

Developing a healthcare service for patients experiencing late effects from cancer – a new role for community pharmacy?

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Core**Main supervisor**

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Project lead

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professional
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Cancer Society

Co-supervisors**Patient perspective and involvement:**

Line Hjøllund Pedersen, specialist consultant
Science to Society, Danish Cancer Society

Intervention design and implementation:

Assistant professor Ramune Jacobsen
UCPH, Department of Pharmacy.

Associate Professor Afonso M. Cavaco,
Department of Social Pharmacy, University of
Lisboa. Possible stay abroad.

**Linda Aagaard Thomsen, Head of Rare
Diseases, Danish Medicines Council**
Previously Head of Science to Society & Core
Facilities at the Danish Cancer Society

Professional sparring group**Late effects of cancer:**

Professor Christoffer Johansen
Professor in Late effects of Cancer, Chief
physician at CASTLE research unit for late
effects, Rigshospitalet











Representing cancer survivors:

Marianne Nord Hansen, chair of the Late
Effects Group

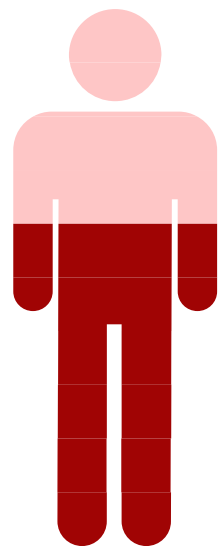
Malene Lindgaard Kloster, consultant, Patient
Support and Voluntary Activities, Danish Cancer
Society

Supervisors and confirmed sparring group participants

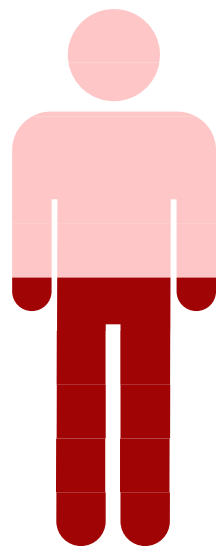
Late effects from cancer include, but are not restricted to:

-  Scar tissue formation
-  Osteoporosis
-  Diarrhea and constipation
-  Incontinence
-  Dry mucous membranes
-  Sexual dysfunction
-  Dryness of mouth
-  Problems with eating and swallowing
-  Sleep problems
-  Fatigue

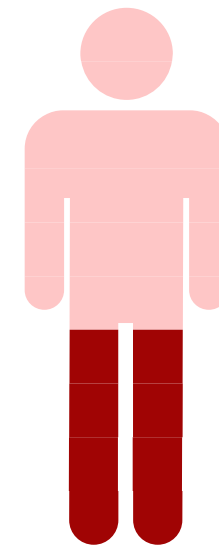
More than **50 %** of cancer survivors experience late effects of the disease and/or the treatment hereof



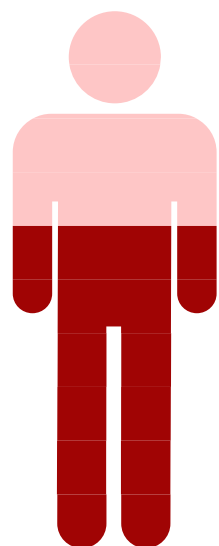
60 % of the patients experienced *obstacles* in their everyday life 2.5 years after the diagnosis



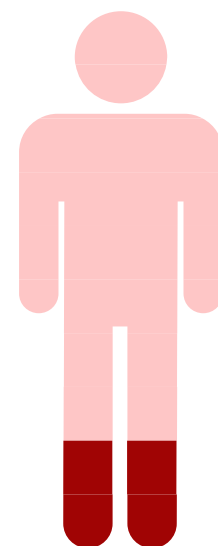
50% of the patients had no or very little *knowledge* about symptoms of late effects



30% of the patients did not know *whom to contact* with signs of late effects



60% of the patients expressed *needs for support* and help with physical and mental challenges or late effects, practical help or counselling on work-related or financial issues



25 % felt that they carried a responsibility, which they considered could have been carried more appropriately by health care personnel

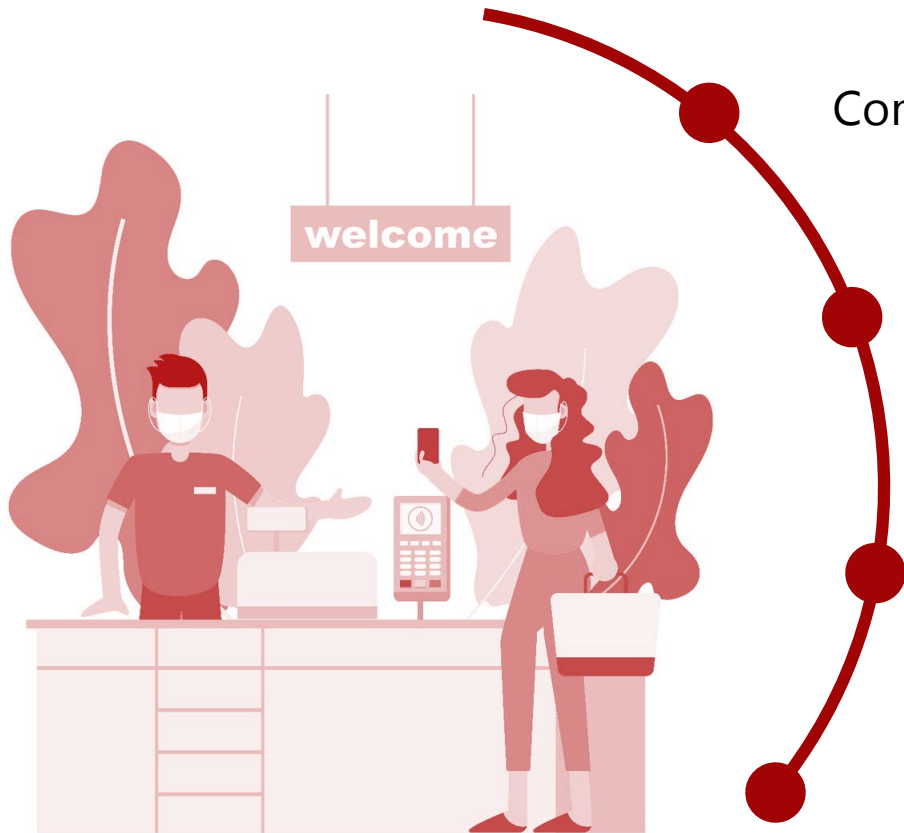
Patients' needs and experiences about the follow up process from treatment

What's the problem?

- LEC can arise long after a cancer follow-up program is over
- Cancer patients and survivors are at a risk of "falling between chairs" when referred from secondary to primary sector
- Municipalities offer rehabilitation and other services for LEC, but the content and quantity vary and require referral from doctor (GP or hospital)



Help from pharmacy might be part of the solution:



Community pharmacies have local anchoring and easy access

Pharmacies in Denmark are in contact with 94 % of the Danish population each year

Pharmacy staff is already in contact with socially disadvantaged groups

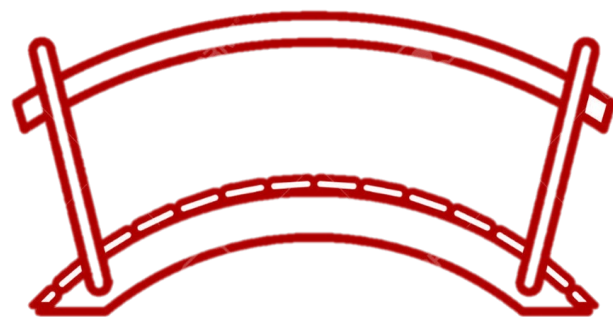
Pharmacy staff is highly educated

Aim

- To develop a *cross-sectional* and *interdisciplinary* health care service (HCS) targeting late effects of cancer, which includes participation of community pharmacies



Cancer survivor
experiencing late
effects of cancer



Community pharmacy



Health care system



Phase 1 - development

Data collections

- Questionnaire: community pharmacies and cancer survivors
 - Actor analysis
- Focus group interviews with patients



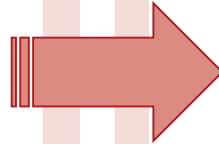
Cross-sectional cross-professional workshop

4D model

- Describe results from pre-studies
 - Dreams for the intervention
 - Define the intervention content
- Deliver the pilot version of the intervention



Ready for phase 2



Feasibility

Phase 2 – testing

Realist evaluation



Driver diagram



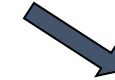
Test

Improvement model
PDSA



Data

Feedback



Evaluation



Prototype



Other data
collections

Interviews
Focus groups
Meetings



Phase 1 - development

Data collections

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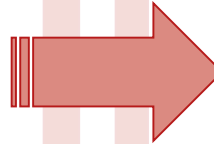
Cross-sectional cross-professional workshop

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Feasibility

Phase 2 – testing

Realist evaluation



Driver diagram



Test

Improvement model
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Data

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Evaluation



Prototype



Other data
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Questionnaires – method and content

Cancer survivors:

Sent electronically all 611 cancer patients in the Danish Cancer Society's patient panel in August 2021

Items (19 questions):

- 1) Needs of, preferences for, experiences with counselling on LEC
- 2) Attitudes towards involving community pharmacies in LEC counselling

Pharmacy staff:

Sent to all 452 pharmacies and pharmacy branches in Denmark

Items: (84 questions):

- 1) Staff's self-perceived knowledge and educational needs
- 2) Barriers when counseling cancer patients
- 3) Interests in participating in education regarding cancer



Olsen N.L et al, 2022 Cancer survivors' views on involving community pharmacies in an intervention on late effects of cancer. *International Journal of Integrated Care* 22(S3):45 DOI: doi.org/10.5334/ijic.ICIC22045

CONFERENCE ABSTRACT

Cancer survivors' views on involving community pharmacies in an intervention on late effects of cancer

22nd International Conference on Integrated Care, Odense, Denmark, 23-25 May 2022

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1: Danish Cancer Society, Denmark

Introduction: More than 50 % of all cancer survivors experience one or more late effects following the cancer disease and treatment. Current models of follow-up care are inadequate in meeting the needs of many cancer survivors, leading to unresolved late effects. Community pharmacists are the most accessible healthcare professionals for the public, and evidence-based pharmacy services focusing on patient-centred care have shown to improve health and quality of life and lower mortality rates. Thus, it is relevant to explore if and how community pharmacies can contribute to an intervention targeting late effects of cancer.

Aim and method: The study explored cancer survivors' views on involving community pharmacies in managing late effects of cancer. A questionnaire was developed based on validated questionnaires, altering selected questions to fit the study purpose. The questionnaire was pilot tested on cancer patients in four Danish community pharmacies and sent electronically through Survey Xact to all 611 cancer patients in the Danish Cancer Society's patient panel in August 2021. Quantitative data were analysed using descriptive statistics, and qualitative comments were analysed using content analysis.



Article

Community Pharmacy Staff's Knowledge, Educational Needs, and Barriers Related to Counseling Cancer Patients and Cancer Survivors in Denmark

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Abstract: Objective: The study aimed to determine Danish community pharmacy staff's knowledge, educational needs, and barriers when communicating with cancer patients/survivors. Furthermore, the study investigated whether pharmacy staff was interested in participating in education about cancer. Methods: A cross-sectional questionnaire survey was conducted among community pharmacy staff (pharmacists and pharmaconomists) in Denmark. Descriptive and bivariate (t-test and chi-square) statistics were used to analyze the data. Results: In total, 134 staff members responded to the questionnaire. Their self-reported knowledge of cancer-related topics was between 'very little knowledge' and 'some knowledge'. The most well-known topics concerned risk factors for cancer and side effects from cancer treatments. The importance of learning more about the same topics was rated between 'important' and 'very important'. The largest barriers identified in counseling cancer patients/survivors were a lack of knowledge about cancer, a focus on healthcare problems other than cancer, and a traditional view of community pharmacies as a place to pick up medication. Pharmacy staff expressed interest in participating in educational programs about cancer treatment (91.0%), communication with cancer patients (88.1%), and late effects of cancer (93.3%). Conclusion: Community pharmacy staff show interest in participating in education regarding cancer, but need more knowledge to properly counsel cancer patients and survivors at the community pharmacies. This important barrier should be addressed in future educational programs for community pharmacy staff.

Keywords: cancer; educational needs; barriers; community pharmacy; pharmacists; pharmaconomists; Denmark

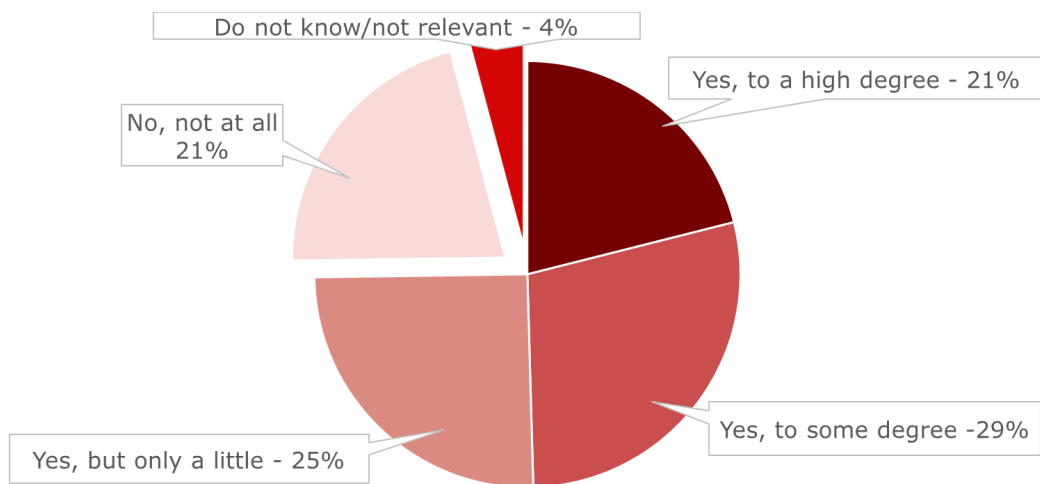
Citation: Buhl, C.; Olsen, N.L.; Nørgaard, L.S.; Thomsen, L.A.; Jacobsen, R. Community Pharmacy Staff's Knowledge, Educational Needs, and Barriers Related to Counseling Cancer Patients and Cancer Survivors in Denmark. *Int. J. Environ. Res. Public Health* 2023, 20, 2287. <https://doi.org/10.3390/ijerph20032287>

Questionnaires – results – Cancer survivors

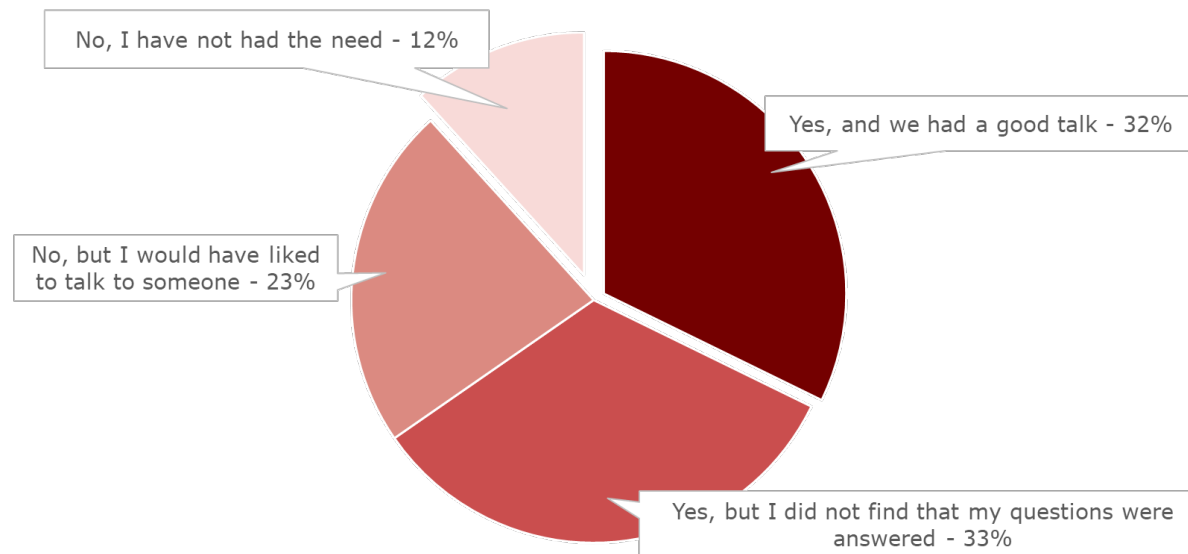
Cancer survivors:

354 patient panellists responded
(response rate 58)

Have you lacked any kind of advice, help or anything else in relation to your symptoms/problems?

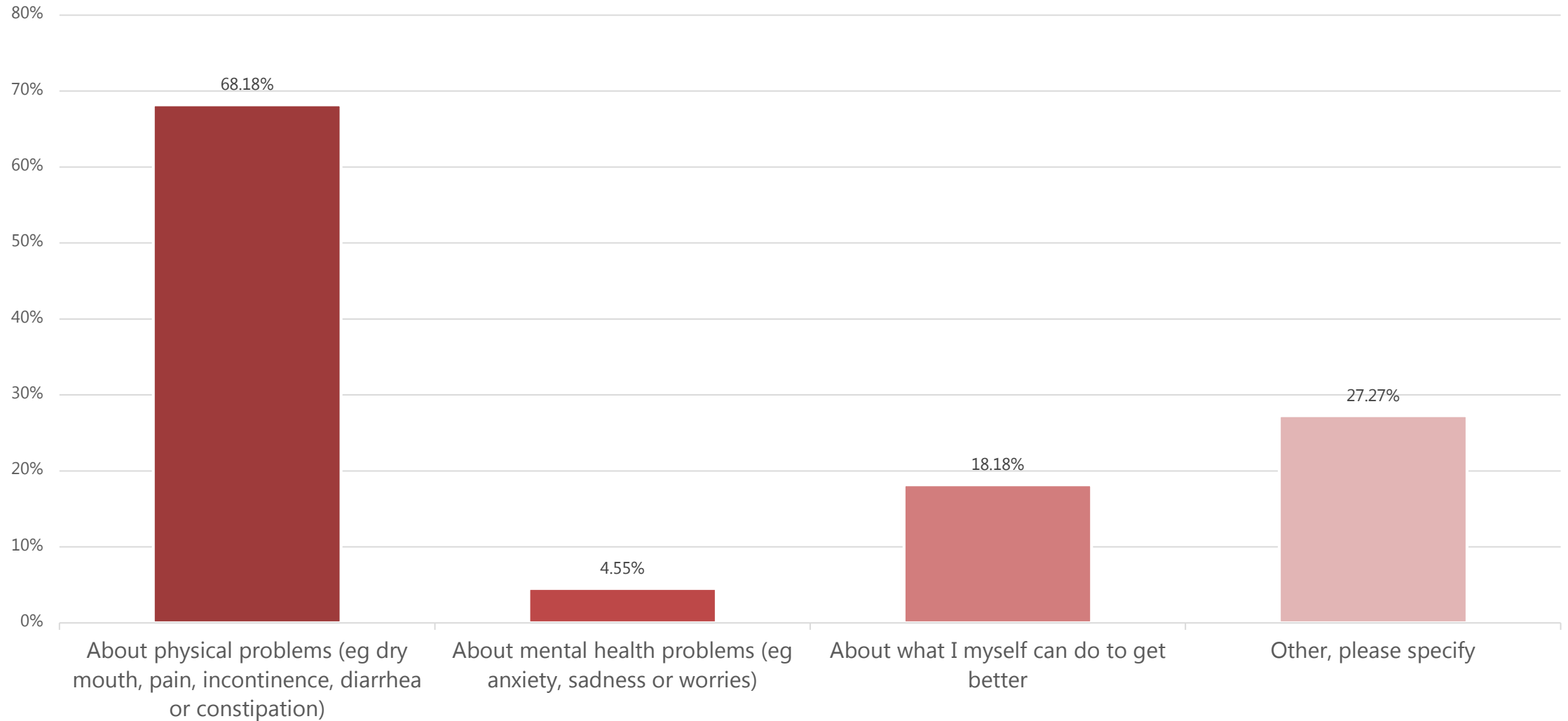


Have you talked to a healthcare professional about your late effects after cancer?



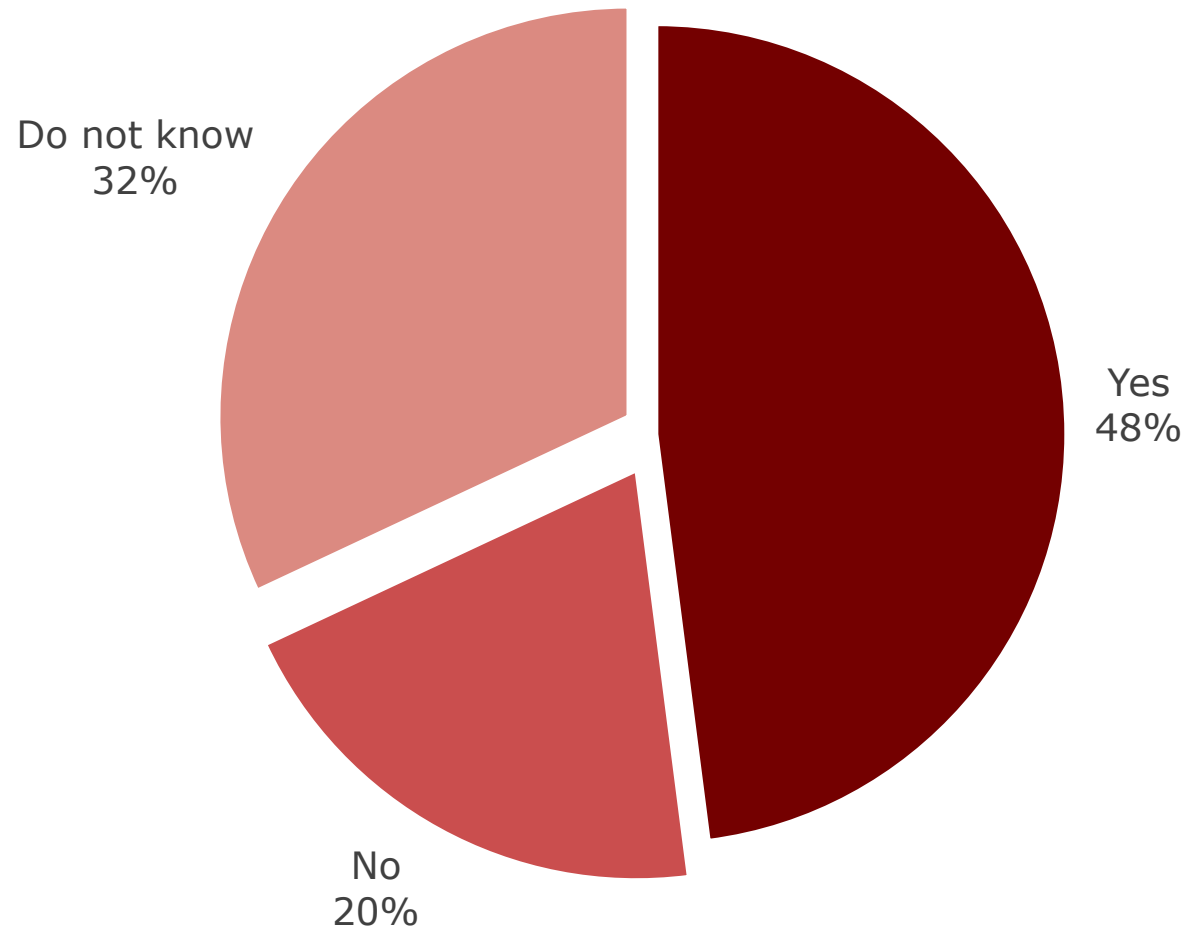
Questionnaires – results – Cancer survivors

What did you talk with the community pharmacy staff about?



Questionnaires – results – Cancer survivors

If you were made aware of a free counselling service on late effects at your local pharmacy, would you choose to participate in such an offer?



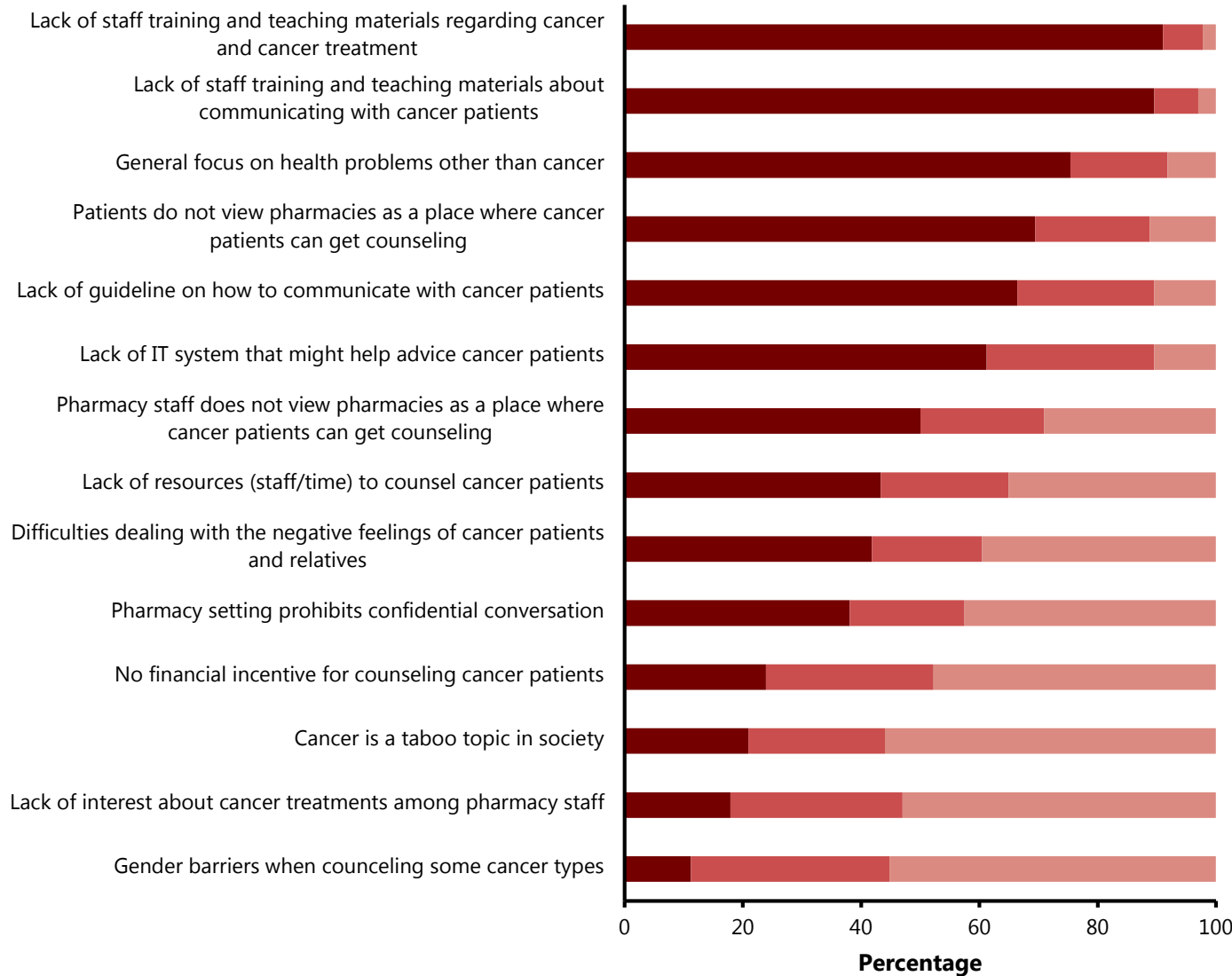
Questionnaires – results – Pharmacy staff

134 pharmacy staff responded

Self-perceived level of overall knowledge valued between 'very little knowledge' to 'some knowledge'.

Knowledge of cancer from	Pharmacists (n=79)		Pharmaconomists (n=51)	
	Frequency	Percentage	Frequency	Percentage
No knowledge	3	3.8	4	7.8
Pharmacist-/ pharmaconomist education	50	63.3	25	49.0
Continuous education (e.g. courses)	14	17.7	3	5.9
Work experience	37	46.8	23	45.1
Selfstudy	29	36.7	18	35.3
Cancer trajectories I have experienced or been close to (e.g. own or relatives')	42	53.2	33	64.7
Other	7	8.9	4	7.8

Questionnaires – results – Pharmacy staff (n=134)



Potential *barriers* concerning counseling current/former cancer patients at a community pharmacy.

- Agree/strongly agree.
- Neutral.
- Disagree/strongly disagree.

91.0% were 'interested'/'very interested' in learning about cancer and cancer treatment

Actor analysis

- 13 semi-structured, qualitative interviews with GPs, late effect clinics and municipalities.
- Items: definition of late effects, work tasks, management of late effects, description of patients/target group, diagnosis and registration of late effects, screening for late effects, competencies and problem solving, collaborations, pharmacies, placement of responsibility for management of late effects, future, snowballing
- Data being analysed now
- Some preliminary results:
 - *Lack* of terminology and clear definitions
 - Few clinicians *screen* for LEC, but agree that *collaboration* between multiple HCPs is essential for successful management of LEC.
- *Health centers* should have special competencies in managing LEC, but lack employees...
- *Lack of strategies* on whom to help
- Lack of offers for those who cannot be helped. *How do you live with LEC and create a new everyday life?*
- *Navigators and liaisons* between the various agencies needed. Difficult for the patients themselves to be their own calendar managers and advocates.
- A need for information and attention at *national level*, as well as a collective *collection* of experience/knowledge sharing.

Conclusion and next step

- Cancer survivors suffer from unresolved LEC and there is a potential for including community pharmacies in a cross-sectorial and interdisciplinary health care service targeting LEC.
- Next steps:
 - Focus group interviews with patients
 - Cross-sectional cross-professional workshop:
 - Describe results from pre-studies
 - Dreams for the intervention
 - Define the intervention content
 - Deliver the pilot version of the intervention
 - Feasibility testing

Aim

- To develop a *cross-sectional* and *interdisciplinary* health care service (HCS) targeting late effects of cancer, which includes participation of community pharmacies

