

# NATURAL HISTORY STUDY (NHS) REGISTRY ADVISORY COMMITTEE CHARTER

## FORMAT FOR COMMITTEE CHARTER

|                              |   |
|------------------------------|---|
| <b>Role</b>                  | <p>A general statement of the committee's purpose or role should be set out. The role should be relevant to the work of the board.</p> <p><i>Example</i></p> <p>The role of the Natural History Study (NHS) Registry Committee is to advise [name of organization] on matters relating to the [name of project], including protocol development; governance structure; patient recruitment and retention; data management, sharing and analysis; and research collaborations.</p>   |
| <b>Responsibilities</b>      | <p>A specific list of activities the committee is to undertake, usually without detailing the process the committee is to follow.</p> <p><i>Example</i></p> <p>NHS Registry Committee responsibilities might include:</p> <ul style="list-style-type: none"><li>• Advise on the development and revisions to the study protocol</li><li>• Advise on data elements</li><li>• Advise on governance issues related to the study protocol</li><li>• Advise on patient recruitment and engagement</li><li>• Advise on data management, sharing and analysis</li><li>• Advise on research collaborations</li><li>• Advise on strategic direction of study</li></ul> |
| <b>Membership and Voting</b> | <p>Set out the number of appointed and <i>ex-officio</i> committee members, including whether they are voting or non-voting members.</p> <p><i>Example</i></p> <p>Voting members:</p> <ul style="list-style-type: none"><li>• Chair of the board</li><li>• At least four directors appointed by the board</li><li>• CEO as an <i>ex-officio</i> member</li></ul> <p>Non-voting member:</p> <ul style="list-style-type: none"><li>• Head of Research</li></ul>   |
| <b>Chair</b>                 | <p>Describe who the NHS Registry Committee chair will be.</p> <p><i>Example</i></p> <p>A member of the committee appointed by the board</p>   |

## FORMAT FOR COMMITTEE CHARTER (continued)

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| <b>Frequency of Meetings and Manner of Call</b> | <p>Specify if a minimum number of meetings must be held.</p> <p><i>Example</i></p> <p>At least quarterly at the call of the committee chair</p>   |
| <b>Quorum</b>                                   | <p>If there are non-board members on the committee, the quorum should reference the board members.</p> <p><i>Example</i></p> <p>51% of the committee members, provided a majority of those present are board members. -OR-</p> <p>51% of the members entitled to vote</p> |
| <b>Resources</b>                                | <p>Specify if a member of management is to be assigned to the committee as a resource and /or committee support.</p>  |
| <b>Reporting</b>                                | <p>Specify how the committee reports. It will usually be to the board, but a subcommittee may report to a committee.</p> <p><i>Example</i></p> <p>To the board</p>  |
| <b>Date of review</b>                           | <p>Note the date the committee reviews the document</p>   |