March 27, 2018

VIA ELECTRONIC SUBMISSION

Office for Civil Rights
Department of Health and Human Services
Attention: RIN 0945-ZA03
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, SW
Washington, DC 20201

Re: Protecting Statutory Conscience Rights in Health Care; Delegations of Authority [RIN 0945-ZA03]

The Medicare Rights Center (Medicare Rights) appreciates the opportunity to comment on the proposed rule entitled, “Protecting Statutory Conscience Rights in Health Care; Delegations of Authority.” We are concerned that this rule would put people with Medicare at risk of lacking access to medically necessary treatment and information they need to make educated, person-centered choices. Medicare beneficiaries, their families, and caregivers need to know their medical needs and choices will be honored within the Medicare program and the health care system as a whole.

Medicare Rights is a national, nonprofit organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Each year, Medicare Rights provides services and resources to over three million people with Medicare, family caregivers, and professionals.

The Department of Health and Human Services (“HHS” or “the Department”) has introduced this NPRM in an effort to ensure that the religious and conscience rights of medical providers and practitioners are not infringed. While Medicare Rights respects the exercise of such conscience rights, we have serious concerns with the proposed rule, including how the rule fails to balance the potential conflict between providers’ conscience rights and the rights of citizens to access needed health care without discrimination or undue barriers, as well as the potential implications for emergency care, and the need for informed choice and transparency.

Below, please find our comments on (1) Balancing Rights, (2) Emergency Care, and (3) Informed Choice and Transparency.
Balancing Rights

We are very concerned that the proposal fails to address two vital things: (1) How this rule will interact with existing federal and state laws that already protect sincerely held religious beliefs; and (2) How this rule will interact with the rights of patients. These omissions make uncertainty, confusion, and disorder surrounding the rights and obligations of patients, physicians, other health care providers, and health care institutions more likely, not less.

In the preamble, the Department states that the proposed rule is an attempt to “ensure that persons or entities are not subjected to certain practices or policies that violate conscience, coerce, or discriminate, in violation of such Federal laws.” While protecting those who provide health care from discriminatory policies that may force them to choose between their beliefs and their continued or future employment is an important goal, the right of a provider to conscientiously object is not absolute. Rather, the rights of providers to deny patients access to care must be balanced against the rights of patients to access the care and information they need, consistent with their own sincerely held conscience and religious beliefs. Here, the rule falls far short. It appears instead to prioritize the conscience rights of organizations and personnel at the expense of the needs and rights of patients to receive care and information that is appropriate, medically necessary, freely chosen, transparent, and person centered, and to which they are entitled under federal law.

Patients are the reason health care exists. Ensuring that patients have the care they need, to the extent they want such care, must be the primary goal of any health care system. The proposed rule is silent on the needs of patients, including what disclosures must be made to them, how care can be ensured, or what remedies they will have if their rights are infringed. Given the rule’s silence, it is hard to know if the proposal intends religious objections to take precedence over patient needs and rights.

Additionally, the proposal does not address the limitations necessarily placed on the implementation of this rule by Title VII of the Civil Rights Act of 1964, or the careful balance that Act creates between religious rights, beliefs, and practices, and the need for employers and institutions to serve people. This failure will cause confusion for providers as practitioners, and expose them to liability and uncertainty as employers.

Title VII already requires that employers accommodate employees’ religious beliefs to the extent there is no undue hardship on the employer. Yet, the proposed regulations make no reference to Title VII, current Equal Employment Opportunity Commission (EEOC) guidance, or the extensive, controlling case-law interpreting these provisions and carefully balancing the rights of employers and employees under which an employer many not discriminate against an employee based on that employee’s race, color, religion, sex, and national origin, but an employee must be able to perform

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2 42 U.S.C. § 1395w–22
the essential functions of the job. The proposed rule must ensure that the long-standing balance set in Title VII between the right of individuals to enjoy reasonable accommodation of their religious beliefs and the right of employers to conduct their businesses without undue interference is maintained.

While the proposal does identify “avoidance of undue burden on the health care industry” as a policy objective, that is limited to the newly proposed section 88.4 regarding assurance and certifications of compliance. Nowhere does it discuss, even in passing, the complex issues that will arise if employees or institutions cannot meet their obligations under existing employment, anti-discrimination, or provision-of-service law because of their conscientious objections.

As Title VII provides protection for individual beliefs while still ensuring employers can operate their businesses as they see fit, so too do other existing federal and state civil rights laws balance the religious and other rights of providers with the very real need to protect patients against discrimination—including the adverse consequences of health care refusals—based on a variety of characteristics, such as race, gender, sexual orientation, immigration status, disability, and HIV status.

For example, the Medicare program places conditions of participation on providers and institutions, including requiring Medicare Advantage organizations to provide access to all of the benefits of the Medicare fee-for-service program and holding hospitals to “Conditions of Participation” to ensure that patients’ rights are respected and that they received medically appropriate care. Troublingly, the proposed rule does not explore the interaction between its mandate and these kinds of existing protections.

Additionally, the proposed rule does not define “discrimination.” This lack of clarity regarding what constitutes discrimination may undermine anti-discrimination laws. Because of the potential harm to individuals if religious refusals were allowed, courts have long rejected arguments that religiously affiliated organizations can opt out of anti-discrimination requirements. Instead, courts have held that the government has a compelling interest in ending discrimination and that anti-

4 NPRM at 3880.
5 NPRM at 3897.
7 42 U.S.C. § 1395w–22
8 42 CFR 482.13 (b) (2) (The patient or his or her representative (as allowed under State law) has the right to make informed decisions regarding his or her care. The patient's rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment. . . .
9 (3) The patient has the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives)
9 See e.g., Bob Jones Univ. v. United States, 461 U.S. 574 (1983) (holding that the government’s interest in eliminating racial discrimination in education outweighed any burdens on religious beliefs imposed by Treasury Department regulations); Newman v. Piggie Park Enters., Inc., 390 U.S. 400 (1968) (holding that a restaurant owner could not refuse to comply with the Civil Rights Act of 1964 and not serve African-American customers based on his religious beliefs); Dole v. Shenandoah Baptist Church, 899 F.2d 1389, 1392 (4th Cir. 1990) (holding a religious school could not compensate women less than men based on the belief that “the Bible clearly teaches that the husband is the head of the house, head of the wife, head of the family”); Hamilton v. Southland Christian Sch., Inc., 680 F.3d 1316 (11th Cir. 2012) (reversing summary judgment for religious school that claimed a religious right to fire teacher for becoming pregnant outside of marriage).
discrimination statutes are the least restrictive means of doing so. Indeed, the majority opinion in *Burwell v. Hobby Lobby Stores, Inc.* makes it clear that the decision should not be used as a “shield” to escape legal sanction for discrimination in hiring on the basis of race, because such prohibitions further a “compelling interest in providing an equal opportunity to participate in the workforce without regard to race,” and are narrowly tailored to meet that “critical goal.” The uncertainty regarding how the proposed rule will interact with anti-discrimination laws is extremely concerning.

Illustrating how organizations or personnel will be able to abide by each of these laws and regulations as well as this proposal is an absolutely vital step in rulemaking—but this proposed rule fails to make these interactions clear. As a result, its expansive definitions and seemingly broad application leaves open the question of whether health care personnel or institutions could potentially refuse to provide some or all services to entire categories of patients.

**Emergency Care**

In addition to the need for more specificity regarding the general balance between individual conscience rights and patient needs, there is the question of the rule’s balance between a provider’s right to object and the provider’s obligation to provide emergency care.

Federal and state laws reflect the long-standing obligation of health care institutions to provide assessment and care in an emergency. For example, this issue is expressly addressed in the Social Security Act. The Emergency Medical Treatment and Labor Act (EMTALA) requires Medicare-participating hospitals to stabilize patients who come to the emergency room in medical emergencies. Yet, the rule does not address the interplay of conscience rights with physicians’ and hospitals’ legal obligations under EMTALA. Any final rule must clarify these interactions.

It is concerning that the proposed rule avoids discussion of EMTALA and other existing legal obligations to provide care in an emergency situation, and even more so that, as outlined below, the proposed rule appears to suggest there should be no such obligation at all.

In the preamble, the Department gives several reasons for this proposed rule, the first being that “allegations and evidence of discrimination and coercion have existed since 2008 and increased over time.” To support this claim, the Department states that the previous rule was promulgated to address “an environment of discrimination toward, and attempted coercion of, those who object to certain health care procedures based on religious or moral convictions” and that rescinding the guidance has allowed this discriminatory environment to prosper. As evidence of this growing trend, the Department cites regulatory comments, lawsuits, news reports, and polling data.

In this discussion, the Department also points to the American Congress of Obstetricians and Gynecologists (ACOG) 2016 reaffirmation of an ethics document as confirmation of the

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12 42 U.S. Code § 1395dd
13 *NPRM* at 3887.
aforementioned “environment of discrimination” toward health care providers.\textsuperscript{15} The referenced ACOG guidance—“The Limits of Conscientious Refusal in Reproductive Medicine”\textsuperscript{16}—was originally issued in 2007 and, according to the Department “at least, in part, prompted the 2008 rule.”\textsuperscript{17}

While reproductive medicine is fertile ground for those seeking conscience exceptions and therefore may have a reasonable place in this policy making discussion, the Department does not to cite a reproductive health-related section of ACOG’s ethics document as an example of provider coercion. Rather, HHS focuses on the following provision, in which ACOG addresses a provider’s obligation to treat a patient in an emergency situation:

“[i]n an emergency in which referral is not possible or might negatively affect a patient’s physical or mental health, providers have an obligation to provide medically indicated and requested care regardless of the provider’s personal moral objections.”\textsuperscript{18}

By citing this ACOG recommendation as a reason for the proposed rule, the Department is suggesting that it disagrees with this specific provision, and that providing medically-indicated, requested, and potentially life-saving care in an emergency runs counter to the purpose of the rule. We are extremely concerned about the impact such an approach to care provision would have on patients in emergent situations. For example, could the proposed rule allow institutional health care providers, such as hospital emergency rooms, to refuse to provide emergency care? If so, this puts patients who need emergency medical care at grave risk and would run afoul of EMTALA’s requirements to, at a minimum, stabilize patients who come to the emergency room in medical emergencies.\textsuperscript{19}

The lack of clarity in the proposed rule will cause confusion and put the health and lives of patients at risk. Any final rule must make clear that a provider’s right to refuse access to health care must not come at the expense of a patient’s right to needed services, including emergency care.

\textbf{Informed Choice and Transparency}

We are also concerned that the under the rule, covered entities would be free not only to refuse to perform any given health care service, but also to deny patients access to information about or referrals for such services, by defining “referral” in a staggeringly broad way.\textsuperscript{20}

Specifically, the proposal would allow an objecting provider to withhold any information regarding any service, procedure, or activity when the provider “sincerely understands the particular health care service, activity, or procedure [to which he or she objects] to be a purpose or possible outcome

\textsuperscript{15} Ibid.
\textsuperscript{17} NPRM at 3388, Footnote 37.
\textsuperscript{18} NPRM at 3388.
\textsuperscript{19} 42 U.S. Code § 1395dd
\textsuperscript{20} NPRM at 3894.
of the referral.”  

This would permit providers to refuse to give patients any information that they could then use to access care they want, but which the provider finds objectionable. This overly-broad definition is intentional, as “[t]he Department believes defining referral or refer in a more narrow way…would fail to implement Congress’s broad protection for entities unwilling to be complicit in the provision of items or services they cannot in good conscience themselves provide.”  

To support its seeming overreach, the Department lays out the underlying statutes that it claims support the “broad protection” Congress has bestowed upon providers. Though this discussion is focused on abortion, importantly, the proposed definition of “referral” would extend far beyond this one service. The Department acknowledges as much, stating that the underlying statutes allow providers to refuse to issue referrals “for abortion in a broad way” or “for other kinds of services.”  

The breadth and vagueness of this definition could lead providers to refrain from providing information vital to patients out of anxiety and confusion of what the proposed rule permits, or requires, them to do.  

The proposed regulation would allow a provider to refuse to counsel patients for services or provide medical information and options for any medical treatment without a mechanism to ensure patients get the information they need to make informed health care decisions. Cutting patients off from critical information without a disclosure that the information, services, or referral may be incomplete may not be the intent of the rule, but there is no requirement in the text that objectors be transparent about their refusals. The expansion of refusals as proposed under this rule will exacerbate disparities and undermine the ability of individuals to access comprehensive and unbiased health care, including sexual and reproductive health information and services. Any efforts by providers or other health care personnel to limit the information and access that patients are entitled to receive, even when the organization may not provide those services itself, is incompatible with true consumer choice and individual decision making.  

The NPRM establishes that transparency and openness are valuable, and we agree that “poor communication negatively affects continuity of care and undermines the patient’s health goals.”  

In addition to such practical concerns, ethical and legal standards also require that professionals ensure patients have the information they need to provide informed consent to care. However, the rule does not appear to require any disclosure on the part of objecting providers or institutions. Indeed, one case highlighted in the NPRM revolved around a hospital’s lack of transparency about provider unwillingness to assist a patient through California’s Aid-in-Dying rule.  

As it stands, the proposed regulation threatens to fundamentally undermine the relationship between providers and patients, who will have no way of knowing which services, information, or referrals they may have been denied.  

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21 NPRM at 3895.  
22 Ibid.  
23 Ibid.  
24 NPRM at 3917.  
25 NPRM at 3889.
By contrast, Medicare rules require that Medicare Advantage organizations that object to paying for particular referrals or counseling must notify both the Centers for Medicare & Medicaid Services and any current or prospective enrollees of their refusal, with advance notice for current enrollees. Such notice allows patients and their families to determine for themselves if the provider or institution offer sufficient services to meet the patient’s wants and needs. Any finalized rule should use such notice requirements as a model and must be explicit in requiring that such notice be given, in writing, and in advance whenever possible, to ensure patients and their families have the information they need to make informed, person-centered choices.

Conclusion

The center of all health care decision making must be the person receiving care. The patient, in the medical context, is supposed to be the focus, in close partnership with their families if they choose and always with practitioners in order to “ensure that decisions respect patients’ wants, needs and preferences and solicit patients’ input on the education and support they need to make decisions and participate in their own care.”

No system that ignores or overrides the person’s wants, needs, or preferences, or that fails to provide necessary information, can ever be person centered. While person centeredness is an aspirational goal for the health care system, it must be at the forefront of our thinking, not shunted aside when there are other considerations on the table.

Similarly, no regulatory action in health care can succeed unless it accounts for the fundamental purpose of health care—patient well-being. Yet, the proposed rule does not appear to take the patient into consideration at all when discussing the rights of providers and other entities. Coupled with the proposed rule’s silence about its interaction with various statutes, this omission would create chaos and confusion if the rule were finalized as-is.

We urge HHS to abandon this approach and instead explore ways to bring the goals of this proposed rule into harmony with existing law, to find a balance in the rights of patients and practitioners, to protect the health, well-being, and access to care of all patients, and to promote person-centered practices that must be at the heart of our health care system.

Thank you for the opportunity to provide comment.

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