

# **Cancer outcomes that matter:**

## **Do PROMS add value?**

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# Goals of cancer care

*Adding years to life*

&

*Adding life to years*

# Why a priority?

- 359,000 cases UK 2015
- 166,000 deaths from cancer UK 2016
- 50% 10 y survival UK 2010-11
  - 24-50 % in last 40 years
- 50% cases breast, colorectal, lung, prostate

## Why bother with aftercare/outcomes?

- 2.5 million living with and beyond cancer in England
  - Increase of 500,000 in last 5 years
  - Prevalence increases by 3.2% p.a
  - 4 million by 2030 years
- 1 in 4 estimated to live with adverse consequences of their cancer

<https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/trowinglightontheconsequencesofcanceranditstreatment.pdf>

Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202

[https://www.macmillan.org.uk/images/cancer-statistics-factsheet\\_tcm9-260514.pdf](https://www.macmillan.org.uk/images/cancer-statistics-factsheet_tcm9-260514.pdf)

# National Cancer Survivor Initiative

## Vision: 5 Key Shifts

- Cultural shift to focus on recovery, health and well-being after treatment
- Shift towards assessment and personalised care planning based on individual risks, needs and preferences
- Shift towards support for self-management
  - Supported self management
- Shift from “one model fits all” clinical follow-up to a personalised information prescription and specialist support allowing early recognition of signs/symptoms secondary, recurrent or advanced disease
- Shift from emphasis on measuring clinical practice to measuring experience and outcomes for cancer survivors through PROMS in aftercare services

# Patient Reported Outcome Measures (PROMS)

- Promote more effective interactions with professionals
- Trigger “information prescriptions”
- Monitor change
- Measure outcomes
- Identify & target populations with needs

# National Cancer Survivorship Initiative

## National Cancer PROMS Programme

DH PROMs & Cancer Policy Teams  
*then*  
NHS England

# The Bigger Picture

## Cancer Quality Account

*question*

*data*

*process*

•Do I survive?

Mortality statistics

NCRAS

•Was I looked after well?

Patient experience

NCPES

•What will I be like?

Quality of survival

PROMs



# National Cancer PROMs Programme Objectives

- Embed routine collection of PROMS within core business of the NHS cancer programme alongside survival data
- Utilise PROMS to
  - describe the quality of survival
  - identify consequences of survival and impact on function
  - identify factors that impact on outcome, including Tx
  - enable provision of appropriate health & social care
  - compare outcomes by service provider organisations

# Progress report

2011	Pilot	4 tumour sites	n=5,000	66% response	<i>BMJ Open 2013 Glaser et al</i>
2013	England Survey	Colorectal	n=35,000	63% response	<i>JCO 2015 Downing A et al</i> <i>JCO 2015 Wright EP et al</i>
2014	Pilot	Gynaecological cancers and bladder cancer			<i>BJC Mason S et al, 2018</i>
2016	UK	Prostate Cancer	n=50,000	60% response	<i>Lancet Oncology 2019 Downing A et al</i>



## **Health-related quality of survival after cancer in England:**

**A patient reported outcomes study of 21,000 individuals  
diagnosed with colorectal cancer**

*Downing et al  
JCO 2015*

# Objectives

- Establish methodology for routine evaluation of patient reported outcomes
- Identify the characteristics of colorectal cancer patients with poor health outcomes

# National Colorectal Cancer PROMs Survey

## Methodology

- All cases identified in National Cancer Registration Service
  - ICD10 C18-20
  - Diagnosed in 2010 and 2011
  - Treated in NHS in England, aged 16y+
- 2 death checks
- Questionnaire in post survey provider Picker Europe
- 2 reminders
- Dedicated *freephone* helpline
- Survey data linked to existing datasets
  - Tumour site colon, rectum, rectosigmoid, Dukes' stage *cancer registry data*
  - Treating hospital, surgical information *Hospital Episode Statistics*
- Data compared to *Health Survey England 2011 (EQ5D)*

# National Colorectal Cancer PROMs Survey

## *Questionnaire*

- Generic and condition specific PROMs
  - Patient demographics
  - Treatment
  - Disease status
  - Generic HRQL *EQ-5D*
  - Colorectal Ca specific outcomes *FACT C individual items*
  - Social problems *Social Difficulties Inventory*
  - Physical activity
  - LTCs
  - Experience of care *National Cancer Patient Experience Survey*
  - Free text comments

# Response rates and Patient characteristics

- NCRS identified 35,213 survivors  
2% died prior to receiving questionnaire **final sample size of 34,467**
- 21,802 returned partially or fully completed questionnaires generating a **response rate of 63%**
  - Individuals less likely to participate if
    - aged over 85
    - from a non-white ethnic group
    - living in the most socio-economically deprived areas
  - 62% colon cancer  
31% rectal cancer  
7% rectosigmoid tumours
  - 76% reported being in remission  
10% uncertain of their disease status
  - Other long-term conditions (LTCs) were common
    - 21% stating they had no LTCs
    - 44% reporting two or more

# Characteristics of the respondents

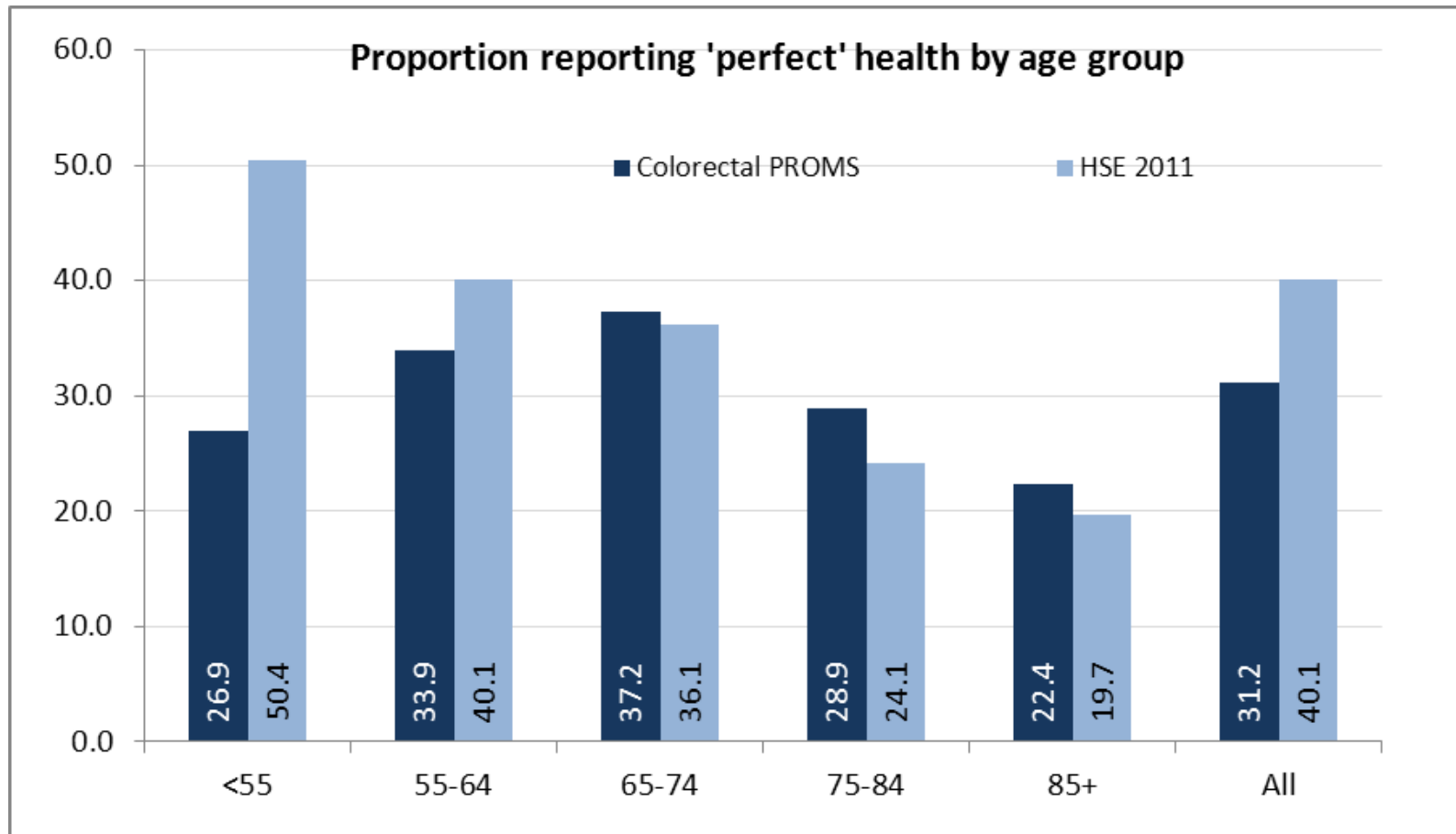
- Treatment
  - 92% had surgery
  - 47% chemotherapy
  - 20% radiotherapy
- Use of surgery and chemotherapy was similar across the three sites
- A higher proportion of the rectal group received radiotherapy
  - 54% rectum 4% colon 17% of rectosigmoid respondents
- Stoma present
  - 10% colon cancer respondents
  - 21% rectosigmoid
  - 42% rectal
- Stoma reversal reported by 35%



# General health *EQ5D*

- 'Perfect' health reported by 35%
  - Colon 37%
  - rectosigmoid 36%
  - rectal 29%
  - Stoma status
    - No stoma 39.8%
    - Reversed 34.9%
    - Present 19.7%
- LTCs, disease status & stoma status were the strongest predictors of HRQL
- Predictive factors of lower HRQL
  - Being aged <55 or over 85
  - being female
  - living in a more deprived area
  - receiving treatment including radiotherapy and/or chemotherapy
- Lower HRQL of rectal cancer respondents was accounted for by inclusion of other factors

# Comparison with Health Survey England 2011



# Social distress

- Utilising the 21 item Social Difficulties Inventory SDI
  - Everyday living
  - Self and others
  - Money matters
  - Sexual matters, plans to have a family, plans to travel, where you live, any other difficulty
- Social distress if score  $\geq 10$

# Social distress

- Overall 15% exhibited social distress
- No gender difference
- High levels of distress in
  - the youngest <55 y
  - those living in the most deprived areas
  - non-white respondents
  - those with 3 or more LTCs
  - Patients who were carers

# Social distress

- Higher social distress in rectal (18%)
  - c.f. rectosigmoid (15%) and colon (14%)
- Rectal cancer
  - With stoma 25% in distress
  - Stoma reversal 12%
  - Never had a stoma 12%
- High levels of distress in those with recurrent or non-treatable disease (29%) or Dxt (23%)

# Summary

- Reassuring that 35% of individuals surviving 12-36 months from a diagnosis of colorectal cancer report being in 'perfect' health and 85% do not demonstrate social distress
- However, HRQL is poor relative to the general population particularly for those aged under 55 years
- Both cancer and non-cancer related factors affect HRQL and social outcomes
- We have confirmed that a survey approach is a practical method of collecting whole population patient-reported outcomes

# More information

Quality of Life of Colorectal Cancer Survivors in England:

Report on a national survey of colorectal cancer survivors using Patient Reported Outcome Measures (PROMs). March 2015.

<http://www.england.nhs.uk/wp-content/uploads/2015/03/colorectal-cancer-proms-report-140314.pdf>

Link for access to tool-kit:

<http://www.england.nhs.uk/resources/cancer-resources/>

Health-Related Quality of Life After Colorectal Cancer in England: A Patient-Reported Outcomes Study of Individuals 12 to 36 Months After Diagnosis.

Downing A et al. 2015. *Journal of Clinical Oncology*, 33, 616-624.

Identifying Social Distress: A Cross-Sectional Survey of Social Outcomes 12 to 36 Months After Colorectal Cancer Diagnosis

Wright P et al. *Journal of Clinical Oncology* published on line ahead of print August 17, 2015, doi: 10.1200/JCO.2014.60.6129

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## **Co-investigators** *including*

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# Prostate Cancer UK

47,000 cases                      UK    2015

11,631 deaths                    UK    2016

84% 10y survival    2010-11

Cancer Research UK

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality>

## Study aim

The *Life After Prostate Cancer Diagnosis* study aimed to report functional outcomes (urinary, bowel, sexual and vitality/hormonal) and health related quality of life in men with PCa in order to:

(a) Quantify and compare outcomes across all disease stages and treatment groups

(a) Identify implications for healthcare delivery

- All diagnosed with PCa (ICD10 C61)  
18-42 months post-diagnosis
- Identified through cancer registration  
systems

## Method

- 82% of eligible men invited to  
participate
- Postal survey with 2 reminders



# The Questionnaire



## Topics covered

- Urinary and bowel functioning 
- Sexual functioning 
- Psychological and social well-being
- Physical social and financial concerns

## Additional items cover

- Treatment received
- Socio-demographic characteristics
- Patient perspectives (decisional regret and patient empowerment)

# Results: Respondent characteristics

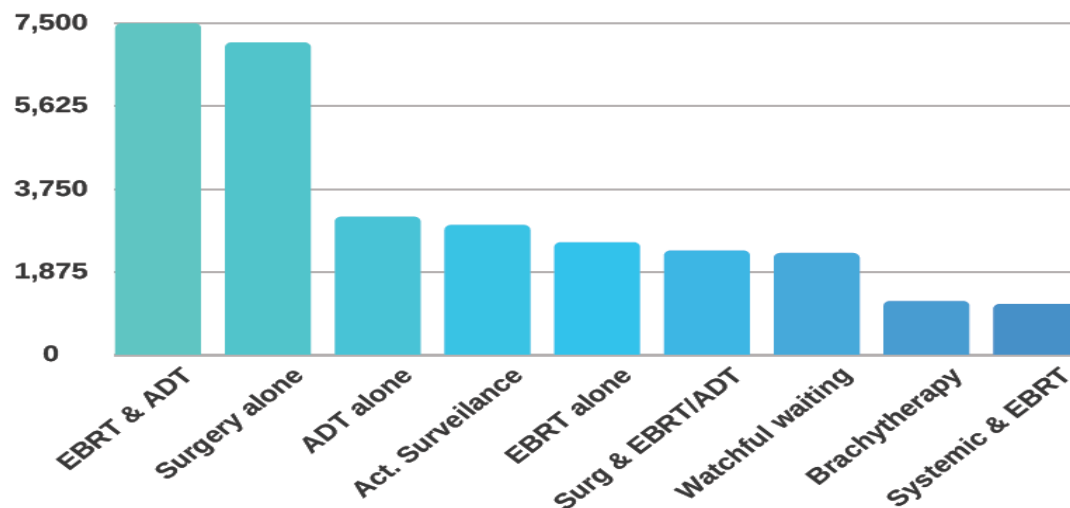
- 35,823 men responded (60.8%)
- Men aged <55 or 85+, from non-white ethnic groups and from most deprived areas were less likely to participate
- Stage at diagnosis known for 85.8% of men. Of these 63.8% had stage I/II disease, 23.4% stage III and 12.8% stage IV

		N	%
Stage at diagnosis	Stage I/II	18,055	63.8
	Stage III	6,792	23.4
	Stage IV	3,759	12.8
Age at survey	<55 years	661	1.8
	55-64 years	5,594	15.6
	65-74 years	16,638	46.4
	75-84 years	11,082	30.9
	85+ years	1,842	5.1
	Unknown	6	0.02
Socio-economic deprivation quintile	1 - least deprived	9,408	26.3
	2	9,289	25.9
	3	7,381	20.6
	4	5,266	14.7
	5 - most deprived	3,620	10.1
	Unknown	859	2.4

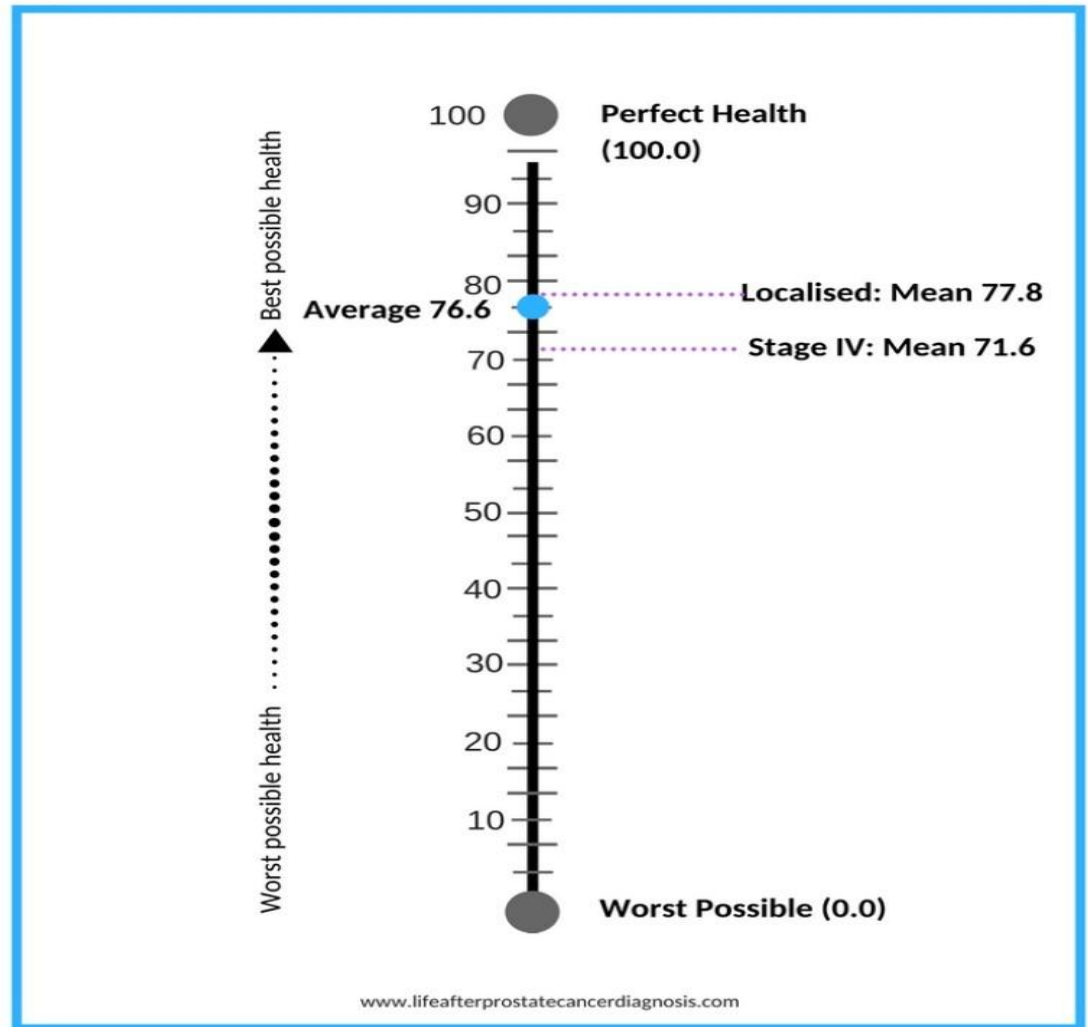


# Treatments reported

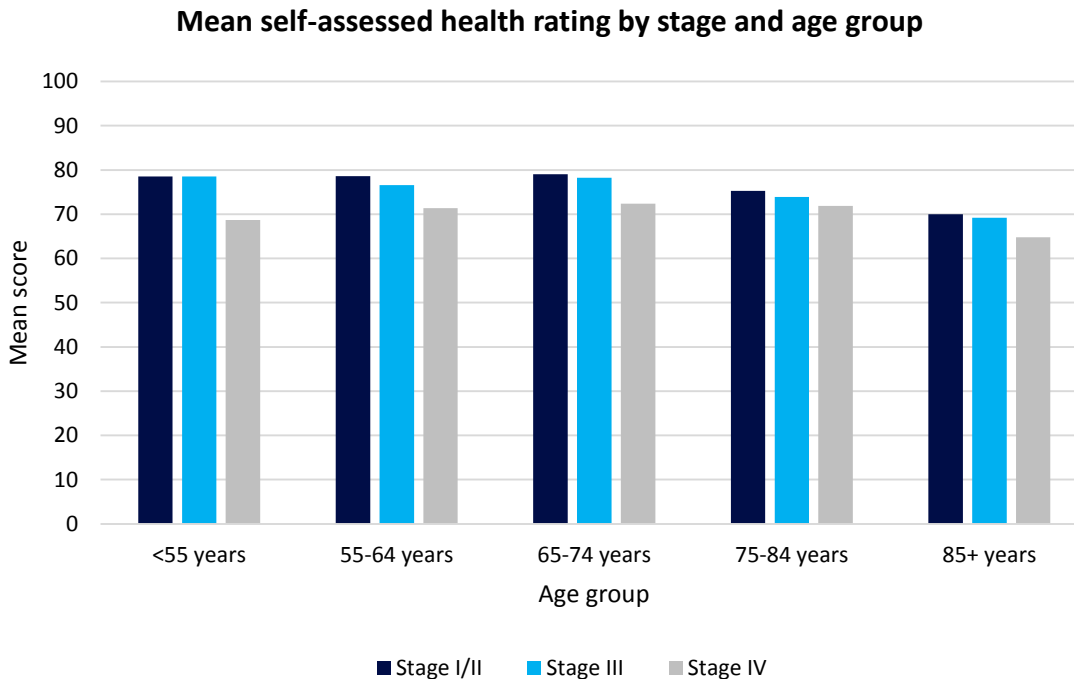
Figure 3. Treatment summary for the UK



# Overall Self reported health EQ5D visual analogue scale



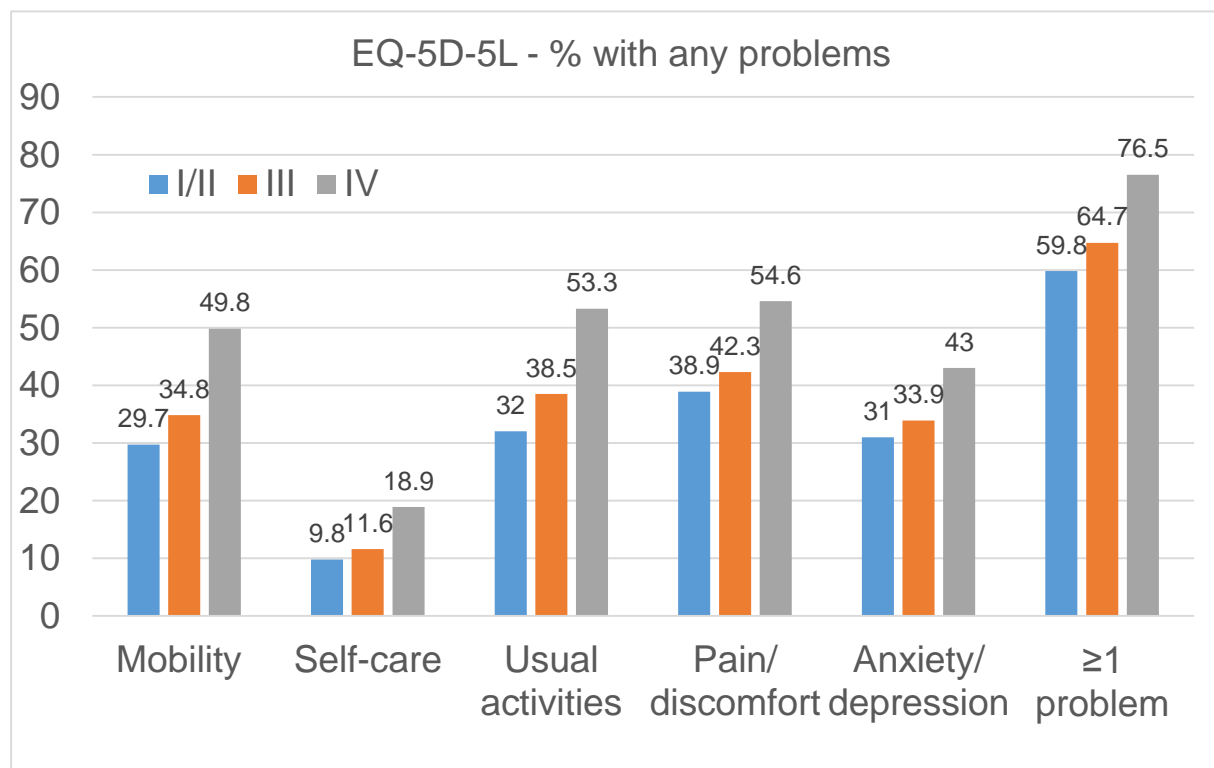
## Results: **Self-assessed health (SAH) by stage and age**



- Mean self-assessed health was 6.2 points lower in men with advanced disease (stage IV) compared to localised disease.
- Difference in SAH by stage was greatest in younger men.

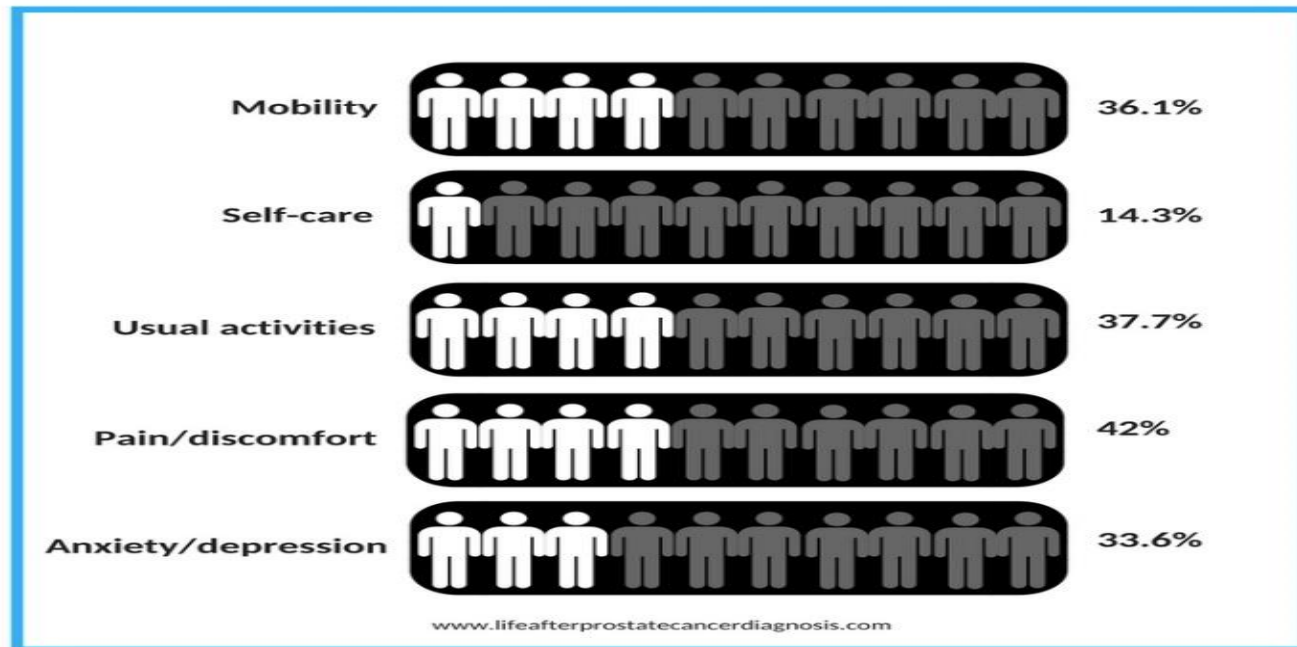


# HRQL by stage



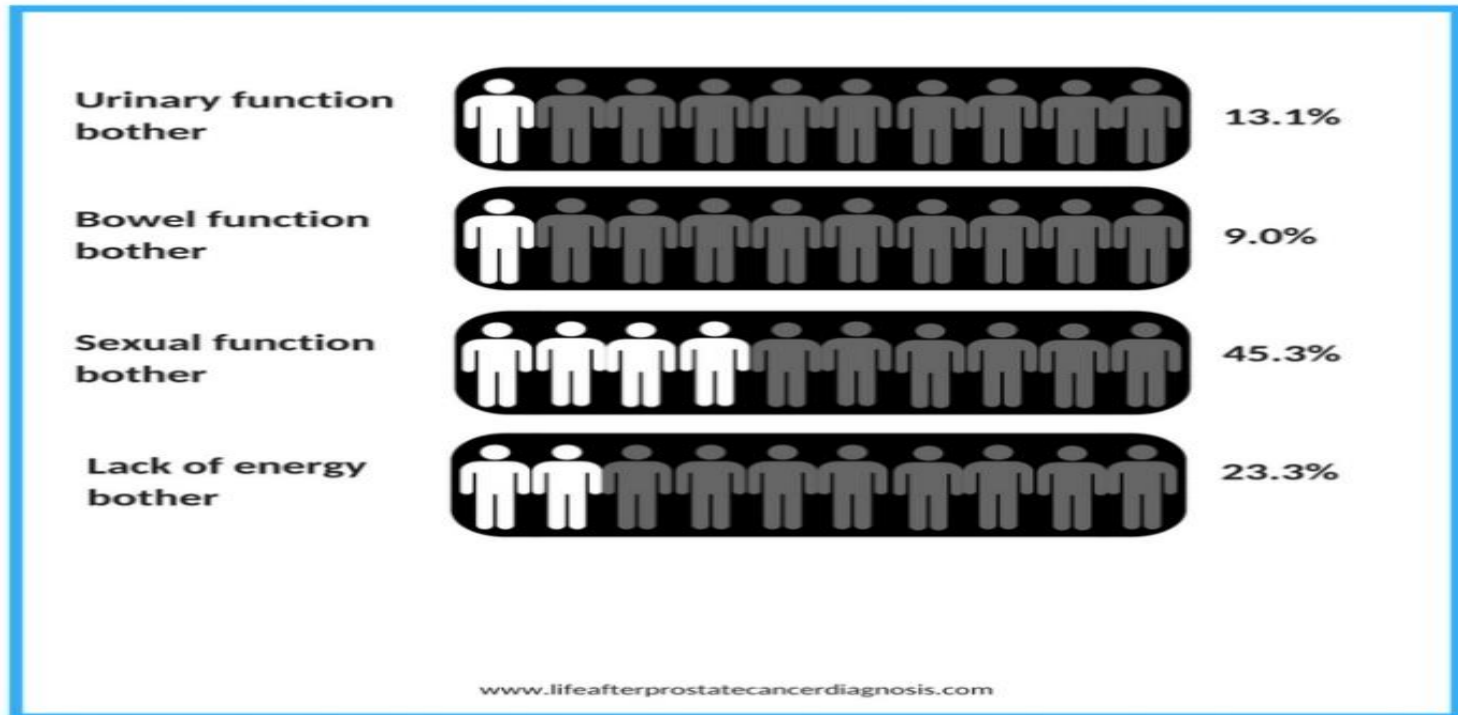
- Problems increase by stage of disease
- However, 24% of men with stage IV disease report no problems

# Overall general health problems



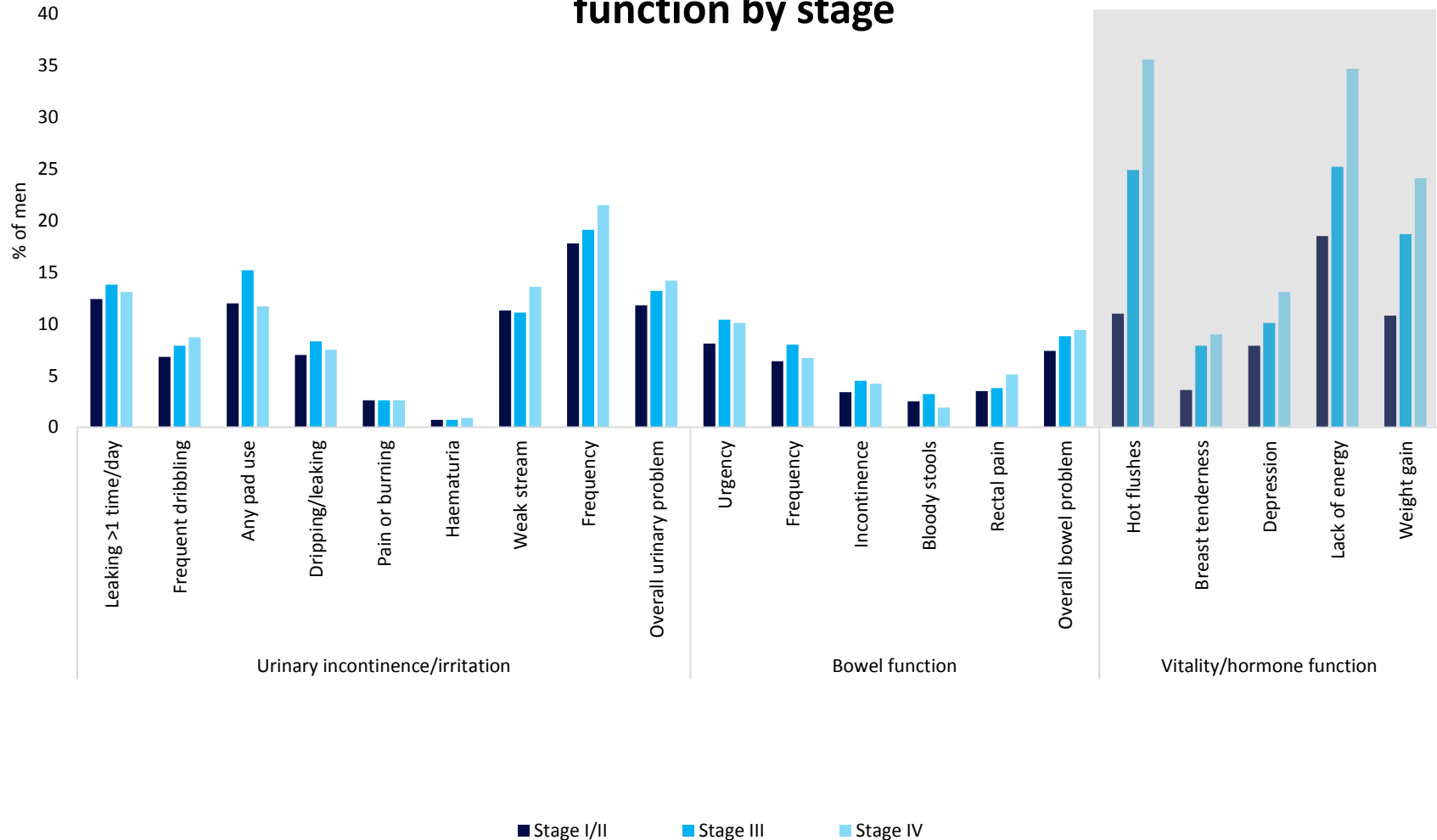
# Functional outcomes:

## Sexual bother greatest



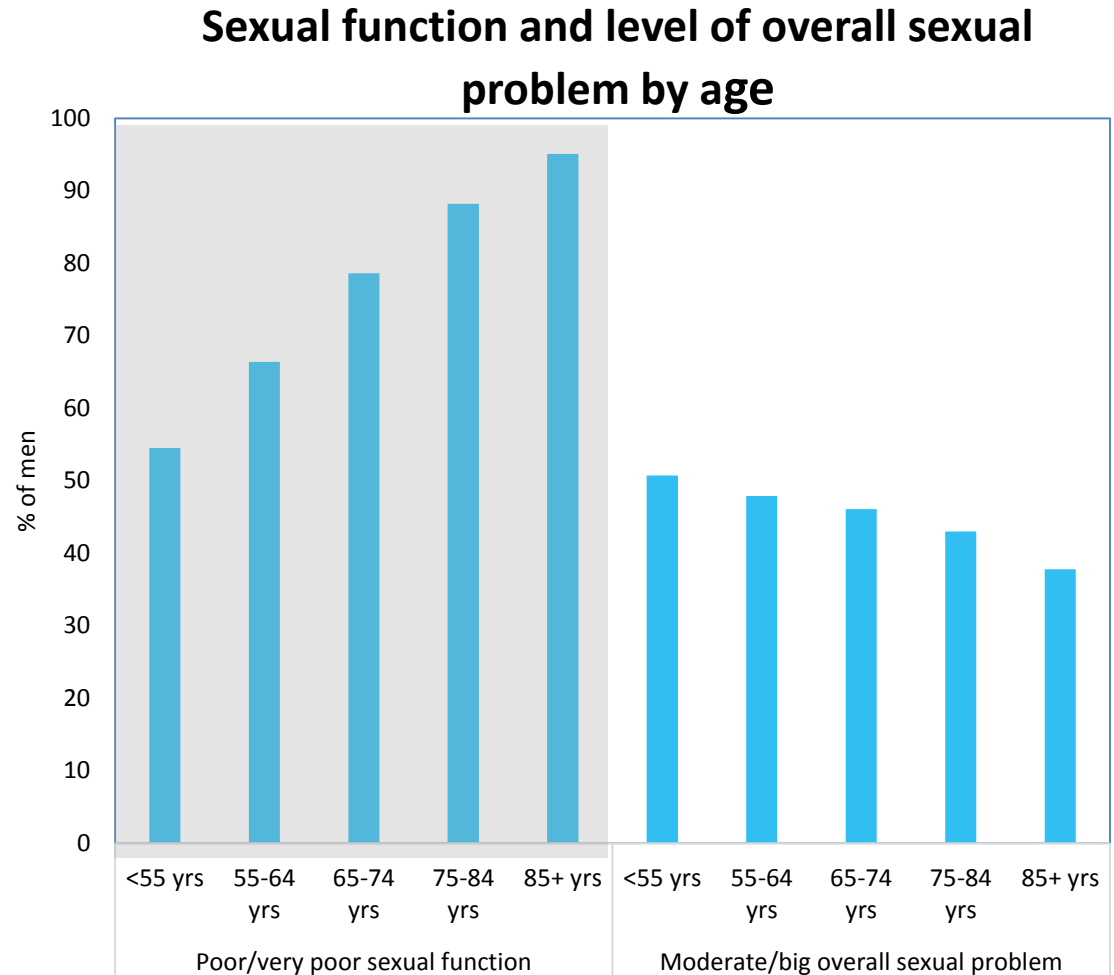
# Functional outcomes by stage

Moderate/big problems with urinary, bowel and hormone function by stage



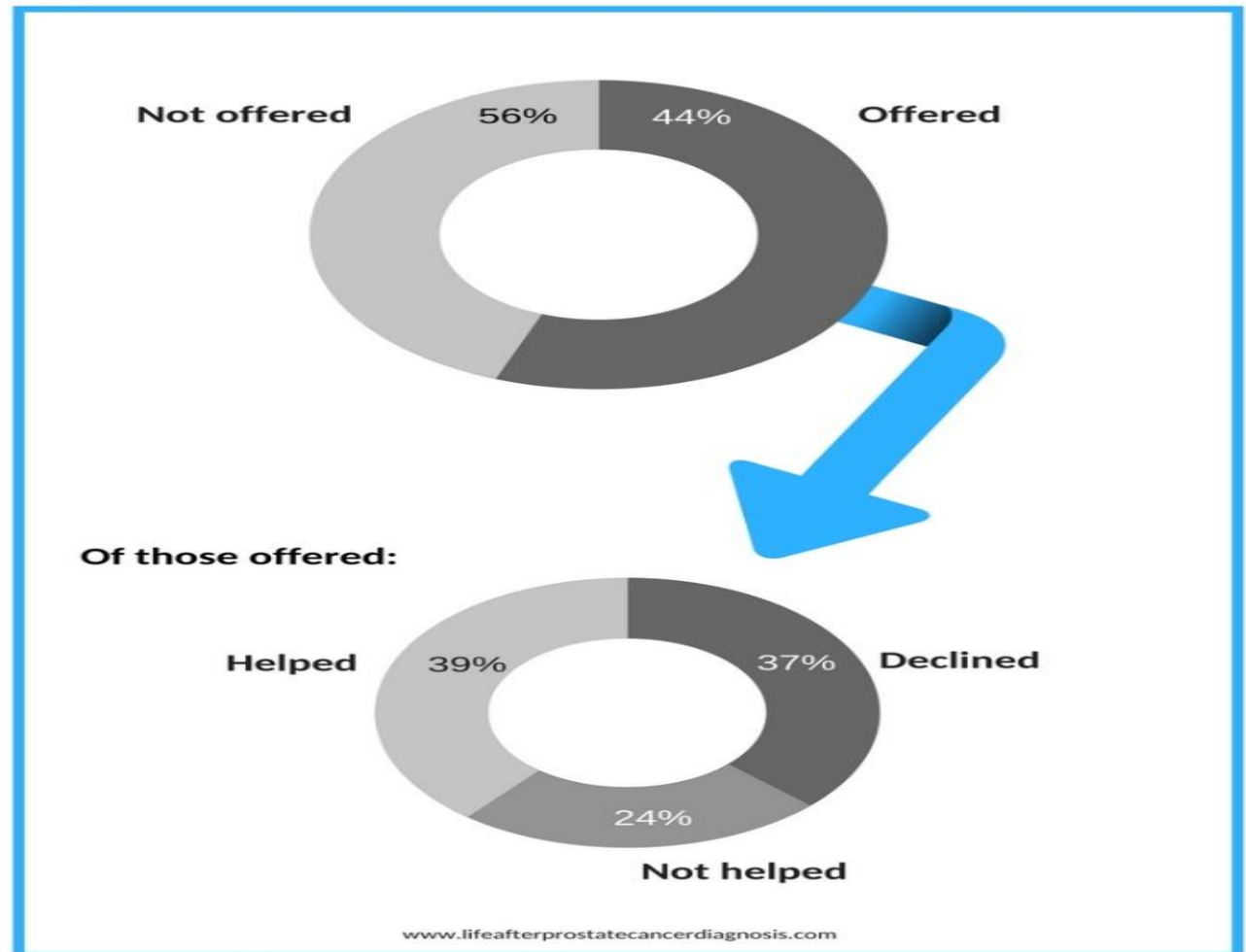
# Sexual function

- Problems with sexual function more common than in other domains
- Poor/very poor function increased with age
- Just under half of men reported this as a problem, although decreased with age

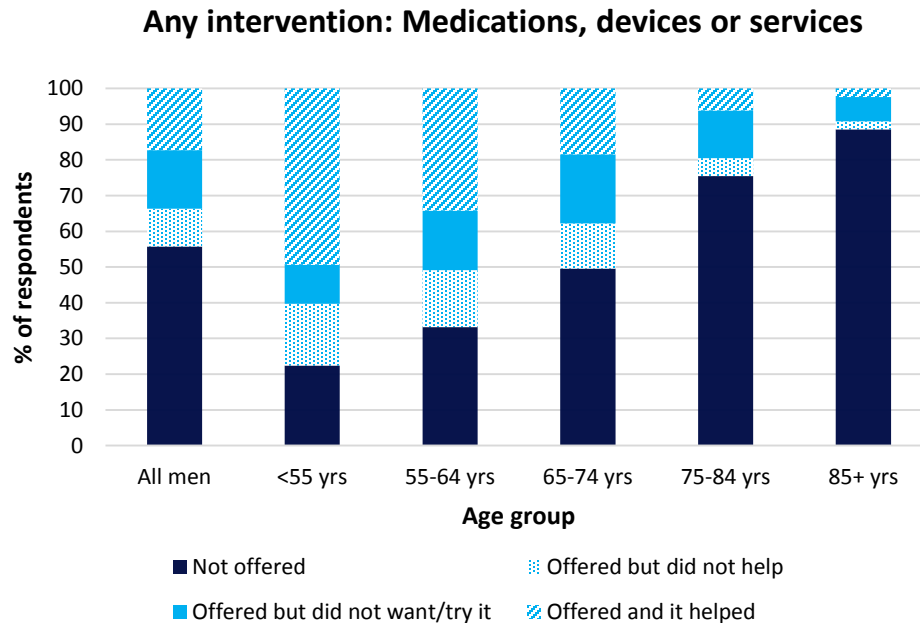


# Help with sexual problems

Overall result 45% reported bother

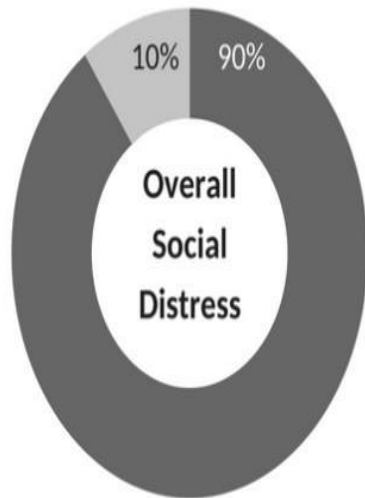


## Results: Sexual interventions



- 44% were offered one or more intervention to aid sexual function
- 41% reported being offered medications to aid or improve erections
- 23% were offered devices to aid erections
- 15% were offered specialist services to help with sex life

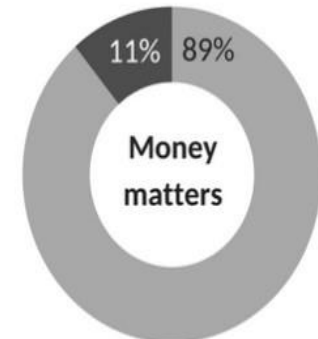
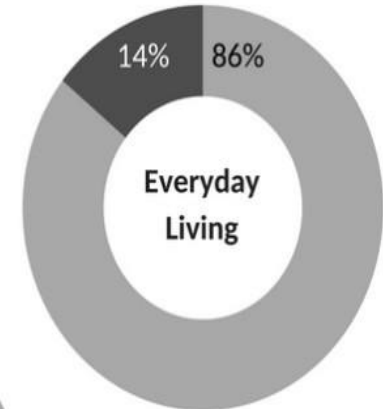
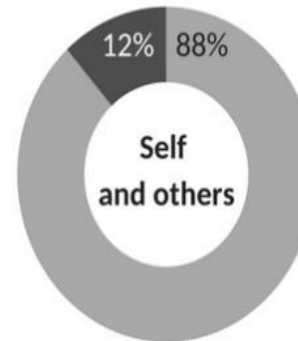
# Overall Social distress



10% of men reported high social distress

[www.lifeafterprostatecancerdiagnosis.com](http://www.lifeafterprostatecancerdiagnosis.com)

Within subscales,  
<15% of men reported high social distress



[www.lifeafterprostatecancerdiagnosis.com](http://www.lifeafterprostatecancerdiagnosis.com)



## Conclusions

- Most men living 18-42 months after diagnosis of PCa can expect to experience good HRQL
- Those with locally advanced and metastatic disease do not report markedly different HRQL outcomes to those diagnosed with localised disease, although significant problems with hormonal function and fatigue are reported as a result of ADT
- Sexual dysfunction is the most common and bothersome late effect

# Funding & Patient Involvement

- The *Life After Prostate Cancer Diagnosis* study was funded by Movember Foundation, in partnership with Prostate Cancer UK, as part of the Prostate Cancer Outcomes programme, grant number BO26/MO
- This study is based in part on information collected and quality assured by the cancer registries in each of the UK nations. Their work uses data provided by patients and collected by health services as part of their care and support. All participants were service users.

# LAPCD collaboration

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IN PARTNERSHIP



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PROSTATE  
CANCER  
OUTCOMES

LIFE AFTER  
PROSTATE CANCER  
DIAGNOSIS



# Limitations

- Response bias – non-responders are likely to have lower HRQL
- No baseline information prior to having cancer and limited comparable information
- EQ-5D scores are highly skewed, modelling is difficult
- Only get to answers to questions asked

# Methodological Issues: Successes

- PROM independent of trial, process, Tx, setting  
*whole condition*
- Large numbers
- High participation rate and data completeness
- Meaningful data to complete “quality” account
- Proof of methodology utilising cancer registrations

# Challenges

- Share the information with the people that matter
- Utilise this intelligence to intelligently design, commission and deliver services that maximise the quality of survival

# Next Steps

*If I had a million dollars.....*

- Roll-out

*Life and Bladder Cancer Yorkshire Cancer Research*

- Embed PROMS in routine clinical practice

*NHS England commitment by 2019!*

# Conclusions

***Cancer survival presents a health of the nation problem that has broad impact***

***PROMS present an exciting opportunity to collect intelligence to support development of robust aftercare services to enhance the quality of survival of the burgeoning population living with and beyond cancer***



**Cancer outcomes that matter:**

**Do PROMS add value?**

**?**

**Questions/Discussion**