



RE: Request for Information: National Directory of Healthcare Providers and Services

Docket File Code: CMS-0058-NC

Docket Name: Request for Information; National Directory of Healthcare Providers & Services

Docket RIN 0938-ZB72

United Ostomy Associations of America, Inc. (UOAA) is a 501(c)(3) national nonprofit organization that supports, empowers, and advocates for people who have had or will have ostomy or continent diversion surgery. There are between 725,000 to one million Americans living with an ostomy or continent diversion, and over 100,000 new life-saving ostomy surgeries occur in America yearly. Approximately, 65% of this patient population are Medicare/Medicaid beneficiaries.

Ostomy surgery is life altering/body altering, but it is also life saving. Finding a healthcare provider/professional with specific training in ostomy care throughout the continuum of their care is crucial for successful patient outcomes and to achieve a desirable quality of life. Patients who have had surgery for an ostomy will face risks of developing a stoma or peristomal skin complication at some point during their life whether the ostomy is temporary or permanent. Ostomy surgery patients have high rates of complications, hospital readmissions (42% within 120 days following surgery) and emergency department visits¹. More than 80% of the patients within two years of surgery will develop peristomal skin complications, such as irritant dermatitis, which is one of the many postoperative skin and stoma complications².

Our national office receives hundreds of calls annually from people trying to locate medical providers with knowledge in ostomy care in their local area. Ideally counseling and care should be provided by a trained medical professional such as a Certified Wound Ostomy Continence Nurse³. This is validated⁴ by the American Society of Colon and Rectal Surgeons Clinical Practice Guidelines (2015) which states "... the optimal care for patients undergoing ostomy surgery includes preoperative, perioperative, and postoperative care by an ostomy nurse specialist, such as a nurse certified by the Wound, Ostomy, and Continence Nurses Society (WOCN) Certification Board.^{5,6}".

We applaud CMS establishing a National Directory of Healthcare Providers & Services (NDH) that could serve as a “centralized data hub” for healthcare provider, facility, and entity directory information nationwide. UOAA is the voice and leading organization advocating for people living with an ostomy. To ensure this underserved population is able to find a care provider, which includes specialty nurses, it is our recommendation that the proposed National Directory of Healthcare Providers and Services include certified Wound, Ostomy and Continence nurses, advanced practice nurses and outpatient ostomy clinic facilities. These nurses are educated to the unique medical needs of those who have undergone surgery for an ostomy which includes the recommendation and fitting of prosthetic pouching systems. These nurses and services are vital after surgery and for the lifetime needs of the person living with an ostomy.

Disparity in care for the ostomy community is seen for several reasons. Less than 1% of nurses are ostomy nurses. This creates a staggering gap in access to care between patients who need a certified ostomy nurse and the number that are available. The majority of these nurses are located in the acute care setting. Few are found in community settings such as outpatient clinics and long term, rehab or skilled nursing facilities. Geography creates further disparities where most ostomy nurses are concentrated in highly populated areas versus rural settings.

UOAA supports a directory if the following concerns can be addressed in the system:

- In our past experience with referral systems the data is self-reported. Oftentimes, the data is not updated consistently. As a result, patients in the ostomy community have found themselves in situations where they are in desperate need of immediate care only to call an inactive number or learn that the provider is no longer in practice or not within the facility listed in the system. They are left frustrated, angry and in some cases resort to seeking medical attention in an emergency department. It is imperative that your directory must be maintained with updated and validated information.
- Ensure all provider types and specialty are included in any search function including key words such as “ostomy”. The user interface must be easy to navigate.
- Your system must interface with the WOCNCB certification verification website (<https://www.wocncb.org/certification-verification>) to verify the nurses and advanced practice nurses listed under the specialty carry the WOCNCB gold standard certification in the specialty.

Thank you for considering these comments for your request for information.

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2. LeBlanc K, Whiteley I, McNichol L, Salvadalena G, Gray M. Peristomal medical adhesive-related skin injury: results of an international consensus meeting. *J Wound Ostomy Continence Nurs*. 2019;46(2):125–136. doi:10.1097/WON.0000000000000513.
3. United Ostomy Associations of America, Inc. Ostomy and Continent Diversion Patient Bill of Rights. https://www.ostomy.org/wp-content/uploads/2021/08/UOAA_Patient_Bill_of_Rights_Poster_20210806.pdf. Accessed November 28, 2022.

4. Burgess-Stocks, Joanna; Gleba, Jeanine; Lawrence, Kathleen; Mueller, Susan. Ostomy and Continent Diversion Patient Bill of Rights: Research Validation of Standards of Care. *Journal of Wound, Ostomy and Continence Nursing*: May/June 2022 - Volume 49 - Issue 3 - p 251-260 doi: 10.1097/WON.0000000000000876
5. Hendren S, Hammond K, Glasgow SC, et al. Clinical Practice Guidelines for Ostomy Surgery. *Dis Colon Rectum*. 2015;58(4):375-387. doi:10.1097/DCR.0000000000000347
6. Wound Ostomy Continence Nurses Society. Clinical Guideline: Management of the Adult Patient with a Fecal or Urinary Ostomy. Wound Ostomy Continence Nurses Society; 2017.