

People's experiences during Covid-19: Insight to inform the recovery of cancer services

August 2020



Introduction

This document provides insight about people's experiences and views of health services during the Covid-19 pandemic and lockdown. People's feedback covers a range of services and is divided into the following four sections:

- 🗣️ A local cancer patient's story
- 🗣️ General feedback, including some from seldom heard groups
- 🗣️ Feedback about digital or remote support
- 🗣️ Feedback from cancer patients and carers, including what has helped

The insight comes from a range of local and national sources and is intended for use around the recovery of cancer services in Dorset, Hampshire and Isle of Wight (HIOW), the area covered by the Wessex Cancer Alliance.

"Being diagnosed was the loneliest place I have ever been, even with support around me. Then for there to be a world pandemic just a month after my treatment finished felt devastating. All the things I looked forward to, keeping me going throughout treatment, were cancelled, worst of all I could not see my fiancé as they work for the NHS. Living at home with my parents has helped hugely.

I had advice from my Consultant and have a named Cancer Nurse Specialist who I can contact as I need. I have use of the 24 hour helpline too if I have any health concerns. My parents shielded with me, keeping me safe.

My recovery is now going to be much, much longer than it should have been because of Covid 19. That has been the most difficult part to come to terms with. But things don't always go to plan, unfortunately that's just life. The important thing is that I survived cancer and I get to have a future."

Wessex cancer patient

General feedback

- Information and clear, timely communication was paramount to people understanding what was happening, what they needed to do and to feel reassured.¹

Whilst most people said they found it easy to get information on generally keeping safe during the coronavirus pandemic, they found it difficult to get information on changes to services they usually used and needed reassurance that hospitals and other locations, e.g. GP surgeries, were being managed safely to reduce risks of Covid-19 transmission.

People in excluded groups, like asylum seekers and refugees, those recently released from immigration detention centres or prison, people affected by trafficking or modern slavery, who are homeless, Gypsy, Roma and Traveller communities, or sex workers² had particularly difficulty accessing Covid-19 guidance and key public health messages. Mainly due to digital exclusion and language barriers, placing them at increased risk of acquiring Covid-19 and presenting a wider public health risk of disease spread. These groups are less like to be able to pay for access to broadband or mobile data (made worse by the closure of voluntary sector organisations that usually provide this); lack of access to technology, including smartphones, computers, tablets and televisions; and lack of digital skills to access information via websites and social media. These factors affect their ability to access digital consultations too (see below).

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<https://www.healthwatchhampshire.co.uk/sites/healthwatchhampshire.co.uk/files/Hampshire%20and%20IOW%20Covid-19%20Healthwatch%20Survey%20Report%20Final.pdf>

² <https://www.doctorsoftheworld.org.uk/wp-content/uploads/2020/05/covid19-brief-rna-report.pdf>

- 🌐 **People access information from sources they trust.**³ A Hampshire and Isle of Wight Healthwatch (HIOW HW) survey shows trusted sources were predominantly family, friends, social media and watching TV. GP surgery websites and communications from service providers received the most negative responses about their usefulness.

The Intercom Trust [reported](#) that LGBT+ people found it difficult to find clear accessible information throughout the South West and 58% of people would rather access support from an LGBT+ specific organisation. This rises to 62% of disabled LGBT+ people, 77% of non-binary people, and 78% of trans people.

- 🌐 **People generally had issues accessing GP surgeries, dentists and pharmacies**⁴ and people were also unsure if they should still attend appointments in person. HW received feedback, both positive and negative, about how GP surgeries are facilitating access to services or not. Queries were about whether it was possible to get a GP appointment, prescriptions etc. There was also confusion over the advice in ‘shielding letters’ and what people should do to protect themselves. People are also beginning to be concerned about access to services if there is a second wave and making sure we learn from experiences to date. Access to NHS dentists continues to be an issue (who also play a role in identifying some cancers).

LGBT+ people, and other seldom heard groups, already experience additional barriers to accessing services, making it difficult for them to receive adequate care.

3

<https://www.healthwatchhampshire.co.uk/sites/healthwatchhampshire.co.uk/files/Hampshire%20and%20IOW%20%20Covid-19%20Healthwatch%20Survey%20Report%20Final.pdf>

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<https://www.healthwatchisleofwight.co.uk/sites/healthwatchisleofwight.co.uk/files/HIOW%20HW%20Covid%20Insight%20report.docx>

- For many people, their mental health and wellbeing have been greatly affected by the Covid-19 pandemic. On the Isle of Wight, Healthwatch insight reports⁵ noted people experiencing increased anxiety, depression and suicidal thoughts.

Specific feedback from Black and minority ethnic women:

- BAME women and men reported high levels of anxiety about having to go out to work.
- More than 4 in 10 BAME women said they would struggle to make ends meet over the next three months.
- 45% said they were struggling to cope with the different demands on their time.
- Over half of disabled or retired BAME women said they were not sure where to turn to for help a result of the pandemic.
- Life satisfaction and happiness were lowest for BAME women.

Feedback from disabled women:

- 53% of disabled women reported high levels of anxiety.
- 56% said social isolation has been difficult to cope with, compared with 42% of non-disabled women.
- 63% have struggled to access what they need from the shops, and 6 in ten also fear missing out on medicines.
- 63% said they were struggling to cope with the different demands on their time.

Feedback from people in later life⁶:

- This age group may be more resilient than some younger people, though they are still experiencing anxiety about employment and finances especially for the longer term.

⁵ <https://www.healthwatchisleofwight.co.uk/report/2020-06-01/intelligence-reports>

⁶ [Feedback from people in later life during lockdown](#)

- This age group report increased eating, smoking and drinking (although this was less for some men less because no pubs were open).
- Women at this age are more likely to have caring responsibilities and help others.
- Problems with housing and being at home during this period include overcrowding, noisy neighbours, the cold and not having access to people for repairs.

Feedback about digital or remote support

🕒 **People are open to using online or telephone appointments, but people want and need choice.**⁷ Unsurprisingly, this generally depends on people's digital literacy and access to technology. While digital offers greater flexibility for patients and clinicians, if it is the only option it is likely to exacerbate existing health inequalities and reduce quality of services for patients. A Citizens Panel's June report (in South West) reported almost two-thirds of 440 participants strongly believed digital technology has made life easier for them⁸, however, people felt more comfortable using video consultations they already knew the healthcare professional. This was stronger if people had serious long-term conditions or have a new or ongoing mental health or emotional wellbeing concern.

Certain groups were uncomfortable with video consultations, including those who are on low incomes, unemployed, state pensioners and 'low tech' individuals. From pre-Covid-19 data, older people are more likely to have never used the internet at all; in 2017 people over 55 made up 78% of those who have never been online, and people over 75 more than half. Further, older women and those living in deprived areas are least likely to go online. But the Healthwatch Leeds Digitisation report also highlights young people

⁷ https://traverse.ltd/application/files/1815/9551/9334/The_Dr_Will_Zoom_You_Now_-_Insights_Report.pdf

⁸ <https://bnssghealthiertogether.org.uk/documents/citizens-panel-survey-5-digital-results/>

can often not afford data, challenging assumptions that most young people are 'digital natives.' There are plans through HW England to gather more feedback from seldom heard groups as digital appointments will likely affect these groups the hardest.

🕒 **Challenges of video consultations include:**

- Access to technology and variable quality of signals/speeds/connections/equipment.
- Lack of technology skills, equipment and broadband, and exclusion of vulnerable people who are not able or do not wish to access virtual support.
- Limitations of the interactions, e.g. no physical examination or face to face support.
- Non-verbal communication is well evidenced as vital within oncology. There is potential risk with no face to face contact as body language can indicate distress.
- Feeling impersonal and awkward.
- Difficulty in explaining the issues sensitively.
- Data protection and security, as well as privacy and confidentiality. Home does not always offer a place to be able to have a private conversation.

🕒 **Both patients and health and care professionals need to be mindful of what they do to ensure people have a good, supportive experience when using digital services.⁹ See Traverse's Dr Zoom useful top tips for supporting remote consultations (p6 of the report).**

🕒 See local patient experience below:

⁹ https://traverse.ltd/application/files/1815/9551/9334/The_Dr_Will_Zoom_You_Now_-_Insights_Report.pdf

“During Covid I received an **unscheduled call** from an oncologist with the results of my scan and the results were not positive. I was in the middle of a family day with my four children; in the very early days of my cancer diagnosis and this phone call completely out of the blue absolutely flawed me. I struggled for weeks to pick myself up. I was unprepared for the call and the news was devastating and had a significant impact on my mental health. I needed support for a phone call like that and planned timings.”

Wessex cancer patient

Feedback from cancer patients and carers

- Access to screening and diagnostic tests have been paused or limited.
- Confusion during the early days of lockdown highlighted the need for more information about whether cancer patients were considered vulnerable or needed to shield, what that meant and around cancelled treatment. As shielding ended, there was anxiety about the easing of restrictions and what this means for people.
- For many cancer patients there has been a significant impact on their testing and treatment. Over two million people were estimated to be waiting for cancer screening, testing and treatments. In addition to this, many cancer patients may have been asked to shield, causing immediate disruption to daily life including not being able to see family and friends or do food shopping. Cancer Research UK's July 2020 report findings:

- 2 in 5 cancer patients surveyed reported that their testing had been impacted.
- 1 in 3 cancer patients surveyed reported that their treatment had been impacted.
- 2 in 3 cancer patients reported that their cancer care had been impacted.
- Ratings of overall cancer care as 'very good' decreased from 75% 'before lockdown started' to 37% 'after lockdown started'.

[Also see the Teenage Cancer Trust Cancer x coronavirus impact on young people report.](#)

Cancer treatment

- People have not been accessing services due to fear of infection, fear of overburdening the NHS or being unclear about if they should be attending appointments if they have health conditions.
- Concerns over own and others' (including healthcare professionals) ability and willingness to stay at home, physically distance and use PPE, and what to expect regarding safety measures when attending appointments.
- Worry about the availability of services, treatment and tests - fear that that these will be cancelled, delayed or whether it is safe to attend.
- People living on the Isle of Wight had specific concerns about accessing cancer treatment on the mainland, due to increased risk of infection caused by needing to get the ferry and Daisy bus.
- Isle of Wight patients have previously reported the additional stress caused by costs of travel for treatment. We have yet to find evidence of the financial impact of Covid-19 on people's ability to pay for travel to treatment but can an assumption be made that this will be increasingly challenging for those most affected?

- The Teenage Cancer Trust report that for young people with cancer treatment has been disrupted.¹⁰ They were having less contact with essential, clinical members of their treatment teams such as consultants, doctors and clinical nurse specialists.

Covid-19 communication and guidance

- There are reports of poor communication and lack of public information about cancer-specific information, do not attempt to resuscitate guidance and access to ventilators.
- Cancer patients echo the general comments above about lack of clarity in shielding information, sometimes being given different advice by different oncologists and how to keep safe when living with others.
- There is a lack of clarity about who to contact regarding follow ups and appointments. People worried about being a nuisance.

Practical challenges and problems, changes to daily life

- Most people were positive about the support received in the community, with comments mentioning the use of prescription collection services and food shopping.
- Some reported a lack of information on or access to priority lists, food delivery slots or community support.
- People are worried about accessing public transport and about Dorset being popular holiday destination, increasing the likelihood of higher infection rates locally.
- There is an increased need for financial information and advice about furlough, redundancy and increased food costs.

¹⁰ https://www.teenagecancertrust.org/sites/default/files/Cancer-coronavirus-report-June-2020-Teenage-Cancer-Trust_1.pdf?_ga=2.177786854.2107343594.1596702353-1695000400.1592818764

Emotional and mental health consequences

- People report feeling anxious and frightened about catching Covid-19, changes to treatment and becoming seriously ill. People reported the feeling that Covid-19 patients are being prioritised over cancer patients. Two thirds of cancer patients in a recent Cancer Research UK survey in May¹¹ said that the NHS's ability to support their emotional well-being or their mental health had been impacted.
- Carers impacted by coping alone as regular support service are withdrawn.
- There are concerns about not able to accompany people to clinics, visit people in hospital and distress at the inability to give or receive support at End of Life Care and in bereavement.
- People are feeling isolation from family and support networks, increased feelings of anxiety, loneliness, vulnerability. The more difficult the person's personal circumstances are the more heightened this can be.
- There is limited access to psychological support or counselling.
- There is a hidden anxiety in the community, and a local of clarity about how to support people to regain confidence to "step back outside" following shielding, with a risk of post-traumatic stress. There is a fear of unknown, breaking the barrier between isolation and re-integration - a fear of end of lockdown.

What would help/what's working to enable people to cope

- Offer safe environments, e.g. Covid-19 free zones, for cancer patients' treatment.
- Ensure NHS staff have adequate access to Personal Protection Equipment.
- Ensure NHS staff and cancer patients are regularly tested for Covid-19, regardless of if they have symptoms or not.

¹¹ <https://www.cancerresearchuk.org/about-us/cancer-news/news-report/2020-07-28-one-third-of-cancer-patients-say-coronavirus-has-impacted-their-treatment>

- Ensure that patients who have potential symptoms of cancer can be tested.
- Improve messaging to the public that the NHS is still open and encourage them to seek help.
- Personal coping strategies: creating and following a routine / Mindfulness, meditation and spiritual practices / exercise and fun activities.
- Advice about exercising and maintaining a healthy lifestyle during lockdown
- Provide help with finding support locally and practical help with e.g. benefit applications, shopping, accessing medicine and seeking clarity on treatment plans.
- Virtual support group meetings and use of technology, including cancer specific support apps and emotional support and reassurance by phone, email, social media, online groups etc are invaluable.

Some examples of feedback from support group leaders and those using them:

“We have been able to provide “virtual” support to our local community of people affected by cancer, who welcome the opportunity to be able to connect and still be part of the group. Since lockdown we have listened to the needs of our clients and offer one-hour group sessions delivered across the week providing a range of support and activities. All sessions are run using Zoom which clients seem to find accessible and easy to use.”

“The weekly virtual drop ins are working well, some people attending would not attend face to face meetings so we reaching a potentially wider audience. Range of things discussed including: story sharing, poems, anxieties, tips for coping.”

“Quarantine is bringing back memories of isolation during chemotherapy raising anxiety levels, being able to join this meeting today has helped and put my mind at rest.”

Social media comments from cancer patients during Covid-19

[Redacted] I'm recovering from the effects of Radiation for throat Cancer and couldn't possibly do telephone groups. I have bouts of coughing and weaknesses in my voice. Good idea but it's not inclusive of everyone.

The below was posted 2 August 2020:

[Redacted] I'm still waiting for a colonoscopy due last March.

Responses below are from July 2020:

[Redacted] Ive been left all alone with all this going on I got told on lockdown that i couldn't have anymore treatment.

[Redacted] Really enjoyed watching this 😊 I was diagnosed with stage 3 breast cancer just as lock down started...been shielding for 3 months and just finished my 12 weekly chemotherapy sessions...start my 8 weeks of EC chemotherapy next week...my Macmillan nurse has been so much support when I needed reassurance 😊

Like · Reply · 2w



[Redacted] That was amazing , I could listen to you both all day , I'm sure you two could become great friends , Mandy I hope you have an easy as possible "journey" love ya . I too have been shielding as had treatment for 2 years for follicular lymphoma non Hodgkins, . I was the same as you joke and laugh your way through it , what else does one do ? You can't sit in a corner and say woe is me , yes it's always in the back of your mind and have down days , but like you I'm independent and don't like asking or relying on others even though I have six kids I just think they have their lives to lead and their own families to care for . Don't get me wrong they all offer to do stuff they haven't abandoned me lol . Take care Mandy and Johnny you lovely people

Like · Reply · 2w



From Breast Cancer Now:

[Redacted] Wishing you well I've been diagnosed with invasive lobular cancer and given a 4week slot for mastectomy but yesterday told no slot so on to tablets to reduce the tumour !!!

Key sources of information

- Wessex Voices - Right By You Literature Review October 2019 (Pre-Covid-19 reference)
- Healthwatch Hampshire, Isle of Wight, Portsmouth and Southampton's combined Insight Report - July 2020
- Healthwatch Isle of Wight Insight Reports - March to May 2020 and Report on Cancer Services for Isle of Wight Residents: Co-ordination, Travel and Urgent Assistance
- The Dr Will Zoom You Now report by Traverse, Healthwatch England and National Voices - July 2020
- Bristol, North Somerset and South Gloucestershire's Citizens Panel's June report 2020
- Healthwatch Leeds Digitising Leeds: Risks and Opportunities for Reducing Health Inequalities 2020
- Doctors of the World UK report on Covid-19 on vulnerable groups, including asylum seekers and refugees - May 2020
- Written reviews for July 2020 for NHS mobile phone app for general information and use in virtual consultations
- The Fawcett Society's reports on the effect of Covid-19 on BAME women and disabled women - April 2020
- Intercom Trust 2020 report about people's experiences during Covid-19
- Ageing Better report about people in later life experiences during Covid-19
- Healthwatch in Sussex Cancer webinar report June 2020
- Teenage Cancer Trust survey report - June 2020
- Cancer Research UK survey report - July 2020
- North Cancer Alliance's app - My Wellbeing Space
- Macmillan Cancer Support report about LGBT+ people with cancer from 2014
- Macmillan Insight Report Impact of Covid-19 on people living with cancer across the UK - April 2020
- Macmillan Covid-19 Insights from people living with cancer in the North West - July 2020
- Cancer 52 survey on cancer and Covid-19