

 Rigshospitalet

Patientens stemme kan spille en større rolle



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Om "patienten"

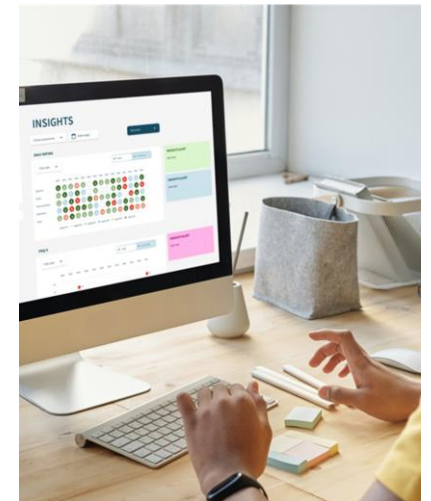
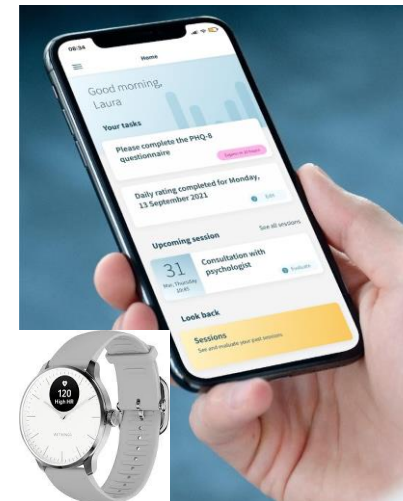
Privat:

- 55 år
- Gift, fire børn (26, 24, 23, 14)
- Passion for at rejse, opleve, spille, dele, dyrke sport
- "Lymfekræftpatient"



Erhverv:

- 30 år som leder i SundhedsIT/IT/Telecom
- DTU, CBS, LBS, Insead
- Monsenso, NetApp, F5, Siemens, Telia, DSC



Mit kræftforløb

- Jul 2023: Symptomstart
- Aug 2023: Udredning
- Sep 2023: DLBCL (high-grade) diagnose
- Sep 2023 – Jan 2024: Høj-dosis kemo
- Mar 2024: Tilbagefald
- Mar 2024: Akutindlæggelse
- Mar 2024: Høst af T-celler og stråling
- Apr 2024: Forberedelseskemo
- Apr 2024: Car-T (Yescarta), CRS og ICANS
- Maj 2024: Udskrevet og rehab træning
- Maj 2024: Komplet remission
- Maj-Sep 2024: Immunoglobulin



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10

Gange kemo

300+

Ture til eller fra
hospitalet

5

Høj-dosis
stråling

20+

Indlæggelses-
dage

60ml

Genmodificerede
T-celler

20+

Udlæggelses-
dage

30+

Læger

0

Sygedagpenge-
udbetaling

0

Videokonferencer

0

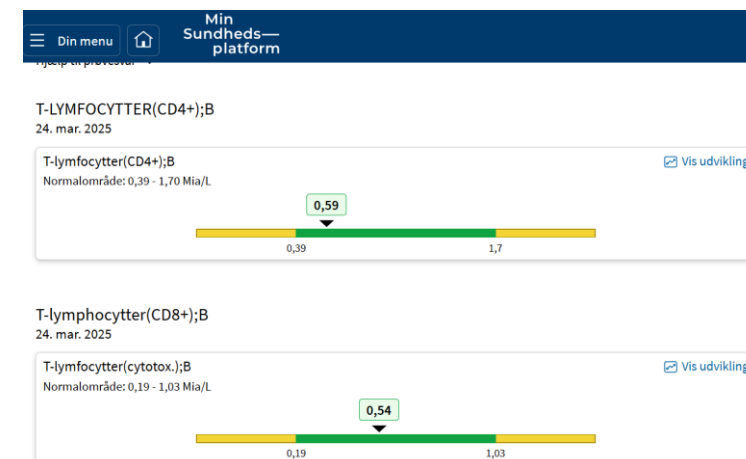
Patientrapporterede
Oplysninger

Uddrag af bivirkninger

- Træt og søvning
- Influenza-ondt i led, muskler og hovede
- Susen for ørene
- Feber op til over 40+
- Skiftende kulde/varme
- Svimmelhed
- Balanceproblemer
- Koncentrationsbesvær
- Hukommelsesbesvær
- Mavesmerter
- Kvalme
- Smags-lugtforstyrrelser
- Høj puls
- Diarré
- Hikke
- Tørhed i munden
- Sår i munden
- Negle/hår/hud
- Impotens
- Hævelse i ansigt/øjne/hals
- Rødme på hals
- Stakåndet
- Rysten på hænder
- Rysten på benene (ved gang)
- Svært ved at tale
- Svært ved at finde ordene
- Diffus/forvirret
- Vægttab (10 kg)
- Neuropati i ben/fødder/fingre
- Mindre birkepollenallergi
- Mindre gråt hår 😊

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Trods...

- Forventning om bivirkninger
- Betragtelige behandlingsomkostninger

...ingen PROMs/opfølgning på:

- Livskvalitet
- Aktivitetsniveau
- Træningsomfang
- Søvn
- Diæt
- Bivirkninger
- Arbejdssituation/produktivitet
- Medicin
- Oplevelse af behandlingsforløb



Dansk Selskab for ledelse i Sundhedsvæsenet

[Om DSS](#) [Kontakt](#) [Søg](#)

[ARTIKLER](#)

[ARRANGEMENTER](#)

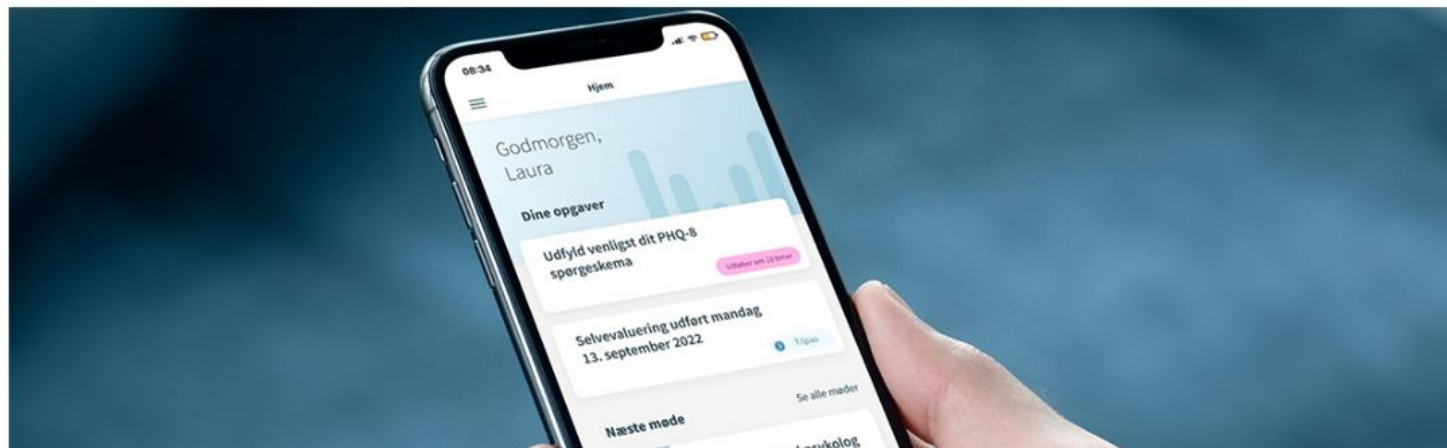
[NYHEDSBREV](#)

[BLIV MEDLEM](#)



Vi har alle teknologiske løsninger, men bruger dem meget lidt

kronik Det blev på flere måder en øjenåbner for it-direktør Thomas Lethenborg at blive patient. Sammen med professor og overlæge Helle Pappot slår han her til lyd for en langt stærkere brugerinvolvering og anvendelse af patientgenererede sundhedsdata.



RESEARCH

Open Access



Feasibility and acceptability of electronic symptom surveillance with clinician feedback using the Patient-Reported Outcomes version of Common Terminology Criteria for Adverse Events (PRO-CTCAE) in Danish prostate cancer patients

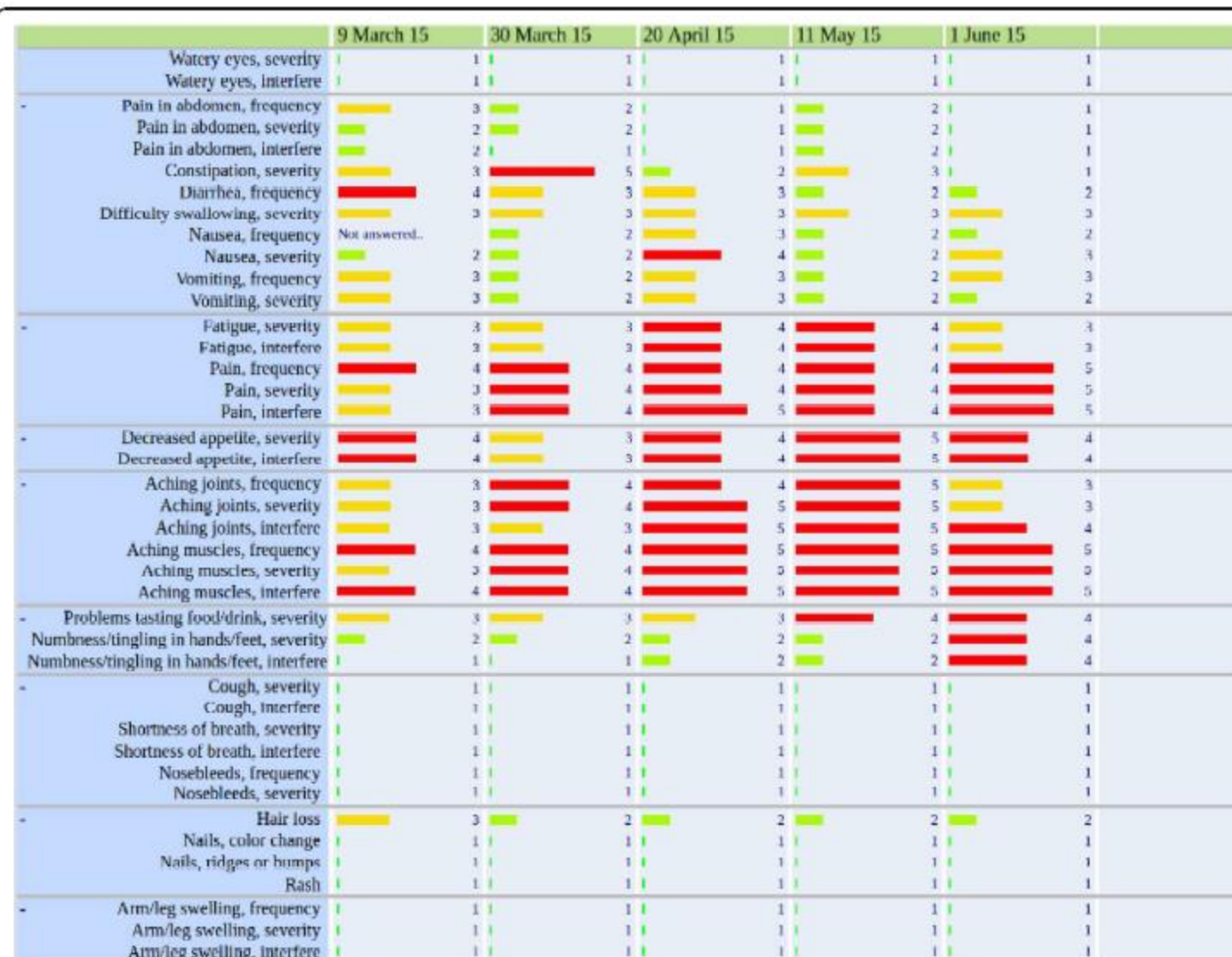
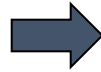


Fig. 2 Overview of patients' reporting available at the oncologists' computers in real-time. Items are presented as bars with different colors (for example, red = very severe, orange = severe, yellow = moderate, light green = mild, dark green = none), lengths and numbers (1–5) for each date of treatment visit. Note: In our study, the symptomatic toxicities were in Danish language, but are here presented in English

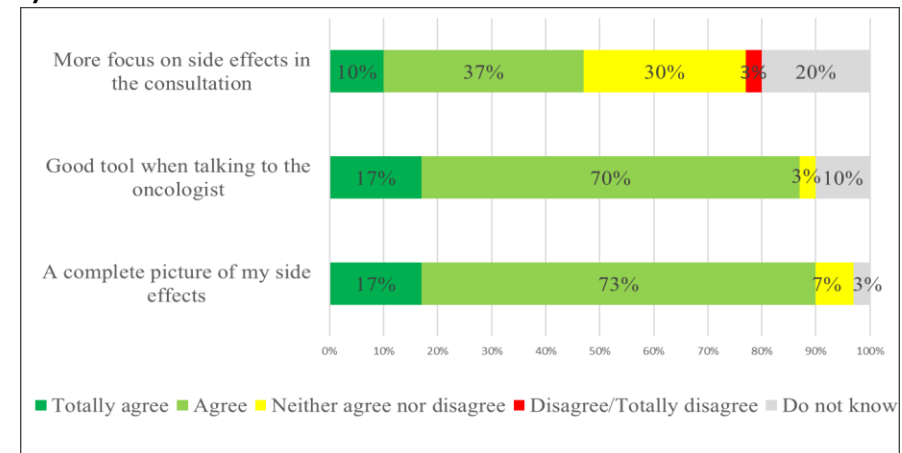
Elektronisk registrering af symptomer under kemoterapi – et feasibility studie af MinKemo blandt prostatakræftpatienter



	9 March 15	30 March 15	20 April 15	11 May 15	1 June 15	
Watery eyes, severity	1	1	1	1	1	1
Watery eyes, interfere	1	1	1	1	1	1
Pain in abdomen, frequency	3	2	1	2	1	1
Pain in abdomen, severity	2	1	1	1	1	1
Pain in abdomen, interfere	2	1	1	1	1	1
Constipation, severity	3	3	2	3	3	1
Diarrhea, frequency	4	3	3	3	3	2
Difficulty swallowing, severity	3	3	3	3	3	3
Nausea, frequency	Not answered	2	3	2	2	2
Nausea, severity	2	2	2	2	2	3
Vomiting, frequency	3	2	3	3	3	3
Vomiting, severity	3	2	3	2	2	2
Fatigue, severity	3	3	4	4	4	3
Fatigue, interfere	3	3	4	4	4	3
Pain, frequency	4	4	4	4	4	5
Pain, severity	3	4	4	4	4	5
Pain, interfere	3	4	4	4	4	5
Decreased appetite, severity	4	3	4	5	4	4
Decreased appetite, interfere	4	3	4	5	4	4
Aching joints, frequency	3	4	4	5	5	3
Aching joints, severity	3	4	5	5	5	3
Aching joints, interfere	3	4	5	5	5	4
Aching muscles, frequency	4	4	5	5	5	5
Aching muscles, severity	5	4	5	5	5	5
Aching muscles, interfere	4	4	5	5	5	5
Problems tasting food/drink, severity	3	3	3	4	4	4
Numbness/tingling in hands/feet, severity	2	2	2	2	2	4
Numbness/tingling in hands/feet, interfere	1	1	1	1	1	1
Cough, severity	1	1	1	1	1	1
Cough, interfere	1	1	1	1	1	1
Shortness of breath, severity	1	1	1	1	1	1
Shortness of breath, interfere	1	1	1	1	1	1
Nosebleeds, frequency	1	1	1	1	1	1
Nosebleeds, severity	1	1	1	1	1	1
Hair loss	3	2	2	2	2	2
Nails, color change	1	1	1	1	1	1
Nails, ridges or bumps	1	1	1	1	1	1
Rash	1	1	1	1	1	1
Arm/leg swelling, frequency	1	1	1	1	1	1
Arm/leg swelling, severity	1	1	1	1	1	1
Arm/leg swelling, interfere	1	1	1	1	1	1

Deltagerprocent: 54/63 prostatakræft-patienter (86 %)

Compliance: 97 %





Contents lists available at ScienceDirect

Computational and Structural Biotechnology Journal

journal homepage: www.elsevier.com/locate/csbj



Mini-review

Patient-reported outcomes used actively in cancer patients undergoing antineoplastic treatment: A mini-review of the Danish landscape

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Pia Krause Møller^g, Ida Marie Lind Rasmussen^h, Trine Lund-Jacobsenⁱ, Dag Rune Stormoen^{a,b},
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^e Danish Cancer Society, Strandboulevarden 49, 2100 Copenhagen, Denmark

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^g Department of Oncology, Odense University Hospital, Denmark

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Table 1

Description of the articles selected in the mini-review, including aims, study type, PRO intervention, and outcomes.

Study	Aim	Study type	PRO-intervention/ Software	Outcomes
Melanoma				
Skovlund et al. [35]	To investigate the potential of using PRO as a dialogue-based tool in consultation with patients with metastatic melanoma.	Prospective non-randomized controlled trial	QLQ-C30/ Ambuflex	HRQoL (FACT-M) Self-efficacy (CBI-B) Patient-Physician interaction (PEPPI) Patient activation (PAM) Reduction of irAEs (CTCAE)
Tolstrup et al. [36]	To investigate the reduction of irAEs and number of reported irAEs, telephone consultations, out-patient visits, days in hospital, days in steroid treatment	Randomized controlled trial	PRO-CTCAE/ Ambuflex	HRQoL (FACT-M, EQ-5D-5 L)
Tolstrup et al. [37]	To examine group differences in HRQoL and associations between irAEs severity and HRQoL.	Randomized controlled trial	PRO-CTCAE/ Ambuflex	Patient Satisfaction Clinician satisfaction (Patient Feedback Form)
Tolstrup et al. [38]	To examine patients' and clinicians' experiences with an eHealth intervention for weekly monitoring of side effects during treatment with immunotherapy.	Mixed methods study	PRO-CTCAE/ Ambuflex	HRQoL (QLQ-C30, QLQ-BLM30) Patient Satisfaction (Patient Feedback Form) HRQoL (QLQ-C30, QLQ-BLM30, HADS)
Bladder				
Tolstrup et al. [39]	Testing how symptoms measured using ePRO in a multimodality app are correlated to HRQoL	Study protocol	PRO-CTCAE/ Mit Sygehus, Journal,	HRQoL (QLQ-C30, QLQ-BLM30) Patient Satisfaction (Patient Feedback Form) HRQoL (QLQ-C30, QLQ-BLM30, HADS)
Taarnhøj et al. [40] 2020	To investigate which PRO-CTCAE symptoms correlate with quality of life domains. Collection of PROs in prospective study during treatment of bladder cancer	Prospective observational study	PRO-CTCAE/ Paper	HRQoL (QLQ-C30, QLQ-BLM30, HADS)
Taarnhøj et al. [41] 2020	To investigate the feasibility of ePRO completion for bladder cancer patients during treatment	Prospective observational study	PRO-CTCAE/ Ambuflex	HRQoL (QLQ-C30, QLQ-BLM30, HADS)
Taarnhøj et al. [42]	To collect ePROs and QoL assessments for bladder cancer patients during chemo- or immunotherapy To determine the rate of hospital admissions and treatment completion	Randomized controlled trial	PRO-CTCAE/ Ambuflex	HRQoL (QLQ-C30, QLQ-BLM30) Treatment completion Hospital admission
Prostate				
Stormoen et al. [43]	Comparing findings with toxicity data from relevant phase 3 registration trials	Sub-analysis of the feasibility trial	PRO-CTCAE/ Ambuflex	Toxicity monitoring compared to the literature
Bæksted et al. [44]	To examine the feasibility, acceptability, and clinical utility of electronic symptom surveillance with clinician feedback	Feasibility study	PRO-CTCAE/ Ambuflex	Patient Satisfaction Clinician satisfaction Technical and clinical barriers and acceptability
Breast				
Bæksted et al. [45]	To explore any differences in the documentation of symptomatic adverse events and the handling of those when patients used ePRO compared to usual care	Randomized controlled trial	PRO-CTCAE/ Ambuflex	Documentation of symptomatic adverse events Prescription of medication Referrals Patient Satisfaction
Bæksted et al. [46]	To examine patient-reported experience measure (PREM) regarding communication and handling of side effects/symptoms	Mixed methods study	Patient Reported Experience Measure (PREM)/ Paper	Patient Satisfaction

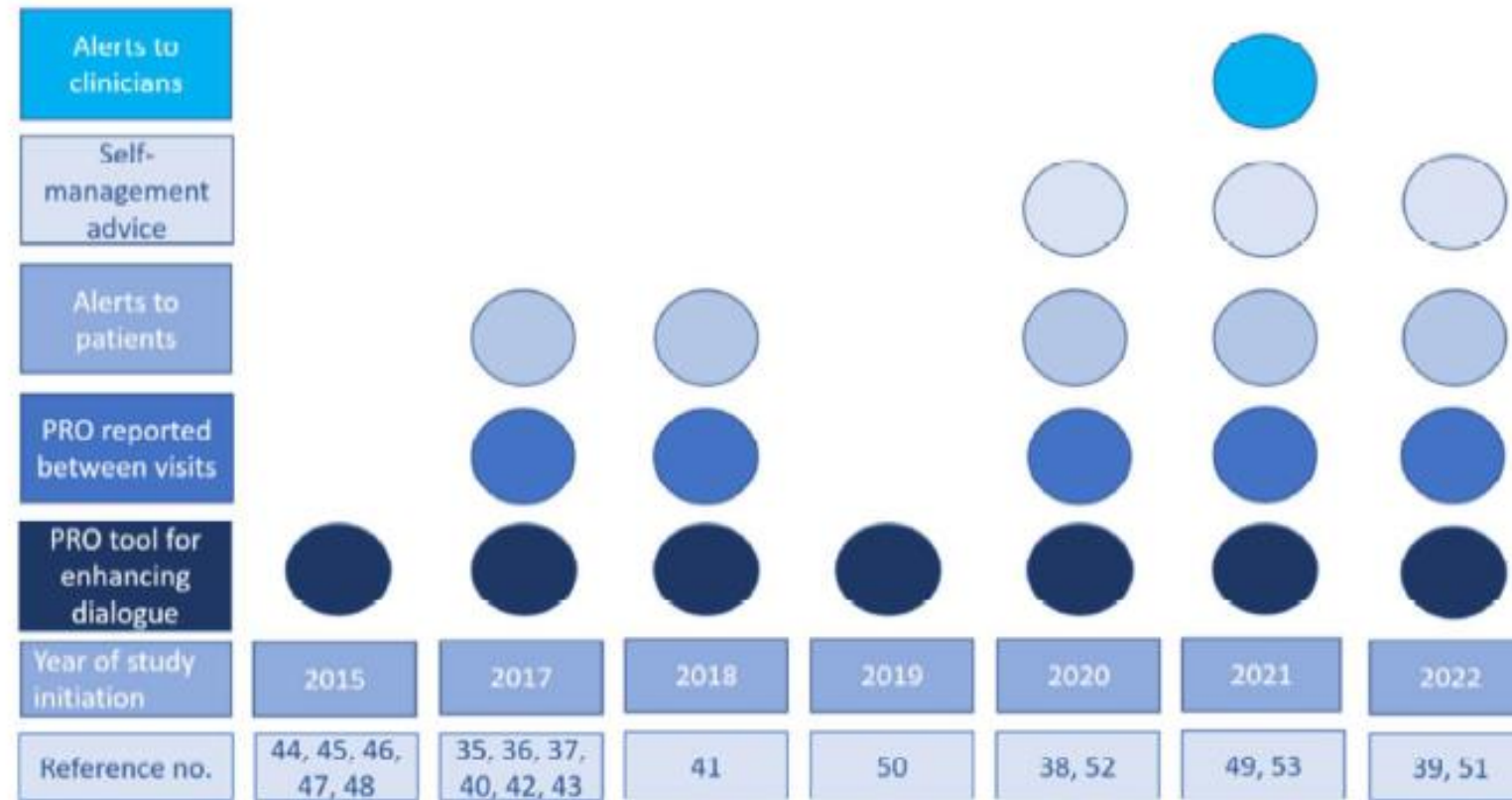


Fig. 2. Change in ways of incorporating PRO across time for 19 scientific reports included in this review (references 47 and 48 represent the same study, where reference 47 is the protocol article and reference 48 includes the results).

Hvem bruger PRO i klinisk praksis i dag?

Eksempler på brug i DK:

- Ålborg fx til prækemo ordination
- Århus fx til kontrol af testikelkræftpatienter
- Odense fx til symptomrapportering og dialog
- Næstved fx til kontrol af brystkræftpatienter

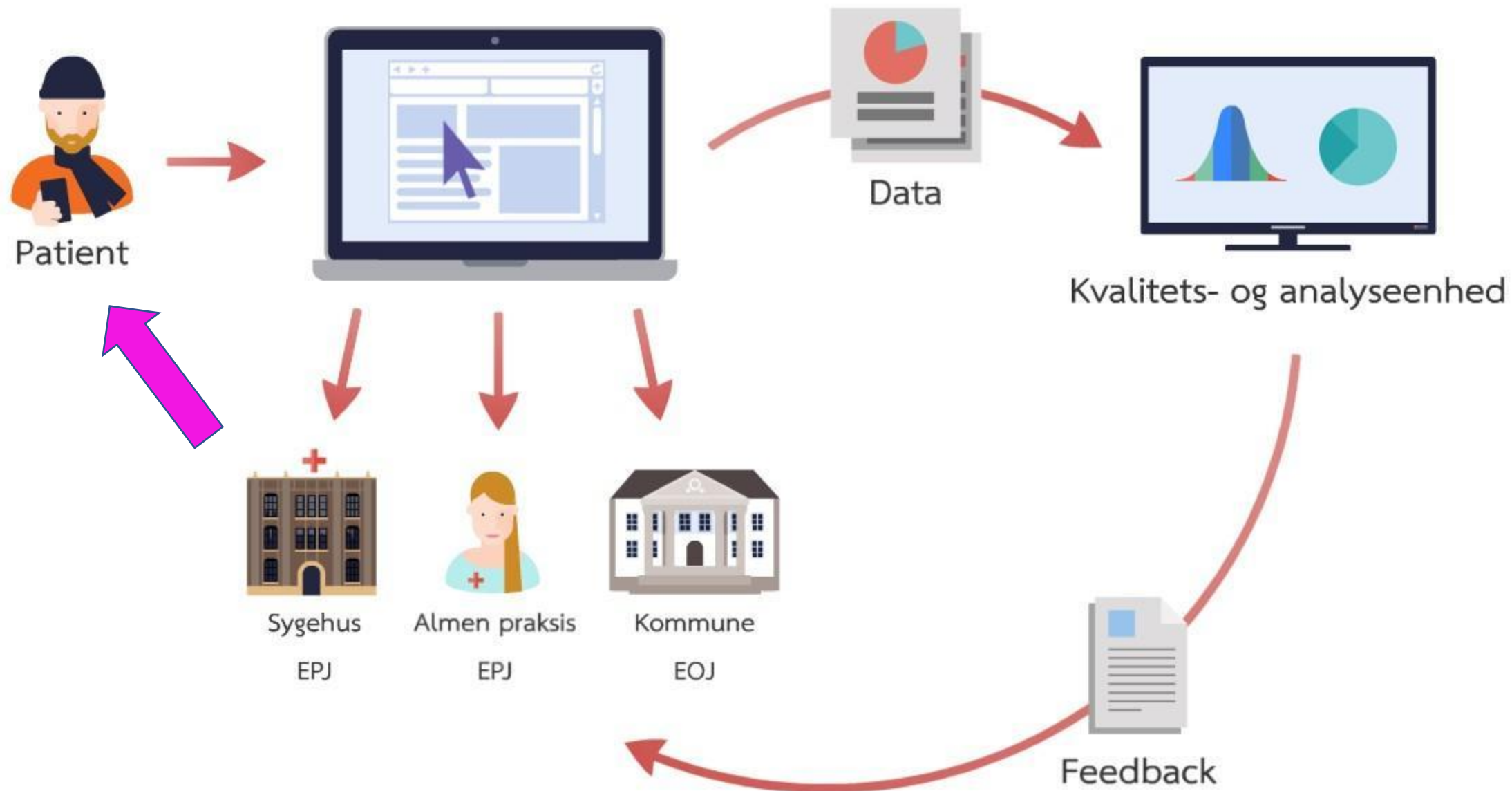
HVAD KAN VI GØRE BEDRE?

PRO til gavn for patienten – self-empowerment

PRO til gavn for behandlingsforløbet – logistik

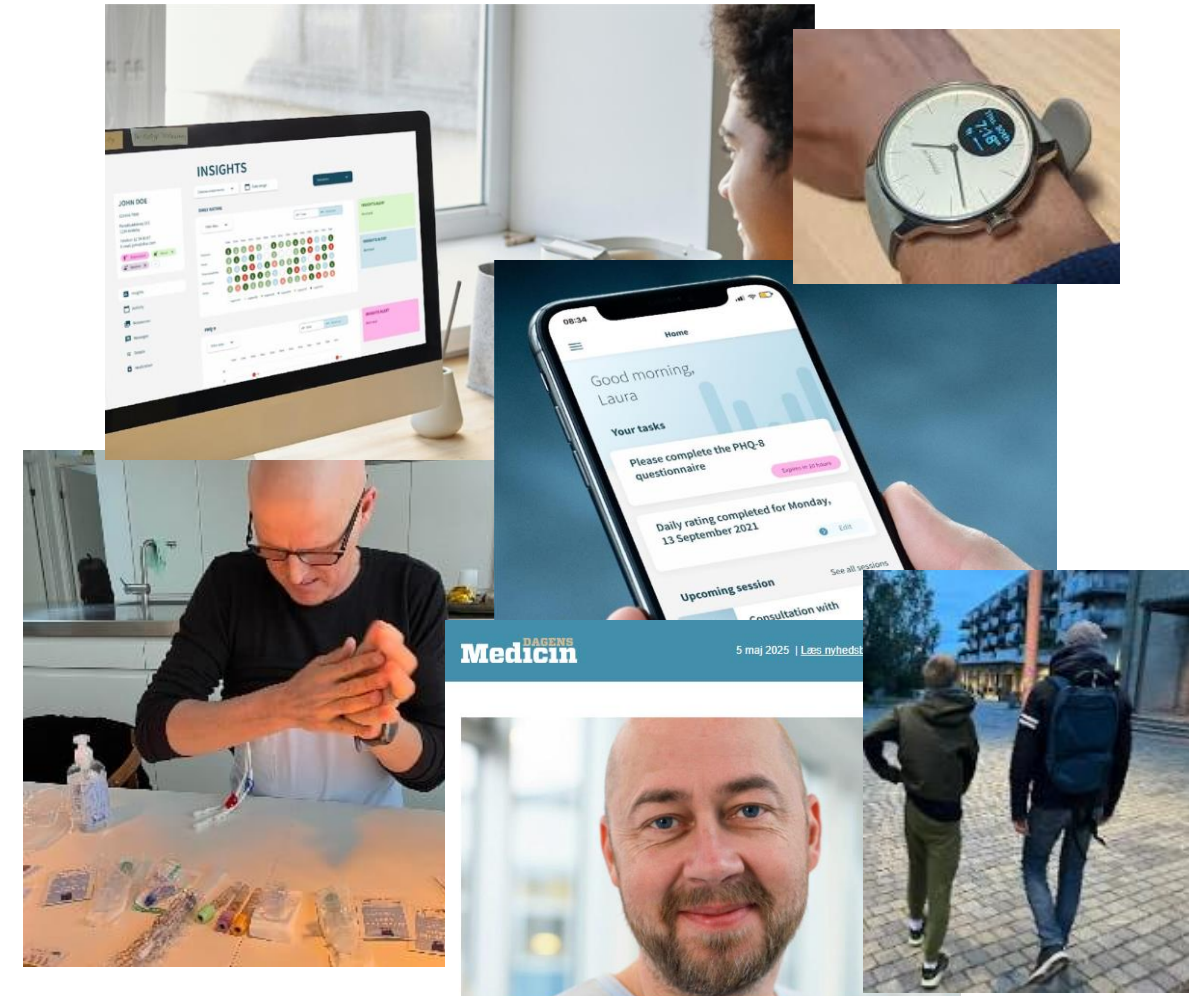
PRO til gavn for samfundet - populationsdata





Opsummering

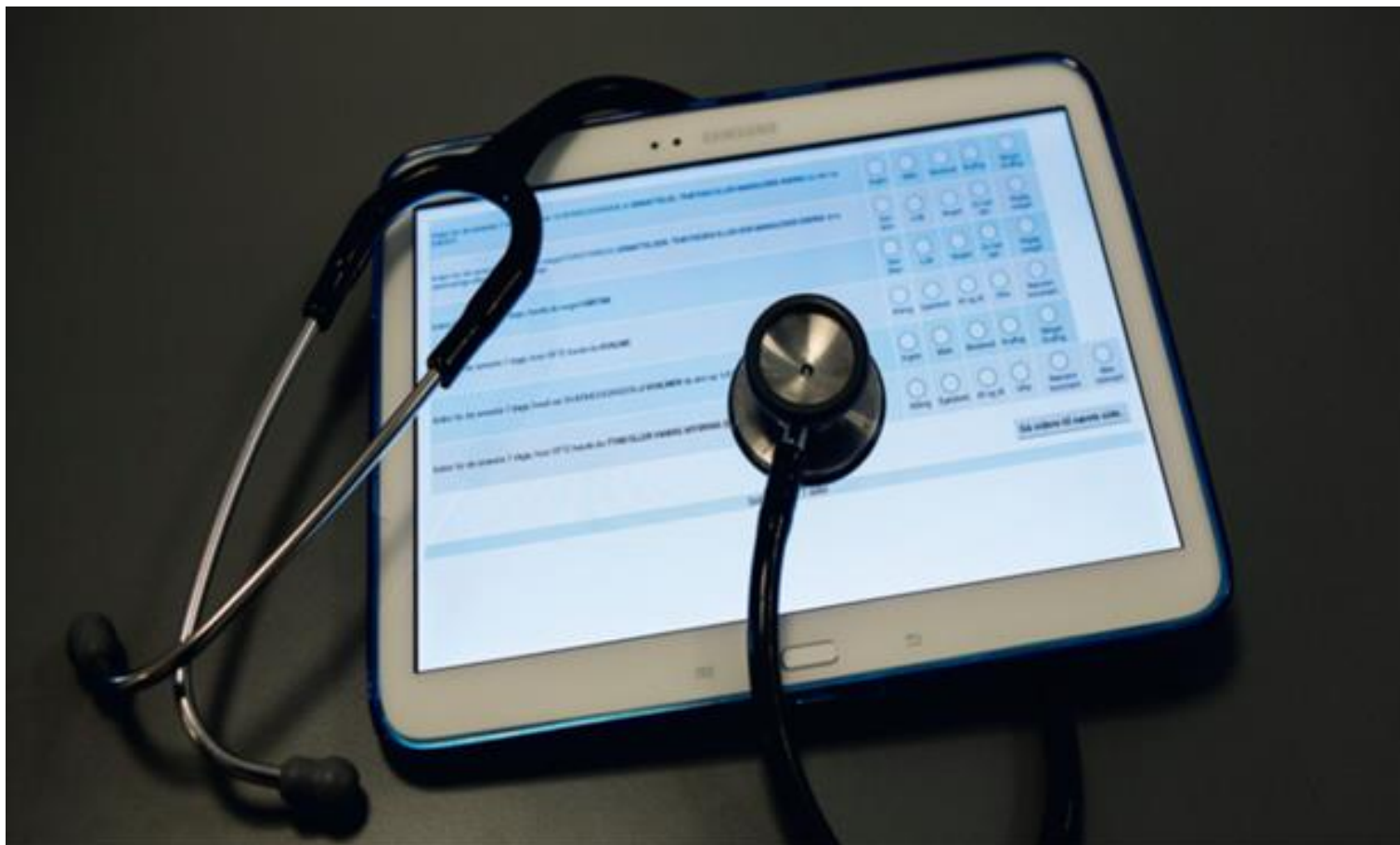
- Patienter kan og vil gerne selv
- Teknologien er der og har været der længe
- Patienter og pårørende kan i højere grad blive ressourcer i behandlingen
- Vigtig viden og indsigter tabes hver dag
- Hvorfor vente?



HÆMATOLOGI

Mange patienter med knoglemarvskræft kan med fordel behandles i eget hjem

Behandlingen af knoglemarvskræft er for mange patienter noget, der foregår over flere år og er forbundet med langvarige behandlingsdage på hospitalet plus transporten til og fra. Et nyt dansk studie viser nu, at mange patienter med fordel kan behandles i eget hjem. Måske kan denne patientgruppe endda selv tage deres medicin, siger overlæge Thomas Lund.



PRO – en ny måde at lytte til patienten

PRO – værdifulde data for patienten, de sundhedsprofessionelle og sundhedsvæsenet