




BMJ Open Organisation and delivery of supportive services for patients with prostate cancer in the National Health Service in England and Wales: a national cross-sectional hospital survey and latent class analysis

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ABSTRACT

Objectives We assessed how often National Health Service (NHS) hospitals reported that they had specific supportive services for patients with prostate cancer available onsite, including nursing support, sexual function and urinary continence services, psychological and genetic counselling, and oncogeriatric services. We identified groups of hospitals with similar patterns of supportive services.

Design/setting We conducted an organisational survey in 2021 of all NHS hospitals providing prostate cancer services in England and Wales. Latent class analysis grouped hospitals with similar patterns of supportive services.

Results In 138 hospitals, an advanced prostate cancer nurse was available in 125 hospitals (90.6%), 107 (77.5%) had a clinical nurse specialist (CNS) attending all clinics, 103 (75.7%) had sexual function services, 111 (81.6%) had continence services and 93 (69.4%) psychological counselling. The availability of genetic counselling (41 hospitals, 30.6%) and oncogeriatric services (15 hospitals, 11.0%) was lower. The hospitals could be divided into three groups. The first and largest group of 85 hospitals provided the most comprehensive supportive services onsite: all hospitals had a CNS attending all clinics, 84 (98.8%) sexual function services and 73 (85.9%) continence services. A key characteristic of the second group of 31 hospitals was that none had a CNS attending all clinics. A key characteristic of the third group of 22 hospitals was that none had sexual function services available. The hospitals in the largest group were more likely to run joint clinics ($p<0.001$) and host the regional specialist multidisciplinary team ($p=0.002$).

Conclusions There is considerable variation in supportive services for prostate cancer available onsite in NHS hospitals in England and Wales. Availability of genetic counselling and oncogeriatric services is low. The different patterns of supportive services among hospitals demonstrate that initiatives to improve the availability of the entire range of supportive services to all patients should be carefully targeted.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A national organisational survey, developed with critical input from patients and a wide range of professional groups, was analysed and a statistical approach was used to group National Health Service hospitals according to the pattern of supportive services available onsite.
- ⇒ The results are representative given the high response rate (129 of the 138 hospitals providing prostate cancer services across England and Wales responded) and most missing data items could be filled in based on publicly available information.
- ⇒ We cannot exclude the possibility that responses may partly reflect circumstances during the COVID-19 pandemic.
- ⇒ The survey responses are 'self-reported' by the hospitals, and they may reflect the 'desired' rather than the actual onsite availability of supportive services.

INTRODUCTION

Worldwide, approximately 1.4 million men are diagnosed annually with prostate cancer.¹ Patients with prostate cancer receive a variety of anticancer treatments, all of which can have short-term and long-term side effects that affect quality of life. There is evidence that patients benefit from supportive services, which provide further help and advice to manage these consequences of treatment.²

A survey conducted about 15 years ago among 749 patients with prostate cancer in England highlighted psychological distress and problems with sexual and urinary function as areas of the greatest need.³ Patients with prostate cancer may also have



comorbidities which require management in parallel by other clinical specialties such as oncogeriatrics.⁴

A clinical guideline developed in the UK for prostate cancer management recommends access to specialist continence and erectile dysfunction services as well as access to a clinical nurse specialist (CNS) to ensure patients receive individualised information regarding treatment and its consequent side effects, tailored to their own individual situation.⁵ Access to specialist genetic counselling is recommended by numerous national and international guidelines.⁶ An international consensus group recommended a comprehensive geriatric assessment for patients who are frail or disabled or who have severe comorbidity.⁷

In the National Health Service (NHS) in England and Wales, an organisational survey was started in 2014 to assess the specialist services available for patients with prostate cancer provided by 138 hospital organisations (English NHS Hospital Trusts or Welsh Local Health Boards; see the Methods section). These services are coordinated within defined local regions by 51 specialist multidisciplinary teams.⁸ This survey, carried out by the National Prostate Cancer Audit (NPCA), has been updated annually and a further full survey was performed in 2021.⁹ Although there is no explicit definition of what constitutes a specialist supportive service; in many health-care systems, it includes the involvement of healthcare professionals trained to provide advice and support for men with specific needs related to their cancer as well as the treatment they receive.

The organisational survey allows hospitals to compare and benchmark the palette of specialist supportive services they provide onsite against the services provided elsewhere.¹⁰ Its results can also be used by patients who want to find out what services are available in hospitals in their local region and beyond. While the 2021 survey collected data on all aspects of prostate cancer care, it had a particular focus on supportive services, including involvement of a CNS, oncogeriatrics, genetic counselling, specialist sexual function services, specialist urinary continence services and psychological counselling.

According to reports from patients and from CNSs, access to supportive services is often patchy and less comprehensive than results published by cancer service providers themselves.¹¹ For example, a survey of 1000 patients with prostate cancer, across 7 countries in 2012 showed that 81% reported unmet supportive care needs.¹² A systematic review published in 2015 demonstrated that there is a need for improved access to CNSs throughout the prostate cancer care pathway.¹³

The aim of this paper is to get a better understanding of the organisation of supportive services for patients with prostate cancer in England and Wales. First, we assessed how often NHS hospitals providing care for patients with prostate cancer reported that specific supportive services are available onsite. Second, we identified groups of hospitals with a similar pattern of supportive services. For example, it is possible that some hospitals provide a

Box 1 Survey questions related to the availability on site of supportive services for patients with prostate cancer in National Health Service hospitals in England and Wales

1. Is there a joint clinic currently available to your patients on site (where urology and oncology clinics take place in the same hospital)?
2. Is there an oncogeriatric service currently available onsite to assess the fitness of elderly patients for chemotherapy or radiotherapy?
3. Do you have clinical nurse specialists (CNSs) present in all your prostate cancer clinics?
4. How many urology CNSs are currently involved in the management of men with prostate cancer?
5. How many CNSs currently work solely in prostate cancer?
6. How many of these CNSs are involved with the management of men with advanced prostate cancer?
7. Are sexual function services (including psychosexual services) available onsite at your hospital organisation?
8. How many sexual function clinics per month are available to your patients?
9. Are continence services available onsite at your hospital organisation?
10. How many continence clinics per month are available to your patients?
11. Is psychological counselling available onsite at your hospital organisation?
12. How many psychological counselling clinics per month are available to your patients?
13. Is genetic counselling available onsite at your hospital organisation?
14. How many genetic counselling clinics per month are available to your patients?

full range of supportive services onsite whereas others may provide a specific and more limited range. Identifying groups of hospitals according to the range and types of supportive services they provide will inform targeted initiatives that aim to enhance full access to these services according to the needs of individual patients.

METHODS AND MATERIALS

Survey questionnaire development

The organisational survey undertaken by the National Prostate Cancer Audit in 2021 was developed from the previous full organisational survey distributed in 2014.⁸ The survey was updated following advice from the Audit's Clinical Reference Group and its Patient and Public Involvement Forum.^{14 15} The survey items assessing the availability of the supportive services onsite are outlined in **box 1**. The full questionnaire can be accessed on the Audit's website.⁹

Survey delivery

The Audit emailed a link for the online questionnaire to the prostate cancer clinical leads for each of the 138 NHS hospitals providing prostate cancer services in England and Wales onsite. These hospital organisations are NHS Hospital Trusts or Local Health Boards, the

organisational units of local secondary care provision in England and Wales, respectively.^{16 17} NHS Trust and Local Health Boards can include one or more hospital sites but within each Trust or Local Health Board, a prostate cancer treatment modality is always delivered on one site. For that reason, we refer to these Hospital Trusts or Local Health Boards as ‘hospitals’.

Contact details of the prostate cancer clinical leads were available from the National Prostate Cancer Audit’s database. The email included information about the expected time it would take to complete the survey questionnaire (ie, no more than 15 min) and the information needed for completion. There was also a link to the Audit’s webpage with further instructions. The time frame of the survey delivery ran from a save-the-date email sent in July 2021 to a final third reminder sent in September 2021.

Cleaning of the survey responses

Multiple responses to the survey were submitted by some hospitals, resulting in 174 responses. These multiple responses were identified, showing that 129 of the 138 hospital organisations (93.5%) responded. The hospitals that had not responded and those that had provided multiple inconsistent responses were asked to submit their ‘final response’. If a final response was not received, we filled in missing information and reconciled inconsistencies between the multiple responses based on publicly available information about the services available onsite as much as possible. We sent the reconciled and filled in responses back to all relevant hospitals asking them to confirm if they were correct: we assumed that this reconciliation process had produced the correct responses if hospitals did not reply.

Data analysis

Latent class analysis can be used to identify qualitatively different unobserved groups, or latent classes, that share certain outward characteristics.¹⁸ It derives probabilities that respondents belong to these latent classes from patterns of categorical responses, for example, to survey questions. We used the generalised structural equation model estimation command in Stata V.17, which can work with incomplete data, although our dataset had very few missing values.¹⁹

The categorical variables were responses to the yes/no questions of the organisational survey and the entities that were being grouped were the hospitals. All data items related to provision of specific support services were included unless they were highly correlated with one another. Provision of a joint clinic was excluded as this was expected to be a strong indicator of surgical centres. Seven questions remained for the latent class analysis of the supportive service available onsite (box 1): oncogeriatric services (item 2), a CNS attending all prostate cancer clinics (item 3), advanced prostate cancer CNS (item 6), sexual function services (item 7), continence services (item 9), psychological counselling (item 11) and genetic counselling (item 13). These seven services represent all

the major prostate cancer support services, corroborated by other research.^{2 4 12 13}

When using latent class analysis, it is necessary to decide how many distinct groups the data contains. To do this, we ran the analysis four times, with two groups the first time, then repeating with three, four and five groups. For each of the four models, we recorded the value of the Akaike information criterion, which was then used to decide which model gave the best solution, a smaller value indicating a more optimal balance between model precision and parsimony.

Additional hospital characteristics

Various hospital characteristics were compared with get a better understanding of the grouping of hospitals according to the latent class analysis. Treatment type, provision of joint clinics of surgery and oncology, and hosting of a specialist multidisciplinary team were all identified using the results of the organisational survey. University hospitals were identified using the University Hospital Association membership²⁰ and the size of a hospital was characterised using bed numbers^{21 22}: hospitals were divided into three equally sized groups. Socio-economic deprivation was estimated from the national Index of Multiple Deprivation quintile²³ of patients with prostate cancer between 2019 and 2021: for each hospital the average quintile of its patients was calculated and hospitals were then divided into three equally sized groups. Rurality was characterised using a Nuffield briefing document identifying the 27 rural and remote hospitals in England.²⁴ The prevalence of each characteristic described above was compared between the latent class groupings using the χ^2 test.

Patient and public involvement

The National Prostate Cancer Audit has a Patient and Public Involvement Forum that provides advice and support.²⁵ Members of this Forum contributed to the design of the Audit’s organisational survey and to the analysis and reporting of the survey’s results: they are, therefore, included as coauthors. In addition, we also summarised some of the comments from Forum members, also highlighting their own relevant care experiences, in box 2.

RESULTS

The reported availability of supportive services onsite varied greatly among the 138 hospitals (table 1). A CNS attended all prostate cancer clinics in 107 hospitals (77.5%), an advanced prostate cancer CNS was present in 125 hospitals (90.6%) and sexual function services were available in 103 hospitals (75.7%). Continence services were available in 111 hospitals (81.6%) and psychological counselling was provided in 93 hospitals (69.4%). In contrast, genetic counselling was only available in 41 hospitals (30.6%) and oncogeriatric services in 15 (11.0%). We had very little missing data: availability

Box 2 Comments from members of the Patient and Public Involvement Forum of the National Prostate Cancer Audit in response to results of the Audit's organisational survey:

- ⇒ 'The support services have been excellent, driven by the CNS nurses'.
- ⇒ 'I am currently having three monthly PSA checks and 6 monthly telephone consultations with one of the CNS nurses. I have been fortunate in not having any urinary or bowel issues other than some very mild symptoms towards the end of the radiotherapy, but the nurse always asks about this. Sexual function support has been offered and discussed'.
- ⇒ 'I don't recall psychological support being discussed specifically—but I guess the calls themselves do that'.
- ⇒ 'On a couple of occasions when I've had things to ask, I have phoned them and always had a call back from a nurse the same day'.
- ⇒ 'It is not especially important to have a named CNS nurse but that the team of nurses are in place and contactable'.
- ⇒ 'Someone who was treated elsewhere was being rather critical of the information he had been given about side effects, especially sexual function'.
- ⇒ 'Clearly a well-functioning CNS nursing team is critical'.
- ⇒ 'Some of the most useful things I have personally experienced have been non-hospital based: two examples are Yorkshire Cancer Research's 'Active beyond Cancer' programme and the '5K Your Way' initiative'.

of sexual function and continence clinics, genetic counselling and oncogeriatric services was unknown for two hospitals, and availability of psychological counselling was unknown for four hospitals.

From the four latent class models that were fitted, the model which divided the 138 hospitals into 3 groups had the lowest value of the Akaike information criterion and

was, therefore, chosen as the best grouping according to the pattern of the 7 supportive services available onsite. The value of the Akaike information criterion was 912.0 with three groups, increasing to 923.0 and 918.5 with two or four groups, respectively. The 3 groups comprised 1 large group of 85 hospitals and 2 smaller ones of 31 and 22 hospitals (table 1).

Group 1, the largest grouping, provided the most comprehensive range of supportive services. All hospitals in this group had a CNS attending all prostate cancer clinics, 98.8% provided sexual function services, 85.9% continence services, 78.6% psychological counselling and 38.1% genetic counselling. The distribution of group 1 hospitals across England and Wales is represented in figure 1. The map demonstrates that the majority of group 1 hospitals are clustered around major cities, including London, Cardiff, Manchester and Liverpool.

Of the 31 hospitals in group 2, a similar proportion to group 1 provided continence services (82.8%). However, fewer hospitals provided sexual function services (65.5%) and psychological (65.5%) or genetic counselling (20.7%). Of note, none of the hospitals in this group had a CNS attending all prostate cancer clinics.

The 22 hospitals in group 3 had high CNS provision: all had a CNS available in every prostate cancer clinic and an advanced prostate cancer CNS available. However, none of the hospitals in this group provided sexual function services. Continence services were available in 63.6%, which is lower than in groups 1 or 2. Provision of both psychological and genetic counselling was also lower at 38.1% and 14.3%, respectively.

Table 2 shows that the cancer treatment types available onsite did not vary significantly between the three groups

Table 1 Services provided by NHS hospitals in England and Wales, grouped according to the latent class analysis

Services provided	Group 1 (n=85)		Group 2 (n=31)		Group 3 (n=22)		All (n=138)	
Clinical nurse specialist attending all prostate cancer clinics	85	(100%)	0	(0.0%)	22	(100%)	107	(77.5%)
Advanced prostate cancer clinical nurse specialist	84	(98.8%)	19	(61.3%)	22	(100%)	125	(90.6%)
Sexual function services	84	(98.8%)	19	(65.5%) Missing 2	0	(0.0%)	103	(75.7%) Missing 2
Continence services	73	(85.9%)	24	(82.8%) Missing 2	14	(63.6%)	111	(81.6%) Missing 2
Psychological counselling	66	(78.6%) Missing 1	19	(65.5%) Missing 2	8	(38.1%) Missing 1	93	(69.4%) Missing 4
Genetic counselling	32	(38.1%) Missing 1	6	(20.7%) Missing 2	3	(14.3%) Missing 1	41	(30.6%) Missing 2
Oncogeriatric services	13	(15.3%)	0	(0.0%) Missing 2	2	(9.1%)	15	(11.0%) Missing 2

%=percentage of hospitals with available data.
NHS, National Health Service.

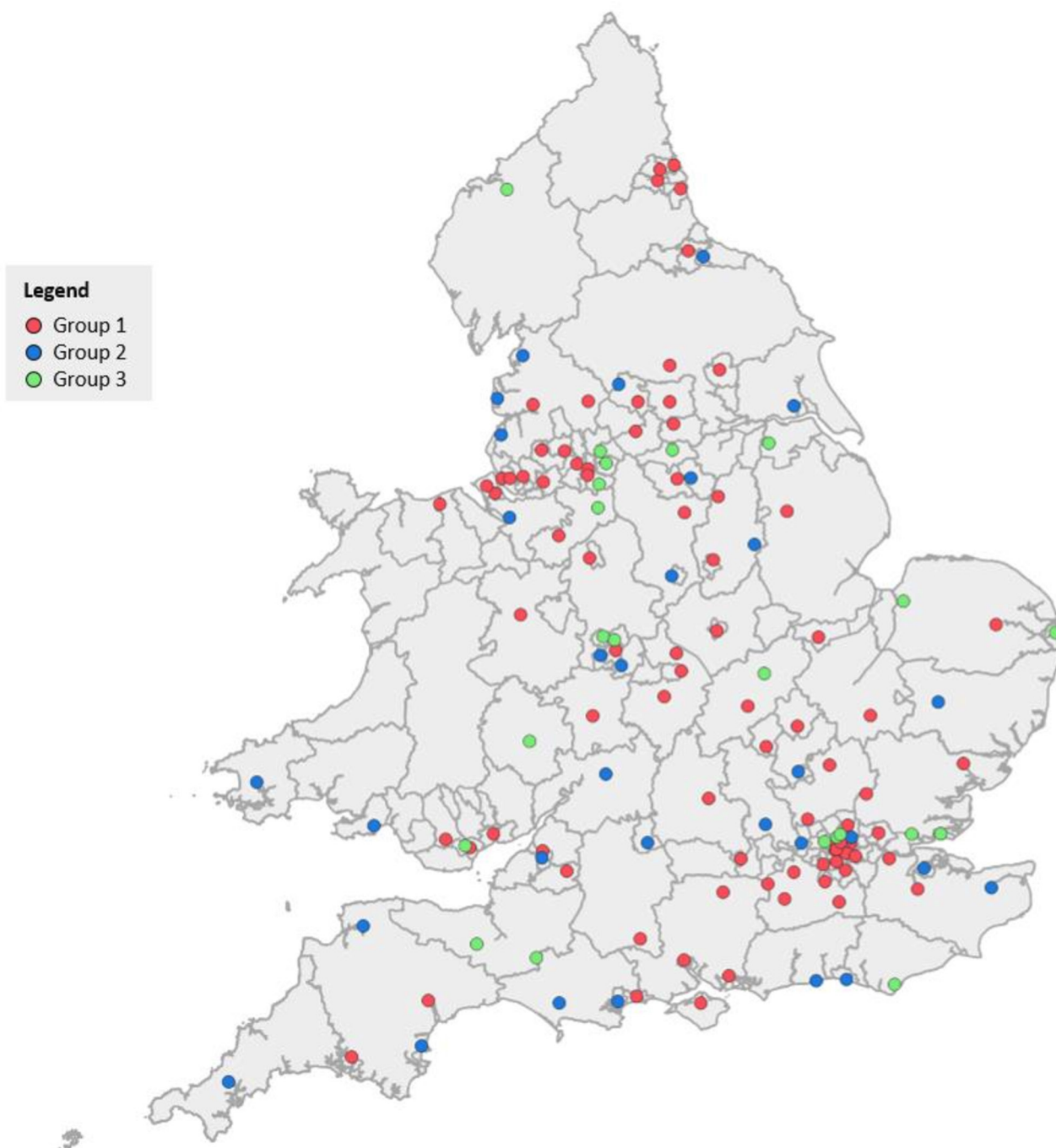


Figure 1 Distribution of the NHS hospital organisations in England and Wales included in each group (as defined according to the latent class analysis; see text for further explanation). NHS, National Health Service.

($p=0.27$), although a greater proportion of hospitals in groups 2 and 3 had neither radiotherapy nor surgery available onsite. Hospitals in group 1 were significantly more likely to run a joint clinic: 57.7% of hospitals in group 1, compared with 6.9% in group 2 and 31.8% in group 3 ($p<0.001$). Hospitals in group 1 were also significantly more likely to host the specialist multidisciplinary team: 47.1% in group 1 compared with 27.6% in group 2, and 9.1% in group 3 ($p=0.002$). There were no statistically significant differences between groups in the proportions of university hospitals, size of the hospital, deprivation of patients or rurality of the hospitals' location.

DISCUSSION

Summary of key results

We found considerable variation in the range of supportive services available onsite in hospitals providing prostate cancer services in England and Wales. An advanced prostate cancer CNS is available onsite in most hospitals (90.6%) and the majority have a CNS attending all prostate cancer clinics (77.5%), sexual function services (75.7%), continence services (81.6%) and psychological counselling (69.4%). The availability of other supportive services, such as genetic counselling

Table 2 Hospital characteristics and available treatments according to the latent class analysis of the supportive services

	Group 1 (n=85)		Group 2 (n=31)		Group 3 (n=22)		All (n=138)
Treatment available							
Neither RT nor surgery	31	(36.5%)	17	(54.8%)	10	(45.5%)	0.270
RT only	13	(15.3%)	4	(12.9%)	6	(27.3%)	
Surgery only	11	(12.9%)	1	(3.2%)	2	(9.1%)	
RT and surgery	30	(35.3%)	9	(29.0%)	4	(18.2%)	
Runs joint clinic							<0.001
Yes	49	(57.7%)	2	(6.9%)	7	(31.8%)	
No	36	(42.4%)	27	(93.1%)	15	(68.2%)	
				Missing 2			
Hospital hosts the specialist multidisciplinary team							0.002
Yes	40	(47.1%)	8	(27.6%)	2	(9.1%)	
No	45	(52.9%)	21	(72.4%)	20	(90.9%)	
				Missing 2			
University hospital							0.086
Yes	27	(31.8%)	7	(22.6%)	2	(9.1%)	
No	58	(68.2%)	24	(77.4%)	20	(90.9%)	
Size of hospital (mean bed no)							0.222
Small (448)	23	(27.1%)	12	(38.7%)	11	(50.0%)	
Medium (827)	31	(36.5%)	8	(25.8%)	7	(31.8%)	
Large (1532)	31	(36.5%)	11	(35.5%)	4	(18.2%)	
Socioeconomic deprivation							0.607
1—least deprived	31	(36.5%)	11	(35.5%)	4	(18.2%)	
2	27	(31.8%)	10	(32.3%)	9	(40.9%)	
3—most deprived	27	(31.8%)	10	(32.3%)	9	(40.9%)	
Rural/remote hospital							0.308
Yes	9	(10.6%)	5	(16.1%)	5	(22.7%)	
No	76	(89.4%)	26	(83.9%)	17	(77.3%)	

%=percentage of hospitals in a group providing each service.
RT, radiotherapy.

(30.6%) and oncogeriatric services 11.0%), is much lower.

A key element of this study is that it used latent class analysis, a statistical method that identified groups of hospitals with a similar pattern of supportive services available onsite. In about two-thirds of the hospitals (labelled as group 1 in this study), the availability of most of the supportive services was relatively high. In two other smaller groups (labelled as group 2 and 3), the onsite availability of supportive services was lower and followed different patterns. For example, in group 2, none of the hospitals had a CNS available at every prostate cancer clinic and in group 3 none of the hospitals had sexual function services.

Implications

These different patterns of availability of supportive services onsite demonstrate that there is not a one-size-fits all approach to improve the availability of supportive services for patients. Relevant quality improvement initiatives should consider first if patients whose care is managed in hospitals where some of the supportive services are not available onsite have access to the full palette of supportive services in other hospitals nearby. A second consideration is whether a possible gap in the availability of some of the supportive services exists because of a 'clinical barrier', in other words the need for supportive services is not always recognised, or because of 'structural barriers', for example, linked to a lack of

financial resources, staff shortages or organisational inefficiencies.

We identified one group of hospitals (group 2) without a CNS available at every prostate cancer clinic. This is a key finding because a recent study reported that patients who were given a 'named CNS' reported a better overall experience of care.²⁶ With a named CNS, it is likely that patients have a greater opportunity to discuss treatment-related side effects, including sexual, urinary and bowel function and psychological distress, especially those men who are reluctant to discuss these issues due to the perceived stigma associated with them.³ The comments from members of the Patient and Public Involvement Forum of the National Prostate Cancer Audit, summarised in [box 2](#), underline the key role that a CNS played in the care that they have received.

Our findings confirmed that provision of oncogeriatric services for patients with prostate cancer is poor in the NHS across England and Wales. Other recent studies also found that few centres in the UK offer formal multidisciplinary geriatric assessment.^{27 28} Many elderly patients with prostate cancer have complex clinical needs and geriatrician-led interventions can improve the 'tolerance' for radical prostate cancer treatment through modifying and optimising comorbidities²⁹ as specified in a recent international clinical guideline.⁷

An explanation for the relatively high availability of most of the supportive services in hospitals in group 1 could be that they also were more likely to provide radical treatment (surgery, radiotherapy or both), to have clinics jointly run by surgeons and oncologists, to host the regional specialist multidisciplinary team that coordinates radical treatment in a region, and to be located in major urbanised areas. These observations suggest that centralisation of prostate cancer services, perhaps with a focus on creating comprehensive centres that provide both surgery and radiotherapy, may also facilitate more inclusive access to supportive services.

Finally, the availability of supportive services onsite may depend on the type of treatment services available at a particular hospital. For example, 41 of the 85 hospitals in group 1 (48.2%) provided prostate cancer surgery and only 6 of the 22 hospitals (27.3%) in group 3, which may explain why none of the hospitals in group 3 had sexual function services and only a few continence services available onsite.

Strengths and limitations

A key strength of this organisational survey is that it was developed with critical input from clinical reference group made up of a spectrum of experts in the field, and from the Patient and Public Involvement Forum of the National Prostate Cancer Audit. The involvement of both expert clinicians and patients has strengthened the clinical relevance as well as the patient focus of the survey.

Of the 138 hospitals providing prostate cancer services across England and Wales, 129 responded to this survey. We were able to reduce the level of missing

and inconsistent data by using data from earlier surveys and from the internet, and by requesting hospitals to confirm that these filled in data items were correct. As a consequence, some data items used in the latent class analysis were missing in only four out of the 138 hospitals providing prostate cancer services in the NHS in England and Wales, which underlines the representative nature of our results.

A limitation is that the survey only provides a 'snapshot' of the range of services available within the period between July and September 2021 and that it asked for services that were 'currently available'. Therefore, we cannot exclude the notion that the responses may partly reflect the extraordinary circumstances during the COVID-19 pandemic. This is one of the reasons, in addition to the fact that the organisation of prostate cancer services are constantly changing, that the collection of data on service organisation will need to be repeated. Moreover, prostate cancer service provision has been evolving over time and is likely that this will continue in the coming years.¹⁰

Another limitation is that we report results with hospitals as the unit of analysis. Therefore, the paper does not inform how initiatives that aim to enhance access to these services could be targeted to the needs of specific patient groups.

Finally, the survey responses are self-reported by each hospital: thus, we cannot fully rule out desirability bias. Hospitals may have provided responses that reflect the provision of supportive services as they want it to be rather than the actual provision. Also, the responses reflect whether particular services are available onsite which is not necessarily the same as whether they are actually being used or how patients are being referred. This highlights the additional value of collecting patient-reported experience measures, because patients are the best placed observers of the prostate cancer services that are actually being used and they are least likely to provide biased responses.³⁰

Conclusions

There is considerable variation in the supportive services available onsite for patients with prostate cancer in NHS hospitals in England and Wales. The overall availability of some supportive services, such as genetic counselling and oncogeriatric services, is also low. Three groups of hospitals could be distinguished with distinct patterns of supportive services available onsite, especially according to the availability of a CNS in all prostate cancer clinics and the availability of sexual function services. These results demonstrate that a careful analysis of organisational survey results can target initiatives that aim to make the entire palette of supportive services available to all patients with prostate cancer, either onsite in the hospitals that are responsible for their care or in other hospitals nearby.

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