

# Patients' and partners' views of treatment and care provided for metastatic castrate resistant

## prostate cancer (mCRPC) in the UK



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**BACKGROUND:** Appraisals of information needs, expectations and experiences of treatment in prostate cancer have highlighted the lack of relevant data in advanced disease.

**EXTREQOL (EXperiences of TREATment and Quality Of Life)** is a 6 month longitudinal observational study examining QoL, treatment experiences and information needs from the patients' and healthcare professionals' perspectives, and from interviews with a subgroup of patients & their partners.

**AIMS:** explore in more detail the impact of treatment (Rx) and care on quality of survival (QoS).

**METHODS:** structured interviews in-person or by phone.

**Interviews:** ≤14 days of initiating systemic Rx for mCRPC

- ❖ repeated after 3-months Rx
- ❖ patients & partners interviewed separately
- ❖ most questions had pre-assigned response categories
- ❖ replies to open-ended questions were written verbatim

**Areas covered:** demography & medical history, experiences of Rx decisions, symptoms and Rx-related side effects (SEs), information provision, perceived benefits and harms of Rx, impact of Rx and care on the lives of patients & partners.

**Participant details:** 33 patients, married to their partners and 4 single men were recruited from 15/20 cancer centres.

**Patients:** mean 75.6yrs (min-max 56-91yrs)

- ❖ single men were older
- ❖ 22% (8/37) presented with mCRPC for the first time
- ❖ 60% (22/36) disease had spread to bone, 8 visceral, 6 both
- ❖ Rx for mCRPC were: enzalutamide (13), abiraterone (7), docetaxel (9), radium (5), cabazitaxel (2), & goserelin (1)
- ❖ concurrent Rx: hormone injections (34), bisphosphonates (2) analgesics (18) & radiotherapy for bone metastases (4)

**Partners:** all female, mean 67.6yrs (min-max 54-79yrs).

### RESULTS (1): PAIN AT PRESENTATION

- ❖ pain was the worst symptoms for a majority (43%)
- ❖ 51% needed to discuss pain management
- ❖ 19% attributed their pain to non-cancer origins

*"my pain in the lower back and shoulders is due to degeneration" (P1, 72yrs)*

*"I put the backache down to gardening" (P33, 72yrs)*

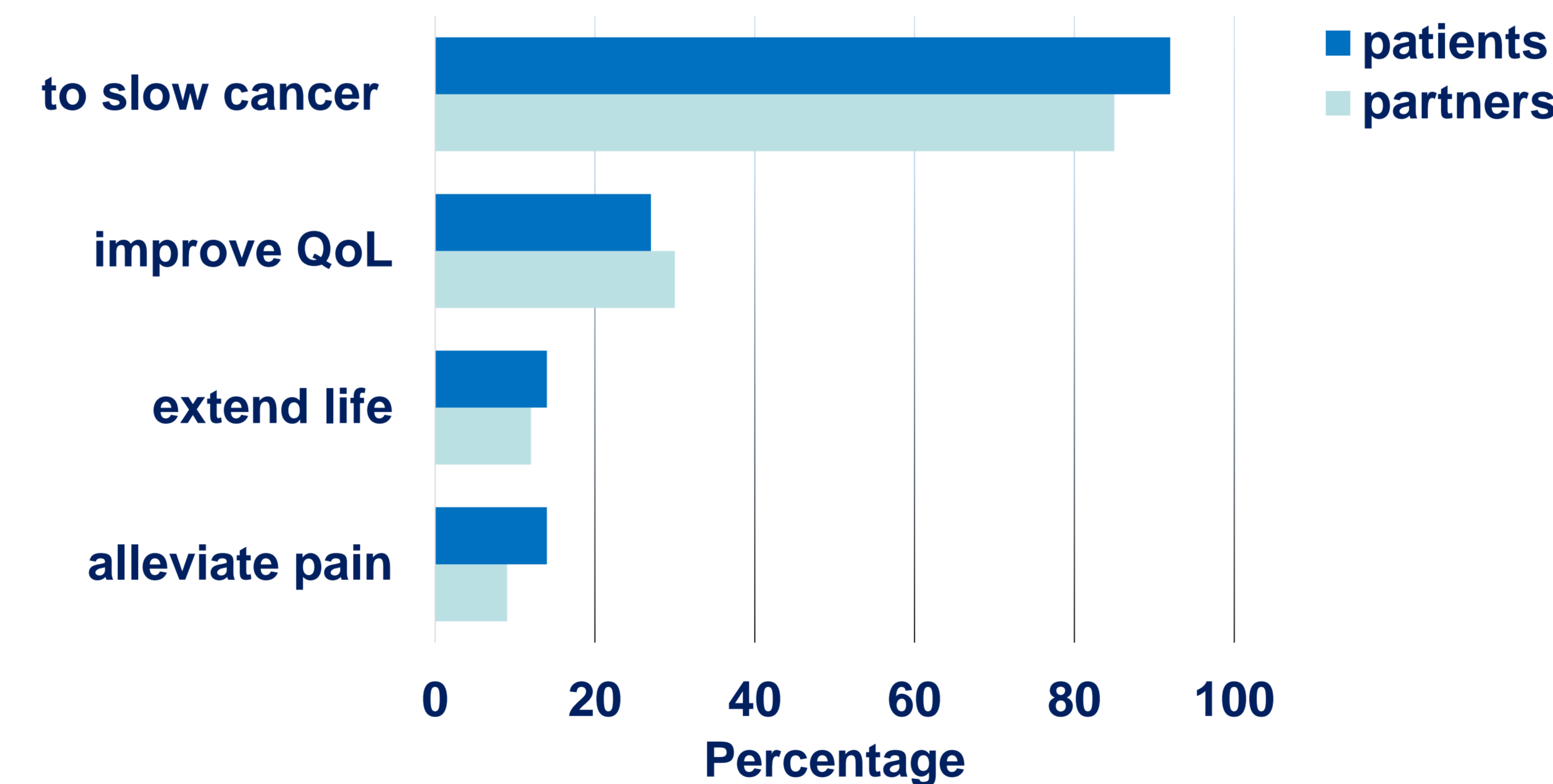
*"pain in my hip could be rheumatic" (P14, 56yrs)*

- ❖ 54% said Rx was a shared doctor-patient decision
- ❖ 87% felt spouses were integral to decision-making

### RESULTS (2): INFORMATION PROVISION

INFORMATION SOURCE	Married men (33)	Single men (4)	Spouse (33)
Clinician discussed SEs	29	1	29
<b>LEAFLETS received</b>			
drug company	16	2	15
Macmillan	15	1	13
hospital own	8	0	5
CRUK	3	0	0
other	2	0	1
None	3	1	4
<b>WEBSITES recommended</b>			
Macmillan	4	0	1
CRUK	1	0	0
Prostate Cancer UK	1	0	1
None	29	4	31
<b>Internet searched for more information about SEs</b>	11	0	18

### RESULTS (3): UNDERSTANDING OF Rx AIMS

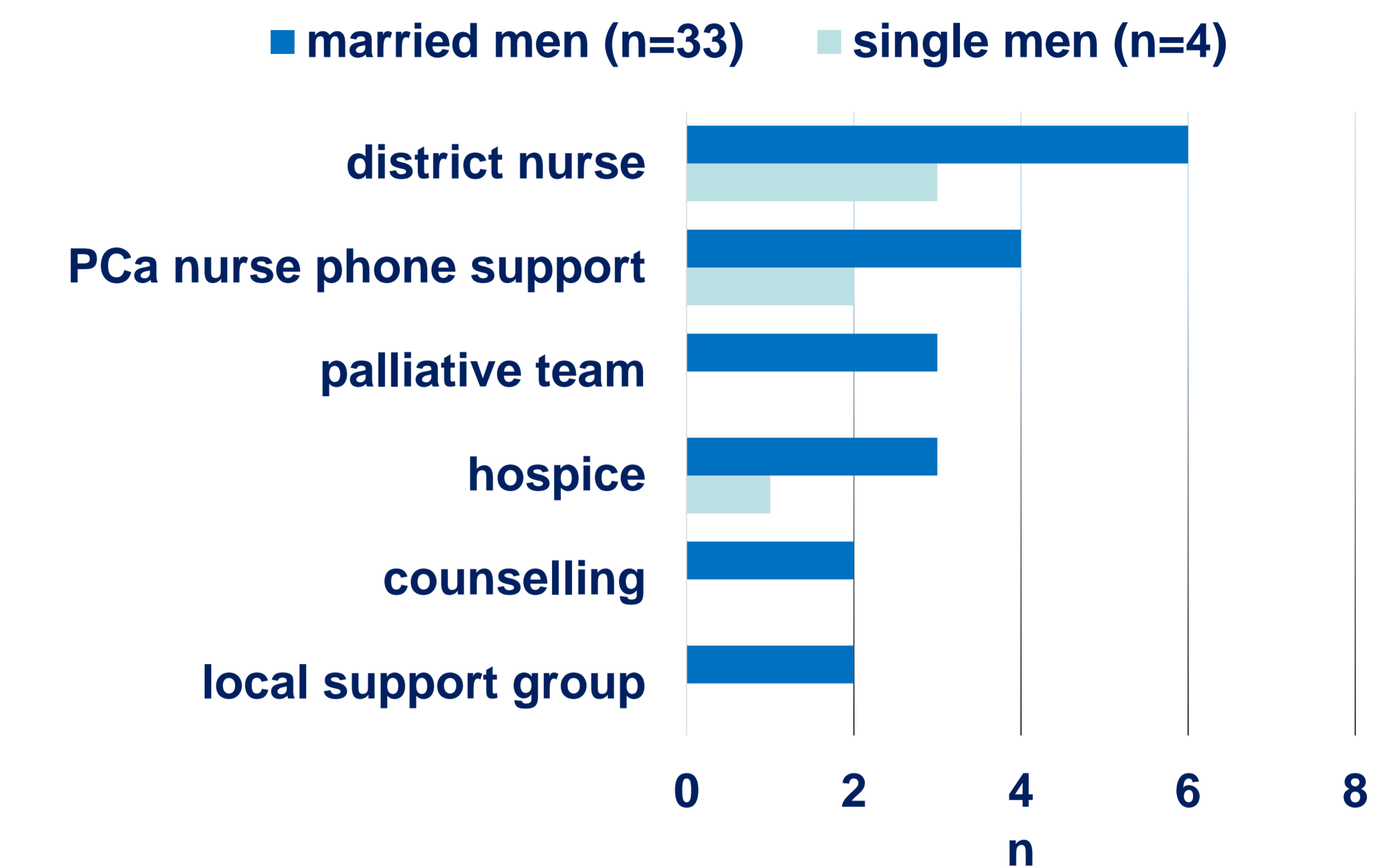


### RESULTS (4): EXPERIENCE AFTER 3 mths Rx

- ❖ 33% had recently had a pain management discussion
- ❖ fatigue was worst Rx-related SE for a majority (43%)
- ❖ 27% experienced unexpected SEs
- ❖ 54% had sought help for their SEs
- ❖ 46% had NO access to a prostate cancer (PCa) nurse in clinic

*"no opportunity to discuss my incontinence with a nurse" (P13, 69yrs)*

### RESULTS (5): SUPPORTIVE SERVICE USE (low utilization)



- ❖ 54% of the men had no interest in joining a support group
- ❖ it was evident male values hindered help-seeking

*"he doesn't like to look weak and ask for help" (S6, 69yrs)*

*"I think not wanting to have help from the hospice might be a male thing, wanting to keep going on your own" (P2, 68yrs)*

*"I prefer to keep things in the family" (P4, 69yrs)*

- ❖ appeals for partners/family to be supported were apparent

*"I feel particularly unsupported, I don't feel carers are supported enough" (S22, 57yrs)*

*"my 20yr old son's taken it badly, my wife is my rock, I'm very concerned, they need support too" (P14, 56yrs)*

### CONCLUSIONS

- ❖ achieving optimal QoS is challenging
- ❖ essential PCa nurse & palliative care resources increase to enable pain & other symptom amelioration
- ❖ clinicians need to be aware of men's reluctance to report pain, and/or attribute it to other ailments
- ❖ partners/family provide core of support & need help too
- ❖ dedicated mCRPC clinics are warranted