## **Data Access Agreement**

SECONDARY ANALYSIS TO GENERATE EVIDENCE (SAGE), a research and data repository operating under the authority of POLICYWISE FOR CHILDREN & FAMILIES ("POLICYWISE"), a corporation organized and existing in the province of Alberta, with its principle office located on the 6th floor, 9925 – 109 Street, Edmonton, Alberta, T5K 2J8 ("SAGE");

#### **AND**

[Secondary Data User's Name] (the "Secondary Data User") [Address], [Title];

Both SAGE and the Secondary Data User, representing themselves and their Research Team (Exhibit A), wish to enter into this Data Access Agreement effective as of the Effective Date specified on the final page hereof.

#### PRELIMINARY STATEMENT

SAGE has Data in its possession from individuals pursuant to applicable provincial legislation and policy, which include [Please type in the relevant legislation such as the Tri-Council Policy Statement 2 (TCPS), Health Information Act (HIA), Personal Information Protection Act (PIPA), and/or Freedom of Information and Protection of Privacy (FOIP)], collected [Specify the source of data] "[Enter name of study, name of government ministry, name of service delivery organization]". (the "Data").

The Secondary Data User wishes to use the Data to enable [Insert brief description of secondary research project].

Data made available through SAGE have been stripped of all personal identifiers. To protect the confidentiality and privacy of these individuals, the Secondary Data User must adhere to the requirements of this Agreement. Failure to comply with this Agreement could result in denial of further access to Data and prosecution for breach of privacy. Violation of the confidentiality requirements of this Data Access Agreement is considered a breach of confidentiality and may leave Secondary Data Users and/or their host institution liable to legal action by individuals with which the Data pertains, their families, the Provincial or Canadian Government and SAGE.

NOW THEREFORE THIS AGREEMENT WITNESSETH that in consideration of the premises and of the mutual covenants herein set forth, the parties hereto have covenanted and agreed as follows:

### I. DEFINITIONS AND INTERPRETATIONS

1.1.For purposes of this Agreement:

- A. "Secondary Research Project" refers to the project described in Exhibit A, and includes members of the Secondary Research Team.
- B. "Data" refers to the information included in Exhibit B, which has been collected and recorded from [Specify source of Data] as described in Exhibit C.
- C. "Agreement" means this Data Access Agreement
- D. "FOIP" means the *Freedom of Information and Protection of Privacy Act*, R.S.A. 2000, c. F-25, as amended from time to time.
- E. "Metadata" refers to all underlying data about the Data, without identifiers.
- F. "Data Producer" is the [Choose Data Producer] as described in Exhibit C.

### 1.2. Interpretation of Exhibits

This Agreement contains the following Exhibits, which form an integral part of this Agreement.

- A. Exhibit A Proposed Secondary Research Project and Research Team
- B. Exhibit B Requested Data from SAGE
- C. Exhibit C Original Data Source and Data Producer
- D. Exhibit D Ethical Approval Certificate (s)
- E. Exhibit E Security Requirements
- F. Exhibit F Cost Recovery

#### II. AGREED TERMS AND CONDITIONS

- 1. Research work. The Secondary Data User requests access to the Data at their sole risk and at no expense to SAGE solely for the non-commercial purpose outlined in Exhibit A.
- 2. Non-transferability. This Agreement is not transferable. The Secondary Data User agrees that substantive changes made to the Secondary Research Project, and/or appointment by the Secondary Data User of another Researcher to complete the Secondary Research Project, require execution of a new Agreement in which the new Researcher and/or new Secondary Research Project are designated. In addition, changes to the Secondary Research Team are to be communicated to SAGE in writing and may be subject to a new Agreement.
- 3. Cost Recovery. The Secondary Data User agrees to remunerate SAGE a cost-recovery fee of \$[Insert cost here- can be 0 if fee is waived] CAD as outlined in Exhibit F. In addition, the Secondary Data User agrees to reimburse, on the request of SAGE, such reasonable additional costs as SAGE may incur in providing the Data, within sixty (60) days of SAGE making such a request for payment.
- **4. Access to Data.** Access to Data will be provided through a virtual desktop system or other methods as determined by SAGE. Any credentials for secured access to the Data including any username and passwords are not to be shared, even between authorized users.
- **5. Control of Data.** The parties agree that the Data remains solely in SAGE's control.
- **6.** Use of Data. The Secondary Data User agrees as follows:
  - A. Data must be used only for the Secondary Research Project as detailed in Exhibit A and for no other use or purpose. A separate Agreement will be executed for each research project for which Data is requested;

- B. Secondary Data User may not transfer Data to any third parties;
- C. Data will not be used, either alone or in conjunction with any other information, in any effort whatsoever to establish the individual identities of any of the participants from whom Data were obtained;
- D. For data collected under FOIP, despite ss. 39 and 40 of FOIP, the Data must only be used and disclosed as expressly provided in this Agreement;
- E. Except as expressly provided in the Secondary Research Project as approved by the applicable Secondary Data User's Ethical Board, and with the express authorization of SAGE, the Data must not be linked, matched or otherwise combined with other information (including information that is available from other sources):
- F. Any identifiers created by the Secondary Data User will not relate to any data point found in SAGE's records. The Secondary Data User's identifiers are to be used for analysis purposes only;
- G. All works must be written and presented in a way that ensures no individuals are or can be directly or indirectly identified;
- H. The Secondary Data User is to immediately report to SAGE any demand for disclosure;
- I. The Secondary Data User shall abide by any further conditions imposed by SAGE from time to time that may apply to the access to, or use of, the Data.
- **7. Repatriation of derived data.** The Secondary Data User undertakes to return to SAGE the results of the Secondary Research Project analysis (i.e. derived data or new data) for potential future sharing.
- 8. Compliance Monitoring and Investigations. The Secondary Data User shall record and monitor access to any Data the he/she can access in order to establish a chain of responsibility, as follows:
  - A. The Secondary Data User will investigate all suspected or documented cases of:
    - (i) Unauthorized access to or modification of the Data;
    - (ii) Unauthorized use of the Data;
    - (iii) Unauthorized disclosure of the Data;
    - (iv) Breaches of privacy or security with respect to the Data or with respect to any computer system in its custody that is used to access the Data.
  - B. The Secondary Data User shall report to SAGE the results of any such investigations and the steps taken to address any remaining issues or concerns about the security of the Data or computer systems, or the privacy of individuals to whom the Data relates.
- **9. Notice of Breach.** The Secondary Data User shall advise SAGE immediately of any circumstances, incidents or events which to its knowledge have jeopardized or may in future jeopardize; (i) the privacy of individuals, (ii) the security of any computer system in its custody that is used to access the shared Data, and/or (iii) any suspected or apparent risk of a breach, or actual breach, of any term of this Agreement.
- **10. Termination for Unremedied Breach.** SAGE may give the Secondary Data User notice of breach of this Agreement and, if the breach has not been cured to SAGE's reasonable satisfaction (including by retrieving information that has been used or disclosed contrary to this Agreement) within thirty (30) days after the notice is given, SAGE may give notice of termination of this Agreement, which becomes effective

fifteen (15) days after it is given. Within thirty (30) days after termination of this Agreement the Secondary Data User must return all copies of Data in any medium or must securely destroy all copies to SAGE's reasonable satisfaction, as SAGE directs in a notice given to the Secondary Data User. The Secondary Data User's obligations under this Agreement respecting use, disclosure and security of Data remain in force despite termination of the rest of this Agreement.

- 11. Non-Data. Notwithstanding the definition of "Data" or the agreed Terms and Conditions of this Agreement, if SAGE transfers written confidential information concerning the Data along with the Data, then to the extent permitted by law, the Secondary Data User agrees to treat in confidence, any of SAGE's said confidential information. The Secondary Data User's obligations of confidentiality under this Agreement shall not extend to any information:
  - A. that can be demonstrated to have been publicly known at the time of disclosure; or
  - B. that can be demonstrated to have been in the possession of or that can be demonstrated to have been readily available to the Secondary Data User from another source prior to the disclosure; or
  - C. that becomes part of the public domain or publicly known by publication or otherwise, not due to any unauthorized act by the Secondary Data User; or
  - D. that can be demonstrated as independently developed or acquired by the Secondary Data User without reference to or reliance upon Data provided under this Agreement; or
  - E. that is required to be disclosed by law, provided the Secondary Data User takes responsible and lawful actions to avoid and/or minimize such disclosure.

### 12. Stewardship.

- A. Any reports, publications, and materials produced by the Secondary Data User from the Data will be the property of the Secondary Data User but SAGE is hereby granted, without charge, the right in perpetuity to reproduce and distribute the reports, publications and materials, or any portions thereof or extract therefrom for its own purposes in line with PolicyWise' mission as SAGE may choose.
- B. This Agreement does not constitute a transfer of any stewardship rights or title to the Data. Except as provided in this Agreement, no express or implied licenses or other rights are provided to Secondary Data User under any proprietary rights of the Data Producer or Data Producer Institution to the Data. Prior to commercial use of any information generated or product or discovery made through the use of the Data, Secondary Data User will consult the Data Producer in good faith to determine appropriate financial compensation in recognition of the contribution of Data.
- C. The Secondary Data User grants SAGE unrestricted license to use the results for non-commercial knowledge-translation, dissemination, research and teaching, subject to a reasonable embargo period and with acknowledgement to the Secondary Data User.
- D. Existing intellectual property, inventions, and technology that formulate and constitute SAGE are the sole property of SAGE. Whereas existing intellectual property, inventions, and technology that formulate and constitute the Data

**Comment [AL1]:** Is this required? Clause #1 says that the information will not be used for any commercial purposes

Producer are the sole property of the Data Producer. No other Party shall have any claims to rights in such existing intellectual property.

- **13. Publication.** Prompt publication and public disclosure of the results of the Secondary Research Project is encouraged. The Secondary Data User agrees to provide to SAGE and Data Producer a copy of any manuscript or other disclosure document thirty (30) days in advance of submission for publication, in order to ensure compliance with the requirements set forth in this Agreement. The Secondary Data User shall provide a copy of the published document to SAGE and Data Producer within 30 days of publication.
- **14. Acknowledgments.** The Secondary Data User agrees to acknowledge the contribution of SAGE in any and all oral and written presentations, disclosures, and publications resulting from any and all analyses of the Data using the following format:

This study made use of de-identified data from the [Enter the name of the study, government ministry, or service delivery organization], accessed through the SAGE, an initiative of the PolicyWise for Children & Families. The opinions, results and conclusions reported are those of the authors. No endorsement by PolicyWise for Children & Families or any of its funders or partners is intended or should be inferred.

The Secondary Data User shall also acknowledge the original Data Producer as stated in Exhibit C and provide authorship as appropriate in accordance with academic standards

The Secondary Data User acknowledges and accepts that PolicyWise has the right to identify the Secondary Research Project in its reports to funders and on its public website, which can include the Secondary Data User name, the Secondary Research Project title, and a summary of the research objectives.

- 15. Secondary Data User's Compliance with Ethical Board Requirements. The Secondary Data User acknowledges that the conditions for use of the Data are not exempt from review and have been approved by the applicable Ethical Board, or equivalent institution. The ethics approval certificate is hereby incorporated as Exhibit D. The Secondary Data User agrees to comply fully with all such conditions. The Secondary Data User agrees to report promptly to SAGE any proposed change in the Secondary Research Project and any unanticipated problems involving risks to individual for with the Data pertains to or others. This Agreement is made in addition to, and does not supersede, any of the Secondary Data User's institutional policies, where applicable, or any local, Provincial, and/or Federal laws and regulations which provide additional protections for human subjects. The Secondary Data User must update SAGE with all ethics updates (including annual approvals) within 30 days of notice of approval from the corresponding Ethical Board.
- 16. Representations and Warranties. SAGE makes no representations or warranties, either expressed or implied, with respect to the Data and specifically disclaims any implied warranties of non-infringement or merchantability or fitness for a particular purpose, or that the use of the Data will not infringe on any patent, copyright, trademark, or other proprietary rights. SAGE shall in no event be liable for any loss of profits, be they direct, consequential, incidental, or special or other similar or like

- damages arising from any defect, error or failure to perform with respect to the Data, even if SAGE has been advised of the possibility of such damages.
- **17. Destruction of Information.** In instances in which physical copies of Data were provided to the Secondary Data User, and unless otherwise indicated herein, the Secondary Data User will return or destroy the Data five (5) years after final publication of a manuscript arising from this work. This date can be extended upon mutual written consent of both parties, or subject to a separate agreement.
- **18. Governing Law.** This Agreement shall be governed by and construed in accordance with the laws of Alberta and Canada in force therein without regard to its conflict of law rules.
- **19. Duplication of Research.** The Secondary Data User acknowledges that other researchers may have access to this Data through SAGE, and that duplication of research is a distinct possibility.
- 20. Limitation of Liability and Indemnity. The Secondary Data User assumes all liability for loss or damages arising from the use, storage or disposal of the Data and further agrees to indemnify, defend and hold harmless SAGE, Data Producer and/or Data Producer Institution from all claims, actions and damages whatsoever, including legal fees, resulting from or in connection with the use, storage or disposal of the Data. SAGE, Data Producer and/or Data Producer Institution shall in no event be liable for any loss of profits, be they direct, consequential, incidental, or special or other similar or like damages arising from any defect, error or failure to perform with respect to the Data, even if the parties have been advised of the possibility of such damages.

#### 21. General

21.1 Notice: Any notice, direction or waiver which may be or is required to be given under this Agreement must be in writing to be effective and must be delivered or sent by registered mail, fax transmission, or e-mail using the address information set out below. Any notice, direction or waiver that is delivered is considered to have been given on the next business day after it is dispatched for delivery. Any notice, direction or waiver that is sent by fax transmission, or e-mail is considered to have been given on the day it is sent if that day is a business day, but if that day is not a business day, it is considered to have been given on the next business day after the date it is sent. If a party changes its address, fax number, e-mail address or all of them, it must immediately give notice of the new address, fax number or e-mail address to the other party as provided in this section.

#### If to the Secondary Data User:

ATTN: [Secondary Data User's

Namel

[Institution name, if applicable]

[Address]

[City, Province] [Postal Code] Telephone: [Phone Number]

Fax: [Fax] [E-mail]

If to SAGE:

ATTN: SAGE

PolicyWise for Children & Families

601, 9925 -109 Street Edmonton, AB T5K 2J8 Telephone: (780) 944-8630

Fax: (780) 944-8637 data@policywise.com

- **21.2 Designated Representatives.** The parties agree the individuals signing this Agreement are their designated representatives for all purposes of this Agreement. A party may give notice to the other designating a new representative, and must do so promptly after its representative changes.
- **21.3 Binding on Successors.** This Agreement ensures to the benefit of and is binding upon the parties and their respective successors, contractors, trustees, administrators and receivers, despite any rule of law or equity to the contrary. If SAGE ceases to exist, this Agreement terminates and any further use of the Data must be approved by the Data Producer.
- **21.4 Whole Agreement.** This Agreement and its Exhibits, is the entire Agreement between the parties and it terminates and supersedes all previous communications, representations, warranties, covenants and Agreements, whether verbal or written, between the parties with respect to the subject matter of this Agreement.
- **21.5 Waiver.** Waiver of any breach of this Agreement must be expressed and in writing to be effective and a waiver of a particular default does not waive any other default.
- **21.6 Counterparts.** This Agreement may be executed in counterparts and when each of the parties to this Agreement has executed a counterpart, each of those counterparts is considered to be an original and all of those counterparts when taken together constitute one and the same Agreement.
- **21.7 Severance.** If any portion of this Agreement is held invalid by a court of competent jurisdiction, the invalid portion must be severed and neither the decision that it is invalid nor the severance affects the validity of the remainder of this Agreement.
- **21.8 Amendments.** This Agreement may only be amended by a document signed by the authorized representatives of the parties and no other purported amendment is effective.

As evidence of their agreement to be bound by the above terms, the authorized signatories of the parties have executed and delivered this Agreement, to be effective as of [Date] ("Effective Date")

Signed for and on behalf of [Secondary Data User's Name] by:

Name:	<del></del>
Title:	
Date:	
Signed for and on behalf of SAGE	E Executive by its duly authorized officer:
Name:	
Title:	
Date:	

Exhibit A -

# **Proposed Secondary Research Project and Research Team**

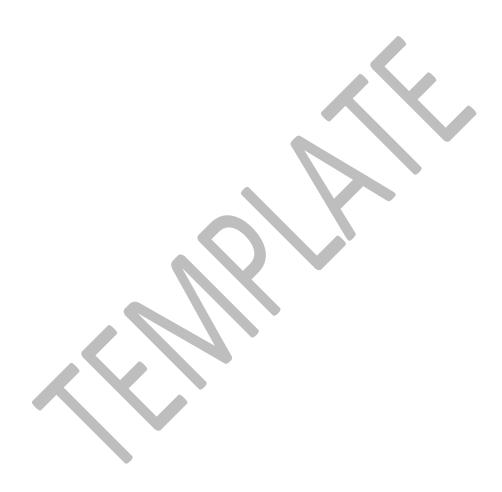


Exhibit B -

# **Requested Data from SAGE**

VARIABLE LIST					
Variable	Variable label	Dataset	Rationale	If Other, please specify	
i.e. Q1MCPC1	Has it been difficult for you to obtain prenatal care?	AOB	Covariate definition		
<u>.                                    </u>					

Exhibit C-

# **Original Data Source and Data Producer**

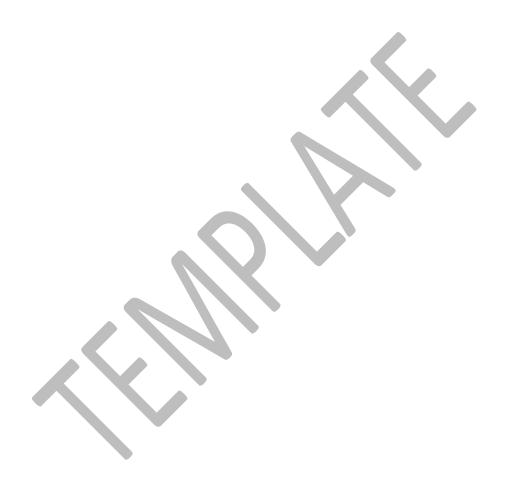
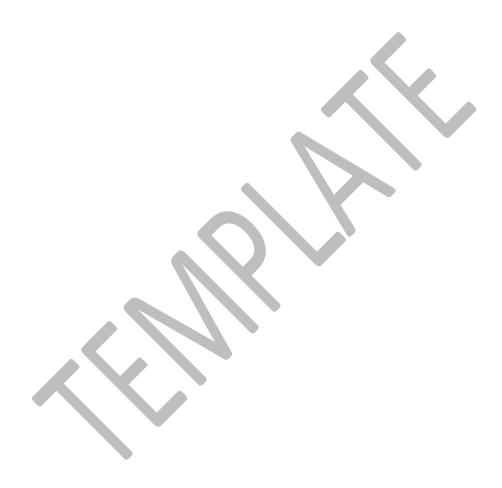


Exhibit D-

# **Ethical Board Approval Certificate(s)**



### Exhibit E – Security Requirements

The security requirements described below are the minimum requirements that Secondary Data Users must comply with.

- 1. The Secondary Data User(s) shall make no attempts to remove or copy any of the Data from the SAGE Analytic Environment.
- 2. The Secondary Data User(s) may request the removal of information subject to the following conditions:
  - a. Any material (such as graphs and figures) to be removed from SAGE by the Secondary Data User(s) must first be screened by SAGE to ensure that there is no risk of disclosure of confidential information

Secondary Data User(s) must take all reasonable precautions to avoid disclosure of confidential information



### **Exhibit F- Cost Recovery**



### Secondary Analysis to Generate Evidence (SAGE)

### Cost Recovery Schedule

A key goal of data sharing is to achieve data legacy over the long term, in a stable repository, therefore sustainability is paramount. PolicyWise for Children & Families and our partners have made significant investments into the development of SAGE. To ensure we are able to provide a consistently high level of service and continue to improve our offerings, some operational costs of SAGE will be recovered through fees to the Secondary Data Users. It is the goal that such fees will be taken into account when applying for funding to support the proposed secondary research.

Note that some costs may be waived in certain situations such as to undergraduate researchers, non-profit organizations and others.

Service	Cost
Project setup	\$2,000 - \$8,000
Analytic Software (per software, per project)	\$0 - \$710.00 (depending on software)
Infrastructure maintenance (per project)	\$480.00
User setup (per user)	\$140.00
User renewal (per year)	\$85.00
Additional consultation (per hour)	\$115.00