

Assessing outcomes of integrated care for people with long-term conditions

<https://neurodegenerationresearch.eu/survey/title-of-piassessing-outcomes-of-integrated-care-for-people-with-long-term-conditions/>

Title of project or programme

Title of PI Assessing outcomes of integrated care for people with long-term conditions

Principal Investigators of project/programme grant

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Source of funding information

Department of Health (DH)

Total sum awarded (Euro)

531031

Start date of award

01-04-2010

Total duration of award in months

30

The project/programme is most relevant to

- Neurodegenerative disease in general

Keywords

Parkinson Disease, Dementia, Motor Neuron Disease, Neurodegenerative Diseases, Health Services for the Aged, Delivery of Health Care

Research abstract in English

Lay summary

Background: The NIHR SDO brief has asked for research that describes how integrated health and social care can be developed in order to for it to work for the benefit of service users and their carers. People with long-term neurological conditions (LTNCs) say that the services and support that they need should be delivered to them in a 'joined-up' way – to be integrated. However, there is little evidence about the best ways of ensuring this and whether it makes any difference to outcomes. Three different things can affect how integrated services are developed and delivered. Health and social care services can be integrated in a single structure (this is the 'macro' level); or health and social care services can use different ways of planning or communicating together to increase the sense of services being joined up (this is the 'meso' level); or the services themselves can be joined-up, with staff working together when they deliver support to people with LTNCs (this is the 'micro' level). These different ways of joining up health and social care vary across the country.

This project will explore how different areas have tried to integrate their health and social care services for people with LTNCs, at these three levels, and what the benefits and challenges of doing this have been. The project will also explore with people with LTNCs what outcomes they want from integrated health and social care services and then work with services to introduce these outcomes into their day-to-day practice.

The research: The research will be carried out in four areas in England that have used different ways of integrating health and social care for people with LTNCs. The four areas are also different in terms of their population make-up, whether they are urban or rural, and whether or not they are deprived.

The methods of the research will be qualitative – talking to people in detail about their experiences of planning, delivering and using integrated health and social care. People with LTNCs will also be asked in detail about the outcomes they would like to experience when they receive integrated care. This part of the project will use findings from earlier research on outcomes and test it with people with LTNCs. Once we have explored the outcomes that people with LTNCs want, we will use these to design a checklist for services to use when people are referred to them. We will work with services to introduce this checklist in their everyday practice and will then follow them up to see how they use them and whether this changes the ways in which they work with people with LTNCs. We will also talk in detail to the people who provide services about their use of the checklist and to people with LTNCs about whether the checklist has helped them to get what they need from integrated health and social care services.

Outcomes of the research: This project will produce messages about integrated health and social care that can be used elsewhere. This will include how structures and ways of working (macro- and meso-level integration) can support how integrated services are delivered at the individual (micro) level. It will indicate which models of integration offer potential for being implemented in other places. It will also outline the outcomes that people with LTNCs, rather than professionals, want from integrated services and demonstrate ways in which these can be used to influence the ways services are delivered.

Ethical issues: We will use a method for identifying service users that maintains confidentiality. We will ensure that people who use languages other than English can participate in the research and will work with service users who use alternative methods of communication to ensure that their views are included. We will adapt methods of gaining informed consent so that people who cannot write are still

able to participate.

The team: The research team is experienced in service delivery and organisation research and is knowledgeable about people with LTNCs. It is currently researching whether and how people with LTNCs experience continuity of care in the services they receive. We already have strong links with the four areas where the research will be based.

Resources requested: This is an in-depth study in four areas of England. It will involve over 120 in-depth interviews, four months of development work to introduce the outcome checklist in the areas, and the equivalent of a month monitoring the use and impact of the checklist. The research skills required for this work at a high level and the project therefore needs experienced researchers. The timetable and budget have been carefully worked out to reflect all these factors.

In which category does this research fall?

- Health and social care research