

NATIONAL NEUROMODULATION REGISTRY (NNR): UNITED KINGDOM

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Introduction: Neuromodulation is an evidence based therapy used to treat chronic refractory neuropathic pain. There is a lack of long term outcome data and adverse event reporting. The NNR will be an effective tool looking at the use of these techniques in the UK. The database is owned by NSUKI and was developed in collaboration with Northgate. NNR is not an electronic record of patients. Its main function is a device registry linking with clinical outcomes which will allow for benchmarking, search facility and MHRA reporting.

Methods

The current data fields include: Demography, diagnosis, work status, EQ5D-5L, implanted device serial numbers, follow up data, drug dosage for ITDD, re-operation data. SCS and PNS for pain, Occipital Nerve Stimulation (ONS) for headache and ITDD for spasticity and pain are currently available. This will be expanded in the near future to include other modalities such as SNS, DBS, and Gastric stimulation.

Results

NNR is live since February 2018 with data entry from March 2018. The follow up data is collected as a third party in patients able to reply emails. We currently have more than 821 new patients registered since 1st March 2018 - 28th Feb 2019 and this is constantly increasing with newer centers joining the database. This is a multicenter third party follow up data on a prospective uncontrolled case series. Patients are sent an email link for completion.

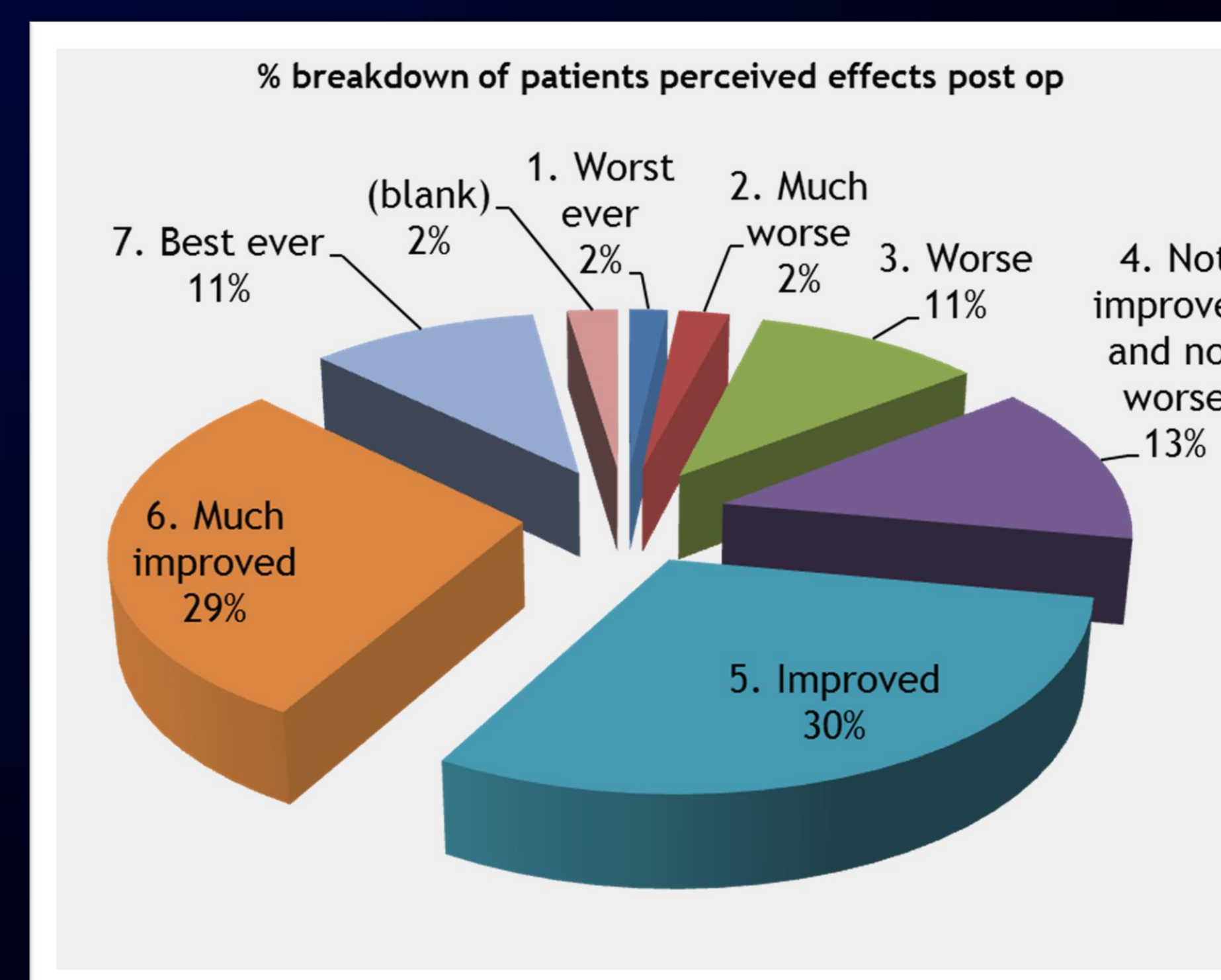
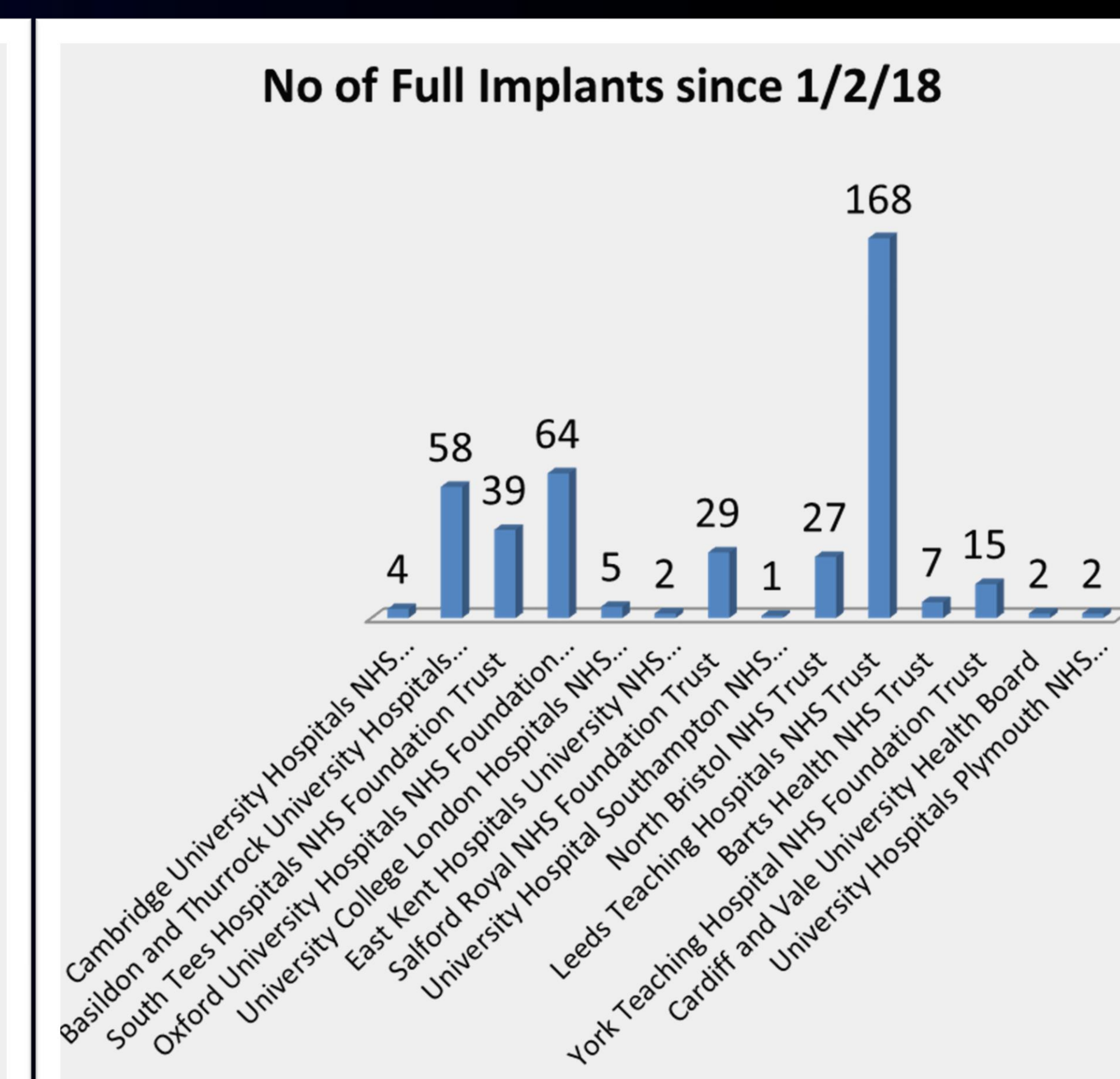
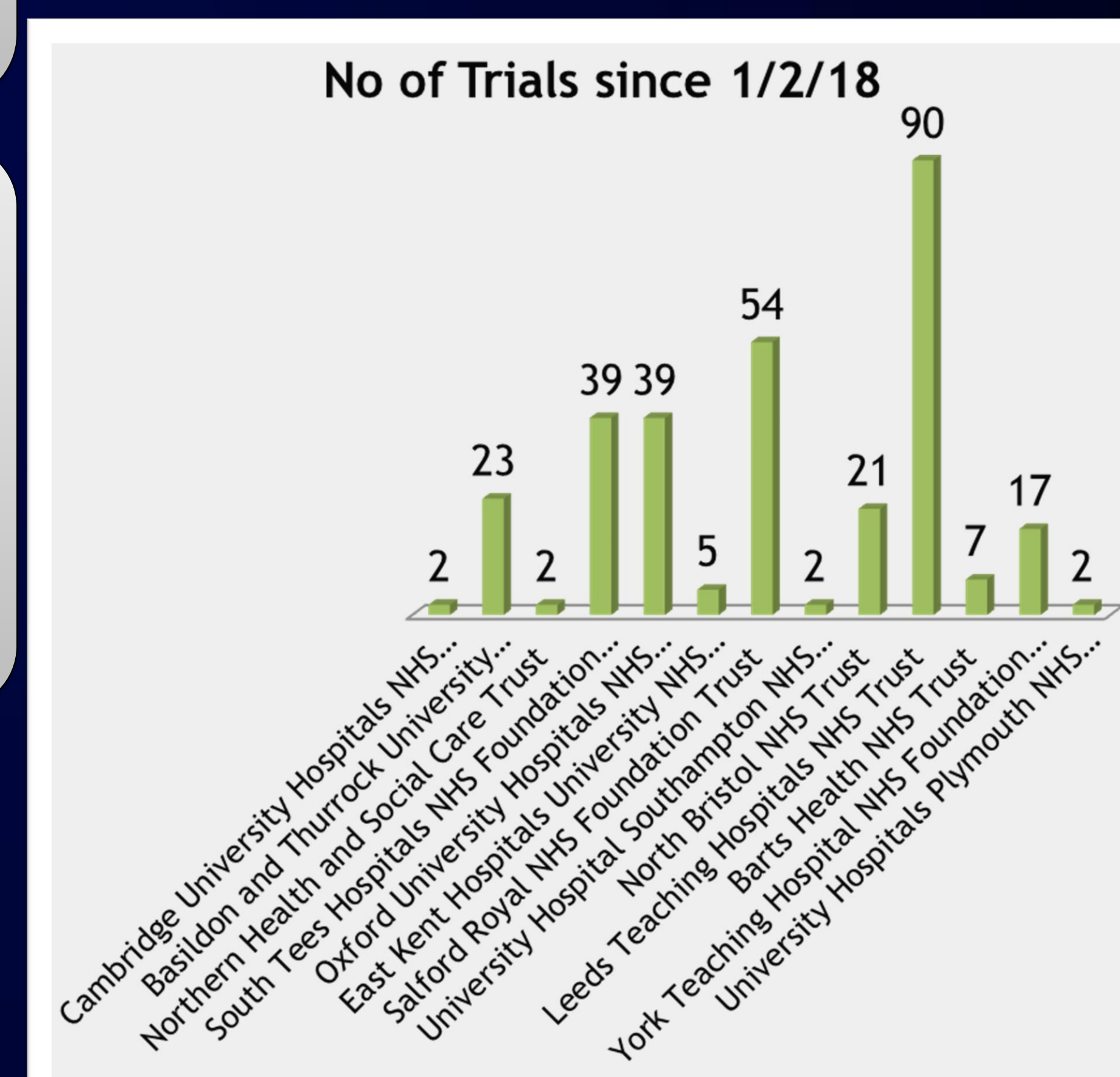
Discussion

The recent media interest on devices internationally, clearly shows a need for these registries. With new devices and technologies being introduced, this is a key development. The Royal College of Surgeons said "the Government must act urgently to reform medical device regulations, including a compulsory registry of all new implants" in the UK. We have already been ahead and use this NNR for Neuromodulation.

Conclusion

National registries are key in collecting outcome data and adverse effects both device and patient related. This will help guide the development of Neuromodulation across the country. This will also help in addressing areas where this therapy is not widely available.

	Av. Pre-op EQ5D5L score	Av. Post-op EQ5D5L score
Peripheral Nerve Stimulation	0.466	0.665
Spinal Cord Stimulation	0.273	0.480



Type of records on NNR

Therapy Type	No of procedures @ 28 Feb 18	No of Implants @ 28 Feb 18	No of Implants since 1 Feb 18
Intrathecal Drug Delivery	53	33	27
Peripheral Nerve Stimulation	50	45	34
Spinal Cord Stimulation	1126	941	760
Grand Total	1229	1019	821