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# Integration Index Health and Wellbeing

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**DO BLACK  
MEN TALK  
ABOUT THEIR  
HEALTH?**



Health and Care Experience Profile 4 Report



# Integration Index Project

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# Integration Index project

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## Introduction

The NHS in England wants to provide people with the best care possible. To do this it is important that hospitals, GP surgeries and community services, like physiotherapists, pharmacies and mental health services, work well together at all times.

These NHS services also have to work well with local social care services, such as care homes and care provided in people's own homes, to ensure the help people receive supports all their needs.

This approach often requires the NHS to think about the role of other public services including things like housing, benefits, transport and education. All of these things play a vital role in supporting people's general wellbeing as well as their health.

For the people receiving care it should feel like they are being supported by one big organisation which is thinking about all their needs and responding together as one.

## How do we get to a world that looks like this?

The NHS has been thinking about how to provide care in this way for some time, and important changes have been made already. But to know if these are working they need to hear from people about their experiences of care. This is what the 'Integration Index' is all about.

It is split into two parts which are being tested over the next few months:

1. **The National bit:** A regular survey of people using the NHS which will ask the same questions in every area of the country. This will ask people whether they think services are working well together or not. It will help areas see how well they are doing compared to other parts of the country.
2. **The Local bit:** A number of methods for local areas to gather more detailed views from people that are relevant to that town, city or county. This will help the NHS and its local partners to understand why things might not be working well and then work with local people to fix things.



## Health and Care Experience Profiles

The profiles project being led by Healthwatch is one of the local methods being developed to help the NHS understand why something isn't working.

We are currently testing this method in five parts of the country, with five groups of people who have lots of interactions with NHS services, care support and other public or charity services. Our five groups are:

- Children and young people with mental health support needs who are becoming adults
- People with diabetes who are of South Asian origin
- People with learning disabilities who have recently been in hospital
- **Black men with a number of health needs including a recent experience of cancer**
- Women with a number of health needs including a recent experience of a heart condition.

Healthwatch England has looked at all the national level user experience data held on each of the groups. We have also looked at the policies which set out what sort of care these people should be getting.

Healthwatch West Sussex has done the same in West Sussex, looking at local data and policies. This will help local NHS leaders understand how well they are doing compared to the national picture.

Healthwatch West Sussex, through community leaders, been speaking with a small number of people from this group (4) to ask them to talk about their experiences of care. These men have been asked about their ideas for improvement and we will expect the NHS to make these changes wherever possible. There will then be a final meeting held later in the process to ask people if their experiences have improved.

Once these tests are completed, we will have a method which the NHS and its partners can use to find out how any group of people might be experiencing care across different services. And because we have a network of 151 local Healthwatch across the country there is a local partner in every area who can be commissioned to help.



# Health and Care Experience Profile 4 - National Context

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## What are the characteristics of this Profile?

A black (African/Caribbean) man living with multiple health conditions, including recent experience of cancer care services. (For this work the focus will be on prostate cancer but not to exclude the voice of those with other forms of cancer.)

## Rationale

This profile:

- Demonstrates the complexity of living with multiple health conditions - and therefore service users who benefit significantly from well-integrated care and support.
- Provides the opportunity to explore both integration between the different health services involved and integration with other relevant services and organisations including any relevant community support, social prescribing and/or social care services.
- Provides the opportunity to engage with Black men, who as a broad group are underrepresented both in health and care research and service user feedback. Black men are also at higher risk of prostate cancer than other men.<sup>1</sup>
- Reflects key broad commitments of the NHS Long Term Plan - better care for major health conditions and stronger action on health inequalities.<sup>2</sup>

## What kind of care should people in this profile be able to expect?

Quality standards from NICE<sup>3</sup> highlight the need for all NHS patients to receive coordinated care with clear and accurate information exchange between relevant health and social care professionals.

“For many people care is not about a single visit to a single service... Health and care services may provide high-quality care individually but may fail people moving between services if they are not working well together with other services. Information needs to be exchanged effectively between services so that care can be coordinated across specialties and between providers.”

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<sup>1</sup> Cancer Research UK, [Prostate cancer incidence statistics](#) (accessed 17/11/2020)

<sup>2</sup> NHS England (2019) [NHS Long Term Plan](#)

<sup>3</sup> NICE (2019) [Quality standards: Patient experience in adult NHS services \[QS15\]](#)



NICE guidance on care for people with two or more long-term health conditions<sup>4</sup>, and older people with social care needs and multiple long-term conditions<sup>5</sup> establish that the approach to care for people with multiple conditions should:

- Focus on how the person's health conditions, and their treatments interact, and how this affects their quality of life.
- Focus on improving the coordination of their care across services - including seamless referrals between practitioners and appropriate information sharing.

NICE guidance and NHS England guidance relating to palliative care for adults with cancer suggests that patients frequently move between sectors, teams, and NHS/local authority/voluntary agencies<sup>6</sup> and their needs constantly change<sup>7</sup>. This means that:

- Coordination among these teams and services should be proactive to enhance continuity of care.
- Implementation of an integrated system of social support between local health and social care services and the voluntary sector should ensure that the needs of patients with cancer and their carers are met in a timely fashion and that different components of social support are accessible from all locations.

For men with prostate cancer, NICE guidance states that healthcare professionals should ensure that mechanisms are in place to allow men with cancer and their primary care providers to gain access to specialist services throughout the course of their disease<sup>8</sup>.

### **What does the national evidence tell us about experiences of integrated care for this profile?**

The National Cancer Patient Experience Survey provides patient experience scores for their cancer care. Whilst this survey is focused exclusively on cancer services and does not address service integration, it is notable that overall, the average (mean) rating Black respondents gave for their care was statistically significantly lower than the mean rating for all ethnicity groups combined.<sup>9</sup>

Healthwatch Wigan and Leigh highlighted the impact of cancer diagnoses on mental health and found that people experienced poor communication and delays in transfers

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<sup>4</sup> NICE (2016) [Multimorbidity: clinical assessment and management \[NG56\]](#)

<sup>5</sup> NICE (2015) [Older people with social care needs and multiple long-term conditions \[NG22\]](#)

<sup>6</sup> NICE (2004) [Improving supportive and palliative care for adults with Cancer \[CS64\]](#)

<sup>7</sup> NHS England (2016) [Enhanced supportive care: Integrating supportive care in oncology](#)

<sup>8</sup> NICE (2019) [Prostate cancer: diagnosis and management \[NG131\]](#)

<sup>9</sup> Picker (2019) [National Cancer Patient Experience Survey 2019: National results summary](#)



of information between primary, secondary and mental health care services. Although there was no breakdown of experiences by ethnicity, it was highlighted that men often feel they shouldn't talk about cancer or mental health, but that involvement in voluntary schemes helped to alleviate this.<sup>10</sup>

In 2019 Healthwatch carried out research with thousands of people from across England living with a range of health conditions, including cancer.<sup>11</sup> This work focused on understanding how people felt the NHS could better support their health and wellbeing. Some of the key findings included:

- Those with cancer reported better experiences of health and social care support than people with other conditions, which related to timeliness of diagnosis and treatment, access to rehabilitation and support courses, complementary wellbeing therapy, and annual check-up. However, those with multiple long-term conditions felt that similar levels of support were not always in place for them.
- People were frustrated by the fact that they had to repeat themselves to different professionals involved in their care; they wanted information sharing between services to be simpler, so they could focus on getting the support they need.

As part of this project, Healthwatch in Lancashire and South Cumbria engaged with 26 people with cancer in which 30% had multiple conditions.<sup>12</sup> Their experiences were not reported on separately, but it was found that some people had positive experiences of joined up working between departments and coordinating care. People felt that they wanted mental health and physical wellbeing (e.g. diet and exercise) support alongside their cancer care.

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<sup>10</sup> Healthwatch Wigan and Leigh (2019) [What mental health support is available to local people who have received a cancer diagnosis; and what would help professionals to support their patients, carers and families in the community?](#)

<sup>11</sup> Healthwatch England (2020) [What people want from the next ten years of the NHS](#)

<sup>12</sup> Healthwatch Blackburn with Darwen, Blackpool, Cumbria, and Lancashire (2019) [NHS Long Term Plan Lancashire and South Cumbria report](#)



# Health and Care Experience Profile 4 - West Sussex Context

What kind of care should people in this profile be able to expect if they live in West Sussex?

Below shows the 2011 Census ethnic background of West Sussex population, and it is notable that the proportion of black people in West Sussex is below the national average. However, for this project, the small proportion of black people against the County’s population is not an issue. Although a smaller proportions of our population their experiences of health and social care should not be excluded, especially as a community who is under-represented in research and other lived-experience engagement.

2011 Census Data	Numbers <i>(Figures rounded so may not sum)</i>			Percentage		
	West Sussex	SOUTH EAST	ENG	West Sussex	SOUTH EAST	ENG
	806,890	8,634,800	53,012,500			
<b>White:</b> English/Welsh/Scottish/Northern Irish/British	717,550	7,359,000	42,279,200	88.9%	85.2%	79.8%
<b>White:</b> Irish	5,980	73,600	517,000	0.7%	0.9%	1.0%
<b>White:</b> Gypsy or Irish Traveller	1,070	14,500	54,900	0.1%	0.2%	0.1%
<b>White:</b> Other White	31,900	380,700	2,430,000	4.0%	4.4%	4.6%
<b>Mixed/multiple ethnic group:</b> White and Black Caribbean	2,890	46,000	415,600	0.4%	0.5%	0.8%
<b>Mixed/multiple ethnic group:</b> White and Black African	2,060	22,800	161,600	0.3%	0.3%	0.3%
<b>Mixed/multiple ethnic group:</b> White and Asian	4,270	58,800	332,700	0.5%	0.7%	0.6%
<b>Mixed/multiple ethnic group:</b> Other Mixed	2,940	40,200	283,000	0.4%	0.5%	0.5%
<b>Asian/Asian British:</b> Indian	9,660	152,100	1,395,700	1.2%	1.8%	2.6%
<b>Asian/Asian British:</b> Pakistani	5,240	99,200	1,112,300	0.6%	1.1%	2.1%
<b>Asian/Asian British:</b> Bangladeshi	2,350	28,000	436,500	0.3%	0.3%	0.8%
<b>Asian/Asian British:</b> Chinese	2,960	53,100	379,500	0.4%	0.6%	0.7%
<b>Asian/Asian British:</b> Other Asian	8,130	119,700	819,400	1.0%	1.4%	1.5%
<b>Black/African/Caribbean/Black British:</b> African	4,570	87,300	977,700	0.6%	1.0%	1.8%
<b>Black/African/Caribbean/Black British:</b> Caribbean	1,340	34,200	591,000	0.2%	0.4%	1.1%
<b>Black/African/Caribbean/Black British:</b> Other Black	1,240	14,400	277,900	0.2%	0.2%	0.5%
<b>Other ethnic group:</b> Arab	1,080	19,400	221,000	0.1%	0.2%	0.4%
<b>Other ethnic group:</b> Any other ethnic group	1,680	31,700	327,400	0.2%	0.4%	0.6%

Source: ONS, 2011 Census

The Sussex Health & Care Partnership (Sussex’s Integrated Care System) reported:

*“There is a higher incidence of certain cancers in black and minority ethnic communities and the general incidence of cancer in these communities is rising.*

*The focus on cancer needs of black and minority ethnic populations within policy documents and data collection needs to continue. The ability to view and analyse local cancer data by ethnicity remains in reality quite limited.*

*Nationally the overall incidence of cancer in the black and minority ethnic (BAME) population is lower than that in the white population. This varies for different BAME*





*groups and cancer types and again gender where the incidence rates are 2 or 3 times the rates when compared to the white population.”*

*Taken from the February 2021 presentation to the Sussex Cancer Board*



The [Black, Asian and Minority Ethnic Communities Joint Strategic Needs Assessment \(2016\)](#) produced by West Sussex County Council speak to deprivation:

*“Deprivation is a well-recognised indicator of poor health outcomes in the population. Many of the minority ethnic communities identified in section 1 live within or near the areas of West Sussex which are the most deprived in the county: central Bognor Regis and Worthing and west Crawley.”*

Healthwatch Milton Keynes comment about risk of linking health inequality to deprivation as this can gloss over someone of the systematic issues.

The February 2021 Sussex Health and Care Partnership’s presentation to the Sussex Cancer Board reported the impact of deprivation:

*“People experiencing deprivation have a higher incidence of certain cancers compared to the national average, for example lung and laryngeal cancers.*

*This is partly due to the fact that many of these (and other) disadvantaged groups face barriers to healthcare, including differences in care-seeking behaviours, health literacy, and language. Over time, some disadvantaged groups face additional barriers too, such as discrimination and unconscious biases. It is widely understood that the pandemic (and associated response) has inadvertently widened the inequalities gap further. This is concerning, particularly given the impact this can have on early diagnosis of cancer and longer-term patient outcomes.”*

Statistically, 47.2% of Crawley residents (in the North of West Sussex) are diagnosed at stage 3 or 4 of cancer. Whilst this is similar to the England average, it is slightly worse than the South East and comparable local authorities (those with a similar demographic). It is in stark contrast to neighbouring areas (some a matter of a few miles away) where people are diagnosed much earlier.

Reviewing the public information (January 2021) available on local websites (see Appendix A) showed that in West Sussex there was lots on Cancer, but nothing of note on multiple health conditions/integrated care. All search roads lead to Macmillan, in particular to the Macmillan Horizon Centre in Brighton. Surrey and Sussex Hospitals NHS Foundation Trust (SASH) is part of the Surrey Heartlands Integrated Care System, which seems to be ahead in terms of what they put online.

There is a Patient Voice Group to provide feedback to Western Sussex Hospitals NHS Foundation Trust (WSHFT) and there are a lot of support groups in the County for people living with Cancer, for example: [The Olive Tree](#) in Crawley.

See Appendix A for web research information.



## What does the evidence for West Sussex tell us about experiences of integrated care for this profile?

At the start of this project, Healthwatch West Sussex did not have any specific insight for this profile but some cancer-related stories (from 2019) suggest integration and palliative care may fall short in meeting needs or be confusing to people, in parts of West Sussex.

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*“My friend has terminal cancer. They are deteriorating and their family has been struggling to know who else to phone. They’ve tried calling their GP practice but simply can’t get through. They waited two hours on call to 111 who then dispatched a 999 response. The paramedic was very good when they came out and successfully treated my friend, so they didn’t have to go to hospital.”*

- Shared with Healthwatch West Sussex, April 2020

A resident called for information on getting aids and equipment installed in her home. She explained she has inoperable stomach cancer and felt she would now benefit from some mobility aids. The person shared that they were in touch with the local hospice, who did an assessment and has their contact details. She is an ex-healthcare professional but was finding it difficult to find out how to access an OT locally.

- Resident, called early 2019

Sally’s husband was diagnosed with lung cancer and a brain tumor in 2019. He was eventually referred to [north of the county] hospice and advised to call if they needed any advice or support. Sally rang them (Summer of 2020, during the pandemic) and asked for help. A community nurse visited and took husband’s blood sugars and left. Sally says, *“it was evident I was struggling. I couldn’t get him out of bed ... the nurse didn’t offer any assistance or advice. I ended up calling for an ambulance and my husband died the following day.”*

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Surrey Heartlands Integrated Care System has shared the Surrey and Sussex Hospitals NHS Foundation Trust’s personalised care work, and we have read this to mean that the start of personalisation is at the point where the Multi-Disciplinary Team (MDT) come together (and not the initial point of GP referral). This suggestion seems worrying and perhaps does not reflect what happens within general practice. This is where patient care is discussed as detailed below:

- NICE advises at the point at which one should be referred as a suspected prostate cancer patient: *refer the man urgently using a suspected cancer pathway referral (for an appointment within two weeks) if:*
  - Digital rectal examination reveals a hard, nodular prostate (suggestive of cancer) or



- PSA levels are above the age-specific reference range. For men 50-69 this is 3.0 nanogram/mL or higher. (Specific figures for ages given).



- SASH two week wait urology proforma referral criteria section for prostate:
  - *Consider the necessity of referring patients with significant co-morbidity and the very frail or elderly. If in doubt consult your local specialist.*
  - *Ideally two PSA tests should be performed if PSA<20ng/ml, repeat PSA after 4-6 weeks.*
  - *If PSA raised in context of UTI, repeat PSA after 6 weeks to confirm if it is truly raised and whether further investigations are required.*

East Sussex Healthcare NHS Trust and the National Cancer Collaborative have a bespoke project focusing on improving communications and resources in multiple formats to prostate cancer patients. They are due to report the key learning from this work to the Sussex Cancer board in Spring 2021.

The Sussex Health and Care Partnership (Sussex's Integrated Care System) has stated a strong ambition to tackling health inequalities and to deliver an integrated plan, with engagement across the system. The aim is to have a real commitment to ensure that development and delivery of this plan benefits from views and insight from local people. The plan focuses both on achieving earlier diagnosis as well as supporting patients to live well '*with and beyond cancer*' and should pick up communication, sharing information and access to psychological/mental health support, highlighted in this document.

The West Sussex Cancer Action Group<sup>13</sup> appears to offer an opportunity for Healthwatch to engage with wider partners/stakeholders around this profile, and we will be attending a future meeting to discuss this.

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<sup>13</sup> Aims to provide a forum for collaborative working across partnerships and stakeholders that delivers safe and effective care, improves cancer clinical outcomes and enhances experience and quality of life for cancer patients and their family and carers. The Group covers Surrey and Sussex Hospitals NHS Foundation Trust (that covers the North of West Sussex), Western Sussex Hospitals NHS Foundation Trust (that cover Coastal West Sussex) and Queen Victoria Hospital (that provides specialist support.)



# Understanding lived experience of people in this profile

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## How we set about understanding people's lived experience?

It was clear from early conversations with local black men about this project that there were significant obstacles to engagement with black African men to talk about their use of health and care services. We were told that fear holds men back from seeking help from GPs and services due to cultural beliefs and childhood connections for example: has this situation been influenced by witchcraft, and a leaning toward traditional medicine over western.

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*Good luck with that! We just don't talk about our health.  
The only way we would is if our mother told us to*

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We have benefitted from being part of the Crawley Local Community Network, and having worked with the Local Authority's Community Team, as these relationships have enabled us to have further discussions with community leaders. These conversations have confirmed the need to recognise that advertising opportunities for men to talk about their long-term health and cancer experiences in a group was unlikely to attract participants - as people need a comfortable space that is owned by the participants and facilitated by trusted people who can enable people to vent but be able to draw out the responses.

Under normal circumstances, families coming together around faith and food may provide a chance to explore attitudes and experiences of health and wellbeing, but the need to social distance has meant this was not possible.

Instead, we have sought the support of two community leaders: Crawley Congregation Leader, Rohan Andrew from the Kingdom Faith Church and Gulu Sibanda, from West Sussex County Council's Partnership and Communities Team.

Having discussed the project with Rohan and Gulu it was clear this was seen by them as an important conversation and together we drew out a semi-structure interview approach, with conversations taking place in late February beginning of March 2021.

The timeline for this project was set nationally and only provided a few months to work up and undertake the engagement. Going forward, any integrated care system wishing to understand the needs and experiences of this Profile (and no doubt other people profiles that reflect those who may be reluctant to talk about their health or who do not engage with those outside their community) must plan and accept time and space is needed. Identifying community connections and getting their 'buy-in'



through enabling them to set the agenda and opportunities is essential to the success of any engagement activity.

## What men said about their health?

Through phone-based interviews, with community leaders, we have learnt the following from black men that provides a greater understanding of health attitudes and behaviours.

Four men from Crawley were interviewed but currently do not have long-term health conditions or experience of cancer. Their ages range from 40 to 50.

- All felt they would access NHS services, but three **sighted reasons for not using services but would look at alternatives first**. It is important to understand these, as they may allude to reasons for later cancer diagnosis. The alternatives being:
  - **Privately**, through newly acquired health insurance, because a recent experience of trying to get an appointment with his GP had resulted in a wait of three weeks. *Now has a plan B because the priority is COVID.*

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*Sometimes they don't nip things in the bud. Instead, they leave things too long.*

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- **Waiting it out**, for a Nigerian man was a **'cultural thing'**. He went on to say he would have no hesitancy if it was an emergency - something he has experienced. However, further into the interview, he shared that when he presented at the hospital the doctor was 'surprised' he was still alive. For 48 hours he'd walked around with appendicitis, which had ruptured during this time.
- One man has experienced malaria countless times and **is used to self-medicating**.
- **Faith and the healing power of prayer** was a key factor, having witnessed and experienced the healing this way, even lumps disappearing. *If the problem didn't go away after praying for some time, then I would go to a doctor.*
- **Embarrassment** - *if there's a private area of my body that has got something wrong with it, I'm not quick to get it looked at... I know that's not a great thing to do but ... there's just an insecurity there.*
- **Experiencing a negative response** from a doctor and then getting a less, more researched second opinion has left one man feeling less willing to trust doctors.
- **Fear** - has come across people who have gone to a doctor for something minor and the doctor has given them the 'worst case scenario', which has resulted in a downward spiral for the individuals concerned. 'Then you just have to deal with it if they can't treat you.'







- One man took over 8 years to register with a GP after moving to the area. He has only recently registered because his wife ‘has nagged him to do it’.

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*Lots of the time I work away from the area during the week. It’s a bit of a faff, as you can only register on a Tuesday and have to call first thing. I’m normally on a train and don’t want to give out my private details (that can be overheard). The fact that I’ve not registered since 2012 is probably telling.*

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- Most had very positive comments for the NHS services, with one exception.

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*Confidentiality is there.*

*If I had to use the service, I’d be confident (from acute hospital experience.)*

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- One suggested that others had experienced challenges in getting medication.
- One had been registered as ‘female’.
- One said he ‘sees no difference between his community and other (white) community members’.

When asked about how things may be improved, the response was, *I can’t think of anything else that you could do to help overcome the cultural aspects, apart from maybe finding some sort of educational reading for us, about the dangers of leaving it late to report health issues.*



## Appendix A

A Volunteer Researcher was asked to adopt this *Profile* as a *mystery shopper* and to do a web-based search for information on integrated care for multiple health conditions, including cancer in Sussex.

**Methodology/Action:** Search term, followed by Search Results (*direct quotes in italics*)

### Searches/Search results:

1. **Joined up care and Surrey and Sussex Hospitals NHS Foundation Trust (SASH) - part of Surrey Heartlands Integrated Care**

<https://surreyandsussex.nhs.uk/about-us/about-the-trust/surreyheartlands>

seems to be a Surrey focus.

2. **Joined up care - Western Sussex Hospitals NHS Foundation Trust (WSHFT) and Integrated Care**

First link is to palliative care. Searching just on **Integrated** = Focus on trainees getting experience of different discipline.

3. **WSHFT and cancer**

<https://www.westernsussexhospitals.nhs.uk/services/cancer-care/support-and-advice/#more-6032>

There are complementary therapies on offer at St Richards to help alleviate the effects of cancer/treatments, but no mention of other medical health conditions.

The main focus is directing to Macmillan for support and advice, with a drop-in

based at St Richards. <https://www.westernsussexhospitals.nhs.uk/services/cancer-care/support-and-advice/macmillan>

There is a **Patient Voice** group which meets five to six times per annum.

<https://www.westernsussexhospitals.nhs.uk/services/cancer-care/support-and-advice/patient-voice>

4. **Cancer. Sussex, Help:** again, directed to Macmillan, in particular the Macmillan Horizon Centre in Brighton

[https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre#about\\_the\\_macmillan\\_horizon\\_centre](https://www.macmillan.org.uk/cancer-information-and-support/get-help/centres/macmillan-horizon-centre#about_the_macmillan_horizon_centre)

This was the best link to finding local support groups

<https://www.macmillan.org.uk/in-your-area/index.html?latitude=50.9280143&longitude=->

[0.4617075&location=West%20Sussex%2C%20UK&radius=30&tridionpromocount=0&nationalorganisationcount=0&nationalresultcount=0&page=1](https://www.macmillan.org.uk/in-your-area/index.html?latitude=50.9280143&longitude=-0.4617075&location=West%20Sussex%2C%20UK&radius=30&tridionpromocount=0&nationalorganisationcount=0&nationalresultcount=0&page=1)

[0.4617075&location=West%20Sussex%2C%20UK&radius=30&tridionpromocount=0&nationalorganisationcount=0&nationalresultcount=0&page=1](https://www.macmillan.org.uk/in-your-area/index.html?latitude=50.9280143&longitude=-0.4617075&location=West%20Sussex%2C%20UK&radius=30&tridionpromocount=0&nationalorganisationcount=0&nationalresultcount=0&page=1)

(Cont/d)



**BUT:** the search function on this page did not have anything after searching for Black, Asian and Minority Ethnic (BAME), Black or Asian, or Integrated Care. **But** search results for **types of cancers** gave specific points of contact.

**West Sussex Healthcare Trust** has psychological support services for people affected by cancer are also available across Sussex at:

[The Olive Tree, Cancer Support Centre in Crawley,](#)

[Cancerwise, Cancer Support Centre in Chichester,](#)

[The Pickering Centre in Tunbridge Wells](#)

For example, The Olive Tree website gives lots of links, but nothing specific for this Profile <https://www.olivetreecancersupport.org.uk/links>

**East Sussex Healthcare Trust** has similar in Eastbourne, Seaford, Uckfield, Bexhill and Hastings areas, with a telephone number and email to access.

5. **East Sussex Healthcare Trust** has a lot more focus on 'Integrated' than WSHFT with a new Chief Operating Officer appointed in the summer 2020 and references to multi-disciplinary teams. <https://www.esht.nhs.uk/?s=Integrated>

6. **BAME and Cancer and Sussex** = a 200-page reported published in 2016 <https://jsna.westsussex.gov.uk/assets/core/Black-Asian-and-Minority-Ethnic-Communities-Needs-Assessment-2016.pdf> Cancer references on p122, Recommendations on p32-34

*“4.4.4 Cancer The overall incidence of cancer is significantly lower in BAME groups. There are some types of cancer more common in some BAME groups. Mouth cancers more common among south Asians; liver cancer is higher among Bangladeshi and Chinese people, and African-Caribbean men are around three times more likely to develop prostate cancer (Cancer equality, 2015) 44. Black groups have significantly higher rates of multiple myeloma, stomach, liver, cervical and prostate cancer. This may be partly due to barriers among BAME groups to engaging with screening programmes (Martins et al., 2015, Marlow et al., 2015) 45, 46 where negative experiences, embarrassment and lack of awareness are considered to play a role (Mundasad, 2014) 47. In terms of disease survival, while breast cancer survival is lower among BAME groups, they do experience improved survival from lung cancer (Cancer Research UK 2014) 48.*



Relevant recommendations within the report are:

**Meaningful engagement and design of culturally appropriate services**

Action required by	Recommendation
Commissioners and providers of health and social care	Ensure there are <b>clear and transparent care packages</b> with <b>clear decision criteria</b> . These care packages should be <b>culturally</b> and <b>linguistically appropriate</b> .
Clinical commissioning groups and local authorities	Support service providers to provide <b>clear pathways</b> for referral into <b>culturally appropriate services</b> (i.e. for <b>end of life and palliative care</b> ) to support BAME <b>families and friends</b> . This should include: <ol style="list-style-type: none"> <li><b>Training</b> to ensure providers and staff are aware of specific <b>cultural issues</b> especially around <b>end of life</b> care in some groups.</li> <li><b>Meaningful</b> engagement with communities to <b>co-design</b> services.</li> </ol>

**Providing and promoting services which are culturally appropriate**

Action required by	Recommendation
Commissioners of healthy lifestyle programmes	<ol style="list-style-type: none"> <li>Ensure that <b>healthy weight initiatives</b> have <b>culturally appropriate targeted activity</b>, especially for Black and South Asian groups and for a range of ages. These should clear <b>self-referral</b> mechanisms.</li> <li>Ensure that there is <b>sufficient provision</b> of, and awareness-raising activity around, <b>culturally appropriate physical activity opportunities</b> across all age groups.</li> </ol>

Commissioners and procurement	<b>Commissioning processes</b> for <b>residential, domiciliary and inpatient facilities</b> should include providing <b>evidence</b> of a <b>comprehensive anti-discrimination policy</b> , which includes <b>training for all staff</b> and a <b>transparent reporting processes</b> for service users and staff where <b>discrimination</b> occurs.
Clinical commissioning groups	<b>CCGs</b> should <b>support GP</b> practices to ensure that frontline <b>staff act</b> in accordance <b>with national guidance</b> regarding <b>registration</b> for services. I.e. practices should not refuse registration on the grounds that a patient is unable to produce evidence of identity, immigration status or proof of address.
All organisations	Efforts need to be made across <b>all</b> organisations to <b>increase</b> the quantity and quality of <b>data recording ethnicity</b> . Commissioners of health and social care services and the voluntary and community sector should ensure that this is <b>explicit in service specifications</b> with their providers.

**Note:** Healthwatch West Sussex carried out web-reviews on all GP practices in West Sussex and the majority require proof of address and ID, suggesting the above recommendations has not influenced a change in practice.

**7 Prostate Cancer and Sussex** - The researcher found four support groups in West Sussex for prostate cancer - Pulborough, Rustington, Chichester and Brighton, and none in East Sussex other than Brighton again.

<https://www.macmillan.org.uk/in-your-area/index.html?latitude=50.9280143&longitude=-0.4617075&location=West+Sussex%2C+UK&radius=30&keyword=Prostate>

**8. Other West Sussex Voluntary Groups for prostate cancer**

<http://www.midsussexprostate.uk>  
<https://pcasoprostatecancersouth.org/pcaso-rustington-group>  
<https://pcasoprostatecancersouth.org/pcaso-groups> details of groups in East and West Sussex.



**9. West Sussex Cancer Action Group** (mentioned in brief) - found nothing to help with this Profile.

**10 Queen Victoria Hospital** - found nothing to help with this Profile.

