

Help us to design a Prostate Specific Antigen (PSA) Passport

Focus Group Outputs

4th July 2017

2pm – 4pm

1. Agenda for the afternoon

Time	
14:00 – 14:15	Arrivals & Refreshments
14:15 – 14:30	Introductions & Background
14:30 – 15:00	Your experiences
15:00– 16:00	Developing the tool
16:00– 16:15	Feedback
16:15 – 16:30	Next Steps

2. Attendees

Name	Borough
AS	Middlesex
GM	Croydon
IRB	Croydon
JB	Croydon
JC	Orpington
JP	Wandsworth
JW	Kingston
KL	Lambeth
MM	Richmond
RH	Croydon
WH	Richmond
WD	Merton
IN ATTENDANCE	
Sandra Dyer	Specialist Nurse
Ann Courtness	Specialist Nurse
Jill Mulelly	Head of Engagement – NHS
Clare Thomas	Engagement Manager – NHS

3. Aim of the session

To work with men who have experience of prostate cancer services, to develop and test out a new patient held record that would help men record their PSA (prostate specific antigen) result and assist in greater self-management in their follow up.

4. Key outputs – overall experience

4.1 What has worked well?

- **Community Support** - People being able to access support groups and meetings peers who have been going through similar experiences. It was felt that there is great support and information online – if individual is able to use the internet.
- **Cancer Centres** - People really valued centres such as The Mulberry Centre in Richmond and The Maggie Centre
- **Signposting** - Support groups being able to sign post individuals to different services in their areas.
- **Staff** – Having a clinical nurse specialist or an oncologist around who is able to help with any questions
- **Pathway** - After seeing GP, being put on the correct pathway and seeing a consultant two weeks after being referred
- **Communication** - Some individuals felt able to speak to their consultant if they had any questions (mixed experience). They felt that their consultant had time for them.
- **Choice** - Some people felt that they had a choice of where they were treated.



4.2 What could have been improved?

- **Administration** - It was noted that simple administration tasks such as name, ethnicity, and date of birth etc. were included in letters. One person mentioned that he received a letter with the wrong ethnicity and age.
- **Administration** - People noted that they were given telephone numbers of staff however these were not kept up to date and they were unable to reach the person they needed to speak to.
- **Follow up appointments** - Having to follow up appointment letters with GPs and the Hospital due to not receiving letters.
- **Continuity of staff** - People felt that there was a large staff turnover which meant that you didn't always see the same person and care could feel disjointed.
- **Staff attitude** – some people felt staff could be more compassionate
- **Communication** - Consultants should talk to the individual about side effects of having prostate cancer and also side effects of any medication taken.
- **Communication** – Advice not given – such as benefits advice, sick pay advice etc.
- **Out of Hours** - One person mentioned that they were discharged on the weekend after having surgery and left to get along with things on their own. He wasn't left with any information and wasn't given enough supplies to last him the weekend.
- **Carer Support** - The role of the Carer was discussed and people felt that they also needed more support and information to help them care for an individual.
- **Signposting** – Making sure that each person knows where support groups are and other information which they may need.
- **Translation services** – More translators should be made available when speaking to someone whom English is not their first language.



5. Key outputs - developing the tool

5.1 Do you think a tool would be helpful to manage PSA levels?

First thoughts:

- It should contain a graph to record PSA levels as well as a table
- Needs to be part of a bigger picture
- Should complement other information that is available
- Should treat a whole person and not just the PSA number
- Should be shared ownership between individual and health service

5.2 What information should be contained in the tool?

- Explain what a PSA level is
- Pitched at a user friendly level
- Should not cover too many options
- More information about what will happen in the future
- Contain mini-cards with information on such as support groups, however all information needs to be regularly updated such as phone numbers. This could be a helpful aid for family/Carer – for example: local support services
- Include a list of things NOT to do before a PSA test
- Financial advice/benefit advice

5.3 Extra information to record

- Record and monitor the level of haemoglobin
- Record and monitor mood level
- Should include a height and weight chart
- Checklists so someone is able to monitor signs and symptoms. For example: how many times you use the toilet.
- Dates for appointments

5.4 How should the information be recorded?

- Visually should be simple
- Graphical and tabular
- Just in ML not NG
- Include pre-printed graph
- Be used as a visual aid – such as a graph so people can see if their PSA level is increasing/decreasing or staying the same.

5.5 What should the PSA passport look like?

- A5 size
- Small
- Have room to fit extra information – like a folder

- Durable
- 2 Parts for home and outside/wallet
- In the future, move to an APP to record information

6. Next steps

What we will do with your feedback and how can you stay involved?

- We agreed to send over the passport for comments
- We agreed to send over the final draft passport
- For those who are able to, offer to sign up to test the pilot