DermReg Data Request Guideline

Application criteria and procedure

- 1. All application for release of data must be made in writing by completing DermReg Data Release Application Form along with other required documents where applicable (see below).
- 2. The application shall include the purpose for the data request and the data sought.
- 3. Release of data can be done depending of the type of data requested:
 - 3.1. **Published results** made available in the public domain (hardcopy or electronic reports) can be used freely for purpose of planning or business or other matters. No additional permission is needed but it is appreciated that the proper citation for these be quoted as advised in the respective documents

3.2. Unpublished aggregate data:

Request for scientific analyses that are otherwise not available in published results in the public domain for purpose of planning or business will be entertained on a case-by-case basis.

3.3. **Raw anonymised data for research**:

This requires submission of the research proposal that is written in English. While the proposal needs not follow any specific format, it should incorporate the following elements:

- Project Title
- Abstract of proposed research
- Detailed project description including rationale, objectives and methodologies to be used.
- Qualifications, disciplines and affiliations of key research personnel (If a student, a letter from the department chair or advisor stating that the applicant is a student working under the direction of the department)
- Current resume or curriculum vitae of the main applicant.
- Reference made to any regulatory and ethical requirements and procedures for safeguarding information security.
- The period of time for which the data would be used and the way in which the data (with all its copies) would be disposed of, returned or destroyed after this period has elapsed.

3.4. **Raw identifiable data**:

NO release of such data will be made to any party except to the source data provider (SDP) who is also the physician attending to the patient. Any request

for such data will be redirected to the SDP. This is because the DermReg is NOT authorized for such release.

- 4. The DermReg Data Release Committee evaluates proposals using the following criteria:
 - 4.1. Scientific and technical feasibility of the project
 - 4.2. Availability of resources at the DermReg office
 - 4.3. Risk of disclosure of restricted information; and
 - 4.4. Whether the proposed project is in accordance with the mission and objectives of the DermReg
- 5. Requesting party is required to enter into an agreement with National Dermatology Registry on release of data. Click to download the <u>Data Release Agreement</u> document.
- 6. A processing fee may be charged, such amount to be determined on a case-by-case basis.
- 7. All simple requests shall be dealt with within 2 weeks, while more complex requests will take up to 2 months to process.