AACVPR Outpatient Pulmonary Rehabilitation Registry: Definitions and Comments for Selected Data Elements

To ensure consistency in the data entered, definitions of several of the data elements in the AACVPR Outpatient Pulmonary Rehabilitation Registry have been standardized. All data entered must conform to these definitions.

Please note the following:

1. We strongly recommend that patients have monitoring of the following outcomes pre and post (and ideally in follow-up):
   a. Functional capacity using 6 minute walk test (6MWT) (see the PR Outcomes Toolkit for resources and competency).
   b. Maximum dyspnea during 6MWT
   c. Health-related Quality of life (HRQOL) using one of the six tools identified (Chronic Respiratory Questionnaire and St. George Respiratory Questionnaire have the strongest evidence base in PR.)
   d. Depression or anxiety using one of the six tools identified
2. If you do not have data for a value, leave the field blank.
3. A zero means zero. Do not enter a zero into a field unless the value is truly zero.
4. For some clinical and functional assessments, be sure to select the appropriate units, e.g., feet/meters or pounds/kilograms, for the reported.

Regarding the symptom, QOL, and psychosocial tools, only one tool needs to be entered. It is not necessary to use all the tools displayed.

The data elements are listed in the order they may be encountered while moving through the patient record.

**Referral Date**
Enter the date the referral document was signed by a physician. For patients referred from an inpatient care team, this may be the date of the discharge orders.

**Enrolled**
If the patient has been referred for PR and enrolls (defined as having completed at least 1 billable exercise session) select “Yes” from the pulldown list and enter the date of the first session under the Enrollment Date. If the patient was referred but did not start, select “No”, leave the Enrollment Date blank and select a primary reason for non-enrollment from the Reason for Non-enrollment field.

**Enrollment Date**
Enter the date of the patient’s first billable exercise session. An evaluation without exercise would not meet this criterion.

**Admitting / Respiratory Diagnosis**
Enter the diagnoses or procedures most related to the referral to PR as well as any secondary pulmonary diagnoses including past medical history. Enter all that apply and select a diagnosis/procedure as the primary diagnosis.

**Most Recent Hospitalization for COPD:**
For pulmonary procedures such as lung transplantation, enter the date of the hospital admission.
Enter the date of the most recent hospitalization for COPD. If the exact day and month are unknown, enter “01/01/year”. This date and any readmissions during PR participation are used to evaluate for 30-day readmission rates.

**FEV1/FVC Ratio**
This is the actual ratio, e.g. FEV1 divided by FVC to give a ratio of the two values. Entries should be in the form of a number to the nearest 2 decimal points.
Severity of Obstruction
Use GOLD guidelines for severity based on airflow obstruction, i.e.,
mild > 80% predicted
moderate 50-80% predicted
severe 30-50% predicted
very severe < 30% predicted (or 30-50% with chronic respiratory failure)
All include FEV1/FVC ratio < 70% predicted

Post-bronchodilator (pre-PB value if post value not available)
Use the values from the most recent test date available.

Pulmonary Function Testing

Clinical Outcomes
Enter values (scores) for tests used for dyspnea (Maximum Borg with 6MWT, MMRC, and UCSD SOBQ, if used), health-related quality of life, and psychosocial (depression and/or anxiety) tools. If tool uses domains or subscales, enter these values. Please refer to the Pulmonary Rehabilitation Outcomes Resource Guide for further information on the tools listed in the registry.

Steps per Day:
Enter the average number of steps taken per day as recorded on a pedometer, accelerometer or other validated physical activity monitor.

Tobacco Status
If the patient has never used tobacco products, select the “Never smoker” option. If the patient has quit using tobacco products by the time of PR enrollment, select the “Former smoker” option. If the patient is actively using tobacco products at the time of enrollment, select the “Current smoker” option, indicating whether he/she is smoking “Every day” or “Some days.” If the patient is using tobacco products, but it is not clear how often, select the “Smoker, current status unknown” option.

If the patient is currently smoking cigars, leave the “Packs per day” field blank and enter the number of years the patient has smoked cigars.

Tobacco Status (DC/FU)
If the patient has not used tobacco products within the past seven (7) days, enter “Abstaining.” If the patient has used tobacco products within the past seven (7) days, enter “Not Abstaining.”

Medication
Long-acting beta agonists (long-acting beta2 agonists, long acting β2-agonists, LABA) trigger smooth muscle relaxation resulting in dilation of bronchial passages with a long duration of action due to the addition of a long, lipophilic side-chain that binds to an exosite on adrenergic receptors. This allows the active portion of the molecule to continuously bind and unbind at beta2 receptors in the smooth muscle in the lungs. This class may reduce the need for shorter-acting β2-agonists. Long-acting beta2 agonists with 12-hour duration of action include salmeterol (Serevent, combined with fluticasone in Advair), formoterol (Foradil, combined with budesonide in Symbicort and mometason in Dulera), and arformoterol (a nebulized medicine available under the brand name Brovana). Long-acting beta2 agonists with 24-hour duration of action include indacaterol (Arcapta) and vilanterol (combined with fluticasone in Breo Ellipta).

Short-acting beta agonists (beta2 receptor agonists, SABA) trigger smooth muscle relaxation, resulting in dilation of bronchial passages. This class of drugs is often used for “rescue” or rapid relief of respiratory symptoms including dyspnea and exercise-induced bronchospasm. Examples include albuterol (salbutamol outside the United States; brand names in the United States include Ventolin, Proventil, and ProAir), levalbuterol (Xopenex), and pirbuterol (Maxair). Albuterol is available in both metered dose inhaler and nebulizer solution.
Long-acting anticholinergics (LAAC) relax and dilate the airways to control dyspnea and reduce bronchospasm. They also may reduce mucus production. Examples include tiotropium (Spiriva), a LAAC which also reduces acute exacerbation of COPD and improves exercise capacity. Duration of action is 24 hours or longer. Tudorza Pressair (aclidinium bromide) is a LAAC used twice daily for the long-term maintenance treatment of bronchospasm in COPD.

Short-acting anticholinergics (muscarinic antagonist, SAAC) relax and dilate the airways to improve dyspnea and reduce bronchospasm. They also may reduce mucus production. Ipratropium (Atrovent) is available in inhaler and nebulizer solution (also combined with albuterol in Combivent Respimat and Duoneb nebulizer solution). Duration of action is typically 4 to 6 hours.

Inhaled corticosteroids (glucocorticosteroids, ICS) treat and prevent inflammation in the airway with minimal amounts absorbed into the body, thereby reducing systemic side effects. Examples are listed below.

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Brand Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>beclomethasone</td>
<td>QVAR</td>
</tr>
<tr>
<td>budesonide</td>
<td>Pulmicort</td>
</tr>
<tr>
<td>ciclesonide</td>
<td>Alvesco</td>
</tr>
<tr>
<td>fluticasone</td>
<td>Flovent</td>
</tr>
<tr>
<td>mometasone</td>
<td>Asmanex</td>
</tr>
</tbody>
</table>

Combinations of an inhaled corticosteroid and a long-acting beta2-agonist include:

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Brand Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>budesonide and formoterol</td>
<td>Symbicort</td>
</tr>
<tr>
<td>fluticasone and salmeterol</td>
<td>Advair</td>
</tr>
<tr>
<td>mometasone and formoterol</td>
<td>Dulera</td>
</tr>
<tr>
<td>fluticasone and vilanterol</td>
<td>Breo Ellipta</td>
</tr>
</tbody>
</table>

Oral corticosteroids (glucocorticosteroids) reduce inflammation and swelling in the airway and treat certain inflammatory diseases including significant allergic reactions, autoimmune disorders and risk of organ rejection following organ transplantation. Patients should be instructed in correct use and potential adverse effects. Uses in obstructive lung disease may include acute treatment of exacerbation or pneumonia. Examples of oral corticosteroids include prednisone, prednisolone, and methylprednisolone.

**Weight**

Weigh the patient prior to exercise without shoes and while wearing his/her typical or usual exercise clothes. Record weight to the nearest half pound or kilogram if using a digital scale, to the nearest quarter pound if using a balance beam scale. The scale should be placed on a solid, level surface. Select the units used for measurement (pounds or kilograms).

**Height**

Measure the patient’s height in stocking feet to the nearest quarter inch or whole centimeter. Have the patient stand erect with the heels, buttocks, back of shoulders and back of head against the vertical scale. With the patient holding their breath, bring the horizontal bar into contact with the highest point on the head. Select the units used for...
measurement (inches or centimeters).

Oxygen Tank Size

6-Minute Walk Distance
Report the distance attained during the 6-minute walk test in feet or meters. (Please refer to An official European Respiratory Society/ American Thoracic Society technical standard: field walking tests in chronic respiratory disease Anne E. Holland, et al.

Program Discharge Date
Enter the date of the last billed Phase 2 exercise session or discharge assessment session.

Completion Status
The patient is defined as having completed PR when he/she has undergone a final, formal discharge assessment session and updated treatment plan. If neither of these criteria is met, the patient has not completed PR and reason(s) for non-completion should be entered.

# of Sessions Completed
Enter the number of billed outpatient pulmonary rehab exercise sessions the patient completed.

Untoward Events
Untoward events are events that require immediate cessation of exercise, assessment by PR staff, and intervention, e.g., immediate contact of physician, transport to emergency department, rapid response call, code blue, and/or other acute intervention. It is assumed that the physician will be contacted regarding the patient’s findings and disposition. These are tracked and reported during the PR program.

Exacerbation
Exacerbation is defined as an increase in or the new onset of more than one respiratory symptom (cough, sputum, sputum purulence, wheezing, or dyspnea) lasting three (3) days or more and requiring treatment with an antibiotic or a systemic corticosteroid. Exacerbations are reported during both PR and the follow-up period (six months from the start of PR).