AuSCR
Australian Stroke Clinical Registry

Hospital User Manual

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1 Document Overview

This user manual is designed as a guide for hospital staff to access and enter data into the Australian Stroke Clinical Registry (AuSCR), an online web-based tool (referred to as **AuSCR Database** throughout this document). Users are assumed to have a basic level of computer skills and be familiar with browsing the internet. After logging into the secure AuSCR Database, there are two main steps to enter data - 1: each patient must be created (New Patient), 2: each episode must be recorded (Episode Details). This manual will guide staff through each of these steps and will explain other user options, such as printing reports and importing and exporting your hospital's data to and from the AuSCR Database.

2 Background Information

A PowerPoint presentation can be accessed electronically by contacting the AuSCR office or by viewing the online version on the website www.auscr.com.au. The presentation provides an overview of the AuSCR project and includes information on its purpose, governance, data collection and the benefits of participating in AuSCR. First-time users are encouraged to view the presentation prior to accessing the AuSCR database. You will also need to have your user id and password set up before being able to access the AuSCR database.

3 The Opt-Out Consent Model

To ensure data are representative of all strokes in your hospital, it is important that particular attention is given to ensuring that complete data are collected on all patients and that all eligible patients with stroke and transient ischaemic attack (TIA) are included in the AuSCR Database. If an incomplete set of patients is collected from a hospital then biases in the data may occur, and the usefulness of the data will be limited.

To ensure as complete a set of patients as possible from each hospital, AuSCR uses an 'opt-out' consent model with a waiver of consent for those who die in hospital. This means that all patients admitted with stroke or TIA at your hospital should be entered in the AuSCR Database unless they, their parent/guardian or next-of-kin formally requests not to be included on the registry. All patients who die in hospital should be entered and families/next-of-kin do not need to be informed of this data entry.

To ensure informed consent that is in line with the ethics approval, it is the responsibility of the participating hospital to provide the approved AuSCR Information Sheet to all patients admitted with stroke and TIA. This information sheet clearly explains the purpose of AuSCR and how patients may *opt* to have some, or all, of their data removed from the AuSCR Database. In general, the process for providing this information to patients within your hospital should be:

- All patients or their relatives are provided with the AuSCR information sheet (your hospital approved version (Attachment 1);

- If a patient requires an interpreter to understand medical information, AuSCR recommends that an interpreter be used to explain the information in-line with your usual hospital practices;
- For those patients aged under 18 years, or those unable to understand the opt-out consent processes, the information sheet should be given to the parent/guardian or next-of-kin;
- It is important to clarify that the patient/guardian or next-of-kin may request to remove or opt-out, any information at any time, and that this right does not end on discharge from hospital and will not affect their care;
- If a patient, their parent/guardian or next-of-kin asks to opt-out of the Registry they can do so by contacting the AuSCR office by telephone or email (as described in the information sheet). They may also sign the opt-out form (Attachment 2);
- When hospital staff are advised that the patient (or their next-of-kin) would like to opt-out of AuSCR, it is important to clarify ***which variables they would like removed***; it is possible to keep only details about their stroke in the database while still removing all personal and identifiable information about the patient;
- The signing of the opt-out form (Attachment 2) ensures that a record of the patient's request to remove variables from the AuSCR Database remains on their medical file for all future admissions. **The AuSCR office requires that a form is completed for each opt-out received**. The original, signed copy of the opt-out form should be kept in the medical record and a copy faxed to the AuSCR office **secure fax number on (03) 8888 4990**.
- **Please note:** If a patient is discharged before being given an AuSCR Information Sheet, they must be sent this information sheet along with the Patient Contact Post-Discharge letter prior to their three month follow-up (Attachment 6).

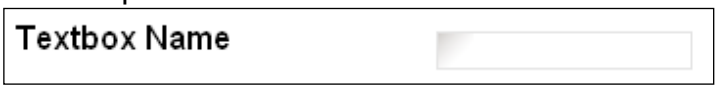
4 General Information about the AuSCR Database

The following information should be understood by all AuSCR Database users:

- The term **click** is used throughout this manual to refer to a **left mouse click.**
- Mandatory fields are denoted by a **red asterisk** (*). If you fail to enter data for a mandatory field, an error message will flash onto the screen when you try and save data on that particular page of the AuSCR Database.
- Blue labelled buttons are used throughout the AuSCR Database and require a left mouse click to activate.

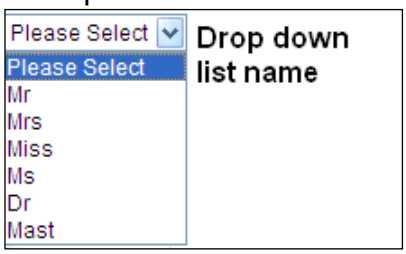
Data are entered into the AuSCR database using:

1) **Text boxes** – a blank white box into which you type data.
   Example



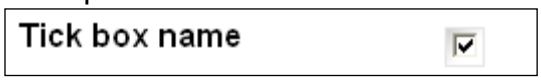
- Before typing data you must ensure the cursor (indicated by a flashing black bar) is in the correct field text box.
- To move the cursor to a text box click in it.
- The **Tab** button on your keyboard can be used to move to the next field text box.

2) **Drop down lists** – a list of options from which you select.
Example



- These are white boxes which contain either a default option or the words **Please Select** and a small blue box with a down arrow.
- To select an option, click the down arrow, and then **click the option required**.
- For large option lists, you can either scroll down the list using the blue scroll bar to the right of the list (click and hold the left mouse button down while moving the scroll bar down the page until the option required appears) or type in the first letter/s of the option you require.

3) **Tick boxes** – a small white box in which you click to mark with a tick.
Example

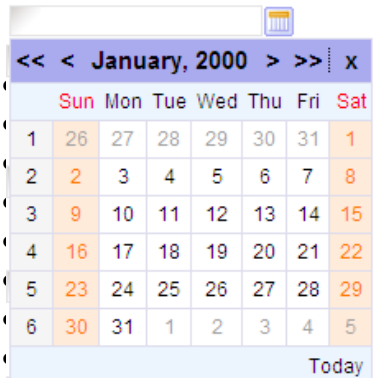


- To remove the tick click in the box a second time.
- In some instances, where it is not applicable, the tick box may be inactivated.

4) **Radio buttons** – a small white circle in which you click to mark with a dot.
Example

- If there is more than one radio button for a field, only one button can be marked.
- Clicking an alternative radio button for a field will unmark all other radio buttons for that field.

5) **Calendar** – Dates can be entered by either typing them in the text box or by using an embedded calendar to select the date. **The use of the embedded calendar is the preferred option in order to reduce errors.**
Example



-

- To use the calendar, click the calendar icon to the right of the text box and click the date required.
- Click the **Today** button at the bottom of the calendar to enter today's date.
- Click the arrows at the top of the calendar to navigate as follows:

  << to move back by one year

  < to move back by one month

  > to move forward by one month

  >> to move forward by one year

  x to close the calendar

6) **Episode –** An 'Episode' details the care provided in hospital to a patient. Patients can have multiple episodes e.g. if they are readmitted to hospital for a recurrent stroke. This section is where patient clinical data are recorded.

   It is preferable that episodes are recorded in chronological order. However, if the episode IDs are not sequential, it will not be a problem.

7) **Saving Data** – Clicking the **Save** button at the bottom of the page will save the variables that have been entered.

8) **Variable Definition –** All variables collected are defined in the AuSCR Data Dictionary (Attachment 4). Variable definitions and formats, where possible, are consistent with the electronic National Health Data Dictionary (METeOR). (http://meteor.aihw.gov.au/content/index.phtml/itemId/181162)

   Where a (METeOR) definition does not exist we have used the definitions from reputable international stroke organisations, the National Stroke Foundation and the Queensland Statewide Stroke Clinical Network.

5 How to Obtain a Password

Each hospital will have a Hospital Administrator created by the AuSCR office. **The Hospital Administrator is then able to create all Hospital users.**

To request a user name and password to access the AuSCR Database the Hospital Administrator must:

1. Complete a **User Request form** (Attachment 5) and email or fax it to the AuSCR office. Contact the AuSCR Office to obtain a form either by email or fax.
2. A "Registration Alert" email will be generated with your username and password and sent to you.
3. You must change the generic password given to you when you first login to the AuSCR database.

To become a Hospital User:

1. Complete a **User Request form** (Attachment 5) and email or fax to the AuSCR Hospital Administrator for your hospital.

2. A “Registration Alert” email will be generated with your username and password and sent to you.
3. You must change the generic password given to you after you login to the AuSCR database for the first time.

How to create a Hospital User if you are a Hospital Administrator

1. Click the **Administration** button on the navigation menu.
2. Click the **Users** button on the navigation menu.
3. Scroll down to **New User** button at bottom of the **User List.**
4. Click on **New User** button (Figure 5.1).
5. Complete new user details on **User** page (Figure 5.2).
6. Create a **generic password**. The password must be longer than 4 and shorter than 9 characters and contain both letters & numbers.

> **Important note:** Passwords are case sensitive

7. Click the *Receive Email* tick box.
8. Select Hospital User in the *Role* text box.
9. Select your *Hospital* from the drop down list.
10. Click the **Save** button.
11. An email will be automatically generated and sent to the email address you have entered (Figure 5.3).

Figure 5.1 Creating New User Page

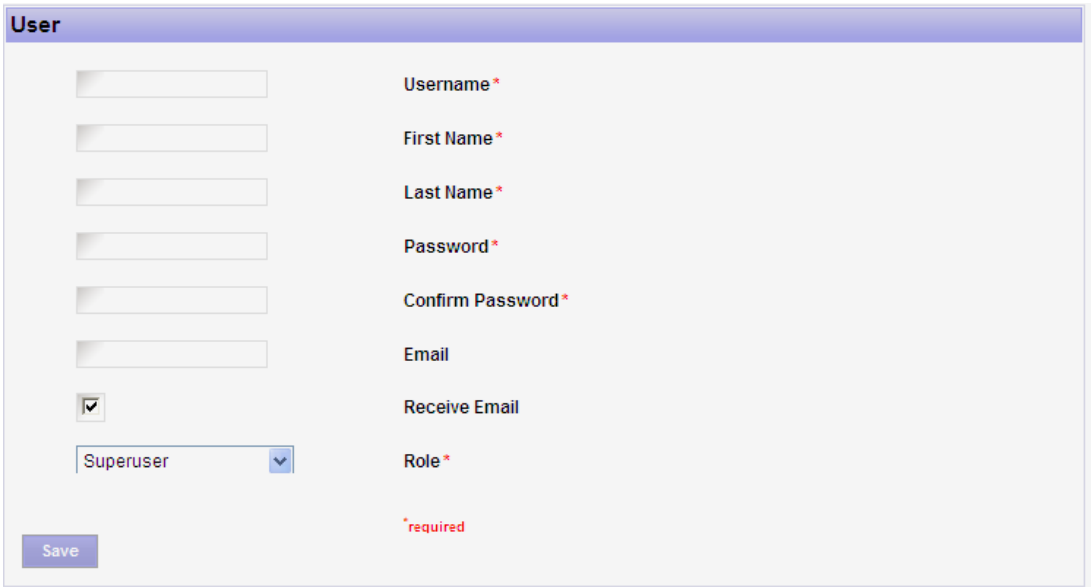


Figure 5.2 User Details Page

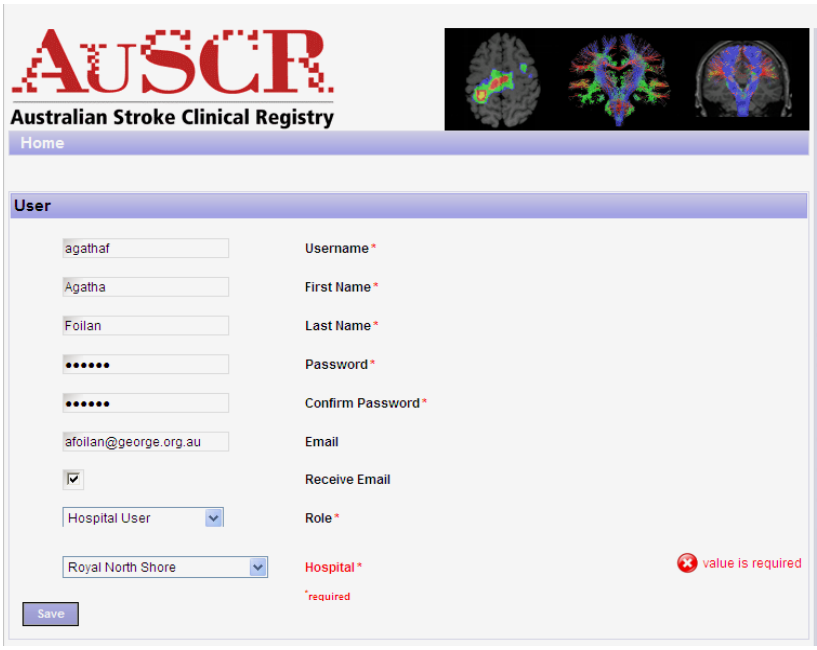
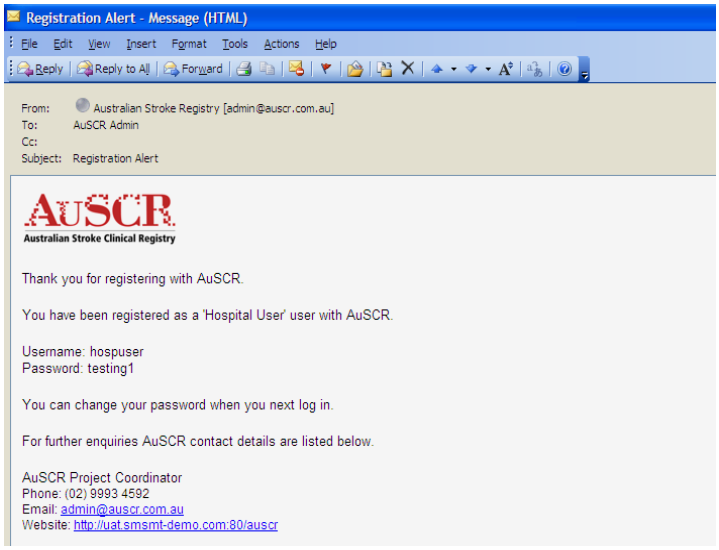


Figure 5.3 Registration Alert Emails

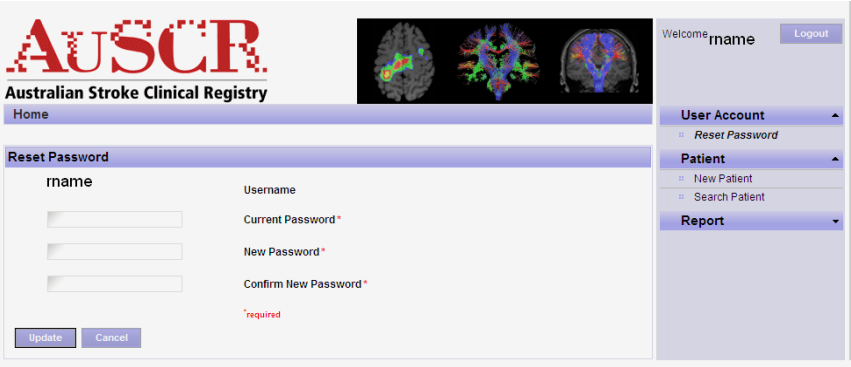


6 How to Change your Password

To change your password:

1. Click the **User Account** button on the navigation menu.
2. Click the **Reset Password** button on the navigation menu and the **Reset Password** page will be displayed (Figure 6.1).
3. Type your **current password** in the ***Current Password*** **text box.**
4. Type your **new password** in the ***New Password*** **text box.**
5. Re-type your **new password** in the ***Confirm New Password*** **text box.**
6. Click the **Update** button to save your new password (or click the **Cancel** button if you do not want to change your password).

Figure 6.1 Reset Password Page



Important note: If you forget your password, email the AuSCR office admin@auscr.com.au stating that you have forgotten your password and include:

- First name and Last name
- Role in AuSCR (e.g. Hospital User)
- Hospital name

A new password will be emailed to you

7 Logging In

Once you have obtained your username and password via an email you will be able to log into the AuSCR Database.

Important note: You must only ever access the AuSCR Database using your own username and password.

To login to the AuSCR Database:

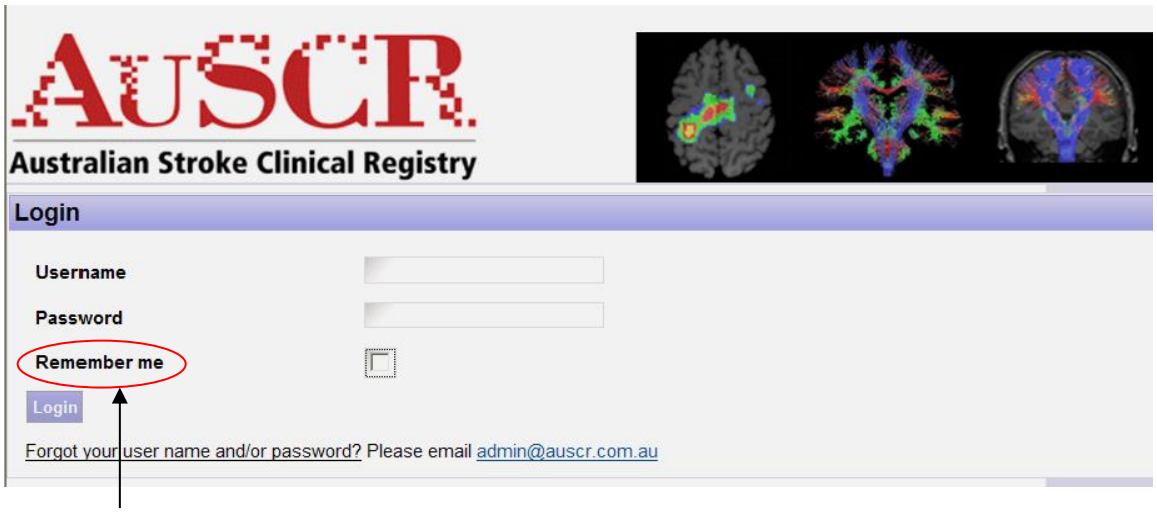
1. Open a web browser and navigate to: http://www.auscr.com.au. The AuSCR **Home** page will be displayed (Figure 7.1).
2. Click **Registry Login** towards the bottom of the right hand side of the page and the **Login** page will be displayed (Figure 7.2).
3. Type your **username** in the ***Username*** **text box**.
4. Type your **password** in the ***Password*** **text box**.
5. Click the ***Remember me*** tick box if you want the computer to automatically show your username the next time you login to the AuSCR Database.
6. Click the **Login** button.

Important note: you will still need to enter your password each time you login. Only use **"Remember me"** function if you are the only person who will be entering data on the computer you are using.

Important note: The system will timeout after 15 minutes of inactivity and you will be required to login again.

Figure 7.1 AuSCR Home Page

Figure 7.2 Login Page



See Note under point 5

8 Navigation Menu

Once you have logged in, the AuSCR Database **Home** page will appear with the navigation menu displayed on the right hand side (Figure 8.1). The navigation menu then appears on each page while you are logged in. Table 8.1 briefly describes the features of the navigation menu.

The word **Home** also appears in a blue bar at the top of each page (under the AuSCR logo). Clicking the word **Home** will take you back to the **Home** page.

Figure 8.1 Navigation Menu

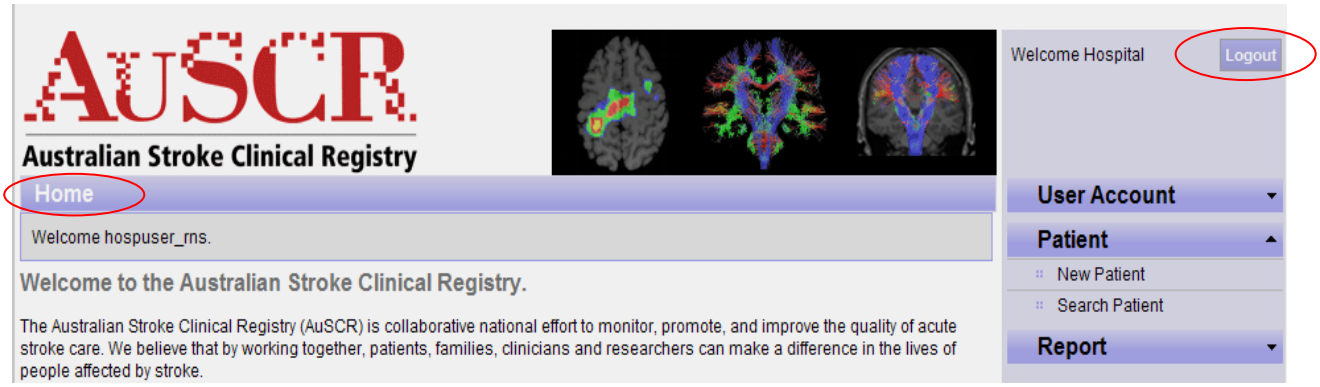


Table 8.1 Features of the Navigation Menu

Navigation Menu		Features Provided	Access
Logout		This button allows you to securely log out of the AuSCR Database	Hospital User
User Account	Reset Password	Enables you to change your password	Hospital User
Patient	~ New Patient	Allows you to add a new patient including personal information, addresses, contacts and episode data	Hospital User
	~ Search Patient	Allows you to search for an existing patient by first name, last name or medical record number	Hospital User
Report	~ Reports	Allows you to download pre-specified hospital reports. Please note that the data in these reports have not been verified by the AuSCR office and are for internal review purposes only.	Hospital User
Data	~ Export Excel	Allows for export of “raw” data from your hospital input into an Excel spreadsheet.	Hospital Administrator
	~ Import Excel	Allows for XML import from hospital database to AuSCR	AuSCR Office

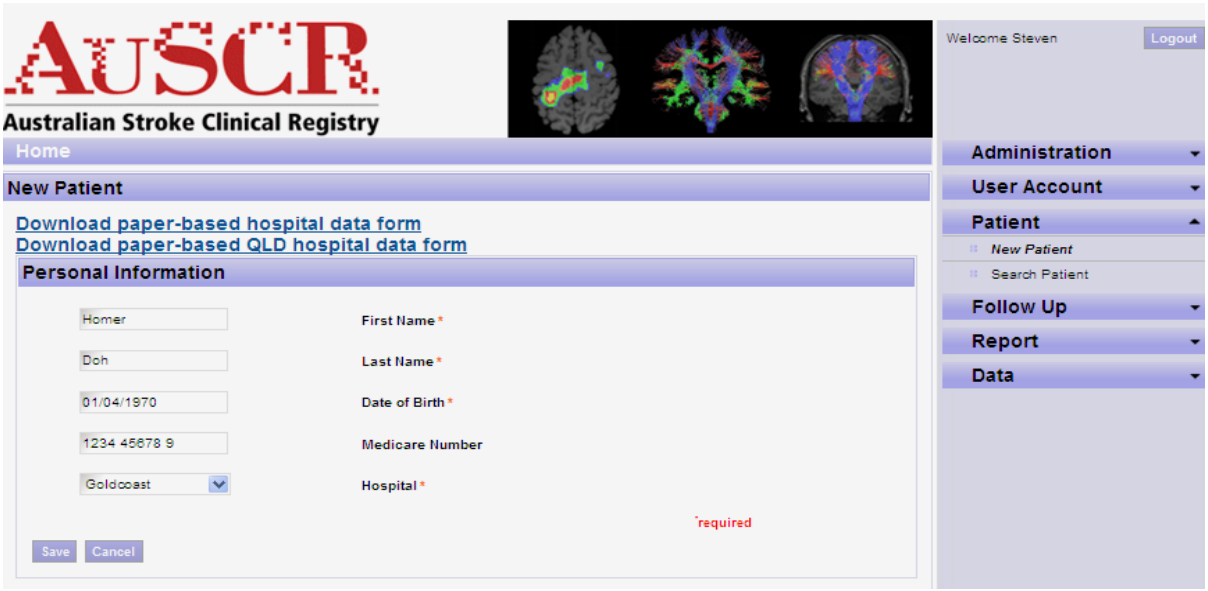
9 Adding a New Patient

Important note: Fields with a * are mandatory

To add a new patient:

1. Click the **New Patient** button on the navigation menu and the **New Patient** page will be displayed (Figure 9.1).
2. Type the patient's *First Name, Last Name* and *Date of Birth* into the appropriate text boxes. Type in the **patient's *Medicare Number*** (if known). Do not enter DVA numbers.
3. **Please check all details against the medical record before saving. Once saved a Patient ID link within the database will be created and cannot be changed.**
4. Once the details have been checked, click the **Save** button to save the new patient's personal information (or click the **Cancel** button if you do not want to add a new patient).
5. Once the new patient has been saved, a **Patient Record** page will be displayed (Figure 9.2).

Figure 9.1 New Patient Page



Important notes:

- The patient's name, date of birth and Medicare number **cannot be edited once saved.** If an error is made in these fields, the incorrect 'New Patient' must be deleted and a 'New Patient' must be created with the correct details entered.
- If you have noted an error such as an incorrectly spelt name, you may request that AuSCR office fix these minor corrections. Please prepare a list of all the changes and email them to the Data Manager (admin@auscr.com.au).
- If you enter a new patient with the same *First Name, Last Name, Date of Birth* and *Medicare Number* as an existing patient, the system will automatically find the existing patient record and display their details for editing. To create a new episode of care for an existing patient, refer to Section 10 - Adding a New Episode (page 19).

The **Patient Record** page is used to add further patient information under the headings: **Personal Information**, **Address** and **Contacts** (Figure 9.2).

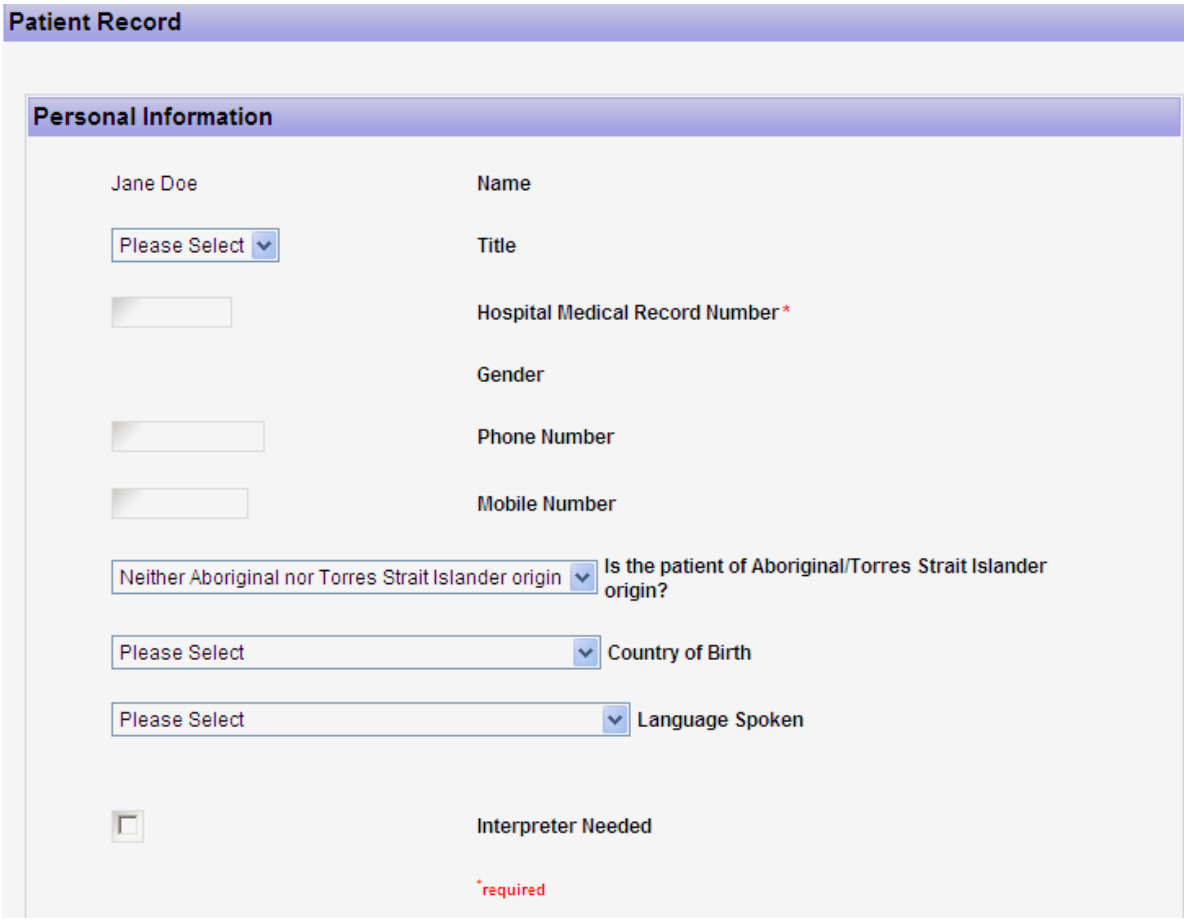
To add personal information:

1. Select the patient's *Title* from the drop down list. Once title is selected, the gender will appear automatically.
2. Type in the *Hospital Medical Record Number.*

   Important note: This is a mandatory field.

3. Select *Gender* if the title selected is *Dr* or if the title is unknown. For all other titles the gender cannot be altered.
4. Type in the *Phone Number* (including area code) and *Mobile Number*. In the case of international landline phone numbers there is only space for 10 numbers, therefore only the phone number can be entered; exclude the international and the area codes.
5. Select the *Aboriginal/Torres Strait Islander origin* from the drop down list.
6. Select the *Country of Birth* and *Language Spoken* from the drop down lists. The 10 most common countries/languages appear at the top of the lists with all others listed below in alphabetical order. Typing in the first letter will move you to the next country/language in the list starting with that letter. Each time a new letter is typed you will be moved to the next country/language starting with that letter.
7. If required, click the *Interpreter Needed* box to mark it with a tick. This box cannot be marked if *English* is selected as the *Language Spoken*.

Figure 9.2 Patient Record Page, Personal Information



To add addresses:

1. Click the *Mailing Address* tick box if the address being entered is to be used as the mailing address. At least one address has to be ticked as a mailing address.
2. Select the *Address Type* from the drop down list.

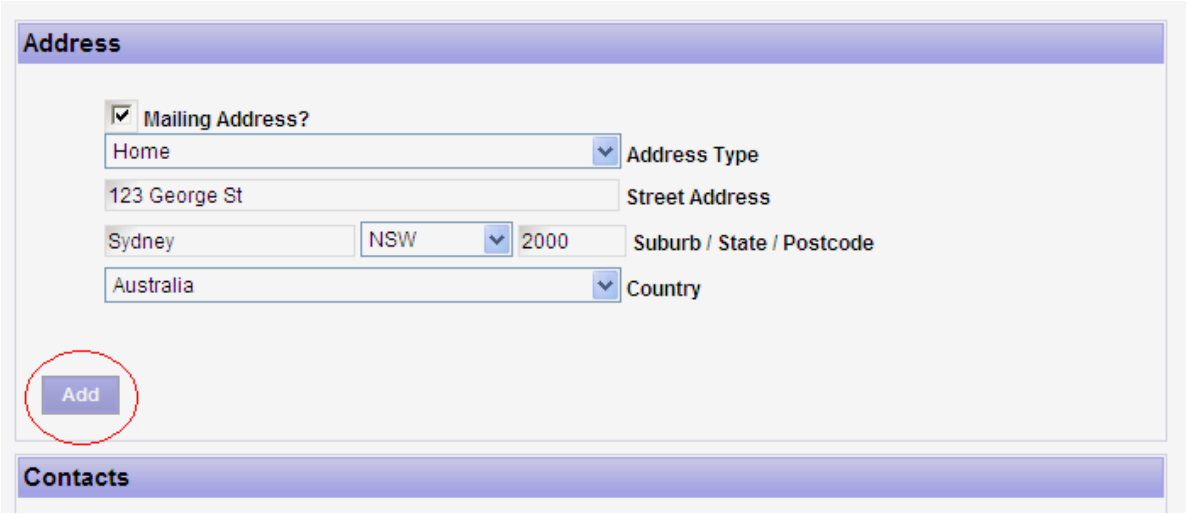
Important note: The default option is *Home*.

3. Type in the *Street Address* in the Street Address text box.
4. Type *Suburb* into the Suburb text box.
5. Select the *State* from the drop down list (or Overseas if applicable).
6. Type the *Postcode* into the Postcode text box.

Important note: Once the State has been selected only postcodes eligible for that State can be entered.

7. If it is an overseas address, select “Overseas” for the *State* and this will allow free text in the *Postcode* box in order to be able to enter an overseas postcode.
8. Select the *Country* from the drop down list.
9. Additional addresses can be added by following steps 1-8 above for each address to be added after clicking the **Add** button at the bottom of the Address section (Figure 9.3).

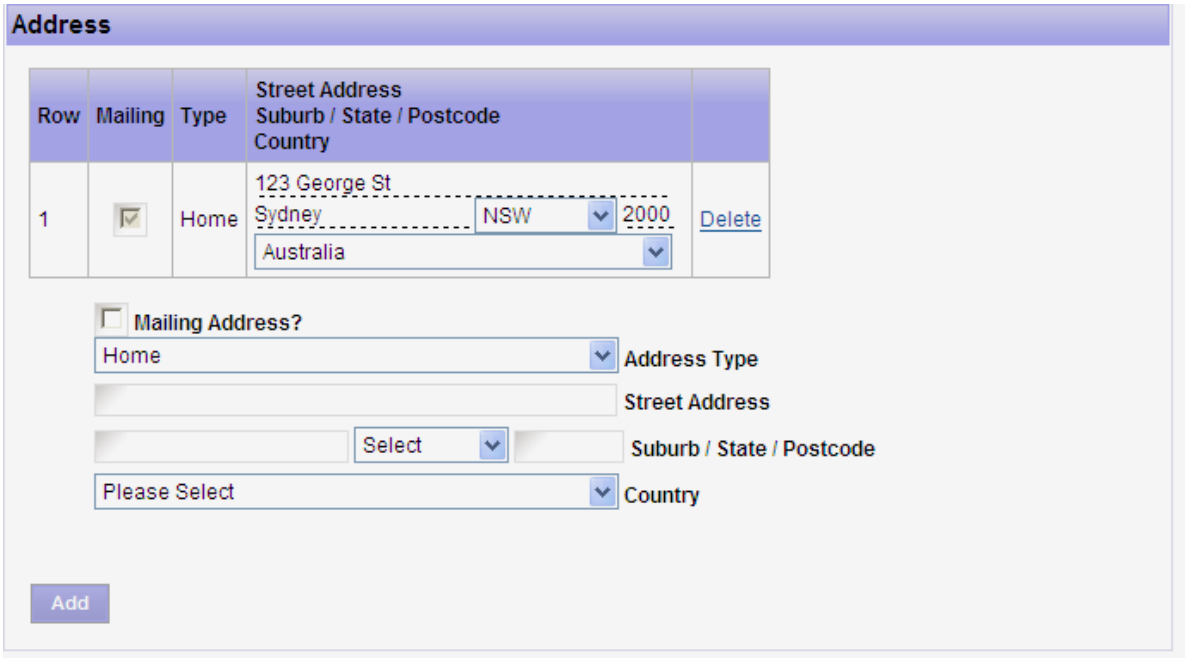
Figure 9.3 Patient Address Section



Important notes: Any existing addresses can be edited in the table by clicking directly on the address to be changed, altering as necessary and then clicking the **Add** button.

Addresses can also be deleted by clicking the *Delete* link to the right of the corresponding address. Once the *Delete* link is clicked, a *Warning* message will display, asking you to confirm that you want to delete the address. Click the **Yes** or **No** button to confirm or cancel the deletion.

Figure 9.4 Patient Address Table



Patient Contacts

Outcome determination is the most fundamental requirement of any clinical registry, including AuSCR. In AuSCR, out-of-hospital outcomes are determined by contacting patients three months after discharge and asking a small number of key questions. It is very important that we are able to contact patients after they leave hospital. Therefore, to avoid loss to follow-up at least **two alternate contacts should be recorded in addition to the patient's own address**.

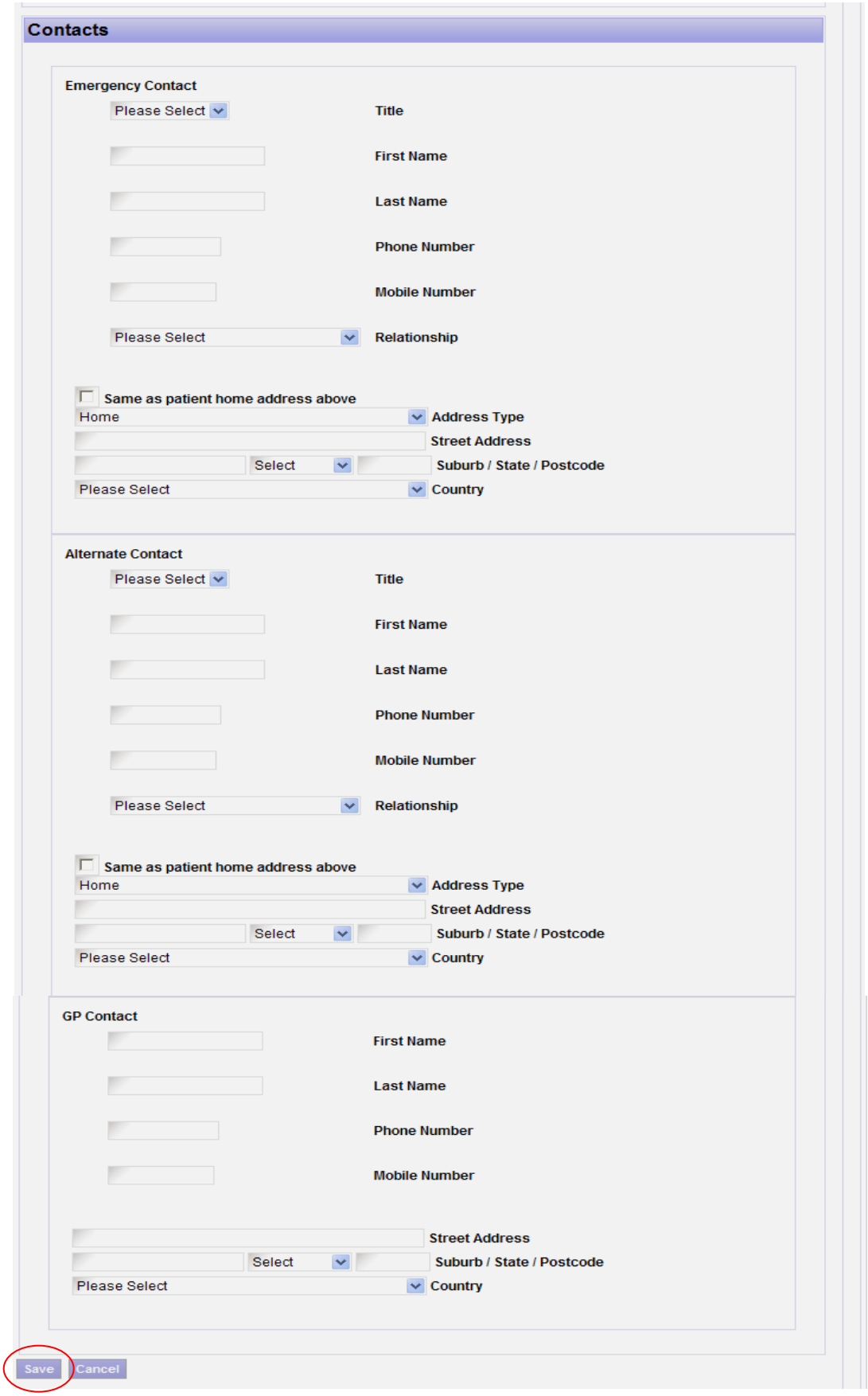
To add contacts:

1. Select the contact's *Title* from the drop down list and type in their *First Name, Last Name, Phone Number* and *Mobile Number***.**
2. Indicate the *Relationship* to the patient (for Emergency and Alternate Contacts) by selecting one of the options in the drop down list.

   Important note: If *Other Relative* is selected, an *Other Relative* text box will appear. Type the relationship to the patient.
3. If the Contact's address is the same as the patient address, click in the **Same as patient home address above** tick box.
4. Complete address detail entry (refer to: **To add addresses** section above).

Important note: Once all of the data have been entered, click the **Save** button at the bottom of the page to save the information on the **Patient Record** screen. An **Information** page will be displayed showing all information entered for the patient (Figure 9.5).

Figure 9.5 Patient Contacts Section



10 Adding a New Episode

The AuSCR Database requires that clinical information for the current admission is recorded as a separate episode of care.

Patients may have multiple admissions for stroke or have a stroke while in hospital for another condition. A new episode should be created for every new admission for stroke experienced by the patient.

If a patient has already been recorded in the AuSCR database, you will be made aware of this once you have entered their details (refer to Section 11 – Adding a New Patient). Refer to the AuSCR Data Dictionary for definitions, explanation and help notes on all the variables required to be entered in the database.

To add a new episode:

- Click the **New Episode** button at the bottom of the patient **Information** page and the **Episode** page will be displayed allowing for the entry of **Admission**, **Clinical, Discharge** and **Death Information**.

Admission Information (Figure 10.1)

If the patient was transferred from another hospital, or has a stroke while in hospital, refer to the AuSCR Data Dictionary for correct date and time entries for the different scenarios of admission information. This will ensure consistency.

1. Enter the following **Admission Information** and indicate whether each date or time is *Accurate* or an *Estimate* by clicking one of the corresponding radio buttons:

- ***Date of arrival to Emergency Department****:* Type a date using **DD/MM/YYYY** format or use the embedded calendar next to the date box to permit auto-completion of date.
- ***Time of arrival to Emergency Department (ED):*** Enter the time, which has been electronically generated on the emergency face sheet, for the patient's arrival at the hospital ED. If this time is not available use written documentation by nursing or ambulance staff. If there is conflicting data, use the earliest time recorded. The format used for time is always the **24 hour clock** with a colon automatically inserted to separate hours and minutes (**hh:mm**).
- ***Onset of stroke date:*** Type a date using the **DD/MM/YYYY** format or use the embedded calendar next to the date box to permit auto-completion of date.
- ***Onset of stroke time:*** The format used for time is always the **24 hour clock** with a colon automatically inserted to separate hours and minutes (**hh:mm**).
- ***Date of admission to hospital:*** Enter the date the patient is electronically admitted to hospital. Type a date using DD/MM/YYYY format or use the embedded calendar next to the date box to permit auto-completion of date.
- ***Time of admission to hospital*****:** Enter the time that the patient was admitted to the hospital. The format used for time is always the **24 hour clock** with a colon automatically inserted to separate hours and minutes (**hh:mm**). This time should be listed on the hospital admission front sheet or via electronic records. If the time has not been recorded, use written documentation by the nursing, medical or allied health staff to estimate a time.

Important note: If the patient has been transferred from another hospital, enter the date that the patient arrived in the ED of the first hospital. In some cases, the date will not correspond with the date of admission to hospital. Take care to record the date of arrival in the ED, not the date of admission to the first hospital – the two may differ if the patient arrives close to midnight and is actually admitted the following day.

2. Select the appropriate response from the drop down lists for each of the following questions:
   - *Was the patient transferred from another hospital?*
   - *Did this stroke occur while the patient was in hospital?*
   - *Was the patient able to walk independently on admission?*
   - *Is there documented evidence of a previous stroke (focal neurological signs persisting for more than 24 hours)?*

Important notes for recording dates:

- The format used for date is always **DD/MM/YYYY**
- Each date must be marked as ***Accurate*** or ***Estimate*** by clicking the corresponding radio button.
- If the *Accurate* (exact) date is unknown and not obtainable, the *Estimate* radio button located below the entered date should be clicked.
- When **the day is unknown,** but the month and year are known, the date should be recorded as **01/MM/YYYY** and the *Estimate* radio button located below the entered date, should be clicked.
- When **only the year is known,** the date should be recorded as **01/01/YYYY** and the *Estimate* radio button located below the entered date, should be clicked.

Important notes for recording times:

- The format used for time is always the **24 hour clock** with a colon automatically inserted to separate hours and minutes (**hh:mm**).
- If an exact time cannot be recorded (i.e. not in the chart or is unknown), the best estimate should be given. Descriptions of time such as “two hours prior to arrival”, “about 1 hour ago” or “approximately 2 and half hours ago” are specific enough to perform a calculation or express a time as ***Accurate***.
- If a time cannot be clearly determined, use the following guidelines (see Table 10.2) for estimating times in conjunction with other times that are recorded (E.g. the time of arrival to the Emergency Department).
- As the last resort, **if a time is unknown, enter ‘99:99’.**

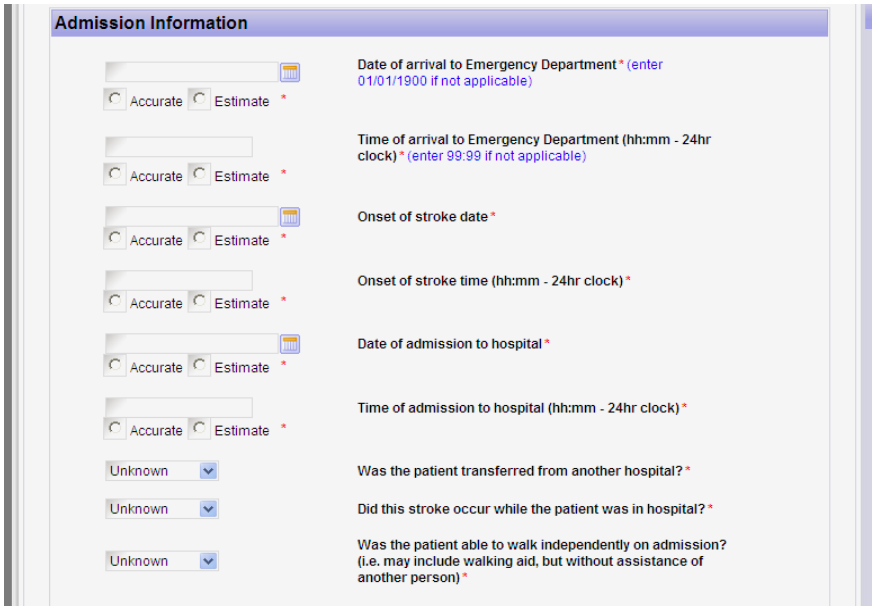
Table 10.1 Hints for Recording Time

Time	Record Time as:
Midnight (12:00 am)	23:59
Noon (12:00 pm)	12:00
12:15 am	00:15
6:00 am	06:00
4:00 pm	16:00

Table 10.2 Guidelines for Estimating Times

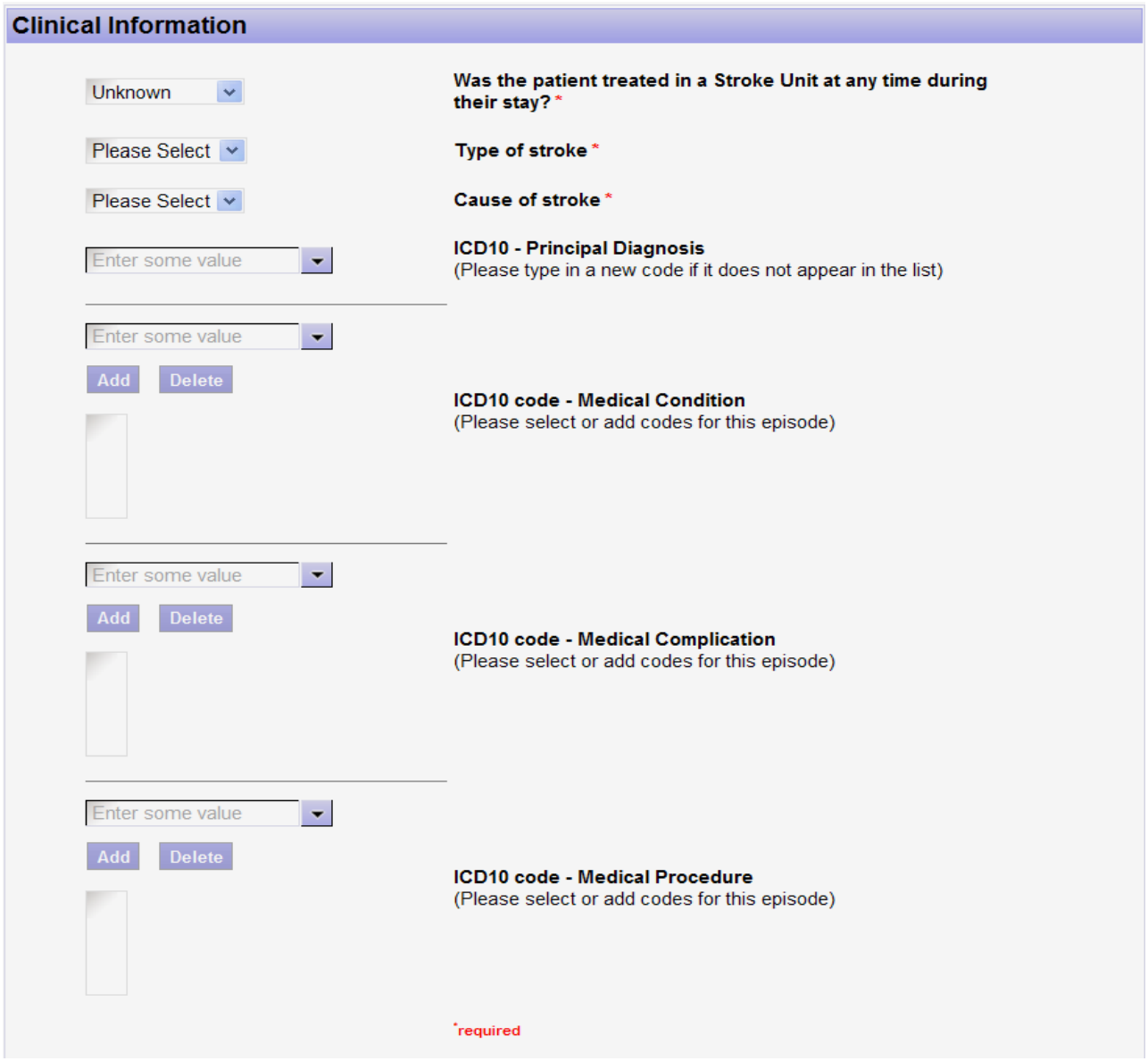
Description of Time	Record Time as:
The middle of the night	03:00
Breakfast	08:00
Early morning	08:00
Morning	09:00
Late morning	10:00
Lunch	12:00
Midday or 12 Noon	12:00
Early afternoon	14:00
Afternoon or mid afternoon	15:00
Late afternoon	16:00
Dinner/Supper	18:00
Early evening	19:00
Evening	21:00
Late evening	22:00

Figure 10.1 Admission Information Section



Clinical Information questions and variables (Figure 10.2)

Figure 10.2 Clinical Information Section



Was the patient treated in a Stroke Unit at any time during their stay?

Please select from the drop down box **Yes**, **No** or **Unknown**.

Type of Stroke

Please select from the drop down box **Ischaemic, Haemorrhagic, TIA or Undetermined**.

Important note: If the *Type of Stroke* selected is *Ischaemic* the following question will appear.

If an Ischaemic stroke, did the patient receive intravenous Thrombolysis (tPA)?

Please select from the drop down box **Yes**, **No** or **Unknown**.

Cause of Stroke
To ensure a systematic and consistent approach to defining known *Causes of Stroke*, the TOAST classification system is used. *For further information please refer to the AuSCR Data Dictionary.* The modified TOAST criteria should be applied to determine if the *Cause of Stroke* is '**Known**' or '**Unknown**'.

Table 10.3 TOAST classification

Cause would be 'Known' if:	Cause would be 'Unknown' if:
• Large-artery atherosclerosis • Cardio embolism • Small-vessel occlusion • Stroke of other determined etiology - illicit drug use - metabolic disorder - intervention/post-operative	• Stroke is of undetermined etiology. i.e. cause cannot be identified • Two potential causes are present but it is unknown which is likely to be the cause • Evaluation is incomplete

Important note: ICD10 codes may not be available until after the patient is discharged. These codes can be entered later. Please complete all other data. AuSCR office will send a regular reminder for the data missing from these fields.

ICD Codes

1. **ICD10 - Principal Diagnosis:** Select a stroke ICD10 code from the Principal Diagnosis drop down list. If the Principal Diagnosis is not stroke or the stroke codes provided do not match the Medical Record Principal Diagnosis, then enter this code directly into the Principal Diagnosis box. This text box will only permit valid ICD10 codes to be entered according to the following format: ANN {.N[N]} (refer to the Data Dictionary for details).

2. **ICD10 code - Medical Condition:** Enter an ICD10 code for the Medical Condition(s) available from the Medical Record into the drop down list. The system will attempt to auto-complete the code. After entering each code click the **Add** button before entering the next Medical Condition ICD10 code. Clicking the **Add** button will append the code to the list box under the **Add** button.

3. **ICD10 code – Medical Complication:** Enter an ICD10 code for the Medical Complication(s) available from the Medical Record into the drop down list. The system will attempt to auto-complete the code. After entering each code click the **Add** button before entering the next Medical Complication ICD10 code. Clicking the **Add** button will append the code to the list box under the **Add** button.

4. **ICD10 code – Medical Procedure:** Enter an ICD10 code for the Medical Procedure/s that is/are available from the Medical Record or hospital records into the drop down list. The system will attempt to auto-complete the code. After entering each code click the **Add** button before entering the next Medical Procedure ICD10 code. Clicking the **Add** button will append the code to the list box under the **Add** button.

Important note: To remove a code from the list box, select the code in the list box then click the **Delete** button.

Important note: Once all of the clinical information has been entered, click the **Save** button at the bottom of the page before entering the discharge information.

Discharge Information

1. Click the ***Date of discharge known*** tick box if applicable. This will expand the **Discharge Information** section to display additional data entry fields.
2. Type or use the embedded calendar to select the ***Date of discharge***. Indicate whether the date is ***Accurate*** or an ***Estimate*** by clicking one of the corresponding radio buttons.

Important note: If the patient died in hospital *the Date of discharge* should be the same as *Date of death.*

3. Select the appropriate option from the drop down list for each of the following questions/fields:
   - *Discharge destination/mode (Table 10.4).*

Important note: The following two questions below will ***not*** appear if "*Died in hospital"* is selected as the *Discharge destination/mode.*

- *Discharged with Antihypertensive agent*.
- *Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient (or family if patient has severe aphasia or cognitive impairments)?**

Figure 10.8 Discharge Information

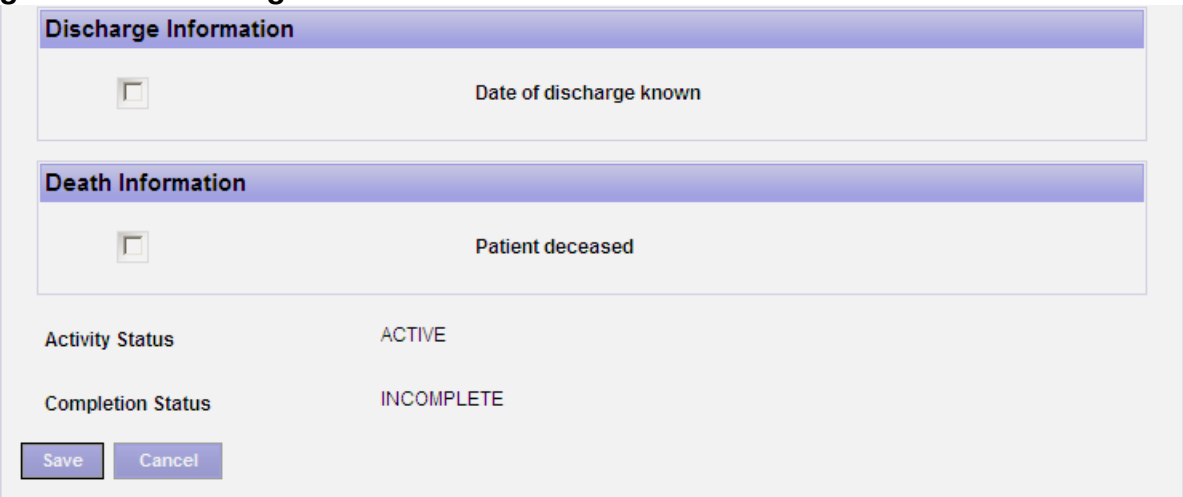


Table 10.4 Discharge Destination/Mode List
For further information please refer to the AuSCR Data Dictionary.

Discharge Destination/Mode	Explanation of where the patient is discharged to:
Hospital	A different hospital while patient is still in the acute phase of care.
Rehabilitation (inpatient)	Rehabilitation unit/ hospital
Low level Residential care	Aged Care Hostel/ Special accommodation facility
High level Residential care	Nursing Home/ Aged Care facility; **Note:** private palliative care nursing homes may also be classified under this category.
Home with supports	Living at home with some support structure
Home without supports	Living at home entirely alone
Transitional care service	A community-based health care service program
Died in Hospital	Died while in hospital
Other	Include welfare institution such as prisons, group homes e.g. boarding houses providing primarily welfare services.
Missing	Documentation regarding destination is lost or was not recorded/completed

Important note: If *Died in hospital* is selected, the **Death Information** section must be completed.

Death Information (Figure 10.9)

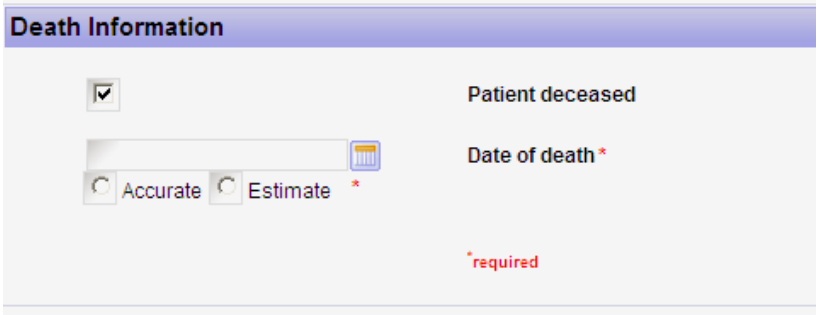
1. Click the ***Patient deceased*** **box** if applicable. This will expand the **Death Information** section to display additional data entry fields.
2. Type in or use the calendar to select the ***date of death*** and indicate whether the date is ***Accurate*** or an ***Estimate*** by clicking one of the corresponding radio buttons.

Important notes:

- If a patient is discharged from hospital but dies before data entry is complete, or if a patient is known to have died within 3 months of admission, please enter death data so that the AuSCR office staff do not contact family members, to complete a 3 month follow-up questionnaire.
- The AuSCR Database includes logic to minimise data entry errors (e.g. Date of death cannot occur before Date of birth).
- If you do not complete **all of the mandatory fields** in the admission screen, an error message will alert you when you click **save**. However, **should you attempt to ignore the message and exit the screen, none of the information will be saved.**
- Once all of the data have been entered, click the **Save** button at the bottom of the page to save the Episode information. An **Admission Information** page will be displayed showing all information entered for the episode.

Important notes: When **Completion Status** shows "Incomplete" it means you can return to the episode at a later stage and make changes to complete the data collection. You should not "Complete" the episode until all known episode details have been entered.

Figure 10.9 Death Information



11 Searching for a Patient or to Edit Patient Data

To search for a patient:

1. Click the **Search Patient** button on the navigation menu and the **Patient Search** page will be displayed (Figure 11.1). This page displays the list of existing patients, and their corresponding episode/s, sorted by the date when the patient record was last updated (the most recently updated record is listed first).
2. Search for patients by entering the *First Name*, *Last Name* or *MRN* (or a combination of these) into the search text boxes at the top of the screen and clicking the **Search** button.
3. Click the page numbers or arrows at the top of the **Patient List** to scroll between the pages of patients as follows:

   << << to move to the first page

   << to move to the previous page

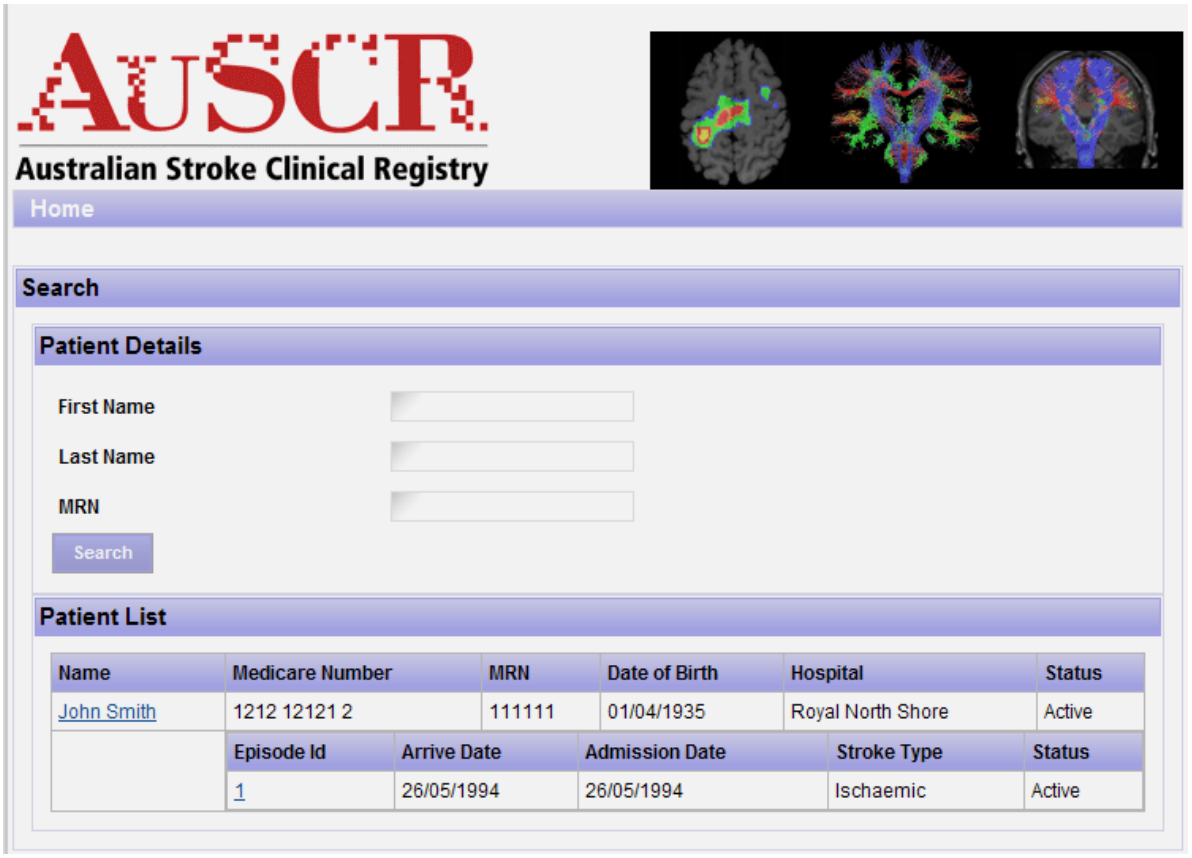
   >> to move to the next page

   >> >> to move to the last page
4. Click on the hyperlinked **Patient Name** to view the patient details. To edit the patient details, click the **Edit** button at the bottom of the page.
5. Click on the hyperlinked **Episode Id Number** to view the details of a specific episode. To edit an episode, click the **Edit** button at the bottom of the page.

Important notes:

- You will only be able to search for, and see, patients from your hospital
- Episode numbers are sequential by the date that data were entered, not by the date of the stroke admission.
- If the episode is locked, the episode cannot be edited and the **Edit** button will not appear. A request can be made to the AuSCR office to unlock the episode to enable editing of the episode.

Figure 11.1 Patient Search Page



12 Locking an Episode

The AuSCR Database allows users to lock an episode and therefore prevent it from being edited. **All episodes must be locked once completed.**

> **Important notes:** Do not lock episodes unless ICD10 information is complete and all other data has been cleaned and checked by AuSCR office.

To lock an episode:

1. Search for the patient with the episode to be locked.
2. View the episode to be locked by clicking on the hyperlinked Episode Id.
3. Click the **Complete and Lock** button located at the bottom of the page.
4. This will change the **Completion Status** of the episode to 'COMPLETE' and it can no longer be edited.

> **Important note:** Only a Superuser or the Data Manager can unlock a locked (i.e. 'Complete') episode. To unlock an episode, please contact AuSCR office.

13 Request Deletion of an Episode

All users are able to request the deletion of an episode, however this action needs to be confirmed by a Superuser or the Data Manager from AuSCR office before the record is actually deleted.

To request the deletion of an episode:

1. Search for the patient with the episode to be deleted in the “Search Screen” using the Patient list.
2. View the episode to be deleted by clicking on the hyperlinked Episode ID.
3. Click the **Delete** button located at the bottom of the page.
4. This will change the **Activity Status** of the episode to ‘INACTIVE’ and it will no longer be able to be edited and used by Hospital Users or Hospital Administrators.
5. The **patient episode** requested for deletion will automatically be added to the **Delete Episode List.** This list is only accessible to Superusers and the Data Manager from AuSCR office.
6. The Superuser or the Data Manager from AuSCR office will perform the actual deletion, using the **Delete Episode List,** during scheduled data management processes.

Important note: Actual deletion can only be performed by a Superuser or the Data Manager from AuSCR office. **Once deleted it cannot be reversed**.

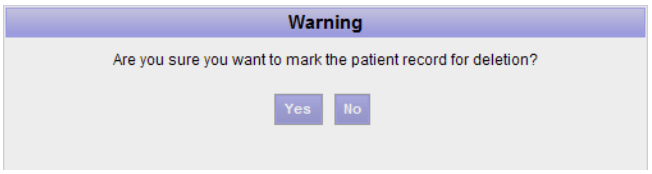
14 Request Deletion of a Patient Record

All users are able to request the deletion of a patient record, however this action needs to be confirmed by a Superuser or the Data Manager before the record is actually deleted. To request the deletion of a patient episode:

1. Search for the patient to be deleted.
2. View the patient to be deleted by clicking on the hyperlinked Name.
3. Click the **Delete** button – a warning panel will appear (Figure 14.1).
4. Click the **Yes** button to confirm the deletion (or the **No** button to cancel the deletion).
5. If the **Yes** button is selected, the Status of the patient will now appear as ‘Inactive’.
6. The **patient record** requested for deletion will automatically be added to the **Delete Episode List.** This list is only accessible to Superusers and the Data Manager from AuSCR office.
7. The Superuser or the Data Manager from AuSCR office will perform the actual deletion using the **Delete Deletion List,** during scheduled data management processes.

Important note: Actual deletion can only be performed by a Superuser or the Data Manager. **Deleting a patient will delete all associated episodes linked to the patient. Once deleted it cannot be reversed.**

Figure 14.1 Delete Patient Warning



15 Request to Opt-out Data from AuSCR

A patient who has been added to the AuSCR Database may request to 'opt-out' or have certain data elements removed e.g. their contact information. AuSCR Hospital Users need to request to have these data removed by the Data Manager from AuSCR office on behalf of the patient. ***Hospital staff cannot opt-out or remove data from the AuSCR database.***

The **opt-out request** occurs in two stages –

1: The request by the Hospital User.

2: Confirmation by the Superuser or the Data Manager.

To request data to be opted out for a patient:

1. Search for the patient to be opted out.
2. Click the hyperlinked Name for the patient to be opted out and the **Patient Information** screen will be displayed.
3. Click the **Opt-out** button at the bottom of the page and the **Opt-out** page will be displayed (Figure 15.1).
4. Select the corresponding radio buttons of the item/s the patient/guardian or next of kin has requested to opt-out.
5. Add any comments to describe why the data are being opted out.
6. Click the **Save** button and a warning panel will appear (Figure 15.2).
7. Click the **Yes** button to confirm the request (or the **No** button to cancel the request). It will bring you to the Opt-out information save page (Figure 15.3).
8. The request will automatically be added to the **Opt-out List,** accessible only to Superusers and the Data Manager from AuSCR office.
9. The Superuser or the Data Manager from AuSCR office will perform the actual opt-out using the **Opt-out List,** during scheduled data management processes.

Important notes:

- If you have made a mistake or incorrectly entered a patient who did not have a stroke, then you should **Delete** this case and not request this person to be Opted-out.
- If a patient is happy to have their details in the AuSCR Database, but does not want to be contacted again at follow-up (post-discharge), you should only then click the **Do not Contact Patient at Follow Up** box, which appears beneath the discharge information screen. This is not a request for this person to be Opted-out.

Important notes: The actual opt-out can only be performed by a Superuser or the Data Manager. **Opt-out cannot be reversed once it is confirmed.**

Please re-read the ***Opt-out Consent Model*** in Section 3, before proceeding with an opt-out request.

Figure 15.1 Opt-out Page

Figure 15.2 Opt-out Warning

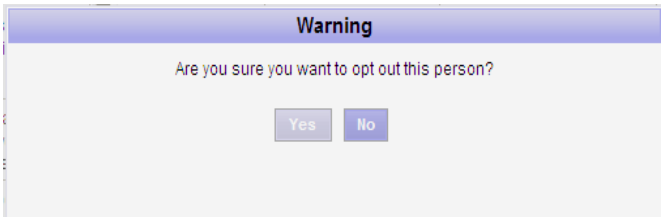
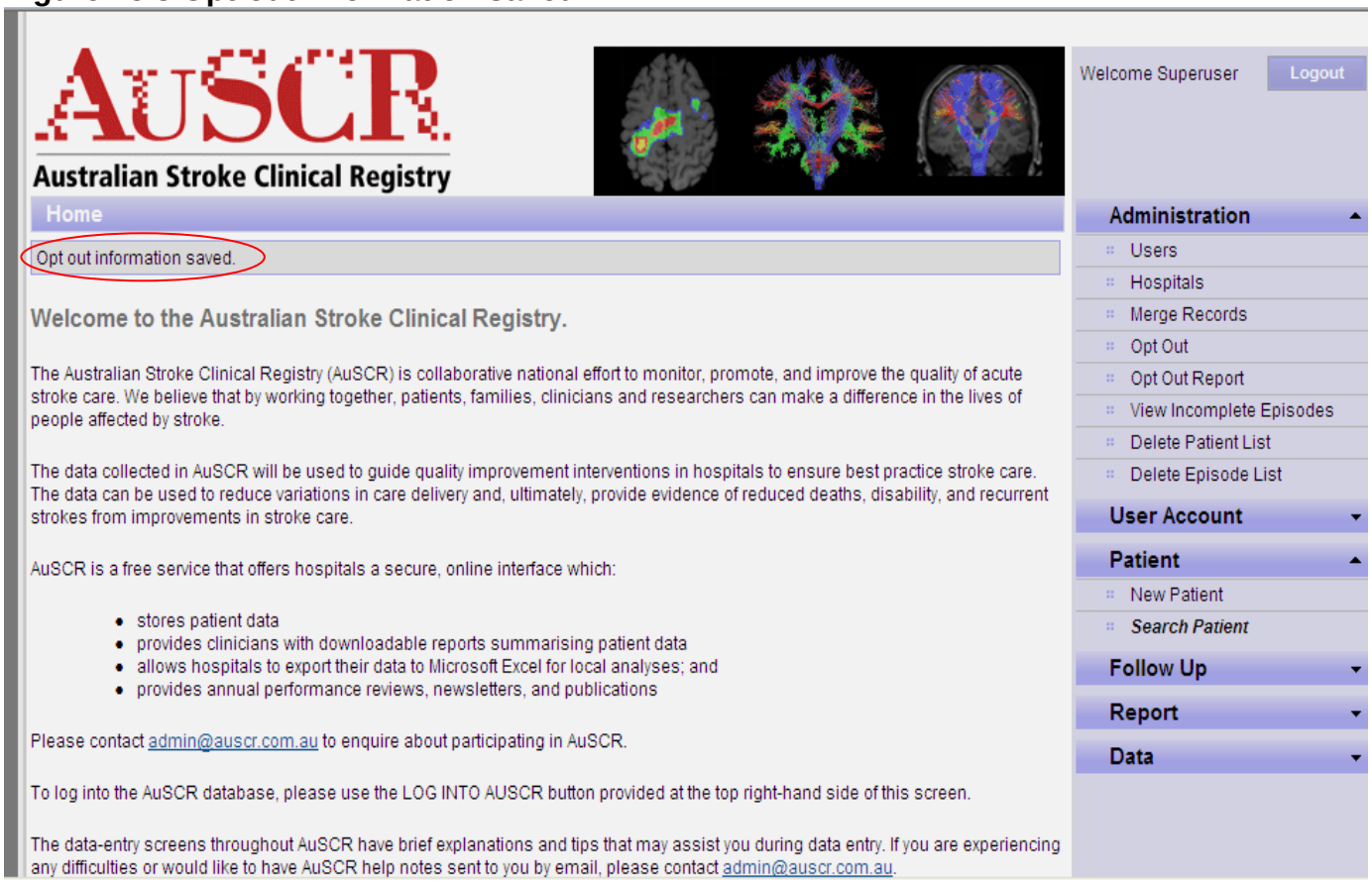


Figure 15.3 Opt-out information saved



16 AuSCR Acute Data Collection Form

The AuSCR Acute Data Collection Form is a hard copy version of the variables to be recorded in the AuSCR Database. Please use the version appropriate to your state.

The Acute Data Collection Form (Attachment 3) is available for:

- Hospitals that are not entering data directly from the medical record into the AuSCR Database.
- Hospitals experiencing technical difficulties using the AuSCR Database.
- Hospitals that do not have the capacity to enter data into the AuSCR Database.

Obtaining Acute Data Collection Forms

The AuSCR office can send the Acute Data Collection forms to you via

- email as a PDF document.
- mail – when contacting the office provide a name and mailing address where the forms can be sent along with the number of forms required.

  or alternatively

- **Download directly** from the Database from the New Patient screen.

To download a copy of the AuSCR Acute Data Collection form:

- Log in to the Database.
- Click the **New Patient** button on the navigation menu and the **New Patient** page will be displayed.
- Click on the hyperlinked **Download paper-based hospital data form** **(Figure 16.1)**.
- The Acute Data Collection form will be displayed which can then be printed.

Figure 16.1 Download Acute Data Collection Form

Using the Acute Data Collection Form

- The form can be filled out on the ward during the hospital stay.
- The form should be checked at patient discharge and any missing data entered.
- The person responsible should sign and date the completed form.
- Once the form has been completed, the data can be entered into the AuSCR Database.
- "Good Clinical Practice" guidelines must be used in completing the forms. (NHMRC National Statement with TGA annotation /ICHGCP CPMP/135/95E6)
- Examples of correctly completed and poorly completed forms are attached (Attachment 3a and 3b).

Completing the Acute Data Collection Form

- Write neatly and legibly with black ink;
- Write Patient Name, Date of Birth, and Hospital name or place a Bradma patient ID sticker at the top of each page of the form (this will ensure that the record remains intact, even if pages get separated).
- All patient information details must be completed with as much information as you can obtain. This is to assist in follow-up of the patient at 3-6 months.
- Mandatory questions are marked with an asterisk (*). These questions must be completed.
- If the information is not available, write the reason next to the question (e.g. to be obtained later, not available).
- With estimated or unspecified times and dates, use the rules for estimating times and dates that are outlined in the data dictionary.
- If you are using the hospital label and the name of the hospital is not printed on the label, please ensure your *Hospital Name* is entered in the box provided.
- Some hospital labels do not indicate Medicare numbers, MRN or DOB next to the numbers. If this is the case, please complete the MRN and DOB box on the form.

Correction of errors

- If an error is made when completing the form, please cross out using a single line, place the correct information next to or above the correction; initial and date the change.
- Do not use whiteout.

Storage of completed Acute Data Collection forms

- Completed Acute Data collections forms are to be stored in a secure and confidential manner in accordance with hospital policies.

17 Downloadable Reports of summary data

Individual, pre-specified, hospital reports are available to all hospital users via the AuSCR database. The reports may be generated at any time and use the current data available in the AuSCR Database.

Therefore, data in these reports have not been verified by the AuSCR office and are for internal use only (Table 17.1). The downloadable reports will provide summary data for the date range selected and are provided in tables and graphs for your convenience. These tables and graphs will include results from your hospital, as well as a summary estimate from all the cases entered from all participating sites.

The Hospital Administrator also has the ability to export your hospital data into an Excel spreadsheet so you can run your own data analyses. These data will also include any unlocked cases. Annual reports of verified data including follow-up data that have been adjusted for differences in patient case-mix will be provided on the AuSCR website. Your hospital will be notified when an annual report is available to download.

To access hospital reports:

1. Click the **Report** button on the navigation menu.
2. Click the **Reports** button on the navigation menu and the **Select Report** page will be displayed (Figure 17.1).
3. Select the ***Report Type*** from the drop down list.
4. Type in or use the calendar to select the ***Start Date*** for the report.
5. Type in or use the calendar to select the ***End Date*** for the report.
6. Click the **Generate Report** button.
7. A dialogue box will open with an option to open or save the chosen Report (Figure 17.2).
8. “Open” option will open the chosen Report for viewing and saving can be done later.
9. “Save” option will allow you to save the chosen Report to a folder in your computer.

Important notes: If there is an error, a **new error window** will appear. Close the new error window and go back to the original window to correct your errors.

Table 17.1 Reports Table

Pre- Specified Reports Available
Patient Episode Totals
Characteristic of Patients
Age-group Profiles
Summary Age Data
Destination on Discharge
Summary of Discharge data
Length of Stay
Processes of Hospital Care - Patients treated in a stroke unit at anytime during stay - Patients transferred from another hospital - Strokes that occurred while patients were in hospital - Number of patient episodes with ischaemic stroke that received tPA
Stroke Type by Age
Stroke Type by Gender
Patients per Month

Figure 17.1 Reports Page

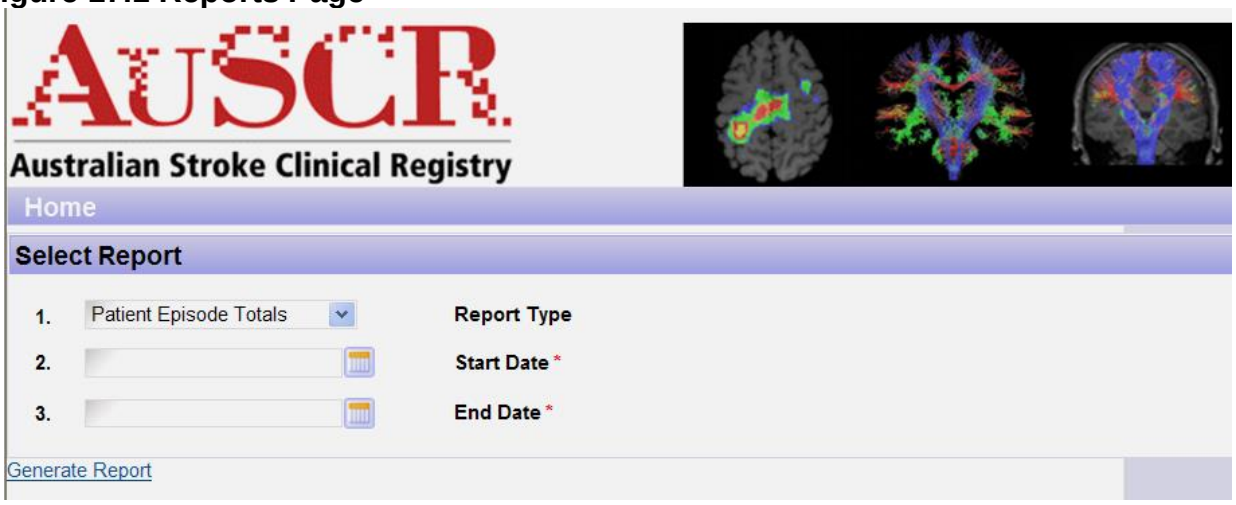


Figure 17.2 Report Dialogue Box

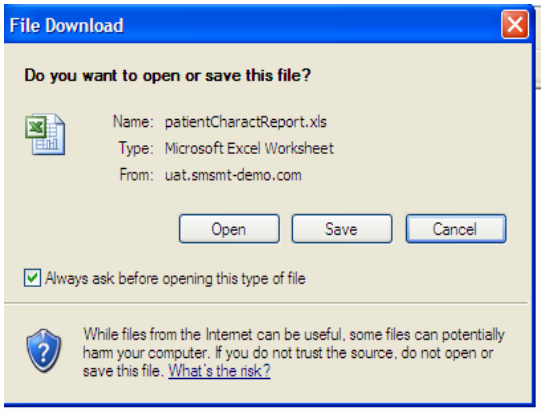


Figure 17.3 Examples of Reports

Processes of Hospital Care

Start date: 01/01/2011
End date: 31/12/2011
Hospital/s:

Total episodes for the period	Hospital/s						All					
	n (Yes)	%	n (No)	%	n (Missing/Unknown)	%	n (Yes)	%	n (No)	%	n (Missing/Unknown)	%
Patients treated in a stroke unit at anytime during stay	262	81.6	59	18.4	0	0	2014	76.8	598	22.8	10	0.4
Patient transferred from another hospital	62	19.3	259	80.7	0	0	344	13.1	2251	85.9	27	1
Strokes that occurred while the patients were in hospital	24	7.5	297	92.5	0	0	129	4.9	2459	93.8	34	1.3

Total episodes for the period	Hospital/s						All					
	n (Yes)	%	n (No)	%	n (Missing/Unknown)	%	n (Yes)	%	n (No)	%	n (Missing/Unknown)	%
Number of patient episodes with ischaemic stroke that received tPA	21	9.8	190	88.8	3	1.4	230	13.2	1459	83.5	59	3.4

Date report generated: 24 Oct 2013

DISCLAIMER: Please note the data given in this report have not been verified or checked by the AuSCR Management Team and are for internal information only

Patient Characteristics based on admission episodes

Start date: 01/01/2011
End date: 31/12/2011
Hospital/s:

	Hospital/s						All					
	Male	%	Female	%	Missing/Unknown	%	Male	%	Female	%	Missing/Unknown	%
Gender	162	50.5	153	47.7	6	1.9	1370	52.3	1222	46.6	30	1.1
	Australia	%	Overseas	%	Missing/Unknown	%	Australia	%	Overseas	%	Missing/Unknown	%
Country of birth	202	62.9	108	33.6	11	3.4	1783	68	693	26.4	146	5.6
	Yes	%	No	%	Missing/Unknown	%	Yes	%	No	%	Missing/Unknown	%
Patient able to walk independently on admission	163	50.8	152	47.4	6	1.9	936	35.7	1457	55.6	229	8.7
Previous stroke	80	24.9	237	73.8	4	1.2	478	18.2	1925	73.4	219	8.4

Date report generated: 24 Oct 2013

DISCLAIMER: Please note the data given in this report have not been verified or checked by the AuSCR Management Team and are for internal information only

18 Data Export Function (Hospital Administrator Only)

The AuSCR Database has a data export function. This function allows for the export of "raw" data directly entered from your hospital for the date range selected. The "raw" data are provided in an Excel spreadsheet and can be manipulated for internal hospital reporting as desired.

Outside of the date ranges for which the AuSCR office has verified the data, it is your hospital's responsibility to check and clean the "raw" data.

Important notes: All data exports must be saved securely with a password or spreadsheets with identifying information deleted.

To export data:

1. Click the **Data** button on the navigation menu.
2. Click the **Export Excel** button on the navigation menu.
3. The **Export Excel Data** screen will be displayed (see Figure 18.1).
4. Type in or use the calendar to select the date range desired.
5. Click the **Export** button.
6. The data will be exported to the email address that you provided to AuSCR when you created your log-in. A message will come up on the top of the "**Export Excel Data**" screen (see Figure 18.2).
7. Go to your email and click on the link within the email message.
8. Save the file to a folder in your computer. The file will include personal identifying information of patients and **needs to be 'password protected'** on a computer with a directory that also requires password access. For instructions on how to set a password for an Excel file please refer to the Encrypting Excel data files section.

Figure 18.1 Export Excel Data

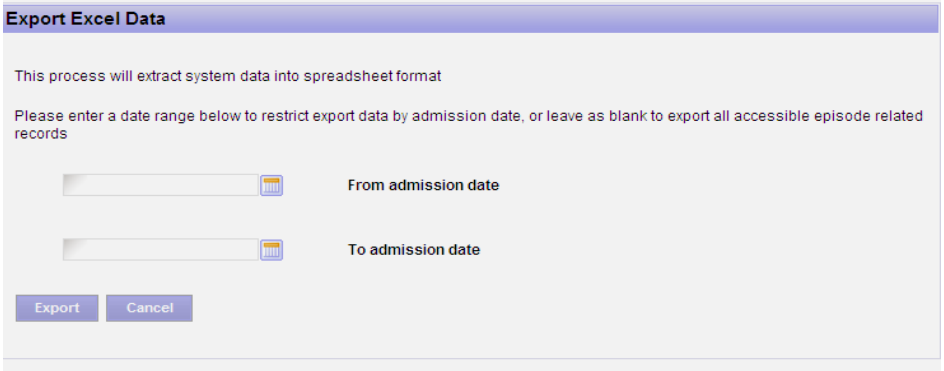
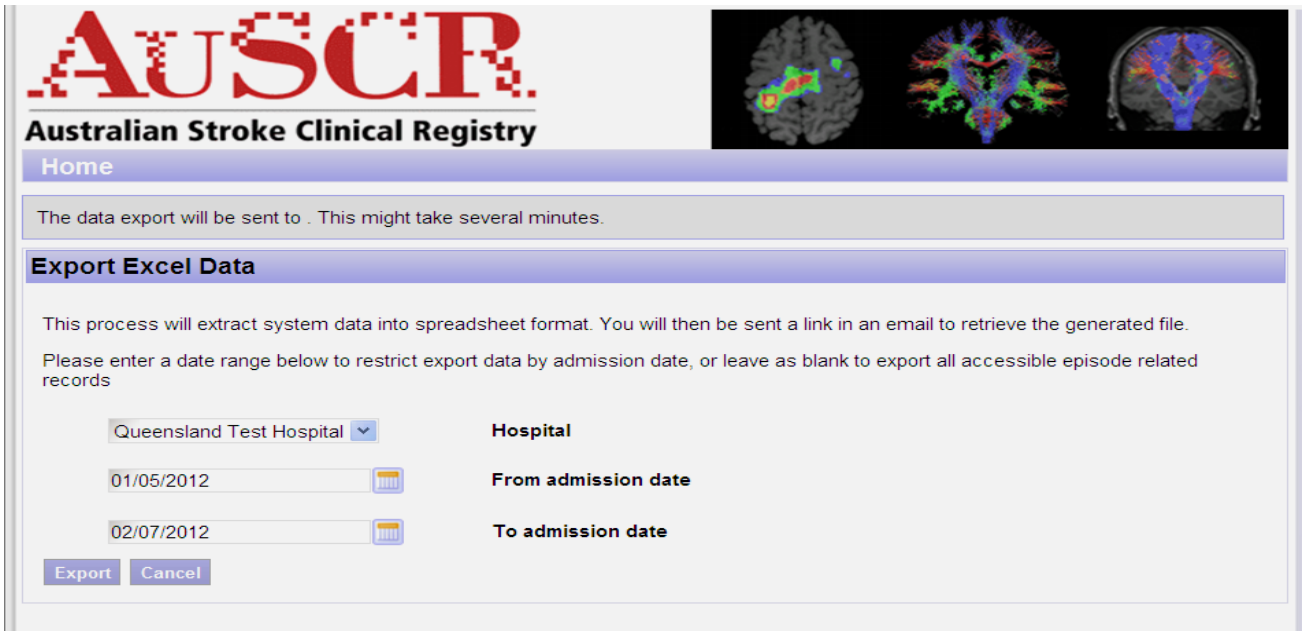


Figure 18.2 Export Excel Data Message



Important note: The data will be exported to an Excel workbook containing a series of worksheets showing some of the variables from the Database (i.e. hospital users only have the acute hospital data available for export).

These worksheets include several unique (numeric) identifiers that can be linked to a patient. ***Unfortunately, the unique identifiers for a patient (person ID and patient record ID) are not always reported on each worksheet, so care is needed if wanting to link data between one worksheet and another.***

The system was designed this way since patients may have multiple admissions to the same hospital for different stroke events, which are then eligible to be recorded as a different episode of care. Patients may also go to different hospitals.

To enable an individual patient to be tracked in the AuSCR Database each individual is assigned a unique Person ID. For a particular hospital they will have a Patient ID created and each episode of care will also generate a unique Episode ID. In addition, for each contact list for a patient, a Contact ID will be created (e.g. Emergency, Alternate, and General Practitioner). The relationships between the worksheets and the IDs available in each worksheet are summarised in Table 18.1.

Table 18.1 Summary of the worksheets

Worksheet	Linked Worksheet	Link
Hospital	Patient Record	Hospital Id
Hospital	Follow Up Patient	Hospital Id
Person	Patient Record	Person Id
Person	Follow Up Patient	Person Id
Patient Record	Patient Address	Patient Record Id
Patient Record	Patient Contact	Emergency Contact Id; Alternate Contact Id; GP Contact Id
Follow Up Patient	Follow Up Patient Address	Follow Up Patient Id
Follow Up Patient	Follow Up Patient Contact	Emergency Contact Id; Alternate Contact Id; GP Contact Id
Follow Up Patient	Follow Up Questionnaire	Follow Up Id

19 Importing Data

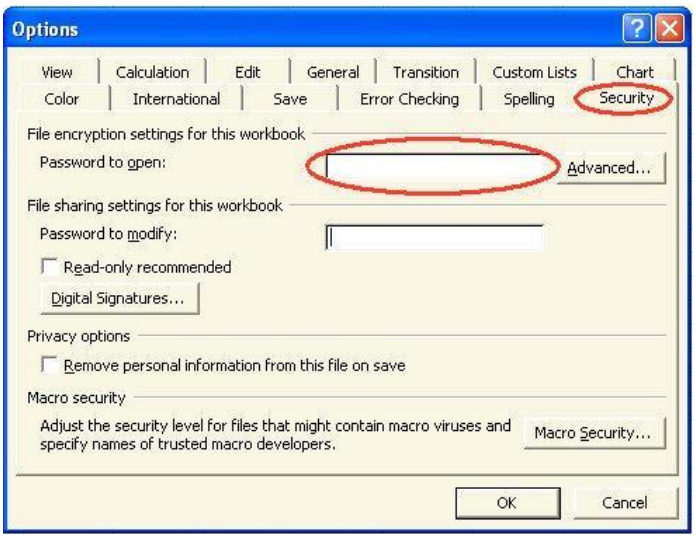
The AuSCR database has an option available for hospitals that would like to have their data imported into the webtool to reduce data entry. Please contact the Data Manager at AuSCR office for this option.

20 Encryption of Excel Workbooks

Encrypting Excel workbooks for transmitting stroke data to AuSCR.

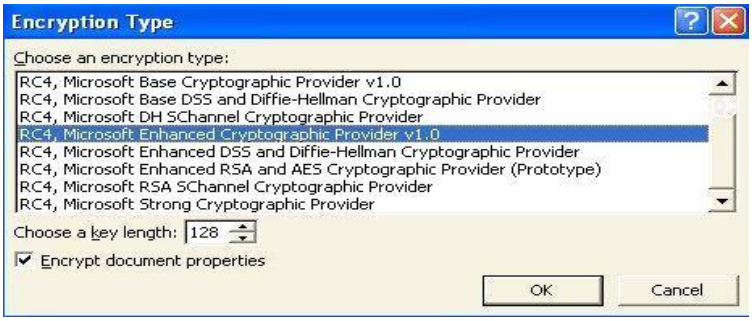
1. Open the **saved Excel file** you wish to password protect, then click **Tools / Options**
2. This will open the "**Options**" screen.
   Click the **Security tab**. (Fig 20.1).
3. Click the Advanced button to the right of the Password to open field.

Figure 20.1 Security tab



4. This will open the "**Encryption Type**" dialogue box.
5. Select "**RC4, Microsoft Enhanced Cryptographic Provider v1.0**" from the "Choose an encryption type" list (Figure 20.2).
6. Select "**128**" from the "**Choose a key length**:" field.
7. Ensure that "**Encrypt document properties**" is checked.
8. Click "**Ok**" button.
9. On the "**Options**" screen: enter a ***strong password*** (see below) into the "**Password to open"** field.
10. Click "**OK**" button.

Figure 20.2 Encryption type



Important notes: A strong password has the following properties:

- Minimum of 10 characters.
- Complexity of characters - use both alpha numeric and mixed -case characters.

AuSCR Office will negotiate with user and send via email to the user.

Send your password protected file as an email attachment and clearly state your site ID and period that the data cover to admin@auscr.com.au.
Ensure that you have saved a copy of each file in a local hospital computer directory for AuSCR data. Each file should be given a unique name which will ensure each new set of extracted files are not duplicated or misplaced. For example, the date range should be listed as part of the file name.

To Import Data use the AuSCR Import Excel Data Screen
Currently, data is uploaded by AuSCR office staff. Once a reliable version of the import file can be independently produced at the local hospital, a hospital user can import their file directly into AuSCR

21 Follow-up

Approximately three months but up to six months after admission to hospital, patients will be followed up by AuSCR staff via a postal and/ or telephone survey. They will be asked to complete questions about their current living circumstances and health status including questions about their quality of life. To assess quality of life, the EuroQol or EQ-5D is used

for adults and the PedsQL is for those aged less than 18 years. At this time, information will be provided again to each patient to explain their right to opt out any or all information in the registry and/or their option to refuse to participate in the follow-up survey. It is essential for timely follow-up of patients that their hospital data are completed within three months of their stroke or they may not be eligible for follow-up.

22 Error Screens

Occasionally, the system may encounter an error that it cannot handle. In these situations, please contact admin@auscr.com.au.

There are several errors that will not normally need intervention from the AuSCR admin. These are:

- **Optimistic Lock Exception** (Figure 22.1) - this occurs when more than one user tries to update the same record at the same time. The system prevents this occurring because data may be lost if simultaneous updates occur. If you encounter this error, you will have to navigate through the right menu and reapply your updates again.
- **Access Denied** - this occurs when the user tries to access a page that they do not have authority to access (Figure 22.2). If you encounter this error, you will have to use the menu located on the right of the screen, to navigate back to an area that you do have access to. Contact AuSCR office if you need to revise your user access.

Figure 22.1 Optimistic Lock Exceptions

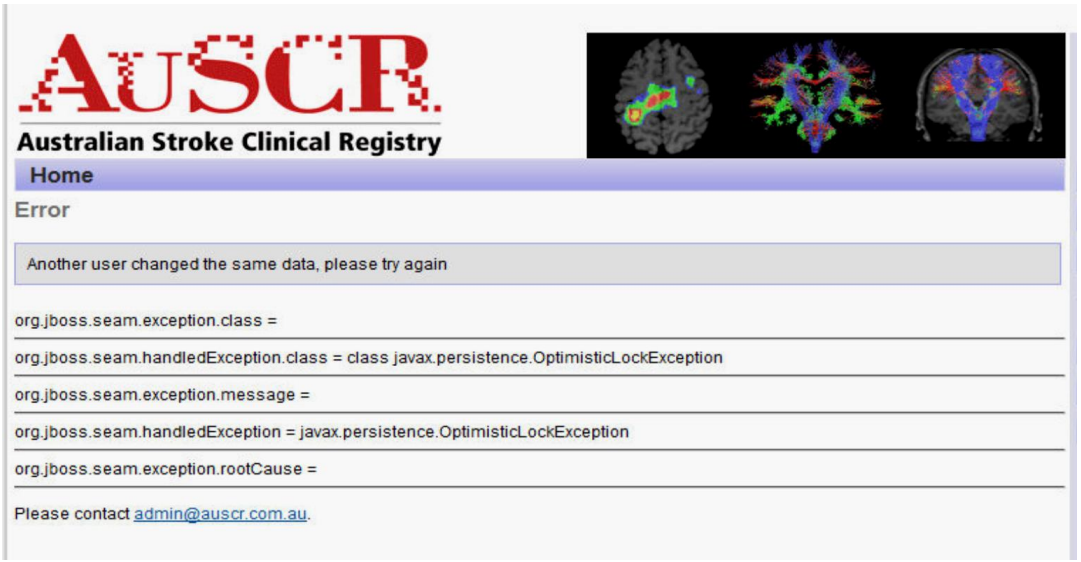
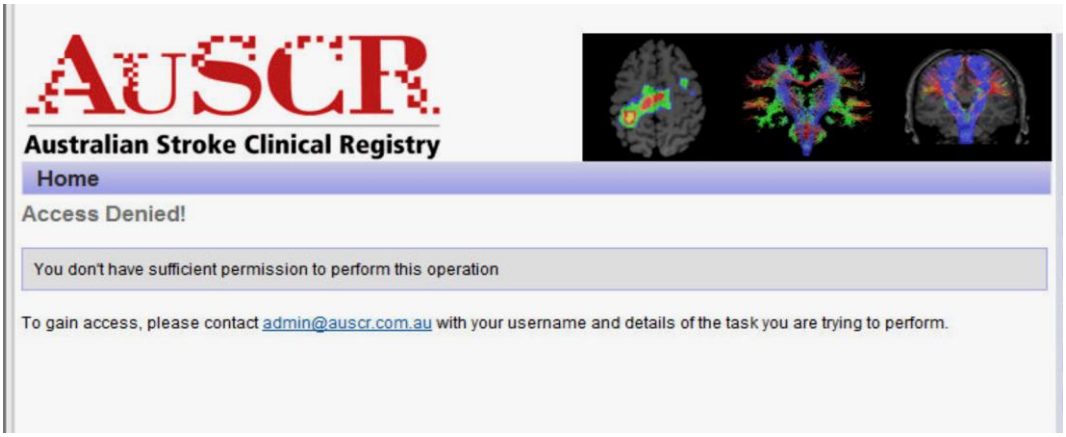


Figure 22.2 Access Denied



23 Quality Assurance Data Management Processes

The AuSCR Database has many in-built logic checks in place to prevent inaccurate information being entered. However, additional data checking processes are required by the AuSCR office at routine intervals. This will include:

- The AuSCR office running routine data queries which will identify missing data and data discrepancies. These reports will be sent to the hospital administrator/hospital user for verification prior to locking the patient episodes.
- Cross-referencing of ICD10 discharge codes from the hospital patient administration system (database) with cases entered in the AuSCR database to ensure all eligible admission have been captured may be requested up to twice a year.
- Random medical record auditing by the AuSCR office following a pre-arranged site visit may also be undertaken to assess the accuracy of data. The registry data collection processes and conformity with variable definitions will also be assessed during this site visit. This process usually occurs after the first 50 cases have been entered followed bi-annually unless concerns about data quality have been identified.

24 Feedback

Your feedback is valuable to assist us with further improvements to the database and registry processes and procedures. AuSCR will generally schedule feedback one week following initial training and one month following commencement of data collection. As required, please email any other feedback to admin@auscr.com.au.

25 Frequently Asked Questions

What do I do if the same person is entered twice?

- If you enter a new patient with the same *First Name*, *Last Name*, *Date of Birth* and *Medicare Number* as an existing patient, the system will automatically find the existing patient record and display their details for editing, rather than creating a duplicate record for the same person.

- If the same person is entered twice because incorrect data has been entered in one of the records, you can request that the incorrect record be deleted, following the steps outlined in Section 14 of this manual.

What do I do if I don't know the ICD10 code?

- The ICD10 codes must be obtained from the Medical Records Department following completion of coding.
- Proceed to complete all other data.
- AuSCR office will prompt you for the data throughout the year when they are missing.

What do I do if there are no contact details?

- Leave fields blank (Refer to the Data Dictionary).

What do I do if the patient is from overseas?

- All cases are to be included unless the patient chooses to "opt-out".
- All data can be entered as usual.
- Record their temporary Australian contact details, as other address type.
- Record their usual home overseas as home address type.
- Select "Overseas" as the State/Territory. An overseas postcode can be entered if "Overseas" has been selected.

What do I do if I get an error message?

- Press "Alt" +"Print screen" simultaneously on your keyboard to capture the active screen only containing the error message.
- Open a word document and paste it in. Write below it what happened prior to you getting the error message. Save it as an "error message – hospital name".
- Email the document as an attachment to admin@auscr.com.au

How do I obtain a password?

- Each hospital will have a Hospital Administrator created by the AuSCR office. Your Hospital Administrator can issue you with a username and password. Once created, your username and password will be emailed to you.
- If your Hospital Administrator is unavailable, then contact AuSCR office to generate one for you.

How do I edit information in the AuSCR Database?

It is not possible to edit any errors or add to the Patient Information screen once you have pressed **Save**. This includes the Patient's Name, Date of Birth and Medicare Number. To

edit this information, you should contact the AuSCR office, or delete this patient and start again with the correct information.

If you would like to edit the stroke episode details (such as date of stroke, date of arrival, or even type of stroke) you may do so at any time up until you "lock" the episode. Once you have completed the corrections, you should save the episode, and then lock the episode (this will allow the person to be followed up in the community).

To edit the stroke episode details *after* you have locked an episode of care, you must contact the AuSCR office. However, once editing is completed you must lock this episode again to permit follow-up to occur.

There seem to be some questions missing for the patients who die in hospital.

The following two questions below will not appear if "Died in hospital" is selected as the Discharge destination/mode:

- *Discharge on Antihypertensive agent.*
- *Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?*

If 'Died in hospital' is selected, you must complete the Death Information that opens up in the web tool. You should also make sure that Date of discharge is the same as Date of death.

What do I do for people who go home and were not given an information sheet?

It may be that a person has been admitted and discharged without receiving an information sheet. It is imperative that *everyone* receives an information sheet; therefore patients must be contacted by letter following hospital discharge by their treating doctor to provide them with a copy of the Participant Information Sheet.

A sample copy of a Post-Discharge letter is attached in Attachment 6.

Appendix 1 Technical Specifications for Import File Data Entry

Data Source

The data are commonly sourced from the local Health Information System (HIS). A query is used to extract a cohort of patients with stroke based on diagnostic codes. This candidate list may also contain non-stroke patients and may also miss stroke patients. If necessary, the clinician should remove the inappropriate entries from the list and add the missing patient details. This needs to be formatted according to the following rules:

- Saved on a worksheet in an Excel spreadsheet file.
- A template is available from the AuSCR Database by clicking the link in the main menu Data/Import Excel. Then click the information button and click the hyperlink: “Download the template with sample data here”.
- The name of the worksheet is mandatory “Data Import Form”
- The order of the columns is mandatory.
- The first row is assumed to be a header row.
- All data must be saved as text (including dates and numbers)
- All dates must be formatted as DD/MM/YYYY
- Each column attribute has specific data type (text) or has a set of predefined values compatible with METeOR standards.

Data Entry Constraints

The system requires, as a minimum, the following data:

1. It is recommended no more than 500 rows be in one import per spreadsheet. If there are more than 500 records, break up the records into several imports.
2. First Name – given or Christian name.
3. Last Name or Surname.
4. MRN, local primary key identifier of the Patient in the Hospital HIS.
5. Date of Birth: patient’s date of birth. (DD/MM/YYYY)
6. Date of Admission: date that the patient was actually admitted to acute care or inpatient unit of the hospital. This is not the date of arrival to ED.
7. The First Name, Last Name, Date of Birth, Medicare number, Hospital Identifier and Admission date will create a new record for the patient. If a duplicate is detected during import processing the data will be updated to the database for that patient record.
8. Refer to the Data Dictionary for specific definitions of data values.
9. Refer to the ImportSpecification.xls for data specifications.

Data Mapping

Refer to the spread sheet ImportSpecification.xls for specific instructions for each column attribute. This document specifies the meta-data characteristics for each of the imported data values. The following specifications are covered:

1. Optionality & Notes – whether the attribute is mandatory or optional and any clarification notes.
2. Representation Class – broad information category (text, identifier, code etc.)
3. Data Type – is always String
4. Format – where applicable a representation of how the data needs to be formatted.
5. Max character length – the maximum length of the valid string for a variable.
6. Scope of Values & Notes – where applicable lists the scope of all possible values and notes on usage for correct data mapping.

Uploading/Committing Data

It is possible for users to upload data directly to AuSCR through the web interface. The AuSCR system will return a message if successful. If a problem occurs with the data, the AuSCR system will return a row number and error message to identify the problem. The system will not allow data to commit until all errors have been resolved.

Initially users will send their data as an encrypted attachment to the AuSCR office where the data are analysed and uploaded to the AuSCR system. Feedback will be provided to the hospital user and or local IT support to improve the quality of the imported data and facilitate data entry.

Attachment 1 – Example of Patient Information Sheet

AuSCR
Australian Stroke Clinical Registry

Hospital Logo

Information for patients and relatives

What is the Australian Stroke Clinical Registry (AuSCR)?

The Australian Stroke Clinical Registry is an electronic data management system that collects information about what happens to people who have had a stroke or a 'mini-stroke', called a transient ischaemic attack (TIA).

The Stroke Registry collects information from hospital information systems to tell us how well you have recovered after your stroke. In order for the Stroke Registry to be successful we hope as many people as possible participate.

Why do we collect information for the Australian Stroke Clinical Registry?

Stroke affects more than 50,000 people in Australia every year and by collecting information about your hospital stay, the Stroke Registry aims to:

- ensure that patients and their families affected by stroke receive the best possible care
- improve stroke care and rehabilitation across Australia
- improve stroke treatment in hospitals
- prevent stroke from occurring, and
- improve chances of recovery after stroke.

Who manages the Stroke Registry?

The Stroke Registry is co-coordinated by Stroke Division of the Florey Institute of Neuroscience and Mental Health.

In your area, the Stroke Registry is managed at: _____ _____
[name of hospital] *[name of local investigator]*

What information is collected, when and by whom?

In hospital

After you have agreed to participate, your treating specialist and/or nursing staff will complete the form that contains the details from your time in hospital. This form includes the following information;

- your name
- date of birth
- your country of birth
- your preferred language
- your address
- your telephone and/ or mobile number
- contact details of your next of kin or health contact person
- Medicare number
- hospital identification number
- name of the hospital
- type of stroke
- medical treatment and care, in hospital
- complications, if any
- living arrangements after discharge from hospital

This information is necessary to accurately link a person's hospital stay with any subsequent rehabilitation. This information allows us to collect further information regarding your health care needs from other linked hospital and health information systems so we know how well you have recovered. No other personal information is included.

After discharge

As a participant of the stroke registry, you or your next of kin will be contacted either by telephone or mail at approximately 3-6 months after your discharge from hospital, unless a request has been made not to be contacted. If your next of kin is contacted, you consent to us disclosing the fact that you had a stroke/TIA and when/where you were treated. At this time the following information will be collected:

- your name
- date of birth
- address
- current health condition
- living arrangements
- support that you have received since leaving hospital.
- If after discharge you need more care, rehabilitation or are admitted back to hospital, information about your ongoing care will also be collected.

How will we keep your information confidential?

All personal information is kept strictly confidential and cannot be used outside the Registry. Information is stored in a specially designed password protected database which can only be accessed by a small number of approved Stroke Registry staff.

QLD-AuSCR Information Sheet for Patient and Relatives and Consent-Final-V9.1-28January2014-Clean.doc

Once your information is entered into the registry, it will be given a unique identification number for analysis. ***This means that your name will not be identified in any reports that are produced, and your privacy and confidentiality will be maintained.***

How will your information be used and reported?
Your information is protected and we are not allowed to identify you by law. The Stroke Registry will produce reports on factors that influence the success of stroke care and rehabilitation; aspects of such reports may be presented at conferences or submitted for publication in medical journals. It will not be possible to identify any individuals in any reports.

To maintain absolute security and confidentiality, anyone wanting to use any of the data from the Registry will be required to obtain ethics approval from an Ethics Committee.

What are the risks and benefits to you?
There are no risks to your health by having your details stored in the Stroke Registry. It is anticipated that information in the Stroke Registry will be used to further medical knowledge and improve stroke patient care. After discharge, all participants will have the opportunity to ask to speak with a representative of the National Stroke Foundation about available services at the end of their 3-6 month follow-up. However no direct benefit to you as an individual may be forthcoming from your participation in the Registry.

Will this affect your care?
The way your treating doctors and the stroke team approach your treatment and long-term care will not be affected, regardless of whether or not you participate in the Stroke Registry.

Participation is Voluntary
Participation is voluntary. **To remove all or some of your details** from the Australian Stroke Clinical Registry, please use the form at the bottom of this page or contact the Stroke Registry on 1800 673 053 (freecall). The signed slip can be given to the nursing staff while you are in hospital, or mailed at anytime to **AuSCR**, c/- Public Health, Stroke Division, Melbourne Brain Centre, 245 Burgundy Street, Heidelberg, VIC 3084

If you choose to remove Medical information and/or Personal information on the form below, you will be contacted to confirm the specific information you wish to have removed. Please provide your contact details for AuSCR office staff to contact you.

An invitation from the Stroke Registry to participate in future research projects
During your follow-up, you will be asked if you would like to be contacted in the future to receive more information about stroke or participate in future research studies that might be appropriate for you

A decision on whether or not you wish to be contacted about future research projects does not affect your registration in the Registry. If you agree, the Registry staff will be responsible for contacting you. You are under no obligation to participate and can change your mind at any time.

If you have any questions about the Stroke Registry, would like further information, or have any other Registry-related issues please contact the **AuSCR Project Coordinator on telephone 1800 673 053 or email admin@auscr.com.au.**

Any person with concerns or complaints about the Stroke Registry can contact the Executive Officer of the (insert name of Research Ethics Committee) on (Insert phone number) or email: (insert email)

The Stroke Registry project has been approved by the .....
[name of relevant research ethics committee].

OPT-OUT FORM *Please tick the box next to the information you do not want recorded in the Registry Database*

I do not wish to have the following information included in the Australian Stroke Clinical Registry (AuSCR): ☐ Medical information *(information about your stroke)*
☐ Personal information *(information such as your date of birth, address, and GP contact details)*

I do not wish to be ☐ contacted after discharge and asked about how I am managing *(known as follow-up)*

Patient Name:..... **Date of Birth** .....

Phone/ Mobile contact: .....

Signature of Patient or Authorized Proxy: ..... **Date:** .....

QLD-AuSCR Information Sheet for Patient and Relatives and Consent-Final-V9.1-28January2014-Clean.doc

Attachment 2 – Example of Opt out Request

Opt Out Request (Victoria)

Removing information from the Australian Stroke Clinical Registry database

AuSCR
Australian Stroke Clinical Registry

Please send this form to the AuSCR office. Hospitals should also retain a copy of this form filed in the hospital medical record to document the patient's decision **NOT** to join the Stroke Registry.

I have read the Stroke Registry patient information sheet. I understand the purpose and the benefits of my details and medical records entered into the Stroke Registry.

I also know that I have a choice to request exclusion from any section of the Stroke Registry and at anytime.

Please ☑ tick the information that you would like removed from the Stroke Registry.

Personal information about me

- ☐ Name
- ☐ Medicare Number
- ☐ Date of Birth
- ☐ Country of Birth
- ☐ My address
- ☐ My mobile number
- ☐ Telephone numbers/s of my Next of Kin and/or Alternate Contacts
- ☐ Name of my GP
- ☐ GP Telephone number
- ☐ Title (Mr, Mrs, etc)
- ☐ Gender
- ☐ Aboriginal/Torres Strait Islander status
- ☐ Language spoken
- ☐ My telephone number
- ☐ Name/s of my Next of Kin and/or Alternate Contacts
- ☐ Address/s of my Next of Kin and/or Alternate Contacts
- ☐ GP address
- ☐ All of my personal information

Information about my stroke and care I received in hospital

- ☐ Date of the onset of the stroke
- ☐ Date of arrival to Emergency Department
- ☐ Date of admission to hospital
- ☐ Whether you were transferred from another hospital
- ☐ Whether or not this was your first stroke
- ☐ Whether you were able to walk when you were admitted to hospital
- ☐ If you were treated in a Stroke Unit
- ☐ Date of discharge from hospital
- ☐ If you were given a careplan at discharge
- ☐ Date of death if applicable
- ☐ Time of the onset of the stroke
- ☐ Time of arrival to Emergency Department
- ☐ Time of admission to hospital
- ☐ Whether you arrived at the Emergency Department by ambulance
- ☐ Whether the stroke occurred while you were in hospital
- ☐ Hospital codes that define your diagnosis, medical condition, and any complications or procedures
- ☐ Type of stroke
- ☐ Discharge destination
- ☐ If you received an antihypertensive agent at discharge
- ☐ All of my stroke and hospital care information

☐ Being contacted and having follow–up details recorded in the Stroke Registry (eg. support services, who I live with, and my quality of life)

☐ All of the above information

Patient's Name

Name of Hospital

Date of birth

Phone /mobile contact

Signature of Patient/Authorised proxy

Date

For more information about the Australian Stroke Clinical Registry please call the *AuSCR Project Coordinator* on telephone 1800 673 053 or visit our website at www.auscr.com.au

Postal: Public Health, Stroke Division, Melbourne Brain Centre, 245 Burgundy St, Heidelberg, VIC 3084

Fax: Attention AuSCR: (03) 8888 4990

Opt-out Form MasterV5-Victoria-V1-11February2014-Clean

Attachment 3 – Example of Acute Data Collection Form

DATA COLLECTION FORM

AuSCR
Australian Stroke Clinical Registry

Please complete the form:
- Neatly and legibly
- Write in **black ink** and press firmly
- Each question must be completed;
- Place ☑ in appropriate boxes.
- Required fields marked with * must be completed

Return form to AuSCR Office via
- Fax: (03) 8888 4990

Or
- Post: AuSCR, Public Health, Florey Neuroscience Institutes, 245 Burgundy Street, Heidelberg, VIC, 3084

Hospital Name:

AFFIX PATIENT STICKER HERE

Patient Information

Title ☐☐☐☐☐☐☐☐☐☐☐☐

First Name* ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Last Name* ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Address type ☐ Home ☐ Business ☐ Other

Street Address ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Suburb ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Post Code ☐☐☐☐☐☐☐☐☐☐ State ☐☐☐☐☐☐☐☐

Country ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Phone Number ☐☐☐☐☐☐☐☐☐☐ Mobile Number ☐☐☐☐☐☐☐☐☐☐

Medicare No ☐☐☐☐☐☐☐☐☐☐ Hospital MRN* ☐☐☐☐☐☐☐☐☐☐

Date of Birth * ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) Gender ☐ Male ☐ Female

Country of birth ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Language spoken ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Interpreter needed ☐ Yes ☐ No

Is the patient of Aboriginal and/or Torres Strait Islander origin?*
- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☐ Neither Aboriginal nor Torres Strait Islander origin

Acute Data Collection Form v3.2 9072012

Patient Name: _____ DOB: ___/___/_____ Hospital: _____

Emergency Contact

First Name

Last Name

Address type ☐ Home ☐ Business ☐ Other

Street Address

Suburb

Post Code State

Country

Phone Number Mobile Number

Relationship to participant

Alternate Contact

First Name

Last Name

Address type ☐ Home ☐ Business ☐ Other

Street Address

Suburb

Post Code State

Country

Phone Number Mobile Number

Relationship to participant

General Practitioner

GP First Name

GP Last Name

Street Address

Suburb

Post Code State

Country

GP Telephone Number

GP Fax Number

Patient Name: _____ DOB: ___/___/_____ Hospital: _____

Admission Information

Date of arrival at Emergency Department* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Time of arrival at Emergency Department* ☐☐:☐☐ (24-hour clock) ☐ Accurate ☐ Estimate

Date of stroke onset* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Time of stroke onset* ☐☐:☐☐ (24-hour clock) ☐ Accurate ☐ Estimate

Date of admission* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Was the patient transferred from another hospital?* ☐ Yes ☐ No ☐ Unknown

Did this stroke occur while the patient was in hospital?* ☐ Yes ☐ No ☐ Unknown

Able to walk independently on admission?* ☐ Yes ☐ No ☐ Unknown
(i.e. may include walking aid, but without assistance from another person)

Is there documented evidence of a previous stroke?* ☐ Yes ☐ No ☐ Unknown
(i.e. focal neurological signs persisting for more than 24 hours)

Clinical Information

Was the patient treated in a Stroke Unit at any time during their stay?* ☐ Yes ☐ No ☐ Unknown

Type of stroke* ☐ TIA ☐ Ischaemic ☐ Haemorrhagic ☐ Undetermined

If an ischaemic stroke, did the patient receive intravenous thrombolysis (tPA)?* ☐ Yes ☐ No ☐ Unknown

Cause of stroke * ☐ Known ☐ Unknown

ICD10 code – Diagnosis ☐☐☐☐☐

Separation (Discharge) Information

Patient Deceased ☐ No ☐ Yes, date of death: ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

Discharged Alive

a) Date of discharge* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) ☐ Accurate ☐ Estimate

b) Discharge destination/mode*

- ☐ Hospital
- ☐ Rehabilitation (Inpatient)
- ☐ Low level Residential Care
- ☐ High level Residential Care
- ☐ Home with support
- ☐ Home without support
- ☐ Transitional care services
- ☐ Died in hospital
- ☐ Other: _____

c) Discharged with antihypertensive agents* ☐ Yes ☐ No ☐ Unknown

d) Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?* ☐ Yes ☐ No ☐ Not applicable ☐ Unknown

Opt-Out Request

Place ☑ in appropriate boxes

☐ Medical information ☐ Personal information ☐ Do not wish to be contacted for *follow-up*

Form completed by: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Date: ☐☐/☐☐/☐☐☐☐ Contact Number ☐☐☐☐☐☐☐☐☐☐

Attachment 3a – Example of Correctly Completed Acute Data Collection Form

Correctly completed Data Collection Form

DATA COLLECTION FORM

AuSCR Australian Stroke Clinical Registry

Please complete the form:

- Neatly and legibly
- Write in **black ink** and press firmly
- Each question must be completed;
- Place ☑ in appropriate boxes.
- Required fields marked with * must to filled

Return form to AuSCR Office via

- Fax: (03) 8888 4990

Or

- Post: AuSCR, Public Health, Florey Neuroscience Institutes, 245 Burgundy Street, Heidelberg, VIC, 3084

Hospital Name: ROYAL JOHNS HOSPITAL: HEAVENSVILLE (RJHH)

B009085
BLOGGS, OSCAR M
12 Registry Street
Heavensville
2150
M-
DOB 12/12/1921

Patient Information

Title: MR

First Name*: OSCAR BLOGGS

JMP 9/8/09

Last Name*: BLOGGS

Address type: ☑ Home ☐ Business ☐ Other SEE PATIENT STICKER

Street Address:

Suburb:

Post Code: State* NSW

Phone Number* 0291811234 Mobile Number 0765865[illegible]

Medicare No. 1234567891 Hospital MRN B009085

Date of Birth: /__/__/____ (dd/mm/yyyy) Gender ☐ Male ☐ Female

Country of birth: AUSTRALIA

Language spoken: ENGLISH

Interpreter needed ☐ Yes ☑ No

Is the patient of Aboriginal and/or Torres Strait Islander origin?*

- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☑ Neither Aboriginal nor Torres Strait Islander origin

created 19 June 2009

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OSCAR BLOGGS DOB 12/12/21 RJHH

Emergency Contact

First Name: MARY

Last Name: CREAM

Address type: ☑ Home ☐ Business ☐ Other SEE PATIENT STICKER

Street Address:

Suburb:

Post Code: State: NSW

Phone Number: Mobile Number:

Relationship to participant: SPOUSE

Alternate Contact

First Name: JOSEPH

Last Name: BLOGGS

Address type: ☑ Home ☐ Business ☐ Other

Street Address: 20 FREDDIE STREET

Suburb: HEAVENSVILLE

Post Code: 2150 State: NSW

Phone Number: 0298156788 Mobile Number: 0766666

Relationship to participant: SON

General Practitioner

First Name: JOHN

Last Name: SMITH

Street Address: 50 RED STREET

Suburb: COLOURSVILLE

Post Code: 2151 State: NSW

created 19 June 2009

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GP Telephone Number ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Mobile Number ☐☐☐☐☐☐☐☐☐☐

Admission Information

Date of arrival at Emergency Department* 09/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of arrival at Emergency Department* 09:45 (24-hour clock) Estimated time: ☐

Date of stroke onset* 09 09/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of stroke onset* 02:00 (24-hour clock) Estimated time: ☑

Date of admission* 09/08/2009 (dd/mm/yyyy)

Was the patient transferred from another hospital?*	☐ Yes	☑ No	☐ Unknown
Did this stroke occur while the patient was in hospital?*	☐ Yes	☑ No	☐ Unknown
Able to walk independently on admission?* (i.e. may include walking aid, but without assistance from another person)	☐ Yes	☑ No	☐ Unknown
Is there documented evidence of a previous stroke? (i.e. focal neurological signs persisting for more than 24 hours)	☐ Yes	☑ No	☐ Unknown

Clinical Information

Was the patient treated in a Stroke Unit at any time during their stay?* ☐ Yes ☐ No ☐ Unknown

Type of stroke* ☐ TIA ☑ Ischaemic ☐ Haemorrhagic ☐ Undetermined

If an ischaemic stroke, did the patient receive intravenous thrombolysis (tPA) ☐ Yes ☐ No ☐ Unknown

Cause of stroke * ☐ Known ☐ Unknown

ICD10 code – Diagnosis ☐☐☐☐☐

Separation (Discharge) Information

Patient Deceased ☐ No ☐ Yes, date of death: ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) Estimated date: ☐

Discharged Alive

a) Date of discharge* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) Estimated date: ☐

b) Discharge destination/mode*

- ☐ Hospital
- ☐ ~~Rehabilitation (Inpatient)~~
- ☐ Low level Residential Care
- ☐ High level Residential Care
- ☐ Other: _____
- ☐ Home with support
- ☐ Home without support
- ☐ Transitional care services
- ☐ Died in hospital

c) Discharged with antihypertensive agents* ☐ Yes ☐ No ☐ Unknown

d) Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?* ☐ Yes ☐ No ☐ Not applicable ☐ Unknown

Form completed by: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Date: ☐☐/☐☐/☐☐☐☐ Contact Number ☐☐☐☐☐☐☐☐☐☐

created 19 June 2009

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Attachment 3b – Example of Poorly Completed Acute Data Collection Form

Incorrectly completed Data Collection Form

DATA COLLECTION FORM

AuSCR
Australian Stroke Clinical Registry

Please complete the form:

- Neatly and legibly
- Write in **black ink** and press firmly
- Each question must be completed;
- Place ☑ in appropriate boxes.
- Required fields marked with * must to filled

Return form to AuSCR Office via

- Fax: (03) 8888 4990

Or

- Post: AuSCR, Public Health, Florey Neuroscience Institutes, 245 Burgundy Street, Heidelberg, VIC, 3084
- Post: AuSCR Office, C/O TGHT O Box M201, Missenden Road, Camperdown, NSW 2050.

Hospital Name:

B009085
BLOGGS, OSCAR M
12 Registry Street
Heavensville
2150
M-
DOB 12/12/1921

Patient Information

Title MR

First Name* OSCAR BLOGGS

Last Name* BLOGGS

Address type ☐ Home ☐ Business ☐ Other

Street Address

Suburb

Post Code

State*

Phone Number*

Mobile Number

Medicare No.

Hospital MRN

Date of Birth (dd/mm/yyyy)

Gender ☐ Male ☐ Female

Country of birth AUSTRALIA

Language spoken ENGLISH

Interpreter needed ☑ Yes ☑ No

Is the patient of Aboriginal and/or Torres Strait Islander origin?*

- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☑ Neither Aboriginal nor Torres Strait Islander origin

Emergency Contact

First Name MARY

Last Name CREAM

Address type ☐ Home ☐ Business ☐ Other

Street Address

Suburb

Post Code State

Phone Number Mobile Number

Relationship to participant SPOUSE

Alternate Contact

First Name

Last Name

Address type ☐ Home ☐ Business ☐ Other

Street Address

Suburb

Post Code State

Phone Number Mobile Number

Relationship to participant

General Practitioner

First Name NIL

Last Name

Street Address

Suburb

Post Code State

created 19 June 2009

GP Telephone Number ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Mobile Number ☐☐☐☐☐☐☐☐☐☐

Admission Information

Date of arrival at Emergency Department* 09/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of arrival at Emergency Department* 09:45 (24-hour clock) Estimated time: ☐

Date of stroke onset* 09 09/08/2009 (dd/mm/yyyy) Estimated date: ☐

Time of stroke onset* 02:00 (24-hour clock) Estimated time: ☑

Date of admission* 09/08/2009 (dd/mm/yyyy)

Was the patient transferred from another hospital?* ☐ Yes ☑ No ☐ Unknown

Did this stroke occur while the patient was in hospital?* ☐ Yes ☑ No ☐ Unknown

Able to walk independently on admission?*
(i.e. may include walking aid, but without assistance from another person) ☐ Yes ☑ No ☐ Unknown

Is there documented evidence of a previous stroke?
(i.e. focal neurological signs persisting for more than 24 hours) ☐ Yes ☑ No ☐ Unknown

Clinical Information

Was the patient treated in a Stroke Unit at any time during their stay?* ☐ Yes ☐ No ☐ Unknown

Type of stroke* ☐ TIA ☑ Ischaemic ☐ Haemorrhagic ☐ Undetermined

If an ischaemic stroke, did the patient receive intravenous thrombolysis (tPA) ☐ Yes ☐ No ☐ Unknown

Cause of stroke * ☐ Known ☐ Unknown

ICD10 code – Diagnosis ☐☐☐☐☐

Separation (Discharge) Information

Patient Deceased ☐ No ☐ Yes, date of death: ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) Estimated date: ☐

Discharged Alive

a) Date of discharge* ☐☐/☐☐/☐☐☐☐ (dd/mm/yyyy) Estimated date: ☐

b) Discharge destination/mode*

- ☐ Hospital
- ☐ ~~Rehabilitation (Inpatient)~~
- ☐ Low level Residential Care
- ☐ High level Residential Care
- ☐ Other: _____
- ☐ Home with support
- ☐ Home without support
- ☐ Transitional care services
- ☐ Died in hospital

c) Discharged with antihypertensive agents* ☐ Yes ☐ No ☐ Unknown

d) Is there evidence that a care plan outlining post discharge care in the community was developed with the team and the patient and/or family (if patient has severe aphasia or cognitive impairments)?* ☐ Yes ☐ No ☐ Not applicable ☐ Unknown

Form completed by: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Date: ☐☐/☐☐/☐☐☐☐ Contact Number ☐☐☐☐☐☐☐☐☐☐

created 19 June 2009

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Attachment 4 – Data Dictionary provided to your Hospital

The data dictionary is also available on the AuSCR website at:
http://www.auscr.com.au/health-professionals/forms-manuals/data-dictionaries/

Attachment 5 – Example of User Request Form

Australian Stroke Clinical Registry

AuSCR Online Tool
User Request Form

Please complete this form to obtain a user ID and password to be able to log in to the AuSCR Online Tool.

* required field

Title _____ **Name*** _____

Position _____

Hospital* _____

Email* _____ **Phone*** _____

Signature _____

Access Request for *
(Tick appropriate box)

☐ Hospital Administrator ☐ Hospital User ☐ Follow- up User

Please note that this request must be authorised by the AuSCR:

- Project Coordinator for Hospital Administrator and Follow- up User Request
- Hospital Administrator for Hospital User Request

Authorised by* _____ Title _____

Email* _____ Phone _____

Please return this form by fax or email. If you have any questions, please do not hesitate to contact us.

Project Coordinator
Australian Clinical Stroke Register
(AuSCR)
Public Health - Stroke Division
245 Burgundy Street
Heidelberg VIC 3084

Email: admin@auscr.com.au
Telephone: (03) 9035 7264
Fax: (03) 8888 4990

Office Use Only

Date received _____ *Date created* _____ *User name* _____ *Password assigned* _____

User Request Form (12 Sep 2012) v5.doc

Attachment 6 - Example of Patient Contact Letter Post-Discharge

HOSPITAL LETTERHEAD

AuSCR
Australian Stroke Clinical Registry

[*Date*]

Dear [*NAME*]

We wish to inform you that your hospital [*hospital name*] is participating in the Australian Stroke Clinical Registry (AuSCR), which is a national stroke register to collect important information about what happens to people who have had a stroke or a 'mini-stroke', called a transient ischaemic attack or TIA. The Stroke Registry (AuSCR) collects information from hospitals about patients with different types of stroke, the medical treatments patients receive, complications that occur while in hospital and discharge arrangements e.g. access to rehabilitation. Because we missed you (or your family member),during the recent admission to the hospital with a stroke we are writing to inform you that information about your recent hospital stay and stroke will be included in this national database, as well as your contact details.

People whose information is stored in the Stroke Registry (AuSCR) are contacted by telephone or mail between 3 to 6 months after their stroke to assess the degree of recovery from stroke and any ongoing or new health problems you may have. Information about what happens to people after they leave hospital is important since it will allow health professionals, such as doctors to improve the care that patients with stroke receive while in hospital. If you are unable to answer these follow-up questions yourself, it is possible to have family members answer these on your behalf.

We have enclosed a copy of the **AuSCR Patient Information Sheet**, which we hope you will take the time to read. In brief, the Stroke Registry is a national initiative that is supported by the National Stroke Foundation and the Stroke Society of Australasia. It has been approved by the Human Research Ethics Committee at [*local hospital*]. The Stroke Registry database has been specially designed to ensure that your privacy is maintained. All information about you and your stroke is treated as strictly confidential. Neither your identity or personal details will be revealed in any publications or made available to outside organisations.

Participation is voluntary and to take part in the Stroke Registry you do not have to do anything, the hospital will automatically enter details about your stroke into the database. If you would prefer to have some or all of your details removed from the database, please carefully read the Information Sheet and then contact the AuSCR Project Office and let them know what information you would like to have removed. It is possible to remove only some of your information such as name and address, and keep information about your stroke and your hospital treatment in the database. It is also possible to request that you are not contacted again (that is, at 3-6 months after your stroke) and to still keep important medical details about your stroke provided by the hospital into the database.

If you wish to contact the AuSCR Project Office about removing some or all of your information from the Stroke Registry by telephone on 1800 673 053, email admin@auscr.com.au, or by mailing the enclosed opt-out form to:
AuSCR Project Office,
Public Health, Stroke Division, Melbourne Brain Centre
245 Burgundy Street, Heidelberg, VIC 3084

To speak with your treating doctor about the importance of the Stroke Registry, please contact [HOSPITAL CONTACT NAME] on [HOSPITAL TELEPHONE NUMBER].

Yours faithfully,

D. Cadilhac

[SIGNATURE]
[Name of Patient's Primary/Treating Physician]
[*Title*]
[*Name of Hospital*]

Assoc Prof Dominique Cadilhac
AuSCR Principal Investigator

Enc. Patient Information sheet & Opt-out form

Qld- AuSCR Qld-PatientContactLetterPost-Discharge-Version5-1-28October2013-Clean.doc