SNOMED CT to Orphanet Map package Production Release Notes - July 2026

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Introduction

The SNOMED CT to Orphanet Map Release is the product of a joint project carried out under a collaboration agreement between Institut national de la sante et de la recherche medicale (INSERM) and SNOMED International. The first release, in October 2021, was based on an agreed priority set at disorder level, with new concepts for rare diseases, as defined in Orphanet, added to SNOMED CT. The original work between SNOMED CT and rare disease content in the Orphanet nomenclature was completed in 2021, taking into account the differences in structure and rules of each terminology. A maintenance and updating plan is now in place to ensure alignment is maintained for in scope content overtime.

One of the key use cases for this standardized map is to meet EU requirements to implement ORPHA codes in health systems for Rare Diseases epidemiology and research, including use in registries, enabling linkage from SNOMED CT enabled EHRs, and cross-border interoperability with ICD-based coding systems. Details are found in following links:

- Recommendation on ways to improve codification for rare diseases in health information systems (2014) European Commission Expert Group on Rare Diseases 2014: https://ec.europa.eu/health/sites/default/files/rare_diseases/docs/recommendation_coding_cegrd_en.pdf
- Guideline on the electronic exchange of health data under Cross-Border Directive 2011/24/EU Patient Summary. Release 3.3, June 2023: https://health.ec.europa.eu/system/files/2023-10/ehn_guidelines_patientsummary_en.pdf
- European Commission's Best Practices portal, Orphacodes: https://webgate.ec.europa.eu/dyna/bp-portal/transfered

This document is intended to provide a brief description, background context and explanatory notes on the SNOMED International/INSERM collaborative work and the resulting SNOMED

CT to Orphanet map. The map is being published as the Production release with the plan of publishing annually in October. This document is not intended to provide technical specifications about SNOMED CT or Orphanet. Editorial guidance for SNOMED CT content can be found in the SNOMED CT Editorial Guide. Editorial guidance for Orphanet Nomenclature of Rare Diseases can be found for Orphanet here and for ORPHAcodes here.

Audience

The audience for this document includes National Release Centers, vendors of electronic health records, terminology developers, researchers, genomics experts and individuals who wish to have an understanding of the content of the SNOMED CT to Orphanet map.

Background

SNOMED International (then IHTSDO) and INSERM first started exploring opportunities for linking SNOMED CT and Orphanet Rare Disease in 2012 because of the drivers to link between clinical data using SNOMED CT and the mandated use of Orphanet for rare disease research purposes in Europe and other countries outside Europe. As a consequence, an agreement was signed in 2014 and a priority set of rare diseases was agreed. Since then, the two organizations have worked closely as follows to:

1. Undertake a gap analysis for the defined set at disorder level.
2. Develop textual definitions for the rare diseases based on expert input through the INSERM community.
3. Create new content in SNOMED CT.
4. Create a map between existing and new content in SNOMED CT and Orphanet (**ORPHAcodes at disorder level**).
5. Ensure throughout the development period that new SNOMED CT content aligns with changes in Orphanet.

3533 new rare disease concepts were added to SNOMED CT as part of this collaboration and the resulting map product in 2021 contain 5,652 SNOMED CT and Orphanet concepts/terms.

An updated Agreement was signed in March 2020 signalling commitment from both organizations to maintaining and updating the content and map. A further 1025 Orphanet entries were reviewed for inclusion in the map and work for the update was completed in 2023.

An ongoing maintenance and updating process is in place to ensure this alignment is maintained as changes take place in both terminologies and the map updated accordingly. In line with this, a new agreement was signed as we undertook the 2024 release, reinforcing the scope and purpose of the product for a further 5 years.

Scope and Purpose of Collaborative Work

Under the terms of the Collaboration agreement between SNOMED International and INSERM, the Map will be issued annually by both SNOMED International in RF2 format and INSERM in spreadsheet format. Documented quality assurance processes ensure that the content of both formats are the same and supporting materials are produced jointly.

Design

Content Changes for 2026 Production Release

Maps for content at ‘Grouper’ level in Orphanet have been inactivated for the 2026 production release as these maps are out of scope.

Other key changes made to content for the 2026 Production Release:

1. Update to map for content that has been inactivated in SNOMED CT.
2. Removal of map from production release for entries that have been marked obsolete, deprecated or non-rare in Orphanet.
3. Total active mapped entries - 6545
4. Total new mapped concepts this release - 111
5. Total inactivated mapped entries this release - 315

Map

Discussion about maps between pre-existing and new content in SNOMED CT and Orphanet is an ongoing collaborative effort between both organizations. Validation of the map between SNOMED CT and Orphanet is undertaken by INSERM.

Attribution

Work has been completed to annotate new concepts added to SNOMED CT for this collaboration with attribution to 'Inserm Orphanet'.

Version

The version of Orphanet used is July 2026.

The version of SNOMED CT used is the July 2026 International Edition Release.

Source for Map

The source data is a subset of 6545 SNOMED CT concepts.

Direction of Map

The direction of the map is from SNOMED CT July 2026 International Edition Release to Orphanet July 2026.

Cardinality of Map

The cardinality in the table is one-to-one, one SNOMED CT concept maps to one Orphanet entry.

Obtaining the Release package

Access within SNOMED International member countries is provided by the Member National Release Centre in each country, via the relevant Member page. Affiliates of SNOMED International in non-member countries can access the map file through their Member Licensing and Distribution Service (MLDS) account. Please contact info@snomed.org for more information if required.

The Map in spreadsheet form is available for download from the ORPHAcodes website: https://www.orphacode.org/

If you're having any problems getting hold of the Orphanet Map Package, please contact info@snomed.org.

Users of the map must comply with licensing arrangements for both SNOMED CT and Orphanet.

Feedback

Feedback should be sent jointly to info@snomed.org and contact.orphanet@inserm.fr.

Feedback should include any issues relating to implementation or general comments regarding the map.

Technical Notes

RF2 package format

The RF2 package convention dictates that it contains all relevant files, regardless of whether or not there is content to be included in each particular release. Therefore, the package contains a mixture of files which contain both header rows and content data, and also files that are

intentionally left blank (including only a header record). The reason that these files are not removed from the package is to draw a clear distinction between:

1. ...files that have been deprecated (and therefore removed from the package completely), due to the content no longer being relevant to RF2 in this or future releases, and
2. ...files that just happen to contain no data in this particular release (and are therefore included in the package but left blank, with only a header record), but are still relevant to RF2, and could therefore potentially contain data in future releases.

This allows users to easily distinguish between files that have purposefully been removed or not, as otherwise if files in option 2 above were left out of the package it could be interpreted as an error, rather than an intentional lack of content in that release.

Changes to the Release effectiveTime

After consultation with the community in 2023, SNOMED International changed the date of the effective time for the International Edition releases from the last day of each month, to the first of each month.

The effective time for the "January" editions, for examples, have changed from 31st to 1st January. The effective time for the dependent "July 2026" International Edition, therefore, is 20260701.

To ensure alignment with the dependent International release for the 2026 Orphanet package, the effectiveTime is therefore also set to 20260701 for all Orphanet components.

Metadata now incorporated into the Derivative Packages

After consultation in 2023, SNOMED International are in the process of improving our Derivative release packages by including the relevant metadata in the Derivative packages, as well as in the International Edition.

These Derivatives are solely single refsets/maps, and so don't mean anything to end users without the supporting terms and other components from the International content. The nature of these products is therefore such that we necessarily create Derivative packages that are inherently dependent on the relevant International Edition content. Previously, therefore, we have always created the metadata components (refset/module concepts, descriptions, relationships, etc) in the International Edition release packages, with the Derivative products being dependent on the relevant International content. Whilst this dependency on the International content continues, the transition involves the inclusion the metadata components in the Derivative packages themselves, as well as in the International Edition packages.

The consensus is that including the Metadata components in the Derivative packages will bring benefits to both the Derivative maintainers, and also to the end users who will no longer need to pull this particular data down from the dependent International Edition in order to use the

Derivative products. It enables maintainers to move to a more efficient model of hosting the Derivative content in termServer branches, rather than importing Delta files from external tools. They are included for additional information, and do not have to be consumed - so please utilise them as required.

This means that from the 2025 Orphanet Map release onwards, it will include additional metadata components that used to reside solely in the International Edition. These will include the Orphanet module & refset concepts, as well as the supporting components such as descriptions and language refset records, etc.

If you have any feedback on the metadata components, please contact us on release@snomed.org

Increase to the maximum length of Description Types

The maximum length of Fully Specified Name (FSN) and Synonym descriptions have been increased from 255 to 4096 characters starting from the July 2026 release of the International Edition. The requirement for this change came from the Pharmaceutical / biologic product hierarchy, where the terming guidance for FSNs caused the previous limit to be exceeded where there is a large number of ingredients in a medicinal product, which is particularly common in multivalent vaccines.

This should not impact this Orphanet Map or other Derivative release packages, but as it potentially could in the future, it is being communicated again here to ensure complete coverage of visibility of this change across the community.

For further information, please refer to the International Edition release notes.

Approvals

Final Version	Date	Approver	Comments
1.0	15 août 2026	Suzy Roy	Approved
1.0	28 juil. 2026	Maria Braithwaite	Approved

Draft Amendment History

Version	Date	Editor	Comments
0.1	28 juil. 2026	Andrew Atkinson	Creation, and technical updates
0.2	28 juil. 2026	Maria Braithwaite	Initial Version
0.3	28 juil. 2026	Maria Braithwaite	Update statistics
1.0	15 sept. 2026	Andrew Atkinson	Final updates from INSERM