



# MGBase Scientific Leadership Group (SLG)

## Terms of Reference

A special SLG committee of the MSBase Foundation Limited

### 1 INTRODUCTION

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- a. The MGBase Scientific Leadership Group (the MG-SLG) is a self-constituting special committee of the MSBase Foundation Limited (MSBase).
- b. The MSBase Foundation is a charitable organisation incorporated as a company limited by guarantee in Australia. The MG-SLG is accountable to the MSBase Foundation's Board of Directors and the MSBase Scientific Leadership Group (MSBase-SLG).
- c. The MG-SLG is governed by, and will function according to these Terms of Reference (TOR). The overarching governance documents of the MSBase Board of Directors and MSBase-SLG are applicable to the MG-SLG and should be regularly referred and adhered to. The Terms and Conditions contained within the MSBase Foundation's Participation Agreement for MSBase Members also apply to MGBase Members and must be adhered to at all times.

### 2 PURPOSE

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#### 2.1 The purpose of the MGBase SLG is to:

- a. Determine the MGBase strategic priorities and formulate these into a strategic plan.
- b. Work toward achieving the objectives outlined in the strategic plan.
- c. Monitor the progress of the strategic plan and provide progress update reports.
- d. Act as the data custodians of the pseudonymised MGBase dataset stored on the Foundation's database(s).
- e. Advise the MSBase Board of Directors and MSBase SLG with respect to medical and scientific updates and news in MG.
- f. Advise the MSBase Board of Directors and MSBase SLG with respect to the clinical value of the MGBase Data-collection Software and the MGBase Registry platform and website from the perspective of a MGBase neurologist/member.
- g. Lead on matters relating to the MGBase Registry's research projects, studies and activities.
- h. Make recommendations to the MSBase Board of Directors with respect to financing MGBase Registry activities and projects that promote the objects of the MSBase Foundation (*refer MSBase Foundation Constitution*).
- i. Provide and/or comanage the MGBase Registry content that is hosted on the Foundation's platform.

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- j. Project a positive image, facilitate cohesion and promote the Mission, Vision and Values of the MSBase Foundation.

### **3 POWERS OF THE MGBASE SLG AS A SPECIAL COMMITTEE TO THE MSBASE BOARD OF DIRECTORS**

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- a. The MG-SLG is a special scientific advisory committee, however it may be empowered to carry out certain functions as delegated by the Board of Directors.
- b. Delegated duties will be maintained in the MSBase [Delegations of Authority Policy](#).
- c. Purchasing decisions must be approved by the MSBase Managing Director and made with the assistance of the Operations Team.
- d. All contracts and agreements must be executed by the MSBase Board of Directors.
- e. The MG-SLG may form subcommittees with the approval of the Board, as required to efficiently discharge its role.

### **4 RELATIONSHIP BETWEEN THE MGBASE SLG AND THE MSBASE BOARD OF DIRECTORS**

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- a. The Board of Directors have overarching authority and the MG-SLG are accountable to the Board at all times.
- b. The Chair and Deputy Chair, or other members of the MG-SLG may be invited to join Board meetings as a guest from time to time
- c. The MGBase SLG must seek board approval for all funding requests and contracts, and final execution must be in accordance with the MSBase of Delegations of Authority Policy (i.e. the Managing Director, or another delegated member of the Board will execute the contract).
- d. The MG-SLG strategic plan must be reviewed and approved by the Board

### **5 RELATIONSHIP BETWEEN THE MGBASE SLG AND THE MSBASE SLG**

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- a. MG-SLG members may be invited to attend MSBase SLG meetings from time to time.
- b. If the MGBase Registry members wish to apply for statistical support services, they must apply through the MSBase SLG.
- c. The MG-SLG must adhere to the SLG Regulations at all times.
- d. The MG-SLG can recommend review and amendment to MSBase policy by way of request to the MSBase Board or the MSBase SLG.

## **6 RELATIONSHIP BETWEEN THE MGBASE SLG AND THE MSBASE OPERATIONS TEAM**

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- a. The MSBase Operations Team will provide administrative support to the MGBase SLG.
- b. Duties of the Operations Team include but will not be limited to:
  - i Plan, host, attend and provide mentorship at MG-SLG meetings
  - ii Document and distribute minutes and action lists
  - iii Assist in the development of key documentation including MGBase SLG Terms of Reference, Strategic Plan, and policies and procedures.
  - iv Co-manage the MGBase email correspondence and account
  - v Perform general office administration duties as required

## **7 RESPONSIBILITIES OF THE MGBASE SLG**

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### **7.1 The responsibilities of the MG-SLG are to:**

- a. Set the three-year strategic plan for the MGBase Registry, and monitor its progress.
- a. Actively promote and participate in the MGBase Registry and always act in the Foundation's best interests regardless of personal position, circumstances, or affiliation.
- b. Monitor all MGBase Registry research activities and supervise the general conduct of the registry.
- c. Review and approve/decline data requests
- d. Advise on sub-studies and sub-study requests via the MSBase Operations Team
- e. Review and advise on the membership rules of the registry in line with the Membership Policy of the MSBase Foundation and the Governance Framework.
- f. Review and stay abreast on the privacy rules for patient data documented within the MSBase Participation Agreement.
- g. Recommend future research proposals and recommend publication policy for composite data.
- h. Take all reasonable steps to ensure credibility and integrity of the database.
- i. Act as the standing Steering Committee for investigator initiated sponsored sub-studies.
- j. Actively facilitate collaboration between centres participating in any study.
- k. Secure ongoing financial support from the MSBase Foundation and/or external organisations, noting clause 4d, with review and approval/decline by the MSBase Board of Directors.
- l. Ensure all applicable Policy and Procedures are understood and followed.

## **8 MEMBERSHIP**

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### **8.1 Number of members**

- a. The minimum number of members is 4.
- b. There is no maximum number of members.

### **8.2 Composition**

- a. All members, including the chairperson of the SLG, must be selected among healthcare professionals, scientists and/or people with MG (patient representation)
- b. Patient representatives considered for SLG membership will follow the same membership nomination process as outlined in clause 9.
- c. Membership of the SLG is managed and approved by the existing members of the group.
- d. The MG-SLG must establish and maintain a register of its members which will be listed on the MGBase website [www.mgbase.org](http://www.mgbase.org)

### **8.3 New members**

- a. Nominations for new members should be written and addressed to the Chair and Co-chair, explaining why the nominee would be a valuable addition to the SLG. Their CV should also accompany this endorsement. Once approval has been granted by the Chair and Co-chair, the nominee's CV and nomination from the endorsing SLG member will be circulated to the committee for their consideration and vote.
- b. New members can be elected by two thirds majority vote by circular (email) resolution. Any member of the SLG can call for a deferral of the vote and request discussion of the nomination at the next scheduled SLG meeting where a further vote will be called.
- c. All members are required to complete a Conflicts of Interest (COI) Disclosure Form annually to be reviewed by the Chair and deputy chair of the MG-SLG and coordinated by the MSBase Operations Team.

### **8.4 Term of appointment**

- a. Members of the SLG are appointed for a two-year period. Members can continue their membership following the two-year period on notification to the Foundation through the SLG. Member commencement and retirement dates are recorded in a MG-SLG member register.
- e. At the beginning of each term, members will be emailed to confirm ongoing commitment to MG-SLG membership and agree to the Terms of Reference.

### **8.5 Named officers of the MGBase SLG**

#### Chair/Co-chair

- a. The chairperson shall lead the SLG and chair each meeting.
- b. In their absence, a meeting shall be chaired by the co-chair.

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- c. The chairperson shall be appointed for a two-year period, at which time, the position can be reviewed for re-appointment of chair, co-chair, or active SLG member.
- d. The chairperson can be re-elected to a second two-year term.

#### **Deputy chair**

- a. The deputy chair is the chair-elect of the SLG and may replace the chair in his/her position after two years.
- b. The deputy chair shall be appointed for a two-year term which will be reviewed for re-appointment of deputy chair or an active MG-SLG member.
- c. Upon this review, the deputy chair can be considered for the role of chairperson of the MG-SLG by the MG-SLG committee members.

#### **8.6 Election of Officers**

- a. All MG-SLG members may nominate for the position of co-chair or deputy chair when it becomes vacant, and for the position of chair if the co-chair or the deputy chair is unable or unwilling to fill the position. In case of multiple nominations, there will be a secret ballot of all MG-SLG members, conducted by the chair. The nominee with the most votes is appointed to the position. In case of a tie, the position will be decided by the drawing of lots.
- b. Members can nominate a proxy if they cannot attend a specific meeting. This proxy does have voting rights.

## **9 MEETING FREQUENCY**

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- a. The MG-SLG shall meet by teleconference 3-5 times a year and shall hold an extended face-to-face or virtual annual meeting. Meeting frequency for the coming year will be determined at the annual meeting.
- b. Members may nominate a proxy to attend the meeting on their behalf.
- c. Members (or their proxy) are expected to attend a minimum of 2/3 of the scheduled meetings.
- d. Meetings may be attended by invited non-voting experts.

## **10 VOTING**

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- a. Each member of the SLG has one vote.
- b. Voting may be conducted during meetings or via email.
- c. With the exception of the election and removal of members, all decisions shall be made by a majority of the votes cast. If requested by a member, the vote will be secret.
- d. All decisions of an SLG sub-committee shall be made by a majority of the votes cast. If requested by a member, the vote will be secret.

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- e. Members may nominate a proxy to attend the meeting on their behalf.
- f. Members (or their proxy) are expected to attend a minimum of 2/3 of the scheduled meetings.
- g. Meetings may be attended by invited non-voting experts

## **11 QUORUM**

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A quorum is defined as a minimum of ½ of all members.

## **12 REIMBURSEMENT**

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- a. The MSBase Foundation will aim to reimburse the SLG for all reasonable costs for travel and accommodation if approved in advance and the funding is available / budgeted for.

## **13 RELATIONS WITH EXTRENAL ORGANISATIONS**

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- a. In order to enhance the functionality or fulfil the mission of the MSBase Foundation, the MG-SLG is entitled to seek long-term relationships with external organisations or other groups.
- b. Any contractual relationships with external organisations must be executed by the Board of Directors.

## **14 AMENDMENT, MODIFICATION AND VARIATION**

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- a. Amendments may be put forth to the MGBase SLG committee either via email or at meetings for their consideration and vote.
- b. Amendments will be approved with at least 2/3 majority vote.
- c. Amendments must comply with the MSBase Foundation's Constitution and final approval must be granted by the MSBase Board of Directors.