Research opt out: Improving opportunities to hear about research

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Why let more people hear about research opportunities?

- 89% of people willing to take part in research (NIHR, CRN, 2014)

- Learning from Experience. Telling our Stories of taking part in Research:
  - Overall, people found the experience meaningful and positive
  - Main motivations:
    - To help others
    - To help themselves
    - Being listened to
    - Interest in research and mental health
What’s wrong with current system?

• The current system:
  – Clinicians make first contact

Problems:
  Busy clinicians
  Frequency of visits
  Geography!
How can you get involved?

- Spread the word
  - People you work with
  - Friends and family
- Ask your doctor or clinician
- Get in touch
  - research@sussexpartnership.nhs.uk
  - Join the Research Network
- Take part

Our solutions…empowering patients

RESEARCH SAVES LIVES

Get involved: Sign up to the Research Network today

WELCOME TO THE RESEARCH NETWORK

What is the Research Network?
The Research Network is a group of people who are interested in taking part in mental health research within Sussex Partnership NHS Foundation Trust.

Our Research team is leading nationally-important research into mental health conditions and treatment. By joining the network you will be sent news about the Trust’s research work, and you can then choose to take part in research studies if you want to.

Why is research important?
We know that research leads to better health services and saves lives. We need everyone who uses our services, their carers and our staff to get involved. The more people that are involved the greater the difference it will make to finding new and improved treatments.

Research can be about getting involved in a new type of therapy or trying a new drug, it can also involve completing questionnaires or being interviewed.

What happens once I join the Research Network?
Once you join the Research Network your details will be registered with the Research team and you will receive regular information about research within Sussex Partnership.

Our Research Nurses will regularly check which studies are available to you and send you information about these studies. You can then let us know if you would like to take part.
What is the opt out?

• R&D contacting people directly about research opportunities
• It is about letting people know about research studies not about taking part
• R&D accessing information to send relevant information
• Anyone can opt out at any time
Testing it out

6 month pilot in West Sussex Memory Assessment Service

- 3700 people sent Research Leaflet
- 15% opted out
- 59 queries (1.6%)

Findings:

- An opt out approach is acceptable
- The Research Leaflet was clear and comprehensible
Research: It’s your choice

Patients taking part in research studies are helping to improve the quality of services we provide.

One of our priorities is to increase opportunities for our patients, carers and staff to take part in research. To help us achieve this we’ve changed the way we let people know about research.

If you use Sussex Partnership services, you are now automatically opted-in to hear about research opportunities, unless you choose not to be contacted.

You can get information about how and why the Research and Development team might contact you in our research leaflet. It will also give details of how you can opt out from receiving research information.

The research leaflet is available from:

- a member of your care team or
- online here: www.sussexpartnership.nhs.uk/getting-involved-research-research

Please contact us direct if you have any queries:

T: 01273 265896
E: research@sussexpartnership@nhs.uk
At Sussex Partnership we conduct research studies in order to improve the services we deliver to our patients. All of our studies are of high quality and have been approved by an NHS Research Ethics Committee and the Trust.

When a research study has been approved to run in the Trust, our Research and Development team sends information about that study to patients who may be eligible to take part. We want to ensure that this information goes to the right people, so we need to check patient records. If you are happy for us to check your records you don’t have to do anything. We will send you information about interesting studies from time to time. If you do not want us to look at your records, please let us know by completing the ‘research opt out form’ and we will not send you information about studies.

If we send you information about a study, it is entirely your choice if you want to take part. You can discuss the study with us in more detail before making a decision. If you do not want to take part in the study, you don’t have to.

Only members of our Research and Development team will look at your records to see if a study is right for you. No one from outside the Trust will look at your records.

If you do not want staff from Sussex Partnership’s Research and Development team to look at your records and send you information about research studies, please complete the ‘research opt out form’ and give it to a Sussex Partnership member of staff involved in your care or send it to: Research and Development Department, Sussex Education Centre, Mill View Hospital, Nevill Avenue, Hove BN3 7HZ.

For more information, please contact the Research Manager on 01273 265896 or email research@sussexpartnership.nhs.uk

**Research opt out form**

**Please complete in CAPITALS**

1. **I do not want to hear about research studies**
   - I do not want members of Sussex Partnership NHS Foundation Trust’s Research and Development team to access my records or send me information about studies.
   - Signature: 
   - Date: D D / M M / Y Y

2. **Your details**
   - First name: 
   - Last name: 
   - Address: 
   - Postcode: 
   - Date of birth: D D / M M / Y Y Y Y

3. **What next**
   - Once you have completed the form please return it to a Sussex Partnership member of staff involved in your care or send it to: Freepost Plus RSUY-BTLR-BXAG, Research and Development Department, Sussex Education Centre, Mill View Hospital, Nevill Avenue, Hove BN3 7HZ.
   - You can also complete this form online at: www.sussexpartnership.nhs.uk/getting-involved-research-research
Opt out of hearing about research

I do not want members of Sussex Partnership NHS Foundation Trust’s Research and Development team to access my records or send me information about studies.

First name *

Last name *

Address *
Next Steps

- Contacting people about research studies
- Evaluation
- Other services
thank you!