Scoping Needs and Mapping Rehabilitative Services for Men with Prostate Cancer in North East London.

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St Joseph's Hospice and Barts Health NHS Trust
The Project is funded by Prostate Cancer UK

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Executive Summary

Evidence shows that exercise reduces the risk of prostate cancer disease progression by 57% and recurrence and mortality by 30%. However evidence demonstrates that men having undergone cancer treatment have rehabilitation needs, but hesitate to participate in the rehabilitation services offered.

A growing problem ensues, where men with prostate cancer are not benefitting from the research based positive effects from rehabilitation following a cancer diagnosis with a long term financial impact caused by mortality and disability. To tackle these and other issues the charity Prostate Cancer UK (PCUK) launched the Health and Social Care Programme, working with the NHS and health organisations to test new models of care. St Joseph's Hospice and Barts Health have joined forces to support a 18 month PCUK funded project to 'improve rehabilitation for men with prostate cancer in north east London' headed by a Band 7 physiotherapist with support of a Band 4 Rehabilitation Assistant.

Before rolling out the clinical service, the first work stream aimed to:

- explore what services are available for men with prostate cancer and their partners/ carers and discover how many men are accessing these services
- better understand, the unmet needs of local men with prostate cancer and their carers and discern how this would best be addressed by this AHP led rehabilitation service.

This was achieved through:

- contacting stakeholders
- questionnaires for professional/men/partners/carers
- semi-structured interviews
- observation
- focus groups for men/partners/carers
- online survey.

The main mapping findings are that the incidence and mortality of prostate cancer in North East London (142.8 per 100,000) is higher than the national average (105.8 per 100,000) and prostate cancer is trending to become the most common cancer by 2030.

Despite the high prevalence of prostate cancer in North East London, during the last financial year very few men accessed existing rehabilitation services in the area. At St Joseph's Hospice patients with a primary diagnosis of prostate cancer represented very small percentages of patients supported by the hospice (2.5% of all cancers seen by the community palliative care team, 7% of day hospice, 3.5% of in-patient stays and 1% of physiotherapy out-patients), zero men have completed the Barts Health Trust, hospital

outpatient based 6 week survivorship course. Better gyms are the only service offering a 12 week exercise programme, which caters for those living close enough in Newham and Hackney, however currently we have no data available on the number of men with prostate cancer accessing this service.

The main findings arising from the scoping project are:

- men are best engaged via face to face contact
- men report a lack of information about their condition and support services available
- clinicians report that men with prostate cancer are provided with information but have a poor retention of information
- there is a lack of referrals of men with prostate cancer by professionals to local rehabilitation services
- professionals are keen to improve male participation in rehabilitation
- dominant themes from the focus groups highlighted mens' psychological concerns around fear/worry/sexuality.
- men's health beliefs were divided between no interest in exercise and wanting to return to normality versus an enthusiasm to learn more regarding 'what is best'.

Conclusions from the scoping project are that it is key to ensure men with prostate cancer are provided with information about their condition, the important beneficial effects of exercises to reduced disability and mortality and the rehabilitation services available to them locally throughout the disease pathway. There is a need to ensure professionals working with men with prostate cancer also have a sound knowledge of the importance of rehabilitation so that they can inform men and proactively refer them to local services.

Opportunities exist to engage men in rehabilitation through face to face exercise promotion at prostate clinics, to provide individualised assessment and treatment by an allied health professional and to develop community based 12 week exercise programmes across North East London (as prostate cancer is not currently included in the exercise on prescription criteria).

To address these findings this project will now undertake a 3 month pilot of three rehabilitation interventions: face to face exercise/health promotion in clinics, referral of men impaired physically by prostate cancer to one to one physiotherapy sessions and a 12 week exercise group.

Background

Prostate cancer is now the most common cancer in men in the UK. More than 41,700 men were diagnosed in the UK in 2011 with areas of London identified as having some of the highest incidence rates nationally[i]. While survival has increased substantially over the last 40 years, prostate cancer is the second highest cause of male cancer death in the UK[ii].

Evidence shows that prostate cancer and its various treatments are associated with a wide range of distressing physical and psychological symptoms, including fatigue, lymphoedema, anxiety, depression, hot flushes and impaired mobility[iii] which can affect individuals for many years.

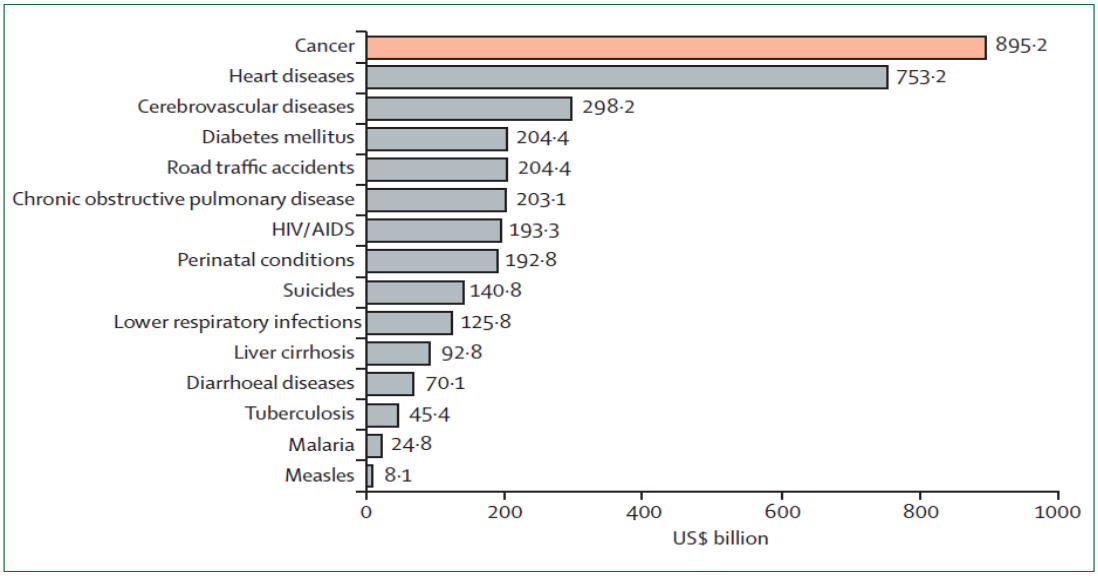
There is increasingly strong evidence that physical activity can help prevent and manage these symptoms[iv]. Evidence shows that exercise reduces the risk of prostate cancer disease progression by 57%[v]and recurrence and mortality by 30%[vi].

The World Health Organisation has Quantified the global burden created by prostate using a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death which is called disability adjusted life years (DALYS)[vii] A 2012 article published by the journal of public health calculated the annual DALYS created by prostate cancer in 2008 in England and Wales is 444 577 (or 341 per 100,000).[viii]

Economic Impact

This data has been utilised to measure the financial burden which in 2008 showed the global impact of cancer in DALYS is greater than all other diseases.[ix]

0.1 **Graph showing the 2008 worldwide cost of cancer due to premature death and disability (not including direct medical costs)**



Men's Health

Rehabilitation is defined by the World Health Organisation (2011) as "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments"[x] Macmillan's evidence review recommends that men with prostate cancer should be assessed at various stages during the cancer pathway to ensure that the appropriate rehabilitation service is identified and provided[xi].

However, research shows that men having undergone cancer treatment have rehabilitation needs, but hesitate to participate in the services offered[xii]. Research is in its early stages regarding how best to engage men into more positive health behaviours[xiii], which may explain why men develop and die sooner from cancers that statistically should affect men and women equally. Men appear to have poorer health habits and less interest in healthy lifestyle and often keep their problems to themselves[xiv]. Therefore exploring how to effectively engage men into optimal physical activity is an important outcome from this project.

Combining the issues of:

- ✓ **The increasing prevalence of prostate cancer[xv].**
- ✓ **The negative impact of prostate cancer disability and death on the economy[xvi].**
- ✓ **Men have reduced participation in cancer rehabilitation[xvii] .**
- ✓ **Increasing evidence base that exercise reduces the risk of prostate cancer disease progression by 57%[xviii]and recurrence and mortality by 30%[xix].**

A growing problem ensues, where men are not benefitting from the research based positive effects from rehabilitation following a cancer diagnosis[xx], a gender divide is being created with a long term financial impact caused by mortality and disability.

To tackle these and other issues the charity Prostate Cancer UK (PCUK) launched the Health and Social Care Programme, working with the NHS and health organisations to test new models of care.

Therapy managers at St Joseph's Hospice and St Bartholomew's Hospital submitted a successful bid to PCUK to fund a band 7 Allied health professional and a Band 4 rehabilitation assistant for 18 months to deliver the project 'Improving Rehabilitation for men with Prostate cancer in East and North London'.

The joint nature of this project between St Joseph's Hospice and Barts Health aims to promote greater integration of treatment between primary, secondary and tertiary care services in north east London. With the hope of better co-ordinated care and transitions between services ensuring men with prostate cancer and their carers receive timely information and rehabilitative support, appropriate to their individual and changing needs.

National drivers

The National Cancer Survivorship Initiative (NCSI) is a partnership between the Department of Health and Macmillan Cancer Support which is supported by NHS Improvement. The aim of the NCSI is to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible[xxi]. This project builds on the National Cancer Survivorship Initiative to ensure that men affected by prostate cancer have access to the specialised care they need across primary and secondary care.

Since 2007, the National Cancer Action Team (NCAT) worked on a range of projects designed to 'improve the provision of rehabilitation services for cancer and palliative care patients in line with National Guidance[xxii]. NCAT has now ended but the evidence-based rehabilitation pathways for urology continues to remain hugely influential in high-lighting the multi-dimensional impairments caused by prostate cancer and it's treatment, which must be addressed by and allied health professional[xxiii].

The Gold Standards Framework (GSF) for End of Life Care (EOLC)[xxiv] was developed within primary care in 2000 but has grown significantly to meet the challenge of end of life care, in the light of the NHS End of Life Care Strategy in England[xxv]. The GSF systematic common-sense approach embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together. Consequently learning through this project about how many men access palliative care services and establishing early referrals for men with prostate cancer to palliative care will be essential when optimising the support services and elevating the disability caused by prostate cancer.

Local drivers

London Cancer is the name given to the Integrated Cancer System in North and North Central London. London Cancer aims to provide 'expert, compassionate care for every patient, every time[xxvi]. Instead of thinking about care at an individual hospital level, London Cancer clinicians at local hospitals will work in partnership with colleagues from across the system to map out a comprehensive, seamless clinical pathway for every patient. London cancer has established a urological pathway boards as well as specialist advisory boards for cross-cutting themes such as Living with and beyond cancer.

This Project

This project aims to develop comprehensive, integrated rehabilitation services tailored to meet the needs of men with prostate cancer and their partners throughout the disease pathway.

In order to achieve this, the first objective and content of this document is to:

- Explore the unmet needs of local men with prostate cancer and their carers and how these can be best managed by an integrated, AHP led rehabilitation service that bridges oncology and palliative care.

It is essential to first understand:

- ✓ What rehabilitation services are available for men with prostate cancer?
- ✓ How many men are accessing these services?
- ✓ What are the stakeholder's opinions on rehab services?
- ✓ Where are the gaps in rehabilitation?

Method

Aim

- Explore what services are available for men with prostate cancer and their partners/ carers and discover how many are accessing them.
- To explore the unmet needs of local men with prostate cancer and their carers and discern how this would best be addressed from the service users point of view.

Design

A guide to improving services published in 2012 by the NHS Change Model is a framework for change to help NHS commissioners and providers improve how they go about improvement and deliver NHS goals for quality and value through a common language for change. This document recommends that before implementing a solution and changing your service, it is essential to understand your current system by mapping the process, collecting and analysing the service data, along with asking patients and staff for their views in order to determine where improvements can be made.

The Mapping Comprised of:

1.0 **Table showing the methods used to map prostate cancer in north east London separated by professional and patient work streams:**

Men with Prostate Cancer and partners/carers	**Clinicians and Professionals**	
Semi-structured Interviews	Semi-structured Interviews	See Appendices
Focus Groups	Emailed questions	
Questionnaires	Questionnaires	
Survey Monkey	Analysis of Trust data	
Observation	Observation	

The scoping comprised of:

1.1 **Table showing the methods used to scope prostate cancer in North East London separated by professional and patient work streams:**

Men with Prostate Cancer and partners/carers	**Clinicians and Professionals**	
Semi-structured Interviews	Semi-structured Interviews	
Focus Groups	Emailed questions	See Appendices
Survey Monkey	Questionnaires	
Questionnaires	Analysis of Trust data	
Observation	Observation	

1.2 **Table showing potential pros and cons of measuring qualitative experience:**

Approach	Main advantages	Main limitations
In-depth interviews	In-depth information Can probe reasons Can handle sensitive topics	Resource intensive May have difficulty interviewing same people over time Generalisability issues with small samples
Focus groups and panels	In-depth information Can reconvene same group over time Group dynamic can spark ideas	Generalisability issues/selection bias Resource intensive May experience high rates of drop out over time
Surveys	Can gain large amount of feedback Can use multiple administration methods (post, kiosks, online, text messages, comment cards, telephone, in-person) Wide range of validated surveys available	May collect only a surface level picture, rather than understanding why people feel a certain way Subject to self-selection and literacy bias Closed-ended questions may be more likely to gain positive feedback
Online rating tools	Increasingly promoted and available to many people, so can get ratings from large numbers	Only those who use websites provide feedback Surface-level information only Only cover selected components of patient experience

[xxvii] The Health Foundation Inspiring improvement (June 2013).

Targeted Population

- ✓ All men and their partner/carers who are living with or beyond prostate cancer and are being managed by Barts Health Hospitals and St Joseph's Hospice, or who live in the corresponding geographical remit of these organisations.
- ✓ Clinicians and professionals who assess, treat and support men and their partner/carers who are living with or beyond prostate cancer and are being managed by Barts Health Hospitals and St Joseph's Hospice.

Contact with clinicians and professionals

For both mapping and scoping purposes making contact with the professionals working within the prostate cancer pathway was imperative to understand what rehabilitative services are currently in place, explore what the unmet needs are from the their viewpoint and to build relationships for the sustainability of this project.

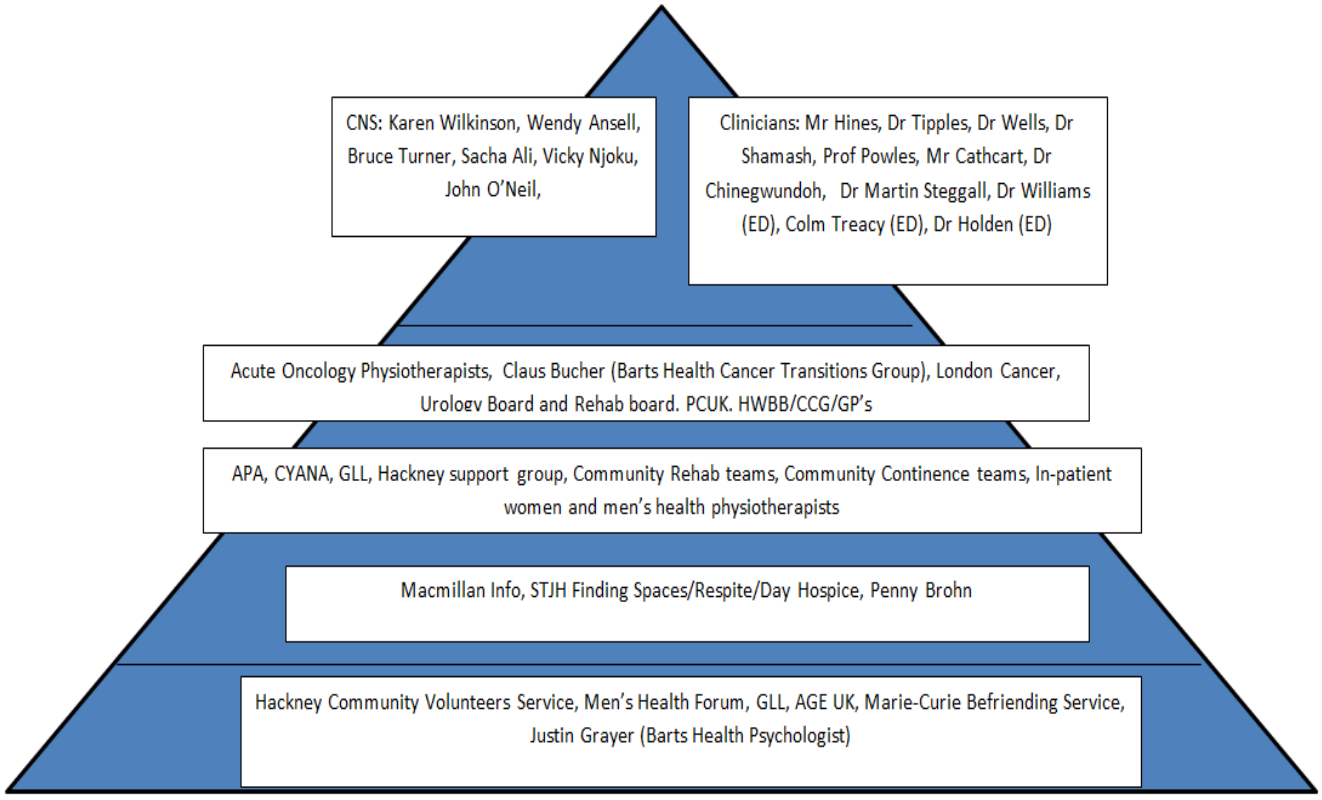
There was no pre-existing directory of the stakeholders in the prostate cancer pathway, therefore I contacted the urology CNS's at each acute hospital and gained knowledge of the urology/oncology clinicians and avenues for onward referral and contacted them all via email or face to face contact.

Limitations:

- There is the possibility that a clinician or professional may have been missed. This is a risk as there has been no map or directory to work from. If this is the case the map and directory will be updated accordingly.

Please see below at the hierarchy map of the clinicians and professionals involved in the care of men with prostate cancer and their partners/carers. The hierarchy is based on those who have the greatest understanding of the prostate cancer pathway and professionals involved from top down. The full list of clinicians/professionals and their contact details are available in the appendices.

1.2 **Diagram representing the clinical stakeholders within the project and the priority of contact:**



Data Source

The NHS Institute for innovation and improvement[xxviii] recommends that service users are engaged via individual and group methods to gain qualitative data, which I have utilised and explained below:

1. Questionnaires for the Clinicians and Professionals

In April 2014 a questionnaire was developed (Appendix 2) for clinicians and professionals involved in the care of men with prostate cancer in east and north east London and emailed and when possible delivered face to face.

2. Questionnaires for men with prostate cancer and their partners/carers

In April 2014 a questionnaire was developed for men with prostate cancer and their partners/carers (Appendix 2). It aimed to explore with open questions what rehabilitation means to them, what interventions or support they received, followed by a 0-5 scale to complete regarding how they would rate exercise/support/rehabilitation in their community.

The questionnaires were distributed in a multitude of ways to maximise engagement and participation:

- Emailed out to the all the clinicians and professionals with a request that they were handed out to the men living with or beyond prostate cancer and returned to myself.
- Questionnaires where left in the out-patient department at St Bartholomew's Hospital.
- I spent 2 days in the Urology/Oncology clinic across Barts Health with a stall and handed out the questionnaires to consenting participants.
- Mailed out with an information sheet (Appendix 2) to all the men with prostate cancer known to St Joseph's Hospice.
- I spent an afternoon in Dalston Library with a PCUK stand to engage the community.

3. Semi- Structured Interviews

For men with prostate cancer who were in-patients in St Joseph's Hospice and limited by pain and fatigue; I discussed the project, gained consent and under-took a semi-structured interview following the same topics as the questionnaire.

4. Observation

I attended clinics that men with prostate cancer would attend in Barts Health and Homerton and gained information for the mapping of rehabilitative services and the clinical pathway for men with prostate cancer in east and north east London.

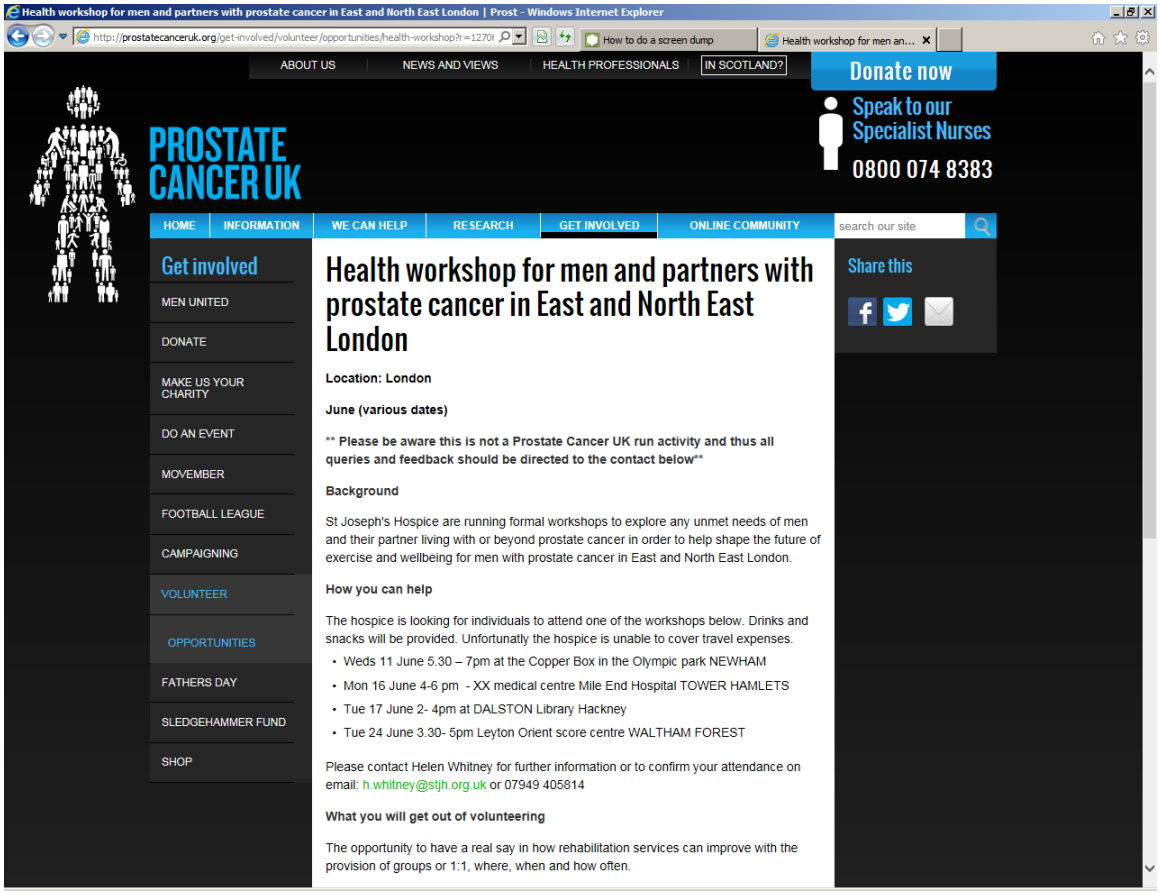
5. Focus Groups

Focus groups were organised in City, Hackney, Newham, Waltham Forest and Tower Hamlets to gather qualitative information in line with the projects scoping and mapping aims. Information sheets where provided and consent was gained to record the session with a Dictaphone (see appendix 3).

Advertising methods for the focus group:

- Met with all CNS's to recruit appropriate men and partner/carer.
- Created promotion poster for each focus group (Appendix 2).
- Emailed promotion posters to all stakeholders to disseminate.
- Positioned promotion posters in urology out-patient clinics with Barts Health, local barbers on Mare Street, GP poly clinic in Waltham Forest.
- Positioned promotion posters on the corresponding borough's Health watch website and CCG website.
- Promotion positioned as screen saver in Tower Hamlets Idea Stores.
- Promotion loaded onto the PCUK website.
- Promoted face to face at Barts Health Urology/Oncology clinics.
- Promotion stall in clinic and Dalston Library

1.3 See example of online advertising for the focus group (more in appendix 2).



6. Online Survey

An online version of the questionnaire was entered onto a web monkey survey (https://www.surveymonkey.com/s/SLG9N7G)

Analysis

All of the data will be documented and thematic analysis used to make meaning of the qualitative data.

Limitations:

- I was unable to mail out the questionnaires to all the men know to Barts health with prostate cancer the questionnaires due the concern of sending it to those who had died which could cause distress.
- Unfortunately no men living in City were recruited, therefore no focus group was organised in this location. Due to low demand in Hackney the Focus Group merged with the other focus groups. The three focus groups followed the agenda in Appendix 2 and the individuals where given an information and consent sheet (see appendix 2).

- Email addresses are not kept on the Barts Health or St Joseph's database therefore there has been no dissemination of the online survey.
- Poor response rate with the clinicians and professionals with regards to handing out the questionnaires due to very busy clinics.

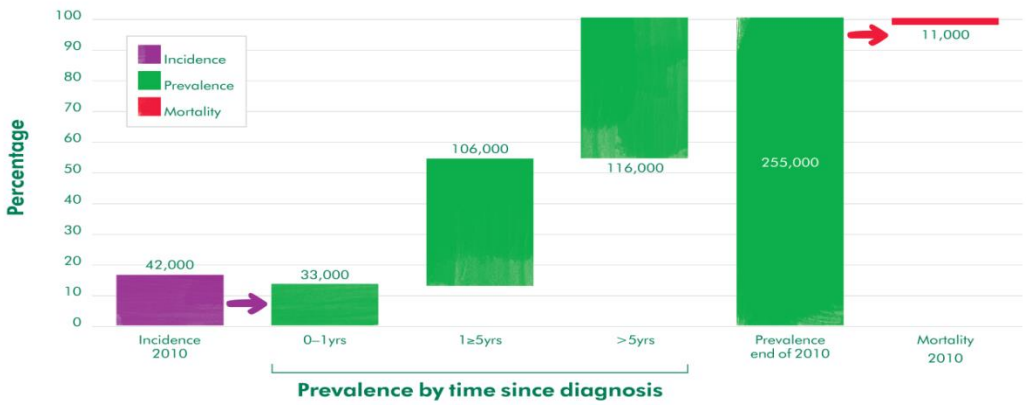
Findings

Mapping

Each number will present a mapping statistic or finding which helps map the service data and current system for men with prostate cancer and their partners/carers. This will be followed by a visual or written format of the findings and an explanation of its meaning and repercussion regarding rehabilitation.

2.0 **Graph showing the estimated prevalence in the UK in 2010 of men who had been diagnosed with prostate cancer that year plus those men who were alive and previously diagnosed in the last 10 years.**

Figure 1: People newly diagnosed, people living with prostate cancer by year since diagnosis and deaths for people with a prostate cancer diagnosis, UK, 2010



Findings:

- Based on survival rates, Macmillan Cancer Support estimated that of the 255,000 men living with prostate cancer in the UK in 2010 approximately 13% (33,000) had been living with the disease for less than 1 year, 42% (106,000) between 1 and 5 years and 45% (116,000) more than 5 years[xxix].
- 255,000 men living with and after prostate cancer in the UK in 2010 represents 30% of all UK men living with and after a cancer diagnosis (850,000 men)[xxx].

Implication on rehabilitation:

- Increasing numbers of men surviving the disease means an increasing number who should be undertaking regular exercise to reduce the possibility of recurrence and progression[xxxi].

- Exploring how the impact of a physiotherapist and rehabilitation assistant can engage these men into healthier behaviours is imperative to manage the socio-economic burden created by prostate cancers rising incidence and survival.

2.1 **The number of men living with and after prostate cancer in the UK is predicted to rise**[xxxii]

	2010	**2020**	**2030**	**2040**
Prostate	255,000	416,000	620,000	831,000
Breast	570,000	840,000	1,212,000	1,683,000

Findings:

- Based on the projected number of cases to be diagnosed in the year 2030, 61,069 for prostate cancer versus 57,442 for breast cancer[xxxiii] . By 2030, prostate cancer is predicted to become the most common cancer in the UK.

Implication on rehabilitation:

- This is a call to arms for stakeholders in prostate cancer to learn more about effectively engaging men to exercise, as the number of men affected is predicted to dominate all other cancers in the UK.

2.2 **Number of men living with or beyond prostate cancer in London 2006.**

Prostate cancer prevalence, UK, 31st December 2006[xxxiv]

Cancer Network	**No. of Patients**
Ten-year prostate cancer prevalence	
N21 West London	4196
N22 North London	4249
N23 North East London	3465
N24 South East London	3581
N25 South West London	4478
Total	19969

Findings:

- As of Dec 2006, 19,969 men where living with and beyond prostate cancer in London and 3,465 in north east London (diagnosed in a 10-year period and alive in Dec 2006).
- Knowing that a proportion of men live with consequences of their treatment, there is 3465 men currently[xxxv] in north east London who will be contributing to the disability adjusted life years (DALY) caused by prostate cancer.

Implication on rehabilitation:

- Therefore when trying to improve rehabilitation for men with prostate cancer, the needs of men living with and beyond prostate cancer should be assessed and addressed. To optimise numbers engaging men in the urology/oncology clinics rather then attempting to pick them out from generic settings will likely be most successful.

2.3 **The 2012 incidence of prostate cancer by borough in north east London:**

	City and Hackney	Newham	Tower Hamlets	Waltham Forest	National average	Combined North East London
Population	252,119	295,800	263,000	258,200	n/a	1,069,119
Incidence of prostate cancer (per 100,000)	136.7	92.2	81.9	154.4	105.8	142.8
Actual Incidence of prostate cancer	344.6	272.2	215.4	398.7	n/a	**1230.9**
Prostate cancer Mortality (per 100,000)	19.2	21.6	16.8	30.1	24	27.9
Actual Prostate cancer Mortality	48.4	64	44.2	77.8	n/a	**234.4**

(Data source found in references[xxxvi], [xxxvii], [xxxviii])

Findings:

- Across north east London 1230 men are diagnosed with prostate cancer per year.
- **The incidence of prostate cancer in north east London (142.8/100,000) is higher than the national average (105.8/100,000).**
- **The mortality rate of prostate cancer in north east London (27.9/100,000) is higher than the national average (24/100,000).**
- Last year alone 234 men died with prostate cancer with 77.8 in the borough covered by the Margaret centre in Whipps cross and 156.6 in St Joseph's Hospice remit.

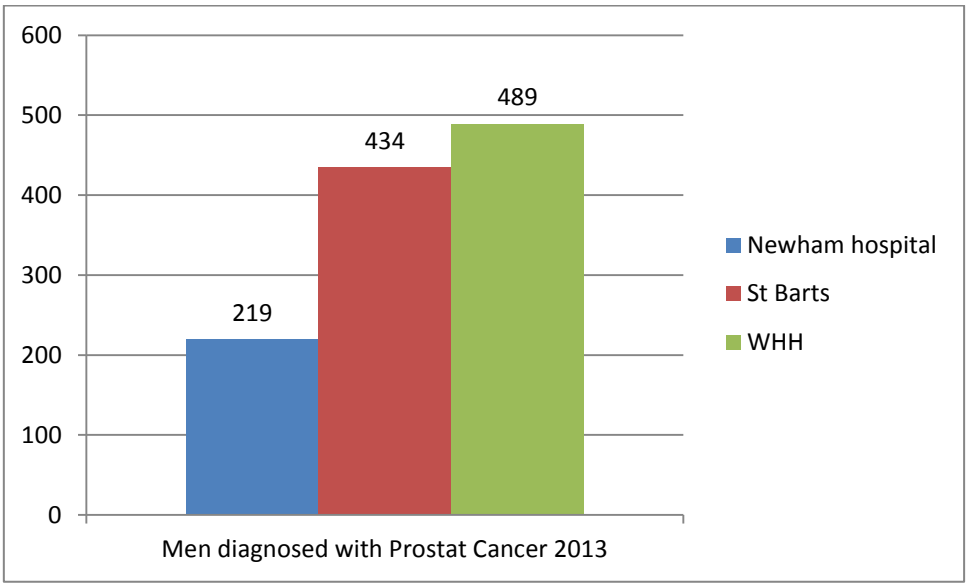
Implication on rehabilitation:

- The north east of London hospital trust and clinical commissioning groups should be tackling prostate cancer as it is a greater burden compared with the national average.
- Local drivers (discussed in the background) must address the importance of exercise for men with prostate cancer to help minimise the known risks of disability and increased mortality in the local NE London population of men living with this condition

2.4 **Number of men diagnosed with prostate cancer in 2013-2014 Barts Health NHS Trust:**

	Newham Hospital	St Bartholomew's Hospital	Whipps Cross Hospital
Men Diagnosed with prostate cancer in 2013	**219**	**434**	**489**

2.5 **Bar chart showing the number of men diagnosed with prostate cancer in 2013-2014 at Barts Health:**



Limitations

- Unfortunately I was unable to gather Homerton Hospital data due to a 3 month completion time for research and development clearance.
- Consequently the rest of the mapping and scoping data is Bart's health and St Joseph's hospice data only.

Findings:

- Newham has the greater population but Barts and Whipps Cross are seeing larger numbers of prostate cancer incidence because Barts is a tertiary centre and Whipps cross geographically sees men from other boroughs.

Implication on rehabilitation:

- This project will aim to deliver a service that covers the men being diagnosed with prostate cancer across Barts Health but it is important to note the Whipps Cross Hospital and St Bartholomew's Hospital see the greatest numbers per year.

2.6 **Tables showing the demographic data of men diagnosed with prostate cancer 2013-2014 in Barts Health**

Borough	Newham	St Bartholomew's Hospital	Whipps Cross Hospital
Barking and Dagenham	7	17	2
Barnet	1	1	0
Bexley	0	3	0
City	0	7	0
Croydon	0	1	0
Enfield	0	3	0
Greenwich	0	3	0
Hackney	0	44	1
Haringey	0	1	0
Havering	1	28	0
Hounslow	0	1	0
Islington	0	12	0
Kensington and Chelsea	0	1	0
Newham	200	64	13
Redbridge	5	37	126
Tower Hamlets	1	124	0
Waltham Forest	4	52	292
Not London	0	35	55
Grand Total	**219**	**434**	**489**

Age	Newham	St Bartholomew's Hospital	Whipps Cross Hospital
40-49	1	4	1
50-59	10	39	32
60-69	33	108	89
70-79	78	164	189
80-89	78	107	141
90-99	19	12	36
100-109	0	0	1
Grand Total	**219**	**434**	**489**

Ethnic Category	Newham Hospital	St Bartholomew's	Whipps Cross Hospital
African	25	26	19
Any other Asian background	4	1	7
Any other Black background	2	11	6
Any other ethnic group	4	24	2
Any other mixed background	0	2	0
Any other White background	5	21	19
Bangladeshi	0	16	1
British	98	228	311
Caribbean	49	55	66
Chinese	2	3	2
Indian	18	7	17
Irish	3	9	12
Not stated	1	15	11
Pakistani	7	9	15
White and Asian	0	0	1
White and Black African	0	4	0
White and Black Caribbean	1	2	0
Any Other Mixed Background	1	0	0
(blank)	0	1	0
Grand Total	**219**	**434**	**489**

Findings:

- Whipps Cross University Hospital sees the highest number of newly diagnosed men with 489. The majority of which are in their 70's, British born from Waltham Forest and Redbridge boroughs.
- St Bartholomew's Hospital sees 434 newly diagnosed men. The majority of which are in their 70's, British born but have a greater spread of borough's with the majority coming from Tower Hamlets.
- Newham University Hospital sees the least number of new diagnoses at 219. The majority of which are in their 70's or 80's, British born and from Newham.
- The second most common ethnicity of men diagnosed with prostate cancer across all the boroughs is Caribbean, illustrating the known high incidence of prostate cancer in this group.

Implication on rehabilitation:

- **Exercise prescription needs to be aimed primarily at men in their 70's and 80's therefore different tactics to engage this population to exercise should be utilised to understand what works best**.

2.7 **How many people have had physiotherapy as an in-patient at St Bartholomew's from the Oncology Physiotherapy team 2013-2014 and how many of them where men with prostate cancer**

Month	How many new patients	How many follow up sessions	How many prostate cancer new patients	Percentage of prostate cancer new patients	How many prostate cancer follow ups	Percentage prostate cancer follow ups
April	94	526	10	10.6%	41	9.6%
May	116	526	6	5.1%	43	10%
June	100	552	3	3%	25	4.5
July	119	528	6	5%	13	2.5%
August	65	279	4	6.1%	9	3.2%
September	95	424	6	6.3%	27	6.3%
October	83	450	3	3.6%	35	7.7%
November	83	493	1	1.2%	19	4.1%
December	94	490	2	2.1%	8	1.6%
January	99	616	3	3%	17	2.75%
February	64	396	3	4.6%	23	5.8%
March	64	396	2	3.1%	14	3.5%
Averages	**89.6**	**427**	**4**	**4.5%**	**23%**	**5.1%**

Limitations:

- This is average quantitative statistics so difficult to draw conclusions from this data as we do not know the common cause for admissions or how this data compares with the actual number of admissions for men with prostate cancer (ie how many with prostate cancer admitted to Barts Oncology service received physiotherapy).

Findings:

- On average 4.5 % of all new patients seen by the in-patient physiotherapy team are men with prostate cancer.
- On average 5.1 % of all follow up sessions seen by the in-patient physiotherapy team are men with prostate cancer

Implication on rehabilitation:

- The implication could be that the numbers are relatively low because men manage to maintain their mobility.
- These statistics can help develop an educational arm of this project to learn more about day to day interactions between in-patient therapies and men with prostate cancer and to teach about the rehabilitative needs of men with prostate cancer.

2.8 **St Joseph's Hospice Patient Data 2013-2014 showing the number of men with prostate cancer who received services at St Joseph's Hospice:**

Service	City & Hackney	Newham	Tower Hamlets	Tower Hamlets NW	Grand Total
CPCT	6	9	6	2	23
Day Hospice	4	3			7
IPU	5	5	2		12
Physiotherapy		2			2
Occupational Therapy					3
Social Work		2			2
Grand Total	**15**	**21**	**8**	**2**	**46**

Findings:

- A total of 46 men with prostate cancer engaged in St Joseph's Hospice services last financial year.
- **Just 2 men with prostate cancer (1%) were seen by physiotherapy out-patients compared with a total number of 259 men and women seen with cancer that year.**

Implication on rehabilitation:

- As described men suffer with disability caused by prostate cancer and the consequences of treatment. St Joseph's hospice offers a wide range of rehabilitative support but a small percentage of men are utilising theses services.
- It appears that the rehabilitative needs of men with advanced prostate cancer are not being proactively recognised and as such this group may be being under referred to palliative rehabilitation services. This project should aim to assess these men, ideally in a urology/oncology clinic to maximise numbers and referred appropriately.
- Professionals supoprting men with advancing prostate cancer may need greater information on the triggers for referrals to rehabilitation services (eg diagnosis of bone metastases) and greater awareness of the rehabilitation services available at St Joseph's (including how to refer)

2.9 **Comparison data of all individuals with a cancer diagnosis, interaction with St Joseph's Hospice 2013-2014:**

	IPU		DH		CPCT		National Average Incidence 2011	National Average Mortality 2011
Cancer Diagnosis	**13/14**	**13/14**	**13/14**	**13/14**	**13/14**	**13/14**		
Digestive organs	131	**32%**	27	**26%**	242	**30%**	13%	10%
Respiratory & intrathoracic	95	**23%**	18	**17%**	191	**24%**	13%	22%
Breast	42	**10%**	14	**13%**	88	**11%**	15%	7%
Testicular and Penile	3	.5%	3	3%	21	2.5%	n/a	n/a
Prostate Cancer	**12**	**3.5%**	**7**	**7%**	**23**	**2.5%**	13%	7%
Urinary tract	23	6%	3	3%	37	5%	n/a	n/a
Other specified sites C40-C49	23	5%	5	5%	35	4%	n/a	n/a
Female genital organs	24	6%	5	5%	35	5%	n/a	n/a
Eye, brain & other CNS	23	5%	11	10%	34	5%	3%	3%
Lip, oral cavity & pharynx	8	2%	1	1%	25	3%	n/a	n/a
Lymphoid, haematopoietic	21	5%	10	10%	51	4%	n/a	n/a
Ill-defined, secondary, unspecified including carcinomatosis	10	2%	0	0%	3	3%	n/a	n/a
Other specified sites C73-C75	0	0%	0	0%	0	0%	n/a	n/a
Independent multiple sites	0	0%	0	0%	1	0%	n/a	n/a
Grand Total	**415**	**100%**	**105**	**100%**	**810**	**100%**	n/a	n/a

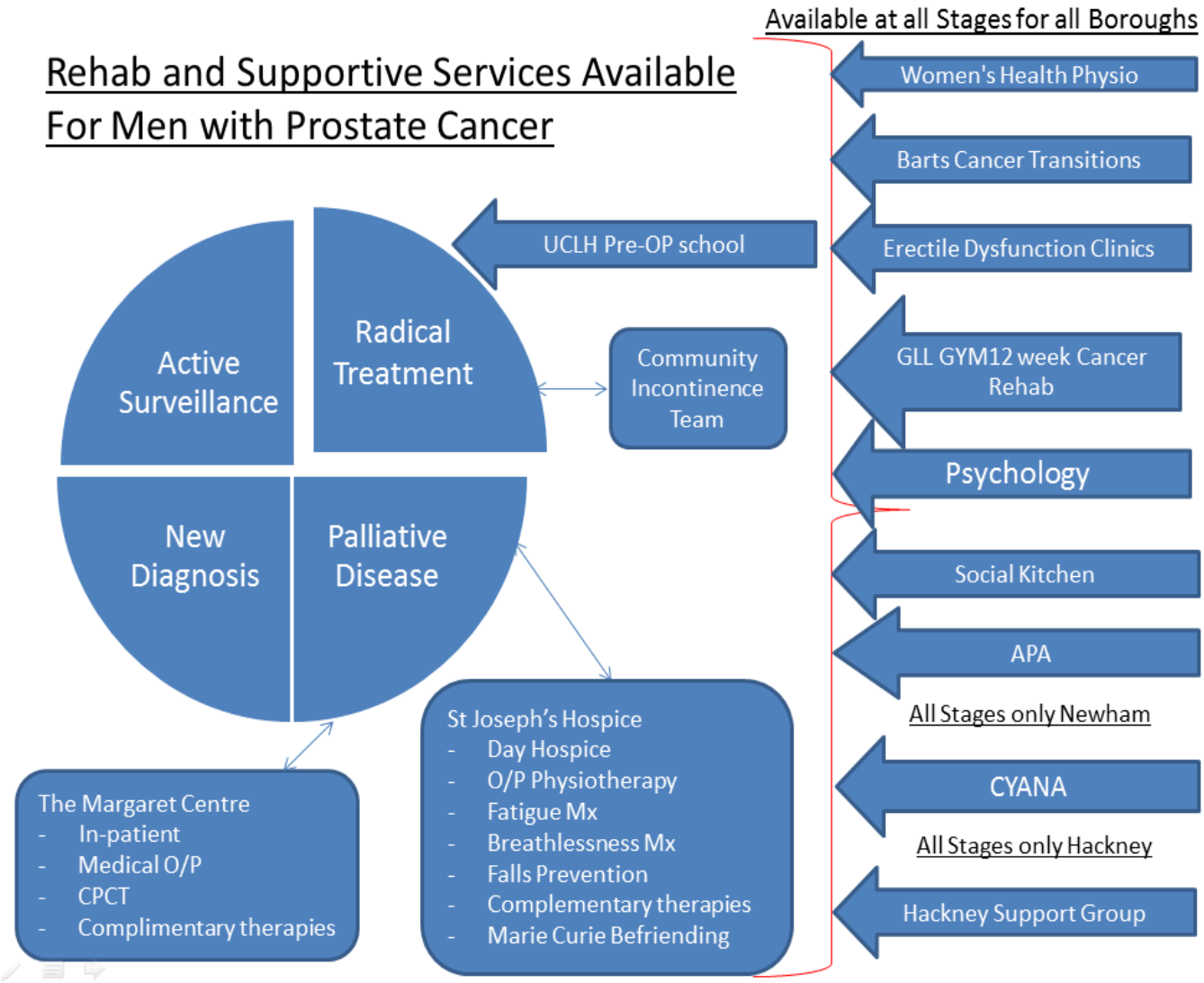
Findings:

- **Men with prostate cancer admitted as an in-patient in to St Joseph's Hospice make up only 3.5% of all cancer admissions within the financial year, compared with 10% breast cancer and 30% bowel cancer.**
- 7% of cancer patients attending day hospice were men with prostate cancer compared with 13% breast and 26% bowel.
- **2.5% of cancer patients seen by the community palliative care team were men with prostate cancer compared with 11% breast cancer and 30% bowel cancer.**
- In 2011 prostate cancer caused 13% of all cancer diagnosis (men and women). In 2013/2014 156.6 men died from prostate cancer in City and Hackney, Newham and Tower Hamlets which are boroughs covered by St Joseph's Hospice.
- The percentage of men seen at St Joseph's hospice who have Prostate cancer is comparatively low compared with the local prevalence, mortality and percentage of other cancer diagnosis seen.

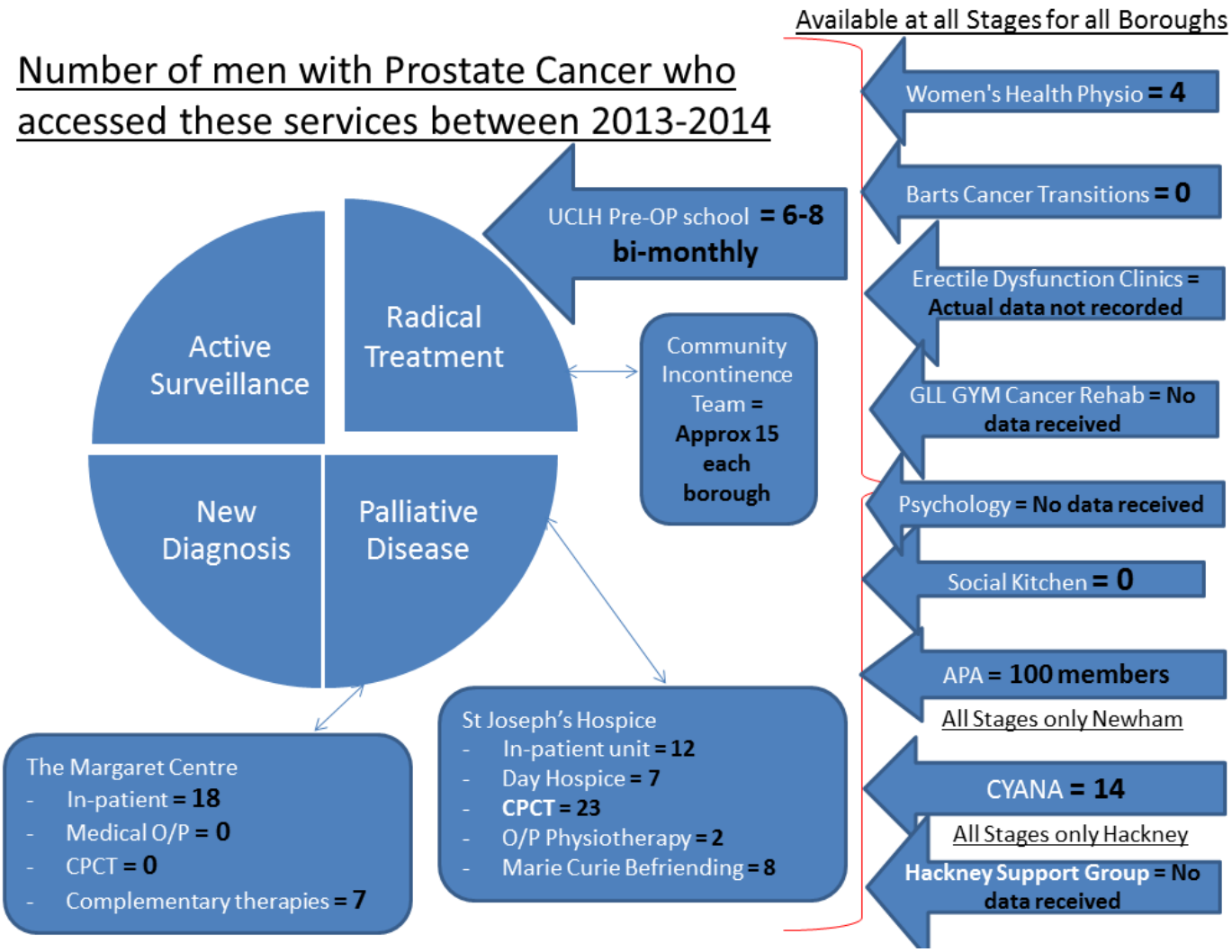
Implication on rehabilitation:

- There appears to be a need to bridge oncology and palliative care rehabilitation to enable more men with advancing prostate cancer to access services if needed.
- Assessing rehab needs in clinical setting which included advanced prostate cancer is paramount.

2.10 **Diagram displaying the community rehabilitative and supportive services currently in place and active in north east London for men with prostate cancer:**



2.11 **Diagram displaying how many men with prostate cancer who accessed the community rehabilitative and supportive services 2013/2014:**



Limitations

- I am still awaiting responses from the services stated 'no data received', therefore the map is not fully completed but this is unfortunately out of my control.
- I do not have the data regarding accessing community physiotherapy or the in-patient data for Newham and Whipps Cross hospitals.

Findings:

- Men with prostate cancer in North East London are not utilising or being referred to Barts cancer transitions programme. During the three years the programme has been running zero men with prostate cancer have attended.
- GLL are the only service offering a 12 week exercise programme (as recommended by the NICE Prostate cancer: diagnosis and treatment January 2014), which caters for

those living close enough in Newham and Hackney, however currently we have no data available on the number of men with prostate cancer accessing this service.

- Cancer You Are Not Alone (CYANA) is the best accessed community support service in Newham. They provided counselling and support services to 14 men with prostate cancer last year.
- Men with prostate cancer do not have access to a 12 week exercise programme in Waltham Forest.

Implication on rehabilitation:

- **There is a need for greater education to the MDT supporting men with prostate cancer regarding services available.**
- **There is a need to develop and provide information about rehabilitation so that men with prostate cancer can self-manage their condition, which can be trialled face to face and booklet only.**
- **Men are not accessing services available which could mean they do not require them or that they are not being referred or that the services do not fit the needs of this group.**
- **Geographically Waltham Forest and Tower Hamlets residents require a 12 week exercise programme.**

Mapping Outputs

From the knowledge I have gathered during this mapping process, I have created two 'outputs' in order to collate the information gained regarding the rehab and supportive services available and to simplify the prostate cancer pathway.

There was no previous resource to utilise, therefore this project's future aims will include dissemination of the below outputs to benefit the professionals who engage men with prostate cancer and their partners/carers to improve referrals to the services in place.

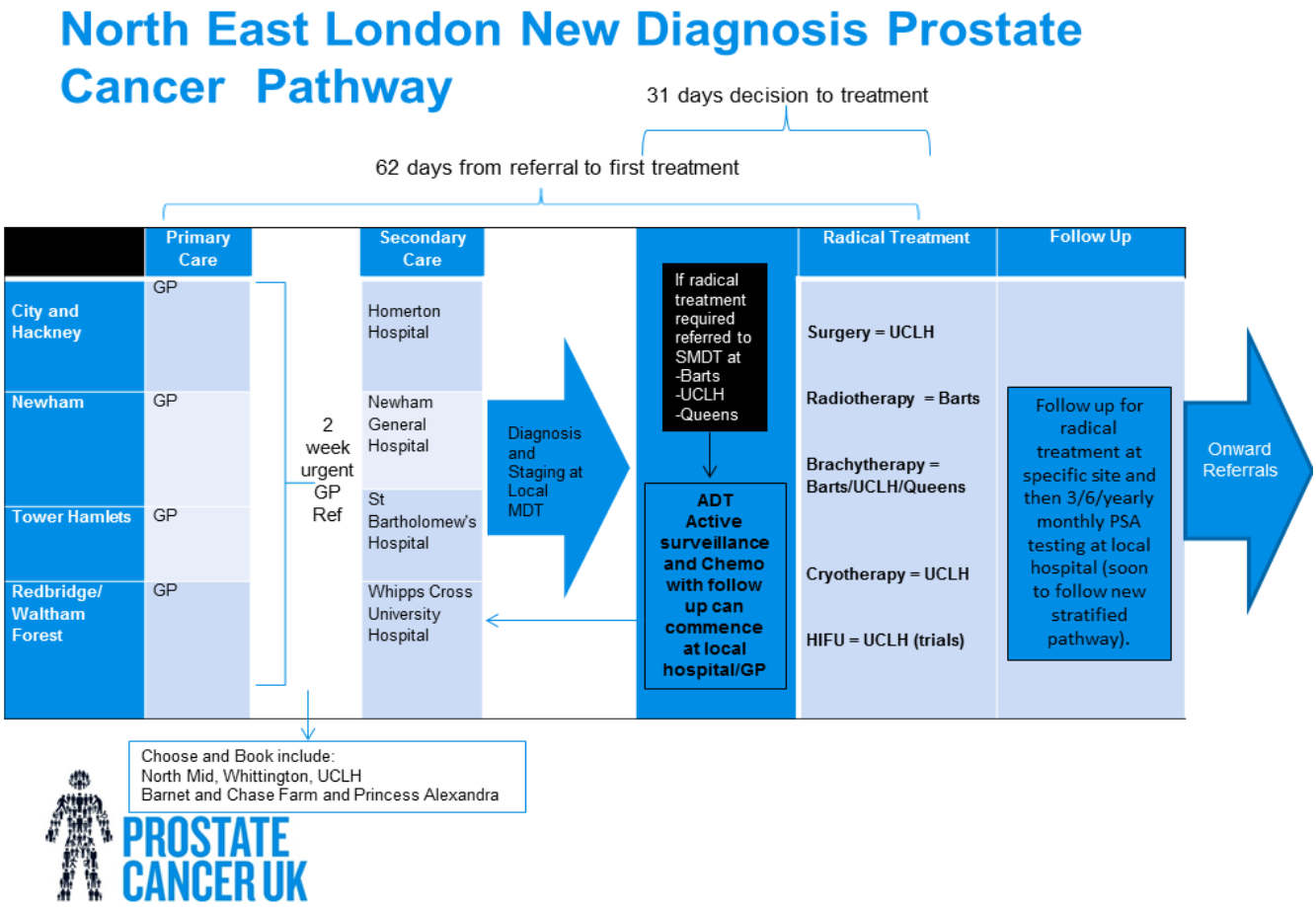
3.0 Summary and Contact Details of the Rehabilitative and Supportive Services in place for Men with Prostate cCncer and their Partners/carers in North East London:

Rehabilitative/Supportive Services	How to Refer
Barts Cancer Transitions A unique exercise and education programme for people who have completed their cancer treatment in hospital. This takes place over a period of six weeks and includes weekly sessions that last for two and a half hours.	Claus Buscher 0203 465 7445 or email Claus.buscher@bartshealth.nhs.uk
Erectile Dysfunction Clinic	Refer to Martin Steggall at The Royal London hospital Refer to Sacha Ali at Homerton hospital. Refer to Dr Simldon Holden at Whipps Cross hospital Refer Eveleyn Gyamsi at Newham University hospital
Community Incontinence Newham A Physiotherapist in the team who currently only treats women. Nurses review the men.	Continence Service East Ham Care Centre 313 Shrewsbury Road East Ham London E7 8QR Tel: 020 8475 2012 Fax: 020 8475 2063 dorothy.adekasi@eastlondon.nhs.net
Community Continence Waltham Forest	Chingford Health Centre York Road Chingford E4 8LF Tel: 020 8430 8246 Fax: 020 8430 8259
Community Continence Hackney No Physiotherapist in the community team.	Tel: 020 7683 4144 Fax:020 7014 7274 Elizabeth.maku@homerton.nhs.uk
Community Continence Tower Hamlets	Continence Service Mile End Hospital Bancroft road London E1 4DG Tel: 020 8223 8887 or 020 8223 8861
Greenwich Leisure Limited 12 week individually tailored Cancer Rehab exercise programme in the Olympic park. Consultant/GP/CNS/AHP referral only	Please contact Alex.Michael@GLL.ORG to get a referral form.

Women's Health Physiotherapy Hackney	Sarah Pierce (sarah.pierce@homerton.nhs.uk) Physiotherapy Homerton Hospital Homerton Row London E9 6SR Fax: 0208 510 5727
Women's Health Bart's Health	WXH- Champa Perera Champa.Perera@bartshealth.nhs.uk Tel: 020 8539 5522 ext 5485 (or bleep 171) RLH- Zoe Pierson Royal London Hospital Tel: 020 3594 1099
St Joseph's Hospice	First Contact: 03003030400
The Margaret Centre	Tel: 020 8535 6604 Fax: 02085356952
The Social Kitchen - Cooking and conversations to explore the relationships between food and wellbeing.	Kye on 07455 737 747 or kye@socialkitchen.org.uk
Association of Prostate Awareness (APA) 5 organisational objectives: -Provide services that relieve and support the effects of Prostate illnesses. -Advance education for the public. -Provide facilities for recreation which aim to improve life for people. -Undertake or sponsor and support research. -Work with and co-ordinate support services for people with prostate illness post operation and beyond.	Newham African Caribbean Resource Centre 627/633 Barking Road Plaistow London E13 9EZ Tel: 0208 471 2258 info@prostate-awareness.co.uk www.prostate-awareness.co.uk
Cancer You Are Not Alone (CYANA) This group is for people affected by any cancer and offers One to one counselling, support groups, Complementary Therapies, home/hospital/hospice visits/advocacy/social opportunities/education and outreach work.	31 Snowshill Road, Manor Park, London, E12 6BE Tel: 020 8553 5366 E-mail: cyana1@tiscali.co.uk
Hackney Prostate Cancer Support Group	Nath: 07501066097 / Grace: 07502399503 Emailhospitalandprisonaction@yahoo.com
Barts Health Psychological Services	Justin.Grayer@bartshealth.nhs.uk Psychologist

3.1 **Flow diagram of the prosate cancer diagnosis pathway in North East London:**

- The flow diagram was emailed to all the CNS's, Consultants and surgeons who attend the Barts SMDT to check accuarcy.



Scoping:

This section will describe each scoping methods results and findings regarding the opinions of clinicians, professionals, men with prostate cancer and their partners/carers; in order to determine where developments can be made to improve rehabilitation.

Questionnaires and Semi- Structured Interviews:

- 14 Men living with or beyond Prostate cancer and 2 Partners consent was gained and they were interviewed in mainly clinical settings.

3.2 Demographic data of the semi-structured interview participants:

Rate rehab services in your community	Gender	Age	Ethnicity	Borough
0	M	60-69	White British	Waltham Forest
1	M	80-89	Caribbean	Newham
2	M	70-79	Black Caribbean	Newham
0	M	70-79	Black Caribbean	Redbridge
1	M	70-79	Indian	Newham
0	M	50-59	Black African	Newham
0	M	60-69	Black African	Newham
1	M	80-89	Black Caribbean	Hackney
0	M	60-69	Black African	Newham
1	M	70-79	White British	Redbridge
1	M	50-59	White British	Hackney
1	M	50-59	Black British	Hackney
1	M	50-59	White British	Redbridge
2	M	70-79	Black British	Hackney
2	F	60-69	Caribbean	Hackney
0	F	40-49	Black African	Newham

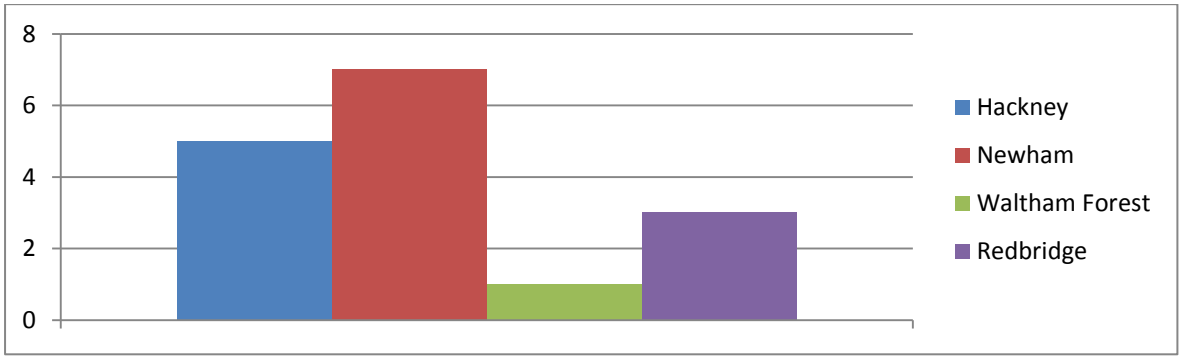
Findings:

- **Despite utilising a multitude of methods to engage participants with the questionnaires and focus groups , successful recruitment of men for this study was ONLY through direct face to face personal contact**

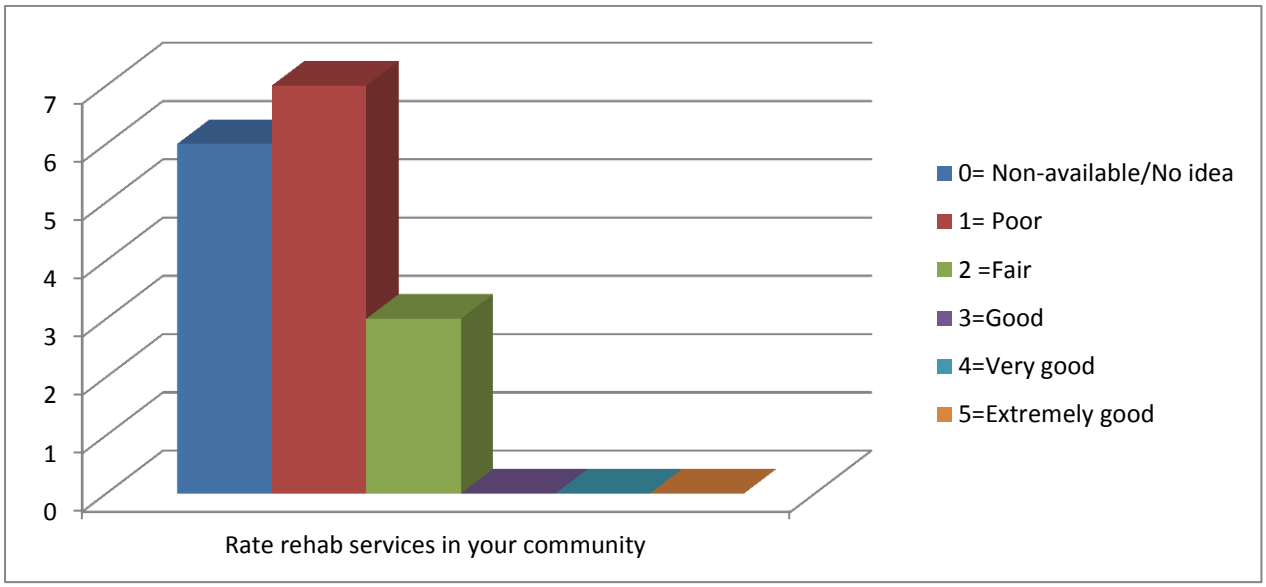
Implication on rehabilitation:

- **Engaging men with prostate cancer may benefit from a greater focus on face to face, personal contact compared with marketing leaflets and posters.**

3.3 Bar chart showing borough distribution of the participants:



3.4 **Bar Chart showing the rated evaluation of local rehabilitative services in the participant's community**:



Qualitative findings from questions posed in the questionnaires:

1. What interventions or support would you have liked after your cancer diagnosis?
2. Were you aware of the role of rehabilitation and exercise post diagnosis?
3. If yes then please explain how you became informed.

3.5 **Table showing quotes taken from the answers which have been grouped into themes following thematic analysis:**

Quotes	Theme
• I have received an erectile dysfunction referral • I Took Viagra for my erections but I stopped as not keen on meds • Good support from Homerton. • I received support from my surgeon. • I was given lots of information when I was diagnosed	Clinical support
• I received physiotherapy previously from St Joseph's hospice • I had physio before but for a stroke	Previous Physiotherapy
• I would like more help with incontinence and ED	No Interventions or support
• I would have liked to know that impotence would last forever	Required more information
• I received lots of information which was overwhelming	Received too many booklets
• No found out the hard way • Not aware of importance of exercise • Suffering with tiredness and no erections but unsure what I can	Lack of info/knowledge/support

do • No but keen to learn • No and I have stopped exercising daily because of diagnosis • No but keen to do what is best	
• I am not keen to meet other men with prostate cancer • You will find me in the pub with my mates • Not all men will or want to exercise	Not open to healthy behaviours Maintain independence
• Yes I understand it's good to keep walking • I already keep exercising and healthy • Understands the importance of exercise but no official information • No, but keen to do what is best	Self-educated or good Self efficacy
• I am on my own and I find it difficult to talk to my mates • I would like support or motivation with coping with the effects of prostate cancer and other health issues	Isolation
• I am worried about death	Fear /worry

Limitations

- All qualitative data was gathered by myself therefore there could be an element of bias when scoping.
- All qualitative data was evaluated using thematic analysis by myself therefore there could be an element of bias.

Findings:

- The main source of support men and their partners received was from clinicians (particularly surgeons) during clinic appointments.
- The main theme was a lack of information and support. Particularly for those who live alone or may not have a partner or close friend. However, overload of information was also mentioned.
- The participants health behaviours divided between individual research and an enthusiasm to learn 'what is best' when living with or beyond prostate cancer, versus wanting to return to normal routine with no interest in regular exercise/rehabilitation.
- **When rating local cancer support services participants perceived there was an over whelming lack of community rehabilitation services available , and as such these were rated as poor by the majority**

Implication on rehabilitation:

- **There is a lack of referrals to rehabilitation services rather than a lack of rehabilitation needs therefore it will be a key aim to improve referral numbers to the current rehabilitation and supportive services.**
- **There is a need for exercise advice for motivated men living with or beyond prostate cancer.**

Qualitative findings from questions posed to clinicians:

As described in the method the questionnaires where emailed out or delivered face to face to all the clinicians and professionals working with men with prostate cancer. Below are the questions posed followed by the anonymised answers.

- Do you feel you meet the needs of local men with prostate cancer and their carers?
- For what reasons would you make an onward referral to therapists/Rehab?
- Where or to whom do you refer for the above reasons?

3.6 Table showing quotes taken from the answers which have been grouped into themes following thematic analysis:

Quotes	Theme
• Ideally a Psycho-social therapist in the erectile dysfunction clinics • The men would benefit from a support group	Psychological/Emotional Emphasis
• I feel drop in clinics would suit prostate men	Informal Approach
• The day hospice not currently doing men specific events/ trips due to fewer men in the group compared with women	Less Gender specific support.
• There is a lacking of post treatment support/exercise/peer support • I feel I meet the men's needs, but community continence could be improved • No support for fatigue, bowels, continence and emotional support • Poor engagement of the community	Lacking of supportive services beyond secondary/tertiary care.
• Not enough CNS's • As a CNS I focus on breaking bad news but info takes a long time to sink in and information needs repeating over many clinics	Provisions
• Respite, physiotherapy and finding spaces at St Joseph's Hospice • We refer to the psychologist, community continence teams and erectile dysfunction • We encourage men to access Macmillan, relationship counselling and PCUK helpline	Current support services in place

Limitations

- All qualitative data was gathered by myself therefore there could be an element of bias when scoping.
- All qualitative data was evaluated using thematic analysis by myself therefore there could be an element of bias.

Findings:

- Primary theme was lack of holistic support for men beyond the clinical setting.
- A theme developed regarding processing of information and that men require revision of the same information.
- Services offered to men with prostate cancer include referrals to psychology, erectile dysfunction clinics, community incontinence teams, local hospice and their services and encouragement to contact the PCUK helpline, Macmillan information centres and relationship counselling.

Implication on rehabilitation:

- Those who work with men with prostate cancer on a regular basis are keen to improve rehabilitative services.
- This project should support the holistic needs of the individuals living with or beyond prostate cancer.
- Need for training of staff working with men with prostate cancer to raise awareness of triggers for referral to rehabilitation.

Focus Groups

Ten men and women agreed to attend one of three focus groups in Tower Hamlets, Newham or Waltham Forest.

3.7 **Demographic data of ten focus group participants:**

Attended which Focus Group	Gender	Age	Ethnicity	Borough
Newham	M	80-89	Black African	Newham
Newham	M	70-79	White British	Newham
Newham	F	40-49	Black African	Newham
Tower Hamlets	M	60-69	Black African	Hackney
Tower Hamlets	M	70-79	Black African	Newham
Tower Hamlets	M	50-59	White British	Tower Hamlets
Tower Hamlets	M	70-79	White British	Tower Hamlets
Waltham Forest	M	70-79	White British	Essex
Waltham Forest	F	60-69	White British	Essex
Waltham Forest	M	70-79	White British	Tower Hamlets

Findings:

- All participants were those who I had recruited verbally, no one attended the focus group via leaflets or posters alone.

Implication on rehabilitation:

- **As described in the method the focus groups were advertised in a multitude of ways, however all the participants (documented above) where recruited via face to face contact with myself. Therefore face to face contact regarding engaging and participating with rehabilitation appears paramount.**

Qualitative findings from focus group questions posed:

- What interventions or support would you have liked after your cancer diagnosis?
- Were you aware of the role of rehabilitation and exercise post diagnosis?
- If yes then please explain how you became informed.

3.8 **Table below showing verbatim quotes taken from the focus groups which have been grouped into themes following thematic analysis:**

Quotes	Theme
• Dr Cathcart, I took a lot from that guy, I got hold of his information and I made it work • Well I haven't had treatment and it is all down to the Dr's and thank god for them • We have got a good heath service, in some countries they wouldn't bother • It is very hard because you put your life in their hands really • I had Macmillan support since I went to the MacMillan centre in UCLH	Clinical support
• I don't think I got enough information • Incontinence has caused me to lose my confidence • Our life's are in the Dr's hands	Loss of control
• The diagnosis affected me mentally rather than physically. I wasn't getting out of the bed because of depression • Mentally of course you suddenly realise that the future is not certain. I do not know if treatment will be successful. Now certain plans have to be short term rather than previously long term • Pressure and stress. For the last 3-4 years we had people coming in day and night. I couldn't be help in the end and I think I was so stressed that is when I got the prostate • I can't concentrate like I used to	Emotional consequences
• I have trouble going to the toilet, proctitis is a real problem, redundant bowel is what the GP has said, had polyps out, fatigue since the bicalutamide	Physical consequences

• If I had known it (incontinence) would be this bad I don't think I would have gone for surgery	
• That word cancer and you think how am I going to get rid of this and how advanced it is, they don't give you enough information. I don't think anyway • I Don't think I got enough information • I went through an operation but not sure exactly, I think the prostate is out • I would prefer to be given information and continue on my own • Yeah we would prefer to get a bit of information for an hour or too • My cancer is advanced and I think this is because I did not know or have the information about prostate cancer • I wanted to make sure if I could take exercise as I have stopped • I would like to learn more about fatigue and what it is	Lack of info/knowledge/ support
• Coming to terms with it is hard, telling you and then sending you home was the hardest part, I Live on my own • He was very short and angry after the diagnosis • It must be terrible if you are on your own	Isolation
• At the beginning they will tell you the worst, they have to. That is the most shattering thing • As soon you hear the word cancer you think you are going to die. I think have I got 2 weeks to live or 2 years • I think everyone is a bit frightened. I asked if I was going to lose my hair. I think people are afraid about radiotherapy • I read your bones can break which worried me • I am an informed guy I am always on the net. But I am a worrier. You go to the doctors but they don't have time so you got to look up • That's right I am a worrier you see and people say don't worry but it is impossible • Life is a bit of a worry now	Fear /worry
• You know I stopped smoking. I have been smoking since I was 15 • Since the diagnosis I feel good because I have stopped smoking, reduced my diet and reduced beer • What I think caused me this was my lifestyle. I was looking after my wife who had a brain tumour and was partially blind. So I looked after her for 20 years, I started smoking, drinking and missing meals • I used to think I was invincible but I reckon your lifestyle has got a lot to do with it • I would attend or listen to whatever is goanna make things better • I like to exercise, could that have caused my prostate cancer? • I would go to any venue in London to learn more about this disease and prostate cancer • A place for men and partners to get together would help to learn from each other and get the best advice	Health behaviours
• Isn't that fantastic you have been living with prostate cancer for 9 years?	Support

• Healthy lifestyle means work, my partner, my family knowing where they are, what they are doing, a good walk to work every day • I think there is something for meeting up in a group and men meeting others who have had it for longer	
• The problem is the NHS is so squeezed at the moment	Provision
• I am with a girl half my age but since the hormones I have no interest in sex • The impact it has on one's sexual life is devastating • I have seen my cousins die of aids but I have never seen a disease which makes one's penis disappear	Sexuality

Limitations

- All qualitative data was gathered by myself therefore there could be an element of bias when scoping.
- All qualitative data was evaluated using thematic analysis by myself therefore there could be an element of bias.

Findings:

- The dominant themes from the focus group were lack of information and fear/worry.
- The focus group also highlighted the impact on sexuality as a major issue which did not transpire from the questionnaires.
- The participants encouraged each other during the focus groups and felt that creating opportunities to have men and their partners/carers together would improve the pathway.
- There is a need for professional advice regarding health lifestyle changes and whether to continue exercising when diagnosed with prostate cancer or when the prostate cancer had progressed.

Implication on rehabilitation:

- **There is a need for simple exercise advice.**
- **Men were recruited to the focus group only by face to face therefore face to face therapy contact is essential to engage men in healthy behaviours which will benefit their health and the long term financial benefits on the NHS.**
- **Men and their partners reported to benefit from being in a group therefore this project should pilot 1:1 and group rehabilitation.**

Observation

I attended clinics that men with prostate cancer would attend in Barts Health and Homerton and gained information for the mapping of rehabilitative services and the clinical pathway for men with prostate cancer in East and North East London.

Limitations

- I was only able to take snapshot information therefore my observations may not depict the full picture.
- All qualitative data was gathered by myself therefore there could be an element of bias when scoping

Anecdotal Findings:

- The holistic needs assessment was not used in the clinical setting.
- There is a huge demand on the clinicians seeing the patients as a large number of men attend the clinic and they have short appointment slots.
- The Urology CNS at Barts splits the clinic list with the consultant/surgeon.
- There are no spare clinic rooms available in Newham University teaching hospital's out-patient department.
- Professionals in the majority did not high-light rehabilitation as a gap in the service therefore there appears to be a lack of awareness.
- To improve attendance to men's groups/intervention clinicians and professionals prefer an opt out policy.

Implication on rehabilitation:

- **Time constraints in the prostate clinics are a major issue therefore it would be valuable to compare onward referrals of men with prostate cancer to rehab services from the clinics clinicians following education, compared with how many onward referrals are generated through the physiotherapist and rehabilitation assistant intervention.**
- **Useful to measure impact on primary and secondary care utilisation by recording number of admissions and unscheduled GP visits for those who attend 1:1 and group rehabilitation interventions.**
- It will be important to document time spent on holistic issues outside of rehabilitation/exercise which may be addresses if the holistic needs assessment was utilised by the MDT.

Online Survey

Because email addresses are not kept on the trusts data system there was no list to use equitability. The web address was advertised on posters but unfortunately no online questionnaires were completed.

Mail Out

To date (two month since the questionnaires were mailed out) no returned questionnaires have been received.

Summary of findings

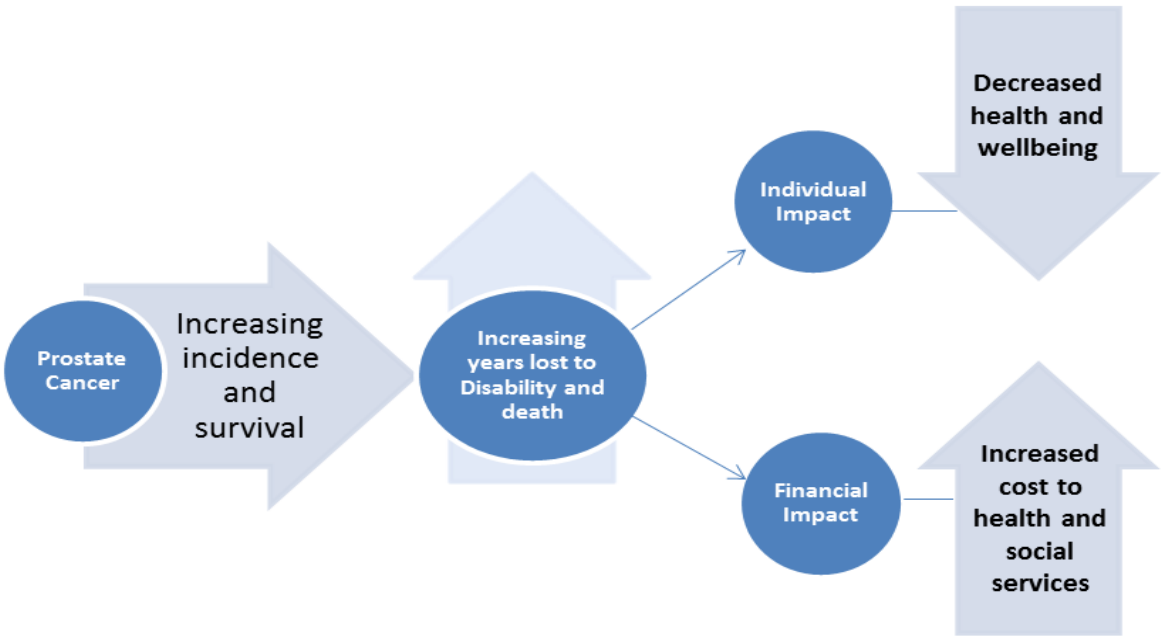
Outline

Evidence shows that exercise reduces the risk of prostate cancer progression by 57%[1]and recurrence and mortality by 30%[1]. The World Health organisation has quantified the burden of disease using disability adjusted life years (DALYs equals healthy years lost due to mortality and disability), which equals 344 DALYs per 100,000 (second highest cancer impact behind lung cancer) for men with prostate cancer per year[xxxix]

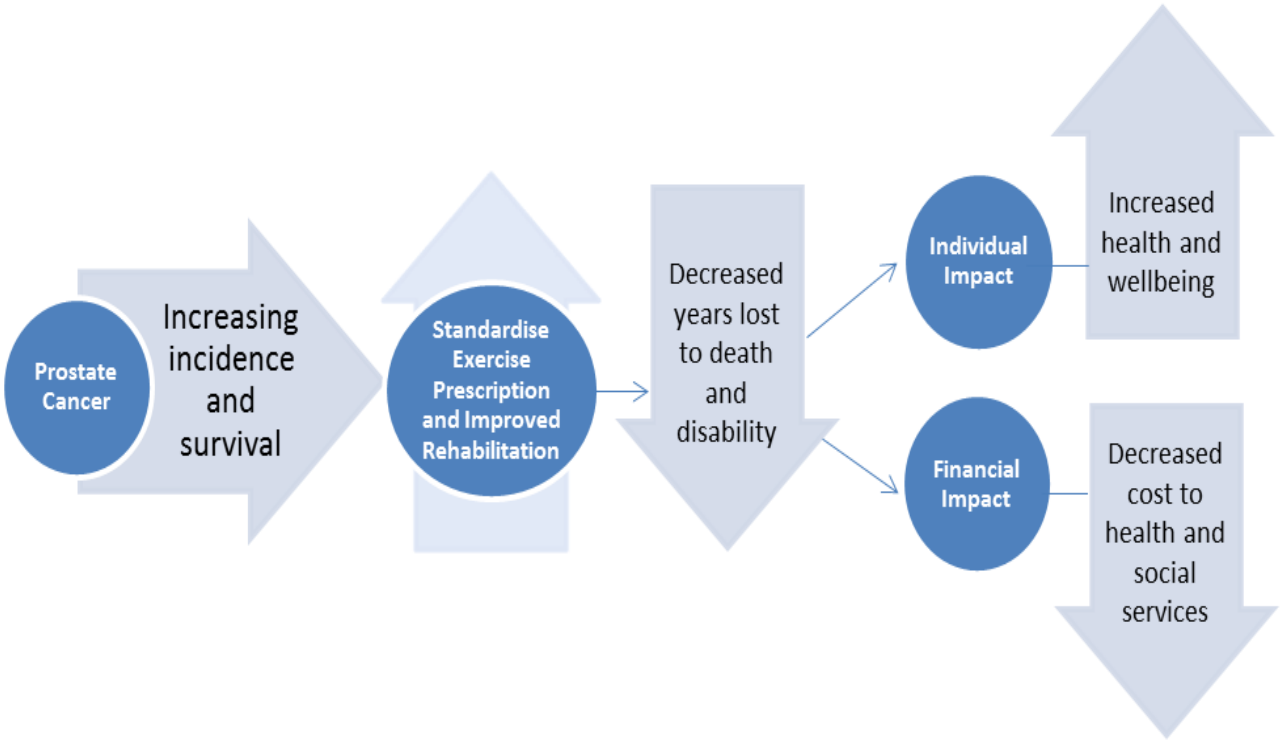
Sullivan et al[xl] in the Lancet Oncology Commission discussed that the burden of cancer is a major economic expenditure for high income countries and that Novel, more effective, and less toxic interventions to be explored as a way of improving the effectiveness of cancer care. If exercise can reduce mortality and progression of prostate cancer [xli] (the years lost to life which contribute to DALYs) and exercise can improve/manage the disability induced by prostate cancer[xlii] (years lost to disability which contributes to DALYs); then standardising exercise and rehabilitation is an effective and non-toxic method to reduce DALYs incurred by prostate cancer.

This is a call to arms to improve rehabilitation; exercise advice and exercise prescriptions for men living with and beyond prostate cancer to reduce the individual cancer burden and incurred national cost.

4.0 **Flow diagram representing the Individual and National Economic Impact of the Increasing Numbers of Men Living with and Beyond Prostate Cancer:**



4.1 **Flow diagram representing the hypothesised Individual and National Economic Impact of Improved Rehabilitation and Standardised Exercise for Men Living with and Beyond Prostate Cancer:**



Key Findings

The findings and their implications on rehabilitation have been high-lighted throughout this report. Below is a summary of the key findings which will inform the action plan to actually improve rehabilitation for men with prostate cancer in North East London.

- ✓ Increasing numbers of men diagnosed and living with prostate cancer and therefore increasing burden on services.
- ✓ There is an increasing economic burden on health and social services caused by prostate cancer induced disability and premature death.
- ✓ Current rehabilitation and exercise services appear not to be succeeding with men either due to non-engagement, low referral rates or a different model of delivery may be required.
- ✓ Currently there is no physiotherapy provision to educate men on pelvic floor/bladder training and best exercise prescription.
- ✓ Evidence shows that regular exercise reduces the risk of prostate cancer disease progression by 57% and recurrence and mortality by 30%.
- ✓ Community services should be engaged to run twelve week cancer rehabilitation (which is missing in Tower Hamlets and Waltham Forest).

- ✓ Provision of training is required for professionals who come into contact with men with prostate cancer, to improve male health behaviours.
- ✓ There is a lack of health and wellbeing clinics for men and their partners/carers.
- ✓ There is a lack of referrals to palliative care in the community.
- ✓ No concise prostate cancer pathway exists which would make info/advice/referrals easier to access.
- ✓ Professional face to face contact encourages a more open assessment of emotional and sexual issues.
- ✓ Men living with or beyond prostate cancer poorly engage with the information contained in posters/leaflets and hand-outs.
- ✓ From this work and previous research men are reticent to join support/exercise groups however subjectively men feel positive about social interaction from group activities.
- ✓ There is low implementation of the holistic needs assessment by professionals for men on the prostate cancer pathway at their key milestones.
- ✓ Short appointment slots and increasing prostate cancer prevalence has created an increased demand on clinicians.
- ✓ To improve attendance of men with prostate cancer to rehab and supportive services an opt-out policy is preferable.

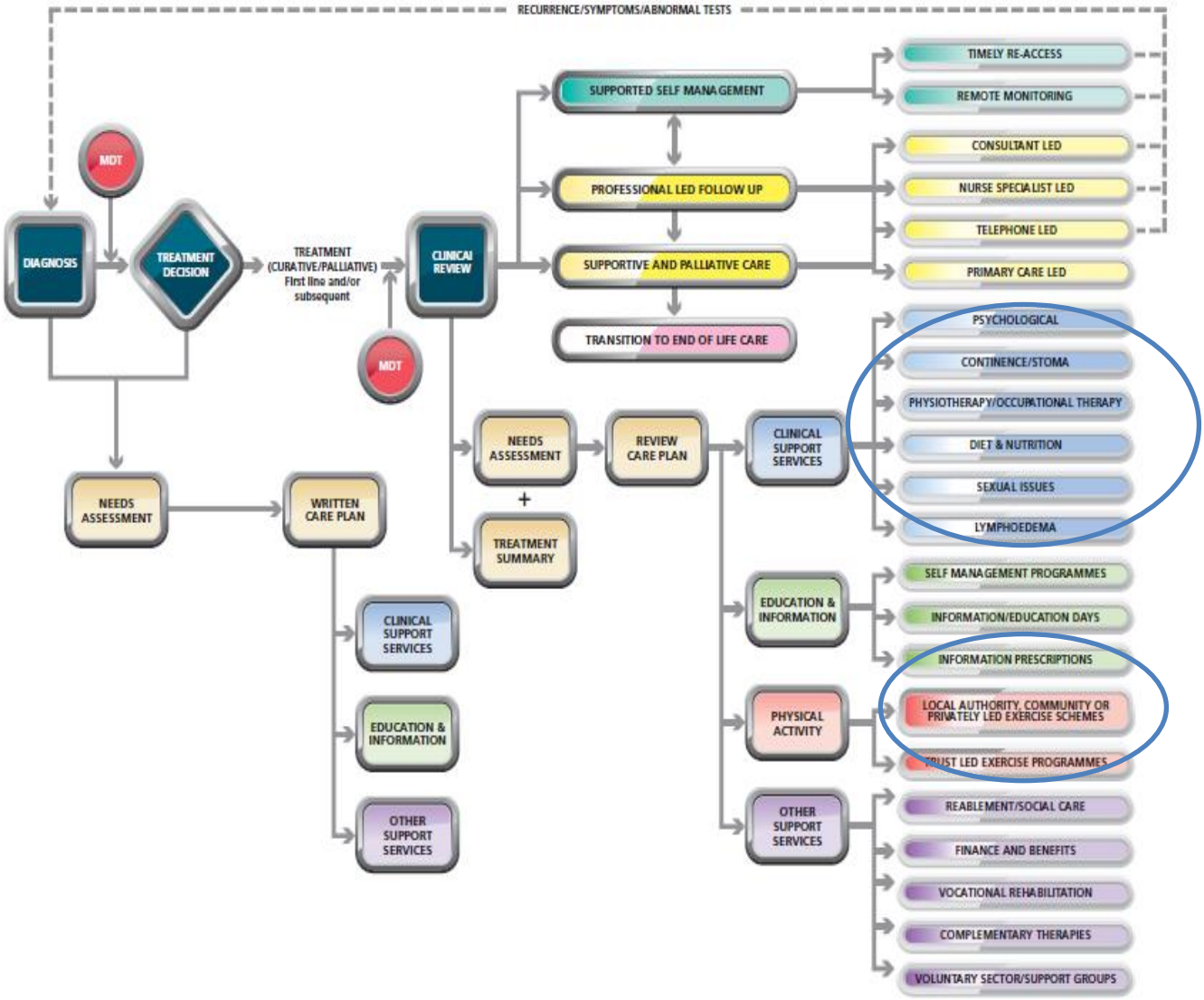
Model of Rehabilitation Services

Scoping needs and mapping rehabilitative services for men with prostate cancer in North East London is the first project of its kind in this area, consequently the rehabilitation service design and delivery will be exploratory in nature to learn what works most effectively for the North East London demographic.

The NHS guidance below and the NCAT urology pathway (in references) offer key pathway components which will be the cornerstones of this rehabilitation model.

The generic NHS Improvement pathway below identifies the key pathway components that need to be considered in commissioning and delivering care. This is a model which provides the efficacy to base the service delivery of improved rehabilitation for men with prostate on.[xliii]

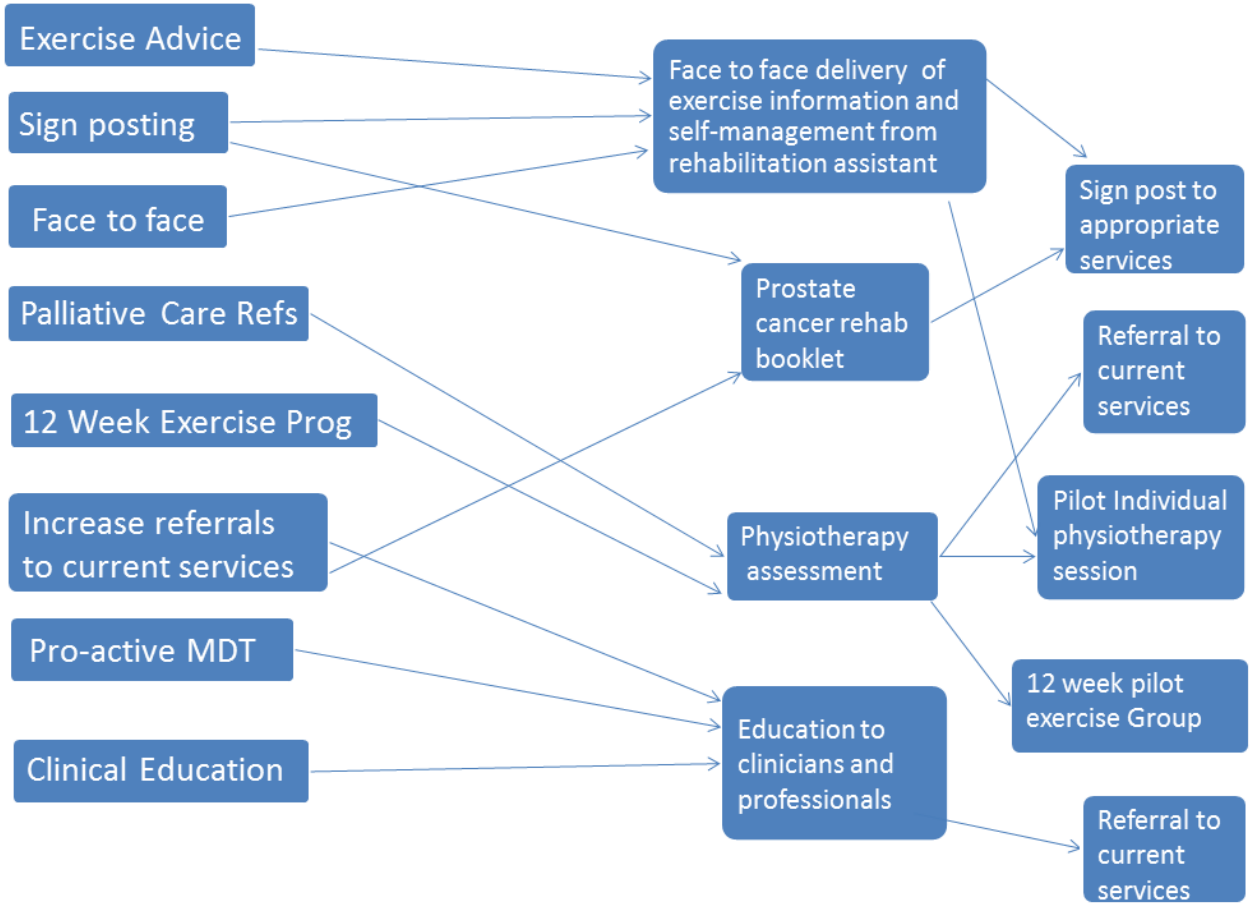
4.2 Flow chart from the NHS Improvement: Cancer Innovation to implementation: Stratified pathways of care for people living with or beyond cancer [xliv]



Action required

The information gathered regarding implications on rehabilitation for men with prostate cancer pose questions and resultant action points in order to deliver better rehabilitation services in North East London. See the below Spider diagram as a reminder of the rehabilitative implications from the scoping and mapping findings, followed by proposed clinical action to address the findings.

4.3 **Spider diagram depicting the Main Implications on Rehabilitation (far left), How this can be addressed (middle) and Actions (far right):**



The diagram depicts viable methods to engage and deliver rehabilitation (within the clinical environment) which will be piloted, with the aim of improving disability and exercise adherence for men with prostate cancer across the pathway in North East London. This will be achieved by a Band 7 physiotherapist and Band 4 rehabilitation assistant through the second project work stream (see table below) 'Tailoring, developing and delivering rehabilitation services.' The project will collect data at 3, 6 and 9 months and present the efficacy findings to various funding streams with an 'invest to save' agenda.

Work Streams

Areas of activity in which this project will be divided into are shown in the table below. The project has been broken into 3 work streams (the report is the outcome for the Scoping arm), the aim of which is to assist with project management and ensuring appropriate outcome measures are used to capture enough data by the end of the project.

4.4 **Table presenting the three work streams of the project and the anticipated method of delivering improved rehabilitation for men with Prostate Cancer in North East London.**

Work Stream	Objective	Outcomes
Scope	**Assessment men and theirs carers unmet needs**	*Questionnaires: Face to face Telephone Email Survey Monkey Focus Groups Attend support group
	Map prostate Cancer Journey in NE London	*Questionnaires: Shadow service/email/face to face
		*Stats/No's: Data from Hospital analyst Data from stakeholders
Tailor, Develop and Deliver	**Improve referrals to current rehabilitation/supportive services by 20%**	*No. of attendees to current services at3, 6 and 9 months
		*No. of attendees at 3, 6 and 9 months into project implementation.
	Develop and pilot rehabilitation services to best meet unmet needs	*Satisfaction score
		*No. of attendees at 3, 6 and 9 months into project pilot service
		*No. of education/sign posting interventions
		*pre and post physical activity questionnaire
		*No. of attendees to current services at 3, 6 and 9 months
	Improve Function, Symptom management, psychosocial wellbeing and QOL	*WHODAS 2
		Socio-economic *No of un planned GP visits *No of unplanned hospital admissions *No. of days spent in hospital
Promo and Education	**Raise Awareness of Rehab needs**	*Teaching pre and post survey
		*No. of men living with or beyond prostate cancer attending current services
	Raise Awareness of services available	*No. of onward referrals
		*No of attendees to teaching
		*No. of men attending current services
		*Teaching pre and post survey
	Promote closer working between Oncology and Palliative care	*No. of onward referral
		*No. of attendees to education
		*Teaching pre and post survey
	Dissemination of men's health prostate specific rehab education	*No. of professionals having received the education intervention
		*Teaching pre and post survey

Sustainability

Beyond the PCUK 18 month funding for this project the NHS Improvement document (cancer innovation to implementation: Stratified pathways of care for people living with or beyond cancer[xlv]) recommends to contact the below funding streams when implementing pathways which is likely to require 'invest to save' funding:

- ✓ Hospital/cancer trust = Barts Health Cancer clinical academic group and St Joseph's Hospice
- ✓ Prostate Cancer UK
- ✓ CCG transformation funding
- ✓ Local research and development committees
- ✓ Charities

Next Steps

- ✓ Dissemination of the scoping and mapping findings.
- ✓ Dissemination of the project implementation.
- ✓ Begin project pilot service in the clinical setting.
- ✓ Collect outcome measures at 3 months.
- ✓ Engage a steering group to influence strategic decisions.

This is a call to arms to improve rehabilitation; exercise advice and exercise prescriptions for men living with and beyond prostate cancer to reduce the individual cancer burden and incurred national cost.

Next milestone = 3 month pilot analysis report January 2015

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