

Health and Care Experience Profile 4

What are the characteristics of this Profile?

A Black man with multiple health conditions, including recent experience of cancer care services.

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.¹
- Reflects key broad commitments of the NHS Long Term Plan - better care for major health conditions and stronger action on health inequalities.²

What kind of care should this Profile be able to expect?

Quality standards from NICE³ 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.”

¹ Cancer Research UK, [Prostate cancer incidence statistics](#)

² NHS England (2019) [NHS Long Term Plan](#)

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



NICE guidance on care for people with two or more long-term health conditions⁴, and older people with social care needs and multiple long-term conditions⁵ 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 agencies⁶ and their needs constantly change⁷. 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 disease⁸.

Having discussed this with healthcare professionals locally, there does not appear to be any specific pathways or processes for black men with multiple health conditions.

What does the 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

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

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

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

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

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



Black respondents gave for their care was statistically significantly lower than the mean rating for all ethnicity groups combined.⁹

Healthwatch Wigan and Leigh highlighted that receiving cancer diagnoses had significant impact on mental health and wellbeing. It was also found that some people experienced poor communication and delays in transfers of information between the primary, secondary and mental health care services that they were receiving support from. 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.¹⁰

In 2019 Healthwatch carried out research with thousands of people from across England living with a range of health conditions, including cancer.¹¹ 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 when compared to cancer care.*
- *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.¹² 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.

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

¹⁰ 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?](#)

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

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



National Cancer Policy

In October 2014, the NHS in England set out how the NHS needed to change in its Five Year Forward View. This document made clear the NHS's intention to support and stimulate the creation of a number of major new care models, including in cancer services. It also began to set out a series of five-year ambitions for better prevention, faster diagnosis and better treatment and care for all.¹³

What kind of care should this Profile receive locally?

There are 350,000 new cases of cancer each year in the UK, with approximately 160,000 deaths from cancer.¹⁴ Figures from Cancer Research UK estimate that throughout the NHS Manchester CCG area there are 2,100 cancer cases per year with approximately 970 deaths.¹⁵

This research also highlighted that Manchester is behind the rest of the country in key indicators. For example, only 45% of people within the Manchester CCG area aged between 60-74 take part in screening for bowel cancer, which is considerably less than the England average (57.7%).¹⁶

Furthermore, 76.7% of patients in the Manchester CCG receive their first definitive cancer treatment within 62 days of an urgent GP referral, which is below the national target of 85%.¹⁷

Greater Manchester Cancer

¹³ 5YFP <https://www.england.nhs.uk/ourwork/futurenhs/nhs-five-year-forward-view-web-version/>

¹⁴ Manchester Join Strategic Assessment Needs, [file:///C:/Users/neilw/Downloads/JSNA_AOP_Cancer_07.08.17%20\(1\).pdf](file:///C:/Users/neilw/Downloads/JSNA_AOP_Cancer_07.08.17%20(1).pdf)

¹⁵ Cancer Research UK (2020) Manchester Central profile, Online https://www.cancerresearchuk.org/sites/default/files/local-cancer-stats/manchester_central_20200210.pdf

¹⁶ Cancer Research UK (2020) Manchester Central profile, Online https://www.cancerresearchuk.org/sites/default/files/local-cancer-stats/manchester_central_20200210.pdf

¹⁷ Cancer Research UK (2020) Manchester Central profile, Online https://www.cancerresearchuk.org/sites/default/files/local-cancer-stats/manchester_central_20200210.pdf



Greater Manchester Cancer is the cancer programme of Greater Manchester's devolved health and social care system. The organisation covers the whole of Greater Manchester as well as Eastern Cheshire, a population of over 3 million people.¹⁸

It describes itself as:

'...having a broad focus, from prevention and early diagnosis to living with and beyond cancer and end of life care. The programme includes, among other things, the work of the Pathway Boards that were set up through Manchester Cancer and the work taking place in the Greater Manchester as part of the national cancer vanguard.'

They published their cancer strategy 'Achieving world-class cancer outcomes' in February 2017, which runs until 2021.¹⁹

The document states that the overall aim,

'...envisioned...an integrated cancer system bringing together cancer research, education and clinical services. They created the Manchester Cancer Provider Board to lead the clinical services arm of Manchester Cancer and committed to fund a full set of cancer clinical directors and their support team.'

One further objective of the plan is to ensure 'earlier integration of supportive care into cancer care'. This recognizes the challenges which present themselves when patients have other health conditions and aims to,

'...ensure that the adverse physical and psychological effects of cancer and its treatment are addressed more fully for patients through expanding access to the enhanced supportive care model.'

Whilst this document is focused mainly on cancer care, there are references to working with services treating patients for other health conditions. For example, on page 29 there is a reference to integrated care pathways with mental health care providers. Given the recent increase in awareness of mental health issues, this is certainly a welcome addition.

'Taking charge of our health and social care in Greater Manchester'

'Taking charge of our health and social care in Greater Manchester' was published in 2019 and it details the collective ambition for the region's devolved health and social

¹⁸ Greater Manchester Cancer <https://gmcancer.org.uk/about/>

¹⁹ Greater Manchester Cancer (2017) Achieving world-class cancer outcomes, Online <https://gmcancerorguk.files.wordpress.com/2016/08/achieving-world-class-cancer-outcomes-in-gm-y1-0-final-02-2017.pdf>



care system through to 2021. The document highlights the need for better integrated care throughout and states that:

*'By working together, unhindered by artificial and bureaucratic barriers, organisations will provide integrated care to support physical, mental and social wellbeing, improving the lives of those who need help most. Our new models of care will build on NHS England's Five Year Forward View by re-orienting our health and care systems so that we focus on preventing the big health and care problems, like cancer, cardiovascular disease, diabetes and respiratory, but also social isolation and deprivation which undermine our prosperity as a city region, and investment in early years and employment.'*²⁰

GM Healthwatch report into cancer services

In 2015 Healthwatch released a report into the experiences of patients using cancer services across Greater Manchester.²¹ All 10 GM Healthwatch participated and 159 responses were received from residents of Manchester.

Participants were asked to comment on waiting times, overall experience, and suggested improvements at two separate points in their patient journey:

- From first presentation to diagnosis
- From diagnosis to commencement of support

Respondents were then asked to tell HW about the support they currently receive and support they would like to receive or would be interested to try. Finally, those who had multiple conditions were asked to what extent they felt that their other conditions were taken into account in their treatment or support.

It is worth noting that out of the overall figures, only 4% of participants identified themselves as 'Black British'.

One of the conclusions of the report was that some people did not always understand the support that they could get to help with their treatment.

In response to the findings, the Greater Manchester Health & Social Care Partnership stated that:

'We have had recent success of cancer care in Greater Manchester over the last five years due to several key factors: We have a comprehensive connected integrated

²⁰ GM Strategic Final Plan, <http://www.gmhsc.org.uk/wp-content/uploads/2018/04/GM-Strategic-Plan-Final.pdf>

²¹ Healthwatch (2015) NHS Long Term Plan - Patients Views of Cancer Services, Online <https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/reports-library/20190807%20Greater%20Manchester%20Cancer%20LTP%20final%20report.pdf>



cancer system led by clinicians and patients driving real change and providing leadership, not just in Greater Manchester, but across England and the UK.

Through the devolved health and social care system we have a supportive system facilitating links across the region, and we have centres of excellence such as The Christie, The University of Manchester, The Manchester Cancer Research Centre, Salford Royal and Manchester 11'

Local treatment & support groups for cancer patients

The Christie Hospital

The Christie is one of the largest cancer hospitals across Europe and treats an estimated 60,000 patients per year.²² They are the first UK centre to be officially accredited as a comprehensive cancer centre and the site provides the following services:²³

- Radiotherapy, in one of the world's largest radiotherapy departments and at their satellite radiotherapy centres in Oldham and Salford. They are also home to the UK's largest brachytherapy service and recently became the first NHS organisation in the UK to deliver high energy proton beam therapy.
- Chemotherapy, in the UK's largest chemotherapy unit, as well as via 10 other sites, a mobile chemotherapy unit and in patients' homes. They also provide prostate cancer community clinics at five different locations.
- Highly specialist surgery for complex and rare cancer.
- A wide range of support and diagnostic services.

CALLplus

CALLplus is a local charity providing emotional support and home-based practical help to people with cancer and other life-limiting illnesses, along with those closest to them, such as family, friends and carers. Their services are delivered by specially trained volunteers who are managed by a team of professional staff.

²² NHS, <https://www.christie.nhs.uk/about-us>

²³ The Christie NHS Foundation Trust, A Profile of The Christie, Online <https://www.christie.nhs.uk/about-us/about-the-christie/a-profile-of-the-christie>



Their staff and volunteers provide a tailored service to each individual or family and they can include the following to help patients manage their condition:²⁴

- Listening and befriending: talking through difficulties and concerns
- Respite sitting, allowing carers time to themselves
- Practical help such as shopping
- Driving and support for a hospital appointment or treatment
- Social activities, days out, coffee mornings, relaxation sessions
- Information about local services and support networks

Macmillan Information and Support Service

The Macmillan Information and Support Service offer a free and confidential service to all residents of Manchester who are affected by cancer directly, their relatives, families and carers. They also support people who are worried about cancer and they do provide training and awareness sessions around cancer for those who would like to know more.²⁵

Prostate Cancer UK

Prostate Cancer UK run a support group for patients who have been diagnosed with prostate cancer. Due to the COVID-19 pandemic and the consequent restrictions, these are currently taking place online and are free to access for residents of Manchester.²⁶

Manchester Lymphoma Association Support Group

Organised by Lymphoma Action, the support group is there for people who have been diagnosed with Hodgkin or non-Hodgkin lymphoma and would like to share their experiences or listen to those of others.²⁷

Maggie's Centre

²⁴ Manchester Foundation Trust, Living with and beyond cancer, Online

<https://mft.nhs.uk/mri/services/cancer/living-with-and-beyond-cancer/>

²⁵ Macmillan, Macmillan Cancer Information and Support Service at Manchester Royal Infirmary, Online

<https://www.macmillan.org.uk/in-your-area/local-dashboard/detail/Information%20and%20support%20centres/7902/Macmillan-Cancer-Information-and-Support-Service-at-Manchester-Royal-Infirmary>

²⁶ Prostate Cancer UK, Out with Prostate Cancer, Online <https://prostatecanceruk.org/get-support/find-local-support/out-with-prostate-cancer-north-of-england>

²⁷ GM Cancer, Charities and Support Groups, Online <https://gmcancer.org.uk/our-areas-of-work/pathway-boards/palliative-care/charities-and-support-groups/>



Maggie's provides free practical, emotional and social support for people with cancer and their families and friends. Their centres offer patients the support they need to find their way through cancer. Maggie's Centres are places to find practical advice about benefits and eating well; places where qualified experts provide emotional support; places to meet other people or simply to sit quietly with a cup of tea. There is also a Maggie's Centre located at The Christie Hospital.²⁸

The organisations mentioned above are just a small snapshot into the local groups and services which are there for the people of Manchester who have been diagnosed with cancer. Further information on other groups can be found on the GM Cancer website and the Manchester University NHS Foundation Trust website. There does not appear to be any specific groups for black men with multiple health conditions including experience of cancer care.

Local pathways and processes for patients with multiple health conditions (including experience of cancer care)

Clinical Pathway Boards

According to Greater Manchester Cancer, Pathway Clinical Directors have formed boards made up of colleagues from across the region and across the professions involved in the pathway of treating the various forms of cancer.

The role of these Pathway Boards and Cross-cutting Boards is to improve cancer care for patients. They are the primary source of clinical opinion to Greater Manchester Cancer.²⁹ There is an extensive list of the different boards on the GM Cancer website.³⁰

From our discussions with local healthcare professionals, there do not appear to be any specific cancer care pathways for black men.

References

Cancer Research UK, Prostate cancer incidence statistics, Online <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/incidence#heading-Six>

NHS England (2019) NHS Long Term Plan, Online <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

²⁸ Maggie's Centre, Online <https://www.maggies.org/our-centres/maggies-manchester/>

²⁹ GM Cancer, Clinical Pathway Boards, Online <https://gmcancer.org.uk/our-areas-of-work/pathway-boards/>

³⁰ GM Cancer, Clinical Pathway Boards, Online <https://gmcancer.org.uk/our-areas-of-work/pathway-boards/>



NICE (2019) Quality standards: Patient experience in adult NHS services [QS15], Online

<https://www.nice.org.uk/guidance/qs15/chapter/Quality-statements>

NICE (2016) Multimorbidity: clinical assessment and management [NG56], Online

<https://www.nice.org.uk/guidance/NG56/>

NICE (2015) Older people with social care needs and multiple long-term conditions [NG22], Online

<https://www.nice.org.uk/guidance/ng22>

NICE (2004) Improving supportive and palliative care for adults with Cancer [CS64], Online

<https://www.nice.org.uk/guidance/csg4>

NHS England (2016) Enhanced supportive care: Integrating supportive care in oncology, Online

<https://www.england.nhs.uk/wp-content/uploads/2016/03/ca1-enhncd-supprtv-care-guid.pdf>

NICE (2019) Prostate cancer: diagnosis and management [NG131], Online

<https://www.nice.org.uk/guidance/ng131>

Picker (2019) National Cancer Patient Experience Survey 2019: National results summary, Online

https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf

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?, Online

<https://www.healthwatch.co.uk/reports-library/what-mental-health-support-available-local-people-who-have-received-cancer-diagnosis>

Healthwatch England (2020) What people want from the next ten years of the NHS, Online

<https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20200128%20-%20What%20people%20want%20from%20the%20next%20ten%20years%20of%20the%20NHS.pdf>

Healthwatch Blackburn with Darwen, Blackpool, Cumbria, and Lancashire (2019) NHS Long Term Plan Lancashire and South Cumbria report, Online

<https://www.healthwatch.co.uk/reports-library/long-term-plan-lancashire-and-south-cumbria-report>

NHS 5YFP, Online <https://www.england.nhs.uk/ourwork/futurenhs/nhs-five-year-forward-view-web-version/>

Manchester City Council, Manchester Joint Strategic Assessment Needs, Online

[file:///C:/Users/neilw/Downloads/JSNA_AOP_Cancer_07.08.17%20\(1\).pdf](file:///C:/Users/neilw/Downloads/JSNA_AOP_Cancer_07.08.17%20(1).pdf)

Cancer Research UK (2020) Manchester Central profile, Online

https://www.cancerresearchuk.org/sites/default/files/local-cancer-stats/manchester_central_20200210.pdf

Greater Manchester Cancer, Online <https://gmcancer.org.uk/about/>

Greater Manchester Cancer (2017) Achieving world-class cancer outcomes, Online

<https://gmcancerorguk.files.wordpress.com/2016/08/achieving-world-class-cancer-outcomes-in-gm-v1-0-final-02-2017.pdf>

Greater Manchester Health & Social Care, GM Strategic Final Plan, Online

<http://www.gmhsc.org.uk/wp-content/uploads/2018/04/GM-Strategic-Plan-Final.pdf>



Healthwatch (2015) NHS Long Term Plan - Patients Views of Cancer Services, Online
<https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/reports-library/20190807%20Greater%20Manchester%20Cancer%20LTP%20final%20report.pdf>

NHS, The Christie - About Us, Online <https://www.christie.nhs.uk/about-us>

The Christie NHS Foundation Trust, A Profile of The Christie, Online
<https://www.christie.nhs.uk/about-us/about-the-christie/a-profile-of-the-christie>

Manchester Foundation Trust, Living with and beyond cancer, Online
<https://mft.nhs.uk/mri/services/cancer/living-with-and-beyond-cancer/>

Macmillan, Macmillan Cancer Information and Support Service at Manchester Royal Infirmary, Online
<https://www.macmillan.org.uk/in-your-area/local-dashboard/detail/Information%20and%20support%20centres/7902/Macmillan-Cancer-Information-and-Support-Service-at-Manchester-Royal-Infirmary>

Prostate Cancer UK, Out with Prostate Cancer, Online <https://prostatecanceruk.org/get-support/find-local-support/out-with-prostate-cancer-north-of-england>

GM Cancer, Charities and Support Groups, Online <https://gmcancer.org.uk/our-areas-of-work/pathway-boards/palliative-care/charities-and-support-groups/>

