

B. IMPROVE THE INDEPENDENCE, QUALITY OF LIFE, AND REHABILITATION (TO THE EXTENT POSSIBLE) OF INDIVIDUALS WITH ESRD THROUGH TRANSPLANTATION, USE OF SELF-CARE MODALITIES (E.G. PERITONEAL DIALYSIS, HOME HEMODIALYSIS), IN-CENTER SELF-CARE, AS MEDICALLY APPROPRIATE, THROUGH THE END OF LIFE

Withdrawal from Dialysis Trends

End Stage Renal Disease imposes a high mortality burden. Life on dialysis has improved, but complex medical and emotional challenges remain. As dialysis has become increasingly accepted as a routine medical intervention, the population receiving this difficult and intrusive treatment has become more elderly, sick, fragile and vulnerable.

It is well known that every year, a substantial proportion of patient deaths are preceded by discontinuation of dialysis treatment. Discontinuation of dialysis means that the patient's regular course of kidney replacement therapy was stopped with the expectation that it would not be resumed even in response to life-threatening complications, and that the patient and / or health care agent made an explicit decision that kidney replacement therapy should be stopped permanently. CMS Form 2746, the Death Notification Form, has data elements about discontinuation of dialysis.

The Network of New England has followed the trends in this important area of end of life care. Table L contains the number of deaths reported in Network 1 for ESRD patients in the six states of New England from year 2000 to 2010. The data were analyzed for the number of patients that discontinued from dialysis prior to death and also by diabetes, the primary cause of ESRD. Recent projections conducted by this Network indicate that less than 50% of patients that have discontinued dialysis were referred to hospice. This is an area for improvement which was identified by raising awareness of palliative care management at the Network annual meeting by a presentation given by Lewis Cohen, MD.

Table M: Network 1 Annual Number of Deaths, Discontinuations by Diabetic Status

	Patient Deaths			Patient discontinued		Total Discontinued	
	Diabetic	Non-Diabetic	Total	Diabetic	Non-Diabetic	N	%
2000	1,081	1,583	2,665	261	552	813	31%
2001*	1,118	1,630	2,748	349	534	883	32%
2002**	1,139	1,638	2,777	338	558	896	32%
2003***	1,234	1,615	2,853	387	574	961	33%
2004	1,217	1,668	2,885	398	620	1,018	35%
2005	1,102	1,848	2,956	378	656	1,034	35%
2006	1,067	1,790	2,857	362	687	1,103	39%
2007	1,090	1,614	2,804	391	633	1,024	36%
2008	1,103	1,620	2,723	393	666	1,059	39%
2009	1,191	1,579	2,770	402	717	1,119	40%
2010	1,161	1,670	2,831	412	686	1098	39%

Note: * Primary diagnosis was missing for 26 patients. ** Primary diagnosis was missing for 10 patients. ***Primary diagnosis is missing for 4 patients. These patients were grouped in the non-diabetic column for all years.

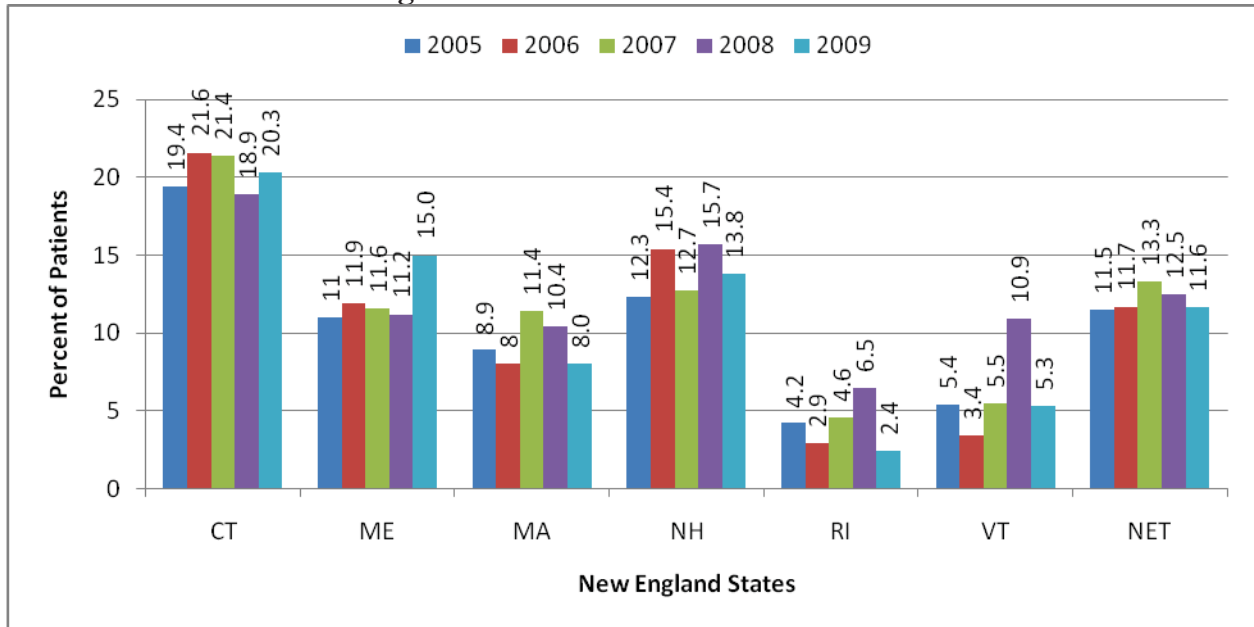
Source: CMS Form 2746

Profile Analysis of ESRD Incidence Population

Network 1 annually profiles the utilization of treatment options available to new patients with ESRD. Network 1 is interested in understanding facility selection of modality options by new patients during the first twelve months of their individual ESRD experience with the emphasis being on self care dialysis or transplantation. In order to accomplish a twelve-month retrospective analysis of “new patient” experiences, a full year must lapse for all patients in the study cohort. Therefore, the most recent data analyzed is representative of the 2009 incidence patient census by first ESRD provider of service.

Network of New England promotes new patients select home dialysis within first one year of ESRD. This rate is 11.64% for the Network in 2009. In recent years home hemodialysis is on the rise. However, the individual state experience ranged from a high of 20.3% in Connecticut to a low of 2.4 % in Rhode Island (Figure 19).

Figure 19: 2005, 2006, 2007, 2008 and 2009 Incidence Patients by First Provider of Service Selecting Home Self-Care With in First 12 Months

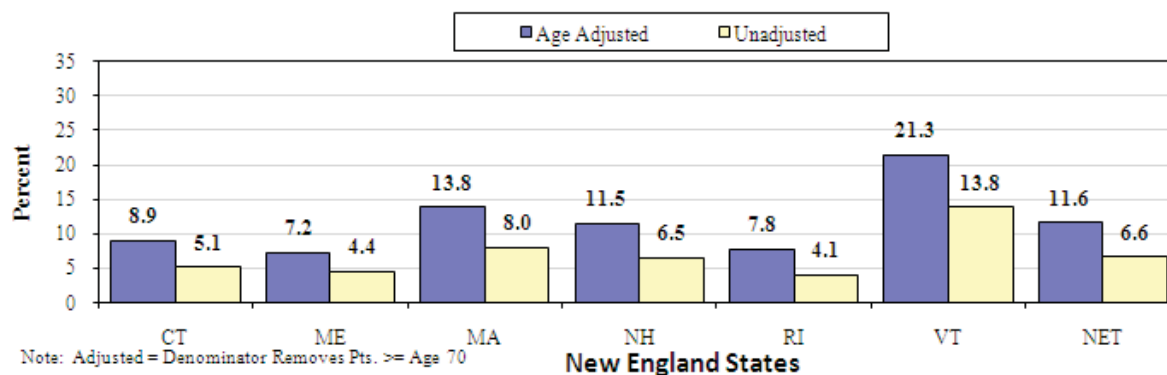


Note: Home patients for each state or Network are divided by the incident population for that state or Network. Source: SIMS data files

There continues to be high utilization of in-center treatment and steady slow growth in the total number of ESRD providers in New England. New England providers continue to expand the number of treatment stations at existing facilities or open treatment centers at new locations. This increased availability of treatment resources may be one factor contributing to a low percent of patients selecting home/self care. Incident patients selecting home/self care is; 1994 - 27.8%; 1995 - 24%; 1996 - 19.9%; 1997 - 17.7%, 1998 - 16.8%, 1999 - 19.7%, 2000 - 15.7%, 2001 - 14.9%, 2002 - 13.7%, 2003 - 13.1%, 12.7% - 2004, 11.5% in 2005, 11.7% in 2006, 13.3% in 2007 12.5% in 2008 and 11.64% in 2009.

The percent of new patients in 2009 who were transplanted in their first twelve-month experience was 6.6%. Adjusted for age by excluding patients over age 70 of the 2009 incidence population reveals a higher transplant activity rate of 11.6 % (Figure 20). Network of New England promotes new patients select transplantation within the first year of ESRD based on age-adjusted population. Table M provides the actual number of incident patients for the past three years.

Figure 20: Transplantation 2009: Incidence Patients Receiving Transplant Within First 12 Months



Note: Transplantations for each state or Network are divided by the incident population for state by residence or Network. Age adjusted category removes patients of age >=70 from the denominator.

Source: SIMS data files

Table N: 2007 - 2009 Incidence Patients by State of Residence Selecting Home Dialysis By 1st ESRD Provider: First 12 Months ESRD Experience

State	New Patients			Transplanted			Home		
	2007	2008	2009	2007	2008	2009	2007	2008	2009
CT	991	1004	1058	55	49	54	212	190	215
ME	268	322	271	17	9	12	31	36	41
MA	1723	1762	1828	164	154	147	196	183	146
NH	268	249	290	23	18	19	34	39	40
RI	326	338	363	17	14	15	15	22	9
VT	128	147	94	25	17	13	7	16	5
Total	3732	3859	3908	301	261	260	495	483	455
Total %	100	100	100	8.1	6.8	6.6	13.3	12.5	11.6

Note: 28 patients residing in NY or other states are not in state totals for New England for YR 2007

37 patients residing in NY or other states are not in state totals for New England for YR 2008

38 patients residing in NY or other states are not in state totals for New England for YR 2009

Source: SIMS data files

Prevalence Population and Employment Status

One of the functions of the ESRD Networks consistent with sound medical practice is to encourage participation of patients and providers in utilizing the services of vocational rehabilitation (VR) programs. As part of the new 2744 (annual facility survey) form, the Networks collect information on vocational rehabilitation referrals, employment and student status among patients between the ages of 18 to 54. This age-range cohort is often referred to as “working age”.

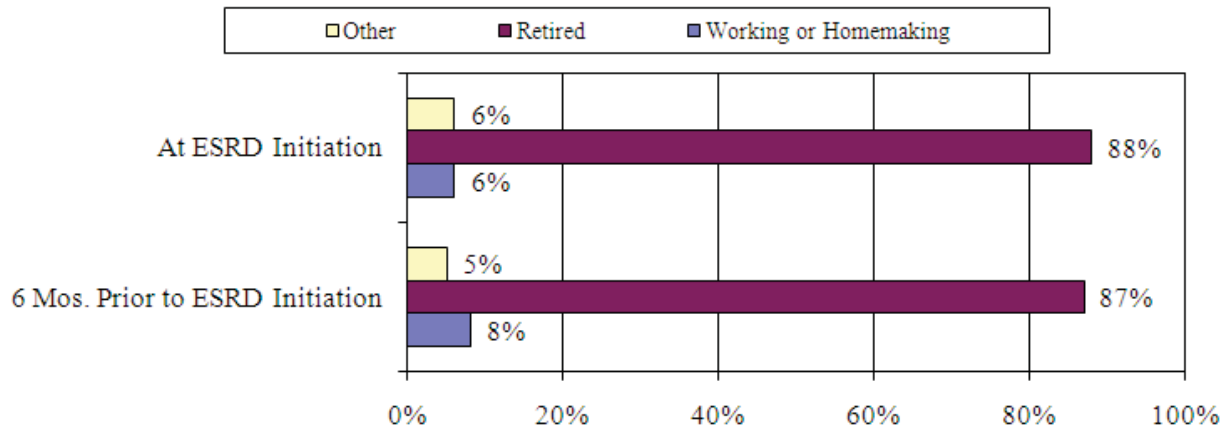
Based on the prevalent population as of December 31st 2010, there were 3160 dialysis patients in New England within the working-age range (See Table 8 in data tables sections). Ninety two

patients, or 2.9% were referred to or receiving VR services during the reporting year. Twenty eight percent (28%) of this patient group were reported as either working or students. Combined, 30.9 % of New England dialysis patients are actively involved in traditional life pursuits (employment or education).

Incident Population and Employment Status

Analysis of the Network of New England’s incident data gives insights into patients’ employment status 6-months prior and at the initiation of the ESRD treatment. CMS’s Medical Evidence Report and Registration (Form 2728) form contains data elements, which provide comparison between patient employment status, six months prior to initiation of ESRD treatment, and at the initiation of ESRD treatment. This form also captures data on the type of employment, such as whether a patient is a student, homemaker, retired due to disability, or retired due to age/preference. In 2010 a total of 3,728 individuals were registered as new patients for the New England states. Of those patients, 56% were over the age of 65 when first becoming ESRD patients. Analysis of the employment status of the incident population over the age of 65, 6-months prior to initiation of ESRD, indicates that 86.5% were retired due to disability, age or by preference, while 8.4% were working or homemaking. However, analysis of the employment status of the same population at the initiation of ESRD indicates that the number of retired increased to 88 % (Figure 21).

**Figure 21: 2010 Incidence Patients ≥ 65 *
Role Functioning Status (N = 2,086)**

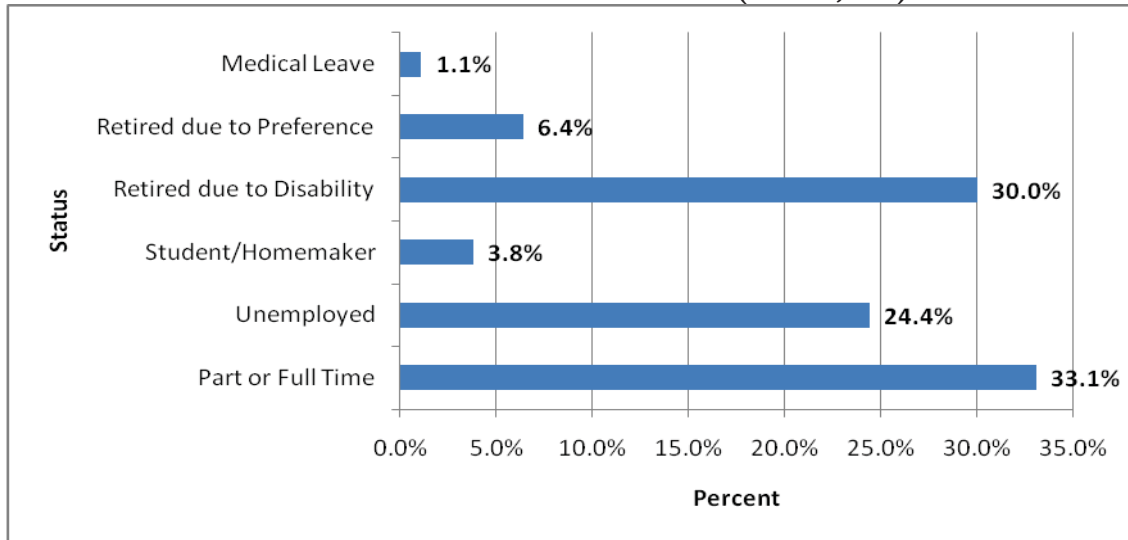


* Percent will not equal 100, due to other functional status categories not included in this figure.

Source: CMS Form 2728

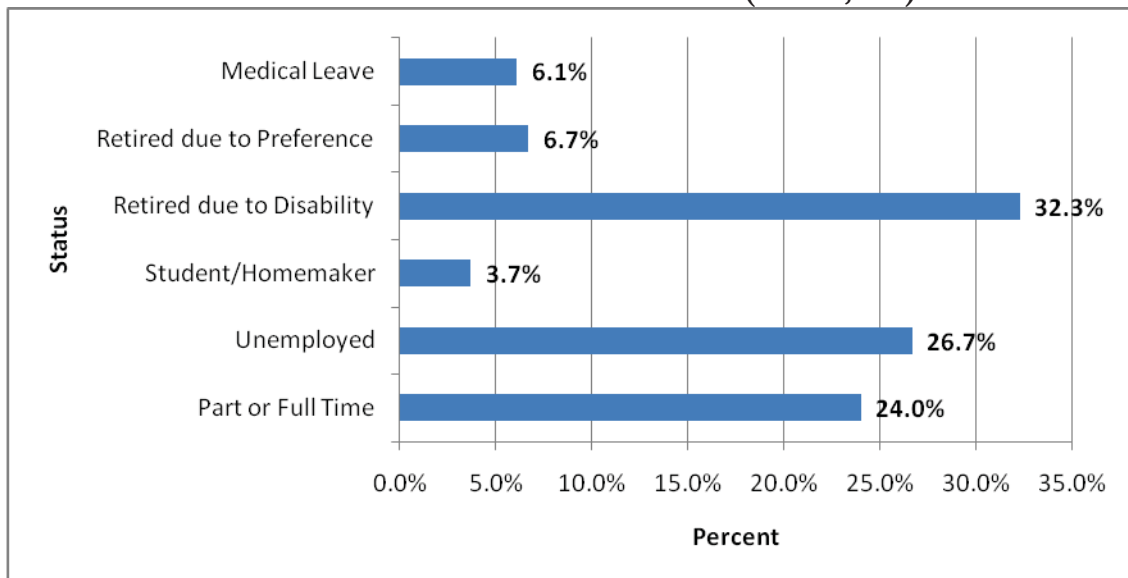
In 2010 there were 1,630 (44%) incident ESRD patients who were under age 65. Six months prior to initiation of ESRD treatment 33% of this cohort group was working, 3.8% were students or homemakers and 37% reported retired due to disability or age preference. Looking at the same group at the initiation of ESRD, 20% were working, 3.6% were students or homemaker, and 39.1% were reported retired due to disability or age preference (Figures 22 and 23).

Figure 22: 2010 Adult Incidence Patients Age <65 Functional Status 6 Mos. Prior to ESRD Initiation (N = 1,630)



Source: CMS Form 2728

Figure 23: 2010 Incidence Patients Age < 65 Functional Status At Initiation of ESRD Treatment (N = 1,630)



Source: CMS Form 2728

Vocational Rehabilitation

Of the 12,428 ESRD prevalence patients residing in the six New England states at the end 2010, only about 3,160 are of “working age” which is defined as between the ages of 18 to 55. That number represents 25.3% of the New England dialysis population.

Among the working age patients treated with dialysis 30.9% are working, going to school or are receiving vocational rehabilitative services. This is an increase from 2009 reported for New England.

This percentage of patients who are engaged in work related life activities is a relatively good outcome. This outcome is considered reasonable when taking into account the number of challenges associated with the demands of a thrice-weekly dialysis schedule, fatigue, medical complications and barriers to employment (Table O).

**Table O: Vocational Rehabilitation by State
Patients Aged 18 - 55 as of December 31, 2010**

PROVIDER STATE	NUMBER OF DIALYSIS PATIENTS AGED 18 –54 (NETWORK LIST)	NUMBER OF DIALYSIS PATIENTS RECEIVING SERVICES FROM VOC REHAB AND OTHER VOC REHAB RELATED SERVICE PROVIDERS (PUBLIC OR PRIVATE)	NUMBER OF DIALYSIS PATIENTS EMPLOYED FULL-TIME OR PART-TIME	NUMBER OF DIALYSIS PATIENTS ATTENDING SCHOOL FULL-TIME OR PART-TIME
CT	1,039	19	272	24
MA	1,372	46	340	53
ME	208	5	41	8
NH	192	8	56	6
RI	271	10	62	5
VT	78	4	10	5
Network	3,160	92	781	101

Source: CMS Form 2744

The Network of New England continues to encourage individual patients to retain or pursue their careers upon initial diagnosis of ESRD and throughout their adjustment to treatment. Network 1 posts current contact information for the six New England State Vocational Rehabilitation programs on its website and distributes educational materials to patients and providers regarding the importance of employment retention for dialysis and transplant patients. Network 1 also serves as an advocate on behalf of patients when requested by social workers or patients, when a patient is threatened with job loss. In these cases advocacy takes the form of telephone conferencing, directing correspondence to existing or potential employers and referral to partner agencies such as Life Options, the Medical Education Institute, AAKP and the Americans with Disabilities Act administered by the US Justice Department.

Network 1 Staff Provide Community Educational Materials

Pre-dialysis, dialysis or transplant patients and provider staff rely on the ESRD Networks as a resource for educational materials. Network 1 warehouses printed materials in large quantities for distribution at no cost to renal healthcare providers in New England upon request. The four most often requested educational products in 2010 were:

- *Your New Life* (New England PAC)
- *Preparing For Emergencies – A Guide for People on Dialysis*
- (CMS) *ESRD Medicare Coverage for Dialysis and Transplantation* (CMS)

- *“BEE” Informed of Your Rights and Responsibilities.*

Network 1 difficulties this year were that some of the requests could not be fulfilled because CMS exhausted stock of Preparing for Emergencies; however Network 1 obtained some copies from the Network Coordinating Center. These four popular multi-page booklets are designed to orient and educate members of the renal community, both patients and providers, on the many aspects of End Stage Renal Disease.

The following types of educational information or materials given to patients and providers of CKD/ESRD healthcare throughout the year:

- QI Information
- Rights and Responsibilities
- Data Research Information
- Complaints and Grievances
- Treatment Options
- Vocational Rehabilitation Information
- Information on Dental Services
- Transient Care
- What the Network functions are
- Website Referral (DFC)
- Reimbursement Issues and Questions
- Coordination of Benefit Questions
- KDQOL questions
- Other Requests

The American Association for Kidney Patients (AAKP) asked the Patient Services Coordinator to write an article on home dialysis for their newsletter called “Renal Life.” The article was called Mind, Body and Soul: Home Dialysis. Together You Can. It was published November 2010.

Achieving Network 1 Goals in Quality of Life for ESRD Patients

The importance of patient quality of life has been a high priority for Network 1. The provision of educational materials on the website and distribution efforts to patients and professionals is an ongoing activity. Random feedback of utilization and effectiveness of these materials is conducted by Network staff. Network 1 leadership serves on the steering committee of the ESRD National End of Life Coalition. Analysis of access to services and employment status of dialysis population is reported annually to the Network Board to assure adequate regional availability of dialysis treatment to help employed patients. A vocational rehabilitation report with comparative data is sent to each dialysis social worker for internal performance assessment.