

## Table of contents

|                                                                                                                                                                        |           |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| <b>Table of contents</b> .....                                                                                                                                         | <b>3</b>  |
| <b>Executive summary</b> .....                                                                                                                                         | <b>5</b>  |
| <b>Acknowledgments</b> .....                                                                                                                                           | <b>6</b>  |
| <b>Chapter 1— Introduction</b> .....                                                                                                                                   | <b>7</b>  |
| 1.1 The importance of having European statistics on diagnoses-based morbidity .....                                                                                    | 7         |
| 1.2 Current data collections completing the information on Health in the EU .....                                                                                      | 12        |
| 1.3 The importance of morbidity statistics in the International context.....                                                                                           | 14        |
| 1.4 The importance of morbidity statistics at National level .....                                                                                                     | 15        |
| 1.5 Background to this report.....                                                                                                                                     | 15        |
| 1.6 Structure of this report .....                                                                                                                                     | 17        |
| <b>Chapter 2 — Examples from the pilots</b> .....                                                                                                                      | <b>18</b> |
| 2.1 Current ‘experiments’ and promising developments .....                                                                                                             | 18        |
| 2.2 Some results achieved by the pilots and lesson learned .....                                                                                                       | 18        |
| <b>Chapter 3 — Main findings</b> .....                                                                                                                                 | <b>29</b> |
| 3.1 The General approach for establishing diagnosis-specific morbidity statistics at EU level.....                                                                     | 29        |
| 3.2 Indicators: from theory to practice .....                                                                                                                          | 30        |
| 3.3 Some diseases-specific examples on the definitions in use .....                                                                                                    | 38        |
| 3.4 Potential data sources at national level .....                                                                                                                     | 39        |
| 3.5 Methods used for producing estimates.....                                                                                                                          | 43        |
| 3.6 Quality of results .....                                                                                                                                           | 44        |
| <b>Chapter 4 — Conclusions and recommendations</b> .....                                                                                                               | <b>53</b> |
| 4.1 Conclusions .....                                                                                                                                                  | 53        |
| 4.2 Specific conclusions and recommendations per disease.....                                                                                                          | 54        |
| 4.3 Recommendations.....                                                                                                                                               | 60        |
| <b>Annexes</b> .....                                                                                                                                                   | <b>63</b> |
| Annex 1— In-depth analysis of pilot studies in 16 Member States: an Assessment of quality and comparability of the provided information across Member States.....      | 63        |
| Annex 2 — Rev 11_11_13 — Report on in-depth analysis of pilot studies in 16 Member States on diagnosis-specific morbidity statistics — Prioritized ShortList MORB..... | 64        |
| Annex 3 — Abbreviations .....                                                                                                                                          | 68        |
| Annex 4 — Guidelines developed by the MSDG (Morbidity Statistics Development Group) and used during the pilot studies .....                                            | 70        |
| Annex 5 — Task Force on Diagnosis-Specific Morbidity Statistics — Terms of reference – Rev. 15.11.2011 .....                                                           | 71        |
| Annex 6 — The self-assessment of sources’ quality done by pilot countries .....                                                                                        | 75        |
| Annex 7 — Data delivered by the pilot countries.....                                                                                                                   | 80        |

|                                                                                                                                 |    |
|---------------------------------------------------------------------------------------------------------------------------------|----|
| Annex 8 — Summary of pilot data and age-standardised estimates reported<br>(range and ratio) .....                              | 87 |
| Annex 9 — Technical descriptions of the call for proposals launched in the years 2004,<br>2007 and 2009 .....                   | 95 |
| Annex 10 — Report on in-depth analysis of pilot studies in 16 Member States on<br>diagnosis-specific morbidity statistics ..... | 96 |