

PATIENTS' PRIORITIES FOR RESEARCH INTO EPILEPSY

A SURVEY OF PATIENT GROUPS 2008

conducted by PatientView, on behalf of DUETS and The James Lind Alliance, in collaboration with the University of Wales Swansea and the University Hospital of Wales

Why this DUETs epilepsy survey?

Medical research could do a lot more for people with epilepsy. Previously, most research has been primarily designed and conducted by doctors, scientists, and industry—healthcare stakeholders who may not always have an intimate knowledge of the wants and needs of patients.

DUETs wanted to know what questions epilepsy patients themselves have about their treatment—questions that doctors cannot currently answer. The DUETs survey is a first step in giving epilepsy patients/carers a bigger and more potent voice in medical research.

Methodology of the DUETs epilepsy survey

Online survey, with open-ended questions. Answered April-July 2008 by 36 patient groups with an interest in epilepsy. The DUETs questionnaire concentrated upon patients' research uncertainties in the following epilepsy subject areas:

- Diagnostic tests.
- Complementary therapies.
- Diets or dietary supplements.
- Prescription medicines.
- Neurosurgical interventions.
- Psychological support or psychological treatments.
- Treatments for children with epilepsy.
- Other treatment areas in epilepsy.
- Non-medical epilepsy services.
- Other illnesses.
- Single most-important consideration.

In each of the above sections, the respondents' answers were classified into one of several categories of uncertainty (some answers could be classified into more than one category of uncertainty).

Contact details

DUETS

(The Database of Uncertainties about the Effects of Treatments)
<http://www.duets.nhs.uk>

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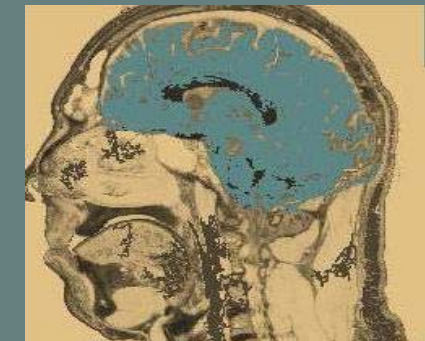
36 patient groups took part

16 respondent organisations wished to be named as participants in the study:

Cambridgeshire Neurological Alliance.
Epilepsy Action (Basildon/Thurrock).
Epilepsy Action (Birmingham Branch).
Epilepsy Action (Brighton/ Hove Branch).
Epilepsy Action (North Devon Branch).
Epilepsy Action (Sheffield/ District Branch).
Epilepsy Action (Tunbridge Wells Branch).
Epilepsy Connections.
Epilepsy Scotland.
Epilepsy West Lothian.
face2face (North-East Lincolnshire).
Gwent Epilepsy Group.
National Society for Epilepsy, The.
Southampton Community Epilepsy Service.
Southampton University Hospital Trust (Specialist Epilepsy Service).
Sunshine Club, The.

Respondents' NINE single most-important considerations for further research:

- Better treatments.
- Ensuring that current treatments are as effective as possible.
- Treatments with fewer side-effects.
- More definitive diagnostic tests for epilepsy.
- The connections between epilepsy and other medical conditions.
- The stigma associated with epilepsy.
- The effectiveness of psychological support.
- Patient information.
- The role of medical research.



Quotes from respondents:

"There is a great need to find treatments (for all types of epilepsy) that can sense the onset of seizures in the brain, and prevent them from occurring in the first place."

"The effects of anti-epileptic medication on cognitive functioning and academic abilities are strong reasons for some people not complying with their anti-epileptic medication regime."

"I felt let down by the electrodes test on my child. It showed no seizure activity. Yet my child fitted two hours later."

"Epilepsy is far more than the occasional seizure. While—obviously—seizure control is the highest priority, greater 'community' knowledge of the 'effects' of living with epilepsy is required among other service providers."