

From: [seth morrow](#)
To: [HRSA Paperwork](#)
Subject: [EXTERNAL] Public comment — National Marrow Donor Program Patient Support Center Survey, OMB 0906-0004
Date: Monday, August 24, 2026 4:01:13 PM

HRSA Information Collection Clearance Officer,

I am submitting a focused public comment on the proposed revision of the National Marrow Donor Program Patient Support Center Survey, OMB No. 0906-0004, noticed July 1, 2026 (91 FR 40004-40005).

The notice says the survey is intended to assess the helpfulness/effectiveness of Patient Support Center services and inform program/resource-allocation decisions. It also says the survey population includes patients, caregivers, and family members who contact the PSC by phone or email, but that online survey invitations will be sent to participants for whom an email address is known.

That creates a coverage-bias risk that is distinct from ordinary survey nonresponse: a person who used the PSC by telephone but has no email address recorded may never enter the survey invitation frame at all. Those participants may systematically differ from email-reachable participants in age, digital access, disability/access needs, socioeconomic circumstances, language/communication preferences, caregiver burden, or acuity of illness. Demographic questions answered only by respondents cannot measure the characteristics or experiences of people who were never invited.

Suggested safeguard:

1. Define and report the survey-frame denominator separately from the underlying PSC-contact population: total eligible contacts, number with a usable email address, number actually invited, number delivered successfully, and number responding.
2. Where practical, provide an accessible alternative invitation/response mode for eligible participants without email or with an undeliverable email (for example, telephone, SMS where consented, or another established contact method).
3. If alternate-mode surveying is not feasible, quantify and disclose the coverage limitation and compare available non-survey service-record characteristics of invited versus non-invited participants, using only data already collected for program operations and appropriate privacy safeguards.
4. Add a survey or administrative field sufficient to distinguish the participant's original PSC contact mode and survey invitation/response mode, so apparent satisfaction differences are not mistaken for service differences when they may reflect mode or coverage effects.
5. Avoid describing results as representative of all PSC contacts unless the uninvited/no-email portion of the eligible population has been evaluated or appropriately accounted for.

A useful validation property would be: every eligible PSC contact is either given a reasonable survey opportunity or is counted in a documented non-invited/coverage category, so no participant silently disappears from the denominator merely because an email address is absent.

This does not require increasing survey burden for every respondent. The main improvement is preserving the distinction between nonresponse and noncoverage so quarterly/annual results used for program improvement are not more representative than the data actually support.

Thank you for considering the comment.

Seth Morrow

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