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# Quality of Life of Cancer Survivors in England

Findings from the Department of Health 2011  
Patient Reported Outcomes Measure (PROM) Survey &  
A Look Ahead to the roll-out of Gynae PROMs in 2013

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In strict confidence

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# Background

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- Growing prevalence of cancer – 3.2% per annum; 3.4 million by 2030
  - Unmet needs
  - Late morbidity recognised – little population based data for adults
  - Growing literature on late effects
  - Very few cancer PROMs for survivors
  - Addressing these issues should benefit the health and social care economy in the future
  - Aim to be able to compare quality of health of those living with, and beyond, cancer with other long term conditions
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## **Objective of Cancer PROMS programme**

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- To embed routine collection of PROMs within core business of cancer services
  - By using PROMs, to
  - Describe the quality of survival – not just about extending life.
  - Identify the consequences of survival/treatment and impact on function in a bid to continuously improve services.
  - Enable the provision of appropriate health & social care services.
  - Compare outcomes by service provider organisations
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## Participants in 2011 pilot PROMs

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- From 4 cancer groups (breast, colorectal, non-Hodgkin's lymphoma and prostate)
- 4 time points (1, 2, 3 and 5 years post diagnosis)
- Patients were identified from 3 cancer registries – ECRIC, WMCIU and TCR
- Around 300 patients with each cancer, and at each time point were surveyed (total 4992)
- Around 200 patients from each cancer/time group responded, with 3300 respondents in total (response rate 68%, plus high completion rates)

# 2011 PROM Survey content

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- Demographics and treatment details (self report)
- Disease status (remission, relapse, uncertain)
- Long term conditions
- Generic quality of life (EQ5D)
- Physical activity
- Social Difficulties Inventory
- Experience of care
- Psychological issues
- Work status
- Functional Assessment of Chronic Illness Therapy (FACT) tumour specific questions



Average – c.70 questions (breast 66;prostate 70;NHL 71;colorectal 72)

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# Demographics of all respondents (n=3300)

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- Median age 69 years (range 36-102)
- Males 52%; Females 46%; Missing 2%
- White 90.4%; Non-white 6.3%; Missing 3.3%
- Socioeconomic status
  - Least deprived 25% (n=826)
  - Most deprived 12% (n=399)
- Almost equal numbers by time since diagnosis
- Presence of long term conditions:
  - Yes = 55%; No = 38%; Not reported = 7%
- Remission status (self-report):
  - Remission 67%; Disease present 17%; Uncertain 17%

## Prostate : Quality of life (EQ5D): Individual domains

	No problems	Slight problems	Moderate problems	Severe/ extreme problems
Mobility	60% <b>62%</b>	16% <b>15%</b>	14% <b>11%</b>	8% <b>8%</b>
Self care	81% <b>82%</b>	8% <b>9%</b>	6% <b>5%</b>	2% <b>1%</b>
Usual activities	57% <b>61.5%</b>	19% <b>17%</b>	14% <b>12%</b>	8% <b>5%</b>
Pain	51% <b>61%</b>	28% <b>19.5%</b>	13% <b>12%</b>	6% <b>4.5%</b>
Anxiety/depression	61% <b>65%</b>	24% <b>21%</b>	10% <b>9%</b>	3% <b>1%</b>

(Figures rounded. Missing around 3-7% on each item)

Merged cohort data in normal font

**Prostate** data in **Bold**

# Quality of life: EQ5D summary score

	“High”	“Medium”	“Low”	Missing
<b>Total (n=3300)</b>	32	53	10	5
Breast (208)	24	60	9	7
Colorectal (255)	31	54	11	3
NHL (247)	32	51	13	4
<b>Prostate (347)</b>	<b>40</b>	<b>45</b>	<b>9</b>	<b>6</b>
<b>Patients in remission (n=2227)</b>				
No LTC (848)	51	44	2	2
1 LTC (691)	36	55	6	3
2+ LTCs (688)	19	61	<b>17</b>	3
<b>Patients not in remission (n=822)</b>				
No LTC (233)	34	56	6	4
1 LTC (277)	23	63	9	5
2+ LTCs (312)	12	53	<b>30</b>	5



# Factors associated with poor quality of life (EQ5D) – all respondents

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- Number of concurrent long term conditions  
(OR No LTC = 1; 1 LTC = 1.8; 2+ LTCs = 7.3)
- Disease status  
(OR remission = 1; Recurrence = 4.7; Not sure = 2.5)
- Deprivation  
(OR Quintile 1 = 1; Quintiles 2-4 = N/S; Quintiles 5 = 3.0)
- Age  
(65-74 year olds have best QOL)
- Physical activity  
(The more, the better QOL)
- Ethnicity and Time since diagnosis  
(NOT significant)

# Fear of recurrence and dying – all respondents

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<b>Time since diagnosis</b>	<b>Fear of recurrence (%)</b>	<b>Fear of dying (%)</b>
1 year	51.5	30.2
2 years	48.3	27.9
3 years	46.7	26.6
5 years	42.5	22.2
Total	47.3	26.8

# Physical activity – all respondents

- Overall: 21.4% of respondents reported taking 30 minutes of physical activity at least five days a week (in line with Government recommended level), but 29.8% reported doing no physical activity



	<b>30 mins x 5</b>	<b>No activity</b>
<b>Prostate</b>	<b>29.0%</b>	<b>27.4%</b>
Colorectal	20.2%	31.5%
Breast	19.0%	27.4%
NHL	16.5%	33.5%

- Higher physical activity levels were associated with better QOL.

# Quality of life – Comparisons with other studies

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	Median age	“High”	“Medium”	“Low”
<b>Cancer pilot PROMS</b>				
- All patients	69 years	32%	53%	11%
- In remission & no LTC	63 years	53%	44%	2%
<b>Health Survey England</b>				
	48 years	54%	39%	7%
	≥ 45 years	45%	46%	9%
<b>GP Patient Survey</b>				
- All patients	48 years	51%	42%	8%
- No LTC	39 years	74%	25%	1%

## Generic Findings

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- Measuring quality of life in cancer survivors in the community, on a population-basis who are 1-5 years post diagnosis, is feasible and acceptable to patients. “Proof of Principle” established
- The 2011 pilot study is the largest European survey of cancer survivors involving multiple cancer types, at defined time points, post diagnosis – to date.
- On the summary EQ5D measure
  - Around one third are scored as having ‘high’ QOL
  - Around one half are scored as having ‘medium’ QOL
  - Around 10% are scored as having ‘low’ QOL

## Generic Findings (2)

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- QOL changed surprisingly little over time since diagnosis (though fear of recurrence/dying decreased)
- QOL is closely associated with disease status and presence of other long term conditions (LTC)
- Amongst those who were in remission with no LTC
  - Over half had 'high' QOL
  - 44% had 'medium' QOL
  - Only 2% had 'low' QOL
- Comparisons with normative data from other surveys using EQ5D are difficult because of age differences

# Prostate - specific Findings

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- Respondents who had surgery reported a better QoL
- Those who did more physical activity reported a better QoL
- 38.5% reported some degree of urinary leakage, significantly associated with poorer QoL
- 12.9% reported difficulty controlling their bowels
- 58.4% reported being unable to have an erection
- 11% reported significant difficulty in having or maintaining an erection
- Surprisingly, erectile dysfunction and difficulty controlling bowels were not significantly associated with QoL

## Next Steps

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- Follow – up, longitudinal survey of the 2011 respondents ended. 85% response rate overall.
- 4 x pilot pelvic cancer PROMs developed – bladder, cervix, ovary and womb cancers.
- 1 x national bowel cancer PROM to be rolled out in early 2013



# Gynae PROMs content

- Demographics and treatment details (self report)
- Disease status (remission, relapse, uncertain)
- Long term conditions
- Generic quality of life (EQ5D)
- Items from the European Organisation for Research and Treatment of Cancer
- FACT
- Physical activity
- Social Difficulties Inventory
- Experience of care
- Psychological issues
- Work status
- Length of surveys – bladder = 100;womb,ovarian,cervical = 106



## The Gynae PROMs...

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- NIGB approval gained
- Involvement of patient volunteers and charities to test length, clarity of purpose and language of surveys.
- Licence agreements with FACIT & EORTC in train
- 3<sup>rd</sup> party survey company about to be appointed, following an open competition process.
- 1250 cohort for each tumour group, at 1,2,3 and 5 years post diagnosis, extracted from all 8 cancer registries.
- Fieldwork will be from January – March 2013
- Final report – early April 2013

# Thank You for Listening

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## Any Questions?

### Contact details

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