

# PATIENT VOICE PROJECT

## Theory of Change

July 2019



Prostate Cancer Research Centre aims to work in two distinctly disengaged areas – Bradford and Great Yarmouth – and engage men with prostate cancer in ‘Food and Science’ events to help them learn more about prostate cancer and why their input in research is valued. These activities have been informed by feedback from men with prostate cancer, and are designed to remove barriers and make medical research accessible, highlighting the importance of their lived experiences to treatment development.

We will help them to empower themselves and become more involved in prostate cancer-related health research by: hosting workshops for men to create content and imagery on what they want the future to look like for their younger men in their family, disseminated to other men to encourage further engagement; and creating a webpage for men to share stories about their cancer journeys and ongoing involvement in research through blogs and video diaries.

We will help build their confidence and enable them to participate in decisions on health research by inviting them to take part in regional advisory groups to our Patient Panel and ensure we fund people-centred research. Their feedback will inform our decision-making process for awarding and assessing grant funding for research into new treatments for prostate cancer.

### Challenges to be addressed

- Men are increasingly facing crises and yet are more resistant to seeking help. [The Young Foundation, ‘INVISIBLE MEN: engaging more men in social projects’ (2012) [https://youngfoundation.org/wp-content/uploads/2012/10/INVISIBLE\\_MEN\\_-\\_FINAL.pdf](https://youngfoundation.org/wp-content/uploads/2012/10/INVISIBLE_MEN_-_FINAL.pdf)]
- Men are rarely considered to be a ‘target’ group and all too often they are not immediately thought of when developing services and projects. (INVISIBLE MEN)
- Fear of stigmatisation and perception within the community that prostate cancer is embarrassing, men are supposed to be strong and shouldn’t/don’t want to scare family member – there is tension between what men should be traditionally and what their new roles are in society, which can lead to social isolation and adverse effects on male vulnerability. (INVISIBLE MEN)
- Limited knowledge and understanding of prostate cancer in terms of diagnosis, management and treatment.
- Prevalence of misinformation and inaccuracies regarding treatment options and related side effects.
- Lack of confidence in ability to challenge assumptions, request second opinions regarding treatment, and/or participate in health research and innovation.
- Recent success in involving men with prostate cancer in our latest grant call, but these participants tended to be from an older, more socially and economically advantaged background.
- It has more been challenging involving men from socially and economically disadvantaged backgrounds.
- To ensure that we are meeting the needs of all men with prostate cancer and funding people-centred research, it is vital that we engage men with lived experience from BAME backgrounds and/or areas of high deprivation.

		Objectives			
Target audience	Recruitment considerations <sup>1</sup>	Engagement (for both target audiences)	Empowerment (for both target audiences)	People-focused research (for both target audiences)	Outcomes (for both target audiences)
		Outputs			
<b>Older men in deprived areas with prostate cancer</b>	<p>Potential facilitators:</p> <ul style="list-style-type: none"> <li>• Encouragement by others</li> <li>• Personal interest in participating</li> <li>• Complimentary refreshments</li> </ul> <p>Potential barriers:</p> <ul style="list-style-type: none"> <li>• Poor health</li> <li>• Inaccessibility</li> <li>• Costs</li> <li>• Lack of interest</li> </ul> <p>Strategies for engagement:</p> <ul style="list-style-type: none"> <li>• Offering adaptable approach according to participants' needs e.g. home visits and within their residential area</li> <li>• Face-to-face contact</li> </ul>	We will hold eight afternoon/evening 'Food and Science' events at local community centre(s) that will engage 160+ men with prostate cancer to learn more about prostate cancer, research into new treatments, the importance of their role and why their lived experiences are needed.	We will (i) hold 20 workshops that facilitate 100+ men with prostate cancer to create content and imagery around what the future could look like for the younger men in their family; and, (ii) create a webpage and facilitate men with prostate cancer to share stories about their cancer journeys and ongoing involvement in research, through blogs and video diaries. This will lead to them feeling empowered and that their lived experiences are valued, as well as engaging more men with prostate cancer to ensure that our messaging is informed by our target audience and meets their needs.	We will invite 60+ men with prostate cancer to take part in regional advisory groups to PCRC's Patient Panel and feedback on elements of research from strategy to design and delivery. This will lead to men with prostate cancer thinking critically about research and ensure that PCRC's research better represents the needs of all men with prostate cancer.	<ol style="list-style-type: none"> <li>1. 160+ men with prostate cancer from socially and economically disadvantaged backgrounds will have an improved understanding of prostate cancer and the importance of research into new treatments.</li> <li>2. 100+ men with prostate cancer from socially and economically disadvantaged backgrounds feel empowered and believe that prostate cancer research and development of new treatments is useful to them personally.</li> <li>3. 60+ men with prostate cancer from socially and economically disadvantaged backgrounds value prostate cancer research and feel confident to participate and comment on medical research into new treatments.</li> </ol>
<b>Older BAME men with prostate cancer</b>	<p>Potential facilitators:</p> <ul style="list-style-type: none"> <li>• Cultural and ethnic aspects e.g. connections to the targeted community through community leaders</li> <li>• Trust – introduction through community clinicians</li> <li>• Personal benefits and benefits to participants family</li> <li>• Social support from family, friends, staff and peers</li> </ul> <p>Potential barriers:</p>				

	<ul style="list-style-type: none"> <li>• Having other priorities</li> <li>• Lack of transportation</li> <li>• Poor health</li> <li>• Lack of motivation</li> <li>• Cultural and language barriers</li> <li>• Lack of confidence</li> <li>• Lack of knowledge</li> </ul> <p>Strategies for engagement:</p> <ul style="list-style-type: none"> <li>• Familiar location i.e. church or community centre</li> <li>• Word-of-mouth</li> <li>• Information easy-to-read (bullet format, photo of research team)</li> <li>• Introductory meetings</li> <li>• Providing transportation</li> <li>• Monetary incentives</li> <li>• Friendly competitions</li> </ul>				
<b>Longer-term impact</b>					
<p>We hope to enable over half of men involved to still be engaged, empowered, and involved in prostate cancer research after three years.</p> <p>We hope to ensure that PCRC's development of new treatments for advanced prostate cancer is patient-centred and informed by the experiences of men with prostate cancer from a range of social and economic backgrounds.</p> <p>We hope to have a diverse panel of patients involved in decision-making and monitoring impact of our research projects.</p>					

<sup>1</sup> Ann E.M. Liljas et al, 'Strategies to improvement engagement of 'hard to reach' older people in research on health promotion: a systematic review' (2017) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5399821/#!po=0.574713>