Should “garbage in–garbage out” be replaced by “little in–little out”? Questionnaire response rates need to be improved in surgical quality registries!

Alexander Sandon^{1,2} · Magnus Forssblad¹ · Martin Häggglund^{3,4} · Markus Waldén^{3,4,5}

Received: 12 March 2019 / Accepted: 29 April 2019 / Published online: 9 May 2019
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Introduction

Surgical quality registries are important tools for both performing research and improving clinical practice. The Swedish National Knee Ligament Registry (SNKLR) has collected patient-reported and surgical data on more than 90% of the anterior cruciate ligament (ACL) reconstructions in Sweden. There has year-by-year been an increasing number of publications using data from SNKLR and the Scandinavian counterparts since their inceptions in 2004–2005 [3]. To date, approximately 50 studies have been published using data from the SNKLR. The primary intent of these knee ligament registries has been to observe the outcome of the surgery and to detect inferior results/failures, and several arguments for why registries are needed are fairly uncontroversial [2]. The major advantage with registry data is the large number of procedures collected in a short period of time, but the saying “garbage in–garbage out” is also particularly true for registry data with potentially lesser control of data quality compared with studies using data collected directly by a specific research group. However, a “little in–little out” situation is sometimes at least as deleterious as illustrated in the example below.

Suboptimal response rates for patient-reported outcome measures

A vital part of modern registries is the collection of different patient-reported outcome measures (PROMs). When using these measures, information is collected directly from the patient mainly through validated questionnaires such as the Knee injury and Osteoarthritis Outcome Score (KOOS) and EuroQol-5D (EQ-5D), as used in the SNKLR. According to the 2017 Annual Report of the SNKLR, the overall response rates to the PROMs at 2 and 5 years postoperatively were, however, as low as approximately 50% and 40% [1]. Low response rates are a well-known problem and a serious cause for concern in terms of validity of the research performed on surgical registries. This gives smaller complete datasets and might potentially lead to non-response bias and, in turn, negatively impact the representativeness of the research sample leading to unreliable outcomes. Very large amounts of patients and a detailed drop-out analysis can, however, mitigate some of these problems and make the results from registries generalizable, as recently shown for the SNKLR [5].

Even worse response rates in elite football players?

In a prospective cohort study being carried out on the highest men’s and women’s football leagues in Sweden, details on ACL injuries have routinely been collected for a varying number of clubs during several seasons since 2001 [4]. Although having relevant epidemiological and surgical data at hand within this study, PROM data are unknown for this cohort. It could, however, be speculated that even if the vast majority of players go back to the previous playing level within a year following ACL reconstruction, their ACL reconstructed knees are probably not symptom-free in

✉ Alexander Sandon
alexander.sandon@ki.se

¹ Department of Molecular Medicine and Surgery, Stockholm Sports Trauma Research Center, Karolinska Institutet, Stockholm, Sweden

² Department of Orthopaedics, Västmanland Regional Hospital, Västerås, Sweden

³ Football Research Group, Linköping, Sweden

⁴ Department of Medical and Health Sciences, Linköping University, Linköping, Sweden

⁵ Department of Orthopaedics, Hässeleholm Hospital, Hässeleholm, Sweden

many cases [4]. We, therefore, intended to cross-match the cohort study data with the PROMs in SNKLR at 1, 2 and 5 years postoperatively. We identified 48 players who had suffered an ACL tear, mean age 23 (SD 4.8) years, in the cohort study between 2005 and 2012. However, when cross-matching them with SNKLR, the very low response rates of the PROMs did not allow any meaningful analysis. In total, 39 of the 48 players (81%) were identified in the SNKLR. Of these players, only 17 (44%) had completed the 2-year KOOS and 13 (33%) the 5-year KOOS, respectively. It is also noteworthy that only nine players (23%) had completed both the 2- and 5-year KOOS, and only six players (15%) had completed all the PROMs at 1, 2 and 5 years.

Elite players and their supporting staff should be role models

There is no good explanation to the unexpectedly poor response rates in this cohort. It is fairly uncontroversial that elite athletes should be role models for amateur and youth players when it comes to traditional sportsman's behaviour such as sleeping, eating and drinking habits as well as doing proper physical and preventive training, etc. In our opinion, however, elite athletes—and their supporting staff—should also be role models when it comes to participating in research and entering data in quality registries. Based on the aforementioned findings, clubs, and particularly the medical teams, need to take a greater responsibility here in making sure that the players fill out the PROMs after surgery. Even if players are transferred between elite clubs domestically, all ACL reconstructed players are identified through the medical screening procedure so no one should be able to “fly under the radar”.

What is in it for the future?

Most patients do not have medical teams that can remind and aid with responding so other strategies to improve the response rates are obviously also needed. We realise that

there is no quick fix to this problem, and multiple sustainable approaches are, therefore, needed. Some of these include incentivising participation, sending out reminders, making the PROMs relevant for the patients and provide personal feedback to their responses, giving options on the method to respond for example by mail or using a smartphone or computer, and to make response rates a greater focus of the registries, etc.

In closing, survey response fatigue is a serious threat to future research and the surgical quality registries. The ethical legitimacy of registries is that they are important for the follow-up of treatment and research, but if that is no longer the case, can we really continue to collect patient data? Getting all patients to fill out all the PROMs is an impossible task, but greater effort is needed to improve the response rates to ensure that the great potential of the registries is better utilised and that the research becomes more reliable.

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