SyntheaTM Module Companion Guide

cerebral palsy

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## Introduction

[Synthea](https://synthetichealth.github.io/synthea/" \l "about-landing)TM is an open-source, synthetic patient generator created by MITRE, that models the medical history of synthetic patients. Clinical disease modules are created using a combination of clinical care protocols and publicly available disease incidence and prevalence statistics. Synthea uses these modules to generate individual synthetic patient records, simulating the progression and treatment of disease from birth to death. Synthea Module Companion Guides serve to orient users to a specific Synthea module. The intended audience includes those reviewing a module under development and/or interested in utilizing the module to generate synthetic patient data.

This document summarizes the scope and intent of the Treatment of Sialorrhea in Cerebral Palsy module. It provides details of the module states and contains a full list of references and data sources used to develop the module.

## Module description

Table 1: Cerebral Palsy Module Metadata contains a list of metadata attributes that help describe the module including, but not limited to, module steward, module developer, date of last update, and other descriptive information.

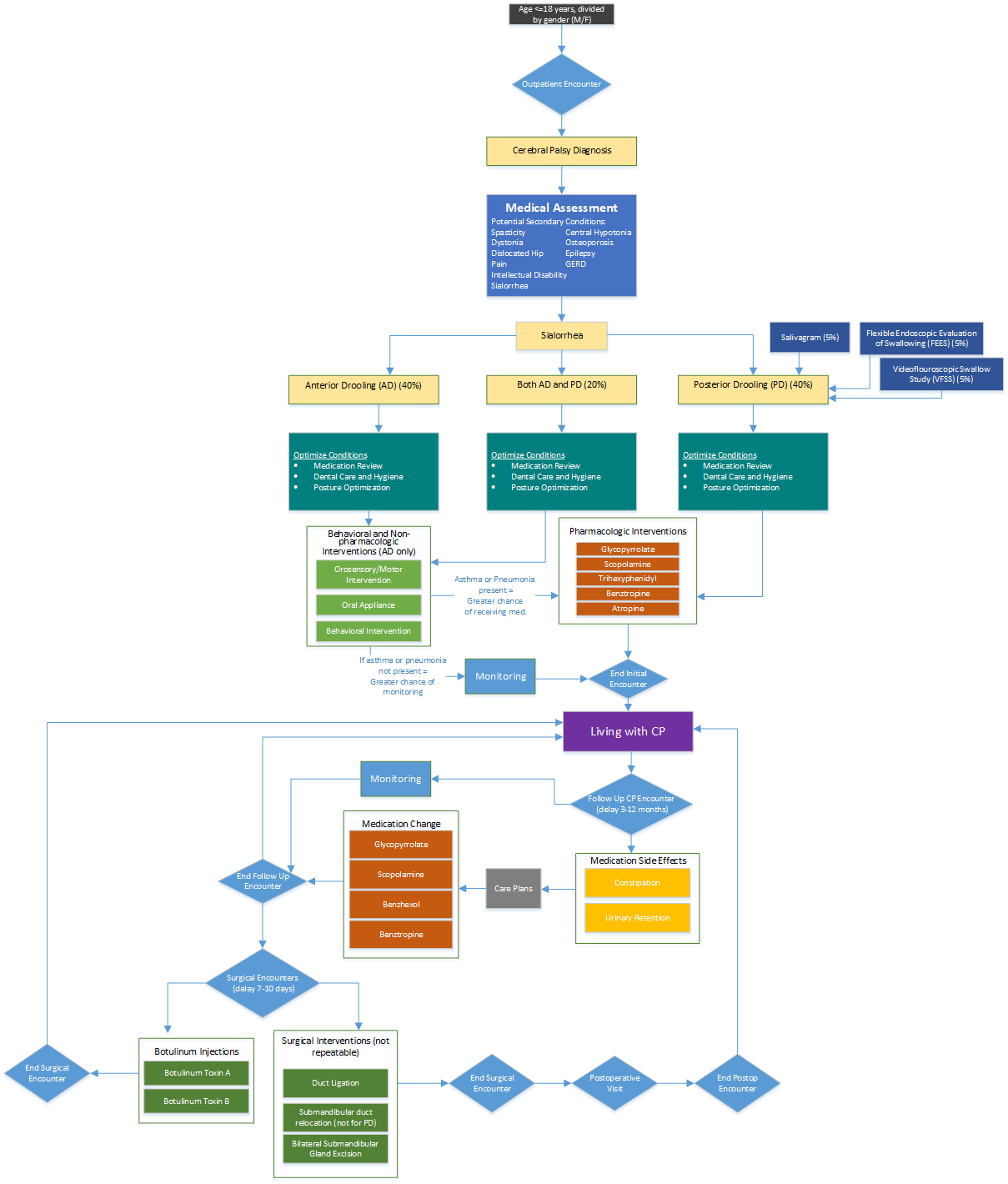
Table 1: Cerebral Palsy Module Metadata

|  |  |
| --- | --- |
| **Metadata** | **Description** |
| Title | Cerebral Palsy |
| Module File Name | cerebral\_palsy.json |
| Version Number | 1.0 |
| Last Updated | September 4, 2020 |
| Module Steward | Office of the National Coordinator for Health Information Technology (ONC) |
| Module Developer | Clinovations Government + Health |
| Description | This module models the treatment of Sialorrhea in Cerebral Palsy in patients age <=18 years of age. It is based on the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) clinical care pathway for Sialorrhea(1). This guideline provides recommendations for treatment of Sialorrhea in outpatient settings for the pediatric patient with cerebral palsy.  While this module contains other conditions that may occur in the cerebral palsy patient, such as dystonia, pain, spasticity, central hypotonia, osteoporosis, epilepsy, gastroesophageal reflux disease, and intellectual disability, treatments for these conditions are not yet modeled in the module. |
| Disclaimer | [Synthea](https://synthetichealth.github.io/synthea/#about-landing)TM is an open-source, synthetic patient generator created by MITRE that models the medical history of synthetic patients. This module is developed using the Synthea Module Builder and is limited to the capabilities of Syntheaand the Synthea Module Builder.  This Synthea module is not a clinical guideline, does not establish a standard of medical care, and has not been tested for all potential applications. THIS MODULE IS PROVIDED "AS IS" WITHOUT WARRANTY OF ANY KIND. |
| Related Module(s) | None |
| Reference(s) | AACDPM Clinical Care Pathway for Sialorrhea |

## Module Diagram

A SyntheaTM module diagram within the Synthea Module Builder is often large and complex to view, as it includes both clinical states and control states. It may be challenging for users to understand and navigate the module within Synthea, especially those who are new to the process. The purpose of the following Visio diagram is to provide a high-level, simplified view of the module contents and flow so users understand the scope and main components of the module before diving into details.

Figure 1: Treatment of Sialorrhea in Cerebral Palsy Visio Diagram



## Module STATEs

## Table 2: The Cerebral Palsy Module States table provides details about each clinical state modeled within the module. State Names are modeled in the Cerebral Palsy module. The Type column indicates the [Synthea](https://github.com/synthetichealth/synthea/wiki/Generic-Module-Framework:-States) state type used to define the state. State Remarks provide detailed documentation for each state, including notes, references, and data sources used to define probabilities. The Terminology column identifies the standard codes used to model the clinical states.

Table 2: Cerebral Palsy Module States

| **State Name** | **Type** | **State Remarks** | **Terminology** |
| --- | --- | --- | --- |
| Initial | Initial | Initial state of a module required by SyntheaTM. | n/a |
| Age\_and\_Applicable\_Time\_Guard | Guard | This Guard state ensures that the module applies to patients age <=18 years. | n/a |
| Male/Female | Simple | These states divide the population by male and female. There are more male patients diagnosed with cerebral palsy (CP) than female patients.  Reference: (2) | n/a |
| Pre-Cerebral\_Palsy | Delay | Delay is set to one month for this module, so the initial encounter does not collide with other module encounters. | n/a |
| Condition\_Onset\_Cerebral\_Palsy | Condition Onset | Probability set to 3.1/1000 patients in Synthea population. Ratio of male to female patients is 1.4:1.  Reference: (3) | System: SNOMED-CT Code: 128188000 Display: Cerebral Palsy (disorder) |
| Cerebral\_Palsy\_Encounter1 | Encounter | This is the first encounter once the patient enters the module presenting with cerebral palsy. Direct transition to symptoms of CP. | System: SNOMED-CT Code: 3391000175108 Display: Office visit for pediatric care and assessment (procedure) |
| Check\_Dystonia | Simple | This state checks the CP population for Dystonia. | n/a |
| Cerebral\_Palsy\_Dystonia | ConditionOnset | Probability set to 16.666% of the CP population. In approximately one in six cases, CP causes involuntary muscle spasms and unwanted movement, described as dystonic cerebral palsy (or alternatively dyskinetic or choreoathetoid cerebral palsy).  Reference: (4) | System: SNOMED-CT Code: 15802004 Display: Dystonia (disorder) |
| Check\_Pain | Simple | This state checks the CP population for Pain. | n/a |
| Cerebral\_Palsy\_Pain | ConditionONset | Probability set to 32.4% of the CP population. Study found that of 2777 children (57% boys) at a median age of 7 years, 32.4% reported pain, with significantly more girls than boys experiencing pain.  Reference: (5) | System: SNOMED-CT Code: 22253000 Display: Pain (finding) |
| Check\_Central\_Hypotonia | Simple | This state checks the population for central hypotonia. | n/a |
| Cerebral\_Palsy\_Central\_Hypotonia | ConditionOnset | Probability set to 45% of the CP population. Hypotonic CP is marked by extremely loose and floppy muscle tone. This type of CP accounts for less than half of all cases.  Reference: (6) | System: SNOMED-CT Code: 398152000 Display: Poor muscle tone (finding) |
| Check\_Spasticity | Simple | This state checks the CP population for spasticity. | n/a |
| Cerebral\_Palsy\_Spasticity | ConditionOnset | Probability set to 77.4% of the CP population. Most (77.4%) of the children identified with CP had spastic CP.  Reference: (7) | System: SNOMED-CT Code: 221360009 Display: Spasticity (finding) |
| Check\_Osteoporosis | Simple | This state checks the CP population for osteoporosis. | n/a |
| Cerebral\_Palsy\_Osteoporosis | ConditionOnset | Probability set to 50% of the CP population. Low bone mineral density is found in more than 50% of adults with a variety of disabilities, including CP. Numbers of children with osteoporosis from CP are still being evaluated, but preventative measures are recommended due to the high number of adults with CP and osteoporosis.  Reference: (7) | System: SNOMED-CT Code: 64859006 Display: Osteoporosis (disorder) |
| Check\_Epilepsy | Simple | This state checks the CP population for epilepsy. | n/a |
| Cerebral\_Palsy\_Epilepsy | ConditionOnset | Probability set to 50% of the CP population. As many as half of all children with CP have one or more seizures. Children with both CP and epilepsy are more likely to have intellectual disability.  Reference: (8) | System: SNOMED-CT Code: 84757009 Display: Epilepsy (disorder) |
| Check\_Intellectual\_Disability | Simple | This state checks the CP population for intellectual disability. | n/a |
| Cerebral\_Palsy\_Intellectual\_Disability | ConditionOnset | Probability set to 50% of the CP population. One in two people with CP have an intellectual disability. One in five people have a moderate to severe intellectual disability. Generally, the greater the level of a person’s physical impairment, the greater the likelihood of an intellectual disability. However, some people who have a profound level of physical impairment do not have an intellectual disability. Conversely, there are those with a mild physical impairment who have an intellectual disability.  Reference: (8) | System: SNOMED-CT Code: 110359009 Display: Intellectual disability (disorder) |
| Check\_GERD | Simple | This state checks the CP population for Gastroesophageal reflux disease (GERD). | n/a |
| Cerebral\_Palsy\_GERD | ConditionOnset | Probability set to 75% of the CP population. Gastroesophageal reflux disease (GERD) is an involuntary passage of the gastric contents into the esophagus. It has a higher prevalence (up to 75%) in CP patients.  Reference: (9) | System: SNOMED-CT Code: 235595009 Display: Gastroesophageal reflux disease (disorder) |
| Hip\_Surveillance | Simple | This state checks the CP population for hip dislocation. | n/a |
| Cerebral\_Palsy\_Hip\_Dislocation | ConditionOnset | Probability set to 17.5% of the CP population. The risk of progression to hip dislocation is 15–20% in the total population of children with CP.  Reference: (10) | System: SNOMED-CT Code: 157265008 Display: Dislocation of hip (disorder) |
| Check\_Pneumonia | Simple | This state checks the CP population for pneumonia. | n/a |
| Cerebral\_Palsy\_Pneumonia | ConditionOnset | Probability set to 50% of the CP population. In a survey almost 50% of children with cerebral palsy developed a pneumonia. (11) | System: SNOMED-CT Code: 233604007 Display: Pneumonia (disorder) |
| Check\_Sialorrhea | Simple | This state checks the CP population for Sialorrhea. | n/a |
| Cerebral Palsy Sialorrhea | Condition Onset | Probability set to 40% of the CP population. Sialorrhea occurs in approximately 40% of children/youth with CP and can have significant medical and psychosocial impact.  Reference:(1) | System: SNOMED-CT Code: 53827007 Display: Excessive salivation (disorder) |
| Anterior\_Drooling | Condition Onset | Probability set to 40% of the CP Sialorrhea population. No data available to determine percentage of patients with anterior drooling and those who undergo testing for posterior drooling. (40% anterior drooling patients, 40% posterior drooling and 20% of patients with both within the CP population). | System: SNOMED-CT Code: 62718007 Display: Dribbling from mouth (finding) |
| Anterior\_and\_Posterior\_Drooling | Condition Onset | Probability set to 20% of the CP Sialorrhea population. Direct transition to Anterior\_and\_Posterior\_Drooling2. | System: SNOMED-CT Code: 62718007 Display: Dribbling from mouth (finding) |
| Anterior\_and\_Posterior\_Drooling2 | Condition Onset | Patient is diagnosed with both anterior and posterior drooling. This is the diagnosis for posterior drooling. Direct transition to Medication\_Review1. | System: SNOMED-CT Code: 288959006 Display: Unable to swallow saliva (finding) |
| Medication\_Review1 | Procedure | Patient will undergo medication review. No prevalence data is available to determine distribution probability. All patients will receive this procedure in the initial encounter. Direct transition to Oral\_Hygiene1. | System: SNOMED-CT Code: 182836005 Display: Review of medication (procedure) |
| Oral\_Hygiene1 | Procedure | Patient will undergo oral hygiene care. No prevalence data is available to determine distribution probability. All patients will receive this procedure. Direct transition to Posture\_Training1. | System: SNOMED-CT Code: 717778001 Display: Mouth care (regime/therapy) |
| Posture\_Training1 | Procedure | Patient will undergo posture training. No prevalence data is available to determine distribution probability. All patients will receive posture training. Direct transition to Behavioral\_and\_Non\_Pharmacologic\_Interventions. | System: SNOMED-CT Code: 229069003 Display: Posture training (procedure) |
| Behavioral\_and Non\_Pharmacologic\_Interventions | Simple | Probability is divided between three behavioral interventions at 33%, 33%, and 33.99% (remainder) of the anterior drooling population. No prevalence data is available to determine distribution probability. Patients with anterior drooling will first undergo behavioral interventions such as Oromotor Exercises, Behavioral Therapy, and Oral Appliance Fitting. These interventions are not appropriate for posterior drooling. | n/a |
| Oromotor\_Exercises | Procedure | Probability set to 33% of the anterior and the dual-diagnosis drooling population. Patient with anterior drooling will perform oromotor exercises. | System: SNOMED-CT Code: 311707005 Display: Oral Motor Exercises (regime/therapy) |
| Behavioral\_Therapy | Procedure | Probability set to 33% of the anterior and the dual-diagnosis drooling population. Patient with anterior drooling will perform behavioral therapy. | System: SNOMED-CT Code: 166001 Display: Behavioral Therapy (regime/therapy) |
| Oral\_Appliance\_Fitting | Procedure | Probability set to 33.99% (remainder) of the anterior and the dual-diagnosis drooling population. Patients with anterior drooling will be fitted for an oral appliance. Direct transition to Pharmacologic\_Interventions. | System: SNOMED-CT Code: 234817001 Display: Insertion of oral appliance for the handicapped (procedure) |
| Flexible (Fiberoptic) Endoscopic Evaluation of Swallowing\_FEES | Procedure | Probability set to 5% of the CP Sialorrhea population because this is a recommendation in the clinical care pathway for diagnosis of posterior drooling, but may not often be used in clinical practice.  This study found clinical judgment to be correct in only 70% of aspiration of saliva cases, so a fiberoptic evaluation of swallowing can be a necessary diagnostic step both for the planning of therapy and development strategies in children and adolescents with neurogenic dysphagia.  Reference: (12) | System: SNOMED-CT Code: 311834001 Display: Fiberoptic Endoscopic Evaluation of Swallowing (procedure) |
| Salivagram\_Radionuclide\_Imaging | Procedure | Probability set to 5% of the CP Sialorrhea population because this is a recommendation in the clinical care pathway, but may not often be used in clinical practice per expert feedback. No prevalence data is available to determine distribution probability. Patient will undergo test for posterior drooling.  Reference: (1) | System: SNOMED-CT Code: 312421008  Display: Radionuclide Imaging- action |
| Videofluoroscopic\_Swallowing\_Study\_VFSS | Procedure | Probability set to 5% of the CP Sialorrhea population. Patient will undergo test for posterior drooling. No prevalence data available to determine distribution probability. This test was added based on expert feedback. | System: SNOMED-CT Code: 241149003  Display: Videofluoroscopy swallow (procedure) |
| Posterior\_Drooling | Condition Onset | Probability set to 25% of the CP Sialorrhea population (for a total of 40% of drooling patients with posterior drooling). No data available to determine percentage of patients with anterior drooling and those who undergo testing or are diagnosed with posterior drooling. Direct transition to Medication\_Review2. | System: SNOMED-CT Code: 288959006 Display: Unable to swallow saliva (finding) |
| Medication\_Review2 | Procedure | Patient will undergo medication review. No prevalence data is available to determine distribution probability. Direct transition to Oral\_Hygiene2. | System: SNOMED-CT Code: 182836005 Display: Review of medication (procedure) |
| Oral\_Hygiene2 | Procedure | Patient will undergo oral hygiene care. No prevalence data is available to determine distribution probability. Direct transition to Posture\_Training2. | System: SNOMED-CT Code: 717778001 Display: Mouth care (regime/therapy) |
| Posture\_Training2 | Procedure | Patient will undergo posture training. No prevalence data is available to determine distribution probability. Direct transition to Pharmacologic\_Interventions. | System: SNOMED-CT Code: 229069003 Display: Posture training (procedure) |
| Pharmacologic\_Interventions | Simple | Patients with drooling undergo pharmacologic interventions and receive one of four commonly prescribed medications, including Benzhexol Hydrochloride, Glycopyrrolate, Scopolamine, and Benztropine. Patients with a diagnosis of asthma or pneumonia as a comorbidity have a higher probability of receiving a pharmacologic intervention. Patients not diagnosed with asthma or pneumonia have a higher probability of transitioning to Monitoring and not receiving a pharmacologic intervention. These comorbidity attributes were added based on expert feedback. | n/a |
| Rx\_Benzhexol Hydrochloride | MedicationOrder | Patient will receive prescription for Benzhexol Hydrochloride. No prevalence data is available to determine distribution probability. Assigned 15% of CP Sialorrhea population of patients without asthma and 25% of the CP Sialorrhea population with asthma. Assigned 25% of the CP Sialorrhea population with pneumonia and 10% of the CP Sialorrhea population withouth pneumonia. | System: RxNorm Code: 905269 Display: Trihexyphenidyl Hydrochloride 2 MG Oral Tablet |
| Rx\_Glycopyrrolate | MedicationOrder | Patient will receive prescription for Glycopyrrolate. No prevalence data is available to determine distribution probability, so the team relied on expert feedback which said Glycopyrrolate is the most commonly prescribed anticholinergic. Assigned 30% of the CP Sialorrhea population with asthma. Assigned 25% of the CP Sialorrhea population without asthma. Assigned 35% of the CP Sialorrhea population with pneumonia and 20% of the CP Sialorrhea population without pneumonia. | System: RxNorm Code: 1437975 Display: Glycopyrrolate 1.5 MG Oral Tablet [Glycate] |
| Rx\_Scopolamine | MedicationOrder | Patient will receive prescription for Scopolamine. No prevalence data is available to determine distribution probability. Assigned 20% of the CP Sialorrhea population with asthma and 15% of the CP Sialorrhea population without asthma. Assigned 30% of the CP Sialorrhea population with pneumonia and 20% of the CP Sialorrhea population without pneumonia.  It has been suggested that anticholinergic drugs such as Benztropine, Glycopyrrolate and Scopolamine could be useful in the treatment of drooling. However, to date, no one anticholinergic has been shown to be more effective than another, so the team relied on expert feedback that said Glycopyrrolate is the most commonly prescribed anticholinergic for Sialorrhea.  Reference: (13) | System: RxNorm Code: 351875 Display: 72 HR Scopolamine 0.0139 MG/HR Transdermal System [Transdermal Scop] |
| Rx\_Benztropine | MedicationOrder | Patient will receive prescription for Benztropine. No prevalence data is available to determine distribution probability. Assigned 25% of the CP Sialorrhea population with asthma and 15% of CP Sialorrhea population without asthma. Assigned 15% of the CP Sialorrhea population with pneumonia and 10% of the CP Sialorrhea population without pneumonia. | System: RxNorm Code: 885219 Display: Benztropine mesylate 0.5 MG Oral Tablet |
| Rx\_Atropine | Medication Order | Patient will receive prescription for atropine drops. No prevalence data is available to determine distribution probability. Assigned 5% of the CP Sialorrhea population without asthma and 5% of the CP Sialorrhea population without pneumonia. |  |
| Monitoring | Procedure | Probability set to 25% of the CP Sialorrhea population without asthma present and 35% of the CP Sialorrhea population without pneumonia. A certain percentage of patients without co-existing complicating conditions, such as asthma or pneumonia, will not receive pharmacologic medications initially, but will continue to be monitored based on expert feedback. Direct transition to End\_Cerebral\_Encounter1. Patients in Monitoring state will not end in a surgical procedure encounter. | System: SNOMED-CT Code: 182777000 Display: Monitoring of patient (regime/therapy) |
| End\_Cerebral Palsy\_Encounter1 | Encounter End | This ends the first encounter in the Cerebral Palsy module. | n/a |
| Living\_with\_CP | Delay | This delays the start of each follow-up encounter to occur 3-12 months after Cerebral\_Palsy\_Encounter1 or the last follow-up encounter. This timing is based on feedback received from experts. Living with CP is a repeatable loop of interventions and follow-up encounters that would typically occur over a patient’s lifetime. All patients with CP and Sialorrhea progress to Living\_with\_CP and then to the Followup\_Cerebral\_Palsy\_Encounter. | n/a |
| Followup\_Cerebral\_Palsy\_Encounter | Encounter | This is the follow up encounter within the Cerebral Palsy module. | System: SNOMED-CT Code: 390906007 Display: Follow-up encounter (procedure) |
| Constipation | Condition Onset | Patients on Benztropine or Benzhexol are diagnosed with constipation as a side effect of their medication in this follow up encounter. | System: SNOMED-CT Code: 14760008 Display: Constipation (finding) |
| Urinary\_Retention | Condition Onset | Patients on Scopolamine are diagnosed with urinary retention as a side effect of their medication in this follow up encounter. | System: SNOMED-CT Code: 267064002 Display: Retention of urine (disorder) |
| End\_Rx\_Benztropine | MedicationEnd | Ends prescription for Benztropine. | N/A |
| End\_Rx\_Benzhexol | MedicationEnd | Ends prescription for Benzhexol. | N/A |
| End\_Rx\_Scopolamine | MedicationEnd | Ends prescription for Scopolamine. | N/A |
| Care\_Plan\_Constipation | CarePlan Start | Care plan for constipation. | System: SNOMED-CT Code: 389082000 Display: Constipation Care (regime/therapy) |
| Care\_Plan\_Urinary\_Retention | CarePlan Start | Care plan for urinary retention. | System: SNOMED-CT Code: 386490009 Display: Urinary retention care (regime/therapy) |
| Rx\_Glycopyrrolate2 | MedicationOrder | Patients who experience side effects on other medications in the prior encounter may switch to Glycopyrrolate in the follow up encounter. | System: RxNorm Code: 1437975 Display: Glycopyrrolate 1.5 MG Oral Tablet [Glycate] |
| Monitoring2 | Procedure | Patients who previously were in the Monitoring state proceed to this state in the followup encounter since medication changes are not needed. Direct transition to End\_Followup\_Encounter. | System: SNOMED-CT Code: 182777000 Display: Monitoring of patient (regime/therapy) |
| End\_Followup\_Encounter | Encounter End | This ends the follow up encounter in the Cerebral Palsy module. Eighty percent of patients transition to Living\_with\_CP and 20% of patients transition to Delay\_Surgical\_Encounter based on expert feedback that few Sialorrhea patients undergo surgical procedures. Patients who have previously received submandibular gland excision, duct ligation or submandibular duct relocation surgery transition to the next follow-up encounter and will not repeat those procedures. Patients in a Monitoring state transition to the next follow-up encounter and will not undergo surgical procedures. | n/a |
| Delay\_Surgical\_Encounter | Delay | This delays the start of both surgical encounters in the Cerebral Palsy module to occur 7-10 days after Followup\_Cerebral\_Palsy\_Encounter. Conditional distribution prevents patients who previously received a surgical procedure from receiving a surgical procedure again. Eighty percent of patients who have not received one of the surgical treatments proceed to Living\_with\_CP. Twenty percent of patients over the age of 4 who have not received one of the surgical treatments proceed to Surgical\_Interventions. | n/a |
| Surgical\_Encounter1 | Encounter | Surgical encounter in the module within which Botulinum Toxin injections are performed. These interventions are repeatable. | System: SNOMED-CT Code: 40274000 Display: General outpatient clinic admission (procedure) |
| Rx\_Botulinum\_Toxin\_A | MedicationOrder | Patient will receive a Botulinum Toxin A injection. Botulinum toxin A (BoNT-A) is the most common neurotoxin used to treat drooling. Botulinum Toxins act by inhibiting the release of acetylcholine at the neuromuscular junction and reducing the amount of saliva produced by the salivary glands. Assigned 75% of the Surgical\_Encounter1 population.  Reference: (14) | System: RxNorm Code: 1789958 Display: Dysport botulinum toxin A 300 UNT Injection |
| Botulinum\_Toxin\_A\_Injection | Procedure | The injection of Botulinum Toxin A that occurs during a surgical encounter. | System: SNOMED-CT Code: 404909007 Display: Injection of botulinum toxin (procedure) |
| Rx\_Botulinum\_Toxin\_B | MedicationOrder | Patient will receive a Botulinum Toxin B injection. Assigned 25% of the Surgical\_Encounter1 population. | System: RxNorm Code: 860182 Display: rimabotulinumtoxinB 5000 UNT/ML [Myobloc] |
| Botulinum\_Toxin\_B\_Injection | Procedure | The injection of Botulinum Toxin B that occurs during a surgical encounter. | System: SNOMED-CT Code: 404909007 Display: Injection of botulinum toxin (procedure) |
| End\_Rx\_Botulinum\_Toxin\_A | MedicationEnd | Ends prescription for Botulinum Toxin A. | n/a |
| End\_Rx\_Botulinum\_Toxin\_B | MedicationEnd | Ends prescription for Botulinum Toxin B. | n/a |
| Surgical\_Encounter2 | Encounter | This is a surgical encounter within the Cerebral Palsy module within which surgical interventions are performed. Surgical interventions are not repeatable. | System: SNOMED-CT Code 371883000 Display: Outpatient Procedure (procedure) |
| Surgical\_Interventions | Simple | Patients in this encounter will undergo surgical interventions for Sialorrhea based on attributes of anterior and posterior drooling. These procedures are not repeatable. | n/a |
| Submandibular\_Gland\_Excision\_ Surgery | Procedure | Probability set to 36% of the anterior drooling population and 50% of posterior drooling population.  The most common procedure was bilateral SMG duct rerouting, which accounted for 21 study subsets (36%). Comparing the 95% CIs for each procedure, bilateral SMG excision with bilateral parotid duct rerouting was statistically superior to bilateral SMG duct rerouting and sublingual gland excision.  Reference: (15) | System: SNOMED-CT Code: 7227006 Display: Excision of submandibular gland (procedure) |
| Duct\_Ligation\_Surgery | Procedure | Probability set to 50% for patients with posterior drooling and 32% for patients with anterior drooling. No data available to determine probability. | System: SNOMED-CT Code: 302351005 Display: Ligation of salivary duct (procedure) |
| Submandibular\_Duct\_Relocation\_ Surgery | Procedure | Probability set to 32% for patients with anterior drooling. No data available to determine probability. This procedure is not recommended for patients with posterior drooling. | System: SNOMED-CT Code: 173521004 Display: Transposition of submandibular duct (procedure) |
| End\_Surgical\_Encounter1 | EncounterEnd | The end of the surgical encounter in the Cerebral Palsy module. | n/a |
| End\_Surgical\_Encounter2 | EncounterEnd | The end of the surgical encounter in the Cerebral Palsy module. | n/a |
| Delay\_Postoperative\_Visit | Delay | A delay of 2-7 days before the postoperative visit following a surgical procedure. | n/a |
| Postoperative\_Visit | Encounter | Patients who receive one of the surgical procedures will undergo a postoperative visit. | System: SNOMED-CT Code: 183646003 Display: Postoperative visit (finding) |
| End\_Postoperative\_Visit | EncounterEnd | The end of the postoperative visit in the Cerebral Palsy module. | n/a |
| No\_CP\_Terminal | Terminal | Ending state of the module required by Synthea. Patients without CP progress to this terminal state. | n/a |

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## Module Parameters

Table 3: Cerebral Palsy Module Parameters summarizes the probabilities used to construct distributed module states where branching occurs in the module flow. A value of 1.0 indicates 100%; 0 indicates 0%.

Table 3: Cerebral Palsy Module Parameters

| **Parameter** | **Value** | **Notes and References** |
| --- | --- | --- |
| Module applicable time frame | N/A | Default applicable time frame for this module. |
| Probability of cerebral palsy (CP) in patients 18 years of age or less | 0.0031-0.0034 | General Distribution is 3.1 per 1000 children. The prevalence was significantly higher in boys than in girls overall (male/female ratio, 1.4:1).  Reference: (16) |
| Probability of male with CP | 0.0034 | See above |
| Probability of female with CP | 0.0031 | See above |
| Probability of Dystonia | 0.17 | In around one in six cases, CP causes involuntary muscle spasms and unwanted movement, described as dystonic cerebral palsy (or alternatively dyskinetic or choreoathetoid CP). This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (4) |
| Probability of Pain | 0.32 | Studies included 2777 children (57% boys) at a median age of 7 years; 32.4% reported pain, with significantly more girls than boys experiencing pain. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (5) |
| Probability of Central Hypotonia | 0.45 | Hypotonic CP is marked by extremely loose and floppy muscle tone. This type of CP accounts for less than half of all cases. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (6) |
| Probability of Spasticity | 0.77 | Most (77.4%) of the children identified with CP had spastic CP. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (3) |
| Probability of Osteoporosis | 0.50 | Low bone mineral density is found in more than 50% of adults with a variety of disabilities, including CP. Numbers of children with osteoporosis from CP is still being evaluated, but preventative measures are recommended due to the high number of adults with CP and osteoporosis. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (7) |
| Probability of Epilepsy | 0.50 | As many as half of all children with CP have one or more seizures. Children with both CP and epilepsy are more likely to have intellectual disability. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (16) |
| Probability of Intellectual Disability | 0.50 | One in two people with CP have an intellectual disability. One in five people have a moderate to severe intellectual disability. Generally, the greater the level of a person’s physical impairment, the more likely it is that they will have an intellectual disability. However, there are people who have a profound level of physical impairment, who do not have an intellectual disability. Conversely, others with a mild physical impairment may have an intellectual disability. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (17) |
| Probability of Gastroesophageal Reflux Disease (GERD) | 0.75 | Gastroesophageal reflux (GERD) is an involuntary passage of the gastric contents into the esophagus. It has been found in a higher prevalence (up to 75 percent) in CP patients.  Reference: (9) |
| Probability of Hip Surveillance | 0.17 | The risk of progression to hip dislocation is 15–20% in the total population of children with CP. This symptom is not modeled with treatment or interventions and must be displayed in a separate generated symptom text file.  Reference: (10) |
| Probability of Pneumonia | 0.50 | In a survey almost 50% of children with cerebral palsy developed a pneumonia.  Refererence: (11) |
| Probability of Anterior and/or Posterior Drooling diagnosis and/or diagnostic tools at the initial encounter for CP Sialorrhea patients | 0.40 | Prevalence data not available. However, expert feedback suggests that clinical tests are not performed frequently in the clinical setting for Sialorrhea. |
| Anterior Drooling Diagnosis | 0.40 | Prevalence data not available. |
| Posterior Drooling Diagnosis | 0.40 | Prevalence data not available. |
| Anterior and Posterior Drooling Diagnosis | 0.20 | Prevalence data not available. Added a dual-condition branch based on expert feedback. |
| Flexible (Fiberoptic) Endoscopic Evaluation of Swallowing (FEES) | 0.05 | Although tests such as Flexible Endoscopic Evaluation of Swallowing (FEES) and Salivagram are included in the clinical care pathway, expert feedback confirmed they are not often used in clinical practice. Probability set to 5% of the Posterior Drooling population. |
| Salivagram Radionuclide Imaging | 0.05 | Although tests such as Flexible Endoscopic Evaluation of Swallowing (FEES) and Salivagram are included in the clinical care pathway, expert feedback confirmed they are not often used in clinical practice. Probability set to 5% of the Posterior Drooling population. |
| Videoflouroscopic Swallowing Study (VFSS) | 0.05 | Videoflouroscopic Swallowing Study (VFSS) added based on expert feedback. Probability set to 5% of the Posterior Drooling population. |
| Probability of behavioral non-pharmacologic treatment options at initial encounter for patients with anterior drooling and dual diagnosis patients | 0.33-0.34 | Prevalence data not available |
| Oromotor Exercises | 0.33 | Prevalence data not available |
| Behavioral Therapy | 0.33 | Prevalence data not available |
| Oral Appliance Fitting | 0.34 | Prevalence data not available |
| Probability of pharmacological options at the initial encounter for both anterior and posterior drooling patients | 0.65-0.75 | Prevalence data not available. Between 65% and 75% percent of patients with Sialorrhea will receive a pharmacologic intervention with a higher chance for patients with asthma or pneumonia. Twenty-five percent of patients without asthma will transition to Monitoring status and will not receive a pharmacologic intervention based on expert feedback. Thirty-five percent of patients without pneumonia will transition to Monitoring status and will not receive a pharmacologic intervention. |
| Probability of receiving Glycopyrrolate | 0.25-0.35 | Assigned 30% of the CP Sialorrhea population with asthma based on expert feedback received that states Glycopyrrolate may be the currently most prescribed anticholinergic for Sialorrhea. Assigned 25% of the CP Sialorrhea population without asthma. Assigned 35% of the CP Sialorrhea population with pneumonia and 20% without pneumonia. |
| Probability of receiving Scopolamine | 0.15-0.30 | It has been suggested that anticholinergic drugs such as Benztropine, Glycopyrrolate, and Scopolamine could be useful in the treatment of drooling. However, to date, no one anticholinergic has been shown to be more effective than another, so the team relied on expert feedback which said Glycopyrrolate is the most commonly prescribed anticholinergic for Sialorrhea. Assigned 20% of the CP Sialorrhea population if the patient has asthma and 15% for the patient who does not have asthma. Assigned 30% of the CP Sialorrhea population with pneumonia and 20% without pneumonia.  Reference: (13) |
| Probability of receiving Benztropine | 0.15-0.25 | Patient will receive prescription for Benztropine. No prevalence data is available to determine distribution probability. Assigned 25% of the CP Sialorrhea population with asthma and 15% of CP Sialorrhea population without asthma. Assigned 15% of the CP Sialorrhea population with pneumonia and 10% of the CP Sialorrhea population without pneumonia. |
| Probability of receiving Benzhexol Hydrochloride | 0.10-0.25 | Patient will receive prescription for Benzhexol Hydrochloride. No prevalence data is available to determine distribution probability. Assigned 25% of CP Sialorrhea population of patients with asthma and 15% of the CP Sialorrhea population without asthma. Assigned 25% of the CP Sialorrhea population with pneumonia and 10% without pneumonia. |
| Probability of receiving Atropine | 0.05 | Patient will receive prescription for Atropine drops. No prevalence data is available to determine distribution possibility. While used rarely in the clinical setting, research suggests this is an area of increasing use per expert feedback. Assigned 5% of the CP Sialorrhea population without asthma and 5% of the CP Sialorrhea population without pneumonia. |
| Probability of treatment options at a Surgical\_Encounter1 for both anterior and posterior drooling patients | 0.20 | Prevalence data not available, but expert feedback stated surgical options are not often performed in the clinical setting. Probability set to 20% for a patient to proceed to a surgical encounter. Botulinum Toxin injections are repeatable while surgical procedures, such as duct ligation, are not repeatable based on expert feedback received. |
| Probability of receiving Botulinum Toxin Type B injection | 0.25 | Prevalence data not available |
| Probability of receiving Botulinum Toxin Type A injection | 0.75 | Botulinum Toxin A (BoNT-A) is the most common neurotoxin used to treat drooling. Some researchers have also used Botulinum Toxin B (BoNT-B). Botulinum Toxins act by inhibiting the release of acetylcholine at the neuromuscular junction and reducing the amount of saliva produced by the salivary glands.  Reference: (14) |
| Probability of surgical procedure options at Surgical\_Encounter2 for anterior drooling patients over the age of 4 years of age | 0.20 | Prevalence data not available, but expert feedback suggests that surgical procedures are not performed frequently in the clinical setting. Probability set to 20% for a patient to proceed to a surgical encounter. Botulinum Toxin injections are repeatable while surgical procedures, such as duct ligation, are not repeatable based on expert feedback received. |
| Probability of submandibular duct relocation surgery | 0.36 | The most common procedure was bilateral SMG duct rerouting, which accounted for 21 study subsets (36%). Comparing the 95% CIs for each procedure, bilateral SMG excision with bilateral parotid duct rerouting was statistically superior to bilateral SMG duct rerouting and sublingual gland excision.  Reference: (15) |
| Probability of duct ligation surgery | 0.32 | Equal distribution of remaining percentage based on above |
| Probability of submandibular gland excision surgery | 0.32 | Equal distribution of remaining percentage based on above |
| Probability of surgical procedure options at Surgical\_Encounter2 for posterior drooling patients over the age of 4 years of age | 0.20 | Submandibular duct relocation and sublingual gland excision remain the procedures of first choice for persistent significant drooling. Prevalence equally distributed between both procedures below. Expert feedback suggests that surgical procedures are not performed frequently in the clinical setting. Probability set to 20% for a patient to proceed to a surgical encounter. Botulinum toxin injections are repeatable while surgical procedures, such as duct ligation, are not repeatable based on expert feedback received.  Reference: (18) |
| Probability of duct ligation surgery | 0.50 | Prevalence data not available. |
| Probability of submandibular gland excision surgery | 0.50 | Prevalence data not available. |
| Proability of Postoperative Visit following a surgical procedure | 1.0 | Prevalence data not available. |

## Sample Synthetic Data Results

Sample Synthea generated data results for this module are included below (see Table 4). The sample results are also displayed as a chart representation in Figure 3. Analysis was performed using 10,009 patients generated in CSV output from Synthea. Note: The general distribution of cerebral palsy disorder is 3.1 per 1000 children. Due to extremely low prevalence rates, it is difficult to validate the population to the same degree of specificity without generating an very large data set.

Table 4: Patients with Cerebral Palsy Synthetic Prevalence

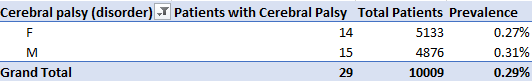
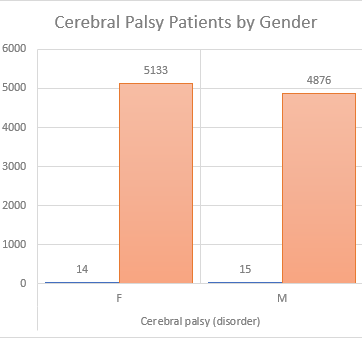


Figure 2: Patients with Cerebral Palsy Synthetic Prevalence Graph



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