



Outcomes for Users and Carers in the Context of Health and Social Care Partnership Working: From Research to Practice

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ABSTRACT

There is currently much policy emphasis on both partnership working between health and social services in the UK and on the outcomes delivered by services. This article provides an account of two consecutive projects centred on these two themes. The first project, at the University of Glasgow, sought to address the lack of evidence about the outcomes delivered to service users by partnerships. Following from this project, the Joint Improvement Team of the Scottish Government commissioned the researchers to develop a toolkit to involve users and unpaid carers in performance management in community care in Scotland. The remit of this second project expanded during 2007 as it became linked with the development of the emerging National Outcomes Framework for community care in Scotland. This article outlines the outcomes-based piloting work currently under way in Scotland.

KEYWORDS: PARTNERSHIP WORKING; USER AND CARER OUTCOMES; SERVICE USER RESEARCHERS; SCOTLAND; PERFORMANCE MANAGEMENT

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Introduction

Both the process of partnership working between health and social care and an emphasis on the outcomes of service delivery have featured prominently in recent policy initiatives. Partnership working across health and social care is seen as being at the heart of providing seamless care and avoiding fragmentation (DoH, 1998). It was given renewed emphasis with the introduction of the flexibilities of the 1999 *Health Act* in England, which enabled pooled budgets between health and local authorities, lead commissioning and integrated provision, and the parallel provisions of the *Community Care and Health (Scotland) Act 2002*.



There has also been a major shift in focus towards the outcomes that services deliver, addressed most recently, for England, in the *New Outcomes Framework for Performance Assessment of Adult Social Care* (CSCI, 2006). In Scotland, *Better Outcomes for Older People* (Scottish Executive, 2004) strongly advocates an outcomes focus, and attention is currently focused on developing a national outcomes framework for community care in Scotland. In the context of the recent spending review in Scotland, a Single Outcomes Agreement for local authorities is currently influencing the development of outcomes approaches in community care at local and national levels (www.scotland.gov.uk/Resource/Doc/923/0054147). User involvement in definition and measurement of outcomes has also been emphasised in policy (DoH, 2001b; Scottish Executive, 2001), and the work currently under way in Scotland involves application of an integrated performance management framework that takes account of the user and carer experience.

This article reports on two research initiatives, from 2004 to 2006 and from 2006 onwards, focusing on partnership and outcomes. The key concern of the first project was to investigate whether policy initiatives driving the development of health and social care partnerships, and associated practice, were delivering improved outcomes, particularly the outcomes valued by service users and their unpaid carers. The second project, building on the findings of the first project, developed a toolkit for evaluating the extent to which services were delivering on key outcomes to service user and carers, with a view to improving community care services, and piloted its implementation in a range of community care settings.

Aims

Details of the objectives and methods employed in the two research projects described in this article are available on the Joint Improvement Team website (Petch *et al*, 2007; Cook *et al*, www.jitscotland.org.uk/action-areas/themes/involvement.html). This

article will provide an overview, drawing out key implications for practice. The aim of the first project, conducted at the University of Glasgow between 2004 and 2006, was to determine whether services delivered in partnership between health and social care deliver the outcomes that service users want (Petch *et al*, 2007). The project sought to meet this overall aim by addressing the following research objectives:

- to determine the outcomes that service users want from services
- to assess the extent to which health and social care partnerships deliver the outcomes that service users value
- to determine the features of partnership working that deliver these outcomes
- to refine the initial interview schedule into a generic user-defined service effectiveness tool.

These objectives were explored in the context of 15 health and social care partnerships supporting older people, individuals with mental health problems or with learning disabilities.

Following completion of the first project, two researchers were commissioned by the Joint Improvement Team (JIT) of the Scottish Government, responsible for supporting partnership working and practice across health, social care and housing, to develop a toolkit to involve users and carers more effectively in informing performance management approaches and information in community care (Cook *et al*, 2007). One of the early goals of this work was to develop a separate outcomes framework for unpaid carers, so that distinct tools for service users and carers could be incorporated into the toolkit. This work progressed alongside development of the National Outcomes Framework for Community Care in Scotland, and the UDSET (User Defined Service Evaluation Toolkit) is at the time of writing being piloted in eight health and social care partnerships in Scotland, including six early implementer partnerships for the Framework.



In the following account, the methods and findings sections describe the research co-ordinated by the University of Glasgow, while the applications section provides the background to the work ongoing on community care outcomes in Scotland.

Methods

The first study was conducted in partnership with three user-led organisations, Service User Research Enterprise, Central England People First and Older People Researching Social Issues, representing the three user groups who would be interviewed about the outcomes of partnership working. In order to address the first aim of the project, identifying the outcomes important to service users, the starting point was work on social care outcomes developed by the Social Policy Research Unit (SPRU) at the University of York (Qureshi, 2001). This work conceptualised the most important outcomes for users of social care services and their carers as falling into three categories; maintenance (quality of life), change (recovery and removing barriers to quality of life) and process (how people are treated by services) reflect services users' priorities. The validity of these outcomes was explored during three focus groups. Key concerns in this process were ensuring that the original work by SPRU, which was based largely on work with older people and focused on social care, was applicable to a wider range of service users and a broader range of services, using language understandable to people with diverse needs. Following from this, an interview schedule was developed based on a revised set of outcomes (Petch *et al*, 2005) and divided into four sections: the help you get, how using the service affects you and your life, what happens when you use the service and, finally, your thoughts on the service overall.

The next phase of the project entailed identifying partnerships to involve in the research, including five for each group of service users. A mapping process had highlighted the diversity and complexity of partnerships operating in the field. As distinct models of partnership were not

discernable on the ground, it was not possible to set up the research in such a way that we could deduce that one model of partnership was more effective than another. This shaped the sampling strategy to focus at the level of specific services **delivered** in partnership, as this was where service users were most likely to notice any difference that partnership working made. Detailed information was then collected on the **strategic level** partnership arrangements for each of these services, so that inferences about the influence of different aspects of these partnership arrangements on the outcomes for service users could be explored. Interviews were conducted with a total of 230 individuals across the 15 partnerships. Most of the interviews lasted between 30 minutes and 90 minutes. Paid and unpaid carers acted as proxies for service users in a small number of the interviews involving people with more severe learning disabilities.

The data gathered in the interviews was used to identify where and how outcomes were delivered by the partnerships. We then considered which partnership features supported delivery of the outcomes described.

Findings

Analysis of the research interviews and discussion with our user research partners led to identification of the key outcomes (from the SPRU framework) that service users want from the services they use. These are detailed in *Table 1*, overleaf.

There were similarities and differences in priorities relating to outcomes, as well as how outcomes were achieved across service user groups (Petch *et al*, 2007). It was important to respondents from all groups to have activity in their lives and to have some form of contact with other people. Interviewees from all three groups indicated that how they were treated by staff in services could be as important as what services achieved with regard to quality of life and change outcomes.

An example of differences between groups related to having contact with other people. In particular, there was strong emphasis by people

**Table 1: OUTCOMES IMPORTANT TO SERVICE USERS**

Quality of life	Process	Change
Feeling safe	Listened to	Improved confidence and skills
Having things to do	Choice	Improved mobility
Seeing people	Treated as an individual	Reduced symptoms
Staying well	Reliability	
Living life as you want	Responsiveness	
Living where you want		
Dealing with stigma		

Table 2: FEATURES OF PARTNERSHIP ASSOCIATED WITH GOOD OUTCOMES FOR SERVICE USERS

Key features of partnership	Related features of services	Outcomes delivered
Co-location of staff	Providing a single point of contact, improving access and communication	Process outcomes especially responsiveness Quality of life outcome: feeling safe
Multidisciplinary team	Providing holistic care	Change outcomes Quality of life outcomes Process outcomes
Specialist partnership	Providing specialist, non-discriminatory treatment	Process outcomes especially being treated with respect
Extended partnership	Providing access to other agencies, and partnership with service users	Quality of life outcomes including activity and contact with other people Process outcome: having choices

with mental health problems on social contact with other service users. For people with learning disabilities, there was more emphasis on relationships with trusted members of staff. In contrast to the other two groups, older people tended not to express preferences about who they wanted to have contact with. A key concern highlighted by many older people in discussing social contact related to their sense of safety, and the importance of knowing that somebody would be keeping an eye on them regularly, and that there would be a timely response if they should become unwell or experience a fall.

A number of barriers and supports to delivering good outcomes to service users were identified by the research. The key barriers identified did not necessarily relate specifically to partnership, but to services more generally. This is

consistent with the findings of other research projects which try to assess the impacts of policy on the ground, that service users are just as likely to describe the impact of funding restrictions as that of improvements in service design (Newman, 2005). Identified barriers were:

- staffing levels and continuity of staffing
- limits to resources
- access to transport, particularly in rural areas
- time-limited services.

Analysis of the accounts from service users in relation to key information gathered about each partnership enabled us to identify the key features of partnership that shaped service delivery in ways that supported the outcomes that service users valued. These features were as shown in *Table 2*, above.



In this project the involvement of user researchers strengthened various aspects of the research, although this collaborative approach was not without tensions (Miller *et al*, 2007). The value added by service user researchers was particularly evident in developing the original interview schedule, in the contribution of the additional insights from user researchers when interviewing and in more general observations on fieldwork sites.

Applications

Since the original research project concluded in May 2006, further work has taken place on applying the research in community care in Scotland. The two researchers from the DoH project were commissioned by JIT to disseminate the research findings to partnerships across Scotland, and to work with stakeholders to develop a toolkit to capture outcomes for service users. This also involved development of a separate outcomes framework for unpaid carers. The resulting toolkit, the User Defined Service Effectiveness Tool (UDSET), therefore contained separate tools for users and carers, designed both to improve outcomes for individual users and carers and to gather data for performance management purposes. The toolkit was also developed in collaboration with the developing national outcomes framework for community care.

Outcomes for and partnership with unpaid carers

Initial consultation with partnerships highlighted the need for a separate outcomes framework for carers, so a separate strand of work was undertaken to identify the outcomes important to unpaid carers specifically, and to work with stakeholders on developing associated tools (Miller, 2007). We looked at previous work done by SPRU on carers, which identified four broad categories of carer outcomes. The work by SPRU had included a number of outcomes relating to the quality of life of the cared for person. However, in focus groups with carers we found that in order to support carers to focus on their own lives, it was preferable to

minimise the focus on the cared for person in one general outcome. We modified the other outcomes categories through focus groups with carers and consultation with carers' organisations.

A key concern that emerged repeatedly during this period was the lack of engagement between agencies and unpaid carers. While staff in statutory services confirmed that they, quite justifiably, tend to prioritise the service user, they also acknowledged that this takes place to the exclusion of the unpaid carer. Staff raised further concerns about the implications of undertaking carers' assessments/support plans, in relation to both the time involved and the ensuing demands on resources. Meanwhile, simultaneous work with carers confirmed that, while access to quality services is important to many carers, the key concerns are lack of partnership with services and a need for access to information. The central concern of carers, to be treated as partners is, however, hindered by staff concerns about managing limited resources and their role as gatekeepers. Details of carers' views are set out in *Table 3*, overleaf.

The toolkit

Preliminary discussions with representatives from 13 health and social care partnerships in Scotland highlighted the potential of an outcomes-focused evaluation and review tool to encourage services to focus on delivering better outcomes to service users and carers and to work in partnership with service users and carers. The UDSET was therefore developed to enable workers to engage in structured conversations with service users and carers about the extent to which services are delivering good outcomes. Ongoing work is focusing on extending outcomes to assessment and care planning. User and carer review tools developed in Orkney, and an outcomes-focused carer's assessment/support plan from East Renfrew, have already been piloted. As with previous research on outcomes-focused tools (Guberman *et al*, 2003), this work has demonstrated that exchanges based on outcomes provide opportunities to improve communication



Table 3: OUTCOMES IMPORTANT TO CARERS

Quality of life for the carer	Managing the caring role	Process
Maintaining health and well-being	Choices in caring, including the limits of caring	Valued/respected and expertise recognised
A life of their own	Feeling informed/ skilled/equipped	Having a say in services
Positive relationship with person cared for	Satisfaction in caring	Flexible and responsive to changing needs
Freedom from financial hardship	Partnership with services	Positive/meaningful relationship with practitioners Accessible, available and free at the point of need

with users and carers and are likely to result in improved decision-making and more relevant interventions (Cook *et al*, 2007).

'It gives you the opportunity to look at your situation from a different viewpoint.' (carer, East Renfrew)

'Most of the care plans resulting from our carer assessments involved modest inputs: access to information, peer support or one-off sessions with professionals.' (team leader, East Renfrew)

'This has been a positive experience for us, revisiting core social work skills.' (social worker, Orkney)

'Moving from an NHS type of assessment to holistic assessment was daunting to start with and involved a different way of thinking but I now prefer this approach.' (physiotherapist, East Renfrew)

As well as the tools themselves, the UDSET contains learning from the pilot sites and guidance on use of the tools, and parallel evaluation tools. The UDSET also refers to the emerging national outcomes framework in Scotland, and indicates how the related measures can be incorporated into outcomes-focused tools.

The National Outcomes Framework in Scotland

During 2007 the National Outcomes Framework for Community Care (www.scotland.gov.uk/Topics/Health/care/JointFuture/NationalOutcomes) has developed, alongside the associated National Minimum Standards for Assessment and Review (under consultation at the time of writing). These processes have both informed development of the UDSET and been informed by the evidence on user and carer outcomes underpinning the UDSET, resulting in considerable overlap between them. The new performance framework requires partnerships to gather data on service user and carer outcomes to report against four of the sixteen measures:

- % users of community care services feeling safe
- % users of community care services and carers satisfied with involvement in their health and social care packages
- % users of community care services reporting satisfaction with the opportunities provided for meaningful interaction
- % carers who feel supported and capable of continuing in their role as carer.

Information on user and carer experiences in local partnerships is also needed to inform development of local improvement targets (LITs).



The UDSET can be used by partnerships to gather data required for both LITS and the four outcome measures. This quantifiable data can be captured in a separate outcomes summary in the Orkney review tool contained in the UDSET.

Eight partnerships in Scotland are currently piloting the UDSET, testing a range of objectives and approaches, and working with users and/or carers and a variety of user groups. In North Lanarkshire, an innovative integrated day service for older people is using the UDSET as part of its service evaluation, and West Lothian is also focusing on service evaluation. Based on user and carer reviews, Angus, Orkney and Midlothian plan to use the data gathered for service planning and development. Glasgow South West Community Health and Care Partnership is dividing its interviews between care managers and third-party interviewers, seeking to identify any differences in how outcomes are reported by users. Dumfries and Galloway is focusing on culture change in working with carers. In most cases, sites are initially focusing on UDSET-based reviews, to apply an outcomes approach in their locality. Although difficulties in combining an outcomes approach with single shared assessment have been identified (Glendinning *et al*, 2006), two pilot sites, East Renfrew and North Lanarkshire, are exploring possibilities for applying the outcomes approach to assessment/care planning for service users. This work should conclude in Spring 2008, and the results will be reported on the JIT website.

Discussion

This article has described the findings of a national research project on the outcomes for service users of partnership working, and the practical implementation of an outcomes-based toolkit developed from the project through a subsequent collaboration between the Scottish Government and the researchers. While care has been taken to ensure that the foundations of the UDSET are solid, it is worth considering two main caveats arising from the earlier project, both relating to the

challenges of researching cause and effect in complex systems.

First, it should be noted that the 15 partnerships involved in the first project were selected on the basis of being well-established and exhibiting, as far as could be judged, elements of good practice. Caution may therefore be needed in considering the findings of the first project in relation to more embryonic or vulnerable partnerships. The second caveat relates to the findings on the features of partnership associated with good outcomes. As it is difficult categorically to isolate the effects of partnership working, reference is required instead to the balance of probabilities on the basis of the range of evidence available.

Despite these caveats, what did emerge from this project was that evaluation based on the outcomes important to service users provides rich data about the impact of services on the ground. Although it is not always possible to identify which aspect of a service delivers an identified outcome, some service users, encouraged by a good exchange with an interviewer, can comment on these connections. Analysis of patterns emerging from data yielded by a relatively small number of interviews in one partnership can identify barriers and supports to delivery of outcomes (Petch *et al*, 2007).

The work on developing outcomes-based tools for carers for the second project has acquired an additional dimension, as it became apparent that something of an impasse has developed between unpaid carers and statutory services. As the population of unpaid carers increases, along with the intensity of the caring role, it is imperative that services work with carers to provide the information and support they require, and that carers are treated as partners by services (Hanson *et al*, 2006). As carers also experience health inequalities in relation to the wider population (Hirst, 2004), health and social care partnerships are well positioned to provide holistic support to this population.

Developmental work on the UDSET confirmed that resources are a key concern for staff, who frequently voiced concerns about raising expectations



that they felt they would be unable to deliver on. While research has established a need for better-quality and more flexible respite (Yeandle *et al*, 2007), there is also scope for improving outcomes for carers by extended partnership working and more effective links with existing community-based resources. Meanwhile, not engaging with carers, and the assumption that this is exclusively the role of the voluntary sector, have critical implications for relationships between carers and services, and for carers' ability to continue coping with caring.

With regard to the second project, this article has described the development and application of an outcomes-based toolkit in Scotland, where the emerging national outcomes framework will continue to interact with piloting of the toolkit over the next few months. Piloting of the outcomes-based review tools and carer assessment/support plan have been viewed positively by both staff and carers. The implementation work is continuing, and includes exploration of the possibilities for outcomes in assessment and care planning for service users. Currently, pilot sites are beginning to work on aggregating the qualitative data gathered via the UDSET, with a view to using this data for planning and improving services. All the pilots are also building quantifiable measures into their UDSET tools in order to be able to respond to the requirements of the national reporting framework as it becomes established. Perhaps the greatest challenge in this phase of work will be maintaining a focus on the outcomes for users and carers in the midst of the dynamic and changing context of community care in Scotland.

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