



LEEDS BECKETT UNIVERSITY

SCHOOL OF HEALTH &  
COMMUNITY STUDIES

# Supporting people with cancer and dementia: The CanDem study

Prof Claire Surr

Centre for Dementia Research, Leeds Beckett University

On behalf of the CanDem Research Study Team



# Why is dementia important in cancer care?



**850,000** people live with dementia in UK

...a number predicted to rise to over 2 million by 2051



**50%** of cancers are diagnosed in people aged 70+



**1 in 4** people in general hospitals have dementia

# What do we know about cancer and dementia already?

- Cancer and dementia are both common conditions that affect many older people
- But, we know very little about people with both conditions
- Estimates of dementia prevalence in people with cancer range from 3-19%

**Little is known about the cancer care needs and experiences of people living with dementia**



# The CanDem study



- Two linked studies: 1 qualitative, 1 quantitative
- Main aim: to identify the cancer care needs and experiences of people living with cancer and dementia
- Started 1 May 2018, ends 31 July 2019
- Funded by NIHR Research for Patient Benefit
- Research team: Claire Surr, Michelle Collinson, Laura Ashley, Amanda Farrin, Rachael Kelley, Alys Griffiths, Ellen Mason, Fiona Cowdell, Ann Henry, Amanda Proctor, June Hennell and Hayley Inman
- Lay Advisory group: June Hennell, Liz Jones, Maria Walsh, Margaret Ogden



This study/project is funded by the National Institute for Health Research (NIHR) RfPB programme (project reference PB-PG-0816-20015). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

# Study 1

## Aim:

To compare the **socio-demographic, clinical and service use characteristics** of people with **both conditions** to those of people with **cancer or dementia alone**

## Quantitative Data:

- Large ResearchOne dataset from **GP records** (391 practices, 5.1% of practices)
- Data from **2005-2016**
- All people **aged 50+** who have a diagnosis of **cancer, dementia or cancer and dementia**



# Numbers of people with cancer and dementia



116,388 people living with **cancer**



49,599 people living with **dementia**



3,616 people living with **both conditions**

This suggests that around:

3% of people living with cancer also have dementia

6.8% of people living with dementia also have cancer

# Age

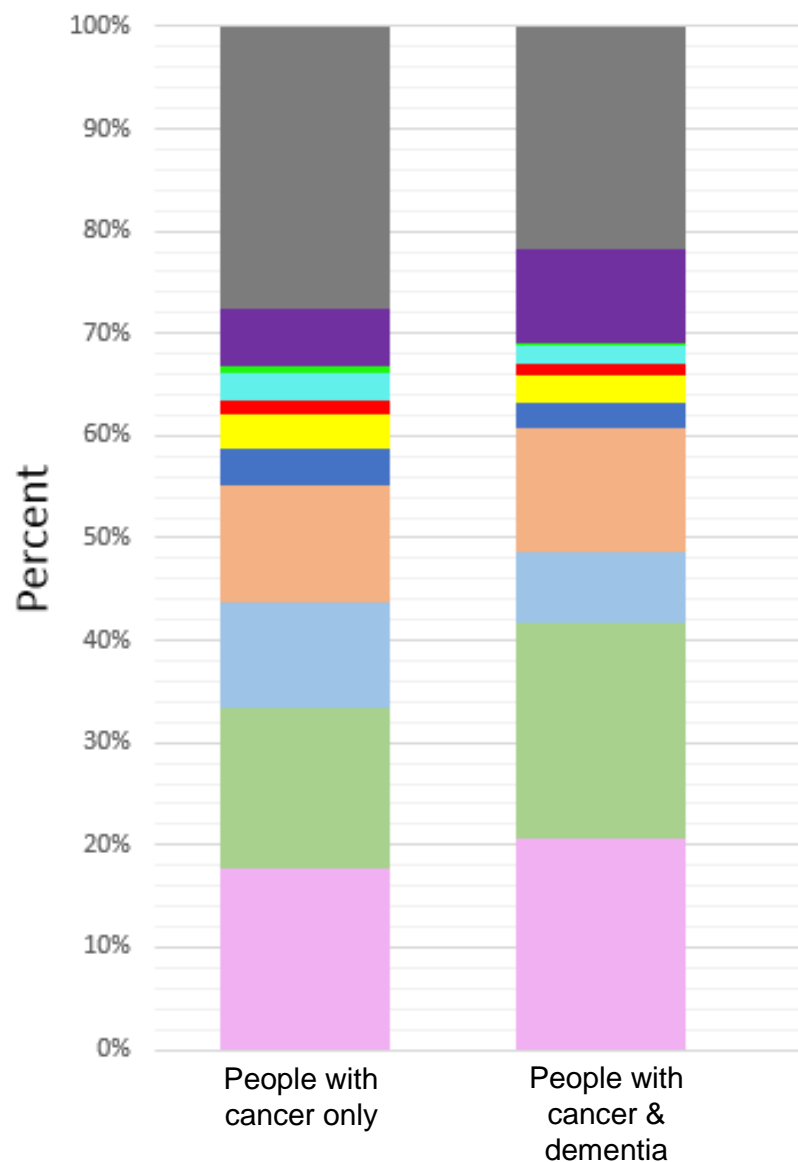
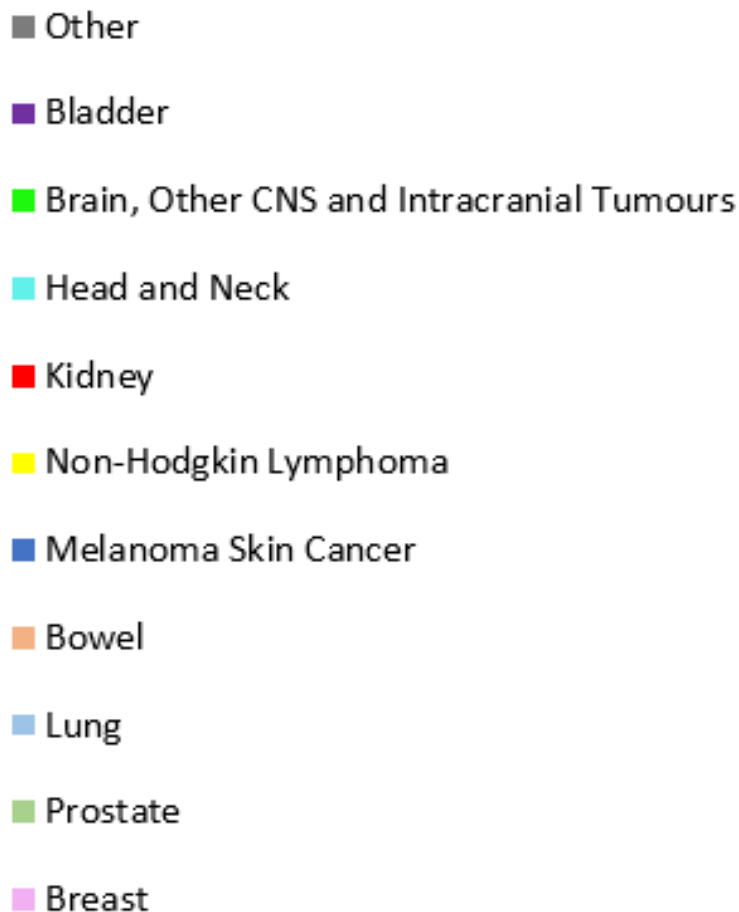
	Cancer only	Dementia only	Cancer and dementia
Mean (s.d.)	69 (12)	82 (8)	81 (8)
Median (range)	70 (38, 106)	83 (41, 113)	82 (46, 105)

# Living in a care home?

	Cancer only	Dementia only	Cancer and dementia
No	107189 <b>(95.0%)</b>	21446 <b>(47.0%)</b>	2282 <b>(56.9%)</b>
Yes	5583 <b>(5.0%)</b>	24140 <b>(53.0%)</b>	1731 <b>(43.1%)</b>



# Type of cancer



# Study 2

## Aim:

To understand cancer care experiences for people living with dementia and their families. What works well and what could be improved?

## Qualitative Data:

- Interviews, observations, conversations and medical notes
- With people living with cancer and dementia and their families
- With hospital staff



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# Data collected to date

**16** people living with dementia

**21** family members

**15** members of staff

**30** interviews (representing the experiences of **39 people**)

Observations and conversations with **10 'dyads'**



# Issues and challenges



Identifying dementia...



Decision making...



Complexity &  
comorbidity...



Person vs process...



Centrality of families...



Environment &  
logistics...



## Identifying dementia...

Oncology staff often did not know and did not ask about whether a person had dementia. Their focus was the cancer.

“I think he [the consultant] saw a man who had got cancer... The consultant just breezed in and out, so I don’t think I ever had a chance to say to him, my father will have forgotten everything you’ve done two minutes afterwards... He [my Dad] probably gave a good impression... I didn’t feel it was my place to say, excuse me, but my father can’t remember what day it was.” (Son of man with cancer and dementia)

Bob: “I don’t know what’s going to happen to me... at hospital they don’t tell you half the time. They think you know what they mean. They don’t say it in English... I just can’t weigh it up.... That’s the most frightening part about it... I cannot understand what is happening to me.”

Penny: “I didn’t know whether it [radiotherapy] would do anything more to his dementia, whether it would make him worse or not... If they had explained it better I probably would have got him treatment.”



## Decision making...

Treatment options were often difficult to understand and challenging to weigh up for people with cancer and dementia and their family members.



### Centrality of families...

**Interviewer:** “It sounds like your father would have struggled to get to the hospital if you hadn’t been able to go with him?”

**Son:** “He wouldn’t have got to the hospital.” “I just knew from him trying to wander off in the car park a few times, I’d have to just be with him all the time.”



### Environment & logistics...

“He almost needed constantly somebody with him... I couldn’t find anywhere to find that support for someone to escort him. It just didn’t exist.” (Social worker of man with dementia living in a care home)





## Complexity & comorbidity...

Other comorbidities added additional complexity to treatment processes and decision-making

The doctor explains that Julia 'can't be on warfarin' to have the procedure, going on to explain in depth what stopping warfarin and the procedure will involve. He concedes it will require 'a bit of organising' but the team felt it was worth doing 'if that's ok?' 'Right. Feel free' replies Julia. Paula checks with her 'Do you understand what's happening?' She replies 'ish' and 'It's a lot to remember all at once'.

(Observations of consultation between Julia (person with cancer and dementia) and Paula her Grand daughter)



“It is hard when you’ve got cancer targets and other things driving you as well [to give the extra time people with dementia need to make decisions]. Okay they might breach, but actually they might have reached an informed choice which is far better than reaching a quick choice which is wrong.’

(Interview with Clinical Nurse Specialist)



## Person vs process...

Oncology services largely process driven rather than person-focussed. Supports around ‘getting people through quickly’

# Things that worked well

## Tailoring information:

“We **wrote things down** for the **family**, so they could **repeat it** for her and **explain it in the way we had**, so **words they could understand and use.**”

## Tailoring appointments:

“We tried to **tailor the appointments around her needs**... she couldn't always get to morning appointments, she'd be a lot more agitated if she was up early, so **we did things later in the day.**”

## Tailoring support:

“Her daughter **visited every day**. There was a lot of things that she was physically doing for her mum. I think for her a lot of things were **around her daughter** rather than... [her mum]”

# Practical ways to improve experiences

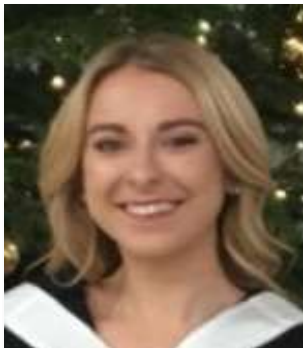
- ✓ **A**sking about, **R**ecording and **C**ommunicating memory problems Using **pictures** and **images** to aid explanations
- ✓ **Personalised written reminders** of the key facts
- ✓ Getting to **know the person** – making a connection
- ✓ **Including family without excluding people living with dementia**
- ✓ **Consistency** in staffing and familiar faces (e.g. CNS 'keyworker' system)
- ✓ **Flexibility, adaptations** and extra **time** and **support** (e.g. patient support service)
- ✓ Improving **patient transport** and **arrival** arrangements



# Other cancer and dementia studies



Mollie Price: Needs of carers of people with cancer and dementia



Olivia Robinson: Care and support needs of people with cancer and dementia in nursing homes



Rebecca Platt: Care and support needs of people with cancer and dementia in residential care



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# Thank you

Any questions?

Web:

[www.leedsbeckett.ac.uk/school-of-health-and-community-studies/research/centre-for-dementia-research/](http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/research/centre-for-dementia-research/)

Twitter: @clairesurr and  
@LBUDementia

E-mail: c.a.surr@leedsbeckett.ac.uk