

# The Danish Smoking Cessation Database

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#### **Abstract**

**Background** The Danish Smoking Cessation Database (SCDB) was established in 2001 as the first national healthcare register within the field of health promotion.

**Aim of the database** The aim of the SCDB is to document and evaluate smoking cessation (SC) interventions to assess and improve their quality. The database was also designed to function as a basis for register-based research projects.

**Study population** The population includes smokers in Denmark who have been receiving a face-to-face SC intervention offered by an SC clinic affiliated with the SCDB. SC clinics can be any organisation, place or person working with a preventive aim. There are no age limits for registering a smoker in the database.

**Data collection** The SCDB contains prospectively collected baseline and outcome data on SC clinics, interventions, and individual smokers. Baseline data include socio-economic, demographic, and prognostic factors. The outcome data are smoking status at the end of the programme and after six months and satisfaction with the SC intervention.

**Validity** Approximately 80-90% of all SC clinics offering systematic face-to-face SC interventions are reporting data to the SCDB. The data completeness of the SCDB is very high, at 95-100%. Validation checks have been implemented to ensure high data quality.

**Conclusion** The SCDB is a well-established clinical database and a priceless tool for monitoring and improving SC interventions in Denmark to identify the best solution to helping smokers become smoke-free. The database is increasingly used in register-based research.

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#### Introduction

Denmark has a long tradition of collecting administrative, healthcare, and social data. Some of the oldest national healthcare registers can be dated back to the 1870s (1). In 1968, the Danish Civil Registration System (CRS) was established, and since then, a unique personal identification number (called the CPR-number) has been assigned to all permanent residents in Denmark (2). The CPR-number is used in all other national registers, making it possible to link information from different registers at a personal level. The CRS initiated a breakthrough in register-based epidemiology in Denmark (3).

In 2001, the Smoking Cessation Database (SCDB) was established as the first national healthcare register within the field of health promotion, offering smoking cessation (SC) clinics a resource for external documentation and evaluation of their SC activities. Since then, face-to-face SC interventions have been docu-

mented and evaluated at the national level to assess and enhance the quality and to improve the effectiveness and cost-effectiveness of individual SC clinics as well as the overall national effort.

In this paper, we will describe the SCDB and the most common types of intervention registered in the database.

# Background and aim of the database

The SCDB was initiated in 2000 as a research project to evaluate the effect of SC interventions in Denmark based on a systematic collection of data. The data collection began in 2001 and continued until the end of 2005. Two studies were published on this research project (4;5).

After the initial research period, the organisation of the SCDB was anchored with a steering committee representing the National Health Authorities and other stakeholders, and a secretariat was included to make the daily decisions.

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Minor changes were made to the questionnaires, and the guidelines were updated. All changes made to the SCDB were in agreement with the standards for the Danish Clinical Quality Databases (6), which are used to assess the quality of health efforts aimed at specific patient groups based on individual patient's continuity of care. Accordingly, the SCDB established a set of indicators and standards (7).

#### Study population

The SCDB contains information on smokers undergoing a face-to-face SC intervention offered by a SC clinic affiliated with the SCDB. In Denmark, all smokers have access to SC interventions in their municipality without referral and without having to pay for the intervention.

Each smoker has to provide informed consent before being registered in the SCDB. There are no age limits for including a smoker in the database, but when smokers are under the age of 15 years, their guardian must consent on their behalf.

Any SC clinic can use the SCDB if it provides a well-described SC intervention and can commit to using the standard registration questionnaires to collect baseline and follow-up data on the enrolled smokers in accordance with existing guidelines.

An SC clinic can be an organisation, place or person working with a preventive aim. It may be a municipal clinic, pharmacy, hospital department, patient association, private company, general practitioner, dentist, midwife, or any other individual offering SC interventions.

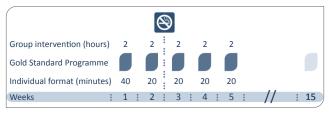
# Smoking cessation interventions in the SCDB

Any type of SC intervention can be documented in the SCDB. The single most commonly used SC intervention in Denmark was developed in 1995 (8). Since then, it has been the standard intervention and is now called the Gold Standard Programme (GSP). More than 90% of the SC interventions registered in the SCDB over time are GSPs. Below, we describe the GSP and other interventions registered in the SCDB.

#### The Gold Standard Programme

The GSP is an intensive intervention consisting of five meetings during six weeks; furthermore, it is recommended to have a sixth meeting covering relapse prevention three months after the quit date (see Figure 1). The programme is based on counselling and a clearly

**Figure 1** Time schedule and the recommended quit date for the GSP smoking cessation intervention.



Each box represents a meeting; the light box is recommended but not mandatory. The minimum duration of the meetings is also listed (8;11).

structured manual-based patient education programme taught by specially trained staff. The programme comprises individually tailored counselling on nicotine replacement therapy (NRT) or other medical support based on the individual's level of dependence, as measured by the Fagerström test score (9). The GSP fulfils the international criteria for an intensive SC intervention (10).

The GSP can be conducted as a group intervention (8) or as individual counselling (11). Allocation to the group or individual programme is at the discretion of the SC clinic or the counsellor as well as the individual smoker (8). The recommended scheme for the intervention is shown in figure 1.

The first two weeks cover educational sessions on preparing to quit, including an introduction to the programme, smoking profiles, ambivalence and motivation, pros and cons of continuing smoking versus cessation, nicotine dependence, withdrawal symptoms and medical support for withdrawal symptoms, and setting a quit date. A quit date is set between the 2<sup>nd</sup> and 3<sup>rd</sup> week (8).

After the quit date, the last three teaching sessions cover maintenance, risk situations and how to manage them, use of reward systems and networks, smoking cessation and health, physical activity, mood swings, stress, relapse prevention, cutting back on supportive medication, and how to manage a completely smoke-free life (8).

In accordance with the guidelines, smokers who attend at least 75% of the scheduled meetings are considered compliant (12).

#### Come & Quit

This intervention was developed to attract male smokers with a low education, a group of smokers who do not frequently visit SC clinics. Before entering the programme, each smoker meets with a counsellor to discuss further developments. Come & Quit is a flexi-



ble programme build on open groups including eight 1½-hour weekly meetings on different subjects. The meetings are offered on a weekly basis and the smoker can begin the intervention anywhere during the 8-week circle (13) (Figure 2).

Figure 2 Time schedule for the Come & Quit smoking cessation intervention



Each box represents a 1½-hour meeting with different themes; all meetings are recommended but not mandatory. Between meetings, the intervention also offers text messages, e-mails and/or telephone calls according to individual needs. The quit date can be scheduled anytime during the programme (13).

Each smoker composes the course for themselves by choosing which meetings to attend, and if they want to receive text messages, e-mails, and/or telephone calls between meetings. There is no recommended quit date, but the smokers should be willing to attempt to quit some time during the intervention (13). Based on the guidelines smokers attending 4 meetings are considered compliant to the Come & Quit intervention (12).

Come & Quit has been registered in the SCDB since 2011.

#### Xhale

Xhale is an intervention targeted at young smokers under the age of 25 years. It is based on the Come & Quit concept, but since smoking habits and dependence is often different in young smokers, the concept was translated accordingly. The pronounced social function of smoking among the young is also taken into account. In addition to the meetings Xhale offers the opportunity of virtual support between meetings (14). Smok-

ers are considered compliant to Xhale after attending 4 meetings.

After completing a test period, Xhale was implemented in the SCDB in 2016.

#### Crash course

Crash courses were held in large groups. They comprise one meeting lasting for approximately 1½ hours. The main focus of the intervention was to provide information on further SC resources. The smokers were introduced to the use of NRT and where to find more help. All smokers attending the intervention were considered compliant.

The crash courses were registered in the SCDB from 2001-2005.

#### Health promotion counselling

This intervention is built on the five stages of change (15), and takes into account the knowledge, attitude and experience of the smoker (16). The health promotion counselling is suited for smokers starting out in one of the first three stages (precontemplation, contemplation or preparation)(16). The aim of the counselling is to support the smoker in moving forward towards SC. This method is based on the smokers knowledge regarding the implications of smoking on his/her health (16). Furthermore, highly effective elements from short interventions to modify alcohol habits are used in the conversation. Smokers who attend at least 75% of the scheduled meetings are considered compliant (12).

The health promotion counselling has been registered in the SCDB since 2006.

#### Alternative treatments

Since 2006 acupuncture and reflexology have been registered through their own separate categories.

#### Other interventions

Any other intervention can be registered as "Other" in the SCDB. This can be other alternative treatments and special treatments. Standard interventions in which some of the face-to-face meetings are substituted by a telephone consultation and interventions including a mixture of other concepts e.g. GSP and Come & Quit are also registered under this category. It is possible to add a short note defining the intervention further.

#### **Data collection**

The SCDB contains prospectively collected data including baseline information on the SC clinic, the intervention provided, and the individual smoker. In addition,



the database also includes outcome data. The data can be divided into three categories: Structure and process, characteristics of participants, and effect and results. All data in the SCDB are collected via standard questionnaires.

Effective January 1, 2006, minor changes were made to the questionnaires according to the knowledge obtained during the research project (see Figure 3). The most substantial change was introducing the CPR-number into the registration information, as this inclusion enabled future linkage of the registered smokers with other national registers.

Furthermore, the guidelines for the follow-up and data collection procedures differed between the two periods (see Figure 3). From 2006, an online self-registration service was established that replaced the existing scanning procedures. The online system also provided a reporting module, making it possible for SC clinics to download baseline and outcome reports in real time.

#### **Outcome measurements**

Outcome measurements are a crucial part of the registration, as they enable evaluations of the effect of the interventions. The main outcomes are smoking status at the end of the programme and after six months and satisfaction with the SC intervention.

#### Baseline data

For each SC intervention (individual or group intervention), the SC counsellor registers information about the

intervention given. This information includes, e.g., the setting of the intervention, the type of intervention, the duration and dates of delivery, the planned quit date, the size of the group and meeting adherence.

Each smoker completes a baseline profile, which includes information on smoking history, nicotine dependency (via Fagerström score), socio-economic and demographic characteristics, and whether they authorize later contact for follow-up. Each smoker has to provide informed consent before being registered in the SCDB.

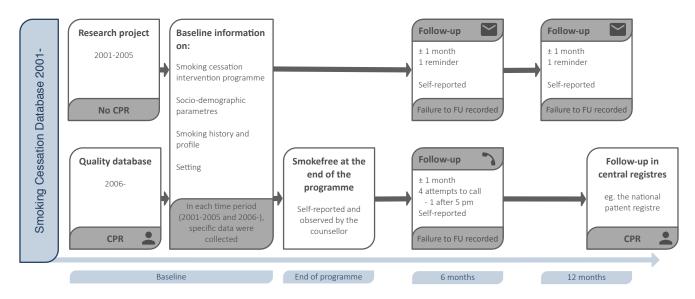
#### Follow-up

The follow-up data contain information on smoking status measured as successful continuous quitting since the intervention and as the point prevalence, follow-up rate, satisfaction with the SC intervention, and use of supportive medication.

When agreeing to participate in the SCDB, the SC clinic commits to follow-up with each smoker according to existing guidelines. The follow-up can be outsourced, and today, approximately half of the SC clinics use the national quit-line to perform the follow-up.

Participants who declare that they do not want to be contacted again are not followed. Smoking status is self-reported, and no validation is required. As the data collection process was designed to be integrated with everyday practice in the clinic, and as it is not standard to meet the participants of an SC intervention after 6 months, the follow-up information is collected by mail or telephone in accordance with standard operating procedures. The follow-up guidelines were changed in

Figure 3 Data collection in the SCDB over time (CPR: a unique number including date of birth and gender assigned to all Danes at birth and to immigrants).





2006. The procedures for the two periods are outlined in figure 3.

#### Follow-up from 2001-2005

From 2001-2005, the SC clinics were intended to follow-up with each patient 6 and 12 months ( $\pm$  1 month) after the quit day. The follow-up was mainly conducted by mail, but it was possible to complete it by phone. At least one reminder was required before the participant could be considered a non-respondent. The reasons for loss to follow-up were registered in the database.

#### Follow-up from 2006 and on

The SC clinic is responsible for the follow-up. Each participant should be contacted by telephone 6 months after their planned quit day (± 1 month), and if no planned quit date was recorded, the date of course completion should be used. At least one of the calls should be in the evening (after 5 pm). After four failed attempts to reach the participant, he/she is considered a non-respondent. The reasons for loss to follow-up are registered in the database.

#### **Data validity**

#### Coverage

The coverage of the SCDB has not been established because there are no valid sources of data describing precisely how many private SC clinics exist throughout the country in addition the public SC clinics. Based on course descriptions, webpages, etc., 80-90% of all SC clinics offering systematic face-to-face SC treatment are estimated to be reporting data to the SCDB.

#### Data completeness

The data completeness of the SCDB is very high. The questionnaire regarding the SC intervention has a rate of completeness of 100%. The questionnaires collecting baseline data on each smoker and the follow-up questionnaires have a completeness rate of at least 95%.

#### Validation

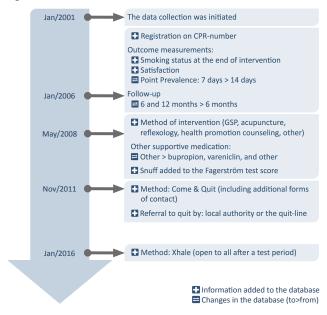
To ensure a high quality of data, validation checks have been implemented in the self-registration service. It is not possible to enter non-existing dates, and it is not possible to terminate a registration without answering all of the mandatory questions. Moreover, the secretariat performs manual checks on the chronology of the data entries to ensure that the beginning and end of an intervention are within a reasonable timeframe. Furthermore, the CPR-numbers are continuously checked in the CRS and corrected if entered incorrectly.

#### Data breaks

Over time, minor changes have been made to the

SCDB. The main changes are shown in Figure 4. The most extensive change was implemented in 2006, as described earlier.

Figure 4 Data breaks in the SCDB over time.



+ indicates something was added to the database, <=> indicates that changes were made (from>to). E.g. in January 2006 the registration of point prevalence changed from 7 days point prevalence to 14 days point prevalence, and in January 2016 Xhale was added to the list of methods.

#### **Quality indicators**

Since 2006, the SCDB has operated in accordance with the following five standards and indicators.

After the research project, the SCDB participated in creating consensus regarding the indicators and quality standards used to measure the improvement and deterioration in the quality of SC activities. Five indicators were developed, each with a corresponding quality standard (Table 1). The standards were chosen to be ambitious but realistic for the individual clinics, which was already reflected in the first annual report published after the standards had been established.

#### **Examples of research**

Several papers have been published in international scientific papers that use data from the SCDB. The publications based on the research project assessed cost-effectiveness and effectiveness (4;5). Subsequently, a broad range of topics has been covered, including the impact of structural changes in the healthcare system, compliance, public smoking bans, and effectiveness of different interventions (12,17–20) and the real-life effectiveness of the GSP for specific subgroups of smokers (21–24).



Table 1 Indicators and corresponding quality standards in the SCDB.

Indicator	Standard
1: Compliance with smoking cessation intervention	
Proportion of participants who have completed the smoking cessation intervention*	80%
2: Smoke-free at the end of the programme	
Proportion of participants who are successful quitters at the end of the smoking cessation intervention	80%
3: Follow-up rate	
Proportions of participants with a 6 month follow-up	80%
4: Smoke-free after 6 months	
Proportion of participants who are successful quitters (continuously abstinent) at 6 month follow-up	50%
5: Satisfaction	
Proportions of participants who are satisfied with the smoking cessation intervention they received	90%

<sup>\*</sup> In accordance with the guidelines, patients who attend at least 75% of the scheduled meetings are considered compliant (12). If no fixed number of scheduled meetings are set (like in Come & Quit and Xhale) at least 4 sessions are required to complete the programme (12).

#### Administrative issues and funding

The SCDB is free of charge for the SC clinic and has been financially supported by the Danish Ministry of Health or the Danish Health Authority. Bispebjerg and Frederiksberg Hospital, Capital Region of Denmark, the Danish Pharmaceutical Association, and the Danish Institute for Health Services Research have also supported the SCDB.

The Secretariat is assigned to the World Health Organisation Collaboration Centre for Evidence-Based Health Promotion in Hospitals and Health Services, at Bispebjerg and Frederiksberg Hospital. See www.scdb. dk for further information.

#### Conclusion

The SCDB is a well-established clinical database and a priceless tool that can be used to monitor and improve SC interventions in Denmark to attain the best solutions for helping smokers become smoke-free. The database is increasingly used in register-based research.

#### Conflicts of Interest/Disclosure

Both authors are members of the research committee of the SCDB. H. Tønnesen is a member of the Steering committee of the SCDB. M. Rasmussen was the national coordinator of the SCDB until 2011. The authors have no other conflicts of interest in this work to disclose.

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