

Outcomes assessment for people with long-term neurological conditions: a qualitative approach to developing and testing a checklist in integrated care

Fiona Aspinal,* Sylvia Bernard, Gemma Spiers and Gillian Parker

Social Policy Research Unit, University of York, York, UK

*Corresponding author

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Plain English summary

People with long-term neurological conditions

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Purpose

We aimed to understand:

- how health and social care organisations work together
- what outcomes people with long-term neurological conditions (LTNCs) want to achieve
- how a list of these outcomes could be used by health and social care staff working together.

What we did

We interviewed:

- health and social care staff to find out how they work together
- people with LTNCs (clients) to find out what is important to them and what they want to achieve (outcomes)
- carers to understand how services work with them.

We developed the outcomes into a single checklist. Health and social care staff then used the checklist with clients as part of the routine assessment process.

We interviewed staff and clients to see how the checklist had worked for them.

Findings

There were different types of integrated care in different places.

There were 20 outcomes covering personal comfort, economic and social participation, and autonomy.

The outcomes checklist prompted staff to discuss some issues in more detail, such as personal decision-making, getting advocacy and support, and intimate personal relationships.

Some outcomes were difficult for clients and staff to discuss. These included finances, emotional well-being and, again, intimate personal relationships. How health and social care staff worked together appeared to influence this.

Conclusions

Integrated care can affect the way outcomes are interpreted, assessed and achieved. There is scope for developing a measure to assess outcomes of integrated care for long-term conditions that reflect service users' needs.

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Editorial contact: nihredit@southampton.ac.uk

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