

User Manual for Data Entry Staff

Brains for Dementia Research Comprehensive Assessment
Database (BDR-CAD) V2



BRAINS FOR DEMENTIA RESEARCH

Increasing knowledge - Finding a cure

A partnership between Alzheimer's Research UK and Alzheimer's Society

About this manual

The user guide has been designed as an introduction to the Brains for Dementia Research Comprehensive Assessment Database (BDR-CAD) for data entry staff. It will provide you with some basic step-by-step guidelines, to allow you to start navigating the database and entering your assessment data.

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Chapter 1: Registration

The first step towards using the database is registering for a user account and grid card (see example below).

In order to register a new user, the database manager at each site will need to email the database manager and provide the full name, email address and BDR site of the new user.

The new user will then receive two separate emails detailing their database username, grid card number and temporary password. It is recommended that you change your temporary password after successfully logging into the database for the first time.

Example grid card:

Serial No: 000000000001							
	1	2	3	4	5	6	7
A	0909	0222	1111	9876	0001	4532	8762
B	0987	1223	1234	5432	5678	7171	8181
C	0927	8973	7324	2332	7654	4444	4543
D	3234	8732	2398	2356	0002	8907	3452
E	0003	1216	1298	1908	9061	0195	2615
F	5432	1112	2212	3030	4986	2345	6523
G	8005	4542	8763	1239	7610	0174	7304

Each grid card is unique and linked to a specific user account, so every user needs to register for their own account in order to be able to access the database. Please let the database manager know if there aren't any spare grid cards on site, as the database coordinating centre will then need to post an assigned grid card to the new user.

Please see [appendix 2](#) for more information on the BDR-CAD system's security and access provisions.

Chapter 2: Logging in




Once you have your username, temporary password and grid card you will be able to log in to

Brains for Dementia Research Clinical Database

Home

Login

[Change password](#)

Language:

Research Centre:

User Name:

User password:

Enter Grid Code F1:

To login:

1. Enter your username and password
2. Enter the 4 digit grid card number indicated by the letter/number code
3. Click **accept**

Note: Language only has one option "English". Research Centre should be set to your centre, even though it could be inferred from your user name.

If all the login details are correct, you will be redirected to your site's database homepage. This will have your site's name and logo displayed at the top of the page. If your details are not accepted, or you are redirected to the wrong homepage, please inform your database manager.

At the top of the login page there is a link which enables you to change your password. It is recommended that you change your temporary password after successfully logging into the database for the first time.

Chapter 3: Database Navigation

From the site homepage you can access all parts of the database using the four tabs along the top left-hand side of the page.



What are the functions of these tabs?

Home – takes you directly back to the site homepage from anywhere on the database.

Form entry – where you can search for any of the assessments already entered into the database (whether saved in the hold or committed to the database) as well as add new assessments or participants

Reports – where you can view reports on the data stored

Services—Only administrators can see this tab. It's where users get managed.

Contact – where you can find all the relevant contact information details for database support.

To sign out of the database you just need to close all of the open database windows. There is currently no "log out" button. Once all of the windows are closed, you will have to input all your account login information again to access the database.

Chapter 4: Adding a new participant/first assessment

The following guidelines are for when you need to add a new participant i.e. someone who has no data currently stored on the database.

If you need to add a new assessment to an existing participant please see [chapter 5](#). To check whether a BDR ID already exists on the database, you can use the search function (please see [chapter 5](#) steps 1-5 for guidelines on searching for a specific BDR ID code).

Adding a new participant with no assessments:

To add a new participant, you first have to search for an existing one.

1. Click on the **Form entry** tab at the top of the database homepage.
2. Click on the **Search subject** menu item
3. Optionally, type some random text into the search box so the search will complete in a reasonable time.
4. Click on **Get search results**
5. Buttons should appear labelled **New participant** and **New participant-First assessment**. If you don't have an assessment, click **New participant** . A new tab should open.
6. Fill in the recruitment details.
7. Click on Participant details on the menu on the left
8. Fill in the participant details, and click **End**

Front

Recruitment details	CAD participant ID	
Participant details	*Consent date (current)	<input type="text"/>
	Consent given by	<input type="text"/>
	*Current Participant EDR site ID	<input type="text"/>
	Current centre ID	<input type="text"/>
	INFORMATION	
	Transfer information	<input type="text"/>
	*Participant gender	<input type="text"/>
	*Participant date of birth	<input type="text"/>
	Participant ethnicity	<input type="text"/>
	*Participant postcode (area and district e.g. BS10)	<input type="text"/>
	Next	

Adding a new participant/first assessment continued

Adding a new participant with assessments:

1. Click on the **Form entry** tab at the top of the database homepage.
2. Click on the **Search subject** menu item
3. Optionally, type some random text into the search box so the search will complete in a reasonable time.
4. Click on **Get search results**
5. Buttons should appear labelled **New participant** and **New participant-First assessment**. If you have an assessment, click **New participant-First assessment**. A new tab should open.
6. Fill in the recruitment details.
7. Click on Participant details on the menu on the left
8. Fill in the participant details
9. Fill in the assessment details.
10. Click on **Save to hold**. **If you don't save it to the hold, the data will be lost.**

It is recommended that you enter the assessments onto the database in chronological order. This way the database can correctly use previous assessment information to pre-populate some areas of the next assessment and to cross-check new data entered.

Chapter 5: Adding the next assessment to an existing participant

The following guidelines are for when you need to add an existing participant's next assessment i.e. they already have at least one assessment currently stored on the database.

If you need to add a new participant (first assessment) please see [chapter 4](#). If you need to edit an existing assessment please see [chapter 7](#).

Adding the next Case assessment:

1. Click on the **Form entry** tab at the top of the database homepage.
2. In the green "Search Participant in Database" table, select BDR code from the first dropdown menu.

The screenshot shows the top navigation bar with tabs: Home, Form Entry, Reports, Services, Contact. Below is a search section with a table titled "Search Participant in Database". The table has a search input field, a dropdown menu with "BDR code" selected, an "=" operator dropdown, and a "GET SEARCH RESULTS" button. On the left, there are links for "Search Subject" and "Form Hold Records".

3. Leave the "=" preselected in the next dropdown menu box.
4. Type the participant's full BDR ID code in the 3rd box.
5. Click on the green **Get Search Results** button to the right of the page.
6. Click on the corresponding **Get assessments** hyperlink. This will take you to a page detailing all the assessments currently available for that participant.
7. Click **Existing participant—New Assessment**

The screenshot shows the search results page. The navigation bar is the same. The search table now shows "Subject: BDR code" with the value "L-01110" and "Birth Date". Below the table is a section titled "Hold Area assessments for the participant" with a table showing "Hold Area Entry Date" and "Assessment Date", both with up/down arrows. Below this table, it says "No records found". At the bottom, there is a yellow button labeled "Existing Participant - New Assessment".

Adding the next assessment to an existing participant continued

8. Enter all data for the assessment (see [chapter 6](#) for instructions on how to navigate around the assessment). Some fields will be pre-populated using information from the previous assessment, but this can be edited if needed.
9. Once you have finished entering the data, click on the **Save to hold** link on the right hand side of the page.
10. A blue line of text will appear at the top of the page saying: “The form has been successfully submitted to Hold Area”. You can now close the assessment window.

Remember to always click **Save to hold** before closing the assessment window, otherwise any data entered on the page will not be saved and will be lost. If you try to close the assessment window before saving to the hold, the database will prompt you to choose whether you would like to leave or stay on the page.

Keep an eye out for a red error notification at the bottom of the page when saving to the hold, as this may mean that the assessment could not be saved due to data errors. If you close the page anyway the assessment will not be saved and so any data entered will be lost.

Chapter 6: Assessment Navigation

On the creation of any assessment (new or next), an assessment window will open in your internet browser. You can navigate around the assessment using the tabs along the top, and down the left hand side, of each page.

The top tabs allow you to move between different sections (or questionnaires) of the assessment e.g. CAMDEX, NPI, BADLS etc.

The tabs on the left hand side of the page then allow you to move around within the selected section/ questionnaire.

You can move through the assessment by clicking on the green **next** button at the bottom of each page, or by selecting the tab (top or side) you would like to move to.

It is recommended that you use the **next** button to proceed as much as possible during data entry. This allows the database to automatically check for and flag up any missing or incorrect data on that page before moving on.

The order of the online assessment has been designed to correspond with the paper source worksheets as much as possible.

Assessment Navigation continued

If at any point you need to save the assessment, click on the ***save to hold*** link which is always situated in the top right hand corner of the page. A blue line of text will appear at the top of the page saying: “The form has been successfully submitted to Hold Area”.

If you do try to close the assessment window before saving, the database will prompt you to choose whether you actually want to leave or stay on the page. If you do choose to leave the page at this point (without saving to the hold) any new data entered on that assessment will be lost.

Keep an eye out for a red error notification at the bottom of the page when saving to the hold, as this may mean that the assessment could not be saved due to data errors. If you close the page anyway the assessment will not be saved and so any data entered will be lost.

Chapter 7: Editing a saved assessment

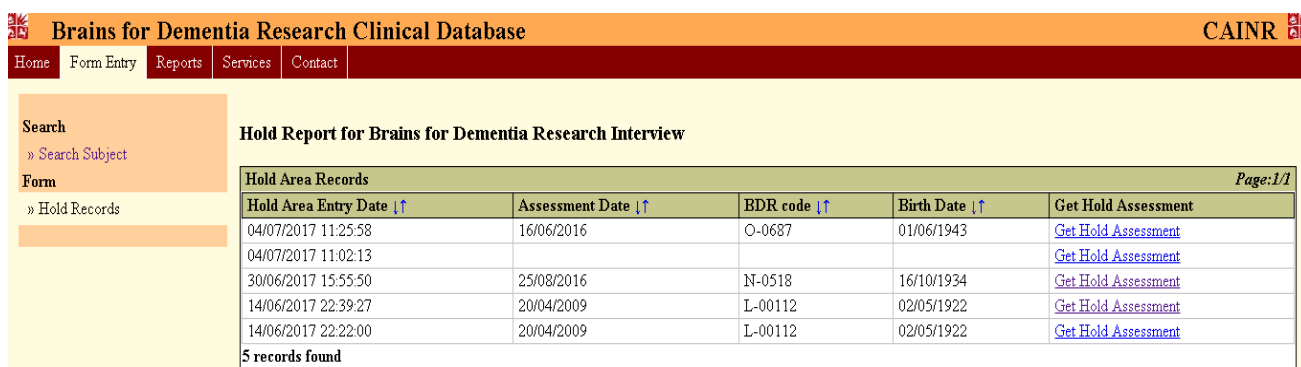
There may come a time when you will need to go back and edit some information on an existing assessment, be it completing an unfinished assessment or correcting an error. Therefore you will need to be able to find and re-open saved assessments. There are two places where an assessment can be saved on the database:

The hold – where an assessment is saved awaiting quality checks by the database manager who will then commit it to the database. Assessments saved to the hold are not yet available for data analysis or reporting.

Committed to the database – where assessments are moved to once approved by the database manager. Assessments committed to the database are now part of the site's dataset and so are available for use in analysis and reporting.

Editing an assessment saved to the hold:

1. Select the **Form entry** top tab
2. Click on the **Hold records** link on the left hand side of the page—this will bring up a list of every assessment currently stored in the hold.



Brains for Dementia Research Clinical Database CAINR

Home Form Entry Reports Services Contact

Search
» Search Subject

Form
» Hold Records

Hold Report for Brains for Dementia Research Interview

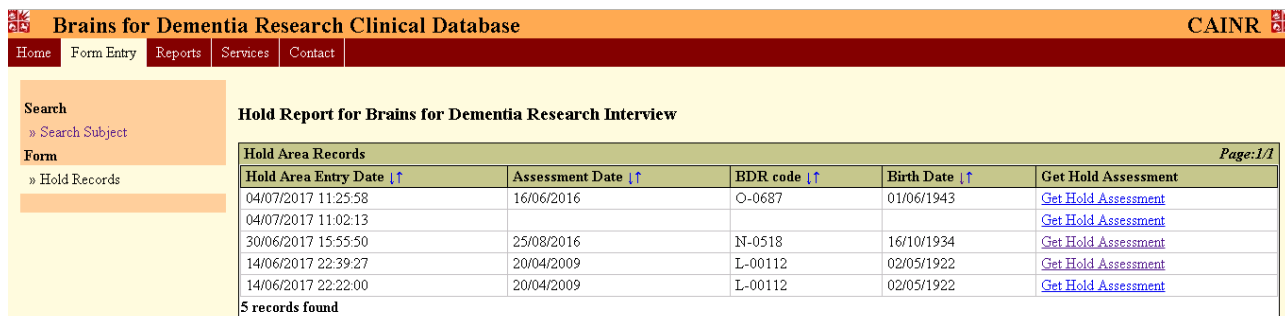
Hold Area Entry Date ↑↓	Assessment Date ↑↓	BDR code ↑↓	Birth Date ↑↓	Get Hold Assessment
04/07/2017 11:25:58	16/06/2016	O-0687	01/06/1943	Get Hold Assessment
04/07/2017 11:02:13				Get Hold Assessment
30/06/2017 15:55:50	25/08/2016	N-0518	16/10/1934	Get Hold Assessment
14/06/2017 22:39:27	20/04/2009	L-00112	02/05/1922	Get Hold Assessment
14/06/2017 22:22:00	20/04/2009	L-00112	02/05/1922	Get Hold Assessment

5 records found Page: 1/1

N.B. You can rearrange the order of the records by hold area entry date, assessment date, BDR code or birth date to make searching for a specific record easier. Just click on one of the arrows next to the field name you want to order them by.

Editing a saved assessment continued

- Once you have identified the assessment you want to edit, click on the corresponding **Get Hold Assessment** link to re-open the assessment in a new window.



The screenshot shows the 'Brains for Dementia Research Clinical Database' interface. The top navigation bar includes 'Home', 'Form Entry', 'Reports', 'Services', and 'Contact'. The 'Form Entry' tab is active. On the left, there is a 'Search' section with 'Search Subject' and 'Form' options, and a 'Hold Records' link. The main content area is titled 'Hold Report for Brains for Dementia Research Interview'. It displays a table of 'Hold Area Records' with columns for 'Hold Area Entry Date', 'Assessment Date', 'BDR code', 'Birth Date', and 'Get Hold Assessment'. There are 5 records listed, each with a 'Get Hold Assessment' link. The page number is 'Page: 1/1'.

Hold Area Entry Date	Assessment Date	BDR code	Birth Date	Get Hold Assessment
04/07/2017 11:25:58	16/06/2016	O-0687	01/06/1943	Get Hold Assessment
04/07/2017 11:02:13				Get Hold Assessment
30/06/2017 15:55:50	25/08/2016	N-0518	16/10/1934	Get Hold Assessment
14/06/2017 22:39:27	20/04/2009	L-00112	02/05/1922	Get Hold Assessment
14/06/2017 22:22:00	20/04/2009	L-00112	02/05/1922	Get Hold Assessment

5 records found

- Make the required edits to the assessment data (see **Chapter 6** for guidelines on how to navigate quickly and easily around an assessment).
- Once you've finished editing the assessment, remember to click on the **Save to hold** link situated in the top right hand corner of the page, otherwise all your changes will be lost.
- A blue line of text will appear at the top of the page saying: "The form has been successfully submitted to Hold Area". You can now close the assessment window.

Keep an eye out for a red error notification at the bottom of the page when saving to the hold, as this may mean that the assessment could not be saved due to data errors. If you close the page anyway the assessment will not be saved and so any data entered will be lost.

Editing an assessment committed to the database:

- Select **Form entry** tab
- Click on the **Search subject**
- Select **BDR Code** in the search drop-down, and enter the bdr-code of the participant in the search box. Click **Get search results**.
- Identify the BDR code of the participant who's assessment you want to edit and click on the corresponding **Get assessments** hyperlink—this will take you to a page detailing all of the available assessments for that participant.
- If the assessment you want to edit is listed, click on the corresponding **Get Assessment** link to re-open the assessment in a new window.
- Follow steps 5-7 from the "Editing an assessment saved to the hold" guidelines above.

Chapter 8: Frequently Asked Questions

1. Where do I find a medication's BDR drug number if it isn't recorded in the source worksheets?

Please refer to the drug code table on [page 17 and 18](#) to identify the BDR drug code by BNF drug code or drug description.

If you do not know which category the drug in question falls into (and don't know the BNF code) it may be useful to register for a Medicines Complete account (www.medicinescomplete.com). This website will be able to provide you with the BNF code for any drug that you search for by generic drug name (not the brand). You can then search for the BDR drug code using this BNF code.

2. What should I do if any other information is missing from the source worksheets?

Some fields e.g. BDR code and visit number are mandatory. This means that the database will flag up if this information is missing and not allow you to move onto the next page without entering the data. You can override this function if needed by clicking on the tab that you want to move to at the top or side of the page. However the assessment will not be able to be committed to the database with this information missing. Mandatory information should be recorded by your site, so ask your site's database manager where to find this.

Some fields are not mandatory so you can save the assessment with this data missing. However, a full data set is preferable. Keep in mind that some information may have already been recorded elsewhere in the assessment or on a previous assessment. For example missing CDR orientation scores can be obtained from the MMSE/MoCA questionnaires.

Please be aware that some of the questionnaires included in the assessments have changed over time. Therefore some of the information asked for on the database will not be recorded in every assessment pack, and so can be left blank.

3. What should I do if a questionnaire score calculated by the database doesn't match the score on the source worksheets?

Firstly check that you have input the answers to the questionnaire exactly as found in the source worksheets, and then recalculate the score.

If there is still a discrepancy, leave the database calculated score as it is and make a note in the source worksheets of the update. Remember to initial and date this source note for data audits. Some sites may wish for data entry staff to keep track of any discrepancies found, but this will be organised locally so please contact your site's database manager if you have any queries.

Remember that the MMSE and CDR orientation questions are scored opposingly (i.e. 1 on the MMSE = correct, but 1 on the CDR = incorrect).

Frequently Asked Questions continued

4. Why do I keep getting an error for the Hachinski Ischaemic score even though it matches the source worksheet?

A participant's Hachinski Ischaemic Scale score cannot decrease across assessments. Thus, if you are completing a "next" assessment, check what the participant scored previously. If they scored higher on their most recent previous assessment, make a note in the newer source worksheets of the discrepancy and update the database with the correct (higher) score. Remember to initial and date this source note for data audits. Some sites may wish for data entry staff to keep track of any discrepancies found, but this will be organised locally so please contact your site's database manager if you have any queries.

If you are getting an error message, but the participant's current score is greater than, or equal to, their most recent previous score, please inform your site's database manager.

5. How do I know whether or not to add a point for education if it's not recorded on the MoCA?

An extra 'education' point is given on the MoCA questionnaire to anyone who has achieved 12 years of education or less. To find out the number of years of full-time education a participant has achieved, refer back to the demographics of the subject (found under **Demographics** when you click on the **Subj Inf Details** top tab).

If the participant has achieved more than 12 years of education, you will need to type '0' in the education box on the MoCA. If the box is left blank the database will flag up missing data and not allow you to progress from the page.

6. There are many handwritten notes around the edge of the source worksheets, should I record this information?

If it is possible to record this information in a text box on the corresponding assessment page on the database, then feel free to add the information in here.

However, if there is no text box available for that section of the assessment, then there is a large text box at the end of the assessment under the **Case Notes** or **Control Notes** top tab. You may record any useful notes here from the entire assessment, and it's suggested that you log anything that helps to explain the participant's performance on the assessment.

It is recommended that you leave out any personally identifiable information (e.g. names) when recording these notes on the database.

Frequently Asked Questions continued

7. Should I record the Cornell responses under Subj Cornell or Inf Cornell?

The Cornell questionnaire should only be completed with the informant. Therefore you should record this information under Inf Cornell (unless it is specified on the assessment that the Cornell was completed with the participant).

8. Can I scan and upload assessment pages onto the database?

Yes, there are 5 places on each assessment where you can upload specific scanned pages:

1. Genogram
2. MMSE (written sentence)
3. MMSE (pentagon drawing)
4. MoCA (clock drawing)
5. Case notes/Control notes (most useful to store an online copy of the BDR communication sheet, but can be used for other notes if preferred).

Only one upload is permitted per space, so if you upload a new page this will overwrite any existing upload in that box.

It is recommended that you use a standard naming format to save, and distinguish between, each of your scanned pages.

An example format is: BDR(BDR code)_questionnaire name_assessment year.jpg

Remember that for MMSE you will need to be able to differentiate between the scanned page containing the written sentence and the one containing the pentagon drawing. Therefore for scans of the MMSE you will need to include the question number in the file name too e.g. BDR(B000)_MMSE17_2014.

As with the assessment notes, it is recommended that any personally identifiable information (e.g. names) is left off, or edited out of, the scanned pages before they are uploaded onto the database.

Appendix 1: BDR Drugs Codes

BDR Code	BNF code / Drug description	BDR Code	BNF code / Drug description
0	Not Asked	36	7.3 Contraceptives
1	13 For skin conditions	37	7.2 For vaginal/vulval cns
2	12 For the ENT	38	7.1 Drugs for obstetrics
3	11 For the eye	39	6.7 Other endocrine drugs
4	10.3 Drugs-soft-tissue inflm	40	6.6 For bone metabolism
5	10.2 Drugs-neuromusclr dis	41	6.5 Hypothalamic/ptry hrms
6	10.1.4 Drugs for gout	42	6.4.3 Anabolic steroids
7	10.1.3 rheumatic disease drgs	43	6.4.2.2 Male sex hormone antgs
8	10.1.2 Corticosteroids	44	6.4.2.1 Male sex hormones
9	10.1.1 Non-strdal anti-inflms	45	6.4.1.2 Progestogens
10	9.8 Metabolic disorders	46	6.4.1.1 Oestrogens and HRT
11	9.7 Bitters and tonics	47	6.4 Sex hormones(unspec)
12	9.6.7 Multi-vitamins	48	6.3.2 Glucocorticoid therapy
13	9.6.6 Vitamin K	49	6.3.1 Replcmnt corticosterds
14	9.6.5 Vitamin E	50	6.2.2 Antithyroid drugs
15	9.6.4 Vitamin D	51	6.2.1 Thyroid hormones
16	9.6.3 Vitamin C	52	6.1.6 Diabetes diag/monitors
17	9.6.2 Vitamin B group	53	6.1.5 For diabetic nephropthy
18	9.6.1 Vitamin A	54	6.1.4 For hypoglycaemia
19	9.5 Minerals	55	6.1.3 Diabetic ketoacidosis
20	9.4 Oral nutrition	56	6.1.2.3 More oral anti-diabtcs
21	9.3 Intravenous nutrition	57	6.1.2.2 Biguanides
22	9.2 Fluids/electrolytes	58	6.1.2.1 Sulphonylureas
23	9.1 Anaemias/blood disrdrs	59	6.1.1 Insulins
24	8.3.4 Hormone antagonists	60	5 For infections
25	8.3.3 Androgens	61	4.11.6 Dementia - Memantine
26	8.3.2 Progestogens	62	4.11.5 Dementia - Tacrine
27	8.3.1 Oestrogens	63	4.11.4 Dementia-gingko biloba
28	8.2.5 Aldsleukin	64	4.11.3 Dementia-galantamine
29	8.2.4 Interferons	65	4.11.2 Dementia-rivastigmine
30	8.2.3 Rituximab	66	4.11.1 Dementia-donepezil (Aricept)
31	8.2.2 Corticosteroids/immmps	67	4.10 For substance depndnce
32	8.2.1 Cytotoxic immunosups	68	4.9.3 For tremors- etc
33	8.1 Cytotoxic drugs	69	4.9.2 Antimuscarinic (prknsnm)
34	7.5 Appl urinary disrdrs	70	4.9.1 Dopaminergic (prknsnm)
35	7.4 Drugs genito-urinary	71	4.8 Antiepileptics

Appendix 1: BDR Drugs Codes continued

BDR Code	BNF code / Drug description	BDR Code	BNF code / Drug description
72	4.7.4.2 Prophylaxis of migraine	106	2.5.7 Tyrosine hydroxylase inh
73	4.7.4.1 For acute migraine	107	2.5.6 Ganglion blocking drugs
74	4.7.3 Neuropathic pain	108	2.5.5.2 Angiotensin-11 antagonists
75	4.7.2 Opioid analgesics	109	2.5.5.1 Angiotensin-converting inhibitors
76	4.7.1 Non-opioid analgesics	110	2.5.4 Alpha-adrenoreceptor blockers
77	4.6 Drugs for nausea/vomiting	111	2.5.3 Adrenergic neurone blockers
78	4.5 Drugs used for obesity	112	2.5.2 Central antihypertensive
79	4.4 CNS stimulants	113	2.5.1 Vasodilator anti-hypertensive
80	4.3 Antidepressants	114	2.4 Beta-adrenoreceptor blockers
81	4.2.3 Antimanic drugs	115	2.3 Anti-arrhythmic drugs
82	4.2.2 Antipsychotic depot injection	116	2.2 Diuretics
83	4.2.1 Antipsychotic drugs	117	2.1 Positive inotropic
84	4.1.3 Barbiturates	118	1.9 Intestinal secretion
85	4.1.2 Anxiolytics	119	1.8 Stoma care
86	4.1.1 Hypnotics	120	1.7 Local prep rectal
87	3.10 Systemic nasal decongestants	121	1.6 Laxatives
88	3.9 Cough preparations	122	1.5 Chronic diarrhoea treatment
89	3.8 Aromatic inhalations	123	1.4 Antidiarrhoeal drugs
90	3.7 Mucolytics	124	1.3 Ulcer-healing drugs
91	3.6 Oxygen	125	1.2 Antispasmodics
92	3.5 Respiratory stimulants	126	1.1 Antacids
93	3.4 Antihistamines etc	127	0.3 Folic acid
94	3.3 Cromoglycate...antagonists	128	0.2 Vitamin/mineral supplement
95	3.2 Corticosteroids	129	0.1 Aspirin
96	3.1 Bronchodilators		
97	2.12 Lipid regulators		
98	2.9 Antiplatelet drugs		
99	2.8 Anticoagulants		
100	2.7 Sympathomimetics		
101	2.6.4.2 Cerebral vasodilators		
102	2.6.4.1 Peripheral vasodilators		
103	2.6.3 Potassium channel activators		
104	2.6.2 Calcium channel blockers		
105	2.6.1 Nitrates		