To contribute to the EMCDDA review of drug related deaths from the GMR in some countries (including the codification practices of DRDs following the WHO revision of ICD coding guidelines)

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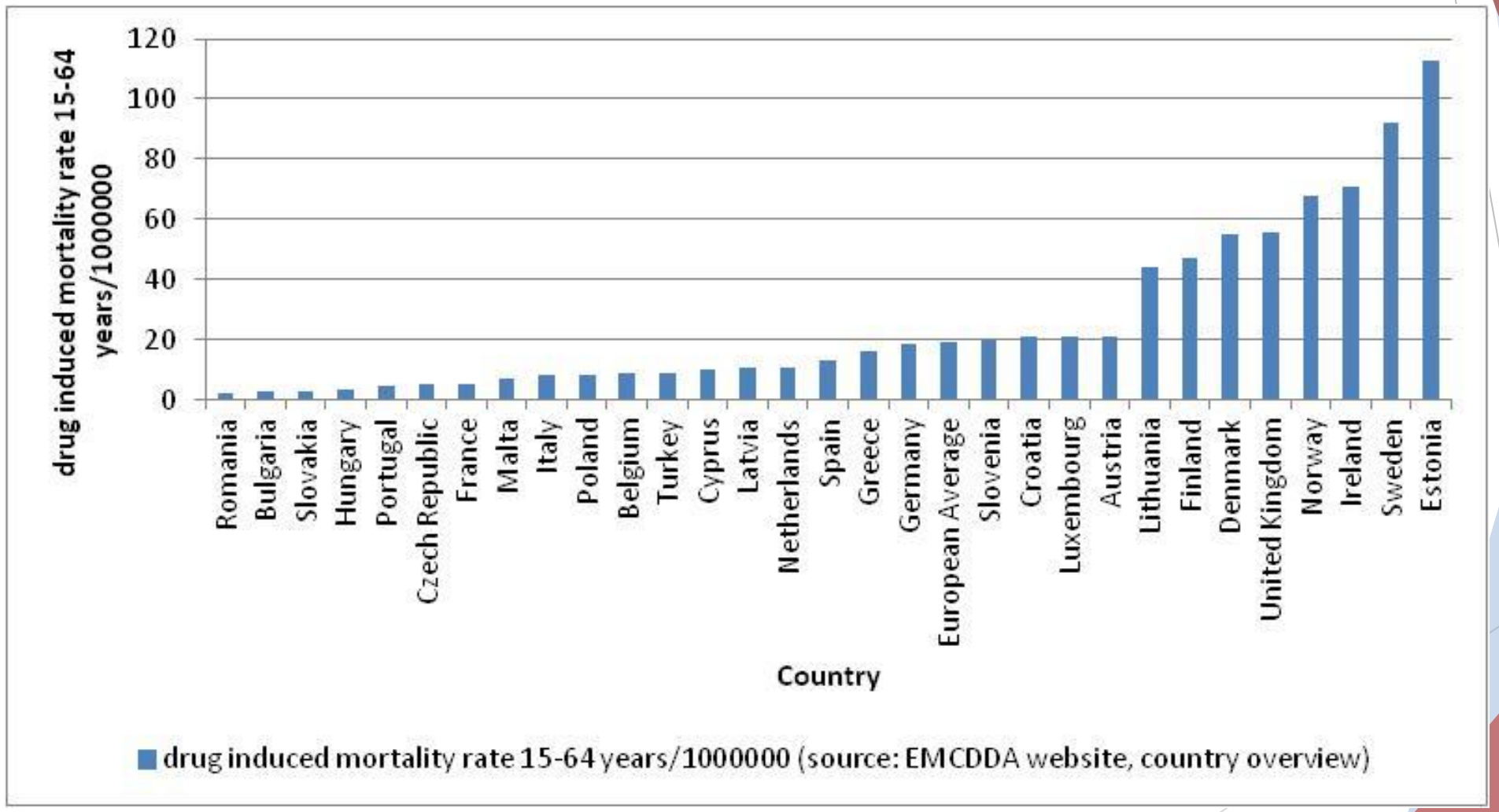
EMCDDA meeting on DRDs

29th September 2016

Are these rates comparable?



Aim of the project

- Reviewing of the Inventory of the national Special Mortality Registries in Europe with a focus on information flow to the General Mortality Registries;
- Identifying examples of good practice and collaboration between the GMR and SR;
- Review coding practices and trends in DRDs in countries following the WHO ICD-10 updates;
- Analysing data on DRDs in a subset of countries to evaluate the use of specific codes such as X44/X64/Y14 codes, non specific codes such as R99, X49 and X69 and the use or non use of T codes.

Reviewing of the Inventory of the national Special Mortality Registries in Europe with a focus on information flow to the General Mortality Registries

Aim:

- Review the information flow to the General Mortality Registries (GMRs) which often determines the completeness and data quality of mortality statistics.

- Identify examples of good practices in countries which have facilitated the collection of good quality data , as well as pitfalls which hinder the collection of complete good quality DRD data by the GMRs.

Methodology

This is a follow up on the project carried out in 2009, and coordinated by Charlotte Klein, at the Austrian Focal point CT.08.EPI.O83.1.0., using the same questionnaire but **focusing the analysis and report on the information flow to the GMR**.

Questionnaire was sent out to 28 EU countries as well as Norway and Turkey; Replies to the questionnaire were obtained from 19/30 countries;

Results

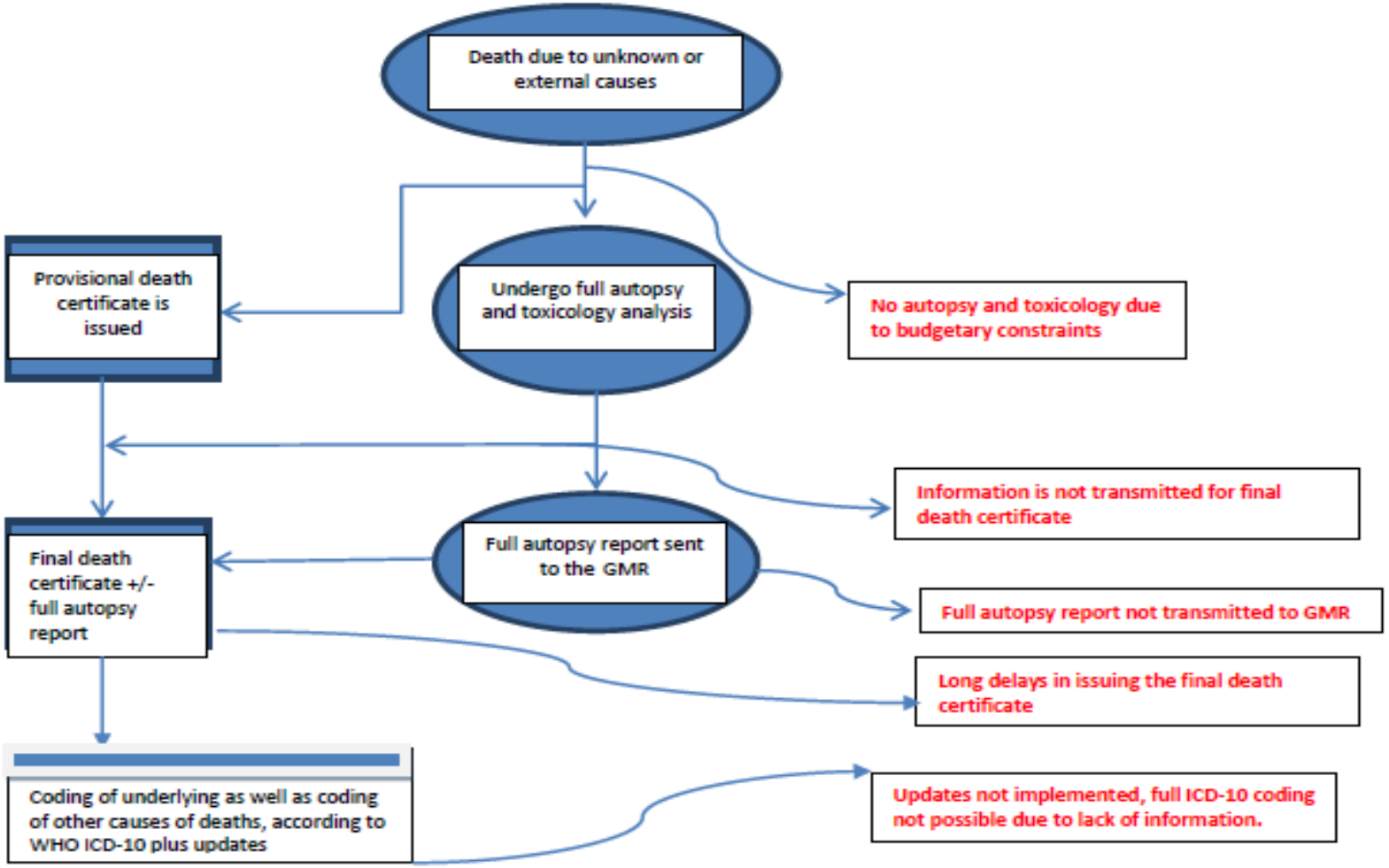
- **Owners of the data of the post-mortem investigation**: Owners of the data often lie with the police and judicial system outside of the departments of health or statistical offices.
- **Systematic data collection:** Only 8 out of the 18 reporting countries (44%) reported as having a systematic data collection with national coverage; Some countries have regional systems. These may only cover part of the country e.g. in Spain;
- **Extraction of data for DRD monitoring:** Many countries 12/18 (67%) reported that the extraction of data for DRD monitoring either by the focal point or by someone else e.g. by an expert working within the institute which collects the data is possible. However sometimes the process is laborious requiring special permission and may not include individual identifiers.

Results

- **Awareness by GMR regarding ongoing medico-legal investigation:** 14/18 countries are aware that a medico-legal investigation is underway.

- **How is the information generated during the post-mortem investigation used in the death registration process?** In most countries information from the medico-legal investigation is received by the GMR through the ‘final’ death certificate. In a very few countries the GMR has access to the post-mortem investigation.

The main problems identified through the process of retrieving, recording and coding DRD cases



Deaths due to unknown or external cause

- While in most countries deaths due to unknown or external causes are investigated, the definition of natural or unnatural death may vary.
- E.g. an elderly person ‘falling’ is considered ‘natural’ by some, but ‘unnatural’ by others (source Netherlands).
- The percentage of deaths undergoing an autopsy varies widely between countries; Also the extent of the autopsy and type of toxicological investigations carried out.

Autopsy Rate: Percentage for all deaths (source: WHO: HFA DB, accessed 24th September 2016)

Countries	First available	Last available
004 Austria	34.7 - 1984	12.7 - 2014
009 Bulgaria	19.9 - 1980	4 - 2014
010 Croatia	10.95 - 1994	6.4 - 2014
011 Cyprus	9.21 - 1992	8.94 - 2014
012 Czech Republic	33.5 - 1970	17.9 - 2014
013 Denmark	52.1 - 1985	3.9 - 2012
014 Estonia	33.5 - 1989	19.2 - 2014
015 Finland	32.6 - 1970	22.7 - 2014
020 Hungary	51 - 1990	37.67 - 2014
022 Ireland	15.01 - 1994	17.88 - 2002
027 Latvia	36.4 - 1980	15.3 - 2014
028 Lithuania	34.6 - 1988	16.9 - 2014
029 Luxembourg	0.9 - 1998	1.9 - 2014
030 Malta	7.59 - 1999	8.31 - 2014
033 Netherlands	12 - 1981	3.9 - 2008
034 Norway	10.6 - 1992	7.9 - 2014
036 Portugal	7.7 - 1980	6.3 - 2005
038 Romania	13.8 - 1988	4.9 - 2014
042 Slovakia	25.1 - 1980	12.72 - 2013
045 Sweden	41.36 - 1980	11 - 2014
049 Turkey	3.1 - 2009	3.6 - 2013
052 United Kingdom	27.02 - 1980	23.16 - 1989
055 EU	23.53 - 1989	15.41 - 2014

Autopsies and toxicological investigation

Pitfalls

Budgetary constraints

Some sudden deaths judged to be natural deaths, are not submitted for further investigation

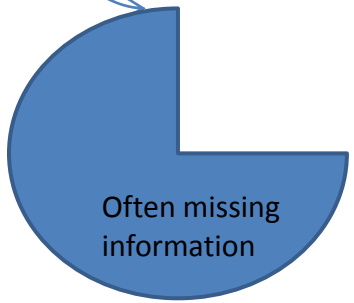
Good practices regarding autopsies in countries include:

- **In Denmark:** The Minister of Justice had decided (in the late sixties), that all deaths brought to the police, and where former, actual or any drug abuse and/or intoxication with illicit drugs is suspected, a post mortem (including toxicological analysis) shall be undertaken.
- **In Norway:** Toxicology is performed with an examination program which includes more than 100 substances, but this may be extended due to circumstances, and specifically requested additional analysis.

How does information reach the GMR?

Results of investigation

Death certificate



Access to autopsy and toxicology report by GMR in a few countries;

Problems identified in the process of retrieving, recording and coding DRD cases

- Not all unknown or suspicious deaths undergo forensic investigation;
- Toxicological and other invesitigation results may not reach the General Mortality Register for varoius reasons but often quoting data protection reasons;
- The GMR may only receive the initial (or provisional) death certificate which would not contain information about the final cause of death.
- Delays in the transfer of information.
- Also when final death certificate is issued it may lack enough detail to properly code the death certificate e.g. death due to ‘overdose‘.

Summary of good practices

- Creating a legal obligation for the transfer of information on autopsies to GMR;
- Specific studies between GMRs and Forensic Institutes;
- Querying forensic institutes on cases where the information on the DC is not enough;
- Access of GMRs to national databases with autopsy and toxicological information;
- Checking all cases of unknown substances or other ambiguous cases with forensic toxicology;
- Amendment of death certificate form to allow more detailed information;
- Creation of electronic databases with information from forensic investigations;
- Including good quality data collection on DRDs as priorities in national strategies;
- Linkage of GMR to SR;
- Training of certifiers in death certification.
- Causes of death transcribed by trained coders.

Coding practices in countries following ICD 10 updates

The 3 main ICD updates in DRDs in 2002/2003 were:

- Giving **priority to codes X and Y over F** when there was a poisoning;

- In selecting the **underlying cause of death** when no component is specified as the main cause of death, clarification should be sought from the certifier. When no such clarification can be obtained, code combinations of alcohol with a drug to the drug. For other multi-drug combination deaths, code to the appropriate category for "Other" combination.

- **Identifying the most dangerous drug:** A priority rule for identification of the most dangerous substance (and respective T code) if not identified by certifier and if no appropriate combination category is available

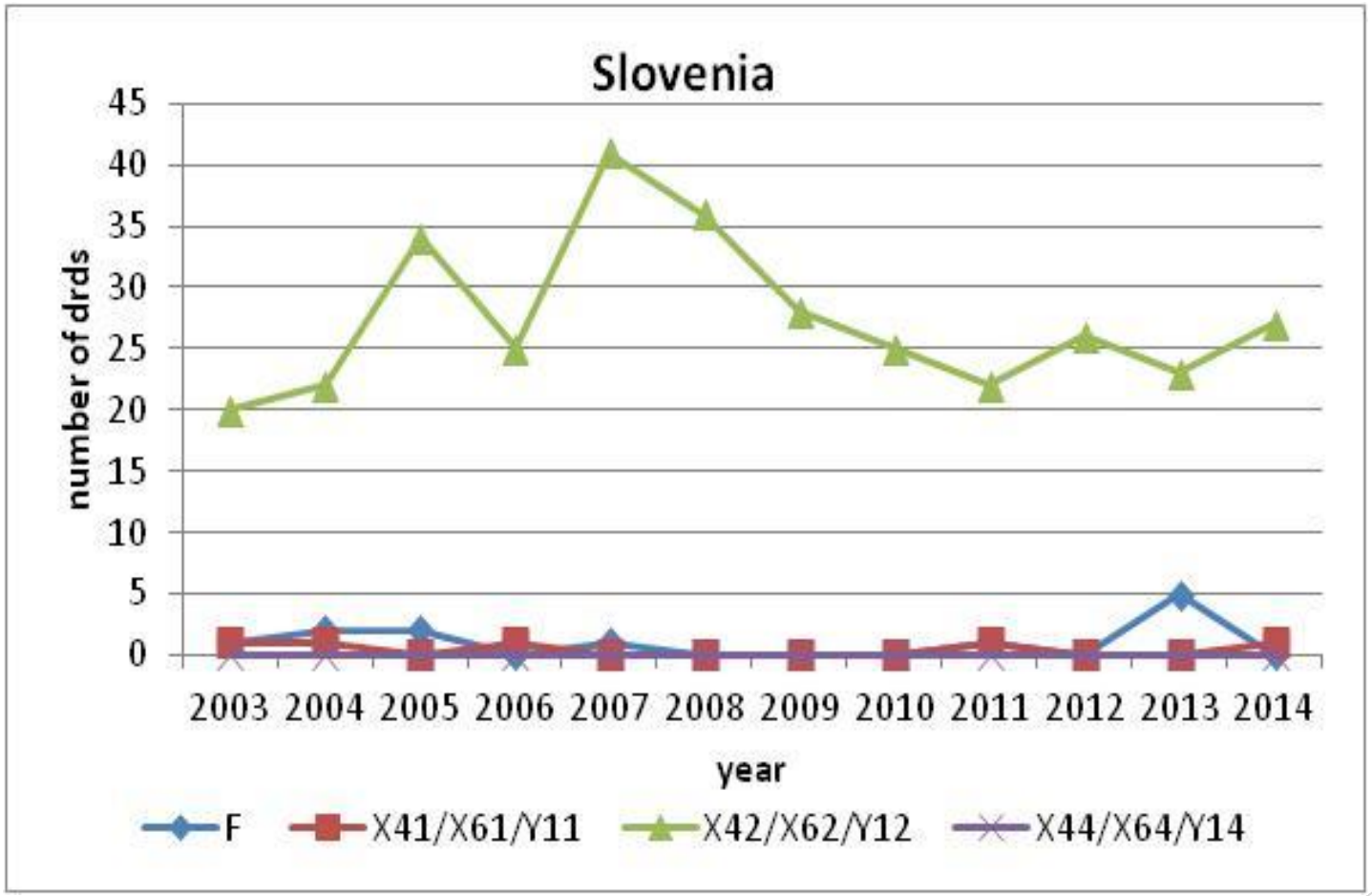
Methodology

- Replies to Questionnaire sent out by EMCDDA on coding practices in 2015;
- EMCDDA website;
- Analysing data on DRDs in a subset of countries to evaluate the use of specific codes such as X44/X64/Y14 codes, non specific codes such as R99, X49 and X69 and the use or non use of T codes.

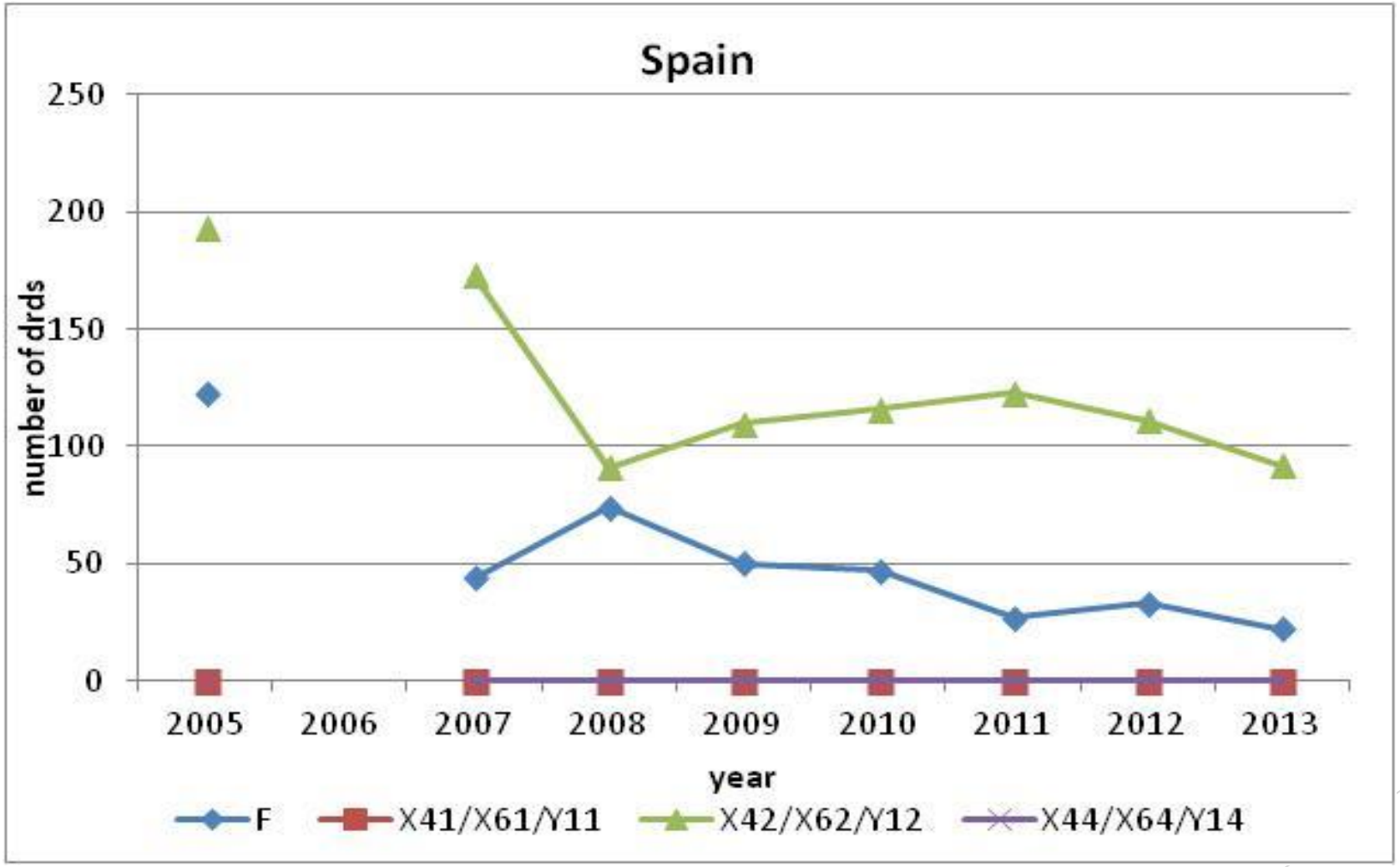
Implementation of ICD-10 updates

Implementation of updates as reported by countries	Number	Countries
No	3	Austria, Bulgaria and Slovenia
Partial	14	Belgium, Czech Republic, Estonia, Finland, France, Germany, Italy, Ireland, Latvia, Lithuania, Netherlands, Portugal, Spain, United Kingdom
Yes	5	Croatia, Denmark, Malta, Norway, Sweden

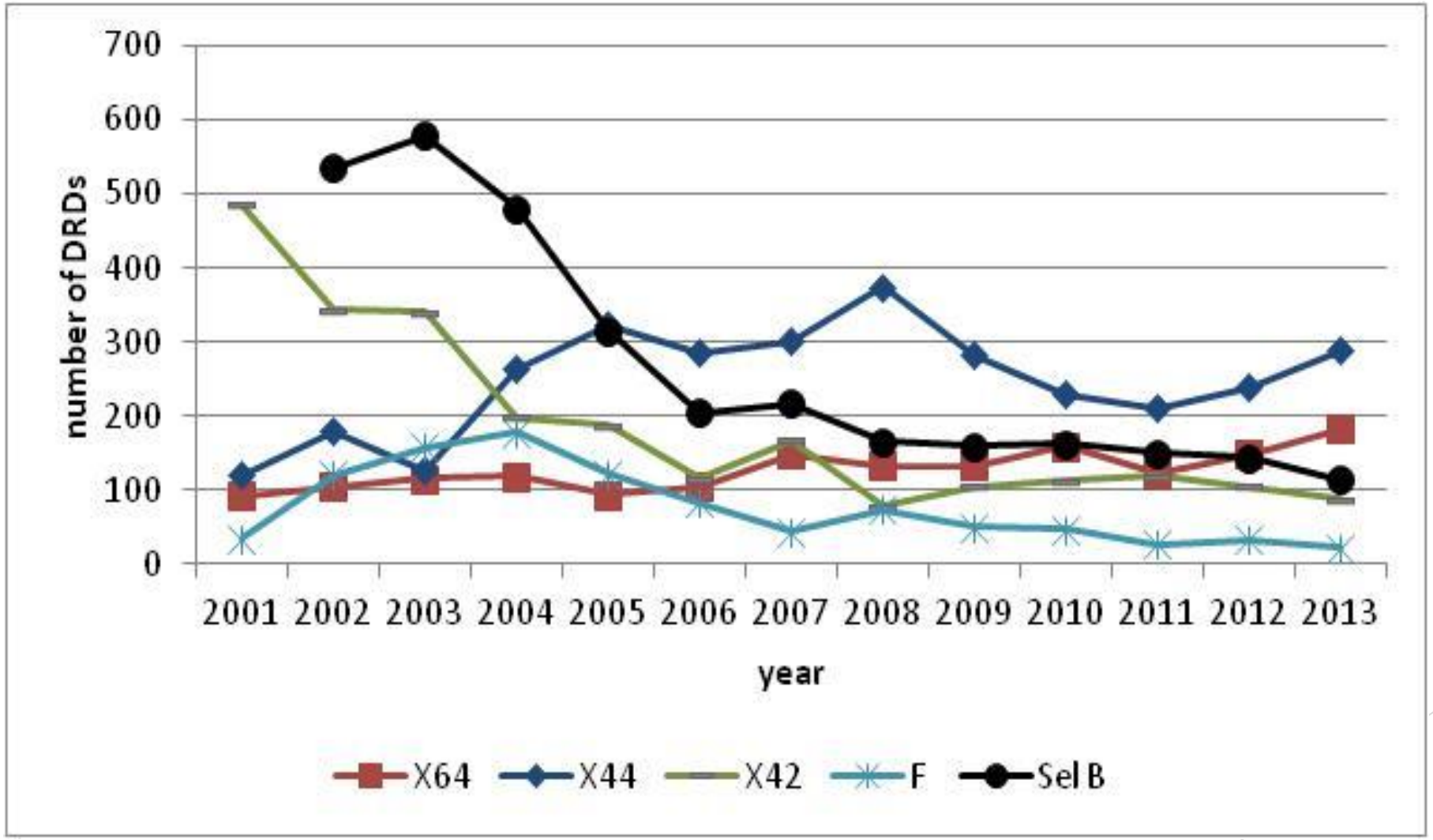
Some country examples: No implementation of ICD 10 updates



Countries with partial updates of ICD 10



Spain


700
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200
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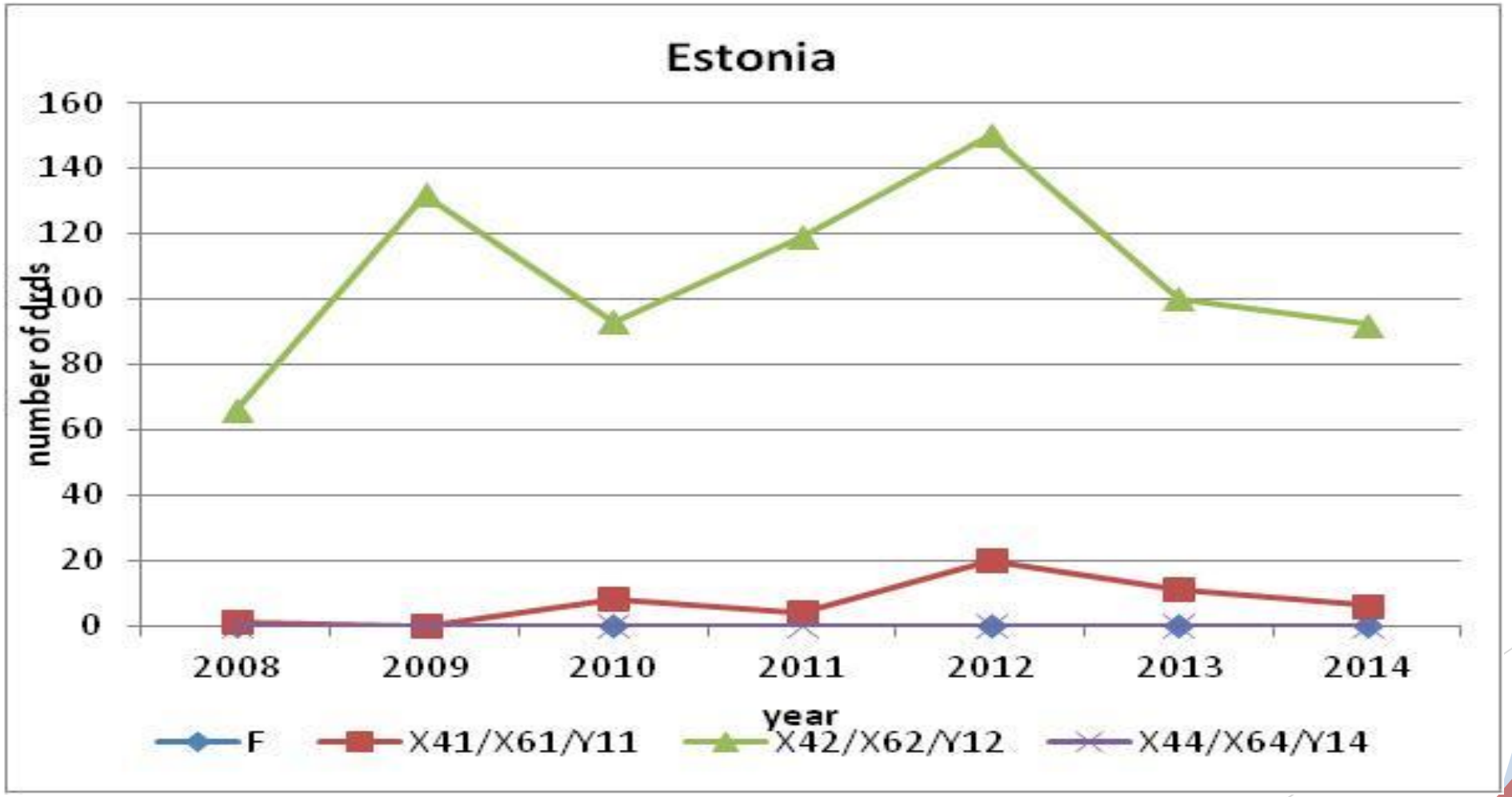
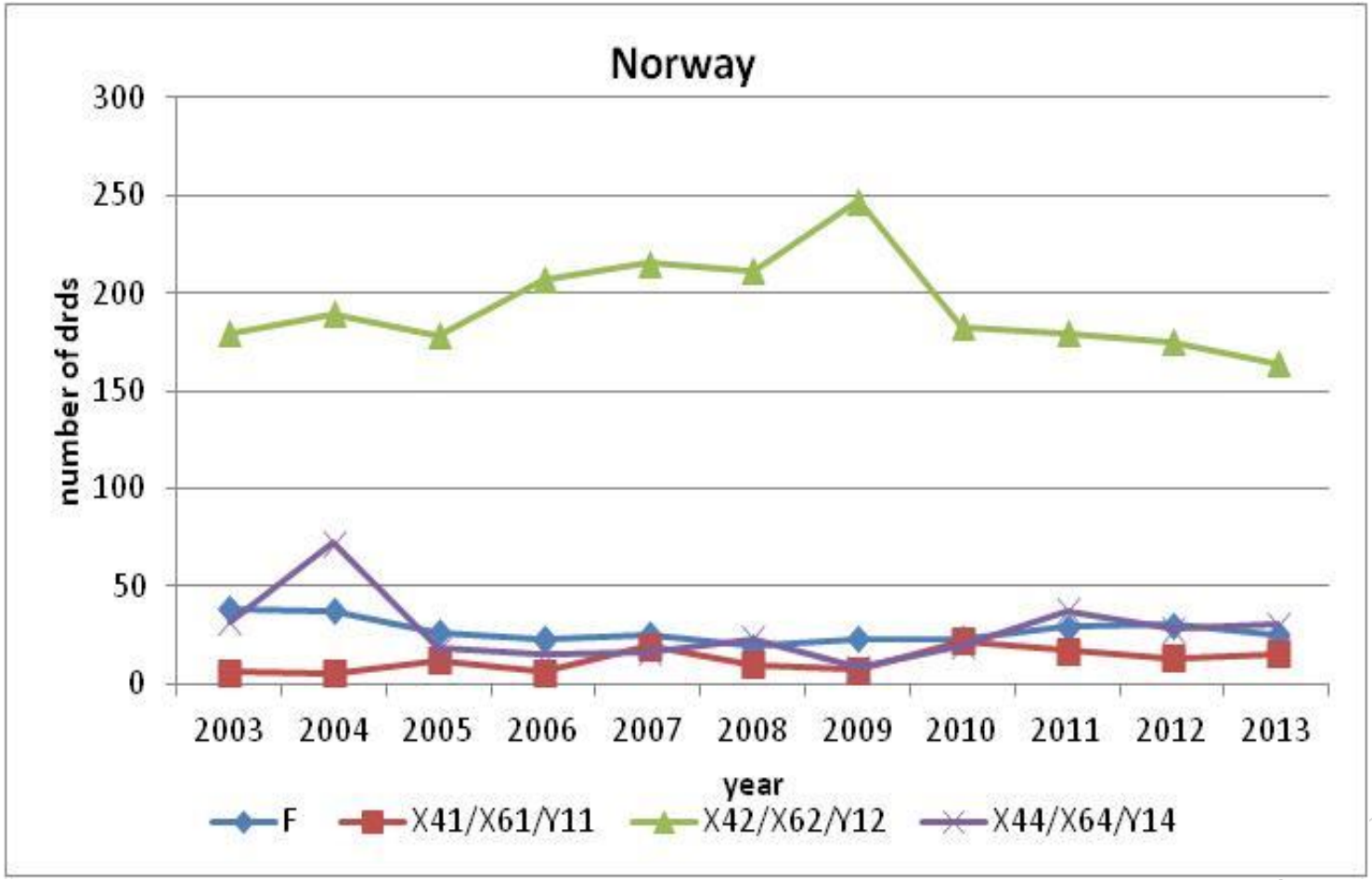
number of DRDs
2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013
year
X64
X44
X42
F
Sel B

Examples of countries with partial implementation of ICD 10 updates



Example of countries with full implementation of ICD 10 updates



Comparisons during earlier versus later DRDs data in ICD codes used, impact of WHO update

- A decrease in the use of F codes was seen mainly in Belgium and United Kingdom, as well as Lithuania (other specific definition);.
- In other countries which report low levels of F codes, this was also so in the earlier period;
- Use of X44 was reported in Belgium, Denmark, Malta, Norway and Sweden in their latest available data compared to no countries reporting X44 except for Norway previous to the ICD-10 updates;
- The use of X44 Poland and Spain is not according to EMCDDA definition;

Comparisons of ICD codes used, impact of WHO update

		% of deaths in the ICD groups					% of deaths in the ICD groups			
ICD code groups	F codes	X41, X61, Y11	X42, X62, Y12	X44, X64, Y14	ICD code groups	Definition	F codes	X41, X61, Y11	X42, X62, Y12	X44, X64, Y14
Belgium (2005)	45.7 (n=48)	0.0	54.3 (n=57)	0.0	Belgium (2012)	Selection B	27.8 (n=20)	4.2 (n=3)	62.5 (n=45)	5.6 (n=4)
Denmark (2005)	17.4 (n=36)	0.5 (n=1)	82.1 (n=170	0.0	Denmark (2013)	Selection B	11.3 (n=25)	0.9 (n=2)	44.6 (n=99)	43.2 (n=96)
Lithuania (2006)	28.6	1.6	69.8	0.0	Lithuania (2014)	Other	1.1 (n=1)	0.0	98.9 (n=86)	0.0
Malta (2006)	0.0	0.0	85.7	14.3	Malta (2014)	Selection B	0.0	0.0	50 (n=1)	50 (n=1)
Norway (2005)	11.1	5.1	76.1	7.7	Norway (2013)	Selection B	10.7 (n=25)	6.4 (n=15)	70.1 (n=164)	12.8 (n=30)
Poland					Poland (2013)	Other	2.0 (n=5)	0.0	48.6 (n=120)	49.4 (n=122)
Spain					Spain (2013)	Other	5.5 (n=22)	0.0	22.8 (n=92)	71.7 (n=289)
Sweden					Sweden (2014)	Selection B	3.6 (n=22)	6.2 (n=38)	47.9 (n=292)	42.2 (n=257)
United Kingdom* (2007)	54.2	2.6	42.3	0.9	United Kingdom* (2013)	Selection B	5.8 (n=142)	5.8 (n=141)	77.7 (n=1902)	10.8 (n=264)

The use or non use of T codes

- **Does your GMR use T-codes? Do you always use T-codes in case of DRD?**
- 20 out of the 22 countries who replied to the EMCDDA questionnaire last year use T codes to some extent while 2 countries do not either because the drug is rarely specified on death certificate or because the GMR does not include toxicological information.
- Of those who reported that they use T codes 16 countries reported that they always do so except in the deaths coded to 'F' category.

- **How many different T-codes can your GMR include in its database? (1 – so the coders are forced to select one- or more)**
- 11 countries reported that multiple T-codes are entered on the GMR. Though some countries collect more than one T code, due to their database they are forced to choose just one.

Other coding issues identified from questionnaire replies

- T50.9 (i.e. Other and unspecified drugs, medicaments and biological substances) is used to code cases where no T codes are available and in poly-drug cases or when no specific T code exists.
- X42/X62/Y12/T43.9 used to code unspecified description “intoxication by drugs” on the death certificate;
- T42.6 used to code drugs like Pregabalin as a prescription drug of new relevance for DRD may be difficult for classification and not included in Selection B;
- No specific T codes for new synthetic substances;
- T43.6 used for substances not applicable to any specific T-code;
- The use of unspecified X and Y codes to code drug related deaths which are non specific may also include X49, X69 and Y19;

Some country examples of the use of T50: England and Wales

Deaths due to X44/X64/Y14 in combination with T50.9

ICD-10 code	plus T code	2011	2012	2013
X44	T50.9	487	471	406
X64	T50.9	157	125	108
Y14	T50.9	97	113	77

Percentage of deaths due to X44/X64/Y14 in combination with T50.9 which fit the EMCDDA criteria for selection B

Selection B	plus T code	2011	2012	2013
X44	T50.9	62.4% (n= 304)	56.2% (n=262)	41.6% (n=169)
X64	T50.9	43.9 % (n=69)	36.8% (n=46)	24.1% (n=26)
Y14	T50.9	37.1% (n=36)	43.4% (n=49)	31.2% (n=24)

Norway

Year	X44/X64/Y14 included	X44/X64/Y14 not included	Total
2012	40 (37.7%)	66 (62.3%)	106
2013	34 (43.0%)	45 (57.0%)	79
2014	46 (47.4%)	51 (52.6%)	97

T codes associated with X44/X64/Y14	**2012 Total**	**2013 Total**	**2014 Total**
Specified T codes	27 (40.9%)	15 (33.3%)	23 (45.1%)
T50.9	39 (59.1%)	30 (66.7%)	28 (54.9%)
Total	66 (100%)	45 (100%)	51 (100%)

Norway: Over half the cases are coded as X44/X64/Y14 and T50.9

Reasons:

- An autopsy was performed, but no toxicological analysis was performed (very rarely in forensic cases, may be seen in hospital autopsies);

- A toxicological analysis was performed, but no drug was clearly identified.

- The type of drug was not clearly stated on the autopsy report (even if the results of the toxicological analysis was known to the pathologist), and there was no response to the GMR query;

- The type of drug was specified, but is classified among the "rest" category in T50.9;

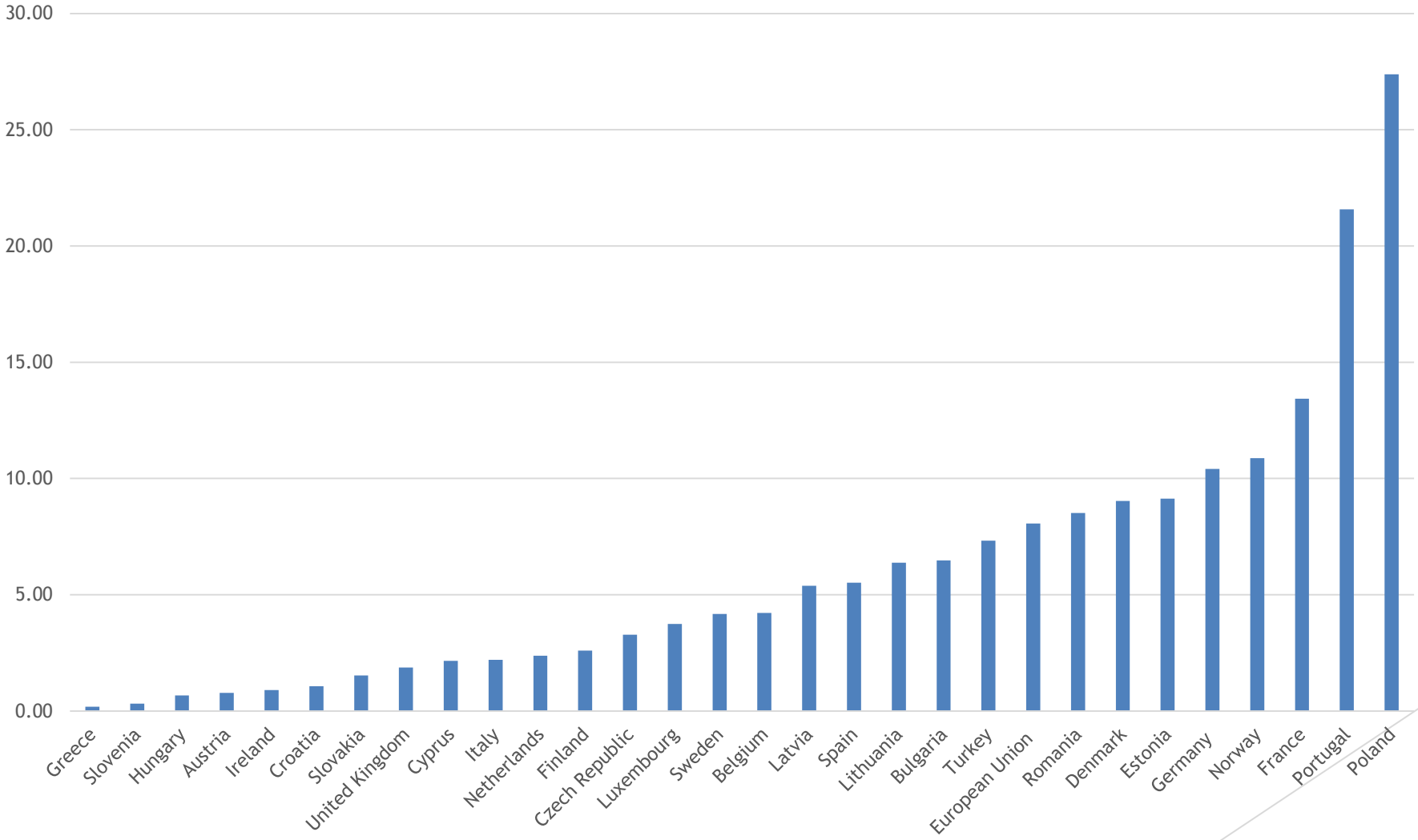
Loss of data on DRDs e.g. Spain

ICD-10 code	number of deaths	% of deaths in these categories
Y14	7	0.86
Y12	0	0.00
Y11	2	0.25
X64	183	22.48
X62	4	0.49
X61	29	3.56
X44	289	35.50
X42	87	10.69
X41	30	3.69
F11,F12, F14-F16,F19	22	2.70
Y19	7	0.86
X69	40	4.91
X49	114	14.00
Total	814	100.00

Loss of data on DRDs e.g. France

Codes	According to selection B	To include	To exclude	Total
F	140	0	26	114
X41/X61/Y11	0	11	0	11
X42/X62/Y12	124	0	25	99
X44/X64/Y14	0	65	0	65
Other codes	0	48	0	48
Total	**264**	**124**	**51**	**337**

Standardised death rate R96-R99, 0-64 years (source: Eurostat database 2011)



New Priority List: WHO 2016 VERSION: ICD 10 VOL II

1. Opioid agonists and partial agonists and other and unspecified narcotics (T40.0-T40.4, T40.6)

Deaths that include multiple opioids classifiable to more than one fourth character subcategory in T40.0-T40.4, T40.6, should be prioritized

2. Inhaled and intravenous anaesthetic agents (T41.0-T41.2, T41.4)

Includes: Propofol

3. Tricyclic and tetracyclic antidepressants (T43.0)

4. Barbiturates(T42.3)

5. 4-aminophenolderivatives (T39.1) e.g. Includes: APAP, acetaminophen, paracetamol

6. Antipsychotics and neuroleptics (T43.3-T43.5)

7. Antiepileptic drugs, antiparkinsonism drugs, and unspecified sedatives (T42.0-T42.2, T42.5-T42.8)

8. Cocaine (T40.5)

9. Psychostimulants with abuse potential (T43.6)

10. MAOI antidepressants and other and unspecified antidepressants (T43.1, T43.2)

Includes: SSRI, Venlafaxine

11. Benzodiazepines (T42.4)

12. Drugs and substances not listed above

Some recommendations

- Provision of guidelines/training for coding of DRDs especially when new updates are to be implemented.
- Discussion with WHO regarding T codes for new drugs.
- Discussion with WHO regarding ICD-11 and any foreseen impact on the DRD protocol.
- Greater efforts to include all T codes rather just one T code in the country databases.
- Further analysis of drugs coded under T50.9 and other non-specific codes.

Consistency and trends of data on DRDS between DIFFERENT sources

(source: DRUG RELATED DEATHS STANDARD PROTOCOL VERSION 3.2, 2009)

	General Mortality Registries (GMR)	Special Registries (SR)
Advantages	Solid indicator of the population impact of health problems Complete coverage (strong legal basis, death certification) International standards for procedures and classification (ICD) Guarantee of continuity	High detection rate (if good quality) More information per case, including toxicology Clearer causal relationship between drug use and death More timely
Disadvantages	Important underreporting/low detection rate in some countries Limited information in death certificate per case (e.g. toxicology, circumstances of death) Divergence across countries in some procedures and application of ICD Slow process and delay	Limited coverage in many countries No standard international classification or procedures Less guarantee of continuity Some cases may not be detected (e.g. dying in hospitals, non-marginalised populations)

Aim

- Analyse overall trends since 2000 in the DRDs numbers , for the country's main source of data according to data obtained from the EMCDDA website.

- Report on the level of agreement between GMR and SR numbers and trends in the various countries.

Trends in DRDs since 2000

↔ :Denmark, Netherlands and Slovakia;

↑ : Finland, Ireland, Lithuania, Romania, Sweden, Turkey and United Kingdom;

↓ :Czech Republic, Italy, Germany, Poland and Spain, Latvia, Hungary (however recent upward trend) Luxembourg and short term downward trend in Cyprus and somewhat in Portugal

↑↓: Austria, Belgium, Bulgaria, Croatia, Estonia, France, Malta, Norway

Reporting according to selection B, D or other definition

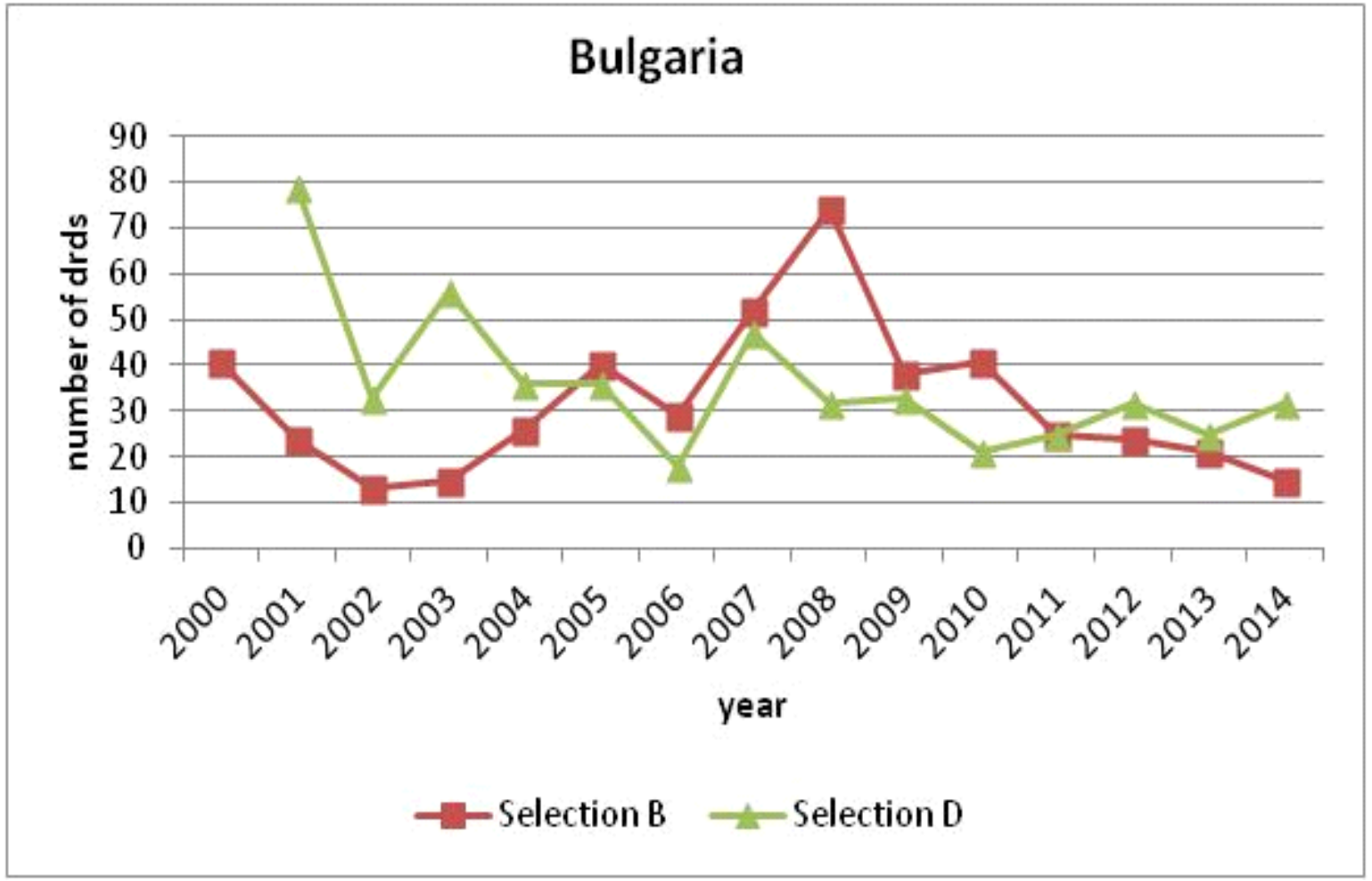
Main source of information:

- Selection B: 14 countries
- Selection D: 11 countries
- Other definition: 5 countries
- 10 countries have till recently reported according to selection B and selection D;
- 8 countries include non-residents

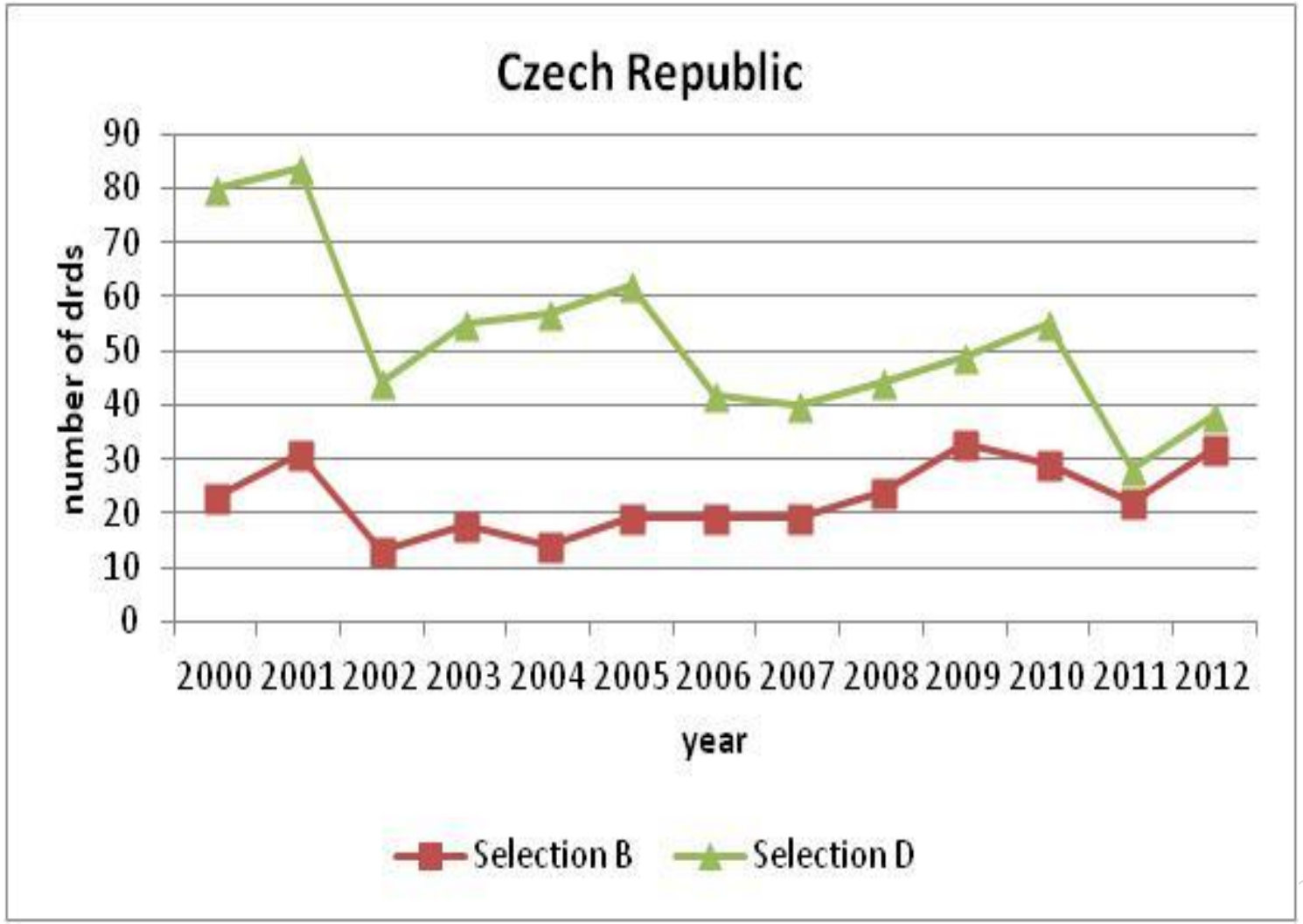
Discrepancies between main source of data and other source

Country	Difference between main source and other source	Average % difference between sources	Trend direction in sel B, sel D and/or national def
Austria	less	9.1	same
Bulgaria	less	15.6	mostly same
Czech Republic	more	56.3	different
Denmark	more	21	same
Finland	more	31.1	same
Hungary	less	22.2	same
Italy	more	19.4	same
Latvia	less	100.6	same
Malta	more	10.6	same
Norway	more	25.1	same
Portugal	more	53.3	same
Spain	more	48.0	same

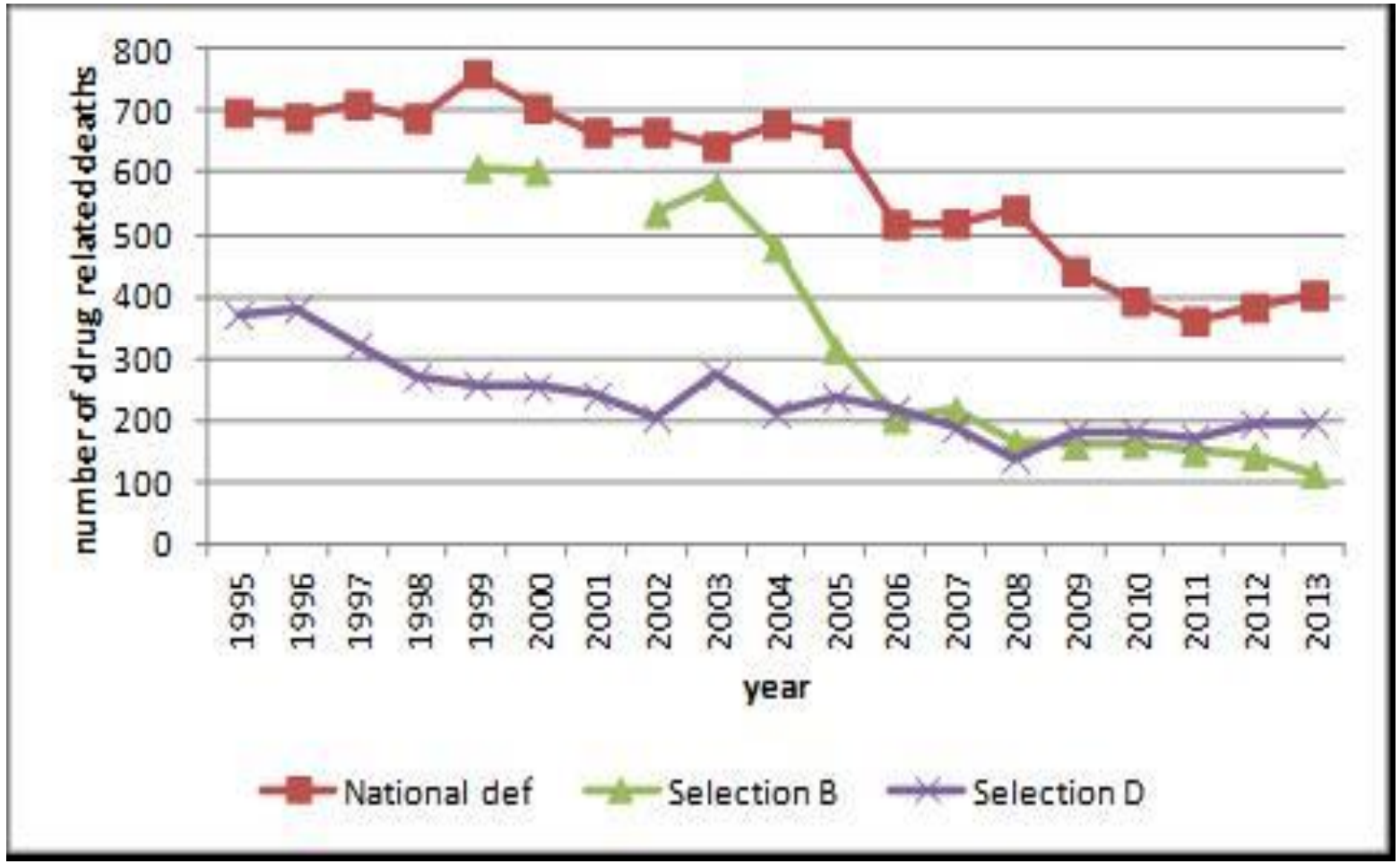
Some country examples



Czech Republic



Spain


number of drug related deaths
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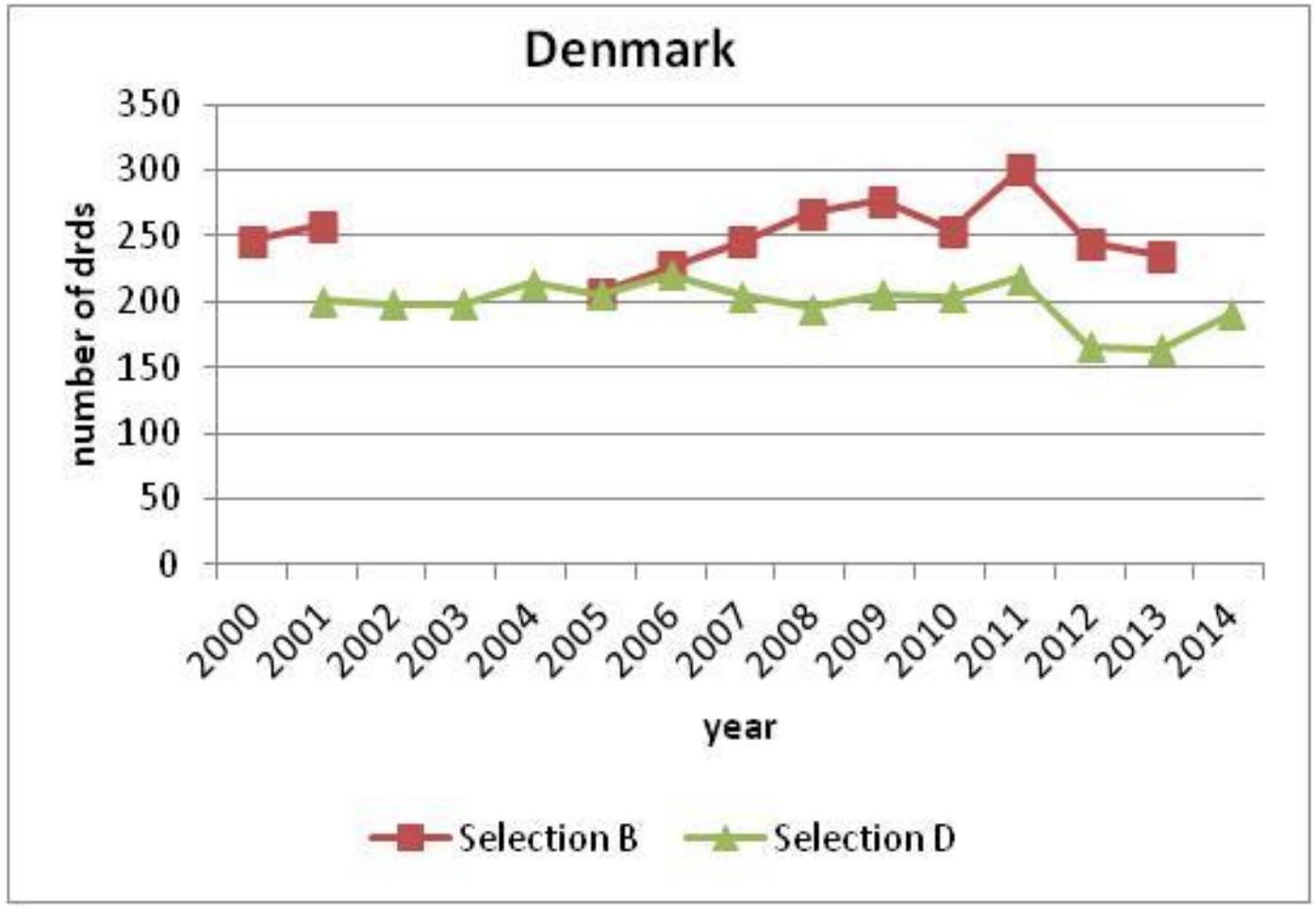
National def
Selection B
Selection D

Denmark


Denmark
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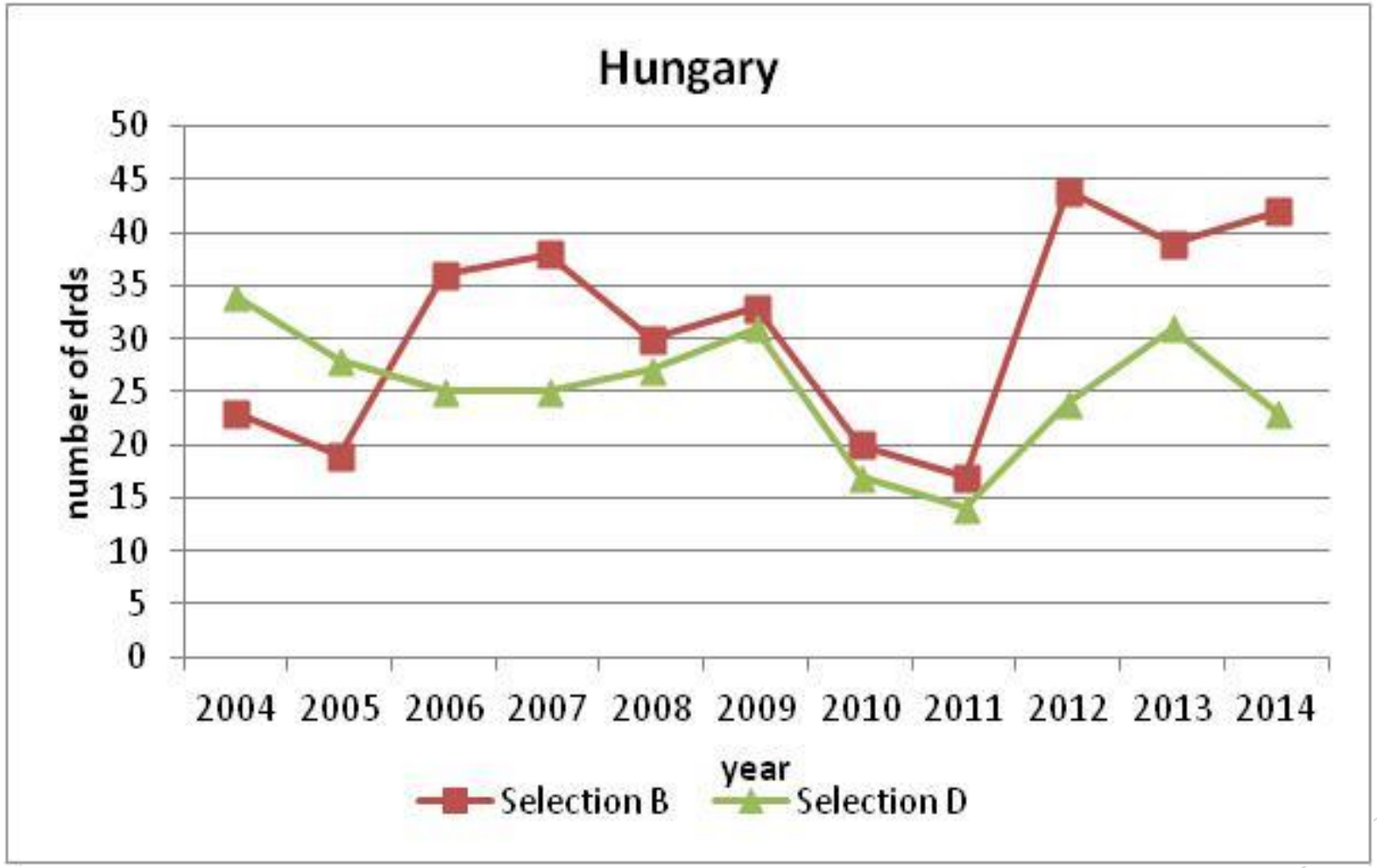
Hungary


Hungary
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year
Selection B
Selection D

Summary of comparisons

- In most countries while discrepancies between the sources may be quite large, however most show the same trend direction in deaths over the years.
- Also for most countries (8/12) the main source of data on DRDs reports more DRDs on average than the other source.

Estimating Burden of DRDs

- **Capture-Recapture technique:** *A statistical procedure to estimate the full size of a given population. E.g. analysis carried out by Janssen in 2011 who estimated that the final estimate is about three times higher than the initial 401 observed cases in France.*
- ***Cohort studies**: Provides insight into causes of death.*
- ***Record-Linkage studies**: requires a personal unique number present in the sources to be linked;*
- ***Using multiple sources of information**:* The Irish NDRDI (National Drug Related deaths index) records data from four sources: the Coroner Service, the Hospital In-Patient Enquiry scheme (HIPE), the Central Treatment List (CTL), and the General Mortality Register (GMR) in order to ensure that the database is complete and accurate.

Conclusion

Under-reporting of DRDs varies between countries and this not only hampers the accurate monitoring of DRDs by the country and also by EMCDDA but also may underestimate the extent of a problem in a particular country.

Acknowledgments

Great appreciation and thanks goes to the EMCDDA, members of the workshop and countries sending the DRD data as well as all the experts and contact persons from National Focal Points who reported back on the questionnaire