



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

First Draft July 2007

Dr Ailsa Cook, RBS Centre for the Older Person's Agenda, Queen Margaret University

Dr Emma Miller, Independent Consultant

Dr Margaret Whoriskey, Assistant Director, Joint Improvement Team

Summary

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

This report describes the development of the toolkit and presents the current versions of the tools with detailed guidance for their use. A second phase of piloting of the UDSET is ongoing and an updated version of this toolkit will be published in October 2007.

If you have any comments on the UDSET or would like to pilot any of the tools please contact Margaret Whoriskey at the Joint Improvement Team: {
HYPERLINK "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 included in decisions around their care and support and that services should focus not just on the nature and extent of support they deliver, but ensure that the support provided delivers good outcomes for service 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 that embrace the 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 User Defined Service Evaluation Toolkit has been developed 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 the experiences of service users and carer 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. Evidence based checklists summarising key findings from this research are available in Appendices A and B of this report. 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.

Over the past year, two researchers from this project, Dr Ailsa Cook and Dr Emma Miller, have been working with the Joint Improvement Team in Scotland to explore how research findings and tools from this project can be implemented in practice settings. To date, the researchers have worked closely with representatives from three Health and Social Care Partnerships: Orkney, Fife and East Lothian to further develop and pilot tools and approaches. They have also worked with carers from VOCAL and other voluntary sector organisations to ensure that the toolkit is applicable to the experience of carers. Representatives from a further seven Health and Social Care Partnerships, as well as voluntary sector organisations, service users and carers and academics have fed into this work through their participation in four workshops).

The Joint Improvement Team have funded this second programme of work, which has been lead 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 distinct frameworks for understanding the outcomes that are important to service users and their carers. These frameworks have been adapted from those developed during a ten-year programme of research on service user and carer outcomes that was conducted 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 was understandable to service users and reflected the priorities of the broadest range of community care service users. The revised framework was then tested out in interviews with 230 service users across the UK.

The University of York outcomes framework for carers has been adapted in collaboration with VOCAL and key stakeholders for carers in Scotland during the course of the research with the JIT to make it more understandable to carers and to ensure it reflects those issue most important to carers. This framework is currently being 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

Quality of Life	Process	Change
Feeling safe	Listened to	Improved confidence and skills
Having things to do	Choice	

Seeing people Staying as well as you can be Living where you want / as you want Dealing with stigma	Treated as an individual Responsiveness Reliability	Improved mobility Reduced symptoms
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Table 2. Outcomes Important to Carers

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

Articulation with 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 will replace the Joint Performance Information and Assessment Framework and be under-pinned by the existing system of Local Improvement Targets (LITS). The framework consists of a suite of just 16 performance measures that have been identified as being crucial to delivering on the four high level outcomes identified earlier in this section. Partnerships are required to report on the first six of these measures in the year 2007 – 2008, with the remaining ten measures coming into place in the year 2008 – 2009. Partnerships will no longer be required to report on LITS centrally, but are expected to continue to set and measure performance against LITS to help them achieve the high level outcomes. 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 service users and carers in the performance management framework has been widely endorsed by policy makers, practitioners and service users and carers across Scotland. This does, however, pose a new challenge for many partnerships that do not currently systematically gather the data required to report on these outcomes. Furthermore, whilst these measures are currently expressed as percentages it is recognised by the National Outcomes Group that merely gathering 'tick box' data on these aspects of service user and carer experience will not drive improvements in performance. Therefore it is vital that partnerships implement robust and rigorous mechanisms for gathering data that both capture qualitative aspects of service user and carer experience and allow for some quantification.

The User Defined Service Evaluation Toolkit 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	
% users of community care services reporting satisfaction with the opportunities provided for meaningful interaction	Seeing people Having things to do	
% users of community care services and carers satisfied with involvement in their health and social care packages	Listened to Treated as an individual Choice	Having a say in services Choices in caring
% carers who feel supported and capable to continue in their role as carer		Valued/respected and expertise recognised Feeling informed/ skilled/equipped Satisfaction in caring Partnership with services

In addition, partnerships can use data gathered under all the UDSET outcomes to set Local Improvement Targets that will drive performance towards the four high level outcomes.

Further Development of the UDSET

Further piloting and development of the UDSET for use in partnership settings to inform performance management, planning, commissioning and service improvement is currently underway. This second phase of piloting is examining the applicability of the tools for use with carers in two partnership settings, Orkney and East Renfrewshire and looking at how partnerships already involved in this work use the information gathered on user and carer outcomes.

A second draft of this toolkit will be published in October 2007 updated with additional learning from these pilots. In the meantime the research team would welcome comments and feedback on the UDSET, in particular from partnerships or organisations that have used any of the toolkit. If you are interested in using the UDSET in your organisation, or have any comments or questions, please contact Dr Margaret Whoriskey at the Joint Improvement Team: { [HYPERLINK "mailto:Margaret.Whoriskey@scotland.gsi.gov.uk"](mailto:Margaret.Whoriskey@scotland.gsi.gov.uk) }

Section 2. The Tools

In this section of the report the three sets of tools that constitute the UDSET are presented in turn, along with detailed guidance for their use. These are the:

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

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 to systematically gather data on outcomes from all service users and carers as part of routine annual care package reviews.

The two Outcomes Focussed Review Forms have been designed for use during a client or carer's annual care package review, i.e. with service users and carers whose needs have already been assessed using the relevant Single Shared Assessment tool. The review form captures detailed information from service users or carers, which can be used to determine the extent to which the package of care provided on the basis of that assessment delivers good outcomes. In addition, the form gives an opportunity for the person completing the review to make an overall assessment as to whether the individual is supported to achieve the key outcomes against which partnerships must report performance as part of the National Outcomes Framework. The data gathered can be used immediately to make decisions about the individual's care and support, as well as being analysed alongside data gathered from multiple individuals and used for performance management, planning and commissioning of services.

Use of the form in Orkney Health and Social Care Partnership

The Outcomes Focussed Review Tool for Service Users was developed in Orkney and has been in use there since April 2007. The form was designed to replace the existing review tools, which gathered much less detailed information on outcomes for service users. Over the course of the pilot work in Orkney, a number of small adaptations have been made to the form and the process through which it is administered, the latest versions of which are featured in this report.

The Outcomes Focussed Review Tool for Carers has recently been developed in collaboration with staff in Orkney and is currently being piloted there and in East Renfrewshire. Learning from these pilot sites and any

adaptations to the tool will be included in the second version of this toolkit to be published in October 2007.

Process for using the Form

Experience of using the form in Orkney has led to the development of the following recommendations:

- The review should be carried out by either the service user or carer’s case manager, or ideally a worker qualified to conduct reviews who is not directly involved in the individual’s care package.
- Information from the service user or carer on their experience of the service in relation to the outcomes should ideally be elicited during the course of a one to one interview in a setting in which the service user or carer feels relaxed and in control. This may mean meeting with the service user or carer before any formal review meeting.
- Where service users or carers have specific communicative difficulties that make answering questions difficult, the reviewer should firstly try to get an understanding of how well that individual is supported to achieve the outcomes through a less structured, client led conversation, as well as through observation of their situation. This information can be supplemented with reports from carers, key workers and friends, though it is important to state in the review form where any given piece of information came from.
- Once a review has been completed it should be signed off by the service lead who can initiate any immediate changes to services for that individual, or in general required.
- Data from the reviews should be stored electronically so that information on outcomes can be collated for use in performance management, planning and commissioning.
- In Orkney, review forms are being held within PARIS, the local information system, however it is recognised that different organisations will need to develop approaches to data management that fit with their existing Information Systems.

Advantages and Limitations

During the course of this pilot work staff and service users in Orkney have 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

Advantages	Limitations
<ul style="list-style-type: none"> • Captures detailed information on service user experience including information that can be used to make immediate changes to provision, not captured previously. 	<ul style="list-style-type: none"> • Takes 2 –3 times as long to complete and write up as the previous review form. • Difficult to get information on outcomes from service users who have communication

<ul style="list-style-type: none"> • Ensures that the service user or carer is included in the review and makes the whole review process more person centred • Ensures that all aspects of care provision covered • Encourages the service user or carer to reflect on the support they get and how best their needs could be met. • Enables the service manager to get a better picture of what is going on in services 	<p>difficulties, e.g. some people with learning difficulties and dementia. Information needs to be supplemented with reports from carers, friends, key workers for these individuals.</p> <ul style="list-style-type: none"> • Some questions need to be paraphrased. • Increased length of review made one service user anxious
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Future Developments

Piloting of both review forms is ongoing in Orkney and a number of other partnerships have expressed an interested in using the form. Over the coming months the Joint Improvement Team will monitor the use of this review tool in practice and amend guidance accordingly. Furthermore, the JIT will continue to work with Orkney and other partnerships to refine processes for managing and reporting on outcomes data once it is gathered.

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SOCIAL SERVICES & NHS ORKNEY**

OUTCOMES FOCUSSED REVIEW FORM

Client's Name:		Date of review:			
Current Address:	Tel No:	CHI:			
		Mobile No:			
		PARIS:			
Post Code:		File:			
Worker Responsible for Review:		Services Used:			
Reason for review:		Date of any previous reviews in last 2 years:			
Changes in circumstances since last assessment / review:					
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.					
What is the view of the client and his/her family carer (s) relating to the above?					
PERSONS CONTRIBUTING TO THE REVIEW			DATE & METHOD OF CONTRIBUTION		
Name:	Designation / Relationship	Phone	Letter/ report	Individual meeting	Attend review
Service User's Signature:			Date:		
Workers Signature:			Date:		
SENIOR WORKERS RECOMMENDATION:					
Signed:			Date:		
PERSON RESPONSIBLE FOR NEXT REVIEW:					
Date of Next Review:					

Details input to Database: YES/NO		Date of input:	
CHANGE OUTCOMES:			
To what extent has the support provided by the service / services impacted on the client's:			
Health		Skills and confidence	
Wellbeing		Mobility	
PROCESS OUTCOMES:			
To what extent does the client feel that staff within the service / services:			
Listen to them		Give them a choice over the nature and timing of support	
Value them and treat them with respect		Do what they say they will	
Are responsive to their needs and wishes			
QUALITY OF LIFE OUTCOMES:			
What difference does the service make to the client's life with respect to:			
Taking part in activities of their choice		Employment and vocational opportunities	
Social contact		Staying as well as they can be	
Living where they want		Feeling safe	

Dealing with stigma / discrimination

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

Please highlight the most appropriate response to the following questions:

Broadly, 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?

Yes No Not reportable

Broadly, 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?

Yes No Not reportable

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

Yes No Not reportable

Broadly is the client satisfied with the opportunities available to them to:
Engage in employment and vocational activities?

Yes No Not reportable

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

Yes No Not reportable

Other information from client or carer:

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:

Actions required	By whom?	Is this a change?	Signature	Date
Essential				
Desirable				

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Comments/other information:

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

CARERS OUTCOMES FOCUSSED REVIEW FORM

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

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

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

Please circle the most appropriate response to the following questions:

Broadly, are the health and wellbeing of the carer supported by their package of care?
Yes No Not reportable

Broadly, is the carer supported by their package of care to have a life of their own?
Yes No Not reportable

Broadly, is the carer supported to make informed choices about whether to care and the extent of caring, including breaks?
Yes No Not reportable

Broadly does the carer feel informed/skilled/equipped to care?
Yes No Not reportable

Does the carer feel that they are a key partner in caring?
Yes No Not reportable

Does the carer feel that they are valued and respected?
Yes No Not reportable

Does the carer feel that the service is responsive to their changing needs?
Yes No Not reportable

Other information from carer:

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2.2 User and Carer Defined Service Evaluation Questionnaires

Background

Research with representatives from 13 health and social care partnerships in Scotland showed that consultation, through surveys, focus groups, one to one interviews and meetings, was the primary approach taken by these organisations to gathering the views of service 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 and can be used with many service users and carers who find it difficult to engage in other forms of consultation, including adults with learning disability and people with dementia. These questionnaires are based on the outcomes frameworks presented in tables 2 and 3 in section 1.

About the UDSEQ and CDSEQ

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

Services have traditionally focused on the needs of service users in setting priorities and allocating resources. Increasingly, attention is being paid to the needs of unpaid carers, as key 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 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

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.

Over the course of the research work with the Joint Improvement Team a number of stakeholders highlighted the limitation of using the original UDSEQ with carers and so a revised version has been developed specifically for use with carers, based on the outcomes framework summarised in Table 3, the Carer Defined Service Evaluation Questionnaire (CDSEQ).

Evidence from the field

The implementation of these tools in partnership settings 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"> • Use of open ended questions in face to face interview facilitates inclusion of 'hard to reach groups' like people with dementia. • Captures detailed information on outcomes including specific examples of good and bad practice • Captures diversity of individual experience which can be lost in surveys and focus groups • Structure of the tool makes it easy to link process to outcome 	<ul style="list-style-type: none"> • Time consuming to administer, relative to other consultation methods (hence use with targeted sub-population) • Requires some interviewing and analysis skills • 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

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

The tools take between twenty and forty minutes 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

To maximise data quality, interviews should ideally be audio recorded for later transcription. If this is not possible then the interviewer should take notes during the interview and supplement these with detailed notes and reflections recorded after the interview. Notes on the interview can be written up using the relevant 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 if applicable for the interview to be audio recorded) 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 audio recording or 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. If the interview is being held in the individual's home, the person conducting the interview should let someone else know the time and location of the interview. They should also show photo identification on entering the service user or carer's home.

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 instances there may be practical barriers to interviewing a person alone (such as communication difficulties or the need to provide continued supervision to another). In other instances the service user or carer may prefer to be interviewed in the presence of another. In these cases the interviewer may have to work hard to ensure that the person being interviewed gets a chance to share their views in the interview and that neither party is denigrated by being spoken about in their presence.

Ensuring data quality

Although the questions in the UDSEQ and CDSEQ are based on the priorities of service users and carers, these questions may not always reflect the experiences of the person being interviewed or they may struggle to understand them. 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. This approach is particularly useful when interviewing people with certain cognitive impairments or communication difficulties. A successful interview is one where a good record of how the service user or carer experiences each of 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

Record relevant biographical information about the individual on the analysis pro-forma. It is also helpful to record notes on the following:

- How the interview went, was the service user or carer comfortable and able to talk freely, or are there any concerns over the reliability of the answers given?
- If there is anything in addition that the others should know to understand the interview that was not talked about in the interview?
- The difference you think the service / package of care is making to the life of the service user or carer.

Data Analysis

The Analysis Pro-formas provide frameworks for summarising the information gathered in interviews with service 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 interviewer should review all of these interviews, looking for common themes across the data and also for key differences. 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 UDSEQ and CDSEQ 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 semi-structured, 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 brief, taking no more than 5 minutes.

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....

with respect to:

- 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

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

Outcome Checklist

Outcome	Experience of service user / carer	Features of service promoting or hindering that outcome
Quality of life outcomes		
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		
Process outcomes		
Being listened to		
Valued and treated with respect		
Choice		
Reliability		
Responsiveness		
Other		

Change outcomes		
Improving skills and confidence		
Improved mobility		
Other		

Carer Defined Service Evaluation Tool

Section 1. The nature and extent of support.

This section should be brief, taking no more than 5 minutes.

1. Can you tell me about the kind of help that the cared for person (name) gets, and who provides that service?

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 have outstanding concerns about the quality of life of the cared for person?
3. Do you get any additional support for your own needs?
(helpful to prompt with both service providers e.g. partnership and carers centre and also types of support, e.g. respite, information, training, emotional support)

Section 2. Impact on you and your life

There are several things that carers have said that are particularly important in life. These are: health and wellbeing, opportunities to have a life of their own, having a positive relationship with the person cared for and freedom from financial hardship. Can you tell me if (name of service) and the support that they give to you and (name of care recipient) makes a difference to you and your life....with respect to:

- Your health and wellbeing
 - Having opportunities to have a life of your own
(includes social contact and employment and/or activities)
 - Having a positive relationship with the cared for person
 - Freedom from financial hardship
4. Is there anything else that you think that the service could or should do for you as a carer?
 5. What difference has this service made to your life?

Section 3. Support to cope with caring

6. Do people in the service support you to make choices about caring, including whether to care, the extent of caring and having breaks from caring?

7. Do you feel informed/skilled/equipped to care?
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 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

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

Outcome Checklist

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

Process outcomes		
Valued and respected/recognised as expert		
A say in services		
Responsive to changing needs		
Meaningful 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
Quality of life			
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 isolation important to sustain health	Access to support both preventatively and in the longer term if required, rather than restricted to crisis times.	Role of staff in supporting access to mainstream and specialist health services
Process			
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
Change			
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
Quality of life outcomes			
Feeling safe	Physical safety – feeling safe in neighbourhood, getting out and about, managing tasks of daily living, avoiding falls (for 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 family and friends. Relationships between service users and wider community often more	Continuity of staffing helped promote supportive relationships with staff Opportunities for informal contact with other users supported by group activity, drop-in and sensitive planning of service use e.g. co-ordinating respite	Extended partnerships also create opportunities to meet people and form relationships

	challenging to establish	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
Process outcomes			
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 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. Only one carer reported wanting a choice of service provider	Choice over daily routines was largely determined by the core service. Person centred planning enabled users to have a say in how they 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	Multidisciplinary team sharing information about individual circumstances. Communication assisted by colocation. Extended partnership increased available 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	Consistency of staffing and adequate staff numbers. Good communication	Colocation can assist with communication

	and advise them.		
Knowing someone will respond	Knowing services would respond at times of need was very important; easy access to services was therefore highly valued. Out of hours support was viewed as vital in an emergency and, even if not used, 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
Change outcomes			
Improving skills and confidence	Following episodes of ill-health, users (especially older people) 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 (especially older people) wanted services to improve mobility where possible, and/or provide adaptations where required	Staff working as a team to meet mobility requirements	Multidisciplinary team
Reducing symptoms	Service users with serious mental and/or physical 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			
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Appendix D: Resources

Reports from the three phases of work undertaken with the Joint Improvement Team to implement the UDSET in partnership settings are available on the Joint Improvement Team Website.

Additional information about the development of the UDSET and also research findings are available in the project final report which is also available from the Joint Improvement Team Website.

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

Miller E, Morrison J and Cook A (2006) Brief Encounter: Collaborative research between academic researchers and older researchers, *Generations Review* 16 (3) September 2006

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

Further information on the National Outcomes Framework can be found on the Joint Future Unit website at

{ HYPERLINK

"http://www.scotland.gov.uk/Topics/Health/care/JointFuture/NationalOutcomes" }

Information on the University of York Outcomes Programmes from 1996 – 2006, including summaries and copies of reports can be found on the University of York website:

{ HYPERLINK

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

Detailed information and guidance on best practice in accessing and interviewing service users is available from a recent report on best practice in Single Shared Assessment by the Infusion co-operative available on the Scottish Executive website:

{ HYPERLINK

"http://www.scotland.gov.uk/Publications/2005/03/20851/54591" }

Further information is available on the INVOLVE website, supporting public participation in the NHS: { HYPERLINK "http://www.invo.org.uk/" }

There are a number of excellent textbooks for those new to research that provide further guidance about managing the research process, the ethics and politics of research, designing a good research project and analysis, including:

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

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

Mason, J (1996) *Qualitative Researching* London: Sage Publications

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

Punch, K.F. (1998) *Introduction to social research: quantitative and qualitative approaches*. London: Sage

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