

# Quality of Life of NHL Survivors in England

Findings from the 2011 pilot Department of Health  
Patient Reported Outcomes Measure (PROMs) Survey

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27<sup>th</sup> September 2012

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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
    - Identify the consequences of survival/treatment and impact on function
    - Enable the provision of appropriate health & social care services
    - Compare outcomes by service provider organisations
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## Patients 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 in each cancer/time group responded, with 3300 respondents in total (response rate 68%, plus high completion rates)

# 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
- Tumour specific questions (Functional Assessment of Chronic Illness Therapy)



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%

# Demographics of NHL respondents n=778

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- Age
    - <55y **20%** 55-64y **22%** 65-74y **31%** 75-84y **22%** 85+y **5%**
  - Males 54%; Female 45%; Missing 1%
  - White 88%; Non-white 8%; Missing 4%
  - Socioeconomic status
    - Least deprived 26% (n=202)
    - Most deprived 12% (n=91)
  - Almost equal numbers by time since diagnosis 25%, 24%, 27%, 24%
  - Long term conditions:
    - Yes = 56%; No = 37%; Not reported = 7 % (don't know 4%; missing 3%)
  - Remission status (self-report):
    - Remission 68%; Disease present 10%; Uncertain 12%
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# Quality of life (EQ5D) for all respondents: Individual domains

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	<b>No problems</b>	<b>Slight problems</b>	<b>Moderate problems</b>	<b>Severe/extreme problems</b>
Mobility	60%	16%	14%	8%
Self care	81%	8%	6%	2%
Usual activities	57%	19%	14%	8%
Pain	51%	28%	13%	6%
Anxiety/depression	61%	24%	10%	3%

(Figures rounded. Missing around 2% on each item)



# NHL Quality of life (EQ5D): Individual domains

	No problems	Slight problems	Moderate problems	Severe/ extreme problems
Mobility	60% <b><u>55%</u></b>	16% <b><u>18%</u></b>	14% <b><u>15%</u></b>	8% <b><u>10%</u></b>
Self care	81% <b><u>78%</u></b>	8% <b><u>8%</u></b>	6% <b><u>9%</u></b>	2% <b><u>2%</u></b>
Usual activities	57% <b><u>53%</u></b>	19% <b><u>20%</u></b>	14% <b><u>16%</u></b>	8% <b><u>10%</u></b>
Pain	51% <b><u>52%</u></b>	28% <b><u>23%</u></b>	13% <b><u>15%</u></b>	6% <b><u>8%</u></b>
Anxiety/depression	61% <b><u>60%</u></b>	24% <b><u>24%</u></b>	10% <b><u>11%</u></b>	3% <b><u>4%</u></b>

(Figures rounded. Missing around 2% on each item)

Merged cohort data in normal font

**NHL** 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
<b>NHL (247)</b>	<b>32</b>	<b>51</b>	<b>13</b>	<b>4</b>
Prostate (347)	40	45	9	6
<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	17	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	30	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)
- Time since diagnosis  
(NOT significant)
- Age  
(65-74 year olds have best QOL)
- Physical activity  
(The more, the better QOL)
- Ethnicity  
(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



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

- Higher physical activity levels were associated with better QOL, but...

# NHL and QoL

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- Physical activity
  - Significant positive association between increasing physical activity and QoL
  - Each additional day of physical activity reduced the odds of poorer QoL by 9% (OR 0.91, 95% CI 0.84,0.98)
- LTCs
  - Presence of 1 or “2 or more” LTCs significantly associated with poorer 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%

## Discussion (1)

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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
- Although this was a pilot study, it is the largest European survey of cancer survivors involving multiple cancer types, at defined time points, post diagnosis.
- 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



## Discussion (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

## Next Steps

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- Follow – up, longitudinal survey of the 2011 respondents just closing. 85% response rate overall; for NHL 79% at 1yr → 89% at 5 years
- 4 x pilot pelvic cancer PROMs being developed – bladder, cervix, ovary and uterus will be rolled out in early 2013
- 1 x national colo-rectal PROM will be rolled out in early 2013
- Presentation being made to central PROMs steering group 28/09/12 including recommendation of 3<sup>rd</sup> data collection point for the 2011 cohort, including NHL, in July 2013

## Thank You for Listening

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Any Questions?

Please direct them to  
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