

UNIVERSAL TRANSFER PROTOCOL PROJECT PHASE ONE FINAL REPORT

SUBMITTED BY im21
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- this report is best viewed online, as a Google doc, so that all the hyperlinks to report sections and web pages are active
- verbatim statements used in this report are not attributed to any individual to protect confidentiality -- unless that individual gave us permission to attach his/her name to a verbatim.
- all references that appear within parentheses, eg. (see Section 2c, parts i, ii, iii, iv), are references to sections in this report

1) Executive Summary

“Universal Transfer Protocol (UTP) is a process across the entire system that gives all partners who have a role in the patient’s care access to the same standardized information and the responsibility to ensure that the information is accurate, current, and supports the patient’s goals and quality of life.”

Heather Johnson, ADRC (Aging and Disabilities Resource Centers) project manager

According to the ACTT proposal, Vermont providers receive an estimated \$850M per year to deliver a diverse range of services to help 40,000 Vermonters live as independently as possible. The UTP project is a significant opportunity to improve comprehensive and integrated service delivery and care coordination. Ultimately the UTP will enable bi-directional electronic and other types of improved communication to support people with the most complex, chronic, and long-term needs for services and supports across the health continuum.

The consultancy, [im21](#), was engaged by the State of Vermont for a five month period to undertake Phase One development of the process for designing the Universal Transfer Protocol (UTP). In addition to this report, the final deliverable is a Project Charter that presents plans for advancing the next phases of the UTP work.

Individuals with complex medical, behavioral, functional, social, and environmental issues receive services across the spectrum of care from hospitals to home. These individuals account for approximately 5% of the population, but require more than 50% of all expenditures for acute care, post acute care, and community based services and supports. They all have complex care requirements and receive care in multiple settings from multiple providers. They are also heavy users of community based services. Despite the benefits of care coordination, there is no communication or technology infrastructure in place to support the exchange of information across the continuum of care for these individuals.

In order to address the triple aim, these high cost individuals must receive complex care that is highly coordinated. This, in turn rests on the ability to reliably exchange information that has a common meaning and meets the needs of the receiving care providers. The UTP process begins with determining the information that the receiving service providers need to receive in order to provide safe, effective, and efficient care. It is at the level of the most basic business processes that we assess these data needs because we know that these processes already have high intrinsic value to the service provider and will be completed because they are essential to the business operation of the entity.

A basic tenet of UTP is that it reflects a profound change in the orientation of the “service system” from provider centric organization to person centric design. As a corollary, the first step in developing a shared vocabulary among the different health, rehabilitation, and support service providers is to create the vocabulary that enables interoperable exchange between service providers and the individual

(including immediate caregivers). Without this link and the ability to identify and exchange what matters most to the individual, the system will remain provider centric.

Ultimately, the Universal Transfer Protocol (UTP) will enable the creation of standardized, interoperable data sets, shared standards for information transfer, and performance metrics -- so that accurate and timely data can be shared amongst all providers involved in patient care. UTP is not a form; it is a process for developing shared data sets and transferring them.

In Phase One of the UTP project, we focused on the populations who, besides being heavy users of acute and post acute providers, also make heavy use of LTSS (long term services and supports). Likewise we focused on LTSS providers who care for a large number of individuals. We did this for several reasons:

1. LTSS providers are involved in the care of almost all high cost individuals.
2. LTSS providers offer the home and community based services that support individuals' abilities to remain at home and practice better preventative healthcare, and therefore avoid costly emergency room visits and repeated hospital readmissions.
3. While there are data exchange systems in place for connecting some acute and post acute care providers, LTSS providers are out of these communication loops.

Through interviews with over fifty providers, patients/clients and caregivers, and ongoing discussions with key area agencies (e.g. Southwestern Vermont Council on Aging) and existing patient care initiatives (e.g. the Aging and Disabilities Resource Centers Initiative and the Vermont Health Care Innovation Project) we gathered and analyzed preliminary data needs, data gaps, and provider data exchange processes. Among our findings were the following:

- Most exchanges involve some form of direct provider to provider contact.
- When patient referrals to entities are made, the referring agency is not aware of the data needs of the receiving agency.
- There are no mechanisms to alert the provider network involved in a person's care about changes in health status, such as emergency room visit, hospital admission, hospital discharge, assignment of case manager.
- There is a gap between providers' job titles and the work they actually do. Providers are not necessarily aware of each other's real roles in patient care.
- Significant time is spent tracking down the agencies and providers involved in the person's care.
- Duplication of effort is not infrequent because there are no mechanisms that alert providers about what care and support efforts are already underway.
- There is the potential for care plans and medication regimens to be unreconciled, duplicative, and potentially harmful.
- Patient/client and caregiver profiles and goals are not typically part of the medical record.

- Technology transparency does not exist. Entities have their own systems which often do not communicate with those of other entities. Some systems allow read access only to some providers.

The UTP development methodology started with these findings and focused on the providers' needs. In this way, UTP engaged providers in building the processes and data elements they will ultimately use. The fundamental processes needed to develop the UTP are:

- Identify the most basic exchanges in the system,
- Determine the information needed to support these exchanges, and
- Establish a shared meaning for the information.

The objective of UTP Phase One was to design the process for developing an initial set of standardized data elements for exchange between providers and receivers of services, as well as a method for continuously refining and enlarging that data set. While the UTP project will ultimately provide the basis for electronic information exchange by all stakeholders, this was not a focus of Phase One.

UTP development is iterative. We began by meeting with patients and their caregivers, as well as providers of healthcare and support services, and asking each of them what data/information they need to receive from other providers and caregivers. We determined what information needs to be exchanged during one important, representative activity -- request for services. Through meetings, and through separate interviews, we created data elements and processes for vetting them and exchanging them. These data elements will be reorganized and expanded over subsequent project phases to the point where they meet the needs of any exchange, and will make the exchange of data more accurate, efficient, timely, and generally more useful.

The iterative methodology we used for UTP process development and testing have several important strengths:

- UTP starts with the most simple exchanges, and more complex processes are built upon these
- UTP is modular (in that data elements are standardized and interoperable in multiple combinations)
- UTP addresses fundamental business needs of the service providers.

With this foundation, and the UTP development methodology, in subsequent UTP phases [increasingly more complex processes](#) can be created and supported with standardized information that can be used anywhere in the system. In this way, the UTP is built upon simple, efficient, and reliable exchanges that have demonstrated that they work.

2) UTP Value Statement, and Focus of the UTP Phase One Project

Why is it important for there to be fluid communication between hospitals, physician practices, post acute care, long term services and supports (LTSS) and the individual and caregivers? There are many compelling reasons:

1. There is increasing recognition that 5% of individuals with complex medical, behavioral, functional, and environmental issues require 50% of all health and support services expenditures. These individuals require most of the long term services and supports as well as a disproportionate share of healthcare expenditures.
2. Much of the avoidable cost comes from the “medicalization” of social, environmental, and functional issues which are addressed in medical facilities (hospitals, skilled nursing facilities) when they could be addressed at home with a different (and much less expensive) mix of services: accident proofing, enhancing functional supports to reduce injury, initiation of service delivery, medication supervision.
3. Preventing hospitalization, as well as re-hospitalization, would be major driver of savings.
4. Medical service delivery should be more like LTSS service delivery in which the individual directs the care and determines the priorities. In the typical medical model healthcare providers set the priorities (which although important, may not be the same as the individual’s priorities).
5. Acute care reverses functional decline, rehabilitation improves function, and LTSS provides individuals and caregivers the extra supports and adaptations that enable them to remain in place and better manage clinical and social challenges.
6. Despite the fact that individuals use acute care, post acute care (PAC) and LTSS, none of these providers of essential services has the vocabulary, the processes, or the technology shared in common with the other two service domains to reliably exchange information across transitions, nor to share a common longitudinal plan of care across multiple sites or teams.

Providers of healthcare services, rehabilitation and post acute care services, and community based providers of long term services and supports need to be involved with each other around the care that they each deliver to the individual and the individual’s immediate caregivers. However, although the individual is the focal point of these diverse activities, there is little else that connects these providers. They do not share an ownership or governance structure, staff, or an information system. They do not share a common vocabulary because of different skill sets and training. They do not share an understanding of what each provides to the individual. Despite connecting through the individual, they do not connect with each other.

Individuals with complex medical, behavioral, functional and environmental issues such as housing and home supports, receive services across the spectrum of care from hospitals to home. Not only do these individuals account for approximately 5% of the population, they require more than 50% of all expenditures for acute care, post acute care and community based services and supports. They include the chronically mentally ill, elderly with more than six chronic conditions, those with substance abuse issues, individuals with traumatic brain injury, and the dually eligible, among others. They all share certain characteristics: frequent hospitalization and emergency room use, skilled nursing facilities (SNF) and home care, as well as heavy use of community based services. They all have complex care requirements and receive care in multiple settings from multiple providers. Despite a premium on coordination, there is no infrastructure in place to support the exchange of information across the continuum of care for these individuals.

“When our care managers are not involved in planning a transition from a hospital to a residential facility, and are therefore not involved in finding a bed, this can cause a ripple effect in terms of the impact this can have on the health status of the individual who is involved; and on other transitions for the next patient who may also be waiting for an available bed. And the costs rise. Our Care Managers are UTP. The system is not”. Mourning Fox, LCMHC, Clinical and Operations Director, Dept. of Mental Health

As a result, care is fragmented, duplicative, inefficient, and often ineffective. The challenge we face to remedy this uncoordinated system is complex. There are no quick fixes, given how diverse the service providers are, ranging from clinical services to in home supports. Before these services providers can coordinate care they have to share a common vocabulary that allows them to understand what the others mean and do. In addition, at each provider site there may be dozens of clinicians each with specific information needs. Multiplied out over several sites and multiple clinicians the data needs for one individual rapidly become very complex.

Ultimately the Universal Transfer Protocol (UTP) will enable the creation of standardized, interoperable data sets, shared standards for information transfer, and performance metrics. UTP is not a form or a data dictionary.

UTP rests on several important process principles:

1. The “receiver” of the individual in a transfer of care situation determines what is needed from the “sender”.
2. It is the “sender’s” responsibility to provide information in a timely manner and in a format that is useful.
3. Patient/Client and caregiver participation and information are essential to the UTP process

2-a) Focus of Phase One of the UTP Project

The purpose of Universal Transfer Protocol is to enable the exchange of essential information among long-term support service (LTSS) providers, patients, and their immediate caregivers, and other healthcare service providers. The objective of Phase 1 was to design the process for developing an initial set of standardized data elements for exchange between providers and receivers of services, as well as a method for continuously refining and enlarging that data set. While the UTP project will ultimately provide the basis for electronic information exchange by all stakeholders, this was not a focus of Phase 1.

The UTP is not a “form.” It is:

1. A set of standardized, interoperable, and reusable data elements
2. Rules that govern the communication/transmission/exchange of these data elements
3. Methods for continuous refinement of these elements and rules
4. Performance metrics for the exchange of the data

“We need UTP to identify key roles and the frequency of information shared to establish goal setting for the patient. Provide a comprehensive list of providers, medications and conditions to clarify and align treatment goals and patient goal. Lay out what the patient and family have to agree to. What’s missing is electronic information sharing and the process to use mass technologies to transfer information and communication. We still have too much fear around transferring information, not having confidence that the processes are in place.” - Blueprint senior team member

UTP development is iterative. We began by meeting with patients and their caregivers, as well as providers of healthcare and support services, and asking each of them what data/information they need to receive from other providers and caregivers. We determined what information needs to be exchanged during one important, representative activity -- request for services. Through meetings, and through separate interviews, we created data elements and processes for vetting them and exchanging them. These data elements will be reorganized and expanded over subsequent project phases to the point where they meet the needs of any exchange, and will make the exchange of data more accurate, efficient, timely, and generally more useful.

We wanted to focus initially on populations that make heavy use of LTSS services and on LTSS providers who care for a large number of individuals. We wanted to identify patients and caregivers with the most costly and complex care coordination needs.

We did this for three reasons:

- 1) LTSS providers are critical because they fill the gaps between what the individual can do and what the environment requires them to do. It is often the failure to close this gap that results in re-hospitalization and ED visits. Therefore, filling these gaps becomes an important strategy to lower costs while improving care.
- 2) LTSS providers are involved in the care of virtually all high cost individuals: traumatic brain injury, Medicaid, substance abuse, high burden of chronic illness, significant functional debility, and mental illness.
- 3) There has not yet been a focus on integrating LTSS providers into the universe of healthcare information exchange, so we can’t simply adopt the findings from elsewhere.

“We need a continuum of care so that we know what’s going on. How do we include the community services? When we meet there are almost 40 organizations. How do we do that so it’s best for the patient so they will not have to do so much of that? These patients don’t even know who is coming in and out of their houses.” Community Health Care Integration Coordinator

Our work was guided by four key operating principles:

1. Recognize the levels of understanding people have about the value of UTP, the impact on them, and their readiness to play a role in developing UTP.
2. Educate people -- as well as listen to them -- about UTP, in particular that it is not a form, but rather a protocol. This represents a shift in understanding for many.
3. Recognize the readiness of providers, patients, caregivers, healthcare organizations, and state constituencies to engage, collaborate, and adopt new practices.

4. Question assumptions. e.g. the meaning of terms like “risk assessment” and “patient consent” don’t mean the same to all types of providers and entities.

3) UTP Design Methodology

Nested Data Sets: The Building Blocks of UTP

In order to address the triple aim, these high cost individuals must receive complex care that is highly coordinated. This, in turn rests on the ability to reliably exchange information that has a common meaning and meets the needs of the receiving care providers. The UTP process begins with determining the information that the receiving service providers need to receive in order to provide safe, effective, and efficient care. It is at the level of the most basic business processes that we assess these data needs because we know that these processes already have high intrinsic value to the service provider and will be completed because they are essential to the business operation of the entity.

A basic tenet of UTP is that it reflects a profound change in the orientation of the “service system” from provider centric organization to person centric design. As a corollary, the first step in developing a shared vocabulary among the different health, rehabilitation, and support service providers is to create the vocabulary that enables interoperable exchange between service providers and the individual (including immediate caregivers). Without this link and the ability to identify and exchange what matters most to the individual, the system will remain provider centric.

The UTP design methodology starts with identifying the data needs for one high value activity and in later project phases progressively addresses more complex business activities. Over time, out of these common needs, a shared dictionary of terms and meaning is developed. This approach has several important strengths: it is built from the most simple exchanges, is modular (in that these data elements are standard and reusable in other combinations), and addresses fundamental business needs of the service providers.

The fundamental processes needed to develop the UTP are:

1. Identify the most basic exchanges in the system,
2. Determine the information needed to support these exchanges, and
3. Establish a shared meaning for the information.

With this foundation, we can create increasingly more complex processes and support them with standardized information that can be used anywhere in the system. In this way, we build the UTP upon simple, efficient, and reliable exchanges that have demonstrated that they work.

Not only is the service system complex, but there are also great disparities with respect to which parts can communicate with which others. For example, there are six different “sub-systems” that often are involved in the care of individuals with complex needs. They are listed here roughly in decreasing order of the degree to which each exchanges information with the other “sub-systems”:

1. traditional healthcare providers: hospitals, physician practices who are well connected with each other and community pharmacists, dentists and other service providers that are less well connected;
2. post acute care providers: home health agencies, hospice, nursing and rehabilitation facilities;
3. behavioral health (including substance abuse): inpatient and outpatient service providers;
4. community based service providers: AAAs, SASH, ADRC, VA and VCIL supported services, legal aid, housing;
5. the individual and immediate caregivers;
6. “governmental” service providers: criminal justice, vocational education, police, EMS.
7. public health agencies
8. payers
9. regulatory bodies

Most “clinical” information emanates from hospitals and physician practices. Information flow in the current system is largely unidirectional. Missing is the information from other service providers and, most importantly, information from the individual. UTP provides a process for developing the shared vocabulary needed to create the bidirectional information flow needed to provide services to individuals with complex needs. A requirement for bidirectional information flow are data elements that are standardized and understood to mean the same thing by all parties in the exchange.

However, the UTP process itself is critical to mitigating some of these challenges. It rests on identifying instances of information exchange that are foundational to the processes of providing services. These are basic processes that have been developed and refined over time to reflect the minimum data needs of the individual service provider. Because these processes are so basic, the data needs of most service providers are more similar than different. Roughly 80% of data elements are similar across all service providers for similar processes. The other data elements are service or site specific. The data elements identified as part of these exchanges are the first to be standardized and start the compilation of the shared “data dictionary”.

This is a time consuming but essential process. A sufficiently representative number of receivers must participate in the process of identifying what is included in these basic data sets; otherwise the data set will be incomplete. And, if the data set is incomplete, the receiver will have to perform additional work to find the missing data, thereby making this entire exchange process less useful. One of the basic drivers of the UTP process is that users derive benefit from standardized exchange of data. Any omission that diminishes value to the user undermines the entire process.

The value derived from this process, while costly at first, will eventually far exceed the “costs” of collecting the data. Because much of the needed data are collected as part of a basic business practice, a good portion of the “cost” has already been incurred. The value of these data for other users is what drives the entire system. Decreased acquisition costs, improved efficiency, avoidance of service gaps

are tangible returns from shared standardized data. The efficiency of the entire system improves as data exchange improves.

This point is best demonstrated by the list of fundamental information exchanges that we developed from discussions with a large number of service providers (see Section 3c, part ii). We refer to these exchanges as “High Value Activities.” There are exchanges that have explicit value for the individual and his or her immediate caregivers; as well as exchanges that provide value to the individual service provider, the individual client, and to the system as a whole.

One high value activity is a statement from the individual indicating which information can be shared with which service providers to enable coordination of services. Another is a statement indicating what he or she want the service providers to know: what is most important, who is most important, what the individual values most from others, goals, priorities, and preferences. These two statements not only directly benefit the individual by defining the care that has the most value, they benefit all of the service providers as well by improving efficiency.

These two statements are ones that EHRs and healthcare providers rarely collect. And yet, without this information it is nearly impossible to provide care that the individual values most. LTSS providers are much more likely to uncover this information as part of their routine processes to define which services to deliver. There are immediate benefits to sharing this with other healthcare providers.

The basic UTP building blocks are based on the following principles:

- A primary tenet of UTP is to build it on the most simple and basic business requirements of LTSS providers. The high value activities start with those that require relatively few data elements. Each sequential activity uses some elements from the preceding activity or activities and adds new ones.
- The second tenet of UTP is that the data items are standardized and share the same meaning across all settings. This is needed in order to gain the efficiencies that result from interoperable data, efficiencies necessary to remove cost without removing care.
- The third tenet is that complexity evolves from simpler forms organically.
- And finally, the fourth tenet is that it is not possible to predict how UTP will develop, except that it will be organic and adhere tightly to the data needs of the service providers, the individual and caretakers. It will, however, become very complex.

3-a) Engagement

Building the UTP as a protocol that intertwines process and data and is not merely creating a list of elements on a form, requires a community-driven approach. If the UTP is the “conversation” providers have with each other, then it is essential that providers be the ones to determine what they have to share with each other, what they want from each other, and how they want to share their information. In addition, we know from change adoption practices that the best way to get people to use something is to involve them in the design process.

Our engagement approach had five components:

- We sought out and built partnerships with existing groups and initiatives already focusing on patient care transfers. Our main connections were with the ADRC and the Vermont Health Care Innovation Project (and their St. Johnsbury Learning Collaborative). We also began preliminary talks with the Vermont Medical Society (their frail elderly project). From these connections, we were able to rapidly get a preliminary understanding of the current state of work on transfers of care; we were able to gain traction with the agencies represented; and we were able to build on these relationships to get referrals for interviews and for involvement in vetting UTP data elements.
- We interviewed over fifty people (see Section 3e, part iv) from providers in acute, post acute, behavioral health, LTSS, and community based settings. In addition we interviewed patients, clients, and caregivers (and many providers spoke of their own experiences as patients and caregivers). These interviewees were invaluable sources of information about how data is currently exchanged, what data is missing, what social data would be valuable, and what patients and caregivers want providers to know about them. We analyzed all this information and incorporated it into the data sets that are included in this report (see Section 3c, parts i, ii, iii, iv).
- We held three “roundtable” discussions with the ADRC and with the Southwestern Vermont Council on Aging (SVCOA) and participated in regular ADRC conference calls. These sessions provided us with multiple provider perspectives on data exchanges, and in particular, what is missing. Two of the most significant missing elements are: knowing who is involved in the patient’s care, and what services are being provided. The SVCOA roundtables provided us with real patient transfer of care stories and a deepened understanding of the complexity of service delivery. In addition, the SVCOA became a highly valued collaborator in piloting the validity of data elements and in introducing us to patients and caregivers.
- im21 collaborated with SVCOA as a beta site and worked with them to validate a set of high value activities (use cases) and data elements for the activity of: Request for Services (see Sections 3c, parts ii and iii).
- Our interviews with patients and caregivers provided us with the real person-centered experience of transfers of care and of coping with a fragmented healthcare system while living with complex medical and social conditions (see Section 5a for a sample client story). We used the data from these interviews to begin to design what we are calling the Client One Pager (see Section 2c, part iv). This represents what clients want their providers to know about them. It also serves to make clients more visible and unique to providers.

3-b) Data Development

While there has been considerable work done developing the data exchanges between acute and post acute care entities, very little attention has been paid to investigating what the LTSS providers need from each other, from acute and post acute settings, and from the individual and immediate care takers -- and what all these groups need from LTSS providers; nor how any of this connects with behavioral

health providers. This is where UTP fills a gap. Our attention in Phase One has been on looking at the information transfer needs that touch on the LTSS universe.

3-b i) UTP Model Essentials

This Universal Transfer Protocol model applies whenever there is an exchange of information between two or more service providers, and/or the individual, and/or the individual's immediate caregivers. In this model (key concepts in italics)

- Each *exchange* has at least one “*sender*” (e.g. a hospital) and at least one “*receiver*” (e.g. a SNF or rehab center).
- It is the receivers (ultimately many receivers participate in the care of an individual) whose data needs drive the formal definition of UTP data elements.
- Each exchange has a specific purpose, which determines
 - the number and type of data elements,
 - the optimum process for exchange, and
 - the timeliness required.
- All service providers perform activities that are essential to the care of their patients/clients. Examples include responding to a request for services, collecting data on the client to determine location and type of services, determining eligibility for services, notification of admission to ED. In the UTP model we call these common activities “High Value Activities” to indicate their significance to the service provider.
- Each of these activities generates data. While this data is generated because it is essential to whomever initiates its collection, much of it is also potentially useful to other providers as well.

3-b ii) Workflows for Creating Data Elements

There are two workflows described below. The first is the process im21 used as our initial Phase One content development strategy. The second is a model workflow that can be used to continue to expand and vet additional data elements going forward.

Methodology for Phase One Content Development:

1. Discover care quality and care transition activities currently underway in target geographies
2. Create collaboration agreements with those initiatives
3. Leverage the provider/patient/caregiver stakeholder networks already convened through the existing initiatives
4. Participate in initiative meetings to present the UTP project and enlist collaborators
5. Contact initiative participants for interviews
6. Using a “snowball” methodology (each contact provides names of additional contacts), reach out to additional relevant contacts and conduct interviews
7. Create survey forms for high value activities and data elements
8. Send survey to a wide stakeholder network
9. Continue to expand and edit the high value activities and data elements based on survey responses

10. Engage in a collaboration with one “hub” entity. This hub entity will pilot several instances of data validation.
11. Analyze findings from these data pilots and use that information to modify the high value activities and data elements.
12. Work with stakeholders to develop criteria for measuring the effectiveness of UTP.

The following workflow represents a practice for creating additional data elements. It was used successfully in Massachusetts for the IMPACT data sets, and it is also part of the process im21 used in Vermont. It is also a recommended workflow for the next phases of the UTP project :

1. Identify the agency with which you interact the most.
2. Determine your most common interaction with that agency .
3. Review and iterate the list of “High Value Activities”:
 - a. If your interaction is not on the High Value Activity list, send a comment to the project manager requesting its addition and provide a list of the essential data elements that you require.
 - b. If there is an interaction on this list that is close to, but not an exact match, to your most common interaction use that as the starting dataset and add those elements that you require. Then send a comment to the project manager indicating those elements.
 - c. If there is a High Value Activity that matches, review the data set and add any data elements that you require which are missing. Then send a comment to the project manager indicating those elements.
 - d. Refine this data set (by using it with 5-10 consecutive referrals after each modification).
 - e. Once you have created the dataset that fully meets your needs, use it to begin a process improvement project with each referrer, by converting into a data collection form, to record whether the data elements are present at the time of the interaction..
 - f. Collect baseline performance data (completeness, timeliness, cost of non-value added work)
 - g. Ask referrer if they have the information required
 - i. if no, start a process to identify, record and transmit that information
 - ii. if yes, start a process to transmit that information
 - h. Measure and report performance to referrer.
4. Repeat this process for the next highest interacting agency (in Step 1 above) or for the next most common interaction (in Step 2 above) until you’ve performed process improvement with agencies that make up 80% of your interactions.

3-c) Data Samples

The data forms presented in this section were created as part of the process of designing the Phase One UTP; none of these forms existed before the UTP work began. The creation of these forms is an example of two critical aspects of the UTP: 1) It is emergent and adapts to the changing needs of its

stakeholders -- providers, clients, and caregivers. 2) It evolves in an iterative manner. Each instance of a set of data elements and the processes for exchanging them are reviewed and modified, repeatedly.

3-c i) 15x15 Provider Grid

Below is a 15x15 grid with 15 service providers across the top, the receivers, and the same 15 service providers down the left, the senders. In the course of an episode of care most service providers are both senders and receivers at different times in the episode.

Across the top starting at the left are the “medical service” providers: hospital, ED, outpatient and office based clinicians. The next five are post acute care providers, LTAC (long term acute care), rehab, SNF (skilled nursing facility), HHA (home health agencies), Hospice; then a group of behavioral health (BH) providers, inpatient, outpatient, and substance abuse service providers; and finally community based services and supports including the special Vermont programs, CBOs (community based organizations) and, most importantly, the individual and caregivers.

Each cell represents an interaction between two entities: an exchange between a sender and a receiver about a care taking responsibility, or information needed for clinical care, scheduling information, or coordination of care. There are hundreds of different exchanges that occur among these 15 providers. This grid can be used as a map that indicates the sets of high value activities and the data elements that support them that will need to be developed for all exchanges. The parties involved in these exchanges (listed on the grid), in many different combinations of senders and receivers, include

- inpatient acute care hospitals
- emergency departments
- outpatient serviced
- office based clinicians
- LTAC (long term acute care)
- rehabilitation
- skilled nursing facilities
- home health agencies
- hospice
- behavioral health - inpatient
- behavioral health - community services
- substance abuse programs
- special Vermont programs
- community based organizations
- individual and caretaker

Transitions to (Receivers)															
Transitions From (Senders)	In Patient Acute Care Hospitals	ED	Out patient Services	Office-Based Clinicians	LTAC	IRF	SNF/ECF	HHA	Hospice	BH In patient Facilities	BH Community Services	Substance Abuse Programs	Special VT Programs	Community Based Organizations	Individual and Caretakers
In patient															
ED															
Out pt services															
Office based Clinicians PCMH/FQHC															
LTAC															
IRF															
SNF/ECF															
HHA															
Hospice															
BH Facilities															
Community based BH sites															
Substance Abuse Programs															
Special VT Programs															
CBOs															
Patient/Family															

More information about this grid model may be found [on the UTP web site](#).

3-c ii) High Value Activities

Part of the work of UTP Phase One was to develop a list of many of the high value activities (use cases) providers and patients/clients engage in in care and transfers of care situations. Each of these activities has a set of data elements nested within it that represent the information that needs to be exchanged to provide comprehensive care. We start with the basics and build toward greater complexity.

Basic Business Practices:

1. Individual gives approval to share information
2. Individual provides information to guide how services should be delivered and what personal information the individual wants the service provider to know
 - 2a Caregiver provides information to other service providers that expands, amplifies and/or corrects the individual's statement
3. Request for potential service providers to identify themselves
4. Response from potential service providers confirming ability to provide service
5. Response from potential service provider requesting additional information
6. Request for service from a specific provider
7. Service provider requests documentation of individual's consent to share information

8. Service provider requests additional information to assess eligibility for services
 - 8a. Service provider requests information from any other service provider working with the individual
9. Service provider confirms a relationship with the client
10. Service provider requests individual's statement of priorities and preferences
11. Service provider confirms termination of relationship with client

UTP starts with the basics. The above High Value Activities, 1-11, are basic business practices. Each service provider will use most of these data sets during the process of responding to service requests, assessing what is required, and gathering additional information. These data sets are “nested” in the sense that the lower numbered sets have fewer data elements which are reused in the larger data sets.

The power of UTP can be seen in the next items, 12-19. It is possible to make standardized requests of each service provider engaged in the care of this individual and, because each service provider has collected similar data elements, create an aggregated picture of the services, service needs, and active issues of the individual based on the observations of all of the service providers. This allows each service provider to query any others. It also supports the collection of information from all responding service providers. Because each is using standardized data, it supports the first aggregation of all currently active service providers, the total services provided, current active conditions, and potential threats to homecare staff.

Services and Service Needs:

12. Service provider requests from another service provider a list of all actively engaged service providers
13. Service provider requests from another service provider a list of current active issues
14. Notification of admission to or discharge from ED, nursing facility, hospice to all service providers
15. Service provider requests from another service provider any issues that might pose a safety threat to in-home staff
16. Service provider requests results of standardized assessments (e.g. OASIS, MDS, IRF PAI, ILA, specific assessments for function, cognitive assessment, depression, fall risk, skin breakdown)
17. Composite list of currently active issues compiled from all responding service providers
18. Composite list of current interventions and outcomes linked to responsible service providers compiled from all responding service providers
19. Composite list of observations of family dynamics, social information compiled from all responding service providers

These next data sets, 20-22, enable the creation of more complex documents which support even more complex activities such as multi-site service coordination, analysis of gaps in services, outcomes of interventions by service provider, and remaining problems.

Complex Service Coordination:

- 20. Complex Service Coordination composite of providers, issues, services, and assignment of responsibilities for specific outcomes
- 21. Identification of Gaps in Services compiled from comparison of active issues and documented interventions.
- 22. Outcome of Interventions composite report of which interventions are effective, partially effective, or ineffective

Item 23 reports can generate assessments of the overall care provided to an individual, as well as the contribution of each service provider to that outcome. Furthermore, it becomes possible to create the first comprehensive pictures of each individual.

Overall Care Contributions:

- 23. Contribution of Service Provider to overall outcome based on assessment of the significance of issue addressed, effectiveness of intervention, overall outcome of care, and contribution of provider to outcome

Once the foundation has been laid for the first comprehensive picture of one individual, it becomes possible, with Items 24-25, to create composites of many individuals to give overviews of service needs and interventions across specific populations, locations, service providers, and payers to inform policy and to balance service availability with need.

Population Health:

- 24. Regional service needs with gaps from a composite of all individual observations in the region
- 25. Outcomes across a population from a composite of all individuals within a specific population

3-c iii) Request for Services Data Elements

Below is the aggregation of data elements that support the High Value Activity: Request for Services. This is a basic, fundamental activity that all providers engage in. The form below was created in collaboration with SVCOA and ADRC partners, among others we spoke with.

Information (data items) from requestor that we think might be useful to you.	
Name and Contact Information of person to call for more information/clarification	
	Name
	Requesting agency

	Title
	Phone
	Email
	Fax
Requested by	
	Name
	Requesting agency
	Title
	Phone
	Email
	Fax
Service(s) requested	
Requested date of start of service	
Zip Code of site of service	
Client is aware of this referral	
Client agrees with this referral	
Client agrees to share information with you	
Client demographics	
	Name
	Date of birth

Information (data items) from requestor that we think might be useful to you.	
	SSN# (or last 4 digits)
	Gender
	Street Address
	City, State, Zip
	Any legal representative or power of attorney involved? Guardian?
How client prefers to be contacted	
	Special accommodations required for communication (e.g. interpreter, assistive devices, ASL, etc.)
Current active issues (as understood by requestor)	
	Individual's stated goal/person centered goals--what is their goal at that point in time (regardless of location of event or services/care).
	Medication list
	Medical
	Behavioral
	Physical functioning
	Environmental
Current Insurance	
Pending Insurance	
Potential program eligibility	

Issues/problems encountered by prior service providers	
Service Providers currently active with client	
	Don't know who other service providers are
	There are no other service providers
	There are other service providers, and here is a list of provider, nature of service, and contact info
Other Care Team Members (if known)	
	Primary Care Physician/NP
	Case Manager
	Social Worker
	Specialists
	Other (role)
Heads-Up -- Other information you should know about this client	
	What have they already tried and has not worked?
Information (data items) from requestor that we think might be useful to you.	
Requests from VA only	
% Service Related Disability	
If Medicare eligible, has application been made?	
If Medicaid eligible has application been made?	
Services client is currently receiving from the VA	

VA services for which client is eligible but not receiving

3-c iv) UTP Additions to MA IMPACT Work

IMPACT, which stands for Improving Massachusetts Post-Acute Care Transfers, was an Office of the National Coordinator (ONC) grant-funded project designed to improve care transitions using an enhanced electronic Universal Transfer Form (UTF) and Electronic Health Information (HIE) exchange for the transmission of the electronic UTF between acute providers and the post-acute care settings.

The Vermont UTP additions represent a significant advance over the IMPACT data set, which was developed to support the exchange of information between acute care and post acute care sites and among post acute care sites. That data set focused mainly on medical issues, cognition, and function, and much less on the issues important to the individual, including their home situation.

Two major differences between UTP and IMPACT are that the UTP includes LTSS and their information needs, and it includes social data -- including a patient statement about his/her care goals. Examples of these differences follow.

The example below is a draft: The *Individual's "One Pager"*-- what the individual wants his/her service providers to know. With this data set, the individuals define the relationships that they are seeking with service providers. They define what matters most to them: the people and activities that are most important to them, how they make decisions, and how they want to share information. This information does not exist in the IMPACT data set nor in the C-CDA R2 2013 Update.

This data set is most important for the LTSS providers who spend the most time with the individual at home, where the individual's care plan is implemented. Examples of some elements in this data set may be found in the table below.

Client One Pager
Relationships that are important to Me
Family
Friends
Pets
Religious communities
Things that are important to Me
activities
interests

plans
accomplishments
Things that people like and admire about me
Things that I appreciate from others
How I prefer to receive information
In person
In writing
Phone
Email
How much information I prefer to receive
I want to know all information about me
I want to know enough to make informed decisions but not all the details
I don't need to know any information that is shared with my designated decision maker(s)
How I prefer to share information about me
Only with those whom I designate and only for information that I designate
Any information about me can be shared with my designated decision makers
Any information about me can be shared with my immediate care team
Any information about me can be shared with anyone providing services to me
There is some information designated by me that cannot be shared with anyone
How I make decisions
Independently
In collaboration with family/friends/caregivers
Rely on trusted family/friends/caregivers to make decisions for me
And they are: _____
Service start date
Advance Directives
Health Care Proxy
Home Characteristics
Pets
Guns
Violent individuals

Unsafe housing
My personal statement: _____

Other elements not in the IMPACT data set include those identified by service providers as essential to performing a critical business process, receiving a Request for Service.

Examples of new elements include:

- Client is aware of this referral
- Client agrees with this referral
- Client agrees to share information with you
- Any legal representative or power of attorney involved? Guardian?
- How client prefers to be contacted
- Special accommodations required for communication (e.g. interpreter, assistive devices, ASL, etc.)
- Issues/problems encountered by prior service providers
- What have they already tried and has not worked?

Requests from VA only

- % Service Related Disability
- If Medicare eligible, has application been made?
- If Medicaid eligible has application been made?
- Services client is currently receiving from the VA
- VA services for which client is eligible but not receiving

As more high value activities are examined by more and different service providers, the list of new data elements will expand.

3-d) Performance Measures

The following table contains a *proposed* list of UTP performance measures along with definitions and examples. Further definition and quantification of these measures can happen in later phases of the UTP project, as additional data elements are developed and tested, and data exchanges are regularly happening.

<i>Measure</i>	<i>At its best...</i>	<i>Examples</i>
completeness of data	the data set contains all the information the receiver needs to know for the designated high value activity	last 4 digits of the clients social security number; percent of service related disability

accuracy of data	the data set is up to date and the information is correct	revised medication list following discharge from the hospital
timeliness	the data set is available to the receiver when it is needed to provide services	data set sent to receiver before services are required to start.
acceptable process for exchange of data	the exchange of data sets is efficient, utilizes available technology, and provides the receiver with the required data	home health agency A receives a faxed form from the VNA that specifies the nature of services required and the form of client payment
decreased gaps in care planning and delivery	the exchange of data supports the timely creation and implementation of effective care plans in which all providers have clear roles and responsibilities	hospital transition care nurses and AAA case manager collaborate on developing the care plan for their shared patient and exchange the plan with other involved service providers
decreased time spent tracking down missing information	the data exchanged is complete and accurate and meet the data recipient's data needs for that high value activity	thirty minutes of nurse case manager time otherwise required to find this information was avoided when the sending organization included the contact information of the other agencies involved.
decreased redundancy of care activities	each provider in the client's care system is aware of the other providers involved and of the services those providers are delivering	care managers from 3 different agencies involved in a patient's care can access information on services already underway and determine the "primary" case manager.
increased patient/client confidence in care management	through the transparent exchange of data among service providers, patients/clients avoid repetitive requests for information creating the impression that service providers don't know who they are and don't speak with each other, thereby decreasing their confidence and satisfaction	as one patient said to us when his providers knew who he was and what help he was already receiving: "It was like they really cared about me."

	levels	
--	--------	--

In future UTP project phases, as more and more High Value Activities and their associated data elements are validated through cycles of exchanges, it will become feasible to measure performance using the above set of indicators; and thereby to assess the ongoing efficacy of these measures and develop additional measures. In addition, as UTP is deployed statewide it will become a source of population health data which can be analyzed at the State level.

3-e) Information Sources and Collaborations

3-e i) Geographic areas

Bennington

Rutland

3-e ii) Agencies

Blueprint

SASH

VNA

DAIL

VITL

Brain Injury Association of Vermont

Vermont Center for Independent Living

Northeastern Vermont Regional Hospital

Southwestern Vermont Health Care

OneCare Vermont

Community Connections

VA Medical Center

Department of Vermont Health Access

Center for Nursing and Rehabilitation

Community Health Accountable Care

Health 1st

Bi-State Primary Care Association

Vermont Medical Society

Southwestern Vermont Council on Aging

Southwestern Vermont Medical Center

White River VA Medical Center

3-e iii) Initiatives

Vermont Health Care Innovation Project

ADRC Project

3-e iv) People

Jennifer Fels

SVMC head of case management, social work and clinical documentation improvement and Blueprint liaison

RN, MS

United Health Alliance

Director Bennington Blueprint

Randy Messier

Tupelo Group and evaluator for ADRC pilot

Bonnie Walker

Tupelo Group and evaluator for ADRC pilot

Marlena Carcone

SVCOA Options Counselor

Virginia Cudahee

SVMC Hospital Social Worker

Heather Johnson

DAIL Contractor and ADRC Project Manager

Kathy Cardiff
SASH: have sites in Bennington, Northshire and Deerfield Valley

Karen Hewson
SVMC-transitional care nurse

Kellie Martin
BIAVT Options Counselor/NRF serving Addison, Rutland, Bennington, Windsor and Windham counties

Trevor Squirrel
BIAVT Executive Director

Terry Reinertson
Bennington Medical Home Lead

Kara Lusa
SVMC health resource management

Tara Grenier
DAIL-Quality Outcomes Specialist and ADRC Project Director

Colleen Arcodia
VCIL Peer Advocate Counselor/Options Counselor

Billie Lynn Allard
Director Transitions of Care Nursing Pilot
SVMC

Donna Smith
Options Councilor SVMC

Barbara Winters
Certified Brain Injury Specialist Trainer (CBIST)
Outreach & Education Coordinator
Neuro-Resource Facilitation Services Coordinator
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Director of Emergency Services
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John Scott MD
Medical Director Bennington Nursing Home

Ginger Ritchie
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Sandra Conrad
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Health Integration Quality Oversight Analyst
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Nancy Marinelli
DAIL'S representative SIM HIE

Miriam Sheehey, RN
Assistant Director, Clinical Quality Operations
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Maura Crandel
Manager Critical Opps
One Care Vermont

Arsi Namdar
VP of IT & CIO
HIPAA Privacy & Security Officer
VNA of Chittenden and Grand Isle Counties

Pam Smart
Community Health at Northeastern Vermont Regional Hospital Care Integration Coordinator
Community Health Improvement, Also leads Community Health Team for Blue Print.

Clare McFadden
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James Poole MD
Chief Medical Officer & Medical Director, Medical Affairs SV Health Care

Susan E. Lott, BSN, MA
Certified Case Manager (CCM)
White River VA Medical Center

Erin Flynn, MPA
Senior Policy Advisor, Vermont Health Care Innovation Project,
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Tammy Moxley
The Center for Nursing and Rehabilitation at Hoosick Falls
Admissions Coordinator & Community Outreach

Brendan Hogan, MSA
When interviewed & BBL team member
Senior Consultant
Bailit Health Purchasing

David Slavitt MD
NYC surgeon

Dana Baker
Case Manager
SVCOA

Aaron Brush
Caregiver Coordinator
SVCOA

Marybeth McCaffrey
Marybeth McCaffrey, DAIL Director of Operations Principal Health Reform Administrator

Heather Skeels
Project Manager Bi-State Primary Care Association

Cy Jordan M.D.
Board member Vermont Medical Society

Mourning Fox, LCMHC
Clinical and Operations Director
Department of Mental Health

Bard Hill
Director info and data unit at state of Vermont

Jenny Samuelson
Assistant Director Blueprint For Health

John Evans
VITL, CEO

Mike Gagnon
VITL CTO

Sandy McDowell
VITL, VP Operations

4) UTP Communication Strategy

UTP is not a form. It is a protocol that links data to providers, providers to each other, and patients and caregivers to providers through the collaborative creation, evolution, and sharing of standardized, interoperable data. In essence, UTP, as a fundamental communication vehicle, rapidly provides a way for people to get the information they need when they need it and determine with whom they need more in depth communication. As such, UTP, a series of processes that connect people and data, is an engagement and communications strategy.

In addition, UTP puts in motion a vehicle for standardizing meaning. Currently, language used across boundaries is not standardized and therefore the meaning of clinical terminology (e.g. “at risk”) can differ. This can confuse treatment expectations. There is a need for standardization of language and simplification of integrated care planning details so that clinicians, agencies, caregivers, and patients/clients can share a common understanding of the patient’s/client’s status and needs.

Some of the common communication themes we heard from providers include:

- Providers recognize the value of and difficulty in cross boundary information sharing.
 - *“The reality is that we just don’t speak the same languages”* - Case Manager, SVCOA
- Some providers spoke of a concern about competitiveness (e.g. “who owns the patient?”) and reimbursement models that can inadvertently reinforce competitiveness. When this competitiveness is resolved, communication and care can improve.
 - *“I work in NY but the improved communication with the hospital in Bennington is critical for me and has improved care.”* - Admissions Coordinator & Community Outreach, The Center for Nursing and Rehabilitation at Hoosick Falls
- Providers realize that there are gaps in the information they receive. However, it is often unclear who has the missing information.
 - *“Sometimes I think we are not getting the whole story.”* - SASH team member
- Communication innovation in one place may not reach beyond the hospital and into the home after discharge.
 - *“The Huddle has been very helpful in the hospital. But after discharge things break down...no way to really continue the approach at home for a treatment plan.”* - Options Counselor, VCIL

4-a) Communication Methods

This UTP communication strategy addresses four different stakeholder groups. While the communication channels for these four groups are independent, they can also intersect where crossover advances information richness and engagement potential. For example, a Vermont citizen, through reading the UTP website, may desire to become more engaged and can become a stakeholder involved in the design of the UTP effort.

4-a i) Citizens of Vermont - Website

A Vermont specific UTP website (<http://im21-utp-vt.com>) has been established that serves as central location for two streams of communication to coincide.

- One stream represents those who are involved in designing and operationalizing the UTP. This stream publishes deliverables such as lists of high value activities and data elements, surveys, updates at the State and national levels, posts on UTP relevant topics.
- The other stream of communication comes from Vermonters. This communication can include responses to posts and surveys, comments on current high value activities and data elements, stories related to transitions of care and the UTP, questions, recommendations, etc.

4-a ii) UTP Collaborators - Bi-Weekly Updates

The design and deployment of the UTP rests on collaborations between the team responsible for delivering the UTP and the many state-wide provider/client/caregiver consortia and agencies involved in transitions of care and care coordination efforts. These groups include (but are not limited to) the

ADRC, the Learning Collaboratives, the Clinical Councils, the ACOs, the AAAs. These stakeholders clearly recognize the common ground they share with the UTP and make an investment in the UTP:

- They recognize that part of their ability to coordinate care is dependant on the communication infrastructure the UTP provides.
- In order to maintain engagement and alignment, these stakeholders and the UTP project team need to participate in regular updates in which they discuss key UTP issues and challenges.

Some of the content of these bi-weekly updates is posted on the public website to elicit further engagement and discussion.

4-a iii) UTP Participants: Interviews, roundtables, surveys

The credibility, accuracy, and usefulness of the UTP is dependant on the direct involvement of acute, post-acute, behavioral health, and LTSS providers; and the recommendations of patients, clients, and caregivers. In other words, the entire spectrum of people and entities involved in care transitions and care coordination (including patients and families) needs to directly participate in the creating, testing, iterating, improving, and deploying of the UTP:

- The input of these stakeholder is obtained through in depth interviews, roundtable discussions, and surveys.
- This information is reviewed by the UTP project team. It informs the content of the UTP and the methodology for exchanging data.
- Some of the people and agencies involved at this level become key design stakeholders and participate in the bi-weekly communication.

4-a iv) UTP Project Team

The consulting team and the Vermont leaders/champions directly involved in and accountable for the success of the UTP need to be in ongoing communication. This close ongoing collaboration is a key critical success factor. In fact one of the main reasons why 70% of IT projects fail is that there is a gap between the business analysis and the technology development. When the entity doing the business analysis, and the customers, and Vermont leadership (including those who will be accountable for technology development), are working together in a shared, transparent environment (such as an online project collaboration space) -- the results are much more likely to meet, and surpass expectations.

The key areas that the consulting team and Vermont leaders need to discuss regularly include:

- the goals and objectives of the project
- the strategic and operational activities of the project
- the need for Vermont leadership interventions (such as brokering introductions to key stakeholders and agencies)
- early risk assessment
- risk management.

4-b) Phase One Major Findings

Phase One focused on data gathering and early piloting to discover what some of the information LTSS and LTPAC need to exchange with each other to provide continuity of patient care. Among the major Phase One findings are:

- most exchanges involve some form of direct provider to provider contact.
- when patient referrals to entities are made, the referring agency is not aware of the data needs of the receiving agency.
- there are no mechanisms to alert the provider network involved in a person's care about changes in health status, such as emergency room visit, hospital admission, hospital discharge, assignment of case manager.
- there is a gap between providers' job titles and the work they actually do. Providers are not necessarily aware of each other's real roles in patient care.
- significant time is spent tracking down the agencies and providers involved in the person's care.
- duplication of effort is not infrequent because there are no mechanisms that alert providers about what care and support efforts are already underway (e.g. application for SASH housing).
- it is not infrequent for care plans and medication regimens to be unreconciled, duplicative, and potentially harmful.
- patient/client and caregiver profiles and goals are not typically part of the medical record.
- technology transparency does not exist. Entities have their own system which does not communicate with those of other entities. Some systems allow read access only to some providers.

“We try to connect people with providers that understand brain injury. We don't have case managers. We connect with homeless agencies, mental health, schools, the legal system. Sometimes, our folks are misunderstood in the legal system. The ADRC primarily focuses on the elders. Long term solutions. I need immediate solutions. Keep them out of jail, find some housing.” - Brain Injury Association of Vermont, team leader

5) UTP Case Histories

In this section are two case histories. The first is an actual history of a client with complex physical, behavioral, and environmental health challenges. The second is an invented story that illustrates a patient experience in an environment in which UTP is optimized and the UTP data elements are fully integrated into the HIE systems.

5-a) Real-life Transfer of Care Scenario

Please consider this story to be confidential and not to be shared publicly.

This is a story concerning an anonymous, but not unfamiliar, client, one who lives with difficult physical health, mental health, and social health complexities. Identifiable elements have been altered and any resemblance to a specific individual is unintended. This story highlights the risks encountered by any individual who receives care from more than one provider, in more than one site across more than one geography with multiple information systems involved. And while this client has her unique set of difficulties, the systemic care issues are ones everyone experiences in greater or lesser degrees.

In this story we can see the systemic ripple effect that happens when information is unavailable or there is incomplete or delayed information exchange. The various parts of the healthcare system may be siloed, but unfortunately data deficiencies cross all boundaries and cause unforeseeable complications, for patients and providers.

Safe and effective transitions require complex processes to assure that the information exchange is complete and timely, in a format that is usable and via a process that is reliable. As the number of transitions for any individual increases, the risks of encountering a failed transition increases as well. Individuals with increasingly complex medical, behavioral, functional and environmental issues (housing, employment, transportation, home supports) facing increasing risks because they experience more transitions of care. As importantly, the individual's priorities may not be adequately reflected as they transition from site to site.

Client X was a woman in her thirties who had recently moved into into Region ABC. She was severely disabled, wheel chair and bed bound, and was receiving twenty-four hour care through Choices for Care.

There was no formal transition of care plan in place to assist her in relocating. In fact the area into which she moved had just experienced a severe decrease in the kinds of services this young woman needed. It was largely because the AAAs of the various areas are in regular communication that some information was made available to the local AAA about this client's situation.

In addition to her physical disabilities, X had a lengthy mental health history, and a history of making abuse allegations against providers. She had also met her current boyfriend in a mental health facility.

She moved into a private apartment in region ABC. The local AAA decided that, given her allegation history, a team of two case managers would visit her at home, assess her situation, and develop a care plan with her.

When they arrived for the first home visit, they found her in unsanitary conditions in a hospital bed, which was the only item of furniture in the apartment. She was in desperate need of adaptive equipment. However her current apartment could not accommodate the equipment she needed. For example, a hooyer lift would not fit in the bathroom.

The AAA case managers did a thorough ILA (independent living assessment). It became clear that 2 personal care assistants would be needed so the AAA case managers obtained a variance for this exception. In addition, the case managers determined that mental health services were an immediate priority, and even contracted with the client that the continuation of their involvement depended on her being in mental health treatment.

While the case managers had designed a comprehensive care plan, the reality on the ground was that services were just not available. The home health agency did not have enough resources. Few mental health providers were willing to accept this client since, the case managers learned, she had lived in this area before and had “burned through” a lot of therapists. They could not hold her to the contract if they could not find a therapist who would treat her. Eventually a therapist, new to this area, accepted her for treatment.

The boyfriend proved to be a dangerous complexity, about whom the case managers had received no information. He appeared to be living with the client, deteriorating mentally, and self medicating with alcohol. One day the client called the case managers to tell them he was having a mental breakdown and that he was abusing her. Given her mental health issues and her boyfriend’s instability, while the case managers did not know what to believe, they called in Adult Protective Services to investigate.

For unclear reasons the client wound up in the local hospital emergency room. The case managers only found out about this upon her discharge. While she was hospitalized, her landlord evicted her from her apartment. She found a new apartment and moved in with the same boyfriend. The AAA case managers did a home visit to work with her on reassessing her care options. During this visit, the boyfriend paced outside. The boyfriend overheard the client saying that she hated him and wanted him gone from her life. When the case managers left the apartment, the boyfriend approached them in a menacing way. The combination of this safety threat and her meager mental health treatment led the AAA to question how they could best serve this client, while protecting their own safety.

Again for unclear reasons, the client wound up back in the hospital. She signed herself out AMA. Also, for unclear reasons, the client decided she wanted to relocate again to another part of the state. The local AAA contacted the AAA that covered the region into which she was moving to supply them with the information they would need about her history and current situation.

This story, with its physical, mental, and social complexities, would be challenging enough to any healthcare system. There is no one program that would be an exact fit for this client’s needs. This story, in particular, demonstrates the critical role LTSS providers play in care coordination and the ways in which they are so close to the client’s daily reality. And we must remember that while the details are unique to this client, the high degree of care management and the multiplicity of services necessary to maintain her are not unique. As baby boomers age and live longer with multiple chronic conditions, and as veterans return home having survived injuries that would have been fatal in previous wars, the healthcare system will be facing increasing challenges of caring for complexity with a scarcity of resources.

The unfortunate lack of systematic information exchange is also not unique to X's story. The region's AAA clearly did a herculean job of coordinating care in a very tangled situation.

The AAA case managers would have benefitted greatly from having advance access to information such as: police and probation reports about the boyfriend's history of violent behavior; mental health history from previous therapists; her case information from DAIL; and information from other agencies about her history of allegations. In addition, the lack of systematic notification of the start and stop of various healthcare interventions, be it hospitalization or prior mental health treatment or medication changes, means that overall care will be uncoordinated, silo'd, redundant, and potentially unsafe. Without these system-driven information exchanges, and the processes and technologies needed to support them, the care burden in our overstretched and under-resourced healthcare system comes at too great a personal and financial cost, to providers, clients, caregivers, and to our healthcare system.

5-b) Future Invented Transfer of Care Scenario (with UTP fully integrated into HIE)

An Optimal Transfer of Care:

- is timely, safe, efficient, with no loss of important information;
- incorporates the needs, knowledge, and point of view of the patient/client and primary caregiver;
- requires that all the clinical and social information needed about the patient/client be available to all providers of the patient/client when they need it, in a form that is accessible, clear, and actionable;
- ensures that the patient/client and primary caregiver are involved in decisions about the care; that the patient/client receives the right care from the right service provider; and that the result of the care is to improve the patient's/client's level of functioning so that she can return to her desired residence with supports that can maintain her safety and quality of life.

The following is a future-oriented invented scenario designed to tell a story about a patient in an environment in which UTP is optimized and the UTP data elements are fully integrated into HIE systems.

The wife of a seventy-seven year old man begins to notice that her husband is experiencing shortness of breath when he climbs up the stairs to reach their apartment. Even though he was diagnosed with what he calls "a touch of emphysema" several years ago, her current observation is a change in his typical pattern. She mentions this to him, and he minimizes it and tells her not to worry so much. She, however, remains worried as she begins to notice other instances where exertion brings on his shortness of breath when doing activities that did not provoke this symptom in the past.

He refuses to visit a doctor. She is uncertain what to do, and her concern grows. A neighbor who is a home health aide suggests she call the local AAA (Area Agency on Aging). She calls, and the help line counselor suggests that the couple speak with their Options counselor (Options counselors provide information on the care and financial options available to clients and support them in making choices for their care) to get a fuller picture of what benefits and services are available to them, with the hope

that a conversation about benefits and services could lead to an appointment with a doctor. The wife is nervous that this conversation will feel intrusive to her husband and that he will refuse to cooperate. The help line counselor assures her that the Options counselor has dealt with many situations like this and will explain an array of services they may be entitled to without pressuring them to sign up for any. The wife agrees to the appointment.

The husband reluctantly agrees to sit in on the conversation with the Options counselor. The counselor, rather than jump into a detailed listing of services, begins by building a relationship with the couple and asks them to talk about their family, their goals, and their current situation. As they respond, the counselor expertly weaves references to services into the context of their descriptions of their lives. They begin to see her offerings as responsive to their needs, not as intrusive or as a defaming of their independence. The counselor soon understands that their presenting problem of his shortness of breath is just the tip of the iceberg. Their top three needs are: a ramp up to their front door; a better understanding of the benefits he is entitled to from his veteran's status and Medicare; and a new primary care doctor, since his previous one retired a year ago.

The Options counselor enlists the help of two other programs within the AAA -- case management and the state health insurance program (SHIP). The case manager meets the family and soon becomes a trusted ally. She organizes a community resource group to build a ramp on the couple's house, and while the SHIP counselor works with them on their benefits status, the case manager starts the process of finding a suitable PCP whose office is nearby and who has experience with an elderly population. She also meets the couple's daughter during one home visit and makes a solid connection with her.

However, before the case manager is able to find a PCP, the husband experiences a level of breathing difficulty that alarms him, and the wife takes him to the local hospital emergency room. He is admitted to the hospital to undergo testing.

In this future scenario, the UTP dataset is fully digitized and operationalized through the HIE. There is a common vocabulary, shared data sets, and information is available to providers, through the HIE, as needed. Because the HIE used by entities in this region of the State is fully integrated with the UTP datasets, what would not have been possible in the past is now standard practice:

- The ED doctors and the pulmonologist assigned to the husband's care now have access to previously unavailable parts of his case history having to do with his living situation and his preferences. They learn that he prefers to learn about every aspect of their treatment and wants to be involved in decision making about his care.
- Because the AAA uses the same UTP data, they can see that a client of theirs was admitted through the ED to the hospital and can remain involved with him during, and after, his hospitalization.
- Because UTP data elements include a list of all current service providers, the hospital pulmonologist who sees the patient can see that he does not have a PCP and refers him to a hospital-based gerontologist.

- The hospitalist also sees, through the social data elements of the UTP, that the patient is poorly compliant with medications and therefore prescribes a medication that only needs to be taken once a week.
- The UTP also has the client's and his primary caregiver's (his wife's) statements describing their values and goals so all providers know that they are committed to supporting each other to remain at home as long as possible.

While the physicians are running tests to assess his pulmonary status, the AAA case manager is already in touch with the hospital's transition team to begin putting in place the services and supports he will likely need upon discharge. Whereas before UTP, they might not have been aware of each other's involvement, now they can collaborate to avoid duplication of efforts and can maximize resources.

Just before the patient is discharged, the transition care nurses and the AAA case manager decide to involve the VNA so that a nurse can support his new medication regimen at home and can monitor him for the first few weeks. Because the VNA's data needs have been incorporated into the UTP data elements, the nurse does not have to track down the referral sources to obtain the patient information she needs, that, before the UTP was implemented, would have been missing from the referral form. She prepares for the home visit by directly reviewing the record of his prior history and of the recent hospitalization and is better able to understand exactly what the medication changes are. She notices that during his hospitalization, some of his previous medications were eliminated, others had the dosages changed, and others were added. Because, through the UTP she gets the data she needs, she is able to contact his new PCP as well as the doctor who attended to his care in the hospital, and without a lot of detective work, she is able to verify his current medication needs, thereby avoiding what might have been a serious medication error.

Because of the UTP, the results of the visiting nurse's evaluation are immediately accessible by the AAA case manager, thereby cutting down on several rounds of phone tag. Again, because of the UTP, the case manager has the data to immediately begin the process of setting the couple up with a home health aide to assist with his activities of daily living for the first few weeks of his recuperation.

In the meantime, the SHIP counselor has sorted out his benefit situation to make sure his hospitalization, new medication, and home-based services will be covered. The AAA case manager has been in communication with the couple's daughter and has enlisted her help in keeping her eye on her father's condition and her mother's stress level.

What we see in this scenario, because of UTP, is a comprehensive, well coordinated network of services customized to the needs of this couple, with the right data (both clinical and social) flowing at the right time to create a relatively seamless series of transitions of care. Moreover, each provider knows who else is involved and what role each provider is playing so that care can be coordinated, redundancies reduced, and potential errors (such as medication reconciliation) can be discovered.

6) Additional Materials

6-a) Surveys

We developed and used the survey forms below. The [actual surveys](#) can be found on the im21 UTP NEWS website (<http://im21-utp-vt.com/>):

- How the UTP Project Should Communicate with Me
- Sources of Patient Information
- Provider Nomination for the UTP Project
- Patient Nomination Form for the UTP Project
- Family/Friend Caregiver Nomination Form for the UTP Project
- What We Heard about UTP Data and Use Cases: Now Cast Your Votes

6-b) PPT Deck

This PPT slide deck presents a complete overview of how UTP fits into the healthcare continuum and why UTP development is so important to Vermonters. You can find the PPT slide deck here:

<https://vtutp.files.wordpress.com/2015/02/im21-terrence-omalley-utp-overview-presentation-1-9-2015-pptx.pdf>