

"We have hopes and dreams and want to live well doing things that bring us joy & hope, not just focussing on the cancer"



## Secondary/Metastatic Cancer Summary Report:

Understanding the healthcare experiences  
of patients living with secondary cancer

January 2025

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## About us

Healthwatch Oldham is the independent champion for people who use health and social care services. We're here to ensure that those running services put people at the heart of care.

Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. We focus on ensuring that peoples' worries and concerns about current services are addressed. We work to get services right for the future.

We use your feedback to better understand the challenges facing the NHS and other care providers nationally. We also provide **information and advice** to help you make the right decisions for your health and get the support you deserve.

## Introduction

Healthwatch Oldham have conducted research into individuals living with secondary cancer and their experience through the health journey; providing a deeper insight reoccurring issues and concerns and the impact this has on patients. This has been summarised into a key findings report. We welcome working collaboratively with services to explore changes that can be implemented for secondary cancer patient experience.

Secondary/metastatic cancer is defined as: **'When a cancer starts in one place in the body and spreads elsewhere, this is a secondary cancer or a 'metastasis'. The place in the body where cancer first starts is the 'primary cancer'. Sometimes, cancer cells can break off from the primary cancer and spread elsewhere in the body. Cancer can then grow in another part of the body. When this happens, this is secondary cancer. Secondary cancer isn't the same thing as cancer coming back in the same place where it first started. This is a local recurrence of the cancer and doesn't mean the cancer has spread.'** (The Christie Website)

### **Limitations**

To enable a wider perspective, we produced a survey for people living with secondary cancer alongside a survey for healthcare professionals working with secondary patients. Although the survey was aimed at patients and professionals in Greater Manchester (GM), many patients completed the survey from across the UK, which is why this report is being produced as a findings only report.

Whilst we did share the survey with underrepresented community support projects, workers and residents. We do recognise that most responses are from White British females. We

therefore still have a limited understanding of equality, diversity and inclusion barriers. We'd recommend for this to be explored in future work around secondary cancer patient insights. In addition, most of our respondents had been diagnosed the breast cancer, and therefore insight into patients experiences across other types of cancer is limited within this report. Again, we'd recommend further research into this area.

**Below is a list of abbreviations that are used within the report by patients and professionals:**

- SC – Secondary Cancer
- SBC – Secondary breast cancer
- CNS – Clinical Nurse Specialist
- SCN – Secondary Cancer Nurse
- SBCN – Secondary breast cancer nurse
- EDI – Equality, Diversity and inclusion
- Stage 4 cancer – Metastatic/Secondary
- HNA – Holistic needs assessment
- Mets – Metastasis
- Scanxiety – scanxiety is defined as stress that many cancer patients feel while getting scans and awaiting results during cancer treatments.

## Methodology

- The project planning took place from December 2023 to April 2024
- The surveys were live between 2<sup>nd</sup> May to 14 July 2024
- The focus groups took place on 27 June and 3 July 2024

A patient survey was compiled for people living with a secondary/metastatic cancer diagnosis. The survey was accessible online, and a paper version was available for those who did not have access to the internet. The survey was completed by 68 patients. We also compiled a professionals' survey for professionals working with patients with secondary Cancer – which was completed by 19 professionals. Finally, we undertook 3 online focus groups (attended by 10 patients in total), for patients across Greater Manchester.

### **Demographics**

Of the 68 survey respondents, 61 were female. 21 respondents considered themselves to have a disability. 63 identified as heterosexual, and 2 identified as a gay woman/lesbian. 40 respondents were in the 50–64 age group, 24 were in the 25–49 age group, and 4 were in the 65–79 age group. 60 respondents were White British/English/Northern Irish/Scottish/Welsh or from a white background (the other 8 did not respond to this question).

30 respondents were diagnosed with secondary cancer before they were 50, 19 were in their 50s, and 5 were 60 or over. 18 respondents were diagnosed with secondary cancer within 5 years of treatment finishing, 13 respondents were diagnosed after 5 years, and 7 were diagnosed during active cancer treatment. 24 respondents had been living with secondary cancer for less than 2 years, 20 for 3–8 years, and 4 over 10 years.

## Key Findings

This section contains a summary of our key themes, highlighting the challenges patients experience from the initial diagnosis to ongoing treatment and support. We hope that this will help establish a set of standards that patients can and should expect throughout their healthcare journey.

### Diagnosis, treatment and referral timelines

It's important to start this section by noting that most (64%) of our survey respondents felt their healthcare professional was helpful, taking their concerns seriously. However, 36% participants did not agree with this; stating that their concerns regarding symptoms/signs were not taken seriously or recognised. In addition, 3 focus group participants felt that they had not been listened to when raising these concerns, with 1 saying that they feel this delayed their diagnosis by 7 months. This is particularly important because 55% of survey respondents had to raise concerns with their healthcare professional to then receive a diagnosis.

In terms of diagnosis, we recognise that a new standard has been activated since October 2023; the 28-faster diagnosis standard. Thus, two survey questions were asked depending on whether patients were referred into the secondary cancer pathway before or after 1<sup>st</sup> October 2023. 70% of respondents saw a specialist within 2 weeks of referral (which we recognise is now an old target), and 65% received a diagnosis within 28 days. This means that these targets were missed for 30-35% of patients. In addition, 25% of respondents stated that treatment did not begin within 31 days of diagnosis, with 20% saying it took 6 weeks or over.

*"We are seeing more young patients and late diagnoses recently (especially diagnosed in A&E with secondary cancer) which is concerning" – **Healthcare Professional***

*"It was my nurse, that dismissed it when I said I had a pain in my gallbladder area. She was like 'up your morphine'. It was only my GP who listened" – **Patient***

*"I was sent away from A&E on four separate occasions. It was only after the fourth visit someone listened to my chest and sent me for an X-ray. I believe someone with my history should automatically be sent for a scan when presenting such symptoms for a prolonged period" – **Patient***

### Access to scans

Our survey asked how long the wait was between referral and scan during treatment. 27% had their scan within 2 weeks. However, most of the respondents (73%) waited longer than 2 weeks and 33% had to chase up (with some stating that this added to their already existing cancer related anxiety and stress – scanxiety) – this was also reflected in the focus groups whereby 9 participants said they had to repeatedly chase scans. In addition, within the focus groups, participants highlighted that the scheduling system for scans/blood tests and results and oncology appointments was not consistent, which led to delays with these appointments.

*“I wish I knew then, what I know now. You have to advocate for yourself and chase up, wait for info and spend a lot of time and energy doing this” - Patient*

*“At my secondary diagnosis, my scan results were lost for over 5 weeks. I had to chase them. The Oncologist acted very quickly after this... my scans since then arrive normally within 2/3 weeks. I’m lucky, my Oncology nurse is always checking” - Patient*

### Information/awareness of Secondary Cancer

Most respondents (74%) said that they did not receive information on the signs/symptoms of secondary cancer at the end of their primary cancer treatment. Of those who did receive information, 15% felt that the information was not adequate, specifying that they wanted signs and symptoms of recurrence at the end of primary cancer treatment, and more digestible terminology. Contrary to this, 78% of professionals responded that they have resources/information on secondary cancer to share with primary cancer patients at the end of treatment, and 86% said it’s standard practice to relay this information to patients. However, when asked for more information on this topic, professionals felt that even though information was being provided, it was not always adequate in terms of symptom awareness.

*“Having worked with patients with secondary cancer, I know there is frustration about the lack of discussion and symptom awareness provided to patients with primary breast cancer about signs and symptoms of secondary cancer” - Healthcare Professional*

### Access to services and specialists (including treatments and clinical trials)

Respondents said they had primarily accessed Macmillan, their GP, and Cancer Support Groups online. Participants from our focus groups who had utilised The Christie, Manchester, felt that there were issues around communication and administration.

In terms of clinical trials, participants from our focus groups communicated that there was not enough information on clinical trials for patients. I reported feeling rushed to sign up when they were presented with information. However, a good quality of care was reported whilst on clinical trials. Professionals highlighted there being insufficient specialist cancer nurses available which meant patients didn't have access to the support they needed. They recommended increasing the volume/capacity of specialist cancer nurses as this would support patients around access to scans and understanding of clinical discussions.

*“There is not a national database of all the clinical trials that are available to secondary breast cancer patients. There is not one central thing that you can log on to see where the clinical trials are in your area, or even if they exist at all... this is what METUPUK have tried to do” - (METUPUK – patient-led SBC advocacy and campaign group)*

*“There is a lack of information on clinical trials available” - Healthcare Professional.*

*“Christie, the treatment is superb the admin is appalling... the number of times I've turned up and my appointment was cancelled, or it was on a different date, or I've waited only to find out clinic isn't happening. I've now had to make a point of checking up. I take a book, I take food, and I take water” - Patient*

### **Support needs (including treatment plans, end-of-life plans and holistic needs assessments)**

The majority (90%) of respondents to our survey felt that their immediate support needs had been met, and that their treatment plan had been discussed with them (87%). Where participants reported that their needs had not been met, this strongly related to equality, diversity and inclusion barriers, including mental health support needs, childcare, age, language restrictions, and the area you live in impacting on the care you receive. In terms of holistic needs assessments, most respondents said these had not been discussed/completed with them, but that they would have benefited from one. In addition, most respondents (83%), reported feeling as though they needed to become an expert patient to receive the best treatment options available.

Most participants (81%) didn't have end-of-life plan discussions, mostly because their healthcare teams had not raised them, but some reported they did not want to discuss them. Respondents did, however, say that it would be helpful to receive better quality and more end-of-life information, including myth-busting information (31% of respondents thought that palliative care meant end-of-life stage). Professionals' responses to our survey indicated that most of them (64%) will only discuss end-of-life information/plans when patients bring it



up/when treatment turns to palliative care. Finally, most respondents (66%), said they don't go to a hospice but would if promoted, 11% said they wouldn't, and 23% said they go already.

*"There is a gap in holistic care. Looking after the whole person, is extremely important. We are more than just our Secondary Breast Cancer diagnosis. We have hopes and dreams and want to live well, doing things that bring us joy and hope, not just focussing on the cancer" – Patient*

*"Some years ago, someone told me that palliative care meant the best care possible, and now I have said that to people too. I have found it so convenient and pleasant to use my local hospice for many hours of chemo and immunotherapy. But still feel most people I meet think it only refers to end-of-life care. It needs to be revisited so people understand" – Patient*

*"End-of-life plans have never been mentioned or discussed even though my liver metastases is very serious" – Patient*

### **Emotional and Psychological support**

Participants from our focus groups felt that clinicians sometimes lacked empathy towards them, and that there needed to be more support aimed at secondary cancer patients and their families (including mental health support, financial advice, and advice on living with a secondary cancer diagnosis). They felt that there is too often a focus on primary cancer prevention, treatment, care and support, and secondary cancer patients are somewhat left behind. Participants did feel that patient-led support groups were useful, but that signposting to these services needed to improve.

*"I think that the clinical staff, nurses, doctors and anybody you come across needs to be aware of the support groups that are available in that area. Local cancer support groups are brilliant, but people need to know about them" – Patient*

*"I was referred to the palliative care team in Wythenshawe and that was the best thing ever for me because they were absolutely brilliant. They looked after all my medications and did a lot for my mental health. I think I'd have been lost without them, to be honest" – Patient*

### **Communication**

Most of our survey respondents (69%) felt that it was easy to communicate with their cancer nurse/specialist, 31% felt that it was not. Participants from our survey also had some positive examples of communication with their healthcare teams. However, just under half of respondents (47%) felt that communication between professionals was inadequate and they

had to repeat themselves and update professionals on their medical history. Professionals who responded to our survey raised that communication and information sharing across agencies is poor and impacts on patient care/experience. Focus group participants raised that language during consultations can be confusing and could generally be less clinical. Participants also reported instances of poor communication (including abruptness) and wanting to receive communication on schemes such as the A&E fast-track service.

*“To keep myself alive I’ve had to learn very quickly how to explain, question and double-check everything medical professionals said, offered and given to me” –*

**Patient**

*“My cousin who attended my diagnosis appointment for support (retired GP) explained that my diagnosis is terminal. No member of my clinical team has used this phrase with me yet. If my cousin hadn’t told me, I would not have known” –*

**Patient**

*“Communication needs to improve, even just the basics would improve care, and take a lot of the stress and anxiety away” –* **Patient**

### **Data, statistics, and recording systems**

Participants in our focus groups agreed that there is a lack of up-to-date statistics on secondary cancer. Participants want up-to-date statistics that 1) report on how many people are living with secondary cancer nationally, regionally, and locally, and 2) treatment, and 3) general secondary cancer relevant information. Participants reported feeling as though the lack of up-to-date statistics impacts access to funding drugs, and other medical treatments available to them. Professionals’ survey free text response demonstrated that professionals agree that there is not enough data on secondary cancer, limiting the ability to inform and improve health outcomes. There was uncertainty from professionals on whether there is a flagging system on medical records to highlight primary cancer. The majority (56%) said there was, but 28% were unsure, and 17% said there was not. Most professionals (61%) said they did not know if they could update patients’ health records from primary to secondary cancer, 28% said they could, and 11% said they could not – demonstrating inconsistencies.

*“Nobody knows how many secondary breast cancer patients that are in the UK. How can you budget if you don’t know how many of us there are? I do think most of the emphasis is put on catching things early and prevention... the focus is on primary cancer. It feels like you are forgotten about” –* **Patient**

## Conclusion

In conclusion, it's firstly important to state that there are clearly positive experiences in healthcare for patients with secondary cancer. Including:

- Positive interactions and support from patients' healthcare teams, palliative care teams, specialist nurses and oncologists
- Support from peer-led support groups
- Good quality of care on clinical trials
- Some participants felt they had a timely secondary cancer diagnosis

However, our findings predominantly highlighted key challenges that secondary cancer patients face which impact negatively on their experience of cancer healthcare.

- Diagnosis, treatment and referral timelines
- Information/awareness of secondary cancer
- Access to scans
- Access to services and specialists (including treatments and clinical trials)
- Support needs (including end-of-life plans and holistic assessments)
- Emotional and Psychological support
- Communication (between teams and to patients)
- Data, statistics, and recording systems

We hope the key findings are used to guide to improve secondary cancer healthcare services and providers to help create a positive impact on patients, clinical staff and teams.

## Acknowledgments

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