INTEGRIS FINAL REPORT

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Executive summary

The goal of the INTEGRIS project was to enhance injury reporting in the official EU health statistics through linking the prevention-oriented European Injury Data Base (IDB) with the routine Hospital Discharge Register (HDR; and possibly also the Emergency Department Registers, EDR). INTEGRIS was to demonstrate and evaluate the feasibility of the IDB-HDR integration by the following objectives:

1. Methodological improvement and increased efficiency in the recording and analysis of hospital treated injuries in IDB hospitals.
2. Reduced burden of data entry for hospital treated injuries.
3. Increased usability of existing hospital data for injury prevention and research, including the development of indicators for injuries disabilities.
4. Development and testing of an integral methodology of data provision, data analysis and reporting in six member states.

Related to objectives 1 and 2 the IDB / HDR data streamlining resulted in an INTEGRIS dataset that comprises 8 (out of 22 non-optional variables) from the routine HDR and EDR (age, sex, country, date/time of admission, treatment, ICD10 diagnoses, length of stay). These HDR/EDR variables replace the respective variables in the IDB data set and don't have to be collected through the IDB anymore. This equals a potential of reduced burden of data collection in the IDB hospitals of about one third. Currently, in the majority of pilot hospitals this potential applies only to admitted patients (IDB and HDR), but in Denmark and Italy also IDB/EDR integration could be demonstrated.
According to the internal project evaluation the overall acceptance for an INTEGRIS-type data collection in the pilot countries is high, just as the specific acceptance in the participating hospitals.

Related to objectives 3 and 4, the public INTEGRIS database – accessible through the INTEGRIS website at www.rp7integris.eu – comprises all the INTEGRIS features that have been developed for enhanced hospital based injury surveillance:

- Integration of external cause information (intent, activity, place, mechanism, products, by EU IDB Standard) with routine diagnostic information (WHO ICD-10 and ICD-9).
- Injury disability indicators for temporary and lifelong consequences, enabling a better health impact assessment of injuries and an enhanced comparability of results across countries.
- Minimum data set definition allowing for two different levels of hospital participation and data provision depending on available resources.
- Quarterly data uploads - directly from the IDB / INTEGRIS hospitals or via a National Data Administrator (NDA) - provide for a more timely and dynamic injury reporting.
- Customized access and query levels for different user groups: an easy-to-use public access to the INTEGRIS minimum data level, a research access to all INTEGRIS data levels and an access for each hospital to their complete data.
- ECHI Indicator on Home and Leisure Accidents, estimates of national incidence rates and confidence intervals, Eurostat compliant metadata.

These are also the main results that have been recommended by the INTEGRIS consortium for implementation in the regular EU IDB data collection through the Joint Action for Injury Monitoring in Europe (JAMIE; DG Sanco Health Programme 2011). The "Proposal for EU-wide implementation" provides country specific requirements for the level of detail and the quantity of IDB / INTEGRIS data to be provided – and to be included in the JAMIE implementation plan.

Summary project context and the main objectives

The injury challenge: Every year about 257,000 citizens of the Member States die as a result of an accident or violence – making injury, after cardiovascular disease, cancer and respiratory disease, the fourth most common cause of death in the Member States. Annually, over 50 million citizens seek medical treatment for an injury and 7.4 million of these are admitted to a hospital - causing up to 10% of all admissions to hospitals in the Member States (Injuries in the EU, KFV 2010). Impairments from injuries, although rare – their prevalence is estimated to be about 0,6% of the EU-25 population (Health in Europe, Eurostat 2006) - are main contributors to the burden of injuries due to their enormous human costs in terms of years of life lived with disability, as well as their substantial proportion of annual health care and rehabilitation costs.

Policy needs: In order to address the injury challenge, the Commission issued in 2007 a "Council Recommendation on the prevention of injury and the promotion of safety" (COM[2006] 329 final / 2006/0106 [CNS]). The Recommendation highlights the role of the health sector in injury prevention - by advocating primary prevention, disseminating evidence-based strategies, increasing the professional capacities for advising people at risk and injury surveillance to quantify the problems and to report risk factors. In the latter respect the Council Recommendation requires the Commission to support Member States in making better use of existing injury data and developing national injury surveillance and reporting systems. A specific role for the Commission is foreseen in gathering, processing and reporting Community-wide injury information based on national injury surveillance systems.

Status quo and shortcomings of the current EU injury surveillance. Despite their significant overall number, the countless ways in which accidents occur vary widely in settings, activities during the accident and objects involved (these are called "external causes"). That is the reason why there are specific requirements for injury data collection where a special focus needs to be on the registration of external causes.

Although there are several general (horizontal: across all diseases) and special purpose data collection systems available which provide information about injury mortality and morbidity at the national and EU level, the Public Health needs as expressed above are not met yet (Kisser R et al.: Injury data needs and opportunities in Europe. Injury Control and Safety Promotion, Vol. 16/2, 2009). For the purpose of injury prevention horizontal health data usually lack the required detail on the external causes of accidents and injuries (activity at the time of the accident, products and mechanisms) and most of the special purpose data systems cover only a certain sector of injuries, like traffic (Community Database on Accidents on the Roads in Europe - CARE) or work place (European Home and Leisure Accident Surveillance System - ESAW). This makes these databases difficult to compare. As a consequence of this mixture of data sources, only estimates with low validity about the burden of certain injury causes can be given and certain key information for guiding public health policy and injury prevention is still lacking. Most obviously missing are valid indicators for the most severe and most costly consequences of injuries - long term and permanent disabilities. Disability prevalence at EU level is only occasionally reported, e.g. within the Labour Force Survey of Eurostat.

A general and routine health statistics with a potential for deriving injury disability indicators for the EU are the national Hospital Discharge Registers (HDR). The HDR is an obligatory medical documentation of diagnoses and procedures for hospital in-patients according to WHO International Classification of Diseases (ICD). ICD has been used for measuring injury severity and injury

disabilities and impairments, e.g. according to the Abbreviated Injury Severity scale (AIS) the AIS-based Functional Capacity Index (FCI). These procedures, however, have not been operationalised for routine health monitoring. A major drawback in the use of HDR data for selective injury surveillance is the lack of information on external causes of injuries. Even though ICD HDR data demand data items to be completed for external causes of injuries (basically for injury mechanism and intent), the coding compliance for external causes in hospitals is extremely poor in most member states.

A special purpose, although not yet a routine injury data source, is the European Injury Data Base (EU IDB). The IDB has originated from EHLASS by expanding the scope from Home and Leisure Accidents to all kinds of all types of accidents and injuries, but has otherwise not changed the data collection procedure: IDB data is collected in a sample of hospitals (Accident & Emergency departments) in the participating countries (currently 12 Member States) and provides unique information on a number of external cause categories according to the International Classification of External Causes of Injuries (ICE-CI). However, as an EHLASS "heritage" there are still major biases that affect the validity of IDB indicators and hence their international comparability. Major shortcomings are the lack of a defined sampling procedure for IDB hospitals and for intra-hospital sampling of recorded cases. Furthermore, there is a lack of a common data model for the calculation of incidence rates and respective confidence intervals from the IDB sample. Due to the fact that the IDB Coding Manual does not provide for validated ICD diagnoses (but only "layman diagnoses") the provision of IDB health indicators on injury disabilities was not possible so far.

The INTEGRIS approach. Given the various shortcomings of individual health statistics in meeting the policy needs for accident and injury indicators, the idea behind the proposed work was to combine the best parts of the most relevant data sources into a new added-value data set. Given their complementary strengths and similar settings – both being hospital based data systems - the integration of the external cause oriented IDB and the routine HDR was considered the most promising approach:

- HDR routine medical data items complement the IDB data items on external causes - specifically, diagnostic and procedural HDR data items provide for the development and implementation of disability indicators (and also cost indicators in the future).
- The exhaustiveness of the HDR data collection complements IDB's cost efficient sampling - specifically, administrative HDR data items provide for the development of a data model and sampling frame for valid and reliable national estimates from the IDB sample

Therefore, the INTEGRIS project proposed to provide the necessary research and technology input for the IDB-HDR integration through an evaluated demonstration project.

The INTEGRIS goals and objectives. The underlying goal of the INTEGRIS project was to enhance injury reporting in the official EU health statistics through linking the prevention-oriented European Injury Data Base (IDB) with the routine Hospital Discharge and Emergency Department Registers (HDR, EDR). INTEGRIS was to demonstrate and evaluate the feasibility of the IDB-HDR integration by the following objectives:

- Methodological improvement and increased efficiency in the recording and analysis of hospital treated injuries in IDB hospitals
- Reduced burden of data entry for hospital treated injuries

- Increased usability of existing hospital data for injury prevention and research, e.g. through meaningful indicators for injuries disabilities
- Development and testing of an integral methodology of data provision, data analysis and reporting

The following specific objectives habe been proposed within the respective INTEGRIS work packages (WP):

OBJECTIVE 1: to develop, validate and provide a data model for the integration of official Hospital Discharge Registers (HDR) with the EU Injury Database (IDB) for an improved reporting of injury indicators at the national and EU level (INTEGRIS - integrated IDB/HDR dataset) - WP2 Data streamlining.

OBJECTIVE 2: to provide an operationalised set of validated indicators for disabilities from injuries based on the HDR medical information as part of the INTEGRIS data set - WP5 Disability indicators.

OBJECTIVE 3: to develop, validate and provide a methodology for obtaining representative samples of injury patients and monthly extrapolations of sample statistics at the national level for EU level aggregation - WP2 Data streamlining.

OBJECTIVE 4: to develop an advanced front-end application and sample database for the INTEGRIS dataset (electronic interfaces to streamline onsite data entry and online transmission to the central server) - WP6 Integration of new technology

OBJECTIVE 5: to pilot the INTEGRIS data collection in seven member states and to evaluate outcomes based on the quality criteria of the European Statistical System (Eurostat) and the public health requirements of the EU Health Indicators (ECHI) - WP3 Data collection pilot and WP4 Evaluation of pilot

OBJECTIVE 6: to propose an EU-level INTEGRIS implementation plan for adoption by relevant stakeholders and decision makers - WP7 Dissemination

Besides the provision of a "model of good practice" for increased cost efficiency of injury data collection the main expected impact of the INTEGRIS pilot was the facilitation of a European injury surveillance system that meets both the criteria of the European Statistical System (Eurostat) and the public health requirements of the EU Health Indicators (ECHI). The ultimate goal is to provide the data needed to make injury prevention strategies in the EU more effective.

Main S & T results/foregrounds

Overview

The IDB/HDR data streamlining resulted an INTEGRIS dataset (deliverable D2.2) that replaces IDB variables with routine HDR/EDR variables (e.g. age, sex, country, data/time of admission, treatment, ICD10 diagnoses, length of stay). These HDR/EDR variables replace the respective variables in the IDB data set and don't have to be collected through the IDB anymore. This equals a potential of reduced burden of data collection in the IDB hospitals of about one third. Currently, in the majority of pilot hospitals this potential applies only to admitted patients (IDB and HDR), but in Denmark and Italy also IDB/EDR integration could be demonstrated. The common INTEGRIS standards and tools that have been made available for the pilot hospitals and comprised the following elements (D3.1):

1. The full INTEGRIS data set definition (D2.1) and coding manual (D2.2), including HDR and IDB data elements, for local and central IT implementation. Also a minimum version of the INTEGRIS data set has been defined (INTEGRIS MDS) in order to better reflect the different levels of details that hospitals across the EU could realistically provide. The INTEGRIS MDS comprises the variables: reporting country, sex, age group (5 years), year of attendance, injury type, temporary disability, lifelong disability, place of injury, intent, injury activity, injury mechanism, injury Sport, and has been made accessible at the public query level of the INTEGRIS database (at https://pilot.rp7integris.eu).
2. A common front-end application for data-collection and transmission to the central INTEGRIS server that consists of an HDR/EDR/IDB "merger software" and a XML data interface (D3.1).
3. The central INTEGRIS pilot database hosted by THALES, Vienna, with an upload interface for direct INTEGRIS data transmission from the hospital to the central server, and for online access to the collected data (D6.1).
4. An "HDR & IDB data protection policy" (D2.4)

The preparation and pre-test phase of the INTEGRIS pilot implementation has eventually rendered a total of 16 hospitals in six countries ready for the INTEGRIS data collection in 2010 (Austria AT, Denmark DK, Germany GE, Ireland IE, Italy IT, United Kingdom UK/Wales). For 2010, a total of about 56.000 hospital injury jury cases have been uploaded for analysis and evaluation, 41.000 of these are merged IDB / EDR / HDR cases. In addition, the INTEGRIS merging procedure could be applied retrospectively to about 57.000 cases of 2009 (D3.3).

The internal INTEGRIS evaluation showed that the overall acceptance, for instance, for an INTEGRIS-type data collection in the pilot countries is high, just as the specific acceptance in the participating hospitals. Barriers encountered in the INTEGRIS implementation were temporary and due to technical aspects of data merging and upload, which were solved with experience of undergoing the pilot. A key aspect of this process was the unique patient identifier for data linkage, and the data protection aspect for certain countries. Overall, the level of achievement (see evaluation chapter/WP4) has been assessed by the internal evaluation to be about 90%, and in view of the sustainability and long term usage of IDB data collection the following achievements have been found the most important ones:

- New information for new target groups without additional efforts (European Community Health Indicator / ECHI for Home and Leisure Accidents, disabilities)
- Reduced burden of data collection at the hospital level

- Increased compliance with the ESS quality criteria (European Statistical System, Eurostat)
- Minimum Data Set (MDS) proposal for less resourced hospitals

More specifically, the public INTEGRIS database (https://pilot.rp7integris.eu, accessible also through the INTEGRIS website www.rp7integris.eu) shows all the INTEGRIS features that have been developed for enhanced hospital based injury surveillance:

1. Integration of external cause information (intent, activity, place, mechanism, by EU IDB Standard) with routine diagnostic information (WHO ICD-10 and ICD-9).
2. Injury disability indicators for temporary and lifelong consequences, enabling a better health impact assessment of injuries and an enhanced comparability of results across countries (through a focus on more severe injuries that, with a high probability, need hospitalization in all health care systems).
3. Minimum data set definition allowing for two different levels of hospital participation and data provision depending on available resources.
4. Quarterly data uploads - directly from the IDB / INTEGRIS hospitals or via a national Data Administrator (NDA) - provide for a more timely and dynamic injury reporting.
5. Customized access and query levels for different user groups: an easy-to-use public access to the INTEGRIS minimum data level, a research access with an advanced tool for all INTEGRIS data levels, an access for each hospital to their complete data and to all INTEGRIS data levels with a simplified query tool.
6. ECHI Indicator on Home and Leisure Accidents, ESS conform metadata and estimates of national incidence rates and confidence intervals.

These are also the main results that have been recommended by the INTEGRIS consortium for implementation in the regular EU IDB data collection through the Joint Action for Injury Monitoring in Europe (JAMIE). The "Proposal for EU-wide implementation" (D4.3) provides country specific requirements for the level of detail and the quantity of IDB / INTEGRIS data to be provided – and to be included in the JAMIE implementation plan (covering also the non-EU JAMIE partner countries Croatia, Iceland, Norway and Turkey).

According to this implementation scenario, in at least one reference hospital per country the full IDB / INTEGRIS dataset is collected. In a total of 267 hospitals the reduced IDB / INTEGRIS minimum dataset (MDS) is collected with one MDS hospital in each NUTS-2 region of each country. In analogy to the US National Electronic Injury Surveillance System (NEISS), also for EU IDB one case per 1.000 residents or a total of about 550.000 cases per year should be sampled. The required cases per member states have been grouped into eight categories ranging from 4.000 in small countries (with less than 0,5 million residents) to 42.000 in the large ones (more than 50 million residents).

Main S & T results by work packages

The following overview lists the most relevant deliverables (D) for each objective within the respective work package (WP):

WP2 Data streamlining / OBJECTIVE 1: to develop, validate and provide a data model for the integration of official Hospital Discharge Registers (HDR) with the EU Injury Database (IDB) for an improved reporting of injury indicators at the national and EU level (INTEGRIS - integrated IDB/HDR dataset).
D2.1 "Implementation plan for data collection pilot"
D2.2 "Manual and Training Guidelines"
D4.2 "Evaluation Report"

WP2 Data streamlining / OBJECTIVE 3: to develop, validate and provide a methodology for obtaining representative samples of injury patients and monthly extrapolations of sample statistics at the national level for EU level aggregation.
D2.3 "Manual and guidelines for a standardized, integrated data model"
D4.3 "Proposal for EU-wide implementation"
D4.2 "Evaluation Report"

WP3 Data collection pilot and WP4 Evaluation of pilot / OBJECTIVE 5: to pilot the INTEGRIS data collection in seven member states and to evaluate outcomes based on the quality criteria of the European Statistical System (Eurostat) and the public health requirements of the EU Health Indicators (ECHI).
D3.3 "Synthesis data report (Process & Content)"
D4.2 "Evaluation Report"

WP5 Disability indicators / OBJECTIVE 2: to provide an operationalised set of validated indicators for disabilities from injuries based on the HDR medical information as part of the INTEGRIS data set.
D5.2 "Set of revised and operationalised indicators".
D3.4 "Valid estimates for permanent disabilities"
D4.2 "Evaluation Report"

WP6 Integration of new technology / OBJECTIVE 4: to develop an advanced front-end application and sample database for the INTEGRIS dataset (electronic interfaces to streamline onsite data entry and online transmission to the central server).
D6.3 "Finalised (Prototype) Sample Database"
D4.2 "Evaluation Report"

WP7 Dissemination / OBJECTIVE 6: to propose an EU-level INTEGRIS implementation plan for adoption by relevant stakeholders and decision makers.
D4.2 "Evaluation Report"
D4.3 "Proposal for EU-wide implementation"

In the following chapters a more detailed description of the results for the S&T relevant work packages WP2, WP3, WP4, WP5 and WP6 are given (for sake of comprehensiveness also WP1 is included).

WP1 Injury data collection state-of-the-art in the pilot countries

In WP1 an inventory of individual IDB and HDR data systems was compiled on aspects of operationalisation, quality and comparability, and recommendations were given for both HDR and IDB data systems, and merging of IDB and HDR in particular. Country reports were based on questionnaires to the country partners on the legal, organizational, technical aspects, and methodological aspects of both HDR and IDB systems in place. The main conclusions and recommendations of the WP1 summary report were (D1.2):

- The HDR data systems vary between countries by unit of registration, hard- and software used and coverage.
- In the majority of the countries no information is available about 'external cause of injury' (only Denmark, the Netherlands, Slovenia and UK, Wales reported that they have some information about mechanism, activity and location available in the HDR).
- The most important data item from the HDR to be used for the INTEGRIS data set is the diagnoses information.
- Both ICD-9 and ICD-10 classifications for diagnoses should be considered.
- The IDB data systems, though more uniform in their implementation, also vary between countries by unit of registration, hard- and software used and coverage.
- The most important data items from the IDB to be used for the INTEGRIS data set are the external causes' information.
- In IDB patient, treatment and ‚external causes' variables are of good quality.
- Only in the Netherlands IDB contains information about disability.
- The principal assumption of the INTEGRIS approach that HDR routine medical data would be important to complement the IDB data items on external causes – and vice versa - has been confirmed by the available country reports.
- Integration of IDB and HDR in an INTEGRIS data set is expected to lead to a reduction of effort in the IDB data collection.
- In none of the participating countries the IDB and HDR data systems are merged.
- In order to adjust the INTEGRIS pilot to the different country specific IDB/HDR conditions, at least two different levels of the INTEGRIS data set should be ‚allowed' (in terms of completeness and quality of available variables). This would better reflect European hospital reality and allow for a pragmatic EU wide INTEGRIS implementation plan in the end.

WP2 Data streamlining

Based on the state-of-the-art report of HDR and IDB data collection of WP1 and the proposal of a HDR–based indicator for injury disabilities by WP5, an integrated IDB/HDR dataset has been developed by WP2 and implemented in the central INTEGRIS database by WP6. Based on the WP1 recommendations a minimum version of INTEGRIS data set was implemented (INTEGRIS MDS) in order to better reflect the different levels of details that hospitals across the EU might be able to provide. Out of the INTEGRIS pilot countries, UK Wales delivered the INTEGRIS MDS only (see WP3). The complete INTEGRIS data sets and procedure was documented in the "INTEGRIS coding manual" as a comprehensive WP2 deliverable (D2.2).

In the full INTEGRIS dataset (D2.2) a number of variables out of the 22 non-optional variables are from the routine HDR or EDR (see list below). These HDR variables replace the respective variables

in the IDB data set for admitted patients and don't have to be collected through the IDB anymore. This indicates a potential of reduced burden of data collection in the IDB hospitals of about one third for admitted patients. For evaluation purposes the diagnoses information of both IDB and HDR origin were kept in the final INTEGRIS dataset.

The minimum INTEGRIS (MDS) comprises the variables: reporting country, sex, age group (5 years), year of attendance, injury type, temporary disability, lifelong disability, place of injury, intent, injury activity, injury mechanism, injury Sport, and has been made accessible at the public query level of the INTEGRIS database (at https://pilot.rp7integris.eu).

The following list shows the data elements (variables) of the full INTEGRIS dataset ("MDS" refers to data elements of the INTEGRIS minimum dataset, "HDR" to data elements that originate from the routine HDR system; the remaining data elements origin from the IDB):

1. Country of reporting hospital (MDS)
2. Country of patient residence (HDR)
3. Patient residence ZIP code (HDR, optional)
4. Citizenship of patient (HDR, optional)
5. Age (HDR, MDS age group)
6. Sex (MDS, HDR)
7. Date of attendance (HDR, Temp)
8. Time (hour) of attendance (HDR)
9. Date of injury
10. Time (hour) of injury
11. Diagnosis 1-3 (HDR)
12. External cause of injury (HDR, optional)
13. Type of injury 1-2
14. Part of the body injured 1-2
15. Treatment & Follow up (HDR)
16. Intent (MDS)
17. Transport injury event
18. Activity when injured (MDS)
19. Mechanism of injury (MDS)
20. Place of occurrence (MDS)
21. Narrative

    ADMISSION module
22. Date of discharge (HDR, temp)
23. Length of stay (HDR)

    DISABILITY module
24. Injury group "Eurocost" (MDS)
25. Temporary disability weight (MDS)
26. Lifelong disability weight (MDS)

    PRODUCT module
27. Underlying object
28. Direct object
29. Intermediate object

    TRANSPORT module
30. Mode of transport

31. Role of injured person
32. Counterpart

    SPORT module
33. Type of sport/exercise activity (MDS)

    VIOLENCE module
34. Victim/perpetrator relationship
35. Sex of perpetrator
36. Age of perpetrator
37. Context of assault

    INTENTIONAL SELF-HARM module
38. Proximal risk factor
39. Previous intentional self-harm

    ADMINISTRATOR module
40. Reporting hospital ID
41. Reporting hospital department (Optional)
42. Source of data
43. Package ID

The INTEGRIS statistical procedures resulted in a novel method for the use of confidence intervals based on a general variance model in order show the statistical variation of the incidence rate estimations (D2.3). The INTEGRIS confidence intervals methodology is considered a real added value for comparative IDB data analysis (between countries or between years) and substantially adds to the compliance of the EU IDB with the quality criteria of Eurostat. The following list shows INTEGRIS improvements for the EU IDB data collection for the respective areas of the European Statistical System (ESS) quality criteria:

1. Relevance

- ECHI indicator for home and leisure accidents (importance for health reporting)
- Indicators for temporary and life-long injury disability (unmet user needs)

2. Accuracy and Reliability

- Confidence intervals for incidence rates (overall accuracy)
- ICD-based assessment of hospital representativeness (sampling errors)

3. Timeliness and punctuality

- Quarterly upload and data availability (timeliness)

4. Coherence and Comparability

- ICD diagnoses included in data set (coherence with HDR)
- Confidence intervals for incidence rates (comparability)
- Reduced health care system bias through disability indicators (comparability

5. Accessibility and Clarity

- State-of-art web presentation (https://pilot.rp7integris.eu)
- Individual database access for hospitals
- Access to single case data for research purposes
- ECHI metadata standard
- Minimum Data Set

For the INTEGRIS incidence rate estimation a patient's registry based method was chosen using the HDR or EDR as a sampling frame for the IDB sample. For the extrapolation procedure the INTEGRIS ICD10 case definition was applied to the HDR dataset: ICD10 S&T codes excluding codes T80-T88 and T90-T98. This definition excludes medical adverse events, abuse, and late consequences.

For the INTEGRIS "HDR & IDB Data Protection Policy" please see chapter on WP6.

WP3 Pilot data collection

Based on the overall INTEGRIS implementation plan provided by WP2, the preparation phase of the pilot has started in June 2009. Due to organisational and technical problems in individual hospitals this phase had to be extended by six months before INTEGRIS data from all hospitals could be initially uploaded.

On purpose, the INTEGRIS pilot hospitals were chosen to represent different levels of implementation of an ED based injury surveillance system: In Ireland, for instance, no such system was implemented, in Austria, Denmark and Germany the IDB was already implemented, without (AT) or only little integration (DK, GE) into the hospital-IT. In UK, Wales a "small scale IDB" was in place without a link to the HDR.

As outlined in the S&T overview all pilot hospitals succeeded in linking the IDB to the HDR system. However, the INTEGRIS data collection is quite complex as it involves the linking of up to three different data sets (see D3.2 "Country Reports"). The different data sets to be merged contain intermediate variables that are omitted from the final data set that will be uploaded (e.g. redundant IDB variables). The procedure for the omission of intermediate variables has been implemented by the pilot partners as defined by the INTEGRIS "IntegrisMerge" provided by WP3 (see D3.1 "Revised implementation plan & guidelines" - User guide – IntegrisMerge Software version 1.5).

The "IntegrisMerge" software merges two (IDB /HDR) or three (IDB/HDR/EDR) files, based on a common key field, e.g. case numbers or person number plus date, and creates an INTEGRIS data file including all records from the sources, and combines the information in the files. The INTEGRIS file is in XML format and ready to upload.

WP3 has provided significant input for the evaluation of data INETGRIS pilot process and pilot data quality, including the disability indicators through the "Country Reports (Process and Content; D3.2), "Synthesis data report (Process & Content; D3.3) and "Valid estimates for permanent disabilities" (D3.4).

WP4 Evaluation of Pilot

The results of the internal evaluation have been summarized in the INTEGRIS evaluation report (D4.2) and served also as an input for the "proposal for an EU-wide implementation of the INTEGRIS data set" (D4.3; see chapter "potential impact").

The following list summarizes the level of achievement that has been reached for each evaluation criteria after the INTEGRIS project. This level is a subjective value assigned to by the evaluation team

in order to provide a quasi-quantitative and comprehensible overview of the various INTEGRIS activities. The level of achievement indicates the percentage of achieved versus expected results as proposed in the INTEGRIS technical annex of the Grant Agreement. The actual achievements are described in detail in the INTEGRIS evaluation report (D4.2).

6.1 Technology & Organisation
Simplification of data entry - 90%
Acceleration of availability of results - 90%
Data Control/Data Management - 80%
Reporting - 100%

6.2 Data Quality
Completeness of data - 75%
Accuracy of survey - 100%

6.3 Pilot Implementation
Acceptance of INTEGRIS within the hospitals - 80%
Barriers for Implementation - 80%
Cost efficiency - 75%
Grade of Innovation - 100%

6.4 Data Integration
Added Value for the hospitals - 80%
Reduction of administrative effort for IDB - 100%

6.5 Disability Indicator
Reliability of implementation - 100%

6.6 Health Statistics
Added Value for the national health systems - 100%
Representativity of data - 100%
Projection of data for the hospitals - 100%
Definition of catchment areas of the hospitals - 90%
Compliance with statistical requirements of Eurostat - 90%
Compliance with ECHI requirements - 100%

6.7 Data Protection Policy
Compliance with EU-regulations - 100%
Compliance with national regulations - 100%

6.8 Maintenance & Expansion
Sustainability and long term usage of developed system - 100%
Expansion of the system into other countries - 100%

The overall level of achievement is about 90%. The least achievement levels have been found in the evaluation dimensions “6.3 Pilot Implementation”. This is due to the fact that not all of the INTEGRIS features – mainly at the hospital level - could be implemented timely enough in order to see the full benefits already during the pilot. Levels of achievement of 100% refer in most cases to criteria that

were judged by whether a potential solution has been developed and implemented or not (e.g. reduction of data set → Reduction of administrative effort, calculation of confidence intervals → Accuracy of survey).

A substantial part of INTEGRIS has been addressing the improvement of the IDB compliance with the statistical requirements of Eurostat, namely in the areas of relevance, accuracy and reliability, timeliness and punctuality, coherence and comparability, accessibility and clarity. These areas have been covered by various criteria and respective analyses in the INTEGRIS evaluation manual, in particular in the chapter health statistics (see list above). For instance, the timely availability of data, the sound methodology of incidence rate calcuation and confidence intervals, and the linkage with the ICD diagnoses were considered as an important step towards an improved compliance of the IDB with the European Statistical System (ESS) at the INTEGRIS stakeholder meeting" (D7.3).

In addition, ECHI indicator 29b for home and leisure accidents (European Community Health Indicators) has been implemented as a separate injury category in INTEGRIS public access. The documentation has been provided in the required standard format (ECHI metadata template). The algorithm for the ECHI 29b calculation uses INTEGRIS/IDB variables intent, transport injury event, place of occurrence and activity and is documented in D6.3.

The "Proposal for EU-wide implementation" (D4.3) was completed at the end of the project (M36) and provides country specific requirements for the level of detail and the quantity of IDB / INTEGRIS data to be provided. The basic assumptions for the required cases and hospital numbers per country are:

- One case per 1.000 residents or a total of about 550.000 cases per year should be sampled.
- The required cases per member states have been grouped into eight categories ("weight"). These country weights have been assigned in analogy to a country's share of votes in the EU Council as this procedure that reflects the size of a country and guarantees a sufficient number of cases also for smaller countries.
- Only one full IDB / INTEGRIS hospital (reference hospital) is required per country. Obviously, in bigger or very heterogeneous countries more reference hospital would add to the representativity of the sample for the details of the full IDB / INTEGRIS data set.
- IDB / INTEGRIS hospitals that collect the Minimum data set (MDS) are recommended one in each official administrative region at NUTS level 2 (for some countries level 1 or 3 was found more appropriate). MDS hospitals are also expected to stimulate regional or local injury prevention; therefore, ideally all hospitals of country should collect the MDS IDB / INTEGRIS data set.

WP5 Disability indicators

The expert group on "disability indicators" under the lead of Erasmus University, Rotterdam reviewed existing methodologies (D5.1) and provided a DALY (Disability Adjusted Life Years) based model for the implementation of a unique INTEGRIS disability indicator (D5.2).

An essential component for DALY calculations is the disability weight. Essential, because it is the factor that allows comparison and addition of time lost through disability to time lost through mortality. The disability weight reflects the impact of a health condition in terms of Health-related quality of life (HRQoL); it has a value ranging from 1, indicating worst imaginable health state,

through 0, indicating full health. The following recommendations for the calculation of the INTEGRIS disability indicator were given by the WP5 expert group:

- Disability model: use the multi-attribute utility instrument (MAUI disability model)
- Incidence data: use both ED and HDR injury incidence data
- Anatomical classification system: apply the EUROCOST injury diagnosis classification scheme (INTEGRIS data element "injury group").
- Disability weights HDR: use disability weights derived with the MAUI-approach for hospitalized patients. For the time being use the set of Polinder MAUI disability weights.
- Disability weights ED: for non-hospitalized patients, use disability weights derived with the MAUI-approach and panel study weights (the latter in case of mild temporary injury consequences)

The INTEGRIS disability indicators are based on 39 diagnostic groups ("EUROCOST") that can be derived from both the ICD-10 diagnoses, as available in the HDR part of the INTEGRIS data set, and the data items ‚type of injury' and ‚body part injured' as available from the IDB part. The INTEGRIS disability indicators will be implemented (operationalized) through disability weight tables (Annex 6 of the WP5 report, D5.2) that allows for the distinction of in- and outpatients as well as short- and long-term disabilities. This procedure can be easily extended for the calculation of the DALY measure (Disability Adjusted Life Years).

WP6 New technology

The INTEGRIS pilot data has been made accessible at https://pilot.rp7integris.eu through an interactive statistics page with three different query levels that were defined by a dedicated database user group and implemented with up-to-date software by THALES Austria under the lead of Swansea University, UK. Within the INTEGRIS pilot three different levels of access have been allowed:

1. The first level provides public access to the aggregated data and is available online on the INTEGRIS website.
2. The second level is for the hospitals involved in the data collection, so each hospital can access its own INTEGRIS data, based on a signed data protection agreement and password protected.
3. The third level is the raw data from all levels and is restricted to the participants in the pilot data collection (national IDB data administrators of Austria, Denmark, Germany, Italy, The Netherlands, United Kingdom and the database operator THALES) and is password protected.

The INTEGRIS pilot data comprises the following "pages":

- Help page: For new users a help page provides information on how to use the interface accompanied by videos, screenshots and examples.
- Hospital Access: This access is intended for data-providing hospitals to gain access to their own data in detail and use the functionality of the query engine.
- Simple Query: Here users can construct queries. It's possible to select any combination of fields and filters. Multiple filters per field can be added and removed as required. Users can save their personal queries and reload them later. The data displayed always resembles the original datasets without modifications to compensate for e.g. incomplete collection of data.

- Advanced Query: The usage of this page is similar to the Simple Query but there are more fields available and they contain all subcategories whereas only the highest levels of codes are displayed in the Simple Query. For fields with loads of values searches are available instead of drop-down choices to improve readability and make the interface easy to use.
- Upload page: Here users can upload files from their local file system. The files are saved and scheduled for import. The uploaded files must be of type xml and implement the integris_dataset.dtd schema. The importer checks for new files periodically and starts importing the data. After the import has finished an error report as well as information about the number of imported and ignored datasets is provided.

In terms of data protection, the INTEGRIS builds on the existing European Injury Database (IDB) by integrating these data with Hospital Discharge Records (HDRs) from participating hospitals. So, to a large extent, the data protection policy is similar to that for IDB (https://webgate.ec.europa.eu). This, in turn, complies with the Data Protection Directive 95/46/EC of the European Parliament and the Council of 24 October 1995 on the protection of individuals with regard to the processing and use of personal data and on the free movement of such data. The INTEGRIS data protection policy (D2.4) ensures that the identity of all individuals who are represented in the data will be protected. The restriction of data against any possibility of identification applies both to the process of loading it into the INTEGRIS database and the ability of users to access it from the database.

The INTEGRIS "HDR & IDB Data Protection Policy" includes a "request for research access" and a draft agreement for research users (INTEGRIS Terms of use of single case INTEGRIS data via the password restricted database access). Furthermore a website certificate exists and the data are uploaded securely by encrypted data transmission.

The great variation in technical and organisational aspects of hospitals in the EU as found by WP1 and WP2 led to the conclusion that no new data collection will be implemented at the hospital level and led to a re-assessment of the need of the envisioned front-end application. As a result the uniform front-end of the INTEGRIS IT-system was confined to a common data interface (XML) for the hospital data to be transmitted to the central INTEGRIS server (provided by WP3). For merging the HDR/EDR/IDB dataset a "merger software" was provided for the hospitals partners through WP3 (see D3.1).

The technical specification and software design of the central online database provides for a sufficient scalability and portability of the application in order to meet future INTEGRIS demands on quantity of data and hosting of the application at alternative hosts. The complete database documentation and installation guide is available as part of D6.4 ("Finalised front-end application (Prototype)"). The technology used comprises the following elements:

- Database: PostgreSQL, JDO2
- PostgreSQL was chosen for its proven durability and its renowned good genetic query optimizer to ensure fast query execution.
- JDO2 was used because it was the best option to work with ever changing data structures without rewriting large parts of the database access layer and to provide theoretical database independence.
- Backend: Java 6, Tomcat 6
- Java and Tomcat 6 where chosen because they are not only industrial standard, they are also among the best and fastest tools for secure web development.
- Frontend: JavaScript, Ajax, jQuery, Raphaël, Highcharts, Wicket, CSS

- JavaScript is the only language working in all modern browsers. By using small, sophisticated and pure JavaScript libraries instead of Flash the INTEGRIS pilot offers fast animations to improve readability and is available on mobile devices like e.g. the iPad.
- The animated map is based on Raphaël a JavaScript library to improve working with and animating vector graphics in Web applications.
- Highcharts is a library offering a range of animated chart types and is written in pure JavaScript. It is being used to illustrate data in the public access.
- jQuery is the largest JavaScript framework in use for modifying the html document model on the fly and was heavily used for the map and charting.
- The frontend uses the Wicket Framework, which was chosen for its flexible design and innovative use of JavaScript for the user interface combined with modular design and the MVC pattern. It is the bridge between Java and JavaScript. It also has great support for Ajax.
- Ajax is used to dynamically reload and change small parts of the web page instead of reloading the hole on every interaction between client and server. It is essential for highly responsive web applications.
- CSS is the language of choice to add design to the web pages.

Potential impact

In view of the ultimate goal of the IDB Network to make the EU IDB an obligatory data collection system in Europe as part of the Community Statistics on Public Health by 2015, DG Sanco, the current IDB host and Eurostat, the possible future IDB host, are considered the main INTEGRIS stakeholders at EU level. Representatives of both Sanco and Eurosat were hence invited to the INTEGRIS Advisory Board and INTEGRIS progress was reported at the annual IDB Network meeting at Sanco in Luxembourg. At the national level the INTEGRIS pilot hospitals were considered the main stakeholders as acceptance by both the interviewers and the respondents is the most important success factor for any data collection.

According to the in the internal INTEGRIS evaluation the overall acceptance for an INTEGRIS-type data collection in the pilot countries is high. At the methodological level the INTEGRIS improvements for the IDB were found to increase the acceptance of data collection in the hospitals that are supposed to collect and provide this data. At the EU health policy level, especially the demonstration of an overall increase in cost efficiency in the hospitals - through HDR/IDB synergies and through less costly minimum data sets - is expected to have a substantial impact on the acceptance of EU IDB as a routine system for reporting on external causes of injuries as part of the Community Statistics on Public Health. At the national health policy level, the IDB / INTEGRIS minimum data set approach should make it much easier to have IDB hospitals in each administrative region of a country (e.g. NUTS-2) and this is expected to stimulate regional injury prevention.

The ECHI indicator 29b for home and leisure accidents (European Community Health Indicators) that has been implemented as a separate injury category in INTEGRIS public access has demonstrated the feasibility of the IDB to produce this indicator in a regular and standardized way. This is considered an important asset for national (and EU) health reporting according to the ECHI short list.

From its very beginnings in 2008, INTEGRIS was planned as a pilot project that would develop, test and evaluate the proposed innovations for the EU IDB. The roll-out of positively evaluated INTEGRIS features was to take place in a next step, together with the whole IDB Network and the member states. Obviously, this next step could not be taken for granted. It is a very advantageous situation that through JAMIE – with governmental authorities from 22 countries cooperating - many of the INTEGRIS developments and recommendations can now be directly implemented. JAMIE (Joint Action for Injury Monitoring in Europe) is a joint action of the 2010 call of the DG Sanco Health Programme (contract number 2010 2205), coordinated by EuroSafe. The aim is to have by 2015 one common hospital-based injury data collection system in all EU-member states.

A close coooperation of INTEGRIS with JAMIE was ensured in order to communicate the INTEGRIS results for future implementation at an early stage of the JAMIE planning. A joint JAMIE-INTEGRIS meeting in order to streamline the INTEGRIS results with the JAMIE project implementation plan took place on the 7th and 8th of April 2011 in Luxembourg. The meeting was part of the JAMIE Kick Off meeting at the EAHC office (Executive Agency for Health and Consumers), with representatives from the Directorate for Health and Consumers, Eurostat, EuroSafe and the JAMIE work package leaders. Based on the INTEGRIS results the following lessons learned were presented and discussed at the meeting - in view of the new IDB requirements to be defined and implemented by JAMIE:

- The diversity of EU hospital settings requires an easy to implement dataset as “common denominator” >> the proposed solution is an INTEGRIS Minimum Data Set (MDS);

- Despite the INTEGRIS MDS quality issues remain to be resolved, especially for IDB newcomers >> the proposed solution is the INTEGRIS upload and importer module of the central database that performs basic quality acceptance test and provides feedback to the NDAs;
- The integration of WHO ICD10 diagnoses into the IDB dataset works well for admitted cases, for ED out-patients no ICD system was established yet in most of the participating countries.
- A common ICD10 (and ICD9) case definition is essential for extrapolation of admitted IDB cases within the HDR population; essential also for comparability between countries; e.g. the inclusion or exclusion of „late effects" ICD diagnoses makes a big difference in the extrapolation results;
- The disability indicator is based on a reduced number of cases (severe cases) but highly increases the comparability between countries (i.e. health systems); this indicator can easily be extension to yield the YLD measure (Years lived with Disabilities);
- Quarterly data uploads have been shown to be possible as the quick availability of data is an important feature for the promotion and increased use of the IDB/INTEGRIS results (extrapolations were still done on an annual basis but shorter intervals are also possible).

From these lessons learned the following general recommendations were derived that were considered feasible for a roll-out within JAMIE:

- Offer a Minimum Data Set (MDS) in order to enable more hospitals to participate in the system
- Provide an interface (xml) for direct hospital data upload in order to implement a decentralized data provision with in-built basic quality checks
- Grant individual database access for hospitals in order to increase the use and identification of hospitals with the system
- Include ICD diagnoses in the dataset for reliable medical information and direct link with routine hospital data
- Calculate indicators for injury disability as part of the IDB results in order to increase comparability of results between countries and to have a unique new feature for injury reporting,
- Use confidence intervals for incidence rates in order to provide a tool for the interpretation of observed differences

As outlined in the S&T chapter on WP4 (Evaluation) INTEGRIS has also proposed a scenario for the EU-wide roll-out of the "INTEGRIS-IDB". The following list shows the proposed sample size and number of MDS hospitals per country (only one full IDB hospital per country is required):

Germany:	42.000 / 16 (Minimum no. cases / Minimum no MDS hospitals)/
Turkey:	42.000 / 12
France	42.000 / 22
United Kingdom	42.000 / 12
Italy	42.000 / 20
Spain	39.000 / 17
Poland	39.000 / 16
Romania	19.000 / 8
Netherlands	19.000 / 12
Greece	17.000 / 13
Belgium	17.000 3
Portugal	17.000 / 5
Czech Republic	17.000 / 8
Hungary	17.000 / 7
Sweden	14.000 / 8
Austria	14.000 / 9
Bulgaria	14.000 / 6
Denmark	10.000 / 15
Slovakia	10.000 / 4
Finland	10.000 / 4
Norway	10.000 / 7
Ireland	10.000 / 2
Lithuania	10.000 / 10
Croatia	10.000 / 3
Latvia	6.000 / 6
Slovenia	6.000 / 12
Estonia	6.000 / 5
Cyprus	6.000 /1
Luxembourg	6.000 / 1
Malta	4.000 / 1
Iceland	4.000 / 2
Total	**561.000 / 253**

The current JAMIE project implementation foresees the roll-out of the "INTEGRIS-IDB" in 25 member states through the following principal steps:

- Within twelve months criteria for IDB data quality, like representativeness and comparability, shall be clearly defined, in line with the respective requirements of the European Statistical System (ESS).
- Over the years 2012-2014 an increasing number of countries will report injury data in accordance with these quality criteria for uploading in the EU central Injury Database (IDB), hosted by the Commission, DG Health and Consumers.
- By end of the action (mid 2014) in at least 26 countries a National IDB Data Administration centre ('NDA') - designated by the competent national or regional authority - shall be in full operation.
- By mid 2014 at least 22 countries shall report IDB data in a sustainable manner, applying the full IDB coding of external causes in at least one reference hospital.
- Four more countries shall have implementation plans in place endorsed by the competent authorities.

JAMIE has started in spring 2011 and aims to have a common hospital-based surveillance system for injury prevention in operation in all member states by 2015. INTEGRIS has been highly beneficial for improving the EU IDB towards a system that is able report on external causes of injuries due to accidents and violence as part of the Community Statistics on Public Health. Furthermore, the INTEGRIS project is an excellent example for a sucessful cooperation of the EU FP7 Research and the EU Health Programme. For more information on JAMIE please visit http://www.eurosafe.eu.com.

Public website address

www.rp7integris.eu and https://pilot.rp7integris.eu

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