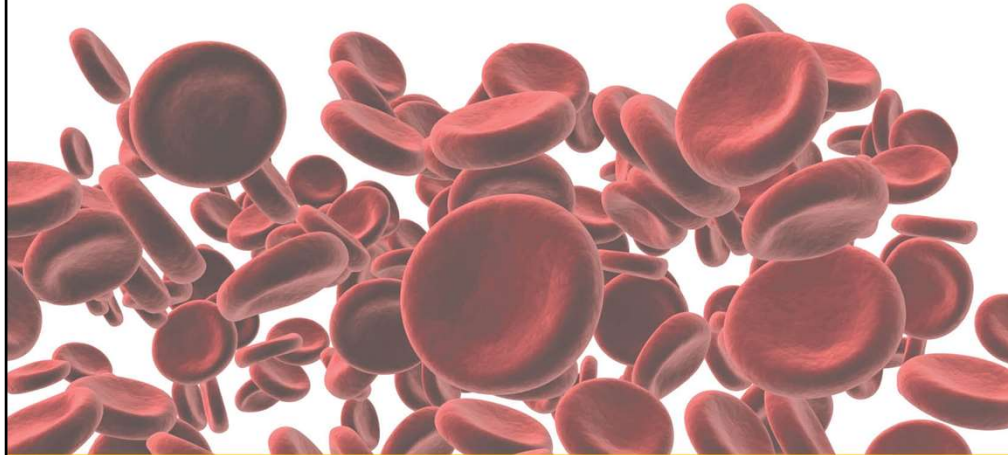


# Challenges and Opportunities for Managing Hemophilia



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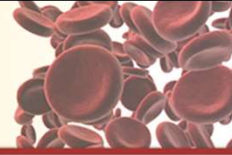
Welcome to the continuing education activity entitled “Challenges and Opportunities for Managing Hemophilia”. We are pleased to provide you with what we hope will be an informative and meaningful program.

We would like to acknowledge that this activity is supported by an educational grant from Novo Nordisk and we would like to thank them for their support.



This presentation, entitled “Collaborating to Improve Patient Management,” will provide information from the Hemophilia Treatment Center, or HTC, Nurse Coordinator Perspective.

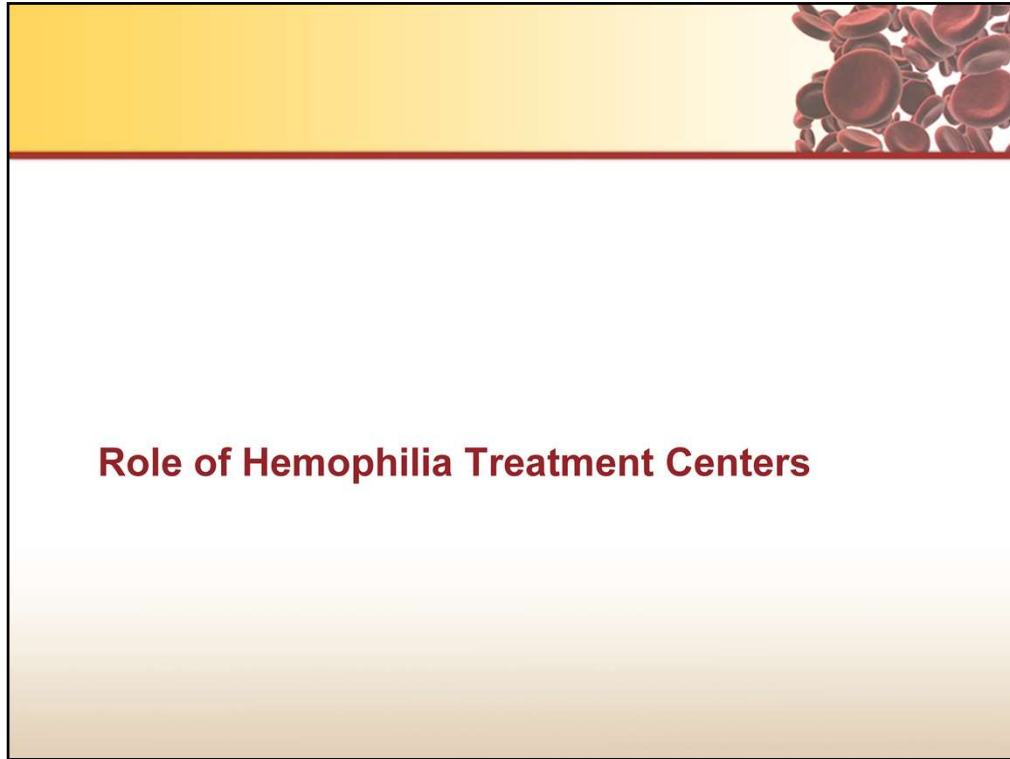
## Objectives



- Increase understanding of the role of the Hemophilia Treatment Centers (HTCs)
- Enable payers to establish better relationships with HTCs
  - *Goal: To better navigate the system on behalf of hemophilia patients*

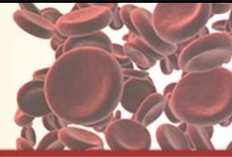
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The objectives of this presentation are to increase understanding of the role of the Hemophilia Treatment Centers, or HTCs, and enable payers to establish better relationships with HTCs for the goal of better navigating the system on behalf of hemophilia patients. We will focus on the management of hemophilia beyond drug therapy and you will see that delivering optimal outcomes requires more than just addressing disease properties.



First, let us examine the role of the HTC, which the hematologist described as state-of-the-art centers where bleeding disorders patients receive care.

## HTC Team Members



### Core Team Members

- Patient / Family
- Hematologist
- Nurse
- Social worker
- Physical therapist

### Additional Team Members

- Other physicians
  - *Primary care*
  - *Orthopedics*
  - *Infectious disease*
  - *Hepatology*
  - *Obstetrics-gynecology*
- Geneticist
- Pharmacist
- Dental
- Educational/vocational counselors

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The HTC team is comprised of a number of members. The patient and their family are at the center of the HTC core team. Many HTCs throughout the country serve both pediatric and adult patients and thus have pediatric hematologists and adult hematologists on staff. Other HTCs are either specifically pediatric or adult centers.

Depending on the number of patients served by the HTC, there will either be a single nurse or multiple nurses, and the nurses tend to have the closest relationship with the patient population.

Most HTCs have social workers to provide support for the patients and their families.

As joint disease is a significant part of the hemophilia sequelae, a physical therapist is therefore a crucial part of the HTC team. Many HTCs have a physical therapist housed within their treatment center, while others rely on physical therapists from the hospital rehabilitation department or from community outpatient physical therapy providers.

In addition to the core team members, there are many other people in the health care environment with whom HTCs collaborate to provide top-of-the-line care for these patients.

The HTC collaborates and coordinates with medical care providers outside of the center. Primary care physicians are crucial for carrying out the treatment plan that the HTC develops for each patient with hemophilia.

Patients are referred to orthopedists when there are signs of joint issues. A close relationship between the HTC and an orthopedic surgeon who is knowledgeable about hemophilia is extremely important.

Infectious disease specialists and hepatologists treat older hemophilia patients who have contracted HIV or hepatitis C and/or B, which was much more prevalent in the 1980s than it is today.

Women with bleeding disorders such as von Willebrand disease or those who are symptomatic carriers of hemophilia often are treated by obstetricians and gynecologists within the community who then collaborate with the HTC to create treatment plans.

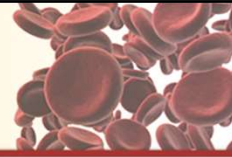
HTCs often have the availability of a genetics counselor who provides genetic counseling and family planning guidance.

Many HTCs have 340B pharmacy programs and/or pharmacists on staff to help dispense clotting factor concentrate. Often this is dispensed at a decreased cost to the patient and their insurer.

Large centers may also have a dentist or dental hygienist on staff, while others may have a list of dentists to whom they refer patients.

Finally, large centers will have educational or vocational counselors on staff.

## Role of HTC: Model of Comprehensive Care for a Chronic Disease



- Coordination of state-of-the-art medical treatment for persons with hemophilia throughout their life span
- Education
- Research
- Outreach
- Emotional support
- Preparation of patient and families for home treatment
  - Identifying candidates
  - Teaching concepts and skills
  - Oversight
- Coordinate use of specialty pharmacies and/or home health

*HTCs provide care for patients, whether or not they have insurance*

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Care provided at HTCs presents a model of comprehensive care for chronic diseases. Hemophilia is a complex disorder that requires care from experts aiming to achieve optimal outcomes. The role of the staff at the HTC is to provide and coordinate state-of-the-art holistic care throughout the patient's life course.

HTC services include patient and family education, as well as education for the community and other healthcare providers. HTCs also focus on research to advance knowledge and treatment of bleeding disorders. Many states have only one HTC; however, those HTCs strive to provide the same level of care to all patients regardless of distance from the treatment center through statewide outreach. Outreach also targets vulnerable, at-risk and underserved populations. Another HTC role is to provide psychosocial and emotional support for patients and their families.

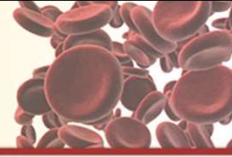
One critical role of the HTC is to help prepare patients and families for home treatment, which is the standard for patients with severe hemophilia. HTCs identify appropriate candidates who can perform home treatment, teach the patient or the caregiver the concepts and skills that they need to do this successfully and safely, and continue oversight of those families to ensure their care is appropriate and their needs are met.

HTCs also coordinate the use of specialty pharmacies and home healthcare companies to provide complete services to patients and families.

Importantly, HTC's do not provide care only to patients with insurance. HTC's see every patient that has hemophilia regardless of insurance status and provide the best services possible for that patient.



## HTCs and Patient Care



- **Individuals with hemophilia are evaluated at the HTC at least annually**
  - *Children may visit the HTC more frequently than adults*
  - *Number of contacts depends on:*
    - *Patient needs*
    - *Geographic access*
- **In-clinic services also include treatment of acute bleeds**
  - *Replace emergency department visits and, perhaps, physician office visits*
- **Staff is available by phone 24/7 to provide consultation with**
  - *Providers for management of emergency situations*
  - *Patients and caregivers about treatment decisions or emergency situations*
- **Staff is available during normal business hours to provide**
  - *Education*
  - *Emotional support*
  - *Coordination with health plans*
  - *Coordination with specialty pharmacy providers*

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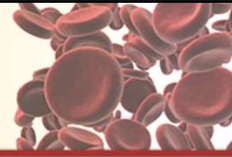
While the frequency of visits per patient varies, persons with hemophilia are seen in HTCs at least once per year. Children tend to visit the HTC more frequently, especially at a young age, to learn about managing hemophilia and to adjust clotting factor treatment doses as they grow. Other patient-specific clinical and psychosocial needs as well as geography and ease of access to the HTC determine the frequency of visits for an individual patient.

In addition to providing education and support, HTCs will evaluate and holistically treat an individual with an acute bleeding disorder five days a week during business hours. This reduces the need for patients and families to utilize emergency department resources, quickens treatment, reduces complications, and lessens the need for visits to other healthcare facilities.

Moreover, staff at all hemophilia treatment centers is available by phone 24 hours a day seven days a week to provide consultations for community providers who have questions or issues in an emergency situation and for patients and caregivers who have questions or concerns about treatment decisions, emergencies, and acute bleeds.

During normal business hours, staff is always available to provide services including education, emotional and psychosocial support, coordination of care with health plans, and coordination with home care companies and specialty pharmacies.

## Nursing Education Addresses...



- Hemophilia and its treatment
- Assisting family with treatment decisions
- Patient understanding proper dosage calculation optimizing clinical outcomes and minimizing resource wastage
- Reconstitution of medication
- Identifying a vein for therapy administration
- Managing the risk of infection
- Managing dosing
- Managing inventory of medication and supplies
- Minimizing impact on activities of daily living

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An important role of the nurse in the HTC is patient and family education. This education is quite broad, starting with hemophilia, what it is, how it's treated, the genetics of hemophilia, and identifying family members at risk.

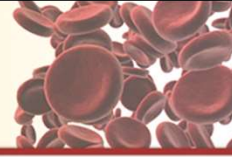
HTC nurses assist patients and families with treatment decisions, treatment products, and treatment regimens. The HTC nurse tries to help patients and families understand not just what their correct dose is on a given day, but how to calculate the correct dose for their weight and for individual clinical scenarios such as minor acute bleeding episodes. The purpose of this is to improve outcomes and minimize the waste of clotting factor concentrate and other resources.

The HTC nurse teaches patients and families how to restore and reconstitute clotting factor products, how to identify the appropriate veins for infusion and how to access those veins to administer therapy. The HTC nurse works with families to manage the patient's risk of infection and safely dispose of biological waste.

HTC nurses help patients manage their dosing, both calculating the correct dose and optimizing the dose in terms of vial sizes and mixing of multiple vials. Another important role is to help the patient manage inventory of medication and supplies to ensure that patients do not run out of factor, and on the other hand, to ensure that they are not stockpiling clotting factor, letting it expire and wasting a valuable resource.

In providing this education, HTC nurses try very hard to minimize the impact that hemophilia has on the activities of daily living for both the patient and the family. The HTC nurse asks, “How can we enhance their treatment regimen so they can best participate in the activities that they choose with minimal interference from their bleeding disorder?”

## HTC and Patient Education: An Example



- Treatment requires IV access and often is administered in patient's home
  - Challenging for patient, caregiver, and family
  - Home therapy reduces resource consumption (e.g., reduces clinic and emergency department visits)
    - Decreases the risk of complications from bleeding
- Outcomes
  - Minimizes lifestyle disruptions
  - Reduces hospital visits
  - Reduces other costs
  - Enables prophylaxis

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Treatment of hemophilia requires intravenous access which is much more difficult than taking a pill or putting on a patch. As mentioned previously, the ideal location for treatment of either prophylaxis or minor acute bleeding for a patient with severe hemophilia is in the patient's home.

Because hemophilia treatment is intravenous, home treatment can present a real challenge for the patient, the caregiver, and the family; home treatment requires support, education, and encouragement from the HTC nurse. This is especially true for parents of young children. Imagine a parent of a two-year-old trying to hold down the child, find a vein, mix the clotting factor concentrate, successfully access the vein and administer treatment to a crying or uncooperative baby.

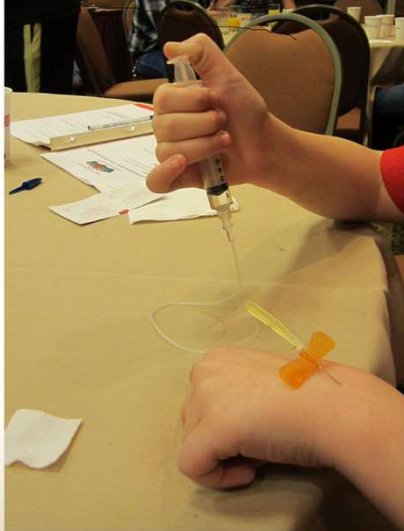
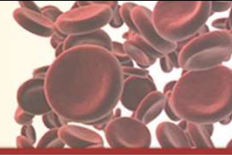
Despite the challenges, home therapy is important because it reduces resource consumption and eliminates many visits to outpatient clinics and the emergency room. Perhaps most importantly, it decreases the risk of complications from bleeding because it allows patients to treat much more quickly, at the first sign of a bleed. Patients do not need to present in clinic or the emergency room if they are able to treat themselves easily at home.

A crucial outcome of home treatment, and an important emphasis in education to families, is the minimization of lifestyle disruptions for the patient, parents, siblings, and caretakers.

Parents do not have to take time off work; children do not have to miss school in order to attend clinic visits for routine treatment or treatment of minor acute bleeding episodes. Home treatment also reduces hospital visits and inpatient admissions, and reduces other associated costs as well.

Importantly, home treatment enables patients to infuse prophylactically on a regular schedule without requiring multiple weekly visits to the HTC. Thus, home treatment optimizes joint health outcomes as well.

## Self Administration of Factor Concentrate

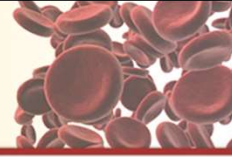


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This slide is a demonstration of a young man with hemophilia who is self-treating. He is able to complete the entire process in approximately 10 minutes, including recording his treatment in a home infusion log. For a well-trained patient, self-infusion at home is a quick and convenient means to achieve optimal treatment, minimize use of healthcare resources, and maximize patient and family time.

## HTCs and Outreach Education



- Education for
  - Primary care providers
  - Hospital providers
  - Dentists and other specialists
  - Schools and employers
- Topics
  - Understanding hemophilia and intermittent nature of episodes
  - Safety measures
  - Emergency protocols
  - Ongoing care
    - Type of care required
    - Impact on patient, caregiver, and family

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HTC nurses not only provide education for patients and families, they also provide education for primary care providers in written and verbal communication every time a patient is admitted to the hospital and when patients come for their routine evaluations.

HTC nurses aim to provide outstanding and effective education to hospital providers, emergency room staff, and inpatient nursing units and residents. Education is provided not just in the HTC-affiliated institutions, but also in the institutions that patients utilize in the community. HTC nurses also provide outreach and education for dentists, dental hygienists, and other specialists who may perform invasive procedures with the patient that require a treatment plan from the HTC.

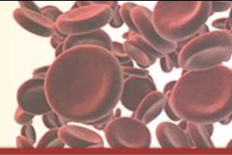
Finally, HTC nurses also do outreach and education for school personnel in schools attended by a child with hemophilia as well as with employers of organizations that employ an individual with hemophilia or the parents of a child with hemophilia.

When doing this education, the HTC nurse emphasizes basic information about hemophilia and especially the intermittent nature of bleeding episodes, which is often misunderstood by lay people. The HTC nurse promotes safety to minimize the risk of injury and bleeding episodes for the patient, and discusses emergency protocols and what to do in specific situations, including who to call and how to access help.

The HTC nurse also conveys the individual's ongoing care needs: what type of care is required and the impact of that care on the patient, caregiver, and family.

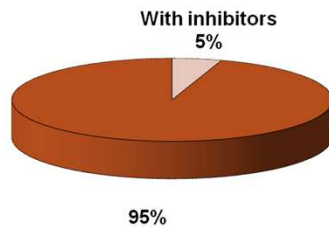


## Patients Who Have Developed Inhibitors Work Closely With the HTC

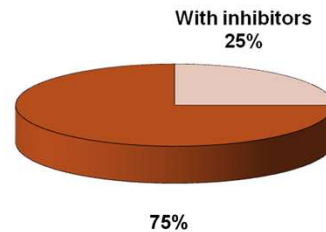


- Patients with inhibitors are the HTC's most challenging patients

**Estimated HTC patient volume**



**Estimated HTC staff time**



- Inhibitor patients require an exponential increase in
  - Treatment plan management to prevent and stop bleeding
  - Telephone interaction
  - Education
  - Support for school or employment
  - Pain management

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Patients with hemophilia and inhibitors are very challenging to the HTC nurse. Development of an inhibitor greatly impacts the life of the patient with hemophilia, as well as the resources of the HTC. Even though patients with inhibitors represent a small percentage of the total number of patients served, they take up a much larger proportion of HTC staff time than do patients without inhibitors.

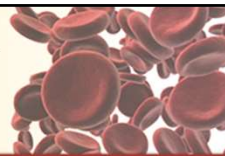
Inhibitor patients require an exponential increase in time of the HTC staff to develop a treatment plan to prevent bleeding and stop frequent bleeding, which is not as straightforward in a patient with an inhibitor as in a patient without an inhibitor. HTC nurses spend a lot of time on the phone with patients' families, emergency providers, and primary healthcare providers to manage these patients on an outpatient basis. HTC nurses provide ongoing education for the patient, the family, and other community resources.

HTC nurses also provide support for schools or employers. Children with hemophilia and inhibitors miss a lot more school than patients without inhibitors; parents of these children are likely to miss more work; and adult patients with inhibitors are likely to miss work more frequently than those without inhibitors. Patients with inhibitors as well as parents of patients with inhibitors need the HTC nurse's support to advocate for themselves with their employer, as well as educate their employer about the inhibitor.

Finally, patients with inhibitors are more likely to have pain issues because of chronic joint

bleeding and other bleeding that they have; and the HTC nurse spends time managing and helping to prevent and relieve pain in these patients.

## Improved Ability to Enhance Quality of Life for Patients with Hemophilia



- **Advances driving improved quality of life**
  - *New medications*
  - *Improved access to care through the HTC*
- **Accomplishments**
  - *Improved quality and reduced cost of care*
    - *Decreased hospitalizations*
    - *Reduction in joint disease*
    - *Decreased complications of bleeding and of treatment*
  - *Improved quality of life*
    - *Improved mobility and function*
    - *Increased attendance at schools*
    - *Increased ability to develop a career*
    - *Decreased absenteeism from work – adult patients and caregivers*
    - *Improved productivity at school and work*
    - *Minimized lifestyle interruption for the whole family*

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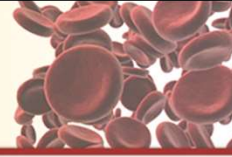
Fortunately over the past several decades, great advances have been made in hemophilia care, and these advances have significantly improved the quality of life of individuals with hemophilia and their families. We can attribute these improvements directly to advances such as new clotting factor products that are available. These are safer products with smaller volume, greater ease of infusion, and prophylactic treatment designations. Improvements are also attributable to improved access to care that patients in the United States have through the HTC network, which has been shown to decrease morbidity and mortality in this population.

Through these advances and with the HTC network, we have been able to improve quality and reduce the cost of care for patients with hemophilia by decreasing hospital admissions. Because of prophylaxis and timely and appropriate clotting factor replacement for acute bleeding episodes, there has been a reduction in joint disease, and then a resulting decrease in complications of bleeding and the treatment of bleeding in patients with hemophilia.

Patients and families are experiencing an improved quality of life. HTC patients have improved mobility and function, they have much less absenteeism from school or work, they are able now to plan, develop, and work towards a career, and there is decreased absenteeism from work for the adult patients as well as for the parents of children with hemophilia. While at work or school, patients are also able to be more productive. They

can concentrate more on their school or work and less on hemophilia or bleeding. HTC's have played an important role in minimizing the lifestyle interruption that hemophilia causes for the whole family.

## HTC Claims Submission



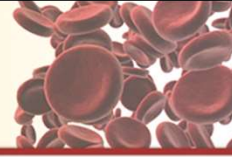
- HTCs submit claims only for direct patient care
- HTCs do not submit claims for the following services
  - *Coordination of care*
  - *Education (e.g., treatment advice that is available 24 hours per day)*
  - *Emotional support*
  - *Research*
  - *Outreach*
  - *Advocacy*
- These services may be duplicated or supplement some of those provided by health plans' case managers
  - *Creates opportunity for improved coordination*

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In terms of payer perspectives and HTCs, it is important to recognize that HTCs submit claims only for direct patient care, a small part of what they do. HTCs do not submit claims for services that are unbillable, such as coordination of care; education provided in person, on the phone, or in the hospital 24 hours a day, seven days a week; emotional and psychosocial support; advocacy efforts; research done to improve care; outreach to improve access to care and reach vulnerable or at risk populations; and advocacy in the community and workplace, in the school, and with government and community agencies.

Sometimes HTCs find that some of the services they provide are duplicated or supplement those same services provided by health plan case managers. HTCs see this as an opportunity to improve coordination and decrease duplication of efforts.

## HTC/Payer Partnership Opportunities



- More efficient communication process and care coordination
  - *Dedicated contact at each health plan to communicate with each HTC*
  - *Expedited contact (e.g., less waiting time to reach the contact at each health plan)*
  - *Standardized forms for pre-certification and prior authorization that are easy to complete*
  - *Streamlined process for updates to requests for pre-certification and prior authorization*
- HTC can provide educational programs for payers and specialty pharmacy providers

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There are opportunities for HTCs and payers to collaboratively develop an approach to care to ensure they are using resources wisely and not duplicating efforts. They can work towards more efficient communications and coordination of care for HTC patients.

For instance, HTCs could have a dedicated contact at a health plan with whom they could more easily communicate. This would provide expedited contact, less waiting to reach the contact at each health plan, and a way to circumvent the long telephone tree that healthcare providers encounter when they contact health payers.

Another opportunity is the implementation of standardized, easy-to-complete forms for precertification or prior authorizations, which would streamline process of getting these approvals. Finally, HTCs are always available to provide educational programs or meetings to assist with collaboration for payers and specialty pharmacy providers.