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

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## Scientific summary

### People with long-term neurological conditions

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# Scientific summary

## Background

Despite the continued emphasis and priority given to integration, there is little consistency in policy and in the literature about its definition and aims. The lack of clarity about what integration means and what it should achieve makes measuring the effects of integration and its impact for service users problematic. The focus so far has been on organisational and professional issues around structural integration, integration at the service level and, to some extent, about the impact of integration on process measures such as service access and user satisfaction. There is limited evidence about the effectiveness of integration for service users and their families or carers. Consideration of outcomes that are important to service users, not just to service managers and professionals, is largely absent.

Failure to demonstrate the effect of integration on service users using conventional outcome measures suggests that research to date has failed to measure the outcomes that actually matter to people with complex long-term conditions (LTCs) and that might result from integrated health and social care. Developing outcome measures that capture the important issues for service users may also help to better reflect the particular ways integrated teams work and what such teams strive to achieve in addressing service user outcomes.

Adults with long-term neurological conditions (LTNCs) pose particularly complex challenges for health and social care integration. Using LTNCs as an exemplar can generate knowledge that is transferable to other LTCs.

## Objectives

This research addressed the need to develop ways of assessing outcomes that can be facilitated by integrated service provision. It aimed to begin to fill the gap in evidence by exploring how user-desired outcomes can be incorporated into assessment processes in service models using different approaches to integration, embedded within different organisational structures.

There were four specific research questions:

1. What facilitates or impedes the development of innovative approaches to health and social care integration?
2. What outcomes do people with LTCs want from integrated health and social care?
3. Can these outcomes be assessed in everyday service delivery?
4. How can different models of integrated health and social care affect outcomes?

## Methods

We undertook in-depth case studies in four primary care trust (PCT) areas, including associated local authorities, in England between 2010 and 2012. We included PCTs that had an integrated neurorehabilitation team (NRT) and reflected different approaches to integration at a strategic and/or commissioning level, different population profiles and different levels of rurality/urbanisation. The research was undertaken in three stages.

### **Stage 1: understanding the service context and identifying outcomes**

- Documentary evidence was analysed and interviews conducted with staff (e.g. PCT commissioners, senior managers, service-level managers and front-line staff) ( $n = 43$ ) to help understand the context in which integrated teams were based.
- NRTs' clients, representing a range of conditions and needs, were recruited ( $n = 35$ ). NRT clients were eligible if they had a LTNC, were existing clients or had been clients of the NRT within the previous 6 months, were aged 18 or over, and were cognitively able to give informed consent and to participate in an interview. In-depth semistructured interviews were conducted to explore and identify outcomes that were important to them.
- In-depth semistructured interviews were held with carers of people with LTNCs to help understand how carers were included in integrated service provision ( $n = 13$ ).

### **Stage 2: developing and implementing an outcomes checklist for use in practice**

- Service user interview data were analysed to identify the outcomes that they wanted to achieve.
- A summary list of outcomes was developed and, working with the NRTs in each case site, this was developed into a checklist that NRTs could use in practice.
- NRTs implemented the outcomes checklist (OC) as part of their usual assessment processes and we audited its use ( $n = 24$ ).

### **Stage 3: evaluating the use of the checklist**

- We conducted team focus groups or individual interviews with NRT staff to establish their views on the checklist and its utility in practice ( $n = 21$ ).
- In-depth semistructured interviews with service users explored experiences of the checklist being used in their assessment and their views on the items included on the checklist ( $n = 12$ ).

Data collected from in-depth semistructured interviews in stages 1 and 3 were managed and analysed using the framework approach. Separate analytical frameworks for staff, service users and carers were developed at each stage, based on the issues addressed in interview topic guides and on key themes emerging in the data. Data from transcripts were charted onto the frameworks and the research team discussed entries throughout this process to ensure consistency and accuracy, and to review the 'fit' of the data. Data within the frameworks were analysed thematically. For focus group data, a 'whole-group' approach to analysis was used but care was taken to include divergent voices.

## **Results**

### **What facilitates or impedes the development of innovative approaches to health and social care integration?**

Integration was viewed positively and was seen as a key priority by strategic staff dealing with organisational integration and by practitioners dealing with care co-ordination issues with, and for, their clients. There was a view across all case sites, including those with integrated services and commissioning arrangements, that integration was not widespread enough. Barriers and facilitators to achieving integration could be at the personal, service and structural levels but these factors were not mutually exclusive. Integration at a practice level, which was often instigated and maintained by practitioners, was facilitated by robust organisational structures supporting integration or by structures and commissioning processes that promoted bottom-up innovation.

Developing and maintaining personal–professional relationships was key to making integration work. However, organisational and service restructuring could fragment integrated arrangements. Current structural changes and insecurity made innovation towards increased integration particularly difficult for practitioners, service managers and commissioners alike.

### ***What outcomes do people with long-term conditions want from integrated health and social care?***

Analysis of interviews with service users identified desired outcomes ranging from those focusing on health benefits and improvements to wider social outcomes concerned with the more everyday aspects of life. Our findings suggested three domains – ‘personal comfort’, ‘economic and social participation’ and ‘autonomy’ – within which outcomes could be framed. The parameters of the constituent outcomes were defined according to the meanings attributed by service users. These outcomes are listed below.

#### **Personal comfort outcome domain**

- Personal hygiene and care.
- Safety/security.
- Desired level of household cleanliness and maintenance.
- Emotional well-being.
- Physical health and functioning.
- Cognitive skills.

#### **Autonomy outcome domain**

- Access to all areas of the home.
- Access to locality and wider environment.
- Being able to communicate.
- Financial security.
- Personal decision-making.

#### **Social and economic participation outcome domain**

- Access to paid employment as desired.
- Access to training or new skills.
- Access to further/higher education.
- Establishing and maintaining social and recreational activities.
- Developing and/or maintaining intimate personal relationships and roles.
- Developing and/or maintaining family relationships and roles.
- Developing and/or maintaining social relationships and roles.
- Access to advocacy and peer support.
- Contributing to wider community/ies.

These outcomes were frequently intermediate steps in attaining ‘higher-level’, less tangible, personal outcomes. We identified five higher-level outcomes in the accounts of people with LTNCs. These were independence, choice, control, ‘normality’ and self-esteem. In addition, lower-level outcomes, for example, achieving functional mobility or personal cleanliness, contributed to achieving the outcomes included in the three domains.

Inter-relationships between outcomes existed, both within a particular domain and across domains. Relationships between outcomes appeared to be linked with participants’ sense of achieving higher-level outcomes. Outcomes at lower and intermediate levels could work together to contribute to the higher-level outcomes in ways that were often complex and varied depending on service user circumstances.

### **Can these outcomes be assessed in everyday service delivery?**

Although the individual outcomes were valued differently across teams, and this influenced the extent to which they were used, it is clear that these outcomes can be assessed as part of practice by NRTs.

We encountered divergent approaches to exploring clients' needs and views differed about whose responsibility it was to identify them. Some of the outcomes were already being assessed, but were conceptualised differently. However, the OC, with the accompanying list of parameters, encouraged some of the NRTs to discuss outcomes in more detail and guided them to prompt clients about the wider interpretation of outcomes that service users had taken. Some of our outcomes added value to existing client assessment practices. In particular, *personal decision-making*, *access to advocacy and peer support*, and *developing and/or maintaining intimate personal relationships and roles* were seen to extend current assessment documentation for some teams.

Some outcomes proved difficult for some NRT staff to broach in client assessments, particularly *financial security*, *emotional well-being*, and *developing and/or maintaining intimate personal relationships and roles*. Perceptions of the outcomes being too sensitive to raise, or not being within the professional's remit, partly accounted for this. Reluctance to raise outcomes in assessment was also linked to an absence of services to address issues related to these outcomes. Additional challenges to using the outcomes in practice included staffing and caseload pressures, changes to service structures and remit, and competing demands of other compulsory paperwork.

Our research suggested that teams whose practice extended beyond an impairment-based approach were better able to use the OC as part of assessment processes, while those with a more biomedical focus had more difficulty using it. All teams welcomed the evidence-based nature of the OC and the way that outcomes were derived from service users' views. Interest in incorporating it into team practice varied across case sites. One NRT felt that it duplicated existing assessments, one felt that it covered issues outside their remit and two felt that the OC worked for them and were keen to think about how to use it in assessments in future. All teams felt the checklist would have use as a training and/or benchmarking tool.

Evidence from service users about their experience of being assessed using the OC demonstrated that it held face validity, reflecting and covering the key issues that were important to those with LTNCs, and could be a useful way of assessing their care needs. Some service users expressed hesitancy in talking about some of the issues, such as intimate relationships and finances, but this was primarily because these issues were seen as being outside the remit/expertise of the team. Participants felt that the checklist covered the things that were important to them. However, the importance or emphasis they placed on each of the outcomes might change over time, based on changes in their condition and/or other circumstances. Nonetheless, service users thought it was useful to use the checklist in its entirety to ensure that all of people's key issues were sure to be covered in assessments.

It was also recognised that achieving outcomes is a dynamic process that requires awareness of the inter-relationships between different types of outcomes. Identifying the three levels of outcomes of lower, intermediate and higher level reflected service user perceptions, as well as providing a useful framework on which to base discussions that could complement existing practice.

### **How can different models of integrated health and social care affect outcomes?**

There are three ways that models of integrated care can affect outcomes: the way outcomes are interpreted, how outcomes are assessed and, ultimately, how outcomes are achieved.

Where the NRT model was concerned more with functioning and medication issues in discrete episodes of care, the interpretation and assessment of outcomes was limited to reflecting these priorities. Outcomes beyond these (e.g. social participation outcomes) were felt to be outside these teams' remit. Embedding interdisciplinarity in the model of integration gave more scope to interpret, assess and potentially achieve the outcomes through professionals working together and sharing expertise.

## Conclusions

The research has a number of implications for policy and practice.

1. Understanding and assessing outcomes.
  - i. Many of the outcomes that are important to service users with LTNCs are not addressed in validated 'outcome measures'.
  - ii. This has implications not only for service users' experiences of the type and quality of care delivered, but also for those commissioning care in identifying priorities for investment.
2. Outcomes assessment in practice.
  - i. Equity of assessment can be compromised if practitioners do not feel the need to raise each outcome.
  - ii. Service availability may affect whether or not outcomes are assessed in practice.
  - iii. In the context of long-term conditions, assessment of service user outcomes must account for potential fluctuation and/or deterioration over time.
  - iv. Understanding of, and meanings attributed to, individual outcomes by service users may differ from conventional staff- or service-derived outcomes.
3. Innovation and integration.
  - i. Restructuring of health and social care services fractures existing integration arrangements.
  - ii. Instability resulting from restructuring affects services' scope to innovate around integration.

## Future research

The research identified several areas for future research.

1. Developing the outcomes into a measurement tool could help address the problem of assessing the full impact of integrated services, such as NRTs, on the lives of people with LTNCs. As well as assessing impact, a measurement tool could demonstrate the breadth of team activity, which would provide a useful way of assessing cost-effectiveness.
2. Many of the outcomes are interdependent. It is therefore important to ensure that all outcomes are considered during assessments. Ensuring that all outcomes are discussed is also important in achieving equity in assessment. Further research may help to understand better the impact of overlooking certain outcomes during assessment.
3. Some of the teams we worked with engaged with the research more so than others. Engagement from NHS and social care staff is vital to the conduct of high-quality research. Further research should examine this issue to understand further the factors that facilitate stakeholder engagement and to help in planning future research.
4. Teams who were involved in this research expressed concern about the future of local community-based specialist integrated services for people with LTNCs once commissioning arrangements were changed. Future longitudinal research could monitor any changes in community services for long-term complex conditions and assess their impact and cost-efficiency.

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