

# **How accurate are ECT patient information leaflets provided by mental health services in England and the Royal College of Psychiatrists? An independent audit.**

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## **Abstract**

**Background:** To assess the accuracy of patient information leaflets about electroconvulsive therapy (ECT) in England, and assess compliance with National Institute for Health and Care Excellence (NICE) recommendations, and the principle of informed consent.

**Methods:** Freedom of Information Act requests were sent to 51 National Health Service Trusts for a copy of their information leaflet. These, and three Royal College of Psychiatrists (RCPsych) leaflets, were scored on a 40-item accuracy measure.

**Results:** Thirty-six Trusts (71%) provided leaflets. The number of accurate statements, from a possible 29, ranged from four to 20, with a mean of 12.8. The most commonly omitted accurate statements included: that previous treatments, including psychological therapy, should be tried first (mentioned by 12 Trusts); cardiovascular side-effects (6); lack of long-term benefits (6); patients' right to take 24 hours to consider giving consent (1); memory loss higher in women and older people (0). The number of inaccurate statements averaged 5.8, out of 11, and ranged from two to nine. The most common inaccurate statements included: ECT corrects biological deficits (28); exaggerated claims of very low mortality risk (28); minimisation of memory loss (23); claims that ECT saves lives (22); claims of very high

improvement rates (19). The current (2020) RCPsych leaflet contained seven inaccurate statements and scored worse than two previous RCPsych leaflets.

**Conclusions.** Information leaflets about ECT comply neither with NICE recommendations nor the principle of informed consent. Patients are being misled about the risks they are taking and the limited nature of ECT's benefits.

**Keywords:** electroconvulsive therapy; informed consent; ethics; adverse effects; cognitive dysfunction; women; older people

Nearly twenty years ago the UK's National Institute for Health and Care Excellence (NICE, 2003), made the following recommendation:

1.10 National information leaflets should be developed through consultation with appropriate professional and user organisations to enable individuals and their carers/advocates to make an informed decision regarding the appropriateness of ECT for their circumstances. The leaflets should be evidence based, include information about the risks of ECT and availability of alternative treatments, and be produced in formats and languages that make them accessible to a wide range of service users.

This was presumably in response to the absence of a consistent, evidence-based information leaflet for patients, 65 years after the first use of ECT in 1938.

Informed consent is an important ethical principle for all health and mental health professionals. The Code of Ethics of the Royal College of Psychiatrists (2014, p. 11) states:

Psychiatrists shall seek valid consent from their patients before undertaking any procedure or treatment. . . . All treatments and procedures have potential detrimental as well as beneficial effects, and so it is important that the patient, and their family if appropriate, is involved in partnership with the treating psychiatrist in the decision-making process. Valid consent must be obtained before embarking on a treatment course or procedure. [This involves] the sharing of sufficient and understandable information to enable the patient to make an informed decision regarding the accepting or rejecting of treatment.

This study, the first of its kind, was designed to assess the accuracy of patient information leaflets about ECT in England, and, thereby, to determine whether NHS Trusts and the RCPsych are complying with NICE recommendations and Psychiatry's Code of Ethics regarding informed consent.

## **METHOD**

In June 2020 a Freedom of Information (FoI) Act request was sent to all 56 National Health Service (NHS) Trusts in England providing mental health services. The FoI Act entitles anyone to request information from public sector bodies, which may refuse to comply if the cost would exceed £450. The request began:

As part of a national review of ECT delivery within mental health services, we would like the following information regarding the delivery of ECT within the Trust. Please note that it is our intention to collate and publish responses to this FOI request.

The question generating data reported in the current paper was:

Please send us a copy of the information leaflet given to patients about safety and efficacy of ECT being used on June 1 2020.

## **Measure**

To generate an Accuracy Score for the leaflets, definitions were drawn up for 35 criteria, based on the research literature and the researchers' knowledge of NHS and RCPsych ECT leaflets. The 25 'positive' criteria represented relevant pieces of information that are accurate or evidence-based. The ten 'negatives' represented inaccurate, non evidence-based statements.

## ***Inter-Rater Reliability***

Two of the researchers scored the leaflets of four randomly selected Trusts, blind to the other's ratings. They agreed on 119 of the 140 ratings, an 85% level of agreement. This translates into a Cohen's kappa inter-rater reliability score (which allows for agreement by chance) of .70, categorised as 'substantial agreement' (0.61 - 0.80; Landis & Koch, 1977).

Eighteen of the 21 disagreements were rater error, wherein one or other of the raters was persuaded during discussion that he had not read the leaflet content and/or the definition carefully enough. Three disagreements related to unclear definitions. For example, the definition of 'long-term/ permanent memory loss' was broadened to 'Acknowledgement that for some people memory loss/cognitive dysfunction is long-term or persistent or permanent, or represents brain damage', thereby rendering it slightly easier to meet this criterion.

Six additional criteria were then added, because of the frequency, and/or inconsistent usage of, two negative statements - "minimising the size or strength or the ECT current", "minimising the convulsions"; and four positives - "Care Quality Commission leaflet given to patient", "consent can be withdrawn", "24 hours to discuss consent" and "driving"(see Table 1). One of the original 35 criteria, 'Appeal to history' to demonstrate efficacy and/or

safety, was removed. It was decided that although such a claim misleadingly implies that ECT must be effective and safe merely because it has existed for a long time, the statement itself is not inaccurate.

This left 40 criteria, in seven domains (see Table 1). To calculate an Accuracy Score (see Table 2) +1 was added for each of the 29 accurate statements, and -1 for each of the 11 inaccurate statement. The potential range was from 29 (all 29 pieces of accurate information and no inaccurate statements) to minus 11 (no accurate statements and 11 inaccurate statements).

All 36 Trusts' leaflets, and two leaflets published by Mind (the UK's largest mental health charity) (Mind, 2016, 2019), were then scored by one of the researchers, using the slightly amended set of criteria and definitions. Three RCPsych leaflets (2007, 2012, 2020) were rated independently by two researchers. Inter-rater agreement was 110/120 (91.7%), representing a kappa of .83, in the 'almost perfect agreement' range (Landis & Koch, 1977).

## **Participants**

Thirty-six of the 56 Trusts provided a copy of their information leaflet (see Table 2).

Nine failed to provide a leaflet or state that they used another party's leaflet (Black Country Partnership; Essex Partnership; Hertfordshire; Norfolk & Suffolk; Sheffield Health & Social Care; South West London & St Georges; Surrey & Borders; Tavistock & Portman; and Worcestershire).

Four Trusts (Barnet, Enfield & Haringey; Oxford; South West Yorkshire; and Tees, Esk & Wear Valley) declined to send their leaflet, using exactly the same words as each other:

The patient information document on ECT provided by our Trust is based on the document produced by the Royal College of Psychiatrists. Please refer to that document.

Three trusts said they do not use ECT (Bradford; East Sussex; Solent). Two were not contactable through the FOI email addresses on their websites (Isle of Wight; Humber). Two had merged with other Trusts (Dudley & Walsall merged into Black Country; 2Gether merged into Gloucestershire).

So, the response rate was 36 out of the 51 Trusts that use ECT (70.6%).

**TABLE 1.** Definitions, and scores, for 40 criteria for evidence-based information leaflets about ECT

CRITERION DESCRIPTION	*	DEFINITION FOR SCORING	NUMBER OF TRUSTS [out of 36]
General anaesthetic	+	Mention of <u>general</u> anaesthetic	34
Electric current	+	Mention of application of electricity/electric current to head/brain	34
Minimising size/strength of current	--	Use of 'small' 'very small' or other diminutive terms	19
Voltage	+	Amount of electricity (volts, milliamperes etc) and/or fact that dosage increases during the course of treatment	0
Convulsion	+	Mention of convulsion/seizure/fit	34
Minimising the convulsions	--	Use of 'mild' 'short' etc. ('controlled' is acceptable)	12
Number	+	Average number of ECTs in a series stated (about ten)	35
Unilateral vs bilateral	+	Information about the two electrode placement options, and that bilateral is more effective and causes more memory loss and unilateral less effective with less memory loss	14

NICE GUIDELINES			
Guidelines	+	Any mention of NICE guidelines	18
Limits on diagnostic group	+	Mention of ‘severe depression’, catatonia and mania.	32
Previous treatment	+	Mention that medication <u>and</u> psychological therapies should have been tried and did not work failed	12
Evidence-based	+	Any accurate reference to a research study	18
Co-production with patients	+	Mention of involvement of patients/service users in writing the leaflet	1
EFFICACY			
False claims of ‘most effective’	-	Any use of ‘most effective’ in general or in relation to other treatments	11
False claims of high improvement %s	-	Claim of > 60% percentage recovery/improvement without reference to placebo response rates	19
False life-saving claims	-	Claim that ECT saves lives/prevents suicide	22
Placebo response rates	+	Statement that some/many people in placebo/sham ECT groups improve/recover	6
Lack of long term benefits	+	Statement that that there is no evidence of long-term benefits (ie beyond end of treatment) <u>or</u> use of ‘short-term’/‘temporary’ to describe benefits, <u>or</u> mention of relapse rates	6
RISKS			
Immediate confusion/headaches /nausea etc.	+	Mention of temporary effects immediately after regaining consciousness	31
Short term memory loss	+	Any acknowledgement of memory loss/dysfunction or other cognitive dysfunction	34
Long term/permanent memory loss	+	Acknowledgement that for some people memory loss/cognitive dysfunction is ‘long-term’/‘persistent’/‘permanent <u>or</u> represents ‘brain damage’	26

Higher for women/older people	+	Statement that the memory loss is more common in women and older people	0
Monitoring	+	Informs that patient will be monitored for memory loss/cognitive dysfunction following each ECT	12
Minimisation re memory	-	Any minimisation/denial of memory loss in terms of severity or prevalence (other than blaming depression )	23
Blames depression	-	Blames the memory loss on depression rather than ECT	15
Cardiovascular problems	+	Any mention of risk of cardiovascular events following ECT	6
Mortality	+	Acknowledgement of mortality risk, <u>without</u> minimising statements (eg comparing to safety of general anaesthetic or ‘minor surgical procedures’)	2
False claims re low mortality risk	-	Unevidenced claims of very low mortality rates (eg 1:10,000 patients or 1:80.000 treatments)	28
Risk of multiple general anaesthetics	+	Acknowledgement that ECT has higher risk than one general anaesthetic because it involves about ten treatments	7
Driving	+	Directions not to drive during the course of treatment (not just for 24 hours after each individual treatment)	21
MECHANISM OF ECT			
Don’t know	+	Any acknowledgement that we don’t know how it works (even if it goes on to offer suggestions/theories)	10
False claims about correcting bio-deficits	-	Claims that ECT corrects biological causes of depression such as biochemical imbalance/activity, brain connectivity etc	28
CAUSES OF DEPRESSION			
Illness	-	Unsubstantiated biological causes of depression such as chemical imbalance, genetics etc. <u>or</u> framing of problems as ‘illness’ or disease, <u>without</u> mention of psycho-social causes	21

Psycho-social	+	Any mention of psycho-social causes of depression, such as loss, abuse, poverty etc.	0
CONSENT			
Rights	+	Information about rights under Mental Health Act	22
Access to legal support	+	How to access legal advocate	9
CQC leaflet # given	+	Provided with Care Quality Commission <i>Your rights about consent to treatment</i> leaflet, or equivalent, and this is verbally explained and documented. Or Link to leaflet on CQC website.	4
False claim that most/all are given ECT voluntarily	-	False claim that most/all are given ECT voluntarily	11
Consent can be withdrawn	+	Patients are informed by both the referring clinician and the ECT team that their consent can be withdrawn at any time. Consent will then be required before any further ECT treatments can take place	32
24 Hours to discuss	+	For every new course of ECT, except in an emergency, patients are given at least 24 hours to reflect on information about ECT and discuss this with relatives, friends, or advisers before making an informed decision regarding consent	1

\* + = accurate statement; - = false/inaccurate statement

# Care Quality Commission (2012)

**TABLE 2.** Accuracy scores for ECT information leaflets

NHS Trust, or organisation	Accurate statements (out of 29)	Inaccurate statements (out of 11)	Accuracy Score *
<i>Mind, 2019</i>	19	0	19
<i>Mind, 2016</i>	22	-6	16
Leicestershire	18	-3	15
Cambridge & Peterborough	17	-4	13
Somerset	20	-7	13
Leeds & York	19	-7	12
<i>Royal College of Psychiatrists, 2012</i>	19	-7	12
East London	19	-8	11
Midlands	17	-6	11
<i>Royal College of Psychiatrists, 2007</i>	17	-6	11
Coventry & Warwick	14	-4	10
Cumbria, Northumberland Tyne & Wear	14	-4	10
Nottinghamshire	16	-6	10
Rotherham, Doncaster & South Humber	13	-4	9
Birmingham	15	-7	8
Dorset	10	-2	8
Greater Manchester	15	-7	8
Mersey Care	15	-7	8
North East London	15	-7	8
Northamptonshire	15	-7	8
Lancashire & South Cumbria	14	-6	8
Pennine	15	-7	8
<i>Royal College of Psychiatrists, 2020</i>	15	-7	8
South London & Maudsley	15	-7	8
Avon & Wiltshire	15	-8	7
Cheshire & Wirral	9	-2	7
Derbyshire	16	-9	7
Devon	11	-5	6

Gloucestershire Health	12	-5	7
Kent & Medway	12	-6	6
Sussex Partnership	13	-8	5
Camden & Islington	11	-7	4
Lincolnshire Partnership	11	-7	4
North Staffordshire	9	-5	4
Berkshire	10	-7	3
Southern Health	9	-6	3
Northwest Boroughs Healthcare	5	-3	2
Central & North-West London;	4	-3	1
Cornwall Partnership	10	-9	1
West London	4	-3	1
Oxleas	4	-6	-2

\*Possible range: 29 to minus 11

## RESULTS

### NHS Trusts

#### *Accuracy Scores*

Table 2 shows that the accuracy scores of the 36 NHS Trusts range from 15 (Leicestershire) to minus 2 (Oxleas), with a mean of 7.00 (sd = 3.82). The average number of accurate statements (out of 29) is 12.81 (sd = 4.23), with a range from 4 to 20. The average number of inaccurate statements (out of 11) is 5.81 (sd = 1.91), with a range from 2 to 9.

#### *Accurate Information*

Table 1 shows that the most frequently included accurate statements are mostly basic descriptors, about number of ECTs (35 out of 36 Trusts); general anaesthetic (34); electric current (34); and convulsion (34); plus acknowledgement of short-term memory loss (34).

The least frequently included accurate statements are: memory loss being higher for women and older people (0); voltage strength (0); psycho-social causes of depression (0); 24 hours to discuss whether to consent (1); co-production of leaflet with patients (1); mortality without minimising (2); CQC leaflet given (4); lack of long-term benefits (6); high placebo response rates (6); and cardiovascular problems (6).

The highest number of accurate pieces of information is 20 out of 29 (69.0%), attained by Somerset, followed closely by Leeds & York, and East London (both 19). The worst performing Trusts, each with only four accurate statements, are Central & North West London; West London; and Oxleas.

### ***Inaccurate Information***

The most frequently made inaccurate statements, made by more than half of the Trusts, are: claims that ECT corrects biological deficits (28); claims of very low mortality risk (28 Trusts); minimisation of memory loss (23); claims that ECT saves lives (22); depression described as an 'illness' (21); minimisation of the current strength (19); and claims of very high improvement percentages (19).

Just over half the Trusts (19; 52.7%) make seven or more inaccurate statements, out of a possible 11. The worst score, of nine, was attained by Cornwall and Derbyshire..

### **Two Mind Leaflets**

Both *Mind* leaflets surpass all other leaflets. The current *Mind* leaflet (2019) is the only leaflet to include none of the 11 inaccurate statements.

### **Three Royal College of Psychiatrists Statements**

The overall Accuracy Scores of the three RCPsych leaflets are 11 (2007), 12 (2012), and 8 (2020). All three include more accurate statements (between 15 and 19) than the Trusts' average of 12.8. All three, however, include high numbers of inaccurate statements (6 or 7 out of a possible 11), all slightly higher than the Trusts' average of 5.8. The most recent of the three has the fewest accurate statements (15), and seven inaccurate statements.

All three RCPsych leaflets wrongly claim that ECT saves lives, that it corrects deficits in the brain, and that the memory loss is partly caused by depression rather than ECT. They all portray depression as an 'illness', while failing to mention any psycho-social causes of depression. None of them mention cardiovascular side effects, or that memory loss is greater in women and older people. None inform patients that they must be given 24 hours to consider giving consent. None mention co-production with user/patient groups.

The current RCPsych leaflet improves on its two predecessors by accurately stating the risk of driving after ECT, and by not claiming that most/all ECT occurs on a voluntary basis. Unlike both the 2007 and 2012 leaflets, however, the recent publication fails to acknowledge placebo response rates, the lack of long-term benefits, or that it is not known how ECT works. The current leaflet is the only one of the three that minimises memory loss, with phrases like 'about 2%', 'a small number', and 'in most people memory difficulties clear within two months of the last treatment and do not cause problems or distress'.

It is also the only one of the three to claim a high recovery rate (68%) with no reference to the fact that a significant proportion thereof would be attributable to placebo effects (Rasmussen, 2009). (It also fails to point out that the 68% figure was based on subjective ratings by the psychiatrists who administered the ECT). Finally, it is the only one of the three not to mention the Mental Health Act.

## **DISCUSSION**

Having ECT is a difficult and important decision for patients and their loved ones. They deserve accurate information. Currently, much of the information provided to them bears little relationship to the evidence-base, or NICE guidelines.

### **Compliance with NICE Recommendations and RCPsych's Code of Ethics**

There is no evidence that the NICE recommendation (2003) that 'information leaflets should be developed through consultation with appropriate professional and user organisations' is being met. Only one Trust leaflet (Coventry & Warwick), and none of the RCPsych leaflets, mention consulting user organisations. It is possible that some consultation occurred but is not reported in the leaflets. Fourteen Trusts do either refer to, or provide a leaflet from, a *professional* organisation. In all cases that organisation is the RCPsych, implying that no other mental health professions are considered 'appropriate' (NICE, 2003).

The NICE recommendation that the information leaflets should be developed on a 'national' level, is still being ignored. This study reveals a plethora of local leaflets, varying greatly in content and accuracy. Furthermore, the ECT Accreditation Service [ECTAS] requirement regarding leaflets (RCPsych, 2020b; Standard 145) is not consistent with the NICE recommendation in that it suggests local leaflets are acceptable:

All patients (and their relatives if applicable), regardless of their capacity to consent to ECT, are provided with an ECT patient information leaflet and/or a local ECT patient information leaflet.

ECTAS is a subsidiary of the RCPsych. The ECTAS standard for leaflets doesn't mention what should be included in leaflets, whether they should be evidence-based (as recommended by NICE), or who should be consulted in their development. So, all Trusts would pass this ECTAS benchmark simply by virtue of having a leaflet, any leaflet, regardless of how many inaccurate statements it makes, or how many core information details it omits.

Clearly, neither NICE's call for 'evidence-based' leaflets nor the RCPsych's call, in its Code of Ethics, for 'sufficient and understandable information to enable the patient to make an informed decision' are being heeded. The Trusts have an average of nearly six misleading statements, and the current RCPsych leaflet has seven. They all omit important information about efficacy, risks or rights.

### **Efficacy**

Most Trusts inform the public that in a very high percentage of cases ECT leads to recovery. The unsubstantiated figure of '80%' or 'about 80%' has been something of a mantra for ECT proponents for several decades now (Read, Bentall, Johnstone, Fosse & Bracken, 2013; Read, Kirsch & McGrath, 2019). For example: 'More than 8 out of 10 depressed patients who receive ECT treatment respond well, making it the most effective treatment for severe depression' (Oxleas). The 19 Trusts (52.7%) that make such a claim, and the RCPsych's current leaflet (which claims a 68% recovery rate), all fail to inform patients that a large proportion are attributable to placebo effects (Rasmussen, 2009; Read et al., 2019). Only six Trusts (16.7%) mention placebo effects at all.

The majority of Trusts (32; 83.3%) fail to inform us that there is no evidence of long-term benefits, or that relapse rates are very high. Finally, more than half of the Trusts (22; 61.1%), and all three RCPsych leaflets, wrongly claim that ECT saves lives by preventing suicide.

Meta-analyses of research into ECT for depression, like many information leaflets, report that ECT is effective. A recent review of these meta-analyses found, however, that they pay scant attention to the extremely poor quality of the 11 placebo-controlled studies on which they were based (there have only ever been 11), all of which are at least 35 years old (Read, Kirsch & McGrath, 2019). The review concluded that after 85 years of usage there is no robust evidence that ECT does, or does not, work in the short-term, i.e. during the treatment

period. It also found, like the meta-analyses (e.g. UK ECT Group, 2003), that there is no evidence of any benefits beyond the end of treatment, compared to placebo. A review of placebo-controlled studies (where the placebo-group receives ‘sham ECT’, i.e. the general anaesthetic but not the electric shock or convulsion) (Rasmussen, 2009, p. 59) concluded:

Rigorously defined endogenously depressed patients did exceptionally well with sham ECT, just as well as with real ECT.

The 2019 review (Read et al.) reported that none of the meta-analyses provided any evidence that ECT prevents suicide, as frequently claimed by ECT advocates. One meta-analysis, by the respected UK ECT Group (2003), states: ‘Although ECT is sometimes thought to be a life-saving treatment, there is no direct evidence that ECT prevents suicide’ (p. 806). A 170-page UK government report concluded: ‘The evidence did not allow any firm conclusions to be drawn regarding the ... impact of ECT on all-cause mortality.’ (Greenhalgh, Knight, Hind, Beverley & Walters, 2005, p. 83). A recent study found that 14,810 ECT patients were 5.8 times *more* likely to have killed themselves in the year after treatment than 58,369 controls; but after controlling for confounding variables the difference was not quite statistically significant (Peltzman, Shiner & Watts, 2020).

## **Risks**

### ***Memory Loss***

Most Trusts (31) inform patients about the immediate confusion and headaches that follow most administrations of ECT, and 34 acknowledge some short-term memory loss. Twenty-six Trusts warn of long term/persistent memory loss. Unfortunately, 23 Trusts go on to minimise the memory loss in terms of severity (eg ‘mild’) and/or prevalence (‘rare’ etc.). Although the

two defunct RCPsych leaflets had not minimised memory loss, the current leaflet does so. Furthermore, 15 Trusts attribute the memory loss at least partly to depression, as did all three RCPsych leaflets.

Estimates of persistent or permanent memory loss from ECT (usually defined as six months or more) range from 12% (Sackeim et al., 2007) to 55% (Rose, Wykes, Leese, Bindmann, & Fleischmann, 2003), with higher rates reported by patients and lower rates by psychiatrists. A New Zealand Government report stated ‘ECT may permanently affect memory and sometimes this can be of major personal significance’ before noting the ‘slowness in acceptance by some professional groups that such outcomes are real and significant in people’s lives’ (Ministry of Health, 2004, p. 16). A manufacturer of ECT machines, Somatics, has recently included ‘permanent brain damage’ in its list of risks (Schwartzkopff, 2018; Somatics, 2018, p. 4).

The oft-made claim that the memory loss is a symptom of depression rather than an effect of the electricity have been repeatedly refuted (e.g. McElhiney et al., 1995; Robertson & Pryor 2006) including by a large-scale prospective study (Sackeim *et al.* 2007). Even if there was a relationship, causality might be in the opposite direction. Losing your memory is depressing. Shortly before killing himself, soon after ECT, Ernest Hemingway wrote: ‘What is the sense of ruining my head and erasing my memory, which is my capital, and putting me out of business? It was a brilliant cure, but we lost the patient’ (Hotchner 1967, p.308).

The large prospective study (Sackeim et al., 2007) also found that memory loss is particularly common in women and older people (the two demographics that receive the most ECT). It is a concern that none of the Trusts or RCPsych leaflets inform women or older people about this.

### ***Mortality***

Twenty-eight Trusts include statements claiming extremely low mortality rates. Some repeat the precise, but unsubstantiated, claim, first made by the American Psychiatric Association, (2001) and unquestioningly repeated ever since, of ‘one per 10,000 patients’ or ‘one per 80,000 treatments’ (Read et al., 2013, 2019). Others minimize the risk of dying without giving specific numbers, or citing any research, e.g.:

Death caused by ECT is extremely rare. . . . The death rate following ECT is less than that for other minor surgical procedures. (RCPsych, 2020).

ECT is among the safest medical treatments given under general anaesthesia – it carries the same very low risks of death or serious injury as having an anaesthetic for dental treatment. (Oxleas)

These statements are, intentionally or otherwise, very misleading. Most ‘minor surgical procedures’ and ‘anaesthetics for dental treatment’ require only a localized injection, whereas ECT requires a general anaesthetic procedure, inducing unconsciousness. Furthermore, it does not just involve one general anaesthetic, but an average of ten. This important fact has been ignored for decades, in misleading statements about the safety of ECT, including, in this study by 29 (80.6%) of the Trusts and the current RCPsych leaflet. Seven Trusts, however, do acknowledge that the risk is not at all the same as having one general anaesthetic because ECT involves multiple such procedures (Coventry; East London; Leeds & York; Midlands; Nottinghamshire; Somerset; Sussex). Two Trusts (Derbyshire; Kent & Medway) do actually acknowledge the mortality risk without minimizing it.

Many studies have found mortality rates much higher than the official version of one per 10,000 people (see Read & Bentall, 2010; Read et al., 2013). Of 8,148 Texan ECT patients, seven died within two days (Shiwach, Reid, & Carmody, 2001). Excluding the two which the

researchers portrayed as ‘unlikely to have been related to ECT’, this is one per 1,630. If one includes the eight that died, of a ‘cardiac event’, within 14 days, the rate is one per 627.

When researchers tried to contact 183 people a year after ECT they found that two had died *during* ECT (one in 91.5) (Freeman & Kendell, 1980). A 1980 study (relying on psychiatrists’ reports of deaths) found that four out of 2,594 ECT patients had died within 72 hours (one per 648.5) (Pippard & Ellam, 1981). A study of 75 French ECT patients reported ‘potentially life-threatening’ complication’ in 12 patients (16%) (Tecoult & Nathan, 2001).

The most common cause of death from ECT is cardiovascular failure (Read et al., 2013). A recent review, of 82 studies, found that one in 50 patients experience ‘major adverse cardiac events’ (Duma et al., 2019). Most of the Trusts (29; 80.6%), all three RCPsych leaflets, and even the two Mind leaflets, fail to mention these cardiovascular problems.

Some of the leaflets are dangerous in another way. 15/36 (41.6%) Trusts failed to tell people not to drive during a course of ECT, despite this being in NICE guidelines.

## **Legal Rights**

About 37% of people given ECT in England are forced to have it against their will, i.e. without giving consent; with some Trusts reporting rates above 70% (Read et al., 2017; Read et al., 2021).

Twenty-two Trusts (61.1%), but not the current RCPsych leaflet, make patients aware of their rights under the Mental Health Act. Only nine Trusts, and none of the RCPsych leaflets, explain how to access a legal advocate. Almost all Trust leaflets (32/36), and all three RCPsych leaflets, do inform patients that after they give consent they can withdraw it later.

Only one Trust leaflet (Gloucestershire) and the two Mind Leaflets inform patients that they should be given a day to think, and consult, about whether to give consent. None of the RCPsych leaflets do so. ECTAS Standard 4.35 states:

For every new course of ECT, except in an emergency, patients are given at least 24 hours to reflect on information about ECT and discuss this with relatives, friends, or advisers before making an informed decision regarding consent.

Standard 4.35 is a level 2 standard, which are ‘standards that an accredited team would be expected to meet’ (ECTAS, 2020, p. 5).

Only four Trusts (Gloucestershire; Kent & Medway; Lancashire; Somerset), and none of the RCPsych leaflets, refer people to the Care Quality Commission’s (2012) document summarising their rights under the Mental Health Act. ECTAS Standard 146 states:

All patients are provided with the Care Quality Commission *Your rights about consent to treatment* leaflet (England), or equivalent, and this is verbally explained and documented

This is a level 1 ECTAS standard, about which ECTAS states:

Failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law. These standards also include the fundamentals of care, including the provision of evidence-based care and treatment;

## **Biological Causes and Mechanisms**

Twenty-one Trusts (58.3%) make claims about bio-medical causes of depression and/or refer to it as an illness or disease, without identifying any possible psycho-social causes of depression that might need addressing. This is also true of all three RCPsych leaflets. The current RCPsych leaflet, for example, uses terms like ‘your illness’, ‘mental illness’, ‘symptoms’ etc., throughout. The only leaflets to mention any psycho-social causes are the two Mind leaflets.

In a similar vein, most of the Trust leaflets (28; 77.8%), and all three RCPsych ones, claim that ECT corrects biological causes of depression. The current RCPsych leaflet (2020, p.1) is far from alone in proclaiming:

It causes the release of certain brain chemicals. These seem to stimulate the growth of some areas in the brain that tend to shrink with depression. ECT also appears to change how parts of the brain that are involved in emotions interact with each other.

An ECT recipient and a Clinical Psychologist at the centre of the ongoing campaign for an independent enquiry into the use of ECT in the UK (Johnstone & Cunliffe, 2020) responded:

This is, frankly, nonsense, and we were astonished to read it. Coupled with frequent, unreferenced and unevidenced statements about 9 out of 10 people improving after ECT, which is regularly described in leaflets as ‘one of the safest treatments in medicine’, and failure to mention the short term nature of effects, it is clear that people are rarely in a position to give informed consent as described in General Medical Council guidelines.

## **Psychological Therapies**

NICE guidelines for depression (2017) state:

Consider ECT for acute treatment of severe depression ..... *when other treatments have failed.*

Do not use ECT routinely for people with moderate depression but consider it *if their depression has not responded to multiple drug treatments and psychological treatment.*

[Italics added]

Most will already be taking, or have tried, antidepressants. The current RCPsych leaflet rightly informs patients that they must also have been offered psychological therapy before being considered for ECT. However, 24 (67%) of the Trusts do not. This is consistent with the finding, in two recent audits, that most Trusts cannot answer the question ‘How many people had ECT without receiving a N.I.C.E recommended psychological therapy?’ The first audit (Read et al., 2018) concluded that:

Failure to record or collate this information suggests that most Trusts are not interested in, or aware of, N.I.C.E guidelines on this matter. . . . It seems some clinicians and managers remain unconvinced of the need for an integrated, evidence-based approach involving the non-medical treatments recommended by N.I.C.E.

In the second audit (Read et al., 2021) only one Trust could answer the question. This lack of interest by service providers is reinforced by the RCPsych’s ECTAS. Its surveys of ECT usage (Buley et al., 2017) and its Standards for Accreditation (ECTAS, 2020) fail to mention N.I.C.E. guidelines about using ECT only ‘when other treatments have failed’.

### **ECTAS Influence over how Trusts Responded to Freedom of Information Request**

Four Trusts (Barnet, Enfield & Haringey; Oxford; South West Yorkshire; Tees, Esk & Wear Valley) declined to send their leaflet but did reply, using the exact same words as each other:

The patient information document on ECT provided by our Trust is based on the document produced by the Royal College of Psychiatrists. Please refer to that document.

We have previously reported that a total of 12 Trusts used replicated, identical (verbatim) statements like this to respond to several of the other questions in our FoI request (Read et al.,

2021). When asked to explain this use of identical phrases, some Trusts denied that the statements were copied from, or influenced by, any external organisation. Others were more forthcoming. Cornwall replied ‘Yes’ to our question ‘Were the statements copied?’ and, in reply to ‘If Yes, from which document were they copied?’, they wrote ‘Circular received from ECTAS’. It is of grave concern that the RCPsych appears to have been trying to influence, via its subsidiary body ECTAS, how NHS Trusts respond to FoI requests, and that its efforts were somewhat successful.

## **Conclusions**

ECT is still used on about 2,500 people a year in England, predominantly women over 60 (Buley, Copland & Hodge, 2017; Read et al., 2017; Read et al. 2021). But the information leaflets given to patients and their families considering ECT is almost always limited, and is frequently misleading. Nearly every Trust mentions ‘a nice cup of tea’ after treatment, but most ignore or minimise potentially life-changing, or life-threatening risks, and disregard the lack of any long-term benefits. Questions need to be asked about how this branch of medicine has been allowed to ignore its own national standards, the principles of evidence-based medicine and informed consent, and established good practice about consulting with the patient groups it serves. The UK is certainly not the only country where false claims about ECT are made by official bodies, with the USA (Read et al., 2013) and Australia (McLaren, 2018) among other countries where misinformation has been documented. Lack of consultation and inadequate attempts to inform smack of a ‘Doctors know best, patients don’t need to worry about the details’ attitude which has no place in modern medical practice.

While there were many instances of exaggerating positive outcomes and minimising negative outcomes, there was not a single instance of minimising positives or exaggerating negatives. The bias was unidirectional and consistent. This implies that the inaccuracies

represent systemic, institutional bias. Perhaps one motivation for this bias is a fear that if people are told the whole truth even fewer will voluntarily accept the treatment. Perhaps the psychiatrists concerned have not read the research and believe the leaflets are accurate.

Perhaps the process of cognitive dissonance (Festinger, 1957) can help explain why some professionals, faced with research showing that they have been causing persistent/permanent memory loss in between 12% and 55% of their patients, choose to either not believe that research, or to believe in unrealistically high efficacy, so as to justify the memory loss; or both.

### **Limitations**

Fifteen Trusts chose not to provide their leaflet. Pressure of work relating to the Coronavirus pandemic may have been partly responsible; but the 71% response rate was higher than the 57% response rate of the earlier audit of the same Trusts several years before the pandemic (Read et al., 2018). It is impossible to know whether these 15 undisclosed leaflets were any more or less accurate than the 36 that were disclosed.

The 40-item accuracy measure had not been used before and may need revision. For example, the criterion requiring a statement that ‘memory loss is more common in women *and* older people’ should probably be divided into two criteria, as some Trusts did mention increased risk in older people, but none acknowledged the same for women. Weighting some items more than others is another possibility.

Another limitation is that the leaflets are not the only source of information. But if one source of additional information is the psychiatrists who are encouraging or permitting the use of inaccurate leaflets, one wonders about the value of that additional information. Future research could address how much psychiatrists administering ECT know about relevant research literature and NICE guidelines.

It must be acknowledged that information leaflets are updated from time to time, so some of the data may be out of date by time of publication.

## **Recommendations**

It is recommended that independent audits like this one continue to monitor all aspects of ECT administration, including informed consent, in England and internationally.

The RCPsych and the NHS have failed to heed the 2003 NICE recommendations. We therefore recommend that the task of developing ‘National information leaflets . . . through consultation with appropriate professional and user organisations’ be taken out of the hands of the RCPsych and delegated to an independent body involving multidisciplinary professionals, service users, researchers and lawyers. In the meantime, Trusts should either amend their own leaflet or adopt the Mind leaflet.

ECTAS should be replaced with a monitoring and accreditation body independent from the RCPsych.

This paper will be shared with the RCPsych and NHS Trusts. It will be submitted to the British Government in support of a call for ‘an independent review into the practice of ECT in the UK’, by 40 ECT experts (Johnstone & Cunliffe, 2020).

## ***Declaration of interest***

The authors report no conflict of interests. The authors alone are responsible for the content and writing of the manuscript.

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