

PROSTATE CANCER OUTCOMES | LIFE AFTER PROSTATE CANCER DIAGNOSIS

IN PARTNERSHIP WITH PROSTATE CANCER UK

PROSTATE CANCER OUTCOMES
LIFE AFTER PROSTATE CANCER DIAGNOSIS

Prostate Data For PROMs

Investigating Patient Understanding of Their Diagnosis

Paul Stacey - Quality Assurance Analyst (LAPCD)

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LAPCD: A study to investigate the full range of issues that could effect men with prostate cancer

This is the largest survey of its kind looking into prostate cancer outcomes in all four UK countries

www.lifeafterprostatecancerdiagnosis.com

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The Study Aims:

- Using qualitative and quantitative methods describe the health-related quality of life (HRQL) of men with prostate cancer

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- Undertake a study of men without prostate cancer to determine levels of symptoms in the community for comparison

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Methodology:

- Identify prostate cancer survivors in all four UK countries

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- Identify prostate cancer survivors in all four UK countries.
- The first cohorts within each country will be surveyed twice, 12 months apart, with second cohorts surveyed once.

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- Develop a comprehensive survey using generic and cancer-specific measures of HRQL, including EQ-5D, EPIC-26 and the Social Difficulties Inventory, plus patient perspectives measures (the Decision Regret Scale and Patient Empowerment Scale).

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- Develop a comprehensive survey using generic and cancer-specific measures of HRQL, including EQ-5D, EPIC-26 and the Social Difficulties Inventory, plus patient perspectives measures (the Decision Regret Scale and Patient Empowerment Scale).
- Conduct telephone interviews with a sample of men who complete the survey (~100) along with a small number of partners/spouses (~20).

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LAPCD Program: Phase 1

111 Participating Trusts

Cohort 1: Men Diagnosed April 2012 to March 2014


NCRAS Identified patients

50,346 Postal surveys sent

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Survey response



60% surveys were returned

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Survey


- First question asked:
Have you ever been told by a doctor that you have prostate cancer?

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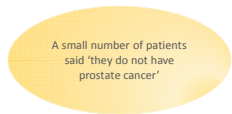
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Response



60% surveys were returned



A small number of patients said 'they do not have prostate cancer'

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Review of patients that stated 'I don't have cancer'

- The patients that stated 'I do not have cancer' are to be reviewed

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- Initial findings are:
 - This is not a localised issue

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- Initial findings are:
 - This is not a localised issue
 - There is evidence that these cases **Do** have prostate cancer

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- Initial findings are:
 - > This is not a localised issue
 - > There is evidence that these cases **Do** have prostate cancer
 - > 74% have pathological confirmation

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- Initial findings are:
 - > This is not a localised issue
 - > There is evidence that these cases **Do** have prostate cancer
 - > 74% have pathological confirmation
 - > Investigate if there are any commonality to these patients - for example age, stage or complexity of disease or treatment

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Next steps

- Feed back results directly to Trusts and clinical teams
- Provide Data Liaison support to assist Trusts to investigate these cases
- Raising Trust awareness nationally
- Phase 2 – Survey of Men diagnosed in 2015

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Questions?

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