Our Vision

Better data. Better decisions.
Healthier Canadians.

Our Mandate

To lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care.

Our Values

Respect, Integrity, Collaboration, Excellence, Innovation

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Acknowledgements

The Canadian Institute for Health Information (CIHI) wishes to acknowledge and thank the extensive network of experts who collaborated on the development of the Canadian Multiple Sclerosis Monitoring System (CMSMS), including people living with MS and their caregivers, the MS Society of Canada, the Canadian Network of Multiple Sclerosis Clinics, clinicians, researchers, international experts and various governments.

CIHI also wishes to acknowledge and thank the individuals who so willingly shared their time, experience and knowledge as members of the Project Advisory Committee and/or Technical Advisory Committee during the development phase of the CMSMS.

The CMSMS is now guided by an operational Advisory Committee, with members representing a variety of key stakeholder groups, including the Public Health Agency of Canada, the Canadian Network of MS Clinics, the MS Society of Canada, jurisdictional representatives, neurologists and an MS patient. For more information, visit our website at www.cihi.ca/ms.

External Tools

The Godin-Shephard Leisure-Time Exercise Questionnaire is used under licence from, and with gratitude to, Gaston Godin, PhD, Canada Research Chair on Behaviour and Health.

The Expanded Disability Status Scale (EDSS) is used with the permission of, and with gratitude to, Prof. John F. Kurtzke, MD, FACP, FAAN.

The Health Utilities Index Mark 2 and Mark 3 is used under licence of, and with gratitude to, © Health Utilities Inc., Dundas, Ontario, Canada.

As well, CIHI would like to acknowledge and thank the many individuals within CIHI who contributed to the production of this manual.

Introduction

About CIHI

The Canadian Institute for Health Information (CIHI) collects and analyzes information on health and health care in Canada and makes it publicly available.

Canada's federal, provincial and territorial governments created CIHI as a not-for-profit, independent organization dedicated to forging a common approach to Canadian health information. CIHI's goal: to provide timely, accurate and comparable information. CIHI's data and reports inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health.

CIHI's Privacy and Security Program

CIHI has developed a Privacy and Security Framework to provide a comprehensive approach to privacy and security management. Based on best practices from across the public, private and health sectors, the framework is designed to coordinate CIHI's privacy and security policies and provide an integrated view of the organization's information management practices. The governance structure includes a chief privacy officer and general counsel (CPO/GC) and a chief information security officer (CISO).

The CPO/GC heads Privacy and Legal Services and is responsible for managing the Privacy program, providing privacy advice and support to program areas, ensuring that the suite of privacy policies and procedures is comprehensive and up to date, providing privacy training and awareness, conducting privacy impact assessments (PIAs) and audits, monitoring compliance and benchmarking. The CPO/GC is also responsible for ensuring that appropriate data-sharing and other agreements are in place and for monitoring legal and other developments in the privacy arena.

The CISO heads Information Security and has overall day-to-day accountability for the confidentiality, integrity and availability of the data holdings within CIHI's custody and control and for ensuring that the Information Security program and suite are robust and up to date. The CISO is also responsible for providing information security training and awareness; conducting risk assessments, audits and benchmarking; and for monitoring industry best practices in information security. The CISO reports all significant audit findings to the Finance and Audit Committee of the Board of Directors.

Canadian Multiple Sclerosis Monitoring System

Background

An estimated 93,500 Canadians are living with multiple sclerosis (MS), according to the Canadian Community Health Survey.[1] Much is unknown about MS, and Canada is estimated to have one of the highest MS rates in the world. The Canadian Multiple Sclerosis Monitoring System (CMSMS) will allow for the recording, measuring and monitoring of the evolution and treatment of MS in Canada. The population of interest for the CMSMS is all individuals with MS or other demyelinating disorders who receive services at MS clinics or who visit community neurologists or general practitioners. The information from the CMSMS will help policy-makers, clinicians, researchers and the public better understand disease patterns across Canada, variation in use of treatments and long-term patient outcomes.

The CMSMS will provide a minimum data set and data standards, adding quality and value to current data collection and analysis capabilities. It will fill an important information gap by providing longitudinal data that is pan-Canadian, that is comparable across jurisdictions and that enables sound policy and effective health system management.

Development of the CMSMS

Development of the CMSMS began in April 2011 with input and advice from an extensive network of experts, including people living with MS and their caregivers, the MS Society of Canada, the Canadian Network of Multiple Sclerosis Clinics, clinicians, researchers, international experts and various governments.

Since September 2012, the CMSMS has been ready to receive data files from MS clinics across Canada, extracted from their local registry and submitted via CIHI's secure data submission services. To provide data submitters with added flexibility, as of April 2013, CMSMS data may also be supplied to CIHI via the secure CMSMS Online Data Entry Tool.

Extensive data validation and data quality checks will ensure that all data, whether submitted through data extraction or the CMSMS Online Data Entry Tool, is fit for use in analytical processing and reporting.

Development of the CMSMS Minimum Data Set

A critical deliverable for the development of the CMSMS was the identification of the information that should be collected—the CMSMS Minimum Data Set (MDS). CIHI uses the term “minimum data set” to define the minimum or essential information needed to fulfill the objectives of the monitoring system and meet the needs of multiple stakeholders. The following activities were conducted to develop and finalize the CMSMS MDS to ensure that it is valid and useful for its stated purpose:

- National consultation to identify priority information needs for the CMSMS;
- Comprehensive environmental and technical scan of national and international MS activities and data systems;
- Meetings with Canadian MS clinics to identify data currently being collected;
- Extensive review of minimum data sets in Canadian and international MS registries;
- Development of a draft MDS;
- Review of the draft MDS by the project’s national advisory committees; and
- Broader validation of the updated MDS through an external field review.

The finalized CMSMS MDS standardizes the collection of essential information on persons living with MS. Appendix G sets out the standards used in the creation of the CMSMS MDS.

How to Use This Resource Manual

The *Canadian Multiple Sclerosis Monitoring System Resource Manual* is divided into three separate modules that are intended to provide comprehensive information to a broad range of partners, stakeholders and data providers.

1. CMSMS Data Dictionary Module

This module provides an overview of the types of encounters, detailed data element definitions, reporting requirements for each data element, guidelines for coding, valid values and rationale for inclusion in the CMSMS MDS.

The Data Dictionary module is intended for personnel at participating organizations responsible for coding and collecting the specified data elements. It may also be useful for those involved in the data submission process or data providers interested in requesting, interpreting and analyzing the data.

2. CMSMS Extract File Submission Module

This module is primarily aimed at organizational personnel who are responsible for extract file submissions to CIHI. This module includes

- Organization setup;
- Extract file creation;
- Extract file submission and processing;
- Extract file submission reports;
- Extract file submission schedules;
- Vendor testing process; and
- Organization testing process.

Detailed data requirements and specifications are made available to data providers and/or vendors who have completed and returned their License Agreement Subscription package.

3. CMSMS Online Data Entry Module

This module is intended for organizations that will submit data to CIHI via the secure CMSMS Online Data Entry Tool. This module includes information on

- Accessing the CMSMS Online Data Entry Tool;
- Using the CMSMS Online Data Entry Tool; and
- Data submission schedules.

Supplemental documentation can be found by clicking the Resources link in the CMSMS Online Data Entry Tool.

Contact Information

The CMSMS team can be reached by email at ms@cihi.ca. For telephone inquiries, please call 416-481-2002 and ask for the Canadian Multiple Sclerosis Monitoring System.

Overview of the Information Contained in the CMSMS System

Reporting Requirements

Each data element in the CMSMS MDS is assigned one of the following reporting requirement classifications.

M—Mandatory	These data elements must be completed and must fully adhere to the specifications (for example, the submitted value must be one of the valid values outlined). Records with mandatory data elements that are missing or do not adhere to the specifications will be rejected. Rejected records will be listed with all applicable error messages in the Submission Details Reports. Organizations will need to fix and resubmit the erroneous data elements.
C—Critical	Organizations are strongly encouraged to complete these data elements, as they are required for data analysis. To ease the burden of data collection, if these data elements are missing or do not adhere to the specifications, the entire record will still be accepted into the CMSMS database. Critical data elements not submitted (that is, blank values) or submitted with invalid values will be flagged with warnings and will be listed in the Submission Details Reports. Flagged records will still be a part of the CMSMS database. Organizations can submit *correction* records for records flagged with warnings to correct invalid values or provide missing information. Values not adhering to the specifications or list of values will be assigned a *blank* in the system. The indicator C* is used to identify data elements that are conditionally critical (that is, they depend on the coding of related data elements) in the Data Elements by Record Type table.
K—Key	CIHI recommends organizations complete these data elements, as they are helpful for analysis. To ease the burden of data collection, the entire record will still be accepted into the CMSMS database if these data elements are not submitted (that is, blank values) or do not adhere to the specifications. Values not adhering to the specifications or list of values will be assigned a *blank* in the system.

For more detailed information on the reporting requirements, see the *CMSMS Resource Manual: Extract File Submission Module*.

Record Types

The CMSMS system collects information on three types of encounters between a client/patient and a participating organization, as outlined below.

I—Initial Enrolment	This record is completed for all new and existing clients/patients and is the first set of data to be collected. It includes record identifier, client identifier, administrative, demographic, clinical, treatment, therapy and outcomes data elements. There are 77 data elements, of which 9 are mandatory, 20 are critical and 48 are key. Note: If a client/patient attends a new organization, an *initial enrolment* Record Type will have to be completed at the new organization.
F—Face-to-Face Follow-Up	This record is completed any time there is a face-to-face follow-up encounter after the *initial enrolment*. It contains fewer client identifier, administrative and demographic data elements than the *initial enrolment* record. Like the *initial enrolment* record, it contains record identifier, clinical, treatment, therapy and outcomes data elements. There are 70 data elements, of which 9 are mandatory, 17 are critical and 44 are key.
N—Non-Face-to-Face Follow-Up	This record is completed whenever there is a non-face-to-face follow-up encounter (such as a telephone call) after the *initial enrolment*. This record contains record identifier, client identifier and administrative data elements. This record has only 12 data elements, of which 8 are mandatory, 1 is critical and 3 are key.

Episodes of Care

Records in an episode of care are linked by the data elements Y1—Source Organization Identifier and the ID_1—Organization Client Identifier. This means that in order to submit a *face-to-face follow-up* or *non-face-to-face follow-up* Record Type, the Source Organization Identifier and the Organization Client Identifier must match that of the corresponding *initial enrolment* Record Type that has been successfully submitted to the CMSMS.

Data Elements by Record Type

The following table charts each of the data elements contained in the CMSMS MDS by Record Type. The legend for the table is as follows:

M Mandatory

C Critical

K Key

***** Conditional status depends on an associated data element or coding within a data element

Blank This element is not applicable to the type of encounter

Data Element ID	Data Element Name	Initial Enrolment	Face-to-Face Follow-Up	Non-Face-to-Face Follow-Up
Z1	Record Type	M	M	M
X2	Submission Type	M	M	M
X1	Record Identifier	M	M	M
Y1	Source Organization Identifier	M	M	M
ID_1	Organization Client Identifier	M	M	M
ID_2	Health Card Number	M	M	M
ID_3	Province/Territory Issuing Health Card Number	M	M	M
ID_4a	Birthdate	C		
ID_4b	Estimated Birthdate?	C		

(cont'd on next page)

Data Element ID	Data Element Name	Initial Enrolment	Face-to-Face Follow-Up	Non-Face-to-Face Follow-Up
ID_5	Sex	C		
ID_6	Health Care Provider Identifier	K	K	K
ADMIN_1	Service Date	M	M	M
ADMIN_2	Referral Received Date	K **(Note: This is considered critical for new clients/patients)**		
ADMIN_3(a–e)	Reason(s) for Service			C
DEM_1	Country of Primary Residence	C	C	
DEM_2	Postal Code of Primary Residence	C	C	
DEM_3	Location of Birth (Nearest City)	K		
DEM_4	Location of Birth (Country)	K		
DEM_5(a–e)	Ethnic/Cultural Origin(s)	K		
DEM_6	Highest Level of Education	K	K	
DEM_7(a–g)	Current Employment	K	K	
DEM_8	Current Marital Status	K	K	
DEM_9(a–h)	Current Living Arrangement(s)	C	C	
DEM_10	Current Living Setting	C	C	
DEM_11a	Currently Smoking Cigarettes/Tobacco Products?	K	K	
DEM_11b	Average Number of Cigarettes/Tobacco Products Currently Smoked per Week	K	K	
DEM_11c	Age Started Smoking Cigarettes/Tobacco Products	K		
DEM_11d	Age Stopped Smoking Cigarettes/Tobacco Products	K		

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Data Element ID	Data Element Name	Initial Enrolment	Face-to-Face Follow-Up	Non-Face-to-Face Follow-Up
DEM_12a	Godin-Shephard Leisure-Time Exercise Questionnaire: Strenuous Exercise: Times per Week for More Than 15 Minutes	K	K	
DEM_12b	Godin-Shephard Leisure-Time Exercise Questionnaire: Moderate Exercise: Times per Week for More Than 15 Minutes	K	K	
DEM_12c	Godin-Shephard Leisure-Time Exercise Questionnaire: Mild Exercise: Times per Week for More Than 15 Minutes	K	K	
DEM_12d	Godin-Shephard Leisure-Time Exercise Questionnaire: Frequency of Sweat-Inducing Activity	K	K	
CLIN_1	Current Diagnosis	M	M	
CLIN_1a	Date of Diagnosis	C	C*	
CLIN_1b	Estimated Date of Diagnosis?	C*	C*	
CLIN_2a	Date of First Symptoms of Current Diagnosis	C*	C*	
CLIN_2b	Estimated Date of First Symptoms of Current Diagnosis?	C*	C*	
CLIN_3	Type/Course of MS at Onset	C*	C*	
CLIN_4	Current Type/Course of MS	C*	C*	
CLIN_4b	Date of Onset of Secondary Progressive MS	K	K	
CLIN_5	Any Comorbid Condition(s)?	C	C	
CLIN_5(a–j)/ CLIN_5(k–o)	Comorbid Condition(s)/Other Comorbid Condition(s)	C*	C*	
CLIN_7	Overall Health Compared to Last Visit		K	
CLIN_8	MS Symptoms Compared to Last Visit		K	
Drug_1	Currently on DMT(s) and/or Corticosteroid(s) (to Treat MS)?	C	C	
Drug_1(a–j)/ Drug_1(k–o)	Drug Name(s)/Other Drug Name(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	C*	C*	
Drug_1(a–j)b/ Drug_1(k–o)b	Drug Start Date(s)/Other Drug Start Date(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	C	C	

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Data Element ID	Data Element Name	Initial Enrolment	Face-to-Face Follow-Up	Non-Face-to-Face Follow-Up
Drug_1(a–j) b(a–e)/Drug_1 (k–o)b(a–e)	Drug Side Effect(s)/Complication(s)/Other Drug Side Effect(s)/Complication(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	K	K	
Drug_2	Previously on DMT(s)?	C	C	
Drug_2(a–o)/ Drug_2(p–t)	Drug Name(s)/Other Drug Name(s) (Associated with Previously on DMT[s]?)	K	K	
Drug_2(a–o)b/ Drug_2(p–t)b	Drug Start Date(s)/Other Drug Start Date(s) (Associated with Previously on DMT[s]?)	K	K	
Drug_2(a–o)c/ Drug_2(p–t)c	Drug End Date(s)/Other Drug End Date(s) (Associated with Previously on DMT[s]?)	K	K	
Drug_2(a–o) d(a–h)/Drug_2 (p–t)d(a–h)	Reason(s) for Drug Cessation (Associated with Previously on DMT[s]?)	K	K	
TREAT_1	Service Provider(s) Related to MS Accessed?	K	K	
Treat_1(a–l)	Service Provider(s) Related to MS	K	K	
Treat_1(a–l) (a–e)	Source(s) of Payment	K	K	
TREAT_2	Other Therapy(s) Related to MS Received?	K	K	
TREAT_2(a–j)a/ TREAT_2(k–o)a	Other Therapy(s)/Additional Other Therapy(s)	K	K	
TREAT_2(a–j)b/ TREAT_2(k–o)b	Other Therapy Date(s)/Additional Other Therapy Date(s)	K	K	
TREAT_ 2(a–j)c(a–e)/ TREAT_2 (k–o)c(a–e)	Complication(s) Arising During or After Other Therapy/Additional Other Therapy	K	K	

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Data Element ID	Data Element Name	Initial Enrolment	Face-to-Face Follow-Up	Non-Face-to-Face Follow-Up
OUT_3	Expanded Disability Status Scale (EDSS)	C	C	
OUT_2a	Health Utilities Index: Vision: Ordinary Newsprint	K	K	
OUT_2b	Health Utilities Index: Vision: Recognize Friend	K	K	
OUT_2c	Health Utilities Index: Hearing: Group Conversation	K	K	
OUT_2d	Health Utilities Index: Hearing: Quiet Room	K	K	
OUT_2e	Health Utilities Index: Understood by Strangers	K	K	
OUT_2f	Health Utilities Index: Understood by Familiars	K	K	
OUT_2g	Health Utilities Index: Happiness	K	K	
OUT_2h	Health Utilities Index: Pain Restricted Activities	K	K	
OUT_2i	Health Utilities Index: Walking	K	K	
OUT_2j	Health Utilities Index: Manual Dexterity	K	K	
OUT_2k	Health Utilities Index: Memory	K	K	
OUT_2l	Health Utilities Index: Problem-Solving	K	K	
OUT_2m	Health Utilities Index: Basic Activities	K	K	
OUT_2n	Health Utilities Index: Mood	K	K	
OUT_2o	Health Utilities Index: Pain Relief	K	K	
OUT_2p	Health Utilities Index: Health	K	K	
OUT_2q	Health Utilities Index: Questionnaire	K	K	
SP_1	Special Project 1	K	K	K
SP_2	Special Project 2	K	K	K

Note

The order of the data elements in the table above does not represent the record layout order required in the extract files. Detailed data requirements and specifications are made available to data providers and/or vendors who have completed and returned their License Agreement Subscription package.

Definitions and Guidelines for Coding

This section provides a detailed description of each data element in the CMSMS MDS applicable to the *initial enrolment*, *face-to-face follow-up* and *non-face-to-face follow-up* Record Types. The following information is provided for each data element:

- Reporting requirements and applicable records;
- Data element definitions;
- Valid values and descriptions;
- Guidelines for coding; and
- Rationale—reason(s) for inclusion in the CMSMS-MDS.

Record Identifiers

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale for Inclusion
Z1	Record Type	Mandatory	All record types	A code used to indicate whether the record is an *initial enrolment* encounter, *face-to-face follow-up* encounter or *non-face-to-face follow-up* encounter.	I—*initial enrolment* F—*face-to-face follow-up* N—*non-face-to-face follow-up*	Complete and submit an *initial enrolment* Record Type for all new and existing clients/ patients as the first set of data to be collected. Complete and submit a *face-to-face follow-up* Record Type any time there is a face-to-face encounter (such as a clinic visit) after the *initial enrolment*. Complete and submit a *non-face-to-face follow-up* Record Type any time there is a non-face-to-face	To identify the Record Type, as the applicable data elements are different for each Record Type.

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Record Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale for Inclusion
						encounter (such as a phone call) after the *initial enrolment*. When submitting a correction or deletion of a previously submitted and accepted record, the Record Type must match that of the original record submitted. See Record Types for more information.	
X2	Submission Type	Mandatory	All record types	A code used to indicate whether the record is a new record or a correction of a previous record.	N—*new* C—*correction*	All new records must be submitted with Submission Type N—*new*. Submit a *correction* record only for a previously submitted and accepted record. For more information on correcting a previously submitted record, review the *CMSMS Resource Manual: Extract File Submission Module*.	To allow for corrections of previously accepted records.

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Record Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale for Inclusion
						To delete a record, a separate deletion record must be submitted. Review the Extract File Submission Module for more information.	
X1	Record Identifier	Mandatory	All record types	A unique organization-assigned number that identifies a record.	Alphanumeric	Each new record submitted must have a unique Record Identifier. The Record Identifier must be unique for all records from a source organization across all years. **IMPORTANT** Do not enter sensitive personal health information (for example, Health Card Number) into this field. When submitting a correction or deletion of a previously submitted and accepted record, the Record Identifier must match that of the original record submitted.	To uniquely identify a record from a source organization and to facilitate corrections and deletions.

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Record Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale for Inclusion
						It is not possible to submit a correction for Record Identifier. First, submit a *deletion* record and then resubmit the record as a *new* record with the corrected Record Identifier.	
Y1	Source Organization Identifier	Mandatory	All record types	A unique CIHI-assigned identifier for the organization rendering the services.	Numeric	Use the identifier assigned by CIHI for your organization. When submitting a correction or deletion of a previously submitted and accepted record, the Source Organization Identifier must match that of the original record submitted. It is not possible to submit a correction for Source Organization Identifier. First, submit a *deletion* record and then resubmit the record as a *new* record with the corrected Source Organization Identifier.	To uniquely identify the organization where services were rendered and to facilitate relationship management with the submitting organization.

Client Identifiers

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
ID_1	Organization Client Identifier	Mandatory	All record types	A unique organization-assigned number (such as a chart number or registration number) that identifies a person who has received or is receiving health care–related services or goods.	Alphanumeric	Each person who receives health care services from the organization must be given a unique number as a client identifier. This means a person with multiple records within an organization will have the same Organization Client Identifier for each record. **IMPORTANT** Do not enter sensitive personal health information (for example, Health Card Number) into this field. When submitting a correction or deletion of a previously submitted and accepted record, the Organization Client Identifier must match that of the original record submitted.	To uniquely identify a person within a source organization and to be able to link multiple records to the same person.

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Client Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						It is not possible to submit a correction for Organization Client Identifier. First, submit a *deletion* record and then resubmit the record as a *new* record with the corrected Organization Client Identifier.	
ID_2	Health Card Number	Mandatory	All record types	A jurisdictionally unique number used to identify a person who has received or is receiving health care–related services or goods.	A valid Health Card Number for the issuing province or territory UNK—*unknown* NA—*not applicable*	Ensure the provided Health Card Number adheres to the guidelines set out by the issuing province/ territory. If the Health Card Number is not known and cannot be retrieved from records within the organization, UNK—*unknown* should be coded. In cases where the Health Card Number is not applicable (for example, if the person is a resident of the United States or	To identify unique persons within the province or territory for the purposes of statistical analyses.

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Client Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						another country), NA—*not applicable* should be coded. NA—*not applicable* must be coded when Province/Territory Issuing Health Card Number = NA—*not applicable*.	
ID_3	Province/ Territory Issuing Health Card Number	Mandatory	All record types	A code that identifies the geographic boundary of Canada that issued the Health Card Number.	NL—*Newfoundland and Labrador* PE—*Prince Edward Island* NS—*Nova Scotia* NB—*New Brunswick* QC—*Quebec* ON—*Ontario* MB—*Manitoba* SK—*Saskatchewan* AB—*Alberta* BC—*British Columbia* YT—*Yukon* NT—*Northwest Territories* NU—*Nunavut* UNK—*unknown* NA—*not applicable*	If the Province/ Territory Issuing Health Card Number is not known and cannot be retrieved from records within the organization, then UNK—*unknown* should be coded. In cases where the Health Card Number is not applicable (for example, if the person is a resident of the United States or another country), then NA—*not applicable* must be coded for Province/Territory Issuing Health Card Number.	Required in association with Health Card Number to identify unique persons within a province or territory.

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Client Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
ID_4a	Birthdate	Critical	*Initial enrolment* record	The year, month and day that represent the date that a person was born or is officially deemed to have been born.	YYYYMMDD	Provide the complete date.	To analyze differences in disease outcomes and to monitor disease progression according to age.
ID_4b	Estimated Birthdate?	Critical	*Initial enrolment* record	A code used to indicate if a person's birthdate contains estimated values.	Y—*yes*, the birthdate entered is an estimated birthdate N—*no*, the birthdate entered is the true birthdate	If the year, month and/or day is an estimate, then code Y—*yes*. If the provided date is accurate and true, then code N—*no*. Examples: Birthdate = 19850519 (true year, month and day), then code N—*no*. Birthdate = 19850501 (true year, month, estimated day), then code Y—*yes*.	An important data qualifier for the data element Birthdate. Note: It is important to track those persons for whom a date of birth cannot be verified by documents or from the person's memory.
ID_5	Sex	Critical	*Initial enrolment* record	A code representing the biological sex of a person at birth.	M—*male* F—*female* OTH—*other*	Code this item consistently with the biological sex of the person.	To analyze differences in disease outcomes and to monitor disease progression according to sex.

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Client Identifiers (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
ID_6	Health Care Provider Identifier	Key	*Initial enrolment* and *face-to-face follow-up* records	A unique organization-assigned number that identifies the person's health care provider.	Alphanumeric	Provide the unique number assigned within the organization for the health care provider.	An organization-defined value for the management of its CMSMS data to enable internal analyses by service provider within the organization.

Administrative Information

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
ADMIN_1	Service Date	Mandatory	All record types	The year, month and day that represent the date of the interaction between a person and a health care provider or providers at an organization.	YYYYMMDD	Provide the complete date. When submitting a correction or deletion of a previously submitted and accepted record, the Service Date must match that of the original record submitted.	To be used in conjunction with other disease, treatment and outcome milestones to support analysis of models of care, evolution of treatment and disease progression.

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Administrative Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						It is not possible to submit a correction for Service Date. First, submit a *deletion* record and then resubmit the record as a *new* record with the corrected Service Date. **NEW** Submission of historical data is at the clinic's discretion. Items for the data provider to consider include how far back in time to submit, which data is most important to submit and how data should be collected. Data providers who elect to submit historical information to the CMSMS should submit historical records for only those clients/patients who are still active at the clinic.	

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Administrative Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
ADMIN_2	Referral Received Date	Key Note: This data element is considered critical for new clients/ patients.	*Initial enrolment* record	The year, month and day that represent the date the organization received the complete referral (that is, enough information for triage).	YYYYMMDD	Provide the complete date.	To measure time between date of referral and *initial enrolment* service date.
ADMIN_ 3(a–e)	Reason(s) for Service	Critical	*Non-face-to-face follow-up* record	A code representing the purpose(s) for the non-face-to-face encounter between a person and a health care provider or providers at an organization.	APT—*appointment/ test results* CLO—*clinic orientation* ACT—*advice on complementary therapies* DMT—*disease-modifying therapy education* MSP—*MS and pregnancy education* NDE—*newly diagnosed patient education* OME—*other medication education* RSE—*relapse and/or steroid education*	Provide up to five reasons for the non-face-to-face encounter.	To identify reasons for accessing services and the effectiveness of different models of care.

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Administrative Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
					SME—*symptom management education* WNE—*wellness education* EDI—*employment/ disability issues (including insurance)* PSI—*psychosocial issues* RES—*research* OTH—*other* UNK—*unknown*		

Patient Demographics

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_1	Country of Primary Residence	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code representing the geographical and/or political region of the world where a person maintains his or her primary residence. Note: A primary residence can be a home or a facility.	Examples: CAN—*Canada* USA—*United States* UNK—*unknown*	Provide the three-character country code for the person's country of primary residence using the ISO 3166-1:2006 Edition 2 list in Appendix A.	To support regional-level analysis related to health service utilization and access to health care services.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_2	Postal Code of Primary Residence	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code designating a region defined by Canada Post for a person's primary residence. Note: A primary residence can be a home or a facility.	The full six characters (ANA NAN) or the three-character forward sortation area (FSA) (ANA) Z1Z1Z1—*postal code is unknown* X1X1X1—*postal code is not applicable*	Provide the person's complete Postal Code of Primary Residence. If the complete postal code is not available, provide the FSA. If the postal code is not known, code Z1Z1Z1. If the postal code is not applicable (for example, the person's primary residence is outside of Canada), code X1X1X1.	To support regional-level analysis related to health service utilization and access to health care services.
DEM_3	Location of Birth (Nearest City)	Key	*Initial enrolment* record	The name of the city, town, village or other community where a person was born.	Free text	Provide the complete name of the city, town, village or other community. If the Location of Birth (Nearest City) is not known, enter UNK or *unknown* into the free-text field.	To analyze differences in disease outcomes and to monitor disease progression among locations of birth.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_4	Location of Birth (Country)	Key	*Initial enrolment* record	A code representing the geographical and/or political region of the world where a person was born.	Examples: CAN—*Canada* USA—*United States* UNK—*unknown*	Provide the three-character country code for the person's country of birth using the ISO 3166-1:2006 Edition 2 list in Appendix A.	To analyze differences in disease outcomes and to monitor disease progression according to locations of birth.
DEM_5 (a–e)	Ethnic/Cultural Origin(s)	Key	*Initial enrolment* record	The ethnic or cultural origins of the person.	AFR—*African* ARA—*Arab* (*for example, Egyptian, Kuwaiti, Libyan*) CAU—*Caucasian* CHIN—Chinese (*includes Chinese and Taiwanese*) EUR—*European (for example, Portuguese, Irish, Norwegian, Russian, Italian)* FLP—*Filipino* FN—*First Nations* INU—*Inuit* JAP—*Japanese* KOR—*Korean* LTAM—*Latin American (for example, Chilean, Costa Rican, Mexican)*	Enter up to five ethnic/cultural origins as self-declared by the person.	To analyze differences in disease outcomes and to monitor disease progression according to ethnic or cultural origins.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
					MET—*Métis* SASI—*South Asian (for example, Bangladeshi, Punjabi, Sri Lankan, East Indian)* SEASI—*Southeast Asian (for example, Vietnamese, Cambodian, Malaysian, Laotian)* WASI—*West Asian (for example, Afghan, Assyrian, Iranian)* OTH—*other* UNK—*unknown*		
DEM_6	Highest Level of Education	Key	*Initial enrolment* and *face-to-face follow-up* records	A code representing the highest level of schooling a person has attained or received.	NF—*no formal education* LS—*some secondary, high school or elementary school education* HS—*high school or secondary school* SP—*some post-secondary education* AD—*apprenticeship, trade or technical certificate or diploma*	Provide the code assigned to the most appropriate response.	To aid in planning MS-related educational resources and programs and to identify potential factors affecting access to health care services.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
					PD—*post-secondary degree/diploma* (that is, person has attained or received a college diploma, CEGEP degree, baccalaureate degree, graduate degree, or doctoral or postgraduate education) UNK—*unknown*		
DEM_7 (a–g)	Current Employment	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the current employment type of a person.	**REVISED** FFT—*self-employed* EFT—*employee* UFT—*unpaid employment* SFT—*student* EAM—*employed, adjusted/modified* RFA—*retired* RFD—*long-term disability* UEM—*unemployed* OTH—*other* UNK—*unknown* See Appendix B for further descriptions and definitions.	Enter up to seven Current Employment codes. **REVISED** If the person is a homemaker, volunteer or caregiver, code UFT—*unpaid employment*. **REVISED** If the person is on short-term disability, code EAM—*employed, adjusted/modified*.	To identify factors affecting access to health care services and to analyze the effect of MS on employability over time. A factor potentially influencing quality of life.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						NEW If the person is on long-term disability, code RFD—*long-term disability*. **NEW** If the person is a casual employee, code either EFT—*employee* or FFT—*self-employed*, depending on the nature of the employment.	
DEM_8	Current Marital Status	Key	*Initial enrolment* and *face-to-face follow-up* records	A code representing the current domestic partnership status of a person.	T—*common law/ domestic partner* D—*divorced (not living common law)* M—*married (and not separated)* L—*legally separated (not living common law)* S—*never married/ single (not living common law)* W—*widowed (not living common law)* OTH—*other* UNK—*unknown*	Provide the code assigned to the most appropriate response. **NEW** If the data provider does not differentiate between T—*common law/domestic partner* and M—*married (and not separated)*, code M—*married (and not separated)*.	To analyze the level of potential support available to the person.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						NEW If the data provider does not differentiate between D—*divorced (not living common law)* and L— *legally separated,* code D—*divorced (not living common law)*.	
DEM_9 (a–h)	Current Living Arrangement(s)	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent with whom a person is living at his or her primary residence. Note: A primary residence can be a home or a facility.	A—*alone* S—*with spouse* SO—*with common law/domestic partner* C—*with child/children* PG—*with parents/ guardians* REL—*with relatives other than spouse, children, parents* NRU—*with non-relatives who are not paid caregivers* NRP—*with non-relatives who are paid caregivers* OTH—*other*	Provide up to eight Current Living Arrangement(s). **Cannot select** A—*alone* and provide other living arrangements. **NEW** If the person lives with a roommate and it is unknown whether he or she is a relative, code OTH—*other*.	To analyze the level of potential support available to the person and to identify changes in living arrangements over time. A factor potentially influencing quality of life.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_10	Current Living Setting	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code representing the type of accommodation that a person currently has based on his or her primary residence. Note: A primary residence can be a home or a facility.	H—*independent household (for example, any house, condominium or apartment, whether owned or rented by the person or another party)* R—*retired community* SL—*supported living* CG—*community shelter/group home* NX—*nursing home/ extended care facility* HL—*homeless* OTH—*other*	Provide the code assigned to the most appropriate response.	To analyze the level of potential support available to the person and to identify changes in living settings over time. A factor potentially influencing quality of life.
DEM_11a	Currently Smoking Cigarettes/ Tobacco Products?	Key	*Initial enrolment* and *face-to-face follow-up* records	A code that represents a person's current and past smoking behaviour.	D—*daily smoker* W—*weekly smoker* I—*irregular smoker* E—*ex-smoker* N—*never smoked*	Provide the code assigned to the most appropriate response.	To analyze a potentially important factor that may impact symptoms, treatment and disease progression.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_11b	Average Number of Cigarettes/ Tobacco Products Currently Smoked per Week	Key	*Initial enrolment* and *face-to-face follow-up* records	A value representing the average quantity of cigarettes smoked or tobacco products used by a person per week.	A value between 0 and 999	Leave blank if person is an ex-smoker or never smoked. It is inappropriate to provide a value when Currently Smoking Cigarettes/Tobacco Products? is left blank.	To analyze a potentially important factor that may impact symptoms, treatment and disease progression.
DEM_11c	Age Started Smoking Cigarettes/ Tobacco Products	Key	*Initial enrolment* record	A value that represents the age when the person first started smoking cigarettes or using tobacco products.	A value between 0 and 120	Leave blank if person has never smoked. It is inappropriate to provide a value when Currently Smoking Cigarettes/Tobacco Products? is left blank.	To analyze a potentially important factor that may impact symptoms, treatment and disease progression.
DEM_11d	Age Stopped Smoking Cigarettes/ Tobacco Products	Key	*Initial enrolment* record	A value that represents the age when the person stopped smoking cigarettes or using tobacco products.	A value between 0 and 120	Leave blank if person has never smoked or is currently a daily, weekly or irregular smoker. It is inappropriate to provide a value when Currently Smoking Cigarettes/Tobacco Products? is left blank.	To analyze a potentially important factor that may impact symptoms, treatment and disease progression

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_12a	Godin-Shephard Leisure-Time Exercise Questionnaire: Strenuous Exercise: Times per Week for More Than 15 Minutes	Key	*Initial enrolment* and *face-to-face follow-up* records	A value that represents the average frequency per week with which the person engages in strenuous exercise for more than 15 minutes (during his or her free time) during a typical seven-day period. Note: Strenuous exercise refers to any exercise where the heart beats rapidly. Examples include but are not limited to running, jogging, hockey, football, soccer, squash, basketball, cross-country skiing, judo, roller skating, vigorous swimming and vigorous long-distance bicycling.	A value between 0 and 672	Each session of 15 minutes or more of strenuous exercise is counted as 1. For example: A person who completes five strenuous workout sessions, each an hour in length, in a typical seven-day period, would enter a value of 5.	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_12b	Godin-Shephard Leisure-Time Exercise Questionnaire: Moderate Exercise: Times per Week for More Than 15 Minutes	Key	*Initial enrolment* and *face-to-face follow-up* records	A value that represents the average frequency per week with which the person engages in moderate exercise for more than 15 minutes (during his or her free time) during a typical seven-day period. Note: Moderate exercise refers to any exercise that is not exhausting. Examples include but are not limited to fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, and popular and folk dancing.	A value between 0 and 672	Each session of 15 minutes or more of moderate exercise is counted as 1.	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_12c	Godin-Shephard Leisure-Time Exercise Questionnaire: Mild Exercise: Times per Week for More Than 15 Minutes	Key	*Initial enrolment* and *face-to-face follow-up* records	A value that represents the average frequency per week with which the person engages in mild exercise for more than 15 minutes (during his or her free time) during a typical seven-day period. Note: Mild exercise refers to any exercise that requires minimal effort. Examples include but are not limited to yoga, archery, fishing from river bank, bowling, horseshoes, golf, snowmobiling and easy walking.	A value between 0 and 672	Each session of 15 minutes or more of mild exercise is counted as 1.	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Patient Demographics (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
DEM_12d	Godin-Shephard Leisure-Time Exercise Questionnaire: Frequency of Sweat-Inducing Activity	Key	*Initial enrolment* and *face-to-face follow-up* records	A code to represent how often the person engages in regular activity long enough to work up a sweat during a typical seven-day period.	O—*often* S—*sometimes* N—*never/rarely* UNK—*unknown*	Provide the code assigned to the most appropriate response.	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

Clinical Information

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
CLIN_1	Current Diagnosis	Mandatory	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the current type of central nervous system demyelinating disorder of a person.	**REVISED** MS—*multiple sclerosis* ADEM—*acute disseminated encephalomyelitis* CIS—*clinically isolated syndrome* NMO—*neuromyelitis optica spectrum disorder* RIS—*radiologically isolated syndrome* CNS—*other CNS demyelinating disorder not otherwise specified*	Provide the code assigned to the most appropriate response. **NEW** If a person has optic neuritis or transverse myelitis and it was not coded by a neurologist as CIS—*clinically isolated syndrome*, code CNS—*other CNS demyelinating disorder not otherwise specified*.	To distinguish between a diagnosis of MS and other demyelinating disorders and to trend disease progression over time.
CLIN_1a	Date of Diagnosis	Critical	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the date that a person received the diagnosis of MS or related condition.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible. Data providers are strongly encouraged to complete this data element. Data providers are strongly encouraged to complete this data element on *face-to-*	To be used in conjunction with date of first symptoms and treatment dates to trend disease progression over time.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						face follow-up records if diagnosis has changed from the last visit. **NEW** For submission of historical data, Date of Diagnosis can be captured via a review of the client's/patient's historical records if the date of diagnosis for the current diagnosis is clearly available in the historical record.	
CLIN_1b	Estimated Date of Diagnosis?	Critical*	*Initial enrolment* and *face-to-face follow-up* records	A code used to indicate if the diagnosis date contains estimated values.	Y—*yes*, the date entered is an estimated date N—*no*, the date entered is not an estimated date	If the year, month and/or day is an estimate, code Y—*yes*. If the provided date is accurate and true, code N—*no*. Examples: Date of Diagnosis = 2012 (true year), then code N—*no*. Date of Diagnosis = 20120101 (true year, month, estimated day), then code Y—*yes*.	Important data qualifier for Date of Diagnosis data element.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						Data providers are strongly encouraged to complete this data element if Date of Diagnosis is completed.	
CLIN_2a	Date of First Symptoms of Current Diagnosis	Critical*	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the initial date that symptoms related to the current diagnosis were first experienced by a person that resulted in the person seeking medical advice from a health care provider.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible. This data element can be completed for all current diagnoses; however, data providers are strongly encouraged to complete it on *initial enrolment* records if current diagnosis is MS. Data providers are also strongly encouraged to complete it on *face-to-face follow-up* records if current diagnosis is MS and diagnosis has changed since the last visit.	To be used in conjunction with Date of Diagnosis and treatment dates to trend disease progression over time.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						NEW For submission of historical data, Date of First Symptoms of Current Diagnosis can be captured via a review of the client's/patient's historical records.	
CLIN_2b	Estimated Date of First Symptoms of Current Diagnosis?	Critical*	*Initial enrolment* and *face-to-face follow-up* records	A code used to indicate if the first symptom date contains estimated values.	Y—*yes*, the date entered is an estimated date N—*no*, the date entered is not an estimated date	If the year, month and/or day is an estimate, code Y—*yes*. If the provided date is accurate and true, code N—*no*. Examples: Date of First Symptoms = 2012 (true year), then code N—*no*. Date of First Symptoms = 20120101 (true year, month, estimated day), then code Y—*yes*.	Important data qualifier for Date of First Symptoms data element.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						Data providers are also strongly encouraged to complete this data element if Date of First Symptoms of Current Diagnosis is completed.	
CLIN_3	Type/Course of MS at Onset	Critical*	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the initial type or course of MS of a person.	PRO—*progressive* REL—*relapsing* UNC—*uncertain*	Data providers are strongly encouraged to complete this data element on *initial enrolment* records if current diagnosis is MS. Data providers are strongly encouraged to complete this data element on *face-to-face follow-up* records if current diagnosis is MS and diagnosis has changed since the last visit. **NEW** If the person had progressive relapsing MS at onset, code PRO—*progressive*.	To trend disease progression over time. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						If the type or course of MS at onset is not known or is undecided, code UNC—*uncertain*. If the Current Diagnosis is not MS, leave blank. **NEW** For submission of historical data, Type/Course of MS at Onset can be captured via a review of the client's/patient's historical records.	
CLIN_4	Current Type/ Course of MS	Critical*	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the current type or course of MS of a person.	PP—*primary progressive* PR—*progressive relapsing* RR—*relapsing remitting* SP—*secondary progressive* UNC—*uncertain*	Data providers are strongly encouraged to complete this data element on *initial enrolment* records if current diagnosis is MS. Data providers are strongly encouraged to complete this data element on *face-to-face follow-up* records if current diagnosis is MS.	To trend disease progression over time. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						If the current type or course of MS is not known or is undecided, code UNC—*uncertain*. If the Current Diagnosis is not MS, leave blank.	evolution and effectiveness of treatment and disease progression.
CLIN_4b	Date of Onset of Secondary Progressive MS	Key	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the date of onset of secondary progressive MS.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible. Leave blank if there is no onset of secondary progressive MS. **NEW** For submission of historical data, Date of Onset of Secondary Progressive MS can be captured via a review of the client's/patient's historical records.	To be used in conjunction with Date of Diagnosis and treatment dates to trend disease progression over time.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
CLIN_5	**REVISED** Any Comorbid Condition(s)?	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code used to indicate if a person has a health condition(s) that has been diagnosed by a heath care provider and that affects his or her functional status and resource requirements.	Y—*yes* N—*no* UNK—*unknown*	If Y—*yes* is coded, data providers are strongly encouraged to provide up to 10 current Comorbid Conditions and/or five Other Comorbid Conditions.	An indicator to determine the presence of comorbid conditions. Needed to distinguish between no comorbid conditions and non-response.
CLIN_5 (a–j)	**REVISED** Comorbid Condition(s)	Critical*	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the health condition(s) that have been diagnosed by a heath care provider and that affect a person's health, functional status and resource requirements.	**REVISED** ME—*depression* MA—*anxiety* HD—hypertension EC—*hyperlipidemia* EF—*diabetes* HF—*ischemic heart disease* OA—cancer EE—*autoimmune thyroid disease* TC—fibromyalgia RA—*chronic lung disease (any of COPD, asthma)*	Provide up to 10 current Comorbid Conditions. Leave blank if Any Comorbid Condition(s)? = N—*no* or UNK—*unknown*. If the health condition cannot be found in the Valid Values and Descriptions, complete the Other Comorbid Condition(s) fields.	To analyze health conditions that may impact disease progression, treatment outcomes and quality of life.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
CLIN_5 (k–o)	**REVISED** Other Comorbid Condition(s)	Critical*	*Initial enrolment* and *face-to-face follow-up* records	Text used to represent the health condition(s) that have been diagnosed by a heath care provider and that affect a person's health, functional status and resource requirements.	Free text	Provide up to five Other Comorbid Conditions using free text. Add one condition per field. If there are more than five conditions, add more conditions to each field, separated by commas. Leave blank if Any Comorbid Condition(s)? = N—*no* or UNK—*unknown*.	To analyze health conditions that may impact disease progression, treatment outcomes and quality of life.
CLIN_7	Overall Health Compared to Last Visit	Key	*Face-to-face follow-up* record	A code used to indicate if a person feels that his or her overall health is better, worse or the same when compared to the last visit.	W—*worse* S—*the same* B—*better*	Provide the code assigned to the most appropriate response.	To analyze the effectiveness of different models of care and treatments and to measure disease progression over time.

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Clinical Information (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
CLIN_8	MS Symptoms Compared to Last Visit	Key	*Face-to-face follow-up* record	A code used to indicate if a person feels that his or her MS symptoms are better, worse or the same when compared to the last visit.	W—*worse* S—*the same* B—*better*	Provide the code assigned to the most appropriate response.	To analyze the effectiveness of different models of care and treatments and to measure disease progression over time.

Medications

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
Drug_1	Currently on DMT(s) and/or Corticosteroid(s) (to Treat MS)?	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code used to indicate if a person is currently on a disease-modifying therapy to alter the course of his or her MS (and not for symptom management) or is on a corticosteroid to treat MS.	Y—*yes* N—*no*	If the person is currently on a DMT or corticosteroid, code Y—*yes*. If Y—*yes* is coded, it is strongly encouraged to provide up to 10 Drug Names and/or 5 Other Drug Names.	An indicator to determine if the person is currently on any disease-modifying therapies or corticosteroid. Needed to distinguish between not currently on DMTs and non-response.

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
Drug_1 (a–j)	Drug Name(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	Critical*	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the name of the disease-modifying therapy or corticosteroid that a person is currently receiving. A disease-modifying therapy is a drug taken to alter the course of the person's MS and not for symptom management.	**DMTs** AZ—*azathioprine (Imuran)* CY—*cyclophosphamide (Cytoxan)* FI—*fingolimod (Gilenya)* GL—*glatiramer acetate (Copaxone)* IA—*interferon beta-1A (Avonex)* IR—*interferon beta-1A (Rebif)* IB—*interferon beta-1B (Betaseron)* IE—*interferon beta-1B (Extavia)* ME—*methotrexate* MI—*mitoxantrone (Novantrone)* NA—*natalizumab (Tysabri)* RI—*rituximab (Rituxan)* TE—*teriflunomide* CL—*clinical trial drug* **Corticosteroids** LD—*low-dose oral corticosteroids* HD—*high-dose oral corticosteroids* IV—*intravenous corticosteroids*	Provide up to 10 DMTs or corticosteroids. Leave blank if Currently on DMT(s) and/or Corticosteroid(s) (to Treat MS)? = N—*no*. If there are more than 10 DMTs or corticosteroids or the DMT or corticosteroid cannot be found in the drug pick-list, complete the Other Drug Name(s) fields.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones.

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
Drug_1 (k–o)	Other Drug Name(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	Critical*	*Initial enrolment* and *face-to-face follow-up* records	Text used to represent the name of the disease-modifying therapy or corticosteroid that a person is receiving. Note: A disease-modifying therapy is a drug taken to alter the course of the person's MS and not for symptom management.	Free text	Provide up to five other DMTs or corticosteroids using free text. Leave blank if Currently on DMT(s) and/or Corticosteroid(s) (to Treat MS)? = N—*no*.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones.
Drug_1 (a–j)b/ Drug_1 (k–o)b	Drug Start Date(s)/Other Drug Start Date(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	Critical	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the date that a person started taking the disease-modifying therapy or corticosteroid.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible. Leave blank if Currently on DMT(s) and/or Corticosteroid(s) (to Treat MS)? = N—*no*. It is inappropriate to provide a date with no corresponding Drug Name.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones.

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
Drug_1 (a–j)b(a–e)/ Drug_1 (k–o)b(a–e)	Drug Side Effect(s)/ Complication(s)/ Other Drug Side Effect(s)/ Complication(s) (Associated with Currently on DMT[s] and/or Corticosteroid[s] [to Treat MS]?)	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the severity of side effect(s)/ complication(s) experienced by the person that resulted from the disease-modifying therapy or corticosteroid.	NO—*none* MI—*minor (required ambulatory care)* MA—*major (required hospitalization)*	Provide up to two side effect/complication values for each disease-modifying therapy or corticosteroid. **Cannot select** NO—*none* and provide other side effect/ complication values. Leave blank if Currently on DMT(s) and/or Corticosteroid(s) (to Treat MS)? = N—*no*. It is inappropriate to provide a side effect/complication value with no corresponding Drug Name.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones.

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
Drug_2	Previously on DMT(s)?	Critical	*Initial enrolment* and *face-to-face follow-up* records	A code used to indicate if a person was previously on (that is, has discontinued) a disease-modifying therapy.	Y—*yes* N—*no* UNK—*unknown*	On an *initial enrolment*, code Y—*yes* if the person has ever discontinued DMT(s). On a *face-to-face follow-up*, code Y—*yes* if the person discontinued DMT(s) since the last visit. If Y—*yes* is coded, it is recommended to provide up to 15 Drug Names and/or 5 Other Drug Names.	An indicator to determine if the person was previously on any disease-modifying therapies. Needed to distinguish between discontinued DMTs and non-response.
Drug_2 (a–o)	Drug Name(s) (Associated with Previously on DMT[s]?)	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the name of the disease-modifying therapy that a person received.	AZ—*azathioprine (Imuran)* CY—*cyclophosphamide (Cytoxan)* FI—*fingolimod (Gilenya)* GL—*glatiramer acetate (Copaxone)* IA—*interferon beta-1A (Avonex)* IR—*interferon beta-1A (Rebif)* IB—*interferon beta-1B (Betaseron)* IE—*interferon beta-1B (Extavia)* ME—*methotrexate*	Provide up to 15 discontinued DMTs. Leave blank if Previously on DMT(s)? = N—*no* or UNK—*unknown*. On *initial enrolment*, provide all discontinued DMT(s). On *face-to-face follow-up*, provide only the DMT(s) discontinued since the last visit.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones.

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
					MI—*mitoxantrone (Novantrone)* NA—*natalizumab (Tysabri)* RI—*rituximab (Rituxan)* TE—*teriflunomide* CL—*clinical trial drug*	If there were more than 90 days between the end and start date of the same DMT, the DMT should be recorded again. If there are more than 15 DMTs or the DMT cannot be found in the drug pick-list, complete the Other Drug Name(s) fields.	To assess sub-optimal treatment outcomes and trend and compare performance across service delivery models and diagnoses.
Drug_2 (p–t)	Other Drug Name(s) (Associated with Previously on DMT[s]?)	Key	*Initial enrolment* and *face-to-face follow-up* records	Text used to represent the name of the disease-modifying therapy that a person has received.	Free text	Provide up to five other DMTs using free text. Leave blank if Previously on DMT(s)? = N—*no* or UNK—*unknown*. On *initial enrolment*, provide all discontinued DMT(s). On *face-to-face follow-up*, provide only the DMT(s) discontinued since the last visit.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones. To assess sub-optimal treatment outcomes and

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
							trend and compare performance across service delivery models and diagnoses.
Drug_2 (a–o)/ Drug_2 (p–t)	Drug Start Date(s)/Other Drug Start Date(s) (Associated with Previously on DMT[s]?)	Key	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the date that a person started taking the disease-modifying therapy.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible. Leave blank if Previously on DMT(s)? = N—*no* or UNK—*unknown*. It is inappropriate to provide a date with no corresponding Drug Name.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones.
Drug_2 (a–o)c/ Drug_2 (p–t)c	Drug End Date(s)/Other Drug End Date(s) (Associated with Previously on DMT[s]?)	Key	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the date that a person stopped taking the disease-modifying therapy.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible. Leave blank if Previously on DMT(s)? = N—*no* or UNK—*unknown*.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction

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Medications (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						It is inappropriate to provide a date with no corresponding Drug Name.	with other disease, treatment and outcome milestones.
Drug_2 (a–o) d(a–h)/ Drug_2 (p–t) d(a–h)	Reason(s) for Drug Cessation (Associated with Previously on DMT[s]?)	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the reason for stopping the disease-modifying therapy.	FIN—*financial* NAD—*non-adherence* PST—*patient requests to stop treatment* PRE—*pregnancy related* SEF—*side effects* TFL—*treatment failure/lack of effect* TNR—*treatment no longer required (for example, goals of the treatment have been met as planned)* OTH—*Other*	Provide up to eight Reasons for Cessation for each discontinued DMT. Leave blank if Previously on DMT(s)? = N—*no* or UNK—*unknown*. It is inappropriate to provide a Reason for Cessation with no corresponding Drug Name.	To analyze drug utilization patterns. To also analyze drug efficacy and outcomes when used in conjunction with other disease, treatment and outcome milestones. To assess sub-optimal treatment outcomes and trend and compare performance across service delivery models and diagnoses

Treatment

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
TREAT_1	Service Provider(s) Related to MS Accessed?	Key	*Initial enrolment* and *face-to-face follow-up* records	**REVISED** A code used to indicate if the person accessed allied health care provider(s) and received a service.	Y—*yes* N—*no*	**REVISED** On *initial enrolment*, code Y—*yes* if the person accessed allied health care provider(s) related to his or her MS in the last 12 months. On *face-to-face follow-up*, code Y—*yes* if the person accessed allied health care provider(s) related to his or her MS since the last visit. If Y—*yes* is coded, it is recommended to provide up to 12 Service Providers and the corresponding source of payment. **NEW** Inpatient visits (e.g., clinic staff visiting a client/patient who is hospitalized for acute care) should not be captured in the Services Provider(s) Related to MS Accessed fields.	An indicator to determine if service providers were accessed. Needed to distinguish between no services received and non-response.

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						Only outreach visits (e.g., clinic staff visiting a client/patient in his or her home or chronic care facility) should be captured in these fields.	
Treat_1 (a–l)	Service Provider(s) Related to MS	Key	*Initial enrolment* and *face-to-face follow-up* records	**REVISED** A code that represents the allied health care provider(s) accessed by the person.	**REVISED** EX—*exercise therapist (for example, physiologist, kinesiologist)* HCA—*home care aide (for example, personal support worker, health care aide, personal care attendant, home health aide)* HCN—*home care nurse (delivers nursing services in the person's primary residence)* NEUPSYCH—*neuropsychologist* NUR—*nurse (includes certified graduate nurse, licensed practical nurse, registered*	Provide up to 12 service providers. Leave blank if Service Provider(s) Related to MS Accessed? = N—*no*. On *initial enrolment* only, record the service provider(s) accessed related to MS in the last 12 months. On *face-to-face follow-up* only, record the service provider(s) accessed related to MS since the last visit. Do not provide duplicate provider codes. Only code each service provider once.	To identify different models of care.

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
					nurse and nurse with specialization in multiple sclerosis) OT—*occupational therapist* OPT—*optometrist (a person who is professionally trained and licensed to examine the eyes for visual defects, diagnose problems or impairments, and prescribe corrective lenses or provide other types of treatment)* PA—*physician assistant/clinical assistant (includes nurse practitioner, but excludes residents and trainees)* PHYSIO—*physiotherapist* PSYCH—*psychologist* RTMR—*radiation technologist in magnetic resonancy (accessed only for*	For example, if the person accessed two occupational therapists, record OT only once. **NEW** Inpatient visits (e.g., clinic staff visiting a client/patient who is hospitalized for acute care) should not be captured in the Services Provider(s) Related to MS Accessed fields. Only outreach visits (e.g., clinic staff visiting a client/patient in his or her home or chronic care facility) should be captured in these fields. **NEW** If the service provider(s) accessed related to MS is a nurse practitioner, code PA—*physician assistant/clinical assistant* and **not** NUR—*nurse*.	

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
					MS-related inpatient and outpatient MRIs [for example, MRI of brain and spinal cord]) SW—*social worker* SLP—*speech–language pathologist* OTH—*other*	**NEW** Nutritionists and dietitians are to be captured using OTH—*other*.	
Treat_1 (a–l)(a–e)	Source(s) of Payment	Key	*Initial enrolment* and *face-to-face follow-up* records	A code representing the entity, organization, government, corporation, health plan sponsor or any other financial agent that pays a service provider for the health care–related services or goods rendered to a person or reimburses the cost of the health care–related services or goods.	**REVISED** PS—*public system (includes medicare, federal agency [e.g., First Nations and Inuit Health Branch] and Workplace Safety and Insurance Board [WSIB])* PO—*other (includes private health insurance, self-pay and charitable foundation/ organization/ individual)*	Both PS—*public system* and PO—*other* can be coded for one Service Provider. Leave blank if Service Provider(s) Related to MS Accessed? = N—*no*. It is inappropriate to provide a Service Provider Payment with no corresponding Service Provider.	To identify factors affecting access to health care.

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
TREAT_2	Other Therapy(s) Related to MS Received?	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to indicate if a person was a recipient of Other Therapy(s) related to his or her MS.	Y—*yes* N—*no*	On *initial enrolment*, code Y—*yes* if the person received Other Therapy(s) related to MS. On *face-to-face follow-up*, code Y—*yes* if the person received Other Therapy(s) related to MS since the last visit. If Y—*yes* is coded, it is recommended to provide up to 10 Other Therapy(s) and/or 5 Additional Other Therapy(s).	An indicator to determine if other therapies were received. Needed to distinguish between no therapies received and non-response.
TREAT_ 2(a–j)a	Other Therapy(s)	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the type of Other Therapy(s) received by a person related to his or her MS.	**In-Country Therapies:** Codes are available in Table 1 in Appendix C. **Out-of-Country Therapies:** Codes are available in Table 2 in Appendix C. UNK—*unknown procedure*	Provide up to 10 Other Therapy(s). Leave blank if Other Therapy(s) Related to MS Received? = N—*no*. On *initial enrolment*, record all received Other Therapy(s) related to the person's MS.	To analyze the details of other therapy approaches and their outcomes when used in conjunction with other disease, treatment and outcome milestones.

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
						On *face-to-face follow-up* only, record the Other Therapy(s) related to the person's MS received since the last visit. To identify therapies received in Canada, use the in-country codes provided in Table 1 in Appendix C. To identify therapies received outside of Canada, use the out-of-country codes provided in Table 2 in Appendix C. If there are more than 10 Other Therapies or if the therapy cannot be found in Appendix C, complete the Additional Other Therapy(s) fields.	

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
TREAT_ 2(k–o)a	Additional Other Therapy(s)	Key	*Initial enrolment* and *face-to-face follow-up* records	Text used to represent the type of Other Therapy(s) received by a person related to his or her MS.	Free text	Provide up to five Additional Other Therapy(s) using free text. Leave blank if Other Therapy(s) Related to MS Received? = N—*no*. On *initial enrolment*, record all received Other Therapy(s) related to the person's MS. On *face-to-face follow-up* only, record the Other Therapy(s) related to the person's MS received since the last visit.	To analyze the details of other therapy approaches and their outcomes when used in conjunction with other disease, treatment and outcome milestones.

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Treatment (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
TREAT_ 2(a–j)b/ TREAT_ 2(k–o)b	Other Therapy Date(s)/ Additional Other Therapy Date(s)	Key	*Initial enrolment* and *face-to-face follow-up* records	The year, month and day that represent the date that the person received the other therapy related to MS.	YYYYMMDD—*full date is available* YYYYMM—*only year and month are available* YYYY—*only year is available*	Provide as much date information as possible for each Other Therapy coded. Leave blank if Other Therapy(s) Related to MS Received? = N—*no*. It is inappropriate to provide a date with no corresponding Other Therapy.	To analyze the details of other therapy approaches and their outcomes when used in conjunction with other disease, treatment and outcome milestones.
TREAT_2 (a–j)c(a–e)/ TREAT_2 (k–o)c(a–e)	Complication(s) Arising During or After Other Therapy/ Additional Other Therapy	Key	*Initial enrolment* and *face-to-face follow-up* records	A code used to represent the severity of complications that resulted from the other therapy received by a person related to MS.	NO—*none* MI—*minor (required ambulatory care)* MA—*major (required hospitalization)*	Provide up to two complications for each Other Therapy coded. **Cannot select** NO—*none* and provide other complication values. Leave blank if Other Therapy(s) Related to MS Received? = N—*no*. It is inappropriate to provide a complication value with no corresponding Other Therapy.	To analyze the details of other therapy approaches and their outcomes when used in conjunction with other disease, treatment and outcome milestones.

Outcomes

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_3	Expanded Disability Status Scale (EDSS)	Critical	*Initial enrolment* and *face-to-face follow-up* records	A standardized measure of global neurological impairment in multiple sclerosis.	0.0 1.0 1.5 2.0 2.5 3.0 3.5 4.0 4.5 5.0 5.5 6.0 6.5 7.0 7.5 8.0 8.5 9.0 9.5 10.0 See Appendix D for descriptions of the EDSS scores. UNK—*unknown*	Provide the most recent EDSS scale rating using the codes and descriptions available in Appendix D.	To measure neurological impairment using a widely utilized assessment instrument in the MS population.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2a	Health Utilities Index: Vision: Ordinary Newsprint	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2b	Health Utilities Index: Vision: Recognize Friend	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2c	Health Utilities Index: Hearing: Group Conversation	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2d	Health Utilities Index: Hearing: Quiet Room	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2e	Health Utilities Index: Understood by Strangers	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2f	Health Utilities Index: Understood by Familiars	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2g	Health Utilities Index: Happiness	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2h	Health Utilities Index: Pain Restricted Activities	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2i	Health Utilities Index: Walking	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2j	Health Utilities Index: Manual Dexterity	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2k	Health Utilities Index: Memory	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2I	Health Utilities Index: Problem-Solving	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2m	Health Utilities Index: Basic Activities	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2n	Health Utilities Index: Mood	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2o	Health Utilities Index: Pain Relief	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2p	Health Utilities Index: Health	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

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Outcomes (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
OUT_2q	Health Utilities Index: Questionnaire	Key	*Initial enrolment* and *face-to-face follow-up* records	The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) is a questionnaire containing a set of questions that ask about various aspects of the person's health. Refer to the Health Utilities Index questions in the *CMSMS Extract File Data Elements* document (available only to data providers) for more information.	Valid values and descriptions are available in the *CMSMS Extract File Data Elements* document (available only to data providers).	This questionnaire is to be self-administered by the client/patient. For instructions on completing the questions from the Health Utilities Index Mark 2 and Mark 3 (HUI2/3), refer to the *CMSMS Extract File Data Elements* document (available only to data providers).	A measure of functional ability and a factor potentially influencing quality of life. Can also be used in conjunction with other disease, treatment and outcome milestones to support analysis of the evolution and effectiveness of treatment and disease progression.

Special Projects

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
SP_1	Special Project 1	Key	All record types	A field used to collect supplemental data (that is, data not already collected through the MDS) that the organization, health authority or ministry would like to collect.	Free text	**IMPORTANT** Do not enter sensitive personal health information (for example, Health Card Number) into this field. Use this field to capture reserved special projects (identified by Special Project Codes 001–499). Send an email to ms@cihi.ca before submitting information in this field. **NEW** Appendix E provides detailed information on reserved projects.	To allow the collection of supplemental data.

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Special Projects (cont'd)

Data Element ID	Data Element Name	Reporting Requirements	Applicable Records	Definition	Valid Values and Descriptions	Guidelines for Coding	Rationale
SP_2	Special Project 2	Key	All record types	A field used to collect supplemental data (that is, data not already collected through the MDS) that the organization, health authority or ministry would like to collect.	Free text	**IMPORTANT** Do not enter sensitive personal health information (for example, Health Card Number) into this field. Use this field to capture unreserved special projects (identified by Special Project Codes 500–999). Send an email to ms@cihi.ca for information on existing unreserved special projects or to set up a data provider–specific project.	To allow the collection of supplemental data.

Appendix A: Country Codes

Country Code	Country Short Name
AFG	AFGHANISTAN
ALA	ÅLAND ISLANDS
ALB	ALBANIA
DZA	ALGERIA
ASM	AMERICAN SAMOA
AND	ANDORRA
AGO	ANGOLA
AIA	ANGUILLA
ATA	ANTARCTICA
ATG	ANTIGUA AND BARBUDA
ARG	ARGENTINA
ARM	ARMENIA
ABW	ARUBA
AUS	AUSTRALIA
AUT	AUSTRIA
AZE	AZERBAIJAN
BHS	BAHAMAS
BHR	BAHRAIN
BGD	BANGLADESH
BRB	BARBADOS
BLR	BELARUS
BEL	BELGIUM
BLZ	BELIZE
BEN	BENIN
BMU	BERMUDA

(cont’d on next page)

Country Code	Country Short Name
BTN	BHUTAN
BOL	BOLIVIA, PLURINATIONAL STATE OF
BES	BONAIRE, SINT EUSTATIUS AND SABA
BIH	BOSNIA AND HERZEGOVINA
BWA	BOTSWANA
BVT	BOUVET ISLAND
BRA	BRAZIL
IOT	BRITISH INDIAN OCEAN TERRITORY
BRN	BRUNEI DARUSSALAM
BGR	BULGARIA
BFA	BURKINA FASO
BDI	BURUNDI
KHM	CAMBODIA
CMR	CAMEROON
CAN	CANADA
CPV	CAPE VERDE
CYM	CAYMAN ISLANDS
CAF	CENTRAL AFRICAN REPUBLIC
TCD	CHAD
CHL	CHILE
CHN	CHINA
CXR	CHRISTMAS ISLAND
CCK	COCOS (KEELING) ISLANDS
COL	COLOMBIA
COM	COMOROS
COG	CONGO
COD	CONGO, DEMOCRATIC REPUBLIC OF THE

(cont'd on next page)

Country Code	Country Short Name
COK	COOK ISLANDS
CRI	COSTA RICA
CIV	CÔTE D'IVOIRE
HRV	CROATIA
CUB	CUBA
CUW	CURAÇAO
CYP	CYPRUS
CZE	CZECH REPUBLIC
DNK	DENMARK
DJI	DJIBOUTI
DMA	DOMINICA
DOM	DOMINICAN REPUBLIC
ECU	ECUADOR
EGY	EGYPT
SLV	EL SALVADOR
GNQ	EQUATORIAL GUINEA
ERI	ERITREA
EST	ESTONIA
ETH	ETHIOPIA
FLK	FALKLAND ISLANDS (MALVINAS)
FRO	FAROE ISLANDS
FJI	FIJI
FIN	FINLAND
FRA	FRANCE
GUF	FRENCH GUIANA
PYF	FRENCH POLYNESIA
ATF	FRENCH SOUTHERN TERRITORIES

(cont'd on next page)

Country Code	Country Short Name
GAB	GABON
GMB	GAMBIA
GEO	GEORGIA
DEU	GERMANY
GHA	GHANA
GIB	GIBRALTAR
GRC	GREECE
GRL	GREENLAND
GRD	GRENADA
GLP	GUADELOUPE
GUM	GUAM
GTM	GUATEMALA
GGY	GUERNSEY
GIN	GUINEA
GNB	GUINEA-BISSAU
GUY	GUYANA
HTI	HAITI
HMD	HEARD ISLAND AND MCDONALD ISLANDS
VAT	HOLY SEE (VATICAN CITY STATE)
HND	HONDURAS
HKG	HONG KONG
HUN	HUNGARY
ISL	ICELAND
IND	INDIA
IDN	INDONESIA
IRN	IRAN, ISLAMIC REPUBLIC OF
IRQ	IRAQ

(cont'd on next page)

Country Code	Country Short Name
IRL	IRELAND
IMN	ISLE OF MAN
ISR	ISRAEL
ITA	ITALY
JAM	JAMAICA
JPN	JAPAN
JEY	JERSEY
JOR	JORDAN
KAZ	KAZAKHSTAN
KEN	KENYA
KIR	KIRIBATI
PRK	KOREA, DEMOCRATIC PEOPLE'S REPUBLIC OF
KOR	KOREA, REPUBLIC OF
KWT	KUWAIT
KGZ	KYRGYZSTAN
LAO	LAO PEOPLE'S DEMOCRATIC REPUBLIC
LVA	LATVIA
LBN	LEBANON
LSO	LESOTHO
LBR	LIBERIA
LBY	LIBYA
LIE	LIECHTENSTEIN
LTU	LITHUANIA
LUX	LUXEMBOURG
MAC	MACAO
MKD	MACEDONIA, THE FORMER YUGOSLAV REPUBLIC OF
MDG	MADAGASCAR

(cont'd on next page)

Country Code	Country Short Name
MWI	MALAWI
MYS	MALAYSIA
MDV	MALDIVES
MLI	MALI
MLT	MALTA
MHL	MARSHALL ISLANDS
MTQ	MARTINIQUE
MRT	MAURITANIA
MUS	MAURITIUS
MYT	MAYOTTE
MEX	MEXICO
FSM	MICRONESIA, FEDERATED STATES OF
MDA	MOLDOVA, REPUBLIC OF
MCO	MONACO
MNG	MONGOLIA
MNE	MONTENEGRO
MSR	MONTSERRAT
MAR	MOROCCO
MOZ	MOZAMBIQUE
MMR	MYANMAR
NAM	NAMIBIA
NRU	NAURU
NPL	NEPAL
NLD	NETHERLANDS
NCL	NEW CALEDONIA
NZL	NEW ZEALAND
NIC	NICARAGUA

(cont'd on next page)

Country Code	Country Short Name
NER	NIGER
NGA	NIGERIA
NIU	NIUE
NFK	NORFOLK ISLAND
MNP	NORTHERN MARIANA ISLANDS
NOR	NORWAY
OMN	OMAN
PAK	PAKISTAN
PLW	PALAU
PSE	PALESTINIAN TERRITORY, OCCUPIED
PAN	PANAMA
PNG	PAPUA NEW GUINEA
PRY	PARAGUAY
PER	PERU
PHL	PHILIPPINES
PCN	PITCAIRN
POL	POLAND
PRT	PORTUGAL
PRI	PUERTO RICO
QAT	QATAR
REU	RÉUNION
ROU	ROMANIA
RUS	RUSSIAN FEDERATION
RWA	RWANDA
BLM	SAINT BARTHÉLEMY
SHN	SAINT HELENA, ASCENSION AND TRISTAN DA CUNHA
KNA	SAINT KITTS AND NEVIS

(cont'd on next page)

Country Code	Country Short Name
LCA	SAINT LUCIA
MAF	SAINT MARTIN (FRENCH PART)
SPM	SAINT PIERRE AND MIQUELON
VCT	SAINT VINCENT AND THE GRENADINES
WSM	SAMOA
SMR	SAN MARINO
STP	SAO TOME AND PRINCIPE
SAU	SAUDI ARABIA
SEN	SENEGAL
SRB	SERBIA
SYC	SEYCHELLES
SLE	SIERRA LEONE
SGP	SINGAPORE
SXM	SINT MAARTEN (DUTCH PART)
SVK	SLOVAKIA
SVN	SLOVENIA
SLB	SOLOMON ISLANDS
SOM	SOMALIA
ZAF	SOUTH AFRICA
SGS	SOUTH GEORGIA AND THE SOUTH SANDWICH ISLANDS
SSD	SOUTH SUDAN
ESP	SPAIN
LKA	SRI LANKA
SDN	SUDAN
SUR	SURINAME
SJM	SVALBARD AND JAN MAYEN
SWZ	SWAZILAND

(cont’d on next page)

Country Code	Country Short Name
SWE	SWEDEN
CHE	SWITZERLAND
SYR	SYRIAN ARAB REPUBLIC
TWN	TAIWAN, PROVINCE OF CHINA
TJK	TAJIKISTAN
TZA	TANZANIA, UNITED REPUBLIC OF
THA	THAILAND
TLS	TIMOR-LESTE
TGO	TOGO
TKL	TOKELAU
TON	TONGA
TTO	TRINIDAD AND TOBAGO
TUN	TUNISIA
TUR	TURKEY
TKM	TURKMENISTAN
TCA	TURKS AND CAICOS ISLANDS
TUV	TUVALU
UGA	UGANDA
UKR	UKRAINE
ARE	UNITED ARAB EMIRATES
GBR	UNITED KINGDOM
USA	UNITED STATES
UMI	UNITED STATES MINOR OUTLYING ISLANDS
URY	URUGUAY
UZB	UZBEKISTAN
VUT	VANUATU
VEN	VENEZUELA, BOLIVARIAN REPUBLIC OF

(cont’d on next page)

Country Code	Country Short Name
VNM	VIET NAM
VGB	VIRGIN ISLANDS (BRITISH)
VIR	VIRGIN ISLANDS (U.S.)
WLF	WALLIS AND FUTUNA
ESH	WESTERN SAHARA
YEM	YEMEN
ZMB	ZAMBIA
ZWE	ZIMBABWE

Source

ISO. *ISO 3166-1:2006 Codes for the representation of names of countries and their subdivisions—Part 1: Country codes, Edition 2*. http://www.iso.org. Accessed July 25, 2012.

Appendix B: **REVISED** Coding Employment Type Definitions

Valid Value and Description	Definition
FFT—*self-employed*	A code used to represent persons who work for themselves to earn their living. This includes casual self-employed persons.
EFT—*employee*	A code used to represent persons who work for an employer for compensation. This includes casual employees.
UFT—*unpaid employment*	A code used to represent persons who perform work without compensation, including volunteers, homemakers and caregivers.
EAM—*employed, adjusted/modified*	A code used to represent persons who participate in modified work or modified hours as a result of injury/illness and require workplace accommodations—modified work or hours may be temporary; this also includes persons on short-term disability who are expected to return to their substantive positions (with or without accommodations).
SFT—*student*	A code used to represent persons enrolled in an accredited school, college, university or vocational training program.
RFA—*retired*	A code used to represent persons who have retired (that is, are not in the labour force). This includes persons who have completed required years of service, retired because of age, retired because of caregiving responsibilities or retired to pursue other activities.
RFD—*long-term disability*	A code used to represent persons with an illness or injury that renders them unable to participate in any employment.
UEM—*unemployed*	A code used to represent persons who may be seeking employment but will not be included in the *self-employed*; *employee*; *unpaid employment*; *employed, adjusted/modified*; *student*; *retired*; or *long-term disability* categories.
OTH—*other*	A code used to indicate that the person's employment does not fall into one of the eight defined values above.
UNK—*unknown*	A code used to indicate that the person's employment is unknown.

Appendix C: Other Therapy Codes and Descriptions

Table 1: In-Country Therapies (Therapies Received in Canada)

Code	Description
ISC	Stem cell transplant (non–bone marrow)
IBM	Bone marrow transplant
IBR	Balloon angioplasty, right jugular vein (vein in the neck)
IBL	Balloon angioplasty, left jugular vein (vein in the neck)
IBA	Balloon angioplasty, azygous vein (vein deep in the chest)
IBU	Balloon angioplasty, vein unknown
ISR	Stent placed into the right jugular vein (vein in the neck)
ISL	Stent placed into the left jugular vein (vein in the neck)
ISA	Stent placed into the azygous vein (vein deep in the chest)
ISU	Stent, vein unknown
IVV	Venous valvular procedure
ICT	Complementary therapies (for example, vibration therapy, functional electrical stimulation [FES] therapy, transcranial magnetic stimulation, tai chi, reflexology, massage, yoga, relaxation and meditation, acupuncture, aromatherapy, hippotherapy, hydrotherapy, herbal remedies, special diets, omega fatty acids)
ILN	Low-dose naltrexone (LDN)

Table 2: Out-of-Country Therapies (Therapies Received Outside of Canada)	
Code	**Description**
OSC	Stem cell transplant (non–bone marrow)
OBM	Bone marrow transplant
OBR	Balloon angioplasty, right jugular vein (vein in the neck)
OBL	Balloon angioplasty, left jugular vein (vein in the neck)
OBA	Balloon angioplasty, azygous vein (vein deep in the chest)
OBU	Balloon angioplasty, vein unknown
OSR	Stent placed into the right jugular vein (vein in the neck)
OSL	Stent placed into the left jugular vein (vein in the neck)
OSA	Stent placed into the azygous vein (vein deep in the chest)
OSU	Stent, vein unknown
OVV	Venous valvular procedure
OCT	Complementary therapies (for example, vibration therapy, functional electrical stimulation [FES] therapy, transcranial magnetic stimulation, tai chi, reflexology, massage, yoga, relaxation and meditation, acupuncture, aromatherapy, hippotherapy, hydrotherapy, herbal remedies, special diets, omega fatty acids)
OLN	Low-dose naltrexone (LDN)

Appendix D: Expanded Disability Status Scale (EDSS)

Code	EDSS
0.0	Normal neurological exam (all grade 0 in all Functional System [FS] scores*).
1.0	No disability, minimal signs in one FS* (i.e. grade 1).
1.5	No disability, minimal signs in more than one FS* (more than 1 FS grade 1).
2.0	Minimal disability in one FS (one FS grade 2, others 0 or 1).
2.5	Minimal disability in two FS (two FS grade 2, others 0 or 1).
3.0	Moderate disability in one FS (one FS grade 3, others 0 or 1) or mild disability in three or four FS (three or four FS grade 2, others 0 or 1), though fully ambulatory.
3.5	Fully ambulatory but with moderate disability in one FS (one grade 3) and one or two FS grade 2; or two FS grade 3 (others 0 or 1); or five grade 2 (others 0 or 1).
4.0	Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade 4 (others 0 or 1), or combination of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 500 metres.
4.5	Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterized by relatively severe disability usually consisting of one FS grade 4 (others 0 or 1) or combinations of lesser grades exceeding limits of previous steps; able to walk without aid or rest some 300 metres.
5.0	Ambulatory without aid or rest for about 200 metres; disability severe enough to impair full daily activities (e.g., to work a full day without special provisions); (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combinations of lesser grades usually exceeding specifications for step 4.0).
5.5	Ambulatory without aid for about 100 metres; disability severe enough to preclude full daily activities; (Usual FS equivalents are one grade 5 alone, others 0 or 1; or combination of lesser grades usually exceeding those for step 4.0).
6.0	Intermittent or unilateral constant assistance (cane, crutch, brace) required to walk about 100 metres with or without resting; (Usual FS equivalents are combinations with more than two FS grade 3+).
6.5	Constant bilateral assistance (canes, crutches, braces) required to walk about 20 metres without resting; (Usual FS equivalents are combinations with more than two FS grade 3+).
7.0	Unable to walk beyond approximately 5 metres even with aid, essentially restricted to wheelchair; wheels self in standard wheelchair and transfers alone; up and about in wheelchair some 12 hours a day; (Usual FS equivalents are combinations with more than one FS grade 4+; very rarely pyramidal grade 5 alone).

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Code	EDSS
7.5	Unable to take more than a few steps; restricted to wheelchair; may need aid in transfer; wheels self but cannot carry on in standard wheelchair a full day; may require motorized wheelchair; (Usual FS equivalents are combinations with more than one FS grade 4+).
8.0	Essentially restricted to bed or chair or perambulated in wheelchair, but may be out of bed itself much of the day; retains many self-care functions; generally has effective use of arms; (Usual FS equivalents are combinations, generally grade 4+ in several systems).
8.5	Essentially restricted to bed much of day; has some effective use of arm(s); retains some self-care functions; (Usual FS equivalents are combinations, generally 4+ in several systems).
9.0	Helpless bed patient; can communicate and eat; (Usual FS equivalents are combinations, mostly grade 4+).
9.5	Totally helpless bed patient; unable to communicate effectively or eat/swallow; (Usual FS equivalents are combinations, almost all grade 4+).
10.0	Death due to MS.
UNK	Unknown

Notes

* Excludes cerebral function grade 1.

EDSS steps 1.0 to 4.5 refer to patients who are fully ambulatory and the precise step number is defined by the Functional System score(s). EDSS steps 5.0 to 9.5 are defined by the impairment to ambulation; usual equivalents in Functional System scores are provided.

EDSS should not change by 1.0 step unless there is a change in the same direction of at least one step in at least one FS.

Sources

Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). *Neurology*. 1983 Nov;33(11):1444-52.

Haber A, LaRocca NG. eds. *Minimal Record of Disability for multiple sclerosis*. New York: National Multiple Sclerosis Society; 1985.

Appendix E: **NEW** CMSMS Special Project Code: 001—Client/Patient Status

Overview of Special Project Fields

The Special Project Fields (SP_1, SP_2) are used to collect supplemental data (that is, data not already collected through the MDS). Reserved special projects (identified by Special Project Codes 001–499) are applicable to all participating organizations, and all organizations are strongly recommended to capture and submit this information to the CMSMS. Unreserved special projects (identified by Special Project Codes 500–999) are meant to collect organization-specific supplemental data. Organizations are to send an email to ms@cihi.ca before submitting information in this field.

CMSMS Special Project Code: 001—Client/Patient Status

The following table provides detailed information on capturing data about a client's/patient's status using the reserved Project Code 001. The collection of client/patient status is recommended for all organizations.

CMSMS Special Project Code: 001—Patient Status						
Data Element ID	**Data Element Name**	**Reporting Requirements**	**Applicable Records**	**Definition**	**Valid Values and Descriptions**	**Rationale**
SP_1	Special Project 1	Key (i.e., optional) Note: The collection of patient status information is not mandatory for submission to the CMSMS, but it is strongly recommended.	All record types* * 001D and 001I are applicable only on non-face-to-face follow-up encounters 001A is applicable to all record types.	A code used to indicate whether the clinic is still actively in contact with the person, the clinic is no longer actively pursuing the person or the person has died.	001A—*client/patient is active* 001D—*client/patient is deceased* 001I—*client/patient is inactive* See Guidelines for Coding for further descriptions and definitions.	To provide a mechanism for capturing information on clients/patients no longer seen in the clinic.

Guidelines for Coding

Capturing a client/patient status of deceased

If a person has died, submit a non-face-to-face follow-up record corresponding to the person's Organization Client Identifier. In the non-face-to-face follow-up record, code

- Reason for Service 1 = OTH (Other);
- Special Project 1 = 001D; and
- The Service Date as the date you create the record. (Note: Service Date is a mandatory field and must be completed, but it will not be used for analytical purposes.)

Capturing a client/patient status of active

If the clinic is still actively in contact with the person or a follow-up encounter is planned, code

- Special Project 1 = 001A for each encounter record while the person is still considered active.

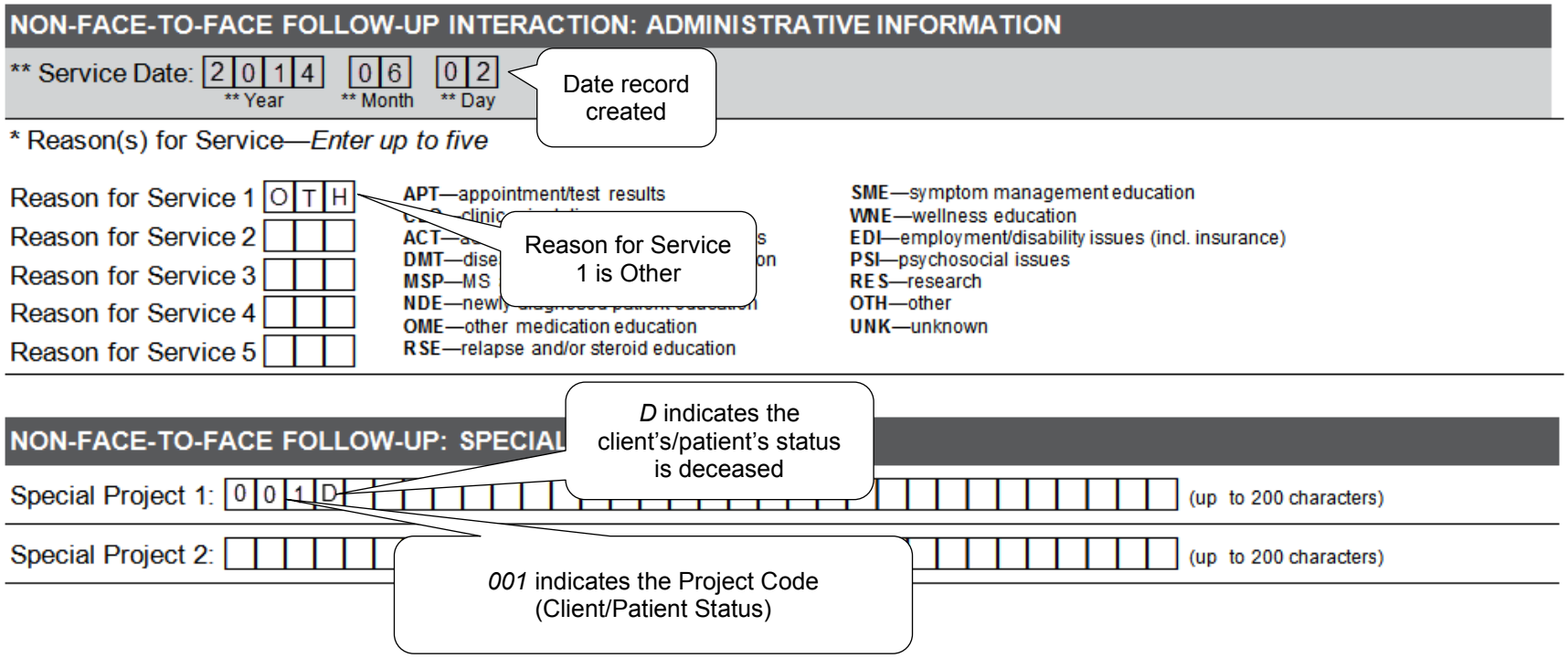
Capturing a client/patient status of inactive

If the clinic is no longer actively pursuing the person (e.g., the clinic has no in-person follow-up or telephone calls planned for the future) **or** if it has been more than two years since the clinic has had contact with the person, submit a non-face-to-face follow-up record corresponding to the person's Organization Client Identifier. In the non-face-to-face follow-up record, code

- Reason for Service 1 = OTH (Other);
- Special Project 1 = 001I; and
- The Service Date as the date you create the record. (Note: Service Date is a mandatory field and must be completed, but it will not be used for analytical purposes.)

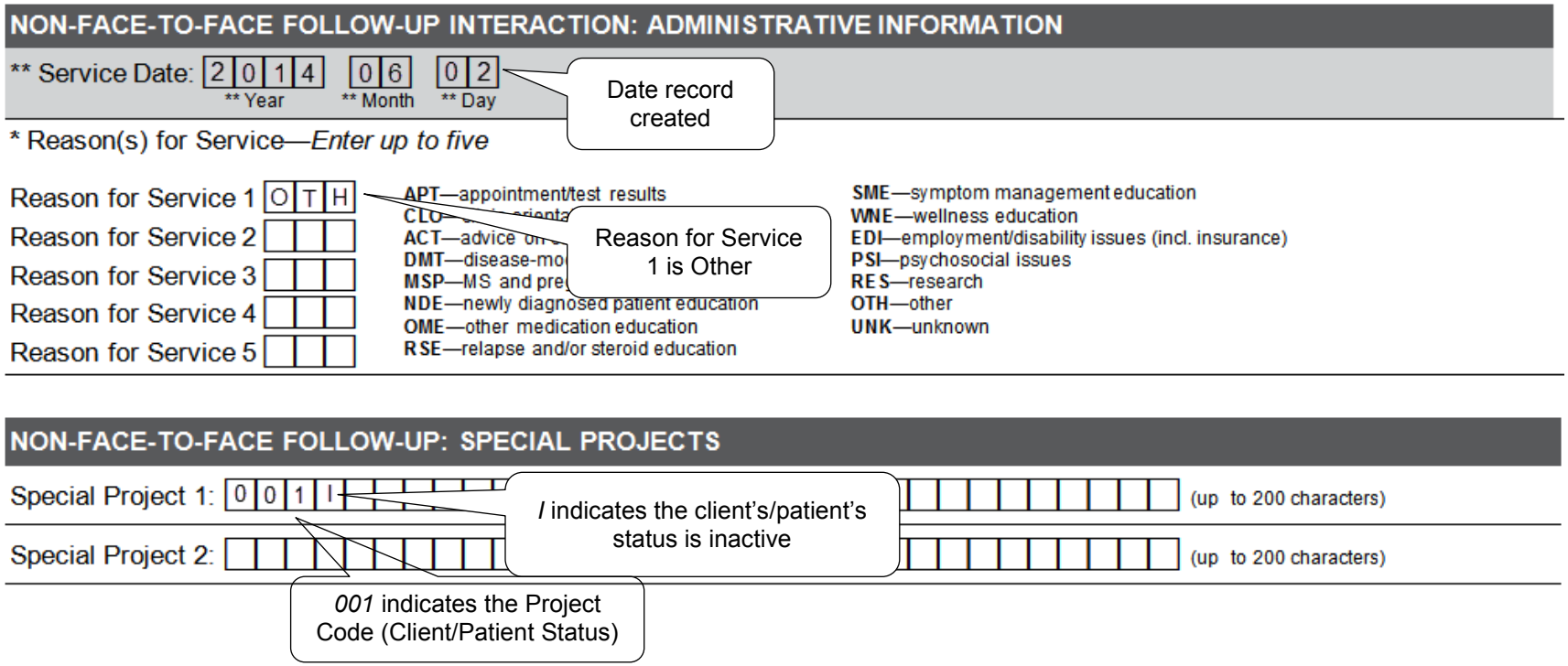
Examples

Figure E1: Capturing a Client/Patient Status of Deceased



Examples

Figure E2: Capturing a Client/Patient Status of Inactive



Appendix F: Summary of Changes to the CMSMS Minimum Data Set

The following table outlines changes between the CMSMS MDS Version 2012 and this updated version that affect data collection. New and revised information in the manual is highlighted in yellow and identified with ****NEW**** or ****REVISED****.

Data Element ID	Data Element Name	Description of Change
ADMIN_1	Service Date	Added a new guideline for coding.
DEM_7(a–g)	Current Employment	Reduced the list of valid values and updated valid value descriptions.
DEM_7(a–g)	Current Employment	Added new and revised guidelines for coding.
DEM_8	Current Marital Status	Added new guidelines for coding.
DEM_9(a–h)	Current Living Arrangement(s)	Added a new guideline for coding.
CLIN_1	Current Diagnosis	Reduced the list of valid values and updated a valid value description.
CLIN_1	Current Diagnosis	Added a new guideline for coding.
CLIN_1a	Date of Diagnosis	Added a new guideline for coding.
CLIN_2a	Date of First Symptoms of Current Diagnosis	Added a new guideline for coding.
CLIN_5, CLIN_5(a–j), CLIN_5(k–o)	Any Comorbid Condition(s), Comorbid Condition(s), Other Comorbid Condition(s)	Updated the data element names, reduced the list of valid values and updated a valid value description.
TREAT_1, Treat_1(a–l)	Service Provider(s) Related to MS Accessed?, Service Provider(s) Related to MS	Updated the data element descriptions, reduced the list of valid values and updated a valid value description.
TREAT_1, Treat_1(a–l)	Service Provider(s) Related to MS Accessed?, Service Provider(s) Related to MS	Added new and revised guidelines for coding.
Treat_1(a–l)(a–e)	Source(s) of Payment	Reduced the list of valid values and updated a valid value description.
SP_1	Special Project 1	Added new guidelines for coding.

Appendix G: Standards Used in the CMSMS Minimum Data Set

When available and applicable, pan-Canadian standards were used to develop the valid values and descriptions for data elements within the CMSMS MDS. The CMSMS team also referred to other CIHI databases and Canadian and international MS data collection tools.

Data Element ID	Data Element Name	Sources for Valid Values and Descriptions
ID_3	Province/Territory Issuing Health Card Number	ISO 3166-1:2006 Edition 2
DEM_1	Country of Primary Residence	ISO 3166-1:2006 Edition 2
DEM_4	Location of Birth (Country)	ISO 3166-1:2006 Edition 2
DEM_5(a–e)	Ethnic/Cultural Origin(s)	Statistics Canada (Population Group); Aboriginal Persons; CMSMS Program Area; CIHI Data Dictionary
DEM_6	Highest Level of Education	HL7 (Education Level); MeTEOR Data Dictionary (Australia); SNOMED CT (Education Received in Past); Statistics Canada; CMSMS Program Area; CIHI Data Dictionary
DEM_7(a–g)	Current Employment	CIHI's National Rehabilitation Reporting System; CMSMS Program Area; North American Research Committee on Multiple Sclerosis (NARCOMS) Enrolment Questionnaire
DEM_8	Current Marital Status	HL7 (Marital Status); CMSMS Program Area
DEM_9(a–h)	Current Living Arrangement(s)	NCVHS Core Health Data Elements Data Dictionary; SNOMED CT (Residence and Accommodation Circumstances); CIHI Data Dictionary; CMSMS Program Area
DEM_10	Current Living Setting	SNOMED CT (Residence and Accommodation Circumstances); CIHI Data Dictionary; CMSMS Program Area
DEM_11a	Currently Smoking Cigarettes/ Tobacco Products?	MeTEOR (Person—Tobacco Smoking Status)
CLIN_1	Current Diagnosis	*National Institute of Neurological Disorders and Stroke (NINDS) Multiple Sclerosis (MS) Common Data Elements (CDES), Version 0.0, Final Draft*
CLIN_3	Type/Course of MS at Onset	*National Institute of Neurological Disorders and Stroke (NINDS) Multiple Sclerosis (MS) Common Data Elements (CDES), Version 0.0, Final Draft*; CMSMS Program Area

(cont'd on next page)

Data Element ID	Data Element Name	Sources for Valid Values and Descriptions
CLIN_4	Current Type/Course of MS	*National Institute of Neurological Disorders and Stroke (NINDS) Multiple Sclerosis (MS) Common Data Elements (CDES), Version 0.0, Final Draft*; CMSMS Program Area
CLIN_5(a–j)	Comorbid Condition(s)	*National Institute of Neurological Disorders and Stroke (NINDS) Multiple Sclerosis (MS) Common Data Elements (CDES), Version 0.0, Final Draft*; CIHI's Continuing Care Reporting System; CIHI's National Rehabilitation Reporting System; CIHI's National Ambulatory Care Reporting System; CIHI's CMSMS Program Area
Treat_1(a–l)	Service Provider(s) Related to MS	National Multiple Sclerosis Society—MS Health Care Team (http://www.nationalmssociety.org); Pan-Canadian Standards Master Terminology Worksheet—Healthcare Provider Role Type; CMSMS Program Area
TREAT_2(a–j)a	Other Therapy(s)	The Alberta Multiple Sclerosis Initiative (TAMSI) Questionnaire; CMSMS Program Area
Drug_1(a–j)	Drug Name(s)	CIHI's National Prescription Drug Utilization Information System (NPDUIS) Database
Drug_2(a–t)d(a–h)	Reason(s) for Drug Cessation	National Multiple Sclerosis Society—Disease Management Consensus Statement (http://www.nationalmssociety.org); CMSMS Program Area
Missing Value Reasons (UNK, NA, OTH)		HL7 (Null Flavor)

Reference

1. Statistics Canada. Canadian Community Health Survey (CCHS). 2010–2011.

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