



**Do Health and Social Care Partnerships Deliver  
Good Outcomes to Service Users and Carers?  
Development of the User Defined Service  
Evaluation Toolkit (UDSET)**

**December 2007**

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## Summary

The User Defined Service Evaluation Toolkit (UDSET) has been developed to enable health and social care partnerships to improve practice through application of user and carer defined outcomes tools, and to gather information from service users and carers on the outcomes that are important to them and use this information for performance management, planning, commissioning and service improvement.

This report describes the development of the toolkit and presents the tools with detailed guidance for their use. If you have any comments on the UDSET or queries please contact Margaret Whoriskey at the Joint Improvement Team: [Margaret.Whoriskey@scotland.gsi.gov.uk](mailto:Margaret.Whoriskey@scotland.gsi.gov.uk)

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## Section 1. Introduction to the UDSET

### Background

Two key priorities for current health and social care policy across the UK are that service users and carers should be better involved in decisions around their care and support, and that the support provided should deliver good outcomes for users and carers.

In Scotland, a key driver for change in these areas has been the development of a new outcomes focussed joint performance framework, the National Outcomes Framework for Community Care. This framework centres around four high level outcomes embracing wider agendas of Public Service Reform, *Changing Lives*, *Delivering for Health* and *Supporting People*. These are:

- Improved health,
- Improved well-being,
- Improved social inclusion and
- Improved independence and responsibility.

The UDSET has been developed to improve practice through application of user and carer defined outcomes tools, and to enable health and social care partnerships to gather data to determine whether they are delivering good outcomes to service users and carers. This data can be used to include user and carer experiences in performance management, planning, commissioning and service improvement. The toolkit has been developed alongside the National Outcomes Framework and has been piloted for use in this context, but can also be used as a standalone toolkit by any organisation interested in the experiences of service users or carers in community care settings.

### About the UDSET

The UDSET includes two components:

1. Two versions of an outcomes focussed care package review form, one for use with service users and the other with carers.
2. Two versions of a user defined consultation questionnaire, one for use with service users and the other for use with carers.

The UDSET is primarily based on findings and research tools developed during the course of a two-year research project which looked at the outcomes most important to users of services delivered in partnership between health and social care. This research was funded by the Department of Health, based at the University of Glasgow and carried out in partnership with three user research organisations: Central England People First, Older People Researching Social Issues and Service User Research Enterprise. Evidence based checklists summarising key findings from this research are available in Appendices A and B of this report.

In Summer 2006, two researchers from the DH project, Ailsa Cook and Emma Miller, were commissioned by the Assistant Director of the Joint Improvement Team (JIT), Margaret Whoriskey, to explore how research findings and tools from this project could be implemented in practice settings in Scotland. Initial piloting was conducted with three Health and Social Care Partnerships: Orkney, Fife and East Renfrew to further develop tools and approaches. The researchers also worked with carers from VOCAL and other voluntary sector organisations to ensure that the toolkit was relevant to carers. Representatives from other Health and Social Care Partnerships, as well as voluntary sector organisations, service users and carers and academics fed into this work through their participation in workshops/events.

The Joint Improvement Team have funded this second programme of work, which has been led by Assistant Director, Dr Margaret Whoriskey. Further information on the research underpinning this toolkit is available from the Joint Improvement Team Website: <http://www.jitscotland.org.uk/>

### **Outcomes for Service Users and Carers**

At the heart of the UDSET are two frameworks of the outcomes that are important to service users and their carers. These frameworks have been adapted from a ten-year programme of research on service user and carer outcomes at the University of York. The research team at the University of Glasgow adapted the University of York outcomes framework for service users, in collaboration with three user research organisations, to ensure that it reflected the priorities of a broad range of community care service users, and used accessible language. The revised framework was then tested out in interviews with 230 service users across the UK. The framework and related review tool were also piloted in Orkney as part of the JIT work.

The University of York outcomes framework for carers was adapted in collaboration with VOCAL and carers representatives in Scotland during the course of the research with the JIT to ensure it reflects those issues most important to carers. This framework was tested in two pilot sites in Scotland, Orkney and East Renfrewshire.

The resulting outcomes frameworks form the basis of all the tools presented in the UDSET and are summarised below.

**Table 1. Outcomes Important to Service Users**

<b>Quality of Life</b>	<b>Process</b>	<b>Change</b>
Feeling safe Having things to do Seeing people Staying as well as you can be Living where you want / as you want Dealing with stigma/discrimination	Listened to Having a say Treated with respect Treated as an individual Responsiveness Reliability	Improved confidence and skills Improved mobility Reduced symptoms

**Table 2. Outcomes Important to Carers**

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

### **The National Outcomes Framework for Community Care**

In Scotland, the National Outcomes Framework for Community Care is central to the drive to improve outcomes for service users. The development of this framework, and the associated National Minimum Standards for Assessment and Review, have both informed the development and piloting of the UDSET for use in partnership settings and been informed by the evidence base on service user and carer outcomes underpinning the UDSET. As a result there is considerable overlap between the UDSET outcomes and the National

Outcomes Framework, with the UDSET outcomes tables providing a break down of the four high level National Outcomes into distinct concepts that are understandable to service users and carers and that can be used as the basis of evaluation and review measures.

The National Outcomes Framework for Community Care is to replace the Joint Performance Information and Assessment Framework and be underpinned by the existing system of Local Improvement Targets (LITS). The framework consists of 16 performance measures that have been identified to deliver on the four high level outcomes identified earlier in this section. For a list of all the measures see the table in Appendix A.

The new performance reporting framework requires partnerships to gather data on service user and carer experiences to meet two ends. Firstly data on service user and carer experience is required to report against the four of the sixteen measures that relate directly to the experience of service users or their carers. These are:

- % 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 to continue in their role as carer

In addition, detailed qualitative information on the experiences of service users and carers within local partnerships is needed to inform the development of specific Local Improvement Targets that will drive achievement of the four high level outcomes.

The inclusion of outcome measures relating to the experience of users and carers in the performance management framework has been widely endorsed by policy makers, practitioners and users and carers across Scotland. This does, however, pose a challenge for partnerships that do not currently systematically gather the data required to report on these outcomes. Further, whilst these measures are currently expressed as percentages it is recognised that gathering 'tick box' data on these aspects of user and carer experience will not drive service improvements. Therefore it is vital that partnerships implement mechanisms for gathering data that both capture qualitative aspects of user and carer experience and allow for quantification.

The UDSET can be used by partnerships to systematically gather the data required for both the performance reporting framework and the LITS. UDSET data can be used directly to report on the four outcome measures relating to service user and carer experience as shown in the table below.

**Table 3. The relationship between National Outcome Measures and the UDSET outcomes**

Measure	Relevant UDSET Outcome	
	Service User	Carer
% users of community care services feeling safe	Feeling safe Social contact Responsiveness Listened to and treated with respect	
% users of community care services reporting satisfaction with the opportunities provided for meaningful interaction	Seeing people Having things to do Dealing with stigma/discrimination	
% users of community care services and carers satisfied with involvement in their health and social care packages	Being listened to Treated as an individual Having a say in services	Having a say in services Expertise recognised Choices in caring, including limits Partnership with services
% carers who feel supported and capable to continue in their role as carer		All carer outcomes

In the following sections, the two sets of tools that constitute the UDSET are presented in turn, along with guidance for their use. These are the:

- Outcomes Focussed Review Forms for Service Users and Carers
- User Defined and Carer Defined Service Evaluation Questionnaires

## **Section 2. The Review Tools**

### **2.1 Outcomes Focussed Review Forms for Service Users and Carers**

#### **Background**

The Outcomes Focussed Review Forms for Service Users and Carers have been developed with colleagues from Orkney Health and Social Care Partnership and Orkney carers centre to systematically gather data on outcomes from all users and carers as part of routine care package reviews.

The two Outcomes Focussed Review Tools have been designed for use during a user or carer's care package review. The review tool captures

detailed information from the user or carer, which can be used to determine the extent to which the package of care delivers good outcomes. Data can also be collated and used for performance management, planning and commissioning of services. In addition, the outcomes summary contained within the tool provides an opportunity to gather data on whether the individual is supported to achieve the key outcomes against which partnerships must report performance as part of the National Outcomes Framework.

### **Use of the service user review tool in Orkney**

The Outcomes Focussed Review Tool for Service Users was developed in Orkney, incorporating various adaptations based on local piloting, and has been in use there since April 2007. The Outcomes Focussed Review Tool for Carers was subsequently developed in collaboration with staff in Orkney and was piloted there in July/August 2007.

### ***Process for using the Tools***

Experience of using the tool in Orkney has led to the development of the following list of hints for practitioners/interviewers:

- The primary objective in using outcomes focused tools is to obtain a holistic picture of the individual's situation, and to identify the outcomes they want to achieve.
- Ideally the format for gathering information about outcomes is a structured conversation. With experience, practitioners can move from asking questions in strict order, and identify intended outcomes from a conversation, using the outcomes framework for prompts.
- Underpinning this approach is the conception of whole systems working, or the need for broader partnership working beyond health and social care services, in order to deliver quality of life outcomes to users and carers.
- When recording information from the interviews, it is important to relate specific providers to specific outcomes where the service user/carer identifies them so that this information can be used locally for service planning.
- It is important to probe for examples to illustrate views on outcomes. If someone identifies that their service is or is not reliable, an example of what they mean by this helps to clarify the user or carer's views and the detail can be useful for improving services.
- Some practitioners have found that individuals get distressed because of questions about aspects of their lives not usually discussed. If this happens, the interviewee should be offered the opportunity to continue at a later date.
- Information should be obtained as far as possible from the user/carer but can be supplemented by other key individuals involved in their lives as necessary.

## **Advantages and Limitations**

During the course of this pilot work staff and service users in Orkney identified a number of benefits of using the new form, as well as some limitations. These are summarised in the table below.

**Table 4. Advantages and limitations of using the Outcome Focussed Review Form**

<b>Advantages</b>	<b>Limitations</b>
<ul style="list-style-type: none"> <li>▪ Revisiting core principles of good practice</li> <li>▪ Captures holistic picture of user that can be used to make immediate (often easily achievable) changes to provision</li> <li>▪ User defined outcomes can help with moderate communication difficulties</li> <li>▪ More person centred</li> <li>▪ Encourages the user/carer to reflect on the support they get and how best their needs could be met.</li> <li>▪ Can provide the service manager with a better picture of what is going on in services</li> </ul>	<ul style="list-style-type: none"> <li>▪ Can take considerably longer to complete, and may pose IT challenges</li> <li>▪ Outcomes approach does not in itself resolve how to get information from individuals with severe communication difficulties. Information needs to be supplemented by reports from other individuals</li> <li>▪ Some individuals may be reluctant to raise issues about how they are treated (process outcomes) with their own care manager. Services should consider how to manage this in conducting interviews</li> <li>▪ Process outcomes can be difficult to respond to for users with cognitive impairments</li> <li>▪ Requires additional effort to collate and make sense of qualitative data</li> </ul>

Additionally, staff identified a number of learning points from using the tool:

- Opening up discussion on areas previously avoided
- Improving communication skills with people with moderate communication difficulties
- Learning to give positive and negative feedback to other providers
- Distinguishing essential from desirable need

## **Outcomes focussed carers tools: Orkney and East Renfrew**

While the service user review pilot was underway in Orkney, a parallel strand of work was undertaken to develop a separate carers outcomes framework. A report on the development of this framework is available on the JIT website (see resources below). The new framework was used to develop parallel tools for carers, which were then piloted in Orkney (carers review) and East

Renfrew (carers assessment/support plan). The evidence included in this section includes general findings relating to barriers and supports to statutory services engaging with unpaid carers, as well as findings relating directly to the UDSET.

### ***Experience in Orkney***

Although the original plan in Orkney was to divide pilot carers reviews between the carers centre and the community care team, in practice, the work was undertaken by the carers centre. The community care team were unable to complete the reviews largely due to staff shortages in the team. However, discussion with staff also identified other barriers to their involvement in assessing and reviewing carers in general. These findings are included here as they echo views expressed by health and social care staff in many other areas during consultation work in developing the UDSET. They confirm resourcing issues and the culture change required if statutory services are to play a role in supporting carers. Orkney community care staff confirmed that:

- Time taken to assess and review carers would take time away from work with service users
- As the carers centre already works directly with carers, this is viewed as the appropriate service to continue to assess and support carers
- Staff expressed anxiety about the consequences of raising carer expectations through undertaking assessment without having the necessary resources to put in place
- Staff would like to be confident that the information gathered would be used to impact on services, in order to justify the time involved in conducting carer assessments/reviews

The barriers identified by the community care team contrasted with the situation for Crossroads in Orkney. Staff in the carers centre are by definition carer focused and confirmed that they had already adopted an outcomes type approach to working with carers. They found that the outcomes focused review provided them with a tool which built on good practice and formalised the gathering of data which was taking place on an ad hoc basis. They reported that the tool was successful in facilitating a structured conversation with carers, and that it flowed easily. They could foresee how the data collated from the forms could be used to shape services in future, and whilst happy to continue using this approach, they shared a concern with the community care staff that the information should be used to plan and develop services.

### ***Experience in East Renfrew***

Alongside the Orkney pilot, an outcomes focused carer assessment/support plan was developed with East Renfrew Older Peoples Team (OPT), reflecting national work on minimum information standards for carers assessments. The tool was piloted with carers known and newly referred to the team. The OPT was not experiencing staff shortages and they were able to complete

eleven support plans for the pilot. The team manager used a questionnaire to audit both carers and staff responses to using this approach to assessment. Staff feedback was mostly positive, and carer feedback was very positive across the board. Interviews with staff identified the following views, relating to carer assessment generally as well as outcomes focused carer assessment:

- The tool allowed the carer to ‘tell their story,’ and conversation flowed well
- The anticipatory approach of the assessment was valued by both staff and carers. Several carers had expressed anxiety about the future and their priority was accessing information to help to manage this
- The tool allowed carers the opportunity to reflect on their situation, confirming that a good assessment/review can in itself be a significant input, as one carer commented in the audit: ‘it gives you an opportunity to look at your situation from a different viewpoint.’
- While it is likely that carer assessments will in some cases identify need for significant resources, most carers in this pilot identified modest requirements such as access to information, training in lifting and handling and peer support
- Taking time to do assessments affords an opportunity to make sure everyone understands what is going on and what is expected, leading to greater transparency and improved trust
- A physiotherapist commented: ‘Carer awareness and involvement leads to better compliance, improves motivation and increases success of rehabilitation.’
- Being part of a multidisciplinary team gave staff greater confidence to undertake assessment as they would be able to seek advice/support from colleagues and their knowledge of other roles was improved

With regard to the low uptake of carers assessments nationally, staff in East Renfrew identified a number of reasons why carers resist assessment, confirming previous statements made by carers from VOCAL:

- The word ‘assessment’ carries negative connotations, with carers fearing their fitness to care is being assessed
- Many carers do not recognise themselves as carers, and may be too focused on the cared for person to be aware of their own needs
- Some carers view a request for assessment as admission of failure
- Carers might fear financial implications of assessment
- Carers might be concerned about intrusion into their privacy and need to know that they do not have to answer every question
- Carers may fear that being critical of services will backfire on the cared for person

Members of the team described how their awareness of these factors resulted in employment of various strategies to promote assessment, including avoidance of particularly stressful times for assessment and reassurance about some of the fears involved.

While staff in East Renfrew saw considerable value in undertaking carer assessment and review the key concern remained the time involved. While it is clear that this work does absorb staff time, a range of benefits were evident where carer tools were used. Staff themselves reported that their understanding of carers improved through doing assessments, and that the outcomes approach gave them a holistic framework to work from. The benefits to carers were significant, including the opportunity to discuss and reflect on their situation, which in some cases resulted in carers working out solutions for themselves, and access to various supports to ease the pressure of caring and manage anxieties about the future. The current position, whereby very few carers' assessments are being undertaken nationally, is not sustainable. If carers are not supported, many suffer from health problems (see report on identifying carers outcomes), which will ultimately affect their ability to care, and may result in two people requiring to use services instead of the original one. Some areas have started to improve uptake by involving carers' centres and non-statutory staff to undertake assessments/support plans. However, there is also considerable value in involving statutory staff in some of this work, as undertaking outcomes focused assessment and reviews can change staff perceptions of carers, improve practice and achieve a key goal of carers, which is to be treated as partners in care by statutory services.

### **Future Developments**

At November 2007 work is continuing in eight pilot sites in Scotland. Key objectives and goals during this stage are

- Collating data for performance management/commissioning/ evaluation
- Obtaining detailed feedback from users and carers on the UDSET
- Managing data for national reporting purposes using scale measures
- How the functions of the UDSET can be maximised to reduce reporting requirements
- Identifying the extent to which users/carers feel able to express views on process outcomes in reviews involving their provider/care manager
- Engaging statutory sector staff in work with carers

Future learning from this phase of work will be reported on the JIT website in 2008.

**ORKNEY ISLANDS COUNCIL DEPARTMENT OF COMMUNITY  
SOCIAL SERVICES & NHS ORKNEY**

**OUTCOMES FOCUSSED REVIEW FORM**

<b>Client's Name:</b>		<b>Date of review:</b>			
<b>Current Address:</b>	<b>Post Code:</b>	<b>Tel No:</b>		<b>CHI:</b>	
		<b>Mobile No:</b>		<b>PARIS:</b>	
				<b>File:</b>	
<b>Worker Responsible for Review:</b>		<b>Services Used:</b>			
<b>Reason for review:</b>		<b>Date of any previous reviews in last 2 years:</b>			
<b>Changes in circumstances since last assessment / review:</b>					
<b>Are there any concerns that the client has or may shortly have difficulties in managing their own financial affairs or making decisions due to incapacity under the Adults with Incapacity (Scotland) Act 2000? Give an indication of which other agencies have been asked to contribute to their view.</b>					
<b>What is the view of the client and his/her family carer(s) relating to the above?</b>					
<b>PERSONS CONTRIBUTING TO THE REVIEW</b>			<b>DATE &amp; METHOD OF CONTRIBUTION</b>		
<b>Name:</b>	<b>Designation / Relationship</b>	<b>Phone</b>	<b>Letter/ report</b>	<b>Individual meeting</b>	<b>Attend review</b>
<b>Service User's Signature:</b>			<b>Date:</b>		
<b>Workers Signature:</b>			<b>Date:</b>		
<b>SENIOR WORKERS RECOMMENDATION:</b>					
<b>Signed:</b>			<b>Date:</b>		
<b>PERSON RESPONSIBLE FOR NEXT REVIEW:</b>					
<b>Date of Next Review:</b>					

Details input to Database: YES/NO		Date of input:
<b>PROCESS OUTCOMES:</b> To what extent does the client feel that staff within the service / services:		
<b>Listen to them</b>	<b>Give them a choice over the nature and timing of support</b>	
<b>Respect them as an individual</b>  (including addressing issues of discrimination and stigma, if appropriate)	<b>Do what they say they will</b>	
<b>Are responsive to their needs and wishes</b>		
<b>QUALITY OF LIFE OUTCOMES:</b> What difference does the service make to the client's life in respect of:		
<b>Taking part in activities of their choice</b> (including employment and training if appropriate)		
<b>Social contact</b>	<b>Staying as well as they can be</b>  (Including general health and wellbeing)	
<b>Living where they want</b>	<b>Feeling safe</b>  (Physical- neighbourhood, home, services. Emotional- feeling at ease, knowing someone will be there for you)	
<b>Daily living skills, confidence and mobility</b>		

**OVERALL**

To what extent is the service / package of support delivering the outcomes that the client wants?

What changes would the client / carer / other most like to see?

What can be changed to deliver these outcomes?

What must be changed to meet the needs of the client?

Is the review of outcomes derived from the clients own reports? If not, what information has been provided and by whom?

**OUTCOMES SUMMARY**

Based on the client's own response where possible, please highlight answers to the following questions:

Is the client supported by their package of care to feel physically and emotionally safe in their own home and environments where community care services are provided?

Strongly agree    Agree    Disagree    Strongly disagree    Not applicable

Is the client satisfied with their involvement in their package of care thinking particularly about whether they have choice, have been supported to make their own decisions and have the information needed to do so?

Strongly agree    Agree    Disagree    Strongly disagree    Not applicable

Is the client satisfied with the opportunities available to them to:  
Engage in leisure and social activities of their choice?

Strongly agree    Agree    Disagree    Strongly disagree    Not applicable

Is the client satisfied with the opportunities available to them to:  
Take part in activities of their choice (including employment and training if appropriate)?

Strongly agree    Agree    Disagree    Strongly disagree    Not applicable

Is the client satisfied with the opportunities available to them to:  
Have social contact with others?

Strongly agree    Agree    Disagree    Strongly disagree    Not applicable

**DETAILS OF UNMET NEED:**

**Unmet Need Form Submitted to:**

**Date:**

**DETAIL ANY NEW RISK ASSESSMENT:**

**Community Care Plan as agreed by review:**

**Original Care Plan date:**

<b>Actions required</b>	<b>By whom?</b>	<b>Is this a change?</b>	<b>Signature</b>	<b>Date</b>
<b>Essential</b>				
<b>Desirable</b>				

**Comments/other information:**

**ORKNEY ISLANDS COUNCIL DEPARTMENT OF COMMUNITY  
SOCIAL SERVICES & NHS ORKNEY**

**CARERS OUTCOMES FOCUSSED REVIEW FORM**

<b>Carer's Name:</b>		<b>Date of review:</b>			
<b>Current Address:</b>		<b>Tel No:</b>		<b>CHI:</b>	
		<b>Mobile No:</b>		<b>PARIS:</b>	
				<b>File:</b>	
<b>Post Code:</b>		<b>Worker Responsible for Review:</b>			
		<b>Services Used:</b>			
<b>Reason for review:</b>		<b>Date of any previous reviews in last 2 years:</b>			
<b>Changes in circumstances since last assessment / review:</b>					
<b>PERSONS CONTRIBUTING TO THE REVIEW</b>			<b>DATE &amp; METHOD OF CONTRIBUTION</b>		
<b>Name:</b>	<b>Designation / Relationship</b>	<b>Phone</b>	<b>Letter/ report</b>	<b>Individual meeting</b>	<b>Attend review</b>
<b>Any other agencies asked to contribute their view.</b>					
<b>Carer's Signature:</b>			<b>Date:.....</b>		
<b>Workers Signature:</b>			<b>Date:</b>		
<b>SENIOR WORKERS RECOMMENDATION:</b>					
<b>Signed:</b>			<b>Date:</b>		
<b>PERSON RESPONSIBLE FOR NEXT REVIEW:</b>					
<b>Date of Next Review:</b>					
<b>Details input to Database: YES/NO</b>			<b>Date of input:</b>		
<b>QUALITY OF LIFE OUTCOMES:</b>					
<b>What difference does the service(s) make to the carer's life in respect of:</b>					

<b>Their health and wellbeing</b>	<b>Having a life of their own</b>
<b>Supporting or improving the relationship with the cared for person</b>	<b>Accessing financial advice</b>
<b>MANAGING THE CARING ROLE:</b>	
Does the service provide support with the following aspects of caring:	
<b>Informed choices about caring</b>	<b>Being informed/skilled/equipped to care</b>
<b>Satisfaction/sense of achievement in caring</b>	<b>Partnership with the service</b>
<b>PROCESS OUTCOMES:</b>	
To what extent does the carer feel that staff within the service:	
<b>Value and respect them and recognise their expertise as carers</b>	<b>Give them a say in service provision and in shaping services</b>
<b>Respond to their changing needs</b>	<b>Have meaningful relationships with them</b>
<b>Provide accessible and available services</b>	

**OVERALL**

To what extent is the service / package of support delivering the outcomes that the carer wants?

What changes would the carer most like to see?

What can be changed to deliver these outcomes?

What must be changed to meet the needs of the carer?

Is the review of outcomes derived from the carers own reports? If not, what information has been provided and by whom?

**OUTCOMES SUMMARY**

Based on the carer's own response where possible, please highlight answers to the following questions:

Are the health and wellbeing of the carer supported by their package of care?

Strongly agree    Agree    Disagree    Strongly disagree

Is the carer supported by their package of care to have a life of their own?

Strongly agree    Agree    Disagree    Strongly disagree

Does the carer feel informed/skilled/equipped to care?

Strongly agree    Agree    Disagree    Strongly disagree

Does the carer feel that they are a key partner in caring?

Strongly agree    Agree    Disagree    Strongly disagree

Does the carer feel satisfied with their involvement in their package of care thinking particularly about whether they have choice, have been supported to make their own decisions and have the information needed to do so?

Strongly agree    Agree    Disagree    Strongly disagree

Does the carer feel supported and capable to continue in their role as carer?

Strongly agree    Agree    Disagree    Strongly disagree

Other information from carer:


**DETAILS OF UNMET NEED:**



## **Section 3: User and Carer Defined Service Evaluation Questionnaires**

### **Background**

Research with representatives from 13 health and social care partnerships in Scotland showed that consultation, using various methods, was the primary approach to gathering the views of users and carers. Information from these consultations is used by partnerships to drive service improvements and to inform planning decisions. However representatives from these partnerships reported that in general consultations did not systematically gather data on service user or carer outcomes and that those service users and carers who were hardest to reach tended to be missed.

In response to this, the research team have developed two consultation tools that can be used with service users and carers, the User Defined Service Evaluation Questionnaire (UDSEQ) and Carer Defined Service Evaluation Questionnaire (CDSEQ). The tools are primarily designed to be used in one to one interviews. These questionnaires are based on the outcomes frameworks presented in tables 2 and 3 in section 1.

### **About the UDSEQ and CDSEQ**

The User Defined Service Evaluation Questionnaire was initially developed as part of the research carried out at the University of Glasgow to determine whether health and social care partnerships deliver the outcomes that service users want. The UDSEQ was developed in collaboration with three service user research organisations and used in interviews with 230 adult users of community care services across the UK. The UDSEQ can be used to:

- Find out how service users experience a service or package of care being provided
- Determine whether the service / package of care delivers the outcomes that service users want
- Understand how different features of service provision impact on the service user or carer experience

Increasingly, attention is also being paid to the needs of carers, as partners in providing care. In order to deliver good outcomes to both service users and carers services need to consider each party individually, which may involve balancing the needs and rights of each. The CDSEQ has been developed as part of the development work commissioned by the JIT and can be used to:

- Find out how unpaid carers' lives are affected by caring
- Identify whether unpaid carers are being treated as key partners in care
- Find out how carers experience a service or package of care
- Determine whether the service / package of care delivers the outcomes that carers want

- Understand how different features of service provision impact on the carer experience

### Evidence from the field

The implementation of these tools has been piloted in Fife and East Lothian. In Fife the UDSEQ was used to gather data on the experiences of a subset of 15 hard to reach carers, who did not participate in other consultation activities. In East Lothian the UDSEQ was used during a focus group with physically disabled adults using Occupational Therapy Services. In addition the tools have been reviewed by members of the Scottish Dementia Working Group, a self-advocacy group for people with dementia. This work has highlighted the following advantages and limitations of using the tools.

**Table 5. Advantages and limitations of using the UDSEQ and CDSEQ in consultations**

Advantages	Limitations
<ul style="list-style-type: none"> <li>▪ Use of open-ended questions in face to face interview facilitates inclusion of ‘hard to reach groups’ like people with dementia.</li> <li>▪ Captures detailed information on outcomes including specific examples of good and bad practice</li> <li>▪ Captures diversity of individual experience which can be lost in surveys and focus groups</li> <li>▪ Structure of the tool makes it easy to link process to outcome</li> </ul>	<ul style="list-style-type: none"> <li>▪ Time consuming to administer, relative to other consultation methods (hence use with targeted sub-population)</li> <li>▪ Requires some interviewing and analysis skills</li> <li>▪ Tool itself is less suitable for use in focus groups, though analysis pro-forma can still be used to make sense of focus group data</li> </ul>

### Using the UDSEQ and CDSEQ in face-to-face interviews

The tools take up to an hour to administer, though more time may be needed to elicit answers to all the questions from people with complex packages of support, or who have had difficult experiences with services.

The questions do not need to be asked by a trained researcher, but it is essential that the person carrying out the interview:

- has good listening and communication skills
- is ready and able to prompt the service user or carer for more information when needed, or ask questions in a different way
- understands the purpose of the interview and how the information gathered will be used
- is able to respond appropriately to difficult or sensitive experiences that the interviewee may share
- is able to summarise the answers the service user or carer gives to the questions in the Analysis Pro-forma

## ***Gaining informed consent***

At the start of the interview, the interviewer should explain the purpose of the interview and what will happen to the information shared by the service user or carer, including who will have access to the answers to their questions. This information should also be presented in an information sheet. The person being interviewed should then be asked to confirm that they consent to be interviewed and to sign a consent form. Verbal consent can be obtained from those unable or unwilling to sign a consent form and should be recorded on the Analysis Pro-forma.

## **Hints and Tips for Successful Use of the UDSEQ and CDSEQ**

### ***Location and safety***

The interview can be carried out in any quiet and private location where both the service user or carer and interviewer feel comfortable. This might be in the individual's home, a service setting or another mutually agreeable location.

### ***Involving carers / care recipients / other family members / care workers***

Where possible the service user or carer should be interviewed alone to ensure that:

- they have the space to talk about their views and experiences
- they are able to talk candidly about the role that others play in their lives
- they share only what they want to about their lives, as opposed to what others see as relevant.

In some cases there may be practical barriers to interviewing a person alone (such as communication difficulties or the need to provide supervision to another). In other cases the user or carer may prefer to be interviewed in the presence of another. In these instances the interviewer may have to work hard to ensure that the person being interviewed gets a chance to express their views in the interview.

### ***Ensuring data quality***

Although the questions in the UDSEQ and CDSEQ are based on the priorities of service users and carers, and using accessible language, some individuals may still have difficulty understanding what is being asked. In this situation, the interviewer should let the person being interviewed guide the conversation, using the outcomes underpinning the questions as prompts to help maintain a focus. A successful interview is one where a good record of how the user or carer experiences the outcomes is captured, and not necessarily where all the questions were followed in order.

It is also important to ask the person being interviewed to give examples to support their answers to each of the questions in sections 2, 3 and 4.

At the end of the interview the interviewer might want to record notes on how they thought the interview went, and their impressions of how the care package was impacting on the life of the user or carer.

## **Data Analysis**

The Analysis Pro-formas provide frameworks for summarising the information gathered in interviews with users or carers. It is recommended that the pro-formas are completed as soon as possible after the interview. Specific examples should be included where available to illustrate each point. Once a number of interviews have been completed the person responsible for data analysis should review all of these interviews, looking for common themes and differences within the data. From this review process conclusions about the extent to which features of the service hinder or promote the outcomes that service users want can be drawn as a whole.

Experienced qualitative researchers may wish to work from transcribed data using a specialist software analysis package such as NVivo. In this case the boxes in the Analysis Pro-forma can be used as the basis for the coding framework.

### ***Using the questionnaires to inform performance management, planning, commissioning and service improvement in health and social care partnerships.***

The UDSEQ and CDSEQ both take the form of a questionnaire and have been designed to be used in a face-to-face interview. The tools do not have to be used in their entirety and partnerships may choose to add additional questions to capture information on specific aspects of service provision pertinent to the local context. Questions from both tools may be adapted for use in postal or telephone surveys, though use of the UDSEQ and CDSEQ for this purpose has not as yet been piloted.

Given the time taken to implement the UDSEQ and CDSEQ partnerships might want to consider using these tools to capture information from a subset of service users or carers, in particular those whose views are not accessed through other methods. This data can be synthesised as described above and used to contextualise and add richness to other forms of consultation information used by planning committees, in the commissioning process and when setting LITS and reporting performance against the four user and carer experience measures in the National Outcomes Framework. In addition specific examples from the data gathered can be used in ongoing supervision and training of staff. The UDSEQ and CDSEQ are also tools that can be used by organisations providing services commissioned by health and social care partnerships, to ensure consistency of data gathered across the partnership.

## User Defined Service Evaluation Questionnaire

### Section 1. The nature and extent of support provided.

This section should be kept as brief as possible.

1. Can you tell me about the kind of help that you get from (name of service / partnership)?

Look for the 'facts':

Tasks get help with,  
how often,  
who by

(may need to prompt with name of service providers if known.)

2. Do you get support from anywhere else?

### Section 2. Impact on you and your life

*There are several things that people have said that are particularly important in life. These are: feeling safe, seeing other people, having things to do, living life as you want as well as where you want and staying as well as possible, avoiding discrimination. Can you tell me if (name of service) and the support that they give you makes a difference to you and your life....in respect of:*

- Feeling safe
- Seeing other people
- Having things to do
- Living life the way you want
- Living where you want
- Staying as well as you can be
- Avoiding discrimination / stigma

3. Is there anything else that you think that the service could or should do?
4. What difference has using this service made to your life?

In this question probe for change outcomes: improved symptoms; increased confidence and skills; increased mobility.

### Section 3. What happens when you use the service

For each question probe for what people in the service do and don't do, and ask for specific examples where possible.

5. Do people in the service listen to you and take into account your own needs, wishes and circumstances?
6. Do people in the service value you and treat you with respect?

7. Do people in the service generally do what they say they will?
8. Do you have choice over the kind of help you get and when you get that help?
9. Are people responsive to your needs and wishes?
10. Is there anything that you would like people in the service to do differently?

**Section 4. Your thoughts on the service overall**

11. Are there ways in which the service could be improved for you?
12. How easy is it to get the service?
13. Have there been any delays in getting help or support from this service?
14. Is there anything else you would like to tell me about (name of service)?
15. Do you have any questions about this interview?

**Close**

## Analysis Pro-forma

### Background Information

<b>Name of Service user / Carer</b>	<b>Anonymised code</b>
<b>Name of Interviewer</b>	<b>Date</b>
<b>Informed Consent obtained?</b>	<b>Audio recording?</b>
<b>Other relevant information and reflections</b>	

### Outcome Checklist

<b>Outcome</b>	<b>Experience of service user / carer</b>	<b>Features of service promoting or hindering that outcome</b>
<b>Quality of life outcomes</b>		
Safety		
Having things to do		
Social Contact		
Staying as well as you can be		
Living life as you want / where you want		
Dealing with discrimination		
Other		
<b>Process outcomes</b>		
Being listened to		
Valued and treated with respect		
Choice		
Reliability		
Responsiveness		
Other		

<b>Change outcomes</b>		
Improving skills and confidence		
Improved mobility		
Other		



8. Do you have a sense of satisfaction and/or achievement in your caring?
9. Do you feel that you are treated as a partner in the care of (name) cared for person?

#### **Section 4. What happens when you use the service**

*For each question probe for what people in the service do and don't do, and ask for specific examples where possible.*

10. Do you feel that you are valued and respected by services and that your expertise is recognised?
11. Do you feel you can have a say in service provision and that you can help to shape services?
12. Do services respond to the changing needs of (name) the cared for person and you?
13. Do you have positive/meaningful relationships with staff?
14. Are the services you need accessible and available to you?

#### **Section 5. Your thoughts on the service overall**

15. Are there ways in which the service could be improved for you?
16. How easy is it to get the service?
17. Is there anything else you would like to tell me about your service?
18. Do you have any questions about this interview?

**Close**

## Analysis Pro-forma

### Background Information

<b>Name of Carer</b>	<b>Anonymised code</b>
<b>Services to carer</b>	
<b>Name of Interviewer</b>	<b>Date</b>
<b>Informed Consent obtained?</b>	<b>Audio recording?</b>
<b>Other relevant information and reflections</b>	

### Outcome Checklist

<b>Outcome</b>	<b>Experience of carer</b>	<b>Features of service promoting or hindering that outcome</b>
<b>Quality of life outcomes</b>		
Health and wellbeing		
Having a life of your own		
Relationship with the cared for person		
Freedom from financial hardship		
<b>Managing caring outcomes</b>		
Choices in caring including breaks		
Informed/ skilled/ equipped to care		

Satisfaction in caring		
Treated as a partner		
<b>Process outcomes</b>		
Valued and respected/ recognised as expert		
A say in services		
Responsive to changing needs		
Positive relationship with staff		
Accessible and available		

## Appendix A: Service Planning and Development Evidence Checklist 1

### The outcomes that adult community care users want from services

This checklist summarises evidence from a UK wide research project conducted at the University of Glasgow on the outcomes that users of community care services want. The information was gathered from interviews with 230 service users, including those who are vulnerable and hard to reach.

This checklist can be used to ensure that service planning and development is informed by the concerns of service users from each of the three community care groups. The checklist should be used in addition to ongoing consultation with local service users and carers.

Outcome	Older people	Mental health	Learning difficulties
<b>Quality of life</b>			
Feeling safe	Knowing someone is there to keep an eye on the person = proactive monitoring Fear of crime in the neighbourhood Fear of falling	Knowing support is available should a crisis occur Fear of discrimination and stigma	Knowing there is someone trusted to talk to in case of crisis or distress Fear of harassment in the neighbourhood or from other service users
Having things to do	Getting out and about Availability of activities valued	Opportunities for employment and other meaningful activities	A choice of activities including physical and recreational Employment opportunities
Contact with other people	Social isolation very common. Home care often the sole form of social contact Groups valued by many (more often by females)	Social contact with other users particularly valued. Opportunities to socialise in a stigma free environment emphasised	Social contact with staff particularly valued. Social contact with other users appreciated. Establishing relationships in the community challenging
Staying as well as you can be	Access to a range of professionals often important in recovering from health crises. Combating social	Access to support both preventatively and in the longer term if required, rather than restricted	Role of staff in supporting access to mainstream and specialist health services

<b>Outcome</b>	<b>Older people</b>	<b>Mental health</b>	<b>Learning difficulties</b>
	isolation important to sustain health	to crisis times.	
<b>Process</b>			
Being listened to	Having a say in services	Having a say in services	Having a say in services
Feeling valued and treated with respect	Not being patronised Treated as an individual	Staff seeing beyond the label valued	Not being patronised
Having choices	Choice over timing of services and tasks undertaken Access to information about services	Choice over treatment options important Choice of activities appreciated Choice of accommodation often restricted	Choice of activities emphasised Choice over where people lived and who with important
Having people to rely on	Staff turning up and on time often problematic, particularly in relation to home care. Communication important in such cases	Knowing that staff would turn up important and a phonecall to inform of changed arrangements appreciated	Knowing that staff would turn up important and a phonecall to inform of changed arrangements appreciated
Knowing someone will respond	Ability to contact someone and rely on a quick response in a crisis	Ability to contact someone and rely on a quick response in a crisis	Ability to contact someone and rely on a quick response in a crisis
<b>Change</b>			
Improving skills and confidence	Most older people using partnership services had experienced health crisis and emphasised the role of services in restoring skills and confidence	Support with re-establishing skills and confidence following hospitalisation	Where periods of ill health had occurred, the role of services in restoring skills and confidence was valued.
Improving mobility	Restoring ability to walk where possible and/or supply of adaptations where necessary.	Support to use public transport	Availability of transport. Support to use transport
Reducing symptoms	Reducing pain and discomfort Reducing symptoms of mental illness where required	Reducing and/or managing anxiety, depression and other symptoms of mental illness	Reducing pain and discomfort Reducing symptoms of mental illness where required

## Appendix B: Service Planning and Development Evidence Checklist 2

### Features of services and partnerships promoting the outcomes that service users want

This checklist summarises evidence from a UK wide research project conducted at the University of Glasgow on the outcomes that users of community care services want. The information was gathered from interviews with 230 service users, including those who are vulnerable and hard to reach.

This checklist can be used to ensure that service planning and development is informed by the concerns of service users from each of the three community care groups. The checklist should be used in addition to ongoing consultation with local service users and carers.

Outcome	Experience of service users	Features of service promoting that outcome	Features of partnership enabling that outcome
<b>Quality of life outcomes</b>			
Feeling safe	Physical safety – feeling safe in neighbourhood, getting out and about, managing tasks of daily living, avoiding falls (older people). Emotional safety – knowing help is on hand, being safe from intimidation, abuse and stigma	Staff working together Regular contact with stable and trusted staff group. Easy access to responsive services, in particular out of hours, enhanced by single point of contact.	Multidisciplinary team working together to promote social and emotional wellbeing and physical and mental health Specialist services treating individuals in a non-discriminatory manner Colocation improving communication and responsiveness
Having things to do	Opportunities for meaningful activity and employment during the day and evening promoted self-esteem, wellbeing and mental health, and supported people to live a 'normal' life.	Good resource base, offering options for activities Self-advocacy groups an additional source of meaningful activity for service users	Extended partnership with voluntary sector, local employers and employment agencies providing meaningful activity, particularly opportunities to engage in mainstream activities.
Contact with other people	Relationships with staff and other service users vital for combating isolation and loneliness for those most excluded. Others needed support to sustain relationships with	Continuity of staffing helped promote supportive relationships with staff Opportunities for informal contact with other users supported by group activity, drop-in and sensitive	Extended partnerships also create opportunities to meet people and form relationships

<b>Outcome</b>	<b>Experience of service users</b>	<b>Features of service promoting that outcome</b>	<b>Features of partnership enabling that outcome</b>
	family and friends. Relationships between service users and wider community often more challenging to establish	planning of service use e.g. co-ordinating respite schedules so people attend with friends.	
Staying as well as you can be	Service users wanted support with all aspects of wellbeing, often emphasising links between quality of life and physical and mental health. Support from regular staff was valued in accessing mainstream and specialist services.	A focus on the various needs of the individual. Facilitating access to mainstream and specialist health services. Health living groups valued.	Multidisciplinary team working together to promote social and emotional wellbeing and physical and mental health. Colocation enabling users to access support from diverse professionals quickly
<b>Process outcomes</b>			
Being listened to	Being listened to is important to service users in order to have a say over their day-to-day life and service use. Being listened to was very important to service users who were fearful or distressed.	Stability of staffing and adequate staff. Good relationships between staff and service users helped communication, sometimes supported by key worker systems. Opportunities for users to collectively have a say.	Colocation can assist with communication
Feeling valued and treated with respect	Key issues for users were being treated as an adult, and as an individual. It was very important to service users not to be stereotyped. There were strong links with being listened to.	Consistency of staffing and adequate staff numbers. Staff who had specialist knowledge of the user group demonstrated understanding of needs, and responded appropriately	Specialist services with shared knowledge and experience of the user group leading to non-discriminatory treatment
Having choices	Service users wanted choice and control over where they lived and how they lived their life, and particularly over their daily routine.	Choice over daily routines was largely determined by the core service. Person centred planning enabled users to have a say in how they	Multidisciplinary team sharing information about individual circumstances. Communication assisted by colocation. Extended partnership increased available

<b>Outcome</b>	<b>Experience of service users</b>	<b>Features of service promoting that outcome</b>	<b>Features of partnership enabling that outcome</b>
	Only one carer reported wanting a choice of service provider	lived their life. Having sufficient staff was important in implementing these plans. Choice over other aspects of life could be enhanced by links with other services	options e.g. of activities, and improved the possibility of accessing appropriate accommodation
Having people to rely on	Service users and carers wanted the security of knowing that staff would adhere to arrangements, and that if unavoidable delays occurred, that someone would contact and advise them.	Consistency of staffing and adequate staff numbers. Good communication	Colocation can assist with communication
Knowing someone will respond	Knowing services would respond if needed was very important; easy access to services was therefore highly valued. Out of hours support was viewed as vital in a crisis; its availability was associated with feeling safe	Single point of contact. Good communication between staff and agencies. Evening and weekend support. Good relationships between service user and staff	Co-location
<b>Change outcomes</b>			
Improving skills and confidence	Following episodes of ill-health, users wanted services to support restoring confidence and skills. People also wanted to remain independent and stay out of hospital.	Staff working as a team to meet various needs Good relationships with staff and opportunities for interaction between service users	Multidisciplinary team working together to promote social and emotional wellbeing and physical and mental health. Informal partnership providing opportunities for activity and social contact
Improving mobility	Following episodes of ill-health, users wanted services to improve mobility where possible, and/or provide adaptations where required	Staff working as a team to meet mobility requirements	Multidisciplinary team

<b>Outcome</b>	<b>Experience of service users</b>	<b>Features of service promoting that outcome</b>	<b>Features of partnership enabling that outcome</b>
Reducing symptoms	Service users with serious health problems wanted support to alleviate symptoms	Staff working together to alleviate pain, reduce symptoms	Multidisciplinary team

## Appendix C: National Outcomes Framework for Community Care

### Summary of the 16 measures of the Performance Framework for Community Care

Outcome	Output	Process	Input
% users of community care services feeling safe	Number of patients waiting more than six weeks to be discharged into a more appropriate care setting	% of user assessments of needs completed in accordance with agreed national standards	Shift in balance of care from 'institutional' to 'home based' care
% users of community care services and carers satisfied with involvement in their health and social care packages	% of care plan reviews carried out within agreed timescale	% of carer assessments of need completed in accordance with agreed national standards	
% users of community care services reporting satisfaction with the opportunities provided for meaningful interaction	Number of people waiting for more than targeted time from referral to completion of assessment		
% older people aged 65+ with intensive care needs receiving services at home	Number of people waiting more than the targeted time for the delivery of community care services following an assessment		
% older people aged 65+ receiving personal care at home	Number of emergency bed days in acute specialities for older patients aged 65+		
% carers who feel supported and capable to continue in their role as carer	Number of older patients aged 65+ admitted for any reason two or more times in a year as an emergency to acute specialities		
Number of older people aged 65+ with two or more emergency admissions in a year who have not had an assessment of their health and social care needs			

## Appendix D: Resources

Reports on the work undertaken with the JIT to develop the UDSET, and a report on the development of the carers outcomes framework are available: <http://www.jitscotland.org.uk/action-areas/themes/involvement.html>

A report on the research by Ailsa Cook, Emma Miller and colleagues at the University of Glasgow on outcomes of partnership working is also available: <http://www.jitscotland.org.uk/action-areas/themes/involvement.html>

In addition the following articles have been published from the report:

Petch A, Cook A and Miller E (2005) Focusing on Outcomes: their role in partnership, policy and practice, *Journal of Integrated Care* 13 (6) 3-12

Cook, A. and Miller, E. (2007) Partnerships and good outcomes for service users *Community Care Works* Issue 65, 1-2.

Miller, E., Cook, A. Alexander, H., Cooper, S. Hubbard, G., Morrison, J., Petch, A. (2007) Challenges and strategies in collaborative working with service user researchers: reflections from the academic researcher. *Research Policy and Planning*, Vol 25 (1) 197-208

Miller, E., Cooper, S., Cook, A. and Petch, A. (forthcoming, 2008) The outcomes important to people with intellectual disabilities *Journal of Policy and Practice in Intellectual Disabilities*

Further information on the National Outcomes Framework:

<http://www.scotland.gov.uk/Topics/Health/care/JointFuture/NationalOutcomes>

Information on the SPRU Outcomes Programmes 1996 – 2006:

<http://www.york.ac.uk/inst/spru/research/summs/outcomes2001-5.htm>

Guidance on interviewing service users is available from a report on best practice in Single Shared Assessment by the Infusion co-operative:

<http://www.scotland.gov.uk/Publications/2005/03/20851/54591>

Further information is available on the INVOLVE website, supporting public participation in the NHS: <http://www.invo.org.uk/>

There are a number of excellent textbooks for those new to research:

:

Bryman, A (2002) *Social Research Methods* Oxford, Oxford University Press

Gilbert, N (ed) *Researching Social Life*, London: Sage Publications

May, T. (2001) *Social Research: issues, Methods and Processes* (3<sup>rd</sup> Ed), Buckingham: Open University Press

Robson, C. (2002) *Real World Research: A Resource for Social Scientists and Practitioner-Researchers*, Blackwell