

NEWSLETTER - Number 2

September 2017

Contact information



Principal Investigator:
Professor Susanne S.
Pedersen
sspedersen@health.sdu.dk



Project Manager: Søren J. Skovbakke sjskovbakke@health.sdu.dk

Dear collaborators

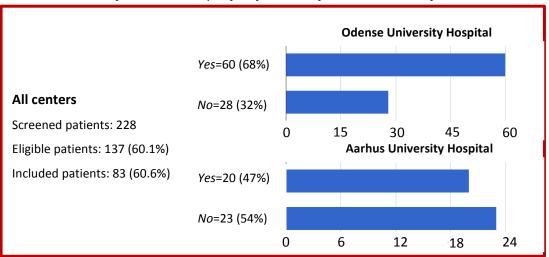
In order to keep you updated on the progress of the ACQUIRE-ICD study, we have decided to send out a newsletter every quarter. The project also has a homepage: http://www.sdu.dk/om_sdu/institutter_centre/institut_psykologi/forskning/forskningsprojekter/acquire-icd

Here you receive the second newsletter. Should you have any suggestions for content for future newsletters, please contact the project manager, Søren J. Skovbakke.

RECRUITMENT STATUS

Recruitment of participants for ACQUIRE-ICD was initiated in February 2017 at Odense University Hospital (OUH) and followed by Aarhus University Hospital (AUH) and Aalborg University Hospital. This means that we are now getting the first 6 months follow-up questionnaires in from patients. This occurs automatically through REDCap, although we of course keep a close eye out on compliance.

Status on inclusion for all centers specified for the major contributors so far:



PRESENTATION OF PROJECT NURSES FROM AARHUS UNIVERSITY HOSPITAL

In this newsletter, we introduce the project team from AUH. See details on page two to the left. AUH implants the highest number of ICDs of the so far participating centers.

"On a day-to-day basis we have 3-5 eligible patients. We have been recruiting patients since March but since we, as ICD-Technicians, also take part in the implantations, it has not been possible to screen and include all eligible patients till now. September 1, 2017 a new project nurse, Lotte Lindskow, was employed with a main focus on the ACQUIRE-ICD study and this has allowed us to increase the enrollment of patients significantly."



Meet the team at Aarhus University Hospital (AUH)



Front: Project Nurse, Lotte Lindskov

Back left: Project Nurse/ICD Technician, Sonja Runge

Back right:Project Nurse/ICD Technician, Kirsten Andersen



Principal Investigator: Jens Cosedis Nielsen Professor and Cardiologist

INTERVENTION: CONTENT AVAILABLE TO PATIENTS ON THE LIVA PLATFORM

As part of the intervention, patients are given professional advice and support, educational information, self-help tools and coping strategies. These are provided via pdfs purpose-designed for the project in combination with vodcasts with patients and health care professionals. These vodcasts were developed by the team behind "Helbredsprofilen" and some of them in collaboration with the ACQUIRE-ICD team: https://helbredsprofilen.dk/en. The topics include:

- Information about ICD and device treatment
- ICD shocks
- Travelling with an ICD
- Home monitoring
- Psychological reactions anxiety, stress, depression
- Transition to a new life
- Relationships, new roles, intimacy and sex
- Stress management tools
- Relaxation and mindfulness exercises
- Changing lifestyle/habits and motivation
- Sleep, tiredness and fatique
- Advice/recommendations on physical activity

Two ICD quizzes of 13 questions are distributed twice as part of the intervention. When the patient enters the reply, the correct answer and an explanation are provided. We expect this to be a motivating way for patients to learn and increase their knowledge

about their device and living with an ICD.

If it is my first shock and I feel fine, there is no need to contact the hospital.

-False or True?

Rigtigt! Hvis du ikke har fået stød tidligere vil vi gerne udlæse din ICD-enhed. Det er i dagtiden muligt at kontakte det ambulatorie du er tilknyttet. Her kan vi aftale, om du skal komme ind til en ekstra kontrol, men ofte vil vi ved hjælp af hjemmemonitorering kunne udlæse din ICD-enhed. Det er i dagtiden muligt at kontakte det ambulatorie du er tilknyttet. Her kan vi aftale, om du skal komme ind til en ekstra kontrol, men ofte vil vi ved hjælp af hjemmemonitorering kunne udlæse din ICD.

Hvis du får stød om aftenen eller om natten, og i øvrigt har det godt, kan du vente med at kontakte os til dagen efter, eller evt. kontakte sengeafsnittet.

Hvis du føler dig utilpas eller utryg efter at have fået et stød, eller får flere stød efter hinanden skal du kontakte 112 og ind på nærmeste sygehus.

Patients are asked to **evaluate the usefulness of the content** after every session to help us target the needs of patients:

- How much of this week's content did you read/watch? (All, Some, Nothing)
- How useful did you find it? (Not useful, Less useful, Useful, Very useful)





The ACQUIRE-ICD forum, exclusively for patients enrolled in the study, was launched on 30 July 2017, with project nurses informing all patients about this feature. The forum offers a platform for patients to reach out to peers, provide social support and advice, and share their experiences.

PRESENTATION OF PSYCHOLOGICAL INTERVENTION

Once a month, patients answer 16 questions to monitor their health status (EQ-VAS) and symptoms of depression (PHQ-8) and anxiety (GAD-7). Below is how the patient sees and can track his / her own scores over time. A vodcast has been made to help patients interpret their scores and the graphs.



If the patient scores ≥10 on depressive symptoms *or* anxiety the nurse contacts the ACQUIRE-ICD psychologist. The psychologist calls the patient for an intake to determine if the patient should be offered the intervention that was designed specifically for the study and is based on value-based cognitive behavioral therapy. During the intake they go through: Responses to items on the PHQ-9 / GAD-7, life with a chronic disease / device, cognitive difficulties, social network and hobbies, marital status, and prior contact with psychologist / psychiatrist.



The 7-week psychological intervention consists of the following steps:

Step 1: ICD and its impact

Step 2: When one's life changes

Step 3: The impact of thoughts on mood and actions

Step 4: Acceptance and values - living a purposeful life

Step 5: How does my daily life look like?

Step 6: Find a good routine

Step 7: To continue to develop and accept stagnation or relapse

After steps 3 and 7, patients are offered respectively a mid-way evaluation and an end evaluation by phone.

The psychological intervention is provided by Charlotte Kettner and Camilla Sødequist, Master's students in Psychology at SDU, who are trained to provide the intervention. They are both supervised by Susanne.

PUBLICATIONS AND PRESENTATIONS (SINCE LAST NEWSLETTER)

Invited keynote speaker at CSANZ 2017

Pedersen SS. Development and evaluation of personalized and interactive web-based innovation to advance the quality of life and care for patients with an ICD (The ACQUIRE-ICD study). 65TH ANNUAL SCIENTIFIC MEETING OF THE CARDIAC SOCIETY OF AUSTRALIA AND NEW ZEALAND (CSANZ), Perth, Australia, August 10-13, 2017.

The ACQUIRE-ICD protocol article is expected to be submitted in January 2018.

THE NEXT NEWSLETTER WILL BE SENT OUT IN JANUARY 2018