Final Deliverable

PROGRAM EVALUATION OF PSAS
PATIENTS DISCHARGED TO HOME

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Booz | Allen | Hamilton

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INTRODUCTION

The purpose of this study is to evaluate the outcomes and services provided to PSAS patients discharged to the home

The Department of Veterans Affairs (VA) contracted Booz Allen Hamilton (Booz Allen) to conduct a Program Evaluation of services provided to veterans who utilize Prosthetics and Sensory Aids Services (PSAS). The main PSAS Program Evaluation study questions evaluate "to what extent is VA achieving its program outcomes for patients requiring prosthetics based on a continuum of care?" This portion of the Program Evaluation concentrates on three specific study questions.

- Do VA patients who have been discharged to the home receive health care services and supplies at a rate comparable to non-VA patients?
- Do these patients report a quality of life comparable to non-VA patients?
- Are the VA prosthetic patients reporting satisfaction rates comparable to non-VA patients?

This report describes the Veterans Health Administration (VHA) system that provides prosthetics and related health services to patients ***with above knee amputations, motorized wheelchairs and home oxygen***. In this report we present the methodology used to assess these patient populations, as well as our findings, analyses and recommendations. The Booz Allen team collaborated with VA to develop an analysis plan for each study population. We utilized several VA databases, as well as some non-VA databases, to conduct the analyses. The findings and analyses are in areas of patient functionality, patient and family education, quality of life, access to care, and patient satisfaction. This report was designed with complete chapters — so that chapters on specific patient populations could be separated and provided to interested individuals.

There are several limitations to this study that should be considered when reviewing the findings

We provide a detailed description of the methodology utilized for each study population group within the respective chapters of this report. A listing of all databases used in this study is provided in Appendix A. Summaries of all analysis metrics and the accompanying results are provided in Appendix B. In order to answer each study question, different data extraction techniques were used. There are limitations in both the data as well as the methodology for each of the three study populations. The limitations are summarized at a high level below. The details of these limitations are provided in Appendix C.

- The sample size of the populations under study became much smaller during the process of data extraction and data matching.
- Data were frequently incomplete.
- Groups of patients for comparisons to VA samples were difficult to identify. A non-VA comparison group for patient satisfaction could not be identified because the survey was only administered to veterans and a valid comparison requires the same survey instrument to be administered to both comparison groups. A non-VA comparison group to evaluate receipt of health services and supplies could not be identified. (For more information related to comparison of benefit levels refer to the Booz Allen Hamilton deliverable *Comparison Analysis of Public and Private Sector's Health Care Benefits for Prosthetics and Sensory Aids* dated 5/27/99)
- Study samples of patients from VA data sets after merging and matching were small.

- Privacy and confidentiality constraints made age calculation impossible.
- We found inconsistent demographic variables, both within VA data sets and comparison groups.
- The algorithms used for the SF-36v are different for role physical and role emotional than the published algorithms for the original SF-36 (Ware, 1993), therefore limiting some direct comparisons.
- Several questions were designed to assess quality of life, functional abilities and participation in life situations. However, validated measures of these functions are not available.
- There were duplicated records in most of the datasets and limited common variables, resulting in potential for records to be lost when files are merged, which influences patient selection bias.
- Quantification of timing for survey completion in relation to dates of pertinent events (e.g., surgery or rehabilitation) was not possible in the non-VA and VA samples, because the exact dates were not recorded. A decision was therefore made to include only those who had a surgery date preceding the rehabilitation admission date. This leads to a loss of patients who might have been admitted to a rehabilitation unit before undergoing amputation surgeries.
- There is concern for general integrity of the data analyzed, which are listed below.
  - There were multiple data sets with missing data in different variables, and in different sets. When merging the data, we automatically lose cases that do not match.
  - In a database such as EPRP, if there were no variables indicating which module was used (oxygen vs. prosthesis), we used our judgment.
  - In the case of NPPSS, no information was available regarding the recoding scheme, which ended up with a dataset with large amounts of missing data.
  - FSOD data were also disorganized (e.g., the dates of admission did not always match up to the admission status--first rehabilitation, continuing rehabilitation, short stay evaluation).

In conclusion, conducting a program evaluation based on data collected for other purposes has inherent data challenges and concerns. Nevertheless, useful information and conclusions can be drawn that can be used to stimulate further research.

The Booz Allen team utilized various methodologies to evaluate the three populations under study

Each of the three populations in the Patients Discharged to Home Study required slightly different analysis techniques to evaluate receipt of health services and supplies, quality of life and satisfaction rates. However, many similar analysis techniques were also used across the study populations as described below.

- SF-36v/SF-36 was used to evaluate patient self-report of quality of life, functional abilities, and ability to participate in life situations.
- Analysis on training and education required the utilization of data from two sources: External Peer Review Program (EPRP) and National Prosthetic Patient Satisfaction Survey (NPPSS).
- Staff interviews during site visits to Veterans Affairs Medical Centers (VAMC) resulted in information on the qualifications of the person making the referral for VA patients.
- The National Prosthetics Patient Database (NPPD) was used to determine the ADL equipment that was provided at discharge.

- The NPPSS was used to assess veteran's satisfaction with the care, device training, and the device provided to them by VA.

The Functional Independence Measure (FIM) ratings were used to measure functional status of the AK amputation population and the motorized wheelchair population. FIM ratings were not available for home oxygen patients since FIM is a rehabilitation clinical assessment tool and not administered to this population.

Specific analysis techniques for the home oxygen population included literature reviews to examine the non-VA utilization of home oxygen services and analysis of additional satisfaction survey questions specific to home oxygen users.

Throughout this report the analysis metrics are identified by question number, which correspond to the refined metrics presented to the VA project team in the November 9, 2001 deliverable, *Phase IIA: Refined Project Plan, Program Evaluation of Prosthetics and Sensory Aids Services.*

ABOVE KNEE AMPUTATION

INTRODUCTION / METHODOLOGY

The Booz Allen Team reviewed care provided to VA patients who were discharged home following above knee amputation

Within the VHA system, local Prosthetic and Sensory Aids Services (PSAS) provides administrative management for above knee (AK) amputation patients who are discharged home. PSAS coordinates provision of AK prostheses and other equipment needed for activities of daily living (ADL) plus other related services, such as education of patients and their family members and friends. To do this, PSAS works collaboratively with many of the clinical service providers within VHA, to ensure that AK amputation patients receive prosthetic equipment and other supportive services that maximize their functionality and participation in daily life activities.

The overall study question posed by VA is, "To what extent is VA achieving its program outcomes for patients requiring prosthetics based on a continuum of care?" This study question applies to several different prosthetic patient populations, and the performance measures and analysis plan for each were tailored to the individual study populations.

One of the objectives of the study question is to evaluate outcomes of services provided to PSAS patients discharged home. For the AK amputation study population, the Booz Allen team designed our evaluation based on the general study questions shown below.

- Are VA AK amputation patients provided prostheses, other ADL equipment and related supportive education at a rate comparable to a population of similar non-VA patients?
- Do VA AK amputation patients achieve functionality levels and quality of life levels comparable to a population of similar non-VA patients?
- Do VA AK amputation patients report access to follow up care that satisfies VA goals for outpatient clinical care?
- Do VA AK amputation patients report patient satisfaction rates comparable to a population of similar non-VA patients?

The specific study questions are stated precisely in the Findings Section below, which describes each of the seven studies in detail.

Summary of findings

Our analysis findings indicate that VA's AK amputation patients generally received prostheses and other ADL equipment, supportive education, and access to follow up care. Their functionality levels and quality of life were generally lower than those of comparison groups. However, lack of comparable non-VA populations and the unique constructs of some of the databases imposed limitations to the studies. We did not identify any published literature addressing the rate of patients receiving ADL or other equipment in non-VA samples.

VA patients report low functional capacity with more dysfunction in the physical constructs and social functioning compared to the mental constructs. Dramatically low functioning was reported in the physical functioning and role physical constructs. Therefore, quality of life was perceived as low in the VA population of people with AK amputations.

More than 85% of veterans in this study population rate the quality of the device and quality of their visit as excellent, very good or good. 33% of patients rate the quality of their device-related care during the last 12 months as excellent.

The Booz Allen team utilized a variety of VA and non-VA databases to evaluate the functionality, quality of life and satisfaction of VA's AK amputation patients

The Booz Allen team designed the analysis plan to include a well-defined study population of VA AK amputation patients that could be linked to descriptive data relevant to specific analysis metrics. This population was then analyzed to determine the results for the specific study. A literature search was made for a comparable non-VA population, and if none could be found, a somewhat similar non-VA population was chosen. Findings from our data analysis are described in detail, and when possible, limited comparisons with a non-VA population were made.

The Booz Allen team utilized the Functional Independence Measure (FIM) to assess clinician-assessed change in functional status. Patients with above-knee (AK) amputations for study years 1997-2000 were identified from VA's Patient Treatment File (PTF) Surgery files. For our analyses on functionality, we merged our AK amputation patients with matched patients from the Functional Status Outcome Database (FSOD) to extract the Functional Independence Measure (FIM) ratings.

To assess patient self-report of functional abilities, quality of life and ability to participate in life situations, the SF-36 was used. The PTF dataset for our AK amputation patients was merged with the SF-36v file to produce a sample of above knee amputation patients who completed the SF-36 survey.

To identify patients who had received an AK prosthesis, the Booz Allen team merged the above knee amputation subset with records from the National Prosthetic Patient Database (NPPD), a database that captures the distribution of all equipment and supplies administered by PSAS. Above-knee amputation prostheses and device records were extracted from NPPD using the following HCPCS codes: L5200-L5230, L5250, L5280, L5320-L5340, L5549, L5560-L5590, and L5701. In order to answer study questions related to patient satisfaction, the same subset was also merged with records from the National Prosthetic Patient Satisfaction Survey (NPPSS), which produced a sample of patients who had an AK amputation, received an AK prosthesis and completed a patient satisfaction survey.

FINDINGS

The AK Amputation Study addresses eight specific analysis metrics collaboratively developed by VA and the Booz Allen team

As part of the larger Program Evaluation of VA's PSAS program, VA and the Booz Allen team developed specific analysis metrics that may be utilized to answer the overall study questions related to AK Amputation patients discharged home with PSAS services. The Booz Allen team reviewed analysis metrics in conjunction with a review of available data. Certain metrics were further refined as a result of identified data limitations. We have organized our findings in line with these analysis metrics. Metrics are labeled in accordance with the November 9, 2001 *Refined Project Plan* of the Program Evaluation of Prosthetic and Sensory Aids Services.

UTILIZATION OF SERVICES

Do VA patients who have been discharged to the home receive health care services and supplies at a rate comparable to non-VA patients?

Our analysis findings indicate that VA's AK amputation patients generally received prostheses and other ADL equipment, supportive education, and access to follow up care. We did not identify any published literature addressing the rate of patients receiving ADL or other equipment in non-VA samples.

Q.8a: What are the qualifications of the person making the referral for VA patients?

The Booz Allen team conducted site visits to seven VA medical centers across the country. During interviews with various members of PSAS, PACT and Rehabilitation, we collected varying responses regarding the qualifications of referring individuals.

- Hines: Chief of PACT and/or physiatrist
- Atlanta: Any physician in Amputee Clinic, anyone (non-physician) can make a referral
- Miami: Any physician can refer
- New York: any one of the clinical services can generate referral
- Richmond: It is unclear who can refer
- Seattle: Any physician can refer
- West Palm: Any physician or PACT coordinator may refer

There do not appear to be formal guidelines related to the qualification required to initiate a referral for a prosthesis. Site visit findings indicate variability among medical centers. The overall practice seems to allow any clinician to refer above the knee amputation patients for a prosthesis.

Q8aB: What ADL equipment was provided at discharge?

No information was available from FSOD or PTF records regarding ADL equipment prescriptions or equipment distribution. We used scrambled Social Security Numbers of the PTF-FSOD AK sample (n=295) to select NPPD records. This procedure yielded 294 patients (99%) who could be matched, resulting in 4,801 NPPD records issued for these 294 patients. Frequencies by "NPPD line" variable for the most frequently dispensed items are presented in the Table 1 below.

Table 1. Frequently Dispensed ADL Equipment

n=294

NPPD ITEM CATEGORIES	DESCRIPTION	N OF RECORDS
900I	Home Safety Equipment (e.g., Bath Items)	536
100D	Wheelchair Accessories	263
100B	Manual Custom Wheelchairs	247
200A-H	Artificial Leg Items	115
900A	Walking Aids (Cane and Walker)	241
999A	All Other Equipment	449
900K	Medical Equipment (e.g., Blood Items)	428
R90A	No Description (All Other)	193
R90A	Mixed Items	168
Total Number of Records*		**4,801**

** Not all categories are presented here.*

Most frequently issued equipment pertained to safety and ADL equipment, artificial limb parts/pieces, wheelchairs and wheelchair parts. Data support that VA patients receive a wide variety of ADL equipment. However, we could not determine the percentage of total AK patients this sample (n=294) represents, and no comparable non-VA sample was identified.

The constructs of the databases imposed the following limitations on our efforts to answer the specific question:

- Much of the data examined were missing or duplicative, hindering analyses.
- Variables across data sets were not consistent, which reduced effectiveness of analyses.
- No standard operational definitions or guidelines are available for grouping categories of ADL equipment, which hindered comparative analyses.
- No comparative data sets were identified, so that the results of VA data analyses could not be compared to comparable populations.

Q. 8aC, 8aD: Was education was provided to the VA patient? Was education was provided to the VA patient's family?

We merged data from PTF representing the AK patient population with records extracted from NPPD that identified those patients who had received an AK prosthesis. We then merged this subset with data from the National Prosthetic Patient Satisfaction Survey (NPPSS). We selected records for those patients who entered an AK device under the "Item" field on the survey. The merged file of NPPD and NPPSS resulted in a total of 171 patients. However, only 70 to 104 of these patients responded to the questions in which we were interested.

The following NPPSS questions and survey results relate to patient education.

Q. 32 (n= 101) asked, "When you asked questions, do you get answers you could understand?"

RESPONSE	NUMBER	PERCENTAGE
Yes, always	81	80.2%
Yes, sometimes	17	16.8%
People did not ask questions	3	3.0%

Q. 33 (n= 102) asked, "During your most recent device-related visit, did someone teach you how to use your prosthetic device in a way that you could understand?"

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	43	42.2%
Yes, somewhat	8	7.8%
No	8	7.8%
No teaching was needed	43	42.2%

Q 35 (n= 102) asked "Did you get as much information about your device as you wanted from your provider?"

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	72	70.6%
Yes, somewhat	24	23.5%
No	5	4.9%

The following questions relate to patient family education.

Q. 26 (n= 102) asked "Was the provider willing to talk to your friends or family about your device-related care?"

RESPONSE	NUMBER	PERCENTAGE
Yes	33	32.4%
No	7	6.9%
No family involvement	59	57.8%

Q. 34 (n= 102) asked "During your most recent device-related visit, did someone teach your family or friends how to help you use your prosthetic device in a way that they could understand?"

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	14	13.7%
Yes, somewhat	3	2.9%
No	13	12.7%
No teaching needed	16	15.7%
No family involvement	54	52.9%

In general, VA patients report satisfaction with the education and training they received related to their prosthetic devices. Over 50% of veterans reported no family involvement in the education and training provided.

FUNCTIONALITY

8bA: What are the patient functionality scores before and after treatment, when age and risk adjusted?

This analysis question concerns assessment of services provided to VA patients who are discharged to home. Sub-populations of patients who received motorized wheelchairs and patients with above knee amputations were analyzed employing multiple questions. In this section, we provide analyses of functional status before and after rehabilitation treatment for patients with above knee amputations, using FIM scores from the Functional Status Outcome Database (FSOD).

Above-knee amputation patient records were extracted from PTF Surgery Files for 1997 through 2000. In addition, records of patients with single above-knee, bilateral above-knee, and bilateral (or double) above-knee *and* below-knee amputations were selected from the FSOD File, based on impairment codes. We selected only those patients who were over 18 year of age, had complete FIM records and had a length of stay between 4 and 120 days. These two databases were merged, which resulted in selecting patients who underwent surgery prior to or within one month of their rehabilitation admission dates.

A picture of patient characteristics was developed to understand the study population

Two hundred ninety five patients were identified in this subset after merging. Of these, 89% (262) had single above-knee amputations and 11% (33) had double above-knee amputations. There were no patients that had double above-knee *and* below-knee amputations. Seventeen patients were admitted to a rehabilitation facility in 1997, 103 in 1998, 97 in 1999, and 78 in 2000. 82.4% (243) received rehabilitation for the first time. Other demographic and clinical patient characteristics are summarized in Table 2. The sum, however, for the following categories does not always add up to 295 because there is missing data in the data sets. For example, data on *gender* for 42 patients' is missing.

Table 2. Characteristics of AK Amputation Patients with a completed FIM (n=295)

CHARACTERISTICS*	TOTAL RESPONSES (n)	SUMMARY	MISSING DATA
Gender	n=253		42
Male	252	99%	
Female	1	<1%	
Ethnicity	n=279		16
Caucasian	158	56%	
African American	72	26%	
Hispanic	47	17%	
Native American	2	<1%	
Marital Status	n=290		5
Single	29	10%	
Married	130	45%	
Widowed	34	12%	
Divorced/Separated	97	33%	
Pre-Hospital Living Setting	n=292		3
Home	272	92	
Board & Care	2	1	
Intermediate Care	4	1	
Acute Unit	1	0	
Subacute Setting/SNF	13	4	
Discharge To:	n=280		15
Home	209	75%	
Board & Care	1	<1%	
Intermediate Care	9	3%	
Acute Unit	22	8%	
Subacute Setting/SNF	34	12%	
Rehabilitation Facility**	5	<2%	
Length of Stay (Days - M±SD)	22±14		
Age (Yrs - M±SD)	67±10		

***Free-standing rehabilitation hospitals abide by certain government regulations and guidelines for special status for reimbursement of services. Typically, such facilities provide 24 hour medical support and 3-hour/day rehabilitation therapy to patients.*

The following table provides a summary of patients' functional status at admission and discharge and notes differences between the scores.

Table 3. Functional Status of AK Amputation Patients Undergoing Rehabilitation

	MEAN	STANDARD DEVIATION
Raw FIM Total at Admission	85	(20)
Raw FIM Total at Discharge	100	(19)
Raw FIM Gain	15	(11)
Motor FIM (Raw Score) at Admission	55	(16)
Motor FIM (Raw Score) at Discharge	69	(16)
Raw Motor Gain	14	(10)
Cog FIM (Raw Score) at Admission	30	(5)
Cog FIM (Raw Score) at Discharge	31	(5)
Raw Cog Gain	1	(2)
Rasch Transformed Motor Measure at Admission[+]	41	(15)
Rasch Transformed Motor Measure at Discharge[+]	54	(15)
Rasch Transformed Gain in Motor Measure	13	(10)

[+] *Raw FIM scores were transformed to Rasch measures.*

Above-Knee amputation patients undergoing rehabilitation treatment improved their functional status, primarily in the motor area. Risk-adjustment was not possible due to the following two reasons.

- It is likely that most of the AK amputees had prior amputations, which automatically put them into the highest risk level
- Data for additional variables used to rank risks (e.g., EPRP "risky foot" variables) were missing for most patients.

The extent to which functional status at discharge correlates with age was examined next. The results showed that age is mildly, but negatively, correlated with discharge FIM ($r=-.23$, $p<.001$), suggesting that older patients had lower discharge FIM scores. The strength of the correlation was weak, but significant. Results from our data support prior research (1, 2, 3) that found intake and discharge FIM measures to be moderately to highly correlated ($r=.77$, $p < .001$).

The discharge motor FIM for the AK study population was also evaluated

Analysis of covariance (ANCOVA) was performed to determine if there were differences in discharge motor FIM measures across age groups, with admission motor FIM as the covariate. ANCOVA allows

control for specific variables, such as the effect of co morbidities, which risk adjusts the outcomes. Use of ANCOVA with admission measures as the covariate tends to risk-adjust differences across groups because some investigators (4) believe the effect of co-morbidities are imbedded within the intake functional measure. Our analysis showed that there was no significant difference among different age groups (F=1.86, p= .14). Table 4 shows the mean discharge motor FIM of each age group after adjusting for admission motor FIM.

Table 4. Mean Discharge Motor FIM* After Adjusting for Admission Motor FIM (n=295)

AGE GROUP	M	S.E.	95% CONFIDENCE INTERVAL
<54	52	1.4	49.2-54.9
55-64	55	1.2	53.0-57.6
65-74	54	.9	52.4-55.9
>75	53	1.2	50.6-55.2

**Rasch transformed 0-100 measures were used in ANCOVA.*
M=Adjusted means
S.E.=Standard errors from ANCOVA.

Rehabilitation of the AK Amputation Population produced Functional Gains in All Age Groups

Effect of age on gain in motor FIM measures was assessed with a one-way ANOVA. Age group did not affect improvement in motor FIM measures (F=2.33, p=.07). Table 5 presents the frequency of patients for each category of motor gain for each age group. Data suggest that 22% of patients in the age group 55-64 gained 20 points or more, compared with 21% in the age group 65-74, and 17% in the age group older than 75. The differences among age groups were not significant.

Table 5. Gain in Motor Function by Age (N=295)

	AGE GROUP				
	<44	45-54	55-64	65-74	>75
Gain* (Mean±SD)	6.4±6.2	9.8±9.6	13.3±9.5	14.1±10.9	13.2±10.3
Category	NUMBER OF PATIENTS PER AGE AND GAIN GROUPS				
<0	0	1	1	2	1
0 to 9.99	5	22	23	38	26
10 to 19.99	1	11	27	44	25
20 to 29.99	0	3	15	24	12
30 or more	0	2	2	5	5
Total	6	39	68	113	69

***Based on Rasch transformed 0-100 measures.*

The functional status in VA patients with above-knee amputations improved following rehabilitation. The gain was primarily in the motor domain (14 raw FIM scores or 13 Rasch-transformed points) compared to the cognitive domain. Eighty five percent of the patients with AK amputations were 55 years of age or older, with the largest number of patients (38%) being in the 65-74 yr age group. However, age did not affect either discharge motor FIM measures or gain in FIM measures following rehabilitation.

The Uniform Data Set for medical rehabilitation (UDSmr) is the largest data set in the world for inpatient rehabilitation and contains data on more than 13,000 patients with above-knee amputations. For this study question, however we decided not to make comparisons in functional status or functional gain between the VA sample and the non-VA comparison group, i.e., the AK sample of the UDSmr, due to several limitations. First, unlike the VA sample, in which we were able to match rehabilitation with surgery

records, no comparable surgery information were available for the UDSmr AK sample. Second, many of the demographic and clinical characteristics are different between the two samples, as shown in Table 6, and the VA sample was small compared to UDSmr AK sample.

Table 6. Differences Between VA Population and Non-VA Sample

Population Characteristics		
	VA Sample = 295	Non-VA Sample = 13288
Gender		
Male	99%	54%
Female	<1%	46%
Ethnicity		
Caucasian	56%	67%
Hispanic	17%	5%
Discharge To:		
Home	75%	94%
Subacute Setting/SNF	12%	1.4%
Length of Stay (Days - M±SD)	22±14	18±11
Age (Yrs - M±SD)	67±10	67.2±13

+The VA sample had missing information on gender for 42 records.

The database constructs imposed several limitations on this study

- The comparison groups were not similar to the VA sample and could not be age-adjusted or risk-adjusted.
- The VA FSOD sample appears small when compared to the possible number of patients with above knee amputations that could have been assessed with the FIM. This disparity could imply selection bias.
- Quantification of timing between FIM completion and date of surgery was not possible in the non-VA sample, so medical and functional stratifications could not be accomplished in the potential comparison sample.
- Quantification of timing between FIM completion, date of surgery and rehabilitation sequence (including type of rehabilitation) was not possible in any data set, so risk-adjustment was not possible across data sets.
- The data were incomplete, increasing selection bias potential for all samples.

QUALITY OF LIFE

Q. 8bB, 8bC: How do VA patients with AK prostheses rate their quality of life? How do VA patients with AK prostheses rate their ability to participate in life situations?

VA patients report low functional capacity with more dysfunction in the physical constructs and social functioning compared to the mental constructs. Dramatically low functioning was reported in the physical functioning and role physical constructs. Therefore, quality of life was perceived as low in the VA population of people with AK amputations.

These study questions concern quantification of patients' perception of their quality of life and patients' ability to participate in life situations following above knee amputations. There are no data in the VA data sets that allow direct assessment of either quality of life or life situation participation. However, the SF-36 constructs health-related quality of life (HRQL), and its assessment permits estimation of both quality of life and participation in life situations (5). The SF-36 constructs for patient perception of quality of life and patient ability to participate in life situations are very similar. Therefore, the two analyses will be grouped together in this report.

Norms for SF-36 constructs were generated during the Medical Outcome Study (MOS). Data were collected as part of the National Survey of Functional Health Status in 1990, using personal interview (not self-administered) questionnaires (5, 7). Respondents were drawn from the General Social Survey in 1990, which surveyed 2,474 non-institutionalized adults in the United States (5). The SF-36 was designed to assess HRQL for people without disease as well as for patients with medical conditions (7).

The SF-36 contains no data that allow for differentiation between respondents' *perception* of participation in life situations and *actual* participation in life situations. Use of the SF-36 facilitates comparisons of functional abilities for:

- VA patients who received above knee amputation surgery
- Non-VA patients, such as patients who received prostheses for above knee amputations (Hart 2000).

Patients in the comparative sample (8) are not exact matches for the VA patient sample in this study. Even so, the comparative sample permits useful preliminary comparisons with the VA sample, subject to certain limitations involved in comparing them.

The Booz Allen team developed a subset of the study population for SF-36 analysis

An electronic file was developed from the inpatient surgery Patient Treatment Files for 1997 through 2000. Patients were selected if they had lower extremity amputations or cardiovascular surgery codes. The file was further refined to include only above knee amputations. Patient records were then merged with the SF-36v database using scrambled social security numbers. Patients were excluded from this subset if dates of surgery followed completion of the SF-36 survey, if patients had more than one surgery, or if discharge was not regular. These exclusions left a sample of 310 patients. Few patients had complete data for independent variables.

The descriptive characteristics for the patient population are displayed in Table 7.

Table 7. Characteristics of Patients with an Above Knee Amputation Who Completed an SF-36v

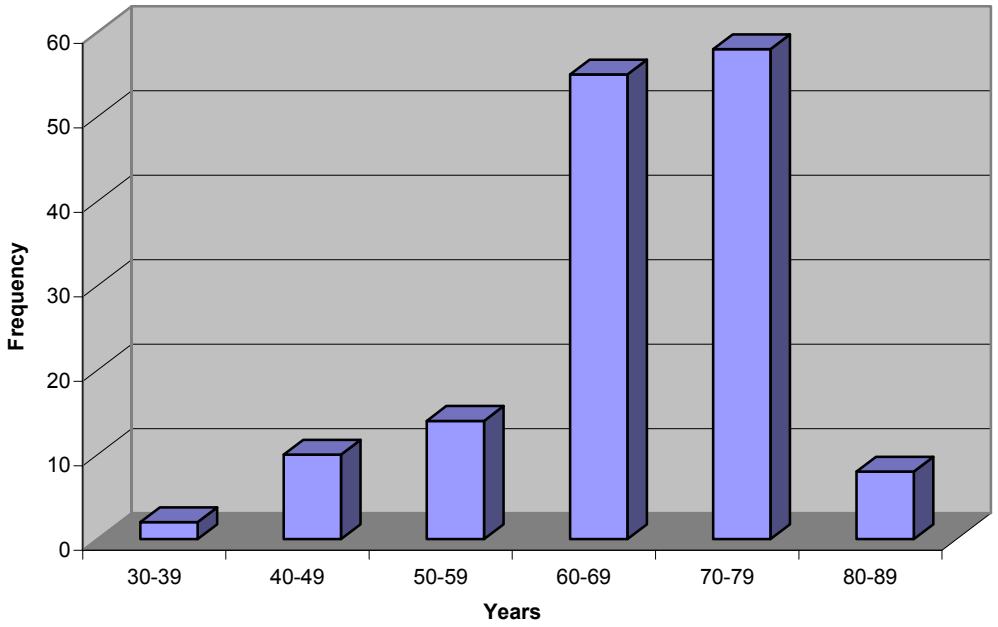
CHARACTERISTICS	RESPONSE TO VARIABLE	SUMMARY	TOTAL RESPONSES	MISSING DATA
		n=310		
Gender			n=147	163
Female	3	2%		
Male (n=147 respondents, 153 missing)	144	98%		
Ethnicity			n=299	11
Caucasian	205	69%		
African American	69	23%		
Hispanic	19	6%		
Native American	6	2%		
Age (yrs – mean±SD, range)		68±10 (38-87)	n=147	163
Employment status			n=299	
Employed for wages	1	<1%		
Self-employed	1	<1%		
Student	1	<1%		
Retired	58	19%		
Disabled	238	80%		
Year of amputation			n=310	0
1997	114	37%		
1998	119	38%		
1999	77	25%		
Co-morbidity (Collected via patient recall)				
Hypertension or high blood pressure	218	73%	300	10
Benign prostatic hypertrophy	69	24%	284	26
Chronic low back pain	98	34%	289	21
Congestive heart failure	123	43%	287	23
Stroke	112	39%	290	20
Arthritis	187	64%	293	17
Angina or coronary heart disease	123	44%	280	30
Heart attack or myocardial infarction	114	40%	283	27
Chronic lung disease	78	27%	285	25
Cancer	49	17%	284	26
Depression	120	42%	284	26
Post-traumatic stress disorder	59	21%	284	26
Schizophrenia	15	5%	276	34
Spinal cord injury w quadriplegia or paraplegia	26	9%	278	32
If your doctor told you that you had diabetes, how long ago were you first told?			n=160	
<1 yr ago	12	8%		298
1-3 yrs ago	20	13%		290
4-10 *yrs* ago	41	26%		269
11-20 yrs ago	40	25%		270
>20 yrs ago	47	29%		263

Table 7. (continued)

CHARACTERISTICS (N=310)	RESPONSE TO VARIABLE	SUMMARY	TOTAL RESPONSES	MISSING DATA
Do you now smoke cigarettes?			n=296	14
Every day	95	32%		
Some days	31	10%		
Not at all	170	57%		
Marital status			n=147	163
Married	95	65%		
Divorced	22	15%		
Separated	2	1		
Widowed	18	12%		
Never married	10	7%		
Lives alone	57	21%	n=275	35
How many times during past month did you have 5 or more drinks on an occasion?			n=281	29
Never or less than once per month	229	81%		
1-3/month	17	6%		
1/week	3	1%		
2-4/week	12	4%		
5-6/week	10	4%		
1/day	2	1%		
>1/day	8	3%		

The ages of the population varied from 30 to 80+ years. Most of the patients were between the ages of 60 and 79. Their age distribution by decades is summarized in Figure 1 below.

Figure 1. Frequency of AK Amputations by Age



The VA Patient Population Was Compared With Three Other Populations

The three groups used for comparison were:

- Norms from the male US population
- Patients with Type II diabetes mellitus (DM) from MOS
- Patients from Focus On Therapeutic Outcomes Inc. who had AK amputations

The latter two of these three groups are discussed below.

MOS SF-36 Sample

Two samples from the MOS SF-36 study (5) were selected for comparison with the VA sample. First, male patients from the normative sample of the MOS SF-36 study were selected (n=1,055). The average age was not reported, but ranged from 18 to 75+ years. Second, patients with Type II diabetes mellitus (n=541) were selected from the MOS SF-36 study (5). There were no data implying the patients with diabetes had amputations. The mean age of this sample was 60 yrs; 38% were over 65 years in age; and 56% were female.

FOTO, Inc. Sample:

From a group of 767 patients with AK, BK or foot/ankle/toe amputations, 38 were selected because they had an above knee amputation secondary to diabetes mellitus and/or peripheral vascular disease (PVD) and had HRQL data at the time of their prosthetic fitting. Descriptive statistics for these patients are provided in Table 8 below.

Table 8. FOTO, Inc. Sample

Patients (n=38)

CHARACTERISTICS	n	SUMMARY
Age (yrs)	38	65±12, 28 to 80
Gender		
Male	26	68%
Female	12	32%
Employment (n=38 respondents)		
Employed	4	11%
Unemployed	6	16%
Retired	27	71%
Housewife	1	3%
Residence (n=38 respondents)		
Home	35	92%
Assisted living	3	8%
Type of prosthesis (n=38 respondents)		
First limb	19	50%
Replacement limb	19	50%

We utilized statistical steps to transform the SF-36 survey responses into numeric scales, which were used in subsequent statistical analyses

SF-36 data for the VA patients were collected using the Health Survey of Veterans (Veterans SF-36 & Health Behaviors). The extracted data contained 35 items from the SF-36 representing eight functional scales (5, 7, 9,10).

Role physical (RP) and role emotional (RE) constructs used rating scales that deviated from published algorithms (5), so item responses were transformed using VA algorithms. The constructs used five response categories rated from high functioning to low functioning. The response categories were “No, none of the time”, “Yes, a little of the time”, “Yes, some of the time”, “Yes, most of the time”, and “Yes, all of the time”. The responses were used to generate scales ranging from 0 to 100. However, for these two scales, the scores were subtracted from 100 to reverse the final scale score, so that higher scores represent higher function in all cases.

The responses for the other six functional scales were transformed following published algorithms (5, p6:17), so the scores ranged from 0 to 100. Hence, the resulting 0 to 100 scores for all eight scales could be interpreted similarly to published interpretations: 0 reflects low functioning, and 100 reflects high functioning (5). The scores have been interpreted as percentages of functioning and health and well-being. Eight SF-36 constructs were evaluated: general health, physical functioning, role physical, bodily pain, mental health, role emotional, vitality and social functioning.

Physical Component Summary (PCS) and Mental Component Summary (MCS) SF-36 scores were calculated following published algorithms (11), using the transformed scale scores above. This produced scores with an expected average of 50 and standard deviation of 10, which are the mean and standard deviations for a normal USA population (11). In this way, the PCS and MCS are norm referenced and can be interpreted in relation to standard deviation units (multiples of 10) away from the expected normal (i.e. 50). For example, if the VA population had a PCS of 39, this means that, on average, the VA population reported lower physical functioning compared to the normal population, and that decrement in functioning was 1.01 standard deviations below the norm.

Only VA patients with complete data were assessed. Descriptive statistics were used to estimate the patient’s ability to function, as well as to estimate quality of life, for each of the eight SF-36 constructs. Results can be compared to normative values from male patients from the MOS SF-36 study (5), patients with Type II diabetes from the MOS SF-36 study (5), and data from patients with diabetes or peripheral vascular disease with above knee amputations who received prosthetic devices (8).

SF-36 scores were transformed into an effect size to compare SF-36 results across populations

For comparisons among the VA patients with normative data, patients with Type II diabetes, and patients receiving prosthetic devices, each pair of scores was transformed into an effect size (12). An effect size was calculated by subtracting the comparative score from the VA score and dividing the result by the standard deviation of the comparative score (6). As an example, if on average, 2,156 VA patients report their physical functioning as 24 out of 100, their effect size would be -3. To calculate the effect size, the 1,055 males used in the MOS SF-36 normative study reported their physical functioning as 87 out of 100 with a standard deviation of 21. The effect size would be [(24-87)/21] = -3 standard deviation units. An effect size was calculated for each available SF-36 scale for an appropriate age-adjusted group. Effect sizes quantify the magnitude of the difference between the two groups and can be interpreted as follows: 0.2 to 0.4 is small; 0.5 to 0.7 is moderate; and greater than 0.7 is large (12). Effect sizes are standardized change scores, which allow direct comparisons of magnitudes of change across studies. In the example on physical functioning, the magnitude of the effect size of –3 is large, and the negative direction means that the VA patients reported (as expected) less physical functioning than the normative males.

The MOS SF-36 male norms are grouped by age, so the VA patients could be compared to age adjusted norms. The SF-36 PCS and MCS data are normed to a mean of 50 (normal population, males and females) with a standard deviation of 10. So, PCS and MCS data can be compared as a group, but the PCS and MCS were not age-adjusted.

VA patients scored low in both physical and mental constructs of the SF-36

Findings for the VA patient population are displayed in Table 9 on the following page. The physical constructs are listed for general health, bodily pain, physical functioning, role physical, and physical component summary (PCS). Mental constructs are listed for mental health, role emotional, social functioning, vitality and mental component summary (MCS).

Table 9. Functional Health Status Statistics for all VA Patients with AK Amputations

Physical Constructs					
	General Health[a]	Bodily Pain[a]	Physical Functioning[a]	Role Physical[b]	PCS[a]
N	296	303	301	169	271
Minimum	0	0	0	0	10
Maximum	96	100	100	100	53
Mean	33	34	15	15	24
Standard Deviation	21	27	28	24	7

[a]*Values calculated using algorithms from MOS SF-36 (5)*
[b]*Values calculated using algorithms from VA*

Mental Constructs					
	Mental Health[a]	*Role Emotional*[b]	*Social Functioning*[a]	*Vitality*[a]	*MCS*[a]
N	300	169 [b]	301	307	271
Minimum	0	0	0	0	6
Maximum	100	100	100	100	75
Mean	54	33	34	36	40
Standard Deviation	23	36	30	22	13

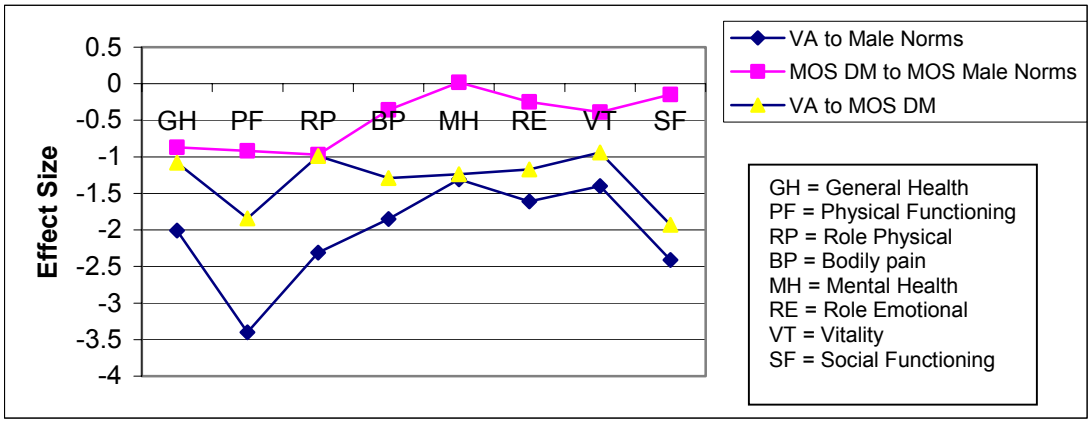
[a]*Values calculated using algorithms from MOS SF-36 (5)*
[b]*Values calculated using algorithms from VA*

SF-36 scales from VA patients with above knee amputations were compared to normative values for men (Reference 5, page10:14), values from male and female patients in the MOS SF-36 study with Type II diabetes mellitus (DM) regardless of age (Reference 5, page 10:24), and values for patients who received a prosthetic device for an above knee amputation. The samples were compared for the bodily pain and physical functioning scales (8) using effect sizes (12). In this way, differences between VA patients and the two comparative samples were transformed into standardized differences.

Figure 2 graphically presents differences among sample groups, including the VA sample and the MOS SF-36 study published in the book *Health Survey Manual and Interpretation* (5). The MOS sample was obtained from data presented in the book, which could not be manipulated. The lower line in Figure 2 (VA to Male Norms) represents the magnitude of the difference between perceived functional abilities of male patients with above knee amputations in the VA system compared to normed males in the MOS SF-36 study (Medical Outcome Study) — represented by line 0 on the graph (5). The largest amount of functional deficit is seen when the VA patients (male/female) are compared to MOS population with DM. The upper line in the graph (MOS DM to MOS Male Norms) represents the magnitude of the difference between perceived functional abilities of patients (males and females) in the MOS SF-36 study with Type II diabetes mellitus regardless of age, when compared to normed males in the MOS SF-36 study without diabetes, represented by line 0 on the graph (5). Individuals with diabetes have perceived lower functional abilities than the male norms. The middle line in the graph (VA to MS DM) represents the

difference between functional abilities of male patients in the VA system regardless of age compared to patients (males and females) in the MOS SF-36 study with Type II diabetes (5). In this comparison the VA population perceives more deficit than the MOS DM sample.

Figure 2. Graphic Presentation of Differences Among Sample Groups



Effect sizes are in units of standard deviations. The 0 value (y-axis) represents the normative value for the US male population (5 p10:14). As the patient becomes less functional for each SF-36 scale (shown on the x-axis), the effect size becomes more negative. As the patient becomes more functional, the effect size becomes more positive (y-axis). The data demonstrate that, in general, patients in the VA system with an above knee amputation and either DM or PVD perceive their functional abilities as more dysfunctional than patients with Type II diabetes or normative males. The magnitude of the comparisons is in standard deviation units, facilitating comparisons. For example, on average, patients in the VA system with DM or PVD and an above knee amputation perceive their physical functioning as worse than the average normed male in the US by three standard deviations. It is of interest that values for the VA patients with above knee amputations are not much worse than those for patients in the MOS with Type II diabetes.

In another comparison, 38 patients who underwent an above knee amputation due to diabetes or peripheral vascular disease and who were measured for prostheses had effect sizes of -0.4 and –2.5 for intake MOS SF-36 bodily pain and physical functioning scales respectively from the FOTO, Inc. data (8). This analysis shows that VA patients reported lower physical functioning and more bodily pain when compared to patients surveyed by FOTO, Inc.

In general, the VA patients demonstrate significant (12) dysfunction in all SF-36 scales, dramatically low dysfunction for the four physical functioning scales (GH, PF, RP and BP) and low functioning for the social functioning scale (SF) when compared to the normed males. Social functioning represents both mental and physical constructs (5). VA patients also reported lower functioning when compared to patients with diabetes, but the difference was not as dramatic as the comparison with the normed males. VA patients reported lower bodily pain (34±27, more pain and interference with physical activities (because of pain), and physical functioning (15±28) when compared to FOTO, Inc. patients (65±23 bodily pain and 26±24 physical functioning). All comparisons appear logical.

SF-36 summary component scales compared to MOS SF-36 norms for above knee amputations were as follows:

	PCS	MCS
Norms General US Population (n=2474)*	50±10	50±10
Norms for Males US Population (n=1055)*	51±9	51±10
VA Males (n=310)	24±7	40±13

**MOS SF-36 Study (11)*

Our study population reported low functional capacity in both physical and mental constructs

VA patients with above knee amputations from diabetes mellitus, peripheral vascular disease, or both conditions report low functional capacity in all eight SF-36 scales, but more dysfunction in the physical and social functioning constructs than in the mental constructs. This result was expected, since lower extremity amputations affect physical functioning more than mental functioning (8). These findings are consistent with the findings for clinically reported gain in functionality as determined using the FIM (see above). Reported functional abilities for patients in the VA study sample were worse than comparison groups of normal males in the US (5), patients with Type II diabetes mellitus (5), and non-VA patients with above knee amputations receiving prosthetic devices (8). The effect of age could not be determined because of the limited VA and FOTO sample sizes.

Male VA patients with above knee amputations due to DM, PVD or a combination of DM and PVD report lower functional capacity in the SF-36 mental and physical component summary scores when compared to US population norms. This reduction is more pronounced for physical scores than the mental scores. This supports the above findings by physical and mental constructs.

The comparison groups were not exactly the same as the VA sample, so interpretations of the comparison should be approached with caution. Similar demographic data were not collected for all patients across comparison groups, so only age risk-adjustments were possible between the VA and the MOS SF-36 samples.

The database constructs imposed a number of limitations on this study

- The VA SF-36v sample appears small when compared to the possible number of patients with above knee amputations that could have been assessed with the SF-36. This disparity could imply selection bias.
- Quantification of timing between SF-36 completion and date of surgery was not possible in the non-VA sample, so medical and functional stratifications could not be accomplished in the potential comparison sample.
- Quantification of timing between SF-36 completion, date of surgery and rehabilitation sequence (including type of rehabilitation) was not possible in any data set, so risk-adjustment was not possible across data sets.
- Algorithms that the VA uses to calculate the role physical (RP) and role emotional (RE) scales do not follow published algorithms (5), which may erode the validity of external comparisons. Refer to page 13, paragraph 4, for explanation of VA algorithms.
- The data were incomplete, increasing selection bias potential for all samples.

ACCESS TO CARE

Q. 8bD, 8bE: What are the wait times that VA patients with AK prostheses experience for clinic appointments? How long do VA patients with AK prostheses wait to see a provider?

A majority of patients had to wait less than 14 days from the day scheduled until they were seen in the clinic and had to wait less than 15 minutes to check in at the clinic. About half of the patients had to wait less than 10 minutes to be seen by provider after check into the clinic. About a quarter of patients traveled 14 miles on average to get to the primary care clinic.

We utilized PTF, NPPD, and NPPSS databases to create a subset of patients who have had AK amputations, received AK prostheses and selected AK prosthesis as "Item" on the NPPSS and responded to applicable questions within the NPPSS. Our subset consisted of 171 patients, yet only 70 to 104 of these patients had completed the questions in which we were interested.

Q 12 (n= 76) asked "How long did you wait from the day you scheduled this visit until the day you were seen?

RESPONSE	NUMBER*	PERCENTAGE
No wait at all	8	10.5%
Waited 1-14 days	40	52.6
Waited 15-30 days	18	23.7%
Waited 1-2 months	2	2.6%
Waited 2-4 months	3	3.9%
Waited over 4 months	3	3.9%

*2 responses were coded in an unrecognizable format

Q. 16 (n= 100) asked "On the day of your most recent device-related visit, how long did you wait in line to check in?

RESPONSE	NUMBER*	PERCENTAGE
No wait	29	29%
Waited 1-15 minutes	39	39%
Waited 16-30 minutes	20	20%
Waited over 30 minutes	9	9%

*3 responses were coded in an unrecognizable format

Q. 19 (n= 101) asked "On the day of your most recent device-related visit, how long did you wait to be seen by your provider after you checked in?

RESPONSE	NUMBER*	PERCENTAGE
No wait	16	15.8%
Waited 1-10 minutes	31	30.7%
Waited 21-30 minutes	18	17.8%
Waited 31-60 minutes	5	5%
Waited over an hour	3	3%
Cannot remember	5	5%

*1 response was coded in an unrecognizable format

Data support most patients schedule appointments, are checked into the clinic, and are seen by a clinician once they arrive in the clinic in reasonable time frames.

Q. 8bF: How far do VA patients with above knee amputations travel to clinic appointments?

The Booz Allen team utilized several VA databases to determine the distance traveled by patient with above knee amputations from their homes to primary care facilities. The zip codes for patients' residences were matched to the closest VA facility providing primary care services to determine average distance traveled by patients. VA databases used in this effort include the VA Zip Code File, VA Station Tracking (VAST) database, Outpatient Clinic/Patient Treatment File (OPC/PTF), and the National Prosthetic Patient Database (NPPD). The Booz Allen team utilized Geographic Information Systems (GIS) to determine travel distance, and conducted data analysis to determine the national average distance for patients with above knee amputations.

According to analysis findings detailed in the Booz Allen Hamilton PSAS Program Evaluation's Time and Distance Study, the total number of patients within our above knee amputation subset (n=5,926) traveled an average 14.189 miles to primary care clinics.

PATIENT SATISFACTION

Q. 12A, 12A.1, 12B, 12B: What is the satisfaction rate with home health care services or products of patients who received prosthetics? What are the areas of customer concern?

Great majority of patients rate the quality of device used and the quality of the visit as excellent, very good or good. About a third of patients rate the quality of the device-related care during the last 12 months as excellent.

We utilized PTF, NPPD, and NPPSS databases to create a subset of patients who have had AK amputations, received AK prostheses and selected AK prosthesis as "Item" on the NPPSS and responded to applicable questions within the NPPSS. Our subset consisted of 171 patients, yet only 70 to 104 of these patients had completed the questions in which we were interested. We utilized specific questions from the NPPSS to respond to these VA analysis metrics.

Q. 4 (n= 104) asked, "Overall, how would you rate the quality of this device?

RESPONSE	NUMBER*	PERCENTAGE
Excellent	16	15.4%
Very good	45	43.3%
Good	24	23.1%
Fair	9	8.7%
Poor	9	8.7%

*1 response was coded in an unrecognizable format

Q. 40 (n= 101) asked, "Overall, how would you rate the quality of this visit?"

RESPONSE	NUMBER*	PERCENTAGE
Excellent	41	40.6%
Very good	34	33.7%
Good	15	14.9%
Fair	8	7.9%
Poor	3	3%

Q. 49 (n= 96) asked "Overall, how would you rate the quality of your device-related care during the past 12 months?

RESPONSE	NUMBER*	PERCENTAGE
Excellent	32	33.3%
Very good	36	37.5%
Good	15	15.6%
Fair	5	5.2%
Poor	7	7.3%

*1 response was coded in an unrecognizable format

Question 12B: What are the areas of customer concern?

We are unable to answer this question because the NPPSS database we received did not code data answering this question.[1]

In conclusion, the NPPSS Data support that most VA patients rate the quality of device and the quality of the visit as excellent, very good or good. Approximately one-.third of patients rate the quality of the device-related care during the last 12 months as excellent.

1 *The question came from Q 59 of 1999 NPPS, which was an open-ended question.*

RECOMMENDATIONS

The Following Recommendations Could Improve Data Collection for Future Studies

VA should improve data collection processes, so FIM and SF-36 surveys are collected at appropriate times before, after and during rehabilitation for an above knee amputation. Recommended time frames are:

- Annually during medical management of patients before amputations,
- One month before amputation surgery, if possible,
- One month after amputation surgery, and
- Six months thereafter during rehabilitation (to include any prosthesis fitting) until patient is independent.

The VA should develop relational data files by collecting the same patient identifying demographic variables, e.g. the formula for the scrambled social security number should be the same in each electronic file. VA should also standardize operational definitions of data variables across the VA system.

The Booz Allen team has recommended performance measures that would support CARF (The Rehabilitation Accreditation Commission) accreditation. The recommended performance measures are listed in Table 10, on the next several pages. Several clinical assessment tools may be utilized to facilitate the evaluation of above knee amputation patients in the future. These tools are listed below.

Northwestern University OPUS

The Northwestern University OPUS LE Prosthesis Functioning Module can be used to assess patient's perception of his or her functioning and quality of life using the prosthesis. The Northwestern OPUS Patient Assessment also allows prosthetists to generate a score for their patient's functional abilities.

FOTO OPOT

The FOTO OPOT allows prosthetists to generate a score for their patient's functional abilities with or without a prosthesis. The FOTO OPOT can be used to assess patient self-report of quality of life. This tool measures the constructs of physical functioning and mental health.

McHorney & Cohen

An Activities of Daily Living (ADL) tool for patients not in rehabilitation (McHorney & Cohen 2000) could track individuals over time to determine how their functional abilities related to changes in performance of ADLs or to determine how successfully rehabilitation has influenced functional abilities related to performance of ADLs. Examples include moving from bed to chair, carry small bag of groceries, wash your feet, etc.

Table 10. Recommended Performance Measures for Above Knee Amputation Patients

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Functional Status	**Inpatient** ➢ Functional assessment – average changes in motor functioning over time (total FIM score) annually (*or VA chosen timeframe) ➢ Discharge location compared to admission location of residence ➢ Severity-adjusted percent of patients (with amputation) who improve functional status from admission to discharge1 ➢ Severity-adjusted distribution of discharge functional status1 Utilize the FIM for people in inpatient rehabilitation to track individuals over time. The FIM will allow VA to determine how patient's functional abilities change over time, therefore providing the ability to determine how successfully rehabilitation has influenced motor functioning. The FIM motor scores would be transformed to measures ranging from 0 to 100 with higher scores suggesting better function or health. Change scores from admission to discharge, either regular (discharge – admission) or standardized [(discharge – admission)/(standard deviation at admission)] could be calculated.	FIM (for inpatient rehabilitation)
	Outpatient – Lower Extremity Prosthetic Users Develop or utilize an assessment tool to capture functional status information on outpatients with lower extremity prosthesis in the following areas: ➢ Ambulation ➢ Pain ➢ Satisfaction with fitting ➢ Skin breakdown	New Tool

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Quality of Life	Measure the eight functional scales from the SF-36 to assess patient self-report of quality of life. The eight scales include: ➢ general health, ➢ physical functioning, ➢ role physical, ➢ bodily pain, ➢ mental health, ➢ role emotional, ➢ social functioning and ➢ vitality. The SF-36 scores per construct would be transformed to measures ranging from 0 to 100 with higher scores suggesting better function or health. Change scores from admission to discharge, or any other two time intervals, either regular (discharge – admission) or standardized [(discharge – admission)/(standard deviation at admission)] could be calculated.	SF-36
Customer Service	**Access** ➢ Percent of amputation patients within travel time and distance requirement --- ➢ Average wait time (in minutes) for amputation patients to be seen by a provider after check in ➢ Percent of amputation patients satisfied with the ease of making appointment ➢ Average wait time (in days) for amputation patients to get an appointment	Zip Code File matched with amputation patients from PTF/OPC or Patient Satisfaction Survey --- Patient Satisfaction Survey
	Education ➢ Percent of patients that state they received education and training on prescribed medical equipment ➢ Percent of time patients state they received understandable instructions for prescribed medical equipment	Patient Satisfaction Survey
	Customer Satisfaction ➢ Percent of patients satisfied with processes of care received at a VA Medical Center or clinic1 ➢ Percent of patients (who were prescribed a new prosthesis) that report satisfaction with the prosthetic device ➢ Percent of patients reporting satisfaction with results of care[1]	Patient Satisfaction Survey

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Management/ Operational	**Utilization** ➢ Number of prescribed prosthesis per year (facility, VISN, national) *workload indicator – not performance based --- ➢ Percent of prosthetic patients using prosthesis at 6 month and 1 year follow up ➢ Hospital admissions for above knee amputations in patients with diabetes per 100,000 population[2]	NPPD --- CPRS or new tracking software
	Cost ➢ Average cost of services per patient/year (Facility, VISN, national)[1] --- ➢ Average cost of prosthesis (facility, VISN, national)[1] ➢ Comparison of average cost of VA produced prosthesis and commercial produced prosthesis Review over time as an indicator of cost only, not performance related	DSS --- NPPD

[1]. Similar to CARF performance measures. (13)

[2]. Similar to AHRQ measures. (14)

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MOTORIZED WHEELCHAIRS

INTRODUCTION / METHODOLOGY

VA strives to provide prosthetic equipment and services to assist patients with their activities of daily living (ADLs). These services and devices are administratively provided and managed by the Prosthetics and Sensory Aids Services (PSAS) within the Veterans Health Administration (VHA). The provision of motorized wheelchairs may significantly impact the quality of life reported by VA patients. Concurrent with Booz Allen Hamilton's Program Evaluation of VA's PSAS program, the Booz Allen team evaluated the prosthetic services provided to veterans discharged home. The motorized wheelchair user population is one of three groups selected by VA for this study. In addition to the types of services provided, VA tasked Booz Allen with evaluating the quality of life and patient satisfaction of motorized wheelchair users within the VHA.

VA developed specific study questions that apply to the motorized wheelchair study population.

1. Do VA patients who have been discharged to the home receive health care services and supplies at a rate comparable to non-VA patients?
2. Do these patients report a quality of life comparable to non-VA patients?
3. Are the VA prosthetic patients reporting satisfaction rates comparable to non-VA patients?

We have summarized our answers to these study questions. Detailed findings of our analysis are provided throughout the document.

Summary of findings

We did not identify any published literature addressing the rate of patients receiving ADL or other equipment in non-VA samples. We did not find a comparable non-VA sample for data related to the distribution of ADL equipment. Our data analysis indicates that VA patients received a wide variety of equipment, including wheelchairs, crutches and walkers, special home safety (bath and toilet) items, as well as many other ADL items such as dressing aids and long handle reachers.

According to analysis of the records which matched between our study population and the SF-36 dataset, veterans report low functional capacity with more dysfunction in physical compared to mental functioning. The quality of life was perceived as low in the VA population of people using motorized wheelchairs. There is no comparable non-VA sample, as SF-36 physical functioning and role physical scales are not appropriate for this sample population.

Patient satisfaction data cannot be compared across studies or populations unless all patients answer the same patient satisfaction survey. Therefore, VA data was not compared to a non-VA sample. Based on our analysis of VA data, 90% of patients rate the quality of their device and quality of their visits as excellent, very good or good. More specifically, 35% of patients rate the quality of their device-related care during the last 12 months as excellent.

The Booz Allen team customized the motorized wheelchair study population by merging different VA databases

We identified veterans who had received a motorized wheelchair during fiscal years 1998 through 2000 by extracting records from the National Prosthetic Patient Database (NPPD), a database that captures the distribution of all equipment and supplies administered by PSAS. Wheelchair user records were

extracted from NPPD using codes E1080-E1082, E1210-E1213, K 0010-K0014. We utilized the patient identification numbers from this subset to match patients' records with other VA databases. We obtained clinical records for the motorized wheelchair subset by extracting their records from VA's inpatient and outpatient treatment files. These files provided pertinent demographic and clinical information. This merged set of data served as the study population for motorized wheelchair users. For the analyses on functionality, we merged the motorized wheelchair subset with matched patients from the Functional Status Outcome Database (FSOD) to extract the Functional Independence Measure (FIM) ratings. To answer study questions related to quality of life and ability to participate in life situations, we used data from the SF-36 survey, a self-administered quality of life survey given to both veteran (SF-36v) and non-veteran (SF-36) populations. Our analysis on training and education required the extraction of data from two sources: EPRP (External Peer Review Program) and NPPSS (National Prosthetic Patient Survey).

FINDINGS

The Motorized Wheelchair Study question addresses eight specific analysis metrics collaboratively developed by VA and the Booz Allen team

The Booz Allen team collaborated with VA to develop and further refine analysis metrics by which program outcomes could be evaluated. To provide analysis based on these metrics, the Booz Allen team extracted specific patient populations from VA databases to create a study population. This study population was further divided into focused subsets, in order to respond to the individual analysis metrics.

We have organized our findings in line with these analysis metrics. The metrics are labeled in accordance with the November 9, 2001 *Refined Project Plan* of the Program Evaluation of Prosthetic and Sensory Aids Services.

UTILIZATION OF SERVICES

Q. 8aA: What are the qualifications of the person making the referral for VA patients?

The Booz Allen team conducted site visits to seven VA medical centers across the country. During interviews with various members of PSAS and Rehabilitation, we collected varying responses regarding the qualifications of referring individuals.

- Hines: Physical Therapist or Rehabilitation Physician
- Miami: Primary Care Physician
- New York: Anyone from a clinical service can refer
- Richmond: Any physician can refer
- Seattle: Any provider can refer
- West Palm: Any provider can refer

Although our findings indicate that referrals may be generated from any number of disciplines, most medical centers convened committees dedicated to the evaluation of patients for motorized wheelchairs or high cost items. One committee included a representative from the local Disabled American Veterans organization, some committees included the patient and/or patient's family, and the majority of sites require the participation of a Rehabilitation Physician. Although the decision to provide a power wheelchair is made by a team, the majority of medical centers had designated a rehabilitation physician as the "leader" of the team. At some sites, this team leader provides the patient with a written letter of explanation if the patient was not approved for a motorized wheelchair.

Q. 8aB: What ADL equipment was provided at discharge?

Equipment records for 9,967 items were identified for the 456 motorized wheelchair users identified as having received rehabilitation and discharged to the home. Patients received a wide variety of equipment, including wheelchairs, crutches and walkers, special home safety (bath and toilet) items, as well as many other ADL items, including dressing aids and long handle reachers.

The motorized wheelchair user population was initially extracted from the NPPD database and matched to the PTF and FSOD files in order to obtain demographic and treatment data. Unfortunately, after matching the scrambled social security numbers, only 456 patients were matched. It is likely that many motorized wheelchair users did not have amputations (e.g., spinal cord injury, stroke) and therefore their data were not included in our PTF amputation file. We then used the scrambled Social Security Numbers of these 456 patients to select NPPD records, and obtained 9,967 records. That is, there were 9,967 records of equipment or device issued to the 456 patients. Among the 9,967 records, 339 were coded as motorized wheelchairs. It is not clear why only 339 records were coded as motorized wheelchair items. Frequencies by "NPPD line" variable for the most frequently dispensed items related to wheelchair use are presented in Table 11.

Table 11. Most Frequently Dispensed Items Related to Wheelchair Use

NPPD ITEM CATEGORIES	DESCRIPTION	n OF RECORDS
100A	Motorized Wheelchairs	339
100B	Manual Custom Wheelchairs	315
100D	Wheelchair Accessories	493
100E	Cushion Foam	264
100F	Cushion Specialized	294
R10	Wheelchair & Accessories	870
900A	Walking Aids (Cane and Walker)	330
900I	Home Safety Equipment (e.g., Bath Items)	864
900K	Medical Equipment (e.g., Blood Items)	989
999A	All Other Equipments	1054
R90A	No Description (All Other)	513
R90A	Mixed Items	514
Total Number of Records		9967

NPPD uses the Health Care Financing Administration Common Procedure Coding System (HCPCS) for items costing more than $50. HCPCS is a uniform coding system that categorizes healthcare services and supplies. We suspect many small but essential ADL devices, such as dressing aids, stocking aids or long handle reachers, are not captured by HCPCS codes. NPPD does contain alpha-numerically coded fields for most of these item descriptions. However, it would be extremely time consuming and labor intensive to group the 5,000 to 9,000 items manually, and there are no standards or guidelines to direct ADL equipment grouping. Therefore, the most reasonable way for us to answer this question was to tabulate NPPD line codes. Tabulating this data confirmed that patients with above knee amputations and patients who use motorized wheelchairs do receive ADL equipment. Since there was so much missing or duplicative data, the frequency of ADL equipment dissemination could not be transformed into rate of use per item per type of patient. Because of this limitation, comparisons across groups of patients, i.e. above knee amputations vs. motorized wheelchair users, were not possible. Finally, we found no comparative data sets from which we could perform anticipated percent of use or rate of use data analyses.

Limitations were identified in the data utilized to answer this question

The constructs of the databases imposed the following limitations on our efforts to answer the specific question:

- Much of the data examined were missing or duplicative, hindering analyses.
- Variables across data sets were not consistent, which reduced effectiveness of analyses.
- No standard operational definitions or guidelines are available for grouping categories of ADL equipment, which hindered comparative analyses.
- No comparative data sets were identified, so that the results of VA data analyses could not be compared to similar populations.

Q. 8aC, 8aD: What education was provided to the VA patient? What education was provided to the VA patient's family?

Overall, patients received training and education on the use and maintenance of their equipment. However, the data analyzed to answer this question did not specify whether patients were motorized wheelchair users, so we can only assume that the responses pertain to this population as well.

The Booz Allen team identified patients who had selected "Motorized Wheel Chair" in the "Item" field from the National Prosthetic Patient Satisfaction Survey file. The NPPSS database manager matched these records with our file of patients who have received a motorized wheelchair. Of the 6,582 patients who indicated using a motorized wheelchair in the Item field, only 1,738 to 2,817 of these records matched with the NPPSS[2], indicating that these patients had completed the questions in which we were interested. The sample sizes in the following tables represent the number of responses to the questions. Also, the rate of missing data in each question is different.

Q. 32 (n= 2817) asked, "When you asked questions, do you get answers you could understand?"

RESPONSE	NUMBER	PERCENTAGE
Yes, always	1991	70.7%
Yes, sometimes	533	18.9%
No	117	4.2%
Did not ask questions	151	5.4%

Q. 33 (n= 2784) asked, "During your most recent device-related visit, did someone teach you how to use your prosthetic device in a way that you could understand?"

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	1551	55.7%
Yes, somewhat	297	10.7%
No	195	7.0%
No teaching needed	691	24.8%

[2] *This is because the file we received from NPPSS database manager had many missing data of the NPPSS fields, but had data in the NPPD fields. It is likely that the database manager merged the two data sets but neglected to remove data that came from NPPD only.*

Q 35 (n= 2793) asked "Did you get as much information about your device as you wanted from your provider?"

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	2049	73.4%
Yes, somewhat	516	18.5%
No	216	7.7%

Q. 26 (n= 2781) asked "Was the provider willing to talk to your friends or family about your device-related care?"

RESPONSE	NUMBER	PERCENTAGE
Yes	1661	59.7%
No	186	6.7%
No family involvement	901	32.4%

Q. 34 (n= 2787) asked "During your most recent device-related visit, did someone teach your family or friends how to help you use your prosthetic device in a way that they could understand?"

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	917	32.9%
Yes, somewhat	208	7.5%
No	345	12.4%
No teaching needed	542	19.4%
No family involvement	710	25.5%

Survey results indicate that veterans are satisfied with the level of training they received, as well as the delivery of the training and education. Findings support the conclusion that veterans within this study population received training on the use of their prosthetic devices. It is assumed that training was provided for the motorized wheelchair, since the motorized wheelchair population was identified as survey respondents, however the survey questions did not specify training for motorized wheelchairs. Also, more than a quarter of veterans in this study population reported that there was no family involvement in the training and education provided.

FUNCTIONALITY

Q. 8bA: What are the patient functionality scores before and after treatment, when age and risk adjusted?

Data analysis indicates that most patients exhibited gains in functionality at discharge when compared to admission. The Booz Allen team analyzed functional status of motorized wheelchair users before and after rehabilitation treatment. We merged our patient file of motorized wheelchair users (a compilation of data from NPPD and PTF) with records from the Functional Status Outcome Database (FSOD).

A total of four hundred fifty six (n=456) patients were matched, of which 73% (335) were undergoing their first rehabilitation. Their need for rehabilitation was due to the following conditions: 15% of the patients had strokes, 4% had brain dysfunctions, 25% had neurological conditions, 12% had spinal cord injuries (SCI), 18% had amputations, 2% had arthritis, 3% had pain syndromes, 10% had orthopedic conditions,

2% had cardiac conditions, 2% had pulmonary conditions, 6% had "debility" (i.e., generalized weakness), and 1% had medically complex conditions. A complete description of the patient population is presented in Table 12.

Table 12. Demographics of Motorized Wheelchair Users in Study Population (n=456)

CHARACTERISTICS*	RESPONSE TO VARIABLE	SUMMARY	TOTAL RESPONSE	MISSING DATA
Gender			456	0
Male	442	97%		
Female	14	3%		
Ethnicity			456	0
Caucasian	301	66%		
African American	96	21%		
Hispanic	44	10%		
Native American	4	1%		
Missing or other	11	2%		
Marital Status			456	0
Single	51	11%		
Married	238	52%		
Widowed	35	8%		
Divorced/Separated	132	29%		
Pre-Hospital Living Setting			446	10
Home	419	92%		
Board & Care	8	2%		
Intermediate Care	4	1%		
Subacute Setting/SNF	15	3%		
Discharge To:			432	24
Home	331	76%		
Board & Care	6	1%		
Intermediate Care	12	3%		
Acute Unit	25	6%		
Subacute Setting/SNF	52	12%		
Rehabilitation Facility	6	<1%		
Length Of Stay (Days- M±SD)		22±16		
Age (Yrs - M±SD)		62±13		

Most patients exhibited gains at discharge when compared to admission. These gains were present for raw FIM data, motor FIM data and cognitive FIM data. Table 13 below provides a summary of admission and discharge functional status and categorizes the gains that occurred.

Table 13. Functional Status of Motorized Wheelchair Users Before and After Rehabilitation*

	Mean	SD
Raw FIM Total at Admission	75	22
Raw FIM Total at Discharge	90	23
Raw FIM Gain	15	13
Motor FIM (Raw Score) at Admission	46	19
Motor FIM (Raw Score) at Discharge	59	21
Raw Motor Gain	14	12
Cog FIM (Raw Score) at Admission	29	6
Cog FIM (Raw Score) at Discharge	31	5
Raw Cog Gain	1	3

** - Scores are Raw FIM Scores*

VA patients using motorized wheelchairs who underwent rehabilitation treatment consisted of a wide variety of patients with different ages and impairments. Stroke, Neurological Conditions, Spinal Cord Injuries, Amputees, and Orthopedic Conditions were the five largest impairment groups in this sample. We compared their functional status before and after rehabilitation and found differences in discharge FIM (total scores) among patients with different impairments after controlling for their admission FIM. The differences in discharge FIM mainly came from the differences in motor FIM. Stroke, orthopedic and amputee patients made more gains than patients with neurological and spinal cord injuries.

The table shows that patients' discharge FIM, as well as discharge motor FIM, are greater than the admission FIM or admission motor FIM. Our findings indicate 15 points in total FIM gain, and 14 points in motor FIM gain (gain = discharge – admission). Our analysis shows that veterans in our study population demonstrated functional gains similar to what is seen in the non-VA sector, though we do not have comparable non-VA data on motorized wheelchair users to make a firm comparison.

Gain in function after controlling for age depends on impairment

To determine if age or impairment affected gain in function for patients using motorized wheelchairs, two separate one-way analyses of covariance (ANCOVA) studies were performed to examine mean differences in total FIM gain or FIM motor gain among impairment groups. The first study used age as its covariate, and the second one used impairment as its covariate. To explain this process in another way, we ran one-way ANOVAs on FIM gain or motor gain while controlling for age (or impairment). We compared the five largest (by sample size) defined impairment groups: Stroke, Neurological Conditions, Spinal Cord Injuries, Amputees, and Orthopedic Conditions. ANCOVA results showed that age did not affect total FIM or motor FIM gains, but impairment did. One-way ANOVAs (analyses of variance) were then performed to examine the effect of the five impairment categories on total FIM gain and FIM motor gain. Impairment affected total FIM gain ($F_{df=4}$=14.4). Post-hoc analyses (Scheffe) showed that stroke patients gained more function than patients with neurological conditions, spinal cord injuries, and amputations. There was no difference in total FIM gain between Stroke and Orthopedic patients. FIM

motor gain results were similar: impairment affected FIM motor gain ($F_{df=4}$=10.85) in a similar pattern as total FIM gain.

Our analyses supported the premise that functional status at discharge correlates with functional status at admission

Previous research has shown that functional status at discharge is moderately correlated with functional status at admission (1, 2, 3). Correlation analyses confirmed this, with Pearson Product Moment Correlations Coefficient ranging from .75 to .89 among different impairment groups. Pearson's Product Moment Correlation measures the linear association between two variables that have been measured on interval or ratio scales, such as the relationship between height in inches and weight in pounds.

Two-way ANOVA (independent variables: impairment, age group) further demonstrated that discharge FIM scores were different among impairment groups ($F_{df=8}$=7.72), and age did not affect discharge FIM scores. One-way ANCOVA (analysis of covariance) was then performed to examine mean differences in discharge FIM scores among the 5 impairment groups, using admission FIM as covariate. Use of ANCOVA (with admission measures as the covariate) tends to risk-adjust differences across groups because some investigators (4) believe the effect of co-morbidities are imbedded within the intake functional measure. Differences in discharge FIM were found ($F_{df=5}$=196.21) after controlling for admission FIM. Similar results were found for discharge motor FIM ($F_{df=5}$=190.88).

Table 14 below summarizes discharge FIM, FIM (total) gain and motor FIM gain among impairment groups.

Table 14. Descriptive Statistics of Discharge FIM, Total FIM Gain and Motor FIM Gain (by Impairment) Among Motorized Wheelchair Users

	Impairment (n = 456)					
	STROKE	NEURO	SCI	AMPUTEES	ORTHO	OTHERS
Number of Patients (n)	69	113	54	82	46	92
Age (Yrs - M±SD)	65±11	56±11	55±16	65±10	66±10	65±12
LOS* (Days- M±SD)	26±13	20±17	28±22	21±14	19±16	20±15
Total FIM (Raw Scores)						
Admission	66	73	64	84	82	79
Discharge	89	83	75	99	100	94
Gain	23	10	11	15	19	14
Motor FIM						
Admission	40	44	33	54	50	50
Discharge	60	53	43	67	68	63
Gain	21	10	10	14	18	13
Cog FIM						
Admission	26	29	30	30	32	30
Discharge	29	30	32	31	33	31
Gain	3	1	1	1	1	1

**LOS=length of stay in rehabilitation.*

We found differences in motor functional status in patients with different impairments

Stroke, Neurological Conditions, Spinal Cord Injury, Amputees, and Orthopedic Conditions were the five largest impairment groups in this sample. We compared patient functional status before and after rehabilitation and found differences in discharge FIM (total scores) among patients with different impairments after controlling for their admission FIM. The differences in discharge FIM came mainly from differences in motor FIM (i.e., no differences were found in FIM cognitive scores among different impairments). Age did not contribute to the differences in discharge motor function, but impairment and admission functional status did. Differences were also noted in functional status gain among impairment groups; age did not affect these functional status gains. Interestingly, patients with strokes had the greatest discharge FIM scores and gained more function as measured by total FIM and motor FIM. When contrasted with patients with SCIs, patients with strokes had lower admission motor FIMs, but made more motor gains than patients with SCIs.

The database constructs produced general limitations that apply to the majority of comparisons made among the sample groups

- Data were selected from NPPD files (i.e. patients who were issued a motorized wheelchair). Then information was extracted from PTF database and matched to the FSOD data. During the matching process, many patients were left unmatched because their data were incomplete. These patients were lost to analysis. Their loss could cause patient bias.
- No comparison group of non-VA patients who used motorized wheelchairs and had a FIM rating was found, so comparative analyses could not be performed.
- The files did not contain key demographic data necessary for risk-adjustment. For example, the reasons for, type of, or compliance with rehabilitation were often absent. The sequence between dates of episode, onset of inpatient stay, or time in rehabilitation was similarly missing. Therefore, many patients had overlapping dates of services, and missing data eliminated many anticipated analyses.

QUALITY OF LIFE

Q. 8bB: How do VA patients with motorized wheelchairs rate their quality of life?

The quality of life was perceived as low among VA motorized wheelchair users in our study population.

These analysis questions concern quantification of patients' *perception* of their quality of life and their *actual ability* to participate in life situations while using motorized wheelchairs. There are no data in the VA data sets that allow direct assessment of either quality of life or life situation participation. However, assessment of the SF-36 constructs of health-related quality of life (HRQL) permits estimation of both quality of life and participation in life situations (5). Because these constructs are very similar, their analyses will be grouped together in this report.

No SF-36 data allows differentiation between respondent *perception* of participation in life situations and *actual participation* in life activities. SF-36v assessment of participation in life situations is only as valid as the accuracy of VA patient self-reported HRQL from the SF-36v survey. If perception of HRQL can be used to estimate actual participation, then quantification of participation in life situations may be assessed by analysis of individual SF-36 constructs. Comparisons between VA and other data would then identify differences in levels of participation in life situations, and in quality of life.

Quality of life can be assessed through administration of patient self-reported HRQL surveys. Such surveys capture the perception of patient's functional abilities by assessing pertinent constructs of general health including physical and mental functioning (5). The SF-36 is considered a "gold standard" of generic HRQL assessments of health status and quality of life. SF-36 allows assessment of physical (general health, physical functioning, role physical, bodily pain) and mental (mental health, role emotional, vitality, social functioning) HRQL constructs. Normative SF-36 values for the US population have been published (5). Researchers use SF-36 norms to compare HRQL across samples (6).

Norms for SF-36 constructs were generated during the Medical Outcome Study (MOS). Data were collected as part of the National Survey of Functional Health Status in 1990, using personal interview (not self-administered) questionnaires (5, 7). Respondents were drawn from the General Social Survey in 1990, which surveyed 2,474 non-institutionalized adults in the United States (5). The SF-36 was designed to assess HRQL for people without disease as well as for patients with medical conditions (7).

Use of the SF-36 facilitates comparisons of functional abilities between VA patients who use motorized wheelchairs and non-VA patients, such as patients seeking rehabilitation for lower extremity impairments (i.e., knee replacement) (6). Patients in the comparative sample described by Jette are not exact matches for the VA patient sample in this study. Even so, the comparative sample permits useful preliminary comparisons with the VA sample, subject to certain limitations in comparing them.

We merged the motorized wheelchair dataset with the SF-36v data to conduct analysis on quality of life

The Booz Allen team developed an electronic file of patients who were initially issued a motorized wheelchair between 1997 and 2000 by extracting data from the National Prosthetics Patient Database. Records were identified based on the NPPD category code representing motorized wheelchairs (NPPD category 100A). Patients in this file were then matched to those in the SF-36v database, which represents veterans who have completed the SF-36 survey.

Descriptive statistics for the patient population that completed an SF-36 and was issued a motorized wheelchair are displayed in Table 15 below. The dataset for this population was missing a large amount of data. Consequently, the percentages used in the table are "valid percentages", operationally defined as the percentage of *the patients who answered the question* (not the percentage of the entire patient population).

Table 15. Characteristics of Patients Issued a Motorized Wheelchair and Who Completed an SF-36v

Total Population Sample (n=2,193)

CHARACTERISTICS	RESPONSE TO VARIABLE	SUMMARY	TOTAL REPONSE	MISSING DATA
Age (years)		63±12	n=1742	451
Gender			n=1747	446
Male	1660	95%		
Female	87	5%		
Diagnoses			n=1827	366
Urinary tract infection (ICD-9 599.0)	67	4%		
Heart failure (ICD-9 428.0)	63	4%		
Multiple sclerosis (ICD-9 340.0)	61	4%		
Obstructive chronic bronchitis, acute (ICD-9 491.21)	58	3%		
Unspecified rehabilitation procedure (ICD-9 V57.89)	57	3%		
Follow-up examination, other (ICD-9 V67.59)	55	3%		
Decubitus ulcer (ICD-9 707.0)	44	3%		
Pneumonia, organism unspecified (ICD-9 486.0)	40	2%		
Coronary atherosclerosis (ICD-9 414.01)	39	2%		
Paraplegia (ICD-9 344.1)	28	2%		
Ethnicity			n=1827	366
Caucasian	1443	79%		
African American	213	12%		
Hispanic	62	3%		
Native American	91	5%		
Asian	12	1%		
Pacific Islander	6	<1%		
Employment status			n=2403	
Employed for wages	48	2%		
Self-employed	26	1%		
Looking for work >1	22	1%		
Looking for work <1	5	<1%		
Homemaker	17	<1%		
Student	17	<1%		
Retired	880	37%		
Disabled	1388	58%		
Co-morbidity (Collected via patient recall – more than one response allowed per individual)	1054	61%	n=1620	573
Hypertension or high blood pressure	474	28%		
Benign prostatic hypertrophy	898	53%		
Chronic low back pain	547	33%		
Congestive heart failure	425	25%		
Stroke	1134	67%		
Arthritis	35	35%		
Angina or coronary heart disease	519	31%		
Heart attack or myocardial infarction	577	34%		
Chronic lung disease	269	16%		
Cancer	844	50%		
Depression	350	21%		
Post-traumatic stress disorder	60	4%		
Schizophrenia	578	34%		
Spinal cord injury - quadriplegia or paraplegia				

CHARACTERISTICS	RESPONSE TO VARIABLE	SUMMARY	TOTAL REPONSE	MISSING DATA
If your doctor told you that you had diabetes, how long ago were you first told?			n=570	1623
<1 yr ago	56	10%		
1-3 yrs ago	88	15%		
4-10 yrs ago	156	27%		
11-20 yrs ago	123	22%		
>20 yrs ago	147	26%		
Do you now smoke cigarettes?			n=1645	548
Every day	315	19%		
Some days	83	5%		
Not at all	1247	76%		
Marital status			n=1728	465
Married	1132	65%		
Divorced	323	19%		
Separated	41	2%		
Widowed	133	8%		
Never married	99	6%		
Lives alone	318	19%	n=1671	522
How many times during past month did you have 5 or more drinks on an occasion?			n=1620	573
Never or less than once per month				
1-3/month	1420	88%		
1/week	86	5%		
2-4/week	16	1%		
5-6/week	36	2%		
1/day	16	1%		
>1/day	11	1%		
	35	2%		
What is the highest grade or year of school you completed?			n=1661	532
Never attended school or only kindergarten	4	<1%		
Grades 1 through 8	198	12%		
Grades 9 through 11	171	10%		
Grade 12 or GED	551	33%		
College 1 year to 3 years	483	29%		
College graduate or graduate school	254	15%		

One third of patients analyzed in this study population are spinal cord injury (SCI) patients, many of whom have been diagnosed with diabetes for some time. The majority of these patients report that they do not smoke and are not habitual drinkers.

The extracted data contained 35 items from the SF-36, representing eight functional scales (5, 7, 8, 9). Role physical (RP) and role emotional (RE) constructs used rating scales that deviated from published algorithms (5), so item responses were transformed using VA algorithms. The constructs used five response categories rated from high functioning to low functioning. The response categories were “No, none of the time”, “Yes, a little of the time”, “Yes, some of the time”, “Yes, most of the time”, and “Yes, all of the time”. The responses were used to generate scales ranging from 0 to 100. However, for these two scales, the scores were subtracted from 100 to reverse the final scale score, so that higher scores represented higher function.

The responses for the other six functional scales were transformed following published algorithms (5, p6:17), so the scores ranged from 0 to 100. Hence, the resulting 0 to 100 scores for all eight scales could

be interpreted similarly to published interpretations: 0 reflects low functioning, and 100 reflects high functioning (5). The scores have been interpreted as percentages of functioning, health and well-being. Eight SF-36 constructs were evaluated: general health, physical functioning, role physical, bodily pain, mental health, role emotional, vitality and social functioning.

The physical component summary (PCS) and mental component summary (MCS) SF-36 scores were calculated following published algorithms (10), using the transformed scale scores above. This produced scores with an expected average of 50 and standard deviation of 10, which are the mean and standard deviations for a normal USA population (10). In this way, the PCS and MCS are norm referenced and can be interpreted in relation to standard deviation units (multiples of 10) away from the expected normal (i.e. 50). For example, if a population had a PCS of 20, this means that on average the population reported lower physical functioning compared to the normal population, and that decrement in functioning was 2 standard deviations below the norm.

SF-36v data was used to compare results of the VA study population to norms in the general population as a reference for understanding the results

Descriptive statistics were used to estimate the patient's ability to function, estimate their quality of life, and imply their participation in life situations for each of the eight SF-36 constructs.

There is evidence that SF-36 scales are related to and can provide estimates of health and health related quality of life (HRQL) (5). Pearson Product Moment Correlations Coefficient was used to estimate health and HRQL, the relationships among the seven SF-36 scales and general health (an eighth scale). The finding that these coefficients are positive and of moderate magnitude (r>.4) provides evidence that the SF-36 scales are related to general health.

For introductory comparisons, SF-36 scales were compared to normative data from the Medical Outcomes Study (5, 7, 8, 9) and to data for patients receiving rehabilitation for knee impairments (6). No similar comparison group of people who used motorized wheelchairs and completed an SF-36 could be identified through literature review. For comparisons between the VA population and normal data or knee impairment data, each pair of scores was transformed into an effect size (11). Effect sizes are standardized change scores that can be compared directly across studies. An effect size was calculated by subtracting the comparative score from the VA score and dividing the result by the standard deviation of the comparative score (5). An effect size was calculated for each SF-36 scale. Effect sizes can be interpreted as follows: 0.2 to 0.4 is small, 0.5 to 0.7 is moderate, and greater than 0.7 is large (11).

Statistical Data for the descriptive categories of the physical and mental constructs are displayed in Table 16 below.

Table 16. Parameters of Physical and Mental Constructs

	Physical Constructs (n=1,742)				
	General Health	**Bodily Pain**	**Physical Functioning**	**Role Physical**	**PCS**
Minimum	0	0	0	0	3.2
Maximum	100	100	100	100	52.9
Mean	26	28	11	14	22
Standard Deviation	21	24	23	23	7

	Mental Constructs (n=1,742)				
	Mental Health	**Role Emotional**	**Social Functioning**	**Vitality**	**MCS**
Minimum	0	0	0		8.2
Maximum	100	100	100	100	75
Mean	54	37	31	26	39.3
Standard Deviation	25	37	28	22	13.9

Response data for the VA patient population is displayed in Table 17 below. Floor and ceiling values are listed for each of the category items and are expressed as percentages.

Table 17. Floor and Ceiling Values for Response Categories

	Response Category Percentages (Responses were reordered if necessary, so low functioning was in the left columns and progressed to higher functioning in right columns.)					
(n=1,742)						
Item	1st	2nd	3rd	4th	5th	6th
General Health						
GH1	49%	32%	14%	4%	1%	
GH2	20%	20%	24%	19%	17%	
GH3	57%	19%	12%	9%	3%	
GH4	39%	21%	27%	5%	8%	
GH5	69%	14%	6%	9%	2%	
Bodily Pain						
BP1	23%	31%	30%	8%	4%	4%
BP2	40%	29%	15%	7%	9%	
Physical Functioning						
PF1	92%	2%	6%			
PF2	86%	7%	7%			
PF3	79%	14%	7%			
PF4	91%	2%	7%			
PF5	83%	10%	7%			
PF6	85%	9%	6%			
PF7	92%	1%	7%			
PF8	91%	2%	7%			
PF9	84%	9%	7%			
PF10	52%	37%	11%			
Role Physical						
RP1	61%	21%	8%	4%	6%	
RP2	65%	21%	7%	3%	4%	
RP3	72%	17%	5%	2%	4%	
RP4	73%	15%	5%	3%	4%	
Mental Health						
MH1	10%	12%	9%	22%	22%	25%
MH2	7%	12%	12%	23%	19%	27%
MH3	19%	25%	26%	11%	16%	3%
MH4	8%	13%	12%	27%	21%	19%
MH5	11%	19%	23%	13%	26%	8%
Role Emotional						
RE1	39%	18%	15%	8%	20%	
RE2	46%	18%	11%	8%	17%	
RE3	39%	18%	14%	8%	21%	
Vitality						
VT1	51%	25%	14%	5%	4%	1%
VT2	55%	22%	12%	5%	5%	1%

(n=1,742)	Response Category Percentages (Responses were reordered if necessary, so low functioning was in the left columns and progressed to higher functioning in right columns.)					
Item	1st	2nd	3rd	4th	5th	6th
VT3	25%	24%	12%	18%	11%	10%
Social Functioning						
SF1	39%	33%	12%	7%	9%	
SF2	30%	31%	22%	9%	8%	

8bC: How do VA patients with motorized wheelchairs rate their ability to participate in life situations?

Relationships between SF-36 scales and general health were assessed by correlating SF-36 scales with the SF-36 General Health scale. In this way, we could estimate, by construct, the relationship between perceived health and actual functioning. This relationship may provide insight into an individual's ability to perform ADLs and participate in life situations. All correlations were positive, of moderate magnitude, and statistically significant ($p<.01$), except for one, physical functioning. These findings support the relationship between health and HRQL. The correlations were similar to those published for the general population (5, p9:24), with the exception of the physical functioning and role physical scales. These two were less for the VA patients using motorized wheelchairs, as an analysis of their clinical disabilities would predict. The full results are presented in Table 18 below.

Table 18. Associations Between SF-36 Scales and General Health for SF-36 Scales

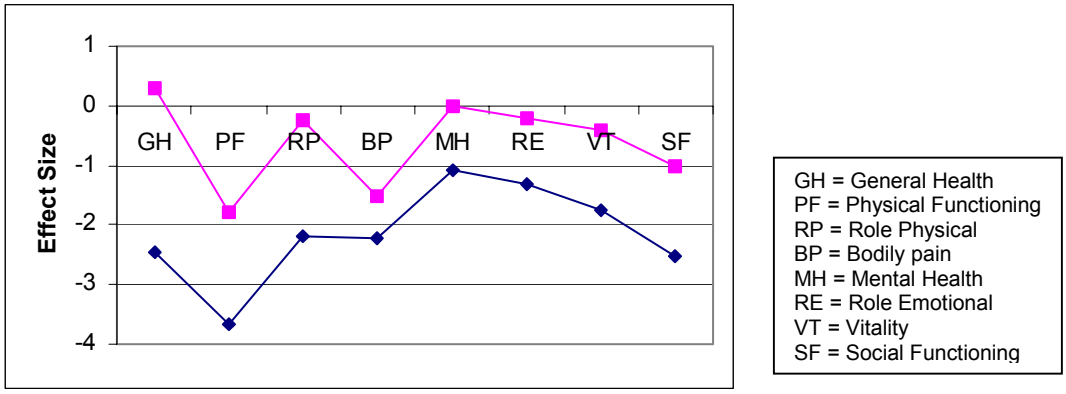
SF-36 Scales	VA Sample r[a]	General US Sample r[b]
Bodily Pain	.47	.58
Physical Functioning	.10	.69
Role Physical	.42	.69
Mental Health	.52	.49
Role Emotional	.45	.43
Vitality	.58	.65
Social Functioning	.57	.57

[a] *n=1,742*
[b] *n=2,474 (5, p9:24)*

VA patients demonstrated dysfunction in all SF-36 scales when compared to other populations

Patients with diagnoses of SCI, stroke, and other impairments (such as the VA study population) would be expected to report more dysfunction (Table 15) when compared to the general population or a population with knee impairments. In this analysis SF-36 scales from VA patients using motorized wheelchairs were compared to normative scale values (5, p10:14) and to scale values for patients receiving rehabilitation for knee impairment at intake (6, p1,183). In this way, differences as assessed by effect sizes (11) among VA patients, patients with knee impairments, and a normal patient population were transformed into standardized differences. The results are presented graphically in Figure 3.

Figure 3. Effect Size Comparison of VA Patient, Knee Impaired Patients, and Normal Patients for SF-36 Scales



Effect sizes are in units of standard deviations. The 0 value represents the normative value for the US population (5, p10:14). As the patient becomes less functional for a given SF-36 scale (scales plotted along the x-axis), the effect size becomes more negative. As the patient becomes more functional, the effect size becomes more positive (y-axis). The lower line represents data from the VA patients using motorized wheelchairs. The upper line represents data (n=426) from patients with knee dysfunction who sought physical therapy in 63 physical therapy clinics in the United States (6). This graph allows comparison of VA patients to a normal population (effect size=0) and patients with knee dysfunction (upper line). VA patients demonstrate large (11) dysfunction in all SF-36 scales, and dramatically low dysfunction for the four physical functioning scales (GH, PF, RP and BP) and for the social functioning scale (SF). Social functioning represents both mental and physical constructs but is commonly recognized as more of a mental dimension (5).

Our analyses indicate that veterans in our study population report significant dysfunction

Analyses confirm that VA patients using motorized wheelchairs have distinct dysfunction in all eight SF-36 scales, with scales representing physical functioning demonstrating the lowest functioning. SF-36 data have been interpreted as valid assessments of quality of life and functional HRQL (5). Distinctions in operational definitions regarding HRQL are frequently not clear. In this study, we interpret SF-36 HRQL data to represent estimates of quality of life in specific constructs. Correlations of seven SF-36 functional scales with the general health scale were all moderate in magnitude and positive in direction except one, physical functioning. This suggests that the six SF-36 scales (bodily pain, role physical, mental health, role emotional, vitality, social functioning) can be interpreted as estimates of quality of life. A review of the "floor and ceiling" effects for the physical functioning scale (and to a lesser degree the role physical scale) demonstrates that the two physical functioning parameters were not assessing functional HRQL of VA patients using motorized wheelchairs very accurately. This finding is predictable, since the SF-36 was designed to assess HRQL in ambulatory adults, who we would predict to be a distinctly different sample from the sample of VA patients using motorized wheelchairs (5, 7).

The data imply that VA patients have significant limitations in ADLs and perceive their functioning, health and well-being much as worse than that of the normal population (5) or the population of patients with knee dysfunction (6). A literature search did not identify any comparison groups comparable to a population that used motorized wheelchairs and had completed SF-36 forms. Therefore, these analyses are based on self-reported state of functioning, state of health and state of well being for patients using motorized wheelchairs.

If the assumption that "perception" of HRQL relates to "participation" in life situations is valid, VA patients are not participating in life situations as well as patients seeking rehabilitation for knee impairments (6) or as well as people in the general US population (5). This finding seems reasonable considering the potential for patients in the VA population to have more complicated co-morbidities in addition to physical limitations. However, interpretation of results should be approached with caution, because the physical functioning scale (and to a lesser degree the role physical scale) did not appear to assess VA population functional HRQL very accurately.

Review of the per item floor and ceiling data demonstrates that many items have floor effects, which are most dramatic for the physical functioning and role physical scales. Floor effects reduce the responsiveness of the instrument, i.e. the SF-36, in tracking change in functioning following any medical rehabilitation intervention. This finding demonstrates the need to develop a better outcomes instrument for this type of patient analysis if responsiveness to functional change is to be measured.

The presence of floor and ceiling effects also implies a potential for non-linearity in the ordinal rating scale of the SF-36 for some items. This psychometric distortion has been improved using Item Response Theory techniques (13, 14, 17), such as Rasch probabilistic models (12, 15, 16). Therefore, it is recommended that the data be assessed using Rasch models to determine if a new index of functioning could be generated, using the current data to improve the psychometrics of the outcomes instrument.

The database constructs imposed several limitations on this study

- The extent to which patients need a motorized wheelchair is not captured in VA databases. This information is needed in order to understand the VA population and to identify a comparison group with similar functional deficits and diagnoses as the VA sample population.
- There are no data indicating if these patients use their wheelchairs.
- Algorithms that the VA uses to calculate the role physical (RP) and role emotional (RE) scales do not follow published (5) algorithms, which may erode the validity and general applicability of the external comparisons.
- Indirect SF-36 scale measures were used to estimate the ability to perform ADLs and participate in life situations. These measurements may not be valid.
- Data were missing for descriptive demographic variables, making group comparisons difficult.
- The sample was heterogeneous, i.e. the top ten diagnoses by frequency were only 30% of the patients, which may make group comparisons difficult by increasing the variance in data.

ACCESS TO CARE

Q.8bD, 8bE: What are the wait times that VA patients with motorized wheelchairs experience for clinic appointments? How long do VA patients with motorized wheelchairs wait to see a provider?

At least 50% of patients reported that they wait longer than 10 minutes to be seen.

We selected patients who designated "Motorized Wheel Chair" in the item field in the National Prosthetic Patient Satisfaction Survey (NPPSS) and merged this file with our study population of motorized wheelchair users. This resulted in a subset of 6,582 patients. However, only 1,738 to 2,817 of these patients had completed the specific survey questions in which we were interested.

Q 12 (n= 1738) asked "How long did you wait from the day you scheduled this visit until the day you were seen?"

RESPONSE	NUMBER	PERCENTAGE
No wait at all	365	21.0%
1-14 days	641	36.9%
15-30 days	347	20.0%
1-2 months	189	10.9%
2-months	114	6.6%
Over 4 months	59	3.4%

Q. 16 (n= 2719) asked "On the day of your most recent device-related visit, how long did you wait in line to check in?"

RESPONSE	NUMBER	PERCENTAGE
No wait at all	1,253	46.1%
1-15 minutes	915	33.7%
16-30 minutes	333	12.2%
Over 30 minutes	193	7.1%

Q. 19 (n= 2717) asked "On the day of your most recent device-related visit, how long did you wait to be seen by your provider after you checked in?"

RESPONSE	NUMBER	PERCENTAGE
No wait at all	630	23.2%
1-10 minutes	698	25.7%
11-20 minutes	513	18.9%
21-30 minutes	417	15.3%
31-60 minutes	184	6.8%
Over 1 hour	132	4.9%

Data analysis supports the finding that veterans do not report waiting long periods to be seen by providers.

Q. 8bF: How far do VA patients with motorized wheelchairs travel to clinic appointments?

The Booz Allen team utilized several VA databases to determine the distance traveled by motorized wheelchair users from their homes to primary care facilities. The zip codes for patients' residences were matched to the closest VA facility providing primary care services to determine average distance traveled by patients. VA databases used in this effort include the VA Zip Code File, VA Station Tracking (VAST) database, Outpatient Clinic/Patient Treatment File (OPC/PTF), and the National Prosthetic Patient Database (NPPD). The Booz Allen team utilized Geographic Information Systems (GIS) to determine travel distance, and conducted data analysis to determine the national average distance for patients receiving motorized wheelchairs.

According to findings detailed in the Booz Allen Hamilton PSAS Program Evaluation's Time and Distance Study, the total number of patients within the motorized wheelchair user subset (n=4,175) travel an average of 15.055 miles to primary care clinics. For more detailed information on travel time and distance for motorized wheelchair users refer to the Booz Allen Hamilton Time and Distance Study (10/10/02).

PATIENT SATISFACTION

Q. 12A: What is the satisfaction rate with home health care services or products of patients who received motorized wheelchairs?

To answer this question, the Booz Allen team utilized the motorized wheelchair user file created from data extracted from both PTF and NPPD, which included only complete patient records. Patient records were then selected from the NPPSS file for patients who indicated a "motorized wheelchair" in the item field on the survey. This file was then merged with the motorized wheelchair user file to develop a subset of data that can be used to analyze patient satisfaction.

This subset included a total of 6,582 patients. However, 1,738 to 2,817 of these patients completed the specific survey questions related to this program evaluation analysis question. The N's in the following tables represent actual number of responses (i.e., non-missing data). The percentage calculated for each question was based on the actual number of responses. Overall, the results show that patients were satisfied with the quality of the device, quality of the visit, and the device related care provided to them.

Q. 4 (n= 2750) asked, "Overall, how would you rate the quality of this device?"

Response	Number	Percentage
Excellent	1190	43.3%
Very good	773	28.1%
Good	537	19.5%
Fair	165	6.0%
Poor	70	2.5%

Q. 40 (n= 2770) asked, "Overall, how would you rate the quality of this visit?"

Response	Number	Percentage
Excellent	1191	39.4%
Very good	833	30.1%
Good	532	19.2%
Fair	178	6.4%
Poor	110	4.0%

Q. 49 (n= 2632) asked "Overall, how would you rate the quality of your device-related care during the past 12 months?"

Response	Number	Percentage
Excellent	917	34.8%
Very good	793	30.1%
Good	553	21.1%
Fair	237	9.0%
Poor	118	4.5%

Question 12B: What are the areas of customer concern?

We are unable to answer this question because the NPPSS database we received did not code data answering this question.[3] This is an open-ended question on the survey.

[3] *The question came from Q 59 of 1999 NPPS, which was an open-ended question.*

RECOMMENDATIONS

The Following Recommendations Could Improve Data Collection for Future Studies

VA should improve data collection processes, so FIM and SF-36 surveys are collected at appropriate times before, after and during rehabilitation. Recommended time frames would be:

- Annually during medical management of patients before amputations,
- One month before amputation surgery, if possible,
- One month after amputation surgery, and
- Six months thereafter during rehabilitation (to include any prosthesis fitting) until patient is independent.

The VA should also develop relational data files relational by collecting the same patient identifying demographic variables, e.g. social security number, in each electronic file. VA should standardize operational definitions of variables across the VA system.

A great need exists in the rehabilitation industry for the development of effective outcomes measurement tools to test the usefulness of medical rehabilitation interventions and products. The VA should evaluate the usefulness of measurement tools to assess a patient's response to medical rehabilitation interventions and technology that enhances mobility, independence, and quality of life.

Table 18 lists recommended performance measures for patients using motorized wheelchairs. These performance measures will provide VA with program information on the functional status and quality of life of patients using motorized wheelchairs, customer service, and the efficiency and effectiveness of management/operations. An important aspect of performance measurement that VA should strive to achieve is the ability to track services and patients over time to determine how successfully rehabilitation has controlled impairments.

Table 19. Recommended Performance Measures for the Motorized Wheelchair Population

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Functional Status	**Physical Functioning** Develop a new assessment tool pertinent to people using motorized wheelchairs that pertains to motor functioning that can be used to track change over time. Measurement areas should include mobility, self care, and activities of daily living, examples include: -Ability to get into and out of the wheelchair -Ability to travel out of the house -Ability to use device with little or no assistance from others The measure would be scored 0 to 100 with higher scores suggesting better function or health. Change scores between any two or more points in time, either regular (discharge – intake) or standardized [(discharge – intake)/(standard deviation at intake)] could be calculated.	New Tool
Quality of Life	Measure the seven of the eight scales from the SF-36 to assess patient self-reported quality of life. The seven scales include: ➢ general health, ➢ role physical, ➢ bodily pain, ➢ mental health, ➢ role emotional, ➢ social functioning, and ➢ vitality. The SF-36 scores per construct would be transformed to measures ranging from 0 to 100 with higher scores suggesting better quality of life. Change scores from admission to discharge, or any other two time intervals, either regular (discharge – admission) or standardized [(discharge – admission)/(standard deviation at admission)] could be calculated. Note: PF-10, Physical Functioning – item 3 should not be used to assess patients utilizing motorized wheelchairs because it overlaps with the physical functioning domain and is targeted at a much higher functioning population.	SF-36

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Customer Service	**Access** ➢ Percent motorized wheelchair patients within travel time and distance requirement --- ➢ Average time for motorized wheelchair to be procured and delivered to patients ➢ Average wait time (in minutes) for motorized wheelchair patients to be seen by a provider after check in ➢ Percent of motorized wheelchair patients satisfied with the ease of making appointment ➢ Average wait time (in days) for motorized wheelchair patient to get an appointment	Zip Code File matched with MW patients from PTF/OPC or Patient Satisfaction Survey --- Patient Satisfaction Survey
	Education ➢ Percent of patients that state they received education and training on prescribed medical equipment ➢ Percent of time patients state they received understandable instructions for prescribed medical equipment	Patient Satisfaction Survey
	Customer Satisfaction ➢ Percent of amputation patients satisfied with the processes of care received at a VA Medical Center or clinic ➢ Percent of patients satisfied with care received at a VA Medical Center or clinic ➢ Percent of patients satisfied with prescribed medical equipment	Patient Satisfaction Survey

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Management/ Operational	**Utilization** Develop a measure that would track whether the ADL equipment is actually being used. ➢ Number of dispensed motorized wheelchairs (facility, VISN, national) *workload/cost indicator – not performance based ➢ Percent of individuals who receive the ADL equipment that use their ADL equipment at follow up. (Measure between 6 months and 1 year after provision of equipment) ➢ Average number of medical, psychological or social service visits used by individuals issued a motorized wheelchair	NPPD CPRS or New Tool OPC
	Cost ➢ Average cost of services per patient/year (facility, VISN, national) review over time --- ➢ Average cost of motorized wheelchairs per year (facility, VISN, national) Review over time as an indicator of cost only, not performance related	DSS --- NPPD

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HOME OXYGEN

INTRODUCTION / METHODOLOGY

The Booz Allen Team reviewed the care provided to VA's PSAS patients discharged to home with home oxygen

Within the VHA system, the local Prosthetic and Sensory Aids Service (PSAS) typically manages the home oxygen services. PSAS coordinates the order, delivery and vendor management of home oxygen equipment and services. PSAS works collaboratively with many clinical services within VHA to ensure that veterans have access to appropriate and necessary home oxygen services.

The overall study question posed by VA is "To what extent is VA achieving its program outcomes for patients requiring prosthetics based on a continuum of care?" This study question applies to several different patient populations, and the performance measures and analysis plan for each were tailored for the individual study populations.

The overall objective of the study question is to evaluate the outcomes and services provided to VA patients discharged to home. For the home oxygen study population, the Booz Allen team designed our evaluation based on the study questions below.

1. Do VA patients who have been discharged home receive home oxygen services and supplies at a rate comparable to non-VA patients?

2. Do these patients report a quality of life comparable to non-VA patients?

3. Are VA patients reporting satisfaction rates comparable to non-VA patients?

The home oxygen population is very different from the other two populations selected by VA (those at-risk for amputation and amputees) and many of the VA-designated metrics do not apply to this study group. Several of the performance measures selected by VA at the outset of our study related to patient functionality and training in ambulation were not applicable to the home oxygen population and were therefore removed from the analysis plan. We have organized our findings by study question. Each study topic is discussed in its own section, and detailed methodology and limitations are addressed within respective sections.

Summary of Findings

Although we cannot compare the volume of home oxygen services provided to the VA and non-VA populations, our findings indicate that veterans receive various types of home oxygen services and equipment. Our literature review findings support the premise that long-term oxygen therapy is commonly used to manage Chronic Obstructive Pulmonary Disease (COPD) patients and has been shown to be an effective treatment option.

Veterans report a lower quality of life than the "normative" non-VA sample, as evidenced by our data analysis of SF-36 survey results. However, comparisons between veteran and non-veteran populations should take into consideration the marked difference in health status, socio-economic factors and other applicable demographics between the two groups.

Veterans report positive satisfaction rates related to home oxygen care and services. Of note is our finding that many patients perceive their home visits to be typically unscheduled and that patients report

that they are unaware whether the person providing the home oxygen service is a VA employee or a contracted vendor.

The Booz Allen team performed this study utilizing several VA databases, as well as comparative non-VA data

The Booz Allen team worked with VA staff to develop an electronic file of VA patients receiving home oxygen therapy. The study population was designed to include veterans diagnosed with COPD who had received home oxygen equipment or supplies for fiscal years 1998 through 2000. Patients were selected by extracting records with an ICD-9 diagnosis code for COPD from the Patient Treatment File (PTF) for the three study years. Then, from the National Prosthetic Patient Database (NPPD), data were extracted using codes 800A, 800B, 800F, R91A, R91B, R91E and R91F, which represents home oxygen equipment and supplies recorded in the PSAS database. These records were separated into ventilator and home oxygen files, to delineate the number of veterans on ventilators. Each file was merged with PTF Oxygen File, and patient identification numbers were unduplicated to generate the study population: COPD patients on home oxygen during fiscal years 1998 – 2000.

We analyzed the merged study population dataset to collect information on the types of home oxygen services provided, the volume of home oxygen patients, the average age and most frequently noted co-morbidities of home oxygen patients and various other data that are detailed in the section entitled, "Utilization of Home Oxygen Services." Information related to non-VA utilization of home oxygen services is provided under the section "Literature Review" and provides discussion on the prevalence of COPD, as well as general information related to utilization of long term oxygen therapy in the non-VA population.

Once the study population was identified, the Booz Allen team utilized additional databases to obtain specific information on various study topics. We will briefly discuss these databases and the overall study methodology, but further information related to specific steps and data limitations will be provided in the sections that address those topics.

The External Peer Review Program (EPRP) database captures results of medical record reviews conducted as part of VHA's Systematic External Review Program (SERP). Cases are selected from more than 20 high risk or high volume inpatient medical, surgery, and psychiatric diagnoses. One of the modules within EPRP is the Tobacco Use Cessation module, which is comprised of six variables relating to the provision of patient counseling on tobacco cessation. The Booz Allen team utilized this dataset to determine what type of education relevant to the home oxygen population is provided to patients. Since patient education is one component of the home oxygen services provided to veterans, findings gleaned from this dataset are also discussed in the section entitled "Utilization of Home Oxygen Services."

The SF-36 survey is a self-reported patient survey that measures a patient's perceived health status. The SF-36v database is a repository of results for veterans who have been administered the SF-36. The project team compared the SF-36v data to published norms for SF-36 results within the general population. A more detailed discussion of how the SF-36v data was utilized to answer study questions, as well as the limitations involved in comparing the VA and non-VA datasets, will be provided under the "Quality of Life" section.

The National Prosthetic Patient Satisfaction Survey (NPPSS) is a survey instrument that collects veteran evaluation of care and services provided by Prosthetics and Sensory Aids Services. In 2001, PSAS added questions targeting home oxygen care and services. The Booz Allen team tried to match the study population to the NPPSS database, however only a limited number of records (895 patients) matched. The team, therefore, extracted records based on those veterans who had responded to the home oxygen

questions in the survey (n=3,733). The Booz Allen team analyzed the results of this patient satisfaction survey to understand and discuss VA home oxygen patients' reported satisfaction with home oxygen services. Results of the analysis are found in the "Patient Satisfaction" section on page 70.

FINDINGS

The Booz Allen team developed the analysis plan for this study utilizing specific analysis metrics identified by VA. Early in the stages of this program evaluation, the Booz Allen team worked with VA to refine the original analysis metrics, based on the requirements and details of the individual analysis questions and the unique study populations. Many of the original analysis metrics did not apply for the home oxygen study, and for others, the data was unavailable. We have organized our findings based on the analysis metrics for this study question. The analysis metrics are identified by question number, which correspond to the refined metrics presented to the VA project team in the November 9, 2001 deliverable, *Phase IIA: Refined Project Plan, Program Evaluation of Prosthetics and Sensory Aids Services.*

LITERATURE REVIEW

Our review of medical literature on home oxygen therapy for patients with COPD revealed several common themes among both VA and non-VA populations

VA tasked the Booz Allen team with comparing utilization rate, quality of life, and satisfaction rates of VA's home oxygen patients to the non-VA population. In response to this task, the Booz Allen team conducted a literature review related to long-term oxygen therapy for COPD patients. The themes that emerged from the literature review include COPD epidemiology, current VA efforts relating to the management of chronic pulmonary disease, treatment options, and results of general patient satisfaction and quality of life surveys. There is no data available that allows for a direct comparison of these areas between VA and non-VA populations.

Overall, we found that home oxygen therapy is a common treatment option in the general population for patients with COPD, and is utilized regularly in the care and management of home oxygen patients. Additionally, our findings indicate that home oxygen patients in the non-VA population report limitations in activities of daily living, such as household chores, social activities and work. Our literature review findings also indicate that comparisons of healthcare services provided to veterans and non-veterans should take into consideration the significant differences in the overall health status of the two groups.

COPD: Prevalence and Cost

We found consistent data among the literature related to the prevalence of COPD. The American Lung Association and Carter et al report COPD as the fourth leading cause of death in the United States (1,2). These sources also cite cigarette smoking as the cause for 80-90% of the incidence of COPD, with the remainder caused by frequent lung infections and exposure to specific industrial pollutants. These findings attribute COPD to more than 10 million doctor visits per year and more than 2 million hospitalizations. The cost of COPD was over $30 billion in 2000 (9,12). The literature also indicates that patients with COPD experience physical and emotional barriers to normal functioning (1,2,3). Wedzicha specifically reports that cognitive impairment, anxiety, and depression are more common in patients suffering from severe COPD than in a control population (13).

Similar to the prevalence in the general population, COPD is recognized by VHA as one of the "most common and costly diseases in the VHA" (14). In 1996, VA data reported more than 23,000 home oxygen patients diagnosed with COPD (VA National Center for Cost Containment Publication National Home Oxygen Program FY 95) (15). Findings from the Booz Allen Hamilton report on Home Oxygen Contracts indicate that VA spent an estimated $78 million in fiscal year 2001 on home oxygen services, comprising 47,501 individual patients within VHA.

Current VA Efforts Described in the Literature

The Booz Allen team came across several articles within the literature describing VHA's efforts to manage COPD in the veteran population. VA is studying various methods to manage both the care as well as the costs of COPD patients. VA is well represented in the literature for exploring the role of telecommunications in the management of COPD (4, 5), researching the roles of various types of clinicians in the management of COPD (6,7), as well as reviewing resource utilization by COPD patients within the VHA (8). Literature review findings indicate that VHA has been active in their efforts to identify new interventions in managing COPD patients while exploring ways to reduce costs, slow the progression of the disease, and improve the quality of life and services for patients with COPD.

Treatment Options

Literature review findings support the premise that there is no cure for COPD. However, there is consensus about the treatment options available to patients to provide symptom relief and slow the progression of the disease (1,2, 9,10,11). Some studies have shown that long term oxygen therapy, combined with pulmonary rehabilitation, improves quality of life (3,4 from Weg article). Long-term oxygen therapy has also been identified as the sole intervention with the capability to increase life expectancy in COPD patients. (16,17)

Our findings identified several treatment options:

- Smoking cessation;
- Patient education;
- Nutrition;
- Exercise,
- Spirometric testing;
- Screening for COPD and Alpha-1 Antitrypsin Deficiency;
- Pharmacotherapy including bronchodilator medications, oxygen therapy, corticosteroids, and pneumonia and influenza vaccines;
- Pulmonary rehabilitation (PR);
- Lung volume reduction surgery (LVRS); and
- Lung transplantation

The National Heart, Lung, and Blood Institute and World Health Organization Global Initiative for COPD (GOLD) discusses the above interventions in stages of prevention, management and treatment of stable COPD, as well as the management of acute exacerbation (10). GOLD guidelines also define COPD and classify COPD into 4 stages ranging from "at risk" for COPD to "severe" COPD. The GOLD committee recognizes a need for consistency in definition and in guidelines for the treatment and management of COPD.

COPD Patient Satisfaction and Quality of Life Survey Results

The American Lung Association published results from a survey, describing patient and physician attitudes about COPD management (11). Both groups are optimistic about the treatment options available. Physicians reported prescribing various medications at a rate higher than patients are taking the medications. Patients reported the medication schedules make compliance and the ability to lead an active life difficult, although the majority of patients stated that proper treatment can make it possible to lead an active life.

In another American Lung Association survey, half of all COPD patients reported their condition limits their ability to work, sleep, participate in social activities and complete household chores (1). In this same survey, 70% of COPD patients reported limitations in physical activity. The American Lung Association concluded better education of patients with COPD is needed, supporting the recommendations of several other authors (3,8,9,11).

Differences in Health Status Between VA and Non-VA populations

Research findings support the premise that veterans have a poorer health status and greater number of medical conditions than the general population. One study by Agha et al analyzed records from the National Health Interview Survey for 1993 and 1994 and compared results of the VA population with results from the general population (18). Results of this study indicated that there are significant differences in not only health status but also socio-demographic status. Such differences should be considered when comparing factors such as utilization of health services, quality of life, and patient satisfaction between VA and non-VA populations.

UTILIZATION OF HOME OXYGEN SERVICES

Do VA patients who have been discharged home receive home oxygen services and supplies at a rate comparable to non-VA patients?

VA tasked the Booz Allen team to determine whether VA patients who have been discharged to home on home oxygen services receive health care services and supplies at a rate comparable to non-VA patients. This analysis question starts with an assessment of services provided to VA patients who have been discharged to home on home oxygen services. Data on the rate that non-VA patients receive home oxygen services is not available. Rather, general information related to the provision of long-term oxygen therapy was provided in the section entitled, “Literature Review.” Since we cannot determine the “rate” of receipt of home oxygen services, we conducted an analysis of VA’s volume of home oxygen patients as well as an analysis of the demographics associated with this population.

The Booz Allen team merged VA databases to identify demographic and utilization information about home based oxygen patients

The Booz Allen team used two databases to determine the rate of utilization of services and supplies by home oxygen patients for this study population. We extracted home oxygen records from the National Prosthetics Patient Database (NPPD) for years 1998-2000 using NPPD codes 800A, 800B, 800F, R91A, R91B, R91E and R91F. These records were separated into ventilator and home oxygen files by year, to determine how many home oxygen users receive oxygen through a ventilator system. Patient identification numbers were collated to extract the total number of unique patients receiving home oxygen equipment or supplies for the designated study years.

In order to obtain patients’ demographic and relevant clinical (e.g., co-morbidity) information, we selected records from VA’s inpatient database, the Patient Treatment File (PTF). We extracted records using COPD diagnosis codes (ICD-9 codes 490-496) to identify the COPD veterans who may use oxygen. These records were then matched by patient identification numbers with the records identified from NPPD to create a file of our study population: COPD patients receiving home oxygen services during fiscal years 1998, 1999 and 2000. We identified a total of 10,563 patients using home oxygen and ventilator services, among them, 220 had missing demographic data. Table 19 describes the demographic characteristics of home-based oxygen patients for the collective years 1998-2000, percentages are reported based on non-missing data (i.e., valid percent based on 10,343). We also calculated mean ages by year, presented in Table 20. As we noted, the sum of Table 20 indicates a total of 12,535 patients, however, when we

combined the three years, there were 1,972 duplicate patients leaving only 10,563 patients in the combined 1998-2000 sample.

Table 20. Demographics of VA Home Oxygen Users Years 98-00 (N= 10,563)

	RESPONSE TO EACH VARIABLE	SUMMARY	MISSING DATA*
Gender	10,343		220
Male	10,111	97.8%	
Female	232	2.2%	
Ethnicity	10,343		220
Caucasian	8,553	82.7%	
African American	1,288	12.5%	
Hispanic	135	1.3%	
Other	41	.4%	
Unknown	326	3.2%	
Marital Status	10,343		220
Separated	404	3.9%	
Married	5,560	53.8%	
Widowed	1,320	12.8%	
Never Married	678	6.6%	
Divorced	2,351	22.7%	
Unknown	30	.3%	
Age (Mean±SD)		68.43 ±9.84 (58.5 – 78.2)	

*Missing data is the same in all categories because these fields were missing for the same 220 patients

The results indicate that the majority of home oxygen patients for the study period of 1998-2000 are Caucasian married males, averaging 68 years of age.

Table 21. Mean Age* of Home Oxygen Patients By Year

YEAR	2000	1999	1998
N	6,594	3,215	2,506
Age (Mean)	69	68	67

Table 21 shows the number of home oxygen patients (n) increased over the three years while the mean age stayed fairly constant. The dramatic increase in volume between 1999 and 2000 is most likely attributed to the fact that data related to home oxygen equipment and supplies were captured in more than one database prior to 2000. In 2000, all home oxygen services were tracked using NPPD, which accounts for the large increase in volume. Prior to fiscal year 2001, VA cost information for home oxygen services was collected through a variety of different databases, such as the Prosthetic and Sensory Aids

Services' NPPD and the Pharmacy Module of the Veterans Health Information Systems and Technology Architecture (VISTA). No one database captured the entire dataset for all medical centers related to volume and cost for home oxygen services prior to fiscal year 2001.

Veterans in our study population have similar co-morbidities throughout the study years

The Booz Allen team sorted the data to determine the top five co-morbidities of the home oxygen patients. The initial PTF record extraction selected oxygen patients from PTF if a diagnosis of COPD appeared in any of the twelve ICD-9 diagnosis code fields. However, not all patients had COPD as their primary diagnosis code during the inpatient stay. In other words, a patient can be hospitalized with pneumonia as the primary diagnosis code, but has a diagnosis of COPD or a history of the disease as a co-existing condition. Therefore, to avoid missing patients who have COPD but a different inpatient primary diagnosis, the data run included the frequency of the primary diagnosis and listed the largest categories of diagnoses. This analysis provides a listing of the most frequently occurring co-existing diagnoses of our home oxygen study population. The data is presented below in Table 22.

Table 22. Top 5 Co-Morbidities for Home Oxygen Patients for Years 1998 - 2000

ICD-9	DESCRIPTION	NO. OF PATIENTS	RANKING
Yr 2000 (n=6594)			
481-486	• Pneumonia	1,545	1
428.0	• CHF	1,242	2
496	• COPD	655	3
160-165 (incl. 162.3 and 162.9)	• Cancer related to respiratory and intra-thoracic system	577	4
411-427.9	• Heart failure /arrhythmia	422	5
Yr 1999 (n=3215)			
481-486	• Pneumonia	716	1
428.0	• CHF	585	2
496	• COPD	539	3
411-427.9	• Heart failure /arrhythmia	237	4
160-165 (incl. 162.3 and 162.9)	• Cancer related to respiratory and intra-thoracic system	179	5
Yr 1998 (n=2506)			
496	• COPD	525	1
481-486	• Pneumonia	497	2
428.0	• CHF	392	3
411-427.9	• Heart failure /arrhythmia	177	4
160-165 (incl. 162.3 and 162.9)	• Cancer related to respiratory and intra-thoracic system	120	5

Table 22 displays a ranking of patients by frequency of diagnosis code with 1 being the most frequent diagnosis and 5 being the least frequent of the top five diagnoses found in the home oxygen study population. As the table shows, the largest cohort of patients using home oxygen services during years 1999 and 2000 had a diagnosis of pneumonia. In 1998, the most frequent diagnosis associated with home oxygen patients was COPD. The same five diagnoses consistently appeared all three years with slight variations in ranking order. These diagnoses are COPD, pneumonia, congestive heart failure (CHF), heart failure/arrhythmia, and cancer related to respiratory and intra-thoracic system.

Of interest is years 1999 and 2000 showing COPD as the third most frequent diagnosis for patients discharged to home with home oxygen services, while CHF and pneumonia ranked second and first respectively. There are a number of possible explanations not conclusively proven by the data for this change in COPD ranking. Differences in the clinical management of COPD patients at home may impact the number of hospitalizations for COPD exacerbations.

What is the volume of home oxygen services utilized in VHA?

The Booz Allen team separated the home-based oxygen patient population into two subpopulations, ventilator and non-ventilator home oxygen users, to determine the number of COPD patients who receive home oxygen services from VHA. Table 23 shows the volume of home ventilator patients and all other home oxygen patients by year.

Table 23. Volume of Patients on Ventilator and Home Oxygen

Year	2000	1999	1998
Ventilator	6	9	4
Home Oxygen	6771	3212	2515
Total Home Oxygen Users	6777	3221	2519

The data presented in Table 22 represent numbers of patients (not records) receiving home ventilator or other home oxygen services. In 2000, there were 96 records of ventilator issuances for 6 patients. In 1999 and 1998, there were 99 and 73 records of ventilator issuances respectively. In 2000, there were 91,021 records of home oxygen issuances for 6,771 patients. In 1999, there was a total of 23,869 records of home oxygen issuances for 3,212 patients and in 1998, there were 20,298 records of home oxygen issuances for 2,515 patients. We created a master list of patient identification numbers for each year and unduplicated them, to determine the total number of unique patients within each year. The data for years 1998 and 1999 do not reflect the true volume of home oxygen patients since home oxygen equipment and services were captured in other databases in addition to NPPD during those years and was not captured fully in either database.

8aA. What guidelines exist regarding qualifications of individual making referrals for VA patients?

We have interpreted “making referrals” in this home oxygen study question to “prescriptive authority” for home oxygen. VHA Handbook 1173.13, dated November 1, 2000 entitled ”Home Respiratory Program” refers to a prescribing “clinician” and does not define the qualifications of this professional. Site visit findings and supplemental telephone interviews indicate that medical centers vary in their guidelines on prescriptive authority for home oxygen. Medical centers with a pulmonologist on staff may require that all home oxygen orders be signed by a pulmonologist. However, there are medical centers that allow primary care physicians and Nurse Practitioners to prescribe home oxygen. These medical centers may

not have a resident pulmonologist on staff. There is variability among medical centers in the qualifications required of individuals who prescribe home oxygen therapy.

VHA's National Program Director for Pulmonary Services reports that there is currently Prosthetic Clinical Management work group focused on home oxygen. One of the goals of this work group is to further refine the definition of "clinician" and to review the clinical practice guidelines related to home oxygen within VHA.

8aB. What activities of daily living (ADL) equipment was provided at discharge?

There was insufficient data to answer this question. The Booz Allen team attempted to match the date of discharge for each patient in our study population with the date of initial delivery of home oxygen equipment. By doing so, we intended to analyze whether equipment was provided at discharge and also to understand how long patients may wait before equipment is delivered to the home. However, the data in PTF does not allow for identification of when a patient was first prescribed home oxygen. Therefore, following an inpatient discharge for any number of possible diagnoses, the home oxygen patient may return home to home oxygen equipment that had been delivered prior to his inpatient admission. The data does not allow us to determine whether the equipment that was delivered was delivered to a new home oxygen patient or to a home oxygen patient who received a routine delivery. We cannot correlate dates of discharge with dates of equipment delivery, given the data available in PTF and NPPD.

8aC. What education was provided to the VA patient?

Our analysis indicates that veterans receiving home oxygen services received a great deal of education and training related to the set-up, use, maintenance and safety of their home oxygen equipment. Detailed findings of patient satisfaction related to patient and family education is provided in the section entitled "Patient Satisfaction." There was insufficient data to conclude whether patients receive tobacco use cessation counseling. However, the data that was available indicate that veterans receive some level of education regarding tobacco cessation.

The Booz Allen team utilized the EPRP database to analyze what type of referral or counseling is provided to veterans regarding smoking cessation during clinic visits and encounters with providers. EPRP focuses specifically on education related to tobacco cessation in the "Tobacco Use Cessation Module." We first matched the patient identification numbers of our home oxygen study population to the EPRP data file (all quarters merged into one file), which resulted in 3,595 patients. However, of these matched records, we evaluated the number of patients who are current tobacco users, to accurately reflect the number of patients who would receive education on tobacco cessation. We identified a much smaller subset of records for which this data was available.

Table 24. Tobacco Status of EPRP-Matched Home Oxygen Study Population

CURRENT USERS	FORMER USERS
132	116

During our analysis of the data associated with "current users" we noted sufficient data for only one specific variable. Missing data may be attributed to the fact that certain questions did not apply to patients in our study population. For example, if a question refers to "during at least three visits to applicable clinics" and the veteran did not have at least three visits, the variable is not captured. It is also possible that EPRP reviewers did not systematically review home oxygen (as opposed to COPD) patient records until late 2000. Another possible reason may be that we retrieved inpatient data to match equipment data, and EPRP may have an outpatient focus in the Tobacco Use Cessation Module.

Whatever the reason is, we did not have many matched data to provide definitive answer to this question. The questions we analyzed, the number of responses available in the dataset, and the results, are listed in Table 25.

Table 25. EPRP Tobacco Use Cessation Module Results for "Current Users"

QUESTION	# OF RESPONSES	RESULTS
Within the past year, during at least three visits to applicable clinics, was the patient counseled regarding risks of tobacco use and/or encouraged o stop using tobacco?	0	N/A
Within the past year, was the patient counseled at least once regarding tobacco use or referred to a tobacco cessation program?	132	YES: 129 (97.7%) NO: 3 (2.3%)
For patients with less than three visits to an applicable clinic in a year, was the patient counseled at every visit regarding risks of tobacco use and/or encouraged to stop using tobacco?	0	N/A

QUALITY OF LIFE

8bB. How do VA patients with home oxygen rate their quality of life?

One of VA's objectives in this section of the PSAS Program Evaluation is to measure and compare the self-reported quality of life of home oxygen patients within VA and non-VA populations. We analyzed veteran and non-veteran perceptions of quality of life by reviewing results of a patient self-reported health-related quality of life (HRQL) survey. As expected, our analysis of SF-36 results indicate that veterans using home oxygen report dramatically worse functioning than the general US population.

The SF-36 was designed to assess HRQL for people without disease as well as patients with medical conditions (20). Norms for SF-36 constructs were generated during the Medical Outcome Study (MOS). Data were collected as part of the National Survey of Functional Health Status in 1990, using data from personal interviews rather than self-administered questionnaires (19,20). Respondents were drawn from the General Social Survey in 1990, which surveyed 2,474 non-institutionalized adults in the United States (19).

Use of the SF-36 facilitates comparisons of functional abilities and quality of life for patients in the VA system who used home oxygen therapy and for patients in the MOS SF-36 US normative sample (19). Patients in the comparison sample are not exact matches for patients in the VA sample for this study. However, the comparison is still useful in understanding the magnitude and direction of differences between the populations. An understanding of the limitations is necessary when reviewing the results of the comparison.

We identified limitations in the data used to conduct our analysis of veteran reported quality of life

There are no available data to indicate compliance with use of oxygen therapy at home. We do not know that these home oxygen patients are appropriately following orders and utilizing home oxygen services in a medically compliant manner. The algorithms used by VA to calculate the role physical (RP) and role emotional (RE) scales do not follow published (19) algorithms, which may erode validity of external

comparisons. SF-36 scale measures were used to estimate health-related quality of life, which may not be valid. Data were missing for descriptive demographic variables making group comparisons difficult.

Self-reported characteristics collected through the SF-36v provide a picture of the COPD patient on home oxygen

Patients from the SF-36v database were selected if their scrambled social security numbers matched patients in the home oxygen study population (veterans diagnosed with COPD receiving home oxygen services). Patients with incomplete SF-36 records were eliminated. Descriptive statistics for patients who received home oxygen therapy and completed an SF-36 are provided in Table 26 below. There was a great deal of missing data, so the percent provided is the "valid percent" operationally defined as the percent of patients answering the question.

Table 26. Self-Reported Characteristics of Home Oxygen Patients Who Completed the SF-36v

(N=994)

CHARACTERISTICS	RESPONSE TO EACH VARIABLE	SUMMARY	TOTAL RESPONSE	MISSING DATA
Age (yrs)		67±9	N=994	0
Gender			N=994	0
Males	967	97%		
Females	27	3%		
Primary Diagnoses (top ten) at Admission*	197	20%	N=994	0
Pneumonia, organism unspecified (ICD-9 486)				
Chronic airway obstruction (ICD-9 496)	177	18%		
Heart failure (ICD-9 428.0)	163	16%		
Other emphysema (ICD-9 492.8)	39	4%		
Intermediate coronary syndrome (ICD-9 411.1)	38	4%		
Pneumococcal pneumonia (ICD-9 481)	21	2%		
Postinflammatory pulmonary fibrosis (ICD-9 515)	18	2%		
Pneumonia due to pseudomonas (ICD-9 482.1)	16	2%		
Angina pectoris other and unspecified (ICD-9 413.9)	16	2%		
Pneumonia due to hemophilus influenza (ICD-9 482.2)	12	1%		
Ethnicity			N=1,025	
Caucasian	880	86%		
African American	86	8%		
Hispanic	15	1%		
Native American	38	4%		
Asian	5	<1%		
Pacific Islander	1	<1%		

CHARACTERISTICS	RESPONSE TO EACH VARIABLE	SUMMARY	TOTAL RESPONSE	MISSING DATA
Employment Status			N=1,342	
Employed for wages	30	2%		
Self-employed	9	1%		
Looking for work >1 year	4	<1%		
Looking for work <1 year	3	<1%		
Homemaker	13	1%		
Student	2	<1%		
Retired	610	44%		
Disabled	721	52%		
Co-morbidity				
Hypertension or high blood pressure	620	64%	N=964	30
Benign prostatic hypertrophy	349	36%	N=959	35
Chronic low back pain	444	47%	N=953	41
Congestive heart failure	605	63%	N=963	31
Stroke	179	19%	N=950	44
Arthritis	609	63%	N=971	23
Angina or coronary heart disease	443	47%	N=946	48
Heart attack or myocardial infarction	370	39%	N=939	55
Chronic lung disease	842	86%	N=974	20
Cancer	236	25%	N=951	43
Depression	446	47%	N=956	38
Post-traumatic stress disorder	169	18%	N=946	48
Schizophrenia	31	3%	N=923	71
Spinal cord injury with quadriplegia or paraplegia	37	4%	N=945	49
If your doctor told you that you had diabetes, how long ago were you first told?			N=320	674
• <1 yr ago	58	18%		
• 1-3 yrs ago	53	17%		
• 4-10 yrs ago	94	29%		
• 11-20 yrs ago	62	19%		
• >20 yrs ago	53	17%		
Do you now smoke cigarettes?			N=933	61
• Every day	143	15%		
• Some days	74	8%		
• Not at all	716	77%		
Marital status (% of 990 responses)			N=990	
• Married	594	60%		
• Divorced	199	20%		
• Separated	32	3%		
• Widowed	105	11%		
• Never married	60	6%		
Lives alone	220	23%	N=949	774

CHARACTERISTICS	RESPONSE TO EACH VARIABLE	SUMMARY	TOTAL RESPONSE	MISSING DATA
How many times during past month did you have 5 or more drinks on an occasion?			N=921	73
• Never or less than once per month	792	86%		
• 1-3/month	49	5%		
1/week	14	2%		
2-4/week	23	2%		
5-6/week	13	1%		
1/day	7	1%		
>1/day	23	2%		
What is the highest grade or year of school you completed?			N=943	51
Never attended school or only kindergarten	0	0%		
Grades 1 through 8	212	22%		
Grades 9 through 11	149	16%		
Grade 12 or GED	303	32%		
College 1year to 3 years	214	23%		
College graduate or graduate school	65	7%		

Self-reported survey results indicate the average veteran within our study subset is Caucasian, male, approximately 67 years old, and predominately either retired or disabled. The top three co-morbidities reported by these veterans were 1) chronic lung disease, 2) hypertension, and 3) congestive heart failure and arthritis (both reported by 63% of the subset). Over 40% of the subset also reported depression, angina or coronary heart disease, and chronic low back pain. The vast majority of these veterans report they do not currently smoke.

We evaluated eight functional constructs and developed summaries of SF-36 scores

We extracted data containing 35 items from the SF-36, representing eight functional constructs (19,20,21,22). These eight constructs include general health, physical functioning, role physical, bodily pain, mental health, role emotional, vitality and social functioning. Descriptive statistics were used to:

- estimate the patient's ability to function,
- estimate quality of life, and
- imply participation in life situations for each of the eight SF-36 constructs.

Role physical (RP) and role emotional (RE) constructs used rating scales that deviated from published algorithms (19), so item responses were transformed using VA algorithms. The constructs used five response categories rated from high functioning to low functioning (No, none of the time; Yes, a little of the time; Yes, some of the time; Yes, most of the time; Yes, all of the time). The responses were used to generate scales ranging from 0 to 100. However, for these two scales the scores were subtracted from 100 to reverse the final scale score, so high scores represent higher function.

The difference between role functioning and physical/mental functioning lies in the difference between a task limitation and a limitation in the performance of work-related tasks affected by the task limitation. For example, a person may be limited in lifting and carrying, but if his/her job or work around the home does not require lifting and carrying, his/her role functioning may not be limited (19).

Role limitations, whether physical or emotional, assess limitations in the

1. kind of,
2. amount of time spent in, and
3. difficulty performing work or other usual activities (19).

The responses for the other six functional constructs were transformed following published algorithms, (19, p 6:17) so the scores ranged from 0 to 100. The resulting 0 to 100 scores for all eight constructs could be interpreted similarly to published interpretations: "0" reflects low functioning, and "100" reflects high functioning (19). The scores have been interpreted as percentages of health, well-being, and functioning.

We calculated a Physical Component Summary (PCS) and Mental Component Summary (MCS) of SF-36 scores following published algorithms (23). PCS and MCS use different scoring algorithms than the constructs above. PCS and MCS algorithms produce scores with an expected average of 50 and standard deviation of 10, which are the mean and standard deviations for a normal US population (23). In this way, the PCS and MCS are referenced as norms and can be interpreted in relation to standard deviation units (multiples of 10) away from the expected normal (i.e. 50). The results for the two constructs are provided in Table 27 and Table 28 below.

Table 27. Physical Constructs

PHYSICAL CONSTRUCTS (N=994)					
	General Health	*Bodily Pain*	*Physical Functioning*	*Role Physical*	*PCS*
Minimum	0	0	0	0	1.6
Maximum	100	100	100	100	67
Mean	21	33	17	16	22
Standard Deviation	17	26	21	22	7

Table 28. Mental Constructs

MENTAL CONSTRUCTS (N=994)					
	Mental Health	*Role Emotional*	*Social Functioning*	*Vitality*	*MCS*
Minimum	0	0	0	0	7.4
Maximum	100	100	100	85	74
Mean	55	39	31	22	38
Standard Deviation	25	36	27	19	14

Our analysis indicates that there is a positive correlation between SF-36 constructs and perceived health related quality of life

There is some evidence that SF-36 scales are related to, and some believe can be interpreted as, estimates for health and health-related quality of life (19). To estimate health and HRQL, the relation between seven SF-36 scales and general health (the eighth scale) were calculated using Pearson Product Moment Correlations. Pearson's Product Moment Correlation Coefficient measures the linear association between two variables that have been measured on interval or ratio scales, such as the relationship between height in inches and weight in pounds. If the coefficients are positive and of moderate (r>.4) magnitude, there will be evidence that the SF-36 scales are related to general health.

Relationships between SF-36 scales and general health were assessed by correlating SF-36 scales with the SF-36 General Health scale. In this way, we could estimate the relation between health and perceived quality of life by construct, which may provide insight into the quality of life of VA patients. Table 29 shows the association between SF-36 scales and general health, by providing the correlation coefficients between the general health scale and the other seven SF-36 scales for the VA population. Correlations of the same scales are included for the general US samples as a comparison.

Table 29. Associations Between SF-36 Scales and General Health

SF-36 SCALES	VA SAMPLE n=994	GENERAL US SAMPLE n=2,474
Bodily Pain	.38	.58
Physical Functioning	.38	.69
Role Physical	.43	.69
Mental Health	.42	.49
Role Emotional	.32	.43
Vitality	.49	.65
Social Functioning	.54	.57

Values are presented as Pearson Product Correlation Coefficients

All correlations were positive, of moderate magnitude and significant (p<.01). According to published interpretations of correlations between general health and the other seven SF-36 scales, these data support the relation between health and HRQL (19). However, five of the eight correlations were lower than those published for the general population (19, p 9:24), implying a weaker relation between general health and the other scales of functioning, both physical (bodily pain, physical functioning, role physical) and mental (role emotional, vitality), than expected for the VA population.

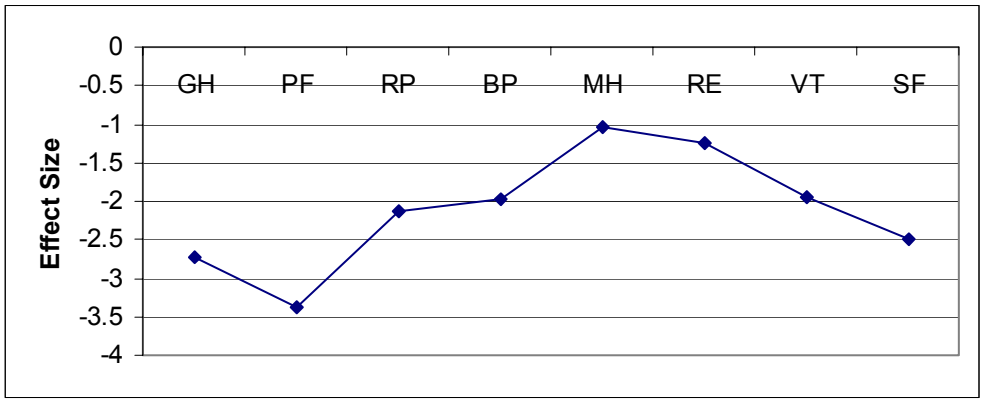
We developed effect sizes to compare SF-36 scales between the VA subset and the non-VA normal sample

For introductory comparisons, SF-36 scales were compared to normative data from the Medical Outcomes Study (19,20,21,22). No comparable comparison group was identified through literature review for people who are receiving home oxygen therapy and who have completed an SF-36 survey. For comparisons between the VA and non-VA populations, each pair of scores was transformed into an effect size (24). Effect sizes are standardized change scores that can be compared directly across studies. An effect size was calculated by subtracting the comparative score from the VA score, and dividing the result by the standard deviation of the comparative score (19). An effect size was calculated

for each SF-36 scale. Effect sizes can be interpreted as follows: 0.2 to 0.4 is small, 0.5 to 0.7 is moderate, and greater than 0.7 is large (24).

Figure 4 below shows a comparison of SF-36 scales from VA patients receiving home oxygen therapy to normative values (19, p 10:14). The differences between the two samples are assessed by effect sizes, (24) which enables a standardization of differences.

Figure 4. Effect Sizes



GH = General Health
PF = Physical Functioning
RP = Role Physical
BP = Bodily pain
MH = Mental Health
RE = Role Emotional
VT = Vitality
SF = Social Functioning

Effect sizes are in units of standard deviations. The line represents data from the VA patients receiving home oxygen therapy (n=994). This graph allows comparison of VA patients to a normal population (effect size=0). The 0 value (y-axis) represents the normative value for the US population (19, p 10:14). As the patient becomes less functional per SF-36 scale (x-axis), the effect size becomes more negative which indicates worse functioning. As the patient becomes more functional, the effect size becomes more positive (y-axis), which indicates better functioning. VA patients demonstrate large (24) dysfunction in all SF-36 scales, and dramatically low dysfunction for the four physical functioning scales (GH, PF, RP and BP) and two of the mental scales (social functioning and vitality). Social functioning and vitality represent both mental and physical constructs but are commonly recognized as mental dimensions (19).

Our data analysis indicates that VA home oxygen patients perceive lower functioning and decreased quality of life than the non-VA (normal) population

SF-36 data have been interpreted as valid assessments of quality of life and functional HRQL (19). Data imply that veterans receiving home oxygen therapy have significant limitations in functional abilities and perceive their functioning and health-related quality of life much worse than the normal population (19). Six scales representing veteran reported physical and mental functioning demonstrate the lowest functioning.

In this study, we interpret SF-36 HRQL data to represent estimates of quality of life in specific constructs. No similar comparison groups were identified through literature review that represented people receiving home oxygen who had completed the SF-36. Therefore, these analyses represent the first description of patient self-report of functioning and health-related quality of life for patients receiving home oxygen therapy. However, it is important to note that these comparisons are between a home oxygen dependent veteran population and a “normal” U.S. population. It is not surprising to see individuals who suffer from conditions requiring home oxygen to report lower functioning and quality of life.

Correlations of all SF-36 functional scales with the general health scale were all moderate or less than moderate in magnitude and positive in direction, but six were lower in magnitude than expected. This

suggests the best construct for assessing quality of life in the VA population is social functioning, and veterans using home oxygen report dramatically worse functioning than the general US population.

ACCESS TO CARE

Q 8bD: What are the wait times that VA patients with home oxygen experience for appointments?

Our data analysis indicates that the majority of patients are seen within a month of calling for an appointment, and wait less than 20 minutes to check in or be seen on the day of the appointment.

The National Prosthetics Patient Satisfaction Survey addresses wait times a veteran experiences for checking in for a scheduled appointment, waiting for an appointment, and waiting to be seen by a provider after checking in. What is not clear about this particular set of questions answered by home oxygen users is what service the appointment was regarding. For example a home oxygen user may have a prosthesis or use a wheelchair so the respondent may be answering this set of questions about devices unrelated to their home oxygen use. We provide the results of the NPPSS questions answered by home oxygen users about wait times for device-related visits below.

(n= 2111) How long did you wait from the day you scheduled this visit until the day you were seen?

RESPONSE	NUMBER	PERCENTAGE
No wait	612	29%
1-14 days wait	584	28.4%
15-30 days wait	377	17.9%
1-2 months wait	226	10.7%
2-4 months wait	152	7.2%
Longer than 4 mo.	121	5.8%

(n= 3274) On the day of your most recent device-related visit, how long did you wait in line to check in?

RESPONSE	NUMBER	PERCENTAGE
No wait	1467	44.8%
1-15 minutes	1153	35.2%
16-30 minutes	412	12.6%
More than 30 min.	198	6%

(n= 3271) On the day of your most recent device-related visit, how long did you wait to be seen by your provider after you checked in?

RESPONSE	NUMBER	PERCENTAGE
No wait	606	18.5%
1-10 minutes	809	24.7%
11-20 minutes	718	22%
21-30 minutes	548	16.8%
31-60 minutes	273	8.3%
More than an hour	163	5%

Q 8bF: How far do VA patients with home oxygen travel to clinic appointments?

The Booz Allen team utilized several VA databases to determine the distance traveled by veterans with home oxygen from their homes to primary care facilities. The zip codes for patients' residences were matched to the closest VA facility providing primary care services to determine average distance traveled by patients. VA databases used in this effort include the VA Zip Code File, VA Station Tracking (VAST) database, Outpatient Clinic/Patient Treatment File (OPC/PTF), and the National Prosthetic Patient Database (NPPD). The Booz Allen team utilized Geographic Information Systems (GIS) to determine travel distance, and conducted data analysis to determine the national average distance for home oxygen patients.

According to analysis findings detailed in the Booz Allen Hamilton PSAS Program Evaluation's Time and Distance Study, the total number of patients within our home oxygen subset (n=7,713) travel an average of 13.658 miles to primary care clinics.

PATIENT SATISFACTION

12A. What is the satisfaction rate with home health care services or products of patients who received home oxygen services?

The Booz Allen team used the National Prosthetic Patient Satisfaction Survey (NPPSS) to determine levels of satisfaction for home-based oxygen patients in areas of education, service, wait times and equipment. NPPSS survey results indicate that home oxygen patients are generally satisfied with the home oxygen services they receive.

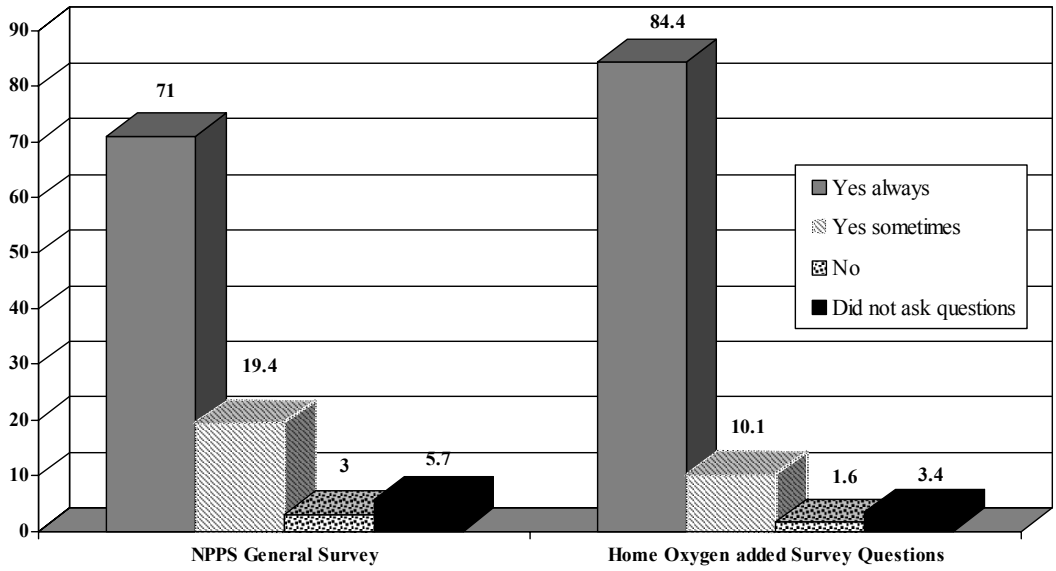
Questions relating specifically to home oxygen care and services were added to the NPPSS in 2001. The Booz Allen team merged the home oxygen study population with the NPPSS database for 2001, to capture home oxygen patients who completed the patient satisfaction survey. We focused on survey questions 64-84, which specifically addressed satisfaction of home oxygen services. There were 3,733 patients in this merged subset. In the following analyses, we present only a valid percent for each question. We operationally define "valid percent" as the percent of patients who answered a specific question[4]. For the 3,733 patients who responded to the questions, there were 3,272 to 3,518 valid responses per question.

8aC and 8aD: What education was provided to the VA patient and the patient's family?

The valid responses to a series of questions about patient and family education and training for the provision of home based oxygen care are displayed in the figures on the following page. Overall, the majority of respondents indicated that

[4] *Although we presented "valid percent", in some questions, there was a "9" coding in addition to "system missing." We are unable to know if "9" is a missing code or a valid code such as "unknown" or "uncodable," therefore, occasionally, the valid percentages do not add to 100.*

Figure 5. "When you asked questions, do you get answers you could understand?"



The majority of patients understood the answers they received to their questions. Of interest is the slight difference in percentages to the survey question that was asked twice in the survey, once as a general survey question and again as a home oxygen survey question.

If patients had trouble understanding answers to their questions, the survey queried if the difficulty was due to a language problem. These results are depicted below.

(n=3233) Did you have trouble understanding the person/team because of a language problem?

RESPONSE	NUMBER	PERCENTAGE
Definitely had problems understanding	69	2.1%
Yes somewhat	81	2.5%
No problems	3059	94.6%

As shown above, less than 5% of the home based oxygen patients responding to the survey attributed language as a factor for their difficulties in understanding answers, which matches the percent of patients who responded that they did not understand the answers to their questions.

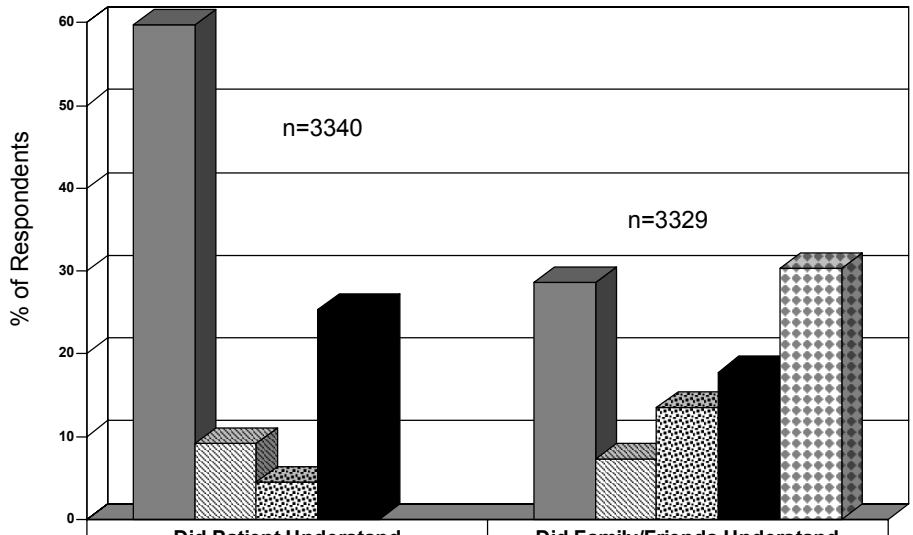
Patients were asked in the general part of the NPPSS if they received as much information as they wanted from their provider.

(N=3349) Did you get as much information about your device as you wanted from your provider?

RESPONSE	NUMBER	PERCENTAGE
Yes, completely	2623	78.3%
Yes, somewhat	555	16.6%
No	162	4.8%

The majority of patients were satisfied with the amount of information they received from their providers and less than 5% did not get enough information. Patients were then asked to respond if they were taught about their prosthetic device in a way they could understand and if someone taught their family/friends about how they could assist the patient with the device and in a way that the family/friends could understand. The results are shown in Figure 6.

Figure 6. Teaching Patient and Family/Friends in Way They Understand



	Did Patient Understand	Did Family/Friends Understand
Yes, Completely	59.7	28.6
Yes, somewhat	9.1	7.3
No	4.5	13.5
Teaching not needed because patient knew	25.3	17.8
No Family/Friends involved		30.3

Following are the results of the last two questions related specifically to teaching and education home based oxygen patients and their family and friends.

(n=3320) Did someone teach you how to care for your home oxygen device?

RESPONSE	NUMBER	PERCENTAGE
Yes, definitely	2693	83.6%
Yes, somewhat	359	11.1%
No	158	4.9%

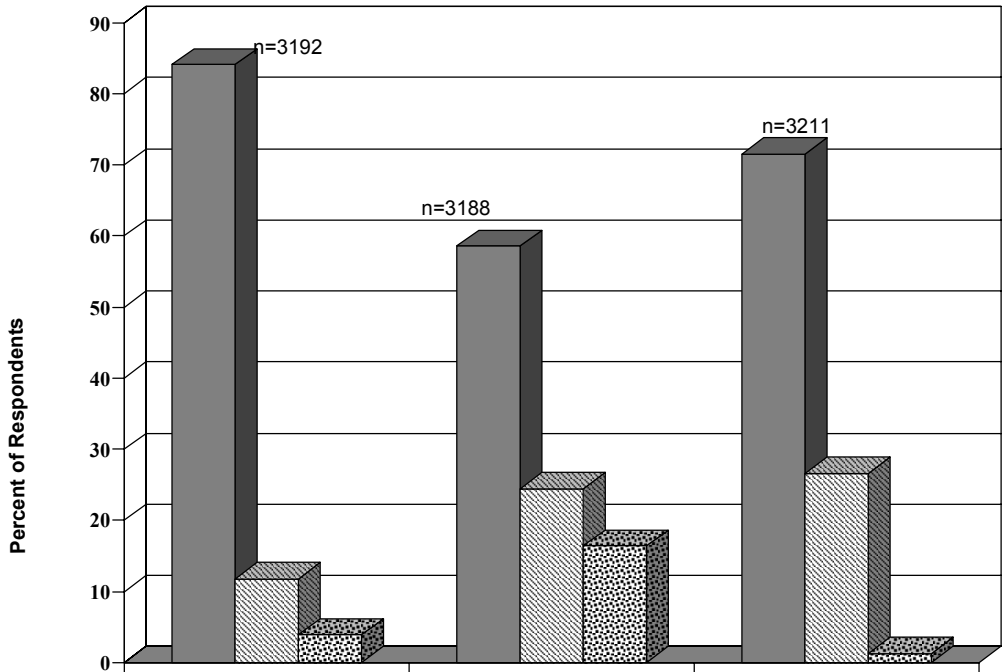
(n=3331) Was the provider willing to talk to your friends about your device-related care?

RESPONSE	NUMBER	PERCENTAGE
Yes	1982	59.5%
No	170	5.1%
No family/friends involved	1150	34.5%

Less than 5% responded negatively to the question regarding whether someone taught the patient to care for the home oxygen device. The negative responses to the second question could be interpreted as either the providers were unwilling to speak to family/friends or that the patient did not have family/friends involved in their care and answered no rather than responding with no family/friends involved.

Three questions related to home oxygen safety were added to the general NPPSS. Figure 7 shows the questions and responses.

Figure 7. Home Oxygen Safety Issues



	Shown how to store tanks in home	Electical outlets and capacity checked	No smoking signs posted in home
Yes	84.1	58.6	71.5
No	11.8	24.5	26.6
Not sure	3.9	16.4	1.3

The majority of patients reported that someone showed them how to safely store portable tanks in their homes, someone checked the electric capacity and outlets in their homes before the first set-up and that someone posted no smoking signs in their homes. Of concern is that a quarter of the patients reported that the electric capacity and outlets were not checked and "no smoking" signs were not posted and almost 12 percent of the patients responding to the survey were not shown how to safely store their oxygen tanks.

12A. What is the satisfaction rate with home health care services or products of patients who received home oxygen services?

This set of survey questions was added to the general NPPSS asking home oxygen users to evaluate their level of satisfaction with home visits and services specifically related to home based oxygen care.

The questions and the responses are below.

(n= 3271) Who comes to your home?

RESPONSE	NUMBER	PERCENTAGE
VA personnel	1148	30.8%
Oxygen company staff	123	3.3%
Both VA and oxygen company staff	97	3.0%
Not sure	1858	56%

More than half of the respondents did not know who was making home oxygen visits to their homes. Data implies that staff making home visits need to identify themselves and the organization they are affiliated with to the patient. The results also imply a need to improve patient instruction about asking for identification before allowing a person into their homes. However, 84.3% (2639/3132) of the survey respondents reported that the person who came to visit them during their most recent in-home visit was the person who usually comes to their home.

Of 3141 respondents, only 3.5% (111) of the respondents reported that their most recent in-home visit was a scheduled/routine visit while 87%(2746) reported that their most recent visit was not scheduled. This finding does not support the VA's view that vendors must schedule appointments with home based oxygen patients and conflicts with the information reported by VA staff during site visits and telephone interviews presented in our report on Home Oxygen Contracts.

In response to questions about wait times for an in-home visit, 75.3%(2328) of a total of 3158 respondents, reported not having to wait at all for the person/team to arrive after the visit was suppose to begin and 11.3% (357) had to wait 1-10 minutes after the scheduled time for the visit to begin. A total of 3041 respondents answered how long it was reasonable to wait for the person/team to arrive. Slightly over half of the respondents, 56.2% (1710) felt that no wait was reasonable and 7% (214) replied that 1-10 minutes was a reasonable wait.

The general NPPSS asked three overall satisfaction questions pertaining to the quality of the device, the visit and device-related care. The questions and answers are shown in Table 10. The answer category of satisfied is the combination of responses "excellent", "very good", and "good".

(n= 3518) Overall, how would you rate the quality of this device?

RESPONSE	NUMBER	PERCENTAGE
Satisfied	3259	92.6%
Fair or poor	224	6.4%

(n= 3321) Overall, how would you rate the quality of this visit?

RESPONSE	NUMBER	PERCENTAGE
Satisfied	3029	91.2%
Fair or poor	261	7.9%

(n=3407) Overall, how would you rate the quality of your device-related care during the past 12 months?

RESPONSE	NUMBER	PERCENTAGE
Satisfied	3051	89.5%
Fair or poor	330	9.7%

Home based oxygen specific questions were added to the general NPPSS regarding the overall quality of services specific to the home based oxygen program. Table 30 provides a summary of the responses with the questions defined below.

Q. 80: "Overall, how would you rate the courtesy of the VA personnel who supplied your home oxygen services?"
Q. 81: "Overall, how would you rate the courtesy of the oxygen company staff who supplies your home oxygen?"
Q. 83: "Overall, how would you rate the prosthetics service response to problems you may have had with your home oxygen care?"
Q. 84: "Overall, how would you rate the oxygen company's response to problems you have with your home oxygen care?"

Table 30. Satisfaction with Quality of Services

	SUMMARY — N (%)			
Response	***Q. 80***	***Q81***	***Q. 83***	***Q. 84***
Poor	55 (1.8%)	43 (1.4%)	97 (4.6%)	89 (2.6%)
Fair	105 (3.4%)	116 (3.7%)	159 (7.5%)	136 (4.1%)
Good	596 (19.0%)	541 (17.0%)	533 (25%)	427 (13%)
Very Good	1043 (33.3%)	1070 (33.7%)	645 (30%)	601 (18.3%)
Excellent	1303 (41.6%)	1393 (43.8%)	695 (32.6%)	797 (24.3%)
Had no problems				1231 (37.5%)
Subtotal*	3102	3163	2129	3281
Missing	631	570	1604	452
Total	**3733**	**3733**	**3733**	**3733**

**Total number who answered the question.*

From the information in Tables 10 and 11, the majority of respondents reported satisfaction with the quality of the device, the visit, the device-related care, courtesy of VA personnel and oxygen company staff. The satisfaction levels decreased to 67.2% ("excellent, "very good", and "good" totals combined)

when asked if satisfied with the oxygen company's response to problems the patient was having their home oxygen. Fifty percent ("excellent, "very good", and "good" totals combined) of the respondents reported satisfaction with Prosthetics Service's response to problems they have had with their home oxygen care. However, out of 3,185 respondents, 80.1% (2550) never reported to someone about problems they were having with their home oxygen services.

Another question related to complaints, "What are the areas of customer concern?" was asked in the general NPPSS. However we are unable to answer this question because the NPPSS database we received did not code the answers for this question.[5] The VA National Customer Service Feedback Center in Durham, NC, has analyzed the survey results for each question on the NPPSS.

NPPSS survey results indicate that home oxygen patients are generally satisfied with the home oxygen service they receive

In summary, the majority (89.5% and higher) of VA patients responding to the NPPSS reported satisfaction by choosing terms "good", "very good", or "excellent" when asked to evaluate the quality of devices, the quality of home visits, the quality of device-related care, the courtesy of the VA personnel, the courtesy of the oxygen company staff and oxygen's company response to patient issues with home oxygen care.

The series of questions addressing wait times surveyed veterans for the length of time they experienced waiting to be checked in for scheduled visit, to be seen by a provider after being checked in as well as the amount of time between the day an appointment was made to the actual appointment date. The veterans' satisfaction per se with their experiences of wait times was not evaluated.

Another series of questions specifically targeted to patients receiving home based oxygen services addressed home visits including wait times. The majority of respondents, 75.3% (2328 of 3158), reported no wait time and 11.3 % reported wait times between 1-10 minutes. When asked how long it was reasonable to wait for a scheduled home visit, 56.2% (1710 of 3041) felt that no wait was reasonable and 7% felt that 1-10 minutes was reasonable. There was not a specific question to measure satisfaction levels with wait times for home visits but we infer the majority of respondents are satisfied with the wait times they are experiencing after comparing the two questions related responses.

The rest of the questions from the NPPSS and the additional home-based oxygen services questions related to patient and family education and training do not specifically address satisfaction levels but rather address if the patient/family/friends understood what was being communicated, if they received as much information as they wanted from their provider, and if training and education were provided.

The Miami VAMC locally administers an internationally recognized patient satisfaction survey tailored for COPD patients

The Booz Allen team conducted site visits to seven VA medical centers across the country. During these site visits we noted that VAMCs have developed patient satisfaction surveys specifically for home oxygen patients. The Miami VAMC utilizes "The St. George's Respiratory Questionnaire" which has been lauded in literature as an effective tool to measure health status in COPD patients. The St. George's Respiratory Questionnaire is a disease-specific outcome measure developed in Great Britain, which can be used to assess health status, measure outcomes, and test the efficacy of preventive initiatives (25). It has been further tested to demonstrate that the American translation (revised to reflect American syntax and vocabulary) of the questionnaire maintains validity and reliability in its ability to measure outcomes in the American COPD population (26).

[5] *The question came from Q 59 of 1999 NPPS, which was an open-ended question.*

RECOMMENDATIONS

VA should collect information related to clinical outcomes and health status for their home oxygen patients

COPD is a major leading cause of death both within VHA and the country at large. It is considered a chronic illness that is currently irreversible. The primary treatment goal is to ameliorate symptoms. VHA expends significant amounts of money and resources for their COPD patients. VA should collect health status data on its home oxygen patients to measure clinical outcomes and effectiveness of pulmonary rehabilitation, pharmacological interventions, and preventive initiatives such as smoking cessation education.

We recommend that VA's PSAS Strategic Healthcare Group sponsor the adoption of an outcome measure tool to be utilized throughout VHA. Data should be collected annually from each VAMC, and reviewed by the Prosthetic Clinical Management work group focused on home oxygen. Data collected from this national effort will provide individual medical centers with information related to health status of their home oxygen patients, and will also provide VA with national data, which can be compared across the system and over time.

The Booz Allen team identified a leading practice in collecting health status outcomes for home oxygen patients. The Miami VAMC is currently utilizing the St. George's Respiratory Questionnaire to track health status of its home oxygen patients. The St. George's Respiratory Questionnaire has been shown in various studies to be an effective tool for outcome measurement in the COPD population. This tool has been shown to not only assess health status but also to measure effectiveness of pulmonary rehabilitation, pharmacological interventions, and preventive initiatives such as smoking cessation education (25). It has also been shown to predict hospitalizations, exacerbations, and has been specifically proven to be a better predictor of mortality than functional measures such as pulmonary function tests (25, 27).

Due to the size of its patient population and its database capacities, VA is in the privileged position to set national directions for the medical care of patient sub-groups through rigorous patient care research. By administering an outcome measure tool for home oxygen patients nationally, VA can collect valuable patient and disease-specific data that may facilitate advances in the clinical management of COPD.

The recommended set of performance measures to assess the Home Oxygen Program are outlined in Table 29, on the following pages. These performance measures will provide VA with program information on the functional status and quality of life of patients on home oxygen, customer service, and the efficiency and effectiveness of management/operations. An important aspect of performance measurement that VA should strive to achieve is the ability to track services and patients over time to determine how successfully pulmonary rehabilitation has controlled impairments.

Table 31. Recommended Performance Measures for the Home Oxygen Program

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Functional Status	***Quality of Life*** **Physical Functioning -** Scores from a health-related quality of life assessment tool Leading Practice Example: St George's Respiratory Questionnaire Measure three component scores: **Symptoms, Activity, Impacts** Symptoms component measures attacks of wheezing, coughing, and other clinical indicators Activity component measures time and ability to perform activities of daily life (e.g. washing, dressing, cooking) Impacts component measures disease influence on social life, exercise, weight gain, mobility, etc. ➢ SCORE = 100 x Summed weights from positive items in that component/Sum of weights for all items in that component One **total** score is also calculated. ➢ SCORE = 100 x Summed weights from positive items in the questionnaire/Sum of weights for all items in the questionnaire	Health-related quality of life assessment tool specific to respiratory diseases
	SF-36 scales recommended as general indicators of health: **physical functioning, general health, role limitations do to physical health problems** and **bodily pain**. ➢ Scales scored 0 to 100 with higher scores suggesting better health. Change in scores, either regular (discharge – intake) or standardized [(discharge – intake)/(standard deviation at intake)] can be calculated.	SF-36v – General health-related quality of life assessment tool
	Fatigue/Activity – ➢ Percent increase in distance during the 6-minute walk test (6-MWD) --- ➢ SF-36v construct for **energy/fatigue**	(6-MWD) captured via the Computerized Patient Record System --- SF-36v
	Mental Health – scores from the SF-36 or other scales to capture mental health. ➢ **Emotional well-being, role limitation due to personal or emotional problems**, and **social functioning**. Scales scored 0 to 100 with higher scores suggesting better health. Change scores, either regular (discharge – intake) or standardized [(discharge – intake)/(standard deviation at intake)] can be calculated.	SF-36v or other scale

PERFORMANCE MEASURE CATEGORY	PERFORMANCE MEASURE/METRIC	DATA SOURCE
Customer Service	***Access*** ➢ Percent of home oxygen patients within travel time and distance requirement --- ➢ Average wait time for home oxygen patients to see a provider after check in ➢ Average wait time for home oxygen patients to obtain an appointment ➢ Percent of home oxygen patients satisfied with the ease of making appointment ➢ Average wait time (in days) for home oxygen patient to get an appointment	Zip Code File matched with home oxygen patients from PTF/OPC or Patient Satisfaction Survey --- Patient Satisfaction Survey
	Education ➢ Percent of patients receiving education and training on prescribed medical equipment ➢ Percent of patients (that are smokers) provided education on smoking cessation ➢ Percent of time patients receive understandable instructions for prescribed medical equipment	Patient Satisfaction Survey and/or Chart Review
	Effectiveness of smoking cessation education ➢ Percent of patients (that are smokers and were provided smoking cessation education) who quit smoking	Chart Review or captured via electronic medical record
	Customer Satisfaction ➢ Percent of patients satisfied with care received at a VA Medical Center or clinic	Patient Satisfaction Survey
	➢ Percent of patients satisfied with care provided by home oxygen vendor (satisfaction rates should also be analyzed by vendor)	
	➢ Percent of patients satisfied with medical equipment	
	➢ Percent of patients receiving medical/home oxygen equipment at the time they expected it to be delivered	
Operational	***Management*** ➢ Rates of hospitalization	NPPD/PTF or Chart Review
	➢ Number of home oxygen therapy prescriptions per patient	PTF
	➢ Number of pulmonary related drugs per patient	VISTA Pharmacy Module
	➢ Number of complaints received from patients categorized by Home Oxygen vendor	Captured by PSAS staff and tracked by VISN Prosthetics Representative
	➢ Average cost of home oxygen services per patient (medical center/VISN/total)	NPPD

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APPENDIX A – DESCRIPTION OF DATABASES USED IN THIS STUDY

Patient Treatment File (PTF) and Outpatient Care File (OPC)

Both files collect nationwide data and are housed in the Austin Automation Center (AAC). The PTF collects discharge data about each inpatient episode of care. It contains demographics, ICD-9 discharge diagnoses, up to 32 ICD-9 procedures for each episode of care including dates of the procedure, and up to five surgical procedures. The corresponding outpatient file collects data on each outpatient visit, but diagnoses have been collected for only the last few years. Its validity has not been studied as widely as that of the PTF. The companion Beneficiary Identification and Records Locator Subsystem (BIRLS) is an administrative database, frequently used to track patient mortality, as it does not require locating veterans through receipt of medical care.

External Peer Review Program (EPRP)

This program uses an outside contractor to measure quality of care processes and outcomes in VA patients through chart reviews in every VA medical facility. The mechanism compares VA care to an external set of criteria drawn from a clinical guideline written by non-VA physicians.

Functional Independence Measure (FIM)

This disability assessment tool is considered the industry standard. It is a basic indicator of the severity of disability and uses an 18-item scale that addresses seven levels of function.

Functional Status and Outcomes Database for Rehabilitation (FSOD)

This database was established in 1997 through a cooperative agreement between the Office of Physical Medicine and Rehabilitation, the Uniform Data System for Medical Rehabilitation (UDSmr), and the Austin Automation Center. It tracks outcomes through the full continuum of rehabilitative care.

National Prosthetic Patient Database

This is a nationwide database that tracks prosthetics-provided equipment and supplies and repairs, and can provide summaries of volume and costs.

Veterans SF36 (Short Form Functional Status Assessment for Veterans)

Adapted from the Medical Outcomes Study (MOS) SF-36, this is a primary measure of health-related quality of life. It measures eight concepts of health: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, energy/vitality, social functioning, role limitations due to emotional problems, and mental health.

Uniform Data System for Medical Rehabilitation (UDSmr)

The UDSmr is the largest national registry of standardized information on medical rehabilitation inpatients in the U.S.

Chronic Disease Care Indicator/Prevention Indicator (CDCI/PI)

This ongoing study is part of EPRP and collects data from chart reviews, focusing on chronic disease and prevention indicators. Patients identified are followed through inpatient and outpatient care. Diabetic patients are specifically identified and followed.

National Prosthetic Patient Survey

This survey, administered by the National Performance Feedback Center, attempts to determine the satisfaction levels of prosthetic patients.

APPENDIX B—ANALYSIS METRICS

PATIENTS DISCHARGED HOME AFTER ABOVE KNEE AMPUTATION

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Referrals for placement, DME and appliance made by a qualified person	8aA. What VISN/VAMC guidelines exist regarding the qualifications of individuals making referrals for VA patients? **Site visits**	Each VISN/VAMC is unique. Overall, the physician coordinates with various disciplines to refer/prescribe the above knee prostheses. Many VAMCs utilize a multidisciplinary team or committee to make the decision.
Necessary equipment for ADL provided at discharge	8aB. What ADL equipment was provided at discharge? **NPPD**	**N=4801 (total NPPD equipment records) for 294 patients** 536 home safety items, e.g., grab bar, shower chairs, commodes 247 manual wheel chairs 241 walking aids (walkers, crutches) 428 medical equipment (incl. ADL items such as reachers, dressing aids) 810 “other” or “non-specified” items (incl. ADL equipment)
Patient and family education, Training in prosthetic device	8aC. Was education provided to VA patient? 8aD. Was education provided to VA patient's family? **National Prosthetic Patient Satisfaction Survey**	**N=101** 81 (80.2%) said that they always get answers they understand **N=102** 43 (42.2%) said someone taught them how use the prosthetic device in a way that they completely understand 72 (70.6%) get as much information about their device as they wanted from provider 33 (32.4%) said the provider is willing to talk to your friends or family about device-related care 14 (13.7%) said someone taught family or friends how to help them use prosthetic device in a way that they could completely understand (70 (68.6% responded that either no teaching was needed or no family involvement)
	8aE. What percentage of VA patients received home assessment?	No VA databases were identified that captured this information.
Patient functionality scores before and after treatment	8bA. What are the patient functionality scores before and after treatment, when age and risk adjusted? **FIM**	Table 3. Functional Status of AK Amputation Patients Undergoing Rehabilitation Table 4. Mean Discharge Motor FIM* After Adjusting for Admission Motor FIM (n=295) Table 5. Gain in Motor Function by Age (N=295) *In order to compare score, please use the

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
		Rasch-transformed motor measures in Table 3, (page 7) last 3 rows.
Ability to perform ADL	8bB. How do VA patients with above knee amputations rate their quality of life? **SF-36v**	Table 9. Functional Health Status Statistics for all VA Patients with AK Amputations VA patients report low functional capacity in all eight SF-36 scales; more dysfunction in the physical constructs compared to the mental constructs. Quality of life in the AK VA sample is also reported as low. QOL is better assessed using constructs of vitality, role emotional, mental health, social functioning and bodily pain because the constructs of physical functioning and role physical are dramatically lower than other constructs.
Participation in life situations	8bC. How do VA patients with above knee amputations rate their ability to participate in life situations? **SF-36v**	Table 9. Functional Health Status Statistics for all VA Patients with AK Amputations VA patients report low functional capacity in all eight SF-36 scales; more dysfunction in the physical constructs compared to the mental constructs. This implies low ability to participate in life situations with dramatically lower functioning in the physical functioning and role physical constructs.
Access to care	8bD. What are the wait times that VA patients with above knee amputations experience for clinic appointments? 8bE. How long do patients with amputations wait to see a provider? **National Prosthetic Patient Survey**	**N=76** 48 (63%) had to wait 0-14 days from the day scheduled until they were seen **N=71** 68 (68%) had to wait 0-15 minutes to check in **N=101** 47 (47%) had to wait 0-10 minutes to be seen by provider after check in
	8bF. How far do VA patients with above knee amputations travel to clinic appointments? **Zip Code File**	According to Time and Distance Study, 5,926 patients with above knee amputations travel an average of 14.189 miles to a primary care clinic.

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Patient responses to inpatient and outpatient satisfaction surveys, in areas of Access, etc.	12A/C What is the satisfaction rate with home health services or products of AK amputation patients? **National Prosthetic Patient Survey**	**N=104** 85 (82%) would rate the quality of device used as excellent, very good, good **N=101** 90 (89%) would rate the quality of the visit as excellent, very good, good **N=96** 32 (33%) would rate the quality of the device-related care during the last 12 months as excellent
	12B. What are the areas of customer concern?	We are unable to answer this question because the NPPS database we received did not code the open-ended answer for this question

PATIENTS DISCHARGED HOME WITH MOTORIZED WHEELCHAIRS

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Referrals for placement, DME and appliance made by a qualified person	8aA. What VISN/VAMC guidelines exist regarding the qualifications of individuals making referrals for VA patients? **Site visits**	Each VISN/VAMC is unique. Overall, the physician coordinates with therapy to then prescribe the motorized wheelchair. Some VAMCs utilize a wheelchair committee to make the decision.
Necessary equipment for ADL provided at discharge	8aB. What ADL equipment was provided at discharge? **NPPD**	**N= 9967 (total NPPD equipment records) for 456 patients** 864 home safety items, e.g., grab bar, shower chairs, commodes 339 motorized wheel chairs 315 manual wheel chairs 330 walking aids (walkers, crutches) 989 medical equipment (incl. ADL items such as reachers, dressing aids) 1054 “other” or non-specified items (incl. ADL equipment)

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Patient and family education, Training in wheelchair safety	8aC. Was education provided to VA patient? 8aD. Was education provided to VA patient's family? **National Prosthetic Patient Survey**	**N=2817** 1991 (71%) said that they get answers they completely understand **N=2784** 1551 (56%) said someone taught them how use device in a way that they completely understand N=2793 2049 (73%) get as much information about their device as they wanted from provider and completely satisfied with it. **N=2781** 1661 (60%) said the provider is willing to talk to your friends or family about device-related care **N=2787** 917 (33%) said someone taught family or friends how to help them use equipment/device in a way that they could completely understand (1,252 (44.9%) reported that no teaching was needed or there was no family involvement)
	8aE. What percentage of VA patients received home assessment?	We do not have data from FSOD or NPPS to address this question.
Patient functionality scores before and after treatment	8bA. What are the patient functionality scores before and after treatment. **FIM**	Age and risk adjustment is not relevant for this population. Rather, impairment and pre-hospitalization function are. Table 13. Functional Status of Motorized Wheelchair Users Before and After Rehabilitation* Table 14. Descriptive Statistics of Discharge FIM, Total FIM Gain and Motor FIM Gain (by Impairment) Among Motorized Wheelchair Users
Ability to perform ADL	8bB. How do VA patients with motorized wheelchairs rate their quality of life? **SF-36v**	Table 16. Parameters of Physical and Mental Constructs
Participation in life situations	8bC. How do VA patients with motorized wheelchairs rate their ability to participate in life situations? **SF-36v**	Table 18. Associations Between SF-36 Scales and General Health for SF-36 Scales

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Access to care	8bD. What are the wait times that VA patients with motorized wheelchairs experience for clinic appointments? 8bE. How long do patients with motorized wheelchairs wait to see a provider? **National Prosthetic Patient Satisfaction Survey**	**N=1738** 1006 (58%) had to wait 0-14 days from the day scheduled until they were seen **N=2719** 2168 (80%) had to wait 0-15 minutes to check in **N=2717** 1328 (49%) had to wait 0-10 minutes to be seen by provider after check in
	8bF. How far do VA patients with motorized wheelchairs travel to clinic appointments? **Zip Code File**	According to Time and Distance Study, 4175 patients with above knee amputations travel an average of 15.055 miles to primary care clinic.
Patient responses to inpatient and outpatient satisfaction surveys, in areas of Access, etc.	12A/C What is the satisfaction rate with home health services or products of patients who receive motorized wheelchairs? **National Prosthetic Patient Satisfaction Survey**	**N=2979** 2704 (91%) would rate the quality of device used as excellent, very good, good **N=2789** 2468 (89%) would rate the quality of the visit as excellent, very good, good **N=2739** 946 (35%) would rate the quality of the device-related care during the last 12 months as excellent
	12B What are the areas of customer concern?	We are unable to answer this question because the NPPS database we received did not code the open-ended answer for this question

PATIENTS DISCHARGED HOME WITH HOME OXYGEN

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Referrals for placement, DME and appliance made by a qualified person	8aA. What VISN/VAMC guidelines exist regarding the qualifications of individuals making referrals for VA patients? **VHA Directive 1173.13** **Site Visits – 7 VAMCs**	VHA Handbook 1173.13, (11/ 1/00) entitled "Home Respiratory Program" refers to a prescribing "clinician" and does not define the qualifications of this professional. VAMCs across the country have developed guidelines relating to varying levels of prescriptive authority, from Nurse Practitioners to Primary Physicians to Pulmonologists.

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
Necessary equipment for ADL provided at discharge	8aB. What ADL equipment was provided at discharge? **NPPD, PTF**	Insufficient level of specificity in NPPD data to determine whether patient receiving delivery of equipment was newly prescribed oxygen. No data existed in other databases to pinpoint when patient was first started on home oxygen. This is necessary to effectively measure waiting time between discharge and delivery of equipment.
Patient and family education, Training in wheelchair safety, crutch safety, ambulation	8aC. Was education provided to VA patient? **NPPSS** **EPRP**	Veterans receive education on use, maintenance and safety of home oxygen equipment. Veterans also receive varying levels of counseling on tobacco cessation in clinics.
	8aD. Was education provided to VA patient's family? **NPPSS**	According to the responses to the National Prosthetic Patient Satisfaction Survey, family and friends of veterans receive education on home oxygen equipment if they are involved in the veteran's care.
	8aE. What percentage of VA patients received home assessments?	N/A – metric removed from study.
Patient functionality scores before and after treatment	8bA. What are the patient functionality scores before and after treatment, when age and risk adjusted?	N/A to home oxygen population, due to lack of data (no functional measurements collected for this patient population)
Ability to perform ADL	8bB. How do VA patients with home oxygen rate their quality of life? **SF-36v**	Veterans report a lower quality of life, as evidenced by our data analysis of SF-36 survey results, than the general population. However, this comparison does not take into consideration other significant variables, such as marked differences in health status, socio-economic factors and other applicable demographics between the two groups. Table 27. Physical Constructs Table 28. Mental Constructs
Participation in life situations	8bC. How do VA patients who receive home oxygen rate their ability to participate in life situations?	N/A to home oxygen population, due to lack of data specific to this group.
Access to care	8bD. What are the wait times that VA patients with home oxygen experience for clinic appointments? **NPPSS**	The majority of patients in our study population is seen within a month of calling for an appointment, and wait less than 20 minutes to check in or be seen on the day of the appointment.

PERFORMANCE MEASURE	ANALYSIS METRIC/ DATABASE(S) UTILIZED	RESULTS
	8bE. How long do patients with home oxygen wait to see a provider? **NPPSS**	The majority of patients in our study population is seen within a month of calling for an appointment, and wait less than 20 minutes to check in or be seen on the day of the appointment.
	8bF. How far do VA patients with home oxygen travel to clinic appointments? **Zip Code File**	The patients within the home oxygen subset (n=7,713) travel an average of 13.658 miles to a primary care clinic.
Patient responses to inpatient and outpatient satisfaction surveys, in areas of Access, etc.	12A. What is the satisfaction rate with home health services or products of patients who receives home oxygen services? **NPPSS**	The majority of VA patients in our study population reported satisfaction by choosing terms "good", "very good", or "excellent" when asked to evaluate the quality of devices, the quality of home visits, the quality of device-related care, the courtesy of the VA personnel, the courtesy of the oxygen company staff and oxygen's company response to patient issues with home oxygen care.
	12B What are the areas of customer concern?	Unable to answer due to insufficient data.

APPENDIX C – LISTING OF LIMITATIONS

- Data fields changed over time within and across data sets, making longitudinal assessments difficult, complicating understanding of operational definitions of specific variables by VA personnel and researchers, and complicating computer programming for statistical analyses. Examples include
  - EPRP: variables had changed names and coding schemes in different quarter files,
  - marital status is called “MS” in PTF, and “marital” in FSOD, and
  - in NPPSS, missing data were coded “9” and “missing”.
- Data were frequently incomplete, which reduced possible or anticipated analyses and also increased the potential for selection bias. Example: missing values for “risky foot” variables in EPRP.
- Groups of patients for comparisons to VA samples were difficult to identify, had different demographic variables within non-VA samples and within VA samples, received treatments that could not be identified, and received treatments for which the timing could not be verified. All of these factors made age- or risk-adjustments statistically awkward and theoretically improbable/impossible.
- Samples of patients from VA data sets were small compared to the possible number of patients with appropriate diagnoses (i.e. diabetes or peripheral vascular disease), or conditions (i.e. above knee amputations), that could have been assessed with the appropriate outcomes measurement tools (i.e. FIM or SF-36), which increases the risk of sampling bias.
- Quantification of timing for outcome survey completion (i.e. SF-36, or NPPS) in relation to dates of pertinent events (e.g., surgery or rehabilitation), was not possible in the non-VA and VA samples, because the exact date of survey completion was not recorded (SF-36v, NPPS), and exact dates of the rehabilitation episode and FIM assessment dates were not released (UDSmr FIM). Although the dates of pertinent events were recorded in VA PTF or FSOD databases, multiple records existed, and often the periods of rehabilitation (FSOD) and surgery (PTF) overlapped without clear pattern(s) or sequences. Without dates of survey completion from SF-36 or NPPSS, it was difficult to select pertinent inpatient stay episodes.
- Because of right of privacy and confidentiality constraints, pertinent patient-identifying data were not available, such as, “date of birth”, which made age calculation impossible. This is particularly problematic with patients who had multiple hospitalization episodes. For these patients we could only extract age data from one PTF unduplicated file.
- Because similar demographic variables were not found in both VA data sets and comparison groups, analyses could not be age- or risk-adjusted consistently.
- Algorithms that the VA uses to calculate the role physical (RP) and role emotional (RE) scales do not follow published algorithms, which may erode validity of external comparisons.
- There were no data to indicate compliance with various treatments/interventions (i.e. use of oxygen therapy at home, use of motorized wheelchairs, actual performance in rehabilitation for patients with lower extremity amputations), which erodes interpretation of change in functionality and health-related quality of life data.
- Several questions were designed to assess quality of life, functional abilities and participation in life situations. However, direct measures of these functions are not available. The validity of the use of SF-36 scale measures to estimate quality of life needs to be assessed.

- It is common to use the FIM to measure functional abilities and the SF-36 to measure health-related quality of life. Many researchers consider both estimates of functional abilities, one from the clinician's perspective (i.e. the FIM), and one from the patient's perspective (i.e. the SF-36). However, distinct differences exist between the strengths and weaknesses of each measure, which complicates comparisons of findings using the FIM and SF-36.
- Due to different reimbursement structures in the VA and non-VA systems, the way clinicians use the FIM to rate patients' functional status may vary within the two samples, which complicates comparisons.
- Although patients receive "rehabilitation," no details can be obtained from FSOD or UDSmr with regards to the content of rehabilitation. The type or time units of rehabilitation services were unknown.
- With duplicated records in most of the datasets and limited common variables, records can be lost when files are merged, which influences patient selection bias.
- There is concern for data "cleanliness". It is our impression that many types of professionals entered data. There was no indication that the professionals were systematically and consistently trained in data entry, which might erode reliability of electronic data.
- Once data were entered in a database, the data were not systematically cleaned or recoded, which might erode reliability of the electronic data.
- Working with multiple data sets requires aggregation, merging and matching. Most patients have multiple records in each data set. In order to answer questions appropriately, we have to "unduplicate" records, so there is one record per patient. The number of patients with pertinent data is dependent on the sorting process and sequence or combinations of each, which is a question of judgment. Therefore, different results may be possible for any question.
- Often patients received multiple pieces of equipment or items on the same day or on sequential days. Examples are patients receiving home oxygen (oxygen concentrator, oxygen tubing and masks) or artificial limbs (several components). Unless we look at each patient separately, we are unable to know whether such duplications are clinically justified or duplicated for billing purposes, which may reduce validity of findings.
- Questions concerning appropriateness or necessity of ADL equipment (i.e. for patients with lower extremity amputations), before discharge are difficult to answer. One analysis metric, the amount of time between patient discharge and patient receipt of equipment, influences the "appropriateness" of the ADL item. Choice of the date of delivery compared to the time or time period in rehabilitation or medical treatment is a matter of judgment. Each choice dramatically affects the number of patients selected.