





ECT Minimum Dataset 2016-17

Activity Data Report – England, Wales, Northern Ireland & Republic of Ireland

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Summary

In 2016/17, 71 clinics in England, Ireland, Wales and Northern Ireland (74% of ECTAS members) submitted data.

Acute courses of ECT

- 1821 courses of ECT were given to 1682 people. 139 people received more than one course of treatment.
- 67% of the patients were female.
- The mean age was 61.
- The most common reason for referral was 'severe depression that is lifethreatening, and where a rapid response is required, or where other treatments have failed'.
- 51.8% of patients were informal and capacitous at the start of treatment.
- The mean number of treatments per course was 9.8.
- 46.4% of people were severely ill at the start of treatment.
- 42.6% of people were much improved at the end of treatment.

Maintenance ECT

- In March 2017, there were 161 maintenance patients receiving maintenance ECT in 48 clinics.
- 74% of patients were female.
- The mean age was 66.
- 88.2% of people were referred for recurrent symptoms of depression.

Introduction

The ECT Accreditation Service (ECTAS) was established in 2003 to improve standards of practice in ECT services in England, Wales, Northern Ireland and the Republic of Ireland, and to award accreditation to clinics that perform well against the standards. ECTAS is managed by the Royal College of Psychiatrists' Centre for Quality Improvement, and 82.1% of clinics in its remit are members of the programme.

Over the years, ECTAS has often received requests for basic national activity data. Since the early 1990s, there has been a paucity of such data, with no body collecting this consistently. In response to these requests, ECTAS undertook a survey in 2012 with the co-operation of its member clinics, with the aim of collecting a comprehensive dataset relating to people in England, Wales, Ireland and Northern Ireland who received ECT over a one year period. In 2014, this survey was repeated.

In 2016, ECTAS made the decision to collect this data on a continuous basis, with the aim of observing trends over time. ECTAS member clinics are invited to take part in the survey every April. This report discusses the findings from the 2016/17 data collection period.

In 2017, further analysis of the data from the first two data collection periods was conducted, and the <u>findings published in The Journal of ECT</u>. This publication focused on England only. Despite an increase in the number of courses of treatment reported to ECTAS between the first two surveys, when the data were adjusted to reflect the total number of ECT clinics in England, an overall decline was observed.

In April 2017, *The Guardian* published an article entitled '<u>Electro-convulsive Therapy on the Rise Again in England</u>'. The report was based on Freedom of Information requests sent to NHS Trusts in England, covering the time periods 2012-13 and 2015-16. This article suggested that ECT use was increasing in England, and subsequently led to further media coverage regarding the use and practice of ECT.

Despite the different conclusions drawn by these two pieces of work, analysis of the dataset data from 2016/17 does suggest the use of ECT is continuing to decline in England.

Definitions

For the purpose of this report an acute course of ECT is defined as a series of individual ECT treatments, usually given twice weekly, to alleviate the symptoms of a diagnosed mental illness, typically depression, mania, catatonia and bipolar disorder and less frequently, schizoaffective disorder and schizophrenia. The course of treatment is discontinued when there is sufficient improvement in the symptoms.

Maintenance ECT (also referred to as continuation ECT) is defined as ECT usually delivered at intervals of between one week and three months, that is designed to prevent relapse of illness. The purpose of maintenance ECT is to give the treatments as infrequently as possible whilst preventing a relapse of symptoms.

Methodology

The dataset survey was carried out with the co-operation of ECTAS member clinic. Every member clinic was invited to complete an online survey for every patient who finished an acute course of ECT between 1 April 2016 and 31 March 2017. This represents a slight change in methodology from the previous two data collection periods, where a survey was entered for every patient who started a course of ECT during the

data collection period. The change enables ECTAS to collect the data on a continuous basis, with no overlap.

One other change was made to the survey in 2016/17. In previous years, the question on 'reason for referral' had been a free-text box. This led to inconsistencies, with different clinics recording the same diagnosis in different ways. As such, the question was changed to a drop-down menu, with options to select based on NICE guidance (CG90). The options were as follows:

- Severe depression that is life threatening, and where a rapid response is required, or where other treatments have failed
- Moderate depression that has not responded to drug treatments and psychological treatment
- Catatonia
- Prolonged or severe manic episode
- Other, please state

Clinics were asked to submit:

- The patients' age;
- Gender;
- Reason for referral;
- Mental Health Act status at the start and end of the course;
- Capacity to consent to treatment at the start and end of the course;
- Severity of illness at the start of treatment using the Clinical Global Impression Scale (CGI);
- Clinical outcome following treatment using the CGI;
- Number of individual treatments;
- Whether the person had received more than one course of treatment during the time period, and if so, how long it had been since the previous course.

In March 2017, clinics were asked to enter a questionnaire for every patient receiving maintenance ECT at that point. Clinics were asked to record:

- The patients' age;
- Gender;
- Reason for referral;
- Mental Health Act status;
- Capacity to consent;
- Frequency of treatments;
- Whether patients received treatment as an inpatient or an outpatient

Acute courses of ECT

ECTAS estimates that there were 117 clinics delivering ECT in England, Wales, Ireland and Northern Ireland between April 2016 and March 2017. Of these, 96 clinics were ECTAS members and 71 (74%) submitted data. Of these clinics, 60 were in England, 6 were in Wales, 3 were in the Republic of Ireland and 2 were in Northern Ireland.

During the data collection period, 1821 courses of ECT were given to 1682 people. This amounts to 17,990 individual treatments. 139 people received more than one acute course of treatment.

Gender

1114 (66.2%) of the people who received an acute course of ECT were female, and 601 (34.8%) were male. In the 2014/15 data collection period, the figures were 65% and 35% respectively, and in 2012/13, the figures were 66% and 34%. The proportion of females to males has therefore remained fairly constant.

Age

Respondents were asked to give the ages of people who received an acute course of ECT. The mean age was 61, the mode was 70 and the median was 64. Table 1 shows the age range breakdown, and figure 1 shows the distribution.

Table 1: Age range breakdown

No people	% of people
2	0.1
92	5.1
134	7.4
206	11.3
307	16.9
436	23.9
416	22.8
207	11.4
14	0.8
7	0.4
	2 92 134 206 307 436 416 207

Figure 1: Age range distribution

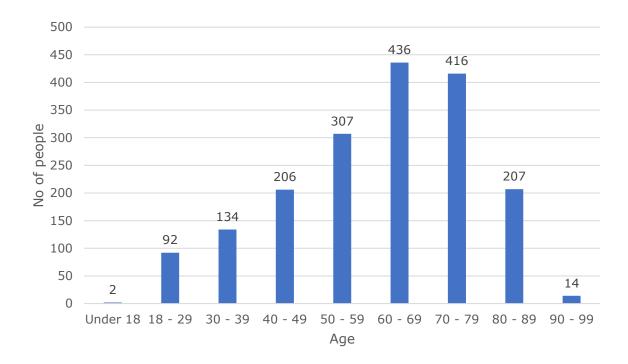


Table 2: Age range breakdown showing under 18s, working age adults and older adults

Age	No people	% of people
Under 18	2	0.1
Working age (18 - 65)	977	53.9
Older adults (65+)	835	46.0

Comparison with previous years

Age distribution remains constant across the data collection periods.

In 2014/15, the mean age was 61, the mode was 70 and the median was 64; exactly the same as for this data collection period.

In 2012/13, the mean age was 62, the mode was 52 and the median was 64.

Reason for referral

Respondents were asked to list the reason for referral. They were presented with a drop-down menu with 5 options to choose from. The results are detailed in table 3 below.

Table 3: Reason for referral

Diagnosis	No of people	% of people
Catatonia	54	3.0
Moderate depression that has not responded to drug treatments and psychological treatment	779	42.8
Severe depression that is life- threatening, and where a rapid response is required, or where other treatments have failed	826	45.4
Prolonged or severe manic episode	60	3.3
Other	102	5.6

Table 4: A breakdown of the category 'other'

Reason for referral	No of people	% of people
Affective disorder	1	0.05
Bipolar	11	0.6
Delusional disorder	1	0.05
Depression - other	9	0.5
Depression with psychosis	21	1.2
Deteriorating mental state	1	0.05
Diagnosis uncertain	1	0.05
Low mood and anxiety	1	0.05
Not responsive to other treatments	5	0.3
OCD	1	0.05
Patient request	8	0.4
Post partum depression	2	0.1
Post traumatic stress with depression	2	0.1
Psychosis	5	0.3
Recurrent depression	4	0.2
Schizoaffective disorder	14	0.8
Schizophrenia	13	0.7
Not stated	2	0.1

ECT in schizophrenia

ECTAS sometimes receives enquiries regarding the use of ECT for schizophrenia. Although ECT is not routinely used in the treatment of schizophrenia in the UK and Ireland, in other countries its use is much more common. Table 4 shows that 13 people were treated for schizophrenia in this data collection period. In 2014/15, the number was 27 and in 2012/13 it was 9.

The average age of people receiving ECT for schizophrenia during this data collection period was 41.5 years; lower than the overall average. 69.2% of people were male, again differing from the overall average. The majority of people (76.9%) were detained and non-capacitous, while 23.1% were informal and capacitous. The average number of treatments was 9.5. This is similar to the overall average.

69.2% of people were rated as severely ill using the CGI at the start of treatment, and 23.1% were rated as amongst the most severely ill. 15.4% of people were rated as 'no change' at the end of treatment; 38.5% as minimally improved; 38.5% as much improved and 7.7% as very much improved.

Comparison with previous years

In previous years, participants were presented with a free text box to record reason for referral. This resulted in a considerable amount of variation in how diagnoses were recorded. As such, the question was amended for this round of data collection in order to collect 'cleaner' data. As such, the data is not directly comparable across the years, although we can see that depression has always remained the most common reason for referral, accounting for 84.4% of referrals in 2014/15 and 86.4% in 2012/13.

Mental Health Act status

Respondents were asked to record the patient's Mental Health Act status and capacity to consent at the start and the end of the acute course of treatment. The majority of patients (51.8%) were informal and capacitous at the start of the course, followed by detained and non-capacitous (40.6%). Figure 2 shows the Mental Health Act status and capacity to consent at the start and end of the course.

At the end of the course, 57.5% of people were informal and capacitous, and 23.9% of people were detained and non-capacitous (see figure 3).

Figure 2: Mental Health Act status and capacity to consent to treatment at the start of the course

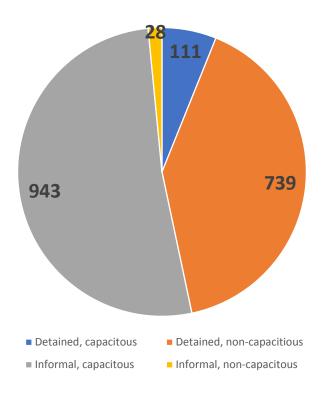
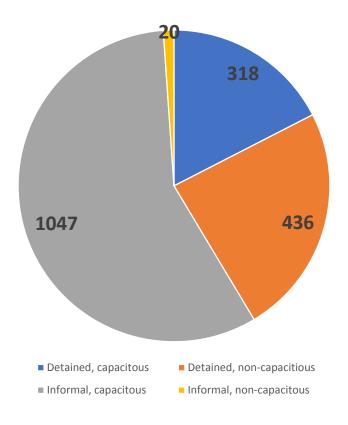


Figure 3: Mental Health Act status and capacity to consent at the end of the acute course



Over the course of treatment, 13.4% of all detained patients became informal, and 43% of all non-capacitous patients regained capacity. Fewer than 2% of patients who were informal ended the course detained, and fewer than 2% of patients who had capacity were deemed not to have capacity by the end of the course.

Comparison with previous years

In 2014/15 and 2012/13, the majority of patients were informal and capacitous at the start of the course, the figures being 51.4% and 54.0% respectively. The second most common status was detained and non-capacitous, with 36.0% of patients detained and non-capacitous in 2014/15, and 35.0% in 2012/13.

In both of the previous data collection periods, there was a similar percentage of people whose status changed from detained to informal by the end of the course, and a similar proportion of people re-gaining capacity over the course of treatment.

Over the three data collection periods, there has been a slight increase in the percentage of people who were detained at the start of the course. In 2016/17, 46.7% of people were detained at the start of the course. In 2014/15, the figure was 45.2% and in 2012/13 the figure was 42.0%. Interestingly, as this percentage has risen slightly, so too has the percentage of people who were detained and who then became informal; from 10.0% in 2012/13 to 10.8% in 2014/15 to 13.4% this year. This may add weight to the speculation in *Buley et al (2017)* that as the proportion of people being treated under the Mental Health Act increases, ECT is being targeted at those who are the most severely ill, and it is those who are the most severely ill whom the treatment most benefits.

Number of treatments

Respondents were asked to record the number of treatments the person received. The mean was 9.8, the median was 10 and the mode was 12. Figure 4 shows the distribution of the number of treatments.

No of treatments 19 17 17 15

Figure 4: Distribution of the number of treatments

Clinical Outcomes

Respondents were asked to use the Clinical Global Impression (CGI) Scale to rate the patient's clinical status at the start of treatment, and clinical outcome at the end. The majority of people (46.4%) were rated as severely ill at the start of treatment, and much improved (42.6%) at the end of treatment.

No of people

Table 5: CGI score at the start of treatment

CGI at start	No of people	% of people
2 = Borderline mentally ill	7	0.4
3 = Mildly ill	43	2.4
4 = Moderately ill	604	33.2
5 = Severely ill	845	46.4
6 = Amongst the most severely ill	322	17.7

Figure 4: CGI score at the start of treatment

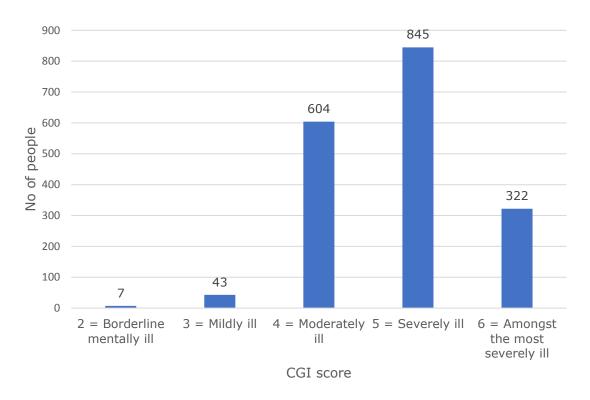


Table 6: CGI score at the end of treatment

CGI at end	No of people	% of people
1 = Very much improved	541	29.7
2 = Much improved	776	42.6
3 = Minimally improved	342	18.8
4 = No change	135	7.4
5 = Minimally worse	14	0.8
6 = Much worse	5	0.3
7 = Very much worse	6	0.3

900 776 800 700 600 541 342 300 200 135 100 14 5 6 0 5 = 2 = Much3 = 4 = No1 = Very6 = Much7 = Veryimproved Minimally much change Minimally worse much improved improved worse worse CGI

Figure 5: CGI score at the end of treatment

The data also indicates that those people who are the most unwell at the start of the course benefit from treatment the most. Table 7 shows the most frequently occurring outcome based on the CGI score at the start of treatment.

Table 7: Most frequently occurring outcome

CGI score at start of treatment	Most frequently occurring outcome	
2 = Borderline mentally ill	2 = Much improved	
3 = Mildly ill	2 = Much improved/3 = Minimally improved	
4 = Moderately ill	2 = Much improved	
5 = Severely ill	2 = Much improved	
6 = Amongst the most severely	1 = Very much improved	
ill		

Comparison with previous years

The data are very similar to that reported in the previous two rounds of data collection. In 2014/15, the majority of people (51.7%) were severely ill at the start of treatment and were much improved by the end of treatment (41.3%). This was also the case in 2012/13, where the figures were 47.0% and 41.7% respectively.

Data from the previous rounds of data collection also indicated that it is those patients who are most unwell at the start of treatment who are the most improved by the end.

Maintenance ECT

In March 2017, there were 161 maintenance patients receiving maintenance ECT in 48 clinics. 74.5% of patients were female and 25.5% were male. 78.9% of people were receiving treatment as outpatients, and 21.1% were receiving treatment as inpatients.

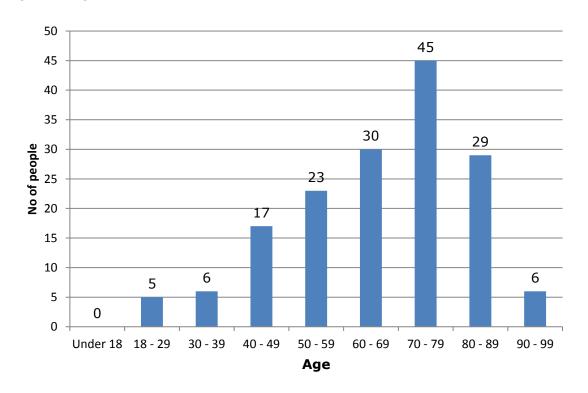
Age

The mean age of maintenance patients was 66, the median age was 69 and the modal age was 77.

Table 8: Age distribution

Age	No of people
Under 18	0
18 - 29	5
30 - 39	6
40 - 49	17
50 - 59	23
60 - 69	30
70 - 79	45
80 - 89	29
90 - 99	6

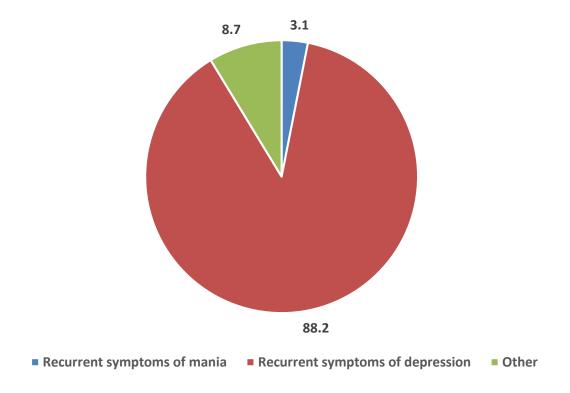
Figure 6: Age distribution



Reason for referral

The majority of people who were referred for maintenance ECT were referred for recurrent symptoms of depression. Figure 7 below shows reason for referral.

Figure 7: Reason for referral



Mental Health Act status

The majority (79.5%) of people receiving maintenance ECT were informal and capacitous.

Table 9: Mental Health Act status and capacity to consent

Status	No of people	% of people
Detained, capacitous	6	3.7%
Detained, non-	16	9.9%
capacitous		
Informal, capacitous	128	79.5%
Informal, non-capacitous	11	6.8%

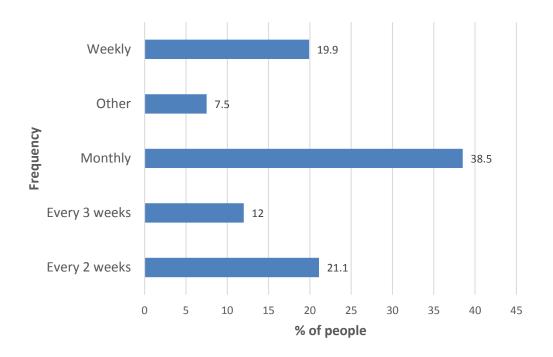
Frequency of treatment

The most common frequency of treatment for maintenance ECT was monthly (38.5%). There were very few people receiving maintenance ECT less frequently than this.

Table 10: Frequency of treatment

Frequency	No of people	% of people
Weekly	32	19.9%
Every 2 weeks	34	21.1%
Every 3 weeks	21	13.0%
Monthly	62	38.5%
Other	12	7.5%

Figure 8: Frequency of treatment



Comparison with previous years

The number of people receiving maintenance ECT has remained constant over the 3 data collection periods; it was 155 in 2014/15 and 160 in 2012/13. The proportion of females to males has also remained very similar, as has the average age. In previous years, as with 2016/17, the majority of patients were informal and capacitous and being treated for recurrent symptoms of depression. Monthly remains the most common frequency of treatment.

Rates of use

In 2014/15, 2148 courses of ECT were recorded in the dataset, an increase of 6% since the previous round of data collection in 2012/13. Two additional clinics did participate in 2014/15, but this did not, in itself, explain the increase.

In the 2016/17 round of data collection, there were 10 fewer clinics participating than there were in 2014/15, and so it is not possible to directly compare rates of use. However, there is some further analysis that can be done.

Buley et al (2017) used the following calculation to estimate the total number of ECT courses in England only (i.e., not for all of the clinics who participated) during the data collection periods:

Total estimated ECT courses = ECT courses in clinics responding X Number of ECT clinics / Number of responding ECT clinics

Using this calculation, we estimate that in 2012/13, there were 2325 courses, and in 2014/15, there were 2302. If the same calculation is used for the most recent data, the estimated number of courses in England is 2153 – a further decline.

Another way of looking at trends over time is to look at all of those clinics who have taken part in all three rounds of data collection. 53 clinics have completed all three rounds, of which 48 are in England. The mean, median and mode number of courses for these clinics are shown in the table below:

Table 11: The mean, median and mode number of courses over 3 data collection periods across all participating clinics

	2012/13	2014/15	2016/17
Mean	28.8	31.1	26.5
Median	25	26	23
Mode	21	22	15

Table 12: The mean, median and mode number of courses over 3 data collection periods for England only

	2012/13	2014/15	2016/17
Mean	28.3	31.2	26
Median	25	26	21
Mode	21	22	15

These data do suggest a slight increase in 2014/15, but then an overall decline. The data do therefore seem to suggest that, in England, rates of use are likely to be declining. It is only through collection of the dataset on a continuous basis that we will be able to build up a clearer picture of trends over time. As such, our thanks are due to ECTAS member clinics, who take the time to enter the data each year. Clinics are encouraged to continue to enter the data, as it is by this means that a clearer picture of rates of use will emerge.

Aggregated data – acute courses of treatment

Clinic	Number of	Number of	Mean	Mode	% rated as
number	courses	treatments	number of	number of	improved
			treatments	treatments	•
2	7	66	9.4	6	100
3	8	83	10.4	10	63%
5	34	341	10.0	12	85%
6	83	792	9.5	12	96%
8	37	296	8	6	97%
9	24	217	9.0	12	96%
10	25	223	9.3	12	100%
11	35	361	10.3	12	97%
12	20	196	9.8	12	95%
13	14	128	9.1	12	100%
14	14	110	7.6	6	100%
15	27	319	11.8	9	92%
17	16	159	9.9	12	100%
18	31	298	9.6	12	94%
19	17	309	18.2	12	94%
20	30	357	11.9	12	93%
22	10	79	7.9	5	80%
23	32	258	8.1	12	94%
28	15	126	8.4	12	100%
29	22	176	8	7	100%
30	31	292	9.4	12	90%
31	17	165	9.7	12	88%
33	32	338	10.6	12	88%
34	36	397	11	12	83%
35	45	413	9.2	12	87%
36	31	294	9.5	12	97%
37	38	372	9.8	12	95%
39	28	268	9.6	12	86%
41	36	333	9.3	12	94%
42	9	107	11.9	12	100%
43	34	472	13.9	10	88%
45	40	432	10.8	12	100%
46	12	77	6.4	1	67%
47	15	186	12.4	10	100%
48	23	261	11.3	12	91%
49	14	179	12.8	12	100%
50	17	203	11.9	12	88%
51	47	451	9.6	12	92%
52	11	128	11.6	12	100%
53	18	176	9.8	12	100%
54	8	72	9	11	88%
56	15	220	14.7	12	100%
57	4	48	12	12	100%
60	22	180	8.2	6	91%
61	11	103	9.4	12	64%
62	13	163	12.5	12	85%
65	16	219	13.7	12	100%
66	25	220	8.8	12	92%

68	45	338	7.5	12	78%
69	36	417	11.6	12	97%
70	12	191	15.9	12	92%
71	31	278	9.0	10	84%
72	42	409	9.7	12	83%
75	49	566	11.6	12	94%
78	14	149	10.6	12	100%
79	44	474	10.7	12	91%
80	94	784	8.3	12	94%
82	2	20	10	8; 12	100%
83	26	213	8.2	12	85%
84	27	230	8.5	12	85%
86	24	171	7.1	4	92%
88	16	128	8	6	94%
89	25	279	11.2	12	80%
90	56	474	8.5	8	100%
91	15	130	8.7	8	93%
92	30	316	10.5	12	93%
94	5	35	7	6	100%
95	30	274	9.1	6	97%
96	19	180	9.5	12	84%
97	10	79	7.9	12	90%
98	20	192	9.6	10	95%

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