

## Connecting Enrollment Assisters, Consumers and Coverage Gap Campaigns

As states determine whether or how to close the coverage gap in the next few years, it will be crucial to elevate the voices of consumers who fall into the gap to ensure they have a say in the policy decisions that impact them. Enrollment assisters can play an important role by identifying consumers who fall into the gap, and either connecting those consumers directly to the advocacy organization working to close the gap, or offering the consumer an opportunity to share their story to help the public and policymakers understand the consequences of the gap.

While federal regulations restrict the ways in which enrollment assisters can use, store and disclose personally identifiable information (PII),<sup>1</sup> or contact information, when providing enrollment assistance, **new guidance from CMS recently clarified that assisters** *can* **obtain and use contact information for reasons unrelated to the enrollment, such as to collect stories,** so long as the consumer understands that the use is unrelated to enrollment, and authorizes this unrelated use.<sup>2</sup>

Using this guidance, this fact sheet explains three ways in which enrollment assisters can obtain, use or disclose PII to connect consumers to coverage gap campaigns.

## 1. Create a separate consent form for consumers to authorize the collection of their PII for advocacy purposes

In a recent assister newsletter, CMS clarified that enrollment assisters and their organizations are permitted to collect consumer stories because it "recognizes that consumer stories can be a powerful tool for raising awareness about the Affordable Care Act and educating the public about the value of health insurance." To obtain consent to use PII to collect stories (or for other advocacy purposes), CMS recommends that assisters create and use a separate consent form from the standard authorization form used for enrollment.<sup>4</sup>

<sup>&</sup>lt;sup>1</sup>Personally identifiable information is any type of information that could be used to distinguish or trace a consumer's identity, as well as information that is linked or a linkable to a specific individual. Examples of PII include a consumer's name, phone number, address, date and place of birth, and social security number. Department of Health & Human Services, Centers for Medicare & Medicaid Services, Center for Consumer Information & Insurance Oversight, *Federally-facilitated Marketplace Assister Curriculum: Privacy, Security and Fraud Prevention Standards*, August 28, 2014.

<sup>&</sup>lt;sup>2</sup> <u>See</u> *How to Obtain a Consumer's Authorization before Gaining Access to Personally Identifiable Information*, Department of Health & Human Services, Health Insurance Marketplaces, November 2014, <a href="https://marketplace.cms.gov/technical-assistance-resources/obtain-consumer-authorization.pdf">https://marketplace.cms.gov/technical-assistance-resources/obtain-consumer-authorization.pdf</a>. See also Centers for Medicare & Medicaid Services, *Assisters Update Webinar: Extended Marketplace Webinar Invitation*, November 7, 2014, <a href="https://goto.webcasts.com/viewer/event.jsp?ei=1043362">https://goto.webcasts.com/viewer/event.jsp?ei=1043362</a>.

<sup>&</sup>lt;sup>3</sup> Centers for Medicare & Medicaid Services, Weekly Newsletter to Assisters, November 18, 2014.

<sup>&</sup>lt;sup>4</sup> <u>See</u> *How to Obtain a Consumer's Authorization before Gaining Access to Personally Identifiable Information*, Department of Health & Human Services, Health Insurance Marketplaces, November 2014,

In addition, CMS recommends that story collection consent forms be as specific as possible regarding how a consumer's PII will be used so that consumers are fully informed of those other uses. For example, consent forms should clearly specify where, how many times and with whom the consumer's story will be shared. In addition, assisters and their organizations should share with consumers the version of their story that will be published, "so that consumers are comfortable with that specific version of the story and can make changes to it before it is publicized, if necessary." Lastly, assisters should "make sure the consumer is aware that once shared, the story will become public and might be used by the public in ways that neither the assister nor consumer could foresee."6

Alternatively, enrollment assisters could ask an advocacy organization involved in a coverage gap campaign to create the consent form. Having a partner organization who does not provide enrollment assistance create the consent form can be an additional way to help clarify that connecting consumers to a coverage gap campaign is a separate service from enrollment assistance.

## 2. Include an area within the standard consent form for consumers to authorize the collection of their PII to be connected to a coverage gap campaign, but they should get approval from CMS before doing so

CMS recently released new templates of standard consent forms that enrollment assisters can use to obtain a consumer's authorization to use their PII during enrollment assistance. The new form includes an area for consumers to give "specific consent" to have their PII used for nonenrollment reasons, such as to "refer that consumer to another source of help," or to "carry out other activities."9

Therefore, it is possible that enrollment assisters could include an area within the standard consent form for consumers to authorize their PII to be disclosed to a campaign working to close the coverage gap. As mentioned above, however, CMS recommends as a best practice that assisters use a separate consent form for any use of PII that is unrelated to enrollment. In addition, CMS recommends that enrollment assisters and their organizations consult with CMS before including a "specific consent" area on the standard consent form.

https://marketplace.cms.gov/technical-assistance-resources/obtain-consumer-authorization.pdf. See also Centers for Medicare & Medicaid Services, Weekly Newsletter to Assisters, November 18, 2014.

 $^{6}$  See id.

See id.

<sup>&</sup>lt;sup>7</sup> https://marketplace.cms.gov/technical-assistance-resources/draft-authorization-form-navigators.pdf

<sup>&</sup>lt;sup>8</sup> Centers for Medicare & Medicaid Services, Assisters Update Webinar: Extended Marketplace Webinar Invitation, November 7, 2014, https://goto.webcasts.com/viewer/event.jsp?ei=1043362.

<sup>&</sup>lt;sup>9</sup> See How to Obtain a Consumer's Authorization before Gaining Access to Personally Identifiable Information, Department of Health & Human Services, Health Insurance Marketplaces, November 2014, https://marketplace.cms.gov/technical-assistance-resources/obtain-consumer-authorization.pdf.

## 3. Provide third-party information about the campaign to close the coverage gap to consumers, and allow them to connect with the campaign

Lastly, enrollment assisters could bring materials with contact information of the organization involved in closing the coverage gap to enrollment appointments, and give them to interested consumers. Enrollment assisters can also host enrollment events with advocates involved in closing the coverage gap, so that a "hand-off" from enrollment assister to advocate can be made as soon as an individual is determined to fall into the gap, without having to use, store or disclose PII.

Overall, enrollment assisters can obtain and use PII for the purpose of collecting stories or other advocacy efforts, so long as the consumer understands and consents to the other uses. To help consumers understand the different ways in which their PII will be used, CMS recommends as a best practice using a separate consent form that explains the specific uses in as much detail as possible. However, all three options discussed above are ways that enrollment assisters can help make consumers aware of the different ways their PII will be used when they provide consent.

Advocates and enrollment assisters should take the approach they feel most comfortable with when connecting consumers to campaigns working to close the coverage gap. To view examples of how advocacy organizations have been connecting consumers to coverage gap campaigns, see **Examples and Resources from States**.

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<sup>&</sup>lt;sup>10</sup> <u>See</u> *How to Obtain a Consumer's Authorization before Gaining Access to Personally Identifiable Information*, Department of Health & Human Services, Health Insurance Marketplaces, November 2014, https://marketplace.cms.gov/technical-assistance-resources/obtain-consumer-authorization.pdf.