



# NECST REGISTRY

## User guide



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# 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
<b>Surveys</b> (RedCap Surveys/Questionnaires)	<ul style="list-style-type: none"> <li>• Patient Demographics and Consent questionnaire</li> <li>• Patient reported outcome measures (PROMs) - EQ-5D questionnaire</li> <li>• PROMs - EHP-30 questionnaire</li> <li>• Clinical Pres Med Hx questionnaire</li> <li>• Clinical Pres Med Hx - Follow-Up</li> </ul>
<b>Search</b> Basic and Advanced search	<ul style="list-style-type: none"> <li>• Person</li> <li>• Episode</li> <li>• Provider</li> <li>• Place</li> </ul>
<b>Person Record</b>	<ul style="list-style-type: none"> <li>• Demographics</li> <li>• Consent</li> <li>• Record Access</li> <li>• Follow-Up</li> <li>• Documents</li> <li>• Episodes (Editable) <ul style="list-style-type: none"> <li>○ Clinical Pres Dx-Clinician</li> <li>○ Medical Management</li> <li>○ Medication</li> <li>○ Imaging – US</li> <li>○ Imaging – MRI</li> <li>○ Surgical Management</li> <li>○ Histopathology</li> </ul> </li> <li>• Episodes (Non-Editable) <ul style="list-style-type: none"> <li>○ Clinical Pres Med Hx</li> <li>○ Clinical Pre Med Hx – Follow-Up</li> <li>○ PROMs EQ-5D</li> <li>○ PROMs EHP-30</li> </ul> </li> </ul>
<b>Patient Record Matching</b>	<ul style="list-style-type: none"> <li>• QA Queue</li> <li>• Matching and Merging</li> </ul>
<b>Document Management</b>	<ul style="list-style-type: none"> <li>• Bulk Document Upload</li> <li>• Document Queue</li> </ul>
<b>Follow-Up</b>	<ul style="list-style-type: none"> <li>• Correspondence</li> <li>• Follow-Up Action Queue</li> <li>• Follow-Up Queue</li> </ul>
<b>Reporting</b>	<ul style="list-style-type: none"> <li>• General Power BI capabilities</li> <li>• Embedded Reports</li> </ul>
<b>Access Control and Configuration</b>	<ul style="list-style-type: none"> <li>• Theme and Branding</li> <li>• Licence</li> <li>• Group</li> <li>• User/Business Operation</li> <li>• Provider</li> <li>• Place</li> </ul>



### 3 Clinician Registry Usage

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

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



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.

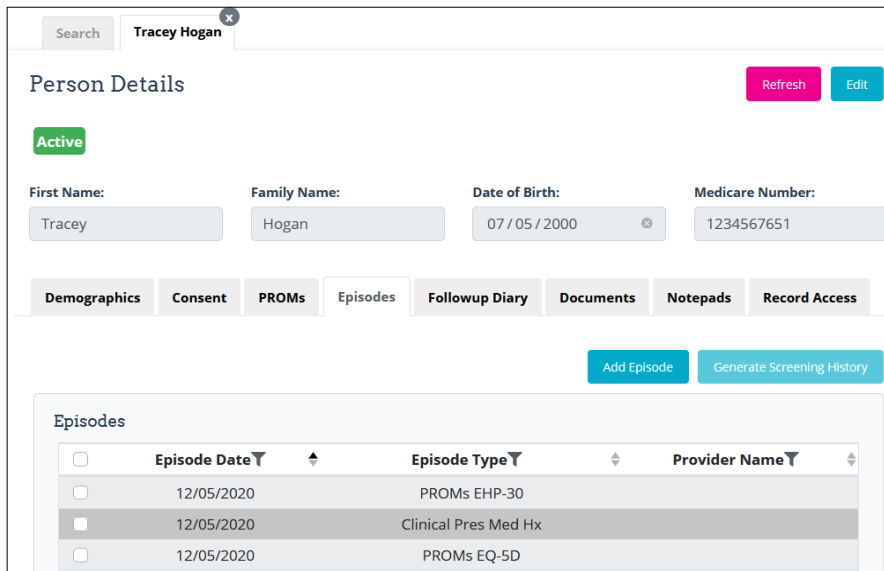
9. Return to the top of screen and click **Save**.
10. Enter a mandatory notepad detailing any changes made and click OK.
11. The person record is now updated to a system status of 'Active' along with a successfully created date on the system.
12. If required, review the patient's Clinical Pre Med Hx 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.



Search Tracey Hogan

Person Details Refresh Edit

**Active**

First Name: Tracey Family Name: Hogan Date of Birth: 07 / 05 / 2000 Medicare Number: 1234567651

Demographics Consent PROMs Episodes Followup Diary Documents Notepads Record Access

Add Episode Generate Screening History

Episodes

<input type="checkbox"/>	Episode Date	Episode Type	Provider Name
<input type="checkbox"/>	12/05/2020	PROMs EHP-30	
<input checked="" type="checkbox"/>	12/05/2020	Clinical Pres Med Hx	
<input type="checkbox"/>	12/05/2020	PROMs EQ-5D	

Search Tracey Hogan Tracey Hogan - Clinical Pres Med Hx

### Episode Details

<b>Episode Type:</b> Clinical Pres Med Hx	<b>Entered By:</b> api.user@necstregistry.org	<b>Person Name:</b> Tracey Hogan
<b>Episode Date:</b> 12/05/2020		

### Episode Reports

Current (12/05/2020 15:05)

#### Clinical Presentation And Medical History

Who referred you to this service?	Gynaecologist
Primary symptom/reason you are seeing the gynaecologist for investigation/management	Abnormal findings on diagnostic imaging of other specified body structures
Other specified body structures (please specify)	Both ovaries Rectum
Secondary/additional symptom(s)/reason(s) you are seeing the gynaecologist for investigation/management	Abnormal finding of blood chemistry Female infertility Other specified irregular menstruation
Age of first menstrual period	Specify Age
Please specify age of first menstrual period.	Other - 10
How old were you when you started to experience substantial period pain?	10 - 14 years old
How long do you periods usually last for (in days)? Shortest number of days - Longest number of days, e.g. 2 - 6, 2 means you may bleed as few as 2 days and 6 means you bleed as long as 6 days.	Other - 4
	Other - 7
What is the usual time between the first day of one period to the first day of the next period?	

### 3.3 Entering a Clinical Pres Dx - Clinician Episode

- 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.
- Double-click the patient record from the Results shown and click the Episodes tab.
- Click **Add Episode**. An add episode screen is displayed to allow you to enter additional information.
- Select the Episode type Clinical Pres Dx – Clinician.
- Enter the episode date (that is, the date the Clinician treated the patient).
- Click **Add**. The top section of each episode displays the episode type, provider, place, episode date and person name for easy reference.
- Scroll to Episode Reports and click **Edit**.
- Episodes that allow multiple answers to questions do not prevent you from selecting the same answer multiple times. You should ensure that the correct answers are selected for multiple choice answers to questions before saving.
- 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.

### Episode Reports

Save
Cancel

Clinical Pres Dx - Clinician

Primary clinical diagnosis

N80.9 - Endometriosis, unspecified

Endometriosis, unspecified

1 - Surgical diagnosis (with histopathological confirmation)

Secondary clinical diagnoses

D25.9 - Leiomyoma of uterus/fibroids

First day of last menstrual period

27/10/2020

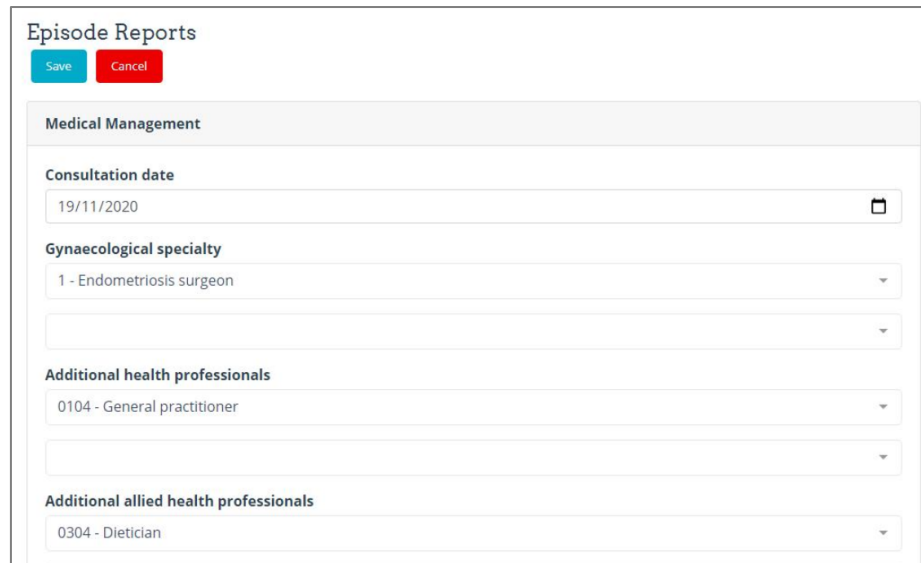
Hormonal Treatment?

2 - Not on hormonal treatment

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 multiple 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.

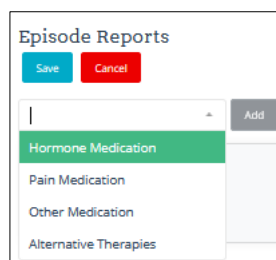


10. Scroll further down the page and upload any Documents to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads to the system that relate to this episode.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

### 3.5 Entering a Medication Episode

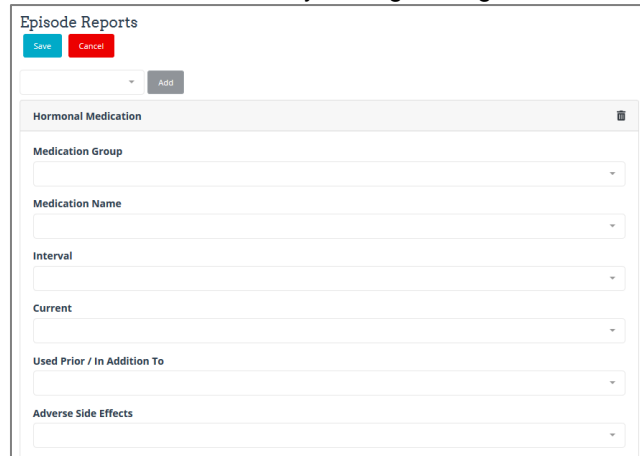
**Note:** In a Medication Episode, you add one record for each type of medication (Hormonal, Pain, Other and Alternative and complementary therapies) in a single episode. Select the Medication type you want to add and complete the details in the Episode Report section for each medication type.

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 multiple 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 navigate 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.

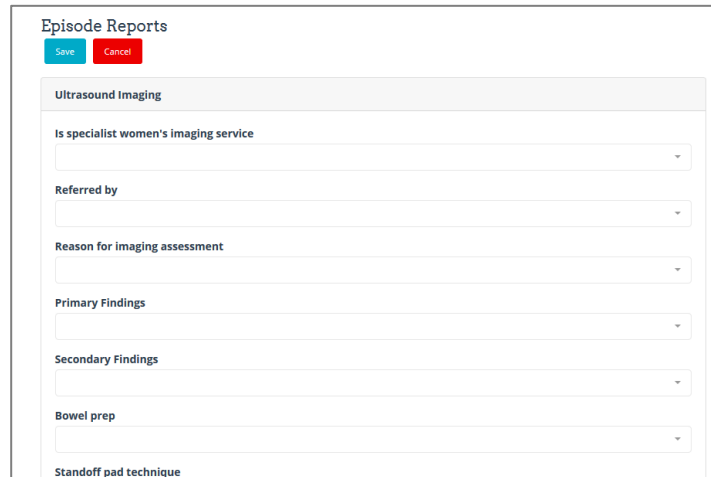
### 3.6 Entering a Surgical Management Episode

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 multiple 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 multiple 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.



The screenshot shows a web form titled 'Episode Reports'. At the top left are 'Save' and 'Cancel' buttons. Below the title is a section header 'Ultrasound Imaging'. The form contains several dropdown menus: 'Is specialist women's imaging service', 'Referred by', 'Reason for imaging assessment', 'Primary Findings', 'Secondary Findings', 'Bowel prep', and 'Standoff pad technique'.

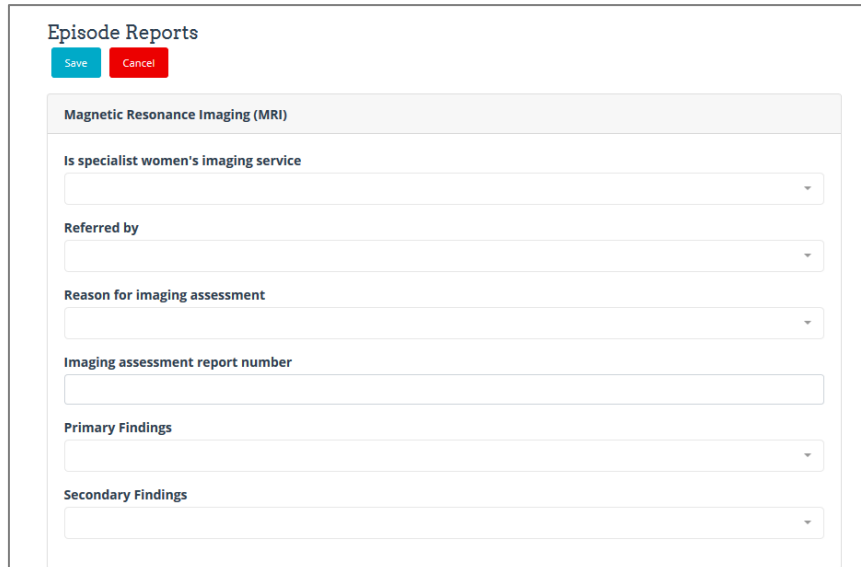
10. Scroll further down the page and upload any Documents (e.g. final ultrasound report +/- images) to the system that relate to this episode. See Uploading Document from Person Details/Episode/Provider/Place Details on page 31 for more information.
11. Scroll further down the page and enter any Notepads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



The screenshot shows a web form titled 'Episode Reports' with a 'Save' button in blue and a 'Cancel' button in red. Below the title is a section for 'Magnetic Resonance Imaging (MRI)'. The form contains several dropdown menus and text input fields: 'Is specialist women's imaging service', 'Referred by', 'Reason for imaging assessment', 'Imaging assessment report number', 'Primary Findings', and 'Secondary Findings'.

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 multiple 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.



### Episode Reports

Save
Cancel

#### Histopathology

**Date of surgery**

**Histopathology assessment report number**

**Primary Findings**

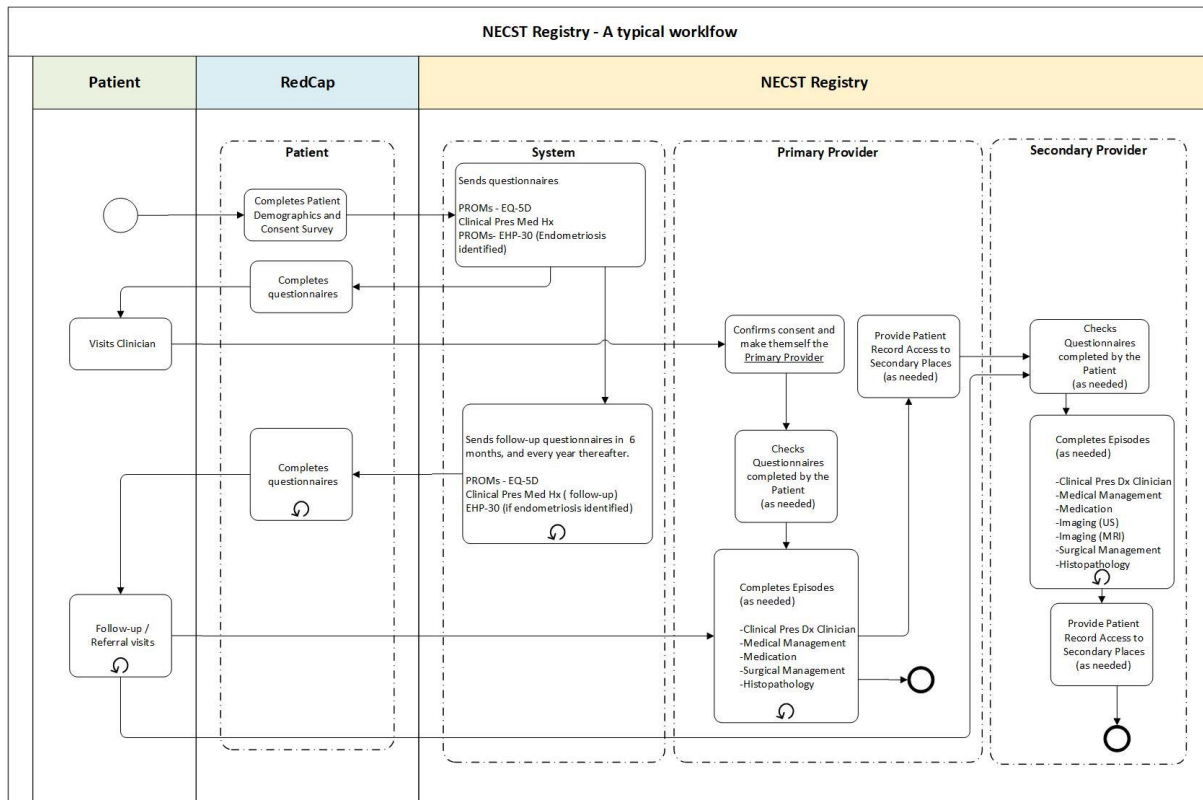
**Secondary Findings**

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. Radiologist/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

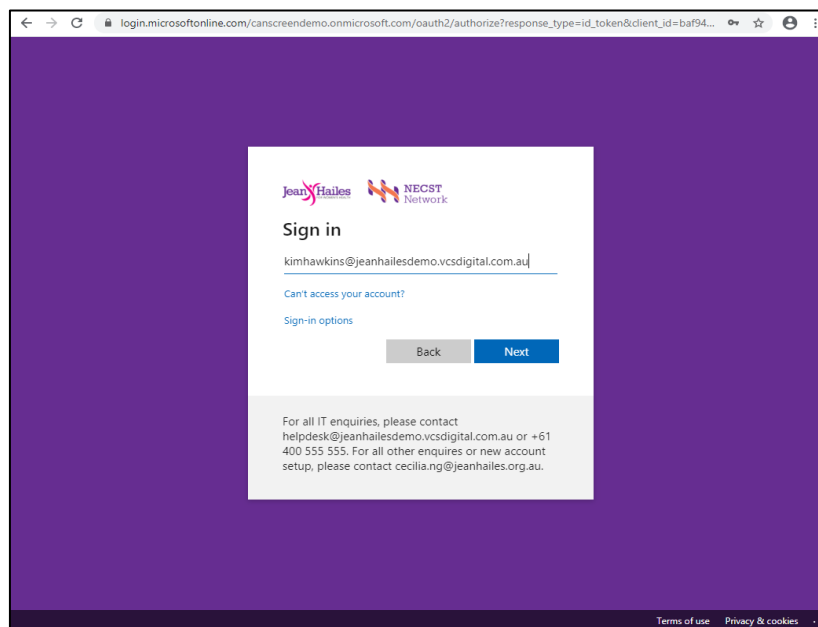
Survey	Description
	<p>Clinical Pre Med Hx survey or has an existing Surgical Episode (with a diagnosis of endometriosis), then the patient will receive this survey.</p> <p>The details from a completed questionnaire are made available in the NECST Registry, under the Patient Record – PROMs or Episodes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

## 4.3 General Navigation and Functions

### 4.3.1 Login

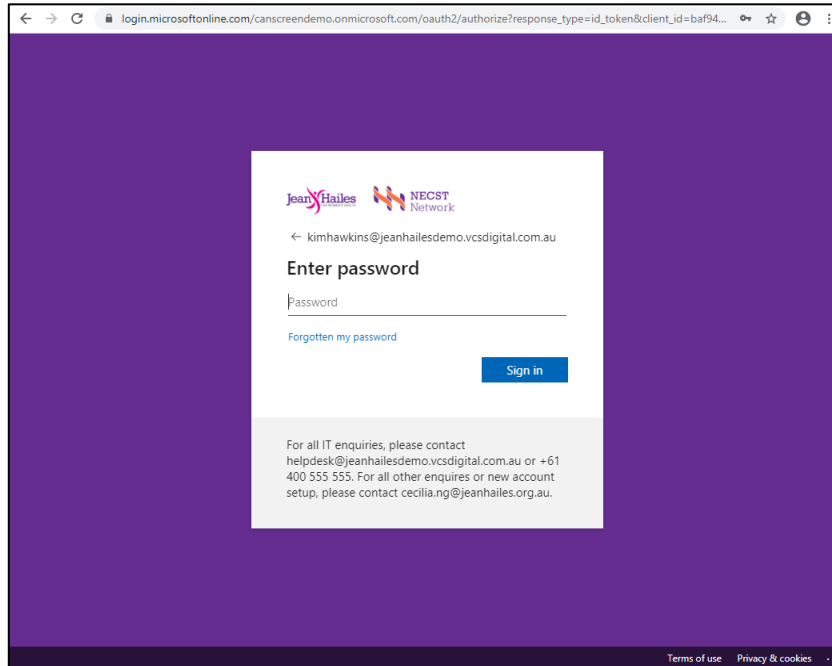
1. Open any web browser and go to <https://register.necstregistry.org/>.

**Note:** for supported browser 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](mailto:admin@necstregistry.org).



login.microsoftonline.com/canscreendemo.onmicrosoft.com/oauth2/authorize?response\_type=id\_token&client\_id=ba94...

← kimhawkins@jeanhailesdemo.vcsdigital.com.au

**Enter password**

Password

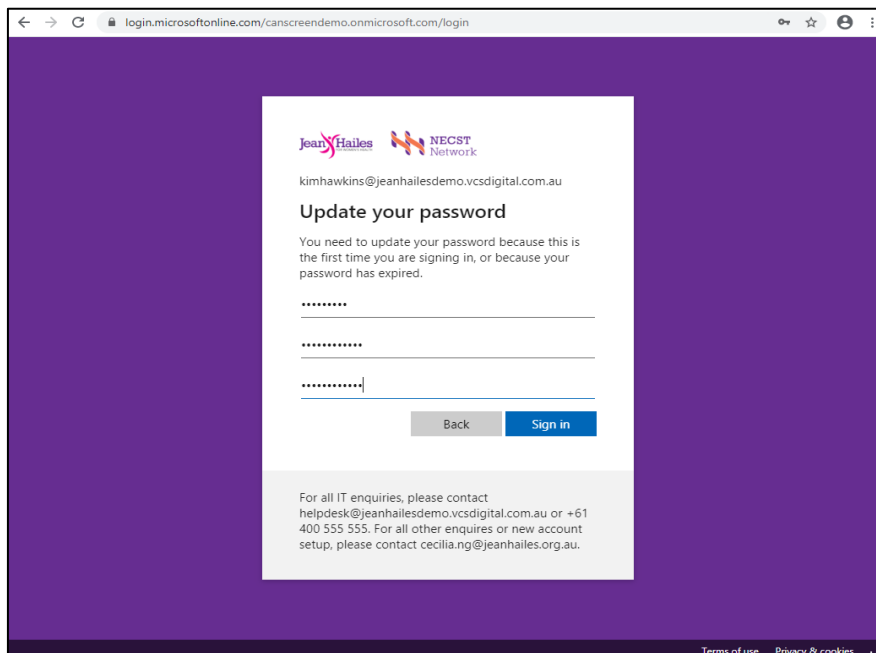
[Forgotten my password](#)

**Sign in**

For all IT enquiries, please contact  
helpdesk@jeanhailesdemo.vcsdigital.com.au or +61  
400 555 555. For all other enquiries or new account  
setup, please contact cecilia.ng@jeanhailes.org.au.

[Terms of use](#) [Privacy & cookies](#) ...

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.



login.microsoftonline.com/canscreendemo.onmicrosoft.com/login

kimhawkins@jeanhailesdemo.vcsdigital.com.au

**Update your password**

You need to update your password because this is the first time you are signing in, or because your password has expired.

.....

.....

.....



**Back** **Sign in**

For all IT enquiries, please contact  
helpdesk@jeanhailesdemo.vcsdigital.com.au or +61  
400 555 555. For all other enquiries or new account  
setup, please contact cecilia.ng@jeanhailes.org.au.

[Terms of use](#) [Privacy & cookies](#) ...

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

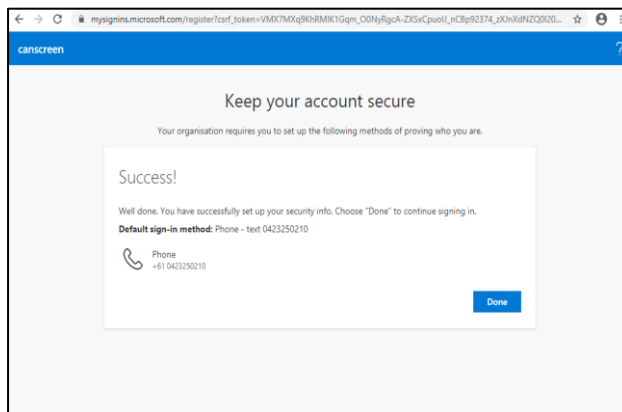
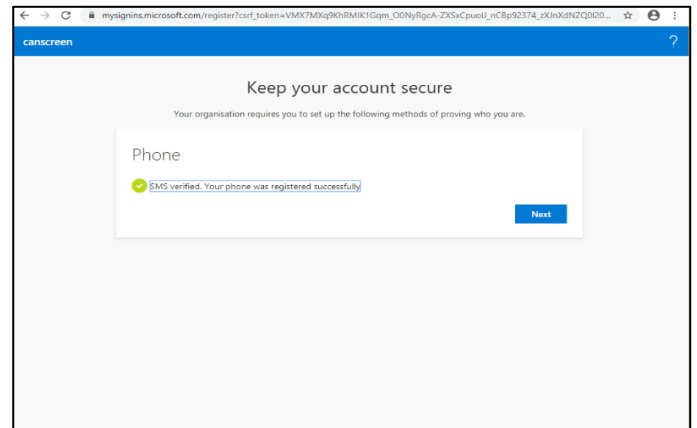
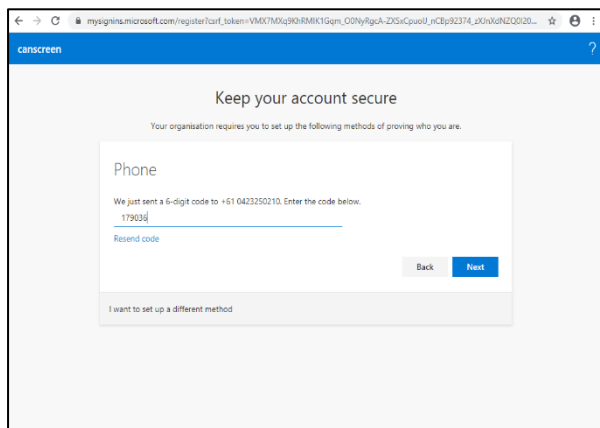
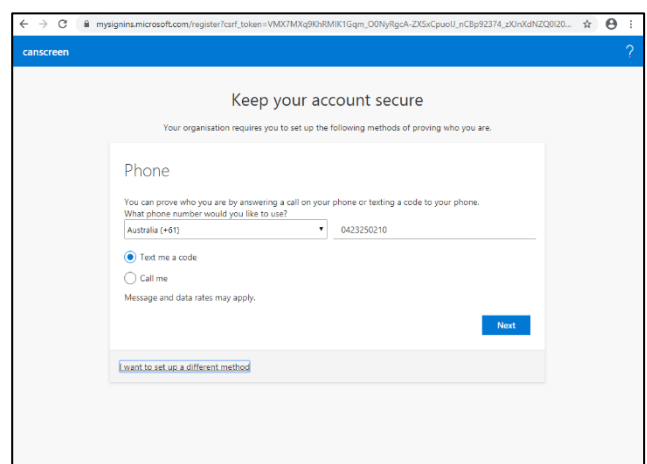
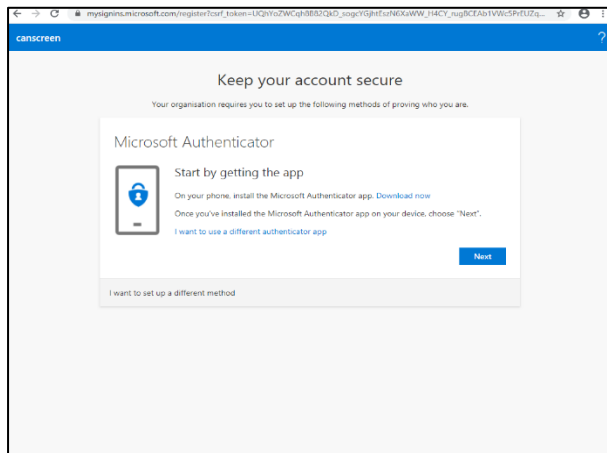
All information collected about people and/or places as part of the notification process is confidential and must be handled with great care. By logging onto the NECST Registry you agree to meet the following guidelines at all times:

- 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

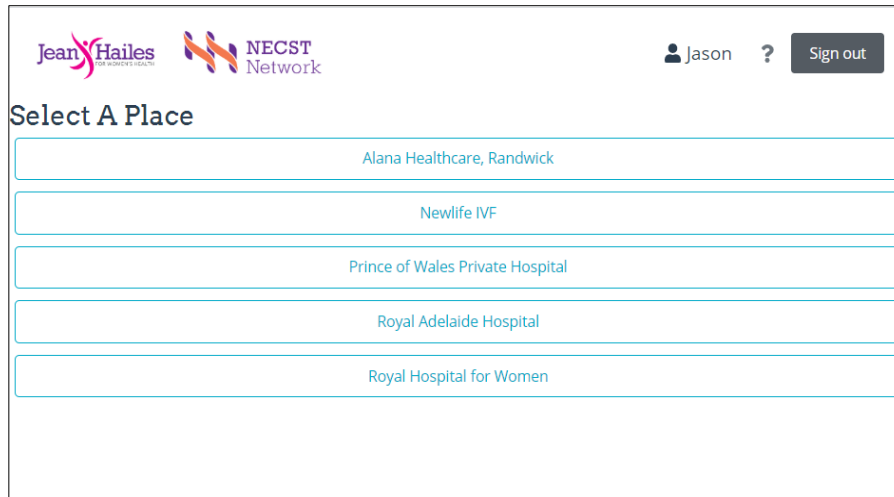
6. Once you have accepted the NECST Registry Terms of Use you will be required to setup MFA (multi-factor authentication) on your first login.





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.



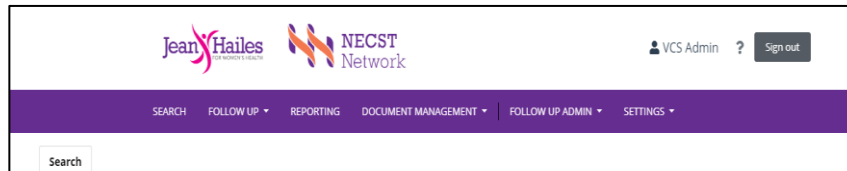


Jason ? Sign out



Select A Place

- Alana Healthcare, Randwick
- Newlife IVF
- Prince of Wales Private Hospital
- Royal Adelaide Hospital
- Royal Hospital for Women

### 4.3.2 Sign out

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



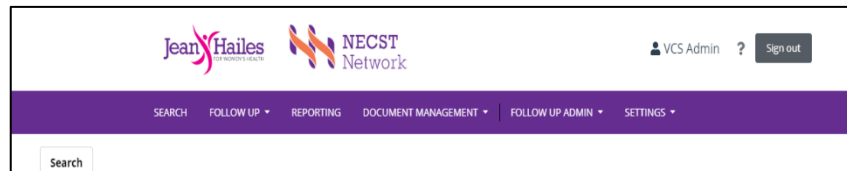


VCS Admin ? Sign out



SEARCH FOLLOW UP REPORTING DOCUMENT MANAGEMENT FOLLOW UP ADMIN SETTINGS

Search

### 4.3.3 Accessing Help

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





VCS Admin ? Sign out

SEARCH FOLLOW UP REPORTING DOCUMENT MANAGEMENT FOLLOW UP ADMIN SETTINGS

Search

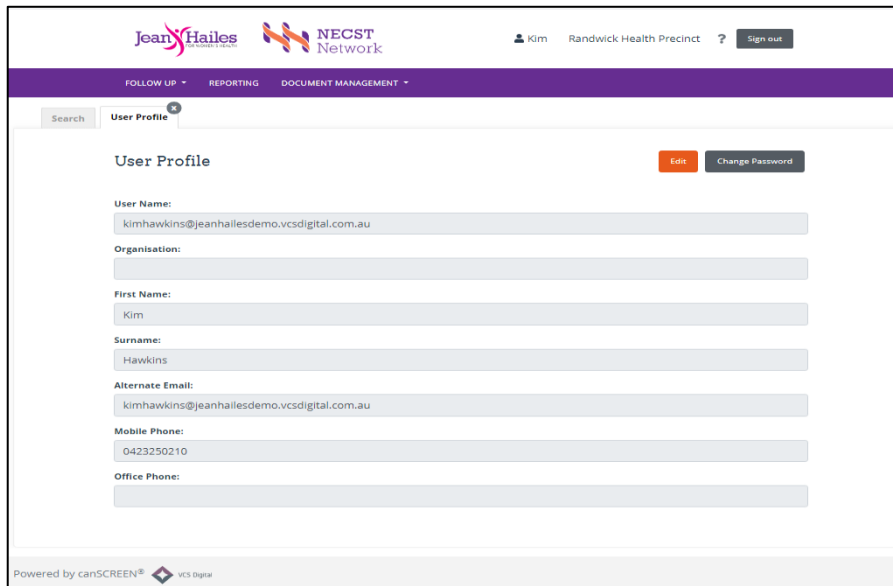
2. This is a context sensitive help file and brings up the topic based on the NECST Registry screen you are on. You may also search on topics as needed.

### 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 your 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 wildcard 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.

Search

PERSON

EPISODE

PROVIDER

PLACE

Person Search

Names:

Date of Birth:

Search

Clear

Add New Person

2 Results Found

First Name	Family Name	Date of Birth	Medicare No
Lisa	Paker	26/03/2000	523424324
Lisa	Wilkinson	26/03/1970	2343432434

#### 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.

Search

PERSON

EPISODE

PROVIDER

PLACE

Episode Search

Episode Type:

Episode Date From:

Episode Date To:

Provider Name:

Place Name:

Search

Clear

5 Results Found

EpisodeDate	Episode Type	First Name	Family Name	Provider Name	Place Name
26/03/2020	PROMs EHP-30	Emily	Bloge		
26/03/2020	PROMs EHP-30	Emily	Bloge		
26/03/2020	PROMs EHP-30	Lisa	Paker		
26/03/2020	PROMs EHP-30	Emily	Bloge		
26/03/2020	PROMs EHP-30	Lisa	Wilkinson		

#### 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.

Search

PERSON EPISODE PROVIDER PLACE

Provider Search Basic Advanced

Provider Name/Provider Number/Locality/State:  
jason

☒ Is Current

Search Clear Add New Provider

5 Results Found

Provider Name	Provider Type	Place Name
Jason Abbott	Obstetrician & Gynaecologist	Alana Healthcare, Randwick
Jason Abbott	Obstetrician & Gynaecologist	Prince of Wales Private Hospital
Jason Abbott	Obstetrician & Gynaecologist	Royal Hospital for Women
Jason Abbott	Obstetrician & Gynaecologist	Newlife IVF
Jason Abbott	Obstetrician & Gynaecologist	Royal Adelaide Hospital

Search

PERSON EPISODE PROVIDER PLACE

Provider Search Basic Advanced

Provider Surname:  
abbott

Provider First Name:

Provider Type:

Place Name:

Search Clear Add New Provider

5 Results Found

Provider Name	Provider Type	Place Name
Jason Abbott	Obstetrician & Gynaecologist	Alana Healthcare, Randwick
Jason Abbott	Obstetrician & Gynaecologist	Prince of Wales Private Hospital
Jason Abbott	Obstetrician & Gynaecologist	Royal Hospital for Women
Jason Abbott	Obstetrician & Gynaecologist	Newlife IVF
Jason Abbott	Obstetrician & Gynaecologist	Royal Adelaide Hospital

#### 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**.

Search

PERSON EPISODE PROVIDER PLACE

Provider Search Basic Advanced

Provider Name/Provider Number/Locality/State:  
jason

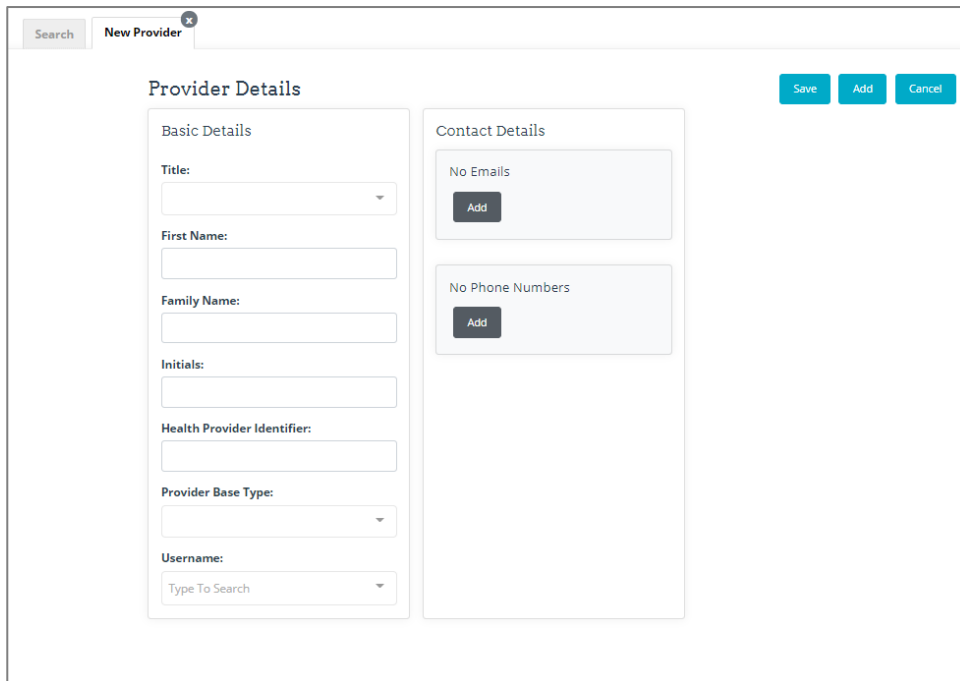
☒ Is Current

Search Clear Add New Provider

5 Results Found

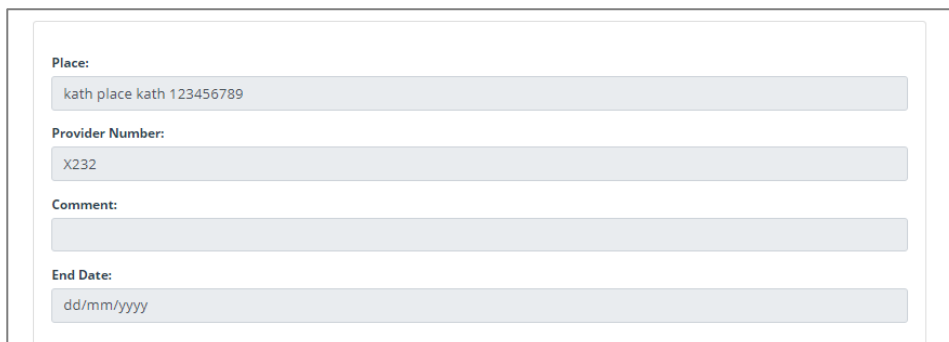
Provider Name	Provider Type	Place Name
Jason Abbott	Obstetrician & Gynaecologist	Alana Healthcare, Randwick
Jason Abbott	Obstetrician & Gynaecologist	Prince of Wales Private Hospital
Jason Abbott	Obstetrician & Gynaecologist	Royal Hospital for Women
Jason Abbott	Obstetrician & Gynaecologist	Newlife IVF
Jason Abbott	Obstetrician & Gynaecologist	Royal Adelaide Hospital

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.

Search

PERSON EPISODE PROVIDER **PLACE**

Place Search Basic Advanced

Place Name/Localty/State:

royal

☒ Is Current

Search Clear Add New Place

8 Results Found

Place Name	Place Phone Number	Street Name	Postcode	State
Royal Adelaide Hospital	0870740000	Port Rd	5000	
Royal Brisbane and Women's Hospital		Butterfield St	4029	
Royal Children's Hospital		50 Flemington Rd	3052	
Royal Hospital for Women		Banker Street	2031	
Royal North Shore Hospital		Reserve Rd	2065	
Royal Prince Alfred Hospital		50 Missenden Rd	2050	
The Royal Women's Hospital, Parkville		20 Flemington Rd	3052	
The Royal Women's Hospital, Sandringham		193 Bluff Road	3191	

Search

PERSON EPISODE PROVIDER **PLACE**

Place Search Basic Advanced

Place Name:

Place Phone Number:

Street Name:

Postcode:

State:

Search Clear Add New Place

#### 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**.

New Place

Place Details

Basic Details

Place Name:

Contact Name:

Health Organisation Identifier:

Place Type:

End Date:

dd/mm/yyyy

Addresses

No Addresses

Add

Contact Details

No Phone Numbers

Add

No Emails

Add

Save Cancel

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.

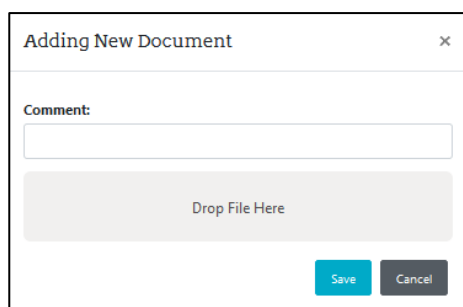
You must also ensure that the provider/place link is end dated in the provider record before the record is saved with the above end date.

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

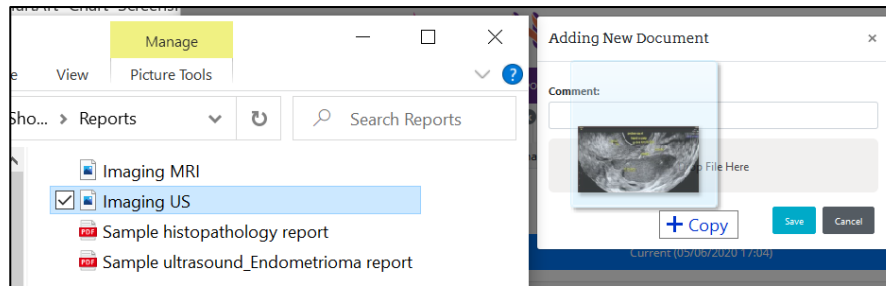
Documents can be uploaded from various areas in NECST Registry. NECST Registry supports documents of size below 5MB.

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.

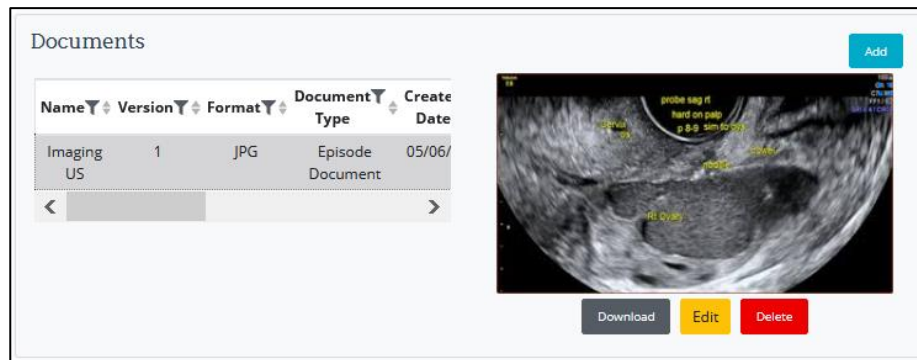
1. Open the record and select the Documents tab.
2. Click **Add**.

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

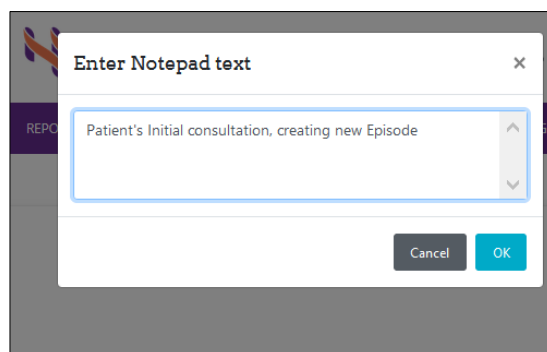
Follow-Up Reason	Description
Check Pregnancy Status	
SMS Failed to send - Transmission Issue	<p>A transmission issue occurred when sending SMS. Relist to resolve.</p> <p>Return to queue and click the record and Resolve button.</p>
Email Failed to send - Transmission Issue	<p>A transmission issue occurred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



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

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

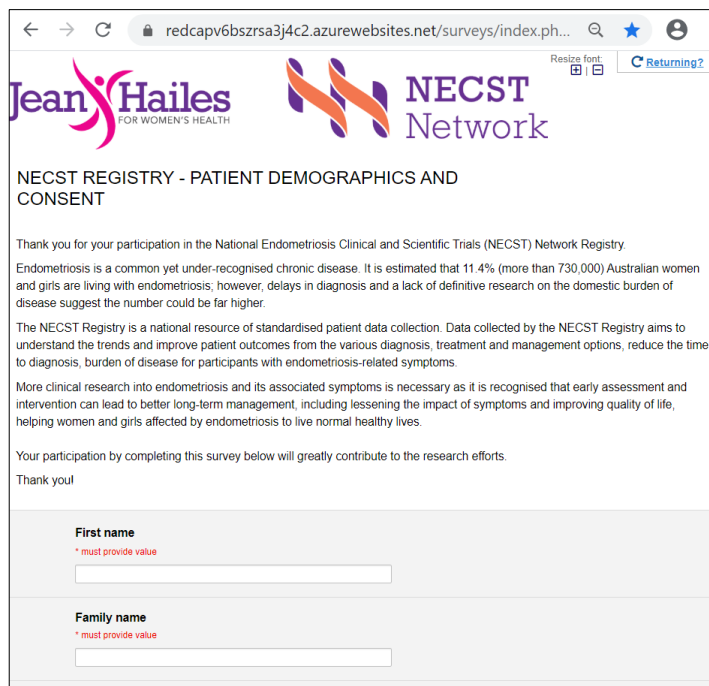
A new person can be added into the NECST Registry:

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

**Note:** Person will need to be 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.



← → ↻ 🔒 redcapv6bszrsa3j4c2.azurewebsites.net/surveys/index.ph... 🔍 ⭐ 👤 ⋮

Jean Hailes FOR WOMEN'S HEALTH

NECST Network

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



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.

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

Search

Provider - Jason Abbott

Tracey Hogan

Tracey McKinnon

PERSON

EPISODE

PROVIDER

PLACE

Person Search

Basic

Advanced

Names:

tracey

Date of Birth:

dd / mm / yyyy

Search

Clear

Add New Person

3 Results Found

First Name	Family Name	Date of Birth	Medicare No
Tracey	Hogan	07/05/2000	1234567651
Tracey	McKinnon	13/05/2000	1234567890
Tracey	Williams	13/05/2001	1234567891

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

Search New Person

### Person Details

Basic Demographics

Title:

Family Name:

\* Required

First Name:

\* Required

Date of Birth:

\* Required

☐ Is Deceased

Previous Family Name:

Mandarin

Do you speak a language other than English at home:

Marital Status And General Health

Current registered marital status:

Height:

Weight:

BMI:

Tobacco smoking status:

Alcohol use:

Save

Cancel

## 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.

Search
Tracey Hogan

### Person Details

Refresh Edit

InActive

First Name: Tracey
Family Name: Hogan
Date of Birth: 07 / 05 / 2000
Medicare Number: 1234567651

Consent

Consent Status: Consent Unconfirmed

Consent Date: 27/05/2020

Primary Provider Bindu (Test) Kakkada

Primary Place Alana Healthcare, Randwick

- 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.

Search
Tracey Hogan
Tracey Hogan - Histopathology

### Person Details

Refresh Edit

Active

First Name: Tracey
Family Name: Hogan
Date of Birth: 07 / 05 / 2000
Medicare Number: 1234567651

Demographics
Consent
PROMs
Episodes
Followup Diary
Documents
Notegads
Record Access

#### Basic Demographics

Title:
Family Name: Hogan
First Name: Tracey
Date of Birth: 07 / 05 / 2000
Is Deceased:
Previous Family Name:
Gender: Female

#### Identifiers

Registry Registration Number: 12
Medicare Number: 1234567651
HSCap ID: 177
Reference Number: 2
Medicare Expiry Date: 07/05/2025

#### Education And Employment Status

Highest education level completed: Graduate diploma and graduate ce
Status of employment: Employer
Full-time/part-time status: Part-time (less than 35 hours per w
Employment status: Fixed term contract
Occupation: Manager

#### Contact Details

Addresses: 12 Sturt Street, South Melbourne, 3001, VIC
Phone Numbers: (HOM) 0423 345 344
Emails: bkakkada@vcs.org.au
Preferred Contact Method: Email

#### Ethnicity And Language

Country of Birth: South Africa
Indigenous status: Neither Aboriginal nor Torres Stral
How well do you speak English: Well
Which language did you first speak as a child: Arabic
Do you speak a language other than English at home: Yes, Arabic

#### Marital Status And General Health

Current registered marital status: Separated
Height: 160
Weight: 70
BMI: 27.3
Tobacco smoking status: Ex-Smoker
Alcohol use: 2 - 3 times a week

- Click **Edit**.
- 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**.

Search Tracey Hogan

### Person Details

**InActive**

First Name: Tracey Family Name: Hogan Date of Birth: 07/05/2000 Medicare Number: 1234567651

Consent

Consent Status:

- Consent Unconfirmed
- Consent Unconfirmed**
- Consent Confirmed
- Consent Denied

Primary Provider: Bindu (Text) Kakkada

Primary Place: Alana Healthcare, Randwick

Participation Consent

Date of consent: 12/05/2020

- ☒ I give permission for health information to be collected from my doctor, medical records or through ethically approved health databases, endometriosis registries or cancer registries
- ☒ I give permission for you to contact me in the future to take part in other research projects or surveys.
- ☒ I consent to the linking of my personal and health information with the government health records for hospital and emergency departments, ambulance service, births, marriage or death registries, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS) and other approved population and health registry and databases (e.g. Australian and New Zealand Assisted Reproductive Database, Perinatal Data Collection, Cancer Registry, Australian Longitudinal Study on Women's Health) The researchers affiliated with the study using my linked health information for the purposes of the study in a manner that does not disclose my identity
- ☒ I do not consent for my health data to be used in this study, release of the data and its use in the NECST Registry will cease from the date of withdrawal

Signature Date: 12/05/2020

**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.

**Alert**

Do you wish to proceed with Patient's 'Consent Denied' status?

On proceeding, Patient's record will be completely removed from the system and non-recoverable.

If you wish to generate the Patient's Screening History prior to removing the Patient Record, please do so by going to the Episode page prior to clicking Proceed here.

Cancel Proceed

**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 Denied”. 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**.



Search Tracey Hogan

Person Details Refresh Go

**Active**

First Name: Tracey Family Name: Hogan Date of Birth: 07/05/2000 Medicare Number: 1234567651

Demographics Consent PROMs Episodes Followup Diary Documents Notepads Record Access

Patient Record Access

Primary Provider: Bindu (Test) Kakkada

Primary Place: Alana Healthcare, Randwick

Secondary Places

Select option Add Secondary Place Refresh

Place	Item	Date Added	Action
Royal Brisbane and Women's Hospital		15/05/2020	<span>Delete</span>

Secondary Places

royal Add Secondary Place Refresh

- Royal Adelaide Hospital
- Royal Children's Hospital
- Royal Hospital for Women's Hospital
- Royal North Shore Hospital
- Royal Prince Alfred Hospital
- The Royal Women's Hospital

Place	Item	Date Added	Action
Royal Brisbane and Women's Hospital		15/05/2020	<span>Delete</span>

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

Secondary Places

Select option Add Secondary Place Refresh

Place

Item	Date Added	Action
Royal Brisbane and Women's Hospital	15/05/2020	<span>Delete</span>

## 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

- EuroQoL-5D (EQ-5D), a standardised measure of health status.
- 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.

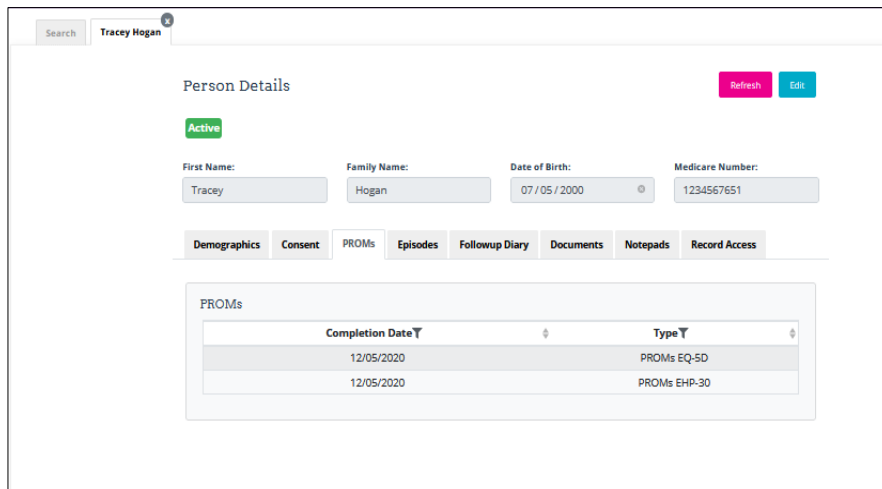
**Note:** A PROMs Episode cannot be directly entered from the NECST Registry.

## 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.



The screenshot shows the 'Person Details' screen for 'Tracey Hogan'. The 'Active' status is indicated by a green button. The 'PROMs' tab is selected, displaying a table of PROMs episodes.

Completion Date	Type
12/05/2020	PROMs EQ-5D
12/05/2020	PROMs EHP-30

Search
Tracey Hogan
Tracey Hogan - PROMs EQ-5D

### Episode Details

Episode Type:  
PROMs EQ-5D

Entered By:  
api.user@necstregistry.org

Person Name:  
Tracey Hogan

Episode Date:  
12 / 05 / 2020

### Episode Reports

Current (12/05/2020 15:05)

#### PROMs EQ-5D

MOBILITY	I have severe problems in walking about
SELF-CARE	I am unable to wash or dress myself
USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)	I have moderate problems doing my usual activities
PAIN/DISCOMFORT	I have slight pain or discomfort
ANXIETY/DEPRESSION	I am not anxious or depressed

We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Please click on the scale to indicate how your health is TODAY.

Other - 26

Date completed Other - 2020-05-12

#### 4.9.1.2 PROMs - EHP-30

See Viewing PROMs on page 42 for more information.

Search
Tracey Hogan
Tracey Hogan - PROMs EQ-5D
Tracey Hogan - PROMs EHP-30

### Episode Details

Episode Type:  
PROMs EHP-30

Entered By:  
api.user@necstregistry.org

Person Name:  
Tracey Hogan

Episode Date:  
12 / 05 / 2020

### Episode Reports

Current (12/05/2020 15:06)

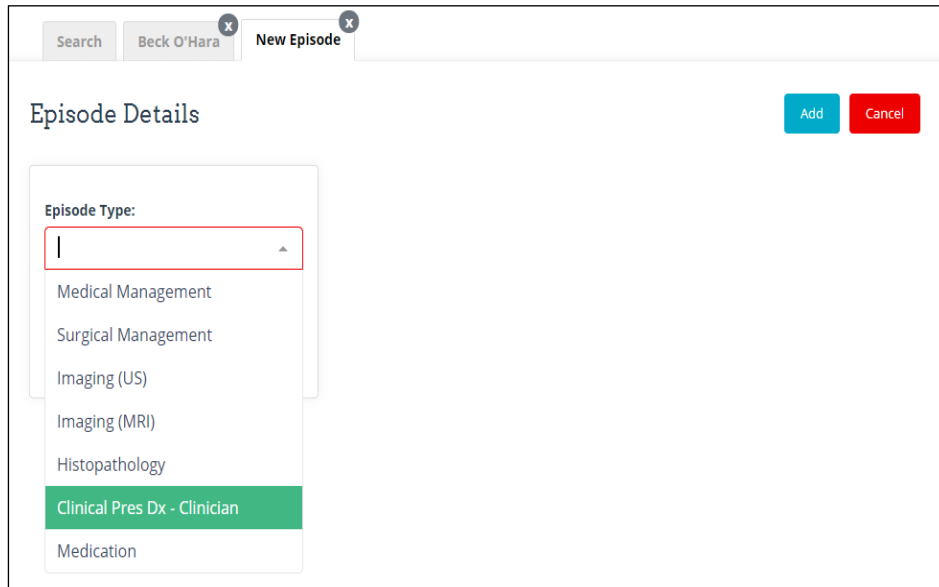
#### PROMs EHP-30

Been unable to go to social events because of the pain?	Often
Been unable to do jobs around the home because of the pain?	Often
Found it difficult to stand because of the pain?	Sometimes
Found it difficult to sit because of the pain?	Sometimes
Found it difficult to walk because of the pain?	Sometimes
Found it difficult to exercise or do the leisure activities you would like to do because of the pain?	Rarely
Lost your appetite and/or been unable to eat because of the pain?	Rarely
Been unable to sleep properly because of the pain?	Sometimes
Had to go to bed/lie down because of the pain?	Always
Been unable to do the things you want to do because of the pain?	Sometimes
Felt unable to cope with the pain?	Rarely
Generally felt unwell?	Rarely
Felt frustrated because your symptoms are not getting better?	Rarely
Felt frustrated because you are not able to control your symptoms?	Sometimes

#### 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.



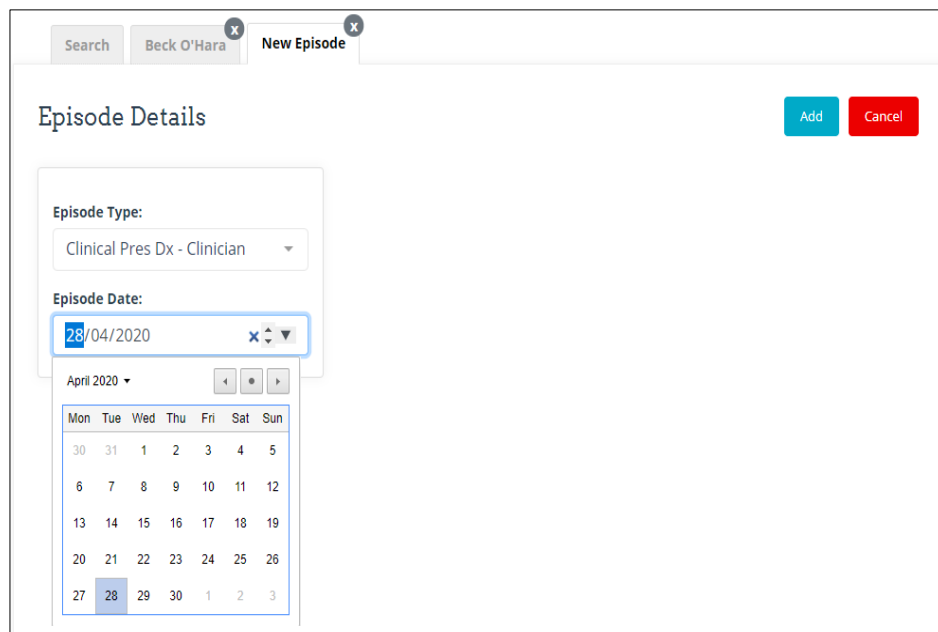
Search Beck O'Hara New Episode

Episode Details

Add Cancel

Episode Type:

- Medical Management
- Surgical Management
- Imaging (US)
- Imaging (MRI)
- Histopathology
- Clinical Pres Dx - Clinician**
- Medication



Search Beck O'Hara New Episode

Episode Details

Add Cancel

Episode Type:

Clinical Pres Dx - Clinician

Episode Date:

28/04/2020

April 2020

Mon	Tue	Wed	Thu	Fri	Sat	Sun
30	31	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	1	2	3

- Click **Edit** in the Episode Report section.
- Edit the necessary details and click **Save**.
- 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.

### Episode Providers

Episode Provider Types:

Provider Search

Basic Advanced

Provider Name/Provider Number/Locality/State:

☐ Is Current

Search

Clear

Add New Provider

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 multiple 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**.

Search Tracey Hogan

### Person Details

Active

First Name: Tracey Family Name: Hogan Date of Birth: 07/05/2000 Medicare Number: 1234567651

Demographics Consent PROMs Episodes Followup Diary Documents Notepads Record Access

Add Episode Generate Screening History

#### Episodes

<input type="checkbox"/>	Episode Date	Episode Type	Provider Name
<input type="checkbox"/>	12/05/2020	PROMs EHP-30	
<input type="checkbox"/>	12/05/2020	Clinical Pres Med Hx	
<input type="checkbox"/>	12/05/2020	PROMs EQ-5D	

- Select the Episode Type you want to add.
- Select/Enter the Episode Date.
- 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.

### Episode Reports

Edit

Original (07/10/2020 12:43)
(22/10/2020 12:24)
Current (22/10/2020 15:23)

- Navigate to Person Search screen and open the Person's Record.  
See Person Search on page 25 for further details.
- Navigate to Person's Episodes tab.
- Double-click on the Episode from the Episode result grid.
- Click **Edit** in the Episode Report section.
- Update/change details and **Save**.
- 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.

## 4.13 Deleting an Episode

- 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.

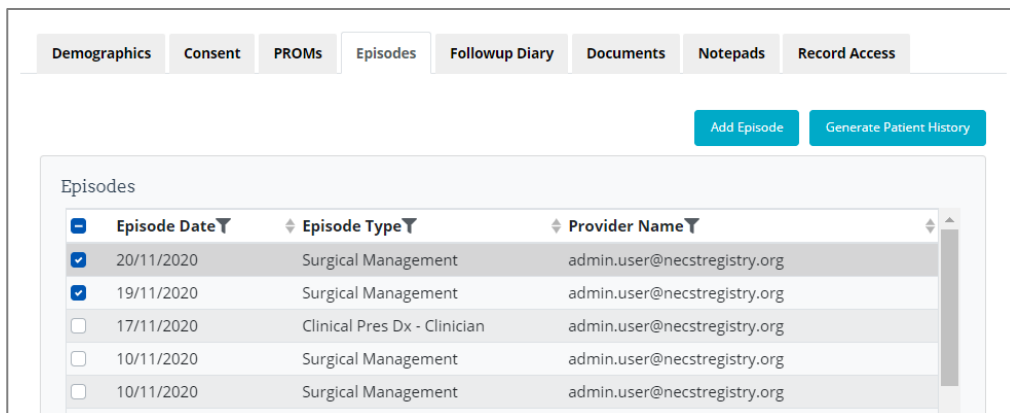
#### 4.14 Generate Patient History

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.



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



Episode Date	Episode Type	Provider Name
<input checked="" type="checkbox"/> 20/11/2020	Surgical Management	admin.user@necstregistry.org
<input checked="" type="checkbox"/> 19/11/2020	Surgical Management	admin.user@necstregistry.org
<input type="checkbox"/> 17/11/2020	Clinical Pres Dx - Clinician	admin.user@necstregistry.org
<input type="checkbox"/> 10/11/2020	Surgical Management	admin.user@necstregistry.org
<input type="checkbox"/> 10/11/2020	Surgical Management	admin.user@necstregistry.org

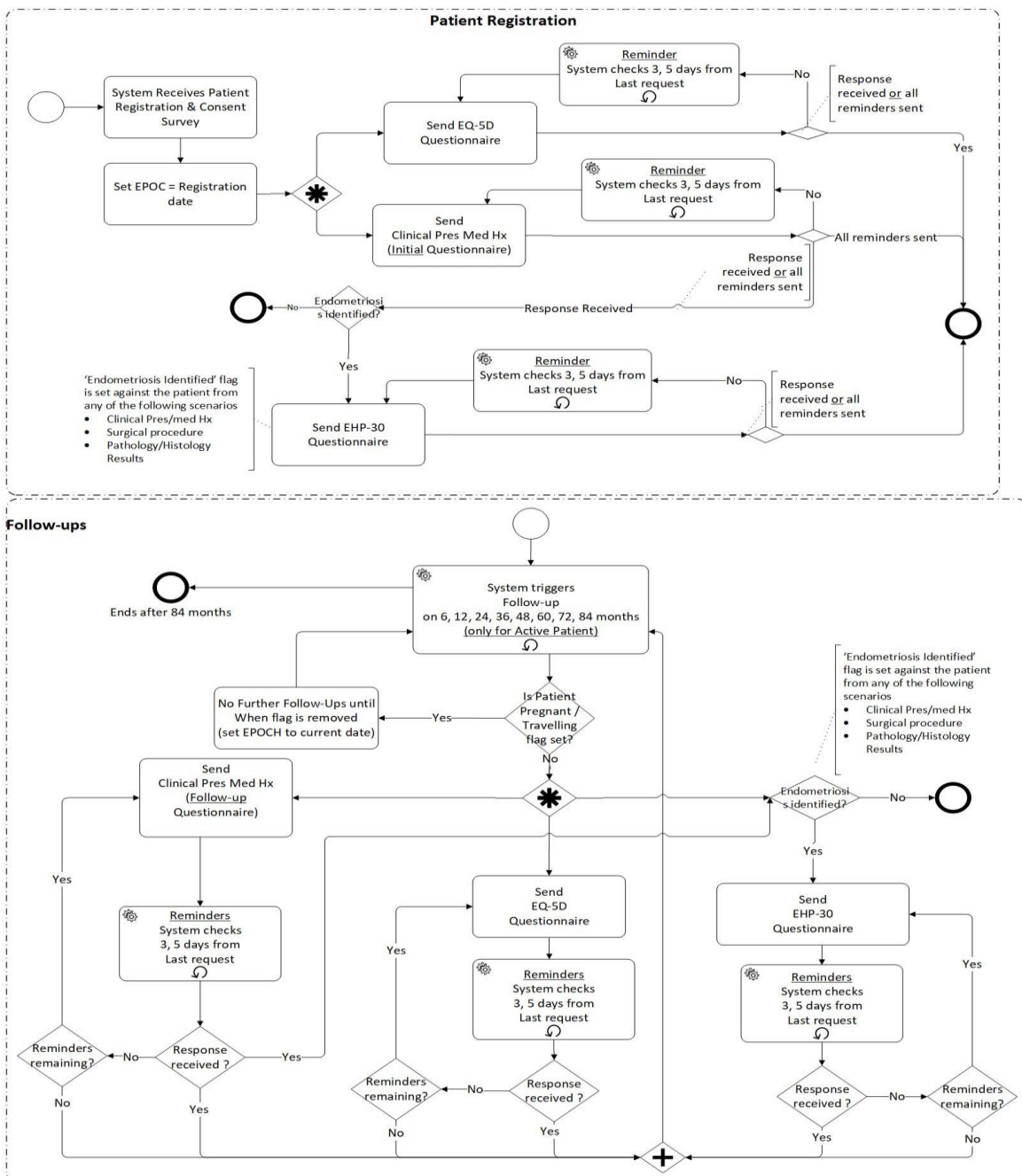
## 4.15 Follow-Up

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.



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.

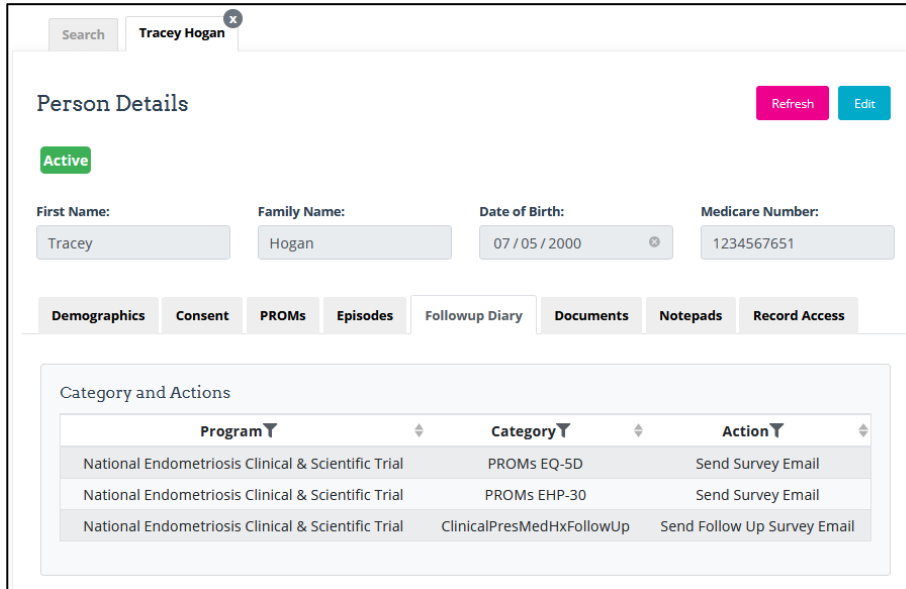




### 4.15.1 Viewing/Editing a Person's Follow-Up

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.



**Person Details** Refresh Edit

**Active**

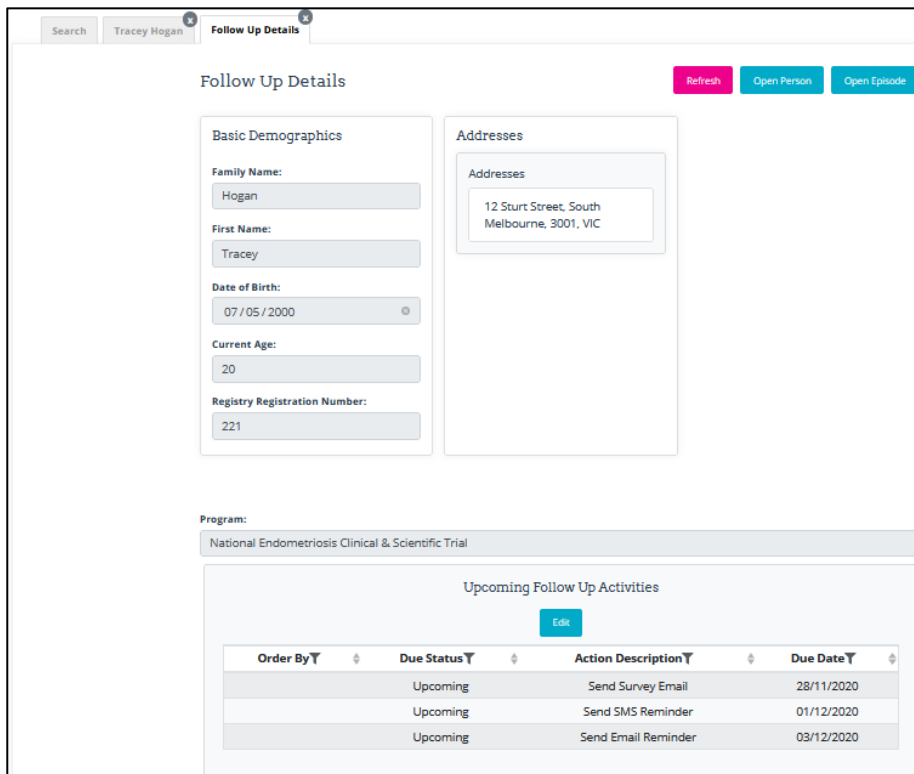
First Name: Tracey Family Name: Hogan Date of Birth: 07 / 05 / 2000 Medicare Number: 1234567651

**Demographics** **Consent** **PROMs** **Episodes** **Followup Diary** **Documents** **Notepads** **Record Access**

**Category and Actions**

Program	Category	Action
National Endometriosis Clinical & Scientific Trial	PROMs EQ-5D	Send Survey Email
National Endometriosis Clinical & Scientific Trial	PROMs EHP-30	Send Survey Email
National Endometriosis Clinical & Scientific Trial	ClinicalPresMedHxFollowUp	Send Follow Up Survey Email

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



**Follow Up Details** Refresh Open Person Open Episode

**Basic Demographics**

Family Name: Hogan

First Name: Tracey

Date of Birth: 07 / 05 / 2000

Current Age: 20

Registry Registration Number: 221

**Addresses**

12 Sturt Street, South Melbourne, 3001, VIC

**Program:** National Endometriosis Clinical & Scientific Trial

**Upcoming Follow Up Activities** Edit

Order By	Due Status	Action Description	Due Date
Upcoming	Send Survey Email	28/11/2020	
Upcoming	Send SMS Reminder	01/12/2020	
Upcoming	Send Email Reminder	03/12/2020	

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

## 7. Click **Save**.

Program:  
National Endometriosis Clinical & Scientific Trial

Upcoming Follow Up Activities

Save Cancel

Delay

By Month:  
0

Or Until:  
01/01/2020

Skip Relist

Order By	Due Status	Action Description	Due Date
	Overdue	Send Survey Email	01/01/2020
	Overdue	Send SMS Reminder	04/01/2020
	Overdue	Send Email Reminder	06/01/2020

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**.

Or Until:  
27/01/2021

Skip Relist

Order By	Due Status	Action Description	Due Date
	Upcoming	Send Survey Email	28/11/2020
	Upcoming	Send SMS Reminder	01/12/2020
	Upcoming	Send Email Reminder	03/12/2020

Type:  
Person Contacted Registry

Free Text:  
Asked to delay the surveys for another 2 months due to ...

Add

Follow Up Diary Entries

Episode Date	Episode Type	RRN	Diary Date	Action Description	Performed By	Delay (days)	Category Description	Follow Up Run Id	Result
16/06/2020			11:59	Asked to delay the survey...	canadmin@canscreendemo.onmicrosoft.com	0	PROMs EQ-5D		

### 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.

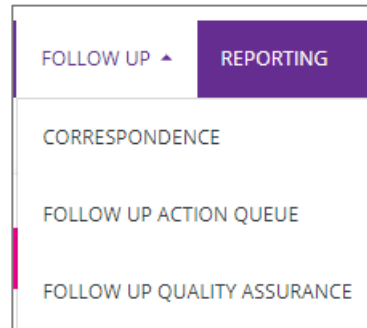
SMS sent to patients are either in a state of “Queued”, “Send” or “Failed” transmission and can be resolved from the queue based on the “Failed Transmission” status.

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

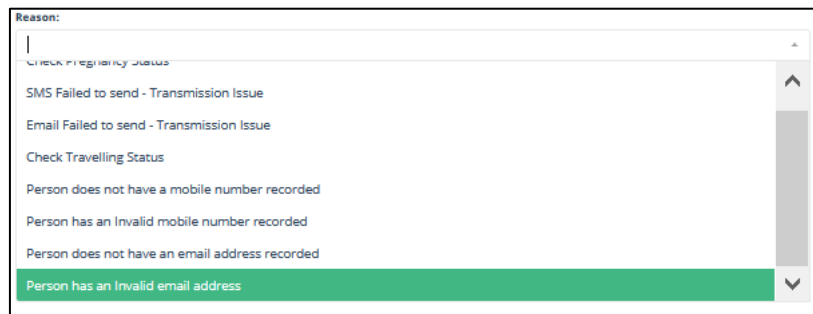
- Is Pregnant – if yes enter the expected due date. If the patient is pregnant the Follow-Up for the patient will be put on hold on the Follow-Up QA queue. Once the expected due date is passed the record will recommend Follow-Up and remove the Is Pregnant system identifier.

- 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.

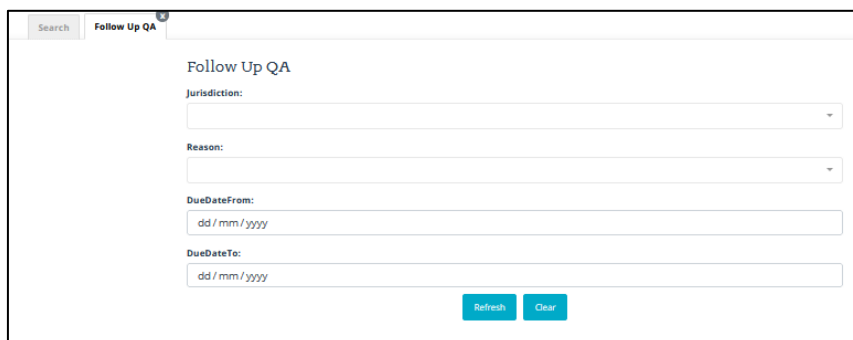
1. Navigate to FOLLOW-UP menu and choose FOLLOW-UP QUALITY ASSURANCE.



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	<p>A transmission issue occurred when sending SMS. Relist to resolve.</p> <p>Return to queue and click the record and Resolve button.</p>

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

#### 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.

Search
Tracey Hogan

Person Details

Refresh Edit

Active

First Name:

Tracey

Family Name:

Hogan

Date of Birth:

07 / 05 / 2000

Medicare Number:

1234567651

Demographics

Consent

PROMs

Episodes

Followup Diary

Documents

Notepads

Record Access

Notepads

Notepad Type	User Text	Entry Operator	Created UTC
Person - Demographics		admin.user@necstregistry.org	17/06/2020 12:03
Episode - Information		vcs.bindu.clinician@necstregistry.org	05/06/2020 17:28
Episode - Information	test	vcs.bindu.clinician@necstregistry.org	05/06/2020 17:04
Episode - Information		vcs.bindu.clinician@necstregistry.org	05/06/2020 17:00
Person - Information		admin.user@necstregistry.org	02/06/2020 21:28
Episode - Information		api.user@necstregistry.org	12/05/2020 15:05
Episode - Information		api.user@necstregistry.org	12/05/2020 15:05
Person - Demographics		api.user@necstregistry.org	12/05/2020 15:00

Change History

Operation	Entity Name	Label	Field	Old Value	New Value
INSERT	AttributeValue	How well do you speak English	PredefinedAttributeValueId		Well
INSERT	AttributeValue	Indigenous status	PredefinedAttributeValueId		Neither Aboriginal nor Torres Strait Islander origin
INSERT	Email	Email	EmailAddress		bkakkada@vcs.c
INSERT	PhoneNumber	Validated	IsValidated		False
INSERT	PhoneNumber	PhoneType	PhoneNumberTypeId		Home Phone
INSERT	PhoneNumber	CorrespondenceUndelivered	CorrespondenceUndelivered		False

## 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.

[Load Read History](#)

Read History

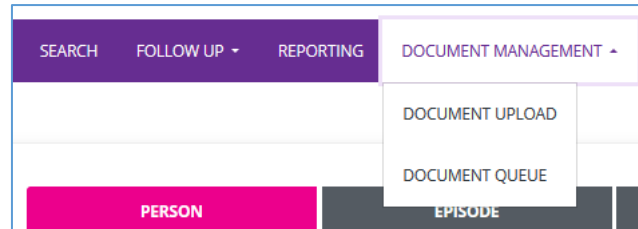
Read By	Read Time
admin.user@necstregistry.org	19/06/2020 10:13
admin.user@necstregistry.org	17/06/2020 12:03
admin.user@necstregistry.org	12/06/2020 12:20
vcs.bindu.clinician@necstregistry.org	11/06/2020 15:27
vcs.bindu.clinician@necstregistry.org	05/06/2020 17:00
admin.user@necstregistry.org	05/06/2020 16:53
admin.user@necstregistry.org	03/06/2020 09:40
admin.user@necstregistry.org	02/06/2020 20:54
admin.user@necstregistry.org	02/06/2020 13:17
admin.user@necstregistry.org	02/06/2020 10:37
admin.user@necstregistry.org	01/06/2020 21:05

## 4.20 Document Management

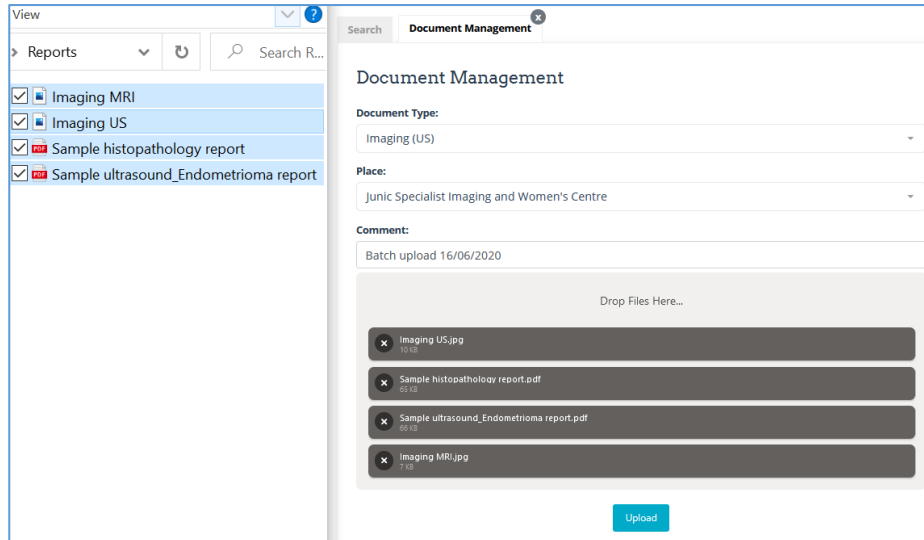
This feature allows upload of documents or images in bulk. Then individually open each document and assign it to a person's record.

### 4.20.1 Document Upload

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

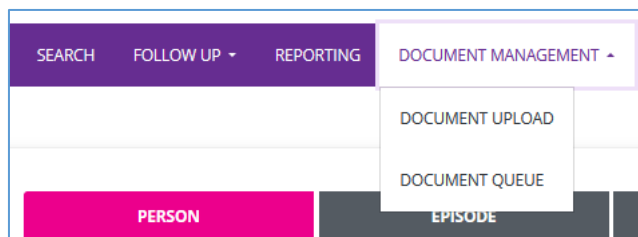


2. Select the drop-down and select Document Type.
3. Select the drop-down and select the Place.
4. Add Comments if required.
5. Drag and drop one or more files into the Drop Files Here... area or double click to navigatge to a folder to select files to upload.
6. Click **Upload**.



#### 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.

Search

Document Management

Document Queue

### Document Queue

**Jurisdiction:**  
 Randwick Health Precinct

**Document Type:**  
 Imaging (US)

**Status:**  
 Outstanding

**Added From Date:**  
 dd / mm / yyyy

**Added To Date:**  
 dd / mm / yyyy

**Processed From Date:**  
 dd / mm / yyyy

**Processed To Date:**  
 dd / mm / yyyy

Refresh Clear

Queue Item	Date Added	Description	Document Name	Status	Jurisdiction	Actioned By	Date Processed
28	27/05/2020	Imaging (US)	TestImage4	Outstanding	Randwick Health Precinct		
32	15/06/2020	Imaging (US)	Imaging MRI	Outstanding	Randwick Health Precinct		
33	15/06/2020	Imaging (US)	Imaging US	Outstanding	Randwick Health Precinct		
34	15/06/2020	Imaging (US)	Sample histopathology report	Outstanding	Randwick Health Precinct		
35	15/06/2020	Imaging (US)	Sample ultrasound_Endometrioma report	Outstanding	Randwick Health Precinct		
37	16/06/2020	Imaging (US)	Sample ultrasound_Endometrioma report	Outstanding	Randwick Health Precinct		

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



Queue Item	Date Added	Description	Document Name	Status	Jurisdiction	Actioned By	Date Processed
33	27/05/2020	Imaging (US)	Testimage1	Outstanding	Randwick Health Precinct		
32	15/06/2020	Imaging (US)	Imaging MRI	Outstanding	Randwick Health Precinct		
33	15/06/2020	Imaging (US)	Imaging US	Outstanding	Randwick Health Precinct		
34	15/06/2020	Imaging (US)	Sample histopathology report	Outstanding	Randwick Health Precinct		
35	15/06/2020	Imaging (US)	Sample ultrasound Endometrioma report	Outstanding	Randwick Health Precinct		
37	15/06/2020	Imaging (US)	Sample ultrasound Endometrioma report	Outstanding	Randwick Health Precinct		

**HISTOPATHOLOGY:**  
 1. 'Low anterior resection'. The specimen consists of a segment of colon with one stapled end and one open end, 60mm in length with a diameter of 30mm. The attached pericolonic fat is 10mm in width. The serosal surface appears congested. There is no evidence of perforation. The mucosal surface shows two ulcerated lesions lying 7mm away from each other measuring 5mm and 10mm in maximal dimension. The smaller lesion lies 10mm from the closest stapled margin. No polyp or tumour identified. Stapled margin inked black and the other margin inked blue. No lymph node identified. Representative sections.  
 A - blue inked margin  
 B - showing both lesions  
 C - small lesion  
 D - larger lesion. 2. 'Right pelvic sidewall'. The specimen consists of three fragments of fibrofatty tissue, 5mm to 10mm in maximal dimension. All embedded. (1 block)  
 3. 'Left pelvic sidewall'. The specimen consists of six fragments of fibrofatty tissue 6mm to 15mm in maximal dimension. All embedded. (Blocks A and B)

**Person Search**  
 Name:   
 Date of Birth:

**Search Results**

First Name	Family Name	Date of Birth	Medicare No
Tracey	Jones	05/05/1988	1234567891
Tracey	Smith	05/05/2000	2345678912
Tracey	Hogan	07/05/2000	1234567891
Tracey	Pickering	18/05/1995	2555678999

## 4.21 Person Duplicate Matching and Merging



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.

Duplicates 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.

**Jean Hailes NECST Network**

SEARCH FOLLOW UP REPORTING DOCUMENT MANAGEMENT FOLLOW UP ADMIN QUALITY ASSURANCE SETTINGS

Search Sarah Burns **New Person**

**Possible Duplicated Person Records**

We have found person details that look similar to the person you are trying to add. Please review the duplicated person records in the table below before choosing whether to merge records or continue completing the new person profile.

ID	Family Name	First Name	Date of Birth	Medicare No
214	Burns	Sarah	2000-03-08T00:00:00	543954543

[Continue With New Person](#) [Continue With Selected Person](#) [Cancel](#)

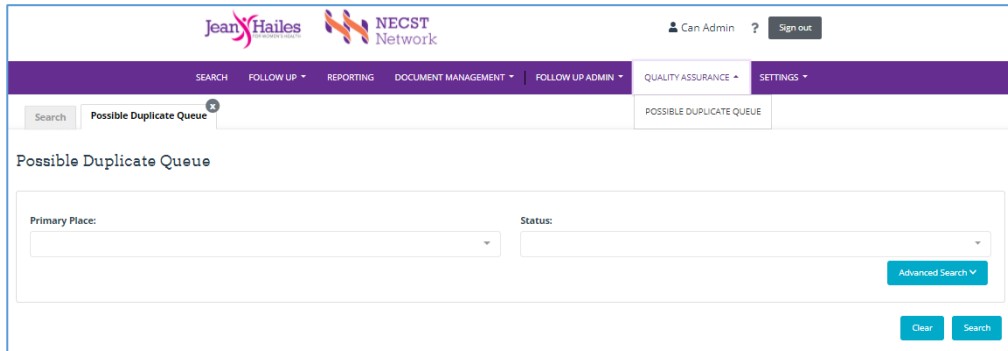
## 4.22 Duplicate Matching and Merging – Quality Assurance

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.

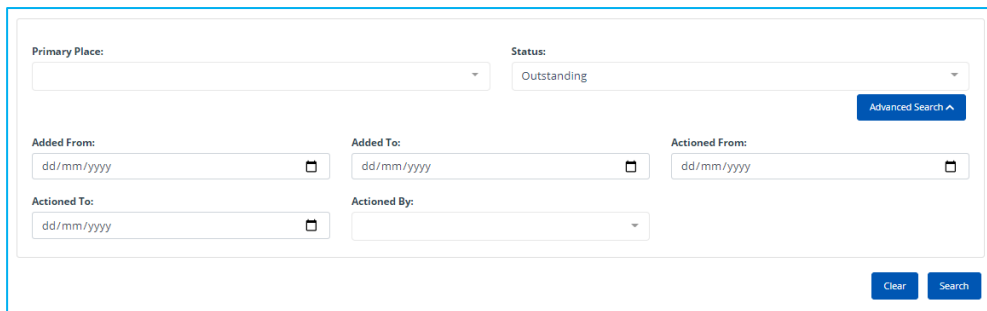
1. Navigate to the menu item, Quality Assurance and choose Possible Duplicate Queue.
2. Choose Primary Place and Status as required.

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.

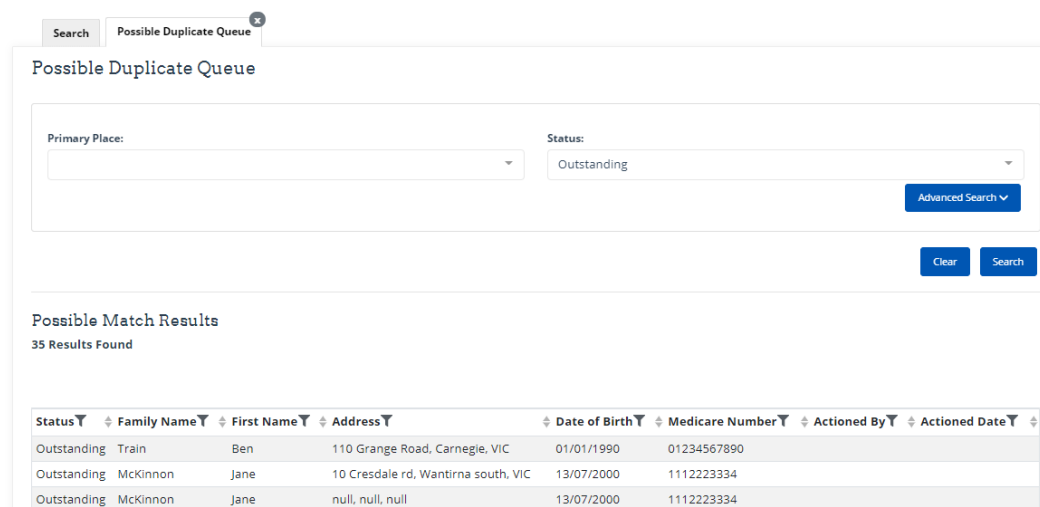
Status allows the operator to view by default all outstanding duplicates or view the completed duplicates on the queue.



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.



Status	Family Name	First Name	Address	Date of Birth	Medicare Number	Actioned By	Actioned Date
Outstanding	Train	Ben	110 Grange Road, Carnegie, VIC	01/01/1990	01234567890		
Outstanding	McKinnon	Jane	10 Cresdale rd, Wantirna south, VIC	13/07/2000	1112223334		
Outstanding	McKinnon	Jane	null, null, null	13/07/2000	1112223334		

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.

Search Possible Duplicate Queue

Possible Match Compare Cancel

Similar Matches Found

Registry Registration Number	Family Name	First Name	Date of Birth	Medicare No
278	HERNANDEZ1	EVA1	01/01/1990	123872312
279	HERNANDEZ2	EVA2	01/01/1990	123872312

Compare Match Results

Potential Person (Registry Registration Number 277)

Family Name:

First Name:

Medicare Number:

Date of Birth:

Similar Person (Registry Registration Number 278)

Family Name:

First Name:

Medicare Number:

Date of Birth:

Exclude Discard Process

- Click **Exclude** to remove the possible duplicate similar match from ever matching to this person incoming record again.
- 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.
- Click **Process** to move to the matching screen.

Search Possible Duplicate Queue

Medicare Number	<input type="text" value="01234567890"/>	<input type="text" value="01234567890"/>	01234567890
PhoneNumber	<input type="text" value="0430043709"/>	<input type="text" value="0430043709"/>	0430043709
Email	<input type="text" value="bpatel@vcs.org.au"/>	<input type="text" value="bpatel@vcs.org.au"/>	bpatel@vcs.org.au
Address	<input type="text" value="110 Grange Road, Carnegie, VIC, 3163"/>	<input type="text" value="110 Grange Road, Carnegie, VIC"/>	110 Grange Road, Carnegie, VIC, 3163
Is Deceased	<input type="text" value="No"/>	<input type="text" value="No"/>	No
Primary Provider	<input type="text" value=""/>	<input type="text" value=""/>	
Identifiers			
Reference Number	<input type="text" value="1"/>	<input type="text" value="1"/>	1
Medicare Expiry Date	<input type="text" value="2020-05-28"/>	<input type="text" value="2020-05-28"/>	2020-05-28
Recruitment Source	<input type="text" value=""/>	<input type="text" value=""/>	

- 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.

- 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.

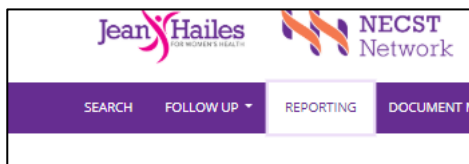
**Note:** A user who has access to the NECST Registry Power BI platform can create ad-hoc reports from Power BI and make it available through the Reporting module.

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

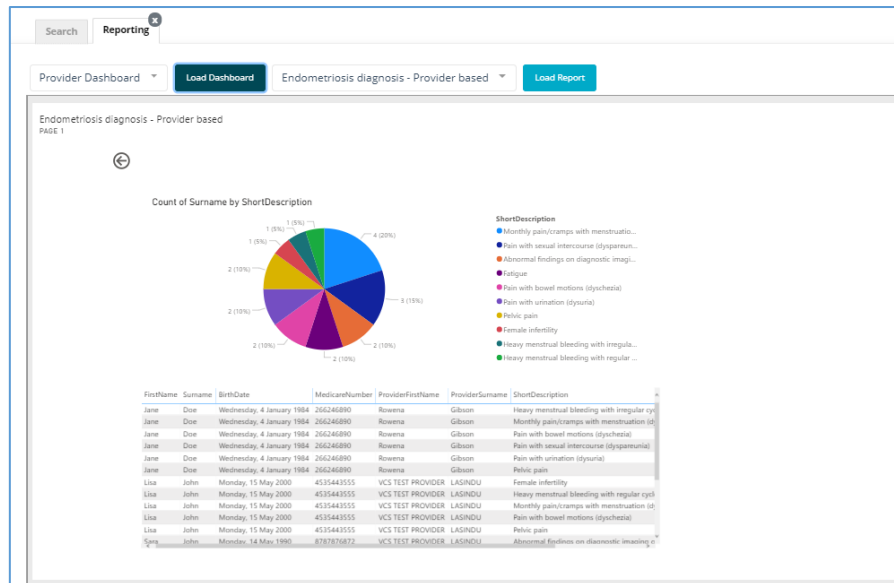
1. Navigate to the drop-down list against Load Dashboard and choose the item.

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



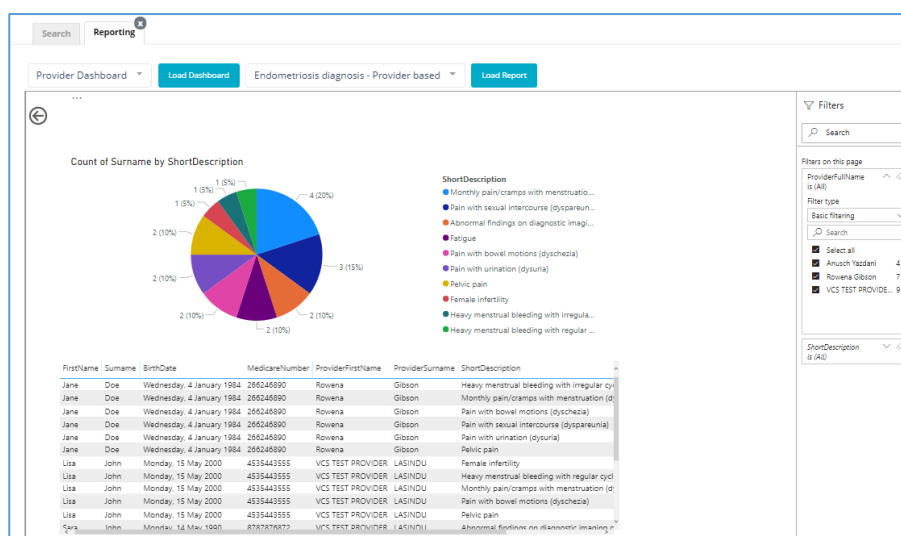
### 4.23.3 Loading a Report

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](mailto: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
<ul style="list-style-type: none"> <li>• Clinical Pres Dx – Clinician</li> <li>• Medical Management</li> <li>• Medication</li> <li>• Imaging – US</li> <li>• Imaging – MRI</li> <li>• Surgical Management</li> <li>• Histopathology</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical Pres Med Hx</li> <li>• PROMs EHP-30</li> <li>• PROMs EQ-5D</li> <li>• Clinical Pre Med Hx – Follow-Up</li> </ul>

### 5.6 What Are the Supported Browsers

The supported browsers are:

- Chrome
- MS Edge

- Firefox
- Safari

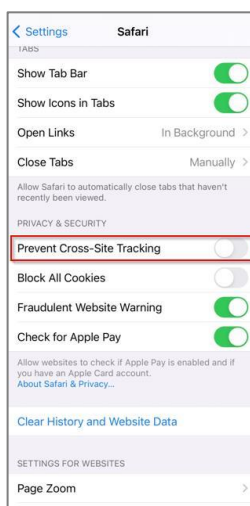
## 5.7 What Are the Supported Devices

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. <a href="https://innovation.ox.ac.uk/outcome-measures/endometriosis-health-profile-ehp/">https://innovation.ox.ac.uk/outcome-measures/endometriosis-health-profile-ehp/</a>
Episode	<p>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:</p> <ul style="list-style-type: none"> <li>• Clinical Pres Dx – Clinician</li> <li>• Medical Management</li> <li>• Medication</li> <li>• Imaging – US</li> <li>• Imaging – MRI</li> <li>• Surgical Management</li> <li>• Histopathology</li> </ul> <p>Below are the episodes automatically created from the questionnaires completed by the patients:</p> <ul style="list-style-type: none"> <li>• Clinical Pres Med Hx</li> <li>• Clinical Pre Med Hx – Follow-Up</li> <li>• PROMs EQ-5D</li> <li>• PROMs EHP-30</li> </ul>
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. <a href="https://en.wikipedia.org/wiki/EQ-5D">https://en.wikipedia.org/wiki/EQ-5D</a> .
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 - <a href="https://en.wikipedia.org/wiki/Multi-factor_authentication">https://en.wikipedia.org/wiki/Multi-factor_authentication</a> .
Microsoft Active Directory	<a href="https://en.wikipedia.org/wiki/Active_Directory">https://en.wikipedia.org/wiki/Active_Directory</a> NECST Registry interface with Microsoft Active Directory to provision the user accounts.
Microsoft Power BI	<a href="https://en.wikipedia.org/wiki/Microsoft_Power_BI">https://en.wikipedia.org/wiki/Microsoft_Power_BI</a> 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	<p>Term Person and Patient are interchangeably used in this document – is the person receiving care for either investigation or management of endometriosis.</p> <p>Term Patient/Participant is mostly used in questionnaires while the NECST Registry sees them as Person.</p>



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	<p><b>Azure AD Premium P2</b> – is an edition includes all of the features of <b>Azure AD Premium P1</b> with the addition of Identity Protection and Privileged Identity Management (PIM). Identity Protection provided management of conditional access to apps and critical data.</p> <p>Every user who need access to NECST Registry will need to be assigned this Licence.</p>
POWER BI PRO	<p><b>Power BI Pro</b> is an individual user <b>Licence</b> that lets users read and interact with reports and dashboards that others have published to the <b>Power BI</b> service. Users with this <b>Licence</b> type can share content and collaborate with other <b>Power BI Pro</b> users.</p> <p>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.</p>

### 7.3 Consent Status

Consent Status	Details
<b>Unconfirmed</b>	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.
<b>Confirmed</b>	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
<b>Denied</b>	<p>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.</p> <p>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 <b>read only</b> in the NECST Registry (unless specified by the participant that all their data are to be deleted from the Registry).</p>

## 7.4 Person Status

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

## 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	<a href="https://en.wikipedia.org/wiki/Multi-factor_authentication">https://en.wikipedia.org/wiki/Multi-factor_authentication</a>
Microsoft Active Directory	<a href="https://en.wikipedia.org/wiki/Active_Directory">https://en.wikipedia.org/wiki/Active_Directory</a>
Microsoft Power BI	Power BI Guided learning <a href="https://docs.microsoft.com/en-us/power-bi/guided-learning/">https://docs.microsoft.com/en-us/power-bi/guided-learning/</a>
RedCap	RedCap Resources and Videos <a href="https://projectredcap.org/resources/videos/">https://projectredcap.org/resources/videos/</a>

## 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.