EB research knowledge and projects from their national countries. Small funding contributions are possible, and they can profit from the peer-reviewing process.

All members can use all materials free of charge on EB Resnet for their national support group but have to acknowledge EB Resnet as the source.

The above-named group/ company wants to apply for membership/partnership of EB Resnet. In doing so, the group/company confirms that it will conform with our Terms of Reference (for funding members and partners only) of EB Resnet.

I accept the personal data protection and processing policy and complete confidentiality (Appendix I).

Name and function (President, Manager, Treasurer, etc.) in capitals:

Signature:

Date:

Appendix 1

PERSONAL DATA PROTECTION & PROCESSING POLICY – for grant applications via EB Resnet



Grant applications and grant awards handed in via EB-Research Network are administered by DEBRA Austria (independent of if funding comes from DEBRA Austria or any other funding party), therefore the European General Data Protection Regulation (EU) 2018 applies to all PERSONAL DATA PROTECTION & PROCESSING:

- 1 This Policy document provides information on: (i) why and how DEBRA Austria (hereinafter 'DEBRA') collects personal data, (ii) which kinds of personal data are collected, (iii) how personal data are used, (iv) data security applied while processing personal data, and (v) the right of the Grantholder and Co-applicants to amend or erase his/her own personal data.
- 2 The protection of personal data is of the highest priority in DEBRA's work. DEBRA fulfils the current European General Data Protection Regulation (EU) 2018 and (because DEBRA Austria is a charity registered in Austria) also the Austrian *Datenschutzgesetz* and the *Telekommunikationsgesetz* (DSG 2018 and TKG 2003).
- 3 By applying for research funding via EB-Research Network (EB Resnet), and registering on the research-grant management system (currently provided by CC Technology and managed by DEBRA) the applicant is required to give following personal data and give consent to DEBRA for its use: Title, First Name, Middle name, Last name, Position, Department, Institution, Address, Telephone number, Email as well as other personal data included in the applicant application and CV details. DEBRA Austria requires these personal data for the fulfilment of its obligations under these terms, i.e. to assess your application and your eligibility for funding.
- 4 Security of the applicant's personal data transmission and processing is provided via the CC Technology (Grant Tracker) system. Data security is provided by the use of Secure HTTP (https in the URL visited to access the system), CC Technology being ISO 27001 Certified, and CC Grant Tracker Data Centre Partner being Certified.
- 5 DEBRA Austria needs to store and process personal data provided in accordance with Clause 3 and any other personal data provided by other means in order to be able to process grant applications and approve/monitor grants.
- 6 Research-grant application and any research reports, including personal data, will be forwarded to members of DEBRA International's MSAP (Medical and Scientific Advisory Panel), or other Expert Panel as appointed, as well as other expert reviewers. Panels and their members, and external reviewers, are required to use personal data for the purpose of reviewing and assessing research-grant application and research grant reports only. The Terms of Reference for MSAP explicitly require MSAP members to treat all content of research-grant applications and reports as confidential; external reviewers are similarly required to observe strict confidentiality in accordance with the accepted standards of academic peer-review. Should a research proposal be appropriate for co-funding by a third-party not currently an EB Resnet member, DEBRA Austria will, with the agreement of the applicant, forward the proposal to such organisations for their independent assessment.
- 7 Whether or not an applicant's research-grant application is successful, DEBRA retains the applicant's data to have a clear history of all applications, and to facilitate assessment of the applicant's possible future applications, including any resubmitted applications. Should grant award offer be made, DEBRA will also use the personal data for correspondence with the Grantholder in relation to both research progress and

financial management of the award and, where relevant, for correspondence with third-party payment processors, and external partners contracted to assist DEBRA with IP management, contracting and licensing.

- 8 DEBRA may also use a Grantholder's personal data:
 - 8.1 to communicate with other offices and employees of the Recipient (for example, finance or grant-management offices, or technology transfer services), but only to the extent necessary for DEBRA to manage the Grant and the Results;
 - 8.2 to communicate with the Grantholder about DEBRA events, initiatives, funding opportunities, working groups, or to invite the Grantholder to meetings or to speak or otherwise participate in DEBRA-associated conferences, or to respond to any requests or queries the Grantholder sends to DEBRA.
- 9 For the majority of the time, DEBRA will not share the Grantholder's personal data with any other organisations. However, on occasions where DEBRA either runs a joint event with another organisation, or where it enlists the services of event organisers or other service providers, DEBRA may share information such as the Grantholder's name, email address, employer's name and any special dietary or accessibility requirements, only for that event, and only to the extent required.
- 10 DEBRA may also share personal information provided by applicants:
 - 10.1 to comply with legal or regulatory requirements and to respond to lawful requests, court orders and legal process.
 - 10.2 to enforce its rights, prevent fraud and for safety: to protect and defend the rights, property, or safety of DEBRA or third parties, including enforcing contracts or policies, or in connection with investigating and preventing fraud.
- 11 The Grantholder and Co-applicants each have the right to request access to his or her own individual personal data as well as data in relation to their grant applications, and to request from us such data held in a structured, commonly used and machine-readable format. You also have the right to amend your data (either to update or correct inaccuracies), or to remove particular items of data, though you should bear in mind that some data are essential to our management of a grant or other communications with you. In certain cases, you may request that the processing of your data is restricted. After your data are no longer needed for the defined purposes, you may request that your data are deleted. Should you believe your rights have been infringed, you have a right to submit a complaint with the competent data protection authority (in Austria: *Datenschutzbehörde*).
- 12 CC Technology may derive and collect aggregate or other non-personal data from the use of the Services for product improvement, analytical, reporting and research purposes, which may involve the Processing of Personal Information. CC Technology will ensure that the results of this Processing do not identify DEBRA's or any applicant's data and that all such Processing is subject to appropriate technical and organizational measures.