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ALR Supplemental Document

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Background:

Activity Level Reporting (ALR) data represents a basic set of data elements required to produce the quality, cost and performance indicators for the Ontario's cancer system. The data elements constitute patient level activity within the cancer system focused on outpatient oncology clinic visits, systemic and radiation therapy services. This data also forms a key component of the Ontario Cancer Registry (OCR), which captures every malignant neoplasm diagnosed in Ontario.

This document was created with a goal to provide supplemental information on the ALR data elements in addition to that already contained in the on-line Data Book which can be accessed via this link: https://www.cancercareontario.ca/en/data-book-reporting-standards

It also discusses topics of interest, such as case selection criteria, cancer of unknown primary, and additional content based on questions submitted by external partners via the Informatics mail box in the past.

This content was created with both new and well versed users in mind, since it can be used as both a training manual for new staff and a reference guide for those already working with ALR data.

Any comments and future content suggestions should be directed to:
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Disease Entity

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Disease Entity

Primary vs secondary disease (cancer)

Primary cancer

A cancer is usually named after the organ of the body where it first started to grow. This is known as the primary site or the **primary cancer**. For example, a cancer that starts in the bowel is known as a bowel cancer and a cancer that started in the lung is called a lung cancer.

Sometimes cancer cells spread to other parts of the body (metastasis). They can travel through the blood or lymphatic system.

Secondary cancer (Metastasis)

If cancer cells spread from the primary cancer to another part of the body, they may go on dividing. This would be called a secondary cancer or a **metastasis**.

This term is not to be confused with *second primary*, which describes presence of *multiple primary cancers* rather than metastasis.

Please note, that the *Diagnosis, Topography and Morphology Code* fields in Activity Level Reporting (ALR) submission file should never contain a secondary cancer/metastasis code, irrespective of whether the patient is being treated for metastasis or not.

Primary and Secondary Disease Reporting Requirements

Primary/Secondary Disease Reporting Defined

A unique case in ALR is defined by CCO as an instance of a **patient** (identified by patient_chart_ number data element) with a **specific diagnosis** (identified by disease_sequence_number data element or disease registration date for those hospitals not submitting a disease sequence number) at a **specific facility** (identified by submitting_hospital_number data element).

Ergo, a primary disease diagnosis is required to register a unique case in ALR. All subsequent 'activity' (i.e. clinic visits, systemic and radiation treatment visits) submitted to CCO are then linked to the original case that was registered. Typically, the primary diagnosis can be changed or refined over time by updating the respective fields and NOT creating a new updated disease. This is expected and has no implications on previous activity that was submitted, as the disease sequence number (or unique registration date) is combined with patient identifiers to uniquely define the cancer case.

It is understood, that along with updates to original disease diagnosis, there can be scenarios where a secondary diagnosis is also identified due to cancer metastasis. **In these scenarios, CCO's expectation is**

that all activity reported through ALR continues to be associated with the primary cancer regardless of the intent of the treatment (whether to primary or metastatic cancer site).

Conversely, in scenarios where a patient is diagnosed with a new primary disease diagnosis, CCO's expectation is that a new unique case will be registered in ALR (i.e. new disease sequence number or new unique registration data). This is known as a second (or third, fourth etc.) primary. Separate reporting will then be required for all activity reported to be linked to this new primary diagnosis. In scenarios where multiple unique primaries are identified, ALR allows a single patient to have multiple cases registered to which activity can be mapped.

Primary/Secondary Disease – Clinical Examples

The following table provides additional clarification on the reporting requirements for primary and secondary diseases in ALR:

Table 1:

SCENARIO	DISEASE			
1	Patient A	Primary Breast Cancer	Registration Date 1	Case 1
2		Secondary (metastatic) Cancer (Breast cancer metastasized to brain)		
3		Primary Colon Cancer	Registration Date 2	Case 2

Table 1 Summary:

In scenarios 1 and 2, the patient can be conceptualized as a breast cancer patient where the cancer has metastasized to the brain. In this case, breast cancer is the primary disease and brain metastasis is the secondary disease. This patient is still considered a breast cancer patient, and so the diagnosis should not be changed. All activity pertaining to the case (primary and secondary cancer) is captured under the primary cancer, breast.

In scenario 3, where the patient had Breast cancer, was treated and is in remission and is then diagnosed with colon cancer, the colon cancer would be considered a second primary and a new case. All subsequent activity should now be linked to the new primary cancer, colon.

Cancer of unknown primary (CUP)

When the origin of the cancer is not identified with confidence, after initial tests, this is described as Cancer of Unknown Primary or CUP.

Please note that a suspicion of the primary cancer stated as such in pathology report, does not meet coding standards, since ambiguous terminology such as 'likely' or 'probably' is not allowed and should never be used for reporting purposes.

It is understood, that sometimes physicians really don't know what the primary site was and have to submit 'unknown primary' to ALR. The expectation is to resend this information, (still using the original disease sequence number or registration date), *once and if a more definite diagnosis becomes available.*

The person collating the ALR disease entity data for CCO should decide with their physicians under what circumstances they should state a definite primary, when there might still be room for error, before submitting or resubmitting this information to ALR.

Source: http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Unknownprimary/AboutCUP/Primarysecondarycancers.aspx and http://www.cupfoundjo.org/

Please consider these scenarios while trying to decide how to report cancer of unknown primary to ALR:

Initial tests are inconclusive
↓
Diagnosis is reported to ALR as Unknown Primary Cancer
↓
Further tests are done

Scenario 1	*Scenario 2*	*Scenario 3*
No additional 'clues' pointing to the primary site are obtained	Inconclusive results, but pointing towards a "highly suspected" diagnosis which drives treatment~~Inconclusive results, but pointing towards a 'highly suspected' diagnosis which drives treatment~~	Definite diagnosis is made
Outcome: ALR diagnosis remains primary unknown	Outcome: ALR diagnosis should be updated to the "highly suspected diagnosis" as per OH's discussion with Provincial Heads for SYS and RAD treatment programs ~~Outcome: ALR diagnosis remains primary unknown as per CCO's discussion with Provincial Heads for SYS and RAD treatment~~	Outcome: ALR diagnosis will be updated to reflect test result findings. A new primary is NOT to be entered.

Commented [DJ1]: Updated Primary Unknown guidance from Systemic Treatment and Radiation Treatment Programs

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List of ICD-10CA and ICD-O-3 diagnostic codes that map to the Primary Unknown Clinical Practice Group

ICD-10CA code	Clinical Practice Group
C77.-	Primary Unknown
C78.-	Primary Unknown
C79.-	Primary Unknown
C80.-	Primary Unknown

C96.7	Primary Unknown
C96.9	Primary Unknown
C97	Primary Unknown

ICD-O-3 topography code	ICD-O-3 morphology code (see note)	Clinical Practice Group
C80.9	*3	Primary Unknown
C80.9	*6	Primary Unknown

Note: In ICD-O-3, topography code C80.9, paired with all morphology codes ending with *3 or *6, that first did not match the distinct 5 digit morphology codes found in Data Book Appendix 1.39 (tab ICDO3 CPG), will map to PRIMARY UNKNOWN.

Coding of multiple primary diseases

Please refer to the SEER 'Multiple Primary and Histology Coding Rules' manual located at:

http://seer.cancer.gov/tools/mphrules/download.html for guidance and complete details.

List of data elements found in Disease entity

Data element	Comments
Patient chart #	
Submitting hospital #	
Diagnosis code	
Diagnosis code ver.	
Topography code	Applies to RCC's only
Morphology code	Applies to RCC's only
Topography/Morphology code ver.	Applies to RCC's only
Basis of diagnosis	Applies to RCC's only
Date of initial diagnosis	Applies to RCC's only Current definition: date of initial diagnosis by a physician for this disease. May be clinical or pathological, but should be chosen with the following priority listing: • Date of 1st histology or cytology confirmation of malignancy (date specimen was taken) • Date of admission to hospital, or 1st outpatient consultation
Diagnosis hospital #	
Diagnosis hospital chart #	Applies to RCC's only
Patient postal code at diagnosis	
(Disease) Registration date (1)	Definition: date this disease was 1st registered at this RCC and/or hospital for this patient (1).

	[1] Please note that these definitions were provided for added clarity and do not reflect the current content found in Data Book which will be adjusted to match them at a later date. NOTE: Registration date is used to derive disease sequence number for sites who do not submit disease sequence numbers to ALR. This is a constant data element, and should remain the same throughout the entire episode of care for a given patient.
Disease sequence #	
Clinical stage @ diagnosis	Applies to RCC's only
Clinical stage (T cat.) @ diagnosis	Applies to RCC's only
Clinical stage (T suffix) @ diagnosis	Applies to RCC's only
Clinical stage (N cat.) @ diagnosis	Applies to RCC's only
Clinical stage (N suffix) @ diagnosis	Applies to RCC's only
Clinical stage (M cat.) @ diagnosis	Applies to RCC's only
Pathological stage @ diagnosis	Applies to RCC's only
Pathological stage (T cat.) @ diagnosis	Applies to RCC's only
Pathological stage (T suffix) @ diagnosis	Applies to RCC's only
Pathological stage (N cat.) @ diagnosis	Applies to RCC's only
Pathological stage (N suffix) @ diagnosis	Applies to RCC's only
Pathological stage (M cat.) @ diagnosis	Applies to RCC's only
Post Therapy stage	Applies to RCC's only
Post Therapy stage (T cat.)	Applies to RCC's only
Post Therapy stage (T suffix)	Applies to RCC's only
Post Therapy stage (N cat.)	Applies to RCC's only
Post Therapy stage (N suffix)	Applies to RCC's only
Post Therapy stage (M cat.)	Applies to RCC's only
Staging ver.	Applies to RCC's only
Analytic flag	Applies to RCC's only

	Current definition: identifies a neoplastic case, and if it qualifies for stage analysis. It identifies if the diagnosis or primary course of treatment is done at the RCC. Definition of valid values: **0** – Class of Case/Reason for referral unknown (should be no more than 5% of cases) or Class of Case not applicable (e.g. non-neoplastic cases, genetic screening, etc.) **1** – Analytic Case: This includes patients: • whose initial diagnosis was done at the cancer centre and/or • whose primary course of treatment was planned and or delivered (partially or fully) at the cancer centre. NOTE: Primary course of treatment includes the full range of interventions planned to cure or manage the disease and typically involves one or more of surgery, systemic therapy, and radiation therapy, delivered over a period of weeks or months. **2** – Non Analytic Case: This includes patients whose diagnosis and primary course of treatment were done elsewhere. These are typically patients whose first visit to the cancer centre was for one or more of the following reasons: • For managing a recurrence of their disease following a disease free interval • For managing progression of disease usually following primary treatment failure (often called secondary courses of treatments). These patients would have not been disease free. • For continued follow-up of the patient's disease, after primary course of treatment has been completed. Often includes annual checkups • For a second opinion regarding the patient's disease management, primary, recurrent or progressed malignancy. NOTE: The Class of Case field is at the Disease Entity level. Within each cancer centre, a case with a specific primary disease can only have one Class of Case. So once a case is Analytic, it stays Analytic even if the patient comes back to the centre for recurrence or other follow up. Similarly, a Non Analytic case cannot become Analytic.

	9 – There is not enough information at this time to choose values 0, 1 or 2.
Date of referral to: **Med. Onc.** **Rad. Onc.** **Sur. Onc.** **Palliative Care Prog.** **Social Work** **Dietitian** **Physiotherapy** **Psychiatry** **Psychology** **Occupational Therapy** **Speech Language Pathologist**	Provision of Referral Dates to either Medical or Radiation Oncologist is mandatory to all sites and the remainder, applies to RCC's only. Current definition: date on which a request (i.e. fax, phone call, etc.) for a consultation with <…> is received by RCC and/or hospital from a referring physician. NOTES: 1. Please use the actual receipt date for requests faxed over the weekend, instead of a next business day, when clinic re-opens. 2. Do not use a "Ready to Book" or other date when you have all of the diagnostic tests or other materials ready for the consult. 3. Do not use a date when the patient is ready; e.g. if the patient delays the appointment, do not change the referral date based on this delay. 4. When it is known/planned that a new patient would benefit from seeing more than one specialist in order to develop a treatment plan, (based on the disease and practice), then the referral date for both specialists is the same, e.g. the date of the fax, phone call, etc. In most sites, the patient would be seen in a multi-specialist clinic, sometimes referred to as Multidisciplinary Clinics, e.g. Head and Neck cancer patients. 5. In the situation where a patient was seen by one specialist (is part way through or has completed treatment with one modality, or is perhaps not doing as well as expected), and that specialist decides that the patient would benefit from a referral to another specialty, the referral date for the second specialty is the date the initial specialist makes the decision to refer the patient to the second specialist (sometimes called a "cross referral", as the referral typically takes place within an RCC).
Laterality	Applies to RCC's only Current definition: identifies the side of a paired organ or the side of the body on which the reportable tumour originated. This applies to the primary disease site only. Definition of current values (designed to capture laterality where ICD-O-3 topography codes currently do not): **0** – Organ is not considered to be a paired side **1** – Origin of primary is right **2** – Origin of primary is left **3** – Only one side involved, right or left origin not specified **4** – Bilateral involvement, side of origin unknown, stated to be a single primary **5** – Paired site: midline tumor

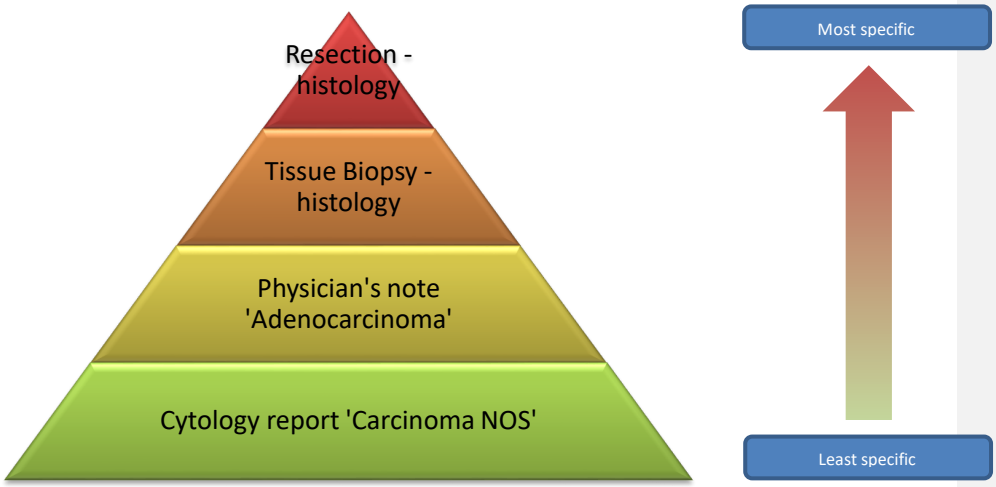
	9 – Paired site, but lateral origin unknown

Notes on disease diagnosis and staging

What information is required to code and stage a disease?

A Pathology Report is almost always required, and when no pathology sample is taken, then discharge summaries or other physician notes should be consulted.

Sources of information in order of specificity:



Does the new diagnosis need to be written in dictation?

Not necessarily – it can just be on the pathology report.

In most situations, however, there would normally be clinical notes regarding the diagnosis. These notes help to inform other health care providers of important information regarding the patient's condition and diagnosis.

NOTE: In the situation where a second cancer is discovered during a visit for the initial cancer diagnosis, either through a pathology report, clinical exam, or other means, then:

- This cancer should be coded with a new Disease Sequence Number (DSN) or disease registration date, if the hospital will be dealing with this second cancer, or
- If the hospital will not be following or treating the second cancer, then it does not need to be coded – it could remain in the dictated note as background information regarding the patient.

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Can we code additional diagnoses that were not originally diagnosed here, but were discussed as part of the consult (while discussing the main diagnosis)?

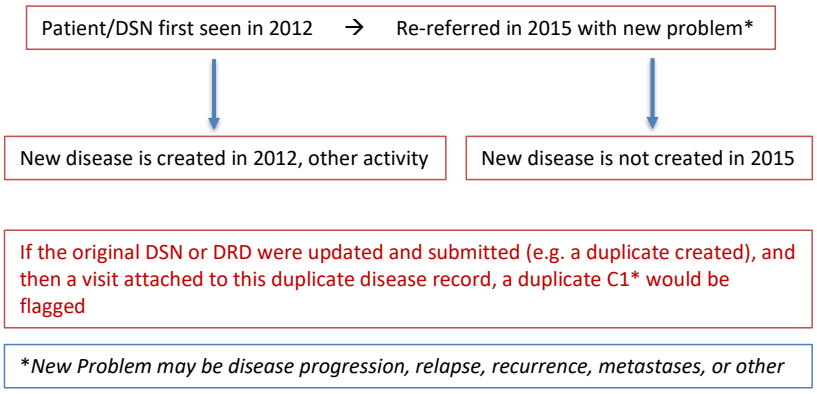
Provision of this information is not required by CCO and sites can decide on individual basis whether or not to submit it. Some centres use it for documenting comorbidities that are important part of the patient's record, and may lead to different treatment paths.

NOTE: no activities, such as a clinic visits, systemic or radiation treatments, or procedures, should be attached to these "additional" (co-morbidity) diagnoses.

Relapse, recurrence and metastasis

If an RCC saw a patient during diagnosis/first course treatment, coders should NOT update the stage for progression, relapse, or metastases.

Nor should progression, relapse, or metastases be entered as a new disease record (with new disease sequence number or registration date) for a patient, even if the patient was re-referred at a later date.



In general and where possible, CCO requires the stage at diagnosis.

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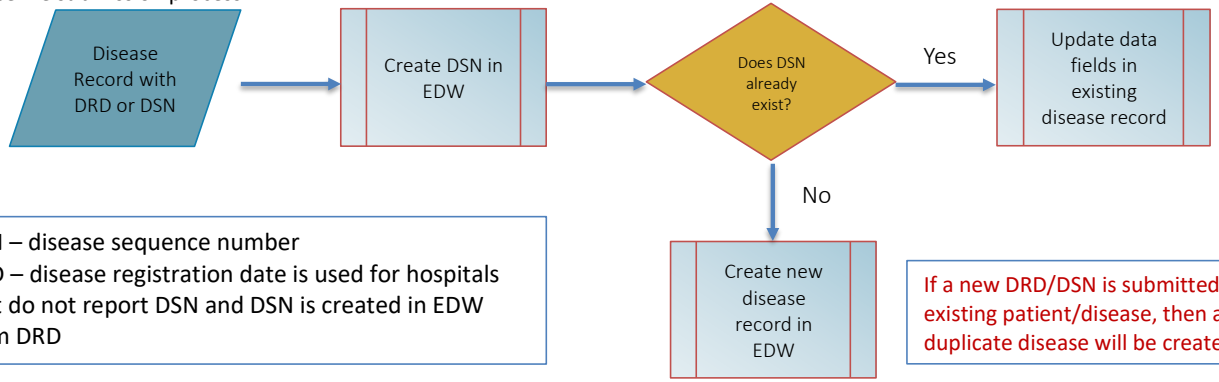
Disease and patient duplication

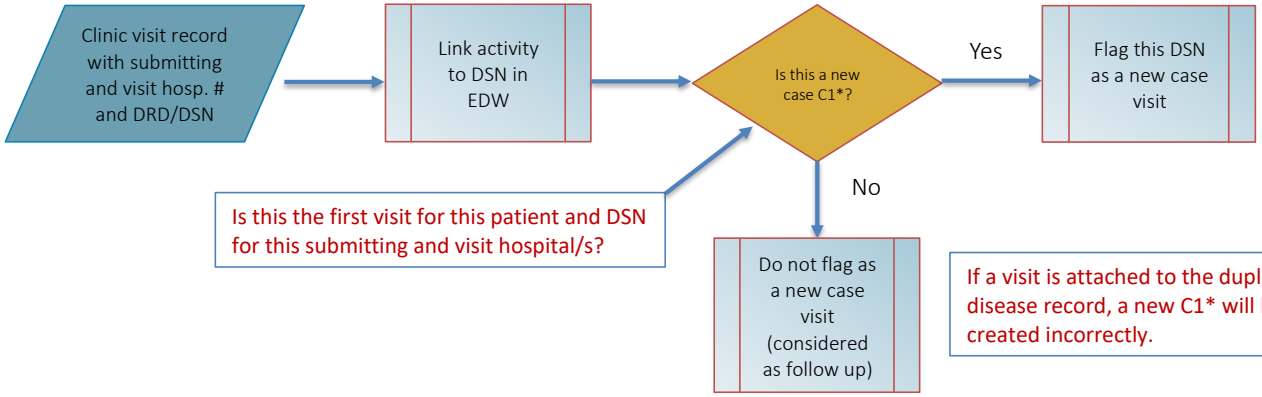
Disease file submission process



DSN – disease sequence number
DRD – disease registration date is used for hospitals that do not report DSN and DSN is created in EDW from DRD

If a new DRD/DSN is submitted for an existing patient/disease, then a duplicate disease will be created.

Clinic visit file submission process



Is this the first visit for this patient and DSN for this submitting and visit hospital/s?

If a visit is attached to the duplicate disease record, a new C1* will be created incorrectly.

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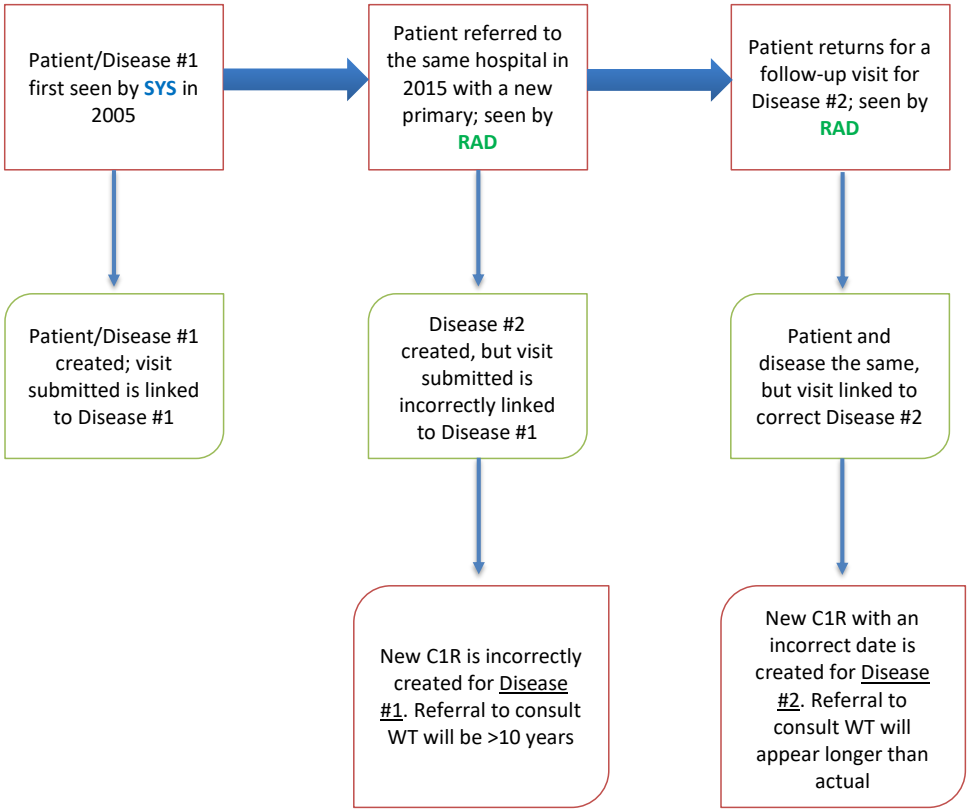
Activity linked to the incorrect patient's disease



Duplicate patient

A Patient record is created in EDW when a hospital first submits a record for a patient registered at that hospital.

Issue – If another record for the same patient is submitted with a different chart number, a duplicate patient record is created.

If activity is attached to the new chart number, both the original and duplicate patient will be active in ALR with potentially duplicated activity volumes.

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Steps for addressing ALR warning error 501 (apparent duplicate patient), 502 (apparent duplicate disease) and creation of chart number mapping file.

ALR warning error 501

Error 501 is triggered when the following condition is met: submitted record has the same Health Card number as an already existing patient, but a different chart number.

Any duplicated patient records that need to be deleted (i.e. that have no associated activity linked to them) should be submitted via 'patient.del' file.

BEFORE sending in a 'patient.del' file, IF there are any activities that need to be moved/linked from one patient chart number to another, site will need to resubmit pertinent activity (clinic, SYS, RAD, procedure) files for each of the affected months with the correct patient chart number.

Steps:

1. Resubmit pertinent activity files for each of the months where the patient chart number was corrected
2. Create patient.del file (for patient records to be removed/deleted from ALR)
    a. This file should contain two columns: patient_chart_number and submitting_hospital_number
3. Submit patient.del file (included in zip package) with next monthly submission, since deleting a patient or disease record before any of the activity corrections are made (i.e. transferred to the new patient or disease) will also delete the activity associated with all 'records being deleted'. Therefore, all corrections have to be completed/made first, before (reference) patient/disease records are deleted.

ALR warning error 502

Error 502 is triggered when the following condition is met: submitted record has the same chart number and diagnosis code (acute care hospitals) or topography, morphology and laterality codes (RCC's), but a different registration date and/or disease sequence number

Any duplicated disease records that need to be deleted (i.e. that have no associated activity linked to them) should be submitted via 'disease.del' file.

BEFORE sending in a 'disease.del' file, IF there are any activities or additional disease information, such as stage, that need to be moved/linked from one registration date to another, site will need to resubmit pertinent activity (clinic, SYS, RAD, procedure) files for each of the affected months with the correct registration date.

Steps:

1. Resubmit pertinent activity files for each month where the registration date was corrected
2. Create disease.del file (for patient records to be removed/deleted from ALR)
    a. This file contains four columns: patient_chart_number, submitting_hospital_number, registration_date, disease_sequence_number
    b. Sites that do not submit 'disease_sequence_number' should leave this column blank
3. Submit disease.del file (included in zip package) with next monthly submission, since deleting a patient or disease record before any of the activity corrections are made (i.e. transferred to the new patient or disease) will also delete the activity associated with all 'records being deleted'. Therefore, all corrections have to be completed/made first, before (reference) patient/disease records are deleted.

Chart number mapping protocol

To transfer all data for a patient from an 'old' chart number to a 'new' chart number, a Chart Number Mapping file needs to be submitted in a monthly (zip) package BEFORE or in the same month any activity using this 'new' chart number, is submitted.

The Chart Number Mapping .csv file name is: chart_number_mapping and it contains two data elements with the following format:

- old_patient_chart_number (CHAR 10)
- new_patient_chart_number (CHAR 10)

If activity is submitted and linked to multiple chart number's belonging to the same patient (i.e. same HCN), the chart number mapping file cannot be used to merge activity from one patient chart number to another. Different steps will need to be taken to link all activity data to the correct patient chart number, and then followed by submitting a .del file which will delete the 'old' patient records. Please follow instructions for error number 501 for further details.