

Abdul Mageed Education Trust – Health Information Session on Prostate Cancer

On 25 November 2024, we were invited to undertake a health awareness session hosted by the [Abdul Mageed Education Trust](#) at the Church St Library in Westminster, on prostate cancer.

Background and development of the session

We were introduced to the Abdul Mageed Education Trust by one of the Imperial Patient Experience Research Centre (PERC) Community Partner steering group members. PERC identified Mr Sami Hamid. Consultant Urologist at Imperial College as a speaker.

Slides used in the session were reviewed by PERC ahead of the session to ensure they were in lay language and accessible however due to technical issues on the day, the slides could not be used. As Mr Hamid speaks Arabic he delivered the session in both Arabic and English.

Format of the session:

The session started at 12pm with the community providing light refreshments.

- Prostate Cancer Session - Mr Hamid
- Q&A
- Completion of feedback forms
- Lunch and refreshments

Aims of the session:

- Sharing health literacy information about prostate cancer
- Increasing awareness about prostate cancer, the current tests and treatments available and current research into prostate cancer

Attendees

The session was promoted through the Abdul Mageed Education Trust's communication channels and across their community networks (see flyer in **Appendix A**). There were 19 attendees, 16 women and 3 men.

Understanding Prostate Cancer – Mr Hamid

During the session, the following topics were covered:

- What is prostate cancer?
 - The prostate is the sex gland of men used for reproduction
 - As you get older the prostate gets larger and can cause problems
 - Other problems are usually the reason prostate cancer is found e.g. blood in urine, peeing a lot
 - There is currently no screening test for prostate cancer

- It is very slow moving
 - If you are identified to be at low risk of prostate cancer – there is a good prognosis, if you are at intermediate risk, it is not clear about the likely prognosis and if you are identified to be at high risk, this could result in metastatic cancer (alike what the cyclist Chris Hoy has)
- What is PSA and a PSA test?
 - PSA is prostate specific antigen (PSA) found in your blood. It is a marker we use to see if we need to do more tests e.g. MRI
 - High levels of PSA may be a sign of a prostate condition but there are other reasons for the PSA level going up e.g. urine infection
 - If the PSA level is 1 or 2 – there is no prostate cancer, a normal PSA level is between 1 and 4 and if the PSA level is 5 or above, more tests are required
 - We find out that PSA tests can cause more problems than it helps as the PSA test is not a screening test.
- What other tests do we do?
 - An MRI scan takes a picture of the prostate to see if something is growing. A growth may not always be cancer (it can be inflammation) and needs to be tested by doing a biopsy.
 - Biopsy
 - These tests can cause anxiety as they are not perfect and your doctor can provide more information
- How do I get a PSA test?
 - If you have a concern about prostate cancer you can ask your GP for a PSA test if you are over 50 but you may be asked to do more tests if the PSA level is high
- What should I look out for?
 - Prostate cancer is a silent cancer as there are no symptoms or pain
- Risks of prostate cancer
 - Genes related to breast cancer are linked to prostate cancer
 - If you have a blood relative with prostate cancer or breast cancer you should get tested
 - Diabetes and heart problems are not a risk for prostate cancer but the more overweight you are, the more you are at risk for prostate cancer
- What is the treatment?
 - Surgery to remove the prostate, radiotherapy and/or hormone treatment for bringing down testosterone levels

- Someone can choose not to have treatment but they need to know the risks. If you are in your 20's you may want to have treatment. If a man has prostate cancer over 80 years, he won't die of prostate cancer
- There are a lot of new treatments but some make you feel very ill
- In the UK we have the best cancer treatments in world. The Royal Marsden hospital treatment is very good. There are only a few hospitals in world at this level. Only a few treatments are not available and this is because we need proof that they really work well before we use them.
- What are some side effects of treatment?
 - Sexual function problems
 - Problems passing urine
- TRANSFORM prostate cancer research study
 - Aims of this research study:
 - To conduct a robust randomised controlled trial (RCT) (a form of research where one group of people in the trial are randomized (by a computer programme) given one treatment or intervention and another group are given a different treatment or intervention so their effectiveness can be compared) of novel prostate cancer screening strategies
 - To provide results that will demonstrate acceptability (by patients), and clinical and cost-effectiveness of the alternative screening strategies to support development of clinical guidelines.
 - To ensure that any future prostate cancer screening programme is constructed using knowledge of barriers and facilitators (of patients and the public) to ensure equitable engagement.
 - Establish a sustainable, long-term model for a Bio-Digital Twin (a virtual model of an individual's biological system) for translational research, including linkage of biomarker (e.g. measurements taken from blood tests) testing with long term clinical outcomes
 - This study needs more men above 45 – 50 years to take part
 - If you are part of the study and the PSA test is below 1 that is fine, if the PSA test is between 1 and 3, the study team will want to check what happens over the next 10 years through various tests including an MRI scan. If a PSA test is 3 and above, this will also result in more tests.
 - There are genetic tests which are part of this trial but we need to look at everything
 - The trial helps to look for markers in the blood to diagnose prostate cancer
 - Engagement from different communities is important as there can be genetic reasons for cancer and we need people from different communities to take part.

Questions asked during the session:

- What is PSA?
 - Prostate specific antigen (PSA) in your blood
- Is the prostate getting larger part of the ageing process?
 - Yes enlargement is normal

- Some men will have a problem peeing and some need medication or an operation to help them pee better
 - The benefit of seeing a urologist when you have a problem peeing is that you get tested for prostate cancer
- Why are tests for prostate cancer not great?
 - We are working on them
- Can high intensity bike riding cause prostate cancer?
 - Cycling and pushing on the prostate can push the PSA level up
- Can a low risk cancer become a high risk cancer?
 - We would keep this under observation and every few months do a PSA test and if it is going up you would get a MRI and if it shows a change, you would have a biopsy
- How do you get a urine infection?
 - An enlarged prostate can lead to not emptying your bladder which results in a urine infection
- What causes excess peeing?
 - This can be caused by an enlarged prostate, drinking too much coffee, tea, alcohol, fizzy drink
 - In women this can be from menopause or diabetes
 - In men, it is usually related to the prostate
- Is water good?
- Why don't antibiotics always treat UTIs?
 - We need to do tests to find out
- How long should antibiotics be taken for?
 - Minimum 3 days but usually 5 days.
- Why are UTIs more common for women when they are older?
 - Because of estrogen levels decreasing from menopause
- Is protein linked to diet?
 - Not for UTIs
- Would I be eligible to take part in the TRANSFORM trial at 72 years?
 - Yes
- Is there a home PSA test?
 - Yes but it is not very good and there is an issue with who you would see with the result, you would have to wait to see a GP
- Is testing for prostate cancer a very grey area?
 - Yes
- Is prostate cancer hereditary?
 - Yes and could also be related to the environment as we don't know what's in the environment
- What about stem cell treatment?
 - We don't use stem cells in urology but they do in haematology
- What about discolouration of urine?

- This is not related to prostate cancer but blood in urine is a problem. If urine flow is a problem, ask your GP.

Comments

- Each antibiotic has different side effects
- Some people think if you have an operation for cancer, it will spread it.

Feedback

At the end of the session, a printed feedback form (see **Appendix B**) was shared with all the attendees to explore their experiences. 11 responses were received and are summarised below

- 81% (n=9/11) of attendees said that after attending this session they knew “A lot” about prostate cancer”
- 54% (n= 6/11) of attendees said that after attending this session, they knew “A lot” about the signs/symptoms of prostate cancer.
- 54% (n= 6/11) of attendees said that after attending this session, they knew “A lot” about the treatment of prostate cancer
- 81% (n=9/11) of attendees said that after attending this session, they think health research could benefit them or their family

Please see the full results of the feedback forms at **Appendix C**. The demographics of those who completed the feedback form are set out in **Appendix D**.

Appendix A: Flyer shared by the community to advertise the session



**NHS PROSTATE
CANCER WORKSHOP**
CANCER SCREEN, DETECT AND PROTECT



DELIVERED BY SAMI HAMID
CONSULTANT UROLOGIST SURGEON

Arabic language interpretation provided by
Naglaa's World Limited

MONDAY 25TH NOVEMBER 2024 - 12PM TO 2 PM

 2nd Basement, Community Space, Church Street
Library, 67 Church Street, London, NW8 8EU

Tube Station:
Edgware Road

Buses:
6, 16, 98
Nearest bus stop
Edgware Road

**DELICIOUS LUNCH
AND REFRESHMENTS
WILL BE PROVIDED**

 **BME**
healthforum

Abdul Mageed Educational Trust in collaboration
with BME Health Forum



Appendix B: Feedback form

PROSTATE CANCER SESSION - 25 NOVEMBER 2024

FEEDBACK FORM

1. After attending this session, how much do you know about prostate cancer? (Please circle one)

Nothing
A Little
A Lot
2. After attending this session, how much do you know about the signs/symptoms of prostate cancer?

Nothing
A Little
A Lot
3. After attending the session, how much do you know about the treatment of prostate cancer?

Nothing
A Little
A Lot
4. After attending the session, do you think health research could benefit you or your family?

I am also happy to share my...

age... No, ☐ Sure, ☐ 26-35 ☐ 46-55 ☐ 66-75 ☐ 86+ ☐
 thanks it's: 36-45 ☐ 56-65 ☐ 76-85 ☐

ethnicity... No, thanks ☐ Sure, it's:

Thank you!

Imperial Biomedical
Research Centre

Appendix C: Responses to feedback form questions (n=11)

Q1. After attending this session how much do you know about prostate cancer (please circle one)

| Nothing | Less than a little | A little | More than a little | A lot |
|---------|--------------------|----------|--------------------|-------|
| | | 2 | | 9 |

Q2. After attending this session, how much do you know about the signs/symptoms of prostate cancer?

| Nothing | Less than a little | A little | More than a little | A lot |
|---------|--------------------|----------|--------------------|-------|
| 1 | | 2 | 2 | 6 |

Q.3 After attending this session, how much do you know about the treatment of prostate cancer?

| Nothing | Less than a little | A little | More than a little | A lot | No answer |
|---------|--------------------|----------|--------------------|-------|-----------|
| | | 4 | | 6 | 1 |

Q.4 After attending the session, do you think health research could benefit you or your family?

| Yes | No | Not sure | No answer |
|-----|----|----------|-----------|
| 9 | | | 2 |

Appendix D: Demographics of attendees who completed the feedback form (n=11)

| Characteristics | n (%) |
|---|----------|
| Age groups (in years) | |
| 26-35 | 0 (0.0) |
| 36-45 | 1 (9.1) |
| 46-56 | 4 (36.4) |
| 56-65 | 5 (45.4) |
| 66 – 75 | 1 (9.1) |
| 76-85 | 0 (0.0) |
| 86+ | 0 (0.0) |
| Prefer not to say | 0 (0.0) |
| Ethnic group | |
| White | |
| English/Welsh/Scottish/Northern Irish/British | 1 (9.1) |
| Irish | 0 (0.0) |
| Gypsy or Irish Traveller | 0 (0.0) |
| Other White background | 0 (0.0) |
| Mixed/Multiple Ethnicity | 0 (0.0) |
| White and Black African | 0 (0.0) |
| White and Black Caribbean | 0 (0.0) |
| White and Asian | 0 (0.0) |
| British and Bangladeshi | 0 (0.0) |
| Asian/Asian British | |
| Indian | 0 (0.0) |
| Pakistani | 0 (0.0) |
| Bangladeshi | 1 (9.1) |
| Chinese | 0 (0.0) |
| Sri Lankan | 0 (0.0) |
| Other Asian background | 0 (0.0) |
| Black/African/Caribbean/Black British | 0 (0.0) |
| African | 0 (0.0) |
| Caribbean | 0 (0.0) |
| Other Black/African/Caribbean background | 1 (9.1) |
| Other | |
| Arab | 1 (9.1) |
| Sudanese | 1 (9.1) |
| Afghanistan | 1 (9.1) |
| Palestinian | 1 (9.1) |
| Any other ethnic group | 0 (0.0) |

| | |
|-------------------|----------|
| Prefer not to say | 4 (36.4) |
|-------------------|----------|