

Towards an evidence-based clinical management of visual hallucinations: prevalence, prognosis, impact and pathophysiology

<https://www.neurodegenerationresearch.eu/survey/towards-an-evidence-based-clinical-management-of-visual-hallucinations-prevalence-prognosis-impact-and-pathophysiology/>

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Country

United Kingdom

Title of project or programme

Towards an evidence-based clinical management of visual hallucinations: prevalence, prognosis, impact and pathophysiology

Source of funding information

NIHR (PGfAR Competition 9 Stage 2 Panel D)

Total sum awarded (Euro)

€ 2,740,940

Start date of award

01/06/2012

Total duration of award in years

6.5

The project/programme is most relevant to:

Alzheimer's disease & other dementias|Parkinson's disease & PD-related disorders

Keywords

Research Abstract

Aims and objectives:The ambition of the programme is to change NHS practice and policy in relation to visual hallucinations. By 2017: i) a companion set of guidelines will be available for NHS professionals and patients for the management of visual hallucinations ii) best candidate treatments for visual hallucinations will have been identified with data to support application for a large-scale pragmatic treatment trial iii) economic, quality of life and current practice evidence will be available to plan and prioritise the NHS response to the problem.

Background

An estimated 2 million people in the UK have visual hallucinations although the true prevalence may be higher and the figure is set to rise as the population ages. The hallucinations occur in a range of clinical conditions of which dementia, eye disease and Parkinson's disease are the most important in terms of the number of patients affected. It is known that the hallucinations cause significant distress for patients and have wider implications for the NHS, for example triggering hospital admission or the move to a care setting from independent living and treatment with medication that poses significant risks without evidence of benefit. Yet despite a clear need for help as evidenced by increasing numbers of patients seeking help and support from voluntary organisations, there are currently no NHS services for such patients and no evidence-based guidance on how to treat the symptom. Furthermore, it is not possible at present to develop guidelines or policy due to a lack of evidence in a number of key areas.

Research plans

The programme will consist of 4 integrated workstreams to provide evidence upon which to base a companion set of guidelines for NHS professionals and patients with visual hallucinations.

Workstream 1 will provide core prevalence and prognosis data on visual hallucinations and identify patients for other workstreams. Workstream 2 will develop disease-specific quality of life questionnaires for use in patients with i) Parkinson's disease and ii) dementia equivalent to those questionnaires developed previously for eye diseases. It will also use qualitative methods to explore current practice for visual hallucinations within NHS and social care settings. Workstream 3 will assess economic and QALY impact of visual hallucinations for the NHS. Workstream 4 will provide pilot and feasibility evidence for large scale treatment trials for visual hallucinations.

Research team

The programme brings together centres with expertise in different clinical contexts and strong track records in applied research to build a unique, internationally competitive, team of visual hallucination and applied methods experts.

Programme management

The overall aims and outcomes of the programme will be overseen by a cross-disciplinary workgroup with representation from key clinical stakeholders, patient / public organisations and patients with visual hallucinations. The monitoring and co-ordination of workstreams will be through a steering committee.

Research environment

The programme involves leading applied research centres in London (Institute of Psychiatry and

Royal Holloway), Cambridge and Newcastle. The Mental Health of Older Adults and Dementia Clinical Academic Group within King's Health Partners will lead the programme. The centres have well established links with public and patient organisations for eye disease, dementia and Parkinson's disease.

Anticipated outputs, outcomes and impact

The programme will produce a companion set of guidelines in 2017 for clinicians and patients focusing on the assessment and management of the symptom, its prognosis and impact in different clinical contexts and information on recognising the symptom, its implications and seeking further help. It will also provide evidence from which to design future large-scale treatment trials and plan and prioritise NHS services.

Dissemination of findings

Findings will be disseminated to: i) NHS professionals ii) NHS commissioners; iii) Social Care; iv) patient / public organisations. Participants will receive a newsletter on developments and progress. The scientific findings will be published in academic papers in high impact journals and presented at conferences.

Patient and public involvement

The programme is a direct response to patient demand for advice on visual hallucinations. Patients themselves and their representative organisations will be members of the working group and play a key role in guideline development.

Ethical implications

Safeguards are in place to i) protect patients with cognitive impairment who lack capacity to consent and ii) support patients who may be discussing their experience of hallucinations for the first time. Provision has been made for patients in whom unsuspected eye disease or dementia is detected as a result of their participation in the programme.

Lay Summary

Further information available at:

Types:

Investments > €500k

Member States:

United Kingdom

Diseases:

Alzheimer's disease & other dementias, Parkinson's disease & PD-related disorders

Years:

2016

Database Categories:

N/A

Database Tags:

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