Guidance for completing UKGPCS initial patient pro-forma

Demographics

Please insert as much patient information as possible and indicate if the patient is still alive. Please also indicate if there is any history of other cancers in the patient.

Diagnosis and staging

The date of diagnosis usually refers to the date of the biopsy. We appreciate that in some cases patients are diagnosed with prostate cancer on the basis of a high presenting PSA, without a biopsy. In these cases, we would suggest giving the date that the high PSA was reported as their date of diagnosis.

For the method of detection, please indicate if the patient was diagnosed following PSA screening or if he presented with clinical symptoms, which then prompted the diagnostic tests.

Stage at diagnosis refers to staging based on the TNM criteria. This is referred to separately on the website (link to TNM staging). Staging is usually found on imaging reports. If uncertain ignore the a/b/c stage and just tick the gross TNM staging (i.e. T1-4). Please tick X if unknown (i.e. TX, NX or MX)

Histological grade is usually presented using Gleason scores 1 to 5, reflecting the degree of differentiation of the tumour. This is made up of 2 separate scores for each tumour, e.g. 3+3, 3+4, 4+3 etc. The order of the scores is important as it signifies the more abundant tumour type seen. This is usually written on the pathology report. Patients diagnosed many years ago might have a histological grade instead, ranging from Grade1 (G1) to Grade3 (G3). Please tick accordingly. Please also attach a copy of the pathology results.

Treatment after diagnosis

This refers to the initial treatment the patient received following diagnosis. Please indicate as appropriate.

Please number the sequence for which each treatment is given in the left hand boxes.

Relapse information (Please ignore this section if the patient has not yet relapsed)

This refers to patients who have had relapse of their disease. Please indicate if this was only a biochemical relapse (i.e. PSA rising only) or if the patient had relapse seen on follow up scans. This would include local relapse (i.e. in the prostate or prostate bed after prostatectomy), lymph node relapse, bone relapse or relapse in other organs.

The PSA doubling time refers to the time taken for the PSA value to double. This might indicate how quickly a cancer is progressing.

Guidance for completing the online UKGPCS patient pro-forma at follow-up

This form is required to be filled online approximately 2, 5 and 10 year post patient registration

Login

Internet access is required to complete the follow-up proforma at the following address http://ukgpcs.icr.ac.uk. A login and password will be provided. A link for the SOP is under the collaborators section in UKGPCS corporate website.

The patient's that are due a follow-up will be listed with their allocated study ID.

If there is a need to stop halfway when completing the questionnaire. Click 'save' and logout. **DO NOT** 'save and submit' as the form will be lost.

Diagnosis

The date of diagnosis usually refers to the date of the biopsy. We appreciate that in some cases patients are diagnosed with prostate cancer on the basis of a high presenting PSA, without a biopsy. In these cases, we would suggest indicating the date that the high PSA was reported as their date of diagnosis. If it is wrong and unable to amend, please add to the comments section.

Stage at diagnosis refers to staging based on the TNM criteria. This is referred to separately on the UKGPCS website (link to TNM staging). Staging is usually found on imaging reports. If uncertain ignore the a/b/c stage and just state the gross TNM staging (i.e. T1-4) Please use X if unknown (i.e. TX, NX or MX)

Histological grade is usually presented using Gleason score 1 to 5, reflecting the degree of differentiation of the tumour. This is made up of 2 separate scores for each tumour, e.g. 3+3, 3+4, 4+3 etc. The order of the scores is important as it signifies the more abundant tumour type seen. This is usually written on the pathology report.

In some cases, patients would have undergone a second prostate biopsy (e.g. patients who are on active surveillance). Please indicate the date and results of this if available.

Demographics

Please complete as much patient details as possible and indicate if the patient is still alive. Please also indicate if there is any history of other cancers in the patient.

Treatment at diagnosis

This refers to the initial treatment the patient received following diagnosis. Please check the boxes that apply; boxes will expand and fill as appropriate.

Treatment after diagnosis

This refers to all the treatments the patient received for prostate cancer following diagnosis. Some patients would have had more than one type of treatment. Please add all recurrences separately even if they occurred at the same time.

Completion

Enter the name and position of the person filling out the questionnaire. Save and Submit.