NURSING HOME

Quality Improvement Task Force Report

SEPTEMBER 22, 2016

PENNSYLVANIA DEPARTMENT OF HEALTH

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pennsylvania
DEPARTMENT OF HEALTH

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EXECUTIVE SUMMARY

More than 80,000 Pennsylvanians reside in more than 700 nursing homes throughout the Commonwealth of Pennsylvania. The departments of Health, Aging and Human Services all have important roles in monitoring nursing home quality in Pennsylvania:

- The Department of Health (DOH) is responsible for the licensing and oversight of nursing homes in the commonwealth. It conducts annual surveys in all nursing homes and handles complaint inspections.
- The Department of Aging operates the Long-Term Care Ombudsman Program (LTCOP), which is designed to support and empower nursing home residents and their families.
- Finally, the Department of Human Services, through the Office of Long-Term Living, offers support and services to aging or disabled residents of the commonwealth.

These roles are regulated through a number of laws, regulations and policies at both the state and federal level. Pennsylvania's nursing care facility licensure regulations were last revised in 1999. Since then, the reason for admissions to nursing home facilities and the clinical complexity of residents has changed. Therefore, the regulations need to evolve to meet the current needs of nursing home residents. These revisions should promote respect for residents' individual values and preferences, while ensuring that safety and quality of care are maintained.

While most of Pennsylvania's nursing homes provide excellent care, concerns have been raised about the variations that exist in the quality of care throughout select facilities. The quality of life for nursing home residents is especially important, with particular focus in the areas of autonomy and sense of self for residents.

Because the quality of care and safety of nursing home residents is a top priority of the Wolf Administration and the Department of Health, the Nursing Home Quality Improvement Task Force (Task Force) was formed in 2015 to offer recommendations on enhancing this mission.

The Task Force identified the following key takeaways:

- Achieving the highest level of quality of care, quality of life and person-centeredness of care requires effective collaboration between and among government agencies and policy makers, long-term care providers, health care professionals and consumers of long-term care.
- Valid indicators that measure quality of care, quality of life and person-centeredness of care are critical elements for assessing success of improvements.
- New directions in policy must support best practices in long-term care, while assuring quality of care and safety for nursing home residents.
- The composition and competencies of the workforce responsible at all levels for care and services in nursing homes are critical determinants of the quality of care and the living environment offered to nursing home residents.

This report addresses both formal revisions to the state licensure regulations and internal policy shifts within the DOH. The recommendations presented herein were developed during a series of Task Force meetings over the course of eight months and reflect the combined expertise and opinions of its members. As part of this process, the Task Force gathered information and data from key stakeholders, including scientific experts, industry representatives, nursing home administrators and, most importantly, the residents themselves.

INTRODUCTION

In August 2015, Pennsylvania Secretary of Health Dr. Karen Murphy commissioned the Nursing Home Quality Improvement Task Force with the goal of reviewing the current state licensure regulations and making recommendations to improve the safety, quality of care and quality of life in nursing home facilities across the state.

The formation of the Task Force was driven by several factors.

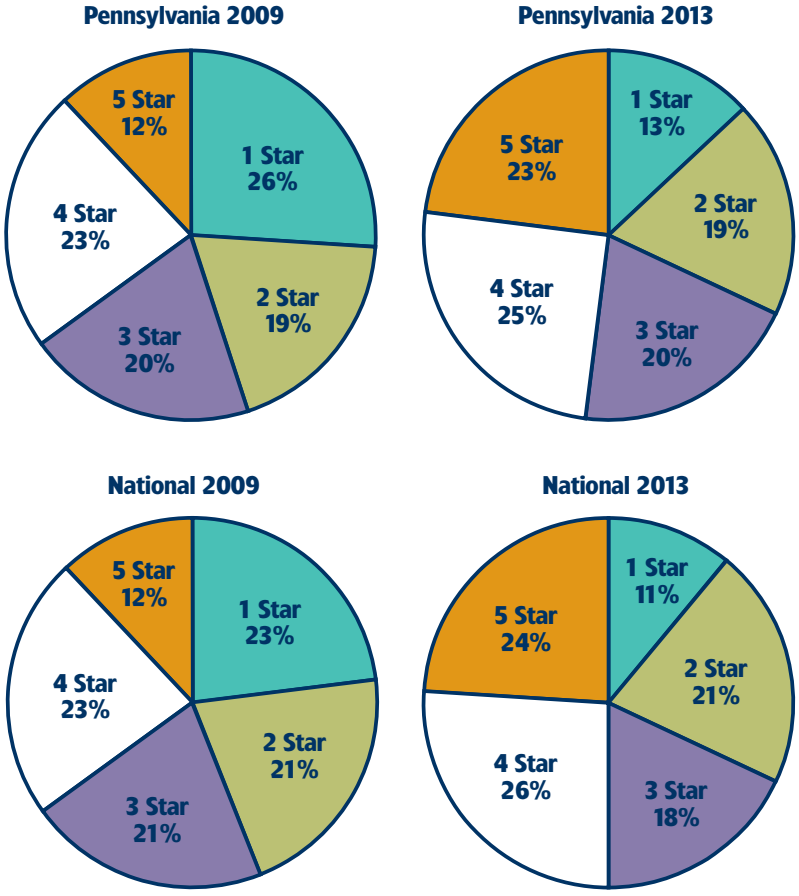
First, the current state licensure regulations have not been updated since 1999. In the 16 years between the last revision and the creation of the Task Force, the clinical complexity of nursing home residents has changed dramatically.

Due to increased availability of home- and community-based care, some individuals formerly needing to receive care in nursing homes now have access to care in other settings. As a result, the nursing home resident population now has a greater proportion of individuals with chronic conditions, complex care needs and greater dependency on caregivers to meet these needs. For example, the proportion of nursing home residents nationally with severe cognitive impairment has increased from 15 percent in 1999 to 37 percent in 2014.[1,2] Prevalence of severe cognitive impairment in Pennsylvania nursing home residents was 36 percent in 2014.[1]

In addition, there has been a shift towards greater use of nursing homes for short-stay rehabilitation. Closure of many psychiatric residential hospitals has also led to an increase in the population of residents who have severe psychiatric diagnoses living in traditional nursing homes.

Second, as of 2013, Pennsylvania ranked slightly below the national average on the Centers for Medicare and Medicaid Services (CMS) Five-Star Quality Rating System[3] for nursing homes, which is based on performance measures in health inspection, staffing and quality.

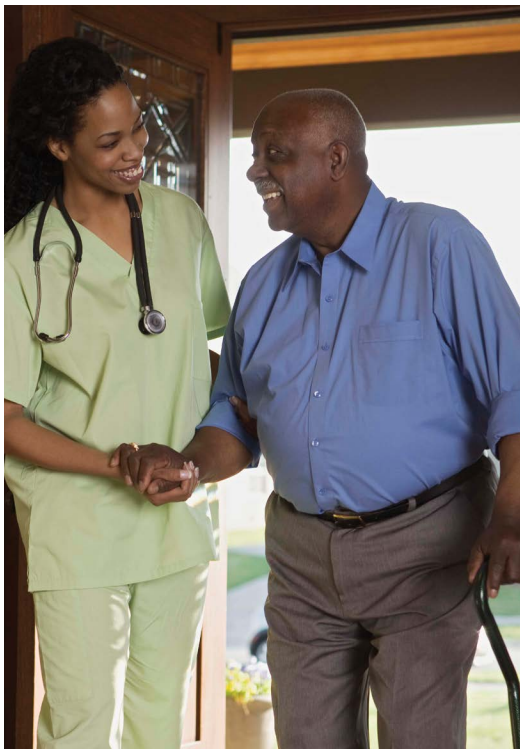
Figure 1. Percentage of national and Pennsylvania nursing homes by the Centers for Medicare and Medicaid Star Ratings in 2009 and 2013[3]



In 2013, 10.5 percent of nursing homes nationally received a 1-star rating in overall quality, whereas 13.2 percent of Pennsylvania nursing homes did (Figure 1).[3] However, Pennsylvania's ratings improved from previous years, with the percentage of 1-star homes falling from 25.8 percent in 2009 to 13.2 percent in 2013.

Additionally, the percentage of 5-star homes in Pennsylvania increased from 11.5

INTRODUCTION

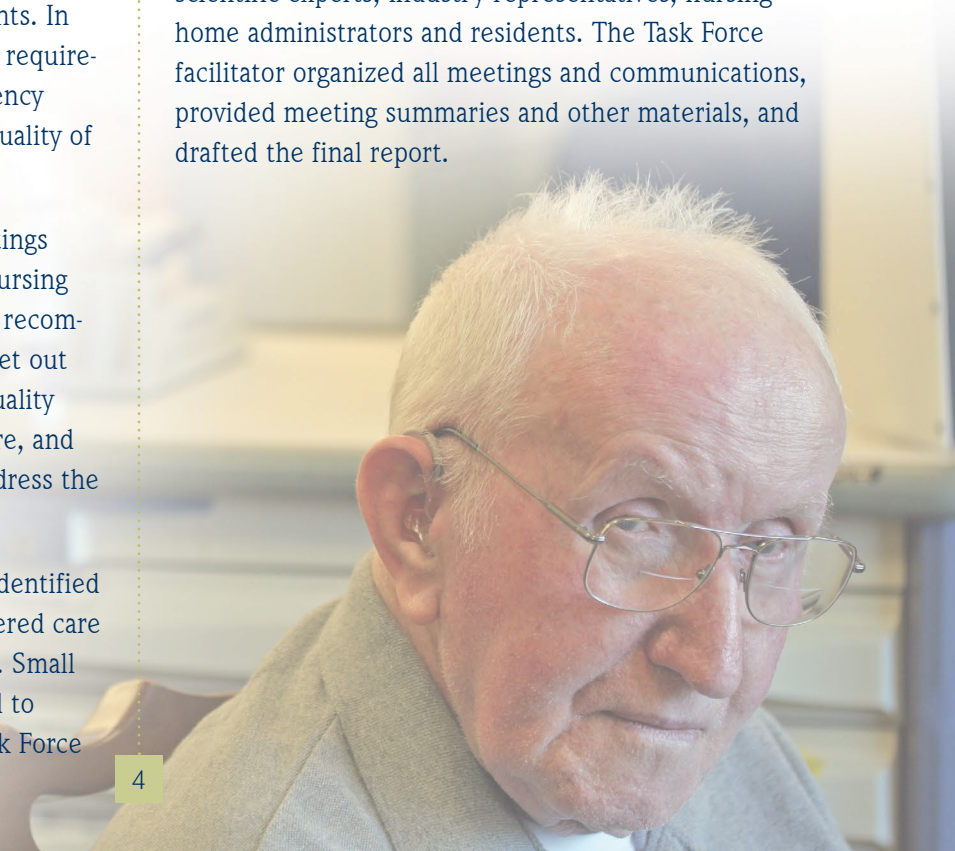


percent in 2009 to 22.9 percent in 2013, paralleling the national trend (Figure 1).[3]

Finally, proposed revisions to federal regulations for participation in Medicare and Medicaid programs emphasize person-centered care and resident rights. In addition, the new federal regulations increase requirements for care plans and ensure staff competency levels and training with the goal of ensuring quality of care for nursing home residents.

Task Force members convened for seven meetings from October 2015 to May 2016 to discuss nursing home care in Pennsylvania and to develop the recommendations reported herein. The Task Force set out to assess the current state of nursing home quality in Pennsylvania, define ideal nursing home care, and provide recommendations that would help address the gap between current and optimal practices.

A conceptual framework was developed that identified quality of care, quality of life and person-centered care as the foundations of ideal nursing home care. Small work groups of Task Force members convened to specifically define these domains. The full Task Force then met to review definitions, identify any overlap in state assessment of these domains in nursing home care, and develop recommendations. Throughout, the Task Force consulted with key stakeholders, including scientific experts, industry representatives, nursing home administrators and residents. The Task Force facilitator organized all meetings and communications, provided meeting summaries and other materials, and drafted the final report.



CURRENT STATE OF NURSING HOME CARE IN PENNSYLVANIA

Demographics

In 2014, more than 80,000 Pennsylvanians resided in nursing homes. Of these residents, 88 percent were over the age of 65, and 9.2 percent were over the age of 95.[1] The majority of the Pennsylvania nursing home population (68 percent) was female, and racial or ethnic minorities constituted 12.5 percent of the population.[1]

Due to the elderly demographics of the majority population, residents in Pennsylvania nursing homes typically have high levels of dependence and impairment. In 2014, 36 percent had severe cognitive impairment, 69 percent needed assistance with at least four activities of daily living, and 31 percent were incontinent.[1]

Of all billed nursing home days in 2014, the majority were paid through Medicaid (66 percent) and Medicare (13 percent). The remainder were covered by self-pay (15 percent), private insurance (4 percent), Veterans Affairs (1 percent), and other sources (1 percent).[4]

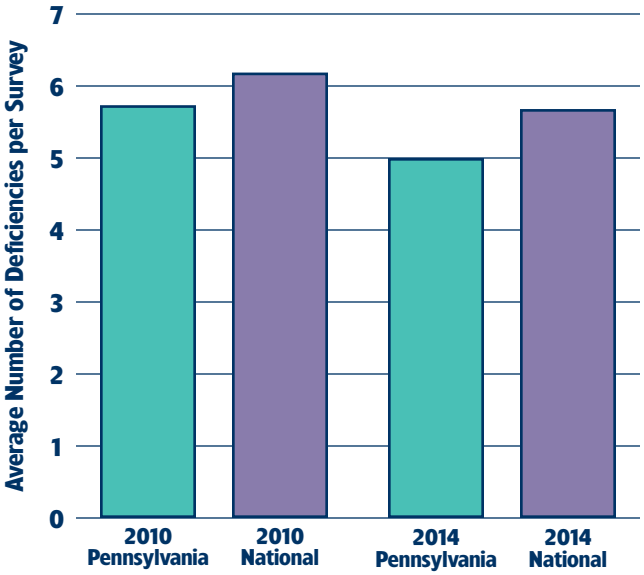
In 2014, 701 nursing home facilities were in operation in Pennsylvania, with one-third located in the commonwealth's 48 rural counties and the remainder in the 19 urban counties.

Current Evaluation Methods

Health inspections of all nursing homes are conducted annually by the nine DOH field offices to ensure that CMS certification and state licensure standards are met. These inspections cover issues such as development of comprehensive care plans, presence of an infection control program, sanitary storage and handling of food, and use of appropriate drug regimens. During these inspections, assessments are made of facility compliance with 180 federal regulatory standards as mandated by the CMS, and deficiencies are reported from these assessments.

Deficiency results reveal that Pennsylvania nursing homes are operating just better than the national average (Figure 2):

Figure 2. Average number of deficiencies per survey at nursing homes in Pennsylvania and nationally in 2010 and 2014[1]

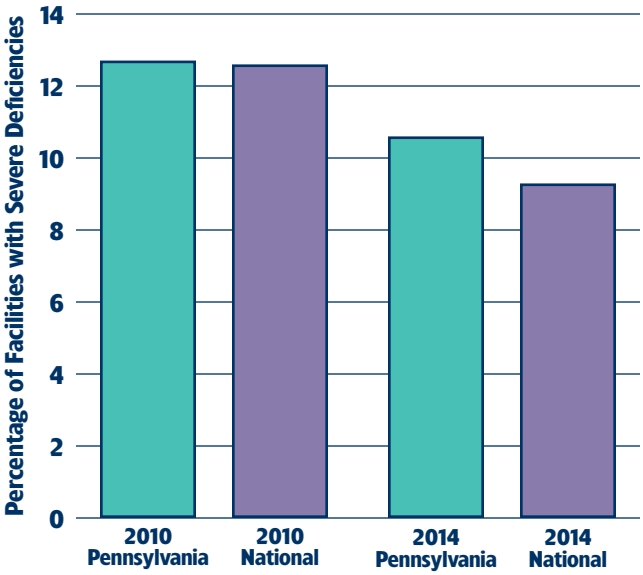


- An average of 5.0 deficiencies per survey were reported in Pennsylvania facilities in 2014, compared to 5.7 deficiencies per survey nationally.[1]
- Surveys at 88.5 percent of Pennsylvania facilities resulted in cited deficiencies in 2014, compared to 89.8 percent nationally.[1]
- In 2014, 9.2 percent of surveys in Pennsylvania identified a severe health deficiency for residents, compared to 10.6 percent nationally (Figure 3).

In recent years, the state has remained relatively stable in the number of deficiencies reported per survey but has improved in the percentage of facilities at which severe deficiencies are reported. In 2010, there were an average of 4.7 deficiencies per survey, and 12.7 percent of surveys resulted in a severe health deficiency for residents in Pennsylvania.[1]

While Pennsylvania is operating close to the national average, there is still opportunity for improvement.

Figure 3. Percentage of nursing home surveys where severe deficiencies were reported in Pennsylvania and nationally in 2010 and 2014[1]



Composite measures such as number of deficiencies are useful and provide a summary that can be easily communicated to the public. Number of deficiencies is a particularly useful measure because it addresses many important domains of safety and care. Deficiencies, along with resident outcome quality measures and staffing ratios, contribute to the widely used Nursing Home Compare Five-Star Quality Rating System.[12] Additionally, since the data is collected under federal regulations, it is publicly available.

The Task Force has identified several issues with the current survey system.

1. While survey ratings have utility, these deficiency reports only capture whether minimum federal standards are being met and do not include facility compliance with state licensure standards nor whether facilities are operating at the highest possible level to ensure the best quality of life for their residents.

   Additionally, research has shown that they do not always align with resident satisfaction with a nursing home.[13] As noted earlier, residents report that daily living concerns are extremely important, but these variables are not captured by measures such as deficiencies or the Five-Star Ratings.

2. There are further concerns with using data from deficiencies detected on inspections, as the survey process can vary by region within the state. While surveys are unannounced, facility administrators note that the timing is predictable and surveys can be anticipated. For that reason, conditions presented during annual inspections may not reflect typical facility conditions throughout the year.

   Additionally, despite regular evaluations to ensure accuracy, reliability and consistency of survey results, some inconsistencies in survey standards across the various field offices have been noted.

3. Third, under state and federal rules, all facilities are subject to annual surveys regardless of past performance. Although current processes typically result in more departmental oversight of facilities that are under-performing, there are currently

no provisions to limit survey time in consistently high-performing facilities to free up additional time to attend to poorer-performing facilities.

4. There has been a growing reliance on nursing homes for short-term, post-acute care, which has not been reflected in the regulations or in the survey process. Many of the needs and quality of life concerns of short- and long-term residents are quite different. As a result, the existing survey process is not specific enough to differentiate and capture the needs of these residents.

Data Resources in Measuring Quality of Care (QOC), Quality of Living (QOL), and Person-Centered Care (PCC)

There are several goals related to measuring quality of care (QOC), quality of life (QOL) and person-centered care (PCC) indicators in nursing homes.

1. Regulations surrounding collected data elements should be updated, as the results of collection determine compliance with current federal and state regulations. As such, any changes in state regulations will likely require updates to the information collected for measurement purposes by state agencies.

2. Measurement of quality indicators allows pertinent information to be available to the public, informing consumer decision-making when choosing a nursing home. Therefore, the information collected from nursing homes needs to be communicated to the public in a concise and understandable fashion.

3. Open reporting of quality measures can also provide market-driven incentives for facilities to improve quality. This is more applicable to markets with sufficient competition and may be less effective in more rural and poorer areas of the state.

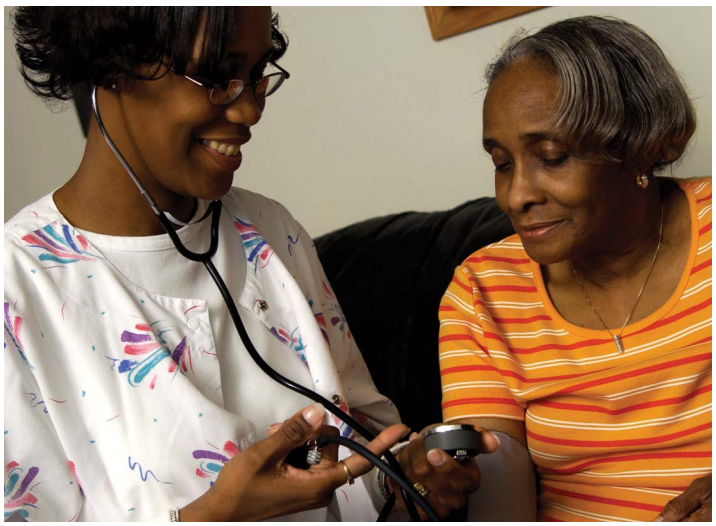
4. Quality measurement can provide indication of systemic problems at facilities, which can then lead to targeted quality improvement interventions.

For all of these goals, it is important to use data collection tools that provide meaningful data that can be used to effect real change in nursing home quality.

The departments of Health, Aging and Human Services all have important roles in monitoring nursing home quality in Pennsylvania. Through existing monitoring efforts, the departments already collect a substantial amount of data.

The DOH collects data on facilities and staffing, such as nursing care hours, training, services available and bed numbers, as well as resident characteristics, such as payer source and health and disability status. The DOH also logs consumer complaints and the results of complaint inspections.

Under the federal Older Americans Act, every state is required to have an ombudsman program. As mentioned previously, the Department of Aging operates the Pennsylvania Long-Term Care Ombudsman Program.



The LTCOP:

- Identifies, investigates and resolves complaints made by or on behalf of residents;
- Provides information to residents about long-term care services;
- Provides technical support for the development of resident and family councils;
- Advocates for changes to improve residents' quality of life and care;
- Represents resident interests before governmental agencies; and
- Seeks legal, administrative and other remedies to protect residents.

The LTCOP conducts annual surveys with nursing home residents through their Pennsylvania Empowerment Expert Residents program (PEER). The PEER program trains nursing home residents to be self-advocates and to advocate on behalf of their fellow residents. Not all nursing homes in Pennsylvania have this program; however, plans call for that to be accomplished by 2020.

As part of Residents' Rights Month in October of each year, data is collected directly from residents through a survey focusing on different themes relevant to resident QOL. These annual surveys currently collect data from more than 800 residents of homes with a PEER presence, and this number is expected to increase as the program expands.

Finally, the Department of Human Services, Office of Long Term Living, oversees data collection for the Minimum Data Set (MDS). The MDS is a federally-mandated clinical assessment that must be completed for all residents in Medicare or Medicaid-certified nursing homes.

The assessment provides a comprehensive overview of a resident's health and functional status and is completed on admission and updated at least annually. The MDS includes data on pain, immunizations, medications, weight loss, depressive symptoms, pressure ulcers, cognitive function and disability status.

Resident Views of Quality Care

The Task Force felt strongly that in defining ideal nursing home care, incorporating the views of the residents themselves was essential. Therefore, the Task Force asked the Pennsylvania Department of Aging LTCOP to conduct focus groups with residents from across the state. Details of this process and the full results are presented in Appendix 1. A brief summary of key points is provided here.

Twenty-nine residents from six facilities participated in the focus group. A majority (62 percent) of residents surveyed were very dissatisfied with the physical care they received. They largely attributed this to inadequate staffing, leading to overburdened staff who are rushed in performing their duties. Residents also reported feeling disconnected from the larger community due to limited access to transportation and communication technologies.

Most respondents (79 percent) felt that they were in charge of their own care and engaged in the care plan process. However, a lack of communication amongst various community-based providers and between providers and residents was noted as a major concern.

When asked what they would change if they were a facility administrator, responses were largely focused on improving resident empowerment and rights and on making facilities more home-like and personal.

Finally, when asked how they would change laws and regulations regarding nursing homes, 37 percent of the responses cited improving staffing levels and training. An additional 28 percent of the responses addressed availability of physician and rehabilitative services.

Despite a large amount of dissatisfaction with care, most respondents (64 percent) indicated that they would stay at the facilities if they had the chance to do it over again. This is likely to be due to the difficulties of moving and a desire not to have to resettle again.

Nurse Staffing

Staffing regulations, in particular, have not kept pace with the increasingly complex case mix of residents in nursing homes. While state regulations dictate minimal staffing of registered nurses (RNs) throughout the day based on census count at a facility, no such requirements are made of the non-RN staff, especially nurse aides and licensed practical nurses (LPNs), who may be providing a large amount of daily direct care.

Additionally, competencies are not currently encompassed by minimum requirements, contributing to the inefficient use of available staff. LPNs and nurse aides are also not required to obtain continuing education credits.

As a result, nursing homes and staff have little incentive to identify, obtain or leverage competencies and education effectively.

Limits of Market-Based Incentives

Improved reporting of outcomes by facilities and better communication of these outcomes with the public will provide market-based incentives for nursing homes to improve care. However, this will have limited impact in markets with minimal competition.

One of the biggest determinants in nursing home choice is geographic location. Therefore, regions that are rural or have lower socioeconomic status will likely see limited impact from such initiatives. Care should be taken to ensure that any implemented changes do not contribute to health disparities by improving care only in those regions that have more choice. However, even in regions with low competition, market-based initiatives promote accountability. Implementation of other incentives, such as value-based payment systems, can work in the absence of market competition.

Medicaid Reimbursement

Medicaid reimbursement levels are not under the purview of the DOH but play a major role in the ability of facilities to provide sufficient care and to implement the changes recommended by the Task Force.

Reimbursement levels can limit the ability of facilities that rely largely on these payments to hire, train and retain staff. This can contribute to health disparities, as the facilities most dependent on Medicaid payments are generally those in poorer, minority or rural areas.

Medicaid payments have not kept pace with the increasing non-direct care responsibilities, such as mandated training and documentation, and resource limitations are a real concern at facilities across the state.

The DOH should be mindful of how any new recommendations may add to this unreimbursed workload. Non-reimbursement incentives as described previously should also be considered as a way to offset any new mandates.

WHAT DOES IDEAL NURSING HOME CARE LOOK LIKE?

The goal of the DOH is to ensure that all nursing home residents are provided the opportunity to reach their highest level of physical, mental and psychosocial well-being. In order to achieve this, nursing homes must be able to promote quality of care, quality of life and person-centered care for all of their residents.

Governmental regulations and compliance management have traditionally focused on quality and safety of care through assessment of facility processes and resident outcomes. Current regulations generally focus on prevention of adverse outcomes rather than on promotion of optimal outcomes.

Recently, there has been an increasing awareness of the importance of person-centeredness in care, which is a core component of the proposed updates to the federal regulations. There is a strong correlation of quality of care, quality of life and person-centeredness; all three are core components necessary to ensure that residents are able to achieve their highest attainable well-being. Long-term care residents frequently cite issues that relate to daily living conditions as their most important concerns.

While current regulations ensure collection of data on components of quality of care and, to a lesser extent, quality of life, person-centeredness is not currently assessed. Therefore, it is difficult to determine how nursing homes are performing on this important component of quality.

In the following sections of this report, the Task Force offers definitions to measure, document, report and promote the three domains of nursing home quality – quality of care, quality of life and person-centered care.

The definitions provided below guide the development of recommendations aimed at ensuring the highest quality of life for nursing home residents in Pennsylvania.

Quality of Care (QOC)

Quality of care (QOC) and safety have been the traditional focus of nursing home regulations. The Institute of Medicine (IOM) defines QOC as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[5]

The IOM further describes six aims of a health care system, all of which apply to nursing home care:

1. **Safety** – aims to avoid harming residents when providing medical or daily care
2. **Effectiveness** – aims to avoid provision of care that will not help or withholding of care that would help an individual
3. **Patient-centeredness** – recognizes the preferences and values of the individual receiving care and is described in more detail below
4. **Timeliness** – seeks to avoid unnecessary and potentially harmful delays in care
5. **Efficiency** – aims to reduce waste, which may include supplies, equipment or personnel time
6. **Equitability** – ensures that quality of care does not differ by characteristics of the individual, including gender, ethnicity, geographic location and socioeconomic status

Many of the reporting requirements in the federal regulations governing nursing homes, such as staffing measures, hospitalizations and deficiencies, focus on aspects of QOC and on prevention of adverse events rather than promotion of optimal outcomes.

Key staffing-related factors include consistent assignment and low staff turnover. Consistency of assignment, particularly with direct care staff, allows for de-

tection of changes in condition of individual residents in a timely manner and provision of care in the way that the resident prefers. Consistency of assignment depends, in turn, on both low turnover rates and staffing patterns that support consistency.

Quality of Life (QOL)

Health-related quality of life (QOL) encompasses many dimensions related to physical, emotional and psychosocial well-being. Core domains of QOL relevant to nursing home residents are defined in Table 1.

Much of the perceived QOL for nursing home residents is driven not by clinical and symptom status but by aspects of their daily living environment and by living in environments that foster feelings of independence, autonomy, individuality and dignity.[9,10]

These concepts refer to a sense of being able to experience and express one's own identity, of being known as a person and sustaining this sense of self.

The essence of QOL in nursing homes is to sustain a resident's individuality and dignity. Inherent in this is the fact that determinants of maximum QOL will differ between individuals. This makes QOL implementation efforts difficult for facilities, as they must be tailored for each individual resident. A focus on shared decision-making and ensuring that the voice of the resident is included in decisions about daily living and medical care is essential to achieve maximum QOL.

In addition, facilities must foster a sense of trust through their policies and practices. Residents must feel that their opinions are not only solicited but are also acted upon. This feeling of trust is particularly important for the most vulnerable residents who may not have a strong voice, for reasons such as a lack

Table 1. Domains of Nursing Home Quality of Life

DOMAIN	DEFINITION	HOW MEASURED IN MINIMUM DATA SET
Symptom status	The perceptions, feelings, and beliefs about the state of bodily health	Many symptoms assessed, including medical diagnoses and pain
Functional status	Physical and cognitive abilities in the context of defined tasks of daily living and that allow participation in preferred activities	Physical and cognitive functional status assessed
Behavioral disturbances	Disruptive behaviors often associated with dementia; may suggest unmet needs of the individual, are difficult to manage, and may disrupt other residents	Mental illness assessed on admission; hallucinations, delusions, wandering, care rejection and behavioral impact on others assessed
Emotional status	Encompasses both positive and negative affect as well as the ability of the emotional system to regulate and negotiate the environment in an adaptive manner	Depressive and anxiety symptoms assessed
Social support	Resources provided by others that enable a person to feel cared for, valued, and part of a network of communication and mutual obligation; includes tangible and perceived support	Participation of family, significant other or guardian in assessment recorded
Patient engagement	Active engagement of residents whenever possible in determining which outcomes matter most to them and how best to achieve those outcomes	Resident goals and expectations assessed; involvement of the resident in assessment recorded
Shared decision-making	Collaborative process whereby residents, family caregivers, clinicians and nursing home staff are involved in developing and implementing resident care plans in a reciprocal and respectful manner	Participation of resident, family, significant other and/or guardian in discharge planning and desire to return to the community recorded; resident's choice regarding bathing, bedtime and family involvement recorded
Perceived QOL	Encompasses the experiences and feelings that a person has about their own life at a given time	Not captured

of family members to act as advocates or because of cognitive impairment.

A shift from the paternalistic medical model of nursing home care to one of choice and an increased emphasis on person-centered care will help achieve optimal QOL for all residents. Further, QOL may be enhanced through environmental design that creates feelings of home and community within the nursing home setting.

Potential Conflicts between QOC and QOL

While there is a strong dependency between quality of care and quality of life, there are times that the two are in conflict with one another; for example, a diabetic resident wanting a second helping of dessert (increased QOL) would interfere with glucose control (decreased QOC).

As facilities move towards a more person-centered model with a greater emphasis on QOL, care should be taken to ensure that these changes don't impact safety and QOC. Generally, increased person-centeredness and an emphasis on QOL will only enhance QOC, but facilities are concerned about the safety and liability implications during situations in which conflicts arise.

The DOH should provide guidance in designing a process that can help resolve the conflicts between QOC and QOL. This process must involve shared decision-making that allows the care team to convey the safety concerns of the resident's decisions without crossing over to coercion.

Person-Centered Care (PCC)

Health care in the past century has been focused on disease-centeredness and organizational efficiency. This has often led to a loss of the individual's voice in decision-making related to health and life goals.

More recently, the importance of incorporating this person-centered view back into medical decision-making has been recognized as important for the mental and psychosocial needs of nursing home residents.

As noted above, patient-centered care is a core principle underlying both QOC and QOL. PCC recognizes that the elements of care and daily living that are of greatest importance to one resident may not be at all important to another.

WHAT DOES IDEAL NURSING HOME CARE LOOK LIKE?

The PCC framework involves residents and allows their preferences and values to drive decision-making. This ensures that individual care and living plans reflect the desired outcomes of each individual resident.

The American Geriatrics Society (AGS) recently published a consensus definition of PCC with a focus on older adults.[11] While the AGS definition focuses on medical care for community-dwelling individuals, it also serves as a guide for defining PCC in the nursing home. AGS states:

> "Person-centered care means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires."[11]

While this definition explicitly focuses on medical care, it can easily be expanded to incorporate the lifestyle and daily care choices that would arise for residents of nursing homes.

Key components of PCC for nursing home residents include:

1. An individualized, goal-oriented care plan should be developed from patient preferences both for medical decision making and daily care. The new proposed federal regulations for participation in Medicare and Medicaid programs require that an assessment of patient preferences be completed at admission to a nursing home and that the care plan reflects these preferences. This care plan should then be reviewed and updated on a regular basis to ensure its effectiveness and allow for changes in the person's status and preferences.
2. Care should be supported by an interdisciplinary team that includes the voice of the resident and/or his/her surrogate. Shared decision-making principles should be adopted by the team with the objective of reaching consensus on the care plan.
3. While teams should have equal voices from various members, a lead contact should be designated to ensure continuity and consistency of care throughout care transitions. Active coordination across health care teams during transitions will ensure maintenance of PCC. Direct care staff who are most familiar with the resident should always be included in care plan development and change.
4. PCC will be enhanced if all providers are adequately trained in the importance and performance of PCC. Performance measurements and quality improvement efforts should incorporate PCC and the voice of residents.

PCC enhances care and care satisfaction by allowing residents or their surrogates to have an active voice in decision-making. In the nursing home setting, this decision-making is relevant both to medical care and to daily life care, such as meal time preferences and activity participation.

Decisional capacity of impaired residents is an important consideration in implementing PCC in the nursing home setting. Decisional support tools are available and can help guide staff in deciding who has decisional capacity and ways that decisional support can be provided to ensure that resident preferences are honored in cases of reduced capacity.

Even for residents who have intact decisional capacity, supporting relationships from family members and other caregivers are important and should be considered in decision-making if the resident so chooses.

TASK FORCE RECOMMENDATIONS

Changes to the Current Survey Process

The Task Force has identified several recommendations to improve the existing survey process, noting the potential limitations imposed by current federal regulations. Any changes must comply with federal regulations to ensure that certification and reimbursements are not affected.

The survey process recommendations are:

1. The DOH should increase efficiency and consistency of the survey process by providing enhanced training to the field offices and surveyors. The Task Force encourages these efforts, as they will not only improve the survey process itself but also stakeholder confidence in the survey results.

2. The Task Force suggests that survey time be reallocated to allow for less time being spent at higher performing facilities, which could act as an incentive for quality improvement. Additional time could then be spent on quality improvement efforts at lower performing facilities, including identification of key areas for improvement, consultation on best practices and training programs.

3. Many of the needs and quality of life concerns of short- and long-term residents are quite different. These differences should be reflected in the survey process. Surveys specific to short-term facilities or to short-term units within larger facilities that would reflect the needs of these residents should be considered.

   The Task Force recommends that formalization of these processes should be undertaken to ensure continued consistency under future administrations.

Added Data Components

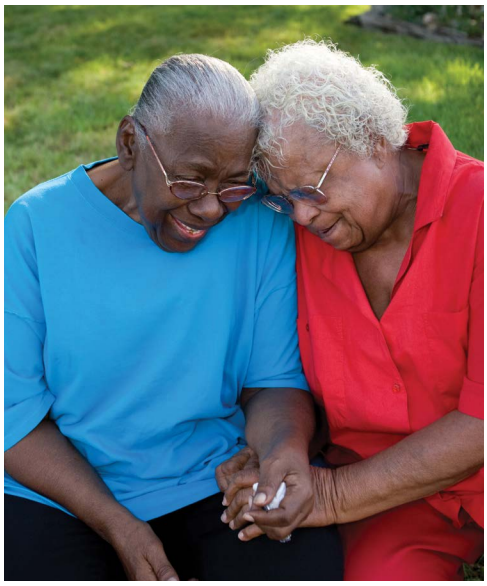
The Task Force recommends that further data collection or novel utilization of existing data be considered to enhance the information provided by the CMS Five-Star Quality Rating System.

Novel Data Collection and Reporting

Novel data collection and reporting efforts will allow for the increased value of current reporting, encourage a move towards more person-centered care, and provide residents and families with the types of information they are seeking when selecting a facility.

The Task Force reviewed a number of measures and tools that are currently available or under development that would allow more robust measure of QOC, QOL and PCC by the state agencies. Efforts should be made to ensure that any new data collection does not result in duplication of existing reporting requirements.

Among the components that should be considered to measure QOC are additional direct care measures, such as transitions in care, 30-day readmissions and potentially avoidable hospitalizations.



In particular, potentially avoidable hospitalization rates may be a good indicator of care. Several initiatives are proposing inclusion of potentially avoidable hospitalizations from nursing homes, including CMS,[14] but a reliable and valid definition has not yet been developed.

Further, attention must be given in use of these types of measures to ensure that they do not penalize facilities that tend to take higher rates of medically complex cases.

QOC Measures

Many of the current QOC measures focus on long-term residents, as they have traditionally made up the majority of residents. However, there has been a growing reliance on nursing homes for short-term rehabilitation patients that has not been well reflected in data collection.

CMS has recently added measures of quality specific to short-term residents, but additional measures may enhance measures of QOC.

Nurse Staffing Measures

Nurse staffing measures can also be informative, and residents often speak of the role of staffing levels in the quality of their care. However, current measures focus primarily on staffing ratios without consideration of staffing mix and competencies.

High staff turnover may also be indicative of low quality care. Limited duration of staff tenure can prevent increase of caregiving staff competencies and can lead to loss of continuity of care for individual residents. Further, high staff turnover may be a symptom of larger problems at the administrative level that affect both quality of the workplace and the quality of care received by residents.

Continuity in leadership positions at nursing home facilities is extremely important for stability of care and is an under-recognized measure of quality.

Much of the data on staffing ratios are already available to the DOH, and competencies and turnover could be incorporated into existing data collection.

Clinical Capabilities Checklist

The Task Force further recommends implementation of a clinical capabilities checklist for each facility.

Such clinical capabilities could include, for example, the types of clinical services provided, such as dedicated dementia units, dialysis, rehabilitation services and cardiac testing. Clinical capabilities also represent both facility-level infrastructure (e.g., on-site phar-

macy or dialysis machines) and staff capabilities (e.g., phlebotomy training).

The checklist would be updated on a regular basis, audited as part of the state survey process and publicly available. This process would ensure transparency and accountability around care capabilities and would help consumers match resident needs with an appropriate facility.

Information from such a checklist could be provided to the public through an online dashboard as described in more detail in a later section. The clinical capabilities checklist from Interventions to Reduce Acute Care Transfers (INTERACT)[15] should be considered (Appendix 2a).

Surveys

A number of surveys exist that could provide novel sources of information on quality at nursing home facilities across the state. These include various consumer satisfaction surveys that are available through commercial entities and the Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS) tool, which would provide information on the perceived quality of care by residents and their families.

The NHCAHPS was developed and endorsed by the Agency for Healthcare Research and Quality (AHRQ)[16] but is not currently mandated by CMS. Three versions were developed, including an in-person, long-term stay (Appendix 2b), a mailed short-term stay, and a mailed family member version (Appendix 2c). Analyses during the development of the NHCAHPS found that, due to physical and cognitive limitations, in-person interviews were the only way to obtain reliable results from most long-term residents.

The Ohio State Long Term Care Ombudsman implemented in-person surveys of long-term nursing home residents but found that the cost of conducting in-person surveys was prohibitive for continuous utilization. The Ohio State Long Term Care Ombudsman's office is now conducting mail surveys of family members to limit costs. However, non-resident reports must be carefully interpreted, because views of the resident's satisfaction can vary quite substantially between informants.

The possibility of conducting surveys with residents using secure videoconferencing, which would reduce costs over in-person surveys, should be explored. If this is found to be unfeasible, use of the mailed family survey could be a suitable alternative to obtain information on resident satisfaction in a timely and cost-effective manner.

The Kansas Culture Change Instrument (KCCI)[17] is a tool to gauge PCC within nursing homes (Appendices 2d and 2e). The KCCI is a comprehensive survey that assesses multiple domains of PCC, including resident-directed care and activities, home-like environment, relationships, staff empowerment, and collaborative management. The KCCI also has demonstrated high validity and internal consistency. One limitation of the KCCI is that it elicits responses from staff but not from residents, limiting its applicability for assessing PCC. However, most other instruments aimed at assessing PCC also rely on staff reporting. Therefore, if the KCCI is adopted on a large scale, it should be supplemented with resident reports.

Residents are already providing feedback on their satisfaction with care through the aforementioned Long-Term Care Ombudsman's Pennsylvania's Empowered Expert Residents (PEER) Program. The Task Force views the PEER Program as a valuable resource and applauds the effort to expand the program throughout the state. Currently, the information from the PEER surveys is used for the creation of training modules and educational materials.

The Task Force encourages the DOH to explore ways in which the information gathered from these surveys can inform regulatory efforts and, to the extent possible, can be shared with the public in a meaningful way, while preserving participant confidentiality.

Another difficulty of expanding data collection efforts is ensuring that the voices of those with dementia or those otherwise decisionally-impaired are included. Eliciting meaningful opinions from these residents can be possible, but it takes extra care, training and time, thereby increasing costs.

Many of the surveys proposed above elicit information from staff or family, in which cases, capacity of the individual resident is not a factor. However, those with severe cognitive impairment should not be excluded from consideration in resident surveys, as they make up 36 percent of the resident population in Pennsylvania.

Initial assessment of decisional capacity of an individual resident can be made using data already collected as part of the MDS, including the Brief Inventory of Mental Status (BIMS) and the Confusion Assessment Method (CAM.)

The DOH should provide guidelines to facilities on how to engage residents in cases in which there are potential limitations in decisional capacity. The Task Force recommends utilizing the "Assisting Someone with Decision Making" framework developed by the South Australian Office of the Public Advocate.[18]

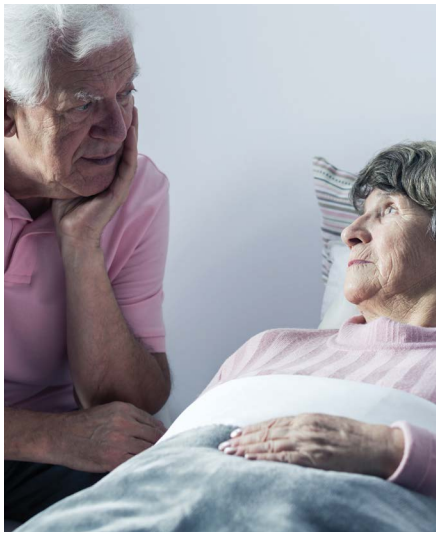
Also, the PEER program makes special efforts to include those with reduced cognitive capacity, and it should be considered a resource in assessing quality of care from the perspective of residents with dementia and cognitive impairment.

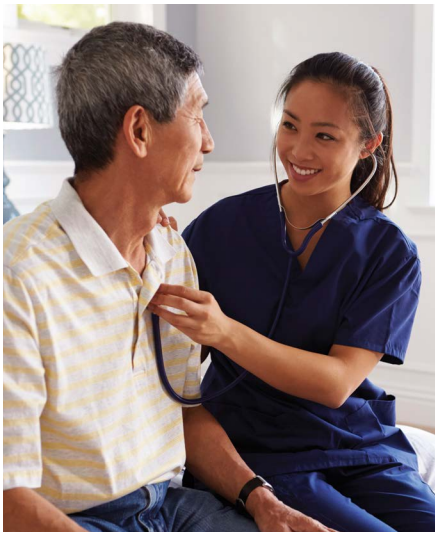
Data Sharing

The Task Force recommends that continuing efforts be made to integrate data collection and data sharing across the many departments responsible for nursing home care in the state, resulting in a collaborative framework for data collection and analysis that could provide easier access to relevant data and limit duplicative efforts.

Under the current leadership, there has been increased communication and data sharing across the departments of Health, Aging, Human Services and State, which all have roles in ensuring quality of nursing home care. The Task Force encourages this openness and recommends that formalization of these communication and data sharing efforts be made to ensure that they continue into the future.

The Task Force also encourages increased engagement with community-based organizations that work to promote resident rights and quality of life. Data sharing from all relevant agencies should also extend to providers in a way that allows them to gauge their own quality and change current practices to improve them. Analysis and benchmarking could be facilitated through the DOH to identify areas for improvement by each facility.





The Task Force recognizes that there may be barriers to overcome in order to make use of these tools. Any effort to increase data collection will likely increase costs and could increase burden on both DOH and nursing home facility staff. The DOH should consider seeking grant funding or using the civil monetary funds collected through fines to help implement any additional data collection efforts and development of an online dashboard for data dissemination. If such efforts are implemented, they should be mandatory for all facilities in order to ensure full participation, which will allow for more meaningful comparisons across facilities. This may lead to upward pressure on lower performing facilities to improve outcomes in order to remain competitive. As any facility staff time devoted to survey completion is likely to be unreimbursed, other incentives for facilities should be considered.

Finally, ways to improve data sharing with the public should be sought. This will allow for more informed decision-making when choosing a home, may promote trust amongst consumers and could provide incentives for lower performing nursing homes to improve.

Several states, notably Maryland[19] and Ohio,[20] currently have online dashboards that provide snapshots of nursing home quality that are free and open to the public. These dashboards often provide information on data that are already collected in Pennsylvania, such as deficiencies, as well as the results of other performance and satisfaction tools that the individual states have implemented.

The Task Force felt the dashboards were extremely useful tools for consumers and encouraged the state to consider adoption of such a platform. However, the Task Force recognizes that such an online tool would require investment in data collection and website development and maintenance. This poses a problem due to limited state budget resources and shrinking Medicaid reimbursements for nursing home operators that may not cover time to complete surveys.

Staffing Requirements

The DOH should consider minimum requirements for staff beyond RNs, although competencies and not just staffing numbers should be assessed. Minimum staffing levels for RNs should also be reviewed to ensure adequate coverage throughout the day, especially given the increased complexity of resident needs.

It is recommended the DOH undertake an assessment of how staffing numbers and competencies vary by facility and whether these variables are associated with quality of care and patient outcomes. This could inform 1) how staffing numbers and mix should best be regulated and 2) the minimum staffing that should be mandated for optimum levels of care.

The focus of future staffing requirements should consider the full care team. Future regulations for all levels of staffing should also be based on demonstrated skills. For example, a single staff member who demonstrates a broader range of capabilities may be able to perform the duties that otherwise may have to be delivered by multiple lesser-skilled members of a care team. As well, someone providing direct resident care should be able to demonstrate a specific set of skills before they can care for residents.

Ongoing training requirements should also be revised. Currently, RNs are required to have continuing education credits, while LPNs and nurse aides are not. The Task Force recommends that continuing education and staff development be required at all levels in a structured manner that includes assessment of competencies. If regulations are adjusted to ensure competency levels, then these staff development trainings should align with the required competencies. Incentives should be provided to LPNs and nurse aides for completion.

There is a need for workforce development, particularly for non-physician positions and in rural areas where chronic staffing shortages exist. The DOH should explore ways to promote entrance into these career fields. Regulations could be adjusted to accom-

modate alternate training opportunities, including apprenticeships, in addition to traditional educational tracks.

Ways to limit turnover should also be considered, as high turnover rates plague the field and interfere with development of competencies by staff members. In addition, high turnover can disrupt care continuity for an individual resident, potentially impacting quality of care.

Culture Change

The culture change movement towards increased QOL began in the 1990s in response to the perception that nursing homes were not sufficiently person-centered and were too task- and schedule-focused. The culture change movement aims to provide residents with greater control over their daily lives, maintain residents' sense of purpose and ensure a sense of home and community within the nursing home facility.

Facilities that have adopted culture change practices not only enhance the quality of life of their residents but also have better indicators of quality of care.[21] Implementation of culture change practices can lead to more efficient use of existing staff without the need for increased staff numbers. Culture change toward person-centeredness also benefits staff by providing more flexibility in scheduling and task performance and by allowing staff to develop relationships with the residents.

These benefits may manifest in reduced staff turnover, which, in turn, can have benefits for resident quality of care and quality of life. The Task Force recommends that all nursing homes in Pennsylvania should be striving to fulfill the goals of culture change.

Traditionally, culture change practices include a shift in the physical environment from a more hospital-like setting to a more home-like one. Many nursing home administrators have been reluctant to implement culture-change practices, likely due to a perception that the changes are not feasible within their existing infrastructure. However, many of the changes can be made even within the constraints of existing infrastructure. Other changes, such as providing more flexible meal times to residents, can prove challenging to implement if administrators are unfamiliar with how to develop new scheduling policies.

The DOH may provide for consultation to identify changes that are feasible within a facility's existing infrastructure without the need for major capital outlays, as well as in development of new policies that are more person-centered. Further, the DOH should identify current regulations that are too restrictive, limiting the ability of facilities to implement culture change practices, and work to revise them.

To lead facilities across the state towards more person-centered care, the DOH should identify the most meaningful and impactful changes that could be made and aim to have all facilities adopt these practices within two years. To ease the process, transition plans for each facility could be created with the guidance of the DOH. These plans would include intermediate milestones and would lead to incorporation of person-centered outcomes in future facility evaluations.

Furthermore, culture change practices and person-centered care should be included as part of the continuing education requirements for NHAs and direct care staff. The DOH should explore possible ways to incentivize these transitions beyond initial consultations. While implemented changes and their effects on resident outcomes must be documented, the administrative burden on facilities should be minimized.

The DOH should also explore partnering with risk-bearing entities to reduce liability concerns of increasing resident decision-making. Finally, monetary incentives, possibly through profit sharing programs, should be considered.

Leadership

Many of the changes that facilitate quality of care and quality of life for nursing home residents must be implemented at the facility level, rather than with individual staff members. This requires a focus on leadership within nursing home facilities.

Nursing home administrators should be supported to make positive changes in their facilities, and regulations must enable administrators to enact the changes that residents are requesting. Current regulations and practices may have unintended consequences that limit improvements at facilities. For example, automation of care documentation has often led to more standardized and reduced person-centered care.

The current minimal educational requirements for certification as a Nursing Home Administrator (NHA) or Director of Nursing (DON) do not fully align with the demands of the jobs. Pennsylvania is one of two states that do not require a degree beyond a high school diploma in order to become an NHA. While most other states require either an associate or bachelor's degree, these may still be insufficient training, as the degree is not required to be in any particular field. NHAs need to operate as chief executive officers (CEOs) of their facilities but frequently are not adequately trained for these roles. An effective NHA must have the skillset to manage large, complex organizations that are providing daily living and medical care.

Facilities operating as part of a chain have the advantage of centralized management of components, such as payroll, and can provide administrative support and skills training. However, this centralization can limit autonomy of individual facilities and the local administration and nursing staff. This can be detrimental to person-centered care if individual facilities are unable to implement changes to accommodate local needs.

While it is important to ensure adequate educational and training requirements for NHA licensure, enough flexibility should be provided to allow for appropriate alternative career paths, such as a mid-career transition from hospital administration to nursing home administration, without completing a six-month supervised experience.

DONs are currently required to be a registered nurse with at least one year of education or experience in nursing service administration. However, DONs are typically clinical experts and may not be sufficiently trained in management skills.

There is currently no formal structure to train RNs to lead and manage nursing home services, and there are no formal career paths. Training programs specifically for DONs have been implemented in other states and could serve as a model for Pennsylvania. These positions are highly demanding, and, when combined with inadequate preparation, can lead to high rates of turnover. This, in turn, may lead to negative consequences for direct-care staff retention and resident outcomes.

The DOH should update the educational requirements for NHAs and DONs to ensure that individuals are sufficiently qualified for these demanding positions.

The DOH should also consider strategies for supporting development of formal career paths to these positions.

Other forms of support may also be provided to nursing home administrators. Systems could be set up, facilitated through the DOH, to allow sharing of best practices between facilities.

Further support could be provided directly from the DOH through provision of consulting for underperforming or newly established facilities to ensure they have the access to the technical expertise that they need.

OUTLINE OF FINAL RECOMMENDATIONS

1. Over the next year, the Department of Health should define strategies to enhance the annual survey process to ensure confidence in the survey process and provide meaningful data that is essential for quality improvement efforts and consumer choice. Achievement of this recommendation will require:
    a. Enhancing training efforts for surveyors to ensure that surveys are conducted consistently across individuals and regions; and
    b. Adopting novel quality metrics into annual surveys that assess aspects of quality of life and person-centeredness that are not currently measured and are needed to reflect the current nursing home population.

2. Over the next two years, the Department of Health, in collaboration with the Department of Human Services, the Long-Term Care Ombudsman Program and nursing home administrators, should revise nursing home licensure regulations in the state of Pennsylvania to emphasize person centered environments designed to advance high quality, high value care and promote high quality of life among the residents. Achievement of this recommendation will require:
    a. Identification of outcome measures that are reliable and valid indicators of person-centered, high quality care;
    b. Revision of core process and outcome measures to include multiple health-related quality of care and life domains that align with preferences, needs and values of residents;
    c. Revision of assessment processes (e.g., surveys) to focus both on core measure achievement and the lack thereof;
    d. Support for the integration of new data elements and preparation of staff regarding collection of new data; and
    e. Support regarding the analysis and use of entire data set to guide performance improvement processes.

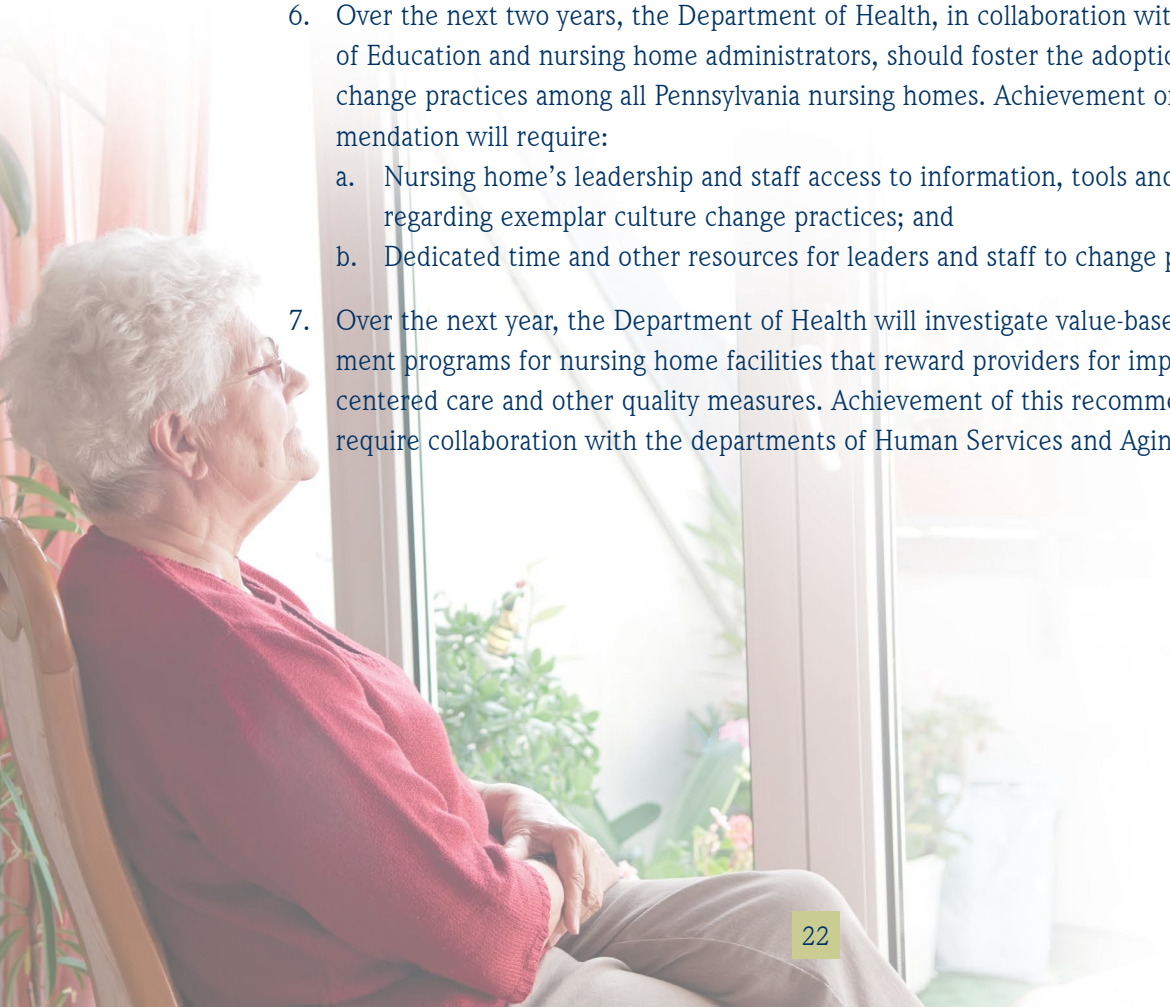
3. Over the next two years, the Department of Health, in collaboration with the Long-Term Care Ombudsman Program and the Department of Human Services should enhance data sharing efforts between agencies, between agencies and industry leaders, and between agencies and consumers. Achievement of this recommendation will require:
    a. Formalization of ongoing efforts to increase communication and data sharing amongst the departments of Health, Aging and Human Services;
    b. Development of efficient and effective data dissemination tools and practices for communication of performance metrics and best practice recommendations with industry leaders; and
    c. Development of an online dashboard for communication of nursing home quality indicators with consumers.

4. Over the next two years, the Department of Health, in collaboration with industry leadership and nursing home administrators, should review and update the regulations concerning staffing requirements. Achievement of this recommendation will require:
   a. Identification of appropriate staffing ratios, staff mix, and competency requirements needed for a care team to provide optimal care;
   b. Development of educational and assessment tools for assuring adequate competencies for all staff providing direct care in nursing homes; and
   c. Review of policies used in other states that could minimize turnover of nursing staff.

5. Over the next year, the Department of Health should develop a plan for collaborating with industry leadership and the Department of Education to advance the recruitment, continued development and retention of high quality leaders at nursing home facilities by:
   a. Revising and updating regulations regarding minimal requirements for nursing home administrators and directors of nursing to ensure that leadership is adequately prepared but that flexibility of career paths is maintained.
   b. Reviewing current regulations to identify and eliminate or revise those that hinder facility leadership from implementing positive, resident-focused changes at their facilities.

6. Over the next two years, the Department of Health, in collaboration with Department of Education and nursing home administrators, should foster the adoption of culture change practices among all Pennsylvania nursing homes. Achievement of this recommendation will require:
   a. Nursing home's leadership and staff access to information, tools and support regarding exemplar culture change practices; and
   b. Dedicated time and other resources for leaders and staff to change practices.

7. Over the next year, the Department of Health will investigate value-based reimbursement programs for nursing home facilities that reward providers for improving person-centered care and other quality measures. Achievement of this recommendation will require collaboration with the departments of Human Services and Aging.



Appendix 1. Nursing Home Quality Improvement Task Force Resident Survey

Background: The Pennsylvania Ombudsman Program was tasked by the statewide Nursing Home Quality Improvement Task Force to facilitate a survey of nursing home residents for purposes of gathering resident perspective and feedback regarding quality of life and quality of care measures in Pennsylvania.

Currently, there is a nationwide rating system (Five-Star Quality Rating System) in place for such a purpose. However, the existing rating system is based on clinical measures and provider self-report. As the Task Force explored ways to better serve Pennsylvania's long-term care consumers, it was imperative that consumer perspective be included in their comprehensive review.

The Pennsylvania Long-Term Care Ombudsman Program has a statewide network of consumers who have successfully completed a standardized, 10-hour curriculum intended to empower and educate them in topics including resident rights, state and federal licensing regulations, and self-advocacy skills and strategies. These residents are known as Pennsylvania's Empowered Expert Residents (PEERs.)

Since 2002, the PEER program has trained and graduated more than 3,000 PEERs. There is an existing network of approximately 1,190 PEERs at the time of this writing.

The PEERs were eager to participate in the discovery process of this survey. Six resident meetings were convened in six homes across the state – all at a facility with a PEER presence.

Two meetings were held in each of our western, central, and eastern regions, and, for comparison, the two facilities selected in each region were on the opposite end of the spectrum of the Five-Star Quality Rating System.

Facilities ranged in size from a bed count of 51 to a capacity of 371 beds.

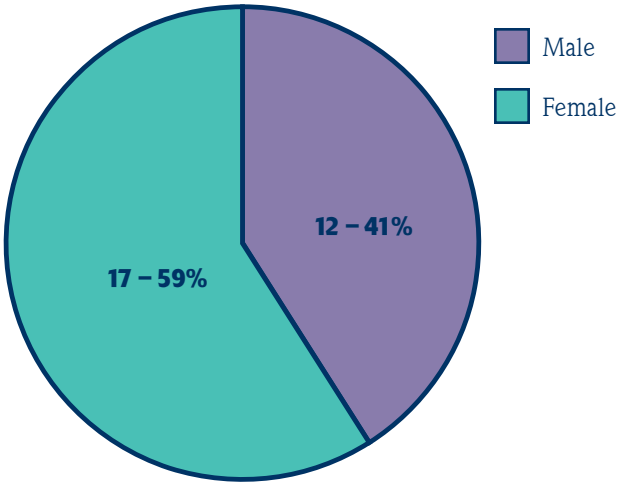
The sample included 29 residents, who varied in age and number of years living in the facility as outlined in the demographics section of this summary.

The intent of the survey was to compare and contrast the resident's experience with the Five-Star Quality Rating assigned to their respective facility.

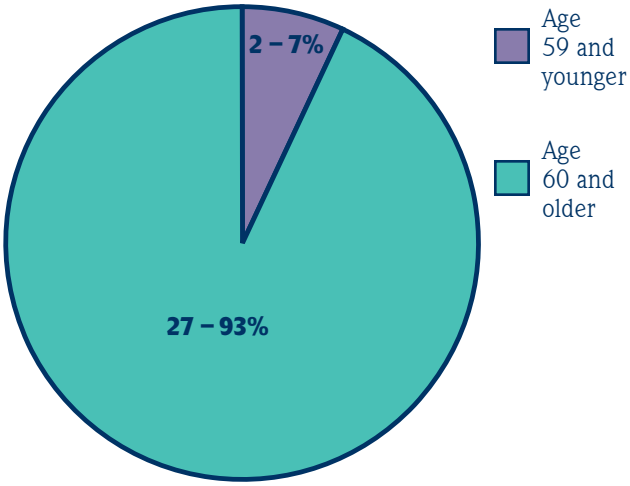
Demographics:

Total Survey Responders: 29
Total Number of Facilities: 6

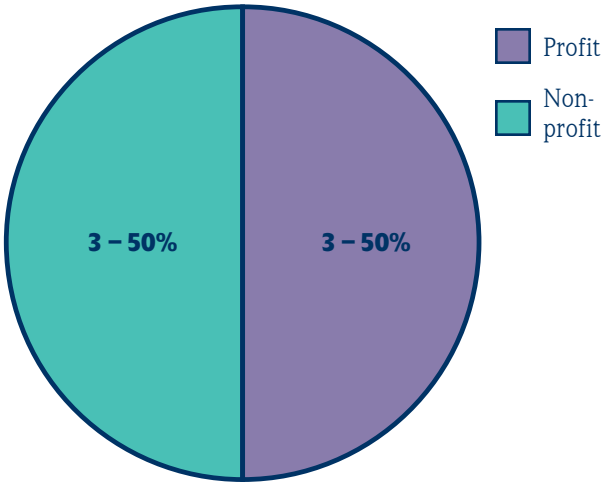
Resident Gender



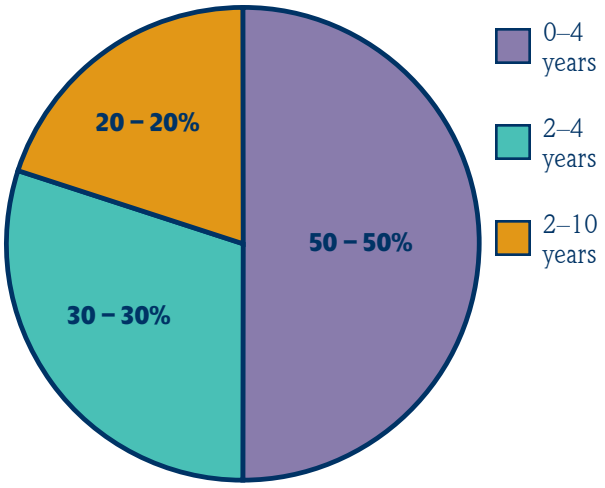
Resident Age



Financial Structure



Comparative Length of Stay of Respondents



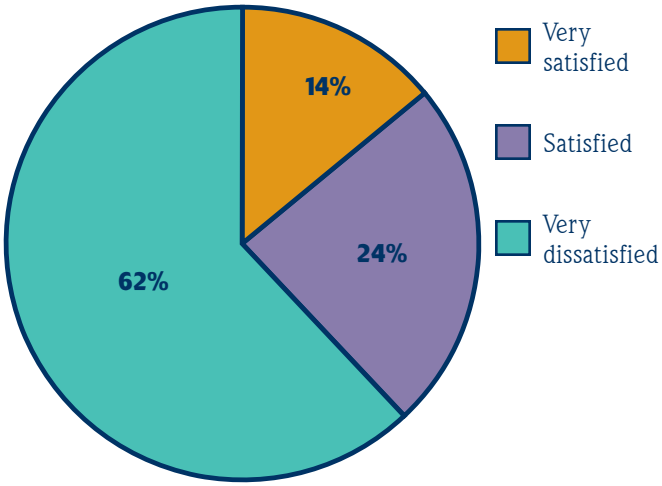
Circumstances Possibly Impacting Accuracy of Data: There were two interviewers/facilitators involved, and the style of the discussion may not have been identical. However, the questions used with each group were standardized and approved by the task force prior to the beginning of the group meetings.

The residents involved were also unfamiliar with their respective facilitator/interviewer, but each group included the local ombudsman who did have an established relationship with the PEERs involved.

Finally, it is important to note that quality of life and quality of care are subjective matters. Each individual has preferences and priorities and individualized experiences that color his/her opinion regarding the overall quality of the facility where he/she resides.

The questions were open-ended and produced narrative and anecdotal responses. For the purposes of this summary, like answers are grouped and trends are identified as much as possible.

Question 1: How satisfied are you with the quality of the physical care provided?

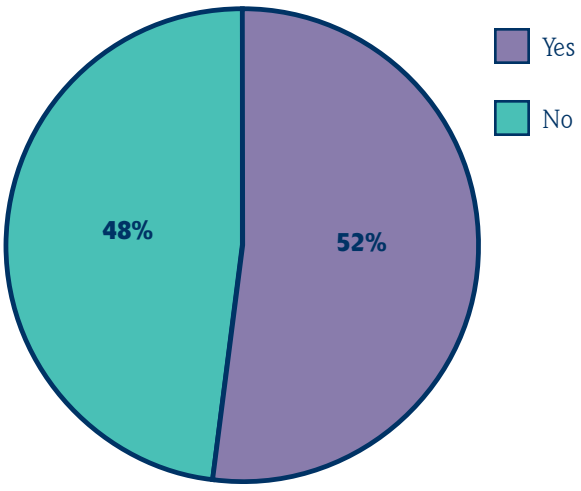


- The size and financial structure of the home appeared to be a factor in the response to this question. In general, satisfaction decreased with the increased size of the home (i.e., bed count).
- The time of day when assistance is requested also is a variable that impacts perception of quality. All residents reported that availability of help/response to requests for assistance vary based on shift and days of the week. For instance, residents who were generally satisfied did report that they can be very dissatisfied on overnights and weekends. Resident acuity also impacted this measure – the more help that is required (two staff members versus one, for instance), the harder it is to secure help and to feel safe and comfortable in the help provided. Residents attributed this to the number of

staff assigned versus the number of staff needed to provide all residents with the care they need.

- Residents overwhelmingly agreed that current resident-to-staff ratio is inadequate.
- Staff often get impatient with residents and appear rushed/pressured to move and perform tasks quickly in order to accomplish everything assigned to them.
- Residents expressed concerns regarding infection control – especially in the shower area and with personal care. They often observe staff "cutting corners" or "skipping steps" in the interest of time. One resident, who is rehabilitating after an amputation, reported refusing showers due to this type of concern. He reports that common shower area with residents "wheeled in/wheeled out" without cleaning between residents concerns him.
- There is a prevalent opinion that call bell response times are too lengthy and residents reported waiting an average of 45 minutes to one hour for a call bell to be answered – especially on evenings, nights, and weekends. Several residents reported that they have attempted to help themselves/taken risks to avoid an incontinent episode when staff is unresponsive to their call bell.
- Four of the six homes reported that showers have been cancelled by staff due to staffing-related issues, yet the residents assert that this reasoning is not accurately reflected in their medical record. For instance, at care plan meetings, they may be asked why they are refusing showers – when they are not refusing at all.
- Some of the residents reported that they have used their personal phone to call the front desk or their family when they have been unsuccessful in obtaining help on their own.
- Residents reported that they have experienced staff coming into their room, turning off the call bell, indicating that they will be right back and then not returning/failing to provide the care. Residents also reported that they have had staff pretend not to hear them or see their light in an attempt to avoid helping them.
- A few of the residents have overheard staff arguing about who was going to have to take care of them. Residents report feeling embarrassed as a result; this impacts their dignity and ability to feel cared for in their home.

Question 2: Do you feel your social and emotional needs are being met?

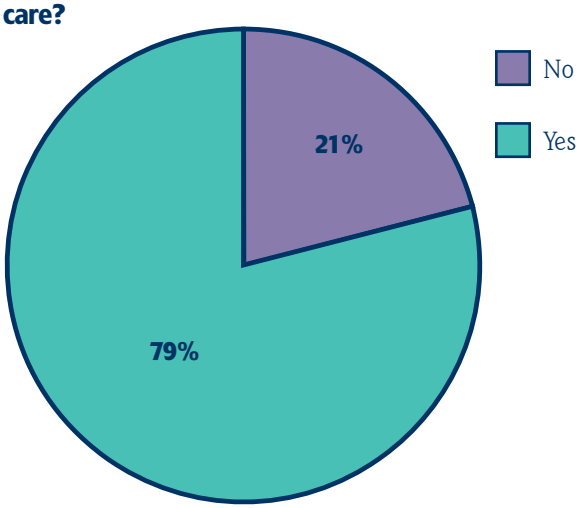


Problematic areas:

- Independent access to outdoor areas/community is limited.
- Wander-guards and hall passes are required of all residents to leave the building, even when cognitive impairment is not present. Residents feel "controlled."

- Email and phone access ranges from none to fair for most residents. Residents with availability of funds can afford a phone/tablet/Internet. For those who are on MA and receive the monthly PNA (personal needs allowance), they use shared equipment that is often not functioning or is difficult to access/lacks privacy.
- Transportation to non-medical appointments/outside activities has been discontinued at four of the six homes involved in this survey, making it very difficult for residents to remain connected to the community beyond the facility and interfering with relationships in their communities.
- PNA impacts ability to connect with the community as well. When a facility offers a trip to the mall (or something similar), residents often have no money to participate. One resident reported that he is having his television disconnected because he can no longer afford the monthly cable fee.
- Residents expressed an interest in facility-based classes on using Internet, Skype, Facebook, and other social media as a means to connect with community.

Question 3: Do you feel you are in charge of your own care?



Problematic areas/points of particular interest:

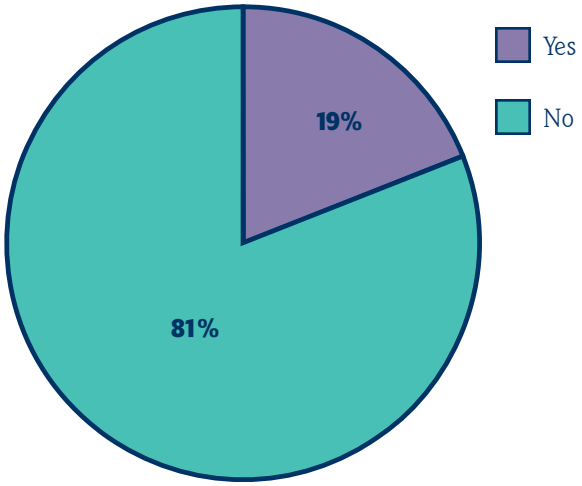
- Residents in two of the six homes indicated that they are engaged in the care plan process, resulting in an increased ability to direct their care.
- Residents want direct, regular and timely access to their physicians. Residents report that physicians rarely visit or, when they do visit, the meeting is very brief and lacks substance. Several residents reported that their medications have been started/changed/discontinued by their doctor – based solely on communication with the nurse. Residents are not always even aware that this type of conversation is occurring. Residents also remarked that the licensed nurses having these conversations with the physicians are the staff members who know them the least.
- Residents report that the staff most familiar with them are the nurse aides.
- Residents are regularly directed by facilities to utilize facility-affiliated providers instead of community-based providers in an attempt to reduce resident travel and related costs.
- Communication between disciplines and various licensed staff was typically described as poor, and most residents agreed that the lack of communication concerns them. It often manifests itself in missed appointments, for example.
- Not all residents have been invited to their care plan meetings. While they all know about the care plan process and their right to attend (via the PEER curriculum), obtaining details about the date/time of the meeting (to facilitate their participation) is often a challenging process.

- Medical test results are not regularly shared with the residents; many reported that they must ask or pursue results.

Question 4: What is one thing you would like to have known prior to admission? Did you choose to come to this facility?

- "What they tell you upon admission is not always true."
- "There wasn't enough staff to take care of me."
- "Resident rights are not always respected."
- "What was the real quality of care here?"
- "Other residents could get into my things."

Question 5: Did you choose the home where you reside?



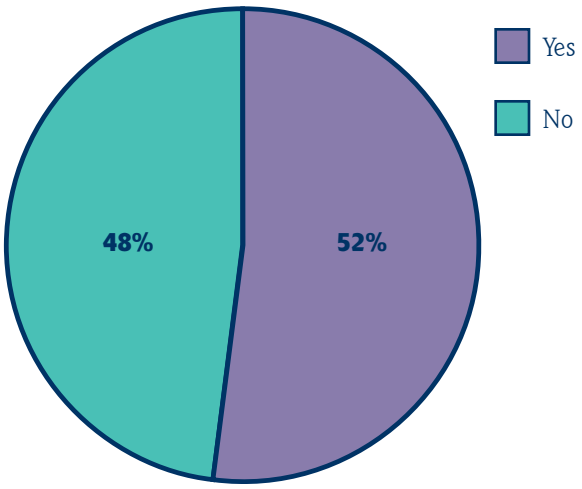
- Only 17 percent of the residents participating in the group discussions selected the facility where they are residing. Family and/or hospital staff made the selection and informed the residents where they would be going.
- Most did not have the opportunity to see the facility prior to admission.
- Most did not realize until after they were admitted that they had a right to decline or select for themselves.

Question 6: If you were administrator for one week what would you change?

Of the residents, 100 percent indicated that they would make changes. Common themes:

- Change the actual administrator and administrative staff; hire someone more compassionate.
- Maintain wheelchairs and make sure wheelchairs are cleaned; provide seating options beyond the two choices most have now: wheelchair or bed.
- Remediate feelings of powerlessness and improve respect for resident rights.
- Improve communication.
- Change menus; improve resident access to snacks.
- Improve overall atmosphere; add music and decorations and comfortable furniture, etc.
- "Staff would ask residents what they want – not tell residents what they have to do."
- Eliminate corporate menus and respond to resident meal requests.
- Improve resident access to private use of a telephone.
- "Add a bar; serve alcohol."
- Automate the entrance doors so residents can get in and out of the building.
- Create a conference room for resident use.
- Reduce background noise – alarms, loud televisions, paging, etc.

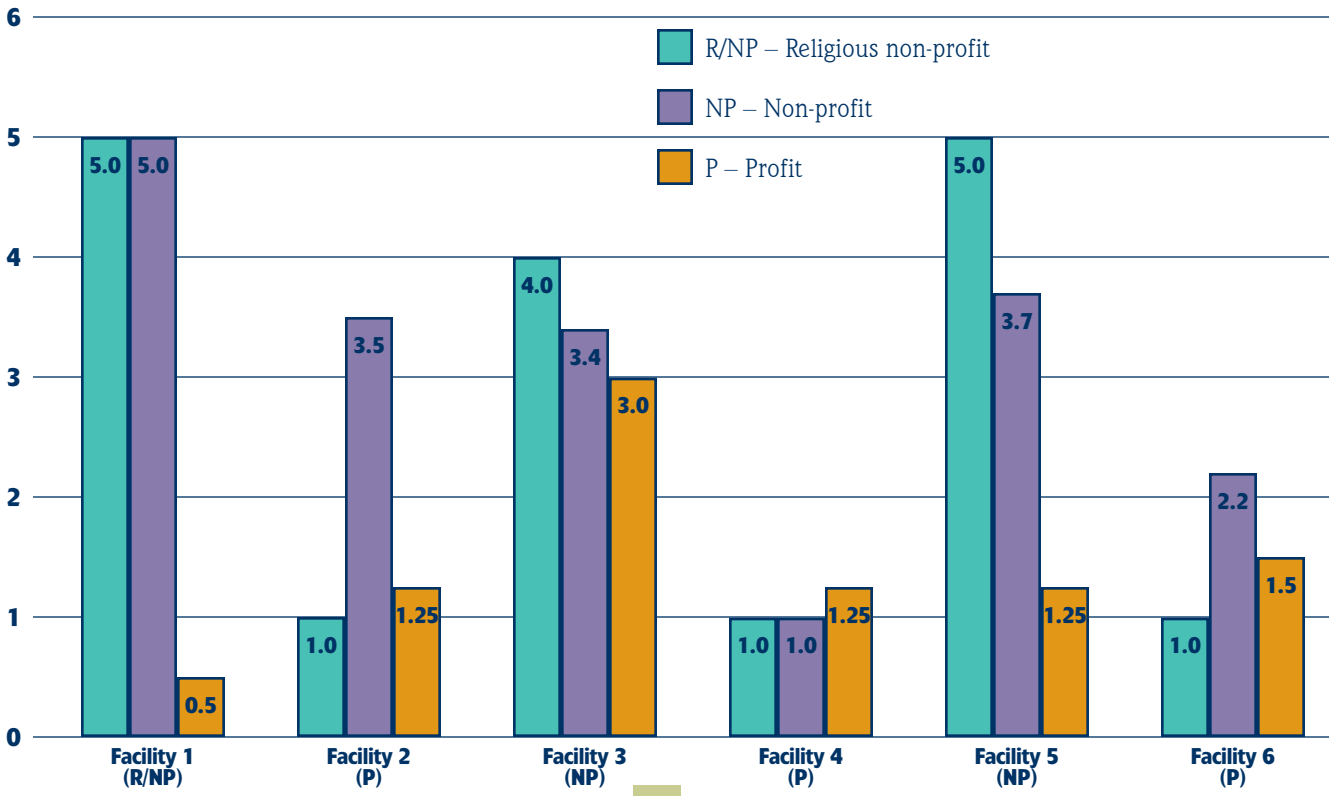
Question 7: Do you feel safe here?



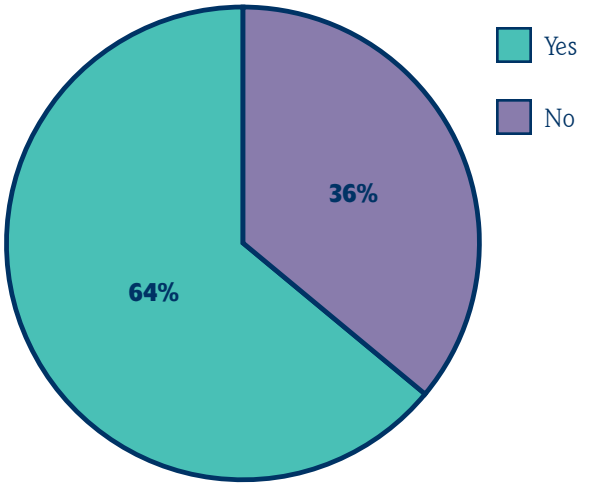
Residents elaborated as follows:

- "I don't speak up because of fear; I often feel powerless, so I just go along."
- One resident reported actual harm that is under investigation by the Department of Health.
- Belongings are not safe and facilities do not make an effort to protect belongings/ replace belongings that go missing.
- Some facilities seem to be admitting "anyone"; residents are encountering shackled/guarded residents in common areas – residents with acute mental health episodes, etc. Residents do not believe there is sufficient facility staff to keep them safe; they are unable to get help quickly via call bell.
- Staff seem to be short-tempered when rushed or forced to work overtime to cover for call-offs.
- A few residents reported that they have been scolded by staff; one resident actually stated she felt as though she deserved to be scolded. She said of herself, "I am a lot of work."

Question 8: How would you rate your facility: 1-star – 5-stars?

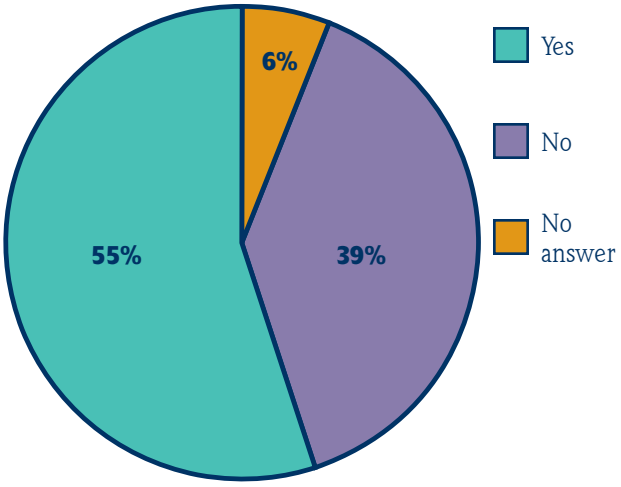


Question 9: If you had the chance to do it over again, would you still live here?



Due to the apparent contradiction of the residents' previous statements and this answer, it was explored in more detail. Most residents expressed a willingness to "settle" rather than be moved and try to adjust all over again. Most were not willing to consider experiencing resettlement again.

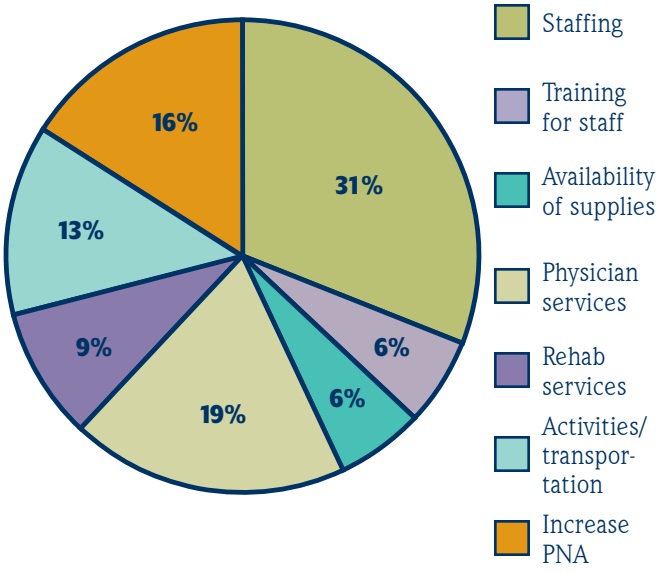
Question 10: Does this feel like your home?



Suggestions/comments from the residents:

- Improve ability for residents to navigate their environment. One resident reported that all the hallways look alike. "It is big and confusing, so I rarely try to venture off my unit."
- Improve lack of control over who becomes their roommate and lack of options when someone is incompatible. Most opt to stay in a less-than-pleasant situation rather than move out of the room they consider "theirs."
- Facility is not "clean/comfortable like my own home would be."
- "In my own home, I'd have my own phone, TV, pets."
- "I have no choice in décor; the common areas look like a hospital; there are no seasonal decorations."
- "Resident council is ineffective and staff fail to follow up on concerns."

Question 11: If you could change the laws and regulations, what would you change?



Availability of equipment: One resident reported that she requires a mechanical lift for transfers, and she always has to wait for two staff and a shared lift – increasing wait times for help.

Question 12: What is the difference between a good day and a bad day?

Resident comments:

- "When I have someone to talk to"
- "Staff who actually care"
- "Bingo"
- "A day without problems"
- "When I'm outside for fresh air"

Summary:

Each group session required between two to 2½ hours to complete. Several of the local ombudsmen involved in the process remarked that the type of questions and allotted time frame allowed for the residents to be more self-disclosing (compared to the resident meetings conducted during a Department of Health survey.)

The residents were all cognitively capable but were very clear in their concern for residents who cannot advocate for themselves or whom they perceive as more vulnerable.

The residents explained that it is often intimidating – and there are possible consequences – for speaking up to facility staff in regards to concerns. There seems to be a willingness to tolerate less than satisfactory care rather than risk making matters worse.

It should be noted that these residents, PEER graduates, are the residents who are best-positioned for self-resolution, so their inability to feel fully satisfied with their care is of noted interest to the long-term care ombudsman program.

The residents were extremely grateful for the opportunity to share this important information with the Task Force. They felt they could do so without fear of retaliation and without concern that their reporting would result in a staff person being fired or disciplined. In addition, it was an important opportunity for the long-term care ombudsman program to learn how we can better serve the consumers who seek guidance from us.

Appendix 2. Materials for proposed additional data collection tools

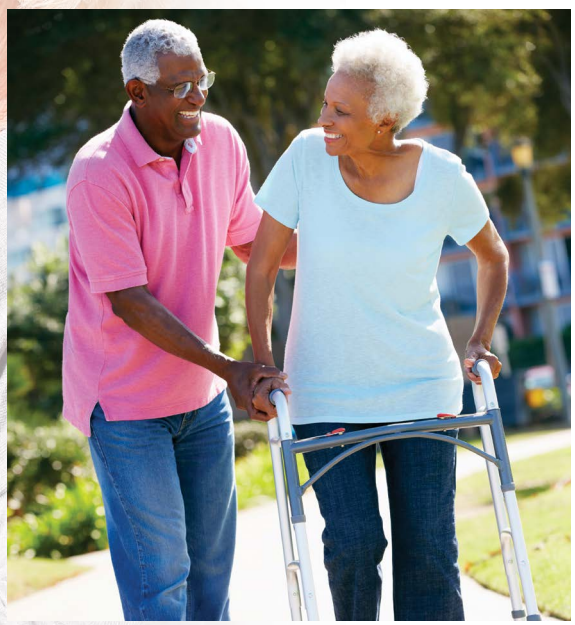
Appendix 2a. Interventions to Reduce Acute Care Transfers (INTERACT) Implementation Checklist; used with permission of the INTERACT program team and Florida Atlantic University

Appendix 2b. Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS), Long-Stay Resident Survey; used with permission from the Agency for Healthcare Research and Quality

Appendix 2c. Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS), Family Member Survey; used with permission from the Agency for Healthcare Research and Quality

Appendix 2d. Kansas Culture Change Instrument (KCCI) for facility leaders; used with permission from Marge Bott, University of Kansas School of Nursing

Appendix 2e. Kansas Culture Change Instrument (KCCI) for facility staff; used with permission from Marge Bott, University of Kansas School of Nursing



Nursing Home Capabilities List

INTERACT®
Version 4.0 Tool

This list is for hospital emergency rooms, hospitalists, and case managers; and for physicians, NPs, and PAs who take off-hours call for the facility to assist with decisions about hospital admission or return to the facility.

Facility _____

Address _____

Tel (_____) _____ **Key Contact** _____

Circle 'Y' for yes or 'N' for no to indicate the availability of each item in your facility.

Capabilities	Yes	No
Primary Care Clinician Services		
At least one physician, NP, or PA in the facility three or more days per week	Y	N
At least one physician, NP, or PA in the facility five or more days per week	Y	N
Diagnostic Testing		
Stat lab tests with turnaround less than 8 hours	Y	N
Stat X-rays with turnaround less than 8 hours	Y	N
EKG	Y	N
Bladder Ultrasound	Y	N
Venous Doppler	Y	N
Cardiac Echo	Y	N
Swallow Studies	Y	N
Consultations		
Psychiatry	Y	N
Cardiology	Y	N
Pulmonary	Y	N
Wound Care	Y	N
Other Physician Specialty Consultations *specify:*	Y	N
Social and Psychology Services		
Licensed Social Worker	Y	N
Psychological Evaluation and Counseling by a Licensed Clinical Psychologist	Y	N
Therapies on Site		
Occupational	Y	N
Physical	Y	N
Respiratory	Y	N
Speech	Y	N

Capabilities	Yes	No
Nursing Services		
Frequent vital signs *(e.g. every 2 hrs)*	Y	N
Strict intake and output (I&O) monitoring	Y	N
Daily weights	Y	N
Accuchecks for glucose at least every shift	Y	N
INR	Y	N
O2 saturation	Y	N
Nebulizer treatments	Y	N
Incentive spirometry	Y	N
Interventions		
IV Fluids *(initiation and maintenance)*	Y	N
IV Antibiotics	Y	N
IV Meds – Other *(e.g. furosemide)*	Y	N
PICC Insertion	Y	N
PICC Management	Y	N
Total Parenteral Nutrition (TPN)	Y	N
Isolation *(for MRSA, VRE, etc…)*	Y	N
Surgical Drain Management	Y	N
Tracheostomy Management	Y	N
Analgesic Pumps	Y	N
Dialysis	Y	N
Advanced CPR *(ACLS capability)*	Y	N
Automatic Defibrillator	Y	N
Pharmacy Services		
Emergency kit with common medications for acute conditions available	Y	N
New medications filled within 8 hours	Y	N
Other Specialized Services *(specify)*		

CAHPS Nursing Home Survey – Long-Stay Resident Instrument (With Instructions)

Instructions for Vendor

- The scripts provided in this document use the questions from the CAHPS Nursing Home Survey – Long-Stay Resident Instrument.
- If you plan to add your own items to this instrument, insert them just before Item Number 39, which begins the "About You" section.
- All questions should include a "REFUSED" response option, which can be on the interviewer's manual notation sheet. Unless otherwise noted, "REF" responses should follow the same skip pattern as the "NO" response option.
- Please be aware that you may need approval from an Institutional Review Board (IRB) in order to conduct this survey. Regardless of whether you need IRB approval, you must get the respondent's consent to participate.

Instructions for Interviewer

- Interviewer instructions appear in [UPPERCASE LETTERS ENCLOSED IN BRACKETS].
- Text in UPPERCASE LETTERS should not be read aloud. For example, "REF" answer categories appear in uppercase and should not be read to the respondent, but may be used for coding a response.
- Interviewers should read aloud all text that appears in **bold, lowercase letters.** Other lowercase text is optional but recommended.
- Interviewers should emphasize <u>text that is underlined</u>.

Introductory Script and Questions

AFTER LOCATING RESIDENT, INTRODUCE SELF & BRIEFLY INTRODUCE SURVEY

Hello, my name is {INTERVIEWER NAME} and I was hoping you'd have some time to talk to me today about how things are going here for you. (IF NEEDED: We're doing a survey to learn about the care that nursing home residents receive and would like your help.)

Would you like to participate in this survey?

- ☐ Yes
- ☐ Yes, but at a later time
- ☐ No

IF R AGREES, GO TO A PRIVATE LOCATION TO CONDUCT INTERVIEW.
IF R DOES NOT HAVE TIME TO PARTICIPATE IN INTERVIEW NOW, ARRANGE AN APPOINTMENT TO GO BACK LATER.
IF NOT, THANK R FOR TIME AND LEAVE.

Before we start, let me tell you a few things about this survey.

The goal of this survey is to learn about the care that nursing home residents receive in this nursing home and to improve the quality of care in nursing homes.

If you agree to take part, we would ask you some questions about your satisfaction with your nursing home care. **This interview should take approximately 20 minutes. Your participation in this study is completely voluntary**. No matter whether you decide to complete the interview or refuse to participate, **your care here will not be affected in any way.**

You can skip over any questions you don't want to answer and you can stop participating at any time.

All of your answers are completely confidential. Your name won't be connected to your answers in any way. No one at the nursing home will know what you said.

By participating in this survey, you will help us develop better ways of assessing nursing home quality. This may benefit residents in the future.

Do you have any questions before we start?

[ANSWER ANY QUESTIONS, THEN GO TO QUESTION 1.]

[HAND R SHOWCARD 1: 0-10]

Now let's talk about how you feel about things at <u>this</u> nursing home and how you feel about the care you get. Remember, when you answer, you can use any number from 0 to 10, where 0 is the worst possible and 10 is the best possible.

1. **First, what number would you use to rate the food here at this nursing home?**

   _____ (0-10)

2. **Do you ever eat in the dining room?**

   1☐ YES
   2☐ NO➔ IF NO, GO TO QUESTION 4

3. **When you eat in the dining room, what number would you use to rate how much you enjoy mealtimes?**

   _____ (0-10)

4. **What number would you use to rate how comfortable the temperature is in this nursing home?**

   _____ (0-10)

5. **Now, think about <u>all</u> the different areas of the nursing home. What number would you use to rate how clean this nursing home is?**

   _____ (0-10)

6. **What number would you use to describe how safe and secure you feel in this nursing home?**

   _____ (0-10)

7. Now, think about all the different kinds of medicine that help with aches or pain. This includes medicine prescribed by a doctor, as well as aspirin and Tylenol. Do you ever take any medicine to help with aches or pain?

1☐ YES
2☐ NO➔ IF NO, GO TO QUESTION 10

8. What number would you use to rate how well the medicine worked to help with aches or pain?

_____ (0-10)

9. What number would you use to rate how well the staff help you when you have pain?

_____ (0-10)

10. What number would you use to rate how quickly the staff come when you call for help?

_____ (0-10)

11. Do the staff help you get dressed, take a shower, or go to the toilet?

1☐ YES
2☐ NO➔ IF NO, GO TO QUESTION 13

12. What number would you use to rate how gentle the staff are when they're helping you?

_____ (0-10)

13. What number would you use to rate how respectful the staff are to you?

_____ (0-10)

14. What number would you use to rate how well the staff listen to you?

_____ (0-10)

15. What number would you use to rate how well the staff explain things in a way that is easy to understand?

_____ (0-10)

16. Overall, what number would you use to rate the care you get from the staff?

_____ (0-10)

17. Overall, what number would you use to rate this nursing home?

_____ (0-10)

[HAND R SHOWCARD 2: YES/NO/SOMETIMES]

For the next questions, you can answer yes, no, or sometimes.

18. Is the area around your room quiet at night?

1☐ YES
2☐ NO
3☐ SOMETIMES

19. Are you bothered by noise in the nursing home during the day?

1☐ YES
2☐ NO
3☐ SOMETIMES

20. If you have a visitor, can you find a place to visit in private?

1☐ YES
2☐ NO
3☐ SOMETIMES

21. Do you visit a doctor for medical care outside the nursing home?

1☐ YES
2☐ NO
3☐ SOMETIMES

22. Do you see any doctor for medical care inside the nursing home?

1☐ YES
2☐ NO
3☐ SOMETIMES

[OBSERVATIONAL SCREENER: IS R ABLE TO MOVE AROUND ALONE - NOT IN WHEELCHAIR?]

1☐ YES➔ IF YES, GO TO QUESTION 26
2☐ NO

23. If you wanted to, can you turn yourself over in bed without help from another person?

1☐ YES➔ IF YES, GO TO QUESTION 26
2☐ NO
3☐ SOMETIMES

24. Are you ever left sitting or laying in the same position so long that it hurts?

1☐ YES
2☐ NO
3☐ SOMETIMES

25. Are you able to move your arms to reach things that you want?

1☐ YES
2☐ NO➔ IF NO, GO TO QUESTION 28
3☐ SOMETIMES

26. We'd like to find out about whether you can reach the things you need in your room. Can you reach the call button by yourself?

1☐ YES
2☐ NO
3☐ SOMETIMES

27. Is there a pitcher of water or something to drink where you can reach it by yourself?

1☐ YES
2☐ NO
3☐ SOMETIMES

28. Do the staff help you dress, take a shower, or bathe?

1☐ YES
2☐ NO➔ IF NO, GO TO QUESTION 30

29. Do the staff make sure you have enough personal privacy when you dress, take a shower, or bathe?

1☐ YES
2☐ NO
3☐ SOMETIMES

30. Can you choose what time you go to bed?

1☐ YES
2☐ NO
3☐ SOMETIMES

31. Can you choose what clothes you wear?

1☐ YES
2☐ NO
3☐ SOMETIMES

32. Can you choose what activities you do here?

1☐ YES
2☐ NO
3☐ SOMETIMES

33. Are there enough organized activities for you to do on the <u>weekends</u>?

1☐ YES
2☐ NO
3☐ SOMETIMES

34. Are there enough organized activities for you to do during the <u>week</u>?

1☐ YES
2☐ NO
3☐ SOMETIMES

[HAND R SHOWCARD 3: DEFINITELY NO/PROBABLY NO/PROBABLY YES/DEFINITELY YES]

For the next question, you can answer definitely no, probably no, probably yes, or definitely yes.

35. Would you recommend this nursing home to others?

1☐ DEFINITELY NO
2☐ PROBABLY NO
3☐ PROBABLY YES
4☐ DEFINITELY YES

[HAND R SHOWCARD 4: OFTEN/SOMETIMES/RARELY/NEVER]

Now I'd like you to use this list of answer choices – often, sometimes, rarely, or never.

36. How often do you feel worried – often, sometimes, rarely, or never?

1☐ OFTEN
2☐ SOMETIMES
3☐ RARELY
4☐ NEVER

37. How often do you feel happy – often, sometimes, rarely, or never?

1☐ OFTEN
2☐ SOMETIMES
3☐ RARELY
4☐ NEVER

[HAND R SHOWCARD 5: EXCELLENT/VERY GOOD/GOOD/FAIR/POOR]

38. In general, how would you rate your overall health – excellent, very good, good, fair, or poor?

1☐ EXCELLENT
2☐ VERY GOOD
3☐ GOOD
4☐ FAIR
5☐ POOR

[HAND R SHOWCARD 6: 0-10]

These next questions are about you.

39. First, we want to know how you feel about your life now. Use any number from 0 to 10 where 0 is the worst possible and 10 is the best possible. What number would you use to rate your life now?

_____ (0-10)

40. In what year were you born?

_____ (YEAR)

41. What is the highest grade or level of school that you have completed?

1☐ **8th grade or less**
2☐ **Some high school, but did not graduate**
3☐ **High school graduate or GED**
4☐ **Some college or 2-year degree**
5☐ **4-year college graduate, or**
6☐ **More than 4-year college degree?**

42. Are you of Hispanic or Latino origin or descent?

1☐ YES, HISPANIC OR LATINO
2☐ NO, NOT HISPANIC OR LATINO

43. What is your race? (IF NEEDED**: Would you say you are...)**

1☐ **White**
2☐ **Black or African-American**
3☐ **Asian**
4☐ **Native Hawaiian or other Pacific Islander**
5☐ **American Indian or Alaska Native**
6☐ **Other (*Please print*)**

_____

44. [INDICATE GENDER]

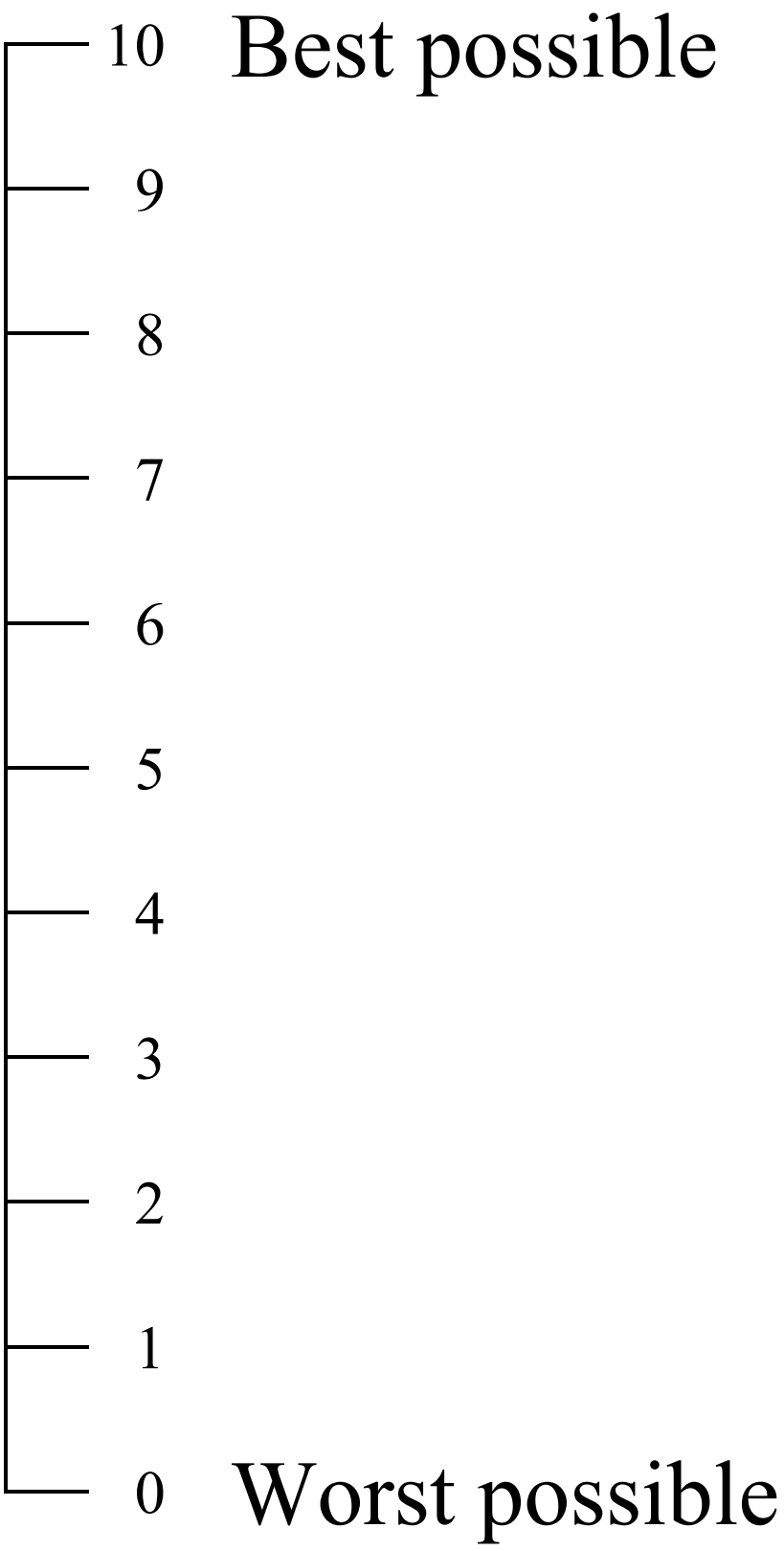
1☐ MALE
2☐ FEMALE

45. [ASK IF NOT OBSERVED] Do you currently have a roommate?

1☐ YES
2☐ NO

Appendix: Showcards With Printed Response Options

(Cards begin on next page)



Showcard #1

Yes

No

Sometimes

Showcard #2

Definitely No

Probably No

Probably Yes

Definitely Yes

Showcard #3

Often

Sometimes

Rarely

Never

Showcard #4

Excellent

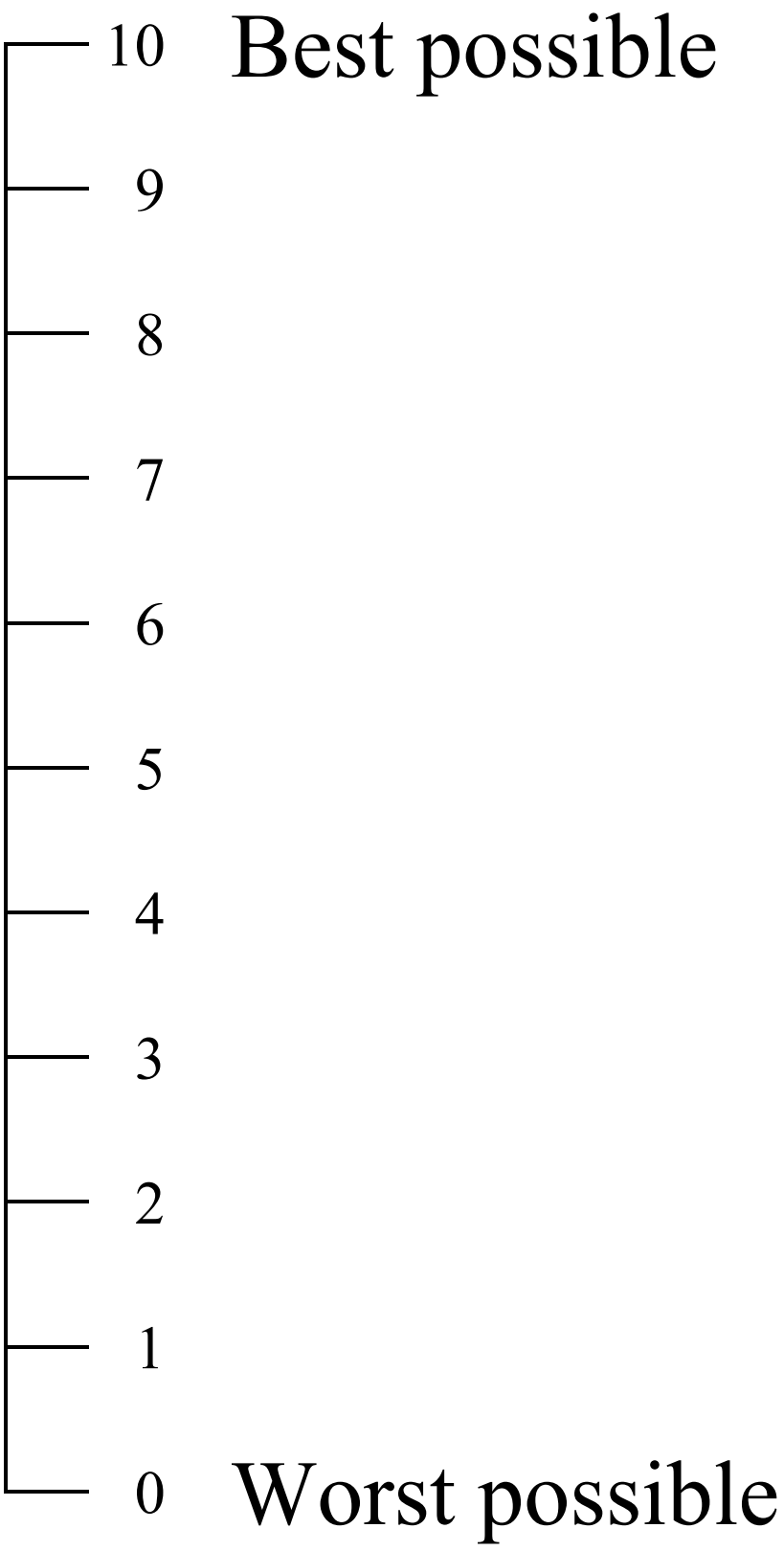
Very Good

Good

Fair

Poor

Showcard #5



Showcard #6

CAHPS® Nursing Home Survey

Version: Family Member Survey

Language: English

Response Scale: 4 points

File name: 1652a_NHFamily_Eng.doc
Last updated: September 1, 2011

Instructions for Front Cover

- Replace the cover of this document with your own front cover. Include a user-friendly title and your own logo.
- Include this text regarding the confidentiality of survey responses:

  Your Privacy is Protected. All information that would let someone identify you or your family will be kept private. {VENDOR NAME} will not share your personal information with anyone without your OK. Your responses to this survey are also completely **confidential**. You may notice a number on the cover of the survey. This number is used **only** to let us know if you returned your survey so we don't have to send you reminders.

  Your Participation is Voluntary. You may choose to answer this survey or not. If you choose not to, this will not affect the care your family member gets.

  What To Do When You're Done. Once you complete the survey, place it in the envelope that was provided, seal the envelope, and return the envelope to [INSERT VENDOR ADDRESS].

  If you want to know more about this study, please call XXX-XXX-XXXX.

Instructions for Format of Questionnaire

Proper formatting of a questionnaire improves response rates, the ease of completion, and the accuracy of responses. The CAHPS team's recommendations include the following:

- If feasible, insert blank pages as needed so that the survey instructions (see next page) and the first page of questions start on the right-hand side of the questionnaire booklet.
- Maximize readability by using two columns, serif fonts for the questions, and ample white space.
- Number the pages of your document, but remove the headers and footers inserted to help sponsors and vendors distinguish among questionnaire versions.

Survey Instructions

Answer each question by marking the box to the left of your answer.

You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

☒ Yes → **If Yes, go to #1 on page 1**
☐ No

The Resident

1. Who is the person listed in the cover letter?

[1] ☐ My Spouse/Partner
[2] ☐ My Parent
[3] ☐ My Mother-in-Law/Father-in-Law
[4] ☐ My Grandparent
[5] ☐ My Aunt or Uncle
[6] ☐ My Sister or Brother
[7] ☐ My Child
[8] ☐ My Friend
[9] ☐ Other

Please print: _____

_____

2. For this survey, the phrase "family member" refers to the person listed in the cover letter. Is your family member now living in the nursing home listed in the cover letter?

[1] ☐ Yes → **If Yes, go to #4**
[2] ☐ No

3. Was your family member discharged from this facility or did he or she die?

[1] ☐ Discharged → **If Discharged, Stop Here. Please return this survey in the postage-paid envelope.**
[2] ☐ Deceased → **If your family member is deceased, we understand that you may not want to fill out a survey at this time.**

If you would like to fill out the rest of the survey, we would be very grateful for your feedback. Please go to #5 and answer the questions about your family member's last 6 months at the nursing home. Thank you for your help.

4. Do you expect your family member to live in this or any other nursing home permanently?

[1] ☐ Yes
[2] ☐ No
[3] ☐ Don't know

5. In total, about how long has your family member lived in this nursing home?

[1] ☐ Less than 1 month → **If less than 1 month, Stop Here. Please return this survey in the postage-paid envelope.**
[2] ☐ 1 month to almost 3 months
[3] ☐ 3 months to almost 6 months
[4] ☐ 6 months to almost 12 months
[5] ☐ 12 months or longer

6. In the last 6 months, has your family member ever shared a room with another person at this nursing home?

[1] ☐ Yes
[2] ☐ No

7. Does your family member have serious memory problems because of Alzheimer's disease, dementia, a stroke, an accident, or something else?

[1] ☐ Yes
[2] ☐ No

8. In the last 6 months, how often was your family member capable of making decisions about his or her own daily life, such as when to get up, what clothes to wear, and which activities to do?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

Your Visits

Please answer the following questions only for yourself. Do not include the experiences of other family members.

9. In the last 6 months, about how many times did you visit your family member in the nursing home?

- [1] ☐ 0 to 1 time → **If 0 to 1, go to #43 on page 6**
- [2] ☐ 2 to 5 times
- [3] ☐ 6 to 10 times
- [4] ☐ 11 to 20 times
- [5] ☐ More than 20 times

10. In the last 6 months, during any of your visits, did you try to find a nurse or aide for any reason?

- [1] ☐ Yes
- [2] ☐ No → **If No, go to #12**

11. In the last 6 months, how often were you able to find a nurse or aide when you wanted one?

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

12. In the last 6 months, how often did you see the nurses and aides treat your family member with courtesy and respect?

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

13. In the last 6 months, how often did you see the nurses and aides treat your family member with kindness?

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

14. In the last 6 months, how often did you feel that the nurses and aides really cared about your family member?

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

15. In the last 6 months, did you ever see any nurses or aides be rude to your family member or any other resident?

- [1] ☐ Yes
- [2] ☐ No

16. In the last 6 months, during any of your visits, did you help your family member with **eating**?

- [1] ☐ Yes
- [2] ☐ No → **If No, go to #18**

17. Was it because the nurses or aides either didn't help or made him or her wait too long?

- [1] ☐ Yes
- [2] ☐ No

18. In the last 6 months, during any of your visits, did you help your family member with **drinking**?

[1] ☐ Yes
[2] ☐ No → **If No, go to #20**

19. Was it because the nurses or aides either didn't help or made him or her wait too long?

[1] ☐ Yes
[2] ☐ No

20. Help toileting includes helping someone get on and off the toilet or helping change disposable briefs or pads. In the last 6 months, during any of your visits, did you help your family member with **toileting**?

[1] ☐ Yes
[2] ☐ No → **If No, go to #22**

21. Was it because the nurses or aides either didn't help or made him or her wait too long?

[1] ☐ Yes
[2] ☐ No

22. In the last 6 months, how often did your family member look and smell clean?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

23. Sometimes residents make it hard for nurses and aides to provide care by doing things like yelling, pushing, or hitting. In the last 6 months, did you see any resident, including your family member, behave in a way that made it hard for nurses or aides to provide care?

[1] ☐ Yes
[2] ☐ No → **If No, go to #25**

24. In the last 6 months, how often did the nurses and aides handle the situation in a way that you felt was appropriate?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

Your Experience With Nurses & Aides

25. In the last 6 months, did you want to get information about your family member from a nurse or an aide?

[1] ☐ Yes
[2] ☐ No → **If No, go to #27**

26. In the last 6 months, how often did you get this information as soon as you wanted?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

27. In the last 6 months, how often did the nurses and aides explain things in a way that was easy for you to understand?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

28. In the last 6 months, did the nurses and aides ever try to discourage you from asking questions about your family member?

[1] ☐ Yes
[2] ☐ No

The Nursing Home

29. In the last 6 months, how often did your family member's room look and smell clean?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

30. In the last 6 months, how often did the public areas of the nursing home look and smell clean?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

31. Personal medical belongings are things like hearing aids, glasses, and dentures. In the last 6 months, how often were your family member's personal medical belongings damaged or lost?

[1] ☐ Never
[2] ☐ Once
[3] ☐ Two or more times

32. In the last 6 months, did your family member use the nursing home's laundry service for his or her clothes?

[1] ☐ Yes
[2] ☐ No → **If No, go to #34**

33. In the last 6 months, when your family member used the laundry service, how often were clothes damaged or lost?

[1] ☐ Never
[2] ☐ Once or twice
[3] ☐ Three or more times

34. In the last 6 months, were you ever unhappy with the care your family member received at the nursing home?

[1] ☐ Yes
[2] ☐ No → **If No, go to #36**

35. In the last 6 months, did you ever stop yourself from talking to any nursing home staff about your concerns because you thought they would take it out on your family member?

[1] ☐ Yes
[2] ☐ No

Care Of Your Family Member

36. In the last 6 months, have you been involved in decisions about your family member's care?

[1] ☐ Yes
[2] ☐ No → **If No, go to #38**

37. In the last 6 months, how often were you involved as much as you wanted to be in the decisions about your family member's care?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

Overall

38. Using any number from 0 to 10, where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate the care at this nursing home?

☐ 0 Worst care possible
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 Best care possible

39. If someone needed nursing home care, would you recommend this nursing home to them?

[1] ☐ Definitely no
[2] ☐ Probably no
[3] ☐ Probably yes
[4] ☐ Definitely yes

40. In the last 6 months, how often did you feel there were enough nurses and aides in this nursing home?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

You And Your Role

Please remember that the questions in this survey are about your experiences. Do not include the experiences of other family members.

41. In the last 6 months, did you ask the nursing home for information about payments or expenses?

[1] ☐ Yes
[2] ☐ No → **If No, go to #43**

42. In the last 6 months, how often did you get all the information you wanted from the nursing home about payments or expenses?

[1] ☐ Never
[2] ☐ Sometimes
[3] ☐ Usually
[4] ☐ Always

About You

43. What is your age?

- [1] 18 to 24
- [2] 25 to 34
- [3] 35 to 44
- [4] 45 to 54
- [5] 55 to 64
- [6] 65 to 74
- [7] 75 or older

44. Are you male or female?

- [1] Male
- [2] Female

45. What is the highest grade or level of school that you have completed?

- [1] 8th grade or less
- [2] Some high school but did not graduate
- [3] High school graduate or GED
- [4] Some college or 2-year degree
- [5] 4-year college graduate
- [6] More than 4-year college degree

46. Are you of Hispanic or Latino origin or descent?

- [1] Yes, Hispanic or Latino
- [2] No, not Hispanic or Latino

47. What is your race? Mark one or more.

- [1] White
- [2] Black or African-American
- [3] Asian
- [4] Native Hawaiian or other Pacific Islander
- [5] American Indian or Alaska Native
- [6] Other

48. What language do you mainly speak at home?

- [1] English
- [2] Spanish
- [3] English and Spanish equally
- [4] Some other language

49. Did someone help you complete this survey?

- [1] Yes
- [2] No → **If No, go to #51**

50. How did that person help you? Mark one or more.

- [1] Read the questions to me
- [2] Wrote down the answers I gave
- [3] Answered the questions for me
- [4] Translated the questions into my language
- [5] Helped in some other way

Please print: _____

_____

_____

Optional

51. Is there anything else you'd like to say about the care your family member gets at this nursing home?

Please print: _____

_____

_____

_____

_____

_____

Thank you.

Please return the completed survey in the postage-paid envelope.

Kansas Culture Change Instrument (KCCI)
Leader Questionnaire

INSTRUCTIONS

PLEASE CAREFULLY READ THE FOLLOWING

"Culture change" is an effort to make a nursing home less like an institution and more like a home while maintaining quality of life for those who live and work there. Core values include choice for residents, improving quality of care, staff empowerment and creating a homelike setting.

Tell us about your nursing home. Please answer each question as you believe it really is, not as you think it should be.

For the following questions please circle the number that best describes the way you feel about each question. For example, if you wish to answer **"Always"** then circle the "4" in the column that is marked **"Always"**

RESIDENT CARE

Please circle the number in the column that best describes your response	Never	Some times	Often	Always
1. Residents choose when they eat each meal.	1	2	3	4
2. At mealtime, residents help themselves or tell staff what they want to eat.	1	2	3	4
3. Residents choose the time of day they bathe.	1	2	3	4
4. Residents choose the way they bathe (for example, shower, bed bath or bathtub).	1	2	3	4
5. Care plans are based on residents' requests.	1	2	3	4
6. Residents can sleep late and still get breakfast.	1	2	3	4
7. Residents go to bed for the night at any time they want.	1	2	3	4
8. This nursing home has activities designed for residents with memory problems.	1	2	3	4
9. Residents, who are able, dress themselves even if it takes a long time.	1	2	3	4

NURSING HOME ENVIRONMENT

Please circle the number in the column that best describes your response	Never	Some times	Often	Always
1. Residents decorate their own rooms.	1	2	3	4
2. Residents can meet with visitors in a living room shared by a small group of residents.	1	2	3	4
3. Residents eat in a dining room shared by a small group of residents.	1	2	3	4
4. This nursing home has live indoor plants and flowers.	1	2	3	4
5. This nursing home has pets here.	1	2	3	4
6. Children from the community come to visit residents.	1	2	3	4
7. This nursing home looks and “feels” like home.	1	2	3	4
8. Spur of the moment activities happen here.	1	2	3	4
9. This nursing home displays residents’ personal items, such as family photos, in common living areas outside of their rooms.	1	2	3	4
10. Residents can get to outdoor spaces without staff help.	1	2	3	4

RELATIONSHIPS

Please circle the number in the column that best describes your response	Never	Some times	Often	Always
1. Staff work with the same group of residents.	1	2	3	4
2. Families know who takes care of their loved ones.	1	2	3	4
3. The outside community is involved in nursing home activities.	1	2	3	4
4. We meet with family members to explain their role in their loved one's care.	1	2	3	4
5. Families visit their loved ones.	1	2	3	4
6. This nursing home has community volunteers.	1	2	3	4
7. Children from the community participate in programs with residents in the nursing home.	1	2	3	4
8. This nursing home takes time to remember residents who die.	1	2	3	4
9. Residents and staff are encouraged to talk about their feelings when a resident dies.	1	2	3	4
10. Residents choose to spend time with each other on their own.	1	2	3	4

Kansas Culture Change Instrument (KCCI)
Leader Questionnaire

For the following questions **"Staff"** refers to all employees of the nursing home in all departments. **"Direct care staff"** refers to employees who provide hands-on resident care. For example, the CNAs, CMAs, licensed nurses, social services, activities, dietary workers and therapy staff.

STAFF EMPOWERMENT

Please circle the number in the column that best describes your response	Never	Some times	Often	Always
1. Direct care staff have input into resident care planning.	1	2	3	4
2. Certified aides take part in resident care plan meetings.	1	2	3	4
3. Direct care staff know when a resident's care plan has been changed.	1	2	3	4
4. Staff teams create their own work schedules.	1	2	3	4
5. Staff work together to cover shifts when someone can't come to work.	1	2	3	4
6. Staff are cross-trained to perform tasks outside of their assigned job duties.	1	2	3	4
7. This nursing home gives raises and other rewards to staff who receive extra training or education.	1	2	3	4
8. Direct care staff take part in quality improvement teams.	1	2	3	4
9. Staff are empowered to contact family directly when a resident has a personal need.	1	2	3	4
10. Staff grow as individuals here.	1	2	3	4

Kansas Culture Change Instrument (KCCI)
Leader Questionnaire

For the next questions, "**Nursing home leaders**" refers to the Administrator, Director of Nursing and Department Heads.

NURSING HOME LEADERSHIP

Please circle the number in the column that best describes your response	Never	Some times	Often	Always
1. Nursing home leaders value team members from all departments.	1	2	3	4
2. Decisions in the home are made by teams that involve direct care staff.	1	2	3	4
3. Nursing home leaders hire staff who really care, not "just anyone".	1	2	3	4
4. Nursing home leaders try to improve working conditions.	1	2	3	4
5. Nursing home leaders ignore ideas from staff.	1	2	3	4
6. Nursing home leaders ask questions with an open mind.	1	2	3	4
7. Nursing home leaders are available when staff need to talk.	1	2	3	4
8. Supervisors treat aides with respect.	1	2	3	4
9. Exit interviews are conducted when staff leave.	1	2	3	4
10. Changes in operations are made as a result of exit interview data.	1	2	3	4

SHARED VALUES

Please circle the number in the column that best describes your response	Never	Some times	Often	Always
Nursing home leaders and staff share values and common goals related to:				
1. Homelike environment	1	2	3	4
2. Choice for residents	1	2	3	4
3. Respect for residents	1	2	3	4
4. Respect for co-workers	1	2	3	4
5. Decision making	1	2	3	4
6. Quality of life for residents	1	2	3	4
7. Quality of work life for staff	1	2	3	4

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For the following questions please circle the number that best describes the way you feel about each question. For example, if you wish to answer **"Strongly Agree"** then circle the "4" in the column that is marked **"Strongly Agree"**

QUALITY IMPROVEMENT

Please circle the number in the column that best describes your response	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
1. Staff turnover at this nursing home is low.	1	2	3	4
2. This nursing home evaluates our care and services to make improvements.	1	2	3	4
3. The data we collect help identify problems with services.	1	2	3	4
4. This nursing home has a plan for lowering turnover.	1	2	3	4
5. This nursing home actively tries to keep employees working here.	1	2	3	4
6. Staff are updated about budget and cost changes.	1	2	3	4
7. Direct care staff, including aides, have input into the budget to care for their residents.	1	2	3	4
8. Staff ideas are used to reduce wasted time and effort.	1	2	3	4
9. The leadership team discusses staff turnover.	1	2	3	4
10. We have a plan to increase staff retention.	1	2	3	4
11. The leadership team uses MDS reports for quality improvement initiatives.	1	2	3	4
12. Direct care staff attend quality improvement meetings.	1	2	3	4

Is your nursing home currently involved in culture change? (Select only one)

_____ There is *no discussion* around culture change

_____ Culture change is *under discussion*, but we *haven't changed* the way we take care of residents

_____ Culture change has *partially changed* the way we care for residents in *some* or all areas of the organization

_____ Culture change has *completely changed* the way we take care of residents in *some areas* of the organization

_____ Culture change has *completely changed* the way we take care of residents in *all areas* of the organization

How many years has your nursing home been involved in culture change activities? (Select only one)

_____ Not involved in culture change
_____ Less than 1 year
_____ 1-2 years
_____ 3-4 years
_____ 5 or more years
_____ I don't know

Do residents in your nursing home live in small households or neighborhoods?

_____ Yes
_____ No

Kansas Culture Change Instrument (KCCI)
Staff Questionnaire

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For the following questions please circle the number that best describes the way you feel about each question. For example, if you wish to answer **"Strongly Agree"** then circle the "4" in the column that is marked **"Strongly Agree"**.

QUALITY IMPROVEMENT

Please circle the number in the column that best describes your response.	**Don't Know**	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
1. Most of my co-workers have been at this nursing home a long time.	0	1	2	3	4
2. This nursing home evaluates our care and services to make improvements.	0	1	2	3	4
3. The data we collect help identify problems with services.	0	1	2	3	4
4. This nursing home has a plan for lowering turnover.	0	1	2	3	4
5. This nursing home actively tries to keep employees working here.	0	1	2	3	4
6. Staff are updated about budget and cost changes.	0	1	2	3	4
7. Direct care staff, including aides, have input into the budget to care for their residents.	0	1	2	3	4
8. Staff ideas are used to reduce wasted time and effort.	0	1	2	3	4

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NURSING HOME QUALITY IMPROVEMENT TASK FORCE MEMBERS

NAME	AFFILIATION
The Honorable Matt Baker	State Representative, Majority Chair, House Health Committee
Barbara Bowers, RN, PhD, FAAN	University of Wisconsin-Madison
Michael Brunelle	Special Assistant to the Governor, Office of the Governor
Jen Burnett	Deputy Secretary of Long Term Living, Pennsylvania Department of Human Services
Corey Coleman	Executive Deputy Secretary, Pennsylvania Department of Health
Ted Dallas	Secretary, Pennsylvania Department of Human Services
Sarah Galbally	Policy Secretary, Office of the Governor
David Grabowski, PhD	Harvard University
Steven Handler, MD, PhD, CMD	University of Pittsburgh
Dana Mukamel, PhD	University of California, Irvine
Karen Murphy, RN, PhD	Secretary, Pennsylvania Department of Health
Mary Naylor, PhD, FAAN, RN	University of Pennsylvania
Teresa Osborne	Secretary, Pennsylvania Department of Aging
Andrea Rosso, PhD, MPH (Task Force Facilitator)	University of Pittsburgh
The Honorable Pat Vance	State Senator, Majority Chair, Senate Public Health and Welfare Committee
Rachel Werner, MD, PhD	University of Pennsylvania
Jacqueline Zinn, PhD	Temple University