

Information for Persons to be included in the BPSD Register

Better quality healthcare for you

National quality registers are made use of to facilitate the development and assurance of quality in our healthcare and nursing system. The registers enable us to follow up and improve our healthcare and nursing, and the more people who are involved, the more assured the results will be. By including information about you in the quality registers, you are helping us make these improvements.

This information is about the BPSD register, a Swedish quality register for **B**ehavioural and **P**sychological **S**ymptoms in **D**ementia. The purpose of the Register is to increase well-being and reduce suffering for people with dementia by reducing their behavioural and psychological symptoms (BPSD). The work with the register is founded on person-centred care measures based on each individual's needs and resources. The information registered includes the person's social security number, diagnosis, care measures taken and medication prescribed.

To develop and secure care and nursing, I (specify caregiver)

wish to enter information about you in the BPSD register. Your information is confidential and is removed when no longer required. You may also have your information deleted, *or* refuse to be registered.

How your information is handled in quality registers

Information about you is collected from you, personally, and from your patient record. The data may only be used to develop and ensure the quality of care and nursing, produce statistics and for research in care and nursing. Anyone intending to use this information within any of the above areas will only be granted access to it following a confidentiality check. When research studies are to be conducted, approval from an ethics review board (EPN) is required.

<u>Confidentiality</u> Your information is protected by confidentiality in accordance with the Public Access to Information and Secrecy Act. This means that information about you held in the register may be disclosed only if it is clear that such disclosure will harm neither you nor anyone close to you. That assessment is made by the principal responsible for the register.

<u>Security</u> Your information is protected through checks made technically, through routines and by way of special authorisation requirements. This is done so that only those people needing the information have access to it and get it in a secure way.

<u>Access to information</u> Your healthcare provider may have access to the information they enter in the register and those people who centrally manage the register can and may have access to your personal data. No other care provider has access to your personal data.

<u>Culling</u> Your personal data will be erased when it is no longer needed in the development and assurance of the quality of care.

Legal basis

All who process personal data must do so from a legal basis.

Name of the registration unit:

and the Regional Board of Region Skåne are permitted to collect and register information in the BPSD register since it is considered necessary information of general interest to society (Article 6.1 e). We are also permitted to process information about health held in the register, because it is necessary for reasons related to occupational medicine and the provision of health care (Article 9.2 h). Furthermore, our staff, together with staff at the Regional Board in Region Skåne, are covered by a statutory duty of confidentiality (Article 9.3). According to the Data Protection Ordinance, legal support under Swedish legislation must also exist when processing personal data in quality registers. Such provisions are found in Chapter 7 of the Patient Data Act (2008:355).

Your rights

Your participation in the register is voluntary and has no impact upon the care you receive. Your healthcare provider, registering information about you, is responsible for ensuring that the registration takes place properly in the quality register. If you do not want your information to be registered, please contact your healthcare provider.

You have the right to have your information erased from the register at any time. In either case, please get in touch with the contact person for the BPSD register (contact information may be found at the bottom of the document)

You may obtain information relating to which care unit and at what time access was made to your personal data.

You have the right to request correction of any of your personal data that is inaccurate and to have incomplete personal data added to where necessary.

You have the right to know (free of charge) what information has been registered about you, in a so-called register extract. An application for such must be made in writing, signed and sent to the contact person for the national quality register named below.

You have the right, under certain conditions, to demand that the processing of personal data be restricted if the accuracy of the personal data is contested

Contact information

The BPSD Register

BPSD-registret VO Kognitiv medicin Ängelholms sjukhus 262 81 Ängelholm Sweden

Website: www.bpsd.se Phone: +46 (0)40-33 55 78 Email: bpsd.sus@skane.se

Central Personal Data Manager (CPUA) for the BPSD register is Region Skåne

Operations Manager Mikael Åström **Email:** Mikael.Astrom@skane.se

Data Protection Officer: Kajsa Thelin

Information management, Dockplatsen, Malmö

Email: Kajsa.Thelin@skane.se

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Data Protection Officer:

Address:

Phone:

Email: