

# Fondation Botnar Databases & Data Protection Guidelines for grant recipients

The guidelines below provide guidance to awarded/contracted grant recipients ("Grantee") of Fondation Botnar ("Foundation") on using databases and protecting data from projects funded by the Foundation. The content of this document is valid at its time of publication, subject to periodic change and update, or as required.

## **Key contact for clarifications or questions:**

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using "Grant Reference Number" in subject line

## **Data & Databases generated by the project**

If the project involves the creation and use of health and/or other personal data, the Grantee agrees to use all necessary care in the handling and storage of such data and to strictly follow all applicable legislations and regulations. The Grantee agrees to have all involved collaborating parties agree to terms and conditions regarding data which are no less strict than those provided in this guideline.

Any database created in the context of a project funded by the Foundation shall be exclusive property of the Grantee and any collaborating third party directly involved in the collection of said data.

Unless prohibited by applicable legislation and regulation, the Grantee is permitted to make the database available to and authorise its use upon written request of a scientific institution. The latter should provide the Grantee with at least the following information: current status of the institution's field research, objective and methods – in particular a statistical analyses plan, expected timelines and impact, and a publication plan with agreement on co-authorship. If the Grantee considers the request inappropriate for scientific or ethical reasons, it is not obliged to provide the database to the requesting institution. The format of data and its extent shall be closely governed by applicable legislation and regulation observing the respective requirement for the data subject's prior consent. Wherever possible, data shall be made available to third

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parties only in anonymous form.

The Foundation is not authorised to provide such databases to any public or private entities without written authorisation of the Grantee and according to the conditions outlined above.

## Data Protection Obligations (DPO)

For all health and/or other personal data collected during the project, especially with respect to data collected or obtained from patients ("Data"), the Grantee – together with all involved collaborating parties – agrees to:

- \* only process Data for the purpose of the Project ("Purpose");
- \* be solely responsible for ensuring the security of Data at all times throughout the term of grant agreement;
- \* comply with all applicable laws, industry guidelines and standards;
- \* not to disclose Data to anyone other than persons working on the Project who need access to Data to meet Grantee obligations under the grant agreement. The Grantee shall ensure that such persons are informed of the confidential nature of Data, have undertaken training in laws related to handling Data and are aware both of the Grantee's duties and their personal duties and obligations under such laws and the grant agreement;
- \* take reasonable steps to ensure the reliability of all persons who have access to Data;
- \* not retain Data for any longer than necessary for the Purpose, or for scientific projects approved by the responsible ethics committee, and only with the applicable requirement of a data subject's prior consent;
- \* only make copies of Data to the extent it is reasonably necessary for the Purpose;
- \* not extract, re-utilise, use, exploit, redistribute, re-disseminate, copy or store Data other than for the Purpose, or for scientific projects approved by the responsible ethics committee, and only with the applicable requirement of a data subject's prior consent;
- \* implement appropriate technical and organisational measures to protect Data against unauthorised or unlawful processing and against accidental loss, destruction, damage, alteration or disclosure;
- \* not undertake, or cause or permit to be done, anything that may result in the Grantee being in breach of these DPO. Any breach by any party of the provisions of the DPO shall entitle the Foundation to terminate the grant agreement;
- \* immediately notify the Foundation in relation to any complaint, notice or communication received in relation to compliance with the DPO.

In the event that the retention of Data is no longer necessary under the grant agreement, the Grantee shall destroy all Data and all copies, electronic or otherwise, thereof.