

**Living with and beyond Prostate cancer:
 A study of the impact on men of increased and
 variable investigation and treatment on the
 Island of Ireland**

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What is known?

- ▶ Prostate cancer most common male cancer, increased with PSA testing
- ▶ 41,000 cases per year UK
- ▶ 1,000 cases per year Northern Ireland (NI)
- ▶ 2,800 cases per year Republic of Ireland (ROI)
- ▶ Currently, limited population-based information on quality of life, physical and psychological side effects of prostate cancer investigation/treatment and decisional regret following treatment
- ▶ Previous research used sub groups of men, mainly qualitative in nature, small sample sizes and mainly hospital based

What is this research about?

- ▶ All Ireland Study – investigating side effects, regret and quality of life post prostate cancer investigation/treatment in the last 15 years
- ▶ All Ireland – similar men, 2 different healthcare systems, incidence, investigation and treatment differences

Differences between NI and RoI

Investigation differences

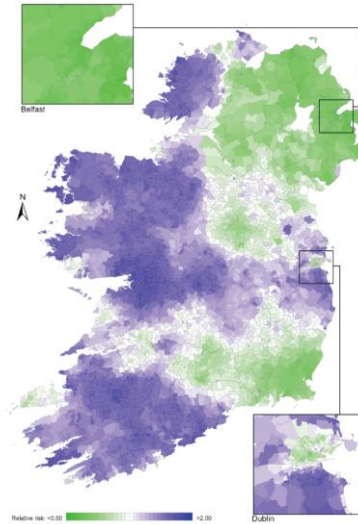
	1996		2006	
	NI	RoI	NI	RoI
PSA Test (Per 100,000)	30,000 (3,702)	10,000 (555)	70,000 (8,202)	131,600 (6,204)
Prostate Biopsy (Per 100,000)	1,500 (185)	900 (50)	2,300 (270)	3,200 (151)

Treatment differences

- RoI patients receive more radiotherapy and surgery and less hormone treatment than NI patients
- More younger men in RoI are diagnosed with prostate cancer than in NI
- Rates of diagnosis have been higher in RoI from 1996 onwards

Why this research in Ireland?

- Incidence of prostate cancer is 34% higher in ROI than in NI



Methods– treatment study

- ▶ –Postal Questionnaire to men, any age, identified by Cancer registries, vetted for exclusions by Research Nurses/Clinicians/GP's
 - end of life care
 - not aware of own diagnosis
 - cognitive/physical impairments
 - treating clinician felt patient should not receive the questionnaire
- 2 reminders

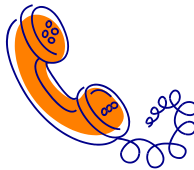
Standardised instruments used

- ▶ Demographics
- ▶ Treatments received
- ▶ Side effects experienced
- ▶ EORTC QLQ C30
- ▶ EORTC PR25
- ▶ DASS
- ▶ Decision regret scale
- ▶ EQ5D-5L
- ▶ Lifestyle changes

Methods – Processes

- ▶ Ethics and research governance
- ▶ Study adopted by National Cancer Research Network and NI Primary Care Network to confirm patient eligibility
- ▶ Honorary contracts and GCP training
- ▶ Questionnaire piloted

- ▶ Freephone facility set up – high volume of calls



- ▶ 13% in both RoI (n=632/4,838) and NI (274/2,106)

Methods – summary

- ▶ Identification of men NI and RoI (n=12,900) from cancer registries
- ▶ Stratified by time since diagnosis (1–2.9, 3–4.9, 5–9.9, 10+ years) – (n=3,225 in each)
- ▶ Eligible cases (n=4,838 RoI [61%], n=2,106 NI [45%])

Response rates

- ▶ Questionnaires returned NI – n= 1,010 (RR 48%)
- ▶ Questionnaires returned RoI – n= 2,494 (RR 54%)
- ▶ Overall response rate NI/RoI – 50% (3,504 questionnaires received from 6,944 issued)

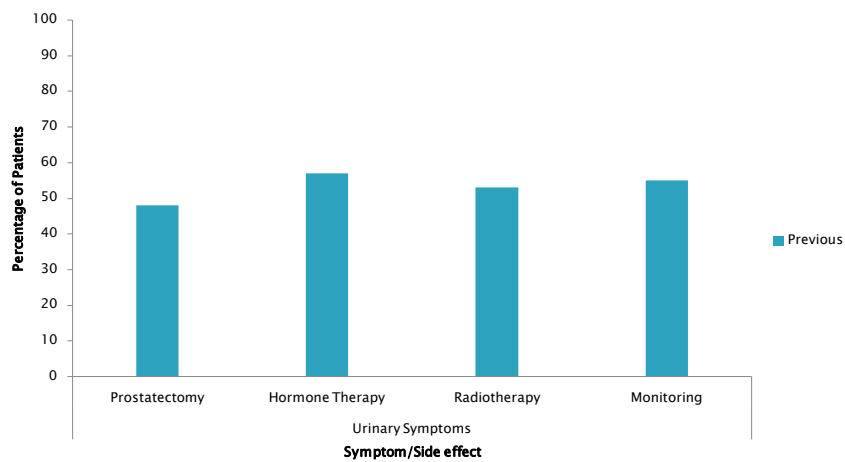
Demographics of respondents

- ▶ Two thirds aged 70–79 years
- ▶ Over 88% married/widowed and of these 6% lived alone
- ▶ One third had only primary level education
- ▶ One third (RoI only) on social welfare
- ▶ One third did not report any other co-morbidities

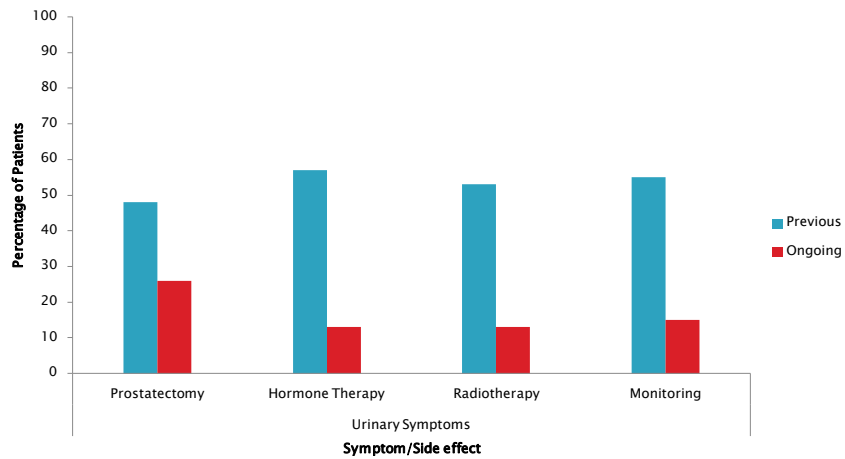
Q. Overall were your side effects ...?

	NI	RoI
Same as expected	27%	27%
Worse than expected	19%	20%
No side effects experienced	13%	18%

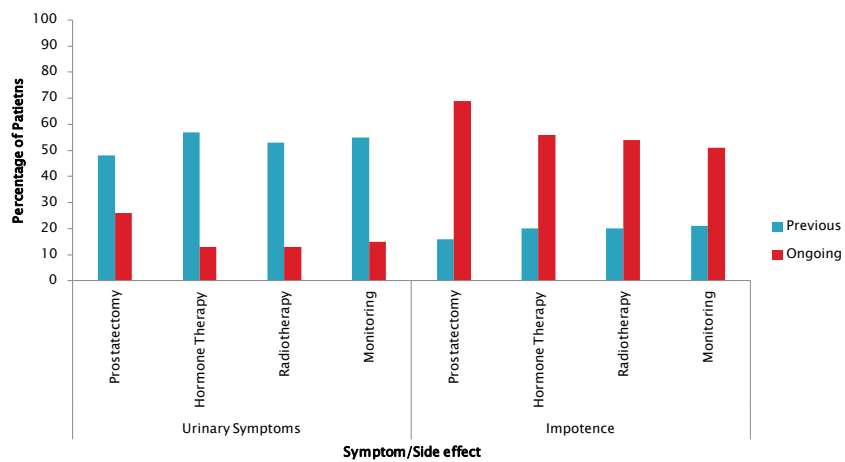
Urinary symptoms



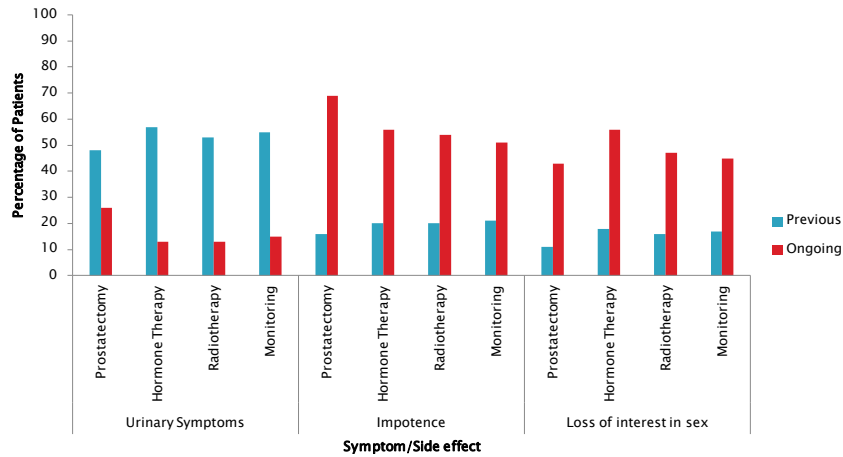
Urinary symptoms



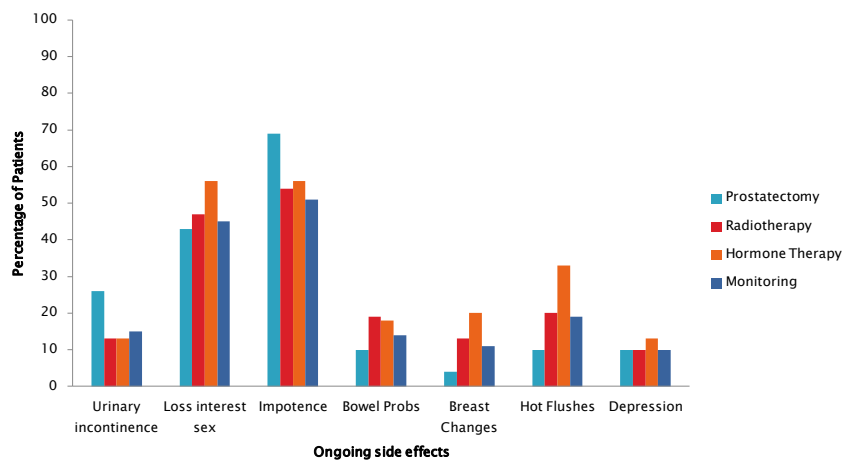
+ Impotence



+ Loss of interest in sex



Ongoing side effects



Multivariate analysis

Covariates		Urinary incontinence
Area	RoI	1.00
	NI	1.42 (1.13–1.78)
Prostatectomy	No	1.00
	Yes	3.37 (2.72–4.18)
Pre treatment urinary symptoms	No	1.00
	Yes	1.51 (1.23–1.86)
Co-morbidities	None	1.00
	1–2	1.33 (1.07–1.66)
	3+	1.98 (1.35–2.91)

Multivariate analysis

- ▶ A significant predictor of having bowel problems was having radiotherapy
- ▶ A significant predictor of having depression was having hormone therapy
- ▶ A significant predictor of having a loss of sexual desire/impotence was having a prostatectomy or hormone therapy
- ▶ A significant predictor of having hot flushes was having hormone therapy

Regret following treatment

- ▶ Each treatment has some disadvantage of unpleasant side effects (sexual, bowel, physical and psychological)
- ▶ Regret regarding impotence or incontinence rated equally in men (based on self report from questionnaire data)
- ▶ Men expressed regret but were still satisfied with their choice of treatment

Decision regret scale

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
It was the right decision	1	2	3	4	5
I regret the choice that was made	1	2	3	4	5
I would go for the same choice if I had to do it over again	1	2	3	4	5
The choice did me a lot of harm	1	2	3	4	5
The decision was a wise one	1	2	3	4	5

Regret following treatment choice

		Prostatectomy		Radiotherapy		Hormone therapy		Monitoring
		Yes	No	Yes	No	Yes	No	Yes
Decision Regret Scale	Little/no regret	82%	91%	90%	88%	90%	87%	92%
	No strong feelings	15%	8%	10%	9%	9%	11%	8%
	High regret	3%	1%	1%	3%	1%	2%	<1%
	P value	p=0.009		p=0.136		p=0.610		p=0.017

Prostatectomy and Monitoring show significance $p < 0.05$
 Prostatectomy shows highest level of regret

Regret – side effects

		Incontinence		Loss of interest sex		Bowel problems		Breast changes		Hot flushes	
		Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Decision Regret Scale	Little/no regret	80%	94%	88%	92%	85%	92%	90%	90%	88%	92%
	No strong feelings	17%	6%	11%	6%	14%	7%	9%	10%	11%	7%
	High regret	3%	1%	1%	2%	1%	2%	2%	1%	1%	1%

Emerging Themes

- ▶ Men are reporting large amounts of side effects following prostate cancer treatments
- ▶ Average regret score low –12.6%
- ▶ No demographic significance for regret scores
- ▶ Prostatectomy and active surveillance showed significance towards regret
- ▶ Men who report incontinence reported the highest levels of regret

Limitations of study and analyses to date

- ▶ Preliminary analysis
- ▶ Biases relating to responders (prostate cancer survivors) and first survey responders
- ▶ Limited to self-reported data
- ▶ Not yet standardised for age, stage, treatment received
- ▶ Multiple treatment groups need to be identified

Strengths of study

- ▶ Large cohort of prostate cancer survivors
- ▶ It compares 2 healthcare systems with different levels of uncovered disease and treatment
- ▶ It contributes to the debate of whether increased investigation and treatment, in the era of increased PSA testing leads to better health
- ▶ It is population-based
- ▶ It used standardised instruments

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