Developing a Disease-Site Specific Oncology Patient Navigation Program
The National Cancer Institute (NCI) estimated that in 2020, approximately 1,806,590 new cases of cancer would be diagnosed in the United States and 606,520 people would die from the disease, with the most common types of cancer being breast, lung and bronchus, prostate, and colorectal. Based on 2015-2017 data, NCI estimated that almost 40% of men and women will be diagnosed with cancer in their lifetimes. Estimated national expenditures for cancer care in the US in 2018 were $150.8 billion, with costs likely to increase as the population ages, more people are diagnosed with cancer, and new, potentially more expensive, treatments become the standard of care.

Based on these data, St. Elizabeth Healthcare in Edgewood, Kentucky, took a firm stance on improving outcomes for patients with cancer. In April 2020, amidst a looming global pandemic with unanticipated downstream financial health care consequences, a disease-site specific oncology patient navigation program started to take shape. Based on the recognition that patients diagnosed with cancer need support, resources, and treatment, this community-based cancer program started laying the foundation for an oncology navigation program that would grow exponentially over the next 2 years.

St Elizabeth Cancer Center At-a-Glance
The cancer program at St. Elizabeth Healthcare is a hub and spoke model, comprised of the main cancer center in Edgewood, Kentucky, 2 additional sites in Northern Kentucky (Grant County and Fort Thomas), and 1 location in Southern Indiana (Dearborn County). In October 2020, a new 250,000-square-foot cancer center opened in Edgewood. This spacious building includes a plethora of resources for patients, caregivers, and staff, including an integrative oncology space with a demonstration kitchen, art therapy room, music therapy and group rooms, massage, acupuncture, on-site counseling services through Cancer Family Care, support groups with on-site assistance from Cancer Support Community, and many other services. Shortly after the building opened, Douglas Flora, MD, LSSBB, executive medical director, Oncology Services, shared, “The oncology nurse navigators are the glue that holds this building together.” These high expectations helped to catapult the oncology patient navigation program forward.

The Oncology Patient Navigation Program
Although oncology nurse navigators had previously existed at St. Elizabeth Cancer Care, the role was unclear to both patients and staff. Many of the nurse navigators felt as though they were the “junk drawer” of oncology—if an issue could not be “fixed,” it was sent to the navigator. The oncology nurse navigators were not disease-site specific, but instead associated with providers, most of whom treated all types of cancer, as well as benign hematologic diagnoses. There was no specialization and oncology nurse navigators did not spend enough time on direct patient care. Specifically, St. Elizabeth senior leadership recognized these areas of improvement:

- Job descriptions for oncology nurse navigators lacked utilization of core competencies and national guidelines.
- Oncology nurse navigator orientation needed to be structured, clearly tailored to the unique aspects of the role.
- Oncology nurse navigators performed many clerical functions; they were not working to the top of their license.
- There were no metrics to report on navigation impact or caseloads.
2 full time thoracic oncology nurse navigators and these short-term program goals:

1. Utilize technology as a means of oncology nurse navigator documentation and communication with other members of the care team and patients.

2. Develop care coordination processes for patients in collaboration with other departments and disciplines, especially during transitions from one treatment modality to the next, from active treatment to maintenance, and into surveillance and survivorship.

3. Establish 2 to 3 navigation metrics to:
   - Develop discrete data fields to measure
   - Determine baseline measurements
   - Implement strategies to improve metrics

Goal 1. Technology: Innovation Without Expense

Funds were budgeted to support the oncology navigation program’s technology needs, including navigation specific software for documentation and metrics tracking. During the planning phase in early 2020, multiple software companies were vetted to determine how to track and measure navigation specific metrics. Although many of these platforms offered desirable capabilities, the team always came back to putting patients first by allowing oncology nurse navigators to spend more time with patients and less time documenting.

Accordingly, senior leadership looked to create an oncology navigation program tailored to the needs of the patients, improving the patient experience and patient outcomes, while also demonstrating sustainability through a proven return on investment.

As a first step, multiple role delineation meetings were held to determine what oncology nurses in the various clinics and roles were currently doing and what these nurses wanted to do. These meetings also helped to begin process mapping, with everyone collaborating to understand current patient pathways and brainstorm ways to make these pathways more efficient. In addition to these meetings, the oncology navigation manager met regularly with a cancer survivor and active member of the Cancer Patient Family Advisory Committee to discuss program planning through the lens of a patient and their family.

The team understood the importance of establishing a physician champion, someone who would help drive necessary practice change that would inherently come with the inception of this new program. With Kentucky’s high lung cancer incidence and mortality rates, St. Elizabeth Healthcare had already developed a robust lung cancer screening program, so the team quickly determined to first roll out thoracic oncology navigation. Based on this decision, the team selected the thoracic surgeon who was most heavily involved in the lung cancer screening program, including the nodule review board, as the physician champion. This physician participated in multiple meetings to explore and identify resources needed from a provider’s perspective. Soon after, a medical oncologist specializing in lung cancer joined the St. Elizabeth Cancer Care team and became an important partner with the navigation program, offering additional physician perspective.

In October 2020, shortly before the new cancer center opened its doors, the oncology navigation program officially launched with

Although many of these platforms offered desirable capabilities, the team always came back to putting patients first by allowing oncology nurse navigators to spend more time with patients and less time documenting.
years, through this partnership, the oncology navigation program has been able to:

- Measure and fine-tune multiple navigation metrics
- Maintain adequate counts of caseload per navigator and per disease-site
- Improve documentation efficiency to maximize oncology nurse navigator time spent directly with patients

The oncology navigation program uses navigation episodes that allow all members of the navigation team to share tasks, as necessary. These episodes follow the patient throughout their trajectory of care. The team uses a standardized flowsheet with discrete data fields to mark patients as active versus inactive, track diagnosis and treatment start dates, and track assessment of barriers to care and interventions initiated. The navigation team also tracks time spent navigating each patient, both per encounter and a cumulative count of total minutes. This metric allows the navigation manager to track how much time the team spends doing different types of tasks. Because of these discrete data fields, the team was able to create an oncology navigation dashboard populated with relevant reports that can be refreshed throughout the workday, outlining the exact tasks each oncology nurse navigator has to follow-up on, and providing a visual of various metrics at a glance.

Putting these barriers aside, after 6 months of thoracic oncology nurse navigation, the time from diagnosis to treatment for lung cancer patients in the navigation program was 24 days compared to 2020 registry data of 31 days.

Goal 2. Care Coordination: Moving Away From “The Way We’ve Always Done It”

Adding another person dedicated to assisting patients and their families throughout the care continuum sounded like it would be simple. Yet securing people as resources can be challenging and embedding these individuals into already established processes and clinics proved to be a more daunting task. “This is the way we have always done it” was being played on repeat. Change is hard, and it was clear that implementing the oncology navigation program would be no different. It was important for the navigation leadership team to utilize the background of tenured oncology nurses in program implementation, as their experience was of great value. To leverage this expertise, the team held regularly scheduled focus groups to introduce the oncology navigation program, discuss goals, and work as a team to outline current processes while proposing ways to make improvements.

St. Elizabeth Cancer Care is fortunate to have many resources for patients, including financial counselors, disease-site specific social workers, dietitians, and many others. Creating a collaborative environment with these support services was essential, and these care team members were also included in the focus groups during the planning phase.

As mentioned previously, provider buy-in was integral. The physician champion identified early on was instrumental in initial planning, participating in the interviews for the first oncology nurse navigators. As the role of the oncology nurse navigator became more clear, multiple physicians became champions for the navigators and the program.

Finally, it was important to incorporate national standards and guidelines, including the Oncology Nursing Society (ONS) Core Competencies for Oncology Nurse Navigators and information around building a navigation program from the Academy of Oncology Nurse and Patient Navigators (AONN+). These resources were folded into the structured orientation and job descriptions developed for oncology nurse navigators.


In a 2018 article discussing standardized oncology navigation metrics, the authors discuss the timeline of navigation coming to the forefront of cancer care. Not all cancer centers implemented navigation programs at the same time. Further, “navigation programs are diverse, and the lack of standardized metrics to evaluate the impact of navigation on patient quality outcomes has made it difficult to measure programmatic success.” In its 2013 publication, Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, the Institute of Medicine wrote that “cancer treatment in the United States lacks in consistent quality and is neither patient-centric nor well-coordinated.” At that time, many cancer centers were still trying to determine how they would tackle this opportunity for improvement.

At St. Elizabeth, the team carefully planned how to measure successful implementation and growth of the oncology navigation program over time. Understanding it would be too large a task to track all
35 AONN+ standardized metrics, the team decided to initially track 2 metrics:
1. Time from diagnosis to treatment (measured by the number of days from the day pathology signs off on biopsy result to the start of treatment: surgery, radiation, and/or chemotherapy treatment).
2. Emergency department (ED) utilization (measured by the number of navigated patient visits to the ED per month).

The measurement of time from diagnosis to treatment was easy to obtain for navigated patients because the team built discrete fields into their EHR documentation to mark the date the pathology was signed off (date of diagnosis) and the date the patient started treatment, including surgery, radiation, or systemic treatment (chemotherapy, immunotherapy, etc.). The challenge came when trying to compare these new data for navigated patients to previous data for non-navigated patients, as the system did not have discrete fields outside of the navigators’ flowsheets to capture the same measurement points. The team used historical data from the Cancer Registry; however, the measurement of the “date of diagnosis” is not as well-defined within this data set. Putting these barriers aside, after 6 months of thoracic oncology nurse navigation, the time from diagnosis to treatment for lung cancer patients in the navigation program was 24 days compared to 2020 registry data of 31 days.

Measurement of ED utilization proved difficult, and the team was not able to track this metric during initial implementation of oncology navigation services. Patient admissions and ED utilization continue to be metrics the team tracks without extensive manual chart diving. This improvement opportunity is explored later in the article.

As the thoracic oncology nurse navigation program began, the technology created prior to go-live assisted the team in tracking additional metrics not initially planned for, including the number of referrals to the oncology navigation program over time. During the first 6 months of the program, growth was rapid. In the first 3 months, there was an average of 33 referrals per month, which increased to an average of 59 referrals per month in the following 3 months. Early tracking of these metrics helped make the business case for both additional oncology nurse navigators and expansion to other disease sites.

**Sustainability**

While research suggested the necessity of implementing navigation programs for cancer centers and oncology practices, would the model be sustainable? At many facilities, navigation programs were non-revenue generating services, and this was also the case at St. Elizabeth. How then, during a global pandemic and an economic downturn that significantly impacted health care and overall hospital staffing, could this type of program be maintained?

This question spoke to the necessity of using metrics to show the value of the oncology navigation program on patient experience, patient outcomes, and return on investment. In her book, *Oncology Nurse Navigation: Transitioning into the Field*, Lillie Shockney, MAS, writes that “in today’s health care landscape, it is essential for

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**Figure 1. Active Patients Per Month, Per Oncology Nurse Navigator (Average)**

![Graph showing active patients per month per oncology nurse navigator (average)](image-url)
a specific patient population based on diagnosis. Additionally, some programs only navigate patients during their initial diagnosis and work-up while others follow the patient through the entire continuum of care, from diagnosis through survivorship or end-of-life. There is no “right way” to establish a patient navigation program, but this variation certainly makes it difficult to establish standardized patient-to-navigator ratios.¹

Finally, not all patients are created equal. This statement may seem obvious, but it is more complicated the deeper one digs. For instance, there is a large difference in the basic care coordination needs of a patient with lung cancer versus a patient with tonsil cancer. Furthermore, a patient with stage I lung cancer likely has very different clinical needs than a patient with stage IV lung cancer. Clearly, diagnosis and staging create a large difference in the time and effort required of the navigator to properly manage patients’ care. Also, patient A with stage I lung cancer may have a great support system, no issues with transportation, no financial struggles related to their health care, and not facing other issues such as food insecurity; patient A may only need the navigator to do initial education, reeducation, and verification of ongoing monitoring and surveillance. Meanwhile, patient B with stage I lung cancer is homeless, does not have reliable transportation or a reliable method of communication with the care team, does not have social support, and is worried about their ability to pay for treatment. Patient B has a much higher acuity, although patient B has the same diagnosis and stage as patient A.

Navigation Caseloads
In the literature, it is difficult to find an answer to the question: How many patients should 1 oncology nurse navigator manage and/or follow? This uncertainty is partially due to many factors, including that fact that not all navigation programs are created equal and that only some are disease-site specific, where each navigator is assigned

Figure 2. Referrals to Oncology Nurse Navigation

<table>
<thead>
<tr>
<th>Month</th>
<th>Number of Patients</th>
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<tbody>
<tr>
<td>Oct</td>
<td>36</td>
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<tr>
<td>Nov</td>
<td>30</td>
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<tr>
<td>Dec</td>
<td>33</td>
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<tr>
<td>Jan</td>
<td>36</td>
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<td>Feb</td>
<td>62</td>
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<td>Mar</td>
<td>77</td>
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<tr>
<td>Apr</td>
<td>66</td>
</tr>
<tr>
<td>May</td>
<td>48</td>
</tr>
<tr>
<td>Jun</td>
<td>75</td>
</tr>
</tbody>
</table>
Thus, many factors play a part in determining what constitutes a reasonable caseload for each navigator.

To meet this challenge and establish program goals, the navigation team at St. Elizabeth started to measure active patients, per oncology nurse navigator and per disease site. These data allowed the team to determine where inefficiencies were hindering growth and patient load and when additional staff would be needed to sustain growth.

To differentiate active patients from inactive patients, a timeline must be determined for key patient touch points, structured for the overall program but customizable based on each disease site and specific patient needs. In this care trajectory, the appropriate timeframe for “closing” a patient was established. At St. Elizabeth, the oncology patient navigation program was built with patients at the forefront of every decision. It was common during program planning to ask the question, “What is best for the patient?” The team holds tight to this mantra today and because of this, “closing” a patient or “discharging” patients from the oncology navigation program seemed harsh and unattached. Instead, the team determined that using the terms “active” and “inactive” allowed oncology nurse navigators to focus on patients with more timely needs; typically, those in their diagnostic phase, those being worked up for staging and treatment planning, and those on active treatment. The team maintained an understanding that inactive patients still had the oncology nurse navigator available if they needed assistance at any point down the road. When patients are determined to be inactive, navigators notify patients that they are available but will not be actively checking on medical charts or providing follow-up calls or visits. This communication puts some responsibility on the patient and family to reach out when a need arises, and some responsibility on providers and clinics to notify oncology nurse navigators about changes in the patient’s plan of care.

Once this timeline was established, beginning in January 2021, the team tracked and reported the average number of active patients during their weekly huddles. These data gave a real time view of how many patients received regular follow-ups, support, and care coordination. The average number of active patients for each oncology nurse navigator for the first 6 months of 2021 is illustrated in Figure 1.

In February of 2021, just 4 months after program initiation, navigation services were extended to patients with gastrointestinal (GI) cancers. The oncology navigation program was seeing a positive growth in metrics and a positive impact on patient experience. A poor patient experience was reported to a provider who supported the navigation program extensively, and the patient was immediately sent to navigation for service recovery. Based in part on the exceptional care the oncology nurse navigators provided to this patient and his family, referrals of GI patients to oncology navigation continued to grow exponentially over the following months (Figure 2).
Growth Over Time
Throughout 2021, the thoracic caseload continued to grow rapidly, and the responsibilities of the nurse navigators grew extensively, largely due to increasing physician and system support of the program and role. At the start of 2021, the team consisted of 1 GI oncology nurse navigator and 1 thoracic oncology nurse navigator. Due to a steadily increasing number of thoracic patients, an additional full-time (FTE) nurse navigator was hired to share this caseload, growing the team to 3 nurse navigators (2 thoracic and 1 GI).

With the ability to share the caseload, the thoracic nurse navigators were able to dive deeper into overall lung program growth. They worked closely with a medical oncologist specializing in lung cancer to develop clinical pathways for patients with lung cancer. These pathways followed National Comprehensive Cancer Network guidelines to ensure patients were receiving the right care at the right time from the right provider, including appropriate imaging to complete work-up and staging.

The oncology nurse navigators are active members on the disease management teams. These teams are made up of disease-site-specific stakeholders so, for example, the thoracic team is comprised of pulmonologists, medical oncologists, radiation oncologists, thoracic surgeons, and various support staff, including oncology dietitians, oncology social workers, palliative care, integrative oncology, and the oncology nurse navigator(s) who manage those patients. The thoracic oncology nurse navigators who created these pathways (with provider assistance) had them approved by the thoracic disease management team, giving the oncology nurse navigators the autonomy to help patients receive the care they needed, and most notably, be completely staged prior to their medical oncology consult. This includes having tissue sent for molecular testing, when appropriate. This process saved the patients time, travel, and money by avoiding unnecessary visits and decreasing their time from diagnosis to treatment by approximately 30%. The thoracic oncology nurse navigators had the honor of sharing their work improving patient outcomes at the 2022 AONN+ Annual Conference, where their poster presentation won an award for best in category. Since then, these data have been shared at multiple conferences and symposiums to highlight the work that the oncology nurse navigation team focuses on to improve patient care.

In addition, the thoracic oncology nurse navigator team wanted to improve its outreach efforts. In December 2021, in collaboration with the lung cancer screening navigators, they started to receive referrals for patients who were identified by the lung nodule review board as likely to have lung cancer. This process allows the oncology nurse navigators to be introduced to and develop a relationship with patients well before a diagnosis. It also gives patients a resource to help them coordinate the care needed to complete a diagnostic work-up. Lastly, it offers an extra layer of emotional support for patients, whether they need assistance with smoking cessation,

Figure 4. GI Navigation: Average Active Patients per Month
coping, or general understanding of the care plan.

Growth of the thoracic oncology nurse navigation program over time is illustrated in Figure 3. Note: the decrease in patients with thoracic oncology is largely due to the navigation team making patients inactive sooner based on better follow-up processes, as well as the large number of patients who are active without a diagnosis, as these are measured separately as of February 2022.

The thoracic and GI oncology nurse navigation programs continued to grow throughout 2021 and 2022, creating a need for additional support while building availability to begin navigating an additional disease site. In February 2022, a new FTE oncology nurse navigator joined the team, taking over the esophageal cancer patients from the GI oncology nurse navigator. Growth of the GI oncology nurse navigation program is illustrated in Figure 4. Later that same year, in June, head and neck cancer navigation was rolled out (Figure 5). Lastly, in November 2022, genitourinary (GU) navigation was rolled out, utilizing current staff but reallocating resources due to efficiencies created by the oncology nurse navigation team—both in system processes, as well documentation and time spent on nonpatient facing tasks. Specifically, the thoracic oncology nurse navigators streamlined processes so that the caseload became manageable for 1 oncology nurse navigator, allowing the second thoracic oncology nurse navigator to build out the additional disease site. The roll out structure followed the other disease sites, starting with a meeting of key stakeholders and an assessment of patient needs; in the first 2 months following roll out, the GU oncology nurse navigator received 40 patient referrals. Figure 6 depicts overall program growth, with time stamps of key points during 2021 and 2022.

**Other Duties as Assigned**

As processes continue to be fine-tuned and the oncology nurse navigation team continues to build on the foundation, many additional functions have been established. A common statement on many job descriptions, the “other duties as assigned” category, also holds true for the oncology nurse navigators. That said, the navigation leadership team at St. Elizabeth is diligent to make sure that these “other” duties are meaningful to patient care, in some way impacting patient experience, patient outcomes, and the program’s return on investment, while allowing the oncology nurse navigators to function at the top of their licenses in a way that is engaging and provides them with autonomy and job satisfaction. Early in the planning process, the

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**Figure 5. Head and Neck Cancer Navigation: Average Active Patients per Month**

![Graph showing average active patients per month for head and neck cancer navigation from May to December 2022.](image-url)
leadership understood and supported the importance of structuring the oncology nurse navigator role in a way that allowed these nurses to work to the top of their license, removing tasks that were clerical in nature, such as scheduling appointments and completing Family and Medical Leave Act paperwork, while retaining other non-patient-facing tasks that directly impact patient care and require clinical expertise to optimize efficiency and functionality.

One such task is management of disease-site specific tumor boards. A large quality improvement (QI) project aimed at restructuring, standardizing, and optimizing tumor boards kicked off at St. Elizabeth in 2021. Part of this QI project focused on creating a leadership team for each disease-site specific tumor board, composed of an RN and an MD who would co-lead the discussion for their respective disease-sites. The disease-site specific oncology nurse navigators run their respective tumor boards, managing patient lists, documenting discussions, following up on and—most importantly—participating in conversations as an integral member of the care team. This oncology nurse navigator responsibility has made tumor board discussions much more structured, meaningful, and geared toward improving patient care.

To continue these QI efforts, the oncology nurse navigators created disease-site specific collaboratives supported by the disease-site specific multidisciplinary teams but facilitated by the oncology nurse navigators and consisting of frontline care team members directly involved in patient care. Participants include nurses and medical assistants from the oncology clinics and referring provider offices, infusion nurses, schedulers, financial counselors and prior authorization specialists, as well as staff from imaging, research, genetics, and more. The goal of these collaboratives is to fix patient-related process problems reported by frontline team members who interact with patients daily. The team at St. Elizabeth recognizes that frontline staff are the best ones to identify and establish solutions to everyday problems that patients face, including long wait times, bottlenecks in the system, poor care coordination, and more. In short, these collaboratives offer a forum for identification and problem-solving.
Long-Term Goals and Opportunities

Oncology nurse navigation program leadership continually looks for ways to grow and improve. Patient referrals to the oncology nurse navigation team continue to increase, with November 2022 being the highest month to date: 140 referrals.

While the oncology nurse navigation team has received over 2100 referrals from more than 259 providers, the team continues to look for ways to improve by streamlining the referral process. For example, although referrals can be made directly through the EHR, the team continues to receive referrals via email, through Teams messages, or in person. This inefficiency creates additional work on the oncology nurse navigators and increases the risk of patients being missed. In addition, the oncology nurse navigation team would like to increase the number of referrals received at diagnosis or sooner, as a large portion of referrals are being received from medical, surgical, and radiation oncologists after patients have already been through some tests and procedures. Often, patients receive their original diagnosis from a specialist, such as pulmonology, gastroenterology, ear-nose-throat, etc., and a referral from these providers as soon as the patient is aware of a diagnosis would be ideal, allowing the oncology nurse navigators to get involved earlier in the care continuum, improving care coordination, providing earlier emotional support for patients, and ideally decreasing the time from diagnosis to treatment initiation.

Another QI opportunity stems from the initial goal of measuring navigated patients’ admissions and ED visits, as mentioned previously. The oncology nurse navigation team developed a process to follow-up closely with patients after an admission or ED visit. After collaboration with a multidisciplinary team, the oncology nurse navigators also developed and are in the process of implementing an oncology admission risk score calculator within the EHR to tailor treatment and care to patients based on their risk of being admitted or visiting the ED.

The oncology nurse navigation team continues to work on ways to fine-tune appropriate caseloads and/or patient-to-navigator ratios. As stated previously, this process is highly correlated to patient acuity and the number of patients who are actively followed. Although a productivity score is combined with average case numbers to gain insight into the current team members’ ability to add or not add cases, using a tested acuity tool will help establish standards and allow us to continue to add staff and disease sites.

Looking to the Future

St. Elizabeth’s oncology nurse navigation team continues to look for ways to improve the care of patients with cancer. As its mission states, St. Elizabeth strives to lead Northern Kentucky to become one of the healthiest communities in America. Patients with cancer require a great deal of support. The oncology nurse navigation team likes to call themselves “friends in the business,” meaning that they are the patients’ people—the ones to call when a patient is unsure where to go or what to do. With patients at the forefront of their plans, the oncology nurse navigation team strives to align the structure described in this article with data and metrics to support program growth to a place where every patient with cancer is offered an oncology nurse navigator to guide them along their cancer journey. It is said frequently that no one walks this path alone, and at St. Elizabeth Cancer Care, the oncology nurse navigators ensure this statement is true.

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References