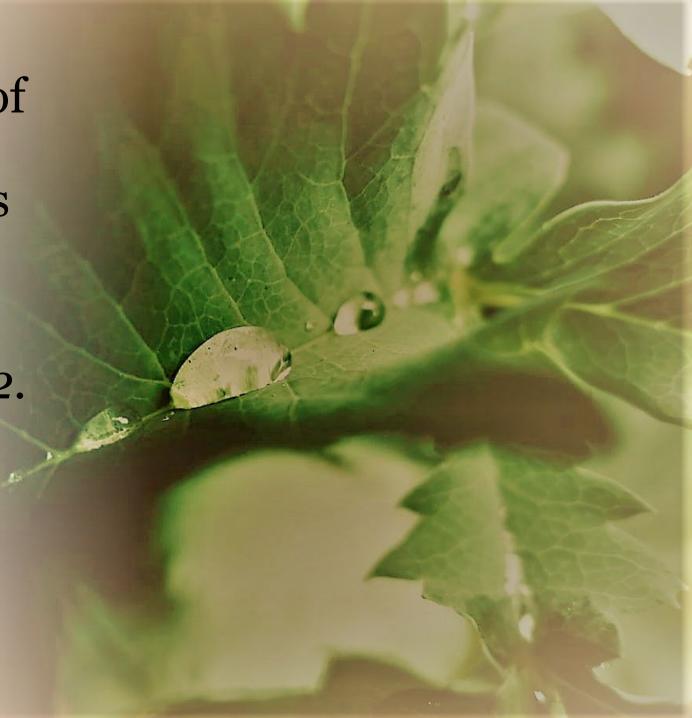
A large exploratory survey of electroconvulsive therapy recipients, family members and friends.

Findings from Papers 1 & 2.







Background and Context

Taking care with this content.

What is electroconvulsive therapy (ECT)?

 UK ECT Improving Standards Campaign Group.

• The survey.

Papers 1 & 2: What are people told and how effective is it?

- Context.
- What does the evidence say?



#### **Electroconvulsive therapy in Northern Ireland**

Number of patients treated between 2016 and 2020

Trust	2016	2017	2018	2019	2020	Trust total
Belfast Trust	22	19	19	27	8	95
Southern Trust	32	11	20	7	21	91
Northern Trust	43	44	45	30	25	187
Western Trust	20	23	23	31	19	116
South Eastern Trust	29	22	16	17	20	104
Annual total	146	119	123	112	93	593

ввс

# **Electroconvulsive** Therapy

in Northern Ireland 2016 - 2020

593

patients given the treatment

25% were detained patients70% were female

Source: NI Health Trusts

Source: HSC Health Trusts

BBC



### Context

- ECT has remained a controversial procedure since its invention in 1938, with no consensus among researchers and clinicians about its risks, benefits, or mode of action.
- Perspectives on ECT vary dramatically, from those who believe it is ineffective and causes brain damage to those who consider it the most effective and safe treatment in psychiatry.
- This lack of agreement contributes to a large variation in its use across different countries and even within regions of the same country. For example, a recent audit in England found a 47-fold difference in usage rates between different areas.

# What does the evidence say?

**Depression:** There are only 11 placebo-controlled studies comparing ECT to "sham" ECT (where anaesthetic is given but no electricity) ever been conducted, with the most recent being 40 years ago, in 1985. A review showed all 11:

- Failed to meet modern methodological standards.
- Results were inconclusive: four found ECT superior to sham ECT, five found no difference, and two had conflicting results depending on who was reporting (psychiatrists or patients).
- The two highest-quality studies showed no significant difference between ECT and sham ECT at one- or six-months post-treatment.

**Schizophrenia:** An analysis of Cochrane reviews concluded that after seven decades of use, there is still a lack of strong and adequate evidence for its effectiveness in treating schizophrenia. UK's National Institute for Health and Care Excellence (NICE) does not recommend ECT for general use in managing schizophrenia.

**Suicide Prevention:** Although ECT is often considered a life-saving treatment, a meta-analysis by the UK Government's ECT Review Group concluded that there is "no direct evidence that ECT prevents suicide".



An international manufacturer of ECT machines in the US has added a warning that their product can cause 'permanent memory loss or permanent brain damage'. Schwartzkopff, 2018; Somatics, 2018.

People being offered ECT should be made aware of all its risks and potential short- and long-term harmful effects, such as memory loss and brain damage.

WHO and the United Nations (2023).

# Salium Val Proate ansterny Jacoby Sylvagology) John Samon S Designed by Decide Mc Cousland

# Why This Research?



# Methodology

• Design.

• Ethical considerations.

Recruitment and participant profile.

Analysis.

Strengths and limitations.

Aim.





Table 3
Responses based on the 682 ECT recipients who recalled at least one piece of information

ECT can be life-saving/prevents suicide	500	(73.3%)
ECT can cause temporary memory problems	468	(68.6%)
ECT is the most effective treatment for severe depression	465	(68.2%)
Depression is caused by chemical imbalance in brain	428	(62.8%)
ECT corrects chemical imbalance or other brain abnormality	311	(45.6%)
Risks from repeated general anaesthesia	204	(29.9%)
Bilateral ECT is more likely to cause memory problems	156	(22.9%)
Legal rights in relation to ECT	156	(22.9%)

# Key Findings: Patient Information

#### *Information withheld:*

- Only 17% were told ECT could cause long-term or permanent memory problems.
- Only 12% were told ECT can cause heart problems.
- Only 28% were told risks associated with repeated general anaesthesia.

#### *Misinformation was common:*

- Patients (58%) and relatives (53%): incorrectly told that depression is caused by a 'chemical imbalance in the brain'.
- 42% of patients and 41% of relatives: incorrectly told ECT works by correcting this chemical imbalance or another brain abnormality.
- Only 12% of patients and 10% of relatives were told there is no evidence of any long-term benefits from ECT.
- Quotes.

Table 5
'Other' things doctors or nurses said about ECT: Ways that memory loss and other adverse effects are minimised

No long-term adverse effects;

short-term only

52 No long-term side effects.

No long-term negative impacts.

Memory problems would go away after 6 weeks. No permanent effects.

No side effects are permanent.

No permanent side effect.

Only temporary memory loss.

All side effects are temporary.

'Safe'

34 Safe.

Extremely safe.

Incredibly safe.

I'm completely safe with ECT, even though I asked about long term memory effects.

Safe & harmless.

Safer than medication.

"Safe & effective." I heard this over and over, like a catchphrase, from everyone involved.

# Key Findings: Efficacy

- Effect on the initial problem:
  - 55% felt ECT made no difference or made the problem worse. 45% of recipients saw improvement.
- **Effect on mood:** 59% said it made no difference or made their mood worse.
- **General helpfulness:** 59% found it was not generally helpful or made things worse.
- Quality of life: 71% reported their quality of life was unchanged or worsened. Notably, almost half of the patients (49%) said their quality of life was made 'much worse' (22%) or 'very much worse' (27%) by ECT.
- **Suicidality:** 67% no effect on suicidality or made it worse. 33% of patients reported reduced suicidality.

**TABLE 4.** How would you describe the problems/symptoms for which ECT was prescribed, just after the end of the treatments, compared to just before?

	Recipients (n = 808)	Family/Friends (n = 248)
1. Very much worse	157 (19.4%)	48 (19.4%)
2. Much worse	89 (11.0%)	36 (14.5%)
3. Minimally worse	50 (6.2%)	21 (8.5%)
4. No change	152 (18.8%)	31 (12.5%)
5. Minimally improved	156 (19.3%)	41 (16.5%)
6. Much improved	123 (15.2%)	34 (13.7%)
7. Very much improved	81 (10.0%)	37 (14.9%)
Mean (SD)	3.93 (1.99)	3.93 (2.12)

### Conclusion

- Patient information does not comply with the ethical principle of informed consent.
- Efficacy has not been established by robust research and although some people are helped, people are being harmed with no redress.
- Human rights implications (United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2008.

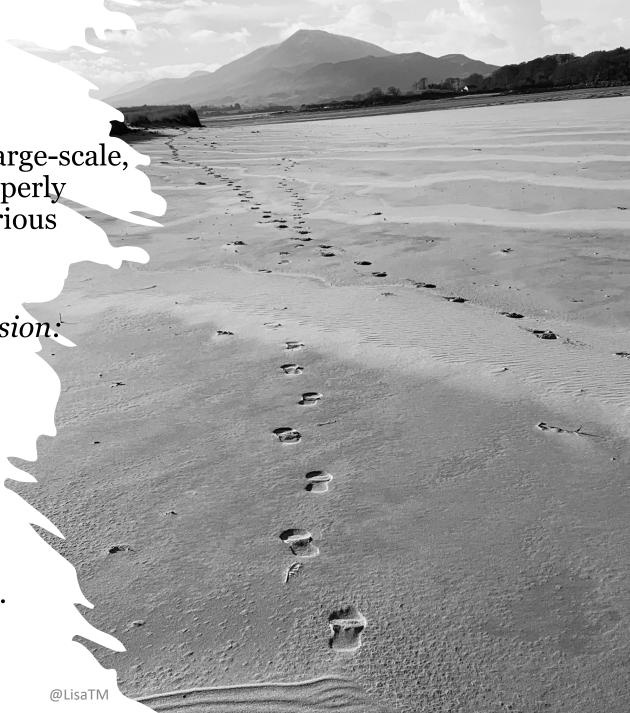


### Recommendations

 Immediate suspension pending the results of large-scale, independent, placebo-controlled studies to properly determine ECT's effectiveness relative to its serious adverse effects.

Actions urgently needed with or without suspension:

- Conduct Placebo-Controlled Studies.
- Monitor Adverse Effects.
- Develop Evidence-Based Patient Information.
- Implement Routine Cognitive Monitoring.
- Establish Standardised Dosing Protocols.
- Offer Cognitive Assessment and Rehabilitation.
- Audit ECT!





All treatments and procedures have potential detrimental as well as beneficial effects...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 (p.11).

The Code of Ethics of the UK's Royal College of Psychiatrists.



Mind echoes concerns raised by this research—the evidence base for ECT has never been fit for purpose and this latest study further substantiates the need for a re-think about whether and when this treatment is offered to patients. The need for better patient information about ECT has never been clearer.

We support calls for more research on ECT, and welcome further scrutiny to ensure only helpful, evidence-based treatments continue to have a place in our healthcare system. There are many effective treatments for mental health problems that do not share this risk profile.

Rosie Weatherley, Information Content Manager at Mind.

Northern Ireland Specific

RQIA Inspections.

Audit of patient information leaflets.

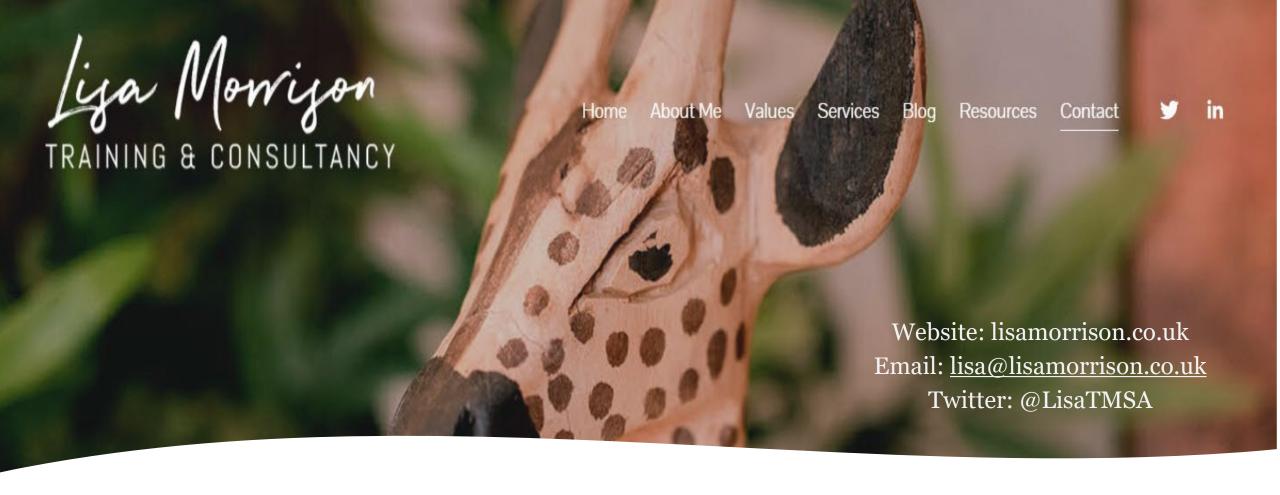
 Health and social care and educational courses.

■ BBC NI Coverage.

## Take Action

- Share links and information widely.
- Advocate for and with people affected.
- Education.





### Thank You!

Lifeline: 0808 808 8000 & Samaritans 116 123

Helplines NI: www.helplinesni.com

Online Co-Produced Safety Planning site for anyone struggling or supporting someone who is suicidal <a href="https://www.stayingsafe.net">www.stayingsafe.net</a>

### References

- https://jme.bmj.com/content/early/2025/08/25/jme-2024-110629. Journal of Medical Ethics. A large exploratory survey of electroconvulsive therapy recipients, family members and friends: what information do they recall being given?
- Journal of Medical Ethics blog: <a href="https://blogs.bmj.com/medical-ethics/2025/08/15/why-are-patients-and-families-not-told-the-truth-about-electroconvulsive-therapy/">https://blogs.bmj.com/medical-ethics/2025/08/15/why-are-patients-and-families-not-told-the-truth-about-electroconvulsive-therapy/</a>
- https://onlinelibrary.wiley.com/doi/10.1111/inm.70109. International Journal of Mental Health Nursing. A Survey of 1144 ECT Recipients, Family Members and Friends: Does ECT Work?
- Medpage blog: <a href="https://www.medpagetoday.com/psychiatry/generalpsychiatry/117007">https://www.medpagetoday.com/psychiatry/generalpsychiatry/117007</a>
- Read, J., Morrison, L. and Harrop, C. (2023) An independent audit of Electroconvulsive Therapy patient information leaflets in Northern Ireland, Scotland and Wales. *Psychology and Psychotherapy: Theory, Research and Practice* 96 (4) 885-901. https://bpspsychub.onlinelibrary.wiley.com/doi/10.1111/papt.12481
- Harrop, C., Read, J., Geekie, J., and Renton, J. (2021) How accurate are ECT patient information leaflets provided by mental health services in England and the Royal College of Psychiatrists? An independent audit. Ethical Human Psychology and Psychiatry, 23, 5-24 <a href="https://www.sciencegate.app/document/10.1891/ehpp-d-21-00003">https://www.sciencegate.app/document/10.1891/ehpp-d-21-00003</a>.
- Code of ethics quoted Royal College of Psychiatrists. Available from: <a href="https://www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/ect.">https://www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/ect.</a>
- Schwartzkopff, D. 2018. "DK Law Group Announces ECT Settlement." <a href="http://ectjustice.com/dk-law-group-announces-ect-settlementSomatics">http://ectjustice.com/dk-law-group-announces-ect-settlementSomatics</a>.
- Somatics. 2018. "Regulatory Update to Thymatron System IV Instruction Manual." <a href="http://www.thymatron.com/downloads/System IV Regulatory Update.pdf">http://www.thymatron.com/downloads/System IV Regulatory Update.pdf</a>.
- Rosie Weatherley, Information Content Manager at Mind quoted in The Mirror <a href="https://www.mirror.co.uk/news/health/electric-shock-therapy-steals-mums-35916152">https://www.mirror.co.uk/news/health/electric-shock-therapy-steals-mums-35916152</a>.
- Other media coverage of surveys: The Times and the Telegraph.

### Links and further information

- Mad in the UK Blog: ECT: New Studies Detail Harms, Lack of Efficacy, Lack of Informed Consent Mad in the UK
- Survey Findings on Electroconvulsive Therapy | Psychology Today <a href="https://www.psychologytoday.com/us/blog/psychiatry-through-the-looking-glass/202508/the-first-papers-from-an-electroconvulsive-therapy.">https://www.psychologytoday.com/us/blog/psychiatry-through-the-looking-glass/202508/the-first-papers-from-an-electroconvulsive-therapy.</a>
- 80 Years On, Do We Know If Electroconvulsive Therapy Works? | Psychology Today <a href="https://www.psychologytoday.com/us/blog/psychiatry-through-the-looking-glass/202008/80-years-do-we-know-if-electroconvulsive-therapy.">https://www.psychologytoday.com/us/blog/psychiatry-through-the-looking-glass/202008/80-years-do-we-know-if-electroconvulsive-therapy.</a>
- Does Electroconvulsive Therapy Have a Place in 21<sup>st</sup> Century Medicine (Lisa Morrison and Prof John Read, Queens University Belfast March 2024):
   <a href="https://youtu.be/MY5CTuMbW2w?feature=shared.">https://youtu.be/MY5CTuMbW2w?feature=shared.</a>
- Sarah Price Hancock (co-author on papers and ECT recipient): The Barbaric Truth About Electroconvulsive Therapy (ECT)
   <a href="https://radicallygenuinepodcast.transistor.fm/199">https://radicallygenuinepodcast.transistor.fm/199</a>.
- Support for people impacted and information: Life After ECT <a href="https://lifeafterect.com/">https://lifeafterect.com/</a>

#### News coverage in NI:

- 2021 BBC(NI) on ECT Regulation in NI: <a href="https://www.bbc.co.uk/news/uk-northern-ireland-58800710">https://www.bbc.co.uk/news/uk-northern-ireland-58800710</a>
- 2021 BBC(NI) on ECT Regulation in NI: <a href="https://www.bbc.co.uk/news/av/uk-northern-ireland-58800716">https://www.bbc.co.uk/news/av/uk-northern-ireland-58800716</a>
- 2023 BBC(NI) on ECT Informed Consent following publication of journal article (also covered on Radio Ulster & Evening News) <a href="https://www.bbc.co.uk/news/uk-northern-ireland-66587095">https://www.bbc.co.uk/news/uk-northern-ireland-66587095</a>

#### Three blogs I wrote and recorded:

- Part 1. Loss and Anger: ECT, background, effects, informed consent and regulation: <a href="https://youtu.be/CDymtc3S021">https://youtu.be/CDymtc3S021</a>
- Part 2. Finding Me: ECT as a last resort, the problem with diagnoses and wider systemic issues <a href="https://youtu.be/c15R51i02kE">https://youtu.be/c15R51i02kE</a>
- Part 3. Justice and Hope: ECT, women and the wider mental health system <a href="https://youtu.be/axEFg6rPR2c">https://youtu.be/axEFg6rPR2c</a>