Rekruttering og fastholdelse af deltagere i klinisk forskning

- Erfaringer fra Models of Cancer Care

Mary Jarden
Professor
Afdeling for Blodsygdomme
Centre for Kræft og Organsygdomme
Rigshospitalet

NO CONFLICT OF INTEREST

MODELS OF CANCER CARE **RIGSHOSPITALET**





MODELS OF **CANCER CARE** A COMPREHENSIVE

SYMPTOM SCIENCE RESEARCH PROGRAM Siden 2017



Center for Kræft og Organsygdomme

https://www.rigshospitalet.dk/mcc

Head of Research Program:

Mary Jarden (1,4) Contact: mary.jarden@regionh.dk

Research Management:

Lars Kjeldsen (1,4) Dorthe Overgaard (2) Karin Piil (1,5) Anders Tolver (4) Dorte Nielsen (3.4)

Daily Research Management: Kristina Nørskov (1,4) Iben Husted Nielsen (1,4) Marta Kramer Mikkelsen (1,3,4) Karin Piil (1,5)

Annelise Mortensen (1,4)

- 1. Copenhagen University Hospital
- 2. University College Copenhagen
- 3. Herlev-Gentofte Hospital
- 4. University of Copenhagen
- 5. Aarhus University

Mille Guldager Christiansen (1,4) Maja Pedersen (1,4) Louise Ingerslev Roug (1,4) Trine Lund-Jacobsen (1,4)

Charlotte Grønset (1,4) Cæcilie Borregaard (1)

Mette Schaufuss Engedal (1)















Models of Cancer Care - cancer symptom research

To develop knowledge and new strategies for management of early and late cancer and treatment-related symptoms in partnership with patients and families to achieve better quality of life during and after cancer treatment

The Research Agenda of the Oncology Nursing Society 2019 – 2022 NOVEMBER 2019, VOL. 46, NO. 6 ONCOLOGY NURSING FORUM

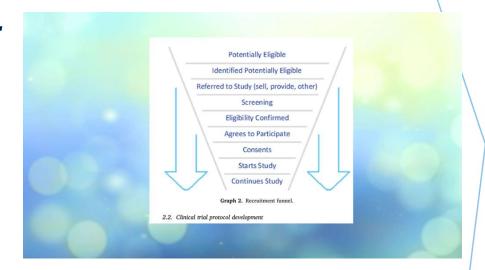
Models of Cancer Project 1: PAS Patient Ambassa Pro Cristina Holmegaard Nørskov Phil Lo	Care Programme Anti-	Cancer Treatment		alet.dk
Project 1: PAS Patient Ambassa Products Of Carroter Ambassa Products of Project 2: PACE-Mobil Engaging Project 2: PACE-Mobil	jekt 9: INTACTatHomo Jise Ingerslev Roug PhD stud Connect trial ePR rojekt 10: Connect trial ePR rojekt 10: Connect trial ePR rojekt 10: Sexu	C.GynOncology		trial
íristina Holmegaard Nørskov Ph <mark>.</mark> Lo	jekt ongerslev Rosson Jise Ingerslev Rosson epper rojekt 10: Connect trial ePR rojekt 10: Connect trial ePR rojekt 10: Connect trial ePR All Sexues of Rosson epperson expenses on the connect trial ePR All Sexues of Rosson expenses on the connect trial ePR rojekt 10: Connect trial ePR All Rosson expenses of trial ePR rojekt 10: Connect trial ePR All Rosson expenses of trial ePR All Rosson expenses of trial ePR All Rosson expenses of trial ePR rojekt 10: Connect trial ePR All Rosson expenses of trial expe	nD student		
Project 2: PACE-Mobil Engaging andomized controlled trial Marta Kramer Mikkelsen PhD Project 3: CARES Addressing Cancer amily nursing and network consultations of the Project 4: Neat-decision Needs assets	rojekt 10: Connect trial of Projekt 10: Connect trial of Projekt 11: SEX_HEM Sexual Projekt 11: SEX_HEM Sexual Nørsko	Health in HSC1	umphoma	a
andomized controlled trial	Mille Gulday HEM Sexu	y PhD postdoc	training in lyllif	
Marta Kramer Mikkelsen PhD	Projekt 11: SEA_Morsko	ania and muscio		
Project 3: CARES Addressing Cancer amily nursing and network consultate arin Piil PhD Project 4: Neat-decision Needs assured Neck Cancer Rehabilitation – a rannelise Mortensen PhD	Kristina Holling	arcope	cancer I patients with pancreation Iy caregiver support zone In caregiver support zone	and relatives
Project 3: CARES Addressing Canc	arojekt 12: Stay st. PhD stu	ute after breast	creation	; cancer di
amily nursing and network consultat	Charlotte Grøne	-better life of the dent	tionts with pancis	LOUV.
ann Pili PhD	ickt 13: Believe Ph	D studer.	l battern	in hematology
Project 4: Neat-decision Needs ass				
nd Neck Cancer Rehabilitation – a r	and 14: FAM-PAC	en PhD posici	ly caregivo.	natology
nnelise Mortensen PhD	Trine Lund-Jacobs And Project 14: FAM-PAC Project 14: FAM-PAC Marta Kramer Mikkelse	Tane Patient and Issue	ad of life in he	Alliars
Project 5: FAMCARE Family Ambas	sador 45. Support	PhD posice	nication at a	
pen Husted Nielsen PhD student	Project 13. Nielsell	cionate Commu	uscT	
pen Husted Nielsen PhD student Project 6: PACE-AL Patient Activation Project 7 and Project 8: Simply Cacuring follow-up Care—a feasibility to Maja Pedersen PhD student	Iben I is	ompassion student	nication at end of life in he in patients after HSCT after PhD, Giulia Local with Henry	atudent, Karin
roject 6: PACE-AL Patient Activation	on throug Project 16. Project	d Myrra	" - 1 UCg	telli PhD stus
Mary Jarden PhD Project 7 and Project 8: Simply Ca uring follow-up <u>Care</u> – a feasibility to Maja Pedersen PhD student	Cæcille	ptoms and MScH	wer PhD, Giulia Lo	
roject 7 and Project 8: Simply Ca	re e-PRO Project 17: 531	Engedar .	rs Tolver with Hen	natological Malignand
uring follow-up <u>Care</u> – a feasibility tr	ial & a rand Mette Schar	motom Databass		
laja Pede <mark>rsen PhD student</mark>	project 18: Sy	den PhD		

Participants and Interventions

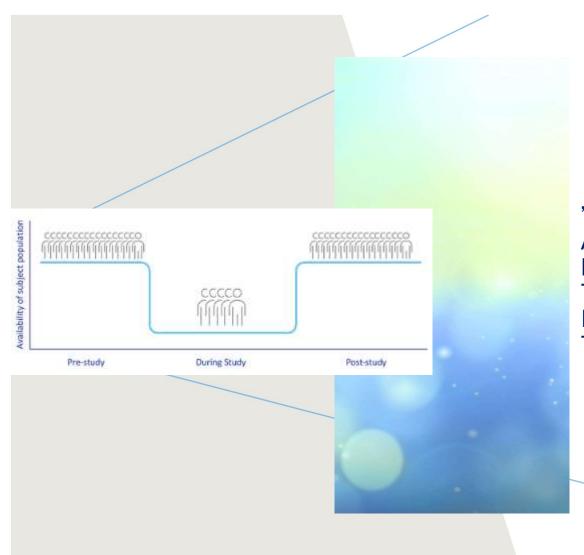
Patients (diagnoses) Family Caregivers	Hematological malignancies (adults (9) & children (1))	Non- pharmacologica I interventions	Exercise and strength training & consultations (3)
	Pancreatic, biliary tract and non-small cell		Family and network counseling (2)
	lung cancer (>65) (2)		Diagnosis-specific IT-based decision tool (1)
	High grade glioma (1)		ePRO in patient consultations (2)
	Head and neck cancers (1)		APP and symptom tracker (1)
	Ovarian (1) and breast cancer (1)		Peer-to-peer ambassador support in patients and caregivers (2)
	()		Home chemotherapy in children (1)
	High grade glioma (1)		Sexual health intervention (1)
	Hematological malignancies (4)		Compassionte communication (1)
			Patient and caregiver support zone (1)
	() number of projects		Late effects clinic (1)
			() number of projects

RECRUITMENT AND RETENTION

MODELS OF CANCER CARE



Bogin V. Lasagna's law: A dish best served early. Contemporary Clinical Trials Communications Vol 22, April 2022



"THE INCIDENCE OF PATIENT AVAILABILITY SHARPLY DECREASES WHEN A CLINICAL TRIAL BEGINS AND RETURNS TO ITS ORIGINAL LEVEL AS SOON AS THE TRIAL IS COMPLETE"

LASAGNE'S LAW 1970

Bogin V. Lasagna's law: A dish best served early. Contemporary Clinical Trials Communications Vol 22, April 2022

CHALLENGES

MODELS OF CANCER CARE



STRATEGIES

MODELS OF CANCER CARE



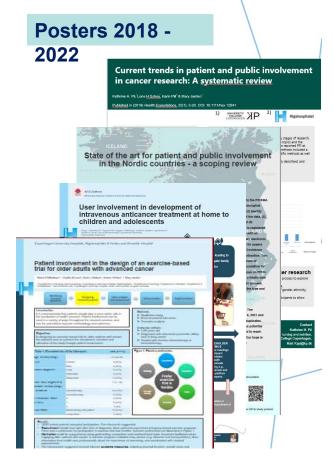
Patient and Public Involvement

PhD course 2022



Publications 2018 - 2022





Sum up ACHIEVING BETTER RECRUITMENT AND RETENTION











Bottlenecks Roadblocks

Monitoring

Strategies

Engaging people

MODELS OF CANCER CARE – A COMPREHENSIVE SYMPTOM SCIENCE RESEARCH PROGRAM

https://www.rigshospitalet.dk/mcc



THANK YOU

MODELS OF CANCER CARE
RIGSHOSPITALET