

Challenges and possibilities with register-based research

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The National Board of Health and Welfare

Our mission statement:

The National Board of Health and Welfare safeguards health, welfare and equal access to good health care and social care



The use of registers in Sweden

- Local level
- Regional level
- National level
- Research



Data usage national level – examples

- **Government – policy making, the national Budget**
- **Follow up governmental “Special initiatives”**
- **National statistics all use purposes – “Official statistics”**
- **Research and development – register based research**
- **Public reporting – open comparisons and performance assessments, international and national**
- **Media**

What we provide at NBHW:

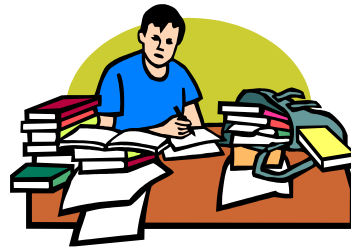
- **Support to researchers, quality registers and other actors who use register data**
- **Tailor-made statistics**
- **Data for research**
- **Answers about the statistics and the reports from The National Board of Health and Welfare**

Support to quality registers:

- Analyses of Coverage and completeness
- Matching Q-Regs to Cause of death-register
- Help to combine Q-regs with other registers and researcher-generated data
- Background statistics for Q-regs (eg. prevalence, mortality etc)
- Online database with variables etc for all Q-regs

Collaborations with authorities and others

- Statistic Sweden
- The Swedish Research Council
- Quality registers and Regional quality register centers
- Researchers



NATIONELLA KVALITETSREGISTER



Challenges

- Laws and legislation for data
 - International collaborations
 - Research databases
- An organization for quality registers that is sustainable for the future
- Efficient organisations
 - Time-to-data
 - Collaboration between stakeholders
- Digital solutions, technical platforms, e-health

Whats new at NBHW?

- Increased resources for Register services
- New format for the in-patient register
- New laws
- Registries in Social sector
- New digital services

Impact developing digital service

- Secure the quality of the request
- Less manual work in handling application
- Meets the raised expectations set by the many other (non-government) services and tools they use every day
- Assemble services more quickly and at lower cost

The screenshot displays the 'Beställa data för forskning' (Order research data) page on the Socialstyrelsen website. The page features a progress indicator at the top with five steps: 1. Uppgifter om projektet (highlighted), 2. Register och statistik, 3. Säkerhets och behandling av personuppgifter, 4. Administrativa uppgifter, and 5. Skicka in. The main content area includes a text input field for 'Projektets titel på svenska:', a dropdown menu for 'Har du beställt data från oss till samma projekt tidigare?' (set to 'Välj'), and a list of 'Bifoga dokument' (Attach documents) with 'Välj' buttons for each: 'Ansökan till etikprövningsnämnd', 'Tilläggsansökan', 'Beslut från etikprövningsnämnd', 'Tilläggsbeslut', and 'Forskningsplan'. A right-hand side box contains instructions: 'Ange en beskrivande projekttitel på svenska. Har ansökan till etikprövningsnämnd gjorts, använd samma projekttitel. Titel ska inte innehålla sekretesskyddad information'. At the bottom right, there are 'Redigera beställning' and 'Spara' buttons. The footer shows the Socialstyrelsen logo and name.

Thank you!