





Norway - Data Collection

How to resuscitate a cardiac arrest registry (Norway)

The Norwegian Cardiac Arrest Registry collected Utstein style data from out-of-hospital cardiac arrests from 2001 and in-hospital cardiac arrests from 2004. In 2009 data collection was suspended, and the registry needed a complete resuscitation! Some of the lessons learned in this process include:

Organizational:

- I. National organization needs national collaboration, and someone must take the lead; Norwegian National Competence Unit for Prehospital Emergency Medicine (NAKOS) hosted the project, and representatives from all academic hospitals in Norway joined the steering committee to oversee the resuscitation. Human factors favoring collaboration, sharing, and trust among partners are essential.
- 2. Political support not only by politicians; NAKOS and the steering committee worked with Oslo University Hospital and all levels in the Norwegian health bureaucracy for local and national support.
- 3. Cardiac arrest as a reportable disease! We achieved resuscitation of our registry and cardiac arrest is now included in the short list of reportable diseases in Norway, and as such registration is now mandatory. By this elegant solution previous concerns about consent and access to data are replaced by requirements for high security IT-solutions.

Resources:

- 1. Seed funding can be vital! Early funding came from diverse sources. Academic staff contributed time and resources from themselves and their institutions, without intentions of ever being repaid!
- 2. Stable funding must be realistic and cover salaries AND expenses! This is a continuous challenge, especially so when costs for digital infrastructure are beyond the registry's control.
- 3. Local ownership to data stimulates local allocation of resources! In our model each hospital/EMS owns their local registry within the national registry they have full access to local data and based on local processes, they can add supplementary data elements for their own quality assurance purposes, within the same legal framework. On the flip-side; mandatory registration without central funding makes it possible for hospital administrators to use cardiac arrest reporting as part of their struggle for resources.

THE WAY FORWARD

Our registry received a national status for reportable disease in 2013, and the participating EMS-organizations and covered proportion of the Norwegian population are steadily increasing. By 2015 we expect 13 of 19 EMS-services covering 78 % of Norwegian population.