Longitudinal studies: an obstacle course. The challenge and the paradox of communication

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Let's assume that a young researcher decides to challenge the great enemy, called "passing time", and to re-contact, after about 10 years, the young patients evaluated by his Professor for rhinological disorders, subjected to Skin-Prick Test (SPT) and nasal cytology. Let's assume that the Professor, with patience and foresight, has not only recorded the clinical data of these 1030 children, but also the landline and mobile phone numbers of their parents, in the hope that one day he could be able to contact them easily for some prestigious study. Let's assume that the young researcher realises that only 578 satisfy the inclusion criteria of the study and thus starts contacting them: this is where he unfortunately comes across the first big obstacle, represented by the telecommunications paradox. As a matter of fact, in the past, each family unit had a unique number in life, indelibly linked to a house and a family. Nowadays, the telephone numbers per household have become at least 2 or 3, and they have a very short life: indeed, only 361 of the re-contacted patients has a telephone number that still exists. The young researcher at least hopes that these patients would pay him due attention. "*I am sure that they will be willing to dedicate a few minutes of their attention! It is still a doctor who is phoning you to talk about the health of your child!*" he thinks naively. But no! Only 213 parents listen to the whole content of the phone call. The list of patients gets shorter and shorter, and the scientific discomfort grows progressively. In addition, the researcher run into another difficult obstacle: the male listener, who certainly does not remember what happened to his son ten years ago, and who suggests contacting his wife. "*She certainly remembers everything, from the period when the child was examined, to the diagnosis, the medicine prescribed, even how much the doctor was paid"*. And so, timidly, the young researcher asks if it is possible to make a follow-up visit: a simple, non-invasive and completely free rhinological examination. Unfortunately, the answers given are not satisfactory: 80

patients does not agree to a follow-up visit, because not interested (33), no longer resident in Apulia (19), or too busy (28); 71 patients fix an appointment immediately; 62 patients initially answer possibly yes, but then only 9 of them get back to the Clinic. In summary, the young researcher visited only 80 (7,8 %) of the 1030 children entered in the database. And no, Covid-19 doesn't matter. We cannot blame negative responses on the fear of going to hospital settings and getting infected. Unfortunately, we have to point out that these investigations were carried out before the start of the pandemic, which would certainly have further reduced the number of positive responses[1].

How, when, and why are patients lost to follow-up is a common question for many doctors and researchers, regardless of their branch. With the advent of technology and the possibility of entering all patient data in computerized databases, studies on the importance of long-term follow-up and on strategies aim at reducing the prevalence of "lost in-follow up" patients are constantly increasing[2,3]. Indeed, beyond the implications for patient care and outcomes, a complete patient follow-up allows to fully understand the risks and benefits of both investigational and established therapies. Therefore, the loss of data inevitably corresponds to a missed opportunity in translating the results of clinical trials into clinical practice[4]. However, according to several studies, percent adherence to follow-up appointments are alarmingly low, also in the field of Oncology[5,6]. Moreover, patients who are teenagers transitioning to adults are considered at higher risk for being lost to follow-up[7]. Hence the importance of additional studies to improve adherence to follow-up and to integrate into the care team figures such as social workers or care coordinators/educators that they can sensitize patients and their parents to the importance of staying in contact with their doctors, adhering to follow-ups.

Meanwhile, the young researcher has also become an expert sociologist, and he just has to search for the remaining 669 on social networks… finger crossed!

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