

South West DeNDRoN Information Assets Procedure

Version	Date	Comments	Composed	Authorised	Status
1.0	22/06/12	Initial draft for comment	MG	MG	Draft
1.1	25/07/12	Amended after comments from Teresa Gudge, IT Security Specialist & Emily Garner, CSO	MG	MG	Draft
1.2	30/07/12	Amended after comments from EG & MG	MG	MG	Draft
1.3	31/07/12	Changes accepted	MG	MG	Draft
1.4	31/07/12	Draft for final revision	MG	MG	Draft
1.5	01/08/12	Changes accepted	MG	MG	Final
2	06/09/12	Revised version after completion of data cleaning exercise.	MG	MG	Final
2.1	12/09/12	Final revision	MG	MG	Final



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1 Purpose of document

To describe the information governance process for the SW DeNDRoN office and the information assets it holds. This plan was instigated from the current work of SW DeNDRoN in developing registers for patients wishing to be contacted about research and from a meeting with Teresa Gudge on 13/06/12 to discuss our information assets.

Further information on information governance can be found on Ourspace:

<http://ourspace/StaffServices/FtoJ/IG/Pages/IGStaffHandbooks.aspx>

2 Scope

This plan covers the information governance process for identifiable data held by SW DeNDRoN in the excel spreadsheet 'SW DeNDRoN Contacts 2012'. This contains the details of those who have requested to:

- be part of the Patient Advisory Panel
- receive the SW DeNDRoN newsletter
- hear of research opportunities

The plan covers the SW DeNDRoN office based in Bristol only.

3 Guiding principles and legislation

AWP works in accordance with the principles of the Data Protection Act 1998. The Data Protection Act 1998 applies to computerised and manually held data, including the Health & Social Care Records of living patients. Almost any type of personal data, and anything that is done with it, is covered by the Act.

SW DeNDRoN are guided by the following principles:

3.1 Caldicott Principles

1. Justify the purpose(s). Is there a justified purpose for using this patient-identifiable information?
2. Don't use patient-identifiable information unless it is absolutely necessary. Staff should consider if they actually need to use the information to do their job.
3. Use the minimum necessary patient-identifiable information. Staff should consider if they really need to see/use all of the information that they have.
4. Access to patient-identifiable information should be on a strict need to know basis. Staff should only view and gain access to information needed to do their job.
5. Everyone with access to patient identifiable information should be aware of their responsibilities.
6. Staff should ensure that they understand and comply with the law whilst handling patient-identifiable data.

3.2 Data Protection Act 1998 Principles

1. Personal information must be fairly and lawfully processed.
2. Personal information must be processed for limited purposes.
3. Personal information must be adequate, relevant and not excessive.
4. Personal information must be accurate and up to date.

5. Personal information must not be kept for longer than necessary.
6. Personal information must be processed in line with the data subjects' rights.
7. Personal information must be kept secure.
8. Personal information must not be transferred to other countries without adequate protection.

4 Declaration on SW DeNDRoN literature

The following declaration appears on SW DeNDRoN patient literature:

“Any personal information submitted by you will be held by DeNDRoN within NHS systems for the purpose of research and development and shall be processed in accordance with the principles of the Data Protection Act 1998 and may be stored for up to 20 years.

If you have expressed an interest in becoming involved in a research study, DeNDRoN will contact you for further details.

We would only share your information with other NHS and non-NHS organisations for your benefit in a secure and appropriate manner.

You have the right to withdraw your information from DeNDRoN at any time.

To discuss what DeNDRoN do with your data please contact Mary Griffin on 0117 3784239.”

5 Access assumptions

Current identifiable information is held on the W drive at W:\SW-DeNDRoN. The following teams have access to this drive:

- SW DeNDRoN
- Research & Development Department
- Mental Health Research Network (MHRN)

6 Consent Requirements

In order to comply with information governance regulations, SW DeNDRoN requires consent, and proof of this consent, in relation to any personal details that are held. In the process of gaining consent, SW DeNDRoN must be explicit about the ways in which personal information is used, stored, accessed and shared.

7 2012 Data Cleaning Exercise

SW DeNDRoN previously held a large spreadsheet containing personal contact details of over 600 individuals. Upon learning of the consent requirements outlined in section 6, it was decided that SW DeNDRoN must undertake a 'data cleaning exercise' to ensure that the individuals whose details were held on the database gave their consent for this, and to retain proof of this consent.

7.1 Contacts database

The contacts “database” is an Excel spreadsheet which had been in place since 2006. It was suggested that a data cleaning exercise should be completed in 2012 and on an annual basis from then on. The data cleaning exercise involved emailing or writing to each individual

contact to explain that their details were currently being stored and to obtain their consent to remain on the database (see Appendices 1 and 2).

Those who responded with such consent were added to a new spreadsheet ('SW DeNDRoN Contacts 2012') and a copy of their consent was stored electronically on the W:\drive (SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents).

The details of those who responded expressing a wish to be removed from the database were not copied across, their correspondence was stored electronically and SW DeNDRoN replied explaining that their details were no longer stored. This correspondence will also be stored electronically as proof that SW DeNDRoN has actioned the request.

Some individuals responded informing SW DeNDRoN of their consent, but requested that they are not contacted on an annual basis to renew this consent. A comment was entered on the spreadsheet documenting this and SW DeNDRoN will await notification from these individuals regarding any changes in consent or personal details.

Other responses, such as out-of-office replies and automatic notifications of maternity leave, are dealt with according to the diagram in section 7.4.

7.2 Patient Advisory Panel

The onus is on members of the Panel to update SW DeNDRoN with their details. Membership of the group is assumed from the details given in the expression of interest, or until SW DeNDRoN are expressly told otherwise, or if the Terms of Reference of the meeting are violated.

After receiving an expression of interest from the enquirer, SW DeNDRoN will send a letter confirming that they are part of the Panel and that their details will be held and used to contact them about the Panel. Any emails sent to the Panel, or to more than one person, using personal emails will be blind carbon copied.

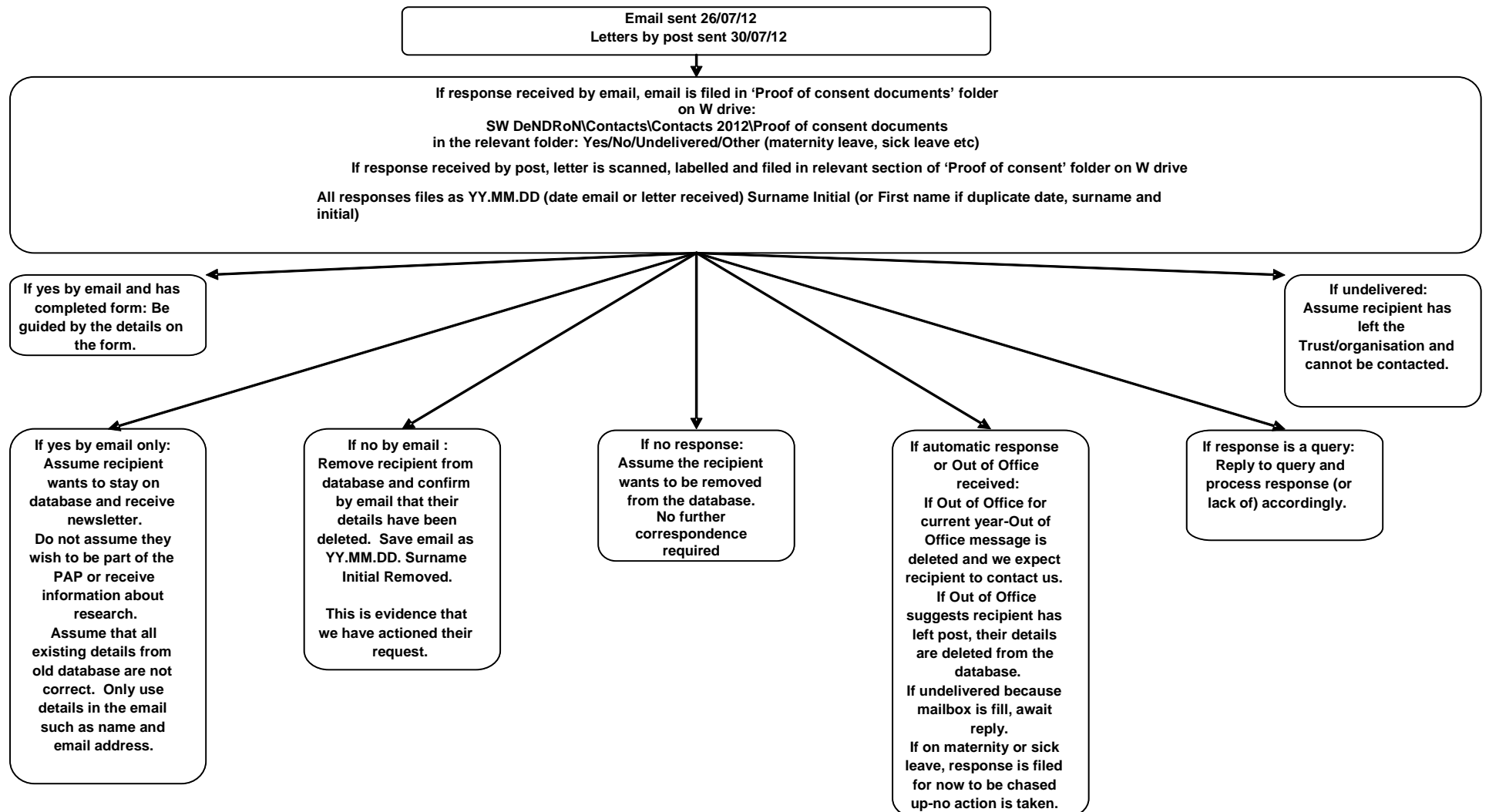
Consent from existing PPI members (AP & JW) will need to be obtained to ensure that they consent for their information to be in the public domain.

7.3 Newsletter recipients

The onus is on recipients of the newsletter to update SW DeNDRoN with their details. Newsletters will be sent out by email or posted (if respondent has specified) to the details held unless expressly told otherwise.

7.4 Process for responses

Please see diagram below for the process:



8 Contact details from INTERACT consultation exercise

The INTERACT 'embedding research in clinical practice' consultation provided respondents with the opportunity to give their contact details and to indicate interest in receiving DeNDRoN news, in being involved in the patient advisory panel and/or in hearing about research opportunities.

Responses were received via a website survey, email, post or face-to-face events over the period May-August 2012. The contact details of those wishing to receive the SW DeNDRoN newsletter, information about the Patient Advisory Panel or opportunities for getting involved in research have been added to the 'SW DeNDRoN Contacts 2012' spreadsheet. The details are clearly marked in the column 'data source' as having been received as a result of the consultation. Proof of consent has been saved electronically as an email, a scan of a paper form or a word document of responses made on Survey Monkey. (Survey monkey responses were copied and pasted into word documents and stored in this format.) All of the proof of consent documents from the consultation process are stored at: W:\SW-DeNDRoN\Projects\Interact Restored\SW2 Embedding research consultation\Consent docs for contact details and can be accessed using the process outlined in section 14.

Any responses received after the close of the consultation period on 31 August will be dealt with as a normal request to register contact details and their forms will be stored in 'SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents\YES from other sources.'

9 Contact details from SW DeNDRoN leaflet response slips

The SW DeNDRoN patient information leaflet "A way to access research in the NHS" V1 20/07/12 contains a slip that can be removed, completed and returned in order to provide SW DeNDRoN with contact details. Slips that are received by post will be scanned and saved in the W\drive folder found at 'SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents\YES from leaflet reply slips' in the format outlined in section 11. Details will then be added to the 'SW DeNDRoN Contacts 2012' spreadsheet.

10 Contact details from other sources

Occasionally correspondence is received from individuals requesting that their details are added to the distribution list. Such correspondence will be saved, either in email or scanned format, as proof of consent to the relevant folder on the W:\drive at 'SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents\YES from other sources' in the format outlined in section 11. Details will then be added to the 'SW DeNDRoN Contacts 2012' spreadsheet.

11 Storing information

- All proof of consent correspondence and documentations received by SW DeNDRoN will be stored with a file name in the following format using the date received, overwriting the original email title:

YY.MM.DD Surname Initial (or First name if duplicate date and surname).

- Emails are stored in the same location as Outlook Message Format (*.msg)
- Correspondence is to be stored in the relevant folder of SW DeNDRoN\Contacts\Contacts 2012\ on the W:\drive.

12 Other queries

Individuals who leave their contact details at an event or call the office will be sent a form (along with a business) reply envelope to complete before their details are added to the database. Alternatively, the form and business reply envelopes will be brought to events. Once received, this completed form will be stored electronically at 'SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents\YES from other sources.' (See Appendix 3.)

13 Removal process

When someone requests that their details are removed from SW DeNDRoN, their details are to be deleted. SW DeNDRoN will write to or email the enquirer to confirm that their details have been deleted (see Appendices 4 and 5). This confirmation letter or email will contain identifiable details and will be stored in the folder SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents\Removal of details confirmation correspondence. The documents will be saved in the following format:

YY.MM.DD Surname Initial (or First name if duplicate date and surname) REMOVED

This correspondence will be kept for legitimate business reasons as evidence that the request has been acted upon.

14 Using the spreadsheet

Any email correspondence to multiple contacts must be blind carbon copied on emails in order to comply with information governance requirements.

14.1 Filtering contacts

The contacts spreadsheet contains contact details of people who have requested to receive information about some or all of 3 of the following options:

- The Patient Advisory Panel
- The SW DeNDRoN newsletter
- Research opportunities

Therefore, when details of all individuals interested in a particular type of information are required (for example, when the latest edition of the newsletter is distributed) the spreadsheet will need to be filtered so only those who indicated interest in this field are contacted. This is done by selecting 'Data', 'Filter' and choosing 'Autofilter'. Each column header will then have autofilter options and the relevant autofilter is to be selected to show only 'yes' responses. This will result in only individuals interested in that field to be shown on the spreadsheet, and for their contact details to be easily utilised.

When the relevant details have been obtained, again select 'Data', 'Filter' and deselect 'Autofilter' for the spreadsheet to return to its complete view.

14.2 Accessing proof of consent documents

For information governance purposes and possible enquiries, it may be necessary to access proof of consent documents. These documents are stored in the 'Proof of consent documents' folder within the W:\drive at 'SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents'. However, due to the range of methods through which such documents are received, there are several locations in which a proof of consent may be stored.

Therefore, the simplest way of accessing a proof of consent document is to 'Copy' the ID of that particular individual from the contacts spreadsheet and to paste this into a search of the following folder:

W:\drive\SW DeNDRoN\Contacts\Contacts 2012\Proof of consent documents.

As the ID number is also the file name of individual proof of consent documents, this search will bring up the proof of consent document.

14.3 Back-up

A back-up copy of the contacts spreadsheet is held within the SW-DeNDRoN finance folder on the W:\drive. The finance area of the W:\drive has restricted access. The Research Network Manager, or somebody to whom the research Network Manager passes this responsibility, will update this back-up copy on a **weekly** basis. Access to the back-up copy of the contacts spreadsheet is restricted and staff must seek approval of the Research Network Manager.

15 Information Asset Register

The R&D Director, Dr Julian Walker, is the owner of the register and Research Network Manager, Mary Griffin, is the administrator. The 'SW DeNDRoN Contacts 2012' spreadsheet will be added to the Information Asset Register.

16 Further information

For further information about Information Governance within AWP, please contact the Trust's Data Protection Officer, Julie Benfell on 01249 468055 or email julie.benfell@awp.nhs.uk

For further information regarding the use of data by SW DeNDRoN, please contact:

Mary Griffin
Research Network Manager
South West Dementias and Neurodegenerative Disease Research Network (DeNDRoN)
AWP Research & Development Office
Blackberry Centre
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 2EW

T: 0117 3784239
F: 0117 9390746
Email: mary.griffin@awp.nhs.uk

General enquires: 0117 3784235

17 Appendices

17.1 Appendix 1: Data cleaning consent request letter

South West DeNDRoN
Research and Development Office
Blackberry Centre
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 2EW

Tel: +44 (0)117 3784239

Email: south-west@dendron.org.uk

26 July 2012

Dear colleague

South West DeNDRoN has been supporting the development and delivery of research into dementia and neurodegenerative diseases since 2006. During this time we have created a database of individuals who have expressed an interest in the organisation and would like to be contacted with news and information about research. This database has proved an extremely useful tool and has played an important role in the success of South West DeNDRoN.

After six years, we think it is important to ensure that those listed are still happy to be contacted and that we only store the details of those who have given us consent to do so. Therefore, if you are still interested in the work of South West DeNDRoN and wish to continue to be kept informed of new studies and developments, please complete the form overleaf. We are planning to do this exercise annually from now on so that our information is kept up to date.

We will assume that you no longer wish to be contacted if we have not received a reply by 10 September 2012 and your details will be deleted from our database. You can, of course, get back in touch with us in the future if you wish to be re-added by contacting us on the details at the top of this letter.

Finally, we would like to thank you for your support and we hope to continue to work with you in the future.

Yours sincerely

Mary Griffin
Research Network Manager

Enc Appendix 1 Consent to remain on the SW DeNDRoN database

Consent to remain on the SW DeNDRoN database

If you wish to remain on the database, please complete and return this form in the prepaid envelope provided by 10 September 2012.

Correspondence after this date should be directed to the address listed overleaf or to south-west@dendron.org.uk

Please tick box (es) that apply:

I would like my details removed from the SW DeNDRoN database

I give my consent for my details to remain on the SW DeNDRoN database

Title:.....

Name:.....

Job title/Patient/Carer:.....

Name of organisation (if applicable):.....

Address:.....

.....

.....

.....

Telephone number:.....

Email:.....

By agreeing to remain on the database you will receive a copy of our newsletter. (Newsletters will be distributed via email unless you indicate otherwise.) Please indicate below if you do not wish to receive a copy of the newsletter.

Please tick box if you do not wish to receive a copy of the SW DeNDRoN newsletter

If you are a patient or carer, you may also be interested in our Patient Advisory Panel or in hearing about opportunities to participate in research studies. The Patient Advisory Panel will work in partnership with many existing local and regional patient advisory groups for dementias, Parkinson’s disease, Huntington’s disease, and motor neurone disease. More information about our Patient Advisory Panel can be found on our website at: <http://www.dendron.nihr.ac.uk/south-west/discover-south-west-lrn/>

Please tick box (es) that apply:

I am interested in joining your DeNDRoN Patient Advisory Panel

I would like to know how to be involved in a research study

Data Protection declaration

Any personal information submitted by you will be held by DeNDRoN within NHS systems for the purpose of research and development. It shall be processed in accordance with the principles of the Data Protection Act 1998 and may be stored for up to 20 years. If you have expressed an interest in becoming involved in a research study, DeNDRoN will contact you for further details. We would only share your information with other NHS and non-NHS organisations for your benefit in a secure and appropriate manner. You have the right to withdraw your information from DeNDRoN at any time. To discuss what DeNDRoN does with your data, please contact Mary Griffin on 0117 3784239.

17.2 Appendix 2: Data cleaning consent request email attachment

South West DeNDRoN
Research and Development Office
Blackberry Centre
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 2EW

Tel: +44 (0)117 3784239
Email: emily.garner@awp.nhs.uk

26 July 2012

Dear colleague

South West DeNDRoN has been supporting the development and delivery of research into dementia and neurodegenerative diseases since 2006. During this time we have created a database of individuals who have expressed an interest in the organisation and would like to be contacted with news and information about research. This database has proved an extremely useful tool and has played an important role in the success of South West DeNDRoN.

After six years, we think it is important to ensure that those listed are still happy to be contacted and that we only store the details of those who have given us consent to do so. Therefore, if you are still interested in the work of South West DeNDRoN and wish to continue to be kept informed of new studies and developments, please complete the form overleaf. We are planning to do this exercise annually from now on so that our information is kept up to date.

We will assume that you no longer wish to be contacted if we have not received a reply by 10 September 2012 and your details will be deleted from our database. You can, of course, get back in touch with us in the future if you wish to be re-added by contacting us on the details at the top of this letter.

Finally, we would like to thank you for your support and we hope to continue to work with you in the future.

Yours sincerely

Mary Griffin
Research Network Manager

Enc Appendix 1 Consent to remain on the SW DeNDRoN database

Appendix 1 Consent to remain on the SW DeNDRoN database

If you wish to remain on the database, please complete and return this form by 10 September 2012 to: emily.garner@awp.nhs.uk

or to the address listed overleaf.

Responses after this date should be directed to: south-west@dendron.org.uk

Please tick box (es) that apply:

I would like my details removed from the SW DeNDRoN database

I give my consent for my details to remain on the SW DeNDRoN database

Title:.....

Name:.....

Job title/Patient/Carer:.....

Name of organisation (if applicable):.....

Address:.....

.....

.....

.....

Telephone number:.....

Email:.....

By agreeing to remain on the database you will receive a copy of our newsletter. (Newsletters will be distributed via email unless you indicate otherwise.) Please indicate below if you do not wish to receive a copy of the newsletter.

Please tick box if you do not wish to receive a copy of the SW DeNDRoN newsletter

If you are a patient or carer, you may also be interested in our Patient Advisory Panel or in hearing about opportunities to participate in research studies. The Patient Advisory Panel will work in partnership with many existing local and regional patient advisory groups for dementias, Parkinson's disease, Huntington's disease, and motor neurone disease. More information about our Patient Advisory Panel can be found on our website at:

<http://www.dendron.nihr.ac.uk/south-west/discover-south-west-lrn/>

Please tick box (es) that apply:

I am interested in joining your DeNDRoN Patient Advisory Panel

I would like to know how to be involved in a research study

Data Protection declaration

Any personal information submitted by you will be held by DeNDRoN within NHS systems for the purpose of research and development. It shall be processed in accordance with the principles of the Data Protection Act 1998 and may be stored for up to 20 years. If you have expressed an interest in becoming involved in a research study, DeNDRoN will contact you for further details. We would only share your information with other NHS and non-NHS organisations for your benefit in a secure and appropriate manner. You have the right to withdraw your information from DeNDRoN at any time. To discuss what DeNDRoN does with your data, please contact Mary Griffin on 0117 3784239.

17.3 Appendix 3: Registration of details form

Registering contact details with South West DeNDRoN



Please complete and return this form to:

SW DeNDRoN
 AWP Research and Development Office
 The Blackberry Centre
 Blackberry Hill Hospital
 Manor Road
 Fishponds
 Bristol
 BS16 2EW

Or e-mail to: south-west@dendron.org.uk

Please tick the box(es) that apply:

I am interested in joining your Patient Advisory Panel*

I would like to receive your newsletter

(newsletters are sent by e-mail unless you indicate that you would like to receive them by post)

I would like to know how to be involved in a research study

*The Patient Advisory Panel is a body of people who are willing to be called upon by South West DeNDRoN on behalf of professionals in the field for advice and comments on research. More information on our Patient Advisory Panel is on our website www.dendron.org.uk/rn.sw.html

Name

E-mail

Address

Telephone number

Data Protection

Any personal information submitted by you will be held by DeNDRoN within NHS systems for the purpose of research and development. It shall be processed in accordance with the principles of the Data Protection Act 1998 and may be stored for up to 20 years. If you have expressed an interest in becoming involved in a research study, DeNDRoN will contact you for further details.

We would only share your information with other NHS and non-NHS organisations for your benefit in a secure and appropriate manner. You have the right to withdraw your information from DeNDRoN at any time.

To discuss what DeNDRoN does with your data, please contact Mary Griffin on 0117 3784239.

17.4 Appendix 4: Confirmation letter of removal of contact details

**South West Dementias and
Neurodegenerative Diseases Research
Network
AWP Research & Development Office
Blackberry Centre
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 2EW**

**T: 0117 3784239
General enquires: 0117 3784235
F: 0117 9390746
Email: south-west@dendron.org.uk**

11 September 2012

Dear colleague,

Thank you for responding to our recent request for consent to remain on the South West DeNDRoN contacts list.

You indicated that you no longer wish for your details to be stored or to receive news and information about research. This letter is to confirm that we have therefore removed your details from our system.

Yours sincerely

**Mary Griffin
Research Network Manager**

17.5 Appendix 5: Confirmation email of removal of contact details

Dear colleague,

Thank you for responding to our recent request for consent to remain on the South West DeNDRoN contacts list.

You indicated that you no longer wish for your details to be stored or to receive news and information about research. This email is to confirm that we have therefore removed your details from our system.

With thanks and best wishes,

NAME
ROLE