



Disability Law Center

Massachusetts Protection and Advocacy

INVESTIGATION REPORT

Death Inside Lemuel Shattuck Hospital: A Case Study on Medical Treatment for Persons with Mental Health Disabilities

May 8, 2023

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Executive Summary

Mr. Harris¹ died on August 22, 2020 after a battle with cancer during his involuntary psychiatric commitment to the Metro Boston Mental Health Units within Lemuel Shattuck Hospital (LSH). At the time of his death at age sixty (60), Mr. Harris had been many things in his life – just to name a few, he was a beloved son, brother, nephew, and uncle, a Black Bostonian, a college student, a good Samaritan, and a person with a mental health disability.

After receiving a complaint and finding probable cause to initiate an investigation pursuant to federal Protection and Advocacy authority, the Disability Law Center (DLC) conducted an in-depth investigation into the circumstances of his death, including review by an independent medical expert. In short, DLC’s investigation revealed that Mr. Harris developed a cancerous lesion on his nose that was not properly diagnosed or treated for more than a year and a half while inpatient within LSH, including a period of eleven (11) months waiting for a surgical referral. DLC found that LSH’s failure to provide Mr. Harris appropriate medical treatment constituted neglect and contributed to his painful, untimely death.

As discussed in detail below, after receiving DLC’s findings and recommendations for corrective action, LSH conducted a comprehensive review of Mr. Harris’ care and concurred with the clinical concerns identified by DLC’s expert. LSH then implemented meaningful and laudable corrective action. DLC now issues this public report to shine a light on Mr. Harris’ story as a saddening and disturbing example of the lack of or unequal access to quality medical care that people with mental health disabilities experience every day.

Studies show that people with mental health disabilities experience disparities in health care access and health outcomes more often than their peers. DLC has received firsthand accounts of these experiences in various settings within the Commonwealth – including psychiatric hospitals, hospital emergency departments, nursing facilities, group living environments, and doctor’s offices. People with psychiatric diagnoses describe being unable to access necessary medical treatment during an involuntary psychiatric hospitalization; having their medical concerns dismissed by medical staff in hospitals, congregate care environments, and their own primary care offices; and being terminated from care for disability-related reasons. And there are certainly more stories of individuals, like Mr. Harris, who are unable to effectively self-advocate for appropriate treatment and rely on learned assistance from medical professionals who care for them daily, but who do not receive the timely care they need. Compounding these experiences are the institutional racism in U.S. health care delivery systems and pervasive health disparities for communities of color, women, people who identify as LGBTQIA+, people with Limited English Proficiency, people with low incomes, and people with other disabilities. While the Commonwealth continues to make efforts to improve health equity,² barriers persist and must be dismantled, especially in our public hospitals.

¹ DLC uses this pseudonym throughout the report, in keeping with 42 CFR § 51.45, to maintain the confidentiality of this individual’s identity.

² For instance, the Massachusetts Health Policy Commission (HPC), an independent state agency, has a mission “to advance a more transparent, accountable, and equitable health care system through its independent policy leadership and innovative investment programs.” Massachusetts Health Policy Commission, <https://www.mass.gov/orgs/massachusetts-health-policy-commission>.

DLC dedicates this report to individuals who have been denied access to appropriate or optimal care because of their mental health disability and urges institutional and community providers to take remedial action.

“[T]here's a hundred other people like [Mr. Harris] at the Shattuck. A lot of them don't have anyone. I went there for three years, and patients would say ‘we wish we had sisters like you.’ During that period at least three or four of those people died.”

– Mr. Harris’ sister and legal guardian

I. INVESTIGATIVE PROCEDURE

The Disability Law Center is a private, non-profit organization designated as the Protection and Advocacy system (P&A) for people with disabilities in Massachusetts. A core function of the P&A is to monitor public and private facilities where people with disabilities live or receive services and to investigate incidents of abuse and neglect that occur within those environments. Because the most serious result of abuse and neglect is death, federal law provides DLC with the authority to thoroughly investigate deaths of individuals with disabilities.³ One of the federal statutes creating the P&A protects individuals with mental health disabilities and is known as the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act.⁴ Pursuant to this federal mandate, DLC is authorized to “investigate incidents of abuse and neglect of individuals if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.”⁵

In our capacity as the P&A, DLC received a complaint in 2020 regarding the troubling circumstances of Mr. Harris’s death. DLC conducted a preliminary assessment and reviewed available documentation and interviewed Mr. Harris’ sister and legal guardian,⁶ who was actively involved in his care and treatment at LSH. Based on the information gathered, DLC found probable cause to initiate an investigation and requested records under our P&A authority, first from LSH, where he had been inpatient for several years and had in-house specialist consultations, and then from Boston Medical Center, where Mr. Harris ultimately underwent surgery and received additional cancer treatment.

³ 42 U.S.C. §§ 10801; 42 C.F.R. § 51.31

⁴ 42 U.S.C. §§ 10801 *et seq*

⁵ *Id.*; 42 C.F.R. § 51.31.

⁶ Mr. Harris’ sister has given her express permission to DLC to make reference to this contact as part of our investigation in the present report and supports the publication of this report as the personal representative of Mr. Harris’ estate.

DLC’s investigation, which included a review by an independent medical expert, concluded that LSH’s failure to provide appropriate medical treatment to Mr. Harris constituted neglect⁷ that contributed to his death.

On March 11, 2022, DLC provided findings and recommendations for corrective action to the Department of Public Health (DPH) and the Department of Mental Health (DMH), the agencies responsible for running LSH and the Metro Boston Mental Health Units (MBMHU) therein, requesting a corrective action plan. DPH and DMH responded on March 31, 2022, to report that it was reviewing the information DLC provided, had “referred the case to the Hospital’s Medical Staff for review of the provider’s care in accordance with the Hospital’s Medical Staff Bylaws,” and were examin[ing] the case for any hospital system issues that may have contributed to the reported delay in treatment and breakdown in communication.” Following its careful review, LSH provided a summary of its findings and corrective action plan on June 1, 2022.

DLC wrote to LSH in July 2022 to follow up on the implementation of LSH’s corrective action plan and certain recommendations from our initial report, to which LSH responded in September 2022 with updates.

II. DISPARITIES IN HEALTH CARE ACCESS AND OUTCOMES FOR PEOPLE WITH MENTAL HEALTH DISABILITIES

It is well-recognized that many individuals with mental health disabilities experience poor health outcomes, particularly people who are diagnosed with persistent psychotic disorders and major mood disorders often labelled as “serious mental illness” or “SMI.”⁸ Stated in the starkest terms, “[t]hose with SMI die earlier, have more medical illnesses, and receive worse medical care than those in the general population.”⁹

“Poor outcomes are linked with a host of patient, provider, and system factors, as well as with the provision of substandard medical care,” resulting in a complex problem requiring targeted action.¹⁰ Symptoms of significant mental health disabilities can, for some people, adversely

⁷ DLC conducted this investigation pursuant to the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI), 42 U.S.C. §§ 10801 *et seq.* The applicable PAIMI regulations define neglect as “a negligent act or omission by an individual responsible for providing services in a facility rendering care or treatment which caused or may have caused injury or death to an individual with mental illness or which placed an individual with mental illness at risk of injury or death, and includes, but is not limited to, acts or omissions such as failure to: establish or carry out an appropriate individual program or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care; and the failure to provide a safe environment which also includes failure to maintain adequate numbers of appropriately trained staff.” 42 C.F.R. § 51.2. A determination of medical malpractice or other forms of negligence was outside the scope of this investigation.

⁸ DLC does not endorse identifying people with lived mental health experience as SMI due to the negative connotation the term carries and the impact such labelling may have but references it herein as a term of art with legal significance under federal and Massachusetts law that is also used in medical and academic literature.

⁹ Mark J. Viron, Theodore A. Stern, *The Impact of Serious Mental Illness on Health and Healthcare*, PSYCHOSOMATICS, Volume 51, Issue 6 (2010), 458, [https://doi.org/10.1016/S0033-3182\(10\)70737-4](https://doi.org/10.1016/S0033-3182(10)70737-4); see Kelly E. Irwin, David Henderson, *Cancer Care for Individuals with Schizophrenia*, CANCER, 323 (February 1, 2014), <https://acsjournals.onlinelibrary.wiley.com/doi/10.1002/cncr.28431>.

¹⁰ Viron at 458.

impact social and cognitive skills that may impair their ability to communicate with clinicians and navigate complex healthcare systems and may lead to lack of motivation or apprehension about addressing medical issues. At the same time, there are serious provider and health care system factors that substantially contribute to poor quality of care for this population.¹¹

Physicians may lack the skills to provide medical care to patients with mental health disabilities, feel uncomfortable, or experience patients with disabilities as “difficult or time-consuming.”¹² Indeed, physicians “often work under extreme time constraints and competing demands that may make them unable or unwilling to provide additional services” or other accommodations to ensure equal access.¹³ “Diagnostic overshadowing,” a phenomenon “where providers attribute a patient’s physical symptoms to [their] mental illness, rather than to a medical illness, has the potential to interfere with the provision of medical care.”¹⁴ For instance, providers may be less likely to refer patients to specialized treatment and to address barriers to optimal care.¹⁵ Moreover, healthcare systems are often fragmented in structure and payment schemes – creating inherent barriers for patients and coordination between medical and mental health providers – and are more accessible to individuals with greater resources from dominant cultural groups.¹⁶ The intersectionality of poverty, disability, and race/ethnicity is a key consideration, as “those with SMI are more likely to live in disadvantaged social circumstances, and people who live in resource-poor conditions are known to experience worse health.”¹⁷

With respect to cancer, all patients have not benefitted equally from the advances in detection, treatment, and supportive care.¹⁸ People of color, low income populations, older adults, and people with mental health disabilities all face lower rates of survival.¹⁹ “Population-based studies in multiple countries with universal healthcare coverage have provided robust evidence that patients with schizophrenia are 1.5 to 2 times more likely to die of cancer than patients without mental illness.”²⁰ The same patient-, provider-, and system-level factors above influence poor outcomes in cancer treatment. Patients with schizophrenia may experience delays in diagnosis and present with more advanced disease; once diagnosed, patients may refuse treatment or have behaviors that disrupt their care.²¹ Disparities in care may be more noticeable when clinical uncertainty about the best manner of treatment exists – for instance, concerns about agitation among people with schizophrenia or other mental health disabilities can influence oncological care.²² However, one study concerning patients with schizophrenia receiving cancer treatment

¹¹ Benjamin G. Druss, *Improving medical care for persons with serious mental illness: challenges and solutions*, J CLIN PSYCHIATRY, 68 Suppl 4:40-4 (2007), 41, <https://pubmed.ncbi.nlm.nih.gov/17539699/>; Viron at 459-460.

¹² Viron at 460; *see id.*

¹³ *See* Viron at 460.

¹⁴ Viron at 460; Graham Thornicroft, *Physical health disparities and mental illness: The scandal of premature mortality*, THE BRITISH JOURNAL OF PSYCHIATRY (2011), 199(6), 441, <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/physical-health-disparities-and-mental-illness-the-scandal-of-premature-mortality/06CD314810155127BFE42EEDFFFE49BB>; *see* Irwin at 324.

¹⁵ Irwin at 324.

¹⁶ *See* Druss at 41.

¹⁷ Viron at 460.

¹⁸ Irwin at 323

¹⁹ *See* Irwin at 323.

²⁰ Irwin at 324.

²¹ Irwin at 328.

²² Irwin at 324.

emphasized that “there was no need to modify the standard chemotherapy regimen if administered in a setting with trained support staff including nurses and social workers and available psychiatric consultation.”²³ Individuals with a history of agitation related to a mental health disability who are in need of chemotherapy, endocrine therapy, or radiotherapy may be best served in a unit with experience in the management of both psychiatric and medical illness or “with close follow-up by psychiatric consultants and additional training of oncology nurses,” while also involving the patient’s sources of social support.²⁴

Addressing this complex problem requires system-wide integration of medical and mental health care and investment in training and systemic reform aimed at changing attitudes and biases of health care professionals about treating and accommodating people with mental health disabilities. In the context of cancer treatment for patients with mental health disabilities, research indicates that early psychiatric consultation should “guide potential modifications to the cancer treatment plan, facilitate illness understanding, assess capacity to consent, assess risk of self-harm and violence, and consider medication interactions and postoperative complications.”²⁵

The experiences voiced from DLC’s client community make clear that the Commonwealth still has a long way to go in accomplishing necessary reform. Indeed, even the acceptance that LSH serves as the repository for patients who cannot be served or who are unwanted in other community hospitals, as discussed below, suggests an acquiescence to the fact that different conditions and standards for treatment are acceptable for certain populations. As this case study illustrates, LSH patients are at risk of falling through the cracks while within the hospital, whether due to the divide between the DMH and DPH sides of the hospital, a lack of coordinated care, a lack of legal guardian or support person involvement, or some combination thereof. Moreover, Mr. Harris’ story offers an example of our healthcare system making treatment decisions for an individual with mental health disabilities based on his perceived limitations and risks, instead of devising a multi-disciplinary approach in order to offer him optimal care for his life-threatening medical condition.

III. LEMUEL SHATTUCK HOSPITAL

LSH is one of four (4) DPH hospitals. It provides acute, subacute, and ambulatory care, managing two hundred fifty-five (255) inpatient beds and a range of outpatient services that include surgical services, specialty clinics, radiological imaging, and clinical laboratory services.²⁶ One hundred fifteen (115) of the beds are for psychiatric admissions to the MBMHU run by DMH. According to the Commonwealth’s website, “[t]he Hospital’s services help economically and socially disadvantaged patients to get high quality, cost-effective care from a

²³ Irwin at 329 (citing Sharma A, Ngan S, Nandoskar A, et al., *Schizophrenia does not adversely affect the treatment of women with breast cancer: a cohort study*, *BREAST* (2010);19:410-412).

²⁴ Irwin at 329.

²⁵ Irwin at 328.

²⁶ *Lemuel Shattuck Hospital*, DPH, <https://www.mass.gov/locations/lemuel-shattuck-hospital>; *Acute care at Lemuel Shattuck Hospital*, <https://www.mass.gov/location-details/acute-care-at-lemuel-shattuck-hospital>.

staff that respects their dignity.”²⁷ LSH serves a significant patient population of color, particularly as compared to the general population of Massachusetts.²⁸

LSH’s Vision Statement includes the aims of “increas[ing] access to high quality care for underserved patient populations of Massachusetts, particularly to clients and patients in health care programs managed by the Mental Health department, Correctional facilities, and Public Health clinical programs”; and “address[ing] the unmet medical and psychiatric needs of patients and clients when the private health care system cannot offer such care.”²⁹ To be sure, LSH plays an important role in the Commonwealth’s health care system, treating those who do not have the funds, sufficient insurance coverage, or the expected behaviors – whether disability related or not – for other health care facilities to treat them.

Most LSH staff are committed health practitioners who choose to work there because of the hospital’s focus on caring for marginalized communities. Still, there have been complaints from current and former LSH staff members about understaffing, the quality of treatment provided, the competence of certain physicians, administrative oversight, and, in the past, retribution exacted by hospital administrators for speaking up about their concerns.³⁰

IV. THE CIRCUMSTANCES OF MR. HARRIS’ DEATH

A. Mr. Harris’ Background

Mr. Harris was a Black Bostonian who grew up in a loving family with his two siblings in the South End, after moving as a youngster from Birmingham, Alabama. He was a bright and kind child. Mr. Harris graduated from the English High School and attended Emerson College as a photography major. An industrious young man, he also worked as a security guard, and, for a time, as a surgical technician at New England Baptist Hospital after completing a surgical technician program. Unfortunately, Mr. Harris’ mental health deteriorated in college, and he was unable to graduate. Around age twenty-two (22), Mr. Harris experienced a psychotic break that resulted in his first involuntary psychiatric commitment. He was initially taken to the old Shattuck Hospital, since torn down, and was then sent to Bridgewater State Hospital because of a health insurance issue. His initial diagnosis was bipolar disorder.

²⁷ *Lemuel Shattuck Hospital*, DPH, <https://www.mass.gov/locations/lemuel-shattuck-hospital>.

²⁸ See, e.g., *2018 Population Health Clerkship Presentations: Incarcerated & Urban Working Poor - Lemuel Shattuck Hospital*, UMASS CHAN MEDICAL SCHOOL FAMILY MEDICINE AND COMMUNITY HEALTH https://www.umassmed.edu/fmch/communityhealth/sep/pophealth/phc_presentations_2018/ (reporting that 2017 admissions showed that the LSH population as 43% non-white, 40% incarcerated, 80% male).

²⁹ This Vision Statement and additional information about LSH is available at *Lemuel Shattuck Hospital mission and history*, DPH, <https://www.mass.gov/location-details/lemuel-shattuck-hospital-mission-and-history#:~:text=The%20Hospital%20strives%20continuously%20to,patient%2Dfocused%20continuum%20of%20care.>

³⁰ Jenifer B. McKim, *Prisoners, their advocates and even some health providers say complaints point to bigger problems in state care*, WGBH (March 15, 2023), <https://www.wgbh.org/news/local-news/2023/03/15/prisoners-their-advocates-and-even-some-health-providers-say-complaints-point-to-bigger-problems-in-state-care> (discussing concerns of current and former staff relayed in letters to the Department of Public Health Commissioner in 2019 and 2020 and in an interview with WGBH). DLC initiated an investigation into LSH concerning its infection control practices during the COVID-19 pandemic.

At Bridgewater State Hospital, his mother would plead for officers to bathe Mr. Harris or allow her to assist him, as he would commonly be found soiled with urine and feces. Due to the troubling conditions, Mr. Harris' sister recalls her mother rushing every morning after finishing her night shift as a nurse to check on her son. Once Mr. Harris obtained necessary health insurance coverage, he was able to get psychiatric care from Beth Israel Deaconess Medical Center and remained largely stable until his mother died in 2003. Thereafter, Mr. Harris was in and out of inpatient and outpatient treatment, but living independently until he experienced a significant decline that began around 2012. Mr. Harris's sister became his legal guardian around this time and he was ultimately committed long-term to Solomon Carter Fuller Hospital. He continued to get electroconvulsive therapy (ECT) treatment and attend groups at Beth Israel Deaconess Medical Center and was frequently able leave the facility on day passes. Ultimately, his provider at Solomon Carter Fuller concluded that he would not improve. Mr. Harris was transferred to LSH in 2017 pursuant to M.G.L. c. 123, §§ 7 & 8 with the understanding that he would remain there. At LSH, he was not permitted to continue his ECT treatment at Beth Israel, requiring him to do so at LSH.

Mr. Harris was ultimately diagnosed with schizoaffective disorder³¹ with chronic catatonic state. He also had several chronic medical issues, including type 2 diabetes, high cholesterol, and high blood pressure. Prior to his final string of commitments, Mr. Harris would volunteer periodically at a nursing home in Boston and do his own shopping, cooking, and banking and assist his elderly neighbor with their banking. Mr. Harris was a beloved son, brother, and uncle. His sister and guardian visited him regularly while he was committed to LSH, taking him out on day passes for several years of his commitment, and sought to be actively involved in his care.

Following his passing, even members of LSH staff took the time to attend his funeral services and share the following kind words for Mr. Harris on his obituary page:

From all the staff, who worked with Mr. [Harris]. We are glad that we met [him]. His smile would light up a room, and his love for music. We will never forget him. Our condolence and sympathy to his family. [He] is at the top of the mountain now with his LORD.

We will miss [Mr. Harris]. And we will remember his joy of music, EARTH, WIND, AND FIRE that he loved to listen to with staff. Fly with the ANGELS. THE 10 NORTH STAFF.

³¹ Schizoaffective disorder “is marked by a combination of schizophrenia symptoms, such as hallucinations or delusions, and mood disorder symptoms, such as depression or mania” and presents differently in each person. See *Schizoaffective Disorder*, MAYO CLINIC, <https://www.mayoclinic.org/diseases-conditions/schizoaffective-disorder/symptoms-causes/syc-20354504>.

B. Mr. Harris' Battle with Cancer During an Involuntary Inpatient Psychiatric Commitment

i. An Overview of Mr. Harris' Cancer-Related Care

On February 16, 2017, Mr. Harris was admitted to the MBMHU at LSH under an order of commitment pursuant to M.G.L. c. 123, §§ 7 & 8. In May 2017, he had his first appointment with LSH dermatologist Dr. Shahla Asvadi to evaluate a lesion on the left side of his nose. During the first appointment, Dr. Asvadi determined, without performing a biopsy of the lesion measuring six (6) millimeters, that it was “most consistent with basal cell carcinoma” and recommended that Mr. Harris apply a topical imiquimod cream called Aldara for six (6) weeks and return for a follow up in two (2) months. Mr. Harris was noted to be sleepy and providing unclear answers during the consultation; records did not indicate that LSH consulted with Mr. Harris' legal guardian concerning the treatment plan, but state two (2) weeks after the appointment that the guardian was “informed” of the diagnosis and the recommended topical treatment and “[s]he did not voice disagreement.” Mr. Harris returned to the LSH dermatologist in August 2017, resulting in a recommendation of six (6) more weeks of topical cream treatment for the lesion that had now flattened, with another follow up in two (2) months. Again, Mr. Harris presented as sleepy and nonresponsive to questions, but there is no indication LSH contacted his legal guardian. At his January 2018 follow up appointment, the LSH dermatologist referred Mr. Harris to surgery for further treatment, as the lesion, now nodular and bleeding occasionally, had not changed. Mr. Harris was not responding to questions and records do not indicate that his legal guardian was involved or even informed about this treatment plan.

Following the January 2018 referral, eleven (11) months passed before Mr. Harris was provided the LSH surgical consultation for the lesion on his nose in December 2018. Throughout that period, Mr. Harris was living inside of LSH, committed involuntarily to the MBMHU and regularly interacting with medical and mental health professionals; indeed, the pendency of his surgical consult was noted during his April 2018 annual physical exam. During the December 2018 LSH surgical referral with Dr. James Petros, the lesion was observed to have grown to twenty (20) millimeters by ten (10) millimeters and appeared fixed to the underlying nasal cartilage. Dr. Petros recommended referral to BMC for excision to remove it.

In February 2019, Mr. Harris and his legal guardian attended his first appointment with BMC dermatology where he finally received a biopsy of his lesion – roughly twenty-one (21) months after his initial appointment with the LSH dermatologist. The biopsy determined that squamous cell carcinoma was a more likely diagnosis than his previous diagnosis of basal cell carcinoma and included sebaceous carcinoma as a potential alternative. In May 2019, Mr. Harris had a consultation with BMC Ear Nose and Throat (ENT), which ordered a full oncological workup with imaging of his lesion that provided a definitive pathological diagnosis of an infiltrating carcinoma, either sebaceous or squamous cell carcinoma. This was nearly two (2) full years after his initial misdiagnosis without biopsy of basal cell carcinoma at LSH.

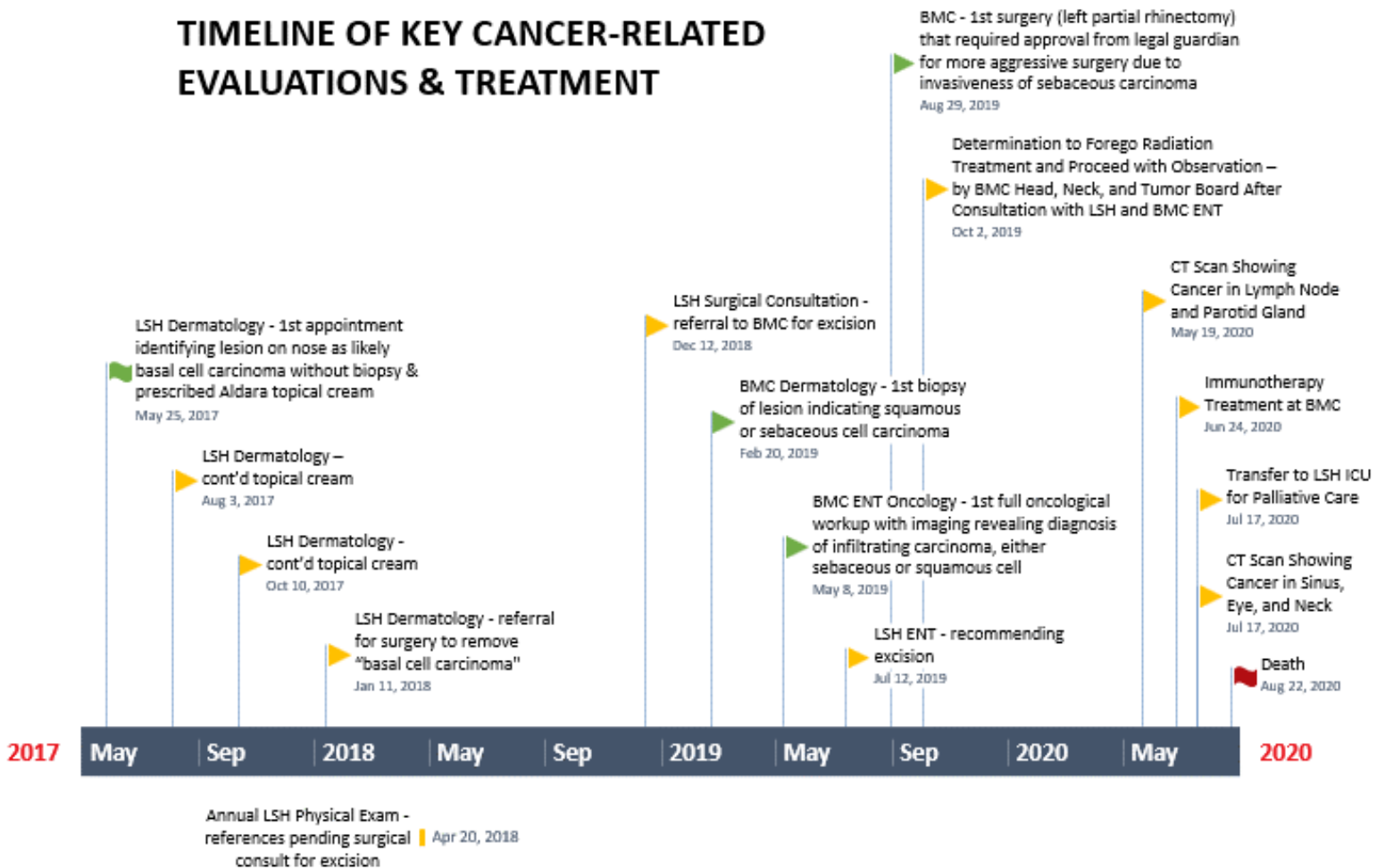
Following additional consults in July 2019 concerning the surgery, BMC performed a left rhinectomy – partial surgical removal of the left side of his nose - in August 2019. The sebaceous carcinoma had grown significantly to involve the full width of the cartilage of Mr. Harris' nose such that, during the surgery, BMC had to seek permission from his legal guardian to perform a more aggressive surgery than planned. Due to the extent of the tumor, the wound on his face could not be completely closed.

Doctors at LSH and BMC consulted about whether to provide Mr. Harris with radiation in September 2019 and the BMC Head and Neck Tumor Board discussed the matter in October 2019. Presuming that Mr. Harris would not be able to tolerate the radiation treatments due to his mental health disability, doctors recommended observation instead, given the close but negative margins achieved during the surgery and because his nose could be easily observed for recurrent growth. Records indicate that Mr. Harris' legal guardian agreed based on the information provided. However, the records do not indicate whether sedating Mr. Harris to undergo radiation treatment or other types of accommodations were considered, and Mr. Harris' legal guardian does not recollect discussing such options.

In May 2020, Mr. Harris developed a raised area on his left cheek and swelling around his left eye. A CT scan revealed cancer in his lymph node and parotid gland, confirmed by later biopsies. In June 2020, he received one treatment with IV pembrolizumab immunotherapy under sedation at BMC with plans for further appointments. July 2020 records indicate that Mr. Harris was complaining of pain while his swelling was increasing; he received morphine. A CT scan the same month showed cancer had progressed to his sinus, eye, and neck. He was in pain and experiencing difficulty swallowing. Mr. Harris' early August 2020 immunotherapy treatment was not successful, as the sedative was not effective, and he would not comply with the IV treatment. BMC and LSH consulted and decided to make no more attempts to provide immunotherapy treatment – though it could theoretically improve the tumor – because of his presentation during the previous appointment. Records do not reflect that any discussions took place about exploring other accommodations that might help facilitate his compliance with IV treatment.

Thereafter, Mr. Harris's condition declined with increased masses and weakness. LSH increased his morphine for pain and provided wound care to try manage the open, bleeding area on his face. LSH transferred Mr. Harris to the hospital's Intensive Care Unit on August 10, 2020 for palliative care. He died there at age sixty (60) on August 22, 2020, in pain and suffering increased secretions draining from his mouth.

TIMELINE OF KEY CANCER-RELATED EVALUATIONS & TREATMENT



C. Expert Findings Concerning Mr. Harris' Treatment

"It is my conclusion that Mr. [Harris'] illness would have had a high chance for survival at initial presentation if treated promptly, despite any challenges associated with his mental health condition."

– Jennifer Stein, MD, PhD

DLC retained Dr. Jennifer Stein, MD, PhD, to conduct a review of the consultations, diagnoses, and treatment Mr. Harris received during the course of his cancer care. Dr. Stein is a professor in the NYU School of Medicine Department of Dermatology, a board-certified dermatologist, and an Attending Physician at Tisch Hospital, New York Harbor Healthcare System VA Hospital, and Bellevue Hospital in New York, NY.

Dr. Stein analyzed Mr. Harris' treatment records and identified in her September 2021 report a number of LSH actions that did not comport with the standard of care. Her analysis was as follows (emphasis added):

[Mr. Harris] presented to LSH dermatology with a sebaceous carcinoma on his nose, which was assumed to be a basal cell carcinoma. Sebaceous carcinoma is a rare and aggressive tumor, whereas basal carcinoma is very common and not aggressive. While it is not uncommon to mistake the two at initial presentation, it is the standard of care to biopsy the lesion before treating a basal cell carcinoma to confirm the diagnosis, which did not happen in this case.

A skin biopsy is a common in-office procedure. Because Mr. [Harris] did not have the ability to consent to the biopsy, one would expect this would be mentioned in the note along with documentation of the discussion with his guardian about why a biopsy was not being performed and the risks and benefits of treating without pathologic confirmation. The social work note from the initial dermatology evaluation simply states, "Sister informed."

Mr. [Harris] was initially treated with a topical cream, imiquimod (Aldara). This treatment could be an appropriate choice for a superficial basal cell carcinoma, which is a particularly low-risk subtype of basal cell carcinoma. In this case, however, there was no histologic confirmation or even clinical notation that this lesion was the superficial subtype of basal cell carcinoma, which is the only subtype of basal cell carcinoma for which imiquimod has an FDA-approved indication. In fact, there is a note from 10/10/17 that states that the lesion was flattening, which would suggest that at least at initial presentation, this was a raised lesion, which would be inconsistent with a superficial basal cell carcinoma. There is certainly evidence that imiquimod can effectively treat other types of basal cell carcinoma, but one would expect a conversation with Mr. [Harris'] guardian about non-standard use of imiquimod to have been documented, which it was not.

After the tumor failed to respond to imiquimod, the dermatologist recommended surgical removal, but there was an eleven-month gap before Mr. [Harris] saw a surgeon, during which time the tumor had grown from what was described at a prior dermatology visit as a 3 mm lesion to a 20 x 10 mm, ulcerated mass that bled when palpated and appeared fixed to the underlying nasal cartilage. This description is particularly suspicious for an invasive cancer, demonstrating that the tumor clearly progressed during that eleven-month gap in treatment.

Ultimately, Dr. Stein determined that “Mr. [Harris’] illness would have had a high chance for survival at initial presentation if treated promptly, despite any challenges associated with his mental health condition.” Informing that conclusion, Dr. Stein determined the following:

1. LSH did not meet the standard of care by failing to diagnose and appropriately treat Mr. Harris’ lesion at its initial presentation.

[T]he development of Mr. [Harris’] cancer was not avoidable, but his extensive progression was potentially avoidable through earlier diagnosis, appropriate treatment at its initial presentation, and timely surgical intervention. In keeping with the above, the failure by LSH providers to diagnose through biopsy and appropriately treat Mr. [Harris’] cancer at earlier stages when it was likely still curable did not meet the standard of care.

2. LSH did not meet the standard of care by failing to ensure that Mr. Harris received a timely surgical referral.

[T]he failure by LSH to effectuate a surgical referral from 1/1/18 to 12/12/18 also contravened the standard of care. During this time the cancer progressed, causing disfigurement, escalating pain, and death

The actions of LSH are especially concerning in light of Mr. Harris’ personal circumstances at the time of his medical issues – throughout the relevant period, Mr. [Harris] was hospitalized in a locked psychiatric unit and under the care of LSH due to his disabilities.

3. LSH did not meet the standard of care by failing to obtain informed consent for Mr. Harris’ treatments from his legal guardian.

Records indicate that [Mr. Harris’] guardian was not advised of his early dermatological care, and generally fail to evidence that sufficient information was provided to his guardian to ensure that her consent on his behalf was informed. Failure to get informed consent from Mr. Harris’ guardian regarding his treatment – particularly about non-standard use of imiquimod on his lesion – would also be a breach of the standard of care.

LSH does not appear to dispute these expert findings, except that LSH contended that its providers had communications about treating the lesion with Mr. Harris’ legal guardian that were not reflected in the medical records.

Related to the broader context of disparate health outcomes for people with mental health disabilities, Dr. Stein also provided an expert opinion as to whether Mr. Harris’ disability impacted his access to care or the quality of care he received. She identified several points in his

cancer treatment when his disability impacted his access to care, such as his refusal to comply with the second immunotherapy IV treatment. One of these is notable for the clear interplay between his mental health disability and treatment decisions made by providers - the September 2019 decision by LSH and BMC to not provide Mr. Harris radiation treatment after his excision surgery.

After Mr. [Harris'] initial surgery, he likely would have been treated with radiation had he not been unlikely to tolerate such treatment. This was a reasonable decision based on the fact that it was felt that Mr. [Harris] would not be able to hold still to safely participate in the many radiation treatments he would need and the surgical margins on his tumor were narrow, but clear. Still, radiation has been shown to decrease the risk of recurrence of sebaceous carcinoma, and the lack of radiation may have ultimately impacted his prognosis.

V. **DLC'S PRELIMINARY INVESTIGATION FINDING OF NEGLIGENCE, RECOMMENDATIONS FOR CORRECTIVE ACTION, AND MEANINGFUL RESPONSES FROM LSH**

Based on our review of the records and the medical expert's findings, DLC made a preliminary finding that LSH's failure to provide Mr. Harris appropriate medical treatment constituted neglect³² that contributed to his untimely death. DLC conveyed these findings and recommendations for corrective action to DPH and DMH on March 11, 2022.

A. **DLC's March 11, 2022 Findings**

LSH had multiple opportunities to timely properly diagnose and treat the lesion that developed on Mr. Harris' face but failed to do so. Indeed, while he was living at LSH subject to an involuntary psychiatric commitment order, aside from brief hospitalizations at other facilities, Mr. Harris was available at any time for diagnosis, treatment, and follow-up care related to the cancerous growth that was plainly visible on his nose to all LSH staff. LSH dermatology failed to perform a biopsy of the lesion – a simple in-office procedure – at any of Mr. Harris' four appointments between May 25, 2017 and January 11, 2019, despite the lesion's changes in appearance and size. Rather, the LSH dermatologist gave Mr. Harris a topical cream FDA-approved to treat a superficial basal cell carcinoma as his sole treatment for more than two hundred thirty (230) days without a confirmed diagnosis or even any note explaining why the dermatologist believed it was a superficial subtype of basal cell carcinoma. At his January 11,

³² The applicable PAIMI regulations define neglect as "a negligent act or omission by an individual responsible for providing services in a facility rendering care or treatment which caused or may have caused injury or death to an individual with mental illness or which placed an individual with mental illness at risk of injury or death, and includes, but is not limited to, acts or omissions such as failure to: establish or carry out an appropriate individual program or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care; and the failure to provide a safe environment which also includes failure to maintain adequate numbers of appropriately trained staff." 42 C.F.R. § 51.2. The expert's determination of medical malpractice or other forms of negligence informs but is outside the scope of this investigation.

2019 visit with LSH dermatology, Mr. Harris was simply referred to surgery without confirmation of his diagnosis or further treatment prescribed. LSH's failure to diagnose through biopsy and provide appropriate treatment for Mr. Harris' cancer in its earlier stages when it was likely still curable did not comport with the medical standard of care and constituted neglect of an individual with significant mental health disabilities.

LSH inexplicably failed over the course of over eighteen (18) months, including a period of eleven (11) months without cancer treatment, to provide Mr. Harris with timely surgical referral or intervention. Despite LSH dermatology referring Mr. Harris to for an LSH surgical consult on January 11, 2019, Mr. Harris did not have a surgical consult until December 12, 2019. It bears repeating that Mr. Harris lived inside LSH and the state of the cancerous lesion on his face was visible to LSH staff on a daily basis throughout his commitment. As concluded by Dr. Stein, "the failure by LSH to effectuate a surgical referral from 1/1/18 to 12/12/18 also contravened the standard of care. During this time the cancer progressed, causing disfigurement, escalating pain, and death."

Despite an active guardianship order and circumstances indicating that Mr. Harris' ability to provide informed consent was compromised, LSH did not obtain informed consent from Mr. Harris' legal guardian regarding the treatment of his cancer. According to LSH records, Mr. Harris' guardian was not actively involved in the medical treatment of the lesion on his face for over twenty (20) months – until February 20, 2019. Aside from a single social work note dated June 8, 2017 that indicated Mr. Harris' guardian was "informed" of the initial dermatology assessment, there is no record elsewhere indicating her role in the early stages of treatment. Mr. Harris' guardian herself has no recollection of being informed of the diagnosis or treatment plan and reports that Mr. Harris' visit to BMC on February 20, 2019 for a biopsy was her first time participating in the treatment of his obviously worsening condition. Mr. Harris' guardian was otherwise very involved at all times with LSH staff in the treatment of Mr. Harris' mental health and other medical conditions. For instance, LSH records include an April 30, 2018 social services note stating, "This writer talks with his sister/guardian a couple times per week."

Given the severity of Mr. Harris' mental health disability and his presentation during appointments, it was particularly important that LSH involve his guardian in all aspects of his cancer treatment. From his first dermatology appointment, Mr. Harris was noted to be "sleepy" and provided "answers to the questions [that were] not at all clear." At his second appointment, Mr. Harris was "sleepy and [was] not at all responding to questions." At his third appointment, Mr. Harris was "rather sleepy," and he was "not responding to any questions" at his fourth appointment. Had Mr. Harris' guardian been properly informed of Mr. Harris' condition and treatment options, she would have been in a position to demand better dermatology care and follow up than he received.

Treatment decisions made regarding Mr. Harris' cancer treatment raise concerns about access to medical treatment for persons with mental health disabilities. DLC has longstanding concerns about inequities in access to medical treatment for people with serious mental health disabilities, which, as illustrated in this case, may contribute to denials of or delays in treatment or being offered different medical treatment options than peers without mental health disabilities. Based on our review, it does not appear that BMC or LSH considered the

possibility of sedating Mr. Harris or offering other options so that he could undergo radiation treatment after his surgery. Given the gravity of the consequences of a cancer reoccurrence for Mr. Harris, DLC would expect to see documentation that all treatment options were thoroughly considered, including a discussion with Mr. Harris' guardian, without being overly influenced by presumptions regarding Mr. Harris' ability to tolerate a certain type of treatment, and considerations of accommodations that could be made to provide him access to the most promising treatment options.

B. DLC's March 11, 2022 Recommendations for Corrective Action

Based on the above findings, DLC made seven (7) preliminary recommendations:

1. Provide additional education and training for LSH dermatology staff regarding treatment protocols for assessing skin lesions.

In keeping with DLC's expert findings, the LSH dermatologist failed to properly diagnose the lesion on Mr. Harris' face, to critically assess how the lesion responded to initial treatment, and to provide a timely biopsy or surgical consult referral. According to the American Academy of Dermatology Association (AADA), proper diagnosis and treatment of a skin lesion includes obtaining a full history of present illness, review of systems, past medical history, family history, medications, and environmental exposures. When a growth is present, key questions include how long the lesion has been present, whether it has changed, and, if so, how it has changed, and whether a patient has had any similar growths previously. There is no indication in the LSH dermatologist's records that Mr. Harris or his legal guardian were given the opportunity to provide the background information necessary for proper diagnosis and treatment. In addition, the AADA recommends performing a shave biopsy when basal cell carcinoma is suspected. The LSH dermatologist did not perform or recommend a biopsy during any of her encounters with Mr. Harris. When BMC finally performed a biopsy in February 2019, one year and nine months after Mr. Harris' initial dermatology appointment, it determined squamous cell carcinoma was a more likely diagnosis than basal cell carcinoma and included sebaceous carcinoma in its differential diagnosis.

2. Require LSH dermatology staff to photograph skin lesions for the medical record.

DLC recommended that LSH impose a requirement that dermatology staff take photographs of all patient skin lesions for inclusion in the patient's medical record. Based on our review of Mr. Harris' file, it appears that the LSH dermatologist did not take photographs of his lesion even though it was common practice to do so at the time he was under her care. Photographing a skin lesion at the time of biopsy is particularly critical for the purposes of identifying the site at a later date if further treatment becomes necessary.

3. Provide LSH patients with access to a board-certified dermatologist.

Dermatology patients at LSH would be best served by seeing a board-certified dermatologist.³³ Board-certified dermatologists have received 1,200 to 1,600 hours of supervised direct patient care. If LSH does not have access to a board-certified dermatologist, then it should use telemedicine to help triage cases. Tele-consults can be conducted with a board-certified dermatologist providing consultation to an on-site health care provider.

4. Perform a root cause analysis of Mr. Harris' case, and peer review of other dermatology cases.

LSH should engage an independent clinician to assess Mr. Harris' case, and a representative sample of recent dermatology cases of LSH patients, to identify systemic issues that may have contributed to the fatal outcome for Mr. Harris and recommend changes to improve quality of care and LSH patient safety.

5. Improve coordination of medical care for patients in the LSH Metro Boston Mental Health Units.

Better coordination of care and monitoring of LSH MBMHU patients' medical conditions is essential to prevent repetition of the circumstances that led to Mr. Harris' death. This includes promptly effectuating referrals within LSH and designating staff responsible for tracking patient appointments and follow-up care. In reviewing Mr. Harris' medical records, it was clear that a number of individual LSH MBMHU staff were concerned about Mr. Harris' lesion and repeatedly documented his referrals to dermatology for treatment. It was not clear, however, who was responsible for coordinating Mr. Harris' dermatology care and follow-up appointments. All MBMHU patients should have a designated staff member who is responsible for ensuring that timely medical appointments occur, informing guardians, and documenting these activities in the medical record.

6. Improve protocols and provide training for LSH staff on communicating with legal guardians and obtaining informed consent.

Mr. Harris' guardian was very involved in all aspects of his care, yet she has no recollection of being informed by LSH of his 2017 dermatology appointments that proved critical to his misdiagnosis and delayed treatment. LSH should review its

³³ The AMA Journal of Ethics notes:

The effectiveness of physician certification has been shown to be closely related to other measures of physician competence. Board examination results have demonstrated a correlation with medical school education, the amount of formal training, and supervisor assessment of clinical skills. A positive relationship also exists between recertification performance and the number of patients seen, as well as the complexity of patient problems reported in practice. Finally, there is evidence that better clinical outcomes are associated with board certification and continued maintenance.

Joseph Lowry, MD, "Board Certification as Prerequisite for Hospital Staff Privileges," AMA JOURNAL OF ETHICS, (April 2005) (citations omitted).

protocols regarding notifying guardians of diagnosis and treatment options and make improvements in its system of communication with guardians.

- 7. Adopt policies and safeguards to ensure that individuals with mental health disabilities are not denied the full range of appropriate medical care due to their disability or any behaviors or manifestations of their disability.**

C. Response from LSH

LSH responded to DLC’s preliminary findings and recommendations on March 31, 2022, with the Interim Chief Quality Officer stating that LSH was reviewing the report and “referred the case to the Hospital’s Medical Staff for review of the provider’s care in accordance with the Hospital’s Medical Staff Bylaws.” In addition, LSH was “also examining the case for any hospital system issues that may have contributed to the reported delay in treatment and breakdown in communication.” The Interim Chief Executive Officer followed up with a substantive response on June 1, 2022, which stated that “LSH undertook a comprehensive review of [Mr. Harris’] care,” including chart review, independent external peer review by a dermatologist, internal medical staff case review, and a root cause analysis. Based on its own review and that of DLC, LSH “concur[ed] with the clinical concerns” identified by DLC’s expert and implemented a number of corrective actions. Specifically, LSH concluded the following regarding Mr. Harris’ treatment:

- (a) there had been a delay by the dermatologist in performing a lesion biopsy that resulted in a missed opportunity to obtain a diagnosis; (b) there was inconsistent and poorly documented communication between the primary care team, specialists, and the patient’s representative; and (c) notwithstanding the fact that the surgical consult was not completed in a timely manner, the patient’s primary care team did refer the case for the surgical consult in a timely manner.

In keeping with DLC’s recommendation, LSH conducted a root cause analysis “to investigate and understand the causes, causal factors, and systemic issues in this case.” Findings included:

- The primary care team’s lack of awareness and appreciation regarding the urgency of the clinical situation due to the lack of a final diagnosis. This was found to be a contributing factor in the lack of adequate follow up in obtaining surgical consultation.
- Despite the fact that the patient’s guardian actively participated in treatment team meetings, was aware of the lesion being treated and attended some of the patient’s appointments, there was no medical record documentation to reflect that the guardian had been informed of the patient’s dermatological consult, the consult findings, or the patient’s treatment plan. The absence of such documentation was determined to be the result of the team’s lack of understanding and awareness of the serious nature of the patient’s clinical condition. See previous note above.
- Lesions and other wounds are best described through photographs to enable caregivers to identify changes in their appearance. Because no photograph of

the lesion had been taken at the time of the patient's initial dermatological consult nor taken subsequently, clinicians responsible for the ongoing assessment of the lesion had no clear frame of reference of the lesion's progression.

- The procedure for specialty consultations was identified as a potential root cause for the delay in obtaining the surgical consult. The hospital's policy/procedure did not clearly define the actions to be taken when expected timeframes for consultative response weren't met, nor did it provide a process for escalation to medical leaders in the event of delays. The hospital's requirement that its providers re-enter consultation appointment orders when there is a need to reschedule them was also identified as a potential contributor to delays in obtaining timely consults.
- The delay in obtaining a surgical consultation was unrelated to any bias or discrimination based on the patient's disability. Both medical and psychiatric providers and their staff provided the patient care based solely on his clinical condition and needs. While the patient did present behavioral challenges, they were appropriately managed by the clinical team, which includes both medical and behavioral health providers, with input from the patient's guardian.

Further, LSH laudably implemented a corrective action plan with the following four (4) components:

Specialty consultations: LSH revised its hospital-wide policy and procedure for specialty consultations. Areas for improvement included "development of clear actions to be taken when expected timeframes aren't met including an escalation process for delays, and consultative appointment management for automatic rescheduling when appointments are cancelled."

Photographic documentation of all lesions and wounds: LSH committed to "standardizing the use of photographic documentation in the assessment and treatment of all lesions and wound care, as well as for documenting any significant changes observed during the course of treatment."

Communication: LSH is committed to "developing patient safety 'best practices' designed to improve communication and quality of care. These include implementation of a "Warm Handoff" and unit "Safety Huddles" policy. The term "Warm Handoff" refers to direct clinical communication, including providing information through direct clinical communication with patients and their authorized representatives when communicating findings from consultations to promote consistent and timely communication between medical providers, consultants, and the patient's primary care team." LSH implemented a written process for "warm handoff," educated medical staff on the process, and started the practice on May 1, 2022. Unit "Safety Huddle" means "a safety discussion at the unit level to identify patient safety risks or concerns so they can be managed more effectively." LSH began piloting "Safety Huddles" on May 1, 2022 and anticipated including all patient care units by mid-August 2022.

Dermatological practice: LSH agreed to require biopsies “on all conditions identified as ‘lesion,’ ‘growth,’ [and] ‘suspicion of skin malignancy’ prior to treatment initiation. Cases with complex presentation will be referred to surgery for biopsy or excision. The expectation for care is that patients will have follow up within 4-6 weeks.” LSH also committed to “monthly case review of all biopsy referrals and/or unresolved clinical cases to include an external review of a representative sample of cases.”

LSH noted that the changes above will benefit all patients receiving care at the hospital. DLC agrees that the changes are impactful.

D. DLC’s Response and LSH’s Additional Response

DLC wrote to LSH on July 27, 2022 to follow up on the implementation of LSH’s corrective action plan and certain recommendations from our initial report. Specifically, DLC requested responses to our recommendations that LSH provide education and training to dermatology staff; access to a board-certified dermatologist; and safeguards to ensure that individuals with mental health disabilities are not being denied the full range of appropriate medical care due to their disability.

LSH responded substantively on September 7, 2022. The Chief Executive Officer reported that the LSH dermatologist registered for a “four-day dermatological educational program” later that month; the hospital changed its policy and procedure related to consultations; and the hospital sent select dermatology records for external review by a board-certified dermatologist. In addition, LSH reported it “has been recruiting for a board-certified dermatologist” and has a collaborative relationship with area teaching and academic hospitals that can provide specialty referrals when necessary. Regarding potential bias or discrimination, the LSH determined the delay in treatment “was related to hospital processes and was not related to any bias or discrimination.” Specifically, the “problem identified was a lack of effective communication between the consultant and the primary team.” LSH again noted its revised policies on medical consultation and photographing of lesions. At the time of its response, LSH was reviewing the results of the external dermatology peer review.

VI. DLC’S FINAL RECOMMENDATIONS WITHIN THE BROADER CONTEXT OF SYSTEMIC DEFICIENCIES IN ACCESS TO CARE FOR INDIVIDUALS WITH MENTAL HEALTH DISABILITIES

DLC has made an undisputed finding that Mr. Harris endured neglect at LSH while committed to the Metro Boston Mental Health Units. While LSH was very responsive to the issues DLC raised in its preliminary findings and took prompt action to remedy a number of issues that contributed to Mr. Harris’ death, the lack of timely care and treatment Mr. Harris received raises questions about the overall quality of care for patients at LSH confined to the MBMHU and provides an extreme example of what can go wrong when an individual with significant mental health disabilities experiences a co-occurring life-threatening medical condition.

With all of this in mind, DLC makes the following final recommendations in the interests of preventing further suffering and improving the overall quality of care for people who receive services at LSH and in other health care environments throughout the Commonwealth.

1. Health care providers and state agencies must acknowledge and target interventions to address the disparities in medical care for people with significant mental health disabilities and provide accommodations to ensure equitable access to care.

“Leaders in mental health treatment emphasize the importance of designating patients with severe mental illness as a vulnerable population.”³⁴ In the face of decades of studies establishing poorer health outcomes and diminished life expectancy, at least in part, attributable to discrimination, exclusion, widespread stigma, and criminalization of individuals with mental health disabilities, providers and Commonwealth agencies should enhance the time and attention spent on addressing the population’s medical needs and barriers to receiving equitable medical care. While the Massachusetts Health Policy Commission does recognize ableism, along with racism, sexism, homophobia, transphobia, and xenophobia, as a social determinant of health, it solely identifies racism as having a direct and harmful impact on health.³⁵ The Executive Office of Health and Human Services’ devotion of resources to its Roadmap for Behavioral Health Reform, which emphasizes integrating crisis care with Community Behavioral Health Centers and primary care practice, has great potential to enhance access to outpatient mental health services and behavioral health equity to account for the diverse community of people with mental health disabilities.³⁶ It does not, however, sufficiently tackle the need for an integrated approach to handling medical issues for people with significant mental health disabilities.³⁷ Of course, as with all measures to address health disparities, there must be a continuing focus on addressing structural racism in the health care system and intersectional discrimination.

2. Given the population it serves, LSH must investigate all patient deaths whenever circumstances suggest the cause of death was treatable or preventable.

LSH did not conduct any review of Mr. Harris’ death prior to being presented with preliminary findings by DLC, even though the records indicated serious deficiencies in the care Mr. Harris received for his cancer and that members of LSH staff conveyed concerns about said care. Basic questions should have been asked immediately, such as: How did the lesion on Mr. Harris’ face develop and fail to improve for such a long time

³⁴ Irwin at 323; see Matthew L. Goldman, M.D, et al., *The Case for Severe Mental Illness as a Disparities Category*, PSYCHIATR. SERV. (2018); 69(6):726-728, doi:10.1176/appi.ps.201700138.

³⁵ *Health Equity*, MASSACHUSETTS HEALTH POLICY COMMISSION, <https://www.mass.gov/info-details/health-equity#racism-directly-affects-health-outcomes->.

³⁶ See, e.g., *Roadmap for Behavioral Health Reform: FAQs*, EOHHS, [https://www.mass.gov/info-details/roadmap-for-behavioral-health-reform-faqs#community-behavioral-health-centers-\(cbhcs\)-](https://www.mass.gov/info-details/roadmap-for-behavioral-health-reform-faqs#community-behavioral-health-centers-(cbhcs)-)

³⁷ See., e.g., Irwin at 323 (“Without increased awareness and targeted intervention, cancer disparities in individuals with schizophrenia will likely worsen over time.”); see Matthew L. Goldman, M.D, et al., *The Case for Severe Mental Illness as a Disparities Category*, PSYCHIATR. SERV. (2018); 69(6):726-728, doi:10.1176/appi.ps.201700138.

while he was under daily care at LSH? Why did it take so long for Mr. Harris to have an in-house LSH surgical consult? Who among the many health care providers treating Mr. Harris was responsible for coordinating his appointments? And why wasn't his guardian kept informed about every step of this process? While DLC sincerely appreciates LSH's responsiveness to our P&A investigation, had DLC not received a complaint to the system about Mr. Harris' death, none of the issues in this report would have been addressed. LSH needs internal mechanisms to address individual and systemic failures impacting patient care, whether through review by an internal committee or external consultant, or both, as in this case. This is all the more essential given the vulnerable patient population that LSH is entrusted to serve.

3. The Commonwealth's public hospitals must provide patients access to board-certified specialists when making a specialty referral.

DLC reaffirms that LSH patients, particularly those who may have difficulty advocating for their own interests, must be provided the highest quality of care by qualified professionals. Those who are inpatient at LSH and individuals who receive outpatient care at LSH, including a large number of incarcerated persons, are generally not in a position to question their providers or get second opinions, making it beholden on the Commonwealth to ensure LSH health professionals provide exemplary care. One reliable way of doing so is to require that specialists are board certified.

For over eighteen (18) months after Mr. Harris was diagnosed with skin cancer, he was provided access only to a physician who was not board certified in dermatology. For roughly eight (8) of those months, he had repeated consults but no definitive diagnosis because no biopsy was performed, and he was treated with a medication that was approved only for a certain type of basal cell carcinoma, which he did not have. Then, when the physician made a surgical referral, it was without the sense of urgency one would expect when dealing with any cancer diagnosis, let alone the aggressive form of cancer that Mr. Harris had, which remained unclear due to the lack of a definitive diagnosis. He received no follow up care for eleven (11) months while he waited for a surgical consultation and his cancerous lesion continued to grow.

While LSH has reported attempting to hire a board-certified dermatologist, it does not appear that LSH was successful. LSH may need to allocate additional resources to hiring a board-certified dermatologist, and other board-certified physicians, or promptly refer all patients requiring specialty care to the area teaching and academic hospitals. All of the Commonwealth's public hospitals should follow this approach. LSH's response that it will provide such referrals "when necessary" still leaves room for uncertainty in cases such as Mr. Harris's, which at first appeared uncomplicated but required prompt attention and a precise course of treatment.

4. Establish a clear protocol and point person for communicating with legal guardians regarding patient care and treatment to ensure that LSH patients receive care only with informed consent.

Despite the fact that Mr. Harris was largely noncommunicative at the time of his first dermatology treatment, his guardian was not present at this appointment or any subsequent dermatology appointment for over eighteen (18) months. There is a single note in Mr. Harris' medical record stating that his guardian was informed two weeks after the first appointment and did not "voice disagreement" with the diagnosis and topical treatment. As previously noted, the guardian was not in a position to form an opinion as she did not have the opportunity to attend the appointment and provide informed consent. LSH's response to DLC's preliminary finding implies that hospital staff made additional communications regarding Mr. Harris' treatment with his guardian, but these communications were not documented in the record. The circumstances of this case, where Mr. Harris' guardian was a regular visitor to the hospital, suggest that there was a serious breakdown in communicating important medical decisions and treatment options, and in providing her with the opportunity to be present at appointments where she could provide informed consent to treatment and important input regarding information such as family and patient health history. DLC acknowledges that LSH's communication with his guardian improved after the severity of his illness came to light in 2019, but the damage had already been done in more ways than one.

5. Re-examine whether systemic bias against people with mental health disabilities and/or people of color may have played a role in Mr. Harris' untimely death.

DLC included in its preliminary recommendations that LSH adopt policies and safeguards to ensure that individuals with mental health disabilities are not denied the full range of appropriate medical care due to their disability or any behaviors or manifestations of their disability. LSH has repeatedly asserted that any delay in Mr. Harris' treatment "was related to hospital processes and was not related to any bias or discrimination." DLC readily acknowledges that LSH serves a high proportion of patients with disabilities and that its staff is very diverse. However, based on its cursory responses, it does not appear that LSH has fully reflected on the circumstances of Mr. Harris' death and asked the difficult questions of whether providers may have made different treatment decisions, and whether Mr. Harris might have had a different health outcome, if he were not a Black man and if he did not, at times, exhibit very challenging behaviors related to his mental health disability.

Appendix A: Chronology of Cancer-Related Care

To provide further context for both DLC's and the expert's opinions, DLC provides the following chronology of the cancer-related medical care that Mr. Harris received taken from his medical record entries:³⁸

- **May 25, 2017:** Mr. Harris had his first dermatology appointment at LSH with Dr. Shahla Asvadi to evaluate a lesion on the left side of his nose. According to the consult note on that date, Mr. Harris had an erythematous (red) lesion measuring six (6) millimeters on the left side of his nose with central erythema (redness) and peripheral hyperpigmentation.
 - Dr. Asvadi determined that the lesion was “most consistent with basal cell carcinoma” and recommended that he apply a topical imiquimod (Aldara) cream daily five (5) times per week for six (6) weeks and follow up in two (2) months.
 - Dr. Asvadi did not perform a biopsy to confirm her diagnosis.
 - Dr. Asvadi noted that Mr. Harris appeared “to be sleepy and his answers to the questions [were] not at all clear.” The note does not indicate whether Mr. Harris’ guardian (his sister) was informed or consulted about the appointment or treatment plan.
- **June 8, 2017:** Two (2) weeks after the appointment, an LSH social services note states that the social worker contacted Mr. Harris’ sister “and informed her of the diagnosis and topical treatment that had been recommended. She did not voice disagreement.”³⁹
- **August 3, 2017:** Mr. Harris had a follow-up appointment with Dr. Asvadi at LSH. The dermatologist noted a reduction in size of the lesion to three (3) millimeters after ten (10) weeks of imiquimod cream and recommended six (6) more weeks of a topical treatment with a follow-up appointment in two months.
 - Dr. Asvadi did not perform a biopsy.
 - Notes state that Mr. Harris appeared “sleepy and [was] not at all responding to questions.” There is no record indicating that his guardian was informed or consulted regarding treatment.
- **October 10, 2017:** Mr. Harris returned to LSH dermatology to see Dr. Asvadi, who noted that there had been flattening of the lesion, but the base still persisted. Dr. Asvadi recommended six (6) additional weeks of imiquimod cream with a follow-up appointment in two (2) months.

³⁸ Mr. Harris’ sister, who is currently the executor of his estate, supports release of this information.

³⁹ Mr. Harris’ sister has no recollection of being informed of the diagnosis or treatment plan. Regardless, her “not voicing disagreement” does not meet the standard of informed consent to Mr. Harris’ treatment. As his legal guardian, she attended Mr. Harris’ medical appointments in person with him whenever possible and does not believe she was invited to any of his LSH dermatology appointments.

- Dr. Asvadi did not perform a biopsy.
- Note state that Mr. Harris appeared “rather sleepy” again and did not answer questions. There is no record indicating that Mr. Harris’ guardian was informed or consulted regarding his treatment.
- **January 11, 2018:** Mr. Harris had an appointment with Dr. Asvadi, who noted that the lesion has not changed, describing it as nodular and bleeding occasionally. Dr. Asvadi referred him to surgery for treatment of “this basal cell carcinoma.”
 - Dr. Asvadi did not perform a biopsy.
 - Notes described Mr. Harris as “not responding to any questions.” There is no record indicating that his guardian was informed or consulted regarding treatment or the surgical referral.
- **January 12, 2018 through December 11, 2018: Despite the surgical referral, Mr. Harris did not receive any additional treatment for the cancerous lesion on his nose, aside from wound care from the MBMHU staff.**
 - There are no explanations in Mr. Harris’ medical records regarding the delay in scheduling his surgical referral and minimal records concerning day-to-day management of the lesion.
- **April 20, 2018:** Mr. Harris had his annual physical exam. Notes from the exam pointed out that he had “failed 2 rounds of treatment with topical Aldara, surgery consult pending for excision.”
- **December 12, 2018:** Eleven (11) months after his referral, Mr. Harris had an LSH surgical consultation with Dr. James Petros. Notes described the lesion as a two (2) centimeter by one (1) centimeter – now measuring twenty (20) by ten (10) in millimeters – ulcerated soft tissue mass on his nose that bled and is noted to bleed when palpated (examined by touch) and appeared to be fixed to the underlying nasal cartilage. Dr. Petros’ note recommended referral to BMC for excision of the mass on his nose with clean margins and possible flap closure.
 - There was no biopsy performed at this appointment.
- **February 20, 2019:** Mr. Harris and his guardian attended an appointment with BMC dermatology during which doctors performed a biopsy that showed carcinoma with clear changes and was positive for an epithelial membrane antigen (EMA) stain.
 - The biopsy determined that squamous carcinoma was a more likely diagnosis than basal cell carcinoma and also included sebaceous carcinoma in its differential diagnosis.
- **May 8, 2019:** Mr. Harris had a medical consultation with otorhinolaryngology, or Ear Nose and Throat (ENT) at BMC. ENT ordered a full oncological workup with imaging.

- Nearly two (2) years after his first dermatology consultation, Mr. Harris got a final pathological diagnosis of an infiltrating carcinoma, either sebaceous carcinoma or squamous cell carcinoma.
- This appointment was originally scheduled after the February 20, 2019 appointment for March 5, 2019, but had to be rescheduled because Mr. Harris was hospitalized for unrelated medical issues at the time.
- **July 12, 2019:** LSH ENT saw Mr. Harris and recommended excision of the cancer with simple reconstruction.
 - Mr. Harris had refused to attend a previously scheduled ENT appointment at BMC on June 3, 2019.
- **July 31, 2019:** Mr. Harris had a “consult at BMC to discuss surgical options with client and sister.”
- **August 29, 2019:** BMC performed a left rhinectomy (partial surgical removal of the left side of his nose) with a simple reconstruction. BMC had to contact Mr. Harris’ guardian in order to approve a different, more aggressive surgery to remove the cancerous mass. The BMC surgeon reported obtaining a clean margin around the mass.
 - The procedure showed a large poorly differentiated invasive sebaceous carcinoma that had grown significantly to involve the full width of the cartilage of his nose.
 - Because of the extent of the tumor, the wound could not be completely closed.
- **September 9, 2019:** Mr. Harris had a follow up appointment at BMC, noting that the wound appeared to be healing well with no signs of infection.
- **September 17, 2019:** After discussion between LSH and BMC ENT oncology about whether to treat Mr. Harris with radiation, which would require five (5) treatments per week lasting two (2) hours each for about five (5) weeks, the BMC head and neck tumor board discussed Mr. Harris’ case on October 2, 2019.
 - Doctors presumed that Mr. Harris would not be able to tolerate lying still in a mask during radiation treatments due to his mental health disability.
 - LSH and BMC recommend, since the margins were negative (though close) and the area could be easily observed for any recurrent growth, observation over radiation treatment.
 - Mr. Harris’ legal guardian was informed and agreed with this course of action based on the information provided.
- **May 8, 2020:** LSH records note a raised area on Mr. Harris’ cheek next to the surgical site. LSH treated it as an abscess with warm compresses.
- **May 19, 2020:** After developing swelling around his left eye, Mr. Harris had a CT scan that revealed recurrent disease in his lymph node and in the parotid gland.

- **May 20, 2020:** Mr. Harris was transferred to the Mass Eye and Ear Emergency Department because of concerns of orbital cellulitis.
 - Mr. Harris was transferred to Massachusetts General Hospital for further treatment. Biopsies performed at Massachusetts General Hospital confirmed the presence of cancer.
- **June 24, 2020:** After another discussion by the BMC tumor board, Mr. Harris went to BMC oncology for treatment with IV pembrolizumab immunotherapy, with plans for further treatment every six (6) weeks.
 - At the visit, he was heavily sedated and slept through almost the entire visit.
- **July 17, 2020:** LSH records note Mr. Harris was complaining of pain and his facial swelling is noted to be increasing. He was given morphine by LSH staff. His treatment team also discussed concerns regarding Mr. Harris's pain and cancer treatment, noting that the left side of his face appeared more red, swollen and painful. The Attending psychiatrist planned to bring these concerns to medical staff to review.
- **July 28, 2020:** A CT scan showed the cancer had progressed into his sinus, eye, and neck. LSH records indicate that Mr. Harris' condition continued to worsen, and he exhibited difficulty swallowing.
 - Notes state that his overall prognosis appeared poor and that the immediate goal of his treatment and his code status (i.e., the type of resuscitation procedures to be followed if his heart stopped beating or breathing stopped) needed to be clarified.
- **August 5, 2020:** Mr. Harris went to BMC oncology for his second immunotherapy treatment. Despite receiving the same dose of sedative, he was awake and would not comply with the IV treatment.
 - Records indicate that the tumor had visibly grown in the six (6) weeks since his last treatment.
 - BMC consulted with LSH staff and decided that although further treatment with pembrolizumab could theoretically improve the tumor over time, the likelihood was low, and further treatment was not likely to be successful due to Mr. Harris' presentation that day.
- **August 6, 2020:** Mr. Harris' LSH treatment team met and noted his decline. Mr. Harris had increased masses and weakness, morphine was increased to treat his pain, and he needed wound care to try to manage the open area on his face that continued to bleed.
- **August 10, 2020:** Mr. Harris was transferred to the Intensive Care Unit at LSH and a consult was placed for palliative care.

August 22, 2020: Mr. Harris was pronounced dead at 4:21a.m. at 60 years old. Records noted that, on the date of his death, Mr. Harris was responsive to his name, experiencing "increase groaning and rapid breathing" for which he was provided additional morphine as pain management, and suffering "increased secretions draining from the right side of his mouth."