The Norwegian Surveillance System for Suicide in Mental Health- and Substance Misuse Services - Combining Registry and Clinical Data

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Background

The National Centre for Suicide Research and Prevention was commissioned by the Directorate of Health to implement a nationwide surveillance system, which collects data on all persons who die by suicide under or within one year after contact with secondary mental health services, substance use services or private mental health specialists. Here we describe the development and design of a nationwide data collection system.

Method

The Norwegian Surveillance System for Suicide is based on the *National Confidential Inquiry into Suicide and Safety in Mental Health* (NCISH) (1). The questionnaire developed by the NCISH was translated and adapted. Then, variables from the questionnaire that could be retrieved from the Cause of Death Registry (2) or the Norwegian Patient Registry (3) were identified.

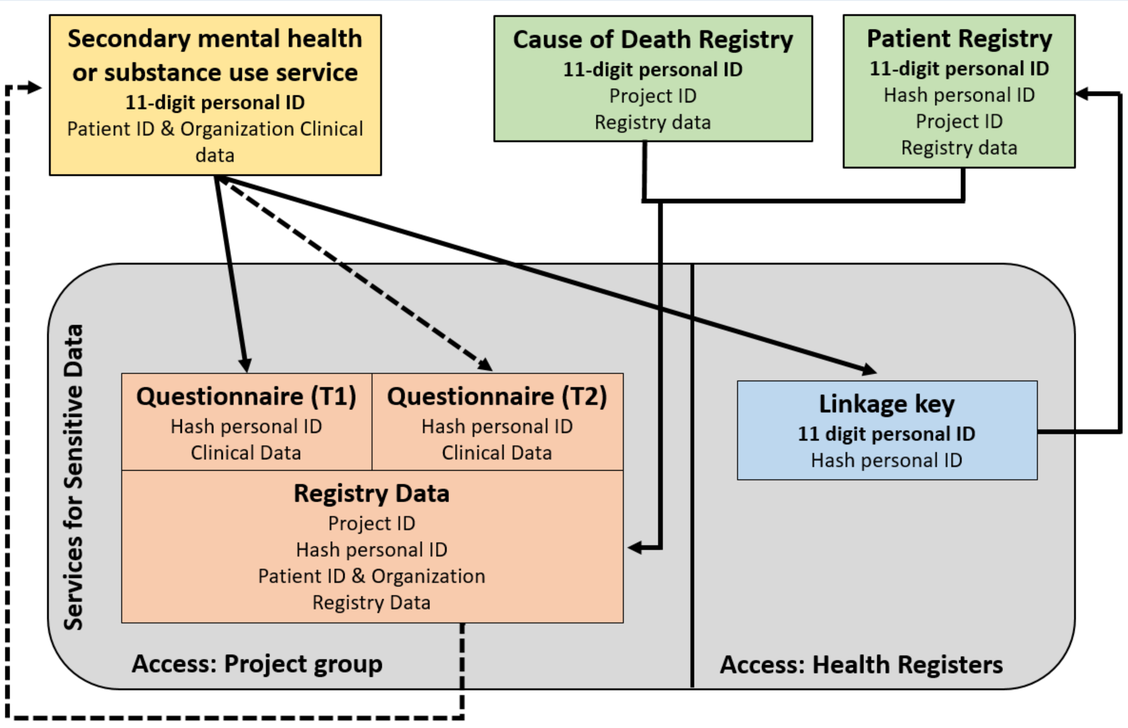

Figure 1. Illustrates data flow. Direct registration is illustrated with the full lines. Prompted registration is illustrated with the dashed lines. Clinical and registry data is stored in a directory where only project members have access (orange boxes), and the linkage key (blue box) in a directory where only authorized personnel from the Health Registers have access.

Results

A hybrid register study design, where registry data is supplemented with clinical data, was developed. All data is stored within a safe environment (4) which has implemented granular access to directories. The clinical data is collected through an encrypted online questionnaire (5), where the unique 11-digit identification number is automatically moved during submission to a directory where only authorized personnel from Health registries have access. The unique identification number is used as input to a cryptographic hash function, and the resulting hash is used as an identifier in the data set. We use Bcrypt (6) as the hash algorithm and a pre-defined random value unknown to the project group, which reduces the risk of reidentification. The nature of cryptographic hash functions make the identifier unique for each personal ID number, which makes linkage with the registries possible without using personal identification number. Consequently, the project can reliably link data sources without using the personal ID number.

Table 1. Description of data flow

Registration		Description
Direct	1.1	Services are acquainted with a suicide in a current patient or person with contact the last year
	1.2	The clinician who last had contact with the patient reports clinical data through the questionnaire
	1.3	Registry data is linked with the clinical data after an annual registry linkage
Prompted	2.1	Suicides not reported through direct registration is identified through annual linkage between the Cause of Death Registry and the Patient Registry
	2.2	The service which last had contact with the person is notified by the Surveillance System.
	2.3	Clinician reports clinical data through the questionnaire.
	2.4	Clinical data is linked with the registry data.

Discussion

An limitation of registry data is that they often lack several variables which are important in suicide research, such as prior suicidal behavior and other clinical variables. The hybrid registry study design complements registry data with clinical variables, resulting in more relevant data for suicide prevention in secondary mental health services. The use of registry data also makes reporting less time-consuming for the clinicians since it utilizes already reported registry data.

An advantage of the data collection system is that it makes linkage between clinical and registry data possible without giving the researchers access to directly identifiable data such as the personal ID number. This is of particular value when informed consent is not possible to obtain as when studying completed suicides**.**

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