Development and Maintenance of Post-Acute Care Cross-Setting Standardized Patient Assessment Data

Focus Group Summary Report

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Post–Acute Care Stakeholders Focus Group Report

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Post-Acute Care Stakeholders Focus Group Report

Introduction

Background

The purpose of this project is to support CMS efforts to develop, implement, and maintain standardized assessment-based data elements for post-acute care (PAC) in order to facilitate care coordination and interoperability and improve Medicare beneficiary outcomes as mandated in the Improving Medicare Post-Acute Care Transformation Act of 2014 (IMPACT Act of 2014).[1] Furthermore, the IMPACT Act intends that such standardized data be used to compare quality across PAC settings, improve hospital and PAC discharge planning, and that the use of the information be applied to reform PAC payments while ensuring continued beneficiary access to the most appropriate setting of care.

The types of providers covered by the IMPACT Act of 2014 include skilled nursing facilities (SNFs), home health agencies (HHAs), inpatient rehabilitation facilities (IRFs) and long-term care hospitals (LTCHs). Existing PAC assessment instruments − Minimum Data Set (MDS), Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI), Outcome and Assessment Information Set (OASIS), and LTCH CARE Data Set (LCDS) − are neither standardized nor interoperable in that the settings use different assessment items, items are created, collected, and reported in many different ways, and conclusions from assessments in one setting cannot be directly compared or transferred across facilities. Implementation of standardized assessment items across PAC settings, facilitated by health information technology (HIT), is compelling at multiple levels and has important implications for Medicare beneficiaries, families, providers, and policymakers.

CMS has contracted with RAND to develop and test standardized post-acute care assessment data elements that could meet the requirements of the IMPACT Act of 2014 and contribute to care planning, quality measurement, cost estimation, better care transitions and interoperable data exchange. The contract name is Development and Maintenance of Post-Acute Care Cross-Setting Standardized Assessment Data. The contract number is HHSM-500-2013-13014I. As part of its item standardization development process, CMS requires that contractors convene groups of stakeholders and experts who contribute direction and thoughtful input to the contractor.

IMPACT Act of 2014 domains under consideration for development by RAND in the first year of the project include: cognition and mental status; medication reconciliation; care preferences; pain; and impairments in hearing, vision and continence.

The specific aims of this project are to:

- To develop and test standardized PAC patient assessment data elements (i.e. assessment items) and associated response codes across the four PAC settings.
- Gather cross-setting feedback on importance, feasibility, usability and potential impact of the item standardization changes under consideration.

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[1] https://www.govtrack.us/congress/bills/113/hr4994

- Identify setting-specific needs/concerns/barriers when standardizing assessment data elements under the specified domains.

Purpose of the focus groups

Stakeholder input is critical to development efforts and comprises central activities in this project. The purpose of the focus groups was to better understand provider and consumer experiences with the current patient assessment process in PAC settings, with a focus on what works well, what challenges arise, and ideas for improving the process in the context of standardized data collection. We also sought provider and consumer input on data elements and assessment approaches across specific clinical domains under consideration for inclusion in a standardized instrument, including medication reconciliation, cognitive function, mood, delirium, urinary and bowel incontinence, vision impairment, hearing impairment, pain, and care preferences. Information from the focus groups will be used to improve the patient assessment process where appropriate through the use of a standardized instrument, guide selection of data elements for pilot testing, and the development of instructions and training manuals. This report summarizes our findings from each of the focus groups we conducted, organized by the key domains under consideration.
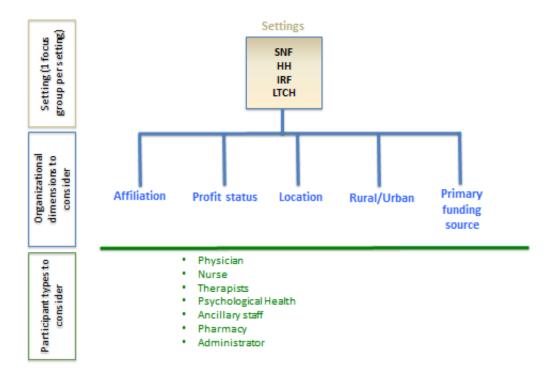
Methods

Approach

We chose focus groups to elicit stakeholder experiences, perspectives and ideas regarding the PAC patient assessment process. In contrast to other one-on-one interview methods, focus groups provide access to comparisons that participants make between their experiences, which can provide 1) an understanding of the consensus and diversity of opinions on a given topic and 2) additional depth and nuance deriving out of group interactions. This was particularly salient to our efforts to obtain input from a broad range of stakeholder participants for the purpose of understanding how to optimally standardize patient data collection across PAC providers and settings.

Participant Selection and Recruitment

We conducted provider focus groups for each of the four post-acute care settings (SNFs, LTCH, HHAs, and IRFs) as well as one consumer focus group for patients, informal caregivers, ombudsmen, and patient advocacy group representatives.

We selected participants to achieve diversity and balance across several dimensions including: participant discipline, geographic location, and experience in rural/urban settings. We also sought to balance participants' experience in facilities or agencies based on: affiliation, profit status, and primary funding source, and to avoid duplication by organization across and within focus groups. The diagram below shows the framework we used to select focus group participants.

Figure 1: Framework for Selecting Setting-Specific Focus Group Participants

We solicited nominations for focus group participants via a formal Request for Nominations sent to a broad range of stakeholder individuals, agencies and associations. Nominators were asked to identify individuals they felt would be suitable for a particular provider or consumer focus group, and to complete a brief nomination form capturing relevant nominee characteristics. We applied objective criteria to selecting nominees from among those that were received by the nomination deadline (we selected among late nominations only if and when optimal balance and diversity within a focus group could not be achieved with on-time nominations). First, we started by assuring diversity and balance across the following dimensions:

1. Discipline (for providers only)
2. Geography (U.S. Census Bureau Region and Division)
3. Rural/urban

In cases where more than one nominee filled a given dimension, we used another dimension to make the selection. For example, if we received nominations for two physicians (discipline) who were both from the Mid-Atlantic division (geography), we used rural/urban setting to break the tie, with preference given to nominees with experience in a setting not otherwise represented in the focus group.

Then, we used the following dimensions to additionally guide our selection of nominees:

- Profit status (for-profit, non-profit, government)
- Affiliation (free-standing, hospital based)
- Where additional information was provided by the nominator, relevance of history, training, or experience of nominee to planned discussion areas

For example, if the nominees described above both had experience in rural settings, we would use profit status to break the tie, with preference for nominees not otherwise represented in the focus group (e.g. choosing the nominee with non-profit experience if the majority of our other focus group selections represented the for-profit setting).

Selected nominees were sent an invitation letter with focus group details. When invited nominees were unable to attend, we identified replacement nominees to invite, prioritizing discipline and avoiding duplication of employing organization within focus groups.

Data collection and analysis

We undertook a traditional approach to conducting the focus groups. Each focus group was led by a primary facilitator (Ahluwalia), with facilitation assistance from a second team member (Saliba). One dedicated note-taker was present at each focus group and additional team members supplemented written and observational notetaking. Each focus group was also audio-recorded, transcribed and reviewed to ensure completeness and accuracy of the key findings.

The facilitator used an approved guide to facilitate discussion, which included the use of key questions and relevant probes to stimulate discussion and collect information regarding feasibility, utility/value, appropriateness, accuracy, comprehensiveness, and patient-centeredness. Questions were organized around the current assessment process in each setting and the assessment process for each of the domains of interest (cognitive function, medication reconciliation, impairments including vision and hearing impairment and urinary and bowel incontinence, care preferences, care transitions). (See Appendix A).

Two research team members independently synthesized and organized focus group notes according to the primary question prompts, with oversight from the domain leads and project director. We also applied a directed content analysis approach to the focus group transcripts, and organized findings by the primary question prompts. This focused analytic approach was informed by the specific questions we sought to answer and the information we hoped to obtain to guide our item selection and pilot-testing process.

Results

Participants

A total of 36 providers and 10 consumers participated in the focus groups. Focus groups included from 7 to 11 participants each. A range of provider disciplines were represented in the focus groups, including physicians (n=5), nurses (n=11), physical therapists (n=5), occupational therapists (n=2), speech and language pathologists (n=3), respiratory therapists (n=2), and pharmacists (n=2), among others (Table 1). In the consumer focus group, attendees included PAC consumers (n=3), family caregivers (n=4), patient advocates (n=2) and 1 PAC consumer who was also a family caregiver. Full participant lists are included in Appendix B.

Table 1: Diversity of Disciplines Represented in the Focus Groups

Discipline	SNF	HH	IRF	LTCH	TOTAL BY DISCIPLINE
Physician (MD, DO)	2		2	1	5
Nurse (RN, LVN/LPN, APRN)	4	4	2	2	12
Physical Therapist	1	1	3		5
Occupational Therapist		1	1		2
Speech & Language Pathologist	1	1	1		3
Respiratory Therapist				2	2
Social Worker	1				1
Psychologist			1		1
Chaplain				1	1
Pharmacy Representative	1			1	2
Administrator	1	1			2
TOTAL BY FOCUS GROUP	11	8	10	7	36

Key Findings

Our discussion of focus group results begins with a presentation of the major themes that arose across the provider focus groups. Then we present in greater detail the findings from each of the four provider focus groups, organized by domain, including: a) the overall assessment process; b) care transitions; c) medication reconciliation; d) cognition, including cognitive function, delirium and mood; e) impairments, including urinary and bowel incontinence and vision and hearing impairment; f) pain; and g) care preferences. Finally, we present separately a summary of the major themes that arose from the consumer focus group.

Cross-setting Themes

Theme 1: PAC staff endorsed the need for standardized, comprehensive assessment that would follow the patient along the continuum of care

Most focus group participants highlighted many benefits of standardized assessment, including promoting care coordination and improving the information available to tailor treatment to a patient's needs. There was some concern about the extent to which unique setting-specific needs would be adequately reflected.

Theme 2: PAC staff discussed limitations and drawbacks of "formal" assessment for some patients or for some domains

Despite their endorsement of standardized assessment, some focus group participants described situations or topics for which observation or clinical opinion was used more often than interview-based or other formal assessments. This theme emerged in discussions of cognitive function, mood, delirium, and hearing and vision assessment. For example, some participants described assessing hearing and vision based on the observation that the patient was wearing glasses or using a hearing aid, rather than through a

formal test. Several PAC staff suggested that performance measures –such as assessing whether the patient could read written materials, could walk safely, or could hear their provider talking to them -- were more meaningful assessment metrics than a standard test of vision and hearing acuity. Similarly, for cognition, several participants thought that assessment information pertaining to the patient's ability to manage their medications (e.g., remember medication instructions) would be useful. The use of formal assessments was somewhat dependent on the availability of resources; participants at facilities with a psychologist or speech and language pathologist on staff described using formal assessment methods more often than those without access to such resources.

Some focus group participants also discussed limitations of assessing pain with existing items, in particular assessing pain on a numeric scale. Others felt the scale worked better with verbal labels. They cited the inherent subjectivity of self-reported pain ratings as a challenge, but also discussed the even greater challenge of assessing pain through observational means (e.g., grimacing, agitation) in patients who were sedated or who were cognitively impaired. Panelists also raised the other concern that screening for certain conditions might lead to labels that could be harmful for the patient. This concern was raised for mood, cognition and continence. Finally, several participants mentioned that obtaining information and completing assessments for patients admitted late on Fridays was an overall challenge.

Theme 3: PAC staff described challenges of current assessment instruments

Some focus group participants, particularly those from the SNF setting, cited the time required to complete the assessments as a challenge. In addition, current assessment instruments were blamed by some PAC staff with increasing the "silo-ing" of care, wherein the complexity of some sections meant that specific providers complete different portions of the assessment, depriving all of a comprehensive view of the patient's situations. Several PAC staff raised the issue that aspects of hearing, vision, bladder and bowel function and status, and cognition are not captured fully or well by existing assessments. Several participants noted challenges around measuring pain, including lack of baseline assessment and the issue of the timing of pain assessment (e.g. during activity versus resting).

Theme 4: Optimal PAC assessment is patient−centered and takes into account patient experiences

Some PAC staff emphasized that optimal assessments would seek to capture how much an impairment or condition bothers the patient (e.g. hearing, incontinence), and the full context around impairments. In the same vein, some focus group participants discussed the importance of understanding the range of preferences and goals, including for daily life and routine care, and patient's priorities for their preferences.

Theme 5: Recommendations for improvements or future assessment

Some focus group respondents recommended including "gateway" questions that had the potential to shorten the overall assessment by gathering detailed information only when a patient's response indicated that further assessment was warranted. The example discussed was the case of assessing mood. Other participants recommended pain screening that would account for timing issues (e.g., episodic or activity-induced pain). Some participants felt that assessing type of vision (e.g., peripheral versus central, visual field assessment) would be an improvement to future assessments. Many participants, particularly from HH and IRF settings, discussed how patient engagement in therapy is an important dimension of PAC

that is not currently assessed. It was noted that engagement could be a useful predictor of outcomes in PAC settings, and that understanding the level of engagement could be informative in addressing patient preferences for care and in developing a patient-centered care plan. Information on the home environment was another area in which many focus group participants suggested that further standardized assessment could support discharge planning. Participants felt that this information was relevant to assess upon admission to a PAC setting to guide the care plan, to prepare and educate caregivers, and to set appropriate goals and expectations with the patient at the outset of treatment.

Theme 6: Care transitions could be improved with better information from the hospital

Overall, focus group participants thought a standard set of information should follow patients across settings: things that any care settings would want on admission should be provided at discharge, to support the care transitions but also the plan of care overall. In all provider focus groups, several participants described insufficient information transfer from hospitals.   Several participants also reported challenges related to getting accurate and timely information about medication for medication reconciliation, especially among patients coming from acute care settings. Other areas noted as important for transfer of information from the hospital included pain levels in the prior setting, last pain medication, bowel patterns, cognition, preferences that "let us plan ahead" and delirium. Some participants felt that hospital diagnosis lists did not tell them the active conditions that would be important in PAC. This was less of a concern for facilities that received all of their patients from facilities with whom they shared an EHR.

Detailed Findings by Domain and Focus Group

Current Assessment Process – Benefits, Challenges, and Recommendations

Home health participants found the OASIS data set helpful, noting it helped to standardize care processes, to develop an "all-encompassing" understanding of the patient, and to develop comprehensive and patient-centered care plans. Participants also cited limitations, including that the tool forces them to evaluate multiple domains and items, without a primary focus; it is not a clinically intuitive assessment; patient data are not immediately available to support care planning; the tool emphasizes completing items, causing clinicians to overlook the tool's value for care planning; and the tool does not assess patient engagement which is critical to successful treatment. One participant summed this up as *"It doesn't seem that it was intended to be decision supported. . .It's data gathering…The feedback to the clinician to the bedside care is not timely and it would be helpful if it were"*. Many participants said the tool took too long to complete and consumed the entire visit, often detracting from important interpersonal relationship and bedside care. Some felt that many of the OASIS items were developed for an institutional context and made less sense in the home context, and also that assessment information from the hospital did not necessarily translate into the home context. They provided the example of assessing the patient's ability to don clothing, which in the hospital means the ability to put on a hospital gown, but at home entails the much more complex task of putting on a shirt, pants and shoes.

SNF participants generally reported positive experiences with the MDS, finding it helpful for patient assessment and focused on patient-centered care. They also mentioned some limitations: the MDS requires multiple clinicians to contribute to the various parts of the assessment leading to silo-ing of the

assessment process, as one participant stated *"The assessment becomes siloed.. You have nursing doing their assessment. You have social services doing their assessment. You have activities doing theirs, you have rehab doing theirs. And then you have an MDS coordinator trying to pull it all together, and that becomes the challenge."* In addition, the language of some items can be very discipline-specific or might not have a standard interpretation. Some found the MDS too long and viewed some of the information collected as less relevant to PAC. An alternative approach espoused by many of the participants was to incorporate "gateway" items, that determined the relevance of a particular domain to the patient, and would allow for skip patterns for domains screened out as less relevant. Another suggestion was to have greater "micro-interoperability" of language between different disciplines.

IRF participants generally liked both IRF-PAI for assessing general patient needs, particularly in the areas of physical function, but less so for psychosocial functioning. They urged assessing patient engagement in care and including information on prior functional status, since a good current performance might be worse than a previous one. Participants expressed concern about adding items and length to the instrument, "assessment fatigue," and the need for more resources (time, money, staff) to complete even longer assessments. Participants generally agreed that a limitation of the assessment process was that it tended to create disciplinary siloes because of the amount of information needed from different providers, which consequently made it difficult to obtain a whole-person understanding of the patient. Participants also wanted a simple but meaningful score, to quickly identify patients who might need additional attention. Some participants commented that the hospital could contribute to this score by projecting where they envisioned the patient going after PAC (e.g. home, nursing home, etc.).

LTCH participants viewed standardization as beneficial if it could reflect the complexities and variability of LTCH patients compared to patients in other PAC settings. To this effect, one participant commented: "*I would like to think that one benefit [to standardization] is that there's a better understanding of the complexity of the patients in the LTCH setting because they're extremely complicated, and I think that that really is missed currently*". They identified challenges in the current assessment process: many clinicians use clinical judgment to assess patients, not standardized tools; most LTCHs still do not use an electronic medical record, complicating standardization and information transfer; the LCDS does not fully reflect LTCH patient needs--for example, not enough attention to preventing multi-system organ failure. Participants noted that some items (e.g., walk 10 feet with a turn) are only relevant to a small proportion of LTCH patients.

Transitions in Care: barriers, facilitators and needs pertaining to information transfer

In general, focus group participants discussed care transitions and needs pertaining to information transfer as they addressed the different domains, and these are described in each of the domain sections. A few comments not specific to the domains are described here.

Home health participants emphasized the disconnect between patient assessment in institutional settings and home health, noting the implications for information transfer. This disconnect primarily hinged on the fact that institutional settings had a structured and systematized processes that are absent in home settings One participant put it as follows: "*They're assessing what they can do in a controlled environment, not what they could do in their home. And that's where there is that disconnect between how they look when they leave and [after] they leave*" . They noted that ADL information from the acute care setting may not translate to the home setting – e.g., patients might be assessed as needing no assistance with eating or

medication reconciliation but in the hospital, these processes are guided by structured timelines and daily reminders or assistance that may not be available at home. One participant commented on how this had a potentially adverse impact on patients being discharged to home unprepared for more independent living: "*People are dumped on, right? That's what happens in the hospital – 'Don't do anything. Stay there. We don't want the liability if you fall. We'll do everything. Oh, guess what? You're going home tomorrow and you can do this, this, this, this, this'.*"

SNF participants emphasized the need for more standardized assessment information from the acute care setting when patients were first admitted to the SNF. They believed the MDS collection time could be shortened if some core data were provided by the hospital. For short stay patients, information that could help start and advance the rehabilitation process was critical to receive at admission. Specific information desired included the reason for the hospital admission, overall physical and cognitive status, medication lists, and accurate active diagnoses. Some participants commented that they relied on the H&P and discharge summary to guide the SNF care plan after admission. Participants also thought the hospital should be part of efforts to improve and standardize the assessment process; standardized patient assessment data should follow the patient across the continuum, starting with acute care. One participant noted: "*What I would love to see is that, it's not just for our four post-acute care settings. If we're going to continue to have the condition of participation that require the hospitalization beforehand then we've got to say, 'Look, Hospital, you've got to provide this, too.' To me, that's the start of breaking down the silos.*" They felt information about the resources available at home should be available at the start of care in order in order to develop reasonable goals and a care plan.

IRF participants also observed that information coming from the acute care setting was often missing, requiring additional time and communication to track the data down. For instance, one participant pointed out that "*It seems that, by and large, we know what we're looking for, but the challenge is whether or not that information gets fed to you.*". Information that participants wanted to receive in a systematic manner included functional status, medical status, prior history, current and prior medications, mental status, vision and hearing ability and some social/environmental information relevant to rehabilitation success. They felt the information they wished to receive at admission should be the same information they send out at discharge, but were unsure about whether this happened routinely. They noted the importance of assessing whether or not care recommendations to a patient could be implemented after discharge, which may depend on the availability and skills of the caregiver: "*We need to do a better job of determining when people are going home whether they can do the things that we're suggesting they do and also whether or not the caregivers can provide the support that we're indicating the person needs.*" Unlike other groups, IRF participants stressed the importance of sending information about the patient to the primary care provider at discharge, to support continuity of care and facilitate post-discharge success.

Medication Reconciliation

Home health participants described medication reconciliation and drug regimen review as distinct processes: the former entailed a side by side comparison of past and current medication lists and addressing mismatches. One participant noted: "*I would say probably 90 percent of the time, they don't match*" and the latter was a review of drug-drug and drug-food interactions to confirm medication appropriateness. They noted challenges to the medication reconciliation process in the home health setting, such as the lack of adequate information about medications from the hospital, particularly since

many discharges happen on Fridays, and including the fact that prescribing staff are often not available over the weekend to assist with the reconciliation process and that the primary care physician often does not know what other providers prescribed in the hospital. Participants viewed patients as the most reliable source of information about their medications, as well as the actual contents of their "shoebox" of medications at home: *"So literally, we actually ask them [patients] to pull all their medications together and put it on the kitchen table so that we can talk to them about it. And that's where it starts."* Participants also felt that it was important to assess the patient's preferences for medications and whether or not the patient chose to take a medication or not, as an indicator of the success of the regime.

SNF participants viewed "medication reconciliation" and "drug regimen review" as distinct but gave different definitions than the home health group: *"They are totally different activities...it can be damaging or frightfully scary with the patient if we start mixing the two. Medication reconciliation is...look at the patient before, during, and future. And get everything aligned. Medication regimen is nothing more than checking the list of what they're taking."* Participants highlighted challenges with receiving information about medications from the acute setting regarding a patient's medications, in particular, a lack of information regarding the rationale for hospital medications, and a lack of information about the medications the patient was taking upon admission to the acute care setting. Some participants felt the medication reconciliation process should extend from the home to the hospital to the PAC setting, to home again, with a focus on assessing current need for any medications that might have been started in the hospital: *"So the 80-year-old who gets discharged from the hospital on 12 medicines doesn't have to go home two weeks later on 12 medicines."* A few participants expressed doubt about whether the MDS or any standardized PAC assessment instrument needed to address medication reconciliation; they felt that it was absolutely part of the care planning and general assessment process but not necessarily part of the MDS. Some participants expressed concern about the burden of time related to the medication reconciliation process.

IRF participants also distinguished between medication reconciliation and drug regimen review but described medication reconciliation as the process of identifying what medications a patient was on before and during the hospital stay, and described drug regimen review as part of that process. The discharge summary and MAR, as well as the pharmacy list of patient medications, were mentioned as the best source of information for medication reconciliation. Participants viewed medication reconciliation as time-consuming but essential: *"It takes a lot of communication, it takes a lot of telephone calls when you don't understand why somebody's on something . . . the medication is such a critical part . . . you can do great damage to somebody if you don't get it right."* They also highlighted a need to assess the patient's experience and understanding of their medications because patients might have strong beliefs and values about their medications that influence the likelihood of adherence. Participants agreed that standardizing the medication reconciliation process would be valuable with provider accountability (e.g.; sign-off) built in, and some indicated that the lack of penalties and accountability for sending missing or incorrect information about medications confounds the medication reconciliation process.

LTCH participants described medication reconciliation as the process of comparing the medications the patient took at home, in the hospital, and then in the LTCH setting. They also noted the importance of assessing whether there is continuity in the patient's medications and whether the medications were all still appropriate and made sense for the patient. One patient noted: " *. . . physicians are often reluctant to make changes to what other physicians have started..."* and another similarly commented: *"I think*

there's a tendency for physicians who are new to the case to just continue everything as it is rather than spending a lot of time doing that critical analysis and review to see what could be modified or reduced or eliminated." Some participants viewed nurses as a reliable source of information about the patient's medications; others relied more on the history and physical from the sending facility. A few said the patient was the most reliable source, depending on how engaged and knowledgeable they are. Most felt that medication reconciliation would be difficult to standardize but was important to assess beyond just whether or not it was done.

Cognitive Function

Home health participants viewed cognition as critical to survival in the home, but felt that the OASIS did not capture the complexity of cognition adequately. They thought that the outcomes of the cognitive assessment were very time-dependent since a patient's cognition varied during the day: *"We don't see them through the day, you know. And your cognition in the morning might be very different than it is in the afternoon."* These participants judged it more important to assess functional cognition-- patient's ability to problem-solve, complete daily tasks, and follow instructions. As one participant remarked: *"It doesn't matter who the President is. But can I actually get the lid off the jar or know to call someone to help me so I can eat? Can the person direct their self-care.? Do they have enough verbal skills? Can they understand two- and three-step direction? Can they read something?"* They viewed transferring information about communication difficulties across settings as important in identifying potential cognitive limitations, and thought a baseline assessment, prior to hospital discharge, would be particularly helpful as a point of comparison.

SNF participants mentioned some limitations to the BIMS, including the perception that scores could vary greatly over the course of a single day: *"the BIMS score could easily range from 9 to 15 depending on the time of day that the social worker completes the assessment"*, and that long-term patients often memorize it and are able to "game" it. A few participants felt that the language of the BIMS and the process of administering it could be insulting to patients. Although some suggested the MOCA as an alternative, most participants felt that it was important to include a simple explanation and lead-up to the cognitive assessment to offset patient anxiety and defensiveness. They thought it also important to know if a patient could read or follow instructions because those capabilities had implications for adherence to medication and care plans and ability to achieve care goals: *"...because they can be totally cognitive and totally with it and they can't read their prescription label and can't take their medicines right, or don't know what to do if the therapist says you need to do this exercise."* Participants wanted basic information about a patient at care transitions, including prior diagnoses of dementia or a mood disorder, and whether or not the patient was evaluated for delirium.

IRF participants reported using a range of different instruments to assess cognitive function. They described important information about cognition that they look for, including the ability to follow instructions and sequence activity and to execute a complex management task, particularly IADLs like medication management. A few noted an apparent disconnect between executive functioning and the FIM, with patients not being able to manage living in the community despite performing well on the FIM. Participants wanted a simple approach to assessing cognitive function that could be delivered by different specialties and be appropriate for different settings. A few participants felt assessing the patient's level of awareness of their cognitive difficulties was critical to treatment and recovery but not currently captured.

LTCH participants remarked that it is challenging to assess cognition because patients may not be conscious, may be heavily medicated, or may be dealing with a lot of trauma. Much of the focus on assessing cognition was described as reviewing medication lists and ensuring that the patient is only on the most appropriate medications, discontinuing unnecessary medications.

Mood

Home health participants stressed the importance of wording when evaluating for depression, and suggested questions such as "what do you enjoy" and "how many bad days did you have last week", with a focus on learning from the patient what makes their mood better or worse. Participants also noted that observation of depression was important while acknowledging that isn't always feasible in HH. Some suggested that finding alternative words to "depression" might be helpful and may mitigate patient fears that they will be negatively labeled if they answer positively to depression screens: *"That questioning may trigger fear, which triggers a non-compliant or a non-truthful answer because no one's really getting to the point of 'I want you to function better, how can I help you?'"*

SNF participants highlighted the importance of recognizing situation depression and the grief pertaining to loss that might arise from being in an institutional setting: *"Who doesn't have a bad mood, but it shouldn't be that you're penalized on an assessment because you've had a bad day."* They also preferred "gateway" screening questions to determine the need for a longer depression assessment. They noted that it was useful to get information from the hospital about existing depression or anxiety medications, as well as any indications of delirium or delirium medications that might cause depressive symptoms. Some participants felt that it was useful to conduct an observational assessment by looking at how much patients are eating, whether the patient is active or engaging with other patients. Said one participant: *"…from my standpoint, it's just more about observation, communication, listening, and talking about it."*

Most IRF participants felt that assessing change in mood (i.e.; what the patient was like prior to PAC) was critical to identifying possible depression. Some relied on staff and family input to identify signs of depression versus administering a formal assessment: *"We have neuropsychologists but the family's absolutely critical in saying, 'Gosh, my loved one is just not sort of the same. They just don't have that level of enthusiasm'."* Participants mentioned some limitations of the PHQ-9, including a) much of what is being asked could be attributed to natural and expected situational depression rather than a more permanent issue; b) communication barriers such as aphasia, limited literacy and cognition might limit the use of the PHQ-9 and c) some of the language of the instrument might be offensive or upsetting to patients. Some also noted that the 2-week lookback period in the PHQ-9 might not be enough time to really capture significant depression. One participant noted that a: *"…challenge is in a three-week length of stay. It says for the last two weeks. And they've only been injured for three weeks by the time we get them. So there hasn't been enough time to distinguish feeling sad or having an acute reaction"*. A few participants thought knowing the extent to which depression has interfered with a patient's therapy was a more useful data point. Despite these perceived limitations, most participants thought a screener like the PHQ-9 might be useful. Participants noted that information about medications, anxiety about the next setting, and family caregiver mood were important to collect and transfer at care transition points.

LTCH participants also had mixed comments regarding screening for mood. Some felt that many of their patients met technical criteria for expected situational depression; that medication would only be effective after the patient was discharged; and that diagnosis of major depression required a 3-month

timeframe, longer than most LTCH patients would be in the setting. Participants did feel that it was important to assess whether the patient was suicidal, on psychotropics, or had resources and coping mechanisms to help manage their mood. Some participants did not find the PHQ-9 salient for their context, expressing concern about false positives due to situational depression and the potential for over-prescribing. Some specifically noted that the item "little interest or pleasure in doing things" was likely to apply to anyone in an acute or PAC setting, where there is not a lot of choice of enjoyable activities. The potential for mood symptoms to contribute to poor outcomes and increased cost was recognized as a possible reason to identify symptoms if labeling could be avoided.

Delirium

 Assessment of delirium was not mentioned frequently; in a few focus groups it was described as a largely informal process relying predominantly on nurse observation and information from the hospital on transfer into PAC. **Some SNF participants** described using the Confusion Assessment Method, or CAM tool, but most described a less formal approach to assessment including observation, particularly of any changes, communication with patient and family, and a reliance on family perceptions of the patient's behavior. One participant noted: *"It is important to not underestimate the value of the family. If family that really does…see that person all the time says 'Mom's just not right', then really hearing that and really not ignoring it."* **Most LTCH participants** said they were not using a formal scale to assess delirium, but rather based assessment on observation and clinical judgment. Some participants relied on a staff psychologist to confirm delirium after an initial screen. They also noted that for many LTCH patients, they are unable to assess delirium at all.

Urinary and Bowel Incontinence

 Home health participants described assessing incontinence usually by the smell *("use your nose!"*), in addition to questions such as "have you ever had urinary incontinence" and "how have you changed what you do because of worry about wetting yourself". They noted that often the cause of an incontinent event is something that can be modified; one participant commented: *"Are you incontinent because you truly have bladder issues or that you have such tremendous knee pain that you put off going to the bathroom for so long that by the time that you go, now it's leaking because as you're scurrying over to the bathroom you're leaking*?" Participants mentioned the kind of information needed to assess bowel incontinence, including pain medications and bowel protocols, hydration, mobility, and the hospital transfer bowel regimen.

SNF participants felt that there are many nuances to an incontinent event that are not captured in the MDS. They described situations where the patient might not have anyone available to help them in time to the restroom: "*Are they incontinent because they've been on their call light for 15 minutes? The aides are all in one room and nobody's there to help them go to the bathroom*" - which would then be documented as an incontinent event. They also described how being labeled as incontinent has important implications for cognition, function, and the ability to go home. Families are particularly concerned about caring for loved ones with incontinence. Said one participant: "*Families can take care of almost anything but bladder or bowel incontinence, taking Mom home, it's all of a sudden, oh, that's a different ballgame."* Most participants thought it essential to talk to a patient about their continence to understand underlying context and reasons, and to evaluate the resources available to a patient – both in the SNF

setting as well as at home, in preparation for discharge - to get them to a toilet in time. They also felt that it was important to assess whether or not the patient was bothered by the incontinence, and the extent to which it was impacting their well-being.

Participants noted the importance of evaluating dietary changes and infections that could contribute to changes in bowel patterns. They felt that assessments should identify constipation early to avoid impaction and to ensure that an appropriate bowel regimen was implemented. One participant remarked: *"I tell students, residents, and young physicians that I believe it's malpractice if you have somebody on an opiate and do not put them on a bowel regimen from day one"*. A few participants also noted another limitation of the MDS - that identifying constipation or bowel impaction on Day 7 is too late: *"You wait your standard of three days, and then you're waiting on day four. Does that make sense to go four days without a bowel movement? In the end, by the seventh day, it's way too late."* This suggests that relying on the MDS may be leading nurses and other providers to not think critically about the issue and talk to patients about it earlier.

IRF participants described urinary incontinence as *"uncontrolled discharge"* or *"involuntary loss of urine,"* emphasizing the importance of evaluating how much the issue bothered the patient. Regarding assessment, they felt it was important to have a conversation with the patient about it in order to capture the nuances and causes of incontinent events and presence of true incontinence. Information about frequency of incontinent events was also described as important. Regarding bowel incontinence, participants felt that descriptions (e.g.; smell, consistency, type) are important to assess, as is opioid use, mobility, whether an abdominal exam was performed, time of last evacuation, and presence of constipation. Some participants noted that information from the prior setting of care regarding the last stool was critical but often unavailable.

LTCH participants said they primarily assessed whether or not the patient had a catheter and if not, whether or not the patient was continent, but acknowledged that the diagnosis of urinary incontinence was loosely defined. Most participants felt that continence in the LTCH setting was largely tied to ringing the call button in time, and having staff arrive in time to provide assistance to the toilet. Incontinence was also described as a nursing diagnosis rather than a medical diagnosis. Bowel incontinence was assessed in a similar fashion, with most participants noting that stool characteristics tended to be on everyone's radar in an LTCH. A challenge is determining whether or not a comatose person feels the urge/sensation to go: *"It's pretty easy with the conscious, cognizant person. Because even if they soil the bed, a nurse comes in and they say something like, 'I just couldn't hold it any longer' or 'I rang the bell and nobody came' or 'oops, news to me.' For the unconscious person, I don't know that we've really figured that out. I mean how do you tell if, in the extreme case, a comatose person had urge and sensation?"* Bowel impaction was also described as important to assess in the LTCH setting; most participants described having a standardized bowel protocol in place for opioid users.

Vision Impairment

Home health participants noted that for the most part, they assessed vision observationally during the assessment process, for example, by noticing whether the patient is able to check a box, sign their name, or read labels or the newspaper; whether the patient bumped into things in the house; and whether they wore eyeglasses. Participants remarked: (P1)*"I am looking for where they pour the pills out onto a plate...is there one that rolled off and they didn't see it because that is how a vision impairment can very*

adversely affect a patient . . . if the medications don't all get into their mouth"; (P2)*"If they don't turn off the knob to the stove...they can't see that it's actually in the off position.";* (P3) *"Safety issues in the kitchen are huge... if the kitchen is dark and they've got sharp objects out, and they don't see that."* Based on this approach, some participants preferred the wording of the question about vision to incorporate "have patients demonstrated…" rather than requiring assessors to ask patients about their vision, particularly since some patients might not be aware of their vision impairments. These participants also suggested a question such as "Can the patient safely do X, Y, or Z" to capture a more functional assessment of vision. A few said that certain disciplines, e.g.; PT or OT, might also detect limitations in vision during their work with the individual.

SNF participants remarked that in general there was no systematic process for assessing vision impairment other than noting whether or not the resident had glasses: *"Either they come in with glasses or they don't, basically. If they don't and they've lost them, it takes a few days to figure that out".* Participants also felt that more attention should be given to evaluating vision. Instead of a formal assessment, however, most preferred asking simple questions such as "can you see enough to read and walk down the hall?" to assess functional vision acuity. Some had residents attempt to read. Some also noted the importance of family as a source of information regarding vision impairment: *"You get that kind of information from family members who have to come in and visit. Because they'll say 'where's his glasses?' That's when you find out he's been wearing glasses for 50 years."*

IRF participants felt that it was important to assess vision (and hearing) impairment because of its impact on the care plan and disposition. Type of vision (central versus peripheral, visual fields, extraocular movements, pupil reaction) was described as being important to collect as part of an assessment. They also described a need for information such as the impact of visual impairment on a patient's function, medical supplies or devices needed, community resources available to patients with visual impairment, and ability to drive as important for supporting a successful transition to home.

LTCH participants described minimal vision assessment, consisting just of asking whether the patient used glasses or contacts and if so, if they had brought them along. One participant felt that hearing and vision were not important for very sick patients. On the other hand, most other participants felt it was important to know whether the patient could hear or read instructions and take medications on their own, but acknowledged that little attention is given to vision or hearing assessment in the LTCH. One described routine professional assessment of vision and hearing in their facility. Most participants noted that little information about a patient's vision was provided at admission (other than if the patient was blind), or sent out upon discharge from the LTCH. Most did not think a formal vision test was necessary, preferring function-focused assessment.

Hearing Impairment

Home health participants mostly described sending patients who they thought, based on an initial screening, might be hearing impaired to see an audiologist for a more formal evaluation. They also raised the issue of distinguishing between a cognitive issue and a hearing-related issue, and some said they incorporated this into their assessment by evaluating whether the patient was able to understand the conversation. One participant described this type of assessment in the following way: *"I said something to you about your medications and I'm asking you to repeat it back to me, you know, teach-back, that's the 'is this a cognitive issue' or 'is this a hearing issue' in terms of why you can't tell me kind of what we*

just talked about type of thing." One participant recommended a screening call prior to the assessment visit to understand how well the patient is able to hear and communicate over the phone.

SNF participants noted that, as with vision impairment, there was no formal hearing assessment, other than identifying the patient's use of a hearing aid; however, they acknowledged that in many circumstances, the patient might not come in with the aid either because they do not like to wear it or because the family wouldn't let them take the aid to the SNF for fear of losing it. Despite the lack of a formal assessment, most participants felt that evaluating hearing was very important because of the safety issues involved; for example, not being able to hear a phone or doorbell ring, not being able to follow and understand directions and thus being unable to participate fully in their therapy.

IRF participants often described evaluating hearing as part of their usual interaction with the patient; one said they assessed basic function with a "clap test". Some IRF participants highlighted the difficulty they faced in obtaining specialty consults to evaluate hearing impairment. They generally felt that it was important to assess, because it could help uncover underlying cognitive impairment but felt that barriers to consults impeded assessment. Some participants also felt that it was important to assess a patient's attitude toward hearing (and vision) impairment, since some patients might not consider hearing loss an issue and consequently might not want to use aids. One participant commented: *"I think an important piece is what is the patient's attitude about their vision and the hearing? The number of years it took for me to get my mother to wear a hearing aid, and she still doesn't acknowledge that she has a hearing problem... versus the individual who recognizes, acknowledges and embraces, and self-limits appropriately around that."*

LTCH participants described minimally assessing hearing impairment, primarily by asking if the patient used a hearing aid. One participant asks patients: *"'Hearing aids, yes or no?' And if the answer is no, then they kind of decide you've got good hearing or kind of marginal hearing."* They noted that it was important to know whether the patient could hear their provider talk, and if they could hear the intercom, but beyond that, were less concerned with actual hearing loss. They also noted that little information about a patient's hearing was provided at admission, or sent out upon discharge from the LTCH. Most did not think a formal hearing test (beyond finger rubs or watch ticking tests) was necessary or even feasible. One participant noted: *"My view of that is that's overkill because what we really want…is can they hear me talk?"*.

Pain

Home health participants noted challenges to assessing pain in the home health setting. Some noted that the OASIS items related to pain were often miscoded because of how the patient perceives or experiences pain. An additional challenge is how to address conflicts between the patient's report of pain and the provider's observational assessment of pain. One participant suggested using two complementary approaches: *"One is absolutely a question you must ask of the patient and you must record their perception of what they think they're experience is. The second one can and should be based on your observation of their performance."* Another consideration was that pain might be identified by multiple clinicians at different times; e.g., by the PT who notices wincing during exercise as well as the nurse who asks the patient about pain, but currently there is only one question and an assumed single assessor, without place for others to contribute their impressions of the patient's pain. Many participants described

relying on and documenting their observational assessment; for example among patients with cognitive limitations or even among patients whose report of pain seemed inconsistent with observation.

SNF participants described using different pain scales in their practice, not in any systematic or standardized manner. They expressed some frustration with the numeric rating scale because of the need to provide additional explanations about the different levels: *"You have to explain 1 to 3 is for mild pain. You have to sort of tell them what 1 to 10 is.";* but agreed that it was necessary to establish at least some understanding of the patient's pain level. They remarked that it was important to know what a tolerable or acceptable pain level for each patient was, giving the example of chronic pain patients for whom a 6 on a 0-10 scale might be acceptable and experienced as "managed" pain. Participants also said that information regarding timing was important, for example, what the patient's pain is before and after therapy, before and after medication, and whether or not the pain assessment was administered when the patient was possibly hungry or tired.

IRF participants said that pain was assessed most commonly using a numeric rating or visual analog scale, and was treated as the 5th vital sign. A few noted that these scales, while necessary, were difficult to use because of their inherent subjectivity: "*We have to objectively interpret their subjective response*"; one participant described pain assessment as a "moving target." Most participants felt that pain should be assessed throughout the day during every shift, and regularly monitored and managed. For patients with cognitive impairment or who were sedated, pain was assessed via facial expression (e.g.; grimacing) and non-verbal behaviors such as restlessness and through changes in vital signs. Participants agreed that pain assessment and management was a challenging issue in IRFs because some amount of pain might be expected with treatment, and there is a need to balance adequate pain control with continued treatment to improve functional ability. Said one participant: *"We tend to [err] on the side of treating the pain especially because the population we see are usually experiencing acute pain... it is difficult to get a really true accurate reflection, but because it's such a big variable in outcomes we do tend to be aggressive about pain management*". Some suggested that a useful approach might be to ask patients how satisfied they are with the level of pain management.

LTCH participants described using a range of approaches to assess pain in their patients, including the faces scale, the numeric rating scale, vital signs and observational cues such as grimacing, agitation and fidgeting. They stressed the importance of observational pain assessment in the LTCH setting and the importance of asking the patient what their tolerable pain level is and their general pain preferences. A participant noted that: *"...our job is not to make your pain go away, it's to improve your function with the pain that you can tolerate*". With unconscious patients, participants described having to make certain assumptions about pain, such as assuming they are in pain if they have a wound. Some suggested additional questions pertaining to pain, including "is your pain adequately treated?" and "is pain interfering with your plan of care?".

Care Preferences

Home health participants described a range of preferences that they thought were important to assess, including how much help a patient would want, how they would like to be cared for, what their goals for care are, including: *"...where do they want to remain? Do they want to stay out of the hospital? Are they open to assisted living and thing[s] like that*", preferences for family involvement in care, preferences for traditional versus alternative therapies, and preferences for daily routine and activities. One way to assess

this is to *"…have them walk through what time do they usually get up, how things would go, how long about, how long it would take between the time they got out of bed and they got to the kitchen for breakfast. And just listen to them talk about what is their daily routine."*. They noted that language was important when asking about care preferences, and suggested a broad question such as "*What does a good day look like? What does a bad day look like*?" to help initiate an assessment of preferences. Many participants agreed that capturing preference information in the acute care setting was critical to setting up the care provided in the home, particularly with identifying what needs to be in place before the transition occurs.

SNF participants provided a range of preferences and goals that they considered important to assess, including preferences regarding hobbies and interests, physical activity, provider gender and time of day for rehabilitation, activities, and goals for beyond PAC such as being able to walk independently or return home. One participant commented: "*It's really that patient's voice for that current setting.*" Participants noted the importance of distinguishing between provider goals for the patient and the patient's goals for care, with an emphasis on assessing the patient's voice to facilitate successful rehabilitation. They also emphasized the importance of a "functional reconciliation" between provider and patient goals, and between desired and realistic patient goals (i.e. what a patient wants to achieve and what they are able to achieve). One participant remarked: "*It's a great opportunity to . . . look at what they want in terms of overall goals and also understanding how they get from one level to the next.*" They felt that it would be important to assess a patient's preferences for involvement in decision-making, particularly where there might be cognition issues, as long as the family voice did not overwhelm the patient's voice.

IRF participants described patient care preferences broadly, including the patient's broad values and goals, advance directives, preferences for personal and family involvement in care, preferences for daily routine, preferred language, and what the patient would like to be called. Some participants noted that patient care preferences were variably assessed in their facilities, and they questioned the extent to which preference information was being documented and shared among the team. They also noted that patient-identified preferences and the provider's recommendations should be clearly distinguished in an assessment process and emphasized the importance of reconciling any differences between patient and provider goals. One participant noted that it is important that: "*There's communication between the therapist and the patient about their goals…some of that is going to be a process because it's an adjustment…they start out with, 'Well, I want to walk,' then over time, okay 'I'd like to at least be able to be independent in my wheelchair' or 'use a walker.' They wouldn't accept that goal to begin with, but come to terms with it over time*" In general, participants felt that it was important and useful to have patients prioritize their goals, given the limitations of what rehabilitation can achieve in a limited time period and the need to focus rehabilitation efforts. They suggested questions such as "what kind of function is most important to you" and "what options are acceptable to you." Participants felt that the spectrum of patient preferences should be transferred across settings, and suggested assessing and documenting preferences for each domain (e.g.; preferences for disposition, preferences for mobility).

LTCH participants had differing perspectives on assessing patient care preferences. Some felt that it was a necessary and important area for assessment, albeit challenging: One participant noted *"It's a hard conversation and we have responsibility to ask the questions"* and another commented "*It's perilous because the patient reserves the right to change on a moment's notice and they often do – 'I want to live. I want to die. I want this treatment. I don't want this treatment'. That's not to say we shouldn't be having*

those conversations regularly, it's just challenging." Others felt that preference assessments are only salient if there are true choices to be offered, and that most LTCH patients have few or no choices in the short-term. Some participants felt that by accepting or seeking care in a LTCH, the patient's preference, i.e., to receive intensive intervention and be willing to endure some pain or discomfort in order to get better, was already implicitly known. This led others to note that it was important to have a patient's preferences explicitly assessed prior to LTCH admission, for example, in the acute care setting. Participants desired specific information from the prior setting of care, including who made the decision to enter an LTCH and when, and whether the patient had expressed preferences regarding IV medications, antibiotics, fluids, dialysis.

Consumer Focus Group: Comments about Patient Assessment

Participants in the consumer focus group echoed many of the comments about the value and challenges of assessment made in the provider groups. They unanimously expressed frustration that patients and their caregivers are often not included in the assessment process. Participants emphasized the importance of involving and engaging patients in care decisions and in the development of the care plan. They thought it important to be asked about their care preferences, particularly around daily activities and routine, and for patient and caregiver involvement in healthcare decision making. One participant noted that her loved one was often not asked about her goals for care because of assumptions regarding her cognitive capacity: *"I have a daughter who is very cognitively [challenged], but when it comes to her well-being...you better believe all of a sudden those neurons kick in. So it would have been helpful for her to have been asked, 'What else are your goals? What do you hope to do when you get home?' That was never asked".*

A few participants stressed the need for assessment items that were more culturally sensitive, given that some minority groups have a lack of trust and fear losing services or being denied care based on their responses to assessment items. One participant noted: *"One of the key issues for a patient to open up is building trust. If you don't trust the doctor or the nurse, you're never going to open up. So step one in any assessment is...does the patient trust me."* Another participant pointed to more institutional and structural factors pertaining to trust that might affect assessment outcomes: *"It's about trust and the fact that trust has not been built in this country...I just think we need to begin to address this...by not putting barriers into the most simple things and saying, 'Yes'. If somebody's on Medicaid and they need the simplest tools, the simplest shower chair, the simplest whatever, how can you say no?"*

Participants also highlighted limited assessment of whether a return to home is feasible, based on caregiver capacity to provide what is needed. One participant noted: *"I think CMS should be asking the question, 'In the return to home, who is at home that is physically and cognitively and intellectually able to care for a stroke patient, spinal cord, any kind of a patient?' And not just able . . . willing and able."* They described a disconnect between the discharge plan and what actually happens once the patient is home, and wished for better resources to support in-home care, include an assessment of social support and community-based resources.

With respect to medication, they noted the need for more information about the rationale for prescribing certain medications and for more consistent and simpler information across pharmacies regarding medication instructions (e.g.; take 3 times per day versus take every 8 hours) to avoid errors.

Reflecting provider participant comments about the need to prepare patients for certain types of questions, they felt strongly that it should be explained to patients why a cognitive test was being administered. One participant described the experience of a friend: "*Her reaction was that she was offended. 'Why are they asking me these questions and making me draw a clock? Do they think I'm losing my mind? Is that why you're asking?' I think it wasn't explained why, that it is just part of good care.*" Most felt that cognitive function was an important domain for assessment.

Participants thought it was important to assess mood and regularly evaluate for depression but expressed some concerns that screening would lead to increased use of medications to treat depression; they expressed a strong preference for non-pharmacologic approaches. This was especially important to participants who felt that mood was directly related to context, i.e.; being in a PAC setting: "*Mood reflects environment. I had a stroke. Of course my mood's going to be impacted and I don't need drugs. I need to know that I have hope and I have a good treatment plan, and I'm going to get better. And don't give me a drug to fix my mood when something like a stroke happened.*" They had mixed responses to the PHQ-2, with one panelist being concerned that background rates of hopelessness in minority communities might present challenges with any data element asking about hopelessness or similar mood components. Some participants suggested alternative questions: "Why are you feeling this way?" and "What can we do today to make your care better?"

The Consumer group viewed the first step in addressing impairments in continence as evaluating the patient's willingness to talk about it, and to have the discussion in terms that patients could understand. They also felt it was important to lay the groundwork to normalizing the topic before asking about incontinence; a few participants noted that there might be particular sensitivities based on gender. Most participants expressed concern that incontinence was more a reflection of staff inattention and lack of assistance, especially at night. Participants also emphasized the importance of bringing in the patient's caregiver where appropriate, to ensure adequate support: "*In addition to asking the patients how are you going to manage this at home, also make sure that, if there is a caregiver involved, that you ask that of the caregiver too…knowing not only that they're willing and able to do, but also making sure that they understand that's going to have to be part of the caregiving responsibilities*".

Vision assessment was underscored as important, with participants mentioning a functional assessment as a robust approach (e.g..; asking whether the patient can read a newspaper with their glasses). Like providers, they thought hearing impairments should be assessed for safety reasons. A few participants noted that formal hearing assessment was also important because of a patients' ability to hide potential impairments; they gave examples of family members pretending to be able to hear by nodding to avoid notice of impairment.

Consumer participants thought trust in the provider and the facility was critical to adequate pain assessment and management. Some expressed concerns about facility reliance on pharmacologic interventions despite patient preferences for non-pharmacologic pain management, while others noted inequities in access to pain medication. They viewed a numerical scale as difficult to consistently attach meaning to: "*Pain is very subjective; if you have a high pain tolerance you can say your pain is a 3, and if you have a low pain tolerance, you can say 10. And you can be totally over-medicated*". Participants suggested that the numerical sale should be anchored with words or labels at least for the two ends of the

pain scale (0 and 10). Some felt that pain questions should ask about the effect of pain on the person's ability to do what they want to do.

Conclusions

The stakeholder input obtained through these focus groups revealed several consistent themes that provide important direction for a standardized patient assessment process in post-acute care. Participants welcomed the possibility of a standardized cross-setting assessment process that could use more patient-centered data elements aimed at providing clinically meaningful information to guide the plan of care. All groups expressed a need for better assessment and transfer of information from hospitals to improve care transitions. Common key themes included the wish for greater patient and consumer engagement in the assessment process, a need for more meaningful metrics centered on the effect of limitations or conditions on the patient's functional ability across each of the assessment domains, and a need for more information regarding the home and community resources available to the patient upon discharge, including the caregiver's willingness and ability to support the patient at home. There was a common concern that an already lengthy, time-consuming, and silo-ed assessment process could be worsened in a standardized assessment, particularly if highly specialized data element are employed. Another cross-cutting theme was the recommendation to utilize more "gateway" questions to increase the salience and patient-centeredness of the assessment to each patient's clinical context.

The different provider groups did differ in some of their comments. In particular, most providers in the IRF group seemed to reflect a more positive attitude toward standardized assessment, while many providers in LTCHs saw less overall need. Home health perceived the greatest barriers to assessment while SNFs were more concerned about the length and complexity of assessment for their highly diverse patient population. Many of the consumers felt that standardized assessment could be beneficial but felt alienated from current assessments. Despite these somewhat varied lenses, there were more commonalities within the range of overall and domain-specific feedback than there were differences.

This stakeholder input is also salient for developing training and instructions for implementing standardized data elements. For example, based on stakeholder comments, it would be important to include in training and instructions that significant fluctuations in performance on cognitive tests could reflect delirium. Other important training themes include underscoring that assessment screeners are not diagnostic and that screeners can indicate areas where follow up, evaluation for causes and care planning are relevant. The commonly expressed concerns about the inappropriate labelling of patients points to an opportunity to capitalize on the recognition that symptom-based screeners are not diagnostic but do open opportunities for follow up about causes. This issue was especially common in the areas of cognition, mood and continence. For example, while all recognized that complicated grief or bereavement may explain low mood, only some providers recognized that this could be important for outcomes and could be addressed as a process separate from a diagnostic label of depression. A related theme was the importance of normalizing the assessment process when approaching patients and families. Variations in comments also point to condition-specific and setting specific opportunities such as understanding the contributions of sensory impairments to delirium, communication and safety.

In summarizing these results, it is important to be cautious. The qualitative nature and limited number of focus groups preclude conclusions about national practice patterns. Indeed, even within each group we

saw a wide range of opinions and approaches driven by variations in organizational culture and how care was organized within different facilities and agencies. The ability to contrast these approaches is a strength of focus groups and the existence of contrasting approaches was sometimes highlighted by participants during their discussions. The significance of our findings lies in the insights we have gained about a possible range of perspectives and about important considerations for work-force and consumer experience as we move toward an ideal state of standardized assessment.

In the next phase of this effort, this stakeholder input will be used to inform the selection of particular standardized data elements for pilot testing across the four post-acute care settings and will guide the development of assessment instructions and training approaches. Findings will also be used to help identify, in conjunction with CMS, additional assessment areas that could benefit from standardization and increased focus on patient-centeredness.

IMPACT Act Identifies Domains for Quality Measures that Use Standardized Assessment Data

- Functional status, cognitive function, and changes in function and cognitive function
- Skin integrity and changes in skin integrity
- Medication reconciliation
- Incidence of major falls
- Communicating and providing for the transfer of health information and care preferences of an individual when the individual transitions.

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What Assessments do we have now?

- 4 different settings, 4 different assessments
  - o Skilled Nursing Facilities (SNF) → **Minimum Data Set (MDS)**
  - o Home Health Agencies (HHA) → **Outcome and Assessment Information Set (OASIS)**
  - o Inpatient Rehabilitation Facilities (IRF) → **IRF-Patient Assessment Instrument (IRF-PAI)**
  - o Long Term Care Hospitals (LTCH) → **LTCH CARE Data Set (LCDS)**
- Assessments lack common standards & definitions

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RAND's work

- RAND's work with CMS includes the following topic areas in 2016:
  - Care Preferences
  - Cognition, including mood and delirium
  - Mental Status
  - Medications (such as medication reconciliation and adverse drug events)
  - Impairments
    - Urinary incontinence
    - Bowel incontinence
    - Vision
    - Hearing
  - Medical Conditions (pain)

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Today's Focus Group

- The **purpose** of this focus group is to discuss your experiences and thoughts regarding the patient assessment process in [setting].
  - What is useful to you about the patient assessment process?
  - What works well? What challenges do you face?
  - What ideas do you have about improving the patient assessment process?

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Discussion Topics

In addition to discussing the assessment process in general, we are also interested in discussing patient assessment across 5 specific domains:

1. **Medications,** including medication reconciliation

2. **Patient Care Preferences**

3. **Care Transitions**

4. **Cognitive Function**, including mood and delirium

5. **Impairments**, including pain, bowel and urinary incontinence, vision, and hearing

We are also interested in hearing about any other categories, or assessment items, that are important to you as providers.

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Your feedback is invaluable to our efforts

- The perspectives you share with us today will be shared with our technical expert panels and used to help:

  o Improve the assessment process

  o Select data elements for pilot-testing

  o Design testing plans

  o Develop assessment instruction manuals

  o Develop training materials

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Focus Group Process

- Group discussion – please freely share opinions and perspectives!

  o Sangeeta will facilitate to keep discussion flowing

- We don't have to agree. We do need to respect a range of ideas

- Everything shared here will be important and valuable to this effort

- We can't provide anonymity or confidentiality. Names of all attendees will be documented as part of our deliverables to CMS.

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Discussion Questions

Current Assessment Process

- What do you feel are the benefits of the patient assessment process in [setting]?
  - To your facility?
  - To your patients?
  - To you as provider or staff member?
- What are some of the challenges and shortcomings of the patient assessment process in [setting]?
- What are some of the barriers to collecting assessment information and completing the process?
- What is your experience with electronic health records? How might they facilitate the patient assessment process?

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Medication Reconciliation

- What does the term "medication reconciliation" mean to you? What does it mean to "reconcile"?
- How do you define "drug regimen review"?
- How could medication reconciliation or medication review be accurately reflected in the current assessment process?
- How do you define and identify a "potentially significant medication issue"?
- Can you walk me through what happens when a potentially significant issue has been identified?

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Care Preferences

- How do you define "care preferences"?
- To what extent are patient care preferences currently assessed in your setting? What tools or supports might help you to assess patient care preferences?
- What information about care preferences is important to collect in the [setting]? How might this information be used?
- How often should care preferences be assessed?
- What kinds of challenges come up in assessing care preferences?
- What information about care preferences is important to transfer during transition points?

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Care Transitions

- What information do you currently receive when a patient is being transferred into the [setting]?
  - What information is most useful to you?

- What information do you typically send when a patient is transferred out of the [setting]?
  - What information is most important to provide?

Cognitive Function

- How does your organization currently assess cognition?

- What information about cognition is most important for you to know in your care of the patient?

- What are some of the challenges you've faced to assessing cognition, and how might these be addressed?

- How well does the [instrument] work for assessing cognition?

  - How suitable is the [instrument] for covering the range of patients you see?

- What information about cognitive function is important to transfer during transition points?

Cognitive Function: Mood

- How can you tell when a patient is depressed?

- What information about mood is important to collect in the [setting]? How might this information be used?

- How well does the [instrument] work for assessing mood?

- What kinds of challenges come up in assessing mood?
  - Patient-related?
  - Provider-related?
  - Institution-related?

- What information about mood is important to transfer during transition points?

Cognitive Function: Delirium

- How can you tell when a patient has delirium? What specific approaches have you found most helpful, and why?

- What is challenging about assessing delirium?

- In your experience, what populations are most likely to get delirium?

Impairments: Urinary Incontinence

- How do you define urinary incontinence?
- What information about urinary incontinence is important to collect in the [setting]?
- Other than the data mandated for collection by CMS in the [instrument], what other information does your organization collect about urinary incontinence? How is this information being used?
- What barriers do you face in assessing urinary incontinence in your patients?
- What information about incontinence is important to transfer during transition points?

Impairments: Bowel Incontinence

- How do you define bowel incontinence?
- What information about bowel incontinence is important to collect in the [setting]?
- Other than the data mandated for collection by CMS in the [instrument], what other information does your organization collect about urinary incontinence? How is this information being used?
- What barriers do you face in assessing bowel incontinence in your patients?
- What information about incontinence is important to transfer during transition points?

Impairments: Risk for complications from constipation

- Which of your patients are most at risk for bowel impaction?
- What are some of the barriers you might face in developing a bowel management regimen for your patients?
- What bowel management options are available to you in your setting, and how does this facilitate or hinder assessment?
- To what extent is this a topic that should be standardized across PAC settings?

Impairments: Vision

- Describe the current process for assessing vision impairment in your setting.
- What is important about assessing vision impairment?
- What information about vision impairment is useful to you in your care of patients?
- How does the [instrument] work for assessing vision impairment?
- Is it feasible to provide a vision test as part of your admission assessment? What would make it feasible? What would make it valuable?
- What information about vision would be important to transfer during transition points?

Impairments: Hearing

- Describe the current process for assessing hearing impairment in your setting.

- What is important about assessing hearing impairment?

- What information about hearing impairment is useful to you in your care of patients?

- How does the [instrument] work for assessing vision impairment?

- Is it feasible to provide a hearing test as part of your admission assessment? What would make it feasible? What would make it valuable?

- What information about hearing would be important to transfer during transition points?

Impairments: Other

We've talked about urinary and bowel continence, risks for bowel impaction, vision and hearing.

- Are there other impairment topics that would be a high priority for including across settings?

Medical Conditions: Pain

- How is pain typically assessed in your setting:
  - In patients with little to no cognitive impairment?
  - in patients with moderate or severe cognitive impairment?
  - In sedated patients?

- How is pain re-assessed in your setting?

- What are some of the staff/provider related factors that make pain assessment/reassessment challenging?

- What are some of the patient-related factors that make pain assessment challenging?

- How could we be sure to incorporate the patient's voice in pain assessment?

Medical Conditions: Other

The [instrument] obtains a range of clinical conditions and diagnoses.

- Are there additional assessment items for other medical conditions that we should consider including?

- Are there additional assessment items for special services that we should consider including?

APPENDIX B: FOCUS GROUP PARTICIPANTS

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