



Humber, Coast and Vale Cancer Alliance

Prostate Focus Group

February 2019

Aim of the Focus Group

The aim of the prostate focus group was to understand the experience from referral, diagnosis, treatment to living with and beyond cancer for those who had experienced prostate cancer.

By understanding both positive and negative experiences of the current prostate pathways across the Humber, Coast and Vale Cancer Alliance we could aim to ensure that any localised pathway steps which add value/increase positive patient experience are not lost when implementing against national guidelines.

Format of the Focus Group

Two focus groups were held on 6th February at the Country Park Inn at Hessle Foreshore. There were 25-30 people in attendance with patients and partners, lead cancer nurses and specialist nurses from Hull University Teaching Hospitals NHS Trust and York Teaching Hospital NHS Foundation Trust. Patients came from across the Alliance, but the majority of patients were from Northern Lincolnshire and Goole Hospital Trust and Hull University Hospitals. Some patients did travel from York Teaching Hospital but a separate engagement sessions is being planned for those affected by prostate cancer in the North Yorkshire area.

Lucy Turner, Programme Director for the HCV CA, gave a presentation on the background to the Cancer Alliance and an overview of our current work priorities to provide attendees with an understanding to the Alliance and their involvement in developing the prostate cancer pathway from what their experience had been.

The event was facilitated by two Lay representatives and supported by members of the Cancer Alliance project team to ensure that feedback from patients was collected.

The focus groups took people from the start of their experience from having signs and symptoms/not having signs and symptoms and presentation to their GP, through the pathway to living with and beyond their cancer diagnosis and treatment.

Key findings

Signs and Symptoms

A number of patients said that they didn't know the signs and symptoms of prostate cancer and until they had prostate cancer, weren't particularly interested in knowing about signs and symptoms. However, once they were diagnosed with prostate cancer, many patients at the group talked about Sky Sports and the Prostate UK cancer 'man' badge that all Sky Sports presenters

wore to raise awareness of prostate cancer. Many of the participants on the day were wearing the Prostate UK badge and were proactive in speaking about prostate cancer once diagnosed. Many patients reported that it was their wife/partner who had suggested that they visit the GP and were a key influencer in their partners going to the GP. Some reported that, where they were regularly passing urine or had blood in their pee, they did not act on these signs and symptoms for a number of weeks and in some instances months.

Primary Care – Education and Information

Many patients in both groups reported that when they attended their GP practice they were referred to hospital but didn't know (or ask) the reason for the referral or that they were being referred under the two week wait referral process. Where the two week wait had been mentioned, patients reported that they didn't know that this could be in relation to prostate cancer.

Patients also could not recall receiving any written information from their GP when they left their appointment.

There was much discussion from patients about routinely carrying out PSA testing and some patients wanted to understand more about PSA testing and Gleeson scores. Patients also raised questions about the maximum age of having the prostate removed as some said that it was 74 and another 84. "I phoned Prostate UK a few times and they were helpful".

Diagnostics and Diagnosis

No-one reported delays in being seen, but once at hospital, some patients still were unsure why they were there, that they may be undergoing tests and what those tests may be. During the focus group one patient said "I didn't know I was being referred for cancer until I saw the Macmillan Nurse". Other patients spoke of their personal lack of awareness that it could be cancer.

Patients did want the whole system to speak to each other so that information about their care and treatment was more joined up. That those who needed to see results in relation to tests and diagnostics from having bloods taken at GP through to other diagnostics in secondary care, all being available as one universal system. Patients couldn't understand why this didn't happen. The groups were asked about their ability and willingness to travel for appointments, whether this was to for quicker access to diagnostics and treatment or to access a Rapid Diagnostic Centre as part of the NHS Long Term Plan.

The majority of patients reported that they would be willing to travel if this meant that they could get diagnostics in one place. Patients did say that whilst they would travel but factors such as parking and travel costs would still worry them i.e. could they get parked for their appointment and how much would it cost. The issue of parking concessions, and information about concessions, varied from patient to patient, and hospital trust to hospital trust. These were important factors for patients with one patient feeding back that the *"diagnosis was slick but was worried about car parking and the costs"*

Diagnosis - Information

This was an area of conversation where some patients reporting receiving too much information, both verbally and written, whilst others felt that they hadn't received enough. Some patients, once they had received their diagnosis, reported that the next steps were made clear and they had been given options but didn't feel that they had the knowledge or understanding to make a decision unless you had read up about it before. Some patients reported asking the clinician what

they would do and felt they were the experts whilst another patient said that the person he was sitting in front of was a surgeon “*you see a surgeon so that that’s what you tend to go for, it’s not biased but you are in a surgery environment, talking to a surgeon, not oncology*”.

Following treatment, the question was asked why was there a need to go back to the consultant to be asked how they were getting on. Patients asked if there was another option to returning to hospital, given that it didn’t involve a physical examination.

Living With and Beyond Cancer

During the focus groups patients did report that they didn’t feel they had support once their treatment had finished, or if they didn’t have treatment, but were *watching and waiting*. Patients described having low moods and not having anywhere to go to outside of hospital. Whilst we may not expect patients to be aware of the term Holistic Needs Assessment (HNA) or Cancer Care Reviews (CCR), it appeared that elements of the HNA or CCR were not experienced by patients and one patient described the end of treatment as “having withdrawal symptoms” as they had been supported through the pathway by clinical teams but once they were living with and beyond, they felt that support had gone.

Recommended Next Steps

The suggested next part of taking forward actions for co-design with patients and staff are:

- Explore support / training in GP practice to give key messages to patients re Two Week Wait referral process, linking with Prostate UK / Cancer Research UK.
- Cancer Champion training – develop additional key messages for trainers to deliver
- Develop draft patient information leaflet devised by Mr Matt Simms, Consultant Urologist which describes, to patients, the reason for the Two Week Wait referral by their GP.
- Work with a hospital trust to develop a draft information prescription, mapping out firstly with staff, when information is provided to patients and in what format and if this is the right time in the pathway and then work with patients to replicate the process. Lastly, at a joint workshop, develop the information prescription pathway collaboratively with staff and patients which details the format and timing of when information is given to patients.
- Project Manager to take some key questions back to clinical lead for prostate cancer where patients have asked for further exploration of options i.e. outpatient follow-up with consultant
- Key messages and updates communicated to patients, around development of the digital roadmap in progress.
- Work with LWAB delivery board to develop and promote the use of HNA and CCRs across the Alliance. Patients to know that these can be accessed and how to access. Explore how the CA website being developed can support the awareness of HNA and CCRs and additionally signposting options to social prescribing organisations.

Conclusion

Patients spoke about having a fast referral and first appointment, to a “slick diagnosis”, timely treatment and support from health professionals during their referral, diagnosis and treatment and were extremely appreciative and complimentary about their interactions with staff.

The areas recommended to be taken forward (with patients and staff) aim to improve awareness of signs and symptoms, to have the right communication messages and information at the right time, for patients to feel supported to live with and beyond prostate cancer, overall improving the experience of those affected by cancer.

Thank you to patients and their partners for giving up their time to attend the focus group afternoon and for describing their own personal experience of being diagnosed with prostate cancer in an open group setting.

Thank you also to:

Julie and Jackie, lead cancer nurses from Hull University Hospitals and York Teaching Hospital and their clinical/specialist nurses who also gave their time to hear what experience patients had of secondary care.

Lucy, Programme Director, for opening the focus group

Zoe and Sally-Ann for facilitating the groups.

Sarah for organising the event. Amina, Rachel and Trish, HCV Cancer Alliance programme team for ensuring that the feedback was recorded accurately.

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