Response on behalf of
The Prostate Cancer Charity

to the call for evidence on cancer inequalities
from the APPG on cancer

The Prostate Cancer Charity is the UK’s leading charity working with people affected by prostate cancer. We fund research, provide support and information and we campaign to improve the lives of men with prostate cancer. We were set up in 1996 with the broad remit of improving the care and welfare of those affected by prostate cancer. We now provide the most comprehensive range of services of all the prostate cancer charities.

Prostate cancer is the most common cancer in men. Each year almost 35,000 men in the UK are diagnosed with prostate cancer and approximately 10,000 men die from it.

The Prostate Cancer Charity welcomes the APPG on cancer enquiry into cancer inequalities. The Charity is happy for its evidence to be published and we would welcome the opportunity to give oral evidence to the APPGC.

The Prostate Cancer Charity’s 2020 goals and 2008-2014 strategy, *Transforming the future for prostate cancer*, sets out a framework for tackling inequalities and improving care and treatment for men with prostate cancer. The goals are:
1. By 2020, significantly more men will survive prostate cancer
2. By 2020, society will understand the key facts about prostate cancer and will act on that knowledge
3. By 2020, African Caribbean men and women will know more about prostate cancer and will act on that knowledge
4. By 2020, inequalities in access to high quality prostate cancer services will be reduced
5. By 2020, people affected by prostate cancer will have their information and support needs addressed effectively

1. What is a cancer inequality? What are the main cancer inequalities?

1.1.1 A cancer inequality can take many different forms. For example, inequalities can exist between the level of care provided for different cancers, between individuals within a tumour group, between different social groups or between geographical locations. An inequality disadvantages people in terms of the level of treatment and care they receive and can impact on their treatment outcomes, survival, and experience.

1.1.2 There are a number of specific inequalities that relate to prostate cancer. The Prostate Cancer Charity feels that the most significant inequalities for prostate cancer relate to the areas of ethnicity, patient
experience, research spend, and geographical variations in treatment and outcomes and we will outline our concerns around these areas below.

1.2 Inequalities relating to ethnicity in prostate cancer

1.2.1. African Caribbean men\(^1\) are at a three times greater risk of being diagnosed with prostate cancer than White men in the UK.\(^1\) They also present at first diagnosis at a younger age than White men. On average African Caribbean men present at 67.9 years compared with 73.3 years for white men. However increasing age remains the biggest risk factor for prostate cancer across all ethnic groups.\(^2\) At present it is not clear what factors cause incidence levels to vary with ethnicity and further UK specific research is needed in this area.

1.2.2. Despite the higher risk of prostate cancer for Black men of African Caribbean and West African origin there is poorer awareness of prostate cancer among this group than among white men. In a recent UK study only 37% of Black men had heard of prostate cancer compared to 64% of White men. White men also showed a greater awareness of the signs and symptoms of prostate cancer compared to Black men.\(^3\) Research commissioned by The Prostate Cancer Charity in 2008 found that 58% of African Caribbean men correctly identified prostate cancer as the most common form of cancer in men,\(^4\) compared (in a different study commissioned by the Charity) to 69% of the general male population.\(^5\) Additionally the Charity’s research found that only 15% of African Caribbean men knew that they had an increased risk of developing prostate cancer.\(^6\) It is very concerning that African Caribbean men who are at greater risk of prostate cancer are less aware of prostate cancer than white men, they should have equal if not higher levels of awareness. This suggests an inequality in levels of awareness and that messages about prostate cancer are not reaching this group.

1.2.3. Existing evidence from the UK does not show any difference in stage of disease at diagnosis between African Caribbean and White men, nor does it show any significant differences in access to diagnostic services. There is evidence that African Caribbean men are more aggressively managed in treatment than White men, however this is likely to be because they are diagnosed at a younger age and it is common to treat younger men more aggressively.\(^7\) However, the evidence in the UK on these issues is currently based solely on the PROCESS study (although a study by the Thames Cancer Registry is due to be published soon). Therefore more in depth research is needed to confirm these results and investigate these areas more extensively to ensure there is equality of access to treatment and care between different ethnic groups, particularly for those increased risk.

1.2.4. In order to address this area of inequality relating to prostate cancer we would like:

\(^{1}\)The research findings show that the heightened risk applies to black men of African Caribbean and West African origin, however for the purposes of this paper the term African Caribbean will be used unless referring to a specific study with different terminology.
• Increased funding for awareness work targeted at African Caribbean and Black African men
• More research into the treatment and patient experience of African Caribbean and Black African men
• More research into the cause of the greater incidence of prostate cancer for African Caribbean and Black African men.

1.3. Inequality in patient experience relating to prostate cancer
1.3.1. Men with prostate cancer consistently report a significantly worse patient experience than people with other common cancers. Both the 2005 NAO report *Tackling Cancer: Improving the Patient Journey* and the NHS National Cancer Patient Survey of 2000 reported that prostate cancer patients responded less positively than patients with other cancers on a range of measures.

- Fewer men with prostate cancer received information on side effects or how their treatment had gone
- Fewer men fully understood the explanation of how their treatment had gone
- Fewer men had a named nurse in charge of their care
- Fewer men were given information about self-help groups
- More men were likely to have to wait longer for their treatment

Although there were improvements in experience between 2000 and 2005 these were minimal, and the percentage of men given information about self-help groups actually decreased from 36% to 34% (this was compared with 66% and 64% for patients with other cancers). The poorer patient experience reported by men with prostate cancer suggests they do not have access to the same level of information and support as patients with other common cancers.

1.3.2. A recent survey (2009) carried out by the Charity into the experiences of men with prostate cancer who are undergoing hormone therapy echo the results of the NAO survey and suggest that men on hormone therapy treatment are still not getting access to the information and support they need. Hormone therapy is a very common treatment for prostate cancer, especially for men with advanced or locally advanced disease, and in many cases it is the only treatment available. However, it can cause significant side effects on physical, sexual and mental wellbeing and can impact substantially on quality of life.

332 men participated in the survey and the results from the survey are alarming and present a very concerning picture of the experiences of men receiving hormone therapy for prostate cancer. The key results are:

- 55% of men reported receiving too little information and support
- 51% of men were not asked whether they were experiencing any side effects from treatment on their sexual function or desire
- 67% of men were not asked whether they were experiencing any effects on mental well-being
• 52% of men were not told about written information on hormone therapy
• 32% of men did not have access to a Clinical Nurse Specialist
• 41% of men were not told about support groups
• 62% of men were not told about general counselling services

These results indicate that key recommendations on access to information and support from both the NICE Improving Outcomes in Urological Cancers (2002)\textsuperscript{10} and the Improving Supportive and Palliative Care for Adults with Cancer (2004)\textsuperscript{11} have not been fully implemented for men with prostate cancer. There are unacceptable gaps in care and men with prostate cancer are missing on vital information and support to help them cope with their treatment. It is crucial that situation this is remedied.

1.3.3. Another serious inequality in access to care is that prostate cancer patients have poorer access to Clinical Nurse Specialists (CNS) than some other major cancers. Research shows that men with prostate cancer who have access to a CNS report a better patient experience than men who do not.\textsuperscript{12} CNS’s provide essential care including the provision of comprehensive information, support with making complex treatment decisions, advice on managing side effects, and emotional and psychological support. However Tackling Cancer reported that only 50% of prostate cancer patients had access to a named nurse compared with 61% of other common cancer patients in England in 2004. These findings were supported by the Charity’s recent (2009) survey into the experiences of men receiving hormone therapy for prostate cancer, which found that 32% of respondents did not have access to a specialist nurse.\textsuperscript{13}

1.3.4. In addition to the high number of men without access to a CNS evidence has shown that the caseloads of CNS’s working in urological cancers in England are significantly higher than in other areas of cancer. In 2007 there were 250 uro-oncology CNS posts in England compared to 434 breast cancer CNS’s.\textsuperscript{14} The case-load for uro-oncology CNS’s is also significantly higher; there is more than double the number of newly diagnosed patients per uro-oncology CNS than there is for a breast care CNS (203 compared to 110).\textsuperscript{15} This shortfall in CNS’s for men with urological cancers was highlighted in the Cancer Reform Strategy.\textsuperscript{16} In addition to new patients CNS’s look after men throughout their treatment and care, therefore actual caseloads are far greater, particularly as they include men living with locally advanced or advanced prostate cancer.

1.3.5 There are also significant geographical variations in the number of CNS’s within different cancer networks across England. In 2007 all cancer networks had at least one Whole Time Equivalent (WTE) CNS working in uro-oncology, however national research has shown a substantial disparity in the number of posts between networks. The cancer network with the highest provision of uro-oncology CNS’s has 23 WTE nurses, whereas the lowest has only one. Even discarding the top and bottom 10% of the networks in terms of provision there is a threefold variation in uro-oncology CNS provision across England.\textsuperscript{17} This variation in provision may go some way to account for the
lower levels of men who report access to a CNS and for the lower levels of patient satisfaction.

1.3.6. The lower numbers of CNS’s and the size of the uro-oncology CNS case-load is undoubtedly a major difficulty in achieving NICE recommendations on patient-centred care made in Improving Outcomes in Urological Cancers (2002)\textsuperscript{18} and Improving Supportive and Palliative Care for Adults with Cancer (2004).\textsuperscript{19} As a result of this men with prostate cancer are missing out on vital support, which significantly impacts on their patient experience. There are a number of specific actions that can be taken to improve this situation:

- The numbers of CNS’s working in urological cancers must be increased to be on par with the best of the other cancers.
- The distribution of CNS’s must match the incidence of prostate cancer to ensure and equal level of access across the country.
- The National Cancer Patient Experience Survey must track patient access to Clinical Nurses Specialists for different cancers and the impact this has on patient experience.

1.3.7. It is clear that men with prostate cancer are facing significant inequality in terms of access to support and information compared to other common cancers. This is unacceptable and action must be taken to improve the patient experience of men with prostate cancer:

- Men with prostate cancer must be provided with adequate support and information at all stages of their treatment and care.
- NICE guidance on patient centred care as outlined in Improving Outcomes in Urological Cancers (2002),\textsuperscript{20} Improving Supportive and Palliative Care for Adults with Cancer (2004),\textsuperscript{21} and Prostate cancer diagnosis and treatment (2008)\textsuperscript{22} must be fully implemented across the country.
- The new, planned National Cancer Patient Experience Survey must be implemented urgently to monitor patient experience.

1.4 Inequality in research spend on prostate cancer

1.4.1. Historically prostate cancer has been a neglected area of research compared to some other common cancers. This has lead to many unanswered questions about prostate cancer diagnosis and treatment. In recent years funding has improved and the National Cancer Research Institute (NCRI) has set up two specific collaboratives to improve the co-ordination of research into prostate cancer. However, funding for research into prostate cancer still lags behind funding for some other common cancers.

1.4.2. Data published by the NCRI shows that prostate cancer research accounted for only 7.9% of the overall NCRI spend on site specific research in 2007, compared to breast cancer which accounted for 18.7% and colorectal cancer which accounted for 10.9%.

1.4.3. The smaller spend on research into prostate cancer is all the more concerning because of the continuing lack of an effective test for prostate cancer. The only test currently available is the PSA test. However the PSA
test does not specifically diagnose cancer but identifies a problem with the prostate that could be cancer. There are also problems with the reliability of the PSA test.\textsuperscript{23} There is currently no national screening programme for prostate cancer despite it being the most common cancer in men because of the lack of an effective enough test. More research is needed into developing a better test for prostate cancer that can differentiate between slow-growing and aggressive prostate cancer. This would enable treatment to be targeted more effectively and reduce the level of over-treatment that currently occurs. A greater spend on prostate cancer research is needed to support the development of this test.

1.4.4. The Prostate Cancer Charity believes that to improve the level of research into prostate cancer and answer key questions on testing and treatment the following needs to happen:

- The spend on research into prostate cancer must be increased to be no par with the amount spent on other common cancers.
- There must be increased research directed at developing a new, specific diagnostic test for prostate cancer, capable of distinguishing aggressive prostate cancers from slow growing forms of the disease.
- There must be increased research into prostate cancer prevention.
- There must be increased research into the improvement of survival and quality of life for men who have advanced prostate cancer.

1.5. Geographical variations in outcomes for prostate cancer

1.5.1. There are considerable variations in death rates from prostate cancer across the country, which suggests variations in treatment and care. A recent report from The Prostate Cancer Charter for Action demonstrates that the gap between the highest and lowest prostate cancer mortality rates in England in 2007 was 45 per 100,000 population. The gap increased by 14 deaths per 100,000 from 2006. At least 18\% of England’s 529 parliamentary constituencies have a death rate from prostate cancer more than 25\% above the England average, with men in Tottenham almost 5 times more like to die of prostate cancer than men in South East Cambridgeshire.\textsuperscript{24} This geographical variation means that 300 deaths a year from prostate cancer could be prevented if all Cancer Networks across the country performed at the level of the nine best-performing Cancer Networks.\textsuperscript{25}

1.5.2. The Prostate Cancer Charter for Action’s report also suggests that a failure to implement the NICE \textit{Improving Outcomes in Urological Cancers Guidance} by some cancer networks has a negative affect on patient outcomes. The average age-standardised mortality rate from prostate cancer in those cancer networks which have implemented the guidance is 4\% higher than those networks which have met the deadline.\textsuperscript{26}

1.5.3. The NICE \textit{Improving Outcomes in Urological Cancer Guidance} highlights a link between the volume of radical prostatectomies carried out in a centre and the mortality rate. Centres with a low or medium volume of prostatectomies had a higher mortality rate than centres with a high volume of prostatectomies. Although the number of centres with a low or medium volume of prostatectomy’s has decreased since 1997/98, in 2007/08 there
were still 65 Trusts carrying out fewer than 40 procedures a year (it is recommended that each team carrying out prostatectomy’s should carry out a cumulative totally of at least 50 operations per year).\textsuperscript{27}

1.5.4. In order to reduce the level of geographical variations in outcomes for prostate cancer it is vital that:
- The Improving Outcomes in Urological Cancer Guidance be fully implemented as a matter of urgency, so as to ensure consistent care across the country
- Services and treatment be available at the same level quality across all Cancer Networks.

1.6. Other areas of inequality
There are also two additional areas of inequality that the Charity would like to highlight:

1.6.1. Gender
1.6.1.1. Prostate cancer only affects men and there are a number of inequalities that are linked to gender within health. Men access healthcare, especially primary care, significantly less than women across a range of health conditions,\textsuperscript{28} and it has been suggested that they often wait until they are in considerable pain or are convinced they have a serious problem before consulting a health professional.

This delay in seeking help can impact on the stage at which cancer is diagnosed in men and later diagnosis can reduce treatment options and survival chances. Research has shown that men are at significantly greater risk of dying of all the common cancers that occur in both men and women (except breast cancer).\textsuperscript{29} For example, UK and Europe-wide data on malignant melanoma shows that while women are more likely to develop this type of cancer, men are more likely to die from it. This is almost certainly because men present when the cancer is more advanced and harder to treat.\textsuperscript{30} There are number of potential reasons for the delay in seeking help. Men often find themselves faced with a number of practical barriers to accessing healthcare, including the demands of long working hours and problems with accessing primary care services near the workplace. Therefore the NHS must ensure that services are accessible to men in the locations and at times that will encourage them to use services.

1.6.1.2. Very little is known about how men deal with cancer and what their support needs are. It is known that the psycho-social aspects of cancer diagnosis and treatment may affect men and women differently, and that there is a gender difference in terms of the psychological responses and social factors that may impact on progress post-diagnosis.\textsuperscript{31} These may include differences in access to social networks and levels of emotional support between men and women and differences in help-seeking behaviours; however the exact nature of these differences is not fully understood and there is a lack of research into the best methods to support men. This lack of knowledge about men and cancer has the potential to cause inequalities in access to support for men.
1.6.1.3. In order to enable the gender inequalities in cancer care to be addressed a number of actions needs to be taken:

- There must be an increase in research into how men deal with cancer and their support needs. The National Cancer Equalities Initiative and the National Cancer Survivorship Initiative should lead on this area of work.
- The NHS must ensure that they do all they can to ensure services are fully accessible to men.

1.6.2. Sexual orientation and prostate cancer

1.6.2.1. It is not known how many gay and bisexual men are living with prostate cancer in the UK as cancer registries do not collect data on sexual orientation. However as prostate cancer is the most common male cancer, we can assume that a significant number of gay and bisexual men are affected by the disease. There are a number of potential inequalities that may be faced by gay and bisexual men, for example gay men may have difficulties dealing with health professionals who are likely to assume a female partner. The impact of side effects of treatments on relationships and identity may also differ, and may lead to different support needs. There is also some evidence of homophobia among health professionals which impacts on the ability of gay and bisexual men to access healthcare generally. Unfortunately there is, a severe lack of research addressing the question of potential inequalities relating to sexual orientation. A Department of Health review of the publications database Medline did not find any research on prostate cancer among gay and bisexual men.

1.6.2.2. In order to begin to address the inequalities in prostate cancer care for gay and bisexual men The Prostate Cancer Charity believes that research is needed into the experience of gay and bisexual men specifically living with prostate cancer so that we can identify any inequalities experienced and ensure their needs are being addressed.

2. Why do you think cancer inequalities exist?

There are a number of potential reasons why inequalities exist in relation to prostate cancer treatment and care which are provided below:

2.1 In order to reduce inequalities in access to care NICE produced a series of guidance for commissioners on commissioning services for cancers called Improving Outcomes Guidance. The recommendations in the guidance focus on aspects of services that are likely to have a significant impact on health outcomes for patients. These include measures to improve patient-centred care like better support and information, and recommendations about Multi Disciplinary Teams such as their staff make-up, role and operational levels.

2.2 Prostate cancer was one of the last major cancers that NICE produced Improving Outcomes Guidance for (in 2002 compared to the Improving Outcomes in Breast Cancer which was published in 1996).
The NHS has therefore not had as long to implement the recommendations for prostate and urological cancers as they have had for other cancers and only 30% of cancer networks in England met the December 2007 deadline in the Cancer Reform Strategy for implementing the guidance.\textsuperscript{35} We believe failure to implement these guidelines has had serious implications for patient outcomes. This view is supported by the fact that in 2008 there was a 4% higher mortality rate from prostate cancer in areas that had not fully implemented the recommendations.\textsuperscript{36} The NHS has had seven years to implement this guidance and The Prostate Cancer Charity believes that it is urgent that this guidance is fully implemented now.

The most vital areas for implementation are the recommendations relating to the provision of information and support to patients, as both our research\textsuperscript{37} and the National Audit Office report\textsuperscript{38} has indicated significant gaps in these areas.

2.3 The provision of services for prostate cancer is also dependent on how local health commissioners choose to use their budgets and whether prostate cancer is a local priority. This means there is considerable potential for geographical variations in service provision to develop. Variation in service provision at a local level has the potential to impact on patient experience, treatment, care and outcomes. It appears that variation in service provision does not always relate to incidence or level of need. This is demonstrated by the variations in the provision of CNS’s between Cancer networks, i.e. the networks with the highest incidence of prostate cancer do not necessarily have the highest numbers of CNS’s. This again demonstrates why it is so important that all providers implement the NICE \textit{Improving Outcomes} guidance and other guidance such as the NICE clinical guidelines for prostate cancer, \textit{Prostate cancer: diagnosis and treatment}, to create a consistent level of treatment, care and service provision.

2.4 The smaller amount spent on research into prostate cancer compared to some other common cancers leads to gaps in knowledge both about the disease and also about the needs of men with prostate cancer. This may have an impact on the provision of support services for men with prostate cancer compared to the provision of support for patients with other cancers. For example insufficient research into the psychological effects of prostate cancer is a barrier to the development and widespread adoption of a range of services and interventions similar to those available for breast cancer to be developed for prostate cancer.\textsuperscript{39}

3. Are there inequalities specific to cancer or do they reflect wider health and socio-economic inequalities?

3.1 Some inequalities discussed are specific to cancer and in particular to prostate cancer whereas others reflect wider health and socio-economic inequalities. For example that men with prostate cancer experience inequality in patient experience compared to other common cancers is a specific issue. Whereas the lower levels awareness of prostate cancer in African Caribbean communities may be viewed as part of wider issues about awareness of
health messaging generally in BME communities. Also, gender inequalities in prostate cancer tend to reflect wider health inequalities.

3.2 Geographical variations in service provision exist across a wide range of health services and are not specific to prostate cancer. However, there may be particular reasons for these variations that are specific to prostate cancer, such as the delay in full implementation of the NICE Improving Outcomes Guidance.

4. What would cancer equality look like?
There are a number of aspects of cancer equality:

- Equality of access to high quality treatment and care regardless of where you live and your individual background.
- Equality of knowledge, research and services between different cancers.
- Equality of treatment outcomes between different cancers and irrespective of geographical location.
- An equally high satisfaction with patient experience for all people irrespective of cancer type, geographical location, ethnicity, age, gender, sexual orientation or any other dividing factors.

5. What should be the priorities for research into cancer inequalities?
5.1. The Prostate Cancer Charity has identified the following priority areas that we believe should be prioritised for research into cancer inequalities:

- Research into why men access healthcare services less than women in order to enable the development of strategies to improve men’s access to healthcare.
- Research into what the particular support needs of men are in order to develop support services, including psychosexual support, that meet men’s needs and improve their patient experience.
- Research into incidence, survival, awareness, barriers to accessing services and support needs of different ethnic groups, including African Caribbean communities so as to enable action to be taken to minimise the impact of the increased incidence in African Caribbean men.
- The extent of and the reasons for the geographical variations that occur in terms of provision of services.

5.2. It is vital that regular patient experience surveys are carried out and their results reported so that areas with lower patient experience can be tackled and the success of work to do so, monitored.

5.3. It is vital that research spend between different cancers be evened out and the amount spent on prostate cancer research to be increased to a comparable level with the highest of the other common cancers. Without this the historical legacy of neglect and underfunding of prostate cancer will continue.
6. Would better data collection help in tackling cancer inequalities? If so, how and why?

6.1. Better data collection would help considerably in tackling cancer inequalities. Currently data is not consistently collected across the UK on a number of areas relating to inequalities such as ethnicity, sexual orientation, or the patient experience of older men. The lack of comprehensive data collection hinders attempts to accurately track and identify variations in incidence, to monitor access to services and treatment, and rates of survival and prognosis between different groups. It also impedes attempts to measure whether targeted work to improve equality have made a difference.

6.2. It is vital that the National Cancer Patient Experience Survey look at issues of ethnicity, sexual orientation, geographic location (cancer network and/or PCT), stage of cancer and age or the data will be meaningless in terms of tracking cancer inequalities.

7. What evidence do you have of cancer inequalities in access, treatment, patient experience and outcomes in either health or social care services?

The evidence of cancer inequalities supporting the issues discussed in this submission are referenced at the end, however there are a number of reports that The Prostate Cancer Charity feels are central to this issue:

- **Hampered by hormones? Addressing the needs of men with prostate cancer** (The Prostate Cancer Charity, 2009) reports on research into the experience of men on hormone therapy for prostate cancer and access to information and support to help them live with the impact of hormone therapy treatment on their lives (provided).
- **To What Outcome? An audit of cancer networks’ implementation of Improving Outcomes Guidance** (Prostate Cancer Charter for Action, 2008) provides evidence of the geographical variations in the implementation of the recommendations of NICE in *Improving Outcomes in Urological Cancers* and the impact that this has on patient outcomes and mortality - [http://www.prostatecharter.org.uk/](http://www.prostatecharter.org.uk/).
- **Because Men Matter: the case for Clinical Nurse Specialists in prostate cancer** (Prostate Cancer Charter for Action, 2007) provides data on the differences in provision of CNS’s and the size of CNS workloads between prostate cancer and other common cancers, and on the geographical variations in the provision of CNS’s for prostate cancer.
- **The Real Man’s Prostate Cancer Journey** (The Prostate Cancer Charity, 2005) highlights areas where standards needs to be improved, such as information provision.
- Research by Ethnibus commissioned by The Prostate Cancer Charity (2008) into the levels of awareness of prostate cancer in African Caribbean men.
8. How should the NHS work with other organisations to reduce cancer inequalities?

8.1. It is vital that the NHS work with a wide range of organisations to enable them to reduce cancer inequalities. This includes working in a co-ordinated way with cancer charities, for example, using their expertise to gather evidence on patient experience and need, and to provide better access to information and support for patients. In addition to working with cancer charities it is important that the Department of Health and NHS work with a wide range of community organisations to maximise the number of different groups they are able to reach with cancer awareness messages and support services. It is important that whichever organisations the NHS works with they do so in a sustainable way, for example offering longer term funding rather than short term grants, as often expertise on inequalities is lost because staff are only able to be employed on short term contracts.

8.2. It is also vital that patients and the public are involved in the commissioning of local services and setting priorities. Although there is patient and public involvement in the health service this is not always conducted in a meaningful way and more must be done to ensure it is not tokenistic. Local Involvement Networks (LINks) have the potential to enable widespread involvement in healthcare by patients and the public, and it is essential that the Department of Health and NHS do everything possible to ensure they can be effective. Additionally it is vital that patient and public representatives are drawn from a cross section of service users to reach minority groups and ensure they are empowered to participate fully in involvement opportunities.

8.3. Many organisations working in healthcare have developed excellent examples of best practice. The National Cancer Equalities Initiative is well placed to identify, co-ordinate and facilitate sharing of best practice work on inequalities and should undertake this role.

9. Do you have any examples of good practice in tackling inequalities?

The Prostate Cancer Charity has developed a number projects that provide examples of good practice in tackling inequalities.

9.1. One of the Charity’s five strategic goals is that by 2020 all African Caribbean men and women will know more about prostate cancer and will act on that knowledge, as they are at higher risk of prostate cancer. In order to achieve this we have undertaken a number of projects within the African Caribbean community. The focus of the Charity’s work with African Caribbean communities is on working directly with the community – with men and their families, support groups, community centres, faith groups – as well as raising awareness amongst health professionals about the increased risk of prostate cancer.

9.2. The African Caribbean Awareness Project was launched in 2003, to raise awareness of the increased risk of prostate cancer in men from the African Caribbean community and promote access to health care services. Five regional advisory groups were set up nationally with key partner agencies to
deliver prostate cancer information, training and resources to both African Caribbean communities and health care professionals.

9.3. More recently (2008) the Charity has launched the ‘Older and Wiser’ Programme, and are currently training members of the African Caribbean community in Newham, Hackney and Lambeth to become “community champions”, delivering awareness sessions about prostate cancer to their own communities.

9.4. High quality training for health professionals is crucial in tackling inequalities. In 2008 the Charity delivered a Prostate Cancer Masterclass in collaboration with the Florence Nightingale School of Nursing and Midwifery, King’s College London. This two-day course provided health professionals with advanced training in prostate cancer and new ideas and resources to enhance service delivery and meet the needs of men with prostate cancer. Training such as this can help improve standards of care, and similar training for health professionals across the country has the potential to make some impact on the geographical variations in prostate cancer outcomes and experiences.

9.5. To address the issue of access to support for men with prostate cancer The Prostate Cancer Charity funded 6 prostate cancer nurse specialists at different centres across the UK, between 2002 and 2005. The nurses were employed to provide emotional support, information and advice, to address the gaps in care and develop services to respond to patients needs. The evaluation of the project showed a better patient experience by men who had access to a specialist nurse than those who had not.

10. What realistic goals can be set for reducing cancer inequalities? What should be the priorities for action? What is one thing you would do to reduce cancer inequalities?

10.1. The Prostate Cancer Charity launched a new strategy for prostate cancer in 2008 which aims to improve the treatment and care of men with prostate cancer. In Transforming the future for prostate cancer: The Prostate Cancer Charity’s 2020 goals and 2008-2014 strategy we set out a series of realistic goals for improving prostate cancer treatment and care, of which most had targets for tackling inequalities in prostate cancer (a copy of the strategy is provided).

- Goal 1 – By 2020, significantly more men will survive prostate cancer.
  - In order to achieve this more research is needed to develop a new, specific diagnostic test for prostate cancer.
- Goal 3 – By 2020, African Caribbean men and women will know more about prostate cancer and will act on that knowledge.
  - In order to achieve this work must be done to increase awareness in African Caribbean communities as to their heightened risk of prostate cancer, and the support and information needs of African Caribbean men must be identified and incorporated into service delivery.
• Goal 4 – By 2020, inequalities in access to high quality prostate cancer services will be reduced.
  o In order to achieve this all men affected by prostate cancer, regardless of where they live in the UK, must have access to the same range of treatment and services, and the patient experience of men with prostate cancer must be increased to be at least equal to that of other common cancers.
• Goal 5 – By 2020, people affected by prostate cancer will have their information and support needs addressed effectively.
  o In order to achieve this all men diagnosed with prostate cancer must have their information and support needs assessed throughout their treatment and care, they must be provided with high quality information and have access to a CNS.

The Prostate Cancer Charity believes meeting these goals will significantly improve the experience of all men with prostate cancer including those who currently experience inequalities.

10.2. The National Cancer Equality Initiative (NCEI) has a central role to play in tackling cancer inequalities. The Prostate Cancer Charity believes the NCEI needs sufficient funding to enable it to take direct action in the same way that the National Survivorship Initiative (NCSI) and the National Awareness and Early Detection Initiative (NAEDI) are planning to do with test sites and similar projects. The NCEI needs to set up projects to tackle the worst inequalities in cancer care and use these projects to promote and facilitate sharing of best practice on tackling inequalities both within the NHS and within external organisations.

10.3. If all the groups and organisations involved in cancer and equality work can start to work together in a co-ordinated way under strong national leadership we can start to make a meaningful impact on cancer inequalities. The NCEI must also ensure that the Cancer Reform Strategy initiatives, such as the NCSI and NAEDI build inequality issues into their work.

11. Is there anything else you think is relevant to this inquiry which you would like to tell the APPG about?
In tackling inequalities we often put people into ‘equality categories’ and tackle one issue at a time. We need to remember that individuals are multifaceted, for example someone can be African Caribbean, homosexual and older.

For more information or to follow up on this submission please contact:
Laura Dunkeyson
Policy Officer
The Prostate Cancer Charity
laura.dunkeyson@prostate-cancer.org.uk
020 8222 7138
3 Rabjabu K et al, Racial origin is associated with poor awareness of prostate cancer in UK men, but can be increased by simple information, Prostate Cancer and Prostatic Diseases 2007; 10, 256-260
4 Ethnibus research for The Prostate Cancer Charity, February 2008
5 I to I research for The Prostate Cancer Charity, November 2008
6 Ethnibus research for The Prostate Cancer Charity, February 2008
9 The Prostate Cancer Charity. Hampered by Hormones? Addressing the needs of men with prostate cancer, Campaign Report, 2009
13 The Prostate Cancer Charity. Hampered by Hormones? Addressing the needs of men with prostate cancer, Campaign Report, 2009
24 Prostate Cancer Charter for Action, Postcode Lottery Blights NHS Prostate Cancer Services, 2009
37 The Prostate Cancer Charity. Hampered by Hormones? Addressing the needs of men with prostate cancer, Campaign Report, 2009
39 The Prostate Cancer Charity. Identification of research needed into the experience of men living with and beyond prostate cancer, Paper for the National Cancer Survivorship Initiative – Research working group, 2009