



sharing data · reducing disease

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WG07: MINIMUM CONTENT OF A COUNTRY SPECIFIC DATABASE

CHARTER

1. Name

1.1. The name of the Working Group shall be WG07: Minimum Content of a Country Specific Database.

2. Purpose

2.1. The Working Group shall produce an HVP Standard or Guideline that:

2.1.1. provides a list of the minimum data fields required to be included for each record in a Country Specific Database, that capture information about a variant, the patient it was found in and the phenotype of the patient;

2.1.2. provides guidance on the minimum level of activities and features that such a database and its accompanying webpage must perform or contain, for example regarding the collection of data and its curation, the description of legal, regulatory and ethical frameworks that the database is operating under.

3. Operations

3.1. The Working Group will operate in accordance with the Human Variome Project's Standards Development Process (see *PD06-2012: Standards Development Process*).

3.2. The initial scope of work for the Working Group is outlined in AP08: Minimum Content of a Country Specific Database.

3.3. The scope of work may be modified at any time by the Sponsoring Council. A request to modify the scope of work can be made in writing by the Chair of the Working Group to the Chair of the Sponsoring Council.

3.4. The Working Group is directed to work closely with WG03: Minimal content for gene variant databases (LSDBs), in recognition of the overlap between their two fields of competency.

4. Sponsoring Council

4.1. The International Confederation of Countries Advisory Council is the Sponsoring Council for this Working Group.

5. Duration

- 5.1. The Working Group shall have two (2) years from the date of its establishment to prepare and submit an Exposure Draft of an HVP Standard or Guideline.
- 5.2. The Working Group may be disbanded before the completion of two (2) years, pursuant to *PD06-2012: Standards Development Process*.

6. Membership

- 6.1. Membership of the Working Group is at the discretion of the Sponsoring Council and/or the Chair of the Working Group.
- 6.2. The Chair of the Working Group is Martina Witsch-Baumgartner (witsch-baumgartner@i-med.ac.at).
- 6.3. A quorum of 50% of Working Group members is required for all votes and meetings.
- 6.4. Decisions will be by consensus of the members present.
- 6.5. Individuals who are not members of the Working Group may be invited to attend meetings at the request of the Chair to provide advice and assistance where necessary. They shall have no voting rights and may be requested to leave the meeting at any time by the Chair.
- 6.6. Members will cease to be a member of the Working Group if they:
 - 6.6.1. resign from the Working Group; or
 - 6.6.2. fail to attend two (2) consecutive meetings without providing apologies to the Chair.

7. Meetings

- 7.1. The Working Group shall set its own meeting schedule at the discretion of the Chair.