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Registry study shows a decline in myocardial infarction

INVITERT KOMMENTAR

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Following analysis of registry data from various sources, the authors of a new original article now present useful, relevant figures that cover the entire population.

In this edition of the Journal of the Norwegian Medical Association, Bønaa et al. present the developments in the incidence of acute myocardial infarction in Norway in the period 2013–2021 (1). The data show a positive trend: the incidence of myocardial infarction has fallen by almost 4 % each year. However, mortality remains high, with a 30-day mortality rate of 20 %.

The authors used data from the Norwegian Myocardial Infarction Register, the Norwegian Patient Registry and the Norwegian Cause of Death Registry. They also used data from the Norwegian Population Registry, as the registries are linked via personal identification numbers and the findings are related to population statistics.

The findings are important and provide a basis for reflection. Why has the incidence decreased so significantly? Why is there a reduction in overall mortality but not after myocardial infarction with ST segment elevation (STEMI)? Why are there differences in mortality between women and men?

There is an important distinction between central health registries, which are not based on consent, and medical quality registries, which may or may not be consent-based. Some quality registries, such as the Norwegian Myocardial Infarction Register (under the Norwegian Cardiovascular Disease Registry), are organised within a central health registry and are not consent-based. These registries therefore include everyone in the relevant patient population. The quality registries contain far more detailed clinical information than the Norwegian Patient Registry, which is based on patient administrative data, and with the data from the Norwegian Myocardial Infarction Register, the authors were able to differentiate between myocardial infarction with and without ST segment elevation.

Access to good-quality registry data is needed to ensure the population's access to healthcare services of a high standard. Significant efforts have been made over many decades to collect registry data with a view to shedding light on the population's health and improving the quality of services. It cannot be assumed that the Norwegian Patient Registry encompasses the entire population's use of government-funded specialist healthcare services or that it can be linked to other registry sources. Prior to 2008, the registry did not contain personal identification numbers, making it impossible to link with other sources or to produce reliable statistics on conditions treated over time or at multiple institutions. Myocardial infarction was used as a key argument in the debate about the need for personally identifiable registry data from the entire specialist health service (2).

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All central health registries were consolidated at the Norwegian Institute of Public Health at the start of 2024 (3). A new milestone in the field of registries was achieved this autumn when the government announced the introduction of a registration requirement for private healthcare providers (4). With accurate and complete data in the registries, the introduction of new methods can be monitored over time and across units. Retrospective data from healthcare providers previously had to be collected via questionnaires, which often had low response rates (5).

Cohort studies can be linked with registry data and follow patients over time, as in the first research project using personally identifiable data from the Norwegian Patient Registry and the Norwegian Mother, Father and Child Cohort Study (MoBa) (6). Patients in randomised clinical trials can also be followed over time using registry data, as demonstrated by Bønaa et al. in their published article on stent types in 2016 (7).

The registries in the Nordic countries are national registries covering long periods, and they can be linked through personal identification numbers. This places us in a unique position with regard to opportunities – and responsibilities. All registered individuals have the right to information and access to their own information (8), and a foundation level of understanding of health registries should be incorporated into all health-related education programmes to ensure that this right is applied in practice.

The myocardial infarction study published in the Journal of the Norwegian Medical Association includes data up to the end of 2021. In this specific context, it is of little consequence that the data is somewhat old. In other areas, such as infection control and monitoring of adverse effects, data that is a few years old will have relatively little value. Because things take time. Factors that determine how quickly researchers can access results from registry linkages include update frequency and quality assurance. All research applications are processed centrally by the Health Data Service and have a processing time of 3–5 months before a decision is made (9). Time is then needed to obtain data from each individual registry, which takes about 2–3 months, before researchers gain access and can start compiling and analysing the data. This also takes time, added to which is the publishing processes of journals before results are released.

The pandemic demonstrated that rapid access to up-to-date health registry data is essential in a crisis. This resulted in the establishment of the Emergency preparedness register for COVID-19 (Beredt C19) (10), which has now been discontinued. Situations where there may be a need for quick access to information about public health could once again arise with the introduction of new vaccines, surgical methods and medications.

Bønaa et al. illustrate in their study how registry data from various sources has generated new knowledge about myocardial infarction in Norway. Maintaining a high coverage rate in the registries is essential for facilitating studies like this.

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