Synthetic Healthcare Database for Research (SyH-DR)

A Synthetic Nationally Representative All-Payer Claims Database

GETTING STARTED GUIDE

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Purpose

The Synthetic Healthcare Database for Research (SyH-DR) Getting Started Guide is intended for researchers who want to apply for access to SyH-DR. This step-by-step guide includes:

1. Instructions to complete and submit the application package,
2. An overview of the AHRQ application review and communication process, and
3. The system requirements for accessing SyH-DR.

The appendixes to this document include the required SyH-DR application forms and a brief introduction to using the SyH-DR data.

Please note: Your application must be approved by AHRQ before you receive access to SyH-DR. The information about accessing and using SyH-DR is provided so that you may prepare for the data download at your convenience.

More information about the data is available in the the SyH-DR Codebook and Sampling, Weighting, and Synthetization Methodologies at https://www.ahrq.gov/data/syh-dr.html.

Email any questions about SyH-DR or the application process to SyH-DR@ahrq.hhs.gov.

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I. How To Apply for Access to SyH-DR

1. Verify that SyH-DR is an appropriate database to use for your research purposes by reviewing all information provided on the SyH-DR web page, including this Getting Started Guide.

Figure 1: AHRQ SyH-DR Web Page (https://www.ahrq.gov/data/syh-dr.html)

2. Fill out the SyH-DR Request Form found in Appendix A of this document. If possible, do not submit handwritten request forms. *Jump to Appendix A*.

3. Review and sign the SyH-DR data use agreement (DUA) found in Appendix B of this document. DUAs may be handwritten. *Jump to Appendix B*.

4. Obtain a signed DUA from each person on your research team who will be a SyH-DR data user. Team members do not need to complete a separate SyH-DR Request Form.

5. Submit your application by emailing SyH-DR@ahrq.hhs.gov. Create a new email with the subject line "Application Package – Applicant Last Name." If possible, do not submit image files.

6. Optional: Attach an RSA Public Key file to the application email. Approved data recipients are required to generate an RSA Key Pair to download the SyH-DR data files. You may want to submit

the RSA Public Key as part of your application package to streamline the data download process after approval. Otherwise, you may send the RSA Public Key once your application is approved. *Jump to Instructions for Creating an RSA Key Pair*.

7. Use the template below as the body of the email. Be sure to complete each of the bolded and bracketed items. Regardless of who sends the Application Package email, the applicant information in the body of the email must be the same as the information on the SyH-DR request form.

Figure 2: Template Application Package Email

The attached SyH-DR Application Package is from:

[Applicant Name]

[Applicant Institutional Affiliation]

[Applicant Email Address]

[Applicant Contact Phone Number]

The following materials are included in this Application Package:

- 1 SyH-DR Request Form
- **[# of DUAs attached]** SyH-DR DUA(s)
- **[RSA Public Key (delete if not submitting)]**

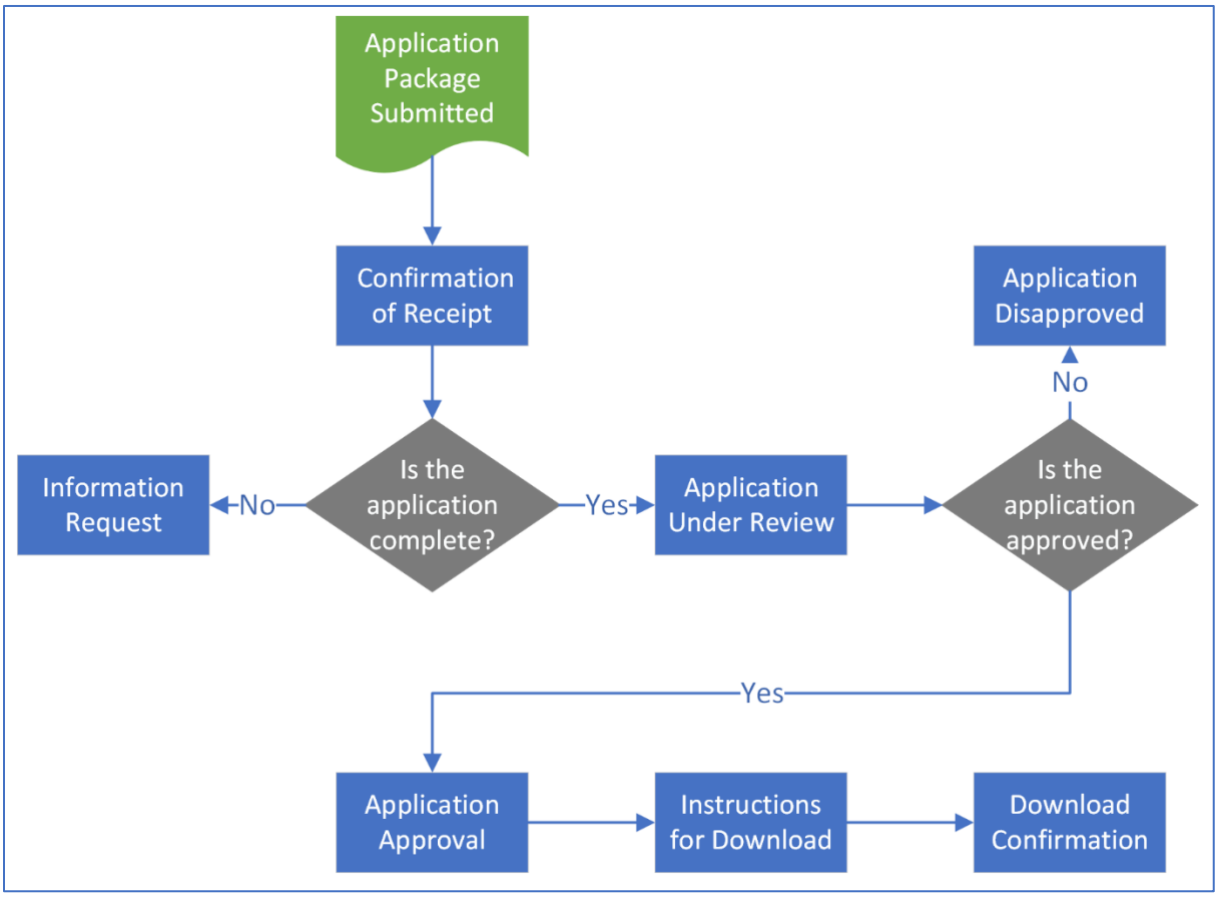
8. Send the email. You will receive a confirmation of receipt within 1-2 business days. If you do not receive a confirmation, resend the email with the attachments.

II. AHRQ Application Review and Communication Process

Overview

After an Application Package is submitted, AHRQ will send email notifications as the application moves through the review process. AHRQ strives to provide access to SyH-DR as quickly as possible, but the exact timing of each notification can vary depending on the content of the Application Package, timeliness of applicant response, and number of applications. The diagram below provides an overview of AHRQ communications through the application review process. Each rectangular box represents an email notification.

Figure 3: Overview of the AHRQ Application Review and Communication Process



Confirmation of Receipt

AHRQ will send a Confirmation of Receipt within 1-2 business days after an Application Package email is submitted.

Information Request

If an Application Package is incomplete, AHRQ will send an Information Request that specifies what component of the application is missing. The applicant should reply to the Information Request email and include the missing information or document.

Application Under Review

Upon verification that an Application Package is complete, AHRQ will send an Application Under Review notification.

Application Disapproved

If an application is not approved, AHRQ will send an Application Disapproved notice to the applicant. AHRQ created SyH-DR based on agreements with entities that provided the original sources of data. In some circumstances, the application may be disapproved because it is not consistent with these agreements.

Application Approval

Once an application is approved, AHRQ will send an Application Approval notification. The Application Approval will include a list of any additional steps that the data recipient must complete so that AHRQ can provide download access, such as generating the RSA Key Pair.

Instructions for Download

Once download access has been established for the data recipient, AHRQ will send the Instructions for Download email. The data recipient should reply to that email with any questions related to downloading the data.

Download Confirmation

AHRQ will track downloads through the secure file transfer protocol (sFTP); however, AHRQ will send a Download Confirmation email to verify that the data download was successful. The data recipient should reply to that email either confirming successful download or stating the nature of the download issue. If AHRQ does not receive a response, download access will be revoked by default after 5 business days.

III. System Requirements for Accessing SyH-DR

General System Requirements

The following general system requirements provide baseline guidance on the hardware and software needed to download and access the SyH-DR data files.

Hardware Requirements

Hard drive space: At least 50GB of available hard drive space is required to download the SyH-DR data files in a single format (CSV, SAS, or Stata). More available hard drive space is required if you want to download the data in more than one format.

RAM: A minimum 1GB of available RAM is required to access the SyH-DR data. Depending on the statistical analysis software used, some SyH-DR data files may require 16GB of available RAM. If your system has less than 16GB of available RAM, we strongly advise that you subset the data using the read-in programs available for download with the data files. Additionally, closing unnecessary programs before accessing the data may increase the amount of available RAM.

File transfer protocol client

The file transfer protocol (FTP) client enables secure handling of file uploads and downloads. The FTP client serves two important functions:

1. First, you will use the FTP client to generate the RSA Public/Private Key Pair. (Instructions for both Microsoft Windows and MacOS users are included below.)
2. Then, you will use the FTP client to connect to the SyH-DR sFTP and download the data files. (Instructions for Download are emailed after Application Approval.)

For Microsoft Windows users: Use WinSCP, an open source FTP application available for Microsoft Windows. **Download WinSCP**.

For MacOS users: Use the Terminal application that automatically comes with MacOS. You should be able to find Terminal by searching your Applications folder or in Launchpad. (You should not need to install this application.)

Email questions about the FTP client requirement to SyH-DR@ahrq.hhs.gov.

RSA public/private key pair

Before you can receive access to download the SyH-DR files, you must generate an RSA Public/Private Key Pair using your FTP client. The RSA Key Pair is required to securely transmit the SyH-DR files. The public key is a unique encryption key that you must send to AHRQ. The private key is a unique decryption key that must be saved to your computer. *Do not share the private key*.

Jump to Instructions for Microsoft Windows.

Jump to Instructions for MacOS.

Note: You may send the RSA Public Key with your Application Package or after approval.

Email questions about the RSA Key Pair requirement to SyH-DR@ahrq.hhs.gov.

Third-party zip utility

The SyH-DR data files are compressed for download efficiency. After you download the SyH-DR data files, you will need to use a third-party zip utility to decompress the files. You may use any zip utility of your choosing. If you do not already have a zip utility installed on your computer, 7-Zip is a popular open source zip utility.

Download 7-Zip for Microsoft Windows.

Download 7-Zip for MacOS.

Statistical analysis software

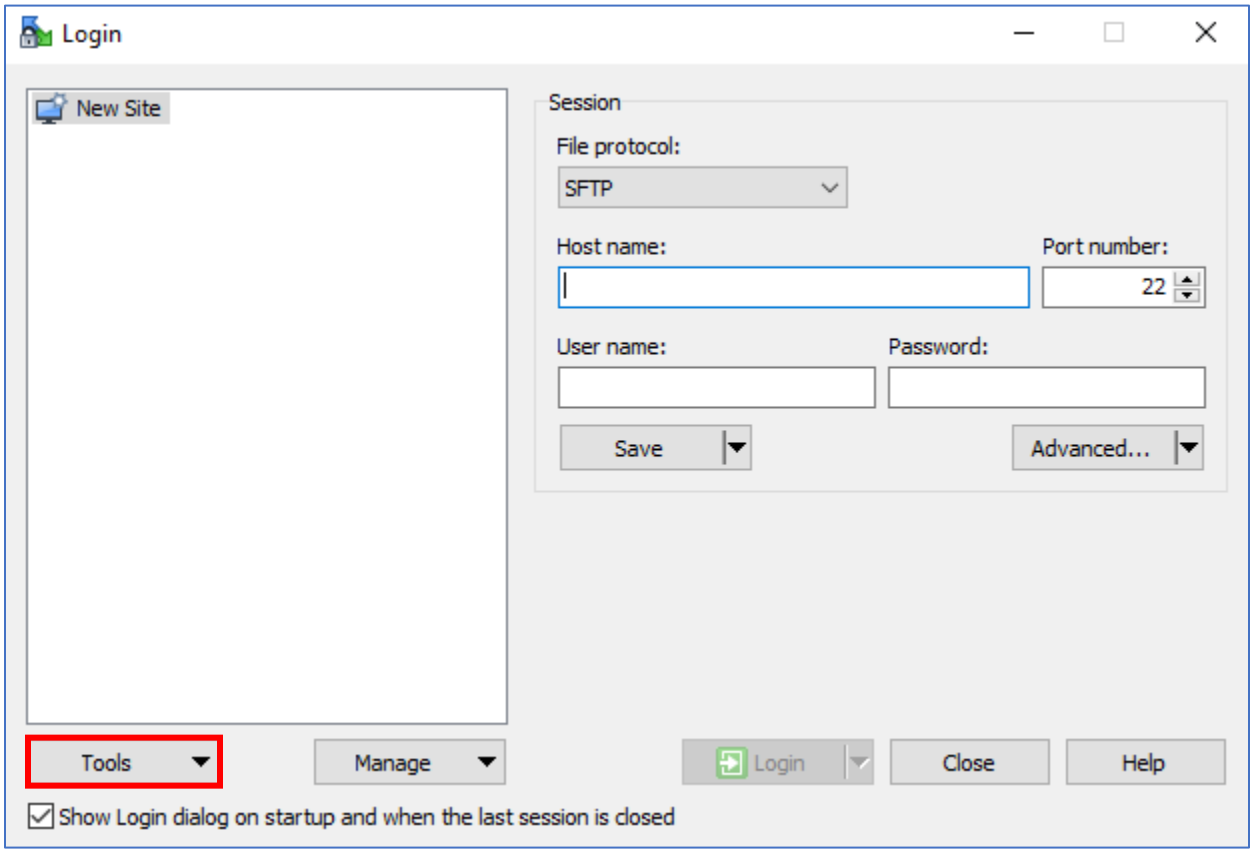
The SyH-DR data are currently available as CSV, SAS, and Stata files. You do not need to have particular statistical analysis software to use the SyH-DR data. You may download some or all of the files and load them into a statistical analysis software of your choosing, such as SAS, Stata, or R.

To accommodate systems with limited processing capacity, SAS and Stata read-in programs are also available for download. The read-in programs provide flexibility to load only the variables and records needed for analysis.

Instructions for Microsoft Windows Users: Generating the RSA Key Pair Using WinSCP

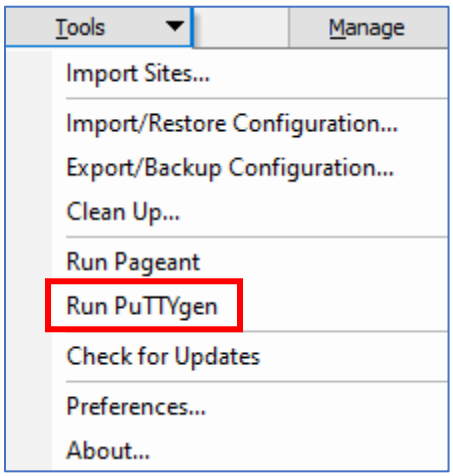
1. Launch WinSCP. The Login window should open automatically.
2. From the Login window, click the **Tools** dropdown button highlighted below.

Figure 4: WinSCP Login Window



3. In the Tools dropdown list, select **Run PuTTYgen**.

Figure 5: WinSCP Tools Dropdown List

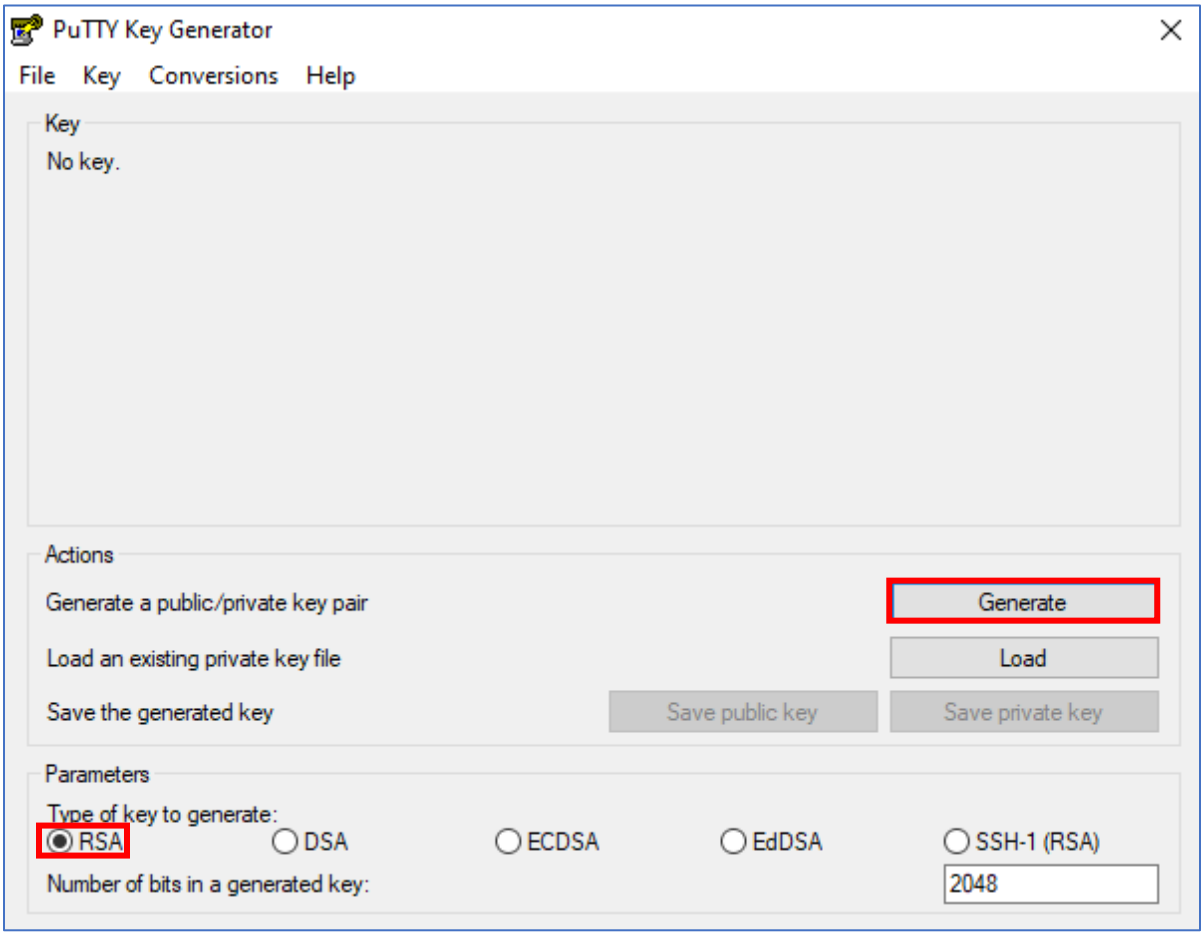


4. The PuTTY Key Generator window will appear.

    a. In the Parameters section of the window, verify that the **RSA** radio button is selected under “Type of key to generate.”

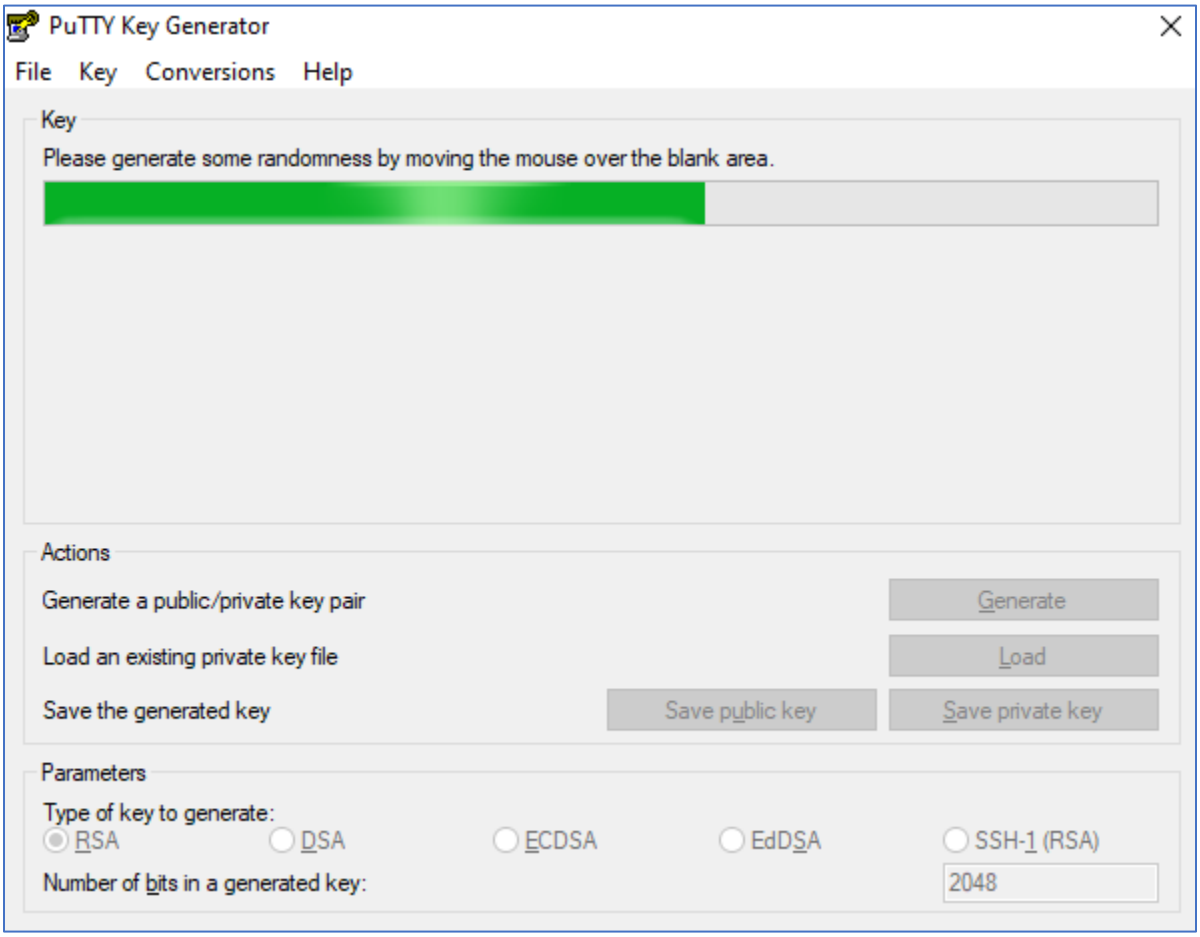
    b. Then select the **Generate** button.

Figure 6: WinSCP PuTTY Key Generator Window



5. The RSA Key Pair generation will begin. Make random movements with your mouse over the blank area of the PuTTY Key Generator window to generate the key.

Figure 7: RSA Key Pair Generation in Progress



6. Once the RSA Key Pair generation is complete, the Public Key and Key fingerprint will appear.

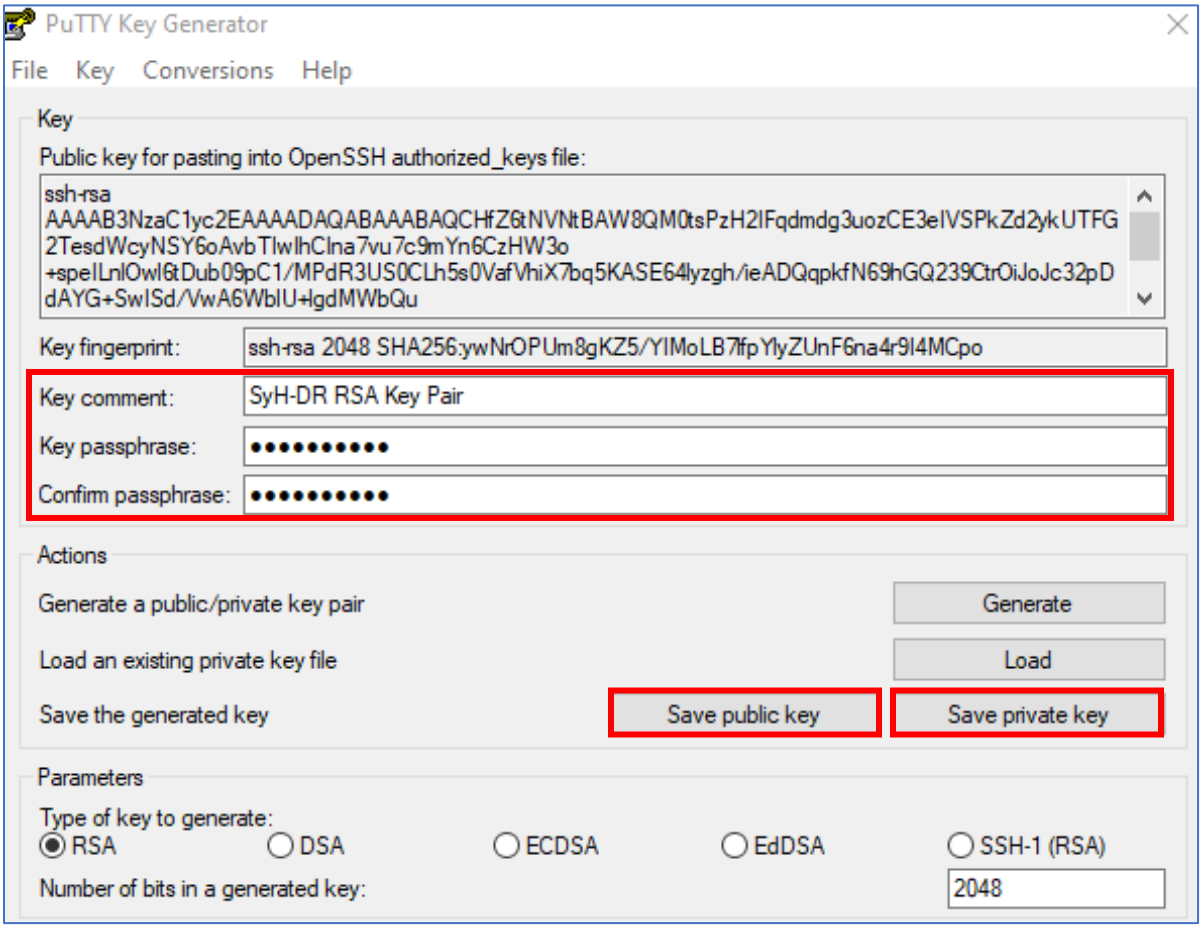
    a. In the Key comment field, type a comment that will help you identify this key in the future. This comment will be displayed whenever WinSCP asks for the Key passphrase.

    b. Then enter a secret passphrase of your choosing in the Key passphrase field and the Confirm passphrase field. *Be sure to securely save this passphrase for future use when downloading the SyH-DR files. We cannot lookup or reset this passphrase on your behalf. If you do not have the passphrase, you will need to recreate the RSA Key Pair.*

7. Select the **Save public key** button and save the public key to your computer. **This is the file that you will send to AHRQ as an email attachment.**

8. Select the **Save private key** button and save the private key to a private drive on your computer.

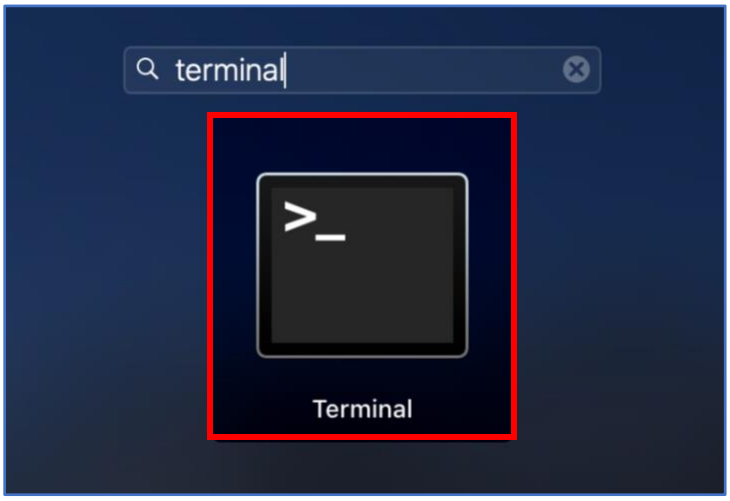
Figure 8: Generated RSA Key Pair



Instructions for MacOS Users: Generating the RSA Key Pair Using Terminal

1. From Launchpad, type “Terminal” in the search bar. Then, select the Terminal icon to launch the application.

Figure 9: Search for the Terminal Application

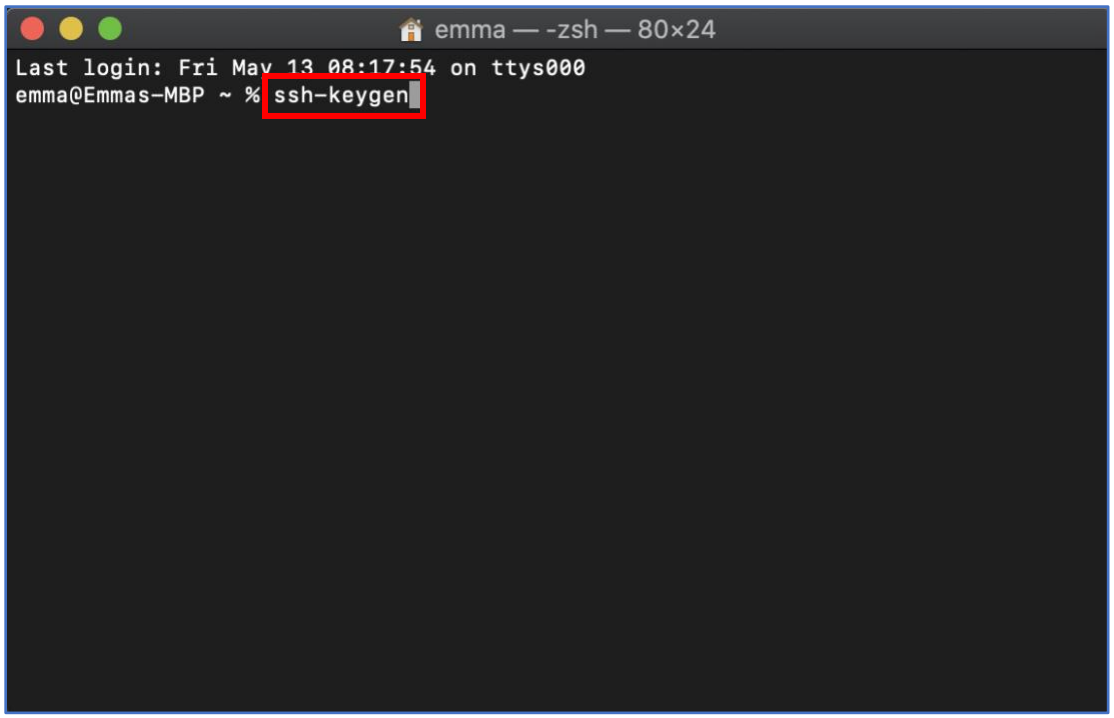


2. A new Terminal session window will appear. *Note: Depending on your system settings, this window may appear with a white or black background.*

3. In the Terminal session window, type “ssh-keygen.”

    a. Press the **Enter** key on your keyboard.

Figure 10: Terminal Session Window

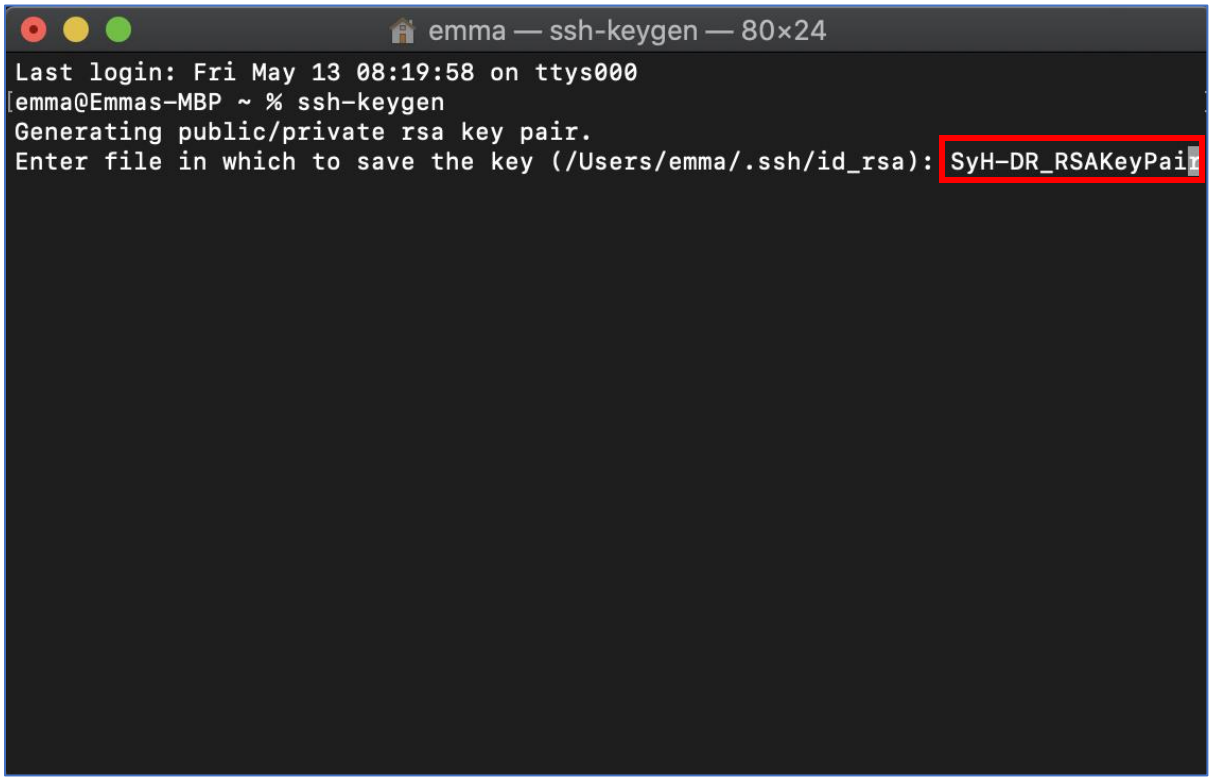


4. The Terminal session window should now say “Generating public/private rsa key pair.”

    a. Type a descriptive file name that will help you identify this key in the future, as shown below.

    b. Press the **Enter** key on your keyboard.

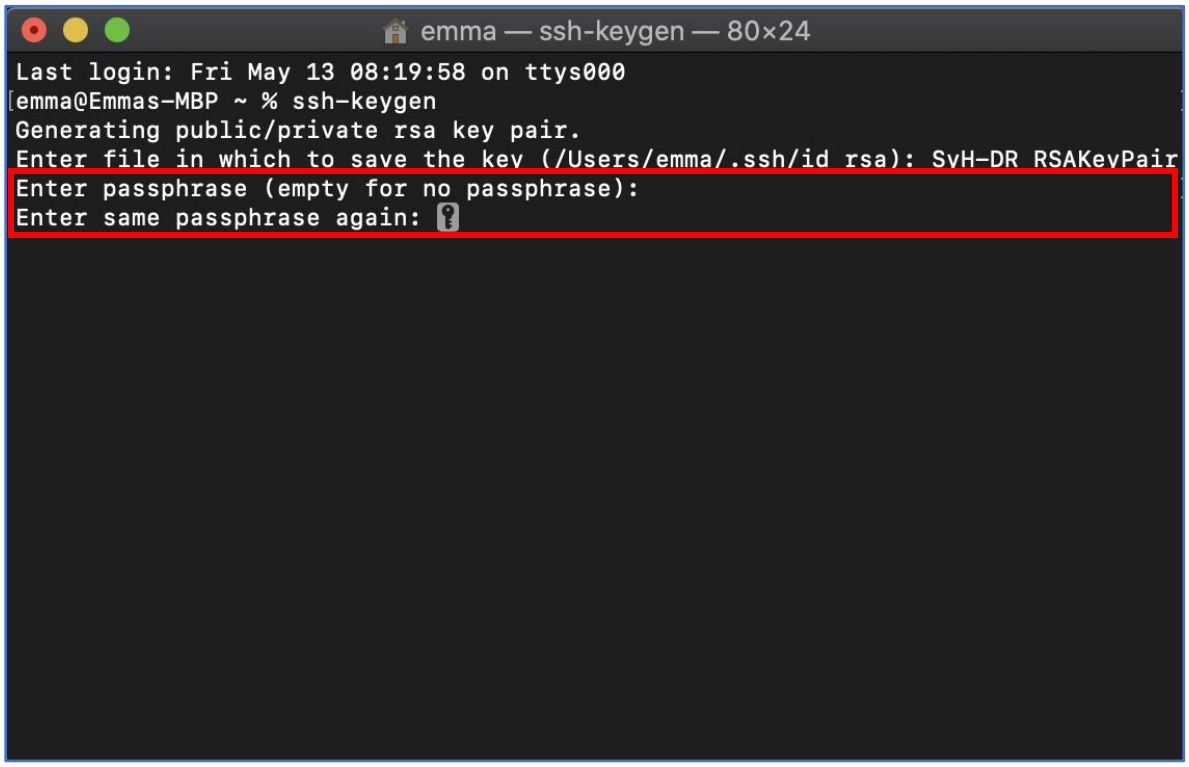
Figure 11: Terminal Generating Key Pair



5. The Terminal session window will prompt you to enter a passphrase.
    a. Enter a secret passphrase of your choosing. *Note: The typed characters will NOT appear on the screen. You will only see a Key icon.*

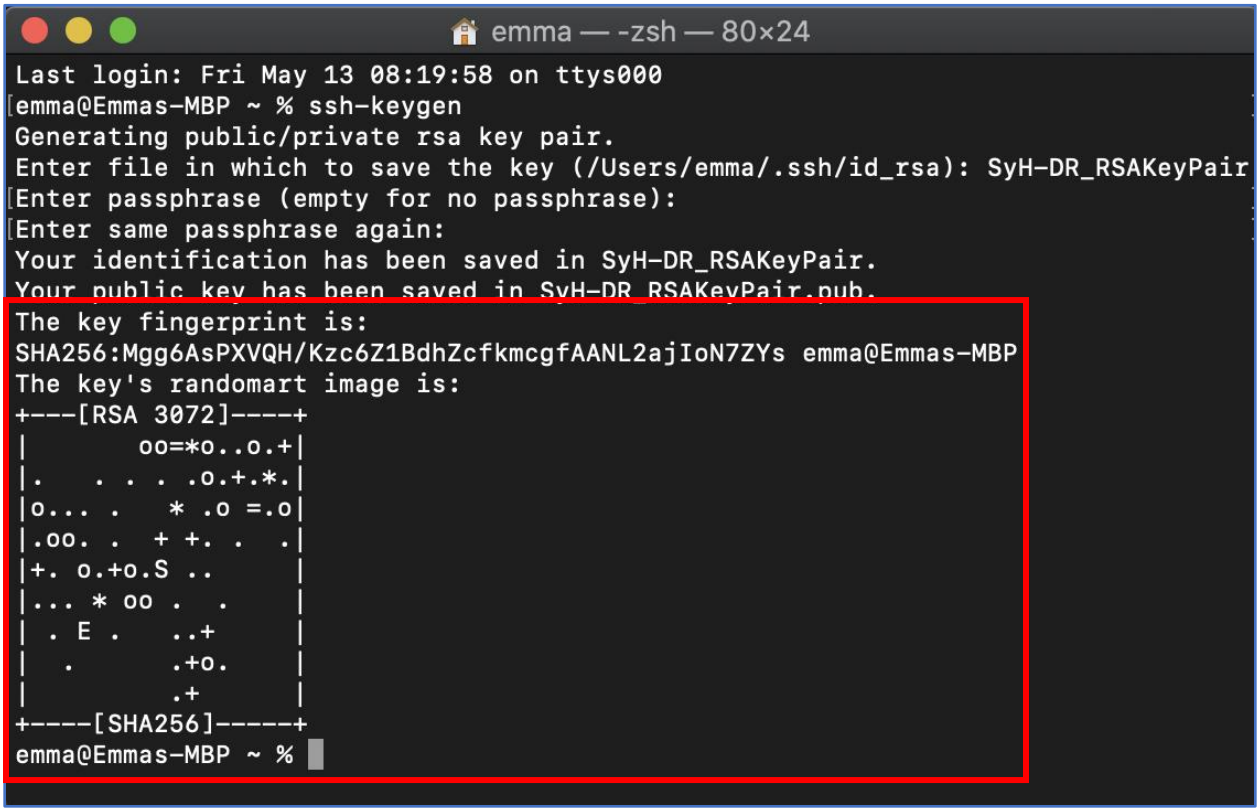
    b. Press the **Enter** key on your keyboard, and then enter the same passphrase again. *Be sure to securely save this passphrase for future use when downloading the SyH-DR files. We cannot lookup or reset this passphrase on your behalf. If you do not have the passphrase, you will need to recreate the RSA Key Pair.*

Figure 12: Enter Passphrase for the RSA Key



6. Press the **Enter** key on your keyboard. The key fingerprint will appear in the Terminal session window.

Figure 13: Key Fingerprint in the Terminal Window

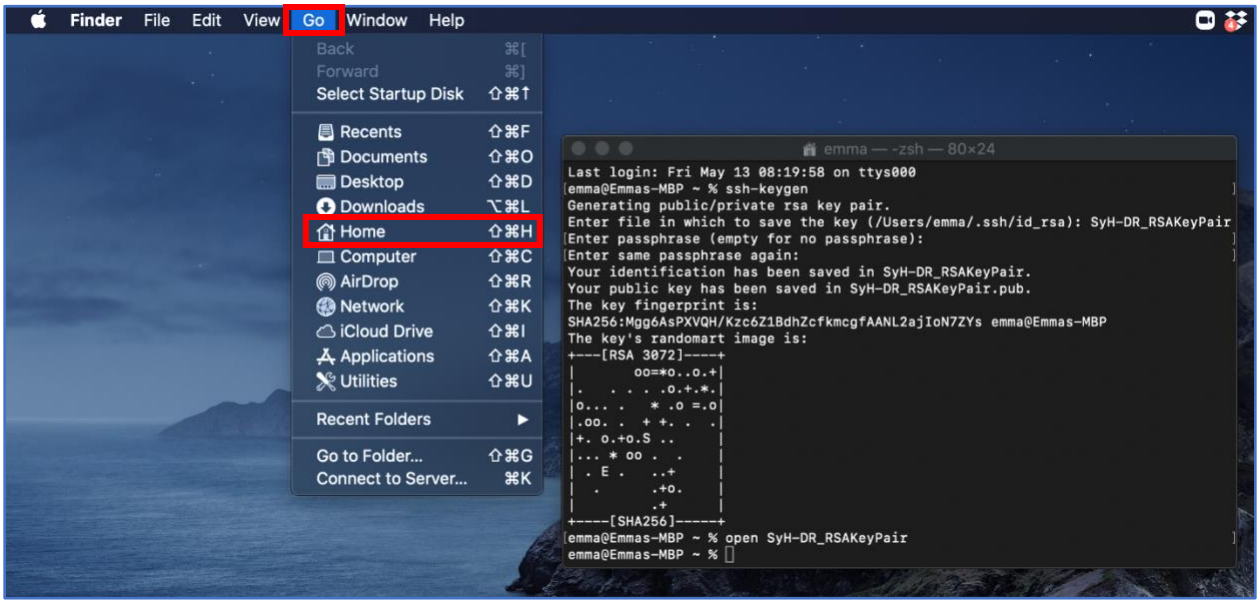


7. Next, verify that the files are saved to your computer.

    a. Click the desktop area outside of the Terminal session window to show the **Finder** menu.

    b. Select the **Go** dropdown menu and select **Home**.

Figure 14: FInding the Public and Private Key Files

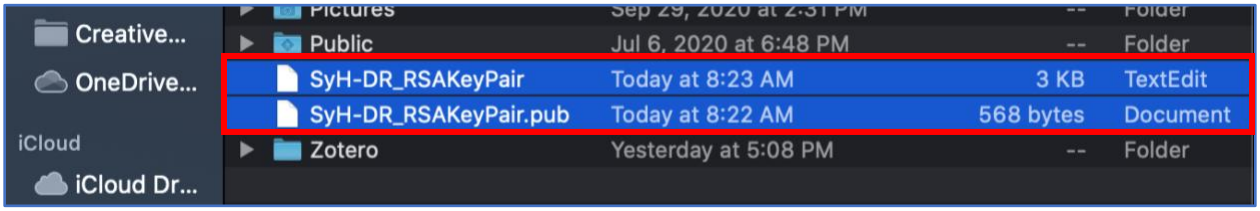


8. Your computer's file finder will open to your **Home** folder. Verify that there are two files with the file name you entered in Step 4.

    a. The file with the ".pub" extension is the **Public key** file. **This is the file that you will send to AHRQ as an email attachment.**

    b. The file that does **not** have the .pub extension is the **Private key**. Make sure this file is saved to a private location on your computer.

Figure 15: Public and Private Key Files



Appendix A:
SyH-DR Request Form

Please submit completed application and signed DUA to SyH-DR@ahrq.hhs.gov.

Agency for Healthcare Research and Quality (AHRQ)
Request for Synthetic Healthcare Database for Research (SyH-DR)

1. Applicant Information

First Name: _____ Middle Initial: _____

Last Name: _____

Title / Position: _____

Institutional/Organizational Affiliation: _____

Type of Organization: ☐ Not-for-Profit ☐ For-Profit ☐ Other _____

Street Address Line 1: _____

Street Address Line 2: _____

City: _____ State: _____ Zip: _____

E-mail Address: _____

Phone Number: _____

2. Please provide the names of all individuals on your research team who may access the requested data as part of this application.

3. **In the space provided below, please describe your intended use of the SyH-DR data (250 words or less). Your response should include the following:**
    - A clear statement of the research question(s) you plan to address.
    - The overall purpose and goals of your research.
    - An explanation of how you and/or your organization will use the output generated from your SyH-DR analyses.
    - The expected final product(s) and anticipated audience(s) (e.g., client reports, peer-review manuscripts). If your audience includes clients, please describe the type of clients you serve.

4. **Confirmation and Signature**

☐ I have read all information on the SyH-DR webpage, including the data use agreement (DUA), and understand that the use of this database is restricted to the individuals named on this application.

☐ A signed DUA for all individuals named on this application is included with this request.

☐ I understand that my complete application must be approved by AHRQ before I receive access to SyH-DR. AHRQ shall have sole discretion with respect to the determination of SyH-DR access approval.

Signature: _____ Date: _____

Appendix B:
SyH-DR Data Use Agreement (DUA)

Synthetic Healthcare Database for Research Data Use Agreement

Agency for Healthcare Research and Quality (AHRQ)
U.S. Department of Health and Human Services

WARNING: ANY EFFORT TO DETERMINE THE IDENTITY OF INDIVIDUALS OR ESTABLISHMENTS IS PROHIBITED BY LAW AND SUBJECT TO FEDERAL PENALTY.

This Data Use Agreement ("Agreement") governs the disclosure and use of data in the Synthetic Healthcare Database for Research (SyH-DR), which is maintained by the Agency for Healthcare Research and Quality (AHRQ). Section 944(c) of the Public Health Service Act (42 U.S.C. §299c-3(c)) ("the AHRQ Confidentiality Statute") requires that data collected by AHRQ that identify individuals or establishments be used only for the purpose for which they were supplied. SyH-DR may only be used for research, analysis, and aggregate statistical reporting projects. AHRQ does not authorize the use of SyH-DR for commercial or competitive purposes affecting establishments; to determine the rights, benefits, or privileges of individuals or establishments; for criminal and civil litigation, including expert witness testimony; for law enforcement activities; or for any other purpose incompatible with the AHRQ Confidentiality Statute.

The undersigned data recipients provide the following assurances concerning SyH-DR:

Protection of Individuals

- I will not release or disclose any information that directly or indirectly identifies persons. This includes attempts to identify individuals through the use of vulnerability analysis or penetration testing.

Protection of Establishments

- I will not publish or report, through any medium, data that could identify individual establishments directly or by inference.

- When the identities of establishments are not provided in the datasets, I will not attempt to use the dataset to learn the identity of any establishment.

Limitations on Data Use, Sharing, and Disclosure

- I will not use or disclose the dataset, or any part thereof, except for research, analysis, and aggregate statistical reporting, and only as permitted by this Agreement.

- I will not use the dataset for unauthorized purposes. AHRQ does not authorize the use of SyH-DR for commercial or competitive purposes affecting establishments; to determine the rights, benefits, or privileges of individuals or establishments; for criminal and civil litigation, including expert witness testimony; for law enforcement activities; or for any other purpose incompatible with the AHRQ Confidentiality Statute.

- I will not redistribute SyH-DR by posting on any website or publishing in any other publicly accessible online repository. If a journal or publication requests access to data or analytic files, I will cite restrictions on data sharing in this Agreement.

Safeguards

- I will ensure that the data are kept in a secured environment and that only authorized users (individuals who have signed the Agreement) will have access to the data.

Responsibility

- I acknowledge and affirm that I am personally responsible for compliance with the terms of this Agreement, to the exclusion of any other party, regardless of such party's role in sponsoring or funding the research that is the subject of this Agreement.

- I acknowledge and affirm that interpretations, conclusions, and/or opinions that I reach as a result of my analyses of the datasets are my interpretations, conclusions, and/or opinions, and do not constitute the findings, policies, or recommendations of the U.S. Government, the U.S. Department of Health and Human Services, or AHRQ.

- I will acknowledge in all reports based on these data that the source of the data is the “Synthetic Healthcare Database for Research (SyH-DR), Agency for Healthcare Research and Quality."

- I will indemnify, defend, and hold harmless AHRQ and the data organizations that provide data to AHRQ for SyH-DR from any or all claims and losses accruing to any person, organizations, or other legal entity as a result of violation of this Agreement. This provision applies only to the extent permitted by Federal and State law.

- I agree to report the violation or apparent violation of any term of this Agreement to AHRQ without unreasonable delay and in no case later than 30 calendar days of becoming aware of the violation or apparent violation.

Terms, Breach, and Compliance

Any violation of the terms of this Agreement shall be grounds for immediate termination of this Agreement. AHRQ shall determine whether a data recipient has violated any term of the Agreement. AHRQ shall determine what actions, if any, are necessary to remedy a violation of this Agreement, and the data recipient(s) shall comply with pertinent instructions from AHRQ. Actions taken by AHRQ may include but not be limited to providing notice of the termination or violation to affected parties and prohibiting data recipient(s) from accessing SyH-DR in the future.

In the event AHRQ terminates this Agreement due to a violation or finds the data recipient(s) to be in violation of this Agreement, AHRQ may direct that the undersigned data recipient(s) immediately return all copies of the SyH-DR to AHRQ or its designee without refund of purchase fees.

Acknowledgment

I understand that this Agreement is requested by the United States Agency for Healthcare Research and Quality to ensure compliance with the AHRQ Confidentiality Statute.

I understand that a violation of the AHRQ Confidentiality Statute may be subject to a civil penalty of up to $10,000 under 42 U.S.C. §299c-3(d) and that deliberately making a false statement about this or any matter within the jurisdiction of any department or agency of the Federal Government violates 18 U.S.C. § 1001 and is punishable by a fine, up to 5 years in prison, or both.

My signature indicates that I understand the terms of this Agreement and that I agree to comply with its terms.

Signed: _____

Print or Type Name: _____

Affiliation: _____

Date: _____

Email: _____

Appendix C:
A Brief Introduction to Using SyH-DR

SyH-DR Files and Data Elements

SyH-DR has 14 data files available for download, provided in both CSV, SAS, and Stata format. In addition, Stata and SAS read-in programs are available for sub-setting each of the CSV files.

Claims Files

- Commercial Inpatient File
- Commercial Outpatient File
- Commercial Person-Level File
- Commercial Pharmacy File
- Medicaid Inpatient File
- Medicaid Outpatient File
- Medicaid Person-Level File
- Medicaid Pharmacy File
- Medicare Inpatient File
- Medicare Outpatient File
- Medicare Person-Level File
- Medicare Pharmacy File

Provider Files

- Medicaid Provider File
- Medicare Provider File

The SyH-DR data files contain a combination of retained, masked, partially synthesized, and fully synthetized data elements.

Retained Data Elements

Inpatient and Outpatient Files:

- Person weight
- Claim type code
- Service begin date
- Service end date
- Length of stay
- Type of bill code

Pharmacy Files:

- Person weight
- Claim line number
- Fill date

Masked Data Elements

Inpatient and Outpatient Files:

- Person ID
- Facility ID
- Claim control number

Pharmacy Files:

- Person ID
- Claim control number

- Pharmacy claim number

Partially Synthetized Data Elements

Inpatient and Outpatient Files:

- Primary diagnosis code
- Diagnosis codes 1-25
- ICD procedure codes 1-25
- CPT procedure codes 1-25

Pharmacy Files:

- Generic drug name

Fully Synthetized Data Elements

Inpatient and Outpatient Files:

- Attending physician specialty
- Admission type
- Discharge status
- Plan paid amount
- Total charge amount

Pharmacy Files:

- Plan paid amount
- Total charge amount

Implications of Synthetization and Deidentification for Research

The SyH-DR is constructed in a way that balances analytical utility with disclosure protection. Since the SyH-DR is partially synthesized and deidentified, it has some limitations for research compared with identifiable claims data. Users should note the following elements of the data:

- Synthetic values were generated from models trained on the original data. Although the models attempt to capture statistical dependencies between key variables, the synthetic data may not capture statistical relationships among any given set of variables. Users with research questions that span multiple variables, one or more of which are synthesized, are advised to validate results from the SyH-DR against other data sources.
- Synthetic diagnoses, procedures, and drugs were generated so that univariate distributions of these variables mimicked distributions in the source data. Due to a stochastic (i.e., random) element in the synthetic data generation process, the frequencies of synthetic diagnoses, procedures, and drugs will differ from those in the source data. While these differences are usually small, they may be pronounced for rare diseases, procedures, or drugs. As such, researchers are advised to exercise caution when using the SyH-DR to study rare diseases beyond the diagnosis category level (i.e., with a more granular ICD-10 diagnosis code than the first three characters), rare procedures beyond the CCS category level, and rare drugs beyond the therapeutic class level. By the same principle, researchers should exercise caution when interpreting results from small domains (e.g., estimating the prevalence of a disease among a certain age group in a ZIP Code).
- All claims that directly identified a newborn were removed, so the SyH-DR cannot be used to study newborns.

- Age is provided only in bins, so researchers cannot use the SyH-DR to analyze events that happen at an exact year of age or for people with an exact birth date. However, the age bins were designed to be consistent with age bins used by the Census Bureau and other data sources so that the SyH-DR can be merged with other data sources by age bin.
- ZIP Codes with a very small population were aggregated to a lower number of digits, so not all five-digit ZIP Codes are available.
- A small amount of random noise was added to length of stay, so use of the SyH-DR for analyses that rely on an exact length of stay should be done with caution.
- The SyH-DR has no mortality data for people insured by commercial plans.
- Mortality data via discharge status are available for Medicare and Medicaid, but they are synthesized, and the ZIP Codes were randomly switched to relatively near ZIP Codes for individuals coded as expired.
- Mortality information is not available via enrollment flags.
- The Children's Health Insurance Program (CHIP) indicator applies only to people less than 18 years of age in the SyH-DR, so pregnant women with CHIP are not indicated.

How To Use SyH-DR for Data Analysis

Choosing Data Elements for Analysis

- Most data elements are provided for all three payer types, but several are specific to certain payers. For example, total charges are not provided for commercial claims. The SyH-DR Codebook details which data elements are available for each payer.
- Although the SyH-DR contains up to 25 diagnosis codes, 25 ICD procedure codes, and 35 CPT/HCPCS codes, the number of diagnosis and procedure codes varies across payers. These are the maximum numbers of each code across payers, except that the SyH-DR does not contain rare "E-codes" present in the source Medicare data. Therefore, claims for some payer types will never have more than a certain number of codes if the source data for the payer has fewer codes than the number present in the SyH-DR. In this case, the data elements will be present but will always be shown as missing (blank).
- All International Classification of Diseases (ICD) diagnosis and procedure codes in the SyH-DR use ICD-10-CM/ICD-10-PCS coding.

Masked Identifiers

- Person ID, facility ID, and claim control number are masked in the SyH-DR to prevent linking them back to the source data and to reduce the risk of reidentification.

Longitudinal Person Analyses

- The SyH-DR supports longitudinal analyses at the person level. The person, inpatient, outpatient, and pharmacy files can be linked at the person level to track a person's hospital visits and pharmacy claims throughout 2016 and to associate that use of medical or pharmacy services with their demographics. Person IDs are specific to a payer, so people cannot be linked across payers. It is possible that people may be insured by multiple payers and are therefore present in the data for multiple payers, but this is not known, and those people would have different identifiers for each payer.

Using Weights for Appropriate Analysis

- To take sampling and weighting adjustments into account, use of person weights is highly recommended. Use the person weight (PERSON_WGHT) to project the demographics and hospital service utilization of the SyH-DR sample to the entire U.S. population with health insurance in 2016. The SyH-DR weights were not designed to project pharmacy use of the sample to pharmacy use of the entire U.S. population with health insurance.
- When creating estimates representing certain populations, users may want to check estimates against other data sources, if available, which is recommended.

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