



NATIONAL ORGANIZATION OF
SOCIAL SECURITY CLAIMANTS'
REPRESENTATIVES
ESTABLISHED 1979

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Executive Director
Barbara Silverstone

February 24, 2021

Acting Secretary Norris Cochran
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Submitted via www.regulations.gov

Re: Proposed Modifications to the HIPAA Privacy Rule To Support, and Remove Barriers to, Coordinated Care and Individual Engagement, 86 Fed. Reg. 6446 (January 21, 2021), Docket No. HHS-OCR-0945-AA00

Dear Acting Secretary Cochran:

These comments are submitted on behalf of the National Organization of Social Security Claimants' Representatives (NOSSCR). NOSSCR is a specialized bar association of attorneys and advocates who represent Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) claimants¹ throughout the administrative adjudication process and in federal court. Founded in 1979, NOSSCR is a national organization with a current membership of about 3,000 members from the private and nonprofit sectors and is committed to the highest quality representation for claimants and beneficiaries.

Under the Social Security Act (the Act), the Social Security Administration (SSA) cannot find that an individual is disabled “unless [he/she] furnishes such medical and other evidence of the existence thereof as the Commissioner of Social Security may require.”² The Act places primary responsibility for the development and submission of evidence on the claimant. As explained in Social Security Ruling (SSR) 17-4p,³ “[SSA’s] regulations require appointed representatives to assist claimants in complying fully with their responsibilities under the Act and [SSA’s] regulations. All representatives must faithfully execute their duties as agents and fiduciaries of

¹ Hereafter collectively referred to as “Social Security disability claimants” unless otherwise noted.

² Sections 223(d)(5)(A) and 1614(a)(3)(H)(i) of the Act, 42 U.S.C. 423(d)(5)(A) and 1382c(a)(3)(H)(i).

³ Social Security Ruling, SSR 17-4p; Titles II and XVI: Responsibility for Developing Written Evidence, 82 Fed. Reg. 46339 (October 4, 2017), available at www.ssa.gov/OP_Home/rulings/oasi/33/SSR2017-04-oasi-33.html#FN06.

claimants. In that regard, representatives must assist claimants in satisfying the claimants' duties regarding the submission of evidence and in complying with [SSA's] requests for information or evidence..." As such, on behalf of their clients, NOSSCR members routinely request medical records from covered entities and their business associates⁴ to submit them as evidence in Social Security disability cases and have a significant interest in the fees and timeframes for receiving a client's medical records, especially after the decision in *Ciox Health, LLC v. Azar, et al.*, No. 18-cv-0040-APM (D.D.C. January 23, 2020), which vacated the extension of the patient rate for fees for copies of protected health information (PHI) sent to third parties.

We appreciate the Department of Health and Human Services' (HHS') proposal to modify the Standards for Privacy of Individually Identifiable Health Information (Privacy Rule) under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH), specifically regarding the applicable fee limitations for third parties.

NOSSCR provides comments on the following sections of the NPRM: III.A.9.bb.; III.A.5.b.; III.A.6.b.; III.A.3.b.ii.; III.B.2.; III.A.7.; III.A.9.cc.

The Privacy Rule should prohibit covered entities from charging fees for copies of PHI when requested by Social Security disability claimants or their appointed representatives (Section III.A.9.bb. of the NPRM)

Copies of medical records requested to support an application for, or appeal of, any claim under the Social Security Act should be provided free of charge when requested by the claimant or his/her appointed representative. Because such records are requested by an appointed representative on behalf of the claimant solely to develop the claimant's disability claim for benefits, there is no reason to apply different fee limitations when medical records are requested by, or directed to be sent to, an appointed representative as a third party. HHS recognizes this general rationale in Section III.A.6.b. of the NPRM,⁵ which is even more pronounced in the context of Social Security disability claims given the affirmative duty placed on appointed representatives by regulation to obtain and submit medical records for their clients.⁶ In addition

⁴ Hereafter, we intend any reference to covered entities to also include their business associates.

⁵ "Section 13405(e) of the HITECH Act created a new way for an individual to exercise the right of access by choosing to send a copy of PHI to a third party, and thus changed the assumptions previously expressed in the 2000 Privacy Rule that disclosures at the individual's initiation are made only to the individual, while disclosures to third parties are always initiated by others. For example, the 2000 Privacy Rule preamble contrasted the limited fees to provide PHI 'for individuals' based on the individual's request with fees allowed for 'the exchange of records not requested by the individual' (i.e., requests made by other persons). The HITECH Act expanded the types of records exchanges that could be requested by the individual pursuant to the right of access, with the result that the identity of the recipient of PHI no longer signifies whether the PHI was provided 'for' the individual (i.e., at the individual's request through their exercise of the right of access). In addition, the same policy rationales expressed in the 2000 Privacy Rule for limiting fees for individual requests for access, to ensure that the right of access 'is within reach of all individuals,' apply when the individual requests to direct a copy of PHI to a third party: In both cases, the individual is choosing where to send their own PHI and often, if not always, will be responsible for paying the fee themselves. Finally, by placing the right to direct an electronic copy of PHI in an EHR within the right of access, which had included access fee limitations since the 2000 Privacy Rule, the Department believes the HITECH Act contemplated that access fee limitations would apply, along with other aspects of the existing access right."

⁶ See footnote 3.

to this affirmative duty, it is much more practical for appointed representatives to request and receive their clients' medical records directly given unique issues often present in the Social Security context (e.g. Social Security disability claimants with mental, educational, and/or linguistic limitations may not understand how to submit the appropriate forms to request records or know what to do with the records once received; transient or homeless claimants may not have a secure or reliable physical address for records to be sent to them, etc.).

Many state laws prohibit medical providers from charging fees for copies of medical records when requested to advance a claim for Social Security benefits. In several of those states, state law prohibits fees from being charged regardless of whether the records are requested by the claimant/patient or his/her representative.⁷ We encourage HHS to adopt a similar rule that includes the right of claimants/patients to direct their medical records be sent to their appointed representatives at no charge under the right of access. A federal rule would also promote national uniformity by simplifying the fees and deadlines for providing medical records, which would promote consistency across the country and help reduce instances of non-compliance.

The right to of access should include the right to direct records to a third party in any format (Section III.A.5.b. of the NPRM)

NOSSCR does not support the first part of proposed 45 CFR 164.524(d)(1) to limit the individual right of access to direct the transmission of PHI to a third party to only electronic

⁷ See e.g. Arizona Revised Statutes § 12-2295.B.5. ("A health care provider or contractor shall not charge for the pertinent information contained in medical records provided to: The patient or the patient's legal representative for the purpose of appealing a denial of benefits under the social security act."); Connecticut General Statutes § 20-7c(d) ("no such charge shall be made for furnishing a health record or part thereof to a patient, a patient's attorney or authorized representative if the record or part thereof is necessary for the purpose of supporting a claim or appeal under any provision of the Social Security Act..."); Massachusetts General Laws, Chapter 111, § 70 ("no fee shall be charged to any applicant, beneficiary or individual representing said applicant or beneficiary for furnishing a record if the record is requested for the purpose of supporting a claim or appeal under any provision of the Social Security Act...") (see also Code of Massachusetts Regulations, Title 243, § 2.07(13)(d)); Nevada Revised Statutes § 629.061(5) ("The custodian of health care records shall also furnish a copy of any records that are necessary to support a claim or appeal under any provision of the Social Security Act, 42 U.S.C. §§ 301 et seq.... without charge, to a patient, or a representative with written authorization from the patient, who requests it, if the request is accompanied by documentation of the claim or appeal."); Ohio Revised Code § 3701.741(C)(1)(e) ("On request, a health care provider or medical records company shall provide one copy of the patient's medical record and one copy of any records regarding treatment performed subsequent to the original request, not including copies of records already provided, without charge to the following: A patient, patient's personal representative, or authorized person if the medical record is necessary to support a claim under Title II or Title XVI of the "Social Security Act," 49 Stat. 620 (1935), 42 U.S.C.A. 401 and 1381, as amended, and the request is accompanied by documentation that a claim has been filed."); Rhode Island General Laws § 23-17-19.1(16) ("No charge of any kind, including, but not limited to, copying, postage, retrieval, or processing fees, shall be made for furnishing a health record or part of a health record to a patient, his or her attorney, or authorized representative if the record, or part of the record, is necessary for the purpose of supporting an appeal under any provision of the Social Security Act, 42 U.S.C. § 301 et seq..."); Texas Health & Safety Code § 161.202 ("A health care provider or health care facility may not charge a fee for a medical or mental health record requested by a patient or former patient, or by an attorney or other authorized representative of the patient or former patient, for use in supporting an application for disability benefits..."); Revised Code of Washington § 70.02.030(2)(b) ("Upon request of a patient or a patient's personal representative, a health care facility or health care provider shall provide the patient or representative with one copy of the patient's health care information free of charge if the patient is appealing the denial of federal supplemental security income or social security disability benefits... The health care facility or health care provider may provide the health care information in either paper or electronic format.").

copies of PHI in an electronic health record (EHR). In the Social Security context, the medical records are necessary to support the claim or appeal regardless of their format so there is no logical reason for imposing different fee limitations and timeframes for providing non-electronic copies of medical records. Certain state laws explicitly recognize this and permit records to be sent to third parties in either paper or electronic format.⁸ However, we understand that expanding the right of access to include non-electronic copies of PHI may require more than a regulatory change. As such, NOSSCR suggests that requests for copies of non-electronic PHI to be directed to a third party should still be subject to the same fee limitations and timeframes for providing the records as electronic copies of PHI pursuant to the right of access, at least for records requested by a Social Security claimant or his/her appointed representative, even if the request must be accompanied by a valid authorization. In addition, we support HHS's statement in this section that "the Department encourages covered health care providers, when feasible, to provide copies to third parties in the electronic format requested by the individual," and encourage HHS to include this in the regulation itself and not only in the preamble of the final rule.

Alternatively, NOSSCR supports the proposed fee structure in proposed 45 CFR 164.524(d)(6) and 45 CFR 164.524(c)(4) (Section III.A.6.b. of the NPRM)

Although we are adamant that copies of medical records should be provided at no cost, regardless of their format (i.e. whether electronic or non-electronic), to Social Security disability claimants and their appointed representatives, alternatively, NOSSCR would support HHS' proposed fee structure set forth in proposed 45 CFR 164.524(d)(6), which would allow covered entities to charge a reasonable, cost-based fee for an access request to transmit an electronic copy of PHI in an EHR to a third party through a non-internet based method that includes only the cost of labor for copying the PHI requested by the individual in an electronic form and the cost of preparing an explanation or summary of the electronic PHI if agreed to by the individual.

We also support the similar proposed fee structure set forth in proposed 45 CFR 164.524(c)(4)(i), which would allow covered entities to charge a reasonable, cost-based fee for requests from an individual/patient for copies of his/her own PHI that includes only the cost of labor for copying the PHI in electronic form and the cost of preparing an explanation or summary of electronic PHI if agreed to by the individual and additional charges for supplies for making copies and actual postage and shipping for mailing for non-electronic copies. We also support the proposed fee structure set forth in proposed 45 CFR 164.524(c)(4)(ii), which would not permit covered entities to charge any fees when the individual inspects his/her own PHI and when an individual uses an internet-based method to view or obtain a copy of electronic PHI, such as requests for PHI that can be fulfilled through an automated process like an online portal or application.

NOSSCR's support of this proposal is based on HHS' statement in this section of the NPRM indicating that the proposed rules intend to charge the same fees applicable under HITECH to

⁸ See e.g. Oregon Revised Statutes § 192.576(1) ("At the election of the individual or the individual's personal representative, the health information shall be provided in paper or electronic format."); and Revised Code of Washington § 70.02.030(2)(b) ("The health care facility or health care provider may provide the health care information in either paper or electronic format.").

requests for electronic medical records via a non-internet based method.⁹ Accordingly, we support this proposed rule because it purports to reinstate the extension of the patient rate for fees for copies of electronic PHI to third parties under HITECH. NOSSCR does not support any rule that would increase the costs for individuals or third parties.

NOSSCR supports shortening the required response time to no later than 15 calendar days with the opportunity for an extension of no more than 15 calendar days (Section III.A.3.b.ii. of the NPRM)

NOSSCR supports HHS' proposal to amend the individual access right provisions in proposed 45 CFR 164.524(b)(2)(i)-(iii) to require covered entities to provide copies of PHI no later than 15 calendar days (with the possibility of one 15-calendar day extension) or less if another applicable federal or state law requires a shorter time period for both direct access requests from an individual and requests from an individual that electronic copies of PHI in an EHR be directed to a third party.

This is especially important for Social Security disability claimants and their appointed representatives, who are required by regulation to submit, or inform the agency about, relevant medical evidence no later than five business days before the date of a scheduled hearing.¹⁰ Regarding the option to only inform the agency about relevant evidence, SSA has explained that "it is only acceptable for a representative to inform [the agency] about evidence without submitting it if the representative shows that, despite good faith efforts, he or she could not obtain the evidence. Simply informing [SSA] of the existence of evidence without providing it or waiting until 5 days before a hearing to inform us about or provide evidence when it was otherwise available, may cause unreasonable delay to the processing of the claim, without good cause, and may be prejudicial to the fair and orderly conduct of our administrative proceedings. As such, this behavior could be found to violate [SSA's] rules of conduct and could lead to sanction proceedings against the representative." Therefore, obtaining medical records in a timely fashion is not only essential for the full development and accurate determination of a claimant's disability claim, but is also significant to representatives practicing Social Security disability law, who could be sanctioned and/or disqualified from representing claimants for routinely informing of evidence instead of submitting it to the agency by the required deadline.

NOSSCR supports recognizing an individual's "clear, conspicuous, and specific" oral request for electronic copies of PHI in an EHR to be sent to a third party (Section III.A.5.b. of the NPRM) and prohibiting covered entities from imposing unreasonable identify verification measures on an individual exercising a right under the Privacy Rule (Section III.B.2. of the NPRM)

⁹ "The costs of electronic media and postage would not be allowed for providing electronic copies of PHI by any method. Pursuant to section 13405(e) of the HITECH Act, 'any fee that the covered entity may impose for providing [an] individual with a copy of such information (or a summary or explanation of such information) if such copy (or summary or explanation) is in an electronic form shall not be greater than the entity's labor costs in responding to the request for the copy (or summary or explanation).' Therefore, the Department is proposing to limit the fees covered entities are permitted to charge for electronic copies of PHI in an EHR based on a plain reading of this statutory requirement."

¹⁰ 20 CFR 404.935 and 416.1435.

NOSSCR supports HHS' proposal in the second part of proposed 45 CFR 164.524(d)(1) to require covered entities to respond to an individual's oral or written request to direct an electronic copy of PHI in an EHR to a third party designated by the individual when the request is "clear, conspicuous, and specific." We believe this will help promote an individual's right of access and eliminate barriers created by the current requirement that the request to direct an electronic copy of PHI in an EHR be in writing and signed by the individual, which is unnecessarily time consuming and burdensome, especially for those with disabilities or other limitations that make presenting a signed writing more difficult. NOSSCR supports the proposed language requiring the request be "clear, conspicuous, and specific," which is an appropriate safeguard to protect against erroneous or fraudulent oral requests that strikes a proper balance between protecting the privacy and security of an individual's PHI and removing unnecessary burdens that impede the right of access.

For similar reasons, NOSSCR supports HHS' proposal to modify paragraph (2)(v) of 45 CFR 164.514(h) to expressly prohibit covered entities from imposing unreasonable identity verification measures on an individual (or his/her personal representative) exercising a right under the Privacy Rule. After the decision in *Ciox Health, LLC v. Azar*, NOSSCR learned that certain copying services serving as the business associates for covered entities were requiring a photocopy of an individual's driver's license in order to charge the patient rate under HITECH. This presented several barriers to access, as not all individuals have a valid driver's license or picture ID, especially those who are homeless, and many do not have convenient access to a photocopier and scanner (or another way to electronically send a copy of his/her driver's license). As such, prohibiting covered entities from imposing unreasonable measures like this would certainly promote an individual's ability to exercise his/her right of access under the Privacy Rule.

NOSSCR supports requiring covered entities to provide advance notice of approximate fees for copies of PHI (Section III.A.7. of the NPRM)

NOSSCR supports HHS' proposal to add new subsection 525 to 45 CFR 164 to require covered entities to provide advance notice of approximate fees for copies of PHI requested under the access right and with an individual's valid authorization. We agree with HHS that this will increase individuals' awareness of the cost of copies of PHI, make access fee requirements more uniform, and promote compliance with the Privacy Rule. On December 20, 2020, HHS issued a report based on audits conducted in 2016 and 2017 of 166 covered entities and 41 business associates regarding their compliance with the requirements of HIPAA and HITECH, which found that nearly all covered entities audited (89%) failed to show that they were correctly implementing the individual right of access.¹¹ A notable recurring theme involved a lack of a clear reasonable, cost-based fee policy or application of blanket fees in violation of the standard.¹² NOSSCR believes this proposal requiring covered entities to post a fee schedule online and make it available to individuals at the point of service upon request will help reduce instances of non-compliance and incorrect implementation of the right of access in regards to

¹¹ "2016-2017 HIPAA Audits Industry Reports," Department of Health and Human Services, Office for Civil Rights, Health Information Privacy Division, December 2020, available at www.hhs.gov/sites/default/files/hipaa-audits-industry-report.pdf, p. 18.

¹² *Id.* at p. 19.

fees. In addition, the proposals in 45 CFR 164.525(a)(2) and (a)(3) requiring the covered entity to provide an individualized estimate of the approximate fees and an itemized list of specific charges for labor, supplies, and postage upon request would prevent surprise, unaffordable charges for claimants who have been waiting to receive their medical records. NOSSCR members' clients frequently report receiving outrageous bills for requested medical records long after the request was made.

The Privacy Rule should prohibit covered entities from denying requests for copies of PHI when the individual is unable to pay the access fee (Section III.A.9.cc. of the NPRM)

NOSSCR believes the Privacy Rule should prohibit covered entities from denying requests to exercise the right of access to copies of PHI when the individual is unable to pay the access fee, especially in the context of Social Security disability and needs-based benefits. Several state laws prohibit a medical provider from denying requests for copies of medical records necessary to support a claim or appeal under any provision of the Social Security Act solely because the patient is unable to pay. For example, in Nevada, a medical provider cannot deny furnishing a copy of the records "solely because the patient is unable to pay the [applicable] fees."¹³

Without such protection an indigent person's right of access is unduly impeded. NOSSCR proposes that any claimant providing proof of an application for, or appeal of the denial of, SSI benefits or Medicaid be automatically deemed unable to pay given the strict financial eligibility requirements for these types of benefits, which are only available to individuals with limited income and few resources.¹⁴ In addition, many SSDI applicants are unable to pay for medical records. HHS can look to certain state laws for ways to determine whether a claimant/patient is indigent or unable to pay for his/her medical records. For example, in New Jersey, a patient is unable to pay if he/she presents either (a) a statement certifying to annual income at or below 250% of the federal poverty level or (b) proof of eligibility for, or enrollment in, a state or federal assistance program.¹⁵ Other states, like Tennessee and West Virginia, consider or presume claimants to be indigent if represented by legal services organizations or pro bono attorneys.¹⁶ Additionally, in West Virginia, a claimant is also considered indigent if he/she submits "reasonable proof that the person is financially unable to pay full copying charges by reason of unemployment, disability, income below the federal poverty level, or receipt of state or federal income assistance."¹⁷ NOSSCR would support HHS implementing a similar standard for covered entities to determine when a SSDI claimant is unable to pay.

Conclusion

NOSSCR appreciates HHS' proposals to make crucial revisions to the right of access provisions in the Privacy Rule, especially in light of the *Ciox Health, LLC v. Azar* decision. We strongly maintain that copies of medical records, in any format, requested to support an application for, or appeal of, any claim under the Social Security Act should be provided free of charge when

¹³ Nevada Revised Statutes § 629.061(5).

¹⁴ See 42 U.S.C. 1382.

¹⁵ New Jersey Revised Statutes § 26:2H-5n.

¹⁶ Tennessee Code Annotated § 68-11-304(a)(2)(B)(i); West Virginia Code § 16-29-2(g).

¹⁷ West Virginia Code § 16-29-2(g)(2).

requested by the claimant or his/her appointed representative as a third party and encourage HHS to adopt such a provision. Alternatively, we support HHS' proposal to only charge a reasonable, cost-based fee for an access request to transmit an electronic copy of PHI in an EHR to a third party through a non-internet based method that includes only the cost of labor for copying the PHI requested by the individual in an electronic form and the cost of preparing an explanation or summary of the electronic PHI if agreed to by the individual. We fully support HHS's proposal to shorten the required response time for records to 15 calendar days; require covered entities to accept an individual's "clear, conspicuous, and specific" oral request for electronic copies of PHI in an EHR to be sent to a third party; prohibit covered entities from imposing unreasonable identify verification measures on individuals exercising a right under the Privacy Rule; and require covered entities to provide advance notice of approximate fees for copies of PHI requested under the right of access and with an individual's valid authorization. NOSSCR also suggests that HHS implement a rule prohibiting covered entities from denying requests for copies of PHI when the individual is unable to pay the access fee to further eliminate standards that impede an individual's ability to exercise the right of access.

Thank you for your consideration of our comments.

Sincerely,

Barbara Silverstone
Executive Director