

What can South West DeNDRoN do for you?

Joanne Hartland
Network Manager

www.dendron.org.uk

- What is DeNDRoN – the vision and the mission?
- How does SW DeNDRoN support research?
- How is South West DeNDRoN set up?
- Real-life benefits of working with DeNDRoN...and plans for the future

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The vision and the mission of DeNDRoN...

DeNDRoN Vision

“Every patient with a dementia or neurodegenerative disease will have the opportunity to participate in high quality clinical research”

DeNDRoN Mission

- Increase the volume of high quality clinical research developed & funded (placed) in the UK
- Develop an NHS infrastructure capable of delivering high quality clinical research, on time, to budget

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How does South West DeNDRoN support research?

SW DeNDRoN as an organisation ...

- Provides research teams with help from our CSO staff
- Provides access to the UKCRN training for staff working on DeNDRoN studies
- Offers various research-related assistance - on approvals processes, set up, good practice, ideas etc
- Advises on getting research project adopted onto the portfolio, and eligible for support
- Organises CSO training days

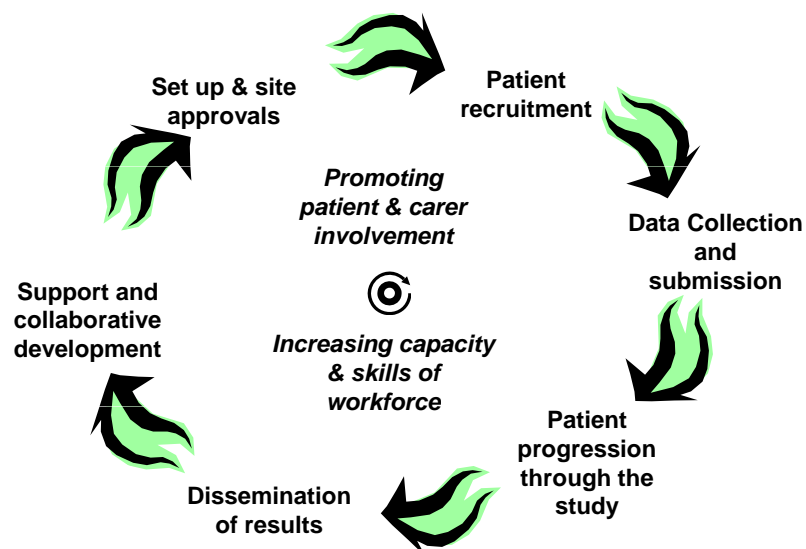
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SW DeNDRoN CSO staff...

- Help identify suitable patients for the various studies
- Discuss studies with potential participants
- Help with organising the consent process
- Help research centres to achieve recruitment targets more easily
- Some of our staff have trained as independent raters for studies
- Help as the patient progresses through the study
- Offer support to the research staff already working on the study
- Build up collaborative working between DeNDRoN staff and the existing research team

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How we plan to develop a sustainable infrastructure



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- **How is South West DeNDRoN Set up to achieve this?**

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The network area...

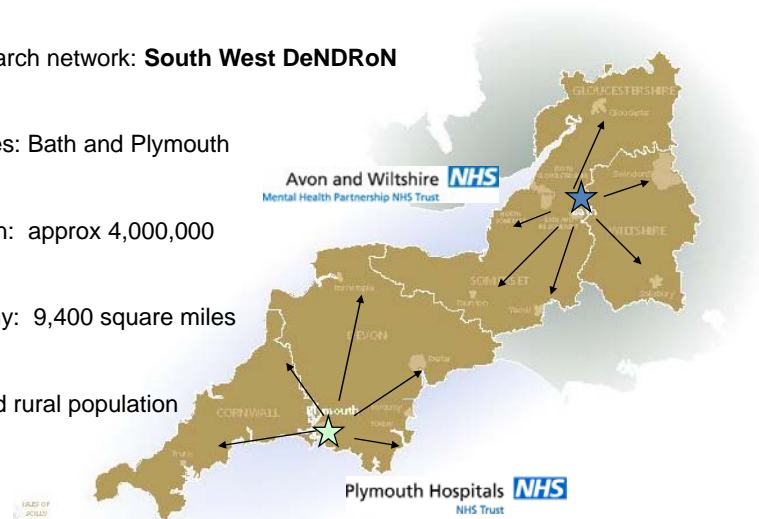
One research network: **South West DeNDRoN**

Two offices: Bath and Plymouth

Population: approx 4,000,000

Geography: 9,400 square miles

Urban and rural population



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Supporting Studies in the South West 1/2

Parkinson's Disease:

- PD Gen, PD Med, GetUp: Exeter, Torquay, Barnstaple, Taunton, Bath, Bristol, Cheltenham, Gloucester, Yeovil
- PD Rehab: Sites to be confirmed start 07/2009
- DeNDRoN 024 Bristol, Exeter
- PRO-DeNDRoN register: Devon and Cornwall
- DBS of the PPN in PD: Bristol

Progressive Multiple Sclerosis:

- CUPID: Truro, Plymouth, Taunton, Bristol, Gloucester
-

Motor Neurone Disease:

- MND DNA Bank: Plymouth, Bristol
- MND LiCALS: Plymouth start 01/2009

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Supporting Studies in the South West 2/2

Dementias:

- DeNDRoN 007 Gloucester
- DeNDRoN 022 & 23 Bath & Swindon
- DeNDRoN 027 Swindon
- DeNDRoN 028 Bath
- DeNDRoN 020 Bath, Plymouth
- MaG D: Plymouth start 01/2009

Huntington's Disease:

- Euro HD Register & Biobank: Plymouth, Exeter, Gloucester, Bristol
- Long-term Neurological Conditions - Support for Carers: Plymouth, Taunton, Bristol, Torquay, Exeter

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Real Life Examples of the benefits of working with South West DeNDRoN:

➤ Study Recruitment:

SW DeNDRoN was the highest recruiting English local research network in 2007.

The South West is the highest recruiting network for PD Med study DeNDRoN 020 – Bath site is highest recruiter in the country (Sept 08)

CUPID study recruited to target

Get Up study – more than two thirds of the patients who took part were identified by SW DeNDRoN staff

New researchers we are encouraging are very positive about our input

➤ New Developments:

Gloucester: New interest in Dementia research being encouraged

Plymouth: MND intervention study to start in new year

Set up of a new Research Centre for Dementias

About to start working with a GP practice in Salisbury

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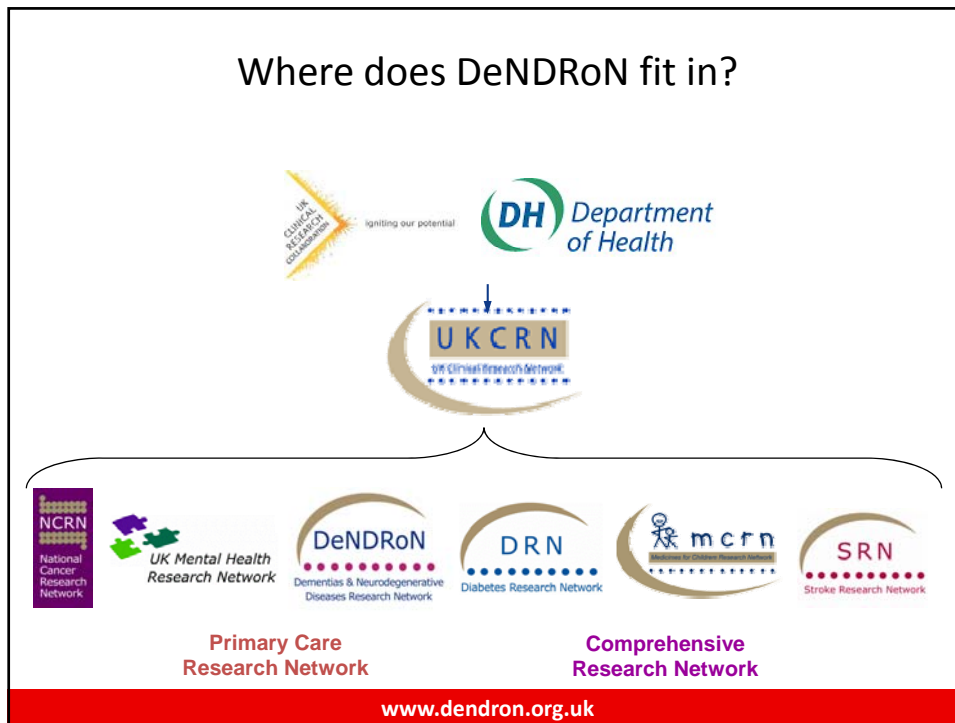
Future plans


National Institute for
Health Research

- More opportunities for Patients, Carers and the Public to become involved in our work
- Creating further links with the Primary Care Research Network, the Comprehensive Networks & other Topic Specific Networks
- Maintaining a balanced portfolio, across all the disease areas, and across our region
- Building on the infrastructure and expertise in place to ensure support is targeted and effective
- To create a sustainable research workforce across the region
- For research opportunities to be an integral part of clinical care

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Where does DeNDRoN fit in?



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