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Involving service users in their mental health care: the CUES Project

AIMS AND METHOD
To assess the impact of Carers' & Users' Expectations of Services – User version (CUES–U) upon clinical care planning in working age adults with mental health problems. Eighty-six individuals who were receiving input from the community mental health team gave their views.

RESULTS
Life and service satisfaction ratings ranged from 49% to 88%. The CUES–U discussion led to a change in clinical care for 49% of respondents. Care coordinators rated CUES–U as a good use of their time in 64% of cases. Women and those with a shorter duration of mental disorder were rated as more engaged in the consultation process.

CLINICAL IMPLICATIONS
CUES–U appears to be a useful tool for supporting individual clinical care and the evaluation of community mental health services.

The benefits of actively engaging mental health service users in their own management is supported by both clinical experience and research evidence (Crawford, 2001; Blenkiron, 1998). The *Mental Health Policy Implementation Guide* (Department of Health, 2001) envisages 'increased meaningful service user and carer involvement and inclusion in service planning', while 'patient and carer experience' is one of the National Service Framework's main areas for determining performance (Department of Health, 1999).

Carers' and Users' Expectations of Service (CUES) arose from the Department of Health Outcomes of Social Care for Adults (OSCA) initiative (Lelliott, 2000). The CUES–U (User version) is a 17-item service user outcome scale in booklet form (Lelliott *et al*, 2001). It was developed by a collaboration formed from the National Schizophrenia Fellowship, the Royal College of Nursing Institute, the University of East Anglia School of Social Work and the Royal College of Psychiatrists' Research Unit. It is an important tool because it covers the issues of quality of life and satisfaction with mental health services that users (rather than professionals) have identified as being their priorities.

The CUES–U covers 16 key areas:

(1) Where you live
(2) Money
(3) Help with finances
(4) How you spend your day
(5) Family and friends
(6) Social life
(7) Information and advice
(8) Access to mental health services
(9) Choice of mental health services
(10) Relationships with mental health workers
(11) Consultation and control
(12) Advocacy
(13) Stigma and discrimination
(14) Medication
(15) Access to physical health services
(16) Relationship with physical health workers.

Each area has three questions. Part A gives a normative statement describing the 'ideal' situation if there was no problem arising. For example, money: 'You should have enough money to pay bills, stay out of debt and not miss meals. You should not have to feel isolated or cut off from society because of lack of money'. The scale then asks how the person's situation compares with this (as good as this, worse or very much worse than this). Part B asks whether the user is satisfied with the issue described (yes, unsure or no). Part C allows space for a free text response, so that the user can describe their particular situation, including any specific problems with their life or the service provided. The CUES–U is designed to be completed by the service user, independently of their care coordinator.

This paper describes the practical implementation of CUES–U within an adult community mental health team. Its three main aims (shared with the National CUES Programme launched by the Royal College of Psychiatrists) were:

- To directly improve clinical care planning, by allowing individuals to tell staff about their experiences and current practical problems.
- To measure users' satisfaction with their life and the local mental health service, acting as a baseline for future service developments.
- To allow comparison of the local mental health service with other areas of the UK (national benchmarking).

Method

An introductory training workshop was organised via the Royal College of Psychiatrists' Multi Centre Audit Team in Spring 2001. The national CUES documentation was then adapted for local use. One hundred and twenty service users aged between 16 and 65 were selected from the electronic records. Users were included in the project if they had mental health problems lasting over 6 months and they were currently seeing at least one community mental health team professional as part of the Care Programme Approach (CPA, Department of Health, 2000).

All participating professionals agreed to hand the CUES booklet, together with a letter of explanation, to users attending for normal clinical care and go through the replies at that meeting or the next CPA review. Respondents were encouraged to seek help from family or friends if they had difficulties filling in the booklet. They were also given contact details for an independent advocacy service provided through the local mental health resource centre for assistance in expressing their views. User participation was voluntary, and booklets were number-coded to preserve anonymity.

Professionals recorded the age, gender, diagnosis and duration of disorder for respondents. In addition, they completed a review form stating what changes to individual care plans had been made, and a questionnaire about the impact and overall usefulness of CUES. A copy of the CUES booklet was kept in the service user's mental health records. Local data analysis, using non-parametric tests, was performed using the Statistical Package for the Social Sciences (SPSS) version 9.0. The original CUES booklet was sent to the Royal College of Psychiatrists' Research Unit for national data comparison.

Results

CUES booklets were returned fully completed by 86 service users (72%). All 86 respondents were of White ethnicity, 44 (52%) were women and the mean age was 44 (s.d. 12.6, range 17–65). The number of cases in each diagnostic category was: schizophrenia 25 respondents (29%), bipolar disorder 9 (11%), unipolar depression 25 (29%), anxiety disorders 14 (16%) and personality disorders in 6 cases (7%). The duration of their main psychiatric illness was between 1 and 5 years for 34 users (41%) and over 5 years in 44 cases (52%). The care coordinator was a psychiatrist in 40 cases (47%), a community psychiatric nurse in 28 (33%), social worker in 8 (9%) and occupational therapist in 5 cases (6%).

Table 1 details the satisfaction of service users in key areas of their lives and Table 2 shows their overall satisfaction with mental health services. In 12 of the 16 CUES areas, local service users are significantly more satisfied than the national comparison data (CUES field trials in 32 UK locations, n=449, Lelliott *et al*, 2001).

The CUES discussion resulted in the identification of one or more areas requiring action for 37/75 (49%) service users, a mean of 1.3 (s.d. 2.3, range 0–13) areas per respondent (Table 3). Table 4 summarises the care coordinators' views regarding the usefulness of CUES–U as a tool to support care planning (73/86 replies, 85% response rate). A longer duration of mental disorder made it more likely that the care coordinator would discuss CUES at their next meeting with the service user (Mann–Whitney U=298.5, P=0.04), but less likely that this discussion subsequently made a difference to their care plan (Mann–Whitney U=249.0, P=0.007). Respondents perceived as actively engaged in the CUES consultation process more often had a mental disorder present for under 5 years (14/29, 48%) compared with those (5/30, 17%) with disorders of a longer duration (χ^2=6.75, df=1, P=0.009). A greater proportion of women (14/31, 45%) than men (5/27, 19%) were rated by their care coordinators as finding CUES a positive experience (χ^2=5.18, df=1, P=0.07). The age of service users did not significantly influence changes to the care plan.

Sixty-two service users (72%) responded to one or more part C (free text) questions, a mean of 4.8 (S.D. 5.15) comments per service user. A total of 138 comments were made about the service, including 63 suggestions for its improvement. Care coordinators' opinion of CUES as being a good use of their time in each case related

Table 1. Service users' satisfaction in key areas of their life

Carers' and Users' Expectations of Services Questions	Part A Responses (% who rated their experience 'as good as' the normative statement) Local (UK)	Part B (% who replied 'yes' to satisfaction questions below) Local (UK)
1. Where you live		
Are you satisfied with the place you live in?	77 (59)**	76 (52)***
2. Money		
Do you have enough money to meet your basic needs?	72 (52)***	73 (50)***
3. Finances		
Are you satisfied with the level of help you get with your finances?	66 (70)	61 (63)
4. How you spend your day		
Are you satisfied with the way you spend your day?	64 (72)	55 (58)
5. Family and friends		
Are you satisfied with your relationships with the people closest to you?	69 (57)*	69 (53)**
6. Social life		
Are you satisfied with your social life?	62 (54)	49 (40)
13. Stigma and discrimination		
Are you satisfied with the way other people treat you?	72 (51)***	72 (45)***

*$P<0.01$, **$P<0.001$, ***$P<0.0001$, (χ^2 test, df=1).

Table 2. Service users' satisfaction with mental health services

Carers' and Users' Expectations of Services Questions	Part A Responses (% who rated their experience 'as good as' the normative statement) Local (UK)	Part B Responses (% who replied 'yes' to satisfaction questions below) Local (UK)
7. Information and advice		
Are you satisfied with the information and advice you get?	76 (52)***	77 (58)**
8. Access to mental health services		
Are you satisfied with your ability to get help when you need it?	73 (50)***	72 (52)***
9. Choices of mental health services		
Are you satisfied with the range of choice you have?	73 (47)***	73 (52)***
10. Relationships with mental health workers		
Are you satisfied with your relationships with mental health workers?	85 (64)***	87 (64)***
11. Consultation and control		
Are you satisfied with the level of consultation and control you have?	84 (59)***	84 (65)***
12. Advocacy		
Are you satisfied with the help you get in difficult situations?	72 (56)**	74 (63)*
14. Your drug treatment		
Are you satisfied with your current medication?	71 (58)*	73 (66)
15. Access to physical health services		
Are you satisfied with your access (general practitioner, hospital, dentist, opticians, chiropodist)?	83 (74)	80 (77)
16. Relationships with physical health workers		
Are you satisfied with the way your physical problems are dealt with?	88 (70)***	86 (74)*

*$P<0.01$, **$P<0.001$, ***$P<0.0001$ (χ^2 test, df=1).

Table 3. Carers' and Users' Expectations of Services – User version and care planning

Area identified for action	No. (%) service users (n=75)	Examples
Care plan review (Changes that need to be made to the existing care plan)	7 (9%)	Client requested more daily activity. Now attends mental health drop-in centre twice-weekly Referred to workplace experience officer Relapse prevention plan agreed to avoid future debts due to mania
Individual work (Issues that service user would like to deal with directly 'in-session')	29 (39%)	Changed antidepressant due to side-effects Discussed debt problems – has now seen Citizens' Advice Bureau and sorted them Ongoing work re: socialising with friends To be able to mix in crowds is a goal – graded exposure work planned Wrote report for ill-health retirement Entitlement to benefits reviewed Client refused increased mental health service involvement despite recognising areas where problems exist
Service issues (Problems that require addressing at service level)	4 (5%)	Wishes to meet people of his own age socially: to investigate local provision Perceives lack of information: psychiatrist agrees to copy out-patient clinic letters to her The in-patient unit does not offer single rooms: this is subject to a local review

directly to the number of free text comments made (Mann–Whitney U=218.0, P=0.013).

A 'total CUES–U score' (maximum=32) was created for part B questions by adding the responses to all 16 items. This correlated negatively with the number of areas identified as requiring individual work (Spearman's r=0.564, $P<0.001$). Hence, if a service user expressed greater overall levels of dissatisfaction, then the care

Table 4. Effect of Carers' and Users' Expectations of Service – User version (CUES–U) on clinical practice

Care coordinators' questionnaire	No. (%) replies
1. To what extent did you discuss CUES with this service user before asking him/her to fill it in?	
In-depth explanation and discussion	11 (15)
Mentioned in passing	30 (41)
No discussion – letter only	32 (44)
2. Did you discuss CUES at your next or subsequent meeting with this service user before asking him/her to fill it in?	
Yes	59 (80)
No (if no, discontinue)	14 (20)
3. To what extent did CUES affect your discussion?	
No difference	24 (41)
Some difference	33 (56)
A great deal of difference	2 (3)
4. Did the discussion highlight new issues, or issues you had not discussed for some time?	
Yes	22 (37)
No	37 (63)
5. On balance, would you say that your discussion around CUES was:	
A good use of your time?	38 (64)
A poor use of your time?	21 (36)
6. What was your perception of the service user's engagement with the process? Did he/she find it:	
A positive experience?	19 (32)
The same as any other meeting with you?	40 (68)
Worse than usual?	0 (0)

coordinator was significantly more likely to take action to address their concerns. There were no gender differences in the satisfaction ratings (median total CUES score for men=28, women=27.5, Mann–Whitney U=596, *P*=0.69).

Discussion

The views of service users and their carers will represent a major social force in determining the shape of mental health services in the future (Bracken & Thomas, 2001). This study shows that CUES–U can be an effective and practicable tool within community mental health teams, both for increasing users' involvement in their care and for service benchmarking. With regard to the service user's engagement in the consultation process and agreed changes to the clinical care plan, CUES–U was rated as more helpful for those with mental health problems of shorter duration. The care coordinator's perception that men were less often engaged in the consultation process may have been more apparent than real, as this study found no gender differences in the number of changes made to the CPA care plan, or in total life and service satisfaction scores. Previous research has shown no consistent difference in expectations between men and women in community mental health care clinics (Blenkiron, 1998).

All respondents in this sample were of White ethnicity, reflecting the very low numbers of individuals from ethnic minority groups currently living within the local population. CUES–U has not as yet been translated into any other language (Lelliott *et al*, 2001). Further evaluation of its usefulness in other cultural settings is indicated.

A limitation of the high overall levels of satisfaction expressed is that service users knew their care coordinator would see their replies. This may have inhibited some respondents from making critical comments. However, a central purpose of CUES–U was to directly facilitate improvements to the clinical care of these individuals, and so 'blinding' of professionals to their replies was neither desirable nor achievable. As 72% of respondents recorded comments in the free text (part C) section, and the majority of these were negative, it is possible that most service users felt able to express their views.

Both locally and nationally, the lowest satisfaction rates were those for 'How you spend your day' and 'social life'. This problem is being addressed locally on three levels: individual face-to-face work (e.g. activity scheduling), improved mental health service provision (group and day care programmes) and better access to social initiatives outside of mental health (e.g. leisure and employment). CUES–U may be an appropriate tool to assess the extent to which service users feel that integration of mental health care and social services provision is being achieved (Kennedy, 2000).

User involvement in developing proposals for change and auditing the effectiveness of services is no longer an optional extra (Barnes & Shardlow, 1997). CUES is important because the Department of Health has recently commissioned the National Institute for Mental Health to evaluate CUES as a national outcome measure. Along with other ratings, CUES will be piloted in four NHS Trusts in 2002–3, as a prelude to national implementation of a minimum mental health data set. The future success of CUES will depend upon several key factors. These include agreeing its purpose clearly, ownership at the front line of mental health care delivery and combating service user consultation fatigue. Service user initiatives should reduce (not add to) the paperwork of mental health professionals, by building feedback from users into the CPA process.

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Further information on the national CUES project is available from Paul Lelliott, Director, Royal College of Psychiatrists' Research Unit, 83 Victoria Street, London, SW1H 0HW, www.rcpsych.ac.uk/cru, tel: 020 7227 5320.

Declaration of interest

None.

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