

Project draft

The Norwegian Surveillance System for Suicide in Mental Health and Substance Misuse Services

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[The National Centre for Suicide Research and Prevention at University of Oslo](#) has established a surveillance system for suicide in mental health and substance misuse services in Norway. The system is commissioned by the Norwegian Directorate of Health, and is based on a developed method from [The National Confidential Inquiry into Suicide and Safety in Mental Health \(NCISH\) at the University of Manchester in UK](#). The model has undergone several modifications in order to make it more suitable for implementation in the Norwegian health care system.

Background

Psychiatric disorders are important risk factors for suicidal behavior, and found in above 90 % of people who die in suicide (1). Patients in the mental health and substance misuse services therefore have a well-known elevated risk of suicide and suicidal behavior (2, 3). This makes mental health and substance misuse services an important setting for suicide prevention, and several agencies including WHO (4) highlights increased access to mental health care and improved quality of care as essential strategies to prevent suicide. Despite this, we have limited knowledge about the people who die in suicide during or after contact with these services in Norway. The aim of the Surveillance System is thus to secure a continuous collection of national data on suicide among people who have been in contact with specialist mental health services in the 12 months preceding their death. Based on systematic data collection we will be able both to monitor the numbers of suicides and to describe the circumstances around the incidents and systematically identify key features of the patients who die in suicide. The overall goal is to identify possible areas for suicide prevention at the system level, develop and implement interventions, and eventually evaluate the effectiveness of suicide preventive efforts.

The Norwegian Surveillance System for Suicide in Mental Health and Substance Misuse Services is built on the influential work conducted by [The National Confidential Inquiry into Suicide and Safety in Mental Health \(NCISH\)](#) based at the University of Manchester in the United Kingdom. Since 1994, NCISH has systematically collected data from clinicians on suicide and homicide by people who have been in contact with mental health services in the 12 months prior to death. Based on findings from the Inquiry, NCISH has provided health professionals, policymakers, and service managers in the UK with the evidence and practical suggestions they need to improve the mental health services (5).

Professor Appleby and the NCISH-group have given The Norwegian Surveillance System approval to use and make adaptations to the inquiry form. Both the NCISH-model and the questionnaire has undergone alterations to make it feasible for use in Norway. Besides translation, adaptation to the Norwegian health care system and other minor issues, we include existing registry data to reduce the number of items in the questionnaire, which the health professionals need to complete when a patient has died in suicide. In order to obtain the registry data we are collaborating with the [Norwegian Cause of Death Registry](#) and the [Norwegian Patient Registry](#). We do not collect data on homicides or accidental overdoses. Neither do we cover treatment given by general practitioners or other services at the community level.

Aim

1. Identify all people who have died in suicide within 12 months after contact with specialist mental health services in Norway.
2. Acquire systematic data about the deceased patients, the treatment they received and details regarding the suicide.
3. Identify possible failures and areas for improvement at the system level. Develop and evaluate the effect of implemented prevention strategies.

The Norwegian Surveillance System is not a health supervision authority: We will not analyze individual cases or single incidents. Supervision of the health and care system in Norway is among [The Norwegian Board of Health Supervision's](#) responsibilities. The information provided by health professionals and the data collected from the Norwegian registries will be analyzed on a group level exclusively. Information regarding cases of suicide will not be shared with health authorities, insurance companies or any others.

Method

The Norwegian Surveillance System for Suicide in Mental Health and Substance Misuse Services collect data from three different sources:

1. Information submitted in an electronic questionnaire by clinicians/health professionals responsible for the patient's care.
2. Data derived from the [Norwegian Patient Registry](#).
3. Data derived from the [Norwegian Cause of Death Registry](#).

Creating a baseline based on historical data from national registries

The Norwegian Surveillance System has been provided with data from the Norwegian Patient Registry and the Norwegian Cause of Death Registry regarding all people who died by suicide in the period 2008 to 2015 within one year after contact with specialist mental health or substance misuse services. These data has given us a baseline for the project, and results have been presented in a [Norwegian report](#) published in December 2018 (6), together with an [English summary](#). The data will be further analyzed and used in future reports and research projects.

Running part of the system

In the running part of the Surveillance System, we are using a two-step model for data collection:

Health trusts (including private practitioners operating with an agreement to be part of the specialist mental health services) continuously report all known patient suicides to the Norwegian Surveillance System by completing an electronic questionnaire at our website. The information is supplemented with data from the Norwegian Patient Registry and the Norwegian Cause of Death Registry.

An annual linkage of the Cause of Death Registry and the Patient Registry is conducted, and here the remaining suicides are identified. The health trust or private mental health specialist that had been in contact with the deceased patient not registered through the first step receives a request to complete the questionnaire. The linkage of the national registries ensures that even suicide deaths that the health trusts were not familiar with are being included in the Norwegian Surveillance System.

Since the questionnaire contains detailed questions regarding the patient, including the treatment and follow-up that the patient received, it is important that a clinician who knew the patient or was responsible for the patient's care completes the questionnaire.

As the health trusts in Norway already are submitting clinical information to the Norwegian Patient Registry, the Surveillance System will use information available in this registry to make the questionnaire less comprehensive and time consuming for the clinicians. This will also improve the data quality and ensure that we avoid unnecessary double reporting.

The data collected from the health trusts will be stored in a secure data solution called [Services for sensitive data \(TSD\)](#) at the University of Oslo. The Surveillance system has approval from the [Norwegian Directorate of Health](#) to collect sensitive and personal data about deceased patients.

The Norwegian Cause of Death Registry contains a unique Scandinavian personal identification number (ID), an 11-digit number unique for every person in Norway. The Norwegian Patient Registry holds this personal ID. When a clinician records a suicide in the Norwegian Surveillance System, they will need to register the personal ID in the electronic questionnaire. This number is necessary in order to link the questionnaire to registry data. The personal ID will however be automatically separated from the electronic questionnaire during the submission of the questionnaire. The personal ID will in no circumstances be available to the Surveillance System as it is electronically parceled out to a designated access-limited folder. This folder will only be accessible for The Norwegian Patient Registry – who will be able to access this number for registry linkage. Using the same principle, data from the questionnaire will only be accessible to the project.

Dissemination of findings/results

The Norwegian Surveillance System are producing annual reports, which will be available [online](#) and sent directly to the Norwegian Directory of Health and other relevant institutions. We do also present the findings through annual meetings, where health authorities, health trust and user organizations are invited to attend. Findings will also be available to the public through our webpage (uio.no/kartleggingssystemet) and through contact with other types of media. Results will also be published in scientific journals and further be disseminated through already established sources, such as scientific and clinical meetings and in several ongoing education initiatives.

All results are based on aggregated data, and it will not be possible to identify individuals, health units or health professionals in reports or other publications.

Evaluation and revision of the system

After a couple of years, it will be necessary to evaluate the system based on experience. There may be limitations that we did not foresee, we might identify variables that are impossible to analyze in a meaningful way, or discover that the system lack essential variables or groups that could be interesting to include in the future. An evaluation will also give an indication of the potential effects of the system's results, including the impact of our communication strategy and the way we disseminate the findings, and highlight unintended consequences in relation to this.

According to the plan, this overall evaluation of the project will be carried out about 3 years after the implementation. Representatives from different interest groups will be included in the evaluation work, thus making the project able to benefit from both professional knowledge, user experiences and additional information from other areas, covering a broader field.

After a systematic evaluation of the system, it will be possible to make revisions and further developments to the system.

Research plan

The main objective of the Norwegian Surveillance System is to establish a national running database covering all patient suicides in the mental health and substance misuse services, in order to develop prevention strategies at the system level and evaluate potential effects. The project was established based on a political decision and commissioned by the Norwegian Directorate of Health. Our main product will thus be annual reports intended for the health authorities, focusing on general descriptive statistics of suicides in this patient group, potential weaknesses in the mental health care system and possible areas for improvement. The large amount of data will however also provide us with a great opportunity to conduct specified research projects – which can give us important insight and detailed knowledge of suicide deaths in this population. We will develop a research plan as more data become available.

We are always interested in discussions and possible cooperation with other research groups and relevant agencies. Feel free to contact us, details given here: [contact us](#).

References

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