



GREAT

LEAP

Virtual Launch of the Historical International Classification for Diseases (ICD10h)

24 July 2024

I. ICD10h: Introduction and overview

Great Leap Working Group 2

Methods and tools for standardisation, coding and classifying causes of death: ICD10h

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Developed in collaboration with:

SHiPP - Scottish Historical Population Platform / Digitising Scotland – all Scottish deaths 1855-1973

Chris Dibben, Lee Williamson, Eilidh Garrett

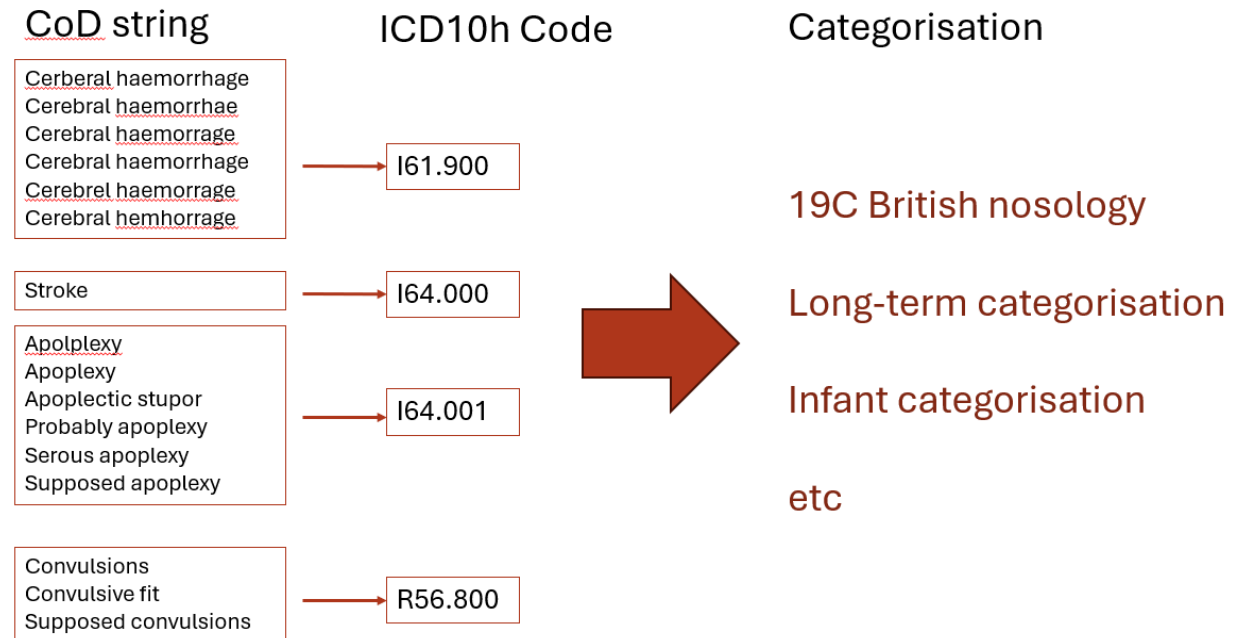
SHiP+ - international comparisons of historic causes of death

Angelique Janssens and many others



ICD10h: what is it?


- An international cause of death coding and classification scheme for historic individual-level causes of death
 - Historic
 - Individual level
 - Coding
 - Categorisation
 - International



ICD10h: why do we need it?

- Challenges:
 - **Historic data**
 - Individual level
 - Categorisation
 - International

The Diseases and Casualties this Week,



A Bortive	2	Imposthume	1
Aged	32	Infants	7
Bleeding	1	Kingevill	1
Childbed	5	Mouldfallen	1
Chrifoms	9	Kild accidentally with a Carbine, at St. Michael Woodstreet	1
Collick	1	Ove-laid	1
Consumption	65	Rickets	9
Convulsion	41	Rifing of the Lights	2
Cough	5	Rupture	2
Dropsie	43	Scalded in a Brewers Mafh, at St. Giles Cripple-gate	1
Drowned at S Kathar, Tower	1	Scurvy	4
Feaver	47	Spotted Feaver	2
Flox and Small-pox	15	Stilborn	13
Flux	3	Stopping of the Stomach	11
Found dead in the Street at Stepney	1	Suddenly	1
Griping in the Guts	15	Surfeit	7
		Teeth	27
		Tifick	12
		Ulcer	1
		Vomiting	1
		Winde	1
		Wormes	1

Christned	Males — 121	Buried	Males — 195	Plague . 0
	Females — 111		Females — 198	
	In all — 232		In all — 393	

Decreased in the Burials this Week — 69

Parishes clear of the Plague — 130 Parishes Infected — 0

The Aſize of Bread ſet forth by Order of the Lord Mayor and Courts of Aldermen,
A penny Wheaten Loaf to contain Eleven Ounces, and three half-penny White Loaves the like weight.

Copyright © 2019 Bills of Mortality,
February 21–28, 1664/Wellcome
Collection, CC BY 4.0

ICD10h: why do we need it?

- Challenges:
 - Historic data
 - **Individual level**
 - Categorisation
 - International

ATHS Registered in the Sanitary District of
 ng the Week [or Month] ending Jan 6th 1913

TICULARS OF DEATHS.

NAME and SURNAME.	SEX.	AGE.	RANK or PROFESSION, and the previous Residence in case of Deaths in Institutions.	CAUSE of DEATH.
Edmund Charles Murchison Rowe	Male	20 Years	Engineering Student	Acute Pneumonia 9 days H. H. Brown, M.D.
Eliza Lockwood	Female	63 Years	Spinster, of no occupation daughter of William Lockwood, occupation unknown (deceased)	Bronchitis Exhaustion Frank Adams Esq. M.D.
Sarah Ann Green	Female	76 Years	Widow of Joseph Green Bricklayer (Pennyman) 8 The Elm Cottages, 9 parish Cady Lane, 9 parish	Cancer of Oesophagus 1 year Aethema J. H. Sladdon M.B.S.
Henry Noble	Male	63 Years	Labourer (Foundry)	Renal Arteriosclerosis Anæmia W. F. Fryer M.B.S.
Charles Bedford	Male	1 1/2 hours	Infant of Mrs. Bedford Music Hall Artist Berlin	Prematurity of 1/2 hours Grunnel's pregnancy L. W. Brogden
William Brooks	Male	12 Years	Son of Walter Brooks Heavy labourer	Pulmonary Tuberculosis W. F. Fryer
Stephen Ingers	Male	69 Years	Jobbing wood Sawyer The Green Upper Borecomb	Heart Disease H. Appleton
Lilian Abund Loomfield	Female	28 Years	Wife of Frederick Loomfield Jeweller, Bloomfield Hampers maker, maker, of the 1st Company, 6th Wickham, Milt. W.D.	Pregnancy Caesarean Section Carcinoma of Cervix Dr. Adams
Berbert Parker	Male	53 Years	General Labourer	Pulmonary Tuberculosis 7 years Hæmoptysis 20 days Dr. Adams
Ernest William Teggles	Male	46 Years	Butter Domestic	Consumption Heart failure Dr. Adams

ICD10h: why do we need it?

- Challenges:
 - Historic data
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1. Enfermedades Generales.
2. Enfermedades del Sistema Nervioso y de los Órganos de los Sentidos.
3. Enfermedades del Aparato Circulatorio.
4. Enfermedades del Aparato Respiratorio.
5. Enfermedades del Aparato Digestivo.
6. Enfermedades del Aparato Genito-urinario y de sus Anexos.
7. Estado Puerperal.
8. Enfermedades de la Piel y del Tejido Celular.
9. Enfermedades de los Órganos de Locomoción.
10. Vicios de Conformación.
11. Primera Infancia.
12. Vejez.
13. Afecciones producidas por Causas Exteriores.
14. Enfermedades Mal Definidas. Otras Enfermedades.

Bertillon, 1899 in J. Bernabeu-Mestre et al. 2003

Heiberg group nr.	Heiberg group name	DK-1875 categories
I	Infectious diseases	1-23
II	Croupous Pneumonia	74
III	Tuberculosis	27-31
IV	Cancer	32-35
V	Alcoholism	24-26
VI	Suicide	49-54
VII	Accidents	40-48
VIII	Diseases in the nervous system	61-71
IX	Respiratory diseases	72, 73, 75-80
X	Cardiovascular diseases	81-84
XI	Digestive diseases	85-92
XII	Genitourinary diseases	93-97
XIII	Others	36-39, 55-60, 98-115

Villefrance Perner, 2023

ICD10h: why do we need it?

- Challenges:
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 - Individual level
 - **Categorisation**
 - International

‘For statistical purposes there can be no such class allowed as the Tubercular; it would violate all our rules. Every disease now put under that class must be referred to the organ of the body chiefly affected; so phthisis must be referred to Diseases of the Respiratory Organs; Hydrocephalus to Diseases of the Brain; Tabes Mesenterica to Diseases of the Organs of Digestion.’ Stark (1864)

DR STARK'S
PROPOSED NEW CLASSIFICATION OF DISEASES
FOR STATISTICAL PURPOSES.
[NEW SCOTTISH CLASSIFICATION.]

Rule I.—The Causes of Death must be only entered once in the Classification.
Rule II.—The Diseases must be classified according to the primary cause or affection which led to the Death.
Rule III.—So far as practicable, every Disease causing Death must be tabulated under the Organ of the body which was primarily and chiefly affected.

<p>CLASS I.—FEVERS. Ague Remittent—Yellow Fever Typhus—all varieties and infantile Small-pox Measles Scarlatina Diphtheria.</p> <p>CLASS II.—DISEASES OF BRAIN, etc. Hydrocephalus Cephalitis Apoplexy Paralysis Chorea Epilepsy Tetanus Insanity Convulsions Brain diseases—indefinite.</p> <p>CLASS III.—DISEASES OF HEART AND ORGANS OF CIRCULATION. Pericarditis Aneurism Disease of Heart, etc.</p> <p>CLASS IV.—DISEASES OF ORGANS OF RESPIRATION. Fiftitis Hooping-cough Croup Laryngitis Bronchitis Influenza Pneumonia Pneumonia Arthma Disease of Lungs (indefinite).</p> <p>CLASS V.—DISEASES OF ORGANS OF DIGESTION. Typhus Diarrhoea Dysentery Cholera Teething Quinsy Gastritis Enteritis Peritonitis</p>	<p>Acute Ulceration of Intestinal Canal Hernia Worms Ileus Intussusception Tuberc Mesenterica Stricture of Intestinal Canal Disease of Stomach Disease of Pancreas Hepatitis Jaundice Disease of Liver Disease of Spleen.</p> <p>CLASS VI.—DISEASES OF URINARY ORGANS. Nephritis Nephria Ischuria Diabetes Stone Cystitis Stricture of Urethra Disease of Kidney (not defined).</p> <p>CLASS VII.—DISEASES OF ORGANS OF GENERATION. Parametria, etc. Ovarian Dropsy Childbirth Metria Disease of Uterus and other Organs Syphilitic Diseases.</p> <p>CLASS VIII.—DISEASES OF ORGANS OF LOCOMOTION. Arthritis Diseases of Joints, Bones, etc.</p> <p>CLASS IX.—DISEASES OF SKIN AND CELLULAR TISSUE. Carbuncle (incl. Boil) Pilegrone Abscess (not serofulous) Erysipelas Noma Ulcer Diseases of Skin.</p>	<p>CLASS X.—DISEASES OF UNCERTAIN SEAT. Hæmorrhage Dropsy Eritids (all kinds) Mortification Cancer Purpura, Scurrey Scrofula Gout Rheumatism Atrophy.</p> <p>CLASS XI.—MALFORMATIONS. Spina-bifida Cyanosis Other malformations.</p> <p>CLASS XII.—DEBILITY AT BIRTH AND PRE-MATURE BIRTH.</p> <p>CLASS XIII.—OLD AGE, no disease specified.</p> <p>CLASS XIV.—SUDDEN DEATHS, cause not ascertained.</p> <p>CLASS XV.—VIOLENT OR UNNATURAL DEATHS. Poison (taken into Stomach) Poisoned Bites, Wounds, Stings Hydrophobia Intemperance (Alcoholic Poisoning) Delirium Tremens Starvation Want of Breast-milk Neglect Cold Burns and Scalds Hæmang Suffocation Drowning Fractures and Contusions Wounds Other violent causes.</p> <p>CLASS XVI.—CAUSES NOT SPECIFIED.</p>
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Dr Stark's proposed new classification of diseases for statistical purposes : (new Scottish classification). 1864. Source: [Wellcome Collection](#).

ENGLAND.—CAUSE

Class.	CAUSES OF DEATH.
I.	<p>ORDER 1. 1 Small-pox 2 Measles 3 Scarlatina 4 Diphtheria 5 Quinsy 6 Croup 7 Whooping-cough 8 Typhus 9 Erysipelas 10 Metria 11 Carbuncle 12 Ecthyma 13 Dysentery 14 Diarrhoea 15 Cholera 16 Ague 17 Remittent Fever 18 Rheumatism 19 Other Acute Diseases</p> <p>ORDER 2. 1 Syphilis 2 Stricture of Urethra 3 Hydrophobia 4 Glanders</p> <p>ORDER 3. 1 Privation 2 Want of Breast-milk 3 Purpura and Scurrey 4 Alcoholism 5 Del. Tremens 6 Intemperance</p> <p>ORDER 4. 1 Thrush 2 Worms, &c.</p>
II.	<p>ORDER 1. 1 Gout 2 Dropsy 3 Cancer 4 Noma 5 Mortification</p> <p>ORDER 2. 1 Scrofula 2 Tabes Mesenterica 3 Phthisis 4 Hydrocephalus</p>
III.	<p>ORDER 1. 1 Cephalitis 2 Apoplexy 3 Paralysis 4 Insanity 5 Chorea 6 Epilepsy 7 Convulsions 8 Brain Disease, &c.</p> <p>ORDER 2. 1 Pericarditis 2 Aneurism 3 Heart Disease, &c.</p> <p>ORDER 3. 1 Laryngitis 2 Bronchitis 3 Pleurisy 4 Pneumonia 5 Asthma 6 Lung Disease, &c.</p> <p>ORDER 4. 1 Gastritis 2 Enteritis 3 Peritonitis 4 Acetis 5 Ulceration of Intestines 6 Hernia 7 Ileus 8 Intussusception 9 Stricture of Intestines 10 Fistula 11 Ovarian Disease, &c. 12 Pancreatic Disease, &c. 13 Hepatitis 14 Jaundice 15 Liver Disease, &c. 16 Spleen Disease, &c.</p> <p style="text-align: right;">(continued at page 124.)</p>

Annual report of the Registrar-General of births, deaths, and marriages in England. Twenty-Seventh Report, 1864

ICD10h: why do we need it?

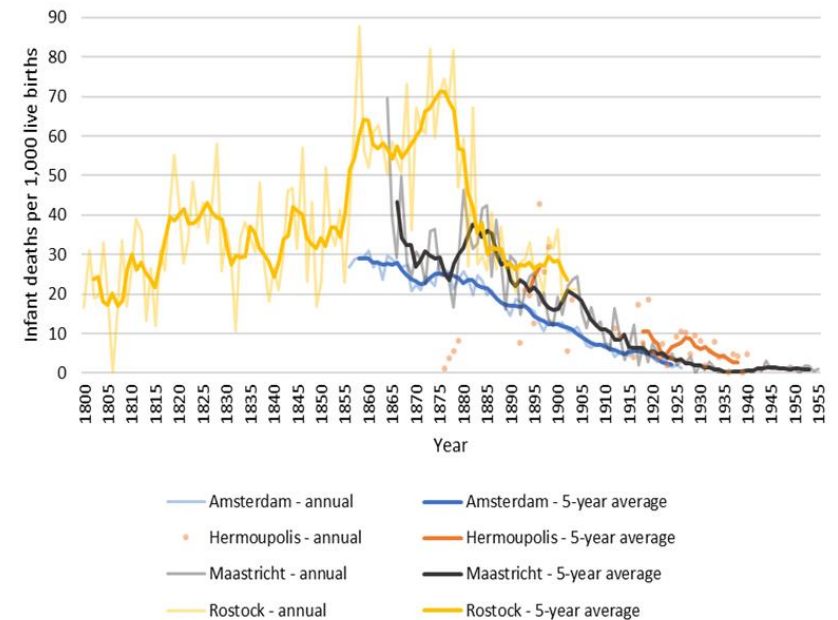
- Challenges:
 - Historic data
 - Individual level
 - Categorisation
 - **International**

cramps
eclampsia
stroke
lung inflammation
children's disease
angina

ICD10h: why do we need it?

- Sensitive treatment of historic data
- Helps place messy individual strings into broader categorisations
- Allows a number of different categorisations, enabling comparisons
 - Across time
 - Between places

Post-neonatal infant mortality rate for convulsions (5-year moving averages), 1800-1955



ICD10h: how to access it

Historic cause of death coding and classification scheme for individual-level causes of death

- Manual [<https://doi.org/10.17863/CAM.109960>]
- Codes [<https://doi.org/10.17863/CAM.109961>]
 - Masterlist with HistCat
 - ICD10h2020 to ICD10h2024 transfer
- English language historic strings [<https://doi.org/10.17863/CAM.109962>]
- Infant Categorisations [<https://doi.org/10.17863/CAM.109963>]

Placeholder for
screenshot of access
page (not yet
available)

ICD10h: how to use it - Manual

Figure 4: ICD10h coding and categorisation overview

1. Get to know your data

- Provenance and form
- Medical practice and knowledge
- Variation and change

2. Prepare your data (parsing and tidying, and creating a list of unique CODs to code)

ID	age	sex	cause of death
1	75 F		old age and infirmity
2	56 M		apoplexy
3	0 F		bronchitis and convulsions

↓

ID	age	sex	cause of death	COD1	COD2
1	75 F		old age and infirmity	apoplexy	infirmity
2	56 M		apoplexy	apoplexy	
3	0 F		bronchitis and convulsions	bronchitis	convulsions

→ Unique causes

- apoplexy
- bronchitis
- convulsions
- infirmity
- old age

3. Code your data

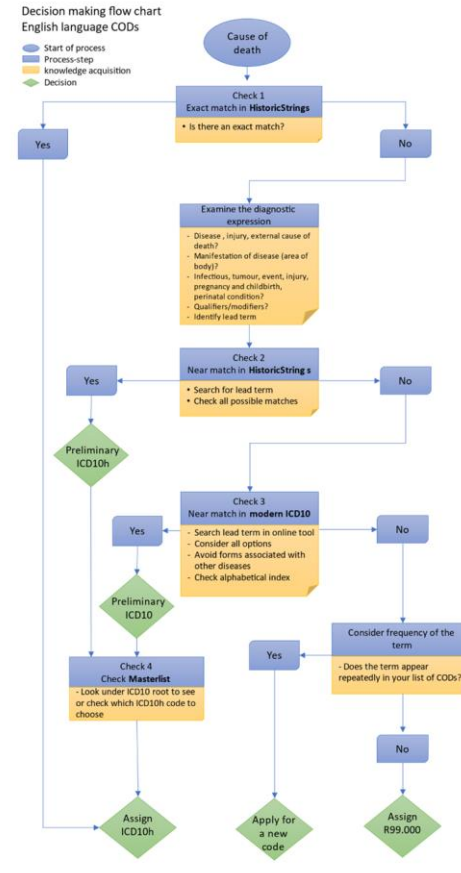
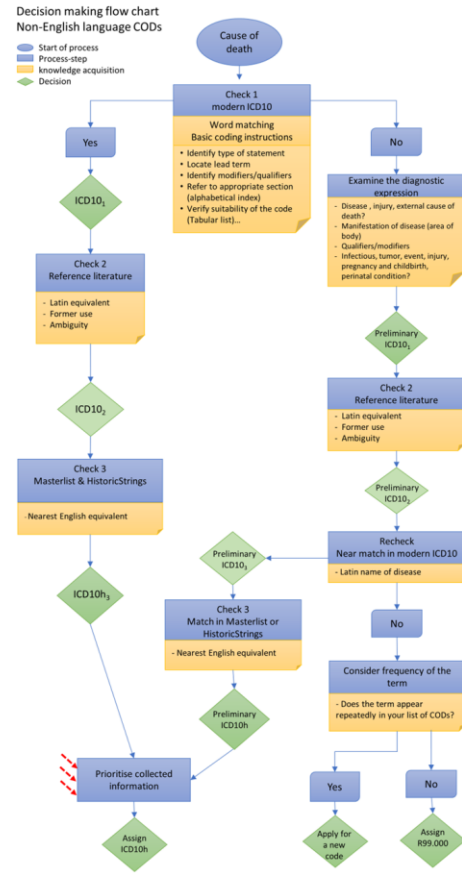
Unique causes	ICD10h
apoplexy	R54.001
bronchitis	J20.901
convulsions	R56.800
infirmity	R53.003
old age	R54.005

4. Apply codes to individual deaths; assign primary cause and classification

ID	age	sex	cause of death	COD1	COD2	ICD10h1	ICD10h2
1	75 F		old age and infirmity	old age	infirmity	R54.005	R53.003
2	56 M		apoplexy	apoplexy		R54.001	R54.001
3	0 F		bronchitis and convulsions	bronchitis	convulsions	J20.901	R56.800

↓

ID	age	sex	cause of death	COD1	COD2	ICD10h1	ICD10h2	Primary cause	HistCat
1	75 F		old age and infirmity	old age	infirmity	R54.005	R53.003	R54.005	Old age
2	56 M		apoplexy	apoplexy		R54.001	R54.001	R54.001	Circulatory
3	0 F		bronchitis and convulsions	bronchitis	convulsions	J20.901	R56.800	J20.901	Respiratory



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ICD10h: how to use it - Codes

- Masterlist

IDMasterlist	ICD10h	ICD10	icd10_2levelCATEGORY	ICD10_2levelCAUSE	ICD10h_DESCRIPTION	HistCat	DoNotUse	NotForUnderlying	GenderSpecific
1	A00.000	A00.0	Cholera	cholerae 01, biovar cholerae	Cholera due to Vibrio cholerae 01, biovar cholerae	Diarrhoea	0	0	0
2	A00.100	A00.1	Cholera	cholerae 01, biovar el tor	Cholera due to Vibrio cholerae 01, biovar el tor	Diarrhoea	0	0	0
3	A00.900	A00.9	Cholera	Cholera, unspecified	Cholera, unspecified	Diarrhoea	0	0	0
4	A00.901	A00.9	Cholera	Cholera, unspecified	Choleraic diarrhoea	Diarrhoea	0	0	0
5	A01.000	A01.0	fevers	Typhoid fever	Typhoid fever	Diarrhoea	0	0	0
6	A01.001	A01.0	fevers	Typhoid fever	Enteric fever	Diarrhoea	0	0	0
7	A01.003	A01.0	fevers	Typhoid fever	Gastric fever	Diarrhoea	0	0	0
8	A01.004	A01.0	fevers	Typhoid fever	Colonial fever	Diarrhoea	0	0	0
9	A01.005	A01.0	fevers	Typhoid fever	Fog fever	Diarrhoea	0	0	0
10	A01.100	A01.1	fevers	Paratyphoid fever A	Paratyphoid fever A	Diarrhoea	0	0	0
11	A01.200	A01.2	fevers	Paratyphoid fever B	Paratyphoid fever B	Diarrhoea	0	0	0
12	A01.300	A01.3	fevers	Paratyphoid fever C	Paratyphoid fever C	Diarrhoea	0	0	0
13	A01.400	A01.4	fevers	unspecified	Paratyphoid fever, unspecified	Diarrhoea	0	0	0
14	A02.000	A02.0	Other Salmonella infections	Salmonella gastro-enteritis	Salmonella gastro-enteritis	Diarrhoea	0	0	0
15	A02.100	A02.1	Other Salmonella infections	Salmonella septicaemia	Salmonella septicaemia	Diarrhoea	0	0	0
16	A02.200	A02.2	Other Salmonella infections	infections	Localised Salmonella infections	Diarrhoea	0	0	0
17	A02.800	A02.8	Other Salmonella infections	infections	Other specified Salmonella infections	Diarrhoea	0	0	0
18	A02.900	A02.9	Other Salmonella infections	unspecified	Salmonella infection, unspecified	Diarrhoea	0	0	0
19	A03.000	A03.0	Shigellosis	dysenteriae	Shigellosis due to Shigella dysenteriae	Diarrhoea	0	0	0
20	A03.100	A03.1	Shigellosis	flexneri	Shigellosis due to Shigella flexneri	Diarrhoea	0	0	0

ICD10h: how to use it - Codes

- 2020 to 2024 Transfer

ID2024Transfer	IDoct2020Masterlist	ICD10h_oct2020	ICD10h2024
1	1	A00.000	A00.000
2	2	A00.100	A00.100
3	3	A00.900	A00.900
4	4	A00.901	A00.901
5	5	A01.000	A01.000
6	6	A01.001	A01.001
7	7	A01.002	R50.905
8	8	A01.003	A01.003
9	9	A01.004	A01.004
10	10	A01.005	A01.005
11	11	A01.100	A01.100
12	12	A01.200	A01.200
13	13	A01.300	A01.300
14	14	A01.400	A01.400
15	15	A02.000	A02.000
16	16	A02.100	A02.100
17	17	A02.200	A02.200

ICD10h: how to use it - HistoricStringsEnglish

IDHistoricStrings	HistoricString	ICD10h	ICD10hInjury	ICD10hDescription	ICD10hInjuryDescription	CancerMalignancyFlag
2641	sarcoma.ribs	C41.303		Sarcoma, ribs		1
2642	sarcoma.scapula	C40.003		Sarcoma, scapula and long bone of upper limb		1
2643	sarcoma.thigh	C76.503		Sarcoma, lower limb		1
2644	scabies	B86.000		Scabies		0
2645	scala.oedema	H66.900		Otitis media, unspecified		0
2646	scald	Y27.000	T30.000	Contact with steam, hot vapours and hot objects,	Burn of unspecified body regions, severity unspecified	0
2647	scald.back	Y27.000	T21.000	Contact with steam, hot vapours and hot objects,	Burn of trunk, severity unspecified	0
2648	scald.face.and.neck	Y27.000	T20.000	Contact with steam, hot vapours and hot objects,	Burn of head and neck, severity unspecified	0
2649	scald.trunk.and.limbs	Y27.000	T29.000	Contact with steam, hot vapours and hot objects,	Burn of multiple regions, severity unspecified	0
2650	scalds	Y27.000	T30.000	Contact with steam, hot vapours and hot objects,	Burn of unspecified body regions, severity unspecified	0
2651	scarlatina	A38.002		Scarlatina		0
2652	scarlatina.and.complications	A38.003		Scarlatina with complications		0
2653	scarlatina.anginosa	A38.002		Scarlatina		0
2654	scarlatina.maligna	A38.002		Scarlatina		0
2655	scarlet.fever	A38.000		Scarlet fever		0
2656	scarlet.fever.acute	A38.000		Scarlet fever		0
2657	scarlet.fever.and.complications	A38.001		Scarlet fever with complications		0

ICD10h: how to use it - InfantCat

IDMasterlist	ICD10h	Infantcat2024	InfantCat2020
95	A09.960	Water-food borne	water-food borne
96	A09.970	Water-food borne	water-food borne
97	A09.971	Water-food borne	water-food borne
98	A09.972	Water-food borne	water-food borne
99	A09.973	Water-food borne	water-food borne
100	A15.000	Common infectious diseases	air-borne
101	A15.100	Common infectious diseases	air-borne
102	A15.200	Common infectious diseases	air-borne
103	A15.300	Common infectious diseases	air-borne
104	A15.400	Common infectious diseases	air-borne
105	A15.500	Common infectious diseases	air-borne
106	A15.600	Common infectious diseases	air-borne
107	A15.700	Common infectious diseases	air-borne

II. Engagement opportunities

If you want to join working group II in some of its endeavours, please fill in this form:

<https://forms.gle/Rugs8pCoCfQf4wU18>

Four different types of working groups

- ❖ Language specific Historic Strings collection and creation
- ❖ New categorisations
- ❖ Underlying causes
- ❖ Code allocation

Four different types of working groups

❖ Language specific Historic Strings collection and creation

- Open to everyone interested
- Different working groups for each language/related languages
- Acknowledgement as author when Historic Strings file is published

❖ New categorisations

- Open to everyone interested
- Different working groups for each categorisation
- Acknowledgement as author when specific Categorisation is published

❖ Underlying causes

- Needs a small committee with expertise, thus restricted number of members
- Acknowledgement as author when code is published

❖ Code allocation

- Needs a small committee with expertise, thus restricted number of members

How do we proceed?

- Everyone can fill in the form:
<https://forms.gle/Rugs8pCoCfQf4wU18>

- Processing of answers early October

But the form will remain open after this date!

- Put together the working groups for which enough people have signed up

If there are not enough people for particular languages or categorisations, we aim to put volunteers into contact with those working on similar topics