The I-DSD Registry

Steering Committee Charter

Prepared By: FA, JB

Date: 11/6/12

A Purpose of the Steering Committee

Primary Functions

The primary function of the Steering Committee is to participate in the planning and oversight of the I-DSD Registry and to advise its project management group. The I-DSD Registry Steering Committee will monitor and review the project status, as well as provide suggestions on its future plans.

The Steering Committee provides a stabilizing influence so organizational concepts and directions are established and maintained with a visionary view. Members of the Steering Committee ensure I-DSD objectives are being adequately addressed and the project remains under control. In practice, these responsibilities are carried out by performing the following functions:

- Monitoring and review of the project at regular Steering Committee meetings once to twice per year;
- Providing assistance to the project when required;
- Reviewing project scope as emergent issues force changes to be considered, ensuring that scope aligns with that of the original aims and targets and key stakeholder groups;
- Resolving project conflicts and disputes, reconciling differences of opinion and approach;
- Formal review of project deliverables.

Ancillary Responsibilities

The Steering Committee is responsible for recommendations and guidance with respect to major project elements such as:

- Prioritization of future projects;
- Quality of deliverables as identified in the project task order;
- Review of schedule:
- Risk management strategies, ensuring that strategies to address potential threats to the project's success have been identified, estimated and approved, and that the threats are regularly reassessed;
- Project management.

B Steering Committee

Membership

The Steering Committee will consist of the following members:

| Name | Role | End of tenure |
|--------------------------|--------------------------------------|---------------|
| Prof. lan Ford | Chair | Oct 2016 |
| Prof. S. Faisal Ahmed | Project Lead | Oct 2016 |
| Dr Jillian Bryce | Project Manager | Oct 2016 |
| Dr. John Achermann | Research Partner UK | May 2015 |
| Prof. Olaf Hiort | Research Partner EU | Nov 2015 |
| Prof. David Sandberg | Research Partner USA | Nov 2014 |
| Prof. leuan Hughes | Clinical Partner UK | May 2014 |
| Prof. Feyza Darendeliler | Clinical Partner EU | May 2014 |
| Dr. Berenice B. Mendonca | Clinical Partner, South America | May 2015 |
| Prof. Claudia Wiesemann | Ethics Adviser | May 2015 |
| Ms. Ellie Magritte | Patient Support Group Representative | May 2015 |
| Dr. Martina Rodie | Co-Investigator | Oct 2016 |
| Prof. Richard Sinnott | Co-Investigator | Oct 2016 |
| Dr. Jipu Jiang | I-DSD developer | Oct 2016 |
| Dr. John Watt | GRID engineer | Oct 2016 |

- Members of the Steering Committee shall have a 2-3 year term
- A quorum will consist of a minimum of 50% of the members
- Initially, members will be approached by the I-DSD Registry management group
- Members will subsequently be selected through a call
- The call should specify the field of representation
- There will be a 6 week deadline for applications
- Applications shall be ranked by the Steering Committee

Role of a Steering Committee member

It is intended that the Steering Committee leverage the experiences, expertise, and insight of key individuals at organizations committed to building professionalism in project management. Steering Committee members are not directly responsible for managing project activities, but provide support and guidance for those who do. Thus, individually, Steering Committee members should:

- Understand the strategic implications and outcomes of initiatives being pursued through project outputs;
- Appreciate the significance of the project for some or all major stakeholders and represent their interests;
- Be genuinely interested in the initiative and be an advocate for broad support for the outcomes being pursued in the project;
- Have a broad understanding of project management issues and approach being adopted.

In practice, this means they:

- Review the status of the project;
- Ensure the project's outputs meet the requirements of the original proposal;
- Help balance conflicting priorities and resources;
- Provide guidance to the project team and users of the project's outputs;

- Consider ideas and issues raised;
- Check adherence of project activities to standards of best practice both within the organization and in a wider context;
- Foster positive communication outside of the Team regarding the project's progress and outcomes;

C Steering Committee Meetings

Meeting Schedule and Process

The Steering Committee will meet twice per year in the first year and then annually or as required to keep track of issues and the progress of the I-DSD Registry and on-going. The project manager will organise and schedule the meetings.

The project lead will prepare the Agenda for Steering Committee Meetings.

D Declaration of Acceptance

Declaration of Acceptance by Steering Committee Member:

Please sign below to confirm your acceptance of the Steering Committee Charter and return to the I-DSD Project Manager (details below)

| | Name: | Date: |
|------------|-----------|-------|
| | | |
| Signature: | Cignotura | |

Dr Jillian Bryce I-DSD Project Manager

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