

HealthTree Cure Hub: A Patient-Derived, Patient-Driven Clinical Cancer Information Platform Used to Overcome Hurdles and Accelerate Research in Multiple Myeloma

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PURPOSE The study of rare diseases, such as multiple myeloma (MM), often experiences unique research hurdles that can delay or prevent lifesaving discoveries. HealthTree Cure Hub is a first-in-class software program designed to overcome these potential research hurdles.

METHODS We assessed whether HealthTree Cure Hub improved four commonly experienced research hurdles such as (1) small numbers of patient accrual to clinical trials and research studies, (2) shallow and isolated data sets, (3) high costs to answer research questions, and (4) lack of long-term follow-up patient data.

RESULTS As of June 2021, HealthTree Cure Hub, with its unique portal features, has attracted 9,225 patients with MM and diverse demographic backgrounds. While completing an online health profile, patients shared comprehensive data, as well as provided consent to contribute data from electronic medical records. Portal use answered research questions using patient-driven real-world data. This also cultivated relationships with patients and established communication channels that enabled continual patient contact to allow for long-term follow-up.

CONCLUSION These results suggest that a patient-driven data capture tool such as HealthTree Cure Hub will help alleviate common research hurdles, which, in turn, will accelerate MM research, develop new hypotheses, and ultimately improve survival.

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INTRODUCTION

Multiple myeloma (MM) is the second most frequent hematologic cancer worldwide.¹ In the United States, the incidence is 32,270 new cases per year, and more than 150,000 individuals live with myeloma in the United States.² Although MM is considered an uncommon cancer, incidence rates have increased by 126% between 1990 and 2016, with rates being two- to three-fold higher in African Americans than in Whites.^{3,4} It is a very heterogeneous disease with several clinical and genetic subtypes. Fortunately, progress has been made in MM care with 13 new therapies being developed in the past 15 years that have resulted in a significant improvement in survival.^{5,6} Despite the development of new therapies and increase in survival, MM remains incurable for the majority of patients. Accumulating reports have found small groups of patients that have maintained prolonged periods of remission being labeled as functionally cured and has led patients to ask if a cure is available to all.⁷

Researchers of less common or rare diseases, including MM, often experience hurdles that slow or prevent progress, such as (1) small numbers of patient accrual to clinical trials and research studies, (2) shallow and isolated data sets, (3) high costs to answer research questions, and (4) lack of long-term follow-up data.⁸⁻¹¹ To determine optimum treatment approaches, sequence of therapy, and ultimately curative approaches for all patients with MM, larger and more comprehensive data sets are needed.¹² This can be achieved through the patient's right to opt out of the Health Insurance Portability and Accountability Act and a transfer of their siloed health data to a centralized patient-driven portal, leading to comprehensive longitudinal data sets, which can be accessed to accelerate research.¹³

Several studies have demonstrated that online patient portals are crucial tools for rare disease research.¹⁴ In early October 2018, HealthTree Cure Hub was released to all patients with MM. Here, we report how our HealthTree Cure Hub, a first-of-its-kind online patient portal, overcame four common research hurdles and accelerated MM research.

ASSOCIATED CONTENT

Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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CONTEXT

Key Objective

Researchers of rare diseases, such as multiple myeloma, often experience pitfalls that obstruct advancement in their research.

Addressing common pitfalls could expedite research. This work examined whether the implementation of a patient-driven online data portal, HealthTree Cure Hub, could overcome these obstacles and be a research accelerator for researchers as well as serve as a disease navigator for patients.

Knowledge Generated

Thorough planning and development of HealthTree Cure Hub indeed aided in the overcoming common research pitfalls, such as small numbers of patient accrual to clinical trials and research studies, shallow and isolated data sets, high costs to answer research questions, and lack of long-term follow-up data. These accomplishments have also led to an acceleration of multiple myeloma research.

Relevance

Use of HealthTree Cure Hub could empower individuals affected by a terminal disease through resources offered in this online data portal as well as through participation in facilitated clinical research.

METHODS

Design

Before designing HealthTree Cure Hub, we established relationships with patients and caregivers over 8 years of myeloma advocacy work at the Myeloma Crowd by the HealthTree Foundation.¹⁵ Over this time, we identified potential barriers that inhibit the sharing of patient health data and throttle research (step 1). In 2016, with help from multiple stakeholders, we began the development of our online patient data portal. Following a patient-centered design approach, we sought the guidance of MM health care personnel (HCP), patients, and caregivers. Together, we thoroughly screened ideas (step 2) and developed a patient portal concept (step 3). After steps 1-3, we enrolled a subset of patients and HCP for testing a HealthTree Cure Hub Minimal Viable Product (step 4). We then finalized and released HealthTree Cure Hub in October 2018 (step 5; Fig 1). Since its release, steps 1-5 have been iteratively repeated to continually improve the online patient portal.

Population and Recruitment

HealthTree Cure Hub included patients who were diagnosed with related disorders including monoclonal gammopathy of undetermined significance, smoldering MM, MM, and other associated plasma cell dyscrasia diagnoses. The 8-year-old Myeloma Crowd patient advocacy programs allowed us to invite our current followers. The use of social media (Facebook and Twitter), television media (NBC's TODAY Show),¹⁶ internet advertisements (Google), e-mail, and word of mouth were also used to notify and recruit the patient population. Existing relationships with HCP, patients, and caregivers through the many Myeloma Crowd by HealthTree Foundation programs were key to patient recruitment.

Workflow

Internet access or cellular data and a computer, tablet, or cell phone were necessary to create a patient profile and to

gain access HealthTree Cure Hub. Once inside, a patient profile checklist was used to guide patients through the easy-to-follow onboarding process (Fig 2). Completion of the checklist collected all necessary health data and enabled patient access to their information and everything HealthTree Cure Hub has to offer (Data Supplement).

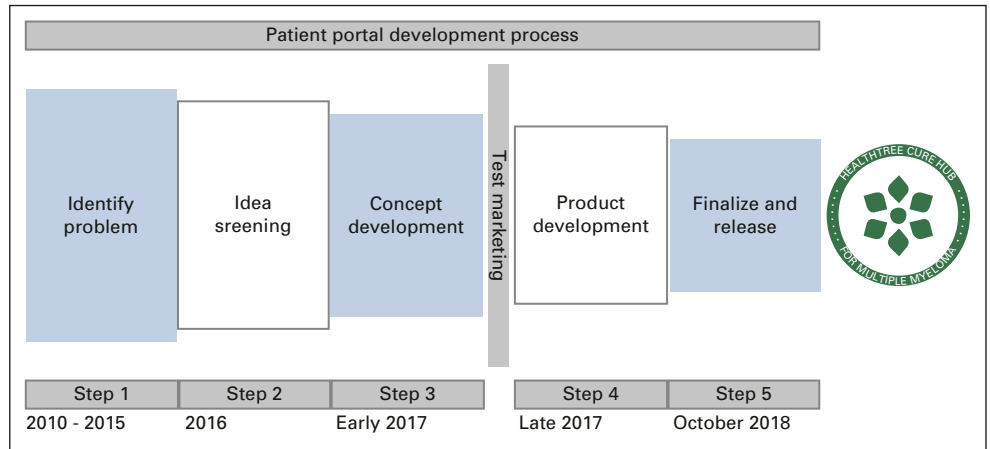
Data Curation

Data were curated from patient electronic medical records (EMRs) after obtaining electronically signed Health Insurance Portability and Accountability Act release forms. Data included patient diagnosis, information about the myeloma team (which included physician and caregiver), health and fitness, treatment history, and laboratory, imaging, and genetic results. After enrollment, patients could provide patient-reported health information such as demographics, type of insurance, patient-reported outcomes, health history, family history, lifestyle, and quality of life. Automated online data import was provided using HealthTree Connect software application connected to all facilities using Apple Health.¹⁷ When required, the data were manually entered from the medical record by a HealthTree Medical Consultant. All data were verified by a HealthTree Medical Consultant and physician before being incorporated in research analyses. Data received from patients were encrypted and then stored in the Google Cloud Platform (Google LLC, Menlo Park, CA) and additionally protected by Google's virtual private network. All accessed data were logged and monitored regularly.

Data Validation

To ensure accuracy and reliability, signed EMR consents were obtained, and all data were verified in a two-step process by a trained HealthTree Medical Consultant and then by a physician. EMR-based data such as laboratory values were automatically imported via the HealthTree Connect phone app when available.

FIG 1. The development process of HealthTree Cure Hub; adapted from the study by Marinissen.²⁰



Data Analysis

All data received from patients are encrypted and then stored in the Google Cloud Platform and additionally protected by Google’s virtual private network. Through an application programming interface, we can safely access and query the data. The results were exported in a .csv or .xlsx format, allowing us to run analyses and generate results.

Outcomes

The primary outcome of HealthTree Cure Hub was to overcome research hurdles for MM. Additional outcomes were to use internal tracking to record the total number of patients, validated patient profiles, and data accrual. We

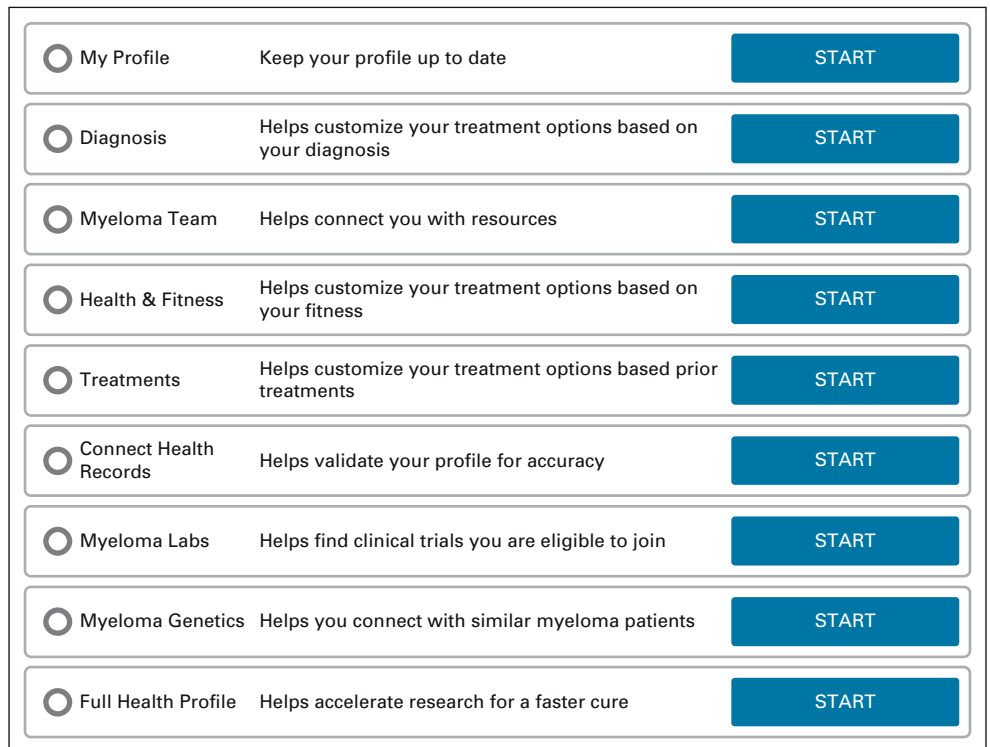
also used Analytics (Google) and Intercom software (San Francisco, CA, version 1.4) to monitor patient engagement and return users.

RESULTS

Hurdle 1: Small Patient Numbers and Insufficient Patient Accrual for Myeloma Research

To invite patients with MM to participate in a patient data portal, we raised awareness for HealthTree Cure Hub by the HealthTree Foundation programs including in-person meetings, social media, and television media, which led to steep increases in HealthTree Cure Hub patient population (Fig 3). In 2020, we conducted a study to understand the impact of the SARS-CoV-2 (COVID-19) pandemic

FIG 2. Screenshot of the checklist from the patient profile used to navigate new patients through the onboarding process.



on MM cancer patients and their experiences, which sparked another large increase in the total patient population. The benefits of internet searches, e-mail, and word of mouth also played a role in the patient population growth as determined by the patient's response to the optional account creation question, "How did you hear about HealthTree Cure Hub?" (Fig 4). As of June 30, 2021, there were 9,225 HealthTree Cure Hub participants.

HealthTree Cure Hub has accumulated a robust patient population with a median age of 65 years (range: 29-94 years), 54% were female and 46% were male, > 10% were either Asian (1.5%), Black (4.8%), American Indian/Alaskan Native (1%), East Indian (1%), Middle Eastern (< 1%), or Native Hawaiian (< 1%), 32% Hispanic White, and < 68% were non-Hispanic White. Patients from each state in the United States were represented. Plasma cell disease subtypes were active MM (77%), smoldering MM (13%), monoclonal gammopathy of undetermined significance (6%), amyloidosis (2%), and plasmacytoma (2%; Table 1).

Hurdle 2: Shallow Data

Although not mandatory, patients are encouraged to digitally sign medical record consents, thereby allowing HealthTree Medical Consultant to transfer significant patient information, which included data regarding the patient's diagnosis, physician(s) and caregiver, health and fitness, treatment history, laboratory, imaging, and genetic results, and full health profile (which included demographics, health history, family history, lifestyle, and quality of life). Patients were also capable of providing longitudinal data by returning to HealthTree Cure Hub and updating their data.

The more of the aforementioned data provided by the patient, the more benefits the patient received from HealthTree Cure Hub. Patients could view personalized treatment options, including personalized clinical trials, on the basis of diagnosis, transplant eligibility, treatment history, health and fitness, and other factors. Additionally, patients were able to find other patients with similar genetic features or on similar treatments through our Twin Machine technology. Patients were also able to view crowdsourced side-effect solutions, become educated using a comprehensive online myeloma curriculum in HealthTree University, participate in community forums, find a Myeloma HealthTree Coach, contribute to research, or interact with live reports. We found providing several benefits within HealthTree Cure Hub in both English and Spanish increased patient engagement, thereby deepening our patient data.

Once the HealthTree Cure Hub patient population was sufficiently large, we were able to study the existing data and invite patients to participate in institutional review board-approved myeloma investigator-supported surveys and studies. In combination with the curated patient data,

there have been 14 studies facilitated by HealthTree Cure Hub. These studies have resulted in 10 scientific publications (nine abstracts and one manuscript).¹⁸

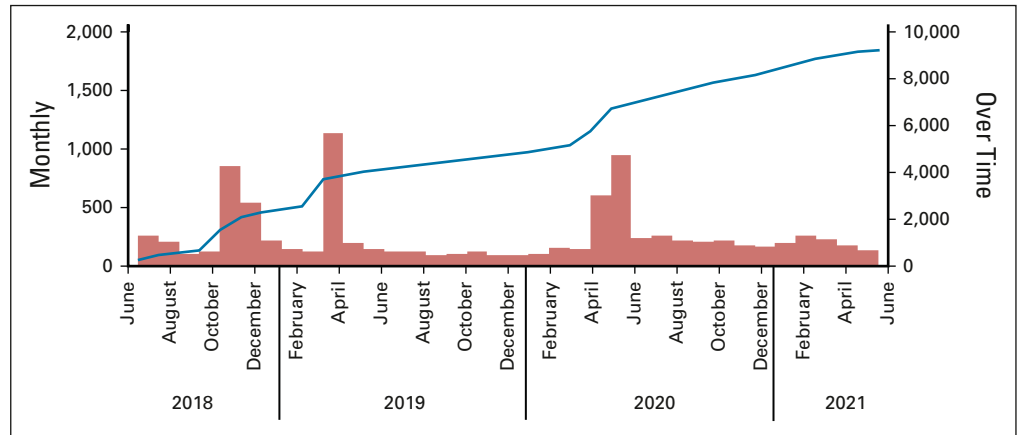
Hurdle 3: High Costs to Answer Research Questions

High costs are associated with disease research.¹⁰ HealthTree Cure Hub provided easy, complete, and free access to patient data, which enabled researchers to answer relevant questions that are not traditionally funded by industry or the federal government. These questions were either short-term or longitudinal in scope and included investigating the optimum induction therapy for standard-risk and high-risk patients, determining late treatment options for the subset of patients with $t(4;14)$, looking at the discordance between guidelines and real-world practice, determining the impact of COVID-19 pandemic, looking at trends in vaccination practice, and investigating links between psoriasis and MM. Additional real-world evidence questions have been researched regarding common comorbidities, demographic disparities, specific subpopulations, quality of life, and more. Using HealthTree Cure Hub, we were able to fill a gap that is historically overlooked by allowing the investigation of real-world data, and in this case, patient-driven real-world data.

Hurdle 4: Lack of Long-Term Follow-Up Data

Through HealthTree Cure Hub, patients were capable of aggregating and storing data from multiple providers, which enabled ongoing patient portal involvement and avoided long-term follow-up challenges such as retention, value, and loss to follow-up. Measures were implemented to ensure patient retention such as beneficial uses inside of the HealthTree Cure Hub platform, a patient experience team, myeloma coaches, community forums, chapters (groups designed to connect, support, educate, and provide resource—groups are based on interest, demographics, treatments, region, or status of myeloma), round table meetings, weekly e-mails, and sharing of study results. The utilization of a patient experience team created a metaphorical two-way road that allowed patients to log-in and use HealthTree Cure Hub but allowed a patient experience team member to reach out to them and provide assistance. At the time of the preparation of this manuscript, there were 126 myeloma coaches mentoring 744 patients, over 25 discussion types within the community forums, 16 chapters (seven pending), and monthly round table meetings keynoted by MM specialists. We examined value by determining the percent of the total number of patients who returned to HealthTree Cure Hub by month. In April 2020, we released the Twin Machine feature and a COVID-19 research study. During that month, we saw an increase of patient engagement from 39% of all patients to 43% (Fig 5). We also saw increases in patient engagement in September 2020, when we released community forums (47%), and in February 2021, when we released patient solutions and a COVID-19 part 2 research study (48%).

FIG 3. Total number of patient profiles created each month (bars) and over time (line).



Based on these observations, we concluded that HealthTree Cure Hub provided value to the patients which led to the return use of the patient portal. Finally, we implemented measures to avoid lost-to-follow-up patients through multiple contact points such as e-mail and phone for patients and family of the patients, as well as annual follow-ups and revalidations.

In the endeavor of overcoming research hurdles, adequate safety and security measures were instituted so that there was no foreseeable harm or unintended consequences experienced by users of the HealthTree Cure Hub online patient portal.

DISCUSSION

Less than 5% of adult patients with cancer are recruited to clinical trials and hence their experience of the disease including response to therapy, side effects of treatment, and survival is not available. The collection of real-world data exploring the outcomes for nonclinical trial patients including both clinical data and patient-reported outcomes is becoming increasingly important. Several data sources are available including billing or insurance claims databases, EMRs, and local/national/international clinical registries. Although each of these data sources is important and useful, none are patient-centered or patient-volunteered or necessarily comprehensive.

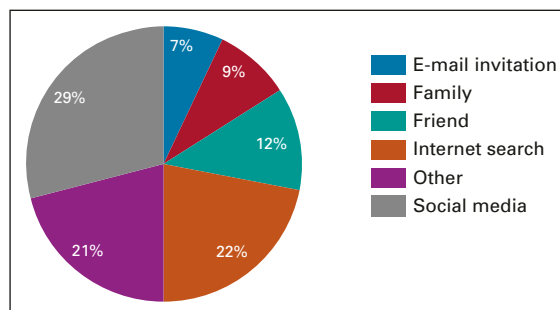


FIG 4. Pie chart spotlighting how patients heard of HealthTree Cure Hub.

In MM, the range of approved therapeutic options is expanding, and treatment decisions are becoming more complex. This places a particular emphasis on real-world data to help understand the evolving treatment practices and therapeutic outcomes in the real-world setting, informing decisions for both patients, caregivers, and physicians. Regulatory agencies are now appreciating the importance of such initiatives as clinical trials are able to provide robust evidence that a treatment is effective in a select homogeneous patient population, whereas real-world data can assess the generalizability of such data to the wider patient population.

In addition to these obvious benefits of real-world data collection, researchers of less common or rare diseases are able to leverage further benefit from such studies including being able to address research hurdles that slow or prevent progress, such as (1) small numbers of patient accrual to clinical trials and research studies, (2) shallow and isolated data sets, (3) high costs to answer research questions, and (4) lack of long-term follow-up data.

With these research hurdles in mind, a novel patient-driven portal for patients with MM was developed. To achieve this, the Marinissen vetted user-centered design process was modified into a research-based process and combined with the *Nail It Then Scale It* entrepreneurship process.^{19,20} With the HealthTree Cure Hub patient portal realized, patients and researchers mutually benefited from one another and the portal, creating a symbiotic relationship that has led to sustained growth over time. An example of its utility can be seen in the speed of patient accrual to research studies. In a recent German study, the researchers collected questionnaires from 552 patients with MM from a large myeloma center in Germany over the course of 3 years.²¹ An identical study was offered through the HealthTree Cure Hub and accumulated questionnaires from 678 patients with MM in just 3 months. Because of the nature of our patient population, this study received research data from individuals with diverse social backgrounds, different races, and treated in different areas of the country, which made these data far more representative than other data collections. In

TABLE 1. Demographic Characteristics of Patients Who Use HealthTree Cure Hub

Characteristics	Value
HealthTree Cure Hub	
Profiles	9,225
Sex, %	
Female	54
Male	46
Age, median (range), year	65 (29-94)
Race, %	
White	89
Non-Hispanic	68
Hispanic	32
Black/African American	4.9
Asian	1.4
American Indian/Alaskan Native	1
East Indian	< 1
Middle Eastern	< 1
Plasma cell disease type, %	
MM	76
Smoldering myeloma	13
MGUS	6
Amyloidosis	2
Plasmacytoma	2
Other	< 1

Abbreviations: MGUS, monoclonal gammopathy of undetermined significance; MM, multiple myeloma.

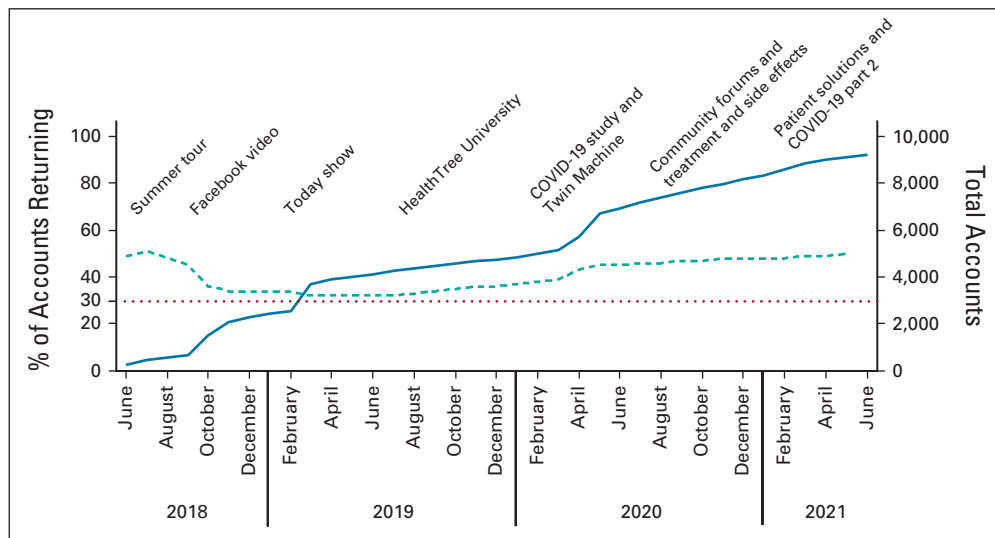
our Multiple Myeloma and COVID-19 Study to assess the acute effects of the pandemic, we had 1,358 participants from April 2020 to August 2020. In February 2021, we released a follow-on study entitled Multiple Myeloma and COVID-19 Study Part 2 (in press) to assess the chronic

effects of the pandemic. At the end of June 2021, we had 991 participants with 535 (54%) of these patients being return participants. This study is a testament to the long-term relationship HealthTree Cure Hub establishes with the patients and that patients are willing to contribute their data and participate in ongoing surveys and studies inside of the platform.

Ehrenstein et al emphasizes that interoperability be achieved to prevent patient data silos within proprietary information systems that make it difficult or impossible to develop large EMR-based registries and conduct research.¹³ With patients with MM living longer, the collection of longitudinal data of real-world patients is an important component of patient registries that desire to track patients for many years. HealthTree Cure Hub's patient-centric design maximizes the depth of data collected by recording data across time instead of a single time point. Some health care data experts argue that EMRs are inadequate without the information provided by the patients themselves as patients are the only stakeholders capable of contributing deep and complete data.²² Therefore, HealthTree Cure Hub practices a patient-input and medical consultant-verified approach to maximize the potential for population-based analyses and to draw reliable conclusions. As a result, we have published nine abstracts, seven to ASCO²³⁻²⁹ and two to the American Association of Cancer Research,^{30,31} and published one peer-reviewed manuscript in *Dermatologic Therapy*,¹⁸ with others in preparation.

The genesis of HealthTree Cure Hub was a result of the MM patient Jenny Ahlstrom who wanted to view patients with similar tumor genetics and sort them by time since diagnosis to identify which treatment might give her the best outcome. Ahlstrom was astonished to find that large corporations such as Google, Microsoft, and IBM attempted similar endeavors but came up short because they failed

FIG 5. Comparison of the total number of patient profiles created over time (solid line), percent of patients returning to HealthTree Cure Hub (dashed line), and the average percent of patients from the 2015 Medicare Electronic Health Record Program accessing their online health information (dotted line). Significant events are shown above the lines at approximate dates.



to engage the patient and lacked patient trust. In scenarios where patient portals are implemented, a recent government report has found that only about a third (30%) of patients use the portal; this is primarily because of a lack of value beyond the ability to access their health data.³² Since patient registries and online portals are crucial tools for rare disease research,¹⁴ Ahlstrom took matters into her own hands and developed a patient portal saturated with value and patient engagement. In addition to recently released features, providing educational courses through HealthTree University was a key feature that encouraged returned visits to the platform. HealthTree University was released around August 2019 and since its release, more than one third of all HealthTree Cure Hub patients return each month (Fig 5). With the addition of the Twin Machine feature, patients were motivated to complete their patient profiles to find other patients with similar cancer diagnoses. Once a virtual MM twin is identified, the patient had the ability to view anonymized treatments and outcomes and had the possibility to connect via private chat with their twin. These features and others not discussed in the paper played a crucial role in promoting patients to join HealthTree Cure Hub, engage, and return on a regular basis.

The use of HealthTree Cure Hub to answer relevant research questions has several advantages. First, HealthTree Cure Hub has amassed a large database of patient health data that is easy to use and free to obtain. In a very short period, this database has enabled numerous publications and disseminated knowledge of MM research, thereby increasing awareness and possibly fostering future collaborations among different institutions that could lead to an even bigger database. Second, in contrast to other databases, HealthTree Cure Hub captured longitudinal data from a diverse patient population as opposed to a single time point and location. The first and second advantages gave way to a third advantage of a large sample size that provided sufficient statistical power. This is

particularly important for rare disease research as statistical power poses a unique challenge, and thus, increasing the sample size can aid in drawing definitive statistically significant conclusions.³³ HealthTree Cure Hub did not exist 3 years ago, yet these capabilities are providing a research revolution in MM.

Loss to follow-up is inevitable with time, even in the best of circumstances. This may be due to patient death, loss of interest, adverse events, change in physicians and locations, or other reasons. Minimizing this loss is possible by building relationships and engaging and supporting the patient community over the lifetime of their disease.³⁴ A number of measures previously mentioned were used to mitigate potential loss. For example, through the Myeloma Coach initiative, patients have found personalized peer-to-peer support from a trained patient or caregiver known as a Myeloma Coach. With the help of a Myeloma Coach, patients are assisted through the HealthTree Cure Hub onboarding process, its capabilities, and welcomed into an MM community. Finally, we implemented measures to avoid lost-to-follow-up patients through multiple contact points such as e-mail and phone numbers for patients and the family of the patients.

In conclusion, our results suggest that the development of the innovative HealthTree Cure Hub by the HealthTree Foundation successfully overcame four common research hurdles experienced in MM research, resulting in the accumulation of the most comprehensive patient-driven longitudinal real-world MM data available today. Importantly, individuals affected by this devastating disease can aid in accelerating research and find help independent of their living conditions, location, and socioeconomic status. All they need is internet access and a computer, tablet, or cell phone. The lessons learned and advantages gained from this initiative provide a template to explore a similar approach in other rare disease areas where barriers to progress exist.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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