

Guided by the patients - Co-creating a set of patient-reported outcome measures within two Danish psychiatric clinical registries

Solvejg Kristensen

Lone Baandrup

Jan Mainz

Maria Bonde

Poul Videbech

Jens Holmskov

Per Bech



(ABSTRACT #37)



In brief PRO-PSYCHIATRY

- Is a national research initiative established in 2016
- Is anchored in the national clinical registries for depression and schizophrenia
- Is led by Aalborg University Hospital - Psychiatry
- Builds upon an organisation, involving
 - a cross professional and cross regional steering group which includes patient representatives (N=20)
 - a cross regional Patient Peer Board (N=10)
 - national and regional experts
 - an in and an out patient unit for primary implementation
- *“Nothing about us without us”*





OBJECTIVES

1. **Select a set of PRO-items**
2. **Define a national measurement concept**
3. **Specify PRO-based indicators**
4. **Collect patient recommendations for implementation**





DEFINITION

PATIENT REPORTED OUTCOME (PRO)

“A PRO is a measurement based on a report that comes from the patient (i.e., study subject) about the status of a patient’s health condition without amendment or interpretation of the patient’s report by a clinician or anyone else”².

CONCEPT

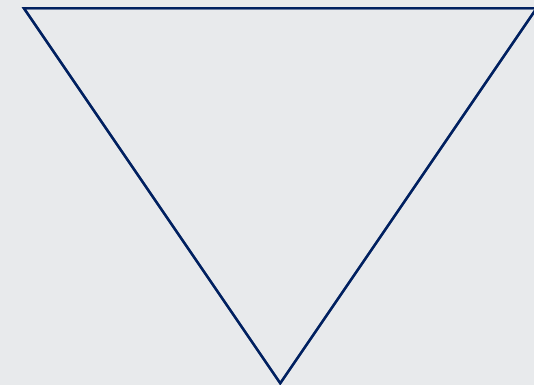
THE PHARMACOPSYCHOMETRIC TRIANGLE¹

Relief of symptom burden

A

Side effects

B



C

Restoring well-being
Restoring social function

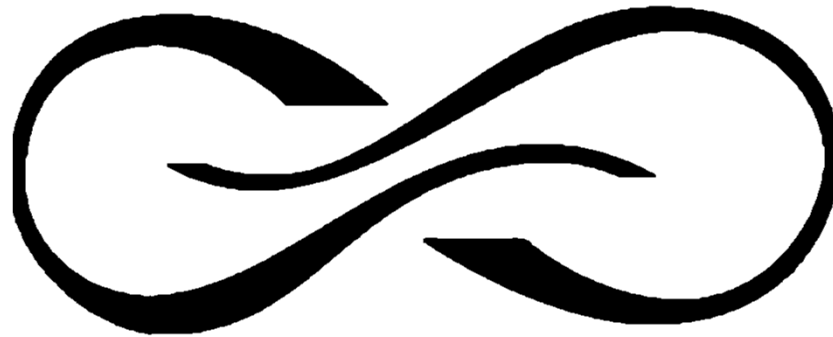
1. Bech P, Timmerby N. An overview of which health domains to consider and when to apply them in measurement-based care for depression and anxiety disorders. Nord J Psychiatry 2018 May 1;1-7.
2. <https://www.fda.gov/Drugs/DevelopmentApprovalProcess/DrugDevelopmentToolsQualificationProgram/ucm370262.htm#pro>



METHOD: ITERATIVE CO-CREATION



Workshops



Working mode:
Ratings
Hearings
Dialogues
Brainstorm
Commenting
Concept definition



Mails, meetings, TC



METHOD: PATIENT PEER BOARD TOPICS

Which topics are most relevant to patients?
Which items are most relevant to patients?
How to phrase the items?
How to collect the data?

Which information do patients need?
In the patient's view, which information do clinicians need?

How to collect data?
How to design the online PROM graphically?
How to design the online self-management portal graphically?

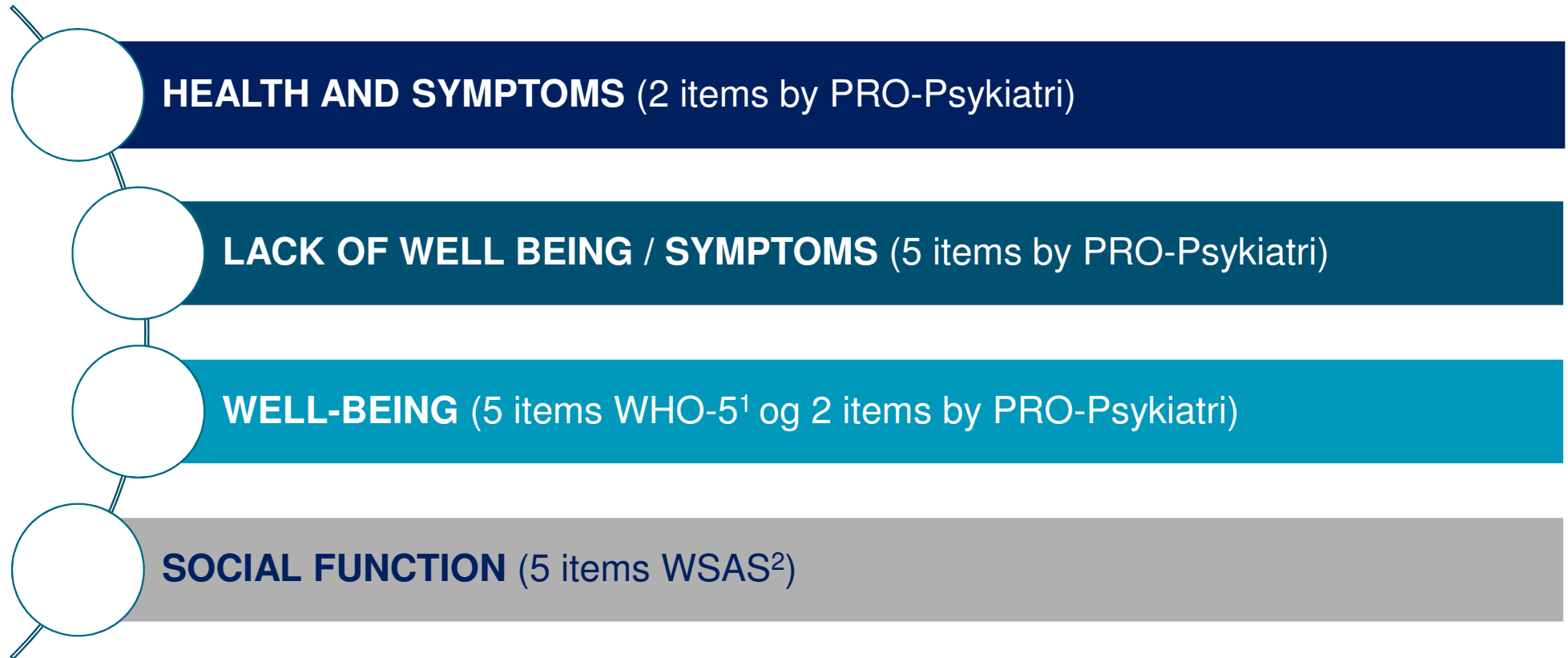
Pro's and con's regarding involvement of family and friends?
Which information do family and friends need?

Are there implications related to answering the PROM when involuntary treatment might be at stake?
Are there implications related to using the PRO results when involuntary treatment might be at stake?

How to present aggregated patient level results most meaningful to the public?



RESULTS: SELECTED PRO TOPICS AND ITEMS



1) WHO's Well-being Index 2) Work and Social Adjustment Scale



RESULTS: TARGET GROUPS

Danish Depression Database (DDD)

All **in and out patients** aged 18 years with a unique personal identifier, diagnosed with a unipolar depression¹.

Danish Schizophrenia Register (DSR)

All **out patients** aged 18 years with a unique personal identifier, diagnosed with skizophrenia²

¹ F32 Depressiv enkeltepisode, F33 Tilbagevendende (periodisk) depression , F34.1 Dysthymi samt F06.32 Organisk depressiv sindslidelse.

² F20.0 Paranoid skizofreni; F20.1 Hebefren skizofreni; F20.2 Kataton skizofreni; F20.3 Udifferentieret skizofreni; F20.4 Post-skizofren depression; F20.5 Skizofren residual-tilstand; F20.6 Simpel skizofreni; F20.8 Skizofreni af anden type; F20.9 Skizofreni UNS



RESULTS: TIMES OF DATA COLLECTION

There must be **at least 14 days between assessments.**

In and out patients diagnosed with a **unipolar depression**

To be assessing own health status:

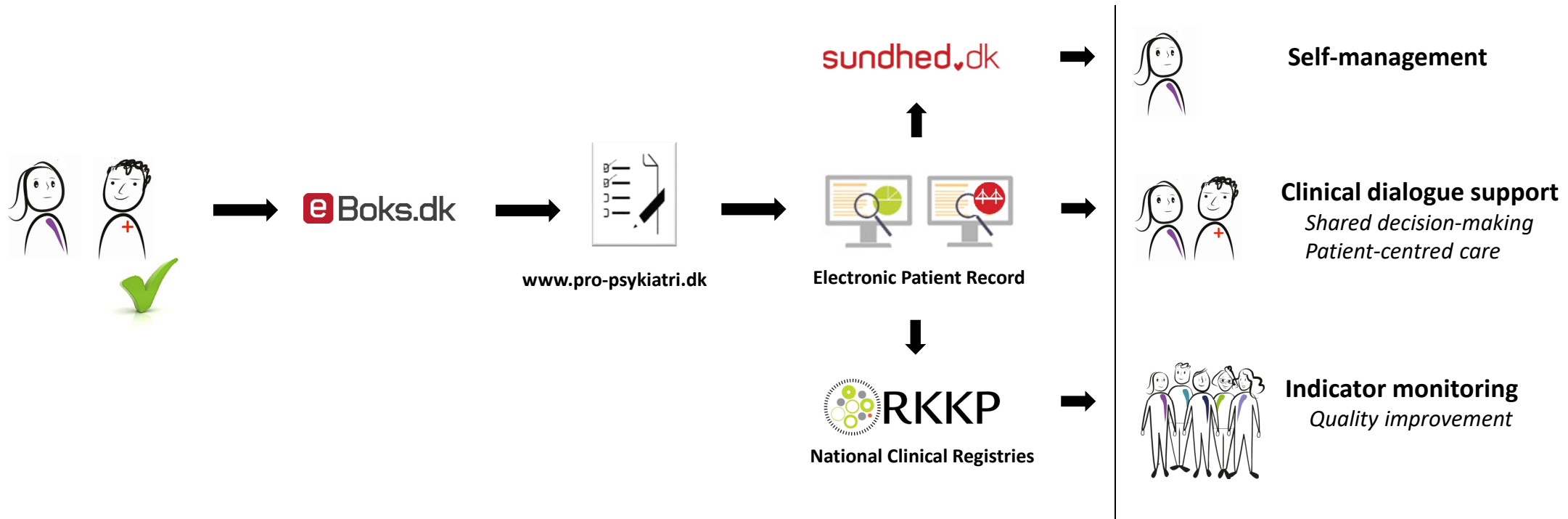
- Before every outpatient visit
- At the admittance and discharge from hospital.

Out patients diagnosed with **skizophrenia**

To be assessing own health status:

- Before every outpatient visit
-

RESULTS: MEASUREMENT CONCEPT



1. Clinical dialogue
Information and consents

2. Invitation
(Outpatient care)

3. Filling in the PROM

4. Data registration
and transfer

5. Use of the PROs

CPR: 9000000011 (ID: 11)

Alder: 118

PRO-psykiatri

	tor 21. jun 18	man 25. jun 18	
Trivsel			
1. Glad og i godt humør	<input type="text"/>	<input type="text"/>	<input type="text"/>
2. Rolig og afslappet	<input type="text"/>	<input type="text"/>	<input type="text"/>
3. Aktiv og energisk	<input type="text"/>	<input type="text"/>	<input type="text"/>
4. Frisk og udhvilet	<input type="text"/>	<input type="text"/>	<input type="text"/>
5. Interessant dagligdag	<input type="text"/>	<input type="text"/>	<input type="text"/>
6. Glæde ved aktiviteter	<input type="text"/>	<input type="text"/>	<input type="text"/>
7. Håb	<input type="text"/>	<input type="text"/>	<input type="text"/>
Mistrivsel			
8. Glemte vigtige ting	<input type="text"/>	<input type="text"/>	<input type="text"/>
9. Koncentration	<input type="text"/>	<input type="text"/>	<input type="text"/>
10. Spisevaner	<input type="text"/>	<input type="text"/>	<input type="text"/>
11. Tanker om døden	<input type="text"/>	<input type="text"/>	<input type="text"/>
12. Selvskade	<input type="text"/>	<input type="text"/>	<input type="text"/>
Funktion			
13. Arbejde/uddannelse	<input type="text"/>	<input type="text"/>	<input type="text"/>
14. Holde hus og hjem	<input type="text"/>	<input type="text"/>	<input type="text"/>
15. Sammen med andre	<input type="text"/>	<input type="text"/>	<input type="text"/>
16. Alene	<input type="text"/>	<input type="text"/>	<input type="text"/>
17. Nære relationer	<input type="text"/>	<input type="text"/>	<input type="text"/>
Helbred			
18. Fysisk helbred	<input type="text"/>	<input type="text"/>	<input type="text"/>
19. Psykisk helbred	<input type="text"/>	<input type="text"/>	<input type="text"/>
Kort besked	Udfyldt: Ja	Udfyldt: Ja	



RESULTS: PRO-BASED INDICATORS



1) WHO's Well-being Index 2) Work and Social Adjustment Scale



RESULTS: PUBLICATION OF INDICATOR RESULTS

Borger **Fagperson** **sundhed.dk** Log på Søg Menu

Forside / Fagperson / Kvalitetsdata / Kliniske kvalitetsdatabaser / Psykiatriske lidelser / **Depression**

Depression

Beskrivelse af Dansk Depressions Database og link til årsrapport.

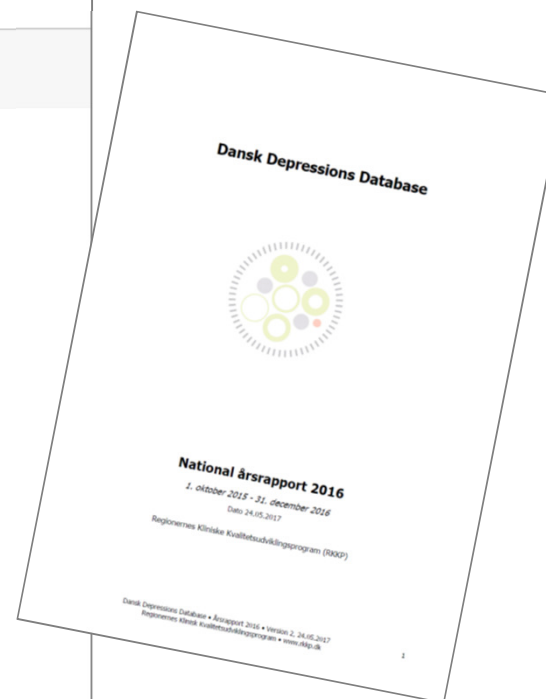
De seneste resultater af kvalitetsmålingerne for behandlingen af depression dækker perioden oktober 2015 - december 2016 og blev offentliggjort i juni 2017. Bemærk, at rapporten er udformet til sundhedsfaglig brug og kan være svært tilgængelig for den almindelige læser.

Resultater for kvaliteten i behandlingen af depression

- [National rapport 2016 \(pdf\)](#)

Vil du vide mere?

- [Gå til RKKP](#)
- [Gå til Lægehåndbogen om depression](#)
- [Hvordan måler vi kvaliteten?](#)



PUBLICATION OF PRO-BASED INDICATOR RESULTS

Recommendations by the Patient Peer Board

1. Diagnose specific results
2. Unit level indicator results
3. Results mirroring the change over time for
 - In patients
 - Out patients
 - The patient pathway
3. Web-based patient-to-patient benchmarking facilities





THANK YOU!

MHSc ♦ PhD ♦ Programme leader

Solvejg Kristensen

E: solkri@rn.dk

M: +45 2462 5669

