

Parkinson's UK policy statement Using patient data for medical research

“Patient data records are essential for medical research and can help us to improve our knowledge and understanding of Parkinson's, identify new treatments and improve the services people with Parkinson's receive. It is important that the NHS promotes a supportive environment that ensures that data is available for researchers while protecting patient confidentiality.”

Steve Ford, Chief Executive, Parkinson's UK

What we believe

Patient data records are vital to health research and the data needs to be shared efficiently within the NHS. There should also be a strong commitment from the NHS to ensure that data is shared safely and securely for health research purposes.

It is important to have safeguards in place to protect patient confidentiality while allowing medical researchers to have access to patient data. There are ways in which the rights of the patients can be protected while still permitting access to data for health research.

- Anonymised data should be available to researchers, along with pseudonymised (key coded) data, provided that researchers do not have access to the codes.
- Access to identifiable data should only be allowed when consent has been provided by the individuals involved. Where it is not possible to get consent from those involved, an independent 'gatekeeper' organisation should regulate the use of the data. Access to the data should only be allowed where there is a clear potential benefit to public health. The organisation's process should be transparent and they should be accountable for the proper administration of access to such data.
- Regulation and governance systems need to be streamlined and applied consistently without compromising patient confidentiality.
- The public should be fully informed of the ways in which their data will be used, who will be able to access it and be made aware of their rights to withdraw it.
- If the way in which data is used changes, the public should be fully informed and given the opportunity to withdraw their data.
- Data sharing technologies and the governing regulations need to keep pace with technological advances so that people can continue to feel their confidentiality is protected.

Why we believe this

Data from patient records can help with many areas of research. For example, the data can be used to:

- observe trends in infectious diseases
- monitor the safety and efficacy of prescribed drugs
- assess occupational, environmental or other risks to public health

- evaluate new treatments and interventions through clinical trials
- carry out audits that will help to inform healthcare management

Patient data can be used to identify new treatments and therapies and understand the causes of Parkinson's.

What's the evidence?

A 2009 survey by the Wellcome Trust suggests that the public is, in general, in favour of sharing patient data for health-related reasons. The survey found that of the 1,179 UK adults questioned, 74% were willing to allow access to their personal medical records for medical research.¹

In addition, an Ipsos MORI poll of nearly 1,000 adults in 2011 found that 80% would like their doctor to offer them the opportunity to allow a researcher confidential access to their medical records with no other involvement from the patient.²

Evidence from Parkinson's UK members

Parkinson's UK has 370 local groups and we held seven separate events across the UK with the members of these groups in order to engage with them on clinical research issues.

From a survey³ conducted with our members at the events, 90% (241 people) reported that NHS data should be available to researchers. Comments about this included: *"Data should be available to researchers because it benefits patients and future cures"* and *"How do they know which areas need research if they don't have statistics and data."*

There was a general consensus among the local group members surveyed that although patient data should be made available for research, it is important to have safeguards in place. 78% of those surveyed stated that data used for research should be anonymised or coded.

Barriers to accessing data

There are inconsistencies in regulations and guidelines and variability in advice on patient data use. This has meant that researchers often face difficulty and significant delays in obtaining access to data. For example, in order for researchers to conduct research in the NHS they need to obtain various approvals from bodies such as research and development departments, ethics committees and from local Caldicott Guardians (senior roles in NHS Trusts that protect patient confidentiality and also enable the sharing of suitable information).

Regulation and governance systems need to be streamlined without compromising patient confidentiality. Standardised methods for gathering and sharing data needs to be

¹ Wellcome Trust Monitor 1, Tracking public views on medical research. 2009. National Centre for Social Research.

² Ipsos MORI, *Public support for research in the NHS, June 2011*

<http://www.ipsosmori.com/researchpublications/researcharchive/2811/Public-support-for-research-in-the-NHS.aspx>

³ 2012 Parkinson's UK Together Events – 7 regional events

implemented and electronic patient records, which are an important source of data for researchers, need to be kept up to date with useful information.

What Parkinson's UK are doing

Parkinson's UK are working to improve the accessibility of patient data, to help with our aim of finding a cure.

Parkinson's UK supports many research projects. Some aim to improve quality of life for people with Parkinson's while others are seeking a cure. Access to patient data may contribute to the success of projects in both these categories.

We will continue to campaign to ensure that the NHS has a strengthened commitment to sharing patient data for the purposes of health research.

We will continue to work to ensure that the Government informs patients about any initiatives that include the use of patient data and any changes made to the use of their data.

We will work to make sure health bodies fulfil their responsibility to promote research, ensure clinicians share patient data and that sufficient systems are in place to access patient data for research, while maintaining patient confidentiality.

We will seek to streamline and standardise regulation and governance systems without compromising patient confidentiality.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel and Research Support Network in shaping this position paper on patient data. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues. The Research Support Network is a group of around 950 people with an interest in Parkinson's research.

Further information

Please contact the Policy and Service Improvement team on **020 7963 9349** or **campaigns@parkinsons.org.uk**

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