

Registry

A place where official [records](#) are kept, or a book or system for keeping an official record of items.

Sometimes a [journal](#) requires that the clinical study be entered into a [registry](#) to be published. The best-known registry is probably www.clinicaltrials.gov, but there are other registries such as www.anzctr.org.au.

By registering the study the authors undertake the commitment to avoid the situation in which if the results of a [trial](#) are negative, a decision has to be made to either not publish the results or delay publication for an unspecified time ¹⁾.

American Spine Registry

see [Patient registry](#)

see [Cancer registry](#)

see [German pituitary tumor registry](#)

see [Rick hansen spinal cord injury registry](#)

[Loss to follow-up](#) may [bias outcome assessments](#) in medical registries. A [cohort](#) study aimed to analyze and compare patients who failed to respond with those that responded to the Norwegian Registry for Spine Surgery (NORspine).

They analyzed a cohort of 474 consecutive patients operated for [lumbar spinal stenosis](#) at four [public hospitals](#) in [Norway](#) during a two-year period. These patients reported sociodemographic data, preoperative symptoms, and Oswestry Disability Index (ODI), numerical rating scales (NRS) for back and leg pain to NORspine at baseline and 12 months postoperatively. They contacted all patients who did not respond to NORspine after 12 months. Those who responded were termed responsive non-respondents and compared to 12 months respondents.

One hundred forty (30%) did not respond to NORspine 12 months after surgery and 123 were available for additional follow-up. Sixty-four of the 123 non-respondents (52%) responded to a cross-sectional survey done at a median of 50 (36-64) months after surgery. At baseline, non-respondents were younger 63 (SD 11.7) vs. 68 (SD 9.9) years (mean difference (95% CI) 4.7 years (2.6 to 6.7); $p = < 0.001$) and more frequently smokers 41 (30%) vs. 70 (21%) RR (95%CI) = 1.40 (1.01 to 1.95); $p = 0.044$. There were no other relevant differences in other sociodemographic variables or preoperative symptoms. We found no differences in the effect of surgery on non-respondents vs. respondents (ODI (SD) = 28.2 (19.9) vs. 25.2 (18.9), MD (95%CI) = 3.0 (-2.1 to 8.1); $p = 0.250$).

Kaur et al. found that 30% of patients did not respond to NORspine at 12 months after spine surgery. Non-respondents were somewhat younger and smoked more frequently than respondents; however,

there were no differences in patient-reported outcome measures. The findings suggest that attrition bias in NORspine was **random** and due to non-modifiable factors. ²⁾.

1)

Chan AW. Out of sight but not out of mind: how to search for unpublished clinical trial evidence. BMJ. 2012 Jan 3;344:d8013. doi: 10.1136/bmj.d8013. Review. PubMed PMID: 22214892.

2)

Kaur S, Alhaug OK, Dolatowski FC, Solberg TK, Lønne G. Characteristics and outcomes of patients who did not respond to a national spine surgery registry. BMC Musculoskelet Disord. 2023 Mar 4;24(1):164. doi: 10.1186/s12891-023-06267-3. PMID: 36871007.

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