**JHM IRB Consent Form Template Language: Open Access Data Sharing**

***Generally, the expectation is that data sharing via open access will be de-identified. If the data you plan to share will not be de-identified, the language below must be revised to reflect this.***

# Open Access Data Sharing

***<<Include the following for all*** ***studies with open access data sharing:>>***

In addition to the types of data sharing that are described in Section 4, this study involves sharing of data via open access.

Open access data sharing includes the following:

* Removal of any personal information from the study data that could identify you (like name, birthdate, age, gender, address including zip code, medical record number, etc.). This is called de-identified data.
* Each participant’s data will be assigned to a code number to distinguish one study participant from another.
* De-identified data from this study are made publicly available (e.g. on a website).
* Anyone can use the data for any purpose in the future.

***<<If participants have the choice as to whether to allow open access data sharing, please include the following:>>***

Because people have different comfort levels about data sharing and about how they approach privacy in general, we give you a choice to decide if you want your data to be shared openly.

***<<If open access data sharing is required, please include the following:>>***

Participation in this study requires that you agree to this open access data sharing.

***<<Include the following for all studies with open access data sharing:>>***

**What risks and benefits are associated with open access data sharing?**

Any research data collected from you, excluding your personally identifiable information, could be included in the open data sharing. However, even with your identifiable information removed, there may be a risk of you being identified. Anybody in the world can have access to information in an open access database. If you tell other people that you participated in this study, you may increase the chance that someone will be able to link your data to you.

We do not know how likely it is that your identity could become re-connected with information shared through open access. As of today, we believe there is a low risk that most de-identified study data could be used to re-identify you. However, data that cannot be used to identify you today could be used to identify you in the future.

If you decide to withdraw from the study after consenting to open data sharing, we will not have any way to know who has already used your data before you withdrew and will not be able to prevent continued use of your data.

There is no direct benefit to you from placing your data in an open access database. If you agree to open data sharing, this will help a wider range of researchers make discoveries that may help others in the future.

***<<If participants have the choice as to whether to allow open access data sharing, please include the following:>>***

**Open sharing of individual study data**

Please indicate your decision regarding open data sharing by checking the appropriate statement below:

❒ I agree to open data sharing of my de-identified data.

❒ I DO NOT agree to open data sharing of my de-identified data.

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Participant Signature Date

(or Parent/Legally Authorized Representative Signature, if applicable)