



A.S.P.E.N.'s National Patient  
Registry for Nutrition Care

## **Sustain Publication Guidelines**

Based on the following section of the Sustain Participation and Data Use Agreement, the Sustain Scientific Council has developed guidelines regarding the use of the data from the Benchmarking Reports.

*Use of Benchmarking Reports. Participant agrees to comply with all publishing or use guidelines established by Sustain from time to time regarding permitted uses and disclosures of Benchmarking Reports. In general, Participant shall only use reports for appropriate internal and external purposes in a manner that is accurate and not misleading.*

### **Guidelines on Use of Sustain Data**

Sustain Participants and Participating Sites engage in the process of collecting Sustain data and utilization of registry-derived information for the purpose of local and national improvement in the quality of Home PN care. This Guideline provides information on the specific and accepted professional use of this data and registry-derived information from Sustain.

#### **1. Participant use of their own site's data**

The participating site will be able use your own site's data in any way that your site wants including publication of such data.

#### **2. Participant use of the Sustain benchmarking data**

The benchmarking data is the site's data as compared to the aggregate Sustain data. Any information from the benchmarking report can be used internally for quality assurance and educational purposes. Such internal utilization may satisfy institution quality assurance requirements such as mortality and morbidity review and confidential service conference discussions. Process improvement within an institution may be monitored for continuous quality improvement impact, using the data and outcomes as reported for and by the Sustain Registry. The benchmarking reports and any data contained therein cannot be disclosed outside of the Participant for any reason, including but not limited to, for marketing or to promote the site's program as compared to others. Participant is prohibited from publishing the benchmarking reports. Data contained within the benchmarking reports cannot be used for publication or research unless all requirements set forth in #3 below in this document are met.

### 3. Use of Sustain benchmarking and aggregate data for research purposes

Individual Participant-specific site data and aggregate data may be used for clinical research by that Participant if reviewed and approved by the Sustain Scientific Council for scientific merit and ethical propriety. Clinical research on aggregated national data may be used to produce one or more of the following forms for reporting and dissemination of information: abstract, scientific meeting presentation, or manuscript for publication in the medical literature under the following conditions:

1. Participants can only publish aggregate data after permission is received by the Sustain Scientific Council.
2. Any abstract, scientific meeting presentation, or manuscript for publication in the literature must have the “Sustain” name in the title or text or presentation materials.
3. Any scientific meeting presentation, or manuscript for publication in the literature must acknowledge the “Sustain” funding support using the following language:

*Sustain is supported, in part, by unrestricted scientific grants from Baxter Healthcare Corporation and the A.S.P.E.N. Rhoads Research Foundation.*

Note: Check the Sustain website periodically for additional supporters and include those as well.

#### **Process for Obtaining Permission to Publish**

Participants may submit requests to Sustain for scientific queries using either the benchmarking reports provided or requiring access to raw **de-identified** patient data from the Sustain Registry. Request for permission should include a full research proposal. All such requests for data queries and publication permissions shall be subject to prior approval by the Sustain Scientific Council who shall give due consideration to scientific merit, the funds and other resources available to address queries and other pertinent factors. As a part of its efforts to promote the use of the Sustain Registry as a tool for the development of beneficial scientific information, Sustain will provide reasonable assistance to the Participant in refining Participant’s requests for queries so as to enhance their potential for approval. Participant may be required to enter into an agreement regarding the use of the data.

The Sustain Scientific Advisory Committee retains the right to update this document on a periodic basis. Check the SUSTAIN website ([www.nutritioncare.org/sustain](http://www.nutritioncare.org/sustain)) for the latest publication guidelines.

*Adopted by the Sustain Executive Council Chairperson November 2012.*