OPEN LETTER TO NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE) RE ELECTROCONVULSIVE THERAPY (ECT)

January 5, 2022

To: Dr Paul Chrisp, Director of Centre for Guidelines, NICE

cc Gillian Keegan MP, Minister for Care and Mental Health

Dr Rosena Allin-Khan MP, Shadow Minister for Mental Health

NICE Draft Guidelines: Top 10 failures to ensure safe, effective and properly regulated ECT practice

We, the undersigned, (including 14 ECT recipients and three relatives thereof, 12 psychiatrists and 7 Professors in mental health disciplines) call upon NICE to radically rewrite the ECT section of its draft Depression in Adults guidelines; to reiterate and uphold the unimplemented recommendations from the 2003 Guidelines; and to take into account recent evidence on serious deficiencies in safety, effectiveness and regulation.

As it stands, the ECT section of the draft is a breach of NICE's own commitments to: Use evidence that is relevant, reliable and robust; propose new research questions and data collection to resolve uncertainties in the evidence; liaise with the research community to ensure they are addressed; take into account the advice and experience of people using services and their carers or advocates; and update recommendations in line with new evidence (https://www.nice.org.uk/about/who-we-are/our-principles).

In line with NICE principles of 'making decisions using a process that is transparent and contestable', we ask the Committee to rectify, or justify, the following **ten serious omissions**:

- No statement about safe dosage, frequency or duration of treatment although NICE 2003 noted that '.... stimulus parameters impact on the safety and efficacy of the technique, and recent research needs to be augmented.'
- No statement about the need for regular cognitive testing, with appropriate measures, for adverse effects after every treatment and at follow up despite the NICE 2003 requirement that 'the individual's cognitive function is monitored on an ongoing basis and at a minimum at the end of each course of treatment.'
- No recommendations on the provision of rehabilitation and compensation for memory loss/brain damage although NICE 2003 noted that 'a number of individuals find their memory loss extremely damaging and for them this negates any benefit from ECT'; and Thymatron machine manufacturers are required to warn of the possibility of 'permanent brain damage.'

- No statement about the failure to produce evidence-based patient information leaflets, as recommended by NICE 2003. A recent audit (Harrop et al., 2021) shows that current leaflets contain numerous serious inaccuracies, confirming NICE 2003 concerns about informed consent: '....the potential for cognitive impairment following ECT may not be highlighted during the consent process.' This requirement is even more urgent in light of the 2015 Montgomery ruling on shared decision making in psychiatry which requires even relatively rare risks to be mentioned (Hughes et al., 2018).
- No comment on the huge regional variation in usage (up to 47-fold between different **Trusts**) raised in previous NICE guidelines and documented in recent independent audits (Read et al., 2018, 2021), although this suggests serious failures in evidence-based decision-making.
- Failure to reiterate NICE 2003's recommendation that since many people are unaware of their rights and may be subject to both explicit and implicit coercion, '....mechanisms to monitor and prevent this from occurring must be developed and implemented'.
- Failure to address NICE 2003's statement that 'RCTs....did not adequately capture the experience of service users' and that their testimony must be taken into account to balance findings from quantitative studies. (e.g. Wells et al., 2021)
- Failure to reiterate important limitations on practice cited in NICE 2003, including 'used only to achieve rapid and short-term improvement of severe symptoms after an adequate trial of other treatment options has proven ineffective and/or when the condition is considered to be potentially life-threatening' and 'Clinical status should be assessed following each ECT session and treatment should be stopped when a response has been achieved, or sooner if there is evidence of adverse effects' and 'not recommended as a maintenance therapy in depressive illness.'
- Abandoning the call for robust research into efficacy and safety made by NICE in 2003 and reiterated in 2009 and 2014. NICE 2003 noted: 'Further research is urgently required to examine the longterm efficacy and safety of ECT... Of particular concern (was) the lack of long-term evidence regarding adverse effects on cognitive function....In addition to the use of appropriately validated psychometric scales, outcome measures should include user perspectives on the impact of ECT, the incidence and impact of important side effects such as cognitive functioning, and mortality....Further research into the mechanism of action of ECT is encouraged, because it may provide important information on aetiology and future treatment strategies.' The Royal College of Psychiatrists has made no attempt to set up such a research programme in the intervening 19 years. The draft fails to cite a single placebo-controlled study justifying the use of ECT, or to refer to recent research reviews and independent audits finding little/no efficacy, major safety concerns and significant procedural/monitoring problems (Read et al., 2018, 2019, 2021), despite these being explicitly made available to the committee.
- Reliance on adherence to the minimal standards of the ECT Accreditation Service (ECTAS) whose own website states 'ECTAS is a voluntary network which uses a system of peer review ECTAS does not provide regulation of ECT'. Elsewhere ECTAS itself stresses that 'ECTAS does not provide regulation or monitoring of ECT' (Sivasanker, et

al., 2022). NICE has no powers to enforce the new recommendation for clinics to be members of ECTAS; NICE guidelines are not legally binding; and the Care Quality Commission does not routinely inspect ECT clinics, and has told us that in relation to ECT it has 'no general investigatory power to address complaints (whether about specific treatments or other matters)' As they stand, these draft guidelines do nothing to change the situation in which ECT will continue to be, in effect, unregulated.

NICE 2003 noted that: 'The ongoing deficiencies in current practice were highlighted to the Committee, and the Committee strongly believed that action is required to ensure that appropriate standards of care are enforced whenever ECT is undertaken and that outcomes are continuously monitored.'

We have raised most or all of the above ten issues with the current Committee over the past year. The Shadow Minister for Mental Health has asked questions in Parliament about the regulation of ECT on several occasions, and a number of MPs have also written to Health Secretaries to raise their concerns.

Ongoing failure to address these concerns would represent a wilful neglect of patient safety, and a breach of NICE's own core commitment to evidence-based practice. The apparent abandonment of any attempt to require the gaps in the evidence to be filled is particularly disturbing. We trust the committee will, even at this late stage, and in line with its own principles and procedures, reconsider the draft in its entirety.

HARROP, C., et al. (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.

HUGHES, J., et al. (2018). The Montgomery ruling, individual values and shared decision-making in psychiatry. BJPsych Advances, 24, 93-100.

READ, J., et al. (2018). An audit of ECT in England 2011-2015: Usage, demographics, and adherence to guidelines and legislation. Psychology and Psychotherapy: Theory, Research and Practice, 91, 263-277.

READ, J., et al. (2019). Electroconvulsive Therapy for depression: A Review of the quality of ECT vs sham ECT trials and meta-analyses. Ethical Human Psychiatry and Psychology, 21, 64-103.

READ, J., et al. (2021). A second independent audit of ECT in England: Usage, demographics, consent, and adherence to guidelines and legislation in 2019. Psychology and Psychotherapy: Theory, Research and Practice, 94, 603-619.

SIVASANKER, V., et al. (2022). ECTAS Response to 'A second independent audit of electroconvulsive therapy in England, 2019: Usage, demographics, consent and, adherence to guidelines and legislation'. Psychology and Psychotherapy: Theory, Research and Practice, in press

WELLS, K., et al. (2021). The experience of living after ECT: a qualitative meta-synthesis. Journal of Mental Health, 30, 526-540.

Signed by:

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