The Molecular Taxonomy of Breast Cancer International Consortium (METABRIC)
Data Access and Use Agreement for non personal data.

Between THE British Columbia Cancer Agency Branch, a branch society of the Provincial Health Services Authority under the Society Act (British Columbia) and having an office at Suite 600, West 10th Avenue, Vancouver, British Columbia, Canada, V5Z 4E6 (“BCCA”), Cancer Research UK (“CRUK”) a company limited by guarantee (registered in England and Wales under number 4325234) and a charity (registered in England under number 1089464 and registered in Scotland under number SC041666) of Angel Building, 407 St John Street, London, EC1V 4AD, United Kingdom (collectively referred to as the “Funders”), and the undersigned parties.

This agreement governs the terms on which access will be granted to the genotype and expression data generated as a result of the activities of the Molecular Taxonomy of Breast Cancer International Consortium and deposited by members of the Consortium including the Funders.

In signing this agreement, you are agreeing with the Funders to be bound by the terms and conditions set out in this agreement.

NOW THEREFORE in consideration of the access to the Data provided by the Funders to You, and for other good and valuable consideration, the receipt and sufficiency of which is hereby acknowledged, and intending to be legally bound hereby, the parties hereto agree as follows:

Definitions:

“Application” means an application made by an entity (including You) to request access to the Data for a specific project and/or purpose.

“Consortium” means the Molecular Taxonomy of Breast Cancer International Consortium.

“Consortium Data Access Committee” means the committee established by the Consortium to consider Applications.

“Data” means non personal data including all and any human genetic and raw expression data obtained from the Consortium (which is currently available through the European Genome-phenome Archive).

“Data Subject” means a person, who has been informed of the purpose for which the Data was collected, is currently held, and the purposes for which it can and will be distributed and disclosed, and has given his/her informed consent thereto. All references to individual Data Subjects have been removed and the Data is no longer personal data.

User means a researcher whose User Institution has signed this Data Access Agreement and has received acknowledgement of the acceptance of its Application.

Publications means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

User Institution means the organisation at which the User is employed, affiliated or enrolled.

For the sake of clarity, the terms and conditions set out in this Agreement apply both to the User and the User’s Institution (as defined below). User Institution and User are referred to within this Agreement as “You” (and “Your” shall be construed accordingly as referring to both User Institution and User).
Terms and Conditions:

1. You agree to preserve, at all times, the confidentiality and privacy of information and Data pertaining to Data Subjects. In particular, you undertake not to use, or attempt to use the Data to compromise or otherwise breach or infringe the confidentiality and privacy of information on Data Subjects.

2. You agree not to attempt to link the Data to any other data source on the same samples, link the Data to any person or otherwise identify any Data Subject from the Data. We have taken organisational and technical measures to ensure this cannot happen.

3. You agree not to transfer or disclose the Data, in whole or part, or any material derived from the Data, to others, except to persons within the User Institution for the fulfilment of the Purpose as reasonably necessary for Data/safety monitoring or programme management. If You wish to disclose the Data to a collaborator outside the User Institution, the third party must make a separate Application for access to the Data and enter into a separate Agreement.

4. You agree to use the Data for the advancement of medical research, and solely for the approved purpose and project described in Your Application and for no other purpose, which is attached hereto as Schedule “B” (the “Purpose”); provided that any use of the Data beyond the scope of the Purpose will require a new Application, approval and Agreement. You agree to destroy the raw data once the project is completed, and upon request of the Consortium, provide written certification of such destruction.

5. You agree that Data may be reissued from time to time, with suitable versioning. If the reissue is at the request of sample donors and/or other ethical scrutiny, you will destroy earlier versions of the Data, and upon request of the Consortium, provide written certification of such destruction.

6. You agree to acknowledge in any work or Publications based in whole or part on the Data, the published paper from which the Data derives, the version of the Data, and the role of the Consortium and the Funders, in accordance with the Publications Policy attached as Schedule “A”.

7. You agree and acknowledge that the Consortium, its members, the original Data creators, depositors or copyright holders, or the Funders:

   a) bear no legal responsibility or liability for the accuracy or comprehensiveness of the Data, or from any use of the Data including further analysis or interpretation of such Data; and
   b) shall have no liability for any direct or indirect, consequential, or incidental damages or losses whatsoever arising out of Your use of the Data, or from the unavailability of, or lack of access to, the Data for whatever reason; and
   c) disclaim any and all representations, conditions or warranties (either express, implied or statutory) regarding the Data, including accuracy of the Data or that the Data corresponds with a particular description or is fit for a particular purpose.

8. User Institution shall indemnify, hold harmless and defend each of the Funders, any members of the Consortium and their respective directors, officers, employees and agents against any and all claims (including all associated legal fees and disbursements actually incurred) arising out of this Agreement, including without limitation against any damages or losses, consequential or otherwise, arising in any manner at all from or out
of Your use of the Data. Section 8 shall not apply to any public body or institution that is prevented by applicable laws from providing indemnification.

9. You understand and acknowledge that the Data is owned by the Funders and protected by copyright, database rights and other intellectual property rights owned by the Funders. You agree that you shall not reproduce or copy the Data, except as reasonably required to carry out the Purpose and for no other purpose, or sell all or any part of the Data in any circumstances.

10. You recognise that nothing in this Agreement shall operate to transfer to You any ownership or intellectual property rights relating to the Data.

11. You accept that this Agreement will terminate immediately upon any breach of this Agreement by You and You will be required to destroy or return any Data, and upon request, provide written certification of such destruction. For the avoidance of doubt clause 3, 7, 8, 14, 15 will continue to operate in full force and effect.

12. You accept that it may be necessary for the Funders to alter the terms of this Agreement from time to time in order to address new concerns. In this event, one of the Funders or a representative of the Consortium will contact You to inform You of any changes and You agree that Your continued use of the Data shall be dependent on the parties entering into a new version of the Agreement.

13. You agree that you will submit a report to the Consortium Data Access Committee, if requested, on completion of the Purpose. The Consortium Data Access Committee agrees to treat the report and all information, data, results, and conclusions contained within such report as confidential information belonging to the User Institution.

14. You agree that the Data is protected by and subject to international laws, which may include without limitation the UK Data Protection Act 1998 the Personal Information Protection and Electronic Documents Act (Canada) (“PIPEDA”), the Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996 c. 165 (“FOIPPA”) and the Personal Information Protection Act, 2003, S.B.C., c. 63 (“PIPA”) and that You are responsible for ensuring compliance with any such laws. The Funders (via the Consortium Data Access Committee) reserve the right to request and inspect Your data security and management documentation to ensure the adequacy of data protection measures in countries that have no privacy legislation comparable with that contained herein.

15. This Agreement shall be subject to English law and the non-exclusive jurisdiction of the English courts. In the event that a dispute relates to Data that originated from BCCA, the parties attorn to the non-exclusive jurisdiction of the courts of British Columbia, Canada.

16. Part or all of any section of this Agreement that is indefinite, invalid, illegal or otherwise voidable or unenforceable may be severed and the balance of this agreement will continue in full force and effect.
Schedule “A”

Publications Policy

Any use of Data must acknowledge METABRIC using the following wording: “This study makes use of data generated by the Molecular Taxonomy of Breast Cancer International Consortium. Funding for the project was provided by Cancer Research UK and the British Columbia Cancer Agency Branch.” and cite the relevant primary METABRIC publication (Curtis et al, Nature 2012, pubmed id number 22522925) which is the source of the Data.

Schedule “B”

Application (approved by the Consortium Data Access Committee)
For and on behalf of User:

Name of Applicant(s):
_____________________________________
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Signature of Applicant(s):
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_____________________________________
_____________________________________

Date:
_____________________________________

For and on behalf of User Institution:

Signature of Institutional or Administrative Authority:
_____________________________________

Print name:
_____________________________________

User Institution:
_____________________________________

Date:
_____________________________________

WHEN SUBMITTING THIS DOCUMENT, PLEASE INCLUDE ALL PAGES OF THE AGREEMENT WITH THIS SIGNATURE PAGE