



Patientskole for mænd med prostatakraft der opstarter medicinsk
kastrationsbehandling

Baggrund

- Projektsygeplejerske på Urinvejskirurgisk afdeling Holstebro – Gødstrup siden 2008
- 2014-2019: Ph.d. projekt om hjemmetræning til mænd med prostatakkræft i medicinsk kastrationsbehandling

Henvendelse fra Canada

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- HOW TO REGISTER
- THE ADT BOOK
- HEAR FROM PROGRAM PARTICIPANTS
- PATIENT VIDEOS
- REFERENCE TABLES FROM THE ADT BOOK
- OTHER RESOURCES
- BLOG ON RECENT ADT LITERATURE
- CONTACT

REGISTER NOW: CANADA

REGISTER NOW: UK / EU

The Androgen Deprivation Therapy Educational Program

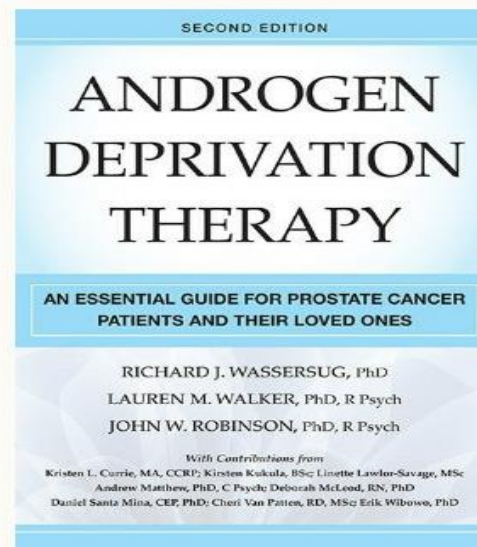
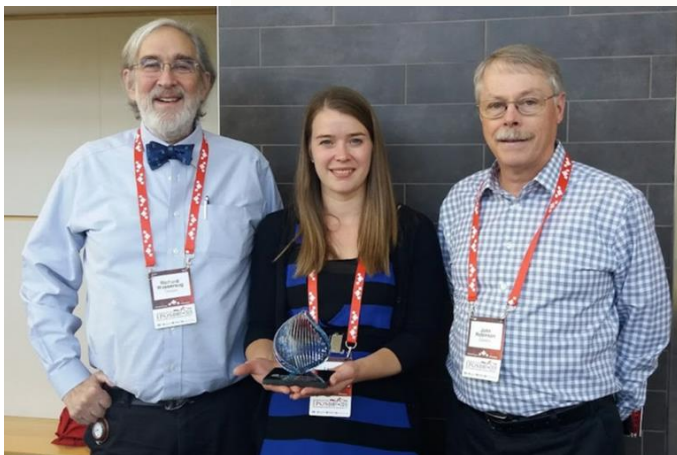
The ADT Educational Program team is the recipient of the 2019 Canadian Association of Psychosocial Oncology (CAPO) Innovation Award, conferred for “the development of quality improvement and innovative clinical, educational, or organizational initiatives aimed at enhancing the performance of psychosocial cancer care or cancer prevention”.

What is the ADT Program?

Androgen Deprivation Therapy (ADT) is an effective treatment for prostate cancer, but has many side effects. The ADT Educational Program is a free 1.5-hour session during which patients and loved ones will:

- Learn about side effects of ADT
- Learn how to manage side effects
- Complete goal setting exercises to teach you how to manage ADT side effects

The program is designed for both patients and their partners or loved ones. Patients who are not partnered are encouraged to invite a family member or close friend to attend the session with them.



Hvilke bivirkninger er der?

Hede-svedeture

Større bryster

Træthed

Manglende sexlyst

Svagere knogler

Mindre kønsorganer

Tab af muskelmasse

Tab af rejsningsevne

Vægtøgning

Mere følelsesladet

**Risiko for diabetes og hjerte-
karsygdomme**

Depression

Tab af kropsbehåring

Ændret eller nedsat hukommelse

Baggrund



Urologic Oncology: Seminars and Original Investigations 31 (2013) 1098–1105

UROLOGIC
ONCOLOGY

Original article

Patients and partners lack knowledge of androgen deprivation therapy side effects

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Abstract

Objective: Androgen deprivation therapy (ADT) is the primary treatment for advanced prostate cancer (CaP). There is growing evidence that ADT negatively affects men's psychosocial well-being (e.g., causing sexual dysfunction, bodily feminization) and physical health (e.g., increasing the risk of osteoporosis and metabolic syndrome). Although strategies for managing the majority of side effects exist, it is not clear that patients are benefiting from this knowledge.

Methods: Seventy-nine newly prescribed ADT patients and 54 of their partners were given a checklist of various common and uncommon ADT side effects. They were asked to indicate the drug side effects that they had heard of or anticipated.

Results: Both patients and their partners were poorly informed about the side effects of luteinizing hormone-releasing hormone (LHRH) agonists used for ADT. More than 70% did not know that anemia, memory problems, loss of body hair, and depression can occur following treatment. Over 50% were unaware of significant potential side effects such as reduced muscle mass, osteoporosis, increased fracture risk, weight gain, genital shrinkage, and gynecomastia. Concurrently, more than 20% mistakenly anticipated dizziness and itching.

Conclusion: The lack of awareness of ADT side effects may partially explain why ADT currently results in significant decreases in the quality of life of patients and their partners. Patients uninformed about side effects do not engage in behaviors to prevent or reduce the risk of adverse effects. Improved efforts to educate patients about treatment side effects and coping strategies may result in improved psychosocial and physical health for CaP patients undergoing ADT. Crown Copyright © 2013 Published by Elsevier Inc. All rights reserved.

Baggrund

- Patienterne husker ikke den information, der gives i amb/klinik
- Personalet informerer kun om en brøkdel af bivirkninger (frygt for information overload)
- Patienter ville ønske, at de vidste mere = var bedre forberedte


Baggrund

Forbedring i patientens tro på egne evner til at håndtere bivirkninger til medicinsk kastrationsbehandling

Original Article

An Educational Program to Help Patients Manage Androgen Deprivation Therapy Side Effects: Feasibility, Acceptability, and Preliminary Outcomes

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sagepub.com/journals-permissions
DOI: 10.1177/1557988319898991
journals.sagepub.com/home/jmh
SAGE

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Abstract

Androgen deprivation therapy (ADT), a common treatment for prostate cancer, is associated with physical, psychological, and sexual side effects that reduce patients' quality of life. The authors designed an educational program to prepare patients for managing these side effects. This paper describes an implementation model for national dissemination of the program, testing its feasibility and acceptability at the institutional and patient level. Postprogram changes in patients' self-efficacy to manage side effects and side effect bother are also explored. Patients on or anticipating ADT enrolled in the educational program. Pre and post intervention questionnaires measured patient satisfaction with the program, side effect bother, and self-efficacy to manage ADT side effects. The ADT Educational Program was deemed feasible and acceptable. Five of six targeted sites successfully launched the program with sufficient patient enrolment.

Patient attendees were highly satisfied. Self-efficacy, bother, and use of management strategies were interrelated. Lower bother was associated with increased self-efficacy and more use of management strategies, and increased bother was associated with lower self-efficacy and less use of management strategies. Based on pre-post scores, improvements in patients' self-efficacy to manage ADT side effects were also observed. Results demonstrate that this brief educational program is feasible and acceptable to patients and cancer care institutions. The program appears to promote self-efficacy and the uptake of ADT management strategies for ADT side effects. The results of this study support the program implementation and suggest that improvements in self-efficacy after program participation may help patients adapt to ADT side effects.

Keywords

androgen deprivation therapy, prostate cancer, patient education, side effects management, self-efficacy, side effect bother



...“115 videos (77%) contained potentially misinformative and/or biased content within the video or comments section with a total reach of > 6 million viewers”.

available at www.sciencedirect.com
journal homepage: www.europeanurology.com



Platinum Priority – Brief Correspondence

Editorial by Benedito Carneiro and Don S. Dizon on pp. 568–569 of this issue

Dissemination of Misinformative and Biased Information about Prostate Cancer on YouTube

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Article info

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Dissemination
Misinformation

Abstract

YouTube is a social media platform with more than 1 billion users and >600 000 videos about prostate cancer. Two small studies examined the quality of prostate cancer videos on YouTube, but did not use validated instruments, examine user interactions, or characterize the spread of misinformation. We performed the largest, most comprehensive examination of prostate cancer information on YouTube to date, including the first 150 videos on screening and treatment. We used the validated DISCERN quality criteria for consumer health information and the Patient Education Materials Assessment Tool, and compared results for user engagement. The videos in our sample had up to 1.3 million views (average 45 223) and the overall quality of information was moderate. More videos described benefits (75%) than harms (53%), and only 50% promoted shared decision-making as recommended in current guidelines. Only 54% of the videos defined medical terms and few provided summaries or references. There was a significant negative correlation between scientific quality and viewer engagement (views/month $p = 0.004$; thumbs up/views $p = 0.015$). The comments section under

neath some videos contained advertising and peer-to-peer medical advice. A total of 115 videos (77%) contained potentially misinformative and/or biased content within the video or comments section, with a total reach of >6 million viewers.

Patient summary: Many popular YouTube videos about prostate cancer contained biased or poor-quality information. A greater number of views and thumbs up on YouTube does not mean that the information is trustworthy.

Evidens



How Are Patients With Prostate Cancer Managing Androgen Deprivation Therapy Side Effects?

Erik Wibowo,¹ Richard J. Wassersug,² John W. Robinson,^{3,4} Andrew Matthew,^{5,6}
Deborah McLeod,^{7,8} Lauren M. Walker^{3,4}

Abstract

Little is known about the way in which patients with prostate cancer manage androgen deprivation therapy side effects. Study participants (n = 91) were surveyed after attending a short educational program designed to help patients manage androgen deprivation therapy side effects. Patients are willing to use a wide array of management strategies with a general preference for behavioral and lifestyle modification over pharmacologic interventions.

Background: Androgen deprivation therapy (ADT) for prostate cancer has numerous side effects. Clinical guidelines for side effect management exist; however, these are not always integrated into routine practice. What remains undocumented and therefore the objective of this study, is to describe patients' willingness to employ established strategies. **Patients and Methods:** Study participants were 91 men who had attended an educational program (ie, attend a class plus read a book), designed to prepare patients for managing ADT side effects. Three months later, patients completed the ADT Management Strategies Inventory, to determine use of strategies. Descriptive analyses were conducted. **Results:** At the time of class attendance, the average ADT duration was 133 days. Patient preferences for a variety of strategies for each side effect are presented. Highlights include: a high degree (> 65%) of patients using or willing to use exercise to manage medical risks and physical side effects. Forty percent of patients continued to engage in non-penetrative sexual activities, despite reduced sexual desire and erectile dysfunction. **Conclusions:** When educated about options, patients are willing to use a wide array of ADT management strategies. Consequently, health care providers should ensure that patients know about side effects and how to manage them. Exercise appears to be the single best strategy to encourage, because it is helpful in managing many side effects (eg, weight gain, muscle weakening, fatigue) and reducing medical risks of ADT (eg, cardiovascular disease, type II diabetes, and osteoporosis). A general trend was patient's preference for behavioral and lifestyle strategies over pharmacologic interventions.

Udbredelsen af patientskoler i DK 2019

Patienter i
kastrations-
behandling:
Aalborg og
Herlev (Feel+
program)

feel+

[Startside](#) | [Om Feel+](#) | [Om hormonbehandling](#) | [MyFeel+ Velvære Tracker](#)

Få styr på dit liv

Velkommen til *Feel+*® programmet for mænd, der er i hormonbehandling mod prostatakræft. Programmet består af et hæfte, som du kan få hos din læge, samt MyFeel+ Velvære Trackeren, som du kan downloade på denne hjemmeside.

Feel+ programmet er beregnet til at støtte og opmuntre dig til at komme gang med at træne, spise sundt, tale om prostatakræft og forbedre dit velvære. Deltagelse i Feel+ programmet kan hjælpe dig til at komme i bedre form, føle dig sundere og gladere og samtidig hjælpe dig med at være forberedt på de virkninger, som hormonbehandling har på sygdommen og din krop.

MyFeel+ VELVÆRE TRACKEREN
Få det bedste ud af din hormon behandling

Kost
Spis varieret af årstidens frugt og grønt og

Del denne side [f](#) [t](#) [in](#) [✉](#)

» Værdien af at tale: Social kontakt er godt for dit humør. Del din smerte med andre og sæt ord på dine følelser. Stil spørgsmål og hør nyt om sygdommen og behandling

Patientskole i forbindelse med
antihormonel behandling
(medicinsk kastrationsbehandling)
på grund af prostatakræft



Hvem

- Patienter der pga. metastaserende c. prostata skal opstarte kastrationsbehandling
- Patienter henvist til kurativ strålebehandling skal IKKE henvises

Indhold

Modificeret og kontraktbundet udgave af det canadiske program

2½ time

60 min undervisning om:

- kastrationsbehandling - virkning og bivirkninger
- håndtering af bivirkninger via konkrete handleplaner og målsætninger
- Præsentation af kommunal kræftrehabilitering
- Præsentation af NEXT træningskoncept og digital forløbsguide

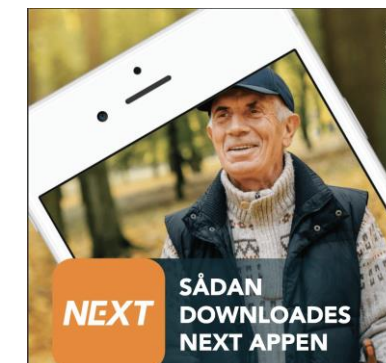
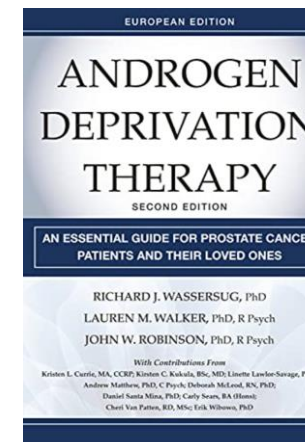
3 x 20 min oplæg ved:

- Kræftrådgivningen
- PROPA
- FC Prostata

Indhold

Materiale til udlevering:

- Bogen Ernæring og fysisk aktivitet ved prostatakræft
- Skriftlig materiale vedrørende NEXT træningskonceptet
- Bogen Androgen deprivation therapy (til dem der kan læse og forstå lægmands engelsk)
- Samtykkeerklæring til spørgeskemaundersøgelse (evaluering og effekt af undervisning)



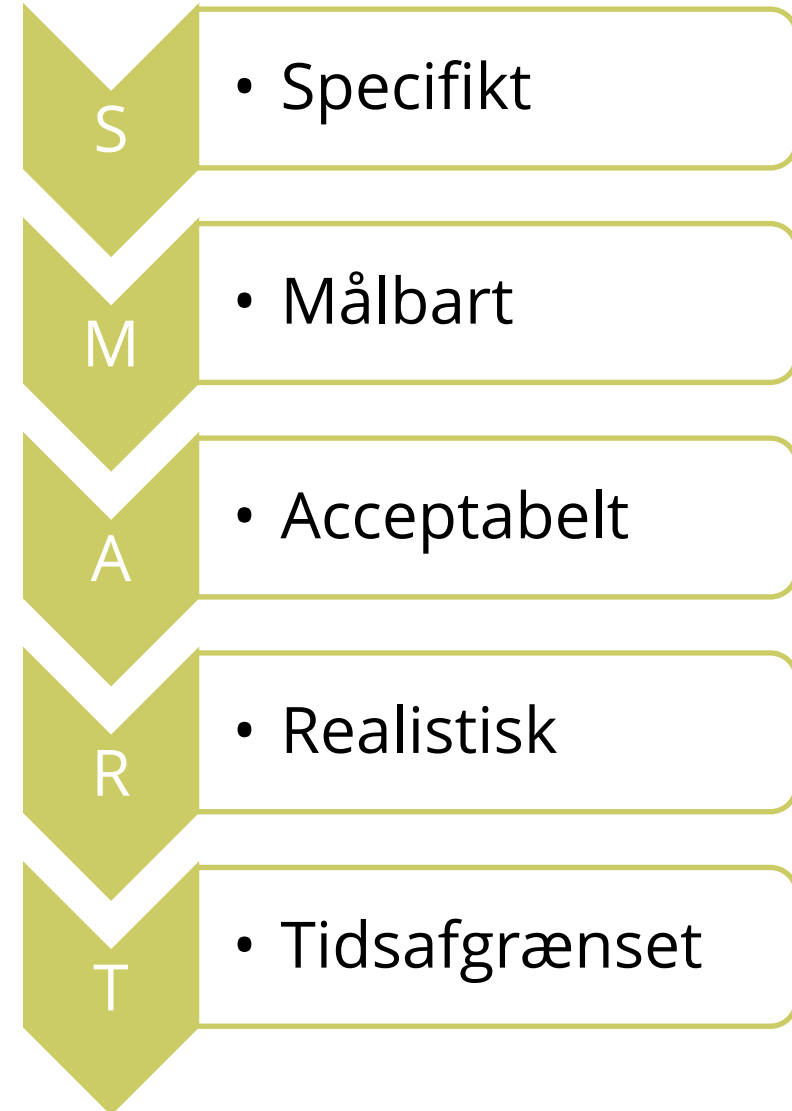
Indhold

30 min arbejde på klassen:

Patienter og pårørende arbejder selv med at udpege områder i deres liv, der er vigtigt for dem at ændre eller booste for at håndtere bivirkninger (handleplaner og målsætninger)

Livsstilsændringer

Den motiverende samtale



Indhold

30 min arbejde på klassen:

Henvisning til kræftrehabilitering drøftes individuelt og sendes efter ønske.

Der indhentes samtykke til videregivelse af journaloplysninger.



Indhold

Umiddelbart efter deltagelse:

Deltagerne tilsendes feed back spørgeskema via eBoks

6-8 uger efter deltagelse:

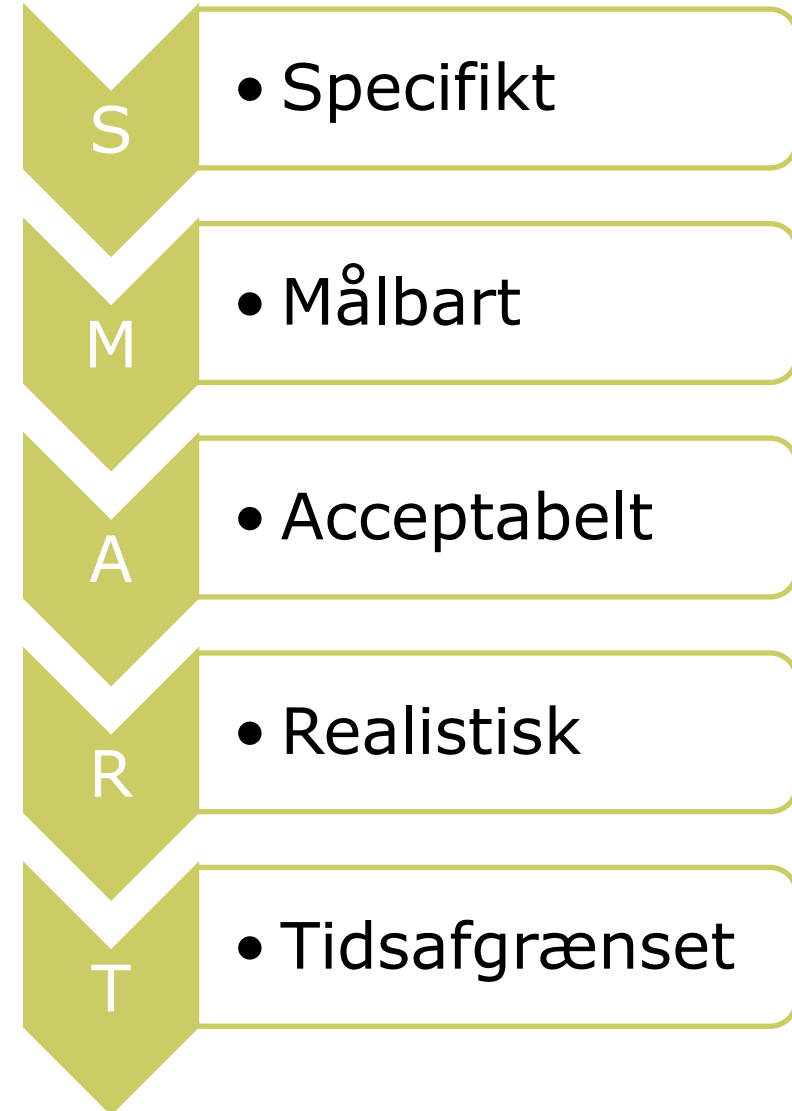
30 min telefonkonsultation:

Opfølgning på handleplaner, målsætninger, kræftrehabilitering og tilbud fra Kræftrådgivningen, PROPA og FC Prostata

Spørgeskema med de spørgsmål, der drøftes under telefonkonsultation

Hvordan skolen adskiller sig fra andre patientskoler:

30 min. arbejde på klassen med handleplaner og målsætninger



Hvordan skolen adskiller sig fra andre patientskoler:

- Henvisning til kræftrehabilitering
- Oplæg ved Kræftrådgivningen, PROPA og FC Prostata

Opslagsværk: Emento-appen

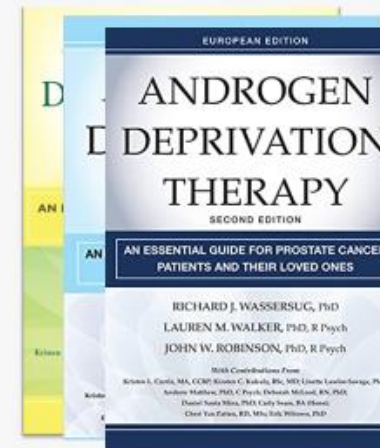
Download Emento-appen via App store eller Play butik

Opret dig som bruger med NemID og 4-cifret adgangskode



emento
DIGITAL FORLØBSGUIDE

Den engelske ADT bog:



Hvordan medicinsk kastration virker

Hvornår indgår medicinsk kastration

Fysiske ændringer

Motion

Ernæring

Indflydelse på parforhold

Psykologiske ændringer

Aktiviteter til egenhåndtering

- Publiiseret af Springer med over 50.000 solgte kopier
- Støttet af de canadiske og europæiske urologiske foreninger

Deltagere indtil 23.8.2022

26 patienter.
Udeblivelser på alle hold trods
indkaldelse

Næsten alle medbringer partner

Aldersfordeling:
Ældste deltager 85 år
Yngste deltager 51 år

16 har besvaret evalueringsskema
14 har besvaret opfølgningsskema

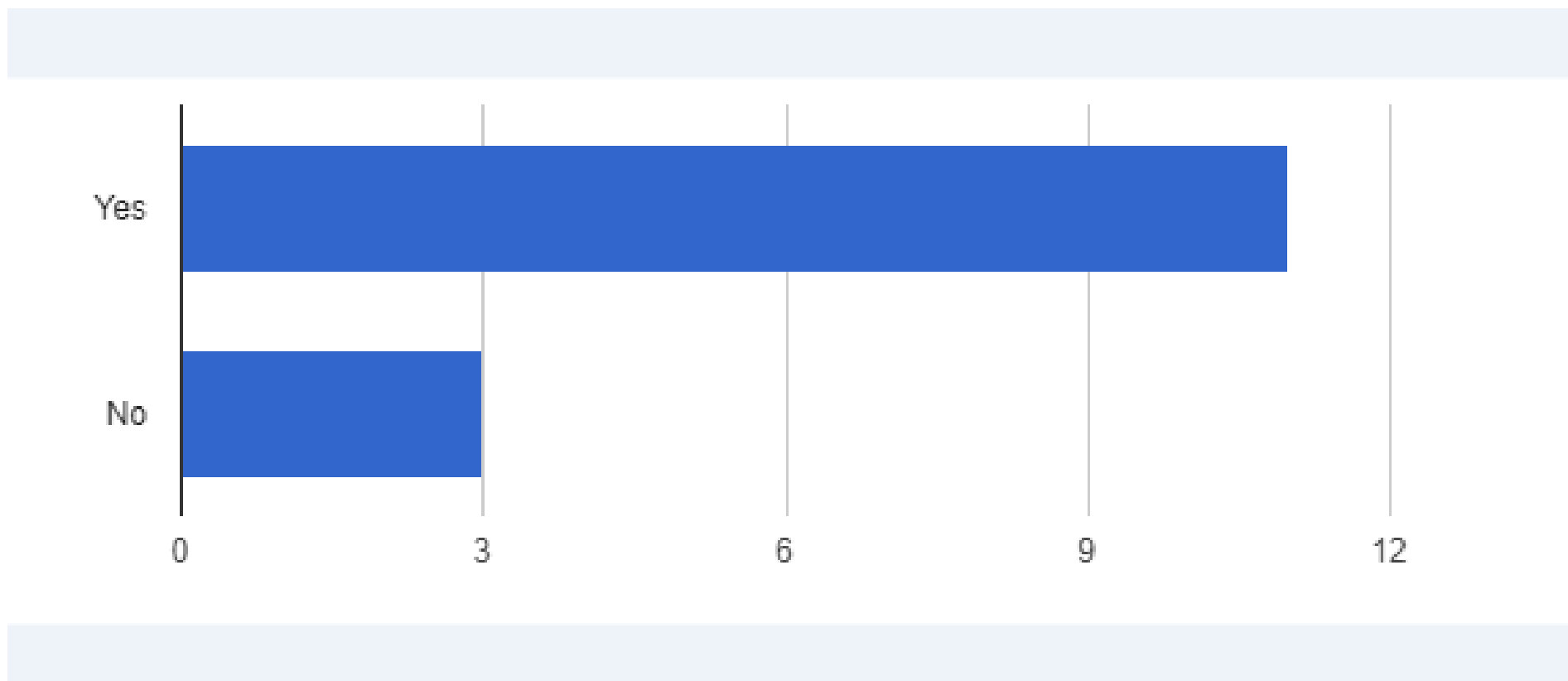


Mest nyttigt indhold og emner

Bivirkninger og forebyggelse af dem

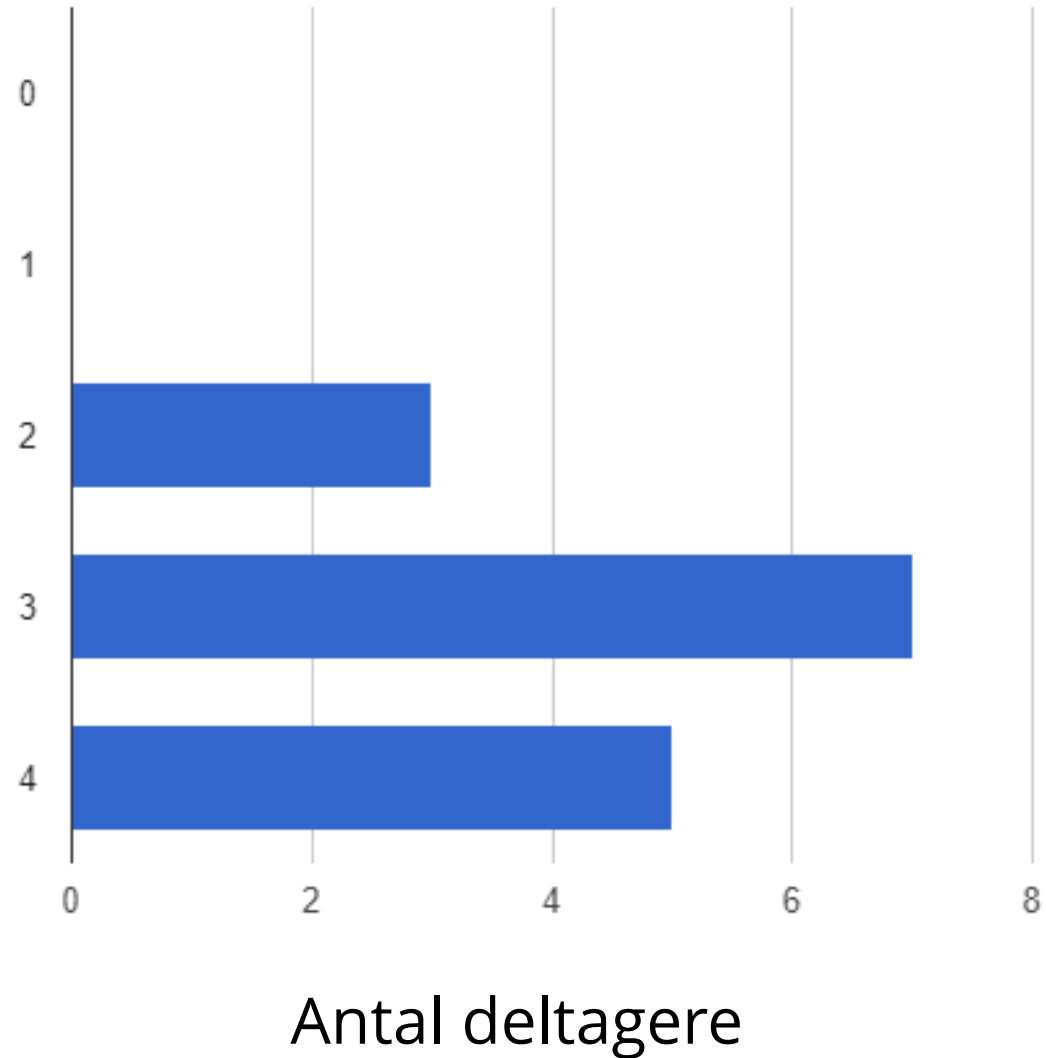
Hvilke bivirkninger er der?	
Hede-svedeture	Større bryster
Træthed	Manglende sexlyst
Svagere knogler	Mindre kønsorganer
Tab af muskelmasse	Tab af rejsningsevne
Vægtøgning	Mere følelsesladet
Risiko for diabetes og hjerte-karsygdomme	Depression
Tab af kropsbehåring	Ændret eller nedsat hukommelse

Deltagere der opsatte målsætninger for håndtering af bivirkninger



Tilfredshed

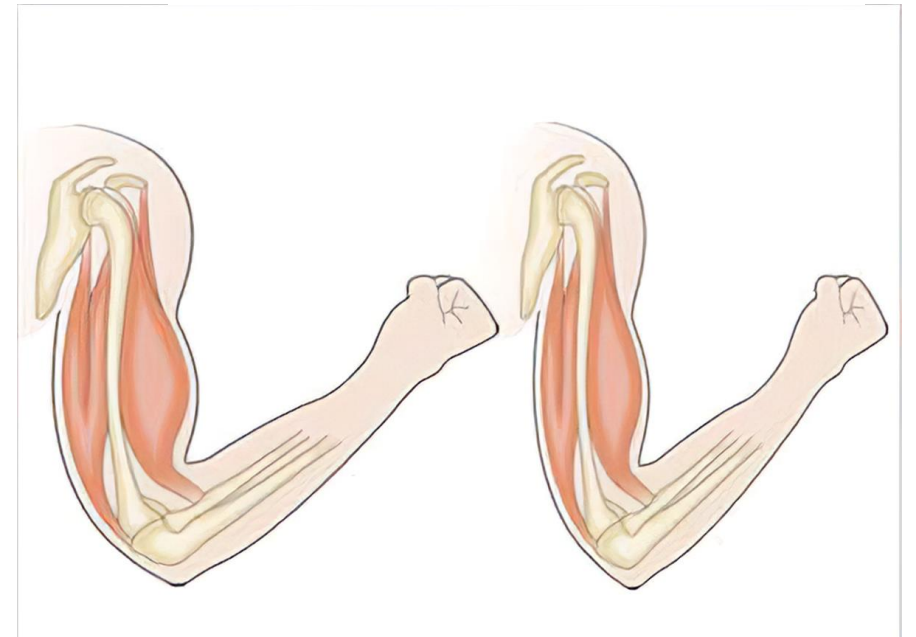
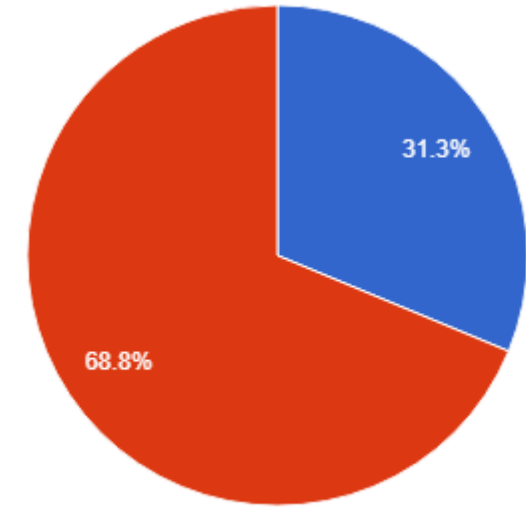
Rating 0-4



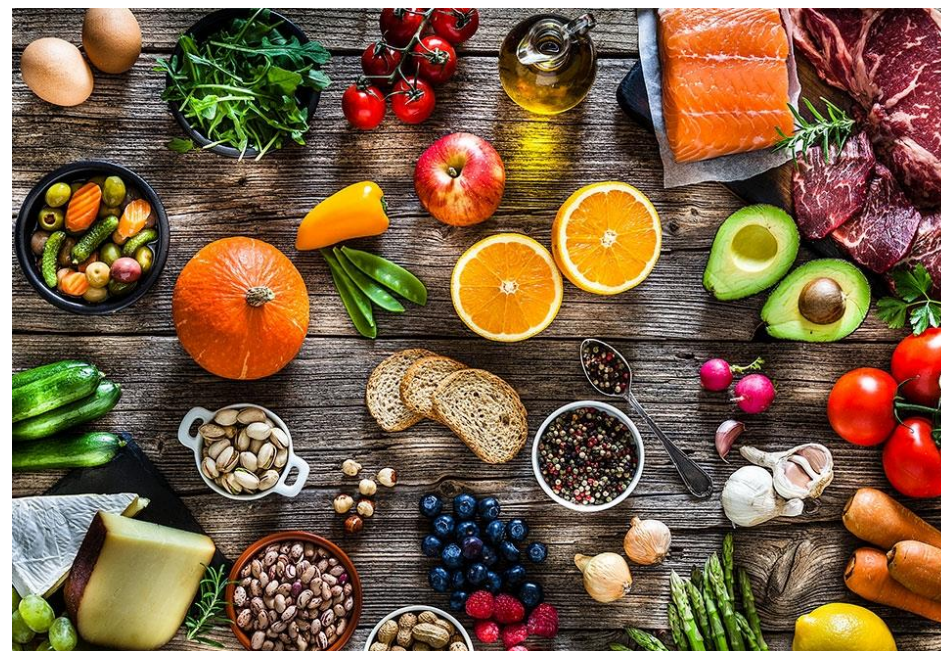
Bekymringer

5/16 = 31,3% blev bekymret
over bivirkninger

Tab af muskelmasse og fysisk
form oftest bekymrende



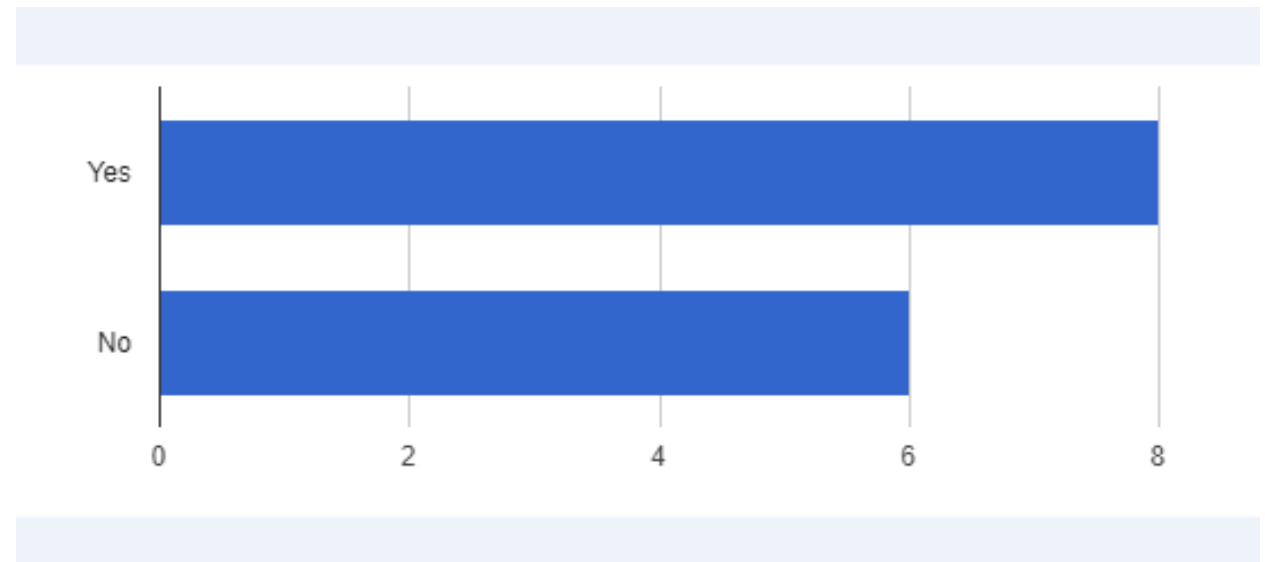
Målsætninger



Telefonopfølgning efter 6-8 uger

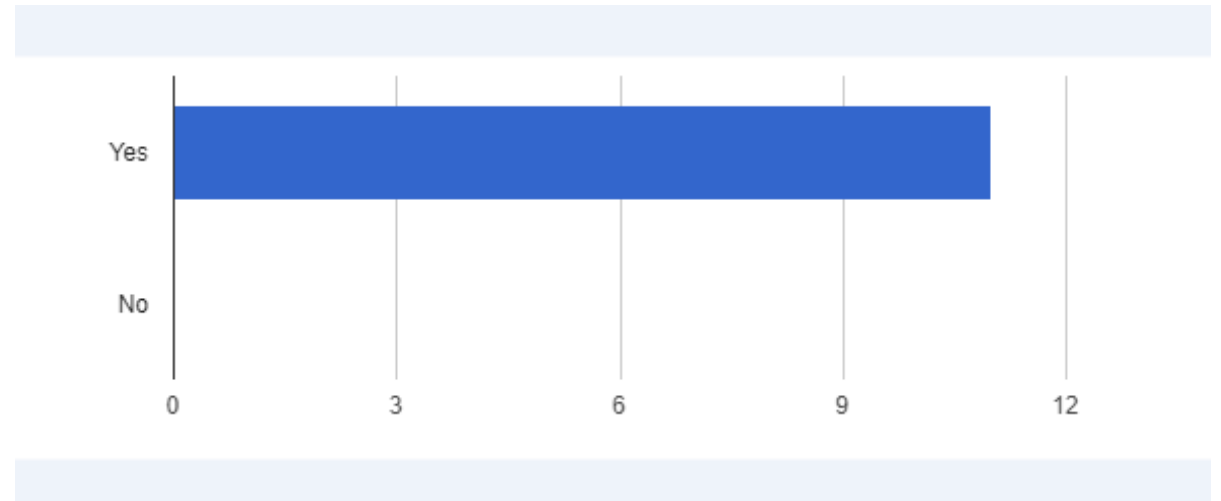
14 har besvaret spørgeskema

8 har takket ja til kommunal kræftrehabilitering



Telefonopfølgning efter 6-8 uger

11 har fulgt selvvalgte målsætninger



Henvendelser til andre organisationer

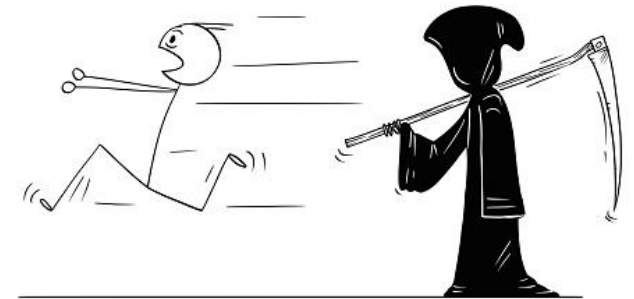
FC prostata	Kræftrådgivningen	PROPA
1	2 (forbehold for mørketal)	3

Take home message

Programmet er for kompakt

Reklameindslag kan reduceres til at blive præsenteret af fagpersonale

Død ved power point tirsdag kl. 16-18.30!



Kontakt

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