2022 Community Health Needs Assessment

RML SPECIALTY HOSPITAL
CHICAGO - HINSDALE

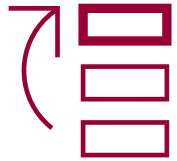
May 2022 – Chicago Campus

CHNA Executive Summary

About our Community

Key Health Indicators

Community Input



Prioritized Health Needs

RML Specialty Hospital - 2022 CHNA

RML Specialty Hospital (RML) conducted a Community Health Needs Assessment (CHNA) from February to May 2022 for its two hospital campuses – RML Specialty Hospital Hinsdale and RML Specialty Hospital Chicago – in accordance with IRS requirements for nonprofit hospitals.

RML desires to continue providing clinical programs and services to respond to patient needs, while also pursuing continuous improvement in existing and future programs to improve the overall health of the communities it serves. As such, RML has conducted a CHNA, using primary and secondary data, to ensure community benefit programs and resources respond to identified significant needs as well as alignment with RML's mission, services and strategic priorities. The CHNA was jointly prepared by RML's two hospitals located in Chicago and Hinsdale.

Based on its specialized focus and understanding of the population it serves, RML defined its CHNA community as people, particularly elderly and low-income, who have suffered a severe, life-changing, debilitating illness and that require extensive psychosocial and health support services when they return home. Home, for patients admitted to RML Hinsdale, is largely Chicago, suburban Cook County, DuPage County, and Will County. For patients at RML Chicago, home is mainly Chicago and suburban Cook County.

RML obtained input through one-on one interviews with chronically critically ill patients, caregivers, and community partners. RML patient data was also compiled and assessed.

Secondary data was assessed including:

- Socioeconomic indicators
- Key health indicators

Information gathered in the above steps was reviewed and analyzed to identify needs for patients served by RML.

RML Specialty Hospital - 2022 CHNA

The process identified the following health needs listed in order of priority:

High Priority
- Training and education for caregivers.
- Post-discharge care coordination, including changes to care plan.
- Post-discharge social services (e.g., assistance with food, utilities, home services.
- Post-discharge answers to medical questions.

Intermediate Priority
- Care giver support (e.g., psychological)
- Access to equipment, prescriptions, and supplies.
- Transition to primary care physicians.

Low Priority
- Setting of realistic expectations of time and energy post-discharge.
- Respite care and/or in-house nursing.
- Financial assistance.

The CHNA process provides RML with opportunities to better understand the quality-of-life issues that are important to the community, engage with former patients to better understand daily struggles, and hear ideas to overcome barriers and improve quality of life. In addition, the process provided an opportunity to build stronger relationships with other service providers for improved coordination and potential partnerships. RML looks forward to strengthening collaborative work to continue to address the priority needs of the community.

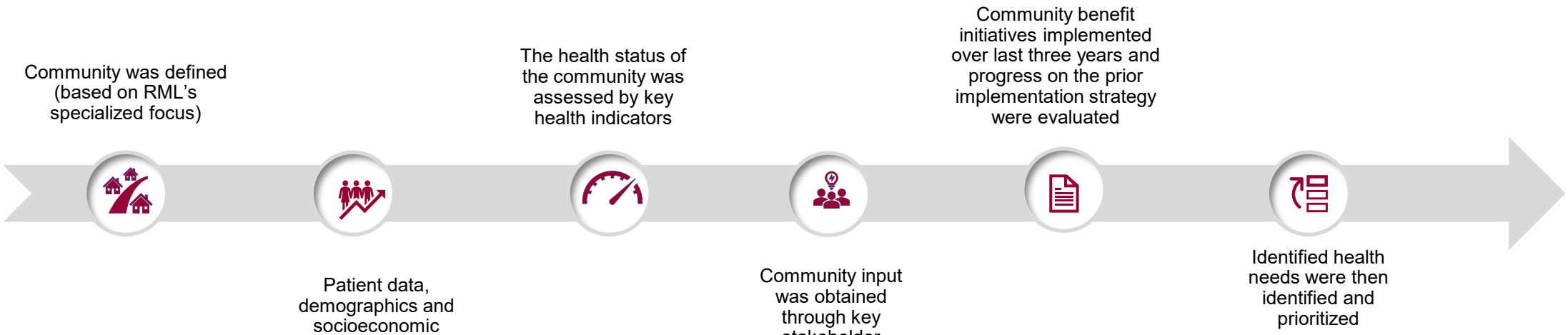
Opportunities for health improvement exist in each area listed above. RML will work to identify areas where the hospitals can most effectively focus their resources to have significant impact and will develop an Implementation Strategy for fiscal years ending 2023-2025.

How the Assessment was Conducted

RML conducted a Community Health Needs Assessment (CHNA) to support its mission responding to the needs in the community it serves and to fulfill the requirements established by the Patient Protection and Affordable Care Act of 2010 and comply with federal tax-exemption requirements. This is the fourth CHNA conducted by RML. The goals were to:

- ✓ Identify and prioritize health issues for RML's unique patient population within RML's service area.
- ✓ Strategically address identified needs to improve the health and quality of life for patients served by RML.

Based on current literature and other guidance from the United States Department of the Treasury, the following steps were conducted as part of RML's CHNA:



Acknowledgements

The Community Health Needs Assessment for RML supports the organization's mission to *"provide quality, compassionate care to patients from our referring community who suffer from prolonged, severe illness."* This Community Health Needs Assessment was made possible because of the commitment toward addressing the health needs in the community. Many individuals across the organization devoted time and resources to the completion of this assessment.

The CHNA process was led by RML's Chief Operating Officer. RML formed a CHNA team to help guide the 2022 CHNA process, review 2022 assessment data, and to provide input and guidance on the identification of priority issues for the 2023-2025 implementation plan.

This Community Health Needs Assessment has been facilitated by Crowe LLP ("Crowe"). Crowe is one of the largest public accounting, consulting, and technology firms in the United States. Crowe has significant healthcare experience including providing services to hundreds of large healthcare organizations across the country. For more information about Crowe's healthcare expertise visit www.crowe.com/industries/healthcare.

Written comments regarding the health needs that have been identified in the current Community Health Needs Assessment should be directed to:

Ken Pawola
Chief Operating Officer
kpawola@rmlspecialtyhospital.org

General Description of RML

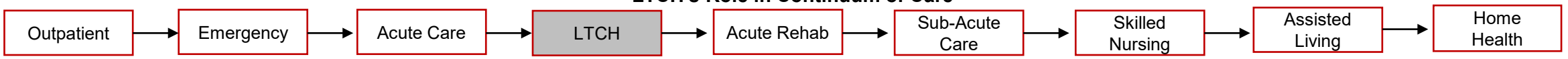
RML Specialty Hospital operates two campuses: a 115-bed hospital in Hinsdale (RML Specialty Hospital Hinsdale) and an 86-bed hospital on the near-west side of Chicago (RML Specialty Hospital Chicago).

RML is a long-term acute care hospital (LTCH). LTCHs are defined by Medicare as hospitals that have an average length-of-stay greater than 25 days

LTCHs are very much like short-stay acute care hospitals (i.e., community hospitals and university hospitals) except for some unique characteristics. LTCHs typically admit only elective referrals from short-stay acute care hospitals and are treatment-based rather than diagnosis-based. LTCHs focus on a patient population that is recovering from critical illness; this population has a long length-of-stay, is largely older adults, and is very ill. Patients in an LTCH face intricate and delicate family issues, often involving end-of-life decisions. Also, they operate on a much smaller scale and have few, if any, outpatient services.

LTCHs provide a specialized role in the overall continuum of care. LTCHs are the first stop in what is known as "post-acute care." About 1% of the patients admitted to a short-stay acute care hospital are eventually referred to an LTCH. An LTCH's role in the continuum of care can be represented as follows:

LTCH's Role in Continuum of Care



The RML Specialty Hospitals in Hinsdale and Chicago admit patients from more than 65 hospitals across Northeast Illinois as well as from out-of-state. The overwhelming majority of RML's patients stay three or more days in the intensive care unit at the referring hospital and have been in the hospital for three weeks or longer.

RML specializes in the interdisciplinary physician-led treatment of patients with catastrophic or acute illnesses and injuries complicated by complex or multiple illnesses or conditions. RML has three major programs. About 65% of the patients come to RML to be weaned from a ventilator. These patients have failed to wean from the ventilator at the short-stay acute care hospitals in spite of repeated attempts following a major surgery or a severe illness.

About 20% of the patients are admitted to the medically complex program. These patients are critically ill and suffer from multiple debilitating conditions and are just starting to take very small steps toward their rehabilitation.

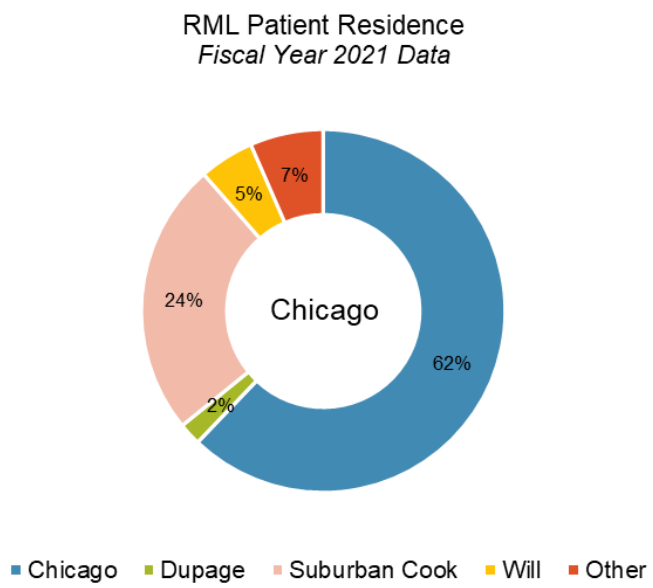
The remainder of patients come to RML with severe, possibly infected wounds, including pressure ulcers, surgical wounds, and burns. In fact, as all of the patients have been in the hospital for a long time, many of the patients in the other two programs are also suffering from skin and tissue injuries.

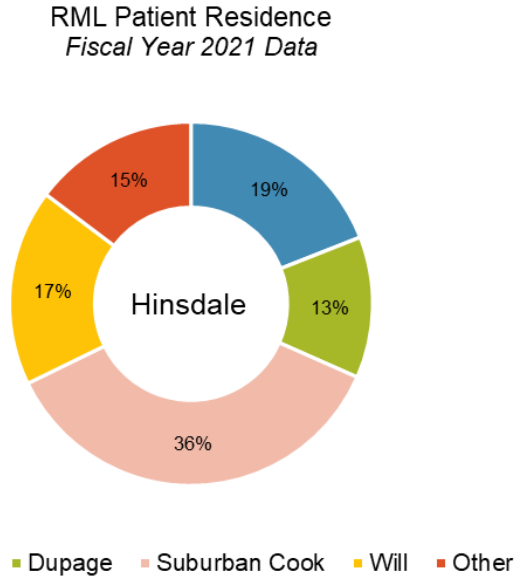
General Description of RML

RML Specialty Hospital Hinsdale was started in 1987 as the Ventilator Support Center within Suburban Hospital. It began as a partnership between Rush University Medical Center, MacNeal Hospital, and Suburban Hospital. In 1997, Suburban Hospital ceased operations. At that time the Ventilator Support Center assumed operations of the entire facility and was recognized as an LTCH by Centers for Medicare and Medicaid Services (CMS). Loyola University Medical Center replaced Suburban Hospital in the partnership in 1998 and the operation became known as RML. MacNeal Hospital left the Partnership in 2001. In 2010, RML Chicago (the former Advocate Bethany Hospital) was added and Advocate Health and Hospital System replaced Rush in the partnership. Loyola and Advocate are the current partners/owners of RML. Over the past 25-plus years, RML has established a national reputation for high-quality, positive outcomes. RML is the only LTCH recognized by US News and World Reports (2011) and is the only LTCH to participate in research funded by the National Institutes of Health (NIH).

Community Definition

Analysis of RML Specialty Hospital's FY2021 patient data shows that the vast majority of RML's patients come from the region that includes Chicago, suburban Cook County, DuPage County, and Will County. The source of RML Chicago's patients is relatively concentrated with 62% living in Chicago and 24% in suburban Cook County. The source of RML Hinsdale's patients is more widely distributed: 19% live in Chicago, 36% live in suburban Cook County, 13% live in DuPage County, and 17% live in Will County.





Given RML's specialty in serving medically complex patients and patients with long-term care needs, RML defined the CHNA communities in the following way:

RML Chicago Community
People in Chicago and suburban Cook County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, RML will focus on these populations.

RML Hinsdale Community
People in Chicago, suburban Cook County, DuPage County, and Will County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, RML will focus on these populations.

Community Overview

To approximate the size of its community, RML evaluated census data. According to census data from 2019, 967,472 older adults age 65 and older live in Cook County, DuPage County, and Will County; over a third of those older adults (336,969) are in the city of Chicago. Older adults living in poverty and living alone may have a more difficult time accessing the resources they need to adapt to home life with a severe, life-changing illness. In the service area, there are approximately 278,500 older adults living alone, and an estimated 168,000 older adults have independent living difficulty.

Target Community for this CHNA

As detailed in the Community Definitions section on page 8, RML's CHNA community of focus includes individuals that have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. The United States Library of Medicine, part of the National Institutes of Health, states: Approximately 80% of the patients admitted into intensive care units survive the acute event; and most remain in this unit briefly. However, a subgroup does not recover sufficiently quickly to become independent and from then they recover slowly. These patients are called chronically critically ill (CCI) patients and, comprise five to ten percent of the patients admitted into intensive care units. CCI patients are the vast majority of RML's patient community.

Select demographic information for the community, including Cook County, DuPage County and Will County, is provided below.

$119,765

Average Family Income

278,528

Households with Seniors Living Alone

12.5%

People Living in Poverty (838,701 persons)

11.9%

Adults Age 18-64 without Health Insurance Coverage (498,586 persons)

68%

Percentage of Medicare Beneficiaries With 2 or More Chronic Conditions

32%

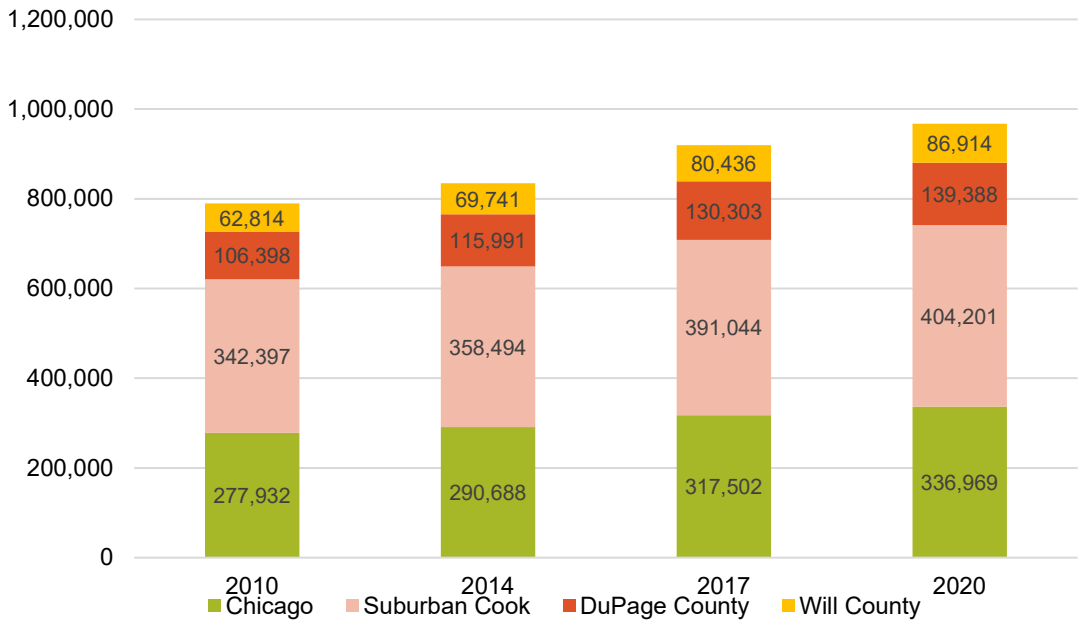
308,333 Persons Age 65+ with a Disability

Population Age 65 and Older

As of 2019, the total population of older adults age 65 and older is 967,472, with 741,170 (77%) of those older adults living in Chicago and suburban Cook County. The population of older adults increased by 5.2% between 2017 and 2019 and has increased by over 22% since 2010.

Persons aged 65 and older generally comprise the Medicare population. As shown in the table on the right side of this page, nearly 20% of the Medicare Population has six or more chronic conditions. Within the RML community, over 180,000 Medicare beneficiaries have six or more chronic conditions.

Population Age 65 and Older, 2010-2020



Source: US Census Bureau, American Community Survey. 2015-19

Medicare Population by Number of Chronic Conditions

	0-1 Chronic Condition	2-3 Chronic Conditions	4-5 Chronic Conditions	6 or More Chronic Conditions
RML Community	301,339	275,287	202,835	180,043
Cook County, IL	229,868	204,432	152,470	140,043
DuPage County, IL	44,682	42,302	28,990	22,389
Will County, IL	26,789	28,553	21,375	17,611
Illinois	628,371	604,046	443,171	368,560
United States	17,420,235	16,293,999	12,399,801	9,917,599

Medicare Population by Number of Chronic Conditions, Percentage

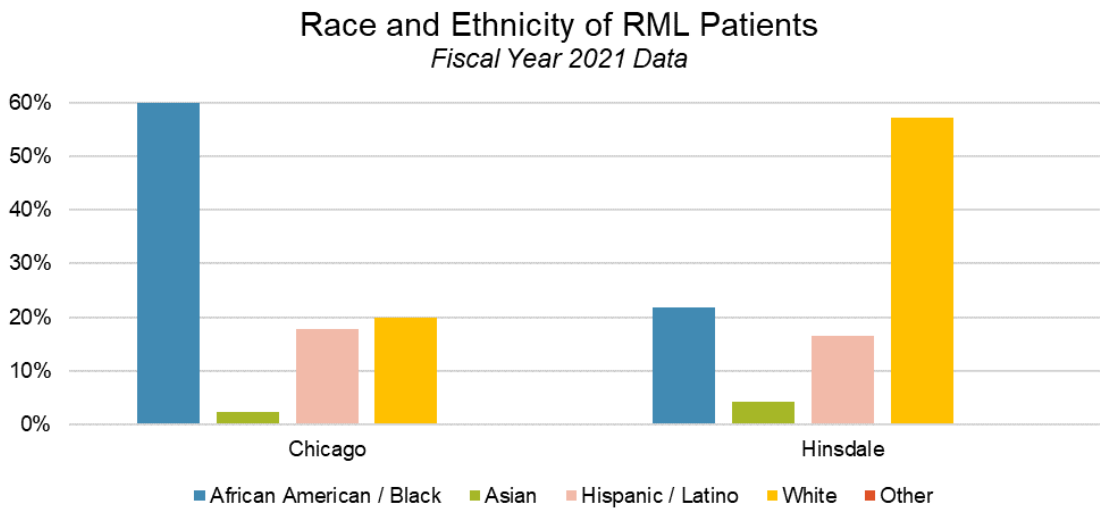
	0-1 Chronic Condition	2-3 Chronic Conditions	4-5 Chronic Conditions	6 or More Chronic Conditions
Cook County, IL	31.60%	28.10%	21.00%	19.30%
DuPage County, IL	32.30%	30.60%	20.90%	16.20%
Will County, IL	28.40%	30.30%	22.70%	18.70%
Illinois	43.50%	41.90%	30.70%	25.50%
United States	31.10%	29.10%	22.10%	17.70%

Source: Centers for Medicare and Medicaid Services. 2018. Source geography: County

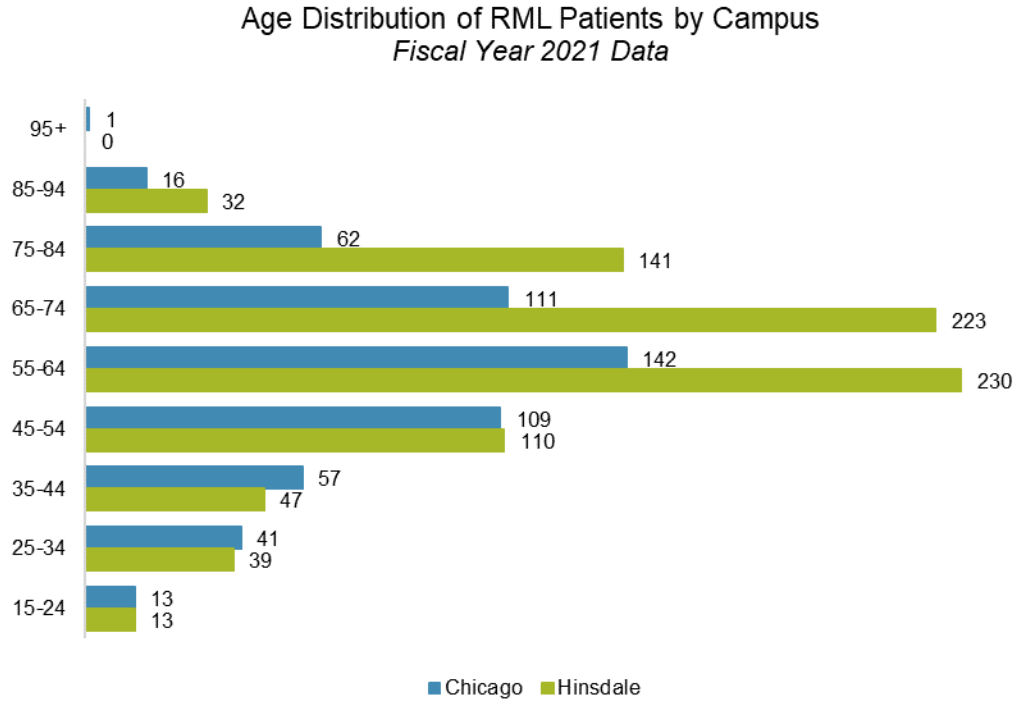
RML Patient Data - Demographics

The largest age group of RML Chicago's patients (45%) are adults ages 45-64 while the largest age group of RML Hinsdale's patients (47%) are 65 and older. RML patients were, on average, older in 2021 than they were in 2018; the proportion of patients 44 or younger decreased on each campus, from 22% to 20% at RML Chicago and from 17% to 12% at RML Hinsdale.

The race and ethnicity of RML patients varies by campus. Over 80% of the patients at RML Chicago are non-white while 57% of the patients at RML Hinsdale are white.



Source: RML Fiscal Year 2021 Data



	RML Chicago			
Age	**2021**		**2018**	
65+	190	34%	183	33%
45-64	251	45%	254	45%
15-44	111	20%	126	22%
Total	552		563	

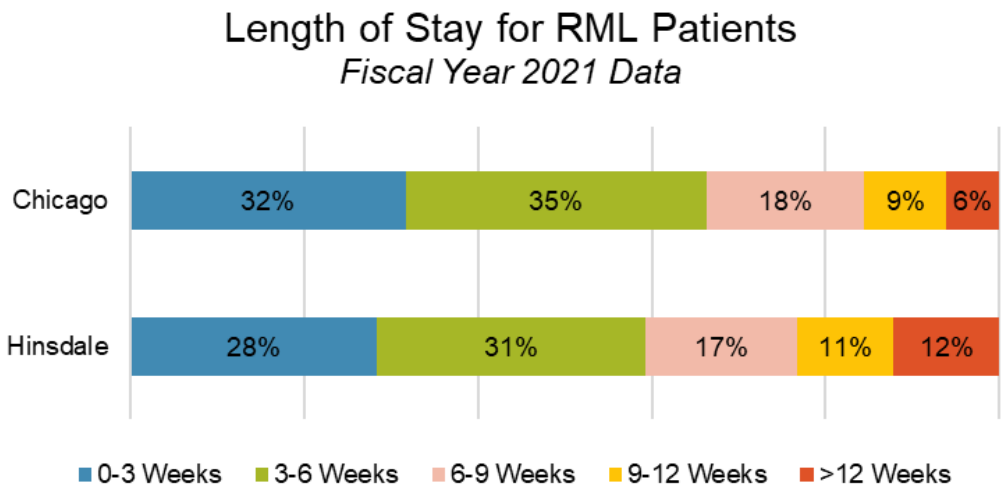
	RML Hinsdale			
Age	**2021**		**2018**	
65+	396	47%	338	44%
45-64	340	41%	301	39%
15-44	99	12%	132	17%
Total	835		771	

Source: RML Fiscal Year 2021 and 2018 Data

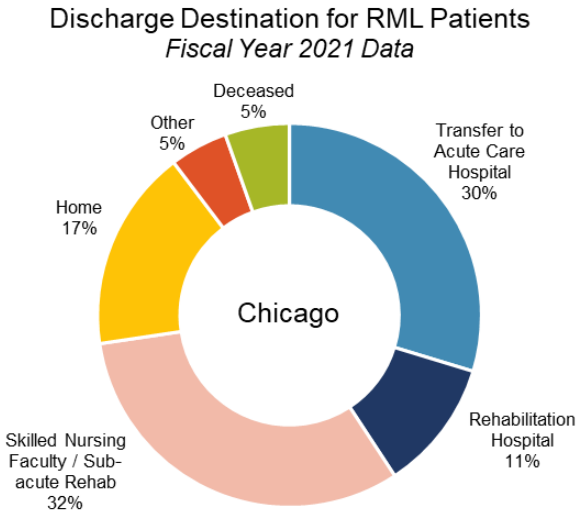
RML Patient Data - Discharge

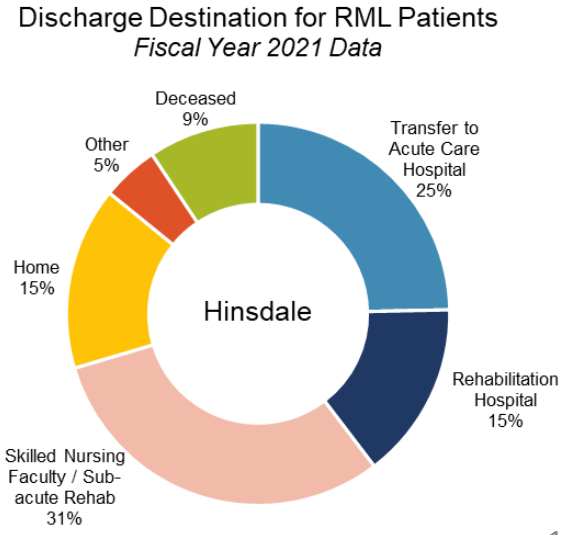
Over 70% of RML patients stay at RML for over three weeks. Patients at the Hinsdale facility tend to stay longer on average than patients at the Chicago facility. As most patients come to RML after three plus weeks in a short-stay hospital as well, the total length of stay in a hospital is usually six weeks or longer, not including the time spent in a rehabilitation or skilled nursing facility after discharge from RML. This emphasizes the severity of the patients' conditions and is indicative of the challenges they will face when returning home.

In 2021, discharge profiles were similar for RML's Chicago and Hinsdale facilities. RML Hinsdale had a higher proportion of transfers to rehabilitation hospitals (15%). RML Chicago had a higher proportion of transfers to acute care hospitals (30%), home (17%) and skilled nursing facilities (32%). Nearly three-quarters of RML patients have at least one intermediate stop before going home, which makes it challenging for RML to follow and assist patients at home.



Source: RML Fiscal Year 2021 Data



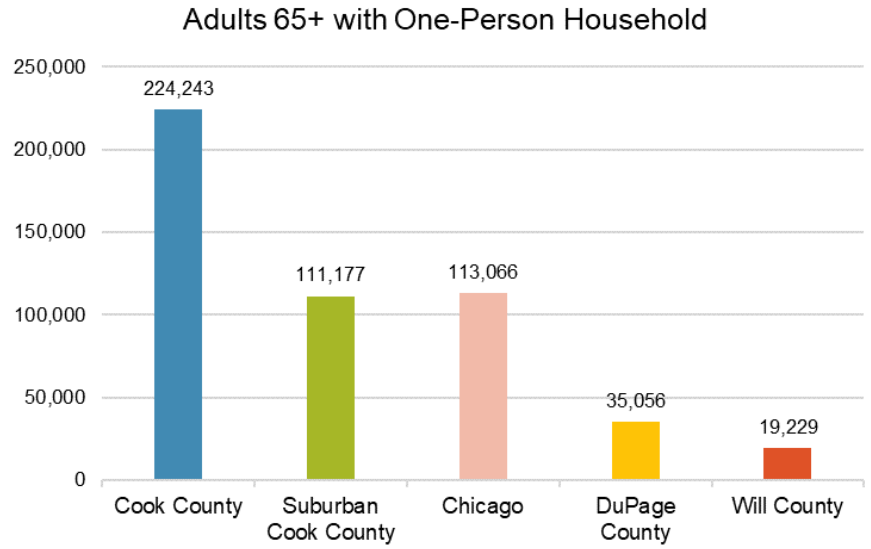


Source: RML Fiscal Year 2021 Data

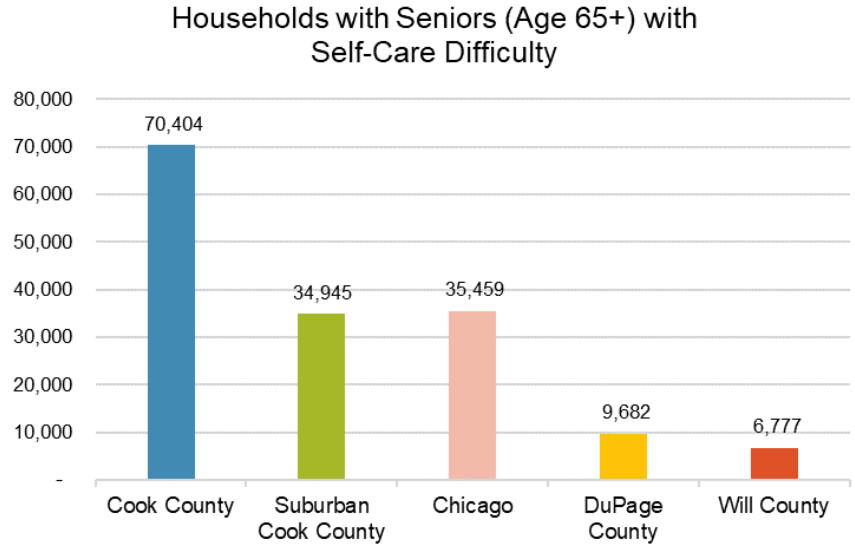
Home Support for Adults (Age 65+)

There were approximately 391,594 households with adults aged 65 and over living alone in the RML service area. The average percentage of senior households among Chicago, Cook County, DuPage County, and Will County was 39%. This indicator is important because older adults who live alone are vulnerable populations who may have challenges accessing basic needs, including health needs.

It is often not possible for patients returning home after a long-term illness to live independently. There were approximately 168,000 older adults with independent living difficulty and approximately 87,000 older adults with self-care difficulty in the RML service area in 2019.



Source: US Census Bureau, American Community Survey. 2015-19



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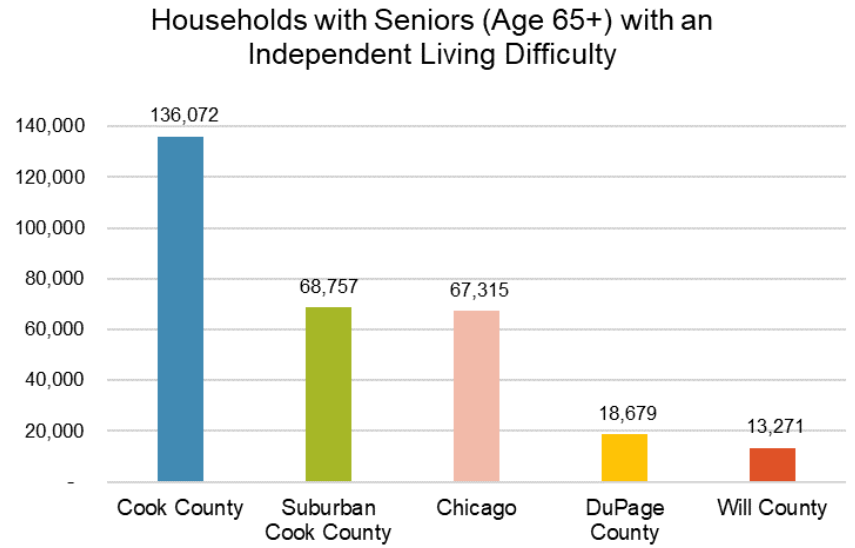
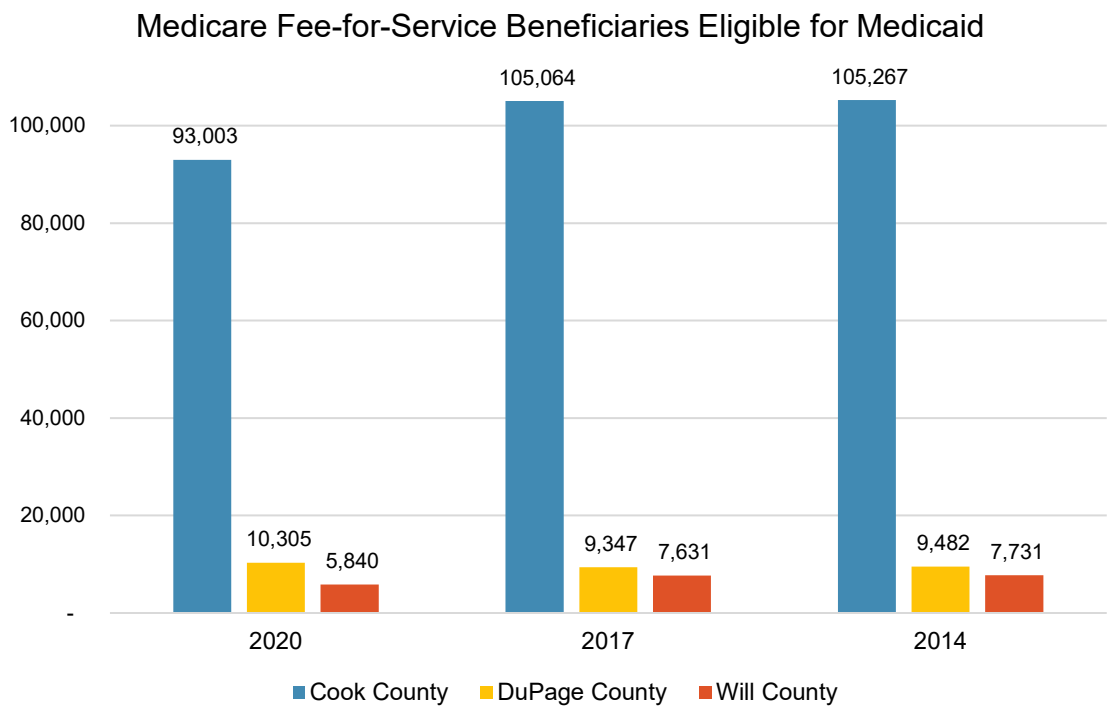


Source: US Census Bureau, American Community Survey. 2015-19

Medicare and Medicaid Dual Eligible Population

Medicare is available for people age 65 or older, younger people with disabilities, and people with End Stage Renal Disease. Medicaid provides health coverage to eligible low-income adults, children, pregnant women, elderly adults, and people with disabilities. Some individuals qualify for both programs, including low-income seniors and younger people with disabilities, and are known as dual eligible beneficiaries. Dual eligible beneficiaries have complex and often costly health care needs and have been the focus of many initiatives to improve the coordination and quality of their care. Roughly 109,000 people in the RML region are considered dual eligible, as measured by Medicare, fee-for service beneficiaries who are eligible for Medicaid for at least one month in the year. The number of dual eligible individuals has declined about 11% from 2014.

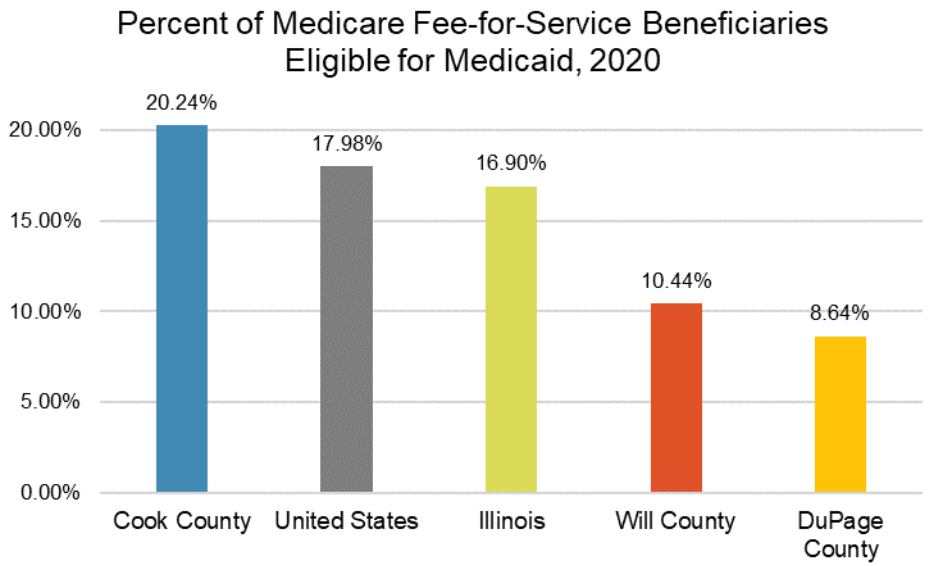


Source: Centers for Medicare & Medicaid Services Geographic Variation Public Use File, 2020

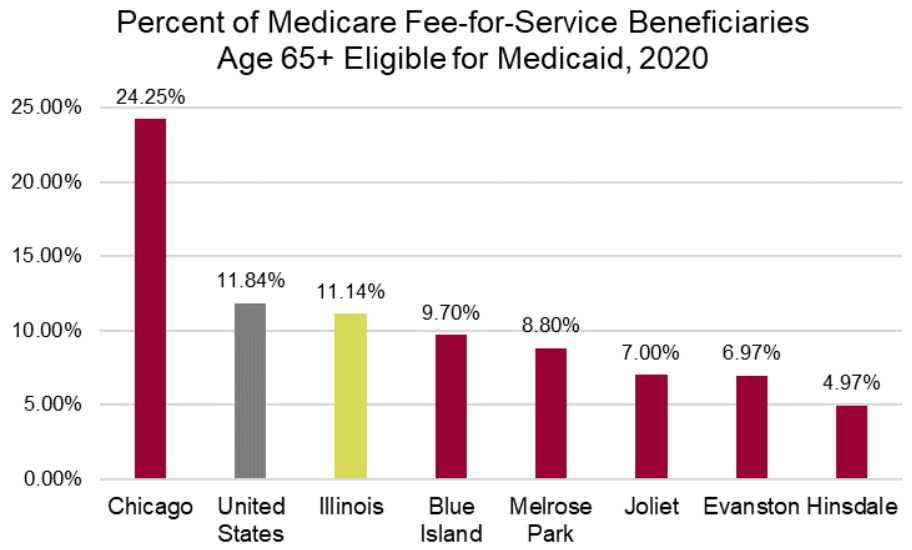
Medicare and Medicaid Dual Eligible Population

Cook County has the highest proportion of Medicare fee-for-service beneficiaries who are eligible for Medicaid (20%), while roughly 9% of DuPage and 10% of Will County Medicare beneficiaries are dual eligible.

Older adults are nearly universally covered by Medicare and some older adults also qualify for Medicaid coverage to assist with payment of deductibles and co-payments. In Illinois, about 11% of Medicare fee-for-service beneficiaries age 65 and over were eligible for Medicaid for at least one month in the year in 2020. The rate for the Chicago Hospital Referral Region (HRR) was over double (24%) while the rate for the Hinsdale HRR was less than half (5%) of the state rate.



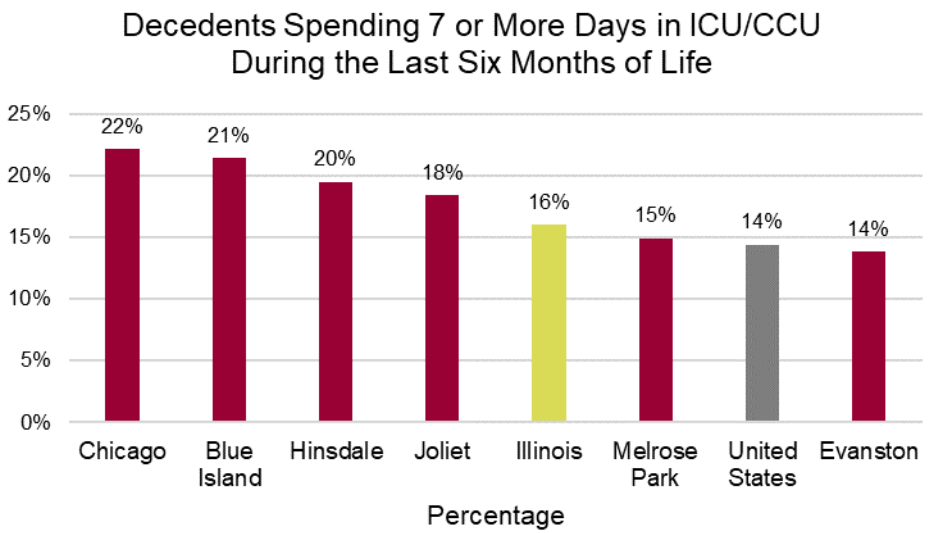
Source: Centers for Medicare & Medicaid Services Geographic Variation Public Use File, 2020



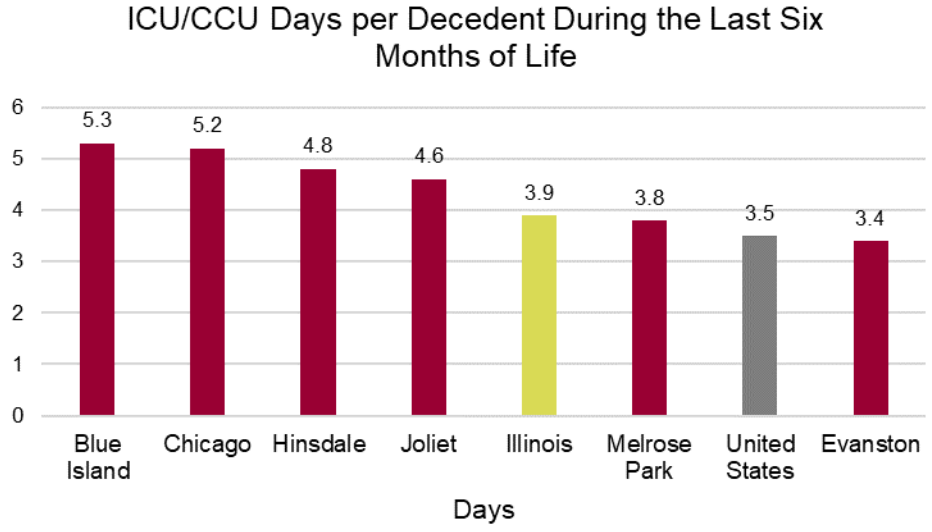
Source: Centers for Medicare & Medicaid Services Geographic Variation Public Use File, 2020

Individuals Living with Chronic Critical Illness

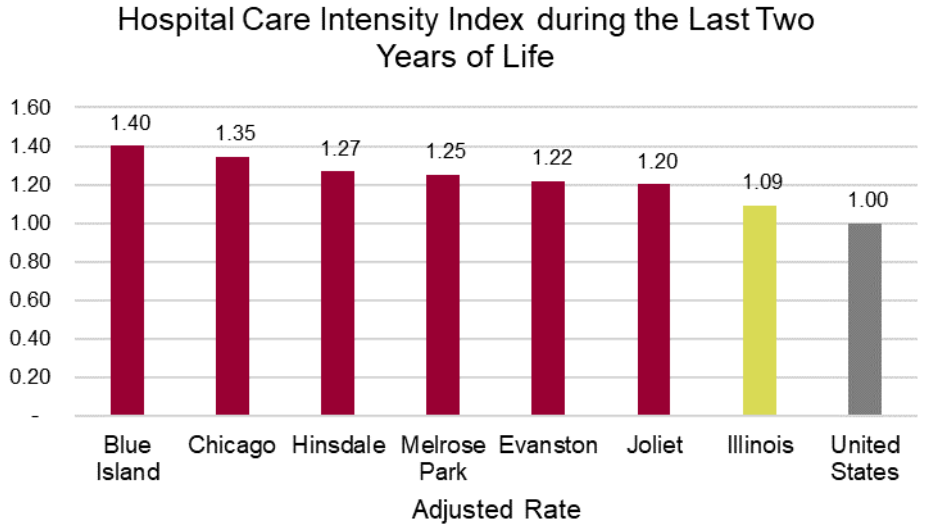
Long-term Acute Care Hospitals (LTCHs) have a high proportion of chronic critical illness (CCI) patients. The definition of CCI varies, but the general characteristics include extended intensive care unit (ICU) stays, presence of sepsis, prolonged mechanical ventilation, and/or multiple organ failures. Data from the Dartmouth Atlas of Health Care suggest that the RML service area has a high proportion of CCI patients compared to the national average.



Source: Dartmouth Atlas of Health Care, 2019



Source: Dartmouth Atlas of Health Care, 2019



Source: Dartmouth Atlas of Health Care, 2019

Key Stakeholder Interviews

Written Summary of Stakeholder Interviews

RML obtained input from ten key stakeholders representing patients, caregivers and community partners who work with RML patients in the community through one-on-one interviews. Interviews were conducted during March and April 2022.

Patient and Caregiver Needs

- Setting Realistic Expectations with Caregivers
- Training for Caregivers
- Access to Prescriptions, Equipment and Supplies
- Post-Discharge Care Coordination

Barriers to Accessing and Receiving Needed Services

- Financial Barriers/Insurance Coverage
- Challenges related to updating patients care plan and revising services
- Lack of Family Support

Unmet Needs and Challenges Once Discharged from RML

- Support for Patient's Families
- In-Home Nursing Care
- Access to Equipment and Supplies

Most Critical Resources Needed (alphabetical order)

- Assistance with coordination of services, checkups, and change orders
- Follow up care such as home care, therapy, visiting physician services, etc.
- Home care
- Psychological support
- Reinforcement of training received at discharge and resources to assist with questions
- Respite Care

Key Stakeholder Interviews

How could RML be most helpful to patients/caregivers?

Stakeholders provided the following recommendations as to how RML could be most helpful to patients and caregivers.

Care Transition: Once patients are discharged from RML, visiting physicians are utilized to oversee patient care in the short-term. In addition, the patient's primary care physician is still responsible for certain aspects of their care. Not many physicians are well-trained to manage CCI patients at home. Stakeholders noted that pulmonologists and intensivists do not see patients at home. When orders and treatment need to be changed for the patient it needs a well-trained physician. Assistance with the transition to the community primary care provider, including training, would be beneficial for the patient and caregiver.

Post-Discharge Follow-up: Once discharged, patients and caregivers feel like they are on their own. To ease their fear, stakeholders expressed the desire for continued follow-up from RML. They suggested RML case manager conduct follow-up calls at regular intervals up to two weeks post-discharge. This would provide additional confidence for the caregiver and questions could be answered for issues that have arisen post discharge.

Education and Coordination of Community Resources: Stakeholders recommended that RML could provide guidance and information on community resources that may be available within the community for social and supportive services. A helpline or referral center for non-medical questions and coordination of community resources for items such as food, utilities, home services, transportation, etc. would be beneficial for patients, caregivers, and their families.

Prescription Procurement: Stakeholders suggested RML send prescriptions to the patient's pharmacy one to two days prior to discharge. This would ensure that specialty medications can be obtained in a timely manner and the caregiver will be able to obtain the prescription prior to bringing the patient home.

"RML case managers are knowledgeable and make sure missing pieces are being taken care of – there is an ability to speak to physicians directly to make sure there is a good plan in place to make sure patient doesn't get readmitted."

"It would be helpful if RML can guide patients to community resources for what they need."

Evaluation of the Impact of Actions Taken Since the Last CHNA

In the spring of 2019, RML conducted its third community health needs assessment (CHNA). RML recognizes that as the first stop in the post-acute care continuum, it is well-positioned to address the needs of chronically, critically ill patients after they leave the hospital and return to the community. Focusing on these needs presents unique opportunities for RML to advance our mission by enhancing the care we provide to the unique patient population we serve. To extend our effectiveness, twenty-two members of RML's community (including leaders in the post-acute provider community, insurance payers, community organizations, tertiary care centers and academic medical centers, as well as former patients and their families) were invited to work alongside three members of RML's leadership team on a "chronically, critically ill action team (CCIAT)". The CCIAT supported the development of the CHNA and the implementation plan. The CCIAT finalized an implementation plan to address the community health needs identified as priorities in the CHNA. With the help of the CCIAT, RML set out to implement the action plan. The CCIAT identified two priorities.

The first priority was to improve coordination of care across the care continuum. The action team's goal was to improve chronically, critically ill patients' quality of life and outcomes through access to long-term care management and community resources. The objectives were to increase linkage to resources to address patient social determinants of health and the best next site of care, implement standardized post-discharge care management processes, and increase awareness and use of palliative care among patients and caregivers.

The second priority was to provide support to the caregivers of chronically, critically ill patients. The team sought to do this in two ways: improve the quality of care provided by caregivers and improve the quality of caregivers' lives through supportive services. The CCIAT set out to do this by developing and increasing access to quality educational resources and increasing emotional support, including access to respite services.

Unfortunately, the covid-19 pandemic put a halt to the CCIAT’s efforts. The CCIAT was not able to meet during the pandemic. Several factors limited the ability of the team to get together: 1) the need to social distance and minimize in-person interactions without uniformly sufficient technology support; 2) abruptly changed priorities that focused on patient and staff safety; and 3) severe staffing shortages limited availability of team members as they were required to provide direct patient care. Even now, as the technology and in-person events have normalized, shifted priorities and the lack of availability of members is still a reality.

Prioritization of Identified Health Needs

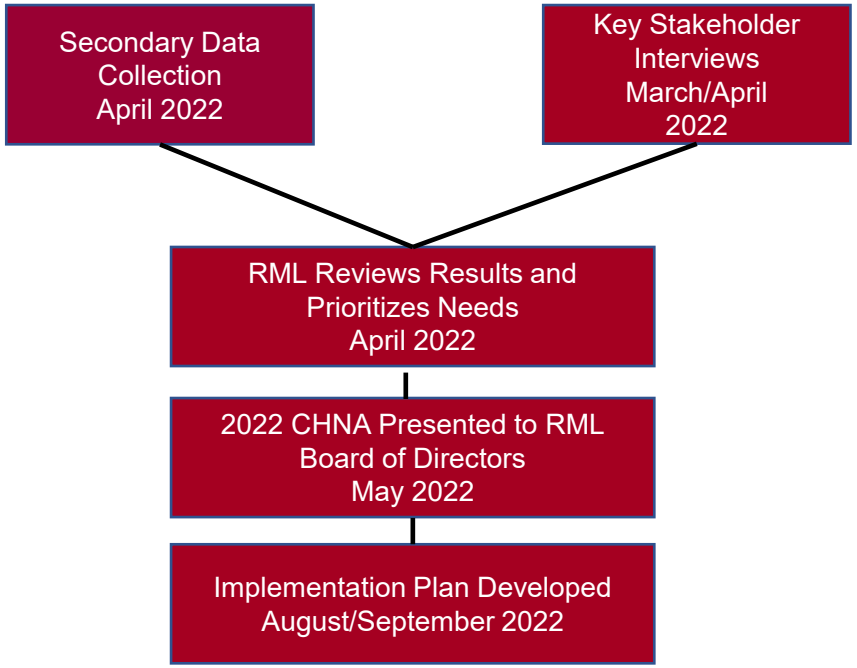
Primary and secondary data was gathered and compiled from February to April 2022. Based on key themes and identified needs gathered through the CHNA process, the following list of priorities was developed with input from a broad base of members of RML's Leadership Team.

RML has capacity to respond to the needs listed below and will focus on the high priority needs.

High Priority (full consideration and development of Implementation Strategy)
- Training and education for caregivers.
- Post-discharge care coordination, including changes to care plan.
- Post-discharge social services (e.g., assistance with food, utilities, home services.
- Post-discharge answers to medical questions.

Intermediate Priority (to be pursued if initiative is quick, easy, and with low resource needs)
- Care giver support (e.g., psychological)
- Access to equipment, prescriptions, and supplies.
- Transition to primary care physicians.

Low Priority (may be re-evaluated at a later time)
- Setting of realistic expectations of time and energy post-discharge.
- Respite care and/or in-house nursing.
- Financial assistance.



Appendix A – Key Stakeholder Interview Summary

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RML obtained input from ten key stakeholders representing patients, caregivers and community partners who work with RML patients in the community through one-on-one interviews. Interviews were conducted during March and April 2022.

The interview questions were intended to identify patient and caregiver needs, gain an understanding of unmet health needs as well as the barriers that prevent access to needed services, and to provide input as to what RML could do to address the identified needs of patients and caregivers. The interview questions for each key stakeholder were identical. A summary of the stakeholders' responses by each of the categories follows. Paraphrased quotes are included to reflect some commonly held opinions and direct quotes are employed to emphasize strong feelings associated with the statements.

This section of the report summarizes what the key stakeholders said without assessing the credibility of their comments.

Patient and Caregiver Needs:

Several questions in the key stakeholder interview were aimed at understanding the patient's needs upon discharge from RML. Patients, caregivers and community partners agreed that patients and designated caregivers receive excellent training from RML's nursing and discharge staff. Training typically starts two weeks prior to discharge. Most stakeholders also acknowledged that discharge is well-coordinated. However, patients discharged from RML tend to have complex care needs and caregivers can become overwhelmed once discharged to home from RML. Themes regarding patient and caregiver needs are provided below.

Setting Realistic Expectations with Caregivers: One theme that emerged through key stakeholder interviews was that patients and caregivers need to understand what they are facing when they are discharged to home from RML. Patients have complex needs and will require 24-hour care. A strong support system is critical and care for the patient can't be provided by a single caregiver. Patients and caregivers desire the patient to return home as soon as possible and often diminish the workload that will be required to care for the patient at home. Caregivers need to be mentally and physically prepared to face challenges associated with caring for the patient around the clock, maintaining a home and necessities for the patient, juggling employment and other family responsibilities, managing follow-up care, and facing the isolation that often accompanies caring for a chronically critically ill (CCI) patient.

"RML understands what it takes to transition people home. They all really exude a patient-centered, passionate mindset and want to see the patient as independent as possible"

"One person cannot take care of these patients alone."

Training for Caregivers

Most of the stakeholders agreed that training for the caregiver is extremely important. RML patients require a lot of care upon discharge and adequate training is critical to achieve the best outcomes for the patient and minimize future emergencies. One-on-one training is important and builds confidence in the caregiver. As noted above, the primary caregiver must accept the fact that they will need help to care for the patient at home. Therefore, multiple caregivers should be trained on how to care for the patient or other arrangements to provide assistance to a single caregiver should be arranged.

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Caring for CCI patients is complex. Many patients don't qualify for in-home nursing care, so the caregivers are charged with providing nursing care for the patient. Areas that are most challenging for caregivers include 1.) how to suction a patient on trach care; 2.) understanding how to operate a ventilator; and 3.) appropriate care related to catheters. Caregivers expressed the desire for more specific guidance related to caring for the patient (once the patient is home and the caregiver has a better idea of the nuances of the care to be provided) and noted there is a lot of gray areas in caring for their loved one.

Several stakeholders noted that caregiver training has been more challenging over the last two years due to visiting restrictions that have been in place due to COVID-19. Visiting restrictions have impacted the amount of time members of the patient's family were able to observe hospital staff caring for the patient.

Stakeholders suggested a comprehensive quick reference guide would be helpful to help coordinate and manage the home health services, therapies, medications, equipment and required medical follow-up for the patient. This guide could also provide more specific guidance related to areas that are most challenging for caregivers. Stakeholders also suggested incorporating a nesting period for caregivers, prior to discharge, where caregivers would stay at the hospital for several days and be the primary caretaker for the patient to identify areas where additional training and support is needed.

"Everything looks easier on paper! There are so many unspoken things that need reinforcement."

"There is a lot of grey areas in caring for my loved one – I'm not sure what I should do."

Equipment, Prescriptions and Supplies: A repeated theme among stakeholders pertained to filling prescriptions for patients. Stakeholders noted that often medications may not be readily available at the pharmacy due to the special nature of the medication and/or due to supply issues. There are instances where it may take two to three days to fill a prescription. Similar delays in securing needed equipment for the home were also noted.

Stakeholders recommended that prescriptions be provided two to three days prior to discharge to allow time for the caregiver to fill the prescription before taking the patient home. Another recommendation was to have an onsite pharmacy provide initial medications at discharge to alleviate this burden once returning home with the patient.

"Some families are struggling with getting the script filled on time."

Care Coordination: The transition from hospital to home requires a great deal of communication between health care facilities, community health providers, equipment suppliers and caregivers. Stakeholders identified the need for clear discharge instructions written in a manner targeted to persons with no medical background. In addition, assistance with coordination of in-home services was identified as an area where RML could provide additional support.

Stakeholders suggested that an online meeting with representatives from all companies providing services and or equipment could be conducted within one to two days after the patient is discharged home to make sure all needed services, supplies and medications have been secured. Discharge orders could be reviewed to ensure compliance with all orders and any insurance issues could be discussed.

"The doctors' orders need to be very clear as to what the patient needs post-discharge."

"Patients get oxygen from one organization, bladder supplies from another, prescriptions from another, IV supplies from another – doctor follow-ups – need coordination of care for all of that. A true universal health record is needed."

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Unmet Needs and Challenges Once Discharged from RML

Stakeholders were asked to identify their medical and non-medical needs that had been the most difficult to fulfill once being discharged from RML. In addition, they were asked to share their experiences in accessing resources and to identify which resources had been the most challenging to access. Most stakeholders acknowledged it is hard to get all the needed resources and that it is challenging to maintain stabilization for the patient. The most significant unmet needs are further described below.

Support for patient's families: Support for the patient's families was the biggest non-medical need identified by stakeholders. Once being discharged home, families have a lot of adjustments to make and may find it very stressful to care for the patient in the first few weeks post-discharge. Additional support is needed for a wide range of items including psychological support, meals, equipment for the patient, respite care, transportation, and financial assistance for those who are unable to afford needed services. Stakeholders recommended RML facilitate connecting patient's families to social services through support groups and/or availability of social workers for post-discharge consultations.

In-home nursing care: Most of the caregivers that were interviewed voiced concerns with not being able to access in-home nursing care due to high cost or lack of insurance coverage. Those caregivers who had in-home nursing care, voiced concerns as to the limited coverage and level of care. In most instances, it was noted that in-home nursing care is generally provided for one to two hours per week and there is significant turnover in the staff providing in-home nursing care. Stakeholders agreed that increased in-home nursing care would provide the additional support that caregivers need in caring for the CCI patient and would provide a small amount of respite care that is often desperately needed.

Equipment and supplies: Dealing with vendors for medical supplies can be challenging. They are very restricted based on Medicaid Laws as to what supplies they can give and how much can be given each month. Some stakeholders noted not being supplied with adequate quantities of supplies based on their patient circumstances.

"A caregiver support group would be helpful."

"So many people don't qualify for home nursing. It would be helpful if Medicare could cover home nursing."

Barriers to Accessing and Receiving Needed Resources

After discussing patient and caregiver needs, stakeholders were asked to share their thoughts regarding barriers that prohibited them from accessing the needed resources. Based on feedback from the key stakeholders, additional supportive resources from RML social workers would help address many of the barriers described below.

Financial Barriers/Insurance Coverage: Stakeholders noted that services are often limited based on the type of insurance coverage the patient has. Often, private duty nursing or in-home care is not covered. In addition, Medicaid guidelines regarding coverage for supplies and prescriptions prohibit the amount and type of supplies which are provided to patients. When supplies are limited by insurance, providers need to advocate for the patient to get higher supply limits.

The financial burden of paying for needed in home care, equipment and medications is very challenging, particularly for the middle class. Financial assistance for housing, utilities and medical supplies not covered by insurance were discussed, but the biggest need is for in-home nursing services for the patient.

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Inability to update secure services: Stakeholders voiced challenges with securing needed services for patients once discharged home. Stakeholders described delays in getting through to providers such as therapists, home health care providers, and visiting physicians and they felt RML could do more to assist with securing these services post-discharge. Based on the complexities of each individual patient, stakeholders recommended nursing staff be involved (in addition to social workers) in assisting with setting up services post-discharge.

Stakeholders acknowledge that RML facilitated setting up services for the patient as part of discharge planning and that RML was available in case of emergencies. As time passes, changes may need to be made to the patient's care plan and services may need to be updated. Care providers are looking for more direction as to how to coordinate and navigate these changes.

Barriers also relate to Medicaid Guidelines for services and supplies. To work around the guidelines, you need a doctor's authorization. The only way to get changes is with the doctor authorization. In an emergency this can be challenging. Community doctors that are not familiar with treating the patient can't change the orders without backing up and learning the patient. The transition from RML doctors to the patient's primary care physician takes time. Stakeholders noted that RML could facilitate more timely communication to primary care physicians and provide education regarding the patient's specific needs and care plan.

Lack of family support: In some instances, the ability for family members to assist with caregiver responsibilities decreases significantly in a short time after the patient is discharged to home. The lack of family involvement leaves a void in caregiver support.

Resources Required to Improve Health and Quality of Life for CCI Patients and Families

Key stakeholders were asked what resources were most critical to improve the qualify of life for patients and their families. The items listed below, in alphabetical order, were identified as the most critical resources which were needed.

•Assistance with coordination of services, checkups, and change orders
•Follow up care such as home care, therapy, visiting physician services, etc.
•Home care
•Psychological support
•Reinforcement of training received at discharge and resources to assist with questions
•Respite Care

How could RML be most helpful to patients/caregivers?

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Stakeholders provided the following recommendations as to how RML could be most helpful to patients and caregivers.

Care Transition: Once patients are discharged from RML, visiting physicians are utilized to oversee patient care in the short-term. In addition, the patient's primary care physician is still responsible for certain aspects of their care. Not many physicians are well-trained to manage CCI patients at home. Stakeholders noted that pulmonologists and intensivists do not see patients at home. When orders and treatment need to be changed for the patient it needs a well-trained physician. Assistance with the transition to the community primary care provider, including training, would be beneficial for the patient and caregiver.

Post-Discharge Follow-up: Once discharged, patients and caregivers feel like they are on their own. To ease their fear, stakeholders expressed the desire for continued follow-up from RML. They suggested RML case manager conduct follow-up calls at regular intervals up to two weeks post-discharge. This would provide additional confidence for the caregiver and questions could be answered for issues that have arisen post discharge.

Education and Coordination of Community Resources: Stakeholders recommended that RML could provide guidance and information on community resources that may be available within the community for social and supportive services. A helpline or referral center for non-medical questions and coordination of community resources for items such as food, utilities, home services, transportation, etc. would be beneficial for patients, caregivers, and their families.

Prescription Procurement: Stakeholders suggested RML send prescriptions to the patient's pharmacy one to two days prior to discharge. This would ensure that specialty medications can be obtained in a timely manner and the caregiver will be able to obtain the prescription prior to bringing the patient home.

"RML case managers are knowledgeable and make sure missing pieces are being taken care of – there is an ability to speak to physicians directly to make sure there is a good plan in place to make sure patient doesn't get readmitted."

"It would be helpful if RML can guide patients to community resources for what they need."

Limitations and Information Gaps

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As with all data collection efforts, there are several limitations related to the assessment's research methods that should be acknowledged. Years of the most current data available differ by data source. In some instances, 2021 may be the most current year available for data, while 2014 may be the most current year for other sources. Likewise, survey data based on self-reports, such as the Behavioral Risk Factor Surveillance Survey (BRFSS), should be interpreted with particular caution. In some instances, respondents may over or under report behaviors and illnesses based on fear of social stigma or misunderstanding the question being asked.

In addition, respondents may be prone to recall bias – that is, they may attempt to answer accurately, but they remember incorrectly. In some surveys, reporting and recall bias may differ according to a risk factor or health outcome of interest. Despite these limitations, most of the self-report surveys analyzed in this CHNA benefit from large sample sizes and repeated administrations, enabling comparison over time. Similarly, while the qualitative data collected for this study provide valuable insights, results are not statistically representative of a larger population due to nonrandom recruiting techniques and a small sample size. Data were collected at one point in time and among a limited number of individuals.

Therefore, findings, while directional and descriptive, should not be interpreted as definitive.