ECTAS
ECT ACCREDITATION SERVICE
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ROYAL COLLEGE OF PSYCHIATRISTS

ECTAS Interim Report – Patient perspectives

March 2013 – April 2014

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Introduction to ECTAS

The ECT Accreditation Service (ECTAS) was established in 2003 to promote better standards of practice in ECT services in England, Wales, Northern Ireland and the Republic of Ireland.

ECTAS is managed by the Royal College of Psychiatrists' Centre for Quality Improvement and works in partnership with the Royal College of Anaesthetists, the Royal College of Nursing and patients.

The ECTAS standards are based on current best available evidence, and are reviewed and re-published regularly by a multi-disciplinary reference group.

The standards are graded into three types:

Type 1: failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law;
Type 2: standards that an accredited clinic would be expected to meet;
Type 3: standards that an excellent clinic should meet.

In order to achieve accreditation a clinic must meet all Type 1, at least 80% of Type 2 and some Type 3 standards. If a clinic does not meet this level, their accreditation will be deferred for a short period of time in order to make the necessary improvements.

The ECTAS model is about more than one-off inspection to assure that minimum standards are met. Its purpose is to encourage clinics to improve continuously and to achieve excellence in ECT practice.

Accreditation entails a rigorous process of self- and peer-review against the standards. This involves an audit of health records, policies and procedures, evaluation of the treatment environment and facilities and structured feedback from clinic staff, referring psychiatrists and people who have been treated in the clinic.

Each ECTAS cycle takes three years. It begins with a full self- and peer-review, after which a full report is sent to the clinic. At 18 months, there is an interim self-review to ensure the clinic is maintaining standards. Once a clinic has completed the full three-year cycle, the process begins again and the clinic moves to cycle 2 and so on.

Further information on the ECTAS standards and process can be found at www.ectas.org.uk.

ECTAS national reports

ECTAS publishes a national report every 2 years which looks at key themes emerging from self review data. The last national report was published in April 2014. This is an interim report exploring patient perspectives of the quality of care received.

Patient feedback

During the self review period, ECT clinics are given 20 patient questionnaires to distribute to people who have finished a course of ECT during the self review period, or up to 6 months prior to this. Patients are provided with an addressed envelope so that they can post their responses directly back to the ECTAS team. All of the questionnaires are confidential and anonymous. Clinics are informed that if patients are likely to require help completing the questionnaire, this should be sought by a member of staff independent from the ECT clinic, an advocate or a friend or relative.

The patient questionnaire is broken down into a number of sections, entitled 'About You'; 'Information on ECT'; 'The Consent Process'; 'Quality of Care'; 'Side Effects' and 'Did ECT Help You?'. There is also a free-text box at the end of the questionnaire for patients to make other comments.

Up until 2015 the feedback received from patients as part of the self review period was used for contextual purposes only. However, feedback from patients is now used to inform the decision-making of the peer review team and the Accreditation Committee, and contributes to rating of the standards.

2013-14 data

Between March 2013 and April 2014, ECTAS sent out 640 patient questionnaires to 32 clinics in England, Wales and the Republic of Ireland who were completing their self-reviews. One hundred and ninety two questionnaires were received back, from 32 clinics across 29 Trusts. This suggests a return rate of 30%, although this can only be estimated, given that ECTAS cannot be sure whether all clinics sent out all of the questionnaires, or whether more questionnaires were handed out.

When interpreting the data from the self review period it is important to bear in mind that many clinics will have used this information to make improvements either prior to, or shortly after, their peer review visit.

About You

At the beginning of the questionnaire, patients are asked their age, sex, whether they were given ECT as an inpatient or day patient, whether they received ECT under the Mental Health Act, and how long ago they completed their last course of ECT.

Of the 192 respondents who completed a patient questionnaire between March 2013 and April 2014, 128 were female and 64 were male. Just over half of the respondents were over 60. Figure 1 shows the age range of the respondents.

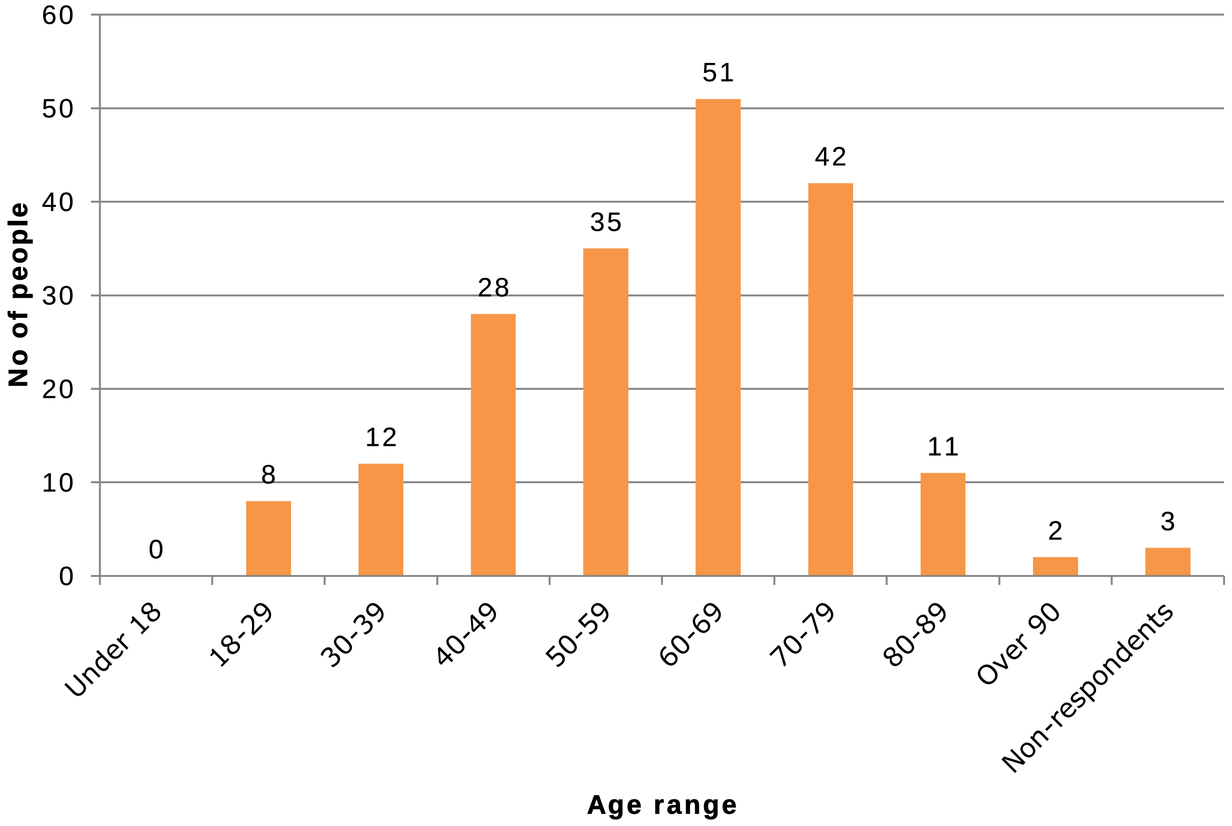

Figure 1 Age range of respondents

Fifty-six (29.2%) patients received ECT under the Mental Health Act, whilst 117 (60.9%) patients were treated informally. Nineteen (9.9%) patients did not respond.

ECTAS encourages clinics to send out questionnaires to patients who have recently completed a course of ECT. Sixty-one percent of patients who responded to the questionnaire had completed their last course of ECT within the 6 months prior. Figure 2 shows a breakdown of the length of time since the patients had completed their course of ECT.

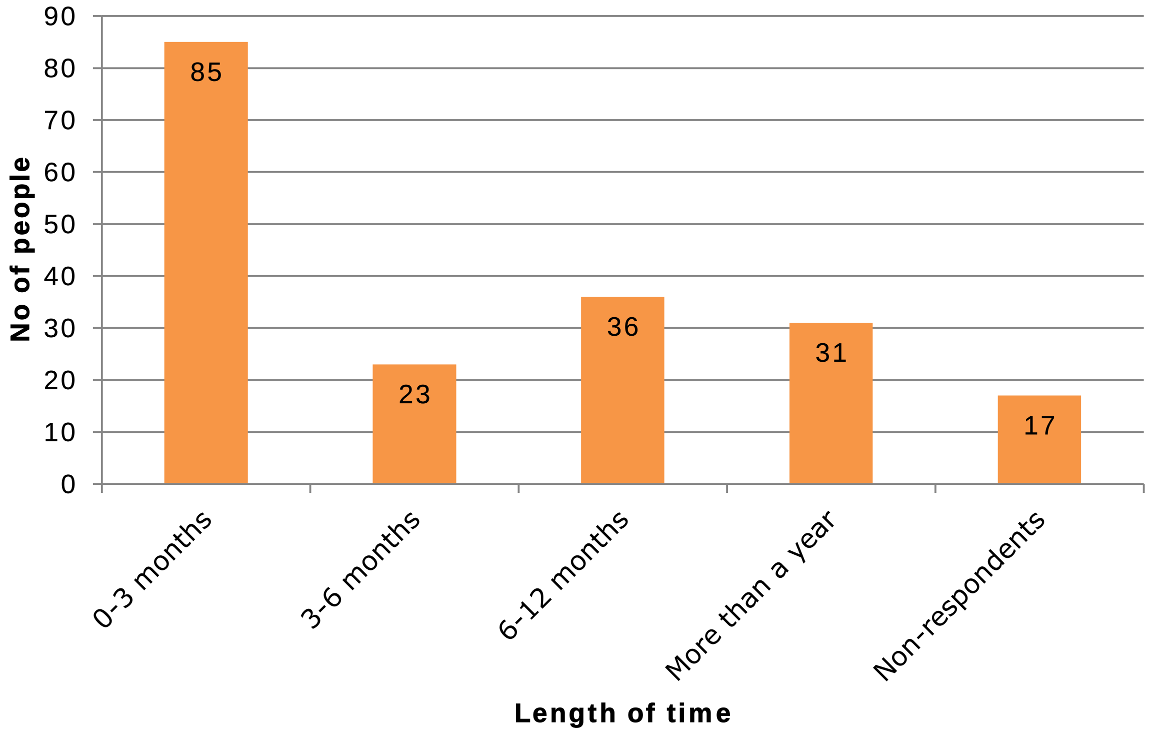

Figure 2 Length of time since last course of ECT

Information on ECT

Patients are asked a series of questions about the information they received on ECT prior to treatment, to which they may answer ‘yes’, ‘no’ or ‘don’t know/can’t remember’. For example:

- *‘Did your doctor speak to you about ECT before you agreed to the treatment?’* - 87% of people said ‘yes’.
- *‘Did you receive any written information on ECT?’* - 63% of people said ‘yes’.

Patients are then asked whether they have received information on a number of different aspects of treatment. The majority of people stated that they had received information on what would happen during the treatment, why they were having the treatment and what ECT was likely to do. Sixty-nine percent of people said they had been given information on potential problems and side-effects. However, less than half the respondents reported having been given information on what other treatments they could have instead and what would happen if they did not have ECT. Table 1 shows a breakdown of the responses to these questions.

	Number of people (% of people)* **Data excludes non-respondents*		
	Yes	**No**	**Don't know/can't remember**
Did your doctor speak to you about ECT before you agreed to treatment?	164 (87%)	5 (3%)	19 (10%)
Did you receive any written information on ECT?	116 (63%)	36 (19%)	33 (18%)
[Were you given information on] what would happen to you during treatment?	147 (80%)	8 (4%)	29 (16%)
[Were you given information on] why you were having the treatment?	157 (85%)	1 (0.5%)	26 (14%)
[Were you given information on] what ECT was likely to do for you?	146 (81%)	6 (3%)	29 (16%)
[Were you given information on] the problems and side-effects of having the treatment?	125 (69%)	25 (14%)	30 (17%)
[Were you given information on] what other treatments you could have instead?	86 (48%)	51 (28%)	42 (23%)
[Were you given information on] what would happen if you didn't have ECT?	84 (47%)	40 (22%)	46 (31%)

Table 1 Information on ECT

Patients were provided with a free-text box to respond to the question, 'how do you think the information you received on ECT could be improved?'. Forty-three of the 89 patients who commented said that they were happy with the information they had been given, and they did not think any improvements were needed.

"I thought the information was very precise and have no comments on how it could be improved."

There were 8 people who stated that they could not remember that point in their treatment, and a further 5 who responded *"don't know".*

Where improvements were suggested, the most common theme to emerge was that people would have preferred more, or more detailed, information about ECT. For example, one person commented they would have liked *"more information on how it works, and why"*, and several mentioned they would have appreciated more information about side-effects. One person felt that *“information [should be] given on a personal basis rather than a run-through of standard information on ECT”.*

In total, there were twelve people who stated that they would have liked more detailed information. In addition to this, there were three people who said they would have preferred *“simpler”* information;

“A more simple explanation of how ECT can improve the current diagnosis of the patient and a simple explanation of its possible negative effects.”

Two patients stated that they would have liked the opportunity to visit the ECT suite beforehand, one saying it would also be helpful if family could visit the suite. Another patient suggested that the information could be given to relatives and patients together before the treatment started. There were a further three patients who made practical suggestions as to how the information could be improved;

“Maybe talk with someone who has had ECT.”

“Perhaps info sheets with pictures i.e. the ECT machine and treatment room.”

“Maybe having a named nurse talk it over with you once you have come out from seeing the doctor - to go over the information again.”

The consent process

Patients are asked 5 questions about the consent process, and as with the questions on information, they may answer ‘yes’, ‘no’ or ‘don’t know/can’t remember’.

- *‘Did you say to your doctor that you agreed to have ECT?’* - 84% of people said ‘yes’.
- ‘*Did you sign a form to say you agreed to have ECT?’* – 68% of people said ‘yes’.

The majority of people felt that they had enough time to discuss their decision with their doctor before agreeing, with 75% responding ‘yes’, and 75% of people also felt they had had enough time to discuss it with other people, such as relatives, friends and other patients.

- *‘Did you feel pressurised or forced to have ECT?’* - 75% of people said ‘no’, 13% of people said ‘yes’ and 13% of people answered ‘don’t know/can’t remember’.

Of those 13% who said they had felt pressurised (23 people), 9 left further comments in the free-text box. Three of those who agreed they had felt pressurised suggested that their interests had been considered in some way.

“Felt slightly pressurised, however felt my best interests were considered.”

“I thought I was pressurised to have ECT because it was [the] right path for my treatment to aid my recovery. Though I thought my mind was not in [the] right place to make the decision.”

“I felt very vulnerable when I first started treatment and needed to confirm what was expected of me, but I also trusted the people who suggested it.”

One person stated that they had felt pressurised initially, but not thereafter. Three people commented that they would have liked more information or discussion around their treatment. One person stated that they did not get well after their treatment, and that it caused them a lot of stress. There was a final person who was clear that they felt they had no choice, stating:

“I had no option but to consent to the severe medical treatment.”

Three of the people who had not felt pressurised or forced to have ECT, made explicit reference to this question in their free text comments. One stated they were *“encouraged rather than pressurised”,* one person stated that while they were not pressurised, they were *“not overly keen”* on ECT either and a final person was clear that they had not been pressurised, and they were aware of the benefits ECT held for them.

In addition to the comments discussed above, a further 51 people left comments in the free text box. Twenty-nine of these stated that they were happy with the consent process, with several describing it as *“straightforward”* or *“thorough”.* Two people specifically mentioned having to sign a consent form before every treatment.

“I do remember being impressed at having to sign consent forms the night before each time I had ECT. Each time, I was also reminded of the details of ECT.”

There were six people who left comments indicating that they felt “*so ill”*, or *“so depressed”*, that they were willing to try anything that might help:

"I guess when you're that ill, you just want help."

A further six people left comments stating that they could not remember that point in their treatment. There were also several people who left comments in this section relating to the efficacy of their treatment; simply stating either that ECT had or had not worked for them.

	Number of people (% of people)* ****Data excludes non-respondents***		
	Yes	**No**	**Don't know/can't remember**
Did you say to your doctor that you agreed to have ECT?	157 (84%)	12 (6%)	18 (10%)
Did you sign a form to show that you agreed to have ECT?	129 (68%)	15 (8%)	46 (24%)
Did you have enough time to think about ECT and discuss it with your doctor before making your decision?	139 (74%)	17 (9%)	33 (17%)
Did you have enough time to discuss your decision with other people, e.g. family, friends or other patients?	138 (75%)	14 (8%)	33 (18%)
Did you feel pressurised or forced to have ECT?	23 (13%)	136 (75%)	23 (13%)

Table 2 The consent process

Quality of care

Patients are asked a series of questions relating to quality of care. The majority of responses were extremely positive, particularly those relating to staff being friendly and reassuring, and the clinic being clean and comfortable. The majority of patients had been accompanied to the clinic by someone they knew, although slightly fewer said that member of staff was with them when they woke up. Seventy two percent of patients said that clinic staff checked that they still agreed to have ECT before their treatment. Table 3 shows the responses to the questions on quality of care.

	Number of people (% of people) ***Data excludes non-respondents**		
	Yes	**No**	**Don’t know/can’t remember**
Did a member of staff accompany you to the ECT clinic?	173 (92%)	12 (6%)	3 (2%)
Did you know the member of staff who accompanied you?	155 (85%)	15 (8%)	12 (7%)
Was the member of staff who accompanied you to the clinic with you when you woke up?	135 (75%)	21 (12%)	24 (13%)
When you arrived at the clinic, were you introduced to all those who would be present during your treatment?	148 (79%)	21 (15%)	19 (10%)
Did clinic staff check that you still agreed to have ECT before your treatment?	135 (72%)	17 (9%)	36 (19%)
Were clinic staff friendly and reassuring?	181 (97%)	5 (3%)	1 (2%)
Was the clinic clean and comfortable?	180 (96%)	2 (1%)	6 (3%)
Do you feel you were properly cared for immediately after treatment?	172 (94%)	3 (2%)	8 (4%)

Table 5 Quality of Care

Patients were given a free text box to leave any comments they had on the quality of care they received, and a total of 89 people left comments. The most common theme to emerge from the qualitative data this generated was general positive comments, with 22 people describing their care as “excellent” or “very good”. The following is illustrative:

“More than properly cared for. Excellent care.”

A second common theme to emerge was praise for staff. Staff were frequently described as *“helpful”, “friendly” and “caring”.* Patients also reported that staff were approachable and reassuring, and that this enhanced their experience and enabled them to ask questions where necessary. Three patients reported that they had met the staff before, and that knowing them already had been helpful.

“The quality of care generally was of a very high standard. Always there was a helping hand or a cheerful face and someone available to answer questions. This applied to all grades of staff. One always felt 'safe'.”

Two patients mentioned previous difficulties with anaesthetic. Having this recognised and their particular needs taken into account had made their experience more positive:

“Due to my previous allergic reaction to anaesthetic/muscle relaxant, my treatment was arranged to take place in a general hospital... I always felt that I was kept informed of what was happening and all the staff were incredibly reassuring and showed great care and patience.”

Patients were also given a free text box in which they could respond to the question ‘can you think of anything that would have improved the experience for you?’. The most common theme to emerge from this was patients stating that there were no improvements necessary.

“No. Everything is to the highest standards.”

Seven patients mentioned that reduced waiting time would have improved their experience. Four people mentioned that the environment could have been nicer. Three people mentioned that further discussion before the treatment would have been helpful – either talking to patients who had had the treatment, having some counselling to improve understanding before treatment started or a *“more simple”* explanation. There were also some patients who suggested improvements to the process, for example:

“Magazines would be useful before treatment to take mind off ECT.”

“Maybe something to moisten the mouth whilst waiting.”

Two patients reported far less positive experiences of the treatment, stating that the only improvement would be *“not to go...in the first place”* or *“don’t have it”*.

Side effects

Patients were asked whether they experienced any side-effects following ECT. Sixty nine percent of people answered ‘yes’, 29% of people answered ‘no’ and 6% answered ‘don’t know/can’t remember’. Patients were then asked to select which side-effects they had experienced; the results are displayed in Figure 3.

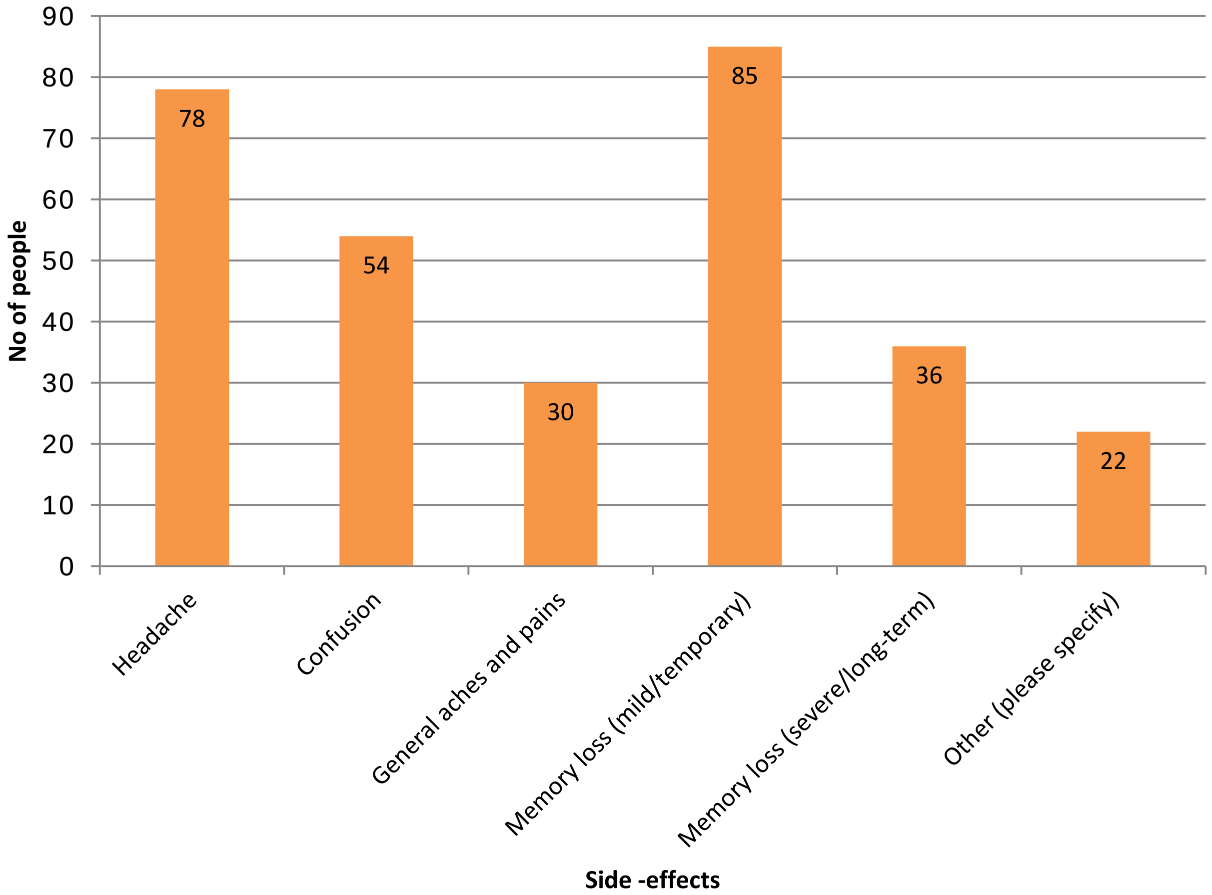

Figure 3 Side-effects

Patients were given a free text box and asked to write down any comments on the side effects they had experienced. Sixty-seven patients left comments, and the majority of these related to memory loss. Of these, 7 people left comments indicating that memory loss was *"mild"* or *"slight"* and twenty-nine patients described more severe or long-term effects. Some of those patients who identified longer-term memory loss reported that this had been in some way negative for them, describing it as *"traumatic"* or *"frustrating"*, for example. Two patients commented that they did not feel that the information they had been given before the treatment had prepared them for the amount of memory loss they had subsequently experienced.

"Was told that memory loss would be short term and unlikely, this wasn't the case - as inpatients 3 of us has ECT and all 3 of us suffered long term memory loss which shows no signs of subsiding."

Other patients reported experiencing headaches, confusion or other side-effects such as shaking. There were several patients who commented that the side-effects they had experienced were mild, or *"nothing to worry about"*. There was one patient who simply stated that the treatment was *"worth them"*.

Did ECT help you?

Seventy one percent of people who responded to the question ‘did ECT help you?’ answered ‘yes’. Fifteen percent of people said ‘no’ and 9% answered ‘don’t know/can’t remember’.

Patients were given a free text box to write down any comments on the effectiveness of their treatment. These comments could be divided broadly into three themes – those who felt the treatment was effective, those who did not feel the treatment was effective and those who were unsure or undecided as to the effectiveness of the treatment, or where it was difficult to determine their personal feelings regarding effectiveness.

Those respondents who felt their treatment had been effective most commonly referred to a lifting of their depression or an improvement in mood.

“ECT lifted depression and was a great help to me. I did not feel it would have lifted otherwise.”

A concomitant reduction in suicidal thoughts and urges was also mentioned by three of these respondents, and two stated that the improvement in their depression had made starting other activities – such as engaging in therapy – possible.

In addition to these 31 respondents, there were 6 people who mentioned a reduction in symptoms – such as loss of appetite or *“thinking about problems”* - without making explicit reference to depression. There were also several people who referred to a return to ‘normality’.

“The effectiveness of my treatment was instant. I was back to my normal self after one treatment.”

There were a number of respondents who simply commented that ECT had been effective for them, most commonly using terms such as *“[ECT] worked”*, *“successful”, “feel better”* or *“recover”.* There were a further 8 people who felt ECT had been partially effective, for example, saying it had helped *“to some extent”*, or for a *“short time”*.

Two respondents felt that ECT had been helpful to them only as part of their overall treatment.

“My theory is that without the three-pronged approach to my illness, the outcome might have been less successful; ECT, high standard of medical and nursing care and appropriate medication.”

There were others who felt far less positively about ECT. Of those 14 respondents who left comments indicating that ECT had not been effective, this most commonly related to not seeing any improvement in their depression or how they were feeling.

"I did not feel it had any affect at all. I still feel I have a problem with depression and anxiety."

A further 2 people stated that there had not been any improvement in their mood, in addition to which, they had experienced negative side-effects, one reporting that their daily life was worse than it had been prior to receiving treatment.

"The only effect ECT had on me was 12 migraines and a lot of memory loss. It has made my day to day living more difficult as I frequently forget things."

There were a further 3 people who left comments relating only to negative side-effects; two out of these three mentioned difficulties with memory.

Of those 25 respondents who were unsure as to the effectiveness of their treatment, the majority simply stated that they were *"unsure"* or having *"difficulty coming to a conclusion".* There were 6 people who felt it had helped them previously, but their most recent course had not been effective:

"ECT worked for me when I was ill several years ago, but not this time."

There were 3 people who were unable to determine whether it was ECT or another factor which had helped them – one person mentioning therapy, another a change of medication and a third simply the passage of time.

A final 7 people left comments where it was difficult to determine their personal feelings regarding the effectiveness of the treatment.

Patient feedback – next steps for ECTAS

It is apparent that the ECTAS patient questionnaires generate rich qualitative and quantitative data, which has the potential to act as a positive mechanism for quality improvement. In 2015, ECTAS has focused on ways in which patient feedback and involvement can become more central to the ECTAS process. The aim of this is to enhance the validity of our findings, to provided constructive feedback to clinics and to harmonise the ECTAS process with that of similar accreditation schemes within the College Centre for Quality Improvement. As such, ECTAS has made the following changes to the process in 2015:

- Patients are now included on the Accreditation Committee.
- Patients now attend a proportion of peer review visits to clinics.
- Patient feedback will inform the decision as to whether standards are ‘met or ‘not met’ during the self and peer review process, rather than acting only as contextual data.

It is hoped that by making patient involvement and feedback a central part of the ECTAS process, our members will continue to benefit from the experience of those who have used their services.

National Recommendations

1. **Ensure patients are given comprehensive written information about ECT**

   Whilst the majority of patients who responded to the survey said they had been given verbal information about ECT, approximately a quarter of patients had not been given any written information, and said they would have appreciated more information about what ECT is and what it involves. A verbal explanation given alongside this, which is tailored to the needs of each patient, will enhance understanding, dignity and respect for patients.

2. **ECTAS to arrange for service users to attend peer review visits**

   ECTAS now has several patients trained as peer reviewers. Patients began attending reviews in June 2015, and ECTAS will continue to support patients to train as reviewers and attend reviews.

ECTAS

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