NECST REGISTRY

User guide

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Document History

Version	Date	Author	Description
1.0	02/06/2020	Bindu Kakkadavath, Senior Business Analyst –VCS Digital Health	Initial draft
1.1	19/6/2020	Bindu Kakkadavath, Senior Business Analyst –VCS Digital Health	Changes as reviewed and added new sections for the new features developed.
1.2	27/08/2020	Kath Ryan – Senior Business Analyst VCS	Updated formatting and screen shots where required.
1.3	07/12/2020	Kath Ryan – Senior Business Analyst VCS	Added details on possible match and supported files types for upload.

Contents

1 Introduction

This User Guide has been written in a procedural style and aims to explain system tasks with details using images taken directly from the application.

1.1 Intended Audience

This user guide is intended to be used by:

- Trainers who train the Providers, who uses NECST Registry to record the care details of a person.
- Administrators responsible for setting up the NECST Registry.
  See section **Error! Reference source not found.** on page **Error! Bookmark not defined.** for more information.

1.2 User Guide Scope

This document includes:

- Information on NECST Registry.
- An overview of the workflow a typical Provider would follow.
- Information on configuring and setting up the NECST Registry.
- This document is only a guideline and will not include a step-by-step instruction on how the end-user would use the system.

1.3 Out of Scope

Details of the below topics are not included in this document.

- **RedCap**

This document does not include details on the management and use of the RedCap system.

See the RedCap links Appendix C: Reference Documents/Links on page 69 for more information.

- **Microsoft Power BI**

This document does not include information on the management and use of Power BI.

The Reporting section in this document provides details on the embedded report feature in the NECST Registry from Power BI.

See the Microsoft Power BI links in Appendix C: Reference Documents/Links on page 69 for more information.

2 NECST Registry Overview

The aim of the National Endometriosis Clinical & Scientific Trials (NECST) Network Registry - Digital Platform Project is to build a national research platform that underpins a comprehensive national program of clinical, basic science and translational research relevant to the needs of Australian endometriosis sufferers, consistent with the research objectives in the National Action Plan for Endometriosis. Specific achievements will include:

- Development of a national Clinical Trials Network (CTN) that co-ordinates support for research organisations and conducts clinical trials for endometriosis treatments and services.
- Development of an Australian Endometriosis Collaborative Research Framework to support co-ordinated patient recruitment, consistent data collection and a national database and bio-repository developed from clinical trials and research projects for national and international research projects specific to endometriosis.

- Formation of a National Collaborative Network capable of responding to a targeted call for integrated endometriosis research focused on translational outcomes.

VCS Digital Health, a division of VCS Foundation Limited, has been engaged by Jean Hailes to establish the Australian Endometriosis Collaborative Research Framework.

VCS will utilise its canSCREEN® cloud platform to deliver the functionality to meet the key capabilities of the NECST program:

- Patient Registration
- National Endometriosis Registry
- Research Management Platform (in future requirements)
- Biobank (in future requirements)
- Platform which is easy to use, flexible, scalable, secure and accessible from a number of locations across Australia on a number of devices including mobile.

2.1 Software System/Application

NECST Registry is split across three components:

- NECST Registry (Survey): the survey system (RedCap) used by the patients to complete their surveys/questionnaires.
- NECST Registry (Core): the system used by the Providers to manage the person's care details.
- NECST Registry BI: a reporting platform for reporting.

2.2 Roles/Personas

Below are the personas/roles of the NECST Registry and RedCap system.

Persona	Group	Description
Participant/Patient/Person	Person	Patient presenting for endometriosis investigation and completing surveys from RedCap.
Provider - Research Lead	Researcher	Researcher looking into endometriosis cause, treatment etc.
Provider - Researcher		
Provider - Clinician	Clinician	Treating Doctor for endometriosis investigation.
Provider - Surgeon		Treating Surgeon for endometriosis investigation
Provider - Laboratory Technician	Clinical staff	Laboratory staff entering/providing information on histopathology.
Provider - Radiologist		Treating healthcare professional for endometriosis investigation.
Provider - Sonographer/Radiographer		
Provider - Fellows/Registrars		Supporting clinicians.
Provider - Clerical Operator	Clinician Admin	Treating Doctor or Surgeon staff entering information about patients
Administrator - Registry Operator	JH Admin	Data operator/Follow-Up operator responsible for daily registry operations
Administrator- Registry Administrator		Jean Hailes administrative staff responsible for some admin ops

- The Participant/Patient/Person only has access to the NECST Registry – Surveys and do not have access to the NECST Registry - Core System.
- The Providers and Administrator roles has access to the NECST Registry – Core System.

2.3 High Level Features

Below are the high level features of NECST Registry:

Feature	Low level Items
Surveys (RedCap Surveys/Questionnaires)	• Patient Demographics and Consent questionnaire • Patient reported outcome measures (PROMs) - EQ-5D questionnaire • PROMs - EHP-30 questionnaire • Clinical Pres Med Hx questionnaire • Clinical Pres Med Hx - Follow-Up
Search Basic and Advanced search	• Person • Episode • Provider • Place

Person Record	• Demographics
	• Consent
	• Record Access
	• Follow-Up
	• Documents
	• Episodes (Editable)
	  ○ Clinical Pres Dx-Clinician
	  ○ Medical Management
	  ○ Medication
	  ○ Imaging – US
	  ○ Imaging – MRI
	  ○ Surgical Management
	  ○ Histopathology
	• Episodes (Non-Editable)
	  ○ Clinical Pres Med Hx
	  ○ Clinical Pre Med Hx – Follow-Up
	  ○ PROMs EQ-5D
	  ○ PROMs EHP-30

Patient Record Matching	• QA Queue • Matching and Merging
Document Management	• Bulk Document Upload • Document Queue
Follow-Up	• Correspondence • Follow-Up Action Queue • Follow-Up Queue
Reporting	• General Power BI capabilities • Embedded Reports
Access Control and Configuration	• Theme and Branding • Licence • Group • User/Business Operation • Provider • Place

3 Clinician Registry Usage

The following section is designed to guide Clinicans (encompassing Clinical Admin, Clinical Staff and Researchers) on using the Registry features:

All of the below scenarios assume you have successfully logged into the Regsitry. See General Registry Usage on page 18 for information on logging in.

IMPORTANT

Each user ID is linked to a Provider record.

Each Provider record is then linked to one or more Hospitals (Public or Private) and/or Private Clinic Practices (called Places in the Registry).

A Provider is then prompted by the system to ask the user to select the Hospital/Clinic at login to associate the patient records with the correct Provider/Place association.

General information on Episodes can be found:
Adding an Episode on page 45.
Viewing/Editing an Episode on page 46.
Enter Notepad text and click **OK**. See Entering/Auditing using Notepad on page 32 for more information.

Enter/upload Documents and click OK. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.

Deleting an Episode on page 46.

Uploading Document from Person Details/Episode/Provider/Place Details on page 31.

Quick Reference links:

- Entering a Clinical Pres Dx – Clinician Episode on page 11
- Entering a Medical Management Episode on page 12
- Entering a Medication Episode on page 13
- Entering a Surgical Management Episode on page 14
- Entering an Imaging (US; Ultrasound) Episode on page 14
- Entering an Imaging (MRI) Episode on page 15
- Entering an Histopathology Episode on page 16

3.1 Adding/Consenting a New Patient to the NECST Registry

1. Provide the patient with the survey link to complete their patient consent and capture demographic details.
   a. https://redcap.link/necstregistry-patientregistration
2. Once the patient has completed the Patient Demographics and Consent questionnaire, the patient record is created in the Registry within five minutes.
   a. The details in the registry are a reflection of exactly what the patient has entered in Redcap as part of the questionnaire collection.
   b. A patient who is new will be in a Consent status of 'Consent Unconfirmed' and overall system status of 'Inactive'.
3. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
4. Click the Consent tab and click Edit.
5. Update the Consent status to 'Consent Confirmed'. See Consent on page 38 for more information.
6. Check the Consent Options (Statements), Consent Date, Primary Provider and Place are correct (these are defaults from your login details and current date). Select the drop-down list to edit.
7. Select the Date of Consent.
8. Review with the patient, the consent provided and enter a Signature Date if the patient wishes to proceed.

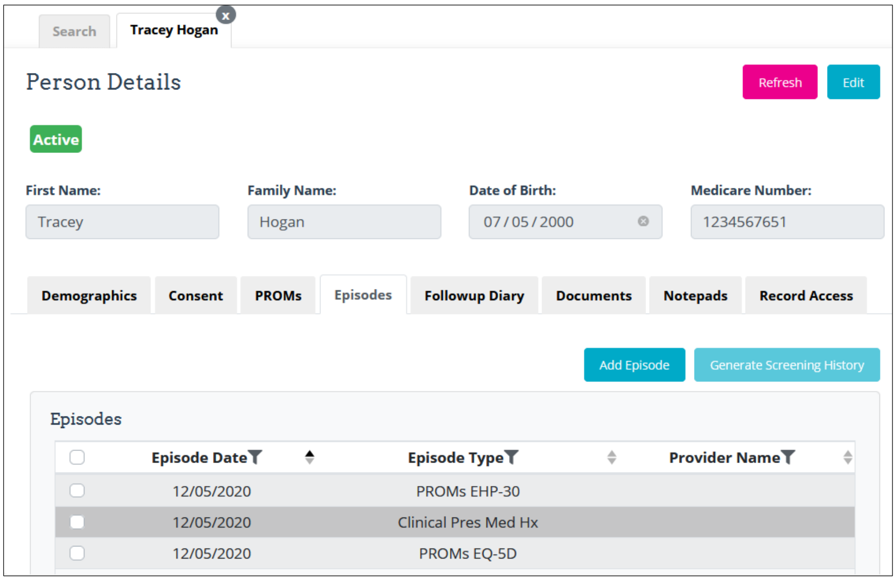
9. Return to the top of screen and click **Save**.
10. Enter a mandatory notepad detailing any changes made and click OK.
11. The person record is now updated to a system status of ‘Active’ along with a a successfully created date on the system.
12. If required, review the patient’s Clinical Pre Med Hx and PROMs (EQ-5D +/- EHP-30) questionnaires (submitted using Redcap).
13. You may now proceed to create one or more episodes of care as detailed in the following section based on your individual patient’s clinical needs.

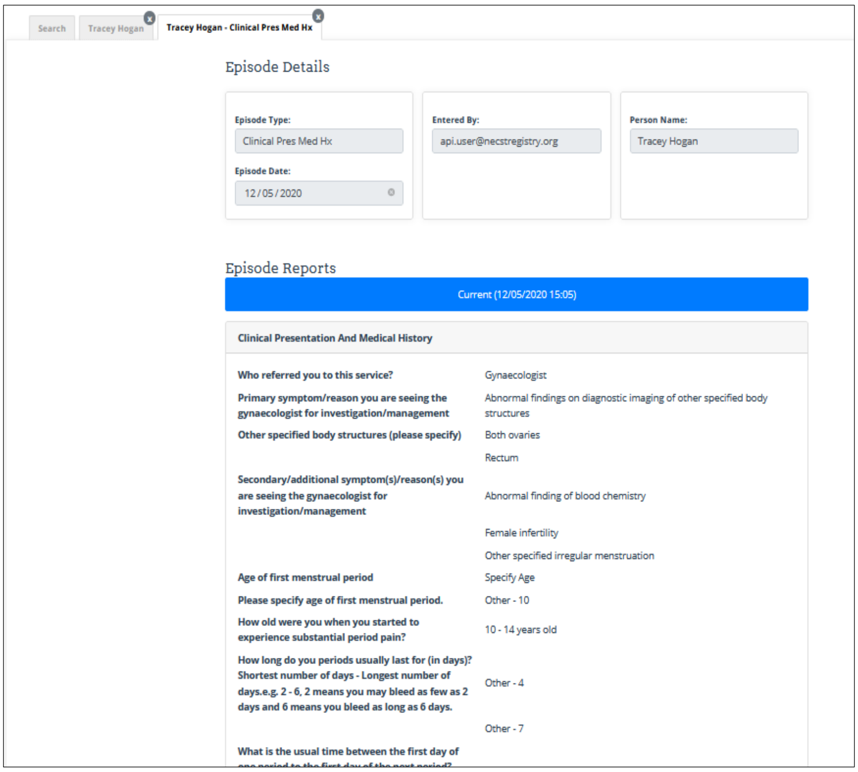
3.2 Clinical Pres Med HX Episode

A Clinical Pres Med Hx Episode is added automatically in the NECST Registry when a person completes their initial Clinical Presentation and Medical History questionnaire via Redcap, which is made available to be viewed from the person’s Episode tab.

Note: A Clinical Pres Med Hx Episode cannot be directly entered or edited from the NECST Registry.

1. To view an Episode, see section Viewing/Editing an Episode on page 46.





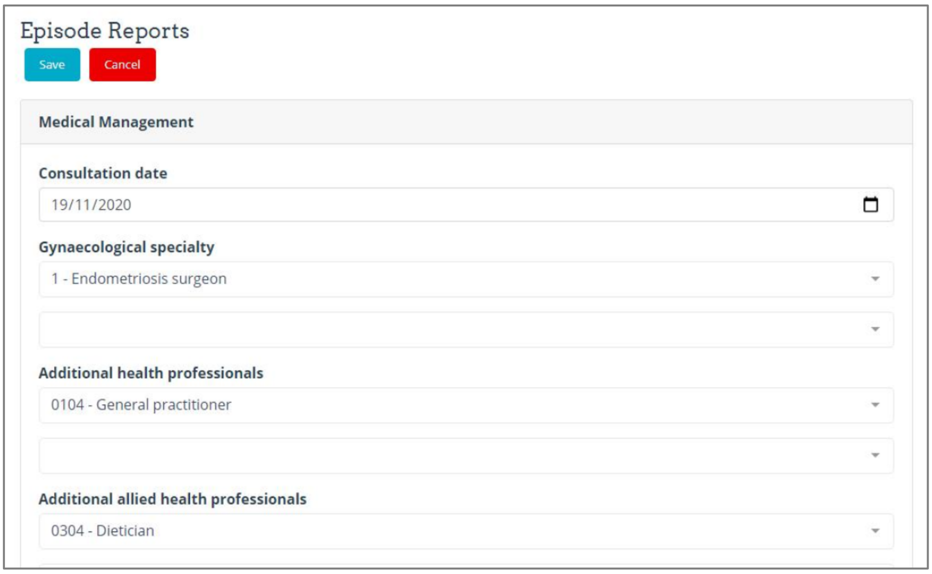
3.3 Entering a Clinical Pres Dx - Clinician Episode

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click **Add Episode**. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Clinical Pres Dx – Clinician.
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click **Add**. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.
8. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
9. Complete the fields specific to the Clinical Pres Dx – Clinician episode and click **Save**.
   Note: Additional fields may display based on the selections you make in providing the data.

10. Scroll further down the page and upload any Documents to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

3.4 Entering a Medical Management Episode

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click Add Episode. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Medical Management.
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click Add. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.
8. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
9. Complete the fields specific to the Medical Management episode and click **Save**.
   Note: Additional fields may display based on the selections you make in providing the data.

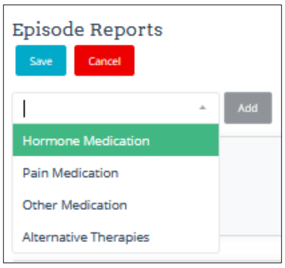


10. Scroll further down the page and upload any Documents to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

3.5 Entering a Medication Episode

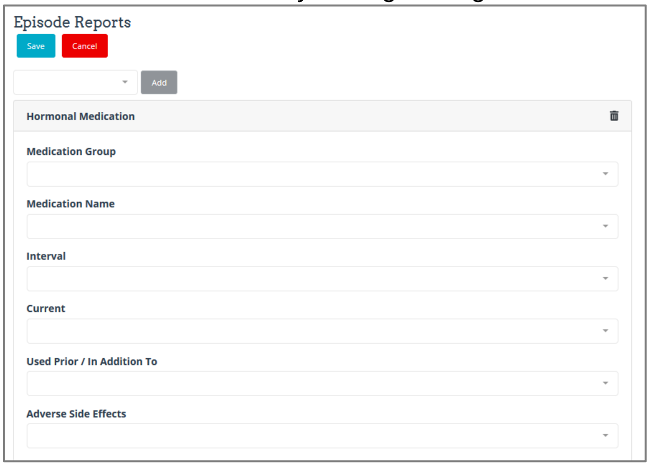
Note: In a Medication Episode, you add one record for each type of medication (Hormonal, Pain, Other and Alternative and complementary therapies) in a single episode. Select the Medication type you want to add and complete the details in the Episode Report section for each medication type.

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click Add Episode. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Medication.
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click Add. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.
8. Select the Report drop down and select the type of medication to add. For example Hormonal Medication.



9. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
10. Complete the fields specific to the type of Medication and click **Save**.

Note: Additional fields may display based on the selections you make in providing the data. For user convenience a save button is located at the top and bottom of the episode report to allow users to easily naviagate large blocks of data entry.



11. Scroll further down the page and upload any Documents to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
12. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

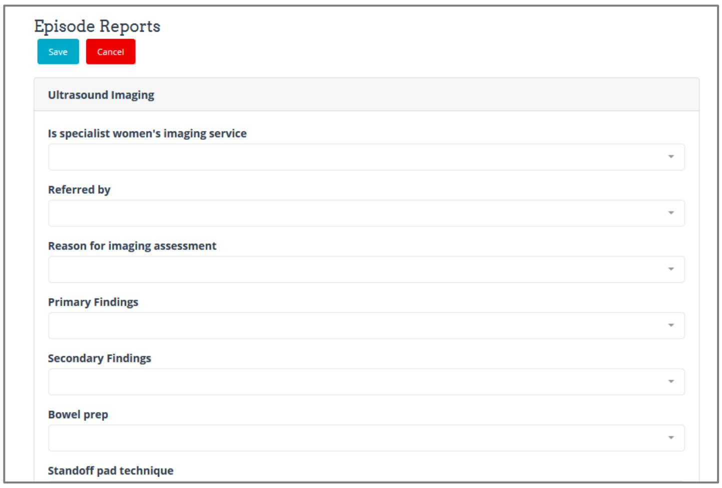
3.6 Entering a Surgical Management Episode

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click Add Episode. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Surgical Management.
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click Add. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.
8. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
9. Complete the fields specific to the Surgical Management episode and click **Save**.
   Note: Additional fields may display based on the selections you make in providing the data.
10. The Endometriosis Fertility Index (EFI) Summary is calculated based on the data entered in the fields relating to the EFI. The calculated EFI Summary is displayed at the bottom of the report.
11. Scroll further down the page and upload any Documents to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
12. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

3.7 Entering an Imaging (US; Ultrasound) Episode

Note: Image attachment sizes are a maximum 50MB per attachment. Maximum of two images per client record.

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click Add Episode. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Imaging (US).
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click Add. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.
8. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
9. Complete the fields specific to the Imaging (US) episode and click **Save**.
   Note: Additional fields may display based on the selections you make in providing the data.



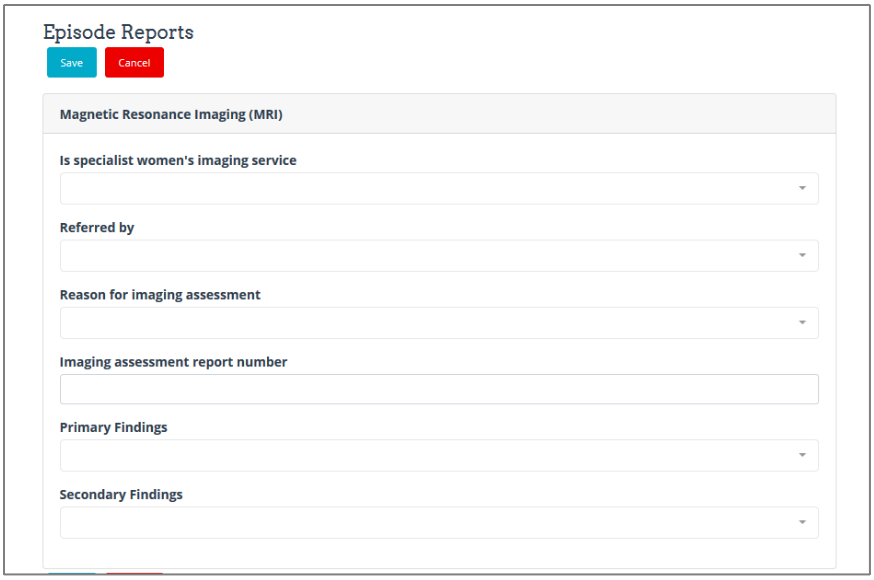
10. Scroll further down the page and upload any Documents (e.g. final ultrasound report +/- images) to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

3.8 Entering an Imaging (MRI) Episode

Note: Image attachment sizes are a maximum 50MB per attachment. Maximum of two images per client record.

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click Add Episode. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Imaging (MRI).
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click Add. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.

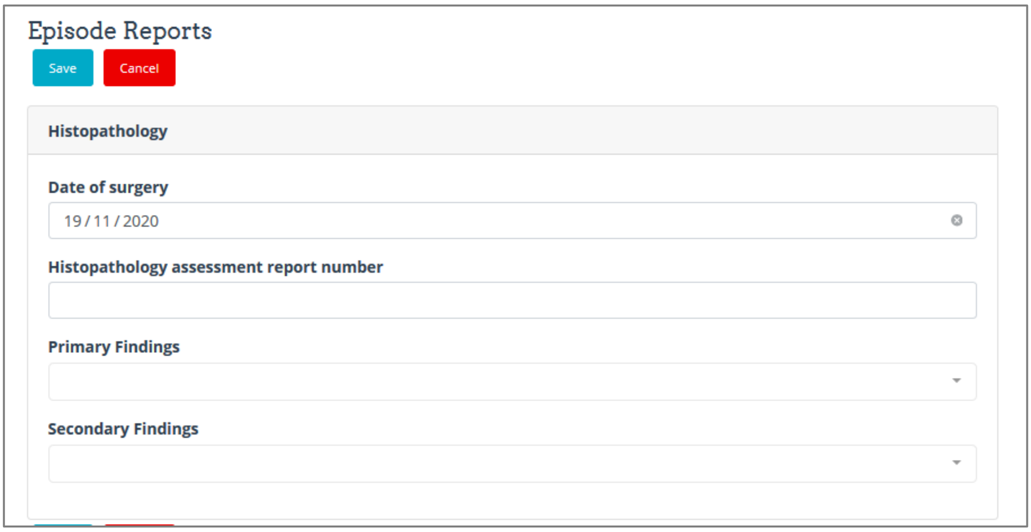
8. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
9. Complete the fields specific to the Imaging (MRI) episode and click **Save**.
   Note: Additional fields may display based on the selections you make in providing the data.



10. Scroll further down the page and upload any Documents (e.g. final MRI report +/- images) to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

3.9 Entering an Histopathology Episode

1. Search for the patient using the patients' Name (basic search) or more details (advanced search). See Person Search on page 25 for more information.
   Or
   Search for the episode using the episode details. See Episode Search on page 26 for more information.
2. Double-click the patient record from the Results shown and click the Episodes tab.
3. Click Add Episode. An add episode screen is displayed to allow you to enter additional information.
4. Select the Episode type Histopathology.
5. Enter the episode date (that is, the date the Clinician treated the patient).
6. Click Add. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
7. Scroll to Episode Reports and click **Edit**.
8. Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
9. Complete the fields specific to the Histopathology episode and click **Save**.
   Note: Additional fields may display based on the selections you make in providing the data.

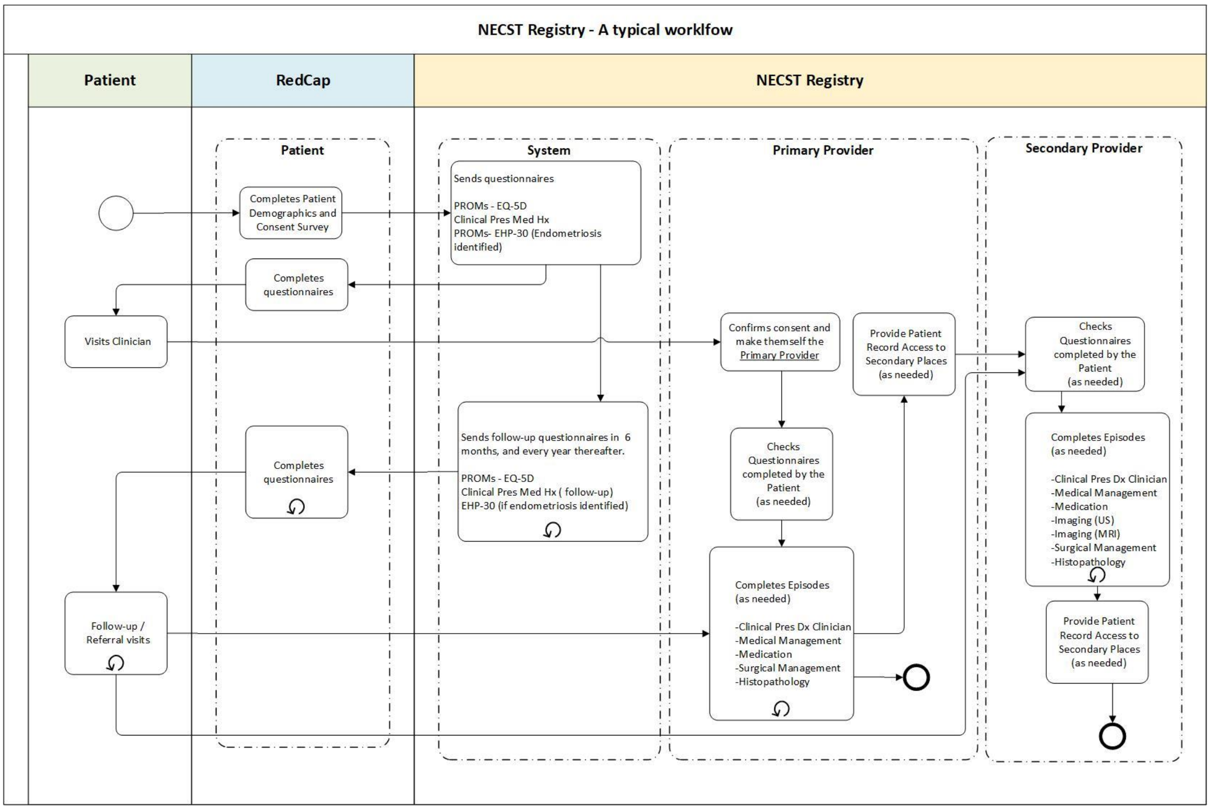


10. Scroll further down the page and upload any Documents (e.g. final histopathology report +/- images) to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads to the system that relate to this episode. Entering/Auditing using Notepad on page 32 for more information.

4 General Registry Usage

4.1 NECST Registry Workflow

The steps below illustrate a typical NECST Registry workflow.



1. Patient completes the Patient Demographics and Consent Questionnaire using the questionnaire link made available to them from various channels at the discretion of the NECST Network.
2. The data from the Patient Demographics and Consent Questionnaire is imported to the NECST Registry.
3. NECST Registry then sends the subsequent questionnaires (Clinical Pres Med Hx, EQ-5D) to the patient to be completed.
4. NECST Registry sends the EHP-30 questionnaire to the patient if the patient is identified to have endometriosis (identified from the Clinical Pre Med Hx questionnaire).
5. Patient completes all the questionnaires sent to them.
6. Patient comes for consultation with the Provider (of type Primary Provider, i.e. Clinician) at the clinic.
7. Provider (of type Primary Provider) logs into the NECST Registry and chooses the Place (location of their practice), searches and opens the person record (i.e. the patient).
8. Provider (of type Primary Provider) then confirms the consent of the person to participate in the registry and make themselves the Primary Provider of the person.
9. Primary Provider, checks the patient's Clinical Pre Med Hx and PROMs (EQ-5D +/- EHP-30) questionnaires (submitted using Redcap).
10. Primary Provider may add new episodes of any of the below type based on the care needed by the patient:
    a. Clinical Pres Dx – Clinician
    b. Medical Management

   c. Medication
   d. Surgical Management (if applicable based on the data available at time of consult)
   e. Histopathology (if applicable based on the data available at time of consult)
11. Primary Provider may identify that the person requires Imaging (US/MRI) to be performed and would make the patient record accessible to the referred Place (Imaging Centre), by adding the Place (Imaging Centre) to the person's Secondary Place.
12. Patient then goes to the Imaging Centre for an US/MRI.
13. Secondary Provider (e.g. Radologist/Sonographer/Radiographer) logs into the NECST Registry, and accesses the patient record.
14. Secondary Provider adds any episode below with the details of the imaging done:
    a. Imaging (US)
    b. Imaging (MRI).
15. Patient may then go for another consultation with the Primary Provider.
16. Primary Provider logs on the NECST Registry, searches for the person and accesses the patient's Imaging episode.
17. Primary Provider may identify that the patient needs surgery.
18. On completion of the surgery, Primary Provider adds any of the below episodes as needed:
    a. Surgical Management
    b. Histopathology.
19. NECST Registry sends the below Follow-Up questionnaires to the person in the next 6 months (from patient registration) and every year thereafter to be completed by the patient:
    a. Clinical Pres Med Hx Follow-Up / Patient demographic update
    b. EQ-5D Follow-Up
    c. EHP-30 Follow-Up (if applicable).
20. Primary Provider / Secondary Providers may add/edit more episodes as needed during patient's Follow-Up consultation.
    Note: Only the provider who creates an episode can delete the episode. If delete is needed outside this system rule it can be performed by the Jean Hailes Administrator.

4.2 Surveys/Questionnaires

Below are the various types of surveys/questionnaires completed by the patient. Once the data syncs from RedCap to the NECST Registry, this data is made available in NECST Registry, under the Person Record.

The system is configured to sync data from RedCap to NECST Registry system, every five minutes.

Survey	Description
Patient Demographics and Consent questionnaire	The details from a completed questionnaire are made available in the NECST Registry, under the Patient Record – Demographics and Consent tabs.
Clinical Pres Med Hx	The details from a completed questionnaire are made available in the NECST Registry, under the Patient Record – Episodes tabs.
Clinical Pres Med Hx – Follow-Up Questionnaire	The details from this questionnaire are made available in the NECST Registry, under the Patient Record – Episodes tabs.
EQ-5D Questionnaire	The details from a completed questionnaire are made available in the NECST Registry, under the Patient Record – PROMs or Episodes tabs.
EHP-30 Questionnaire	If a patient is identified to have endometriosis from their

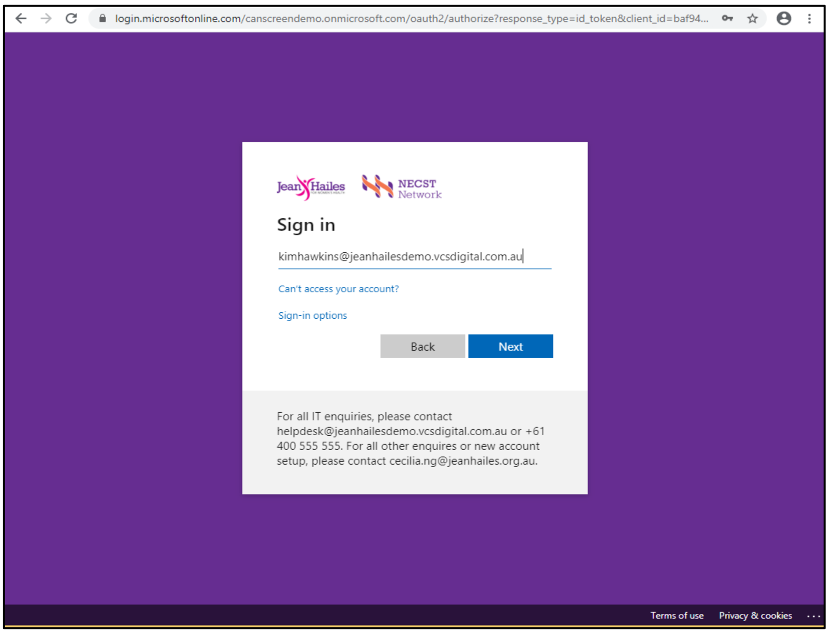
Survey	Description
	Clinical Pre Med Hx survey or has an existing Surgical Episode (with a diagnosis of endometriosis), then the patient will receive this survey. The details from a completed questionnaire are made available in the NECST Registry, under the Patient Record – PROMs or Episodes tabs.

4.3 General Navigation and Functions

4.3.1 Login

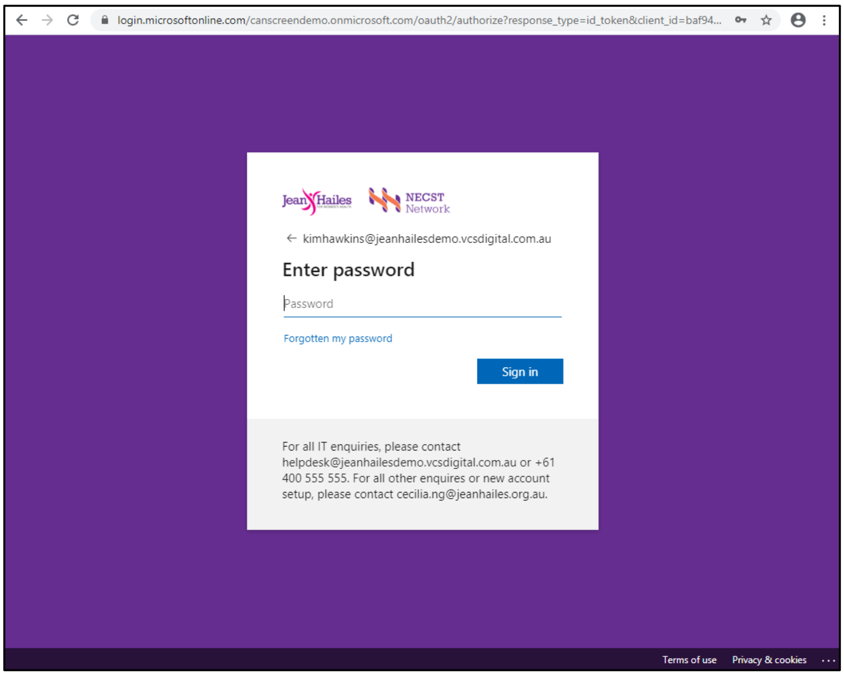
1. Open any web browser and go to https://register.necstregistry.org/.

Note: for supported brower types, see section 6.6 of Frequently Asked Questions page 62.

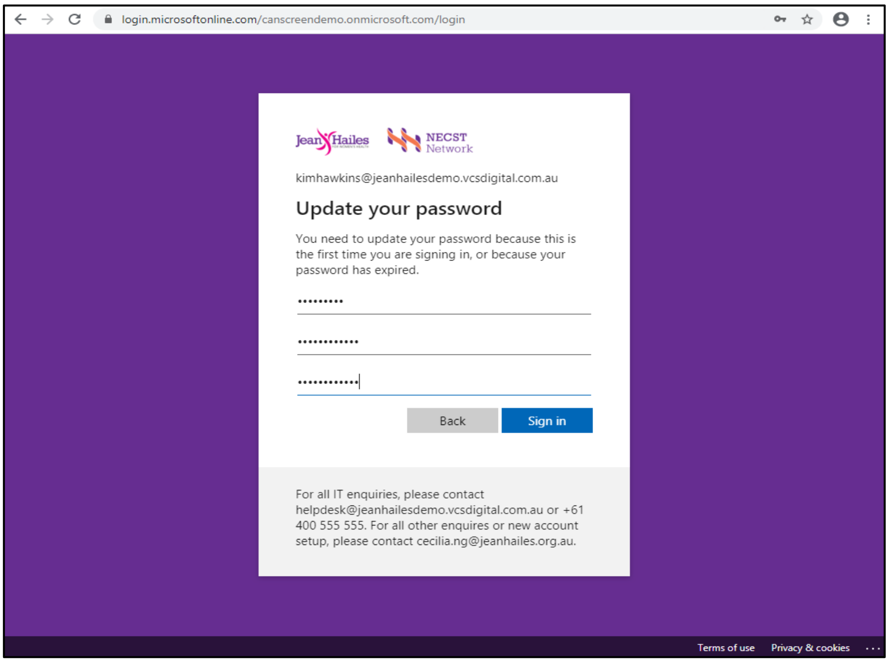


2. Enter your user name and password and **Sign in**.

   Note: Your unique user name and default password will be emailed to you, if you do not have these details or require a user name and password, please contact the NECST Registry Administrator at admin@necstregistry.org.

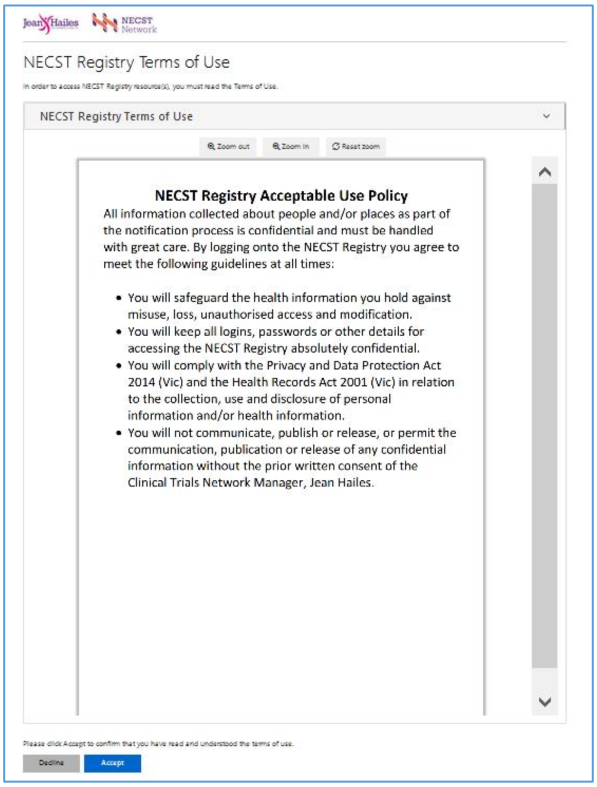


3. If you are logging in for the first time you will be prompted to enter a new password.
4. See Password Policy in Appendix A on page 62 for more information on the password policy.



5. If you are logging in for the first time or you are logging in after you password has been changed, you will be asked to accept the NECST Registry Terms of Use to proceed with the login.

   Note: The System will log you out, if you choose **Decline.**



NECST Registry Terms of Use

In order to access NECST Registry resource(s), you must read the Terms of Use.

NECST Registry Terms of Use

Zoom out | Zoom in | Reset zoom

NECST Registry Acceptable Use Policy

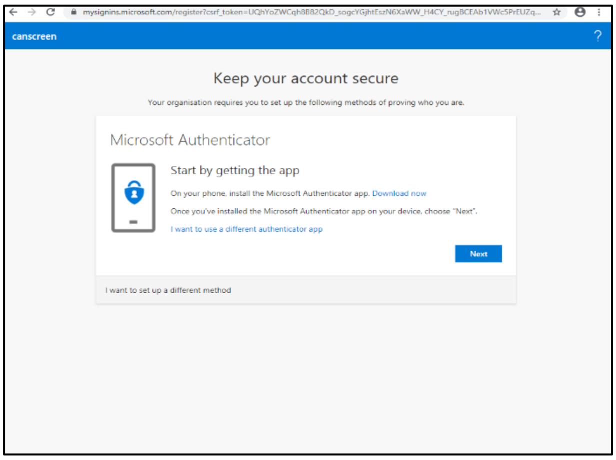
All information collected about people and/or places as part of the notification process is confidential and must be handled with great care. By logging onto the NECST Registry you agree to meet the following guidelines at all times:

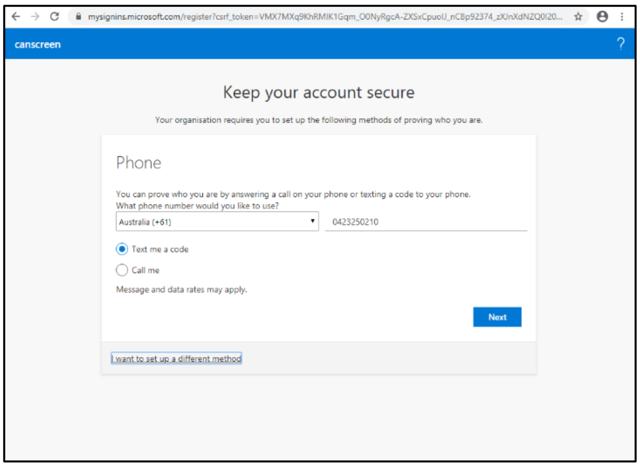
- You will safeguard the health information you hold against misuse, loss, unauthorised access and modification.
- You will keep all logins, passwords or other details for accessing the NECST Registry absolutely confidential.
- You will comply with the Privacy and Data Protection Act 2014 (Vic) and the Health Records Act 2001 (Vic) in relation to the collection, use and disclosure of personal information and/or health information.
- You will not communicate, publish or release, or permit the communication, publication or release of any confidential information without the prior written consent of the Clinical Trials Network Manager, Jean Hailes.

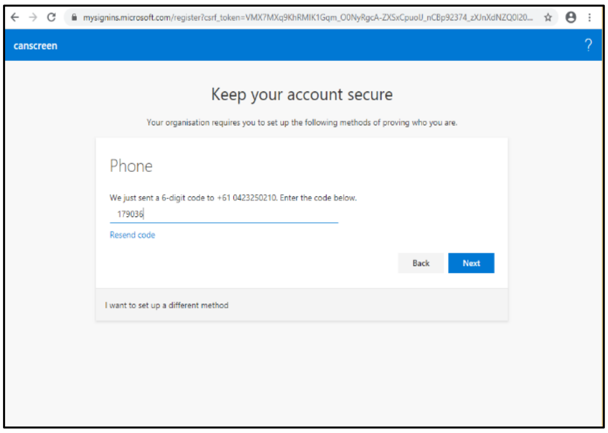
Please click Accept to confirm that you have read and understood the terms of use.

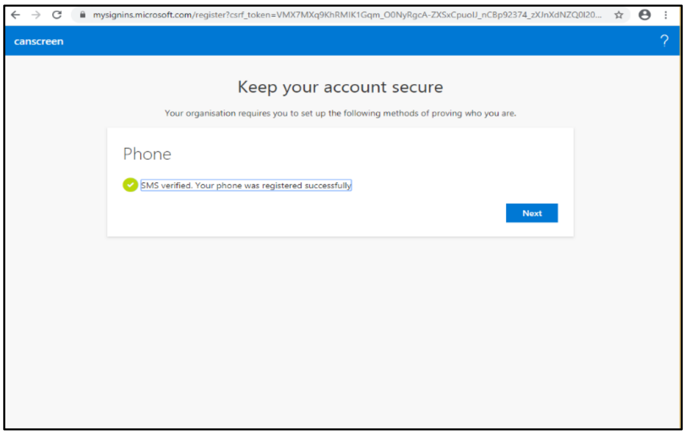
Decline | Accept

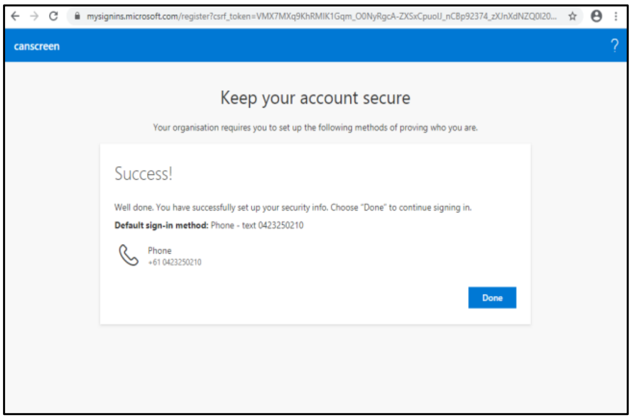
6. Once you have accepted the NECST Registry Terms of Use you will be required to setup MFA (multi-factor authentication) on your first login.





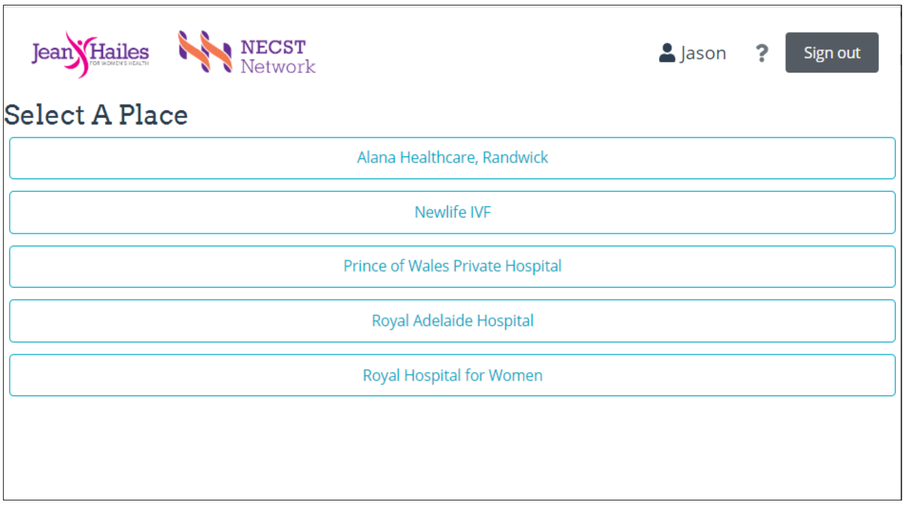






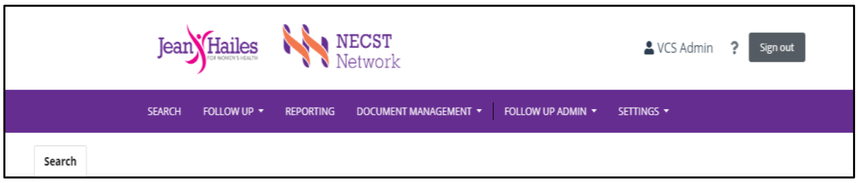
7. Upon successful login you will see the Places that are associated with your Provider account. See Adding a New Provider on page 27 for more information.
8. Select a Place from the list of places.

   Note: An Admin user has access to all the Places and will not have to choose a Place when logging in.



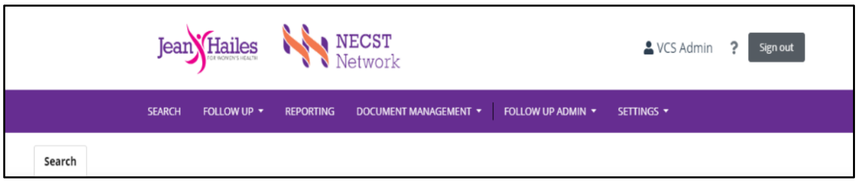
4.3.2 Sign out

1. Click on the **Sign Out** button to sign out.



4.3.3 Accessing Help

1. Click on the **'?'** button to access the help file.

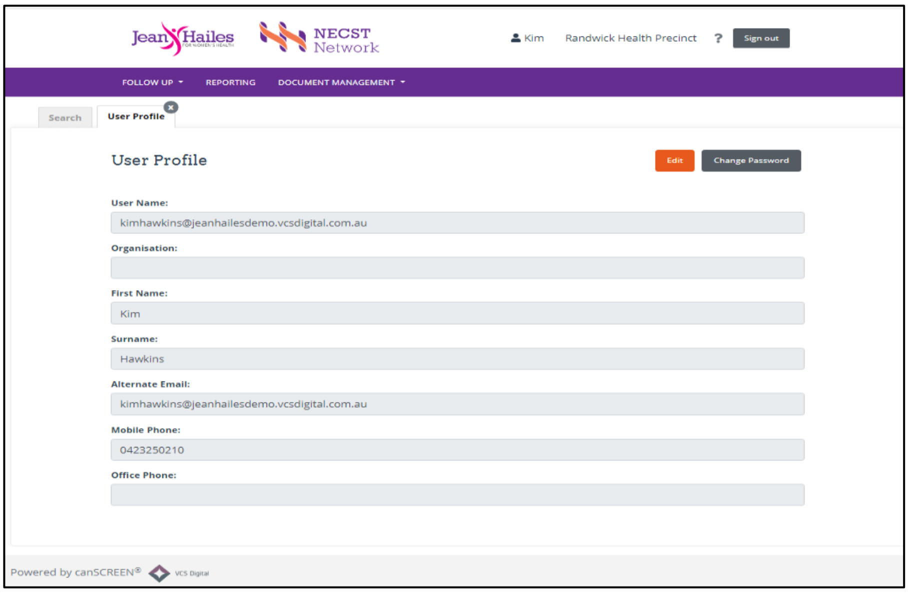


2. This is a context sensitive help file and brings up the topic based on the NECST Registry screen you are on. You may also search on topics as needed.

4.3.4 Viewing User profile

1. View a user profile. For information see **Error! Reference source not found.** on page **Error! Bookmark not defined.**.

2. Click on your name to access you profile details.



4.4 Search

Note: To search for data using the fields you must enter either

- The full value in the field

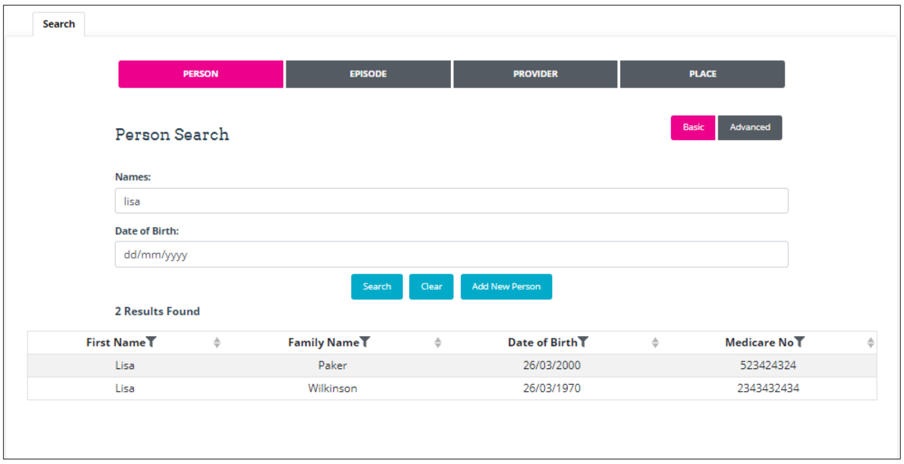
  Or

- Enter %value% to perform a wildcare search.

For example, to search for a partial address, you would enter

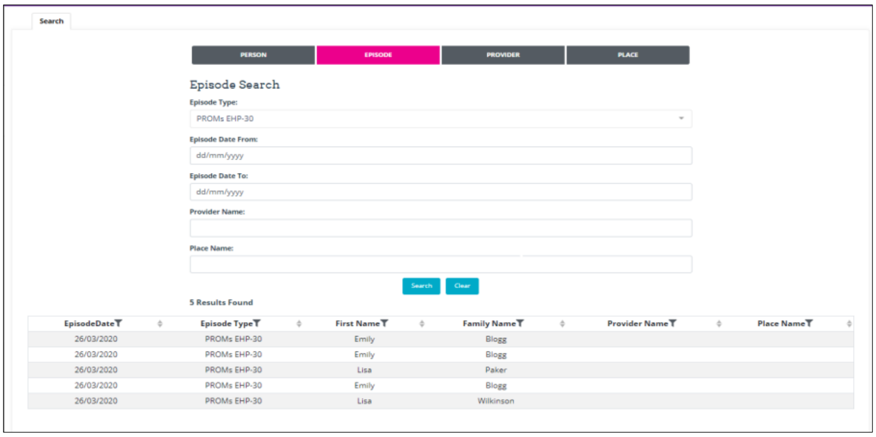
4.4.1 Person Search

1. Enter criteria in the search fields and Click **Search**.
2. Double-click on the record required from the search result grid to view the record.
3. Click **Clear** to start a new search.
4. Clicking the Advanced button will display more fields for search criteria to be entered.
5. Click on **Add New Person** to add a new person.



4.4.2 Episode Search

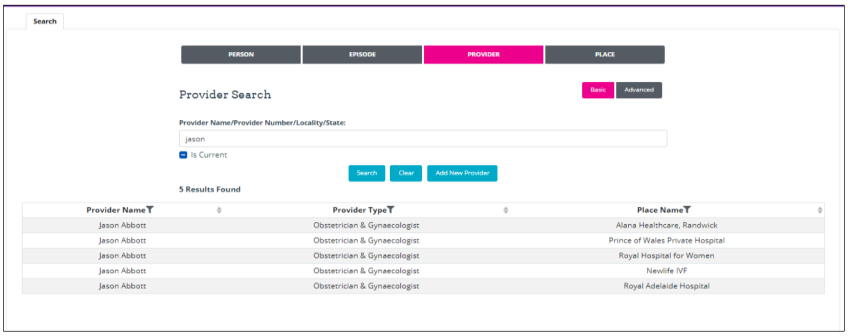
1. Enter criteria in the search fields and Click **Search**.
2. Double-click on the record you wish to view from the search results.
3. Click **Clear** to start a new search.

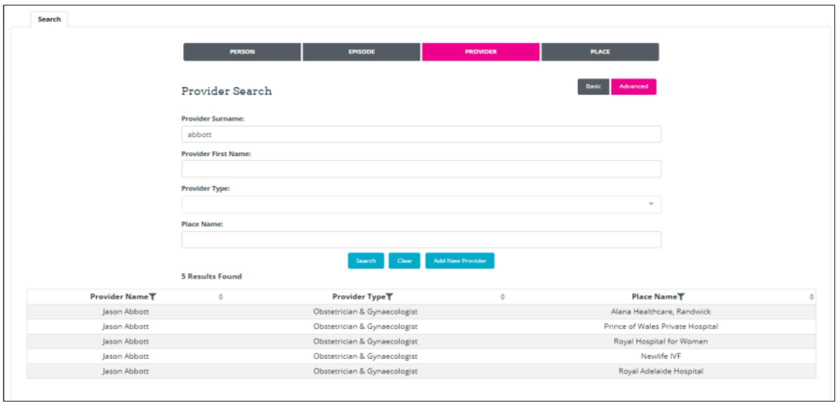


4.4.3 Provider Search

1. Enter criteria in the search fields and Click **Search**.
2. Double-click on the record you wish to view from the search results
3. Click **Clear** to start a new search.
4. Clicking the Advanced button will display more fields for search criteria to be entered.
5. Click on **Add New Provider** to add a new provider.

   Note: Select the 'Is Current' filter to search against records (i.e. current active Providers) that have no end date in the system. To search against the archived records (i.e non-active Providers) clear the Is Current filter on the search.
6. Double-click on the record you wish to view from the search results.



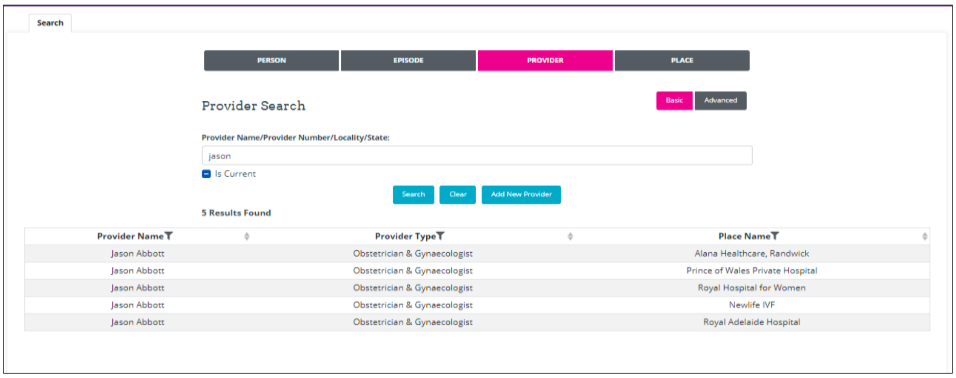


4.4.4 Adding a New Provider

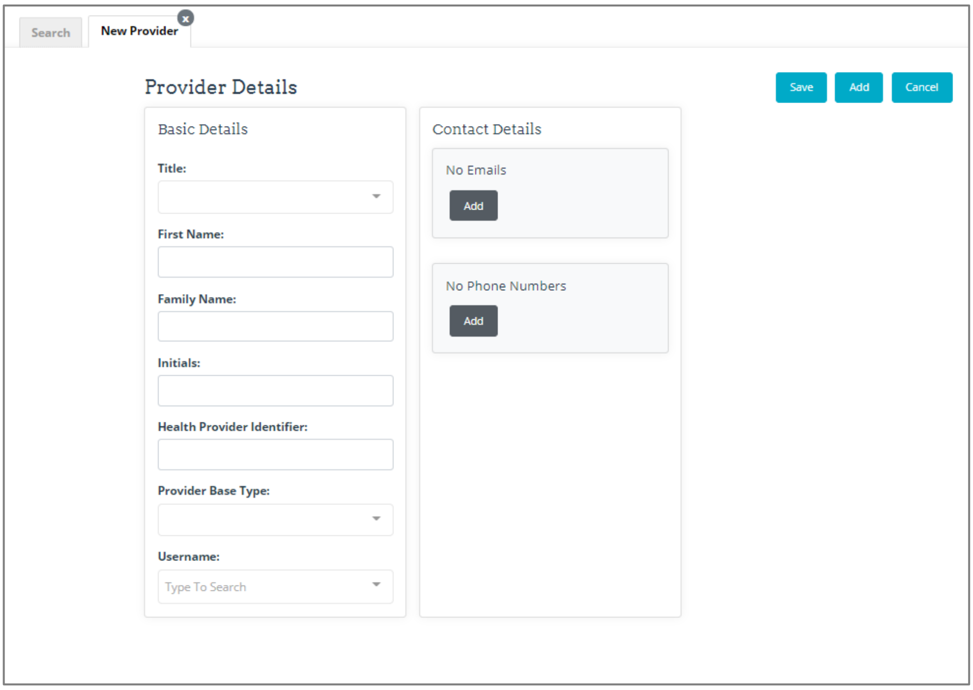
Providers are healthcare workers (can include Gynaecologists and Obstetricians, Radiologists, Radiographers/Sonographers, Nurses, Allied Health Professionals, etc.) involved in the care of the patient/person and may be granted access to the NECST Registry to access the patient details and record the patient's care details.

Note: Username is a mandatory field and should be linked to the user account for a clinical provider. At least one Place is mandatory for the Provider to login to NECST Registry.

1. Search for the Provider from the Provider Search screen.
2. Enter criteria in the search fields and Click **Search**.
3. If the record does not exist, then add the person by clicking **Add New Provider**.

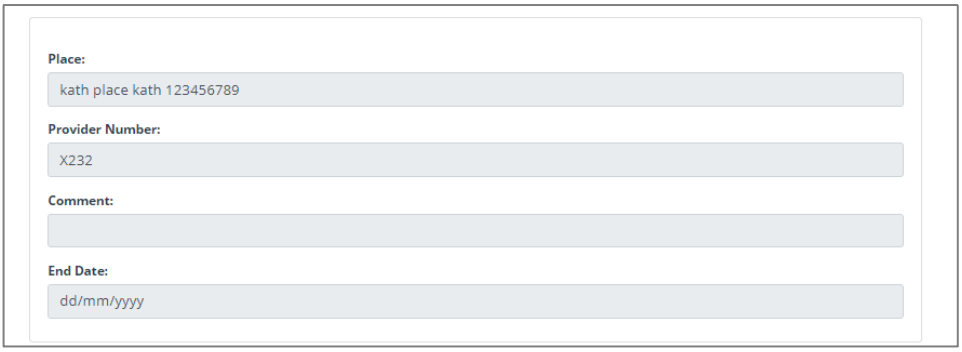


4. Enter the provider details as required.
5. Click **Add** to add a place to the provider record.



6. Search for the place to add it.

   Note: To end date (i.e. remove) a link between Provider and Place you must enter an end date into the end date field of the place record displayed as part of the Provider record. See Deleting a Provider Details on page 29 and Deleting a Place Details – Close Place on page 31 for more information.



7. Add/upload Documents and/or notepads as required. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 or Entering/Auditing using Notepad on page 32 for more information.
8. Click **Save**.

4.4.5 Editing a Provider Details

1. Search for the Provider from the Provider Search screen
2. Enter criteria in the search fields and Click **Search** and double click the record to edit.
3. Click **Edit**.
4. Edit the provider details.
5. Add/upload Documents and/or notepads as required. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 or Entering/Auditing using Notepad on page 32 for more information.
6. Click **Save**.

4.4.6 Deleting a Provider Details

1. Search for the Provider from the Provider Search screen
2. Enter criteria in the search fields and Click **Search** and double click the record to edit.
3. Click **Edit**.
4. Enter an end date for the provider
5. Add/upload Documents and/or notepads as required. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 or Entering/Auditing using Notepad on page 32 for more information.
6. Click **Save**.

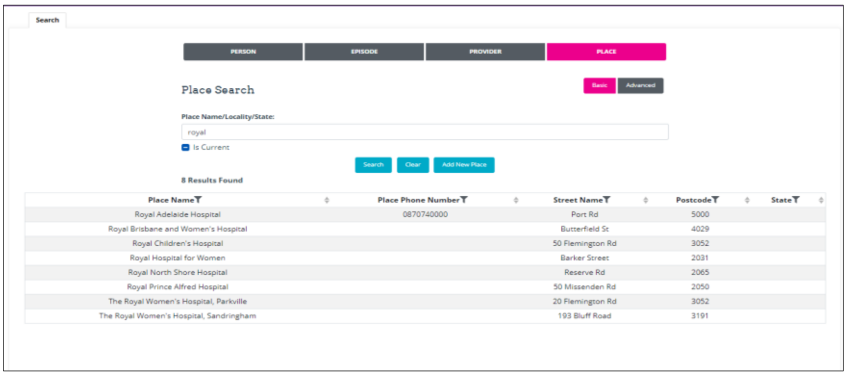
   Note: A provider cannot be end dated (removed) if the provider is the Primary Provider in the person details – Consent tab. You must edit the person consent to assign a different primary provider before the end date can be saved. See Consent on page 38 for more information.

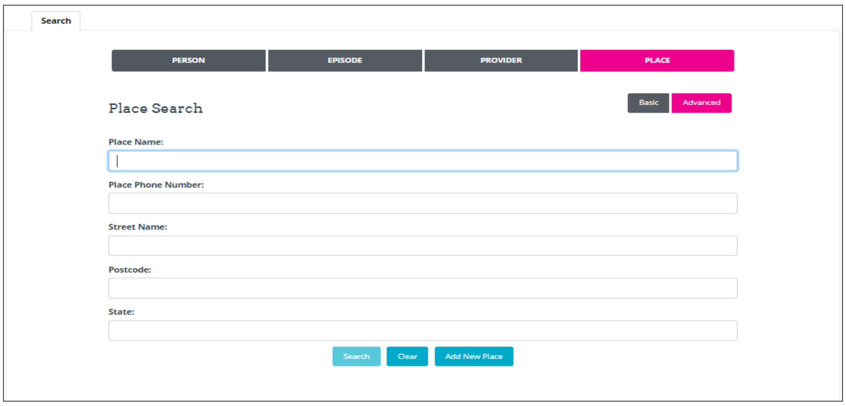
   You must also ensure that the provider/place link is end dated in the provider record before the record is saved with the above end date.

4.4.7 Place Search

1. Enter criteria in the search fields and Click **Search**.
2. Double-click on the record required from the search result grid to view the record.
3. Click **Clear** to start a new search.
4. Advanced allows for more fields for criteria to be entered.
5. Click on **Add New Place** to add a new place.

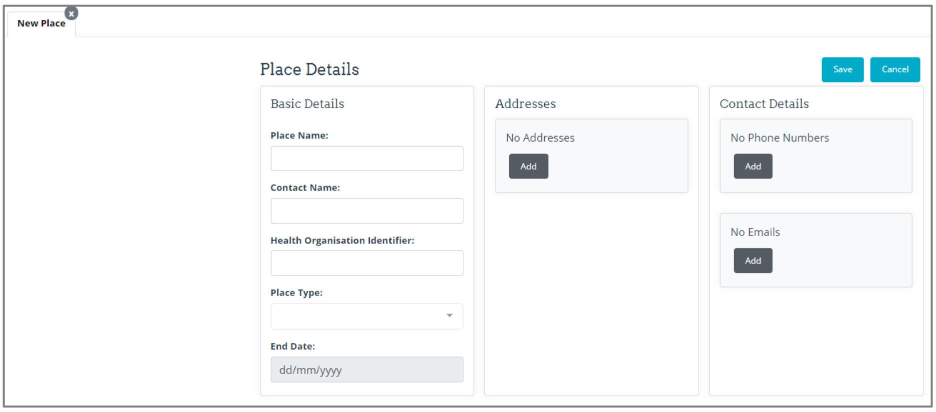
Note: Select the ‘Is Current’ filter to search against records that have no end date (removed) in the system. To search against the archived records clear the ‘Is Current’ filter on the search.





4.4.8 Adding a New Place

1. Enter criteria in the search fields and Click **Search**.
2. Search for the Place from the Place Search screen.
3. If the record does not exist, then add the place by clicking **Add New Place**.



4. Enter the place details as required
5. Add/upload Documents and/or notepads as required. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 or Entering/Auditing using Notepad on page 32 for more information.
6. Click **Save**.

4.4.9 Editing a Place Details

1. Enter criteria in the search fields and Click **Search**.
2. Search for the Place from the Place Search screen and double click the record to edit.
3. Click **Edit**.

4. Edit details
5. Add/upload Documents and/or notepads as required. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 or Entering/Auditing using Notepad on page 32 for more information.
6. Click **Save**.

4.4.10 Deleting a Place Details – Close Place

1. Search for the Place from the Place Search screen
2. Enter criteria in the search fields and Click **Search** and double click the record to edit.
3. Click **Edit**.
4. Add/upload Documents and/or notepads as required. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 or Entering/Auditing using Notepad on page 32 for more information.
5. Click **Close Place** and **Save**.

   Note: A place cannot be end dated (removed) if the place is the Primary Place in the person details – Consent tab. You must edit the person consent to assign a different primary place before the end date can be saved. See Consent on page 38 for more information.

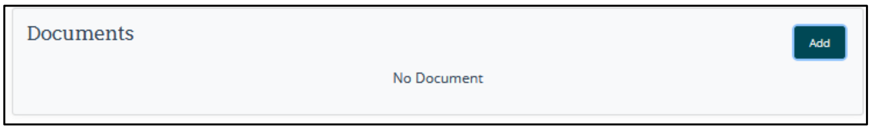
   You must also ensure that the provider/place link is end dated in the provider record before the record is saved with the above end date.

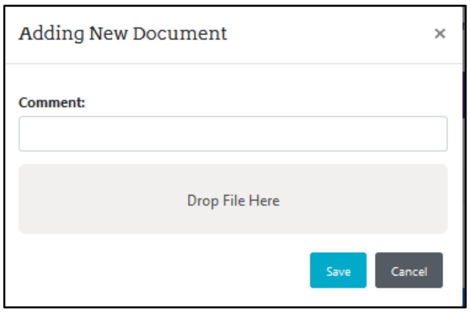
4.5 Uploading Document from Person Details/Episode/Provider/Place Details

Documents can be uploaded from various areas in NECST Registry. NECST Registry supports documents of size below 5MB.

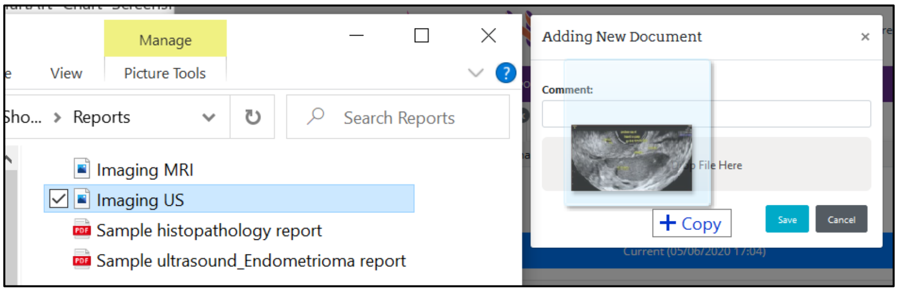
Documents of type jpeg, png, bmp, pdf, tif may be uploaded. When viewing uploaded documents, ensure that your computer/device has the compatible software to view the file.

1. Open the record and select the Documents tab.
2. Click **Add**.

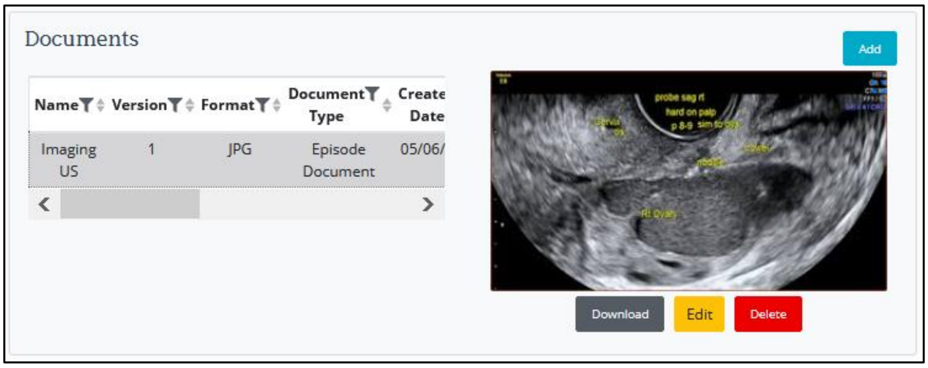




3. Drag and drop the file into the Drop File Here area or double click to navigate to the folder and file to upload.
4. Click **Save**.
5. Click **Refresh** to update the view of the record and see your documents.



6. Click **Download** to download the file.
7. Click **Edit** to replace the existing file.
8. Click **Delete** to delete the file.



4.6 Entering/Auditing using Notepad

When a user selects **Add**, **Edit** or **Delete** from a record in the NECST Registry, on saving that record, the user is asked to enter Notepad text. These details are saved for audit purposes.

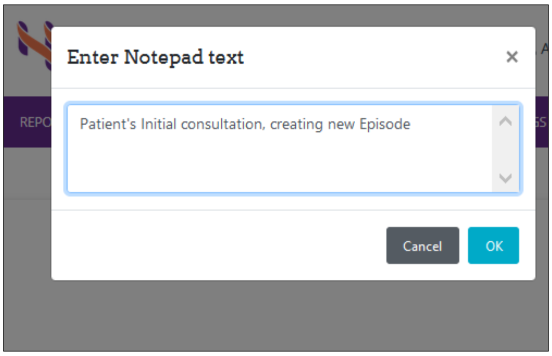
4.7 See Follow-Up QA Reasons

Follow-Up Reason	Description
Check Pregnancy Status	
SMS Failed to send - Transmission Issue	A transmission issue occurred when sending SMS. Relist to resolve. Return to queue and click the record and Resolve button.
Email Failed to send - Transmission Issue	A transmission issue occurred when sending emails. Relist to resolve. Return to queue and click the record and Resolve button.
Check Travelling Status	
Person does not have a mobile number recorded	Person is due for follow-up action and has no mobile number recorded to send SMS. Open person and enter mobile number to resolve.

Follow-Up Reason	Description
	Return to queue and click the record and Resolve button.
Person has an Invalid mobile number recorded	Person is due for follow-up action and has an invalid mobile number recorded to send SMS. That is, not an Australian mobile number that conforms to the Australia format (10 numbers starting with 0). Open person and enter valid mobile number to resolve. Return to queue and click the record and Resolve button.
Person does not have an email address recorded	Person is due for follow-up action and has no email address recorded to send email. Open person and enter email address to resolve. Return to queue and click the record and Resolve button.
Person has an Invalid email address	Person is due for follow-up action and has no valid email address recorded to send email. That is, email address does not contain @ symbol. Open person and enter valid email address to resolve. Return to queue and click the record and Resolve button.

Notepad on page 51 for more information.

1. On Save, a pop-up windows, Enter Notepad text displays.
2. Enter your comments and click **OK**.



4.8 Patient Record

4.8.1 Adding a New Person

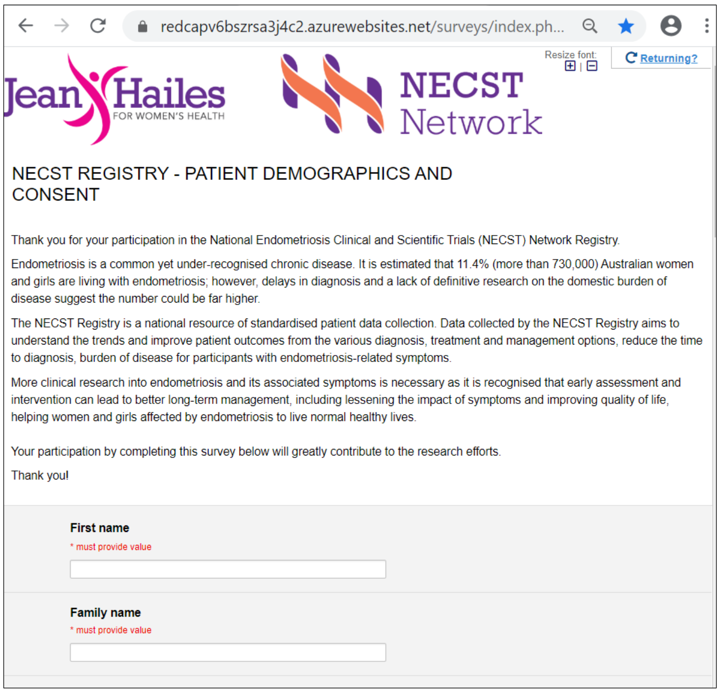
A new person can be added into the NECST Registry:

- Using Survey (Patient Demographics and Consent Survey)
- Directly from NECST Registry

Note: Person will need to matched manually to their RedCap questionnaire results to ensure that scheduled follow up is activated and in place. See section Adding a New Person – from NECST Registry for more information.

4.8.1.1 Adding a New Person - using Questionnaire

1. Complete a Patient Demographic and Consent Questionnaire using the link https://redcap.link/necstregistry-patientregistration.
2. Once the survey syncs with the NECST Registry, the Patient record is automatically added in the NECST Registry.



NECST REGISTRY - PATIENT DEMOGRAPHICS AND CONSENT

Thank you for your participation in the National Endometriosis Clinical and Scientific Trials (NECST) Network Registry.

Endometriosis is a common yet under-recognised chronic disease. It is estimated that 11.4% (more than 730,000) Australian women and girls are living with endometriosis; however, delays in diagnosis and a lack of definitive research on the domestic burden of disease suggest the number could be far higher.

The NECST Registry is a national resource of standardised patient data collection. Data collected by the NECST Registry aims to understand the trends and improve patient outcomes from the various diagnosis, treatment and management options, reduce the time to diagnosis, burden of disease for participants with endometriosis-related symptoms.

More clinical research into endometriosis and its associated symptoms is necessary as it is recognised that early assessment and intervention can lead to better long-term management, including lessening the impact of symptoms and improving quality of life, helping women and girls affected by endometriosis to live normal healthy lives.

Your participation by completing this survey below will greatly contribute to the research efforts.

Thank you!

First name
* must provide value

Family name
* must provide value

4.8.1.2 Adding a New Person – from NECST Registry

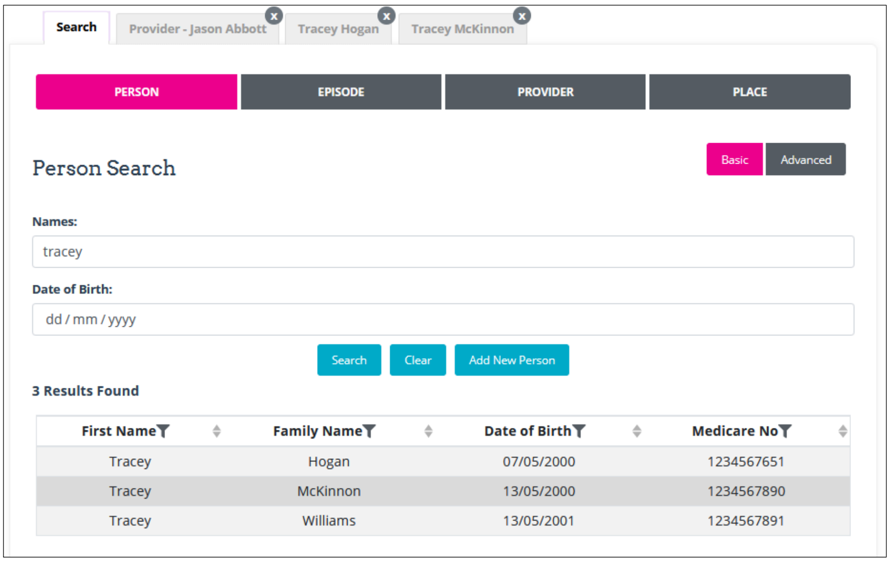
IMPORTANT

Adding a person using this method is not recommended as the system will not be able to send the Follow-Up surveys/questionnaires to the patient from NECST registry.

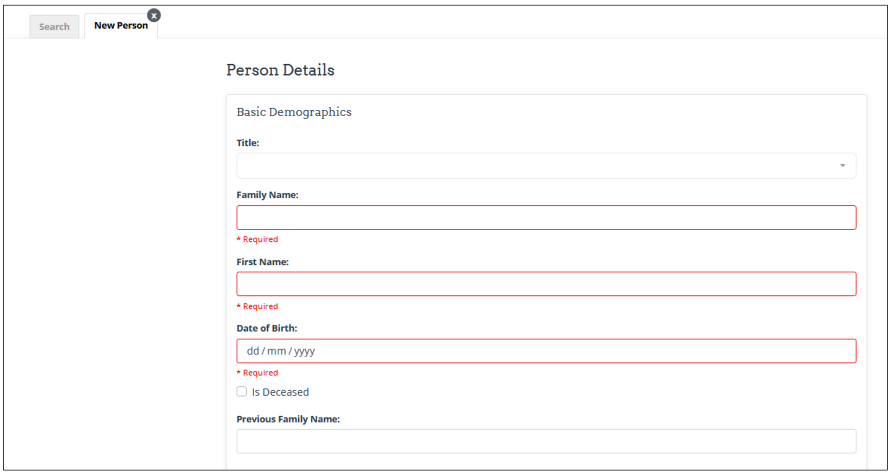
If a person record is created using this method then it is mandatory to also complete a Patient Demographics and Consent questionnaire of this patient and then merge the two records. (See Person Duplicate Matching and Merging on page 57 for more information. This would be performed by registry staff or the Jean Hailes Administrator).

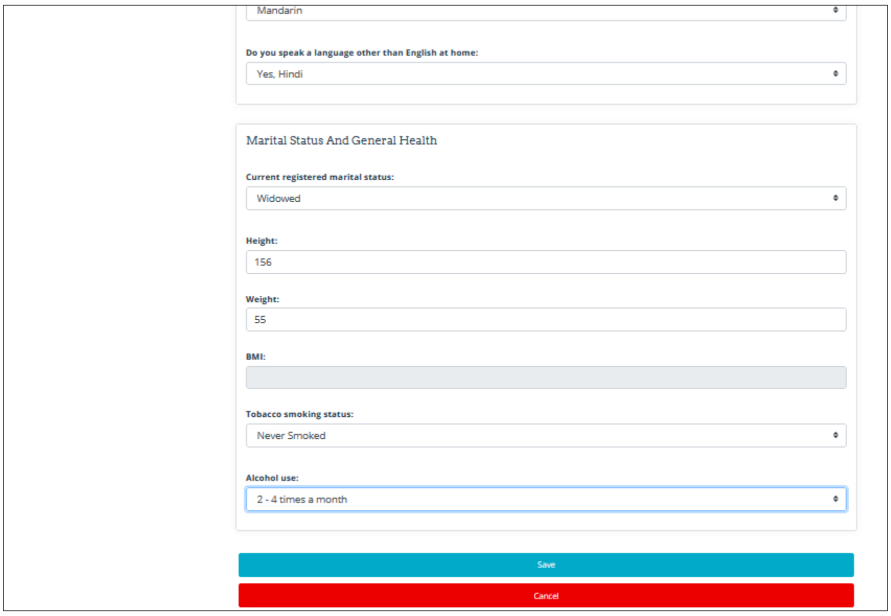
1. Search for the person from the Person Search screen. See Person Search on page 25 for more information.

2. If the record does not exist, then add the person by clicking **Add New Person**.



3. Enter the patients' details, particularly the mandatory fields First Name, Surname, Date of Birth and Medicare Card number and **Save**.

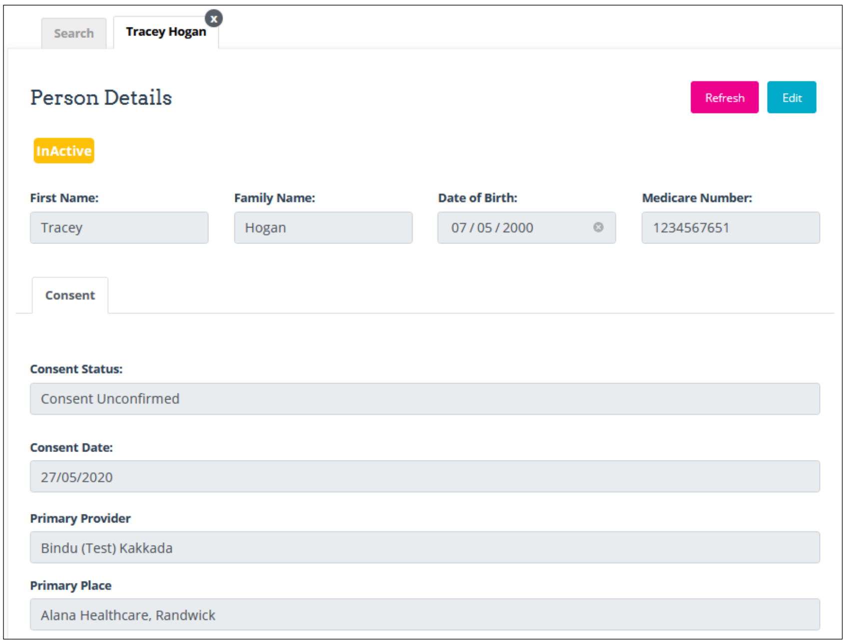




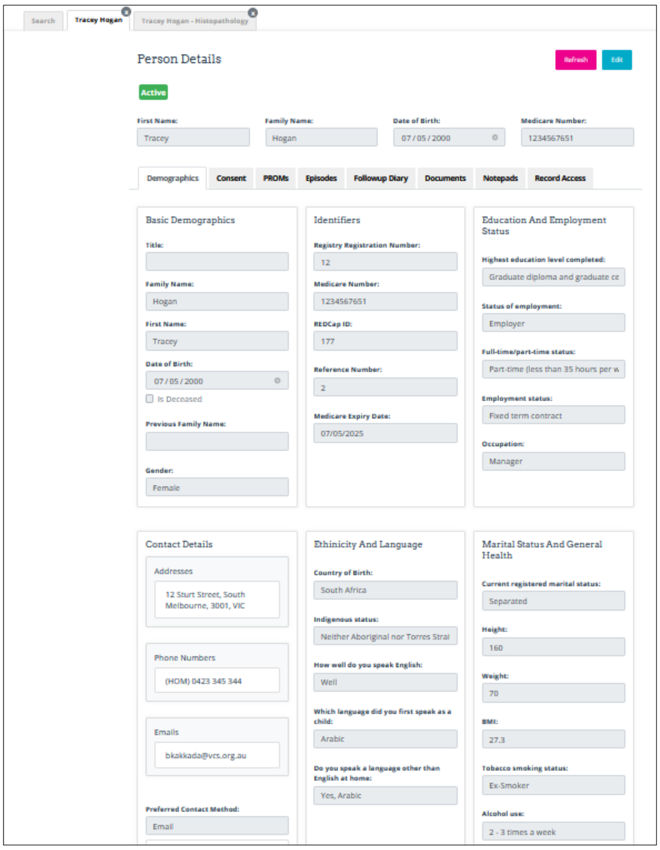
4.8.2 Editing a Person Details

1. Navigate to Person Search and open the person record from the search results. See Person Search on page 25 for more information.
2. If the person record is ‘In Active’, only the Consent tab is available to the user.

   Note: If logged in as a system administrator all tabs are visible to the user.



3. If the person record is in an ‘Active’ status, all the tabs are available to the users based on the Person Record Access rules. See Person Record Access Rules on page 67 for information.



4. Click **Edit**.
5. Edit details and **Save**.

4.8.3 Consent

A person's consent record is created in NECST Registry automatically when a new Person record is created.

The default status of the Consent is 'Consent Unconfirmed' (therefore, the person's record is 'In Active'). See Consent Status on page 66 for more information.

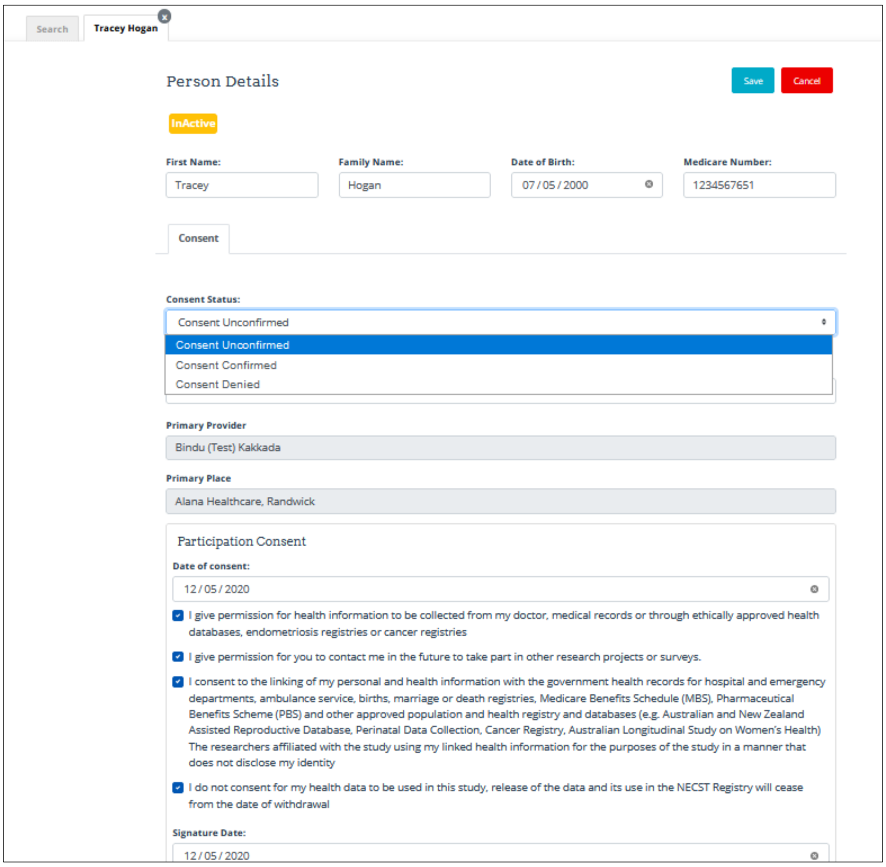
A Jean Hailes Administrator or a Primary Provider has the ability to edit a person's consent. See Person Record Access Rules on page 67 for more information.

An example of who can edit the consent:

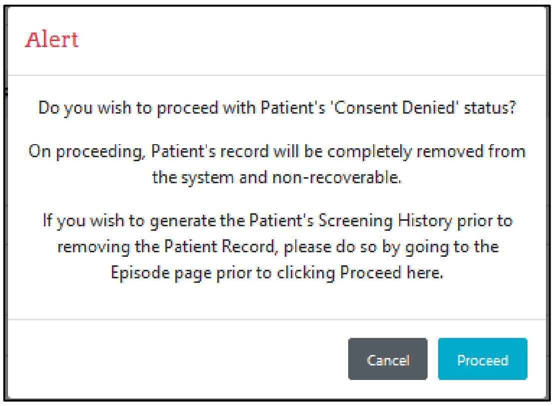
Scenario	Input	Expected result
We have a patient called 'Donna Noble' with status of consent = Consent Unconfirmed.	Change consent	Everyone should be able to search for this person and change the consent.
We have a patient called 'Donna Noble' with status of consent = Consent Confirmed.	Primary Provider = Dr Joe Smith Primary Place = Royal Hospital of Women Dr Smith edits status of consent from "Consent unconfirmed" → "Consent confirmed"	Dr Smith has full access to this record. Record goes from 'In Active' to 'Active'
We have a patient called 'Donna Noble' with status of consent = Consent Confirmed.	Dr Winn also works at Royal Hospital for Women and is recorded as a Provider who has place = Royal Hospital of Women.	Dr Winn has full access to this record.
We have a patient called 'Donna Noble' with status of consent = Consent Confirmed.	In record access, JH Admin or Dr Smith adds a secondary place called Ryan Imaging Clinic. Dr Brown is setup as a provider at Place = Ryan Imaging Clinic	Dr Brown cannot edit the consent details. Dr Brown will have access to this record to add episodes

4.8.3.1 Editing a Patient Consent

1. Navigate to Person Search and open the person record from the search results.
   See Person Search on page 25 for more information.
2. Navigate to Consent tab.
3. Click **Edit**.
4. Select the Consent Status.
   See Consent Status on page 66 for more information.
5. Enter Consent Date.
6. Primary Provider and Primary Place is auto populated (if you are a provider of valid Primary Provider). See Person Record Access rules on page 67 for more information.
7. Edit other details as needed and **Save**.



Note: When the Consent Status is modified from “Consent Unconfirmed” to “Consent Denied”, the person record is permanently deleted from the NECST Registry. This user is alerted before the system proceeds with the permant delete. See section Deleting a Person, page 41, for more information.



Note: When the Consent Status is modified from “Consent Confirmed” to “Consent Denied”, the person record is marked as **read only** from the NECST Registry. This user is alerted before the system proceeds with edit.

4.8.4 Deleting a Person

A Primary Provider can change the the Consent Status (either “Consent Unconfirmed” or “Consent Confirmed”) to “Consent Denied” and save the record.

The person record is permanently deleted from the NECST Registry when “Consent Unconfirmed” is changed to “Consent Denied”. The user is alerted before the system proceeds with the permant delete to generate a Patient History in PDF format if required.

The person record is made **read only** in the NECST Registry when "Consent Confirmed" is changed to "Consent Deniend". The user is alerted before the system proceeds with the read only to generate a Patient History in PDF format if required.

4.8.5 Record Access

See Person Record Access rules on page 67 for information on how the Provider's access to the Person Record can be controlled.

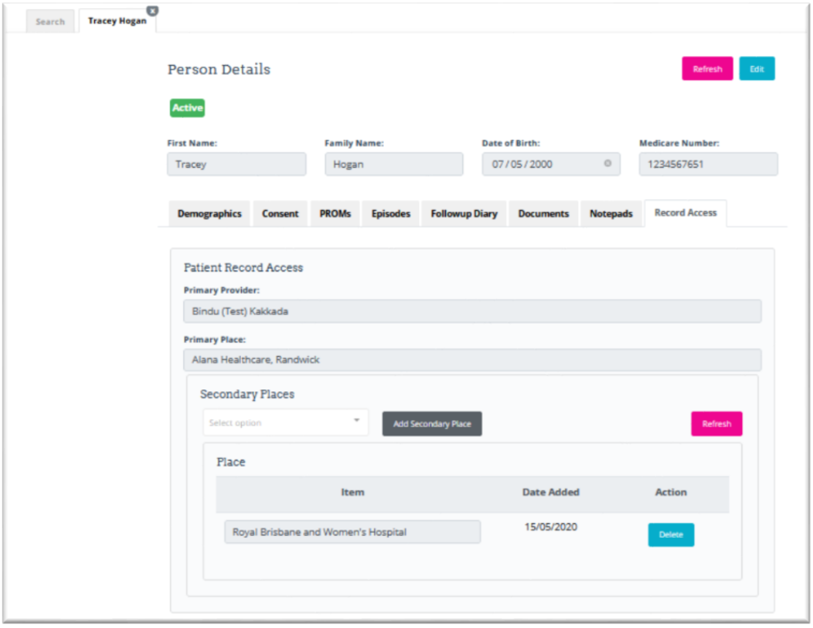
4.8.5.1 Adding a Primary Place

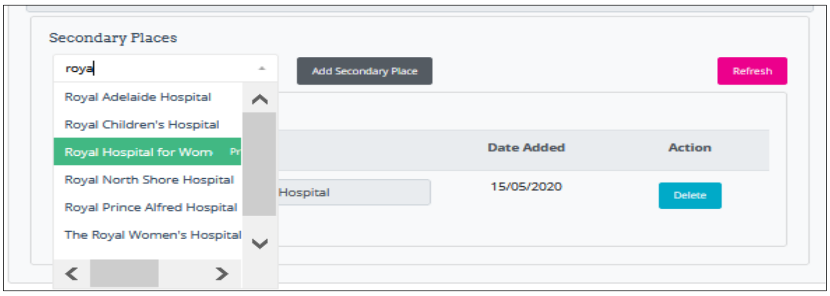
A Primary Place is added from the Consent tab when the user confirms the person's consent which is also displayed in the Record Access tab. All users at the Primary Place will have access to the Person's record.

4.8.5.2 Managing a Secondary Place

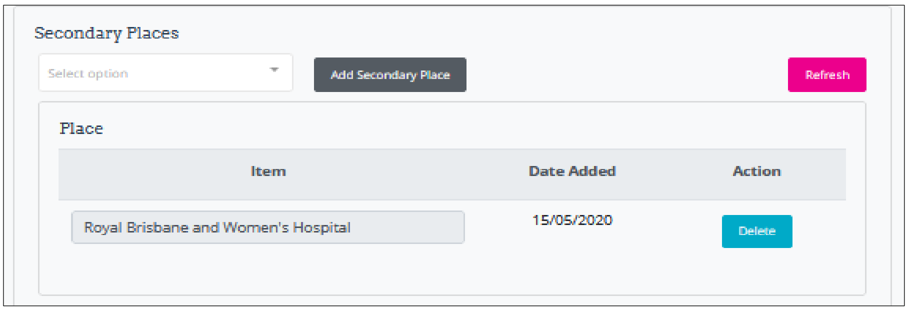
A Secondary Place can be added from the person's Record Access tab, which allows users at that Secondary Place to access the person's record.

1. Navigate to Person Search and open the person record from the search results. See Person Search on page 25 for more information.
1. Navigate to Record Access tab.
2. Click **Edit** (if not already in edit mode).
3. Select a Place from the Secondary Place using the drop-down or keyword search.
4. Click **Add Secondary Place**.





5. Click **Delete** against the Secondary Place to delete a Secondary Place.



4.9 PROMs

Patient Reported Outcome Measures (PROMs) - captures a patient's perception of their own health through validated questionnaires.

For the NECST Registry, the PROMs tools used to evaluate the impact of symptoms on the persons' quality of life are

i. EuroQoL-5D (EQ-5D), a standardised measure of health status.
ii. Endometriosis Health Profile (EHP)-30 (only if the patient has been diagnosed with endometriosis), to measure the wide range of effects that endometriosis can have on women's lives.

PROMs Episodes are added automatically in the NECST Registry when a patient completes their EQ-5D or EHP-30 questionnaire, which is made available to be viewed from the patient's PROMs or Episodes tab.

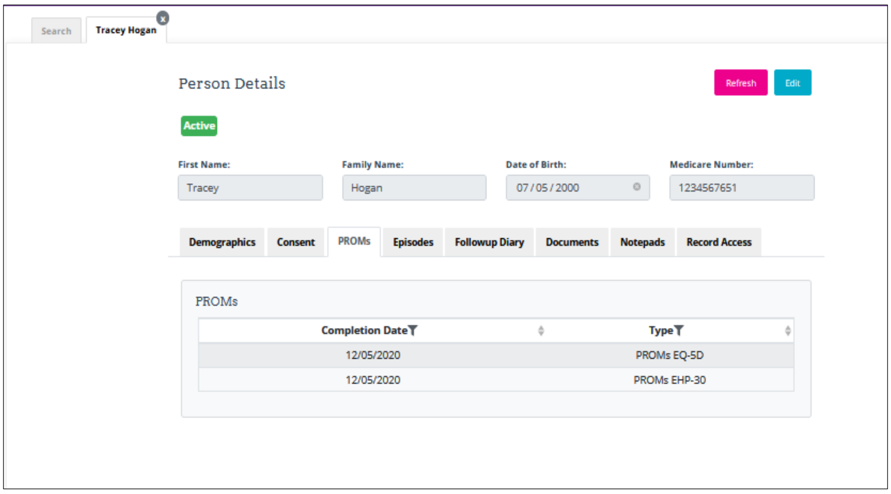
Note: A PROMs Episode cannot be directly entered from the NECST Registry.

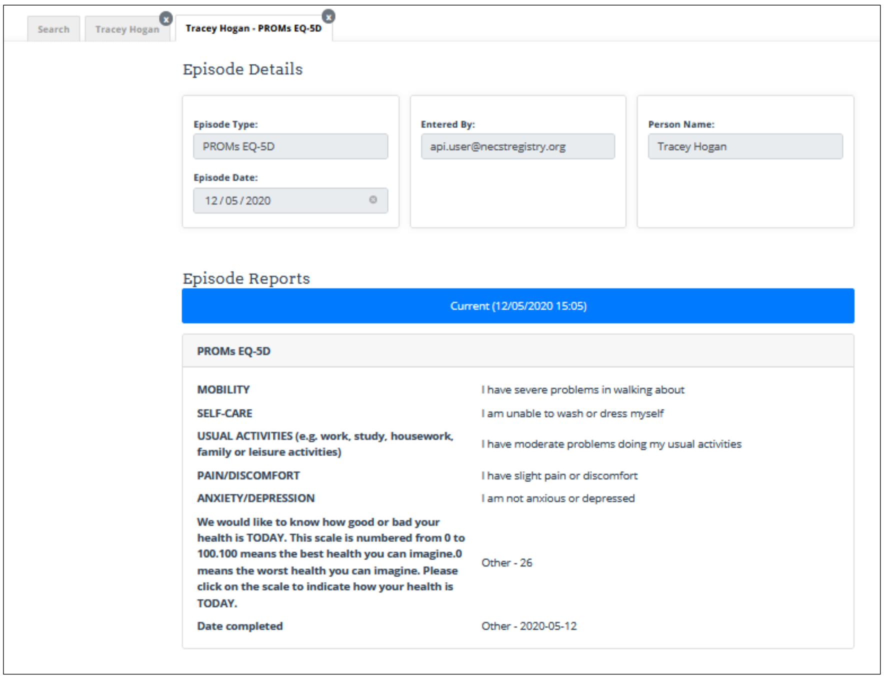
4.9.1 Viewing PROMs

1. Navigate to Person Search screen. See Person Search on page 25 for more information.
2. Enter criteria in the search fields and click **Search**.
3. Double-click on the record required from the search result grid to view the record.
4. Navigate to Person's PROMs or Episodes tab.
5. Double-click on the PROMs episode from the result grid to view the details from the Episode Details screen.

4.9.1.1 PROMs - EQ-5D

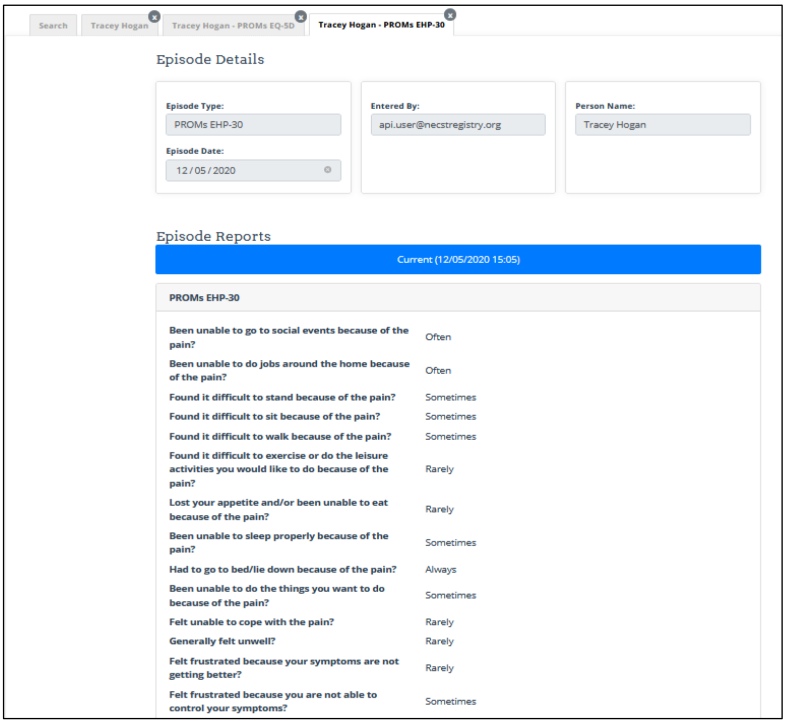
See Viewing PROMs on page 42 for more information.





4.9.1.2 PROMs - EHP-30

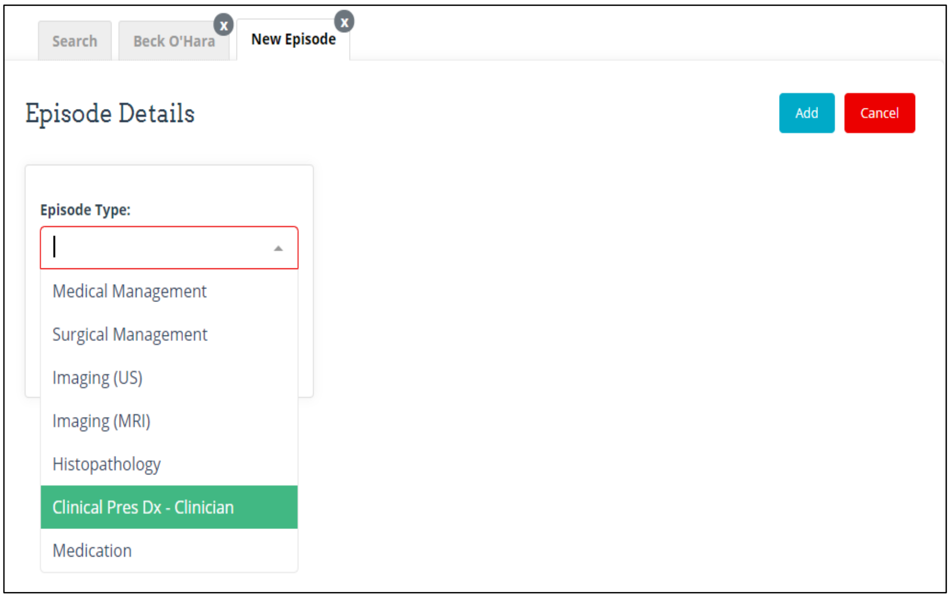
See Viewing PROMs on page 42 for more information.

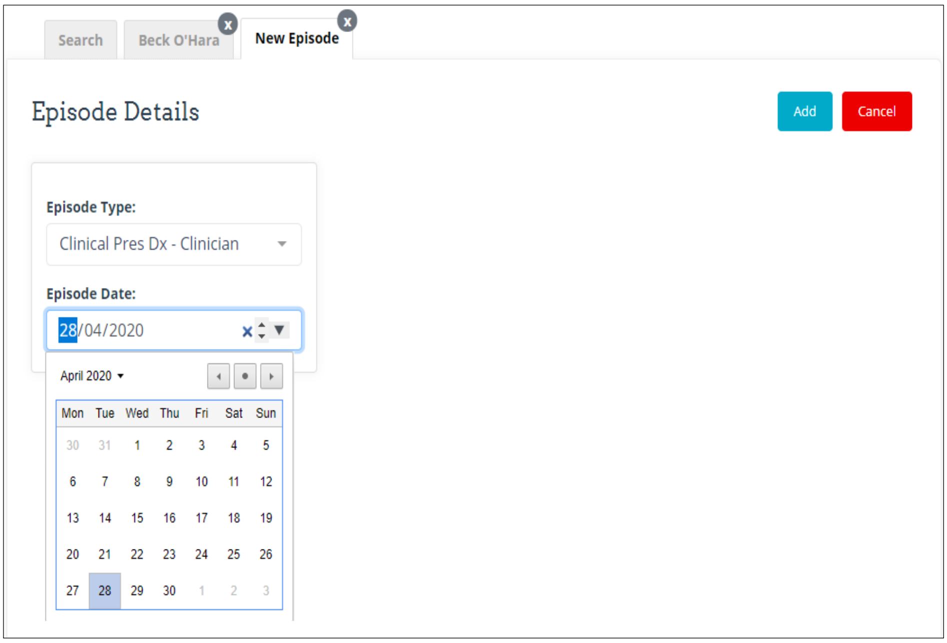


4.10 Clinical Pres Med HX - and Clinical Pres Med HX Follow-Up Episode

A Clinical Pres Med Hx – Follow-Up Episode is added automatically in the NECST Registry when a person completes their Follow-Up Clinical Presentation and Medical History questionnaire via Redcap, which is made available to be viewed from the person's Episode tab.

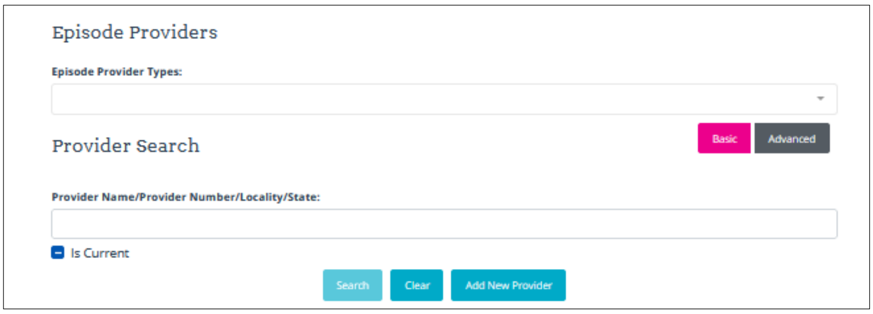
Note: A Clinical Pres Med Hx – Follow-Up Episode cannot be directly entered or edited from the NECST Registry.





6. Click **Edit** in the Episode Report section.
7. Edit the necessary details and click **Save**.
8. Select the Provider Type then search for the Provider and **Add New Provider** as needed.

Note: This is to associate a provider with a specific episode of the patient if they are involved in the patients' care.



9. Add Notepad text and click **OK**. See Entering/Auditing using Notepad on page 32 for more information.
10. Add/Upload Documents and click **OK**. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.

4.11 Episodes

An Episode represents an action or event that has been created against a patient relating to their care.

Note: The patient's Episode is available to a user if the record is in an 'Active' status and if the user belongs to the Primary/Secondary Place of the person.

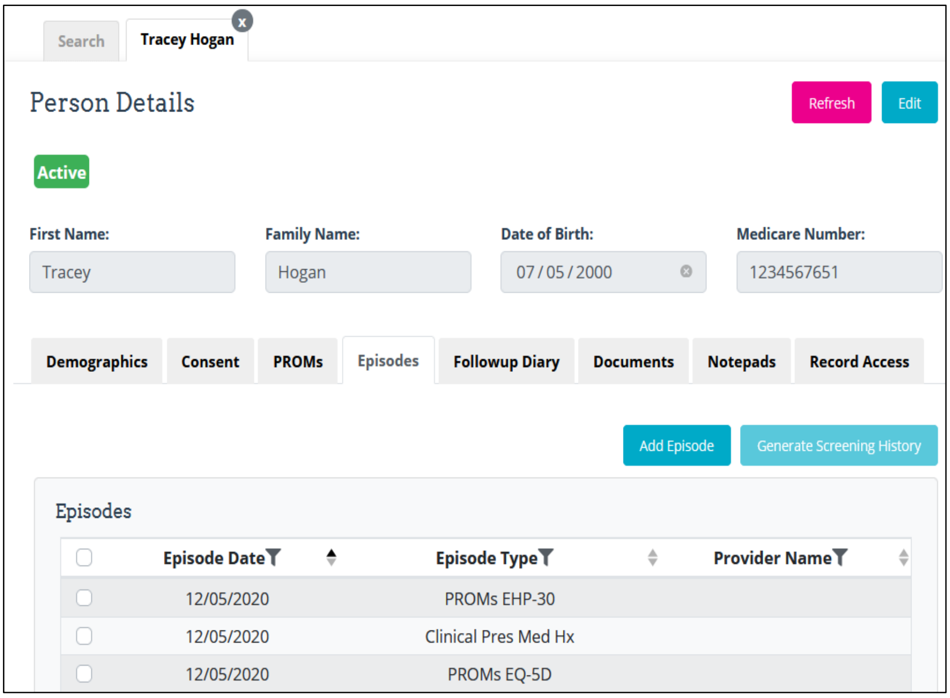
Episodes that allow multiple answers to questions do not prevent you from selecting the same answer muptle times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.

See section Person Record Access Rules on page 67 for more information.

4.11.1 Adding an Episode

1. Navigate to Person Search screen and open the Person's record.

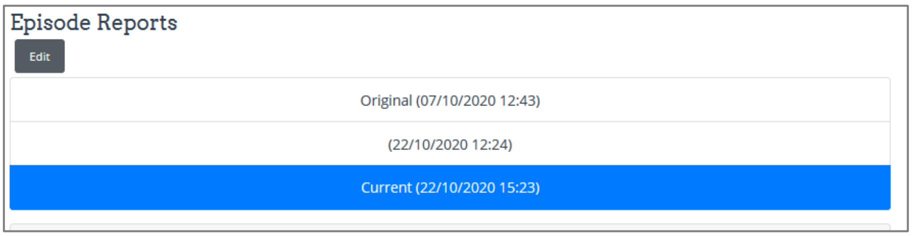
   See Person Search on page 25 for further details.
2. Navigate to Person's Episodes tab.
3. Click **Add Episode**.



4. Select the Episode Type you want to add.
5. Select/Enter the Episode Date.
6. Click **Add**.

4.12 Viewing/Editing an Episode

Note: When editing an Episode Report, the Original Report is retained and displayed in the following view. To review the original or any subsequent amended report click the relevant report displayed.



1. Navigate to Person Search screen and open the Person's Record.
   See Person Search on page 25 for further details.
2. Navigate to Person's Episodes tab.
3. Double-click on the Episode from the Episode result grid.
4. Click **Edit** in the Episode Report section.
5. Update/change details and **Save**.
6. Enter Notepad text and click **OK**. See Entering/Auditing using Notepad on page 32 for more information.
7. Enter/upload Documents and click **OK**. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.

4.13 Deleting an Episode

1. Navigate to Person Search screen and open the Person's Record.
   See Person Search on page 25 for further details.

2. Navigate to Person's Episodes tab.
3. Double-click on the Episode from the Episode result grid.
4. Click **Edit** in the Episode Details section.
5. Click **Delete**.
6. Enter Notepad text and click **OK**. See Auditing using Notepad on page 32 for more information.

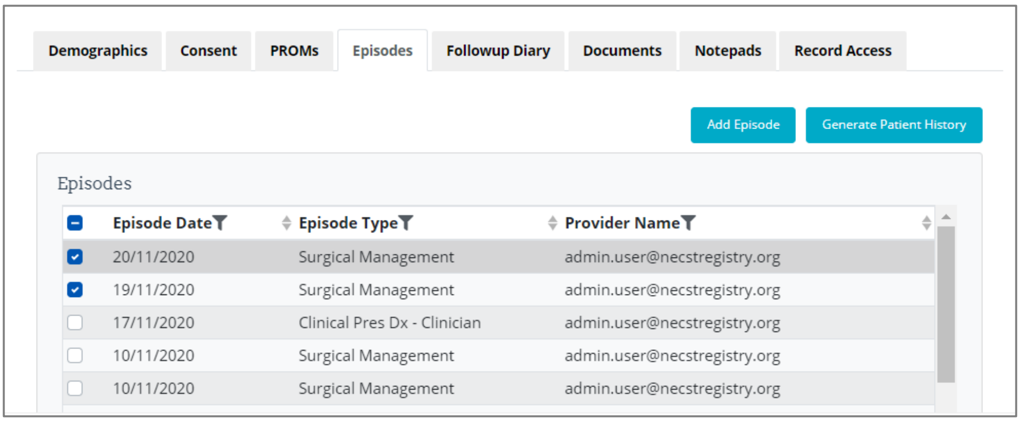
Note: A delete of an episode removes the record from the system but retains the record in the database for auditing purposes. Only the user who created the episode OR the Admin user can delete an episode.

4.14 Generate Patient History

A Person's full care history report can be generated from the Episodes tab of the Person's record.

1. Navigate to Person Search screen, search and open the Person's Record.
   See Person Search on page 25 for further details.
1. Navigate to Person's Episodes tab.
2. Select the episodes to be included in the report.
3. Click Generate History.
4. A Patient History as a report in PDF format is made available for download.

IMPORTANT	If the patient record is deleted by the provider after generating the history PDF, this will be the only record for the deleted patient.



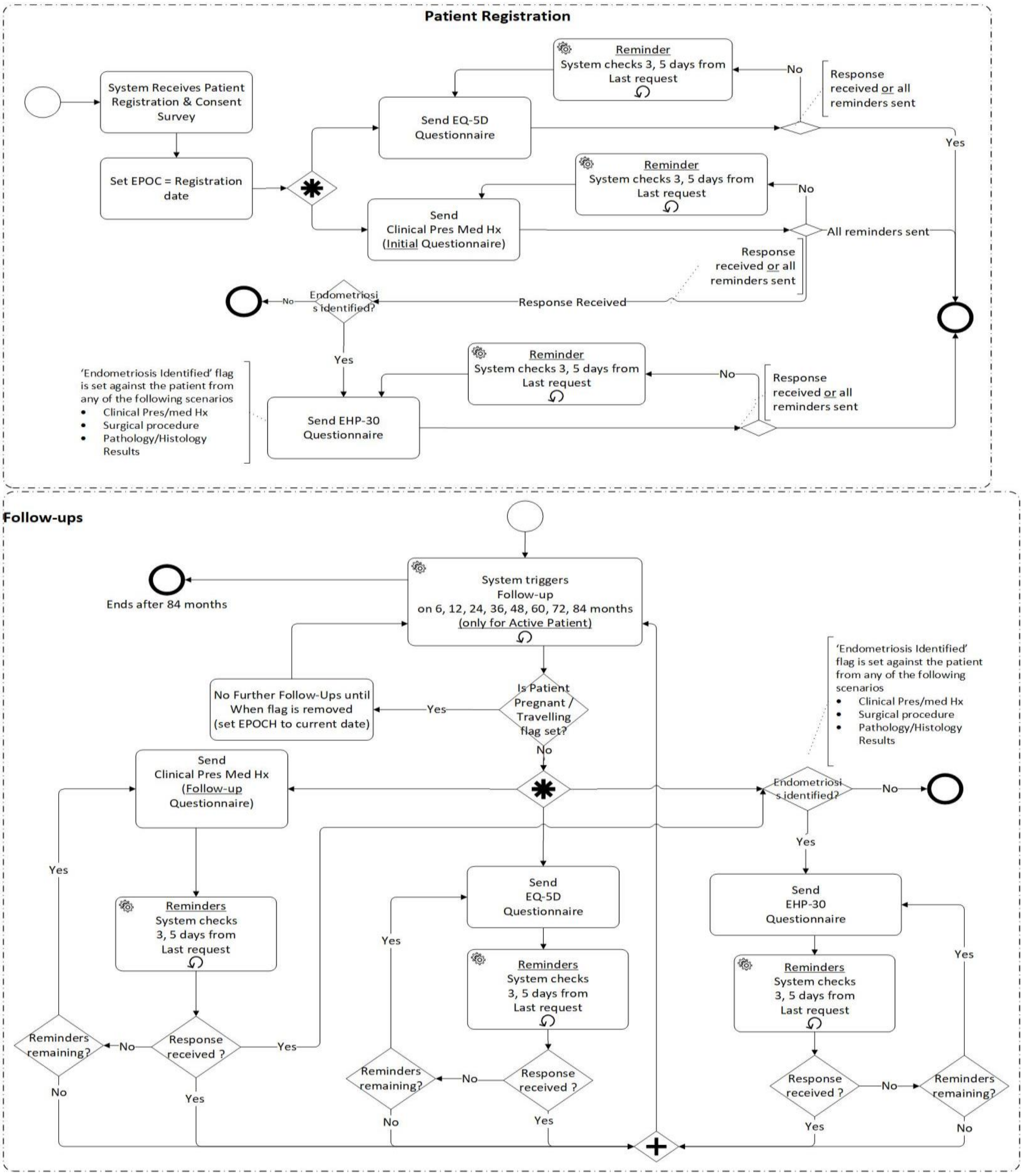
4.15 Follow-Up

Once the initial patient demographics questionnaire has been completed by the person, the system sends follow-up questionnaires to gather further data related to the person's health on a regular basis. This is depicted in the following Follow-Up workflow diagram.

IMPORTANT

A Person Record created directly from the NECST Registry will not trigger a Follow-Up workflow as there is no person record in RedCap for the person to complete their surveys.

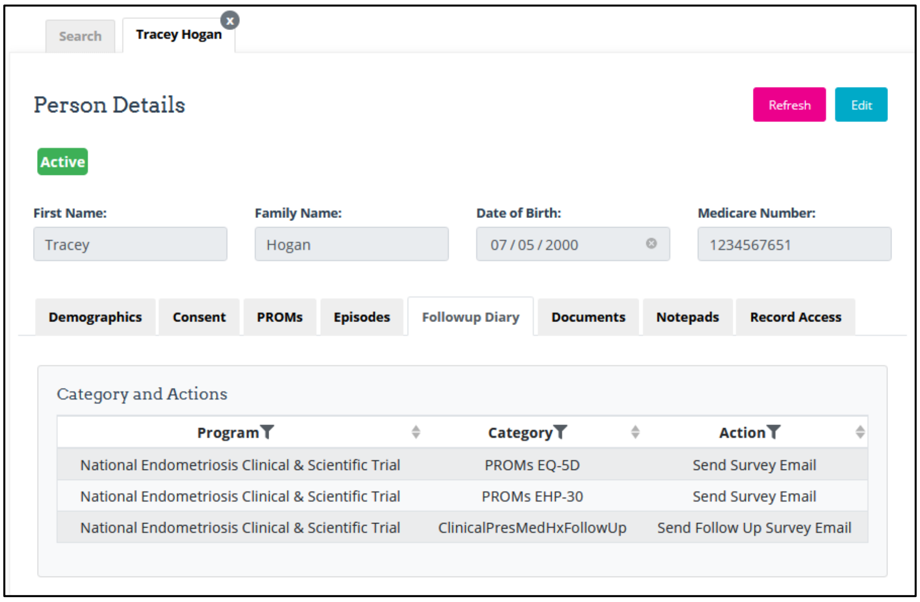
See section Adding a New Person – from NECST Registry on page 36 and Person Duplicate Matching and Merging on page 59 for more information.



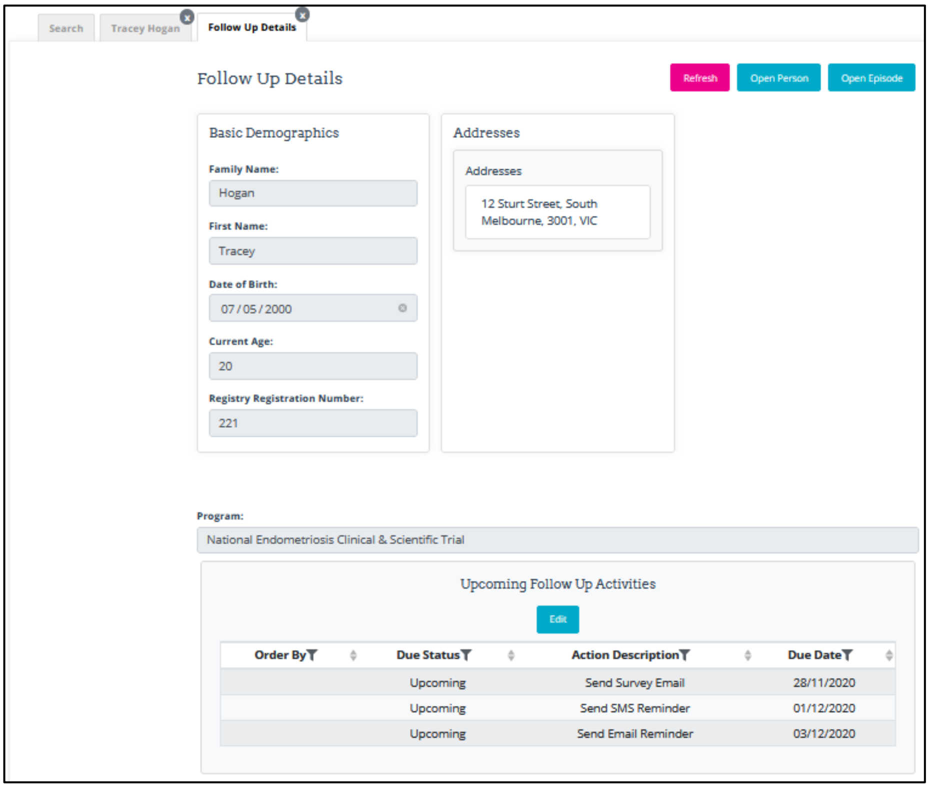
4.15.1 Viewing/Editing a Person's Follow-Up

The upcoming Follow-Up of a Person can be viewed using the Person's Followup Diary tab:

1. Navigate to Person Search screen, search and open the Person's Record.
   See Person Search on page 25 for more information.
2. Navigate to Person's Followup Diary tab.
3. Double-click on any record to open the details.

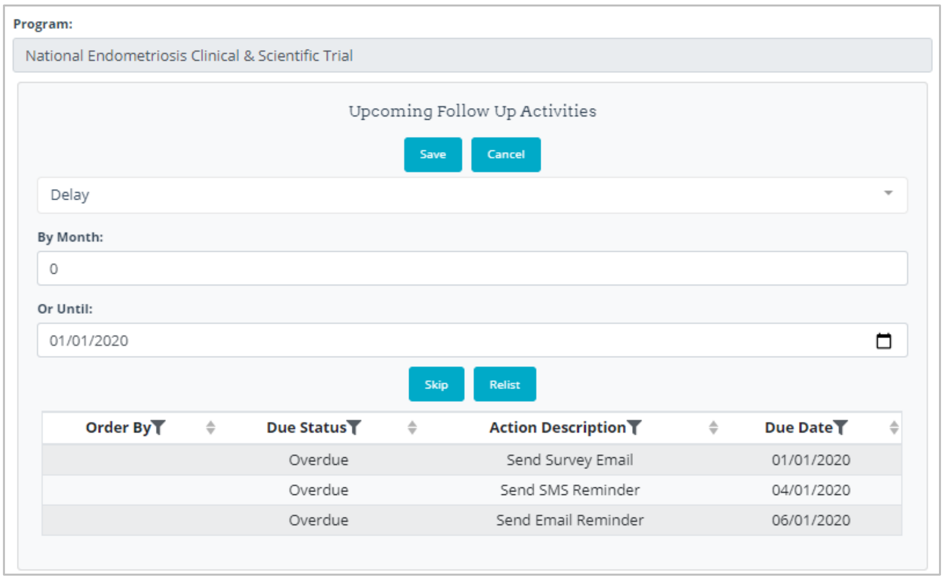


4. Click **Edit** to change the Follow-Up series.



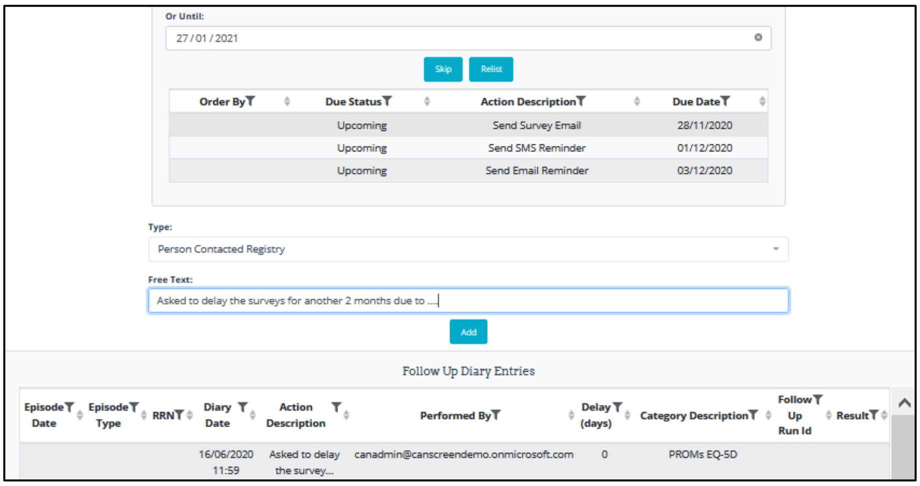
5. Choose Delay / Bring Forward option.
6. Choose by Month or Until and enter the values.

7. Click **Save**.



User may also record the details of the communications with the Person for future reference as as Follow-Up diary, as detailed following:

8. Choose the Type.
9. Enter the details of the communication or reason for the a change to follow up communication in Free Text.
10. Click **Add**.



4.15.2 Follow-Up QA

The Follow-Up QA (Quality Assurance) allows the user to identify any exceptions that have occurred in sending the surveys/questionnaires to the patients.

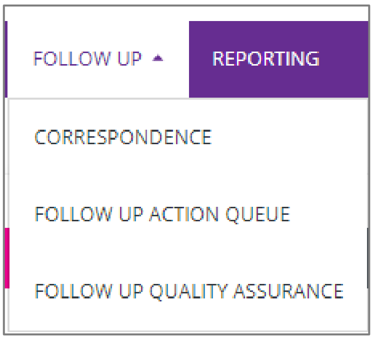
SMS sent to patients are either in a state of “Queued”, “Send” or “Failed” transmission and can be resolved from the queueu based on the “Failed Transmission” status.

A patient record can be set to have the following system identifiers that result in the record being put onto the queue.

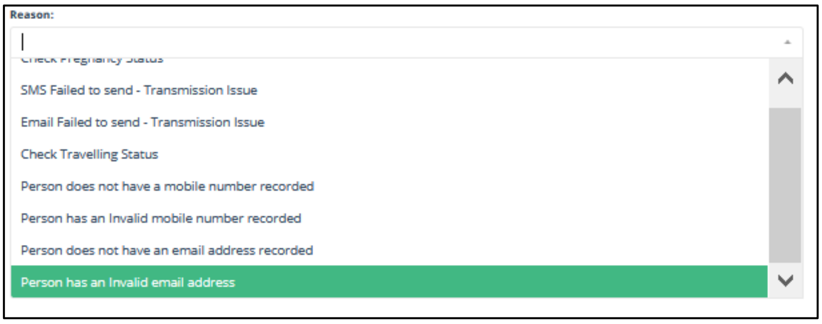
- Is Pregnant – if yes enter the expected due date. If the patient is pregnant the Follow-Up for the patient will be put on hold on the Follow-Up QA queue. Once the expected due date is passed the record will recommend Follow-Up and remove the Is Pregant system identifier.

- Is Travelling – if yes enter the expected return date. If the patient is travelling the Follow-Up for the patient will be put on hold on the Follow-Up QA queue. Once the expected return date is passed the record will recommend Follow-Up and remove the Is Travelling system identifier.

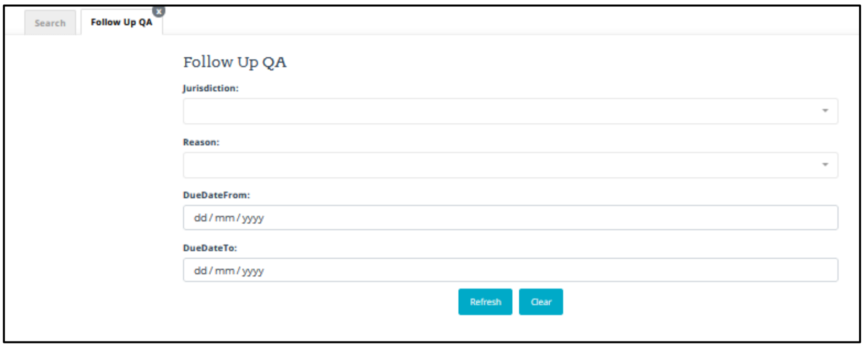
1. Navigate to FOLLOW-UP menu and choose FOLLOW-UP QUALTITY ASSURANCE.



2. Choose the Reason of exception.



3. Click **Refresh**. The Follow-Up records that match the reason will display in the grid.
4. Double click the record in the grid to open the patient's Follow-Up diary for review and actioning.



4.16 Follow-Up QA Reasons

Follow-Up Reason	Description
Check Pregnancy Status	
SMS Failed to send - Transmission Issue	A transmission issue occurred when sending SMS. Relist to resolve. Return to queue and click the record and Resolve button.

Follow-Up Reason	Description
Email Failed to send - Transmission Issue	A transmission issue occurred when sending emails. Relist to resolve. Return to queue and click the record and Resolve button.
Check Travelling Status	
Person does not have a mobile number recorded	Person is due for follow-up action and has no mobile number recorded to send SMS. Open person and enter mobile number to resolve. Return to queue and click the record and Resolve button.
Person has an Invalid mobile number recorded	Person is due for follow-up action and has an invalid mobile number recorded to send SMS. That is, not an Australian mobile number that conforms to the Australia format (10 numbers starting with 0). Open person and enter valid mobile number to resolve. Return to queue and click the record and Resolve button.
Person does not have an email address recorded	Person is due for follow-up action and has no email address recorded to send email. Open person and enter email address to resolve. Return to queue and click the record and Resolve button.
Person has an Invalid email address	Person is due for follow-up action and has no valid email address recorded to send email. That is, email address does not contain @ symbol. Open person and enter valid email address to resolve. Return to queue and click the record and Resolve button.

4.17 Notepad

Notepads are audit records maintained in the NECST Registry to identify the read, create, and edit and delete activities that occurs against a record.

In a Person's record, the audit details can be viewed from the Notepad tab of that Persons Record.

Notepads created by the system itself are not available to delete.

The following notepad types are supported:

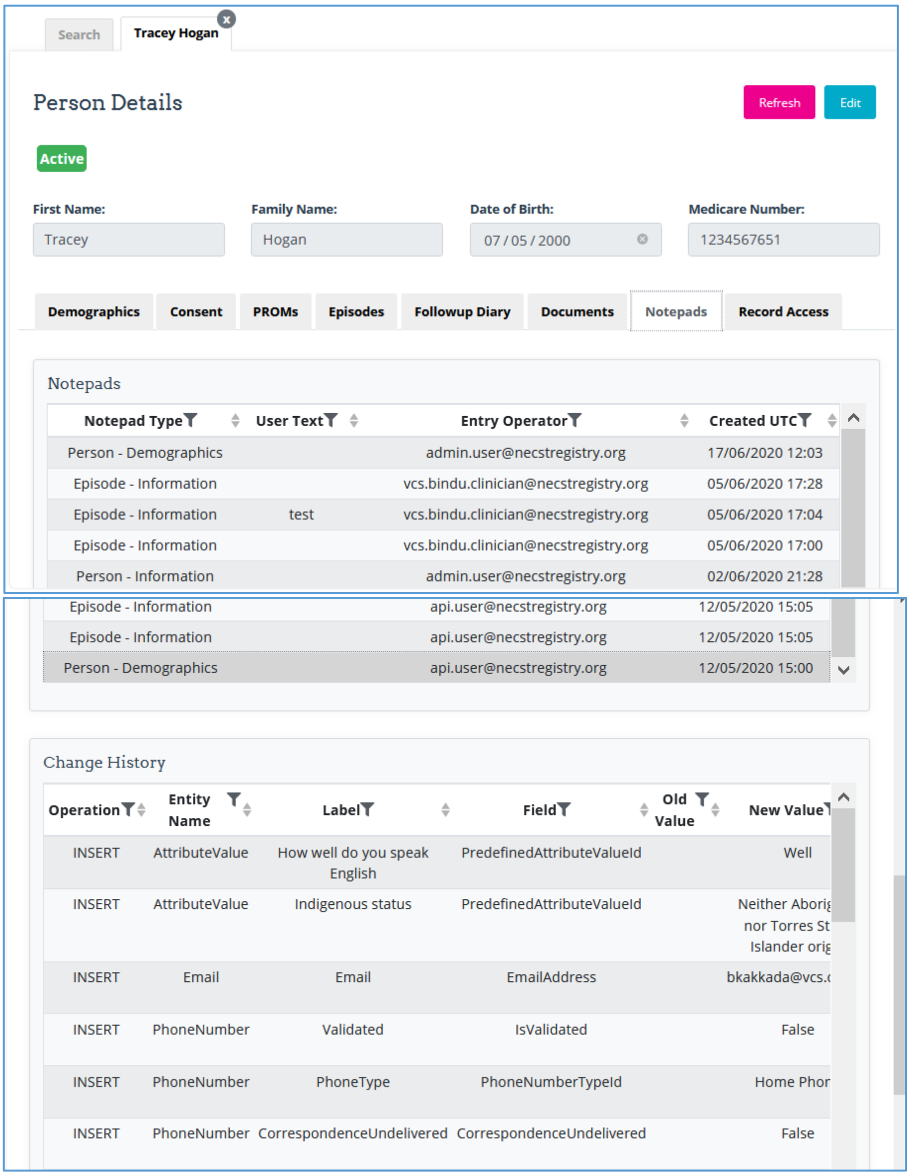
- Episode – Information
- Person – Demographics
- Person – Matching
- Person – Miscellaneous
- Provider Details
- Provider

- Place
- Follow-Up
- Quality Assurance Check

4.18 Viewing Change History

The activities against a person's record related to create, update and deleted can be view form the Notepad as below.

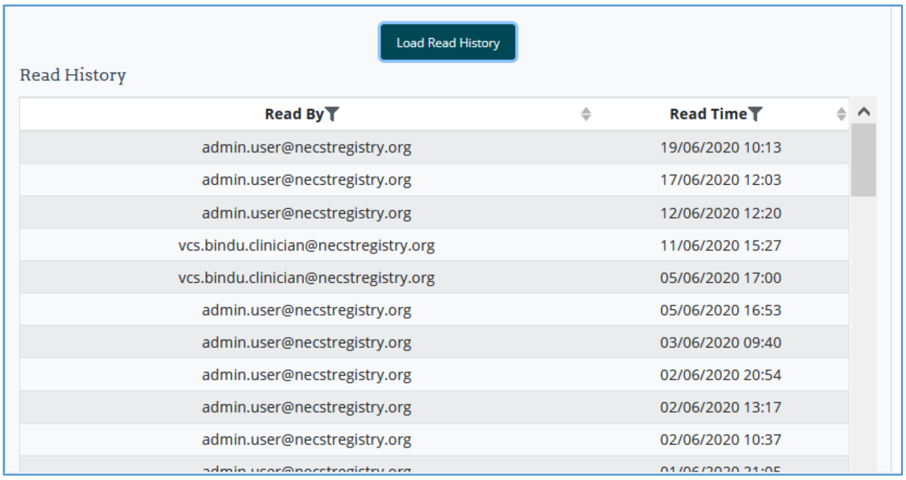
1. Navigate to Person Search screen, search and open the Person's Record. See Person Search on page 25 for further details.
2. Navigate to person's Notepad tab.
3. Double-click on any record to open the details.
4. This opens the details in the Change History grid.



4.19 Viewing Read History

1. Navigate to Person Search screen, search and open the Person's Record. See Person Search on page 25 for further details.

2. Navigate to person’s Notepad tab.
3. Click Load Read History at the bottom of the screen to load all the read histories in the Read History grid.

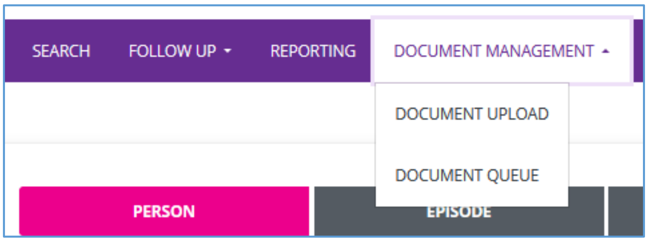


4.20 Document Management

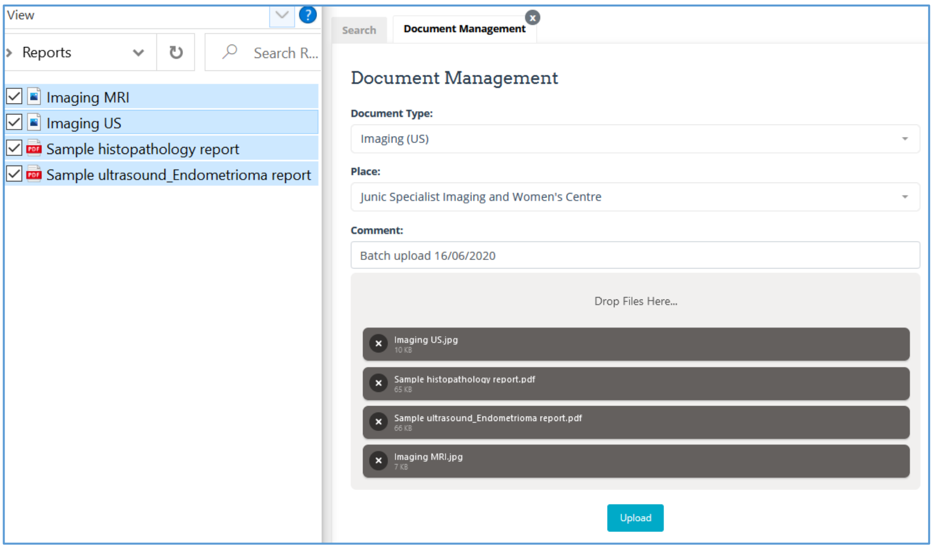
This feature allows upload of documents or images in bulk. Then individually open each document and assign it to a person’s record.

4.20.1 Document Upload

1. Navigate to the Document Management menu and choose Document Upload.

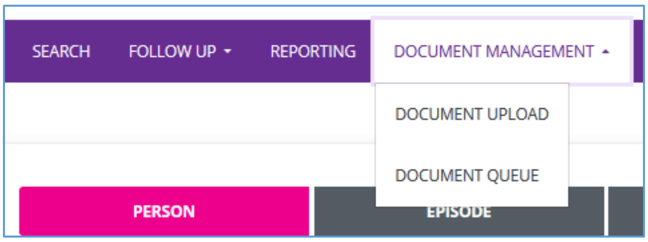


2. Select the drop-down and select Document Type.
3. Select the drop-down and select the Place.
4. Add Comments if required.
5. Drag and drop one or more files into the Drop Files Here… area or double click to navigatge to a folder to select files to upload.
6. Click **Upload**.

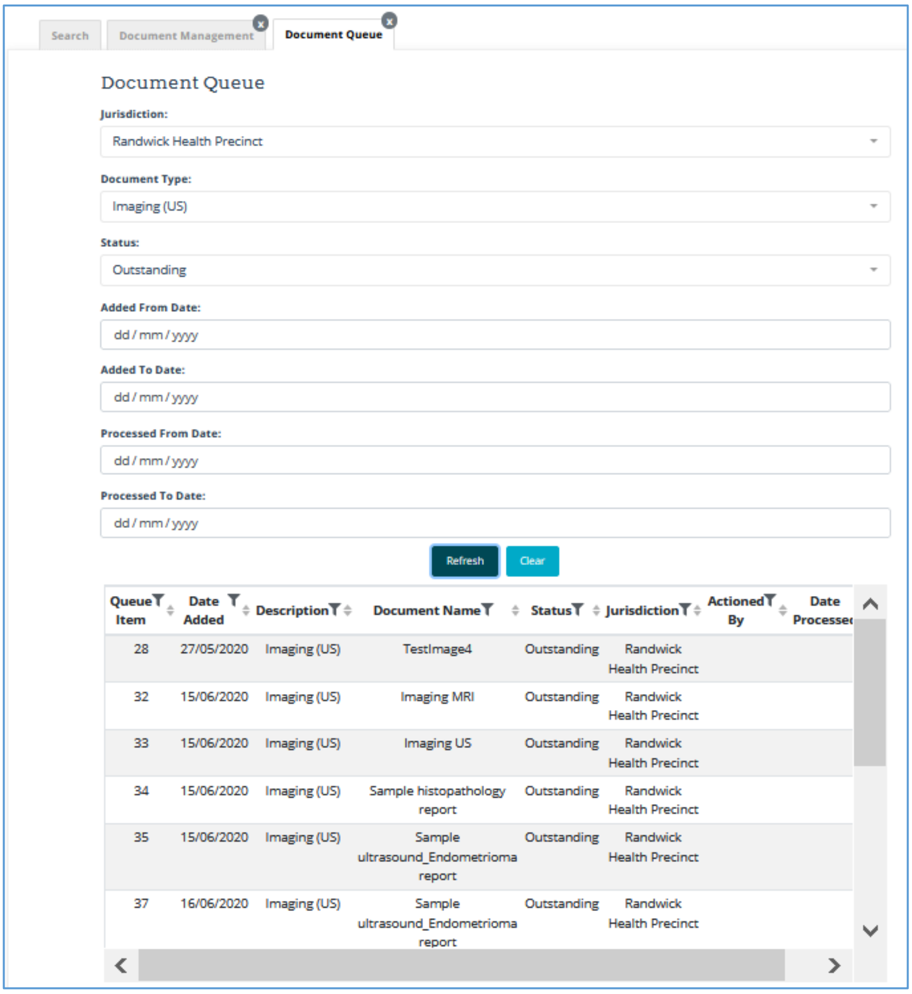


4.20.2 Document Queue

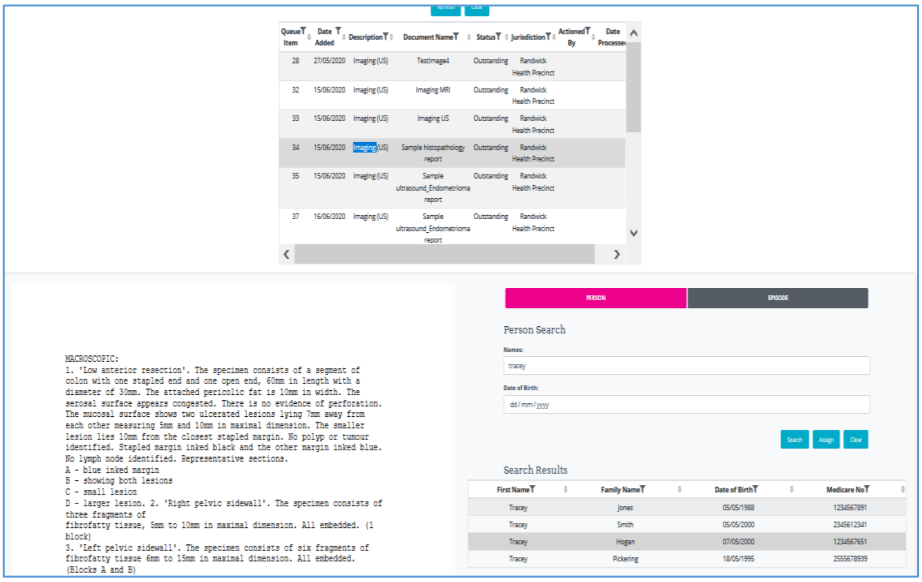
1. Navigate to the Document Management Menu and choose Document Queue.



2. Choose the filter option to view the uploaded documents.
3. Click **Refresh**.
4. The grid displays the documents based on the filter criteria.



5. Double-click on the record in the grid to open it.
   The document opens on the bottom left of the screen.
6. Click **Person** and search for the person.
7. Choose the person from the Person search grid.
8. Click **Assign** to assign the document against the selected person.



4.21 Person Duplicate Matching and Merging

IMPORTANT

The possible duplicate process runs overnight. Any records that meet the possible duplicate matching rules entered within the preceeding 24 hours will be processed and put on the Possible Duplicate Queue.

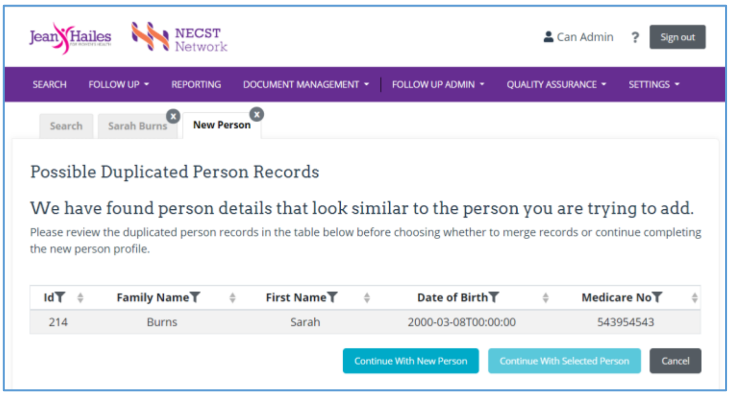
See Person Duplicate Matching Rules – Possible Match on page 68 for more information on matching rules.

Dupicates of person records may exist in the NECST Registry due to adding a person record using the NECST Registry questionnaire and also creating the same person record from the NECST Registry Core System. These duplicate records can be tracked and managed when Adding a New Person record or using the Quality Assurance Queue.

On adding and saving a New Person's Record, if a duplicate of the person is identified, the system presents all the possible duplicate person records for the user to resolve by,

1. Continue with New Person
   if the newly added person is not a duplicate then use this option to proceed with saving the newly added person record.
2. Continue with Selected Person

   if the newly added person is a duplicate then use this option to proceed with the existing person record rather than adding a new person.



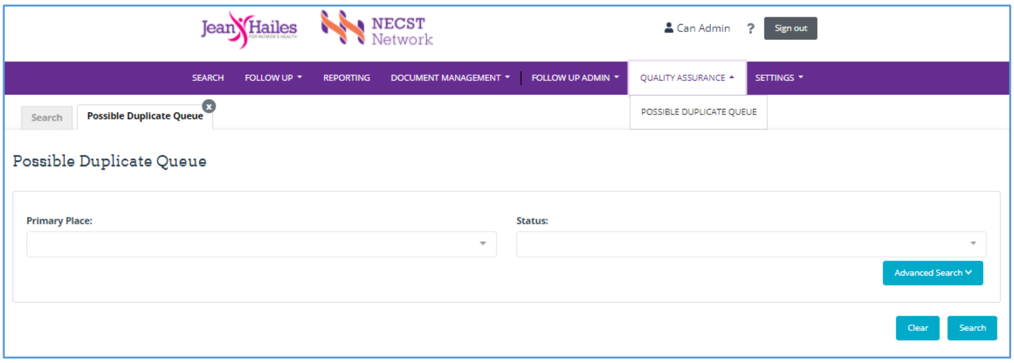
4.22 Duplicate Matching and Merging – Quality Assurance

The system process the possible duplicates of a person's record and make the records available in the Possible Duplicate Queue for the admin to manage these records.

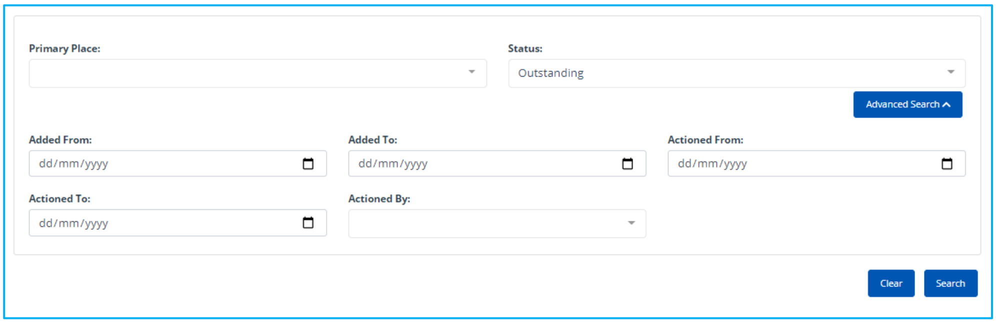
1. Navigate to the menu item, Quality Assurance and choose Possible Duplicate Queue.
2. Choose Primary Place and Status as required.

   Primary Place filter is provided if one particular Clinic creates a larger volume of duplicate records that the operator would like to resolve by priority.

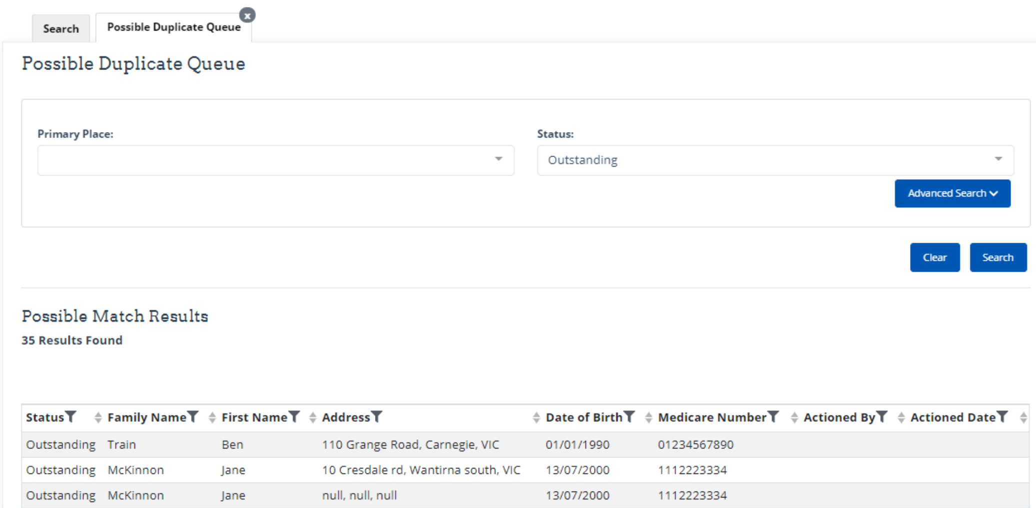
   Status allows the operator to view by default all outstanding duplicates or view the completed duplicates on the queue.



3. Select **Search**, **Clear** or **Advanced Search**.
4. If you have selected Advanced search, additional search fields are displayed. Enter the search criteria as required and click Search.

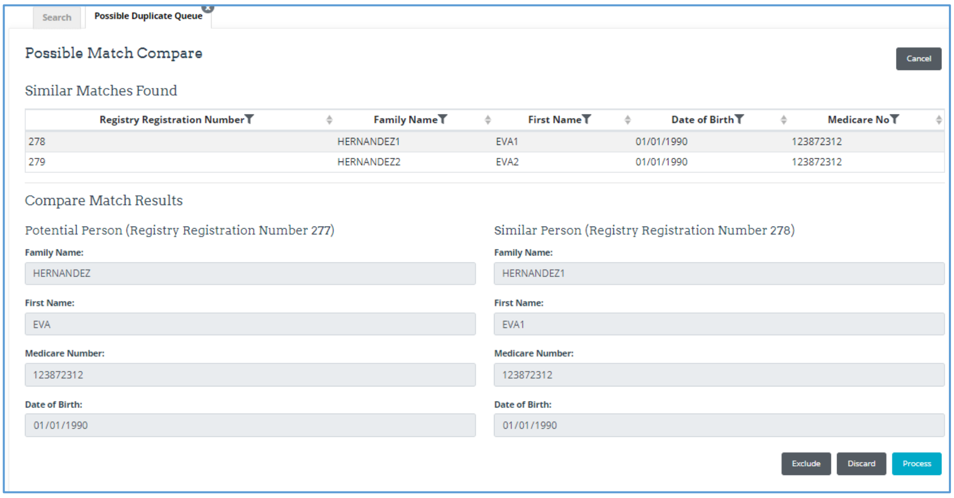


5. View the records where possible duplicates are identified in the Possible Match Results.

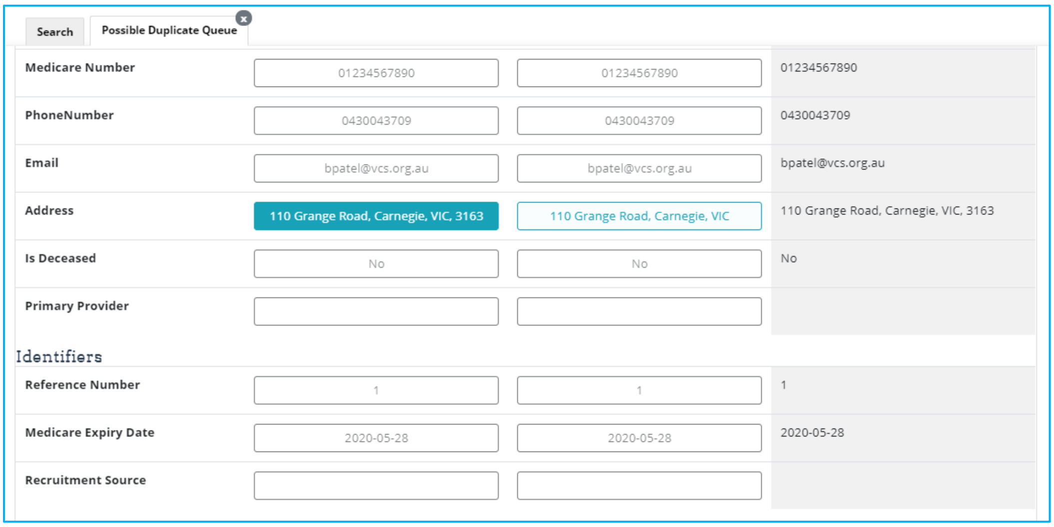


6. Double-click on a record to resolve the duplicates of that person's record.

Note: If more than one duplicate is identified for a person's record, then more than one record displays in the grid and each one will need to be resolved separately.



7. Click **Exclude** to remove the possible duplicate similar match from ever matching to this person incoming record again.
8. Click **Discard** to not match to this incoming record at this time but consider again as a potential match for any future incoming record. **Note:** the record will match again after the overnight follow up task has run.
9. Click **Process** to move to the matching screen.



10. The potential person is displayed on the left. The similar person in the middle and the resultant person created by the merge is on the right.

    The fields that match exactly between records are not highlighted and are created by default in the resultant person.
    The fields that do not match are highlighted in blue text.
11. Click the highlighted fields to determine the data to keep for the resultant person. You can select between the potential person demographics fields or the similar person.

    Note: You cannot merge consent details as this drives system behaviour for the delete or read only setting on a patient record. The consent details in the resultant person is inherited from the oldest created date/time on the similar person record.

    Primary provider is also retained from the oldest created date/time on the similar person record. This is to ensure the correct primary provider/consent status is retained.

12. Select the Client Episode data to be used as part of the Resultant person record. To select click the checkboxes beside the episode on the potential person and/or similar person. To unselect an episode type all together from the resultant person you will need to unclick the checkbox for that episode type from both areas.
13. Select the Secondary Places to merge to the resultant person.
14. Select the Documents to merge to the resultant person.
15. Click **Merge**.

The data associated with the potential person and similar person that is NOT merged is no longer retained. These records are hidden in the database.

A system notepad is written to the Resultant person. To view this notepad, select the ? button in the system text field associated with the notepad.

The follow up for the resultant person is driven by the episodes. Once the merge is performed and episodes are created on the resultant person, the overnight follow up task will re calculate the follow up for the resultant person.

4.23 Reporting

NECST Registry has been integrated with the Microsoft Power BI platform which allows creation of reports and dashboards in Power BI and then made available on the NECST Registry for users to access these reports from the Reporting menu.

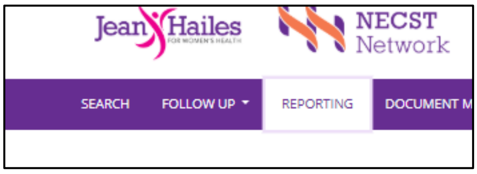
Note: A user who has access to the NECST Registry Power BI platform can create ad-hoc reports from Power BI and make it available through the Reporting module.

A nightly task is scheduled to copy the NECST Registry records into the Power BI platform.

Only patient records that are active ("Consent Confirmed") are copied to the Power BI platform. If the patient record has consent withdrawn (i.e. "Consent Denied") the data is removed from the Power BI during the overnight update.

4.23.1 Viewing Dashboards and Reports

1. Navigate to the Reporting Menu.



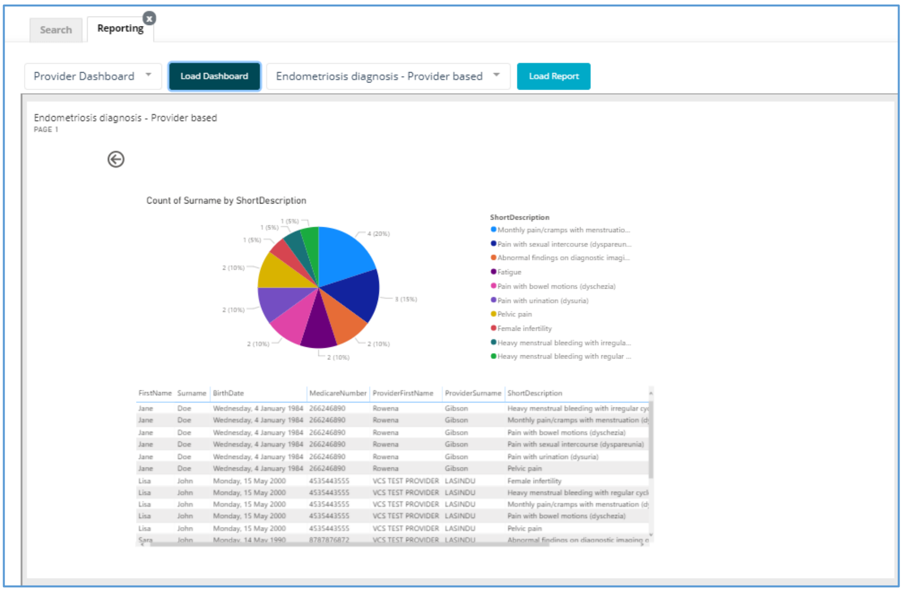
4.23.2 Loading a Dashboard

1. Navigate to the drop-down list against Load Dashboard and choose the item.
2. Click **Load Dashboard**.

   Note: The available dashboards and reports are determined by the workspace in which they are created in, within the Jean Hailes Power BI platform. If the dashboards or reports are not visible in the drop down menu, the reports will need to be moved to the correct workspace in Power BI to resolve. One workspace exists per group.

   Supported Groups are:

   - Clinician
   - Researcher
   - Clinical Staff
   - Clinical Admin



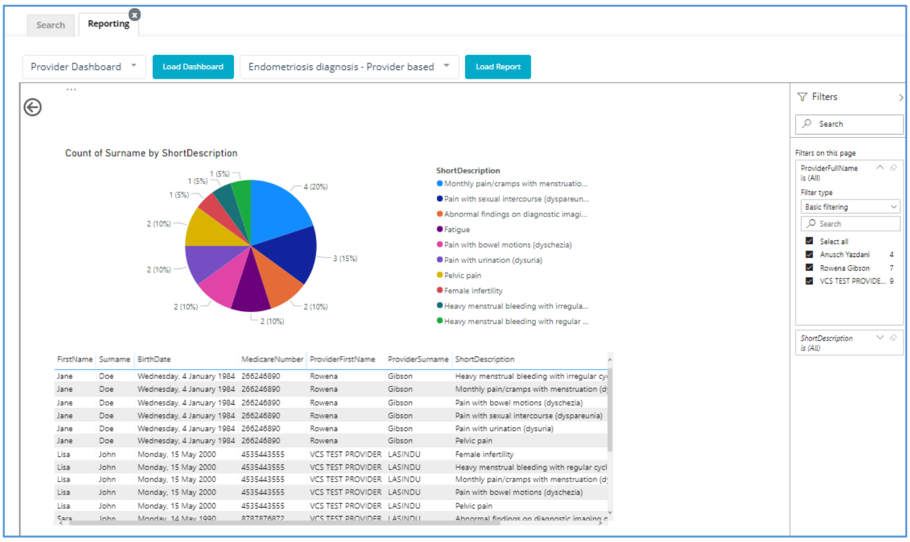
4.23.3 Loading a Report

1. Navigate to the drop-down list against Load Report and choose the item.
2. Click Load Report.
3. Apply the Filters as needed from within the report screen's Filters section.

   Note: The available dashboards and reports are determined by the workspace in which they are created in, within the Jean Hailes Power BI platform. If the dashboards or reports are not visible in the drop down, the reports will need to be moved to the correct workspace in Power BI to resolve. One workspace exists per group.

   Supported Groups are:

   - Clinician
   - Researcher
   - Clinical Staff
   - Clinical Admin



5 Frequently Asked Questions

5.1 How Do I Clear the Cache on Chrome

1. Open your web browser.
2. Click Ctrl+Shift+Delete on your keyboard.
3. Untick Cached Images and files and click Clear data.
4. Proceed to open the link to the registry (https://register.necstregistry.org/).

5.2 How Do I Clear the Cache on Firefox

1. Open your web browser.
2. Click Ctrl+Shift+Delete on your keyboard.
3. Untick Cache and click OK.
4. Proceed to open the link to the registry (https://register.necstregistry.org/).

5.3 How Do I Clear the Cache on Safari

1. Open your web browser.
2. Click on the Safari drop-down list and select Preferences.
3. Click the Advanced tab. Select the Show Develop menu in menu bar checkbox and close the Preferences window.
4. Select the Develop drop-down list. Click Empty Cache.
5. Proceed to open the link to the registry (https://register.necstregistry.org/).

5.4 How Do I Contact Support/Get Assistance

Contact the NECST Registry Support Officer/Administrator on email: admin@necstregistry.org and after triage issues will be raised with NECST Service Desk as required. Once resolved by the NECST Service Desk the information will be returned to NECST Registry Support Officer/Administrator to communicate to the originator of the incident.

5.5 What Are the Types of Episodes

Some of the episodes are automatically created in the NECST Registry, when the surveys/questionnaires completed by the person syncs from RedCap to the NECST Registry. These episodes can be viewed from the NECST Registry but are non-editable. Other episodes can be created and edited directly from the NECST Registry.

Editable Episodes	Non-Editable Episodes
• Clinical Pres Dx – Clinician • Medical Management • Medication • Imaging – US • Imaging – MRI • Surgical Management • Histopathology	• Clinical Pres Med Hx • PROMs EHP-30 • PROMs EQ-5D • Clinical Pre Med Hx – Follow-Up

5.6 What Are the Supported Browsers

The supported browsers are:

- Chrome
- MS Edge

- Firefox
- Safari

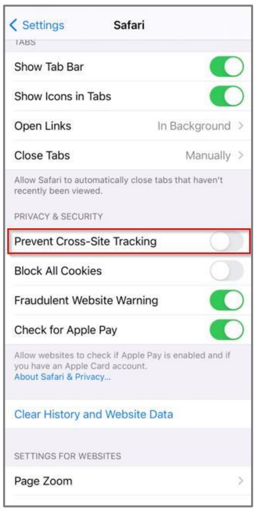
5.7 What Are the Supported Devices

The supported devices are:

- Samsung S9, S10, S20
- iphone 6/7/8 iOS 11
- iphone X iOS 12
- iphone X ios 14
- Any Mac running Safari 14 or higher
- Windows 10 on computer

5.8 What Do I Need to do to Make My Registry Work on Safari (Mac or iOS)

For the Registry to work on Safari (Mac or iOS), you will need to turn off "Prevent Cross-site tracking" (which is on by default).



5.9 Why Can I Not See the Entire Screen

For the Registry to work effectively and allow you to see the entire screen, you must have the highest level resolution that your device can support and the smallest font size.

If you cannot see parts of the screen, click the Ctrl + Mouse Scroll button to zoom out of the screen or resize within the browser window.

6 Appendix A: Glossary of Terms

Term	Explanation
Dx	Diagnosis.
EHP-30	Endometriosis Health Profile. Also referred to as PROMs – EHP-30. This is a questionnaire completed by the patient and made available under the Person Record - PROMs episodes in the NECST Registry. https://innovation.ox.ac.uk/outcome-measures/endometriosis-health-profile-ehp/
Episode	A term for an Episode of Care, representing an action or event that has been matched/created against a Person. Below are the types of episodes available in the NECST Registry: • Clinical Pres Dx – Clinician • Medical Management • Medication • Imaging – US • Imaging – MRI • Surgical Management • Histopathology Below are the episodes automatically created from the questionnaires completed by the patients: • Clinical Pres Med Hx • Clinical Pre Med Hx – Follow-Up • PROMs EQ-5D • PROMs EHP-30
EQ-5D	EuroQoL-5D. Also referred as PROMs – EQ-5D. This is a questionnaire completed by the patient and made available under the Person Record - PROMs episodes in the NECST Registry. https://en.wikipedia.org/wiki/EQ-5D.
Exclusion List	Providers are entered into an Exclusion List, to restrict their access to the Person's Record. They are only allowed to view any previous records created by them against the Person's Record.
Hx	History.
MFA	Multi-factor Authentication - https://en.wikipedia.org/wiki/Multi-factor_authentication.
Microsoft Active Directory	https://en.wikipedia.org/wiki/Active_Directory NECST Registry interface with Microsoft Active Directory to provision the user accounts.
Microsoft Power BI	https://en.wikipedia.org/wki/Microsoft_Power_BI NECST Registry is integrated with Power BI; allowed data from NECST Registry is replicated in Power BI, to enable users in Power BI to manage the reporting.
MRI	Magnetic Resonance Imaging.
NECST Registry	NECST Registry is the software system that Providers login to record the care details of the person being investigated for or managed due to endometriosis.
Person/Patient/Participant	Term Person and Patient are interchangeably used in this document – is the person receiving care for either investigation or management of endometriosis. Term Patient/Participant is mostly used in questionnaires while the NECST Registry sees them as Person.

Term	Explanation
Primary Place	A Primary Place is set against the Person Record when the Primary Provider confirms their consent. All Providers at a Primary Place have access to the Person's Record.
Primary Provider	Providers of type Obstetrician & Gynaecologist or Gynaecologist or General Surgeon are valid to be a Primary Provider of a Person. A Primary Provider is responsible for the Person's care and have the capability to confirm the consent of the Person.
PROMs	Patient Reported Outcome Measures - captures a person's perception of their own health through questionnaires. They enable patients to report on their quality of life, daily functioning, symptoms, and other aspects of their health and well-being, either in relation to their general health or in relation to a diagnosed condition.
Provider	Healthcare workers who is involved in the care of the patient, who access NECST Registry to record the care details of the person.
RedCap	A software system used to record the surveys/questionnaires of patients. NECST Registry is integrated with RedCap to sync the surveys/questionnaires completed by patients into the NECST Registry.
Secondary Place	Providers belonging to Secondary Place will have access to the Person's Record.
Secondary Provider	Any Provider involved in the care of the person other than the Primary Provider. These are Providers from Secondary Place and Primary Place.
Sync / Synchronise	Referred in this document to indicate the data replication from one system to another at a stipulated interval.
US	Ultrasound

7 Appendix B: System Rules/Policies

7.1 Password Policy

The password policy is as below and supported by Azure functionality.

- Minimum of 8 characters and a maximum of 256 characters
- Requires 3 out of 4 of the following:

1. Lowercase characters (a-z)
2. Uppercase characters (A-Z)
3. Numbers (0-9)
4. Symbols (@ # $ % ^ & * - _ ! + = [ ] { } | \ : â€˜ , . ? / ` ~ " ( ) ;) blank space

- Password expiry is after 90 days.
- Password expiry notification before 14 days of expiry.
- User cannot reuse previous 3 passwords.

7.2 Licence Types

Below are the various Licences required to access NECST Registry. Not all Licences are required for all the users.

Licence Types	Details
AZURE ACTIVE DIRECTORY PREMIUM P2	**Azure AD Premium P2** – is an edition includes all of the features of **Azure AD Premium** P1 with the addition of Identity Protection and Privileged Identity Management (PIM). Identity Protection provided management of conditional access to apps and critical data. Every user who need access to NECST Registry will need to be assigned this Licence.
POWER BI PRO	**Power BI Pro** is an individual user **Licence** that lets users read and interact with reports and dashboards that others have published to the **Power BI** service. Users with this **Licence** type can share content and collaborate with other **Power BI Pro** users. A NECST Registry user who needs to access Power BI directly (i.e. for creating ad-hoc reports and manage the reporting), will need to be assigned this Licence.

7.3 Consent Status

Consent Status	Details
Unconfirmed	When a person record is created directly from NECST Registry or using the Patient Demographic and Consent Questionnaire, the default consent status is set as “Consent Unconfirmed”. The person record remains “In Active” when the Consent is in this status.
Confirmed	Once the person verbally confirms their consent to participate in the NECST Registry during their consultation with the Provider, the status can be changed to “Confirmed”. This status will set the person record to an “Active” status.

Consent Status	Details
Denied	If the person verbally denies their consent to participate in the NECST Registry during their consultation with the Provider, the status can be changed to “Denied”. On saving, the patient record is hard deleted from the NECST Registry and is non-recoverable. If the person decides at a later time to withdraw their consent to participate in the NECST Registry, they may do so by informing their provider and completing a Withdrawal of Consent Form (can be made available upon request and is also sent to the person in their follow-up correspondence). The Provider can edit the consent status and be changed to “Denied”. On saving, the patient record will be made **read only** in the NECST Registry (unless specified by the participant that all their data are to be deleted from the Registry).

7.4 Person Status

Person Status	Details
InActive	When a person record is created, the initial status of the record is “In Active”. This is indicated by a InActive banner against the person’s record.
Active	When a person record has a Primary Provider, Primary Place allocated and the Consent Status is “Confirmed”, the person status changes to “Active”. This is indicated by a Active banner against the person’s record.
InEligible	When the age of the person is below 18 years, the status is “Ineligible”. This is indicated by a Ineligible banner against the person’s record.
Deceased	When the **Is Deceased** flag is set in the Patient Record (available from **Patient Demographics** screen), the status of the person changes to “Deceased”. This is indicated by a Deceased banner against the person’s record.

7.5 Person Record Access Rules

- When the person record status is “In Active”, only the Person’s Consent tab is available to the users.
- Only users who is a valid Primary Provider type (any of the provider types below) has edit capability on the Consent tab:
    - Obstetrician & Gynaecologist
    - Gynaecologist
    - General Surgeon
- The person’s record will change to “Active” when the below is set from the Consent tab:
    - Person’s Consent Status is set to “Confirmed” and
    - A Primary Provider and a Primary Place is assigned.

  Primary Provider (logged in user) and Primary Place (logged in place) is automatically assigned if the user is a valid Primary Provider type.
- Once the person’s record is saved with Consent Status as “Confirmed”, the person’s status will automatically change to “Active”.

- When the person record is in an "Active" status, all the users at the person's Primary Place and Secondary Places will have access to full details of the person.
- If a user is added to the Exclusion List of a person's record then this user will only have access to the person's Episode and Documents tab with ability to only view the records they have created against the person.

Note: Group - JH Admin has full access to all the tabs of the person's record and can view/edit full details of the person.

7.6 Person Duplicate Matching Rules – Possible Match

Rule	**Details** Only match not hidden persons for all rules
1	Where Family Name, Family Name, must be 85% similar and Street Name, Suburb, Post Code must be 85% similar
2	Where Family Name, First Name must be 85% similar and Date of Birth must be 95% similar
3	Where Family Name, First Name must be 85% similar and Telephone number must be 95% similar
4	Where Family Name, First Name, must be 85% similar and Medicare Number is 95% similar
5	Where Street Name, Suburb, Post Code must be 85% similar and First Name is 85% similar
6	Where First Name is 85% AND Medicare Number is 90% similar and Date of Birth is 90% similar
7	Where Family name is 85% similar AND Medicare Number is 90% similar and Date of Birth is 90% similar
8	Where First Name is 100% same and Date of birth is 100% same
9	Where First Name is 95% similar AND Medicare Number is 75% similar and Family Name is 95% similar

8 Appendix C: Reference Documents/Links

Topic	Reference Document/Link
MFA - Multi-factor Authentication	https://en.wikipedia.org/wiki/Multi-factor_authentication
Microsoft Active Directory	https://en.wikipedia.org/wiki/Active_Directory
Microsoft Power BI	Power BI Guided learning https://docs.microsoft.com/en-us/power-bi/guided-learning/
RedCap	RedCap Resources and Videos https://projectredcap.org/resources/videos/

9 Appendix D: Notes for System Administrator

The following are a list of notes that should be kept in mind for the System Administrator and Jean Hailes Administrator (once the training has been conducted for JH Admin).

- If you delete a document template from the Follow-Up Admin menu, you will also delete the Follow-Up Action types using this template.