Article:

Spiers, Gemma Frances orcid.org/0000-0003-2121-4529, Aspinal, Fiona Jane orcid.org/0000-0003-3170-7570, Bernard, Sylvia Margaret et al. (1 more author) (2015) What outcomes are important to people with long-term neurological conditions using integrated health and social care? Health and Social Care in the Community. pp. 559-568. ISSN 1365-2524

https://doi.org/10.1111/hsc.12171

What Outcomes are Important to People with Long-term Neurological Conditions using Integrated Health and Social Care?

G. Spiers[1], F. Aspinal[2], S. Bernard[3], G. Parker[3]

[1] BSc (Hons), MSc. Affiliation: Social Policy Research Unit, University of York, [2] BA (Hons), MA, PhD, RGN. Affiliation: Social Policy Research Unit, University of York

[3] BA (Hons), PhD. Affiliation: Social Policy Research Unit, University of York

[4] BA, PhD. Affiliation: Social Policy Research Unit, University of York

This is the peer reviewed version of the following article: Spiers, G., Aspinal, F., Bernard, S. and Parker, G. (2015) What outcomes are important to people with long-term neurological conditions using integrated health and social care?, Health and Social Care in the Community, 23, 5, 559-568, which has been published in final form at http://onlinelibrary.wiley.com/doi/10.1111/hsc.12171/abstract.

Acknowledgements

This project was funded by the National Institute for Health Research Health Services and Delivery Research programme (project number: 09/1816/1004). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. Thanks are extended to members of the project's advisory committee, and all those who participated in the research.

What Outcomes are Important to People with Long-term Neurological Conditions Using Integrated Health and Social Care Services?

Abstract

Measuring the outcomes that are meaningful to people with long-term neurological conditions (LTNCs) using integrated health and social care services may help to assess the effectiveness of integration. Conventional outcomes tend not to be derived from service user experiences, nor are they able to demonstrate the impact of integrated working. This paper reports findings about outcomes identified as being important to people with LTNCs using integrated services. We undertook qualitative work with five community neuro-rehabilitation teams (NRTs) that were integrated in different ways and to different degrees. In-depth, semi-structured interviews were conducted with thirty-five people with LTNCs using these teams. Data were collected between 2010 and 2011 and analysed using an adapted version of the Framework approach. We identified 20 outcomes across three domains: personal comfort outcomes, social and economic participation outcomes and autonomy outcomes. Inter-relationships between outcomes, both within and across domains, were evident. The outcomes, and the inter-relationships between them, have implications for how individuals are assessed in practice.

Keywords: Outcomes, health and social care, long-term conditions, integration

What is known about this topic:

- Standardised tools to assess outcomes overlook some factors that are important to people with LTNCs
- Integrated practice can affect a wider range of outcomes than those usually assessed as part of service evaluations and outcome measurement.

What this paper adds:

- Three domains of outcomes are important to people with LTNCs: personal comfort, economic and social participation, and autonomy outcomes.
- Inter-relationships exist between these outcomes.
- The service user-derived outcomes identified may contribute towards helping to assess the effectiveness of health and social care integration.

Introduction

Integration, an 'organising principle for care delivery that aims to improve patient care' (Shaw *et al.*, 2011p. 3), is a key policy concern in the UK. It is conceptually ambiguous, but in practice, integration can take many forms, for example, pooled budgets, co-location, inter-disciplinary teams, or shared practice tools (Kodner & Spreeuwenburg, 2002). There is a substantial literature about the structures, processes and impact of integration (Hudson *et al.*, 1997b, Hudson *et al.*, 1997a, Glendinning, 2003, Cameron *et al.*, 2012, Cameron *et al.*, 2014). However, evidence about its effectiveness for service users, and achieving the outcomes that are important to them, is largely missing from this literature.

Previous research has investigated the effectiveness of integration for people with long-term neurological conditions (LTNCs) such as brain or spinal cord injury, multiple sclerosis (MS), motor-neurone disease and Parkinson's disease (Department of Health Long-term Conditions NSF Team, 2005). This research has typically focused on outcomes such as physical functioning, health related quality of life, clinical outcomes, and mental health (Parker *et al.*, 2010). However, whilst people with LTNCs argue that integrated care contributes to their quality of life, research employing these 'conventional' health service outcome measures has not provided conclusive evidence of this (Bernard *et al.*, 2010, Parker *et al.*, 2010). It is possible, therefore, that these outcome measures do not capture the impact that integration may have on the outcomes and issues important to people with LTNCs. To measure such outcomes, it is essential to first identify what these outcomes are and understand their relevance in health and social care practice.

To date, no research has examined these sorts of outcomes for people with LTNCs. However, a previous programme of research undertaken by Qureshi *et al.* (1998) and Bamford *et al.* (1999) identified the outcomes important to younger disabled and older people using social care services. These outcomes were conceptualised at the person, rather than service, level, and reflected change, maintenance and service process issues. Later work by Harris *et al.* (2005) refined this work to produce a framework of outcomes rooted in the social model of disability. Harris *et al.'s* (2005) framework comprised the four groups of outcomes listed in Box 1. Although this outcomes work was developed with a wide range of user groups, its focus on person level issues provides a useful starting point for identifying outcomes important to people with LTNCs.

Box 1. Harris *et al.* (2005) Outcomes Framework

Autonomy outcomes	***Personal comfort outcomes***
Access to all areas of the home	Personal hygiene
Access to locality and wider environment	Safety/security
Communication access	Desired level of cleanliness of home
Financial security	Emotional well-being
	Physical health
Economic participation outcomes	***Social participation outcomes***
Access to paid employment as desired	Access to mainstream leisure activities
Access to training	Access to support in parenting role
Access to further/higher education/employment	Access to support for personal secure relationships
Access to appropriate training for new skills (e.g. lip reading)	Access to advocacy/peer support
	Citizenship

Aims of the research and paper

The wider study from which these findings are taken, aimed to explore how service user-derived outcomes could be used in integrated health and social care practice for those with LTNCs. There were three stages of research:

- Stage 1: we identified outcomes important to those with LTNCs
- Stage 2: we developed these outcomes into a checklist and piloted the checklist in practice
- Stage 3: we evaluated the checklist, and the relevance and use of the outcomes, in integrated health and social care practice

This paper presents findings from stage 1, where we built on the conceptual and empirical work described above to understand the outcomes important to people with LTNCs using integrated services. By doing this, we clarified the parameters of the outcomes, explored if, and how, these domains and outcomes were important, and identified additional outcomes important to this client group. We were careful to focus on the things that service users wanted to achieve, rather than the aims and outcomes of the services themselves. From this, we developed a service user-derived ‘checklist’ of outcomes (stage 2).

The aim of this paper is to present findings about the outcomes we identified as being important to people with LTNCs. Findings about the development, implementation and evaluation of the outcome checklist are presented elsewhere (Aspinal *et al.*, 2014).

Methods

Design

The wider study, from which the findings presented here are taken, adopted a case study approach, which was appropriate for the research aims (Patton, 1990, Yin, 2003). However, the findings presented here, draw on service user data that were analysed across sites, rather than *by* site. Nonetheless, it is important to note that across these case sites, there were five community-based neuro-rehabilitation teams (NRTs). The service user sample was recruited via these NRTs. Table 1 provides a summary of the NRTs.

Table 1. Summary of the case site NRTs

NRT	Generic/Condition Specific	Number of staff in team	Integration arrangements
A(1)	Condition specific (MS)	3	Joint working arrangements with social and secondary care.
A(2)	Condition specific (BI)	3	Joint working arrangements with social care when share a client.
B	All neurological conditions	20-23	Joint health and social care team. Multi-disciplinary.
C	Progressive neurological conditions	7-10	Multi-disciplinary. Formal joint working arrangements with social and secondary care.
D	All neurological conditions	2-3	None

Two NRTs were condition specific (Brain Injury (BI) and MS), one supported people with progressive neurological conditions and the remaining two covered all neurological conditions. The non-condition specific teams covered a range of LTNCs.

Data collection and materials

In-depth, semi-structured interviews, a widely used data collection technique in qualitative research (DiCicco-Bloom & Crabtree, 2006), were undertaken with adults with LTNCs who were clients of one of these five NRTs. These interviews explored the outcomes that were important to them. A topic guide, informed by Harris *et al.'s* (2005) outcomes framework, was used. This covered outcomes relating to autonomy, personal comfort, economic and social participation, as listed in Box 1. We also asked service users to discuss issues that they felt were not covered by the framework. Interviews lasted between 30 and 90 minutes, were audio-recorded with participant's consent, and transcribed. Data were collected between August 2010 and June 2011.

Recruitment and sample

We aimed to recruit clients representing the range of conditions and different service needs that the NRTs covered. However, at the time of the research, all non-condition specific team's caseloads had a higher proportion of individuals with MS. Clients were eligible if: they had a LTNC; were existing clients or had been clients of the NRT within the previous six months; were aged 18 or over; and were cognitively able to give informed consent and participate in an interview. The NRTs identified clients who fulfilled these criteria and distributed invitation-to-participate packs. Clients were asked to respond directly to the research team.

We intended to recruit a maximum of forty people with LTNCs across the five NRTs. This decision was based on experience of similar studies with this client group that suggested this sample size would allow us to identify and explore the key issues around outcomes for this client group. Thirty-five people with a LTNC were recruited (see Table 2).

Table 2. Number of participants invited to participate and interviewed by site/NRT

Site/NRT	Invited to participate	Interviewed
A team 1	9	3
A team 2	9	5
B	25	12
C	25	13
D	3	2
Total	**71**	**35**

Of the 36 people who were invited but did not take part, one agreed to take part but had to withdraw due to an exacerbation of their condition, 26 did not respond despite being sent reminders, and nine people declined to participate. Only three people provided reasons for declining, all of which related to their neurological condition.

The neurological diagnoses of sample participants varied, but almost half were diagnosed with MS, reflecting the NRTs' client base. We achieved a spread of ages and gender, but we were unable to recruit any participants from minority ethnic backgrounds, despite at least two of the case areas having relatively high levels of ethnic diversity. Table 3 gives demographic details of the sample.

Table 3. Demographic details of participants

Demographic	**Number in sample**
Gender	
Male	17
Female	18
Primary diagnosis	
Multiple sclerosis	15
Brain injury	6
Motor-neurone disease	2
Parkinson’s disease	4
Stroke	5
Other	2
Prefer not to say	1
Age	
30-39	4
40-49	9
50-59	6
60-65	6
66-75	6
76-85	4
Ethnicity	
Asian	0
Black/Black British	0
White British	35
White Other	0

Ethical considerations

All participants were given information about the research, including their rights as participants, to enable them to make an informed decision about participation. Prior to interview, the consent process explained the research and participant's rights, and participants were given the opportunity to ask questions. Consent was obtained prior to interviews. To account for fatigue and other symptoms related to LTNCs, we advised participants that the interview could be paused so they could take breaks as needed.

The research and associated materials were approved by an NHS research ethics committee in 2010. Local governance approvals were granted by the relevant organisations.

Analysis

We used an adapted version of the Framework approach (Ritchie & Spencer, 1994, Ritchie & Lewis, 2003) to manage interview data. This approach comprises four stages of management: familiarisation and identification of themes, constructing a thematic framework or index, indexing, and charting the data on the framework. The framework is represented visually as a theme-by-case matrix. Applying this approach to the data, we constructed an initial a-priori analytical framework based on Harris *et al.'s* (2005) outcomes. An Excel©

spreadsheet was used for the matrix framework. Transcript data were indexed, and then charted onto the framework.

The framework then underwent several iterations as we explored the ‘fit’ of the data with the Harris et al. (2005) outcomes. We met several times to adapt the framework to better reflect the data, and data were re-charted accordingly. This reflective/re-charting process continued until we arrived at a framework of outcomes that most accurately reflected the data.

Each outcome identified in the final iteration of the framework constituted a framework ‘theme’. Data for each outcome were analysed thematically in the first instance and diversity within themes explored. Relationships and overlap between outcomes were then explored. This analysis assessed how the outcomes were important and provided a thick description of the parameters of each outcome.

Ensuring quality and rigour

The quality and rigour of the presented findings are underlined, first, by the appropriateness of the research design and method. Second, the purposive sample allowed us to access ‘key informants’ (Popay *et al.*, 1998). Third, the analytical approach was rigorous and systematic, a key criterion for the conduct of qualitative research (Ritchie & Lewis, 2003). For example, the iterative re-charting process described above ensured we achieved a framework that accurately reflected the data. Following this, and throughout the subsequent analysis, the three researchers leading on this component (FA, SB and GS) met regularly to discuss and review each other's interpretations of the data; an important process in the validation of findings (Ritchie & Lewis 2003). We also explored and confirmed the validity of the findings through our external advisory group of key stakeholders, and with other individuals with LTNCs as part of the later stages of research (see Aspinal *et al.*, 2014).

Findings

Whilst the outcomes we identified from participants' accounts largely reflected those of Harris *et al.* (2005), key differences were evident. As a result, we made minor revisions to some existing outcomes to reflect nuances in participants' accounts; added new outcomes across domains; and, conflated the economic participation and social participation domains into one. This resulted in twenty 'key' outcomes across three domains: personal comfort, autonomy, and social and economic participation. Table 4 lists the outcomes in each domain, and their parameters.

Where illustrative quotes are used, participant information is limited to their condition and interview number. Other information has been withheld to protect anonymity.

Domain 1: personal comfort outcomes

Six outcomes were identified as being important within this domain (see Table 4).

Personal hygiene was often discussed by participants. Its importance was reflected in language such as it being ‘top of the list’, or, regarding showering, something that ‘ought to be a human right’. It was often implicated in personal wellbeing, and to some extent, other outcomes such as personal safety in the home:

> ‘I want to take showers and things like that, I want it to be easy… its part of your independence, isn’t it, simple things like that? But yeah, it is important for your own wellbeing and your own confidence as well.’ (SU31, MS)

However, participants’ accounts went beyond issues of cleanliness and hygiene. They emphasised the importance of personal care activities, such as choosing clothes to wear, dressing, haircare and shaving. Thus, ‘personal hygiene’ was revised to include ‘personal care’.

The importance participants placed on household *maintenance* as well as cleanliness warranted the revision of the ‘household cleanliness’ outcome to include this. This was an important outcome for participants, although there were contrasting views about whether assistance was acceptable for achieving it. Assistance could be frustrating, but others felt it was acceptable, or even a socially ‘normal’ thing to do:

> There’s enough people who get cleaners in who, you know, just because they can’t be bothered to do it themselves *(*SU23, MS)

Both physical health *and* functioning (e.g. walking) played a key role in participants' lives, hence the revision of this outcome to include the latter. Poor physical health and functioning affected participants' social activities and outcomes, autonomy outcomes, employment and emotional wellbeing.

Similarly, emotional wellbeing permeated most other outcomes and issues. Often, it was linked to the achievement of other things, such as being able to get out of the house. It was described in a number of ways, ranging from issues of self-esteem, confidence and resilience, to having, and addressing, feelings of anxiety and depression.

Personal safety, both in and outdoors, was a critical issue for participants, and was underlined by the strategies and adapted routines that were used to counteract risks. For some, however, taking risks with personal safety outdoors offered a sense of independence and control. This suggests that, for some, independence and control were more important than issues of safety and that service users made personal choices to balance risk and independence in their daily lives:

> I want to get there on me own... If the day comes and I fall, I fall. I'll live with it (SU13, Stroke)

Maintaining and improving cognitive skills was identified as a new outcome in this domain, reflecting the importance of this for those with cognitive difficulties resulting from their condition.

Domain 2: social and economic participation outcomes

Participants' accounts often revealed social, as well as economic, motivations, for economic participation. For example, employment could be important for providing social opportunities and contributing to wellbeing:

> 'cos when you work you meet different people' (SU27, MS)

> '[work] gives you your own self-esteem and makes you [pause] – it makes you feel of value' (SU12, MS)

To reflect better how participants talked about the importance of these types of outcomes, we grouped economic and social outcomes into one domain. Nine outcomes were identified (see Table 4).

For the majority of participants, accessing training, new skills and further/higher education was neither important nor relevant, possibly as a result of the average age of the final sample. In cases where these *were* important, the personal satisfaction and sense of purpose gained from learning a new skill, or the associated social aspects, were highlighted. For some, access to further or higher education was a source of personal fulfilment, keeping motivated after stopping work, or a way of *'just keeping the cogs going'* (SU17, condition withheld).

Participants discussed three types of relationships: intimate and personal; family; and social. Three separate outcomes were included to reflect this. The importance of maintaining and developing familial roles and relationships included aspects of parenting and grand-parenting. It also reflected having time with family that did not involve caring roles:

> I like quality time for them to take me out, whatever, instead of 'em coming and spending hours cleaning for me, you know (SU6, BI)

People with LTNCs were also keen to emphasise that they were not only recipients of 'care' but that they also adopted supportive roles within the family, for example, babysitting nieces or nephews.

Intimate and personal relationships reflected the importance of spousal and partner relationships, and being able to develop new sexual relationships in the face of disability:

> I may be a broken and battered old man, but it doesn't stop the brain thinking about how nice it used to be to be sexual (SU20, MS)

The importance of social relationships and roles reflect both the need to *maintain* existing friendships and relationships so that one did not '*lose touch* *and just fade away*' (SU5, BI) *and* develop new ones. To maintain these relationships, activities and roles were adapted in response to their condition. Other issues, such as environmental accessibility could impact maintenance of friendships:

> It's really quite hard to get into… a friend's house; I can never get
> into their house and even those that maybe I can get in, then they've
> got an upstairs toilet or something and it's impossible now (SU3, MS)

Social participation was also reflected in accounts of accessing advocacy and peer support. The nature of 'peers' described by participants varied, and included those who shared similar life experiences, beliefs and/or social activities and could include friends, neighbours and people who were part of the same social groups. Support and reassurance was seen as an integral element. Therefore, we were careful to distinguish between the support provided via advocacy and peer relationships, and support achieved through social relationships (see Table 4).

'Establishing and maintaining social and recreational activities' replaced 'access to mainstream leisure activities' in Harris *et al.'s* (2005) original list. The revision acknowledges the importance that some participants placed on accessing specialist activities, such as 'disabled' swimming groups and social meetings, not just mainstream activities. Participants also described a wide range of 'mainstream' social activities that they enjoyed, such as going out for meals, watching and/or participating in sport and going to the 'pub'.

“Citizenship” was an ambiguous concept for participants, but many talked about the importance of being able to contribute to the wider community. For example, voluntary work was identified as something that played an important role for participants, and was linked to maintaining personal wellbeing. Some participants focused on the importance to them of political participation, such as voting and being an active member of pressure groups.

Domain 3: autonomy outcomes

Five outcomes were identified in this domain (see Table 4).

‘Being able to communicate’ replaced the original outcome ‘communication access’, and reflected how participants talked about, for example, the importance of regaining speech skills following experiencing a stroke and communicating one’s wants and needs:

> I wanted to get back to being OK and saying what I wanted to say (SU16, BI)

‘Personal decision-making’ was added as an outcome to this domain because of the importance participants placed on this for maintaining choice and control in their decision-making:

> ‘I’ve never had to, to rely on somebody else to make a choice for me. I mean I might have to, I mean who knows? I’m fortunate that, OK,

> I’m physically disabled now, but I’m not mentally disabled, you know’ (SU29, MS)

The three remaining outcomes - access to all areas of the home, access to locality and wider environments and financial security – were unchanged, as was the importance participants placed on them. For example, the importance of being able to access all areas of the home as independently as possible was underlined by the fact that adaptations were used to facilitate access, and that some chose to self-fund adaptation rather than to wait long periods for services to fund these.

Being able to get out to the wider environment was a dominant theme in participants’ accounts. Two discourses of environmental accessibility were evident in the data – *getting to* places and *getting in and around* places. *Getting to* places was the most dominant discourse, and perhaps reflected the difficulties associated with this experienced by many in the sample. It was often implicated in other outcomes such as emotional wellbeing and personal safety.

For example, one participant described difficulties accessing the local area due to safety concerns. This, in turn, had affected his ability to participate in social activities, and subsequently, his emotional wellbeing. Because of this inaccessibility of the local environment, outings could not be spontaneous, required planning ahead and dependence on family, meaning that he felt ‘limited’ in what he was able to do independently. He described the personal implications of an inaccessible environment:

> I’m sick to death of these four walls, I want to go into [town], get myself something nice for tea, prepare it properly how I want to do it. It’s a big thing for me (SU6, BI)

Financial security was linked with a sense of emotional ease and relief (e.g. being happier or avoiding anxiety); it facilitated social activities, funded assistance to ease pressure on family carers, enabled retention of one’s home, and facilitating a sense of independence.

Table 4. Outcomes identified, by domain, and their associated parameters

DOMAIN 1: PERSONAL COMFORT OUTCOMES	
Personal hygiene and care	Being able to maintain routines related to personal cleaning (e.g. washing hair, showering), toileting, and personal care (e.g. dressing, shaving); maintaining these with as much independence as possible (e.g. through adaptations).
Safety/security	General personal safety; personal safety in the home and outdoors; home security.
Desired level of household cleanliness and maintenance	All tasks relating to the maintenance of house (e.g. cleaning, bigger maintenance tasks such as painting) and garden.
Emotional wellbeing	Maintaining general day-to-day wellbeing; being able to cope and maintain personal resilience; dealing with specific and longer-term emotional difficulties.
Physical health and functioning	All aspects of physical health and related issues (such as accessing exercise opportunities), but also physical functioning issues, such as walking, balance, and motor control.
Cognitive skills	Cognitive skills such as memory, concentration, and attention.
DOMAIN 2: ECONOMIC AND SOCIAL PARTICIPATION OUTCOMES	
Access to paid employment as desired	Any activity that involves **paid** employment, full or part-time, wherever based, and that may or may not be related to past activity.

Access to training or new skills	Any training, or acquiring of new skills that may be undertaken for a range of reasons, that may encompass personal, social, work-related or other reasons.
Access to further/higher education	Any educational activity that is undertaken for personal, social, work-related or other reasons.
Establishing and maintaining social and recreational activities	Getting out (for a purpose, or the sake of getting out); being able to start/maintain the social/recreational activities as preferred; adapting how activities are done or changing activities so person is able to continue to take part in social/leisure/recreational activities of their choice
Developing and/or maintaining intimate personal relationships and roles	To include sexual relationships, long-term partnerships, marriages etc.
Developing and/or maintaining family relationships and roles	To include parenting/grand-parenting relationships and roles; relationships, roles and support from/to siblings, children and other wider family members.
Developing and/or maintaining social relationships and roles	Developing and maintaining activities and roles that promote friendships, relationships with neighbours and with wider social groups.
Access to advocacy and peer support	Only that provided by voluntary organisations and other condition specific groups (not by friends, etc.)
Contributing to wider community/ies	Voluntary work, providing advocacy for other people with LTNCs personally or via voluntary organisations, maintaining and developing political engagement.

DOMAIN 3: AUTONOMY OUTCOMES	
Access to all areas of the home	Being able to access different areas of the home and garden as independently as possible.
Access to locality and wider environment	Being able to get to desired destinations, as well as being able to get in and around buildings (other than one's own home – see above); issues around shopping access (including accessibility of shopping areas and general assistance (e.g. for packing/unpacking shopping).
Being able to communicate	All aspects of functional communication (e.g. verbal, sign). This outcome does not include social communication skills (e.g. use of internet)
Financial security	All aspects of financial security, including, for example benefit entitlement
Personal decision-making	All aspects of being able to make decisions about one's own life, including care and support decisions, timely access to equipment and adaptations, choosing one's own shopping, and issues around being informed.

Discussion

The findings presented provide new insight into the outcomes important to people with LTNCs and reflect some movement from previous understanding of outcomes. Here, we place these outcomes in the wider literature, policy and practice context.

How the outcomes we identified differ from the previous outcomes frameworks

Three key differences are evident between the outcomes we identified and those of Harris *et al.* (2005). First, our findings suggested three domains around which outcomes could be framed. Whilst these largely reflect the domains used by Harris *et al.,* the key difference is that we combined social and economic participation outcomes into one domain. This decision reflected the social emphasis participants placed on economic participation outcomes, and the relatively minor emphasis placed on economic motivations for participating in the labour market or training. In the original outcomes work of Bamford *et al.* (1999), social and economic outcomes were also grouped together.

Secondly, we identified additional outcomes, such as cognitive skills and personal decision-making. These were not in Harris *et al.'s* framework and may reflect the nature of our study sample as cognitive difficulties are not uncommon for those with LTNCs. The importance that participants placed on personal decision-making seemed to stem from a desire to be involved in decisions about their care and support and a need for autonomy in, and control of, their lives. Personal decision-making was not in Harris *et al.'s* framework but it reflects an outcome identified in the original outcomes work by Qureshi *et al.* (1998) and Bamford *et al.* (1999) – 'having a say in services' . However, our research extends this outcome to incorporate other aspects of people's lives.

Thirdly, the way participants characterised some outcomes meant that they did not fit in with the pre-existing outcomes framework. Outcomes were revised slightly to reflect the nuances of participants' accounts. These changes may have reflected the different client group in our research, policy or service developments, or changes in service user expectations and life-styles over time.

Petch *et al.* (2013), working with people with mental health problems, learning disabilities and older people, have also recently extended Harris *et al.'s* framework by identifying two additional outcomes - *living where you want* and *dealing with stigma and discrimination*. Although the participants in our research did talk about issues related to their home and housing, *living where you want* did not emerge strongly in our research. *Dealing with stigma and discrimination* was implied through participants' own references to experiencing 'normality' – referring to socially accepted norms (e.g. hiring a cleaner) or comparing themselves now to themselves prior to the onset of illness. However, 'normality', as referred to by participants, was something that was implicated in a number of outcomes in this study, rather than being an outcome in its own right (see Aspinal *et al.*, 2014). There may be several reasons why Petch *et al.* (2013) identified this as an outcome in its own right and we did not. It may, for example, reflect the different samples in the two studies or the different ways we have interpreted participants' accounts.

How the outcomes are verified by quality of life literature for LTNCs

The outcomes identified as important in our study also reflect, and are verified by, evidence about the challenges faced by disabled people, including those specifically with LTNCs. For example, our study shows the importance of social, personal and familial relationships. Elsewhere, compromised social, personal and familial relationships have been shown to affect quality of life after stroke (Lynch *et al.*, 2008). Emotional wellbeing and maintaining social relationships and activities were considered important outcomes in this study. Similarly, being happy and as socially active as possible has been reported elsewhere as being central to quality of life for those with MS (Somerset *et al.*, 2002). Lynch *et al.* (2008) report how difficulties with speech impede self-esteem after stroke; regaining speech following stroke was also found to be implicated in self-esteem and self-worth in our research. Imrie (2004) reports the household restrictions experienced by disabled people, for example, being unable to get out, which resulted in social restrictions. Again, this reflects issues arising in our study, particularly the importance of 'getting out' as part of the outcome '*access to locality and wider environment'*.

Relationships between outcomes

Inter-relationships between outcomes and across domains existed and can be observed throughout the outcomes. These inter-relationships demonstrate a complexity about what is important in the lives of people with LTNCs and also how an impact on one particular outcome can have a 'knock-on' effect with other outcomes. This indicates that outcomes should not be considered in isolation and underlines the importance of a holistic approach to assessing an individual's needs (see also Aspinal *et al.*, 2014).

Implications for policy and practice

The outcomes we identified have implications for practice. Earlier research shows that integrated NRTs can struggle to demonstrate the value and impact of their service to commissioners (Bernard *et al.*, 2010). Outcome measures used by these sorts of teams tend to focus on functional and cognitive status and on emotional health, and often overlook issues that are also addressed as part of the rehabilitation process (Bernard *et al.*, 2010, Aspinal *et al.*, 2014). By identifying a set of comprehensive outcomes important to clients that use these teams, the research has taken a step towards addressing this issue. The identified outcomes, and the inter-relationships between them, may also have implications for how individuals are assessed in practice. This issue was addressed as part of the wider research, and is reported elsewhere (Aspinal *et al.*, 2014).

The findings also have implications for policy on outcomes and integration. The NHS Future Forum's report argued that integration is about better outcomes for people and putting people at the centre of their care. The report also recommended the development of patient reported experience measures (Field, 2012). Our findings can contribute to the development of that approach, by setting out the outcomes defined as important by service users.

Strengths and limitations of the research

We aimed to identify the outcomes important to those with LTNCs, and our approach to this was guided by earlier outcomes research (Harris *et al.*, 2005). However, an immediate challenge we faced was understanding the evidence behind these original outcomes. While this presented initial difficulties, as we had intended to use this framework as a guide when identifying the outcomes with our sample, it also presented us with the opportunity to ‘re-write’ the outcomes according to the meanings attached to them by our participants. Therefore, the outcomes identified were service user-driven and rooted in their experiences of what they considered important in their lives. This is a major strength of the study.

We had aimed to recruit 40 participants across the four case sites. We fell short of this target and achieved 35. Nonetheless, the themes identified were evident across participants’ accounts, suggesting that more data, through a larger sample, was not required to ‘saturate’ existing themes emerging from the analysis. However, there were some limitations with the diversity of the sample. Sample diversity is important in qualitative research, as it facilitates the identification of variation and patterns in experience (Miles & Huberman, 1994). We were able to achieve sample diversity in some respects, but not others. First, we were unable to recruit participants from ethnic minority backgrounds. This raises a question about whether outcomes and issues reflecting culturally diverse circumstances are absent from our data. Secondly, the sample is largely skewed to those with MS. This reflects the caseload of the case site teams at the time of the research. Whilst we were able to include people with other LTNCs, it is possible that other outcomes and issues that are especially important to those with rarer conditions did not emerge as strongly in our dataset. Further work could address this and explore the fit of the outcomes for people with other LTNCs.

Conclusions

Outcome measures used by services tend to focus on functional and cognitive status and emotional health. Our outcomes go beyond these to include issues that might be important for assessing the value and impact of integrated services for people with long-term conditions.

Previous work has identified outcomes important to younger disabled and older people. Our work builds on this by identifying the outcomes important specifically to people with LTNCs. Three sets of outcomes were identified: personal comfort outcomes, autonomy outcomes, and economic and social participation outcomes. Outcomes that had not been included in Harris et al.'s (2005) framework were identified. Outcomes were closely related and participants' accounts exposed how meeting one outcome could affect achievement of other outcomes. This suggests that a holistic view of the individual during assessment may best help people with LTNCs achieve the outcomes that are important to them.

References

Aspinal, F., Bernard, S., Spiers, G. & Parker, G. (2014) Outcomes Assessment for People with Long-term Neurological Conditions: A qualitative approach to developing and testing a checklist in integrated care. *Health Services and Delivery Research, 2.* National Institute of Health Research.

Bamford, C., Qureshi, H., Nicholas, E. & Vernon, A. (1999) Outcomes of Social Care for Disabled People and Carers. *Outcomes in Community Care Practice.* Social Policy Research Unit, University of York, York.

Bernard, S., Aspinal, F., Gridley, K. & Parker, G. (2010) Integrated Services for People with Long-term Neurological Conditions: Evaluation of the Impact of the National Service Framework: Final Report. Social Policy Research Unit, York.

Cameron, A., Larch, R., Bostock, L. & Coomber, C. (2012) Factors that promote and hinder joint and integrated working between health and social care services. Research Briefing 41. Social Care Institute for Excellence, London.

Cameron, A., Lart, R., Bostock, L. & Coomber, C. (2014) Factors that promote and hinder joint and integrated working between health and social care services: a review of research literature. *Health & Social Care in the Community,* **22,** 225-233.

Department of Health Long-term Conditions NSF Team (2005) The National Service Framework for Long-term conditions. Department of Health, London.

DiCicco-Bloom, B. & Crabtree, B. (2006) The qualitative research interview. *Medical Education,* **40,** 314–321.

Field, S. (2012) NHS Future Forum Summary Report - second phase. Department of Health, London.

Glendinning, C. (2003) Breaking down barriers: integrating health and care services for older people in England. *Health Policy,* **65,** 139-151.

Harris, J., Foster, M., Jackson, K. & Morgan, H. (2005) Outcomes for Disabled Service Users Social Policy Research Unit, University of York York.

Hudson, B., Hardy, B., Henwood, M. & Wistow, G. (1997a) Strategic Alliances: Working Across Professional Boundaries: Primary Health Care and Social Care. *Public Money & Management,* **17,** 25-30.

Hudson, B., Hardy, B., Henwood, M. & Wistow, G. (1997b) Working across professional boundaries: primary health care and social care. *Public Money and Management,* **Oct-Dec** 25-30.

Imrie, R. (2004) Disability, embodiment and the meaning of the home. *Housing Studies,* **19,** 745-763.

Kodner, D. & Spreeuwenburg, C. (2002) Integrated care: meaning, logic, applications, and implications – a discussion paper. *International Journal of Integrated Care,* **2,** 1-6.

Lynch, E. B., Butt, Z., Heinemann, A.*, et al.* (2008) A Qualitative Study of Quality of Life After Stroke: The Importance of Social Relationships. *Journal of Rehabilitation Medicine,* **40,** 518-523.

Miles, M. B. & Huberman, A. M. (1994) *Qualitative Data Analysis: An expanded sourcebook,* Sage, Thousand Oaks, CA.

Parker, G., Bernard, S., Gridley, K., Aspinal, F. & Light, K. (2010) Rapid Systematic Review of International Evidence on Integrated Models of Care for People with Long-term Neurological Conditions: Technical Report. *SPRU Working Paper No SDO 2400.* Social Policy Research Unit, University of York, York.

Patton, M. Q. (1990) *Qualitative evaluation and research methods,* SAGE, Newbury, CA; London.

Petch, A., Cook, A. & Miller, E. (2013) Partnership working and outcomes: do health and social care partnerships deliver for users and carers? *Health & Social Care in the Community,* **21,** 623-633.

Popay, J., Rogers, A. & Williams, G. (1998) Rationale and Standards for the Systematic Review of Qualitative Literature in Health Services Research. *Qualitative Health Research,* **8,** 341-351.

Qureshi, H., Patmore, C., Nicholas, E. & Bamford, C. (Eds.) (1998) *Outcomes of Social Care Practice for Older People and Carers,* Social Policy Research Unit, University of York, York.

Ritchie, J. & Lewis, J. (Eds.) (2003) *Qualitative Research Practice: A guide for social science students and researchers,* Sage, London.

Ritchie, J. & Spencer, L. (1994) Qualitative data analysis for applied policy research. IN A. Bryman & R. Burgess (Eds.) *Analyzing qualitative data.* Routledge, London.

Shaw, S., Rosen, R. & Rumbold, B. (2011) What is integrated care? *Evidence for Better health care.* Nuffield Trust.

Somerset, M., Sharp, D. & Campbell, R. (2002) Multiple sclerosis and quality of life: a qualitative investigation. *Journal of Health Services Research & Policy,* **7,** 151-159.

Yin, R. (2003) *Case Study Research: Design and Methods (3rd ed.),* Sage, Thousand Oaks, CA.