



What is your interpretation of the word “essential” in the context of an essential benefit package?

The word essential should be defined broadly.

Medically-necessary care must be informed by generally accepted medical or scientific evidence and consistent with generally accepted practice parameters as recognized by health care professions in the same specialties as typically provide the procedure or treatment, or diagnose or manage the medical condition; must be informed by the unique needs of each individual patient and each presenting situation; and (1) help restore or maintain the member’s health; or (2) prevent deterioration of or palliate the member’s condition; or (3) prevent the reasonably likely onset of a health problem or detect an incipient problem.

In the context of an essential benefits package, essential care also must include the right to information about up to date health care options. Further, reproductive care and the right to decide whether or not to have a child is part of essential care and therefore access to contraception and family planning counseling is critical.

How is medical necessity defined and then applied by insurers in coverage determinations? What are the advantages/disadvantages of current definitions and approaches?

The definition of medical necessity must focus on positive medical outcomes, and should expressly prohibit the consideration of elements that fail to contribute to effective care. These non-relevant and harmful considerations include politics, religion and cost. Using cost as an example, some definitions of medical necessity include recommendations, or even requirements, to analyze the cost of a particular type of care stating that care is only medically necessary if it is the most cost-efficient option. This evaluation of medical necessity, however, is flawed because it focuses on an element, cost, which has no bearing on whether the care is a medical necessity for the patient. It also fails to recognize that a health care provider and patient may decide that a particular method of care is necessary because of complex factors that are not captured in a cost savings analysis. For example, there are many forms of birth control at a wide range of costs; however, not every method of birth control will function properly with every patient. One medication may cause side-effects that warrant a health care provider and patient’s decision to select another method. Because the Patient Protection and Affordable Care Act (PPACA) is focused on providing patient-centered care, the focus of medical necessity must be on the type of medical care that the patient and health care provider deem appropriate for a set of given circumstances. Using a non-relevant element, such as cost, in the determination of what is medically necessary, is flawed and will lead to

inadequate processes and harmful determinations. Elements that are not aimed at determining *medical* necessity and therefore patient care should be expressly banned from consideration in a medical necessity analysis.

Furthermore, the decision of medical necessity must remain with the health care provider and the patient. Some insurers transfer the decision making process from the health care provider and patient to the insurer which increases cost and lowers health outcomes. This transfer of decision making authority raises costs because it requires the insurer to employ an elaborate system of application processes, expert medical review boards, investigations, and appellate procedures to determine if a method of care is a medical necessity in any specific case. These methods also cause health care provider and patient stress by prolonging waiting periods for care and requiring their focus on procedure rather than health outcomes. In addition, removing decision making authority from the trusted health care provider/patient relationship to a complex process of forms and procedures with the insurer will increase health disparities for low income women, women with low education levels, and women who speak English as a second language. These disparities are caused because certain populations are less likely than others to be well versed in complicated procedures, which limit their ability to navigate the process in a manner that will ensure their proper care as an outcome.

Taking these concerns into account, the following definition of medical necessity focuses on patient-centered care and affectively addresses the wide range of situations that occur when addressing community members' health:

- Medically-necessary care means health care services, including preventative services, evaluative services, diagnostic testing, treatment and aftercare, that are appropriate in terms of type, amount, frequency, level, setting, and duration to the patient's health.
- Medically-necessary care must be informed by generally accepted medical or scientific evidence and consistent with generally accepted practice parameters as recognized by health care professions in the same specialties as typically provide the procedure or treatment, or diagnose or manage the patient's care.
- Medically-necessary care must be driven primarily by the unique needs of each individual patient and each presenting situation: and
 - help restore or maintain the patient's health; or
 - prevent deterioration of or palliate the member's condition; or
 - prevent the reasonably likely onset of a health problem or detect an incipient problem.

What criteria and methods, besides medical necessity, are currently used by insurers to determine which benefits will be covered? What are the advantages/disadvantages of these current criteria and methods?

Insurers frequently use non-medically based criteria in determining which benefits they will cover. A recent report from the House of Representative's Committee on Energy and Commerce illustrates this practice in regards to maternity care. That report found that

“[h]ealth insurance companies often exclude maternity care from coverage in the individual market” and that they “severely limit the benefits they provide under maternity riders.” Insurance company decision makers clearly stated that prices, margins, and market share were the primary considerations in whether care was offered, not the health of the patient or family. Executives stated that “optional maternity coverage has a very unfavorable impact on our bottom line” and therefore “[t]his coverage option will be eliminated in stages.” Another executive described a maternity rider as “a loser” in justifying its elimination.

Cost is not the only non-health related factor that insurance companies currently consider in determining which benefits will be covered. Politics and religion also play a role for certain insurers. For example, some insurers do not provide coverage for reproductive health care as some providers have a religious or political objection to providing such care. This restriction is not based on science or evidence of healthy practices and it harms women who need critical family planning services. Therefore, criteria that focus on non-medically relevant factors undermine patient wellness and should be expressly prohibited in determining medical necessity.

What principles, criteria, and process(es) might the Secretary of HHS use to determine whether the details of each benefit package offered will meet the requirements specified in the Affordable Care Act?

The principles of patient-centered care, affordable care, and healthy people/healthy communities should be used by the Secretary of HHS to determine whether the details of each package will meet the requirements specified in the PPACA.

Patient-centered care must function for the primary benefit of patients, families, caregivers, and providers. Better care should expressly address the quality, safety, access, timeliness, equity, effectiveness and reliability of how care, especially reproductive health care, is delivered. This also includes improving the experience of women receiving that care; actively engaging women, families, and caregivers; coordinating care across care settings; and providing the best possible care at all stages of health and disease.

Affordable care eliminates unnecessary costs that fail to produce value and reins in unsustainable costs for women, families, government, and the private sector.

Healthy People/Healthy Communities focuses on improving health and wellness at all levels for all populations through a commitment to chronic disease prevention and management and strong partnerships between health care providers, women and their families, and community resources.

What type of limits on specific or total benefits, if any, could be allowable in packages given statutory restrictions on lifetime and annual benefit limits? What principles and criteria could/should be applied to assess the advantages and disadvantages of proposed limits?

In determining the advantages and disadvantages of proposed limits, the principle of equity should be applied. If a limit would disproportionately impact women of color or other vulnerable populations, it should be avoided. This analysis should be made on a micro level before limits are set to ensure that one decision does not disproportionately harm a particular group of people. However, the analysis should also take place at regular intervals on a macro level to ensure that the cumulative affect of several decisions has not weighed more heavily against a group of people.

Oftentimes, data collection undermines efforts to discover inequities in care and regulations must therefore prevent against this result by specifically requiring that the most up-to-date and dynamic research methods be used in evaluating inequities. For example, often data collection methods group all Asian American ethnicities together and Asian Americans as a whole with Native Hawaiians and Pacific Islanders, thereby masking the disparities that persist within these subpopulations. For example, in general, Asian Americans have the lowest cancer incidence and death rates when compared to non-Hispanic whites, African Americans, and Hispanics in the U.S. However, studies that have looked into sub-populations of Asian Americans have found striking data that contradicts this widely understood notion. Those studies have found that the cervical cancer rate for Vietnamese American women is five times higher than that of white women, representing the highest rate for any racial or ethnic group. These data flaws in the Asian American community have led to a dangerous “model minority” myth that masks these important health inequities. These flaws also occur among Latina populations and studies often fail to recognize the vast number of sub-populations within the Latina community. Therefore, when conducting this, or any analysis, regulations must require the most up-to-date research methods that focus on the proper tracking of sub-population details.

Lastly, regulations should require an in-depth and continuing historical study of health disparities that will be used to prevent the perpetuation of hidden inequities in care. Without such an analysis, seemingly innocuous limitations may be reinstated out of habit or custom, but may seriously undermine the health and wellbeing of discreet segments of the population at a greater rate than others.

How could an “appropriate balance” among the ten categories of essential care be determined so that benefit packages are not unduly weighted to certain categories? The ten categories are: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorders services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; pediatric services, including oral and vision care.

All of these categories are important to Asian American and Pacific Islanders (APIs) and Latinas and we commend the IOM and HHS in their efforts to balance them. Preventive care has a particular importance for women who face health disparities and therefore disparities should be considered in the determination. APIs and Latinas

historical lack of preventive care has resulted in extreme health disparities. For example, AAPIs and Latinas are significantly less likely than non-Hispanic whites to receive recommended levels of screening, counseling, and care and face additional barriers that reduce accessibility of important health programs and services. As a result, these communities are at a disparate risk for preventable diseases. Studies have found that the cervical cancer rate for Vietnamese American women is five times higher than that of non-Hispanic white women, representing the highest rate for any racial or ethnic group.¹ In addition, incidence of cervical cancer for Latina women is almost twice as high as non-Latina white women.² In another example, diabetes is the fourth leading cause of death for Asian Pacific Islander (API) females and sixth leading cause of death for API males.³ While many factors contribute to the high rates of preventable diseases among minority communities, the lack of culturally and linguistically appropriate services, the lack of health insurance and lack of education about preventive care within these communities pushes available services out of reach. Therefore, keeping knowledge and access to preventive care as a central principle will help ensure an appropriate balance among the ten categories of essential care.

How could it be determined that essential benefits are “not subject to denial to individuals against their wishes” on the basis of age, expected length of life, present or predicted disability, degree of medical dependency or quality of life? Are there other factors that should be determined?

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How could it be determined that the essential health benefits take into account the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups?

The Secretary should engage with community partners to make sure needs of diverse segments are properly defined and addressed. The community partners should include specialists that work with diverse segments. Additionally, an annual community assessment should be conducted. The assessment could be in the form of a survey which is conducted in various languages to reach limited English speakers. The survey should be administered where people are located so that travel will not be a barrier to responding to the survey. Finally, the survey administrators should ensure confidentiality and privacy, particularly around immigration status so all populations feel comfortable participating.

¹ National Asian Women’s Health Organization (NAWHO), *Learning from Communities: A Guide to Addressing the*

Reproductive Health Needs of Vietnamese American Women (1998).

² National Cancer Institute, Surveillance Epidemiology and End Results (SEER) Cancer Statistics Reviews, 1975-2003, *available at* seer.cancer.gov/csr/1975-2003.

³ National Center for Health Statistics, 1999

By what criteria and method(s) should the Secretary evaluate state mandates for inclusion in a national essential benefit package? What are the cost and coverage implications of including current state mandates in requirements for a national essential benefit package?

State mandates that protect patients and families and improve wellness should be considered as strong guidance tools in implementing protections and creating a patient-centered program. In many cases, state mandates resulted from the exhaustive work of consumer groups and providers. Often, these mandates implemented protections that ameliorated system failures that created health disparities. Therefore, the Secretary should consider the reasons for adoption of state mandates to determine if they were implemented to prevent discrimination or halt health disparities. Those mandates that were crafted with this type of a patient-centered framework should be carefully considered for their effectiveness at eliminating health disparities and protecting patient wellness. Those mandates that were effective in diminishing disparities and improving patient wellness should be included in the essential benefits package.

What criteria and method(s) should HHS use in updating the essential package? How should these criteria be applied? How might these criteria and method(s) be tailored to assess whether: (1) enrollees are facing difficulty in accessing needed services for reasons of cost or coverage, (2) advances in medical evidence or scientific advancement are being covered, (3) changes in public priorities identified through public input and/or policy changes at the state or national level?

A critical step in updating the essential package will be to conduct a periodic, in-depth and independent survey that captures data from a wide range of enrollees. The difficulty will be obtaining accurate information from those enrollees that are facing barriers because the barriers in obtaining needed services may be the same barriers that keep a woman from responding to a survey. Therefore, research should be conducted in all applicable languages, in diverse geographic locations, and in a manner that protects survey participants from harassment.

First, if a language barrier causes a barrier to accessing essential health benefits, a survey must eliminate that barrier to uncover the problem. Such language barriers may include a foreign language as the primary language in a home, a disability that affects access to written or spoken language, or educational barriers. These barriers prevent a woman from expressing her experience in obtaining essential benefits and will prevent the Secretary from discovering problems in the system if not properly addressed. Second, geographic location must be carefully scrutinized to ensure that experiences from small rural communities are captured as well as the experiences of the many different cultures that live closely to one another within urban city centers. Geographic barriers create unique issues in both access to health care and access to research methods and must be solved to solve access problems. Lastly, the criteria must address confidentiality issues that may expose women to harassment. For example, individuals living in families with mixed immigration statuses often face unique barriers to accessing care. Therefore, formal protections must be afforded to these individuals and those protections must be

clearly communicated so that these individuals and family members may be adequately surveyed without fear of their own, or a family member's, deportation or harassment due to immigration status. In a second example, protections must be in place and communicated regarding individual's sexual orientation or gender identity. A lesbian Latina or AAPI woman may not feel comfortable accessing health care because of her sexual orientation and may not feel comfortable answering a survey for the same reason. Therefore, in order to adequately discover her lack of access to wellness, a survey must first address her lack of access to the research tool. Barriers to research, therefore, must be critically addressed in order to discover the barriers to health care.

In addition, regular open meetings should be scheduled with the scientific community, public involvement programs, and the public. Establishing partnerships with scientists and researchers who study disease progression and development will also help the Secretary stay abreast of scientific advancement and medical evidence. Partnerships should be built with scientists and researchers who work with and have expertise in diverse communities including communities of color, those with limited English proficiency, and those with disabilities.

Changes in public priorities should be determined with public health research and data collection evidence, not politics, religion or cost evidence. As government leaders change with elections, the politics of those in power may impact how they view and approve certain health measures. The lives and health of people who rely on health care coverage should not be subject to political predispositions. Therefore, the Secretary should implement regulations that specifically prevent non-relevant considerations in these deliberations.

Lastly, the regulations should require that the most up-to-date research methods be used and that methods that overlook minority perspectives be deemed inadequate for valuation purposes.