



HOSPITAL DATA PROJECT PHASE 2

FINAL REPORT

The equal need for metadata and data

Extension on DIAGNOSIS and Shortlist PROCEDURES



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FINAL REPORT

Composition of the report parts

**Part I: the final report and annex unrelated to diagnosis and
procedures**

Part II: the annex related to diagnosis

Part III: the annex related to procedures



HOSPITAL DATA PROJECT PHASE 2

FINAL REPORT

Part I

Acknowledgements

HDP2 was considered a challenge, and indeed it was. Interesting as the project was, it was not always an easy task to perform. Being a project on methodology, HDP2 built its foundation in the success of HDP1. Ciara O'Shea from Ireland was the enthusiastic bridge between HDP1 and HDP2. She laid out the plans for HDP2 and helped us to keep on track in the early stages of the project.

Continuity with the approach of developing a methodology was the presence of Björn Smedby. Again, his leadership of the Expert Group proved exemplary by developing a shortlist for procedures. So HDP1 and the Expert Group of Björn Smedby were our solid foundations.

Without the contribution of the participants, methodologies could still not have been tested. The requests for data were always met. Participants were always prepared to join in discussions and to bring forward possible solutions. The attendance at meetings was high, where as the attitude was industrious, serious but also very social. The diners together became a tradition, still discussing the project tasks, but also more personal matters.

Nearly always present were the representatives of Eurostat, WHO and OECD. They played an important role not only in the Core Group, but also during the Full Group discussions. Fons Blankendaal, as a consultant, took care that we remained practical and did not get 'carried away'.

And then for the real hard labour, the data managers of Prismant, Erwin Bendsch and Mark Boll, were never too desperate to continue, at least they did not show it. And after all these hard ships, there was Patrick Lynch from Ireland, whose phlegmatic approach resulted in a high quality product: the CD ROM, a more than useful tool.

As for the last track, the editing of the final report, the Core Group was helped by the presence of Kathryn Knight of The NHS Information Centre (UK), as well as Philippe Oberlin from France.

I think we can be proud of the results. There is always doubt whether we should have tackled topics in more detail. However, there is a more or less (proven) methodology for collecting data on hospital use. We sincerely hope that this will prove to be a solid base to go on and that this data collection will be institutionalised shortly.

On behalf of the Core Group HDP2
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Prismant, The Netherlands
Project Leader HDP2

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CD ROM: Report and Annexes
CD ROM: (meta)data

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Summary

Data without metadata is nothing
Metadata together with data is information

This project is about methodology which enabled
the collection of data and related metadata

Objectives

The main objective of HDP2 was to build on the work of the HDP1 project by expanding the methodology of collecting hospital discharge data. HDP 1 delivered a short list of data to be collected on diagnosis. The objective of HDP2 therefore was to expand this shortlist to important parameters of hospitalisation and morbidity (for both diagnosis and procedures). In order to carry out time series analysis as well as to find a methodology for collecting data on procedures and a number of additional topics, the full group of HDP2 Member States (MS) was asked to collect the data on diagnosis on the short list of HDP1.

To start a follow-up project of HDP was only decided after a discussion on scope and purpose. Although data collection is, of course, necessary for analysis and testing whether the methodology developed is applicable, it was obvious that the project should focus on methodology rather than on the data collection itself.

The objectives of the project have more or less been met, as is shown in section 6 and Annex VI. The New Member States (NMS) did not encounter many obstacles while collecting data on the short list on diagnosis. In general countries that made up the HDP2 group were able to submit data which could be used to test comparability.

Diagnosis

The (further) development of the set of metadata has been a time consuming but successful task. HDP2 Member States needed to bring their metadata up to date and ensure it was in order. The participants of the project feel that this was not only a major achievement, but also that it is imperative for further data collection. One can not stress the importance of the metadata enough.

It was concluded that metadata is especially necessary where the collected data is less accurate and comparable than anticipated. There are many reasons why in spite of the validations the data gathered shows inconsistencies. Although with the proper metadata on hand it is still possible to make comparisons. Also there is now a database which can be used for all kind of studies, as the metadata.

In this context it is also important to note that the International Shortlist for Hospital Morbidity Tabulations (ISHMT), as an accepted product of the HDP1, has been kept as the basis for diagnosing reporting. The (meta)data collection was done straight away for all the participants of HDP2. The extension with the “New Member States” went smoothly. After some consideration it was decided to apply the HDP1 validation in principle again.

It is not feasible to obtain a consistent data collection on new born babies, although there is interesting metadata on this topic. It is recommended that this issue will be noted and handled adequately in future international comparisons based on hospital discharge statistics.

Time series for diagnosis was also possible, but there were differences in what countries could deliver. The data collection was, however, encouraging. The current data collection by Eurostat should also be an interesting basis upon which a further broadening of the scope becomes possible. The (ISHMT) methodology is established and one should build on this method by institutionalising a broad and regular data collection, and thus building up an European database on diagnosis, which in the future can be linked to other international data bases (see also paragraph on integral data collection).

Although it is considered a major topic, solid information on external causes is difficult to obtain. A few countries have data available coded according to ICD9 or ICD10, but several of these countries state that the data is incomplete due to missing information. There are difficulties with the definitions, as quite a number of injury patients are treated immediately in the emergency room and may resemble a day care patient. For these reasons HDP2 did not collect data on external causes of injuries. The HDP2 methodology, based on routinely collected data on hospitalisation, does not seem to be the best method for external causes.

The data collection on 'outpatients' and 'cross border' was also more restricted. This was due to definition problems, as well as coding practices which hindered the collection of an European data collection. Hereby we should also not forget that the project is on hospital discharge data. The relevant definition of outpatient data as well as cross border data differs too much.

Because it is acknowledged that the topics 'outpatients' and 'cross border' are of major importance, and deserve a small project in his own right. In any case there should be a separate collection of statistics on these topics, whereas the metadata of HDP can be useful to begin studies in the respective fields.

Also a connection with the IDB program might be useful.

The collected diagnosis data makes comparative analysis possible. Metadata should be used while explaining and interpreting the results. Not all the questions raised can be answered with statistical certainty, but the results of an analysis together with the metadata can very often give an (statistical) indication of a description or explanation. In this report there are a number of examples of possible questions together with the results. (see under comparability). It is possible for the data to be analysed for different groups such as age and gender. This is made possible by the software used on the CD ROM, which enables users to select the data and analyse from chosen groups, and have the results presented (in table - or graphical form).

Procedures

The other major objective concerned the development of a process for data collection on procedures. For this an expert group was formed, chaired by Professor Smedby. The result is a tested short list of procedures, containing 30 procedures with 6 subgroups. It is recommended to take into account all procedures and not only the principal procedure.

The compilation of the list was a careful process, in close cooperation with all parties concerned within and outside the project.

A lot of effort was made to obtain a list which, like the shortlist on diagnosis, is acceptable for as many parties involved in the data collection on hospital discharge. Linkages to other (existing) short lists of different institutions are certainly possible. The project recommends the management of the mappings concerned, which are included on the CD ROM.

After ample deliberations the project concluded that the procedures short list may not be 'perfect', but it supplies the best possible start for data collection on a bigger scale which is also necessary with the ongoing collection on diagnosis data. As long as the basis for collection and the definitions are kept, there are possibilities to leave out certain procedures for collection. In this way the designated integral data collection on hospital (discharge) data (diagnosis and procedures) on a regular basis can create a comprehensive database for research and policy making.

Comparability

The collection of diagnosis and procedure data within the project gave a sound basis on comparability (mainly of hospital use) between the relevant European countries. And again these statistics can be used more widely outside this European group.

Age and Gender are amongst the keys which can be applied to set up analyses.

Another outcome of the project was that the member states themselves learned a lot not only by comparing metadata (in relation to the data collected) but also by studying their own results here. Omissions and flaws in their own national data collection became clear.

Both for the collection as well as for the enhancement of the comparability it was necessary to improve the software. There is now an excellent and useful CD ROM, which is easy to use with metadata, data, shortlist, mappings, and a manual. A new and a very important option of the software is the development of "standard" reports on differences and similarities (comparability).

As stated, at the beginning of this project there were doubts of whether this project should become a new project, or whether the results of the HDP1 project were sufficient to start with an institutionalised approach. HDP2 proved necessary and successful, but a further project is not needed and the process of regular data collection should now be put in place. As soon as possible the management of the deliveries of the HDP projects should be an institutionalised matter. Only then the strict management of (meta)data, shortlists and mappings can be secured.

Institutional approach of integral data collection

There is the need to organise a regular institutionalised integral data collection on hospitalisation (diagnosis and procedures). This data collection should be more than a set of statistics, but be the basis for policy making and evaluation as well as for all kinds of research. Links with other information sources (indicators, economical analysis) are not only feasible but imperative. DG Sanco can play an important role here, being both a facilitator and user of the data.

The data collection and the management of the related short list, mappings as well as metadata could be carried out by institutions such as WHO or Eurostat.

WHO concentrates more on the technical knowledge in the Health sector, while Eurostat is inclined to safeguard the statistical quality. A cooperation between WHO and Eurostat seems therefore beneficial. Integration with existing data collections appears also relevant. OECD also can be of importance to “broaden” the data collection and also to submit their experience in this field. WHO, Eurostat and OECD were all involved in the project, especially whereas the development of the procedure shortlist was concerned.

However, the project is aware that the transfer of the management from the project to an institution at this present moment might not be feasible. Therefore the project strongly recommends that the data management of HDP2 is retained for another 3-4 months. Secondly, there should be a temporary “hospital data working group” formed from the present Core Group, including DG Sanco, WHO, Eurostat and OECD. This working group should draft a proposal on the institutionalisation and transfer of the management of data collection and of the metadata, etc... Since the costs involved in these activities are limited, there are still funds available in the budget of HDP2.

Conclusion

As a methodology project, HDP2 was successful.

- The foundation laid by HDP1 was strong.
- The extension to new member states proved to work very well.
- The development of metadata as a foundation for the analysis and usage of the collected data is considered to be a major product.
- It is possible and highly desirable to have time series data on diagnosis.
- The procedures short list is a useful tool, which enables a useful, but not perfect, basis for data collection on procedures
- Comparative analyses of morbidity, care developments and institutional organisation of the hospital care and financing systems are possible.
- The extension on the issues “cross border” and “out patient” proved difficult.

The overall conclusion is that the objectives of the project were met and the required deliveries were delivered (see 6 and Annex VI.1). The project was finalised within the planned time scale and within the agreed budget. Now we are ready to start the implementation of the methodology for the regular and integral data collection on a broader scope (diagnosis and procedures), combining already existing data collection.

Recommendations

- The project was able to collect the concerned data, but is it imperative that a real institutional management of (meta)data gathering is in place. Therefore it is strongly recommended that a hospital data working group is asked to formulate all aspects of a transfer from the HDP2 deliveries to an institution.
All of this includes the management of short lists, metadata, mappings, data base and the CD ROM containing the data base and software for analysis. This all with the aim to have regular integral data collection (diagnosis and procedures).
- An implementation project is required which can assist member states to solve their problems and get the best possible results. Capacity for the management of (meta)data as well as for the data collection should be there to support the MS.
- For the future the validation rules may be further developed and closer aligned with those of Eurostat.

- We recommend to investigate whether countries can be provided with the appropriate software.
- The use of the data with related metadata should be harmonised internationally as much as possible, without hampering the build up of a European database. The amassing of the data as well as the international harmonisation will be a gradual process.
- The participants recommend the usage of the data of HDP2 by interested parties. This should be carried out under the conditions that the source of the information is properly recognised, the metadata is addressed and that approval of the participant member states is obtained via the managing institution. This to ensure that a (minimum) number of rules are applied and that the risk of abuse is small. It is suggested that the hospital data working group begins to formulate such rules (including quality assurance issues), also for future regular data collections.
- Healthy New Born Babies. It is recommended that this issue will be noted and handled adequately in future international comparisons based on hospital discharge statistics. Countries that do not include them in their national hospital discharge database should estimate the number of healthy newborn babies from other sources and report the figures separately.
- To accomplish a more valid and reliable picture of cross border patients it is recommended to follow a more exogenous approach and to start with present data collections on migration as a basis.
- The selected list on procedures should thus be kept with the proposed 30 procedures with 6 subgroups.
- Procedure statistics should be based on all reported procedures for a single hospital stay and not only on the principal procedure. The rules for avoiding double counting have to be followed.

1. Introduction and Rationale for the Project

1.1. Background

HDP2 is a follow-up project of HDP1 which was a project under the auspices of the European Union Health Monitoring Programme (HMP). HDP1 delivered its Final Report in June 2003.

HDP1 had two key objectives. The first was the preparation of a detailed and practical methodology for the collection of comparable hospital activity data across Europe. The second was the production of a pilot data set according to the agreed methodology which entailed developing specialised software. HDP1 tried to take into account, systematically, all the real and potential causes on non-comparability. The methodology was based on a detailed inventory of patient level data contents and coverage in each participating country.

A Common Data Set (CDS) was specified which maximised the areas of comparability between countries. An Expert Group was commissioned to develop a new diagnosis shortlist appropriate for hospital activity, based on ICD-10 but also compatible with ICD-9. Data was collected from 16 countries (Annex I.1.a), covering both inpatients and day cases, providing data in the CDS format for diagnoses, external causes of injuries and 18 selected procedures. Detailed metadata was also collected describing national data sets and potential causes of variation from common definitions.

Furthermore, specialised software was developed, implemented and distributed to participants on CD-ROM with the pilot hospital data and metadata. A key feature was the facility to open and consult metadata files concurrently with data analysis and validation.

HDP2 should be seen as a project for further consolidating and enhancing the progress achieved through HDP1 and for applying its approach more widely. The general aim of HDP2 has been to develop a methodology for the collection of data on hospital use (by diagnosis and procedures) to be applied by a group of 22 member states (Annex I.1.b). This group comprises most participants of the HDP1 project and new member states.

Participants

There are 22 participants of HDP2. Of the HDP1 group of 16, 2 participants (Sweden and Iceland) did not participate in HDP2. Additionally there were 8 “New Member States (NMS)”: Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovenia.

<u>HDP 1</u>	<u>HDP 1 and 2</u>	<u>HDP2 NMS</u>
Iceland	Austria	Cyprus
Sweden	Belgium	Czech Republic
	Denmark	Estonia
	Finland	Hungary
	France	Latvia
	Germany	Lithuania
	Greece	Poland
	Ireland	Slovenia
	Italy	
	Luxembourg	
	Netherlands	
	Portugal	
	Spain	
	United Kingdom	

Other organisations

To be able to harmonise the results, there was close cooperation with other organisations, such as OECD, WHO and Eurostat.

1.2. Objectives

The general idea for HDP2 was to build on the work of HDP1 and, in particular, to deal with the priority areas for further work identified by HDP1 in its final conclusions and recommendations. The aims of HDP1 and HDP2 were to develop a general methodology for collecting data on hospitalisation that can test how applicable this data is for analysis and comparison amongst the relevant member states. The parameters are diagnosis and procedures. They tell us about throughput within hospitals and morbidity. Furthermore data collections can also be used for exploration of present and future important emerging topics. Comparable data can assist policy making, and finally, you can compare the data collected with the economics in the hospital and developments over time.

Objectives

- Improve comparability of statistics and develop time series;
- Increase the scope of data collected and identify ways of extending data to other areas;
- Extend to new Member States;
- Improve access to, and use of the data.

Specific objectives

- Hospital activity data inventory and collection for new member states;
- Collect data to permit time series analysis for HDP1 participants/ new member states;
- Development procedures shortlist;
- Harmonisation of efforts with other projects/organisations;
- Communication of results and recommendations from the project.

Additional objectives

- Further develop methodology;
- Extend scope (outpatients/patient mobility);
- Ensure harmonisation/avoid duplication (Eurostat, OECD, WHO, ECHI2 (European Community Health Indicators), SHA).

See also chapter 6 and Annex VI.1.

1.3. Project approach

In connection with these HDP2 objectives, the approach for the project was quite straight forward and laid out in the Project Group/Core Group.

1. Start to bring the metadata up to date and collect the metadata from the new member states. The Project Management/ Core group decided not to separate the new member states and have an integral approach. This was also tackled during a session in which again the principles of the data collection, the urgency as well as the objectives of the project were explained and discussed. Here also the relation with SHA/ECHI was an important issue. This meeting was very important to settle the plan and time schedule for the entire project.
2. Collection and verification of the metadata required was a substantial step. There was much time involved in this, but the investment turned out to be of high importance.
3. The objectives and scope for an Expert Group on procedures was determined and the assignment was given to Professor Smedby.
4. Meanwhile the objectives time series and widening the scope of the data collections with other topics were explored.
5. The data collection on diagnosis with time series for all member states was organised and carried out.
6. The findings of the Expert Group concerned were discussed and a preliminary procedure shortlist was drafted.
7. The pilot based on this shortlist took place.
8. There was a thorough analysis on diagnosis time series and comparability.
9. The results of the pilot on procedures were analysed and tested.
10. The shortlist was formally specified within the project, in close cooperation with WHO, Eurostat and OECD.
11. The final report was written.
12. Software is made available for analysis and dissemination of the collected data.

In chapter 6 and Annex VI.1. There is further justification and details on the activities carried out.

1.4. Positioning of the project

The HDP1 was the foundation for HDP2, which can be seen as a continuation of this project under the Working Party of Health Systems. An important limit is formed by the hospitals. In principle only hospital discharge data has been collected. So it is all about care by the hospitals for patients of the hospitals.

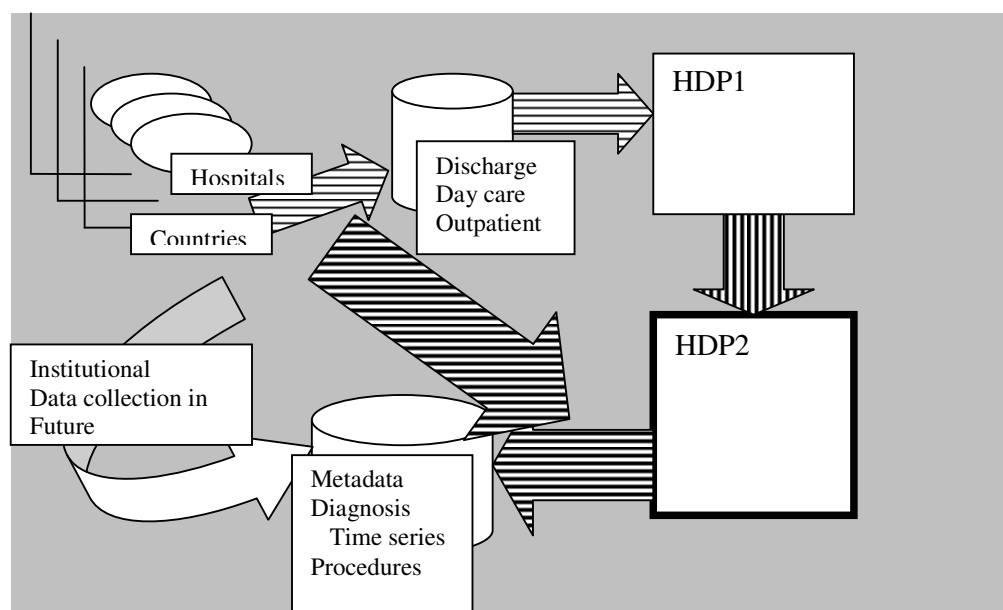
Day patients are within the systems as long there is a discharge record for them.

The already existing relationship with SHA and ECHI developments was laid out in HDP1 and was automatically ingrained here again. The data collected was about hospitalisation primarily defined by diagnosis and procedures. To use the data collected for other purposes is possible and very much welcomed but is beyond the scope of this project.

From the beginning of HDP2 there were discussions whether the HDP2 activities should be carried out by separate institutions instead of by a project. With this discussion in mind there was a close connection with Eurostat and WHO as well as OECD. This was seen as imperative since the results of HDP2 ought to be transferred to an institution.

This close connection with Eurostat and WHO as well as OECD was also important because it was (and is still) envisaged that the project is a step in developing and implementing a methodology to enable a (European/international) database on hospital use to be 'built up'. The transfer of data, metadata as well as short lists and connecting mappings has to be arranged. It has been an objective of HDP2 to prepare such a transfer by seeking close cooperation with institutions concerned.

It is in this context that the importance of the recommendations in Section 6 cannot be emphasised enough. Finally, the relation between HDP1 and HDP 2 including the deliveries of the projects are shown in the figure below. The project deliveries should be the start of institutionalisation of data collection (hospital discharge). This is to be organised and is out side the scope of the HDP project.



1.5. Organisation

The organisation comprised of:

- Project Management;
 - Expert Group on procedures shortlist
- Project Management Group;
- Core Group;
- Full Group.

The Chairman of the Expert Group for a procedures shortlist reports to the Project Management. In practice, the Chairman was present at Core Group meetings and Full Groups as well. See also Annex I.2, which contains also all the meetings.

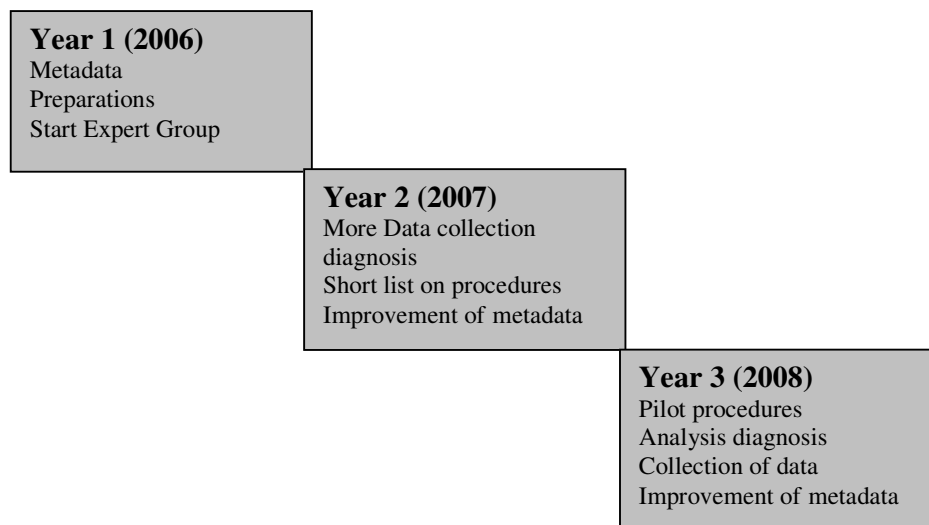
After a first meeting it was decided that a separate Project Management Group was considered inefficient and unnecessary. The Core Group was an important factor to bring together the participants. Here the first rough ideas were drafted and were brought forward to the Full Group. The Project manager coordinated the whole process. The data management was carried out by Prismant, the Netherlands (the Project manager) and the data was processed by Ireland.

1.6. Planning

The start of the project was delayed from 1st of November 2005 until January of 2006 due to administrative matters. In spite of this delay the project was finalised on schedule within 3 years. The activities followed more or less the pre defined work packages.

The spread over the 3 years is shown. In the beginning much emphasis was put on the elementary basics and the importance of metadata.

The metadata was continually further improved during the entire project.



2. Hospitalisation by diagnosis

Planned work was:

- Metadata (up date) and further development for all participants of HDP2;
- Data collection
 - New member states
 - Up date data collection HDP1 participants
 - Time series;
- Deepening and Widening scope of data collection.

2.1. Approach

In connection with the objectives, for the diagnosis there were the following HDP2 actions, all more or less focussed on increasing the comparability between the member states:

- Extension to New Member States;
- Introduction of Time Series;
- Looking at some topics in more depth, e.g. external causes, new born babies;
- Widening the scope with the topics
 - Outpatients
 - Cross border (patient mobility).

(For the last 2 topics see 4.1 and 4.2).

After discussions, it was decided to have one data collection for all participants immediately, instead of a separate one for the new member states as was envisaged. For the diagnosis the ISHMT list was to be applied. This list is based upon the short list compiled and used by the HDP1 project. With the combination of the metadata and the collected data it is possible to carry out analysis, to indicate how the data collections can be used, while the methodology is also tested.

2.2. Extension to new member states

The extension to new member states (8 participants, see 1.1) went well. The foundation here was the metadata. After discussion in the Full Group of the principles, the defining and collecting of the metadata was carried out. A lot of time was invested in this.

Also the differences (coding systems and definitions) were discussed. The differences are not only to be found in the metadata, but the lessons learned of finding solutions together were valuable. Of course not all the problems could be solved, but that was no big hindrance for the data collection(s). It is obvious that for some countries the data collection means a lot of work, but support from the data manager can help. By starting to collect data and solving together the problems that arise, substantial progress is to be made, which decreases the required effort over time.

It is recommended that at the beginning of a new data collection additional care and support for countries concerned is organised.

2.3. Metadata

A substantial amount of time was spent gathering metadata. The result is shown in Annex II.3.a. In II.3.c the metadata is included.

The most important components are:

- Coverage
 - Hospitals: General/special, mental, private and public;
 - Health care services: in-patient and day cases of curative care, in-patient and day cases of rehabilitative care;
 - Nature of individual record on which raw aggregate data is based;
 - Patients place of residence;
- Compliance with Data item definitions
 - Classification system used;
 - Primary diagnosis/main diagnosis;
 - Years for which data is provided;
 - Gender;
 - Age Group;
 - Total inpatients discharges (exclude day cases);
 - Total day case discharges;
 - Total bed days;
 - Mean length of stay;
- Healthy newborns;
- External Causes.

Conclusions

The metadata on diagnosis seems to be very similar in the MS.

- Also the definitions seem to run parallel.
- Main differences occur in applying the definition
 - Day case definition and registration;
 - Coverage differences: e.g. mental disorders, private sector, healthy newborn babies.

2.4. Healthy newborn babies

The HDP1 Expert Group suggested that healthy newborn babies should be included in the analysis of hospital activity. A special group was provided in the shortlist of diagnoses for this category (group 128/2103 defined as ICD-10 code Z38 and ICD-9 code V30-V39).

There were, however, problems in getting data on healthy newborn babies.

In some countries healthy babies are regarded as patients in their own right and registered as patients, while in other countries they will only be registered with their mothers and do not show up in the statistics.

Only babies with a health problem that results in a diagnosis and/or are referred to a pediatric department or ward will be registered and counted as patients. This rule may imply problems because there is no distinct boarder between what should be recorded as a diagnosis and what should not. Hospital reimbursement rules may also influence the decision. Most countries that do register healthy babies seem to use the above mentioned ICD codes for the registration of main diagnosis, but other ICD codes may also be used.

Due to the data collection difficulties HDP1 did not include healthy newborn babies in its pilot data collection and, thus, the shortlist group 128/2103 was not used. The internationally recognised shortlist for diagnoses (ISHMT) has kept the group, however. Furthermore, the indistinct border between which babies will be counted and who will not has caused OECD, Eurostat and WHO/Euro to recommend the inclusion of healthy newborn babies in their hospital discharge data.

The HDP2 data collection on diagnoses did include this group, which thus was used by countries who do register healthy newborn babies as patients with this code in their national hospital database. It turned out that 10 of the 17 countries reporting diagnoses did report data on healthy newborn babies, which are included in the HDP2 database.

Since healthy newborn babies constitute a substantial group one must be aware of how this group is handled in the statistics. The proportion of healthy newborn babies in the HDP2 database varies between 3% and 5% of all discharges for most of the reporting countries. Lower percentages are shown for the Netherlands (1.5% – many deliveries out of hospital) and for England (0.9% – only around 75% births are recorded on hospital systems).

The extent to which healthy newborn babies are included in the statistics is important because it has an effect on comparability. It has an influence on the total discharge rate and average length of stay for a country. The diagnosis pattern among inpatients under one year of age is affected in particular.

In order to get a better understanding of how newborn babies are registered in the HDP2 member states, a special collection of metadata was performed in 2008. For countries that do not register them as patients in their hospital discharge database this did involve use of other sources in order to estimate their numbers. The metadata on newborn babies are given in Annex II.4. (see also CD ROM for data and metadata).

It is recommended that this issue will be noted and handled adequately in future international comparisons based on hospital discharge statistics. Countries that do not include them in their national hospital discharge database should estimate the number of healthy newborn babies from other sources and report the figures separately.

2.5. External causes of injury

Injuries and injury prevention is a major topic for the Commission for several years. An injury is a bodily lesion resulting from acute exposure to energy (mechanical, thermal, electrical, chemical or radiant) or from an insufficiency of a vital element (drowning, strangulation or freezing). Injuries are often classified as unintentional (due to accidents) and intentional (due to self harm or interpersonal violence).

The Commission is extending the data collection and exchange, called the Injury DataBase (IDB). The aim of IDB is to provide all stakeholders with the best available information about the magnitude of the problem including high-risk population groups as well as major risk determinants and risks linked to certain consumer products and services. The Commission supports a Community-wide injury surveillance exchange based on injury data provided by the Member States.

With this in mind, the (meta)data of HDP was again analysed on comparability. Most countries still declare that data on external causes are not available in their national hospital discharge database. A few countries have data available coded according to ICD9 or ICD10. But several of these countries state that the data is incomplete due to missing information on external causes in case of accidents and injuries. For specific metadata for external causes see Annex II.5.

Another issue with respect to external causes is that injury patients mainly present at an emergency room and their injury is treated immediately. This type of patient may resemble a daycare patient, but the definition is not the same as the definition for daycare patients who have planned admissions.

Conclusion

At present national hospital data systems can generate data on external causes to a limited extent from the EU perspective (only few countries are available). However this issue seems so important that it may deserve a small “project” in its own right. May be the need for statistics on external causes of injuries is better met by the existing special accident prevention programs such as IDB. The injured hospital inpatients are included in the HDP statistics, however, since they are registered by the nature of the injury (wound, fracture, intoxication etc), they are coded in chapter XIX of ICD-10, which is part of the diagnosis shortlist. Thus, this type of diagnostic data primarily measures the burden to hospitals of injury care, but it is also of value for accident prevention programs.

2.6. Development of the shortlist for hospital diagnoses

The aim for HDP1 was to improve statistical comparison of hospital activity analysis. One obstacle for achieving comparability was the simultaneous use of ICD-9 and ICD-10, which called for a shortlist of diagnoses consisting of groups defined by both ICD-9 and ICD-10 for comparisons between countries using different ICD revisions and for developing time series statistics.

Within HDP1 an Expert Group was asked to compile a shortlist of diagnoses that could be used for this purpose. Such a list was proposed in the Final Report of HDP1 in June 2003. The proposed shortlist was later discussed with major providers of international hospital statistics such as Eurostat and OECD. After a few minor modifications it was adopted in 2005 by Eurostat, OECD and NOMESCO for data collection and presentation. In October 2005 the list was also adopted by the WHO-FIC Network Meeting to be published at the WHO/Geneva website as the International Shortlist for Hospital Morbidity Tabulation (ISHMT). Currently, OECD, Eurostat and NOMESCO use this list for collecting and dissemination information in their respective databases. WHO/Euro also uses it as one option for data collection to its Hospital Morbidity Database.

The broad use of the ISHMT has resulted in the detection of some inconsistencies and errors in the list. After consultation with the involved international organisations some corrections were decided and published on the WHO/Geneva website in November 2006 and in January 2008. In line with the HDP2 activities further corrections have been decided and published in November 2008

(<http://www.who.int/classifications/apps/icd/implementation/hospitaldischarge.htm>).

Eurostat has also published the ISHMT and the updates in English, French and German on Circa website

(http://circa.europa.eu/Public/irc/dsis/health/library?l=/methodologiessandsdatasc/health_care&vm=detailed&sb=Title).

Most of the changes in the list have been of minor statistical importance. Changes with some statistical impact were made in 2006 in the chapter of diseases in the musculoskeletal system and connective tissue, in January 2008 regarding angina pectoris and other ischaemic heart diseases and in November 2008 with respect to asthma and chronic obstructive pulmonary disease. Some of the corrections have been due to differences between the official ICD-9 version, which was the basis for the original version of ISHMT, and the American adaptation ICD-9-CM, which has been used also in some European countries. This has resulted in the inclusion of some additional ICD-9-CM definitions in the list. The updated list is included in Annex II.6.

Conclusion

The use of the ISHMT by the international organisations and HDP2 has thus been an effective test of the list. It has shown that mapping between classifications is not an easy task, but also that active use of an instrument as ISHMT helps to improve it.

2.7. Data collection and validation

Nearly all the member states participating have delivered data, as can be seen in Annex II.3.

Data collection was mainly following the definitions and the methodology developed by HDP1. See Annex II.3.b also for data form.

For reporting of diagnoses the ISHMT was used. Most countries used the ISHMT version of 2006, a few late reporters did incorporate later updates. The statistical effect of the ISHMT updates is very small in practice.

This mainly refers to the few European countries which still use ICD-9-CM and it affects very few diagnosis groups. The influence on time series analyses is minor for the same reasons. Future data collections should be based on the current ISHMT version. This has also been the case for OECD and Eurostat for their data collection of recent years.

Validation

Concerning the validation there are 3 levels:

- At the hospital level, which is impossible to influence from a project like HDP2;
- At collecting the national data some checks can be done; this was done in close cooperation with the data management centre for HDP2;
- At the HDP level, some checks were carried out in close cooperation with the countries, also using experience from Eurostat.

Eurostat asks the MS to check on sex and age related to diagnosis. We propose that countries are provided with a soft ware tool that is able to perform the validations automatically. HDP2 also had run several checks before the data was processed and asked the MS to correct if necessary and possible. It is recommended that this data management method is applied in the future. The way the validation was carried out, especially the most recent process, is described in more detail in Annex II.7.

The quality of the data is the responsibility of the countries concerned. Even so, it is not to be expected that there are no flaws. The validation process aimed at reducing as many obvious reporting errors as possible. The project holds the opinion that the overall comparability between countries is at a reasonable level and is not at stake.

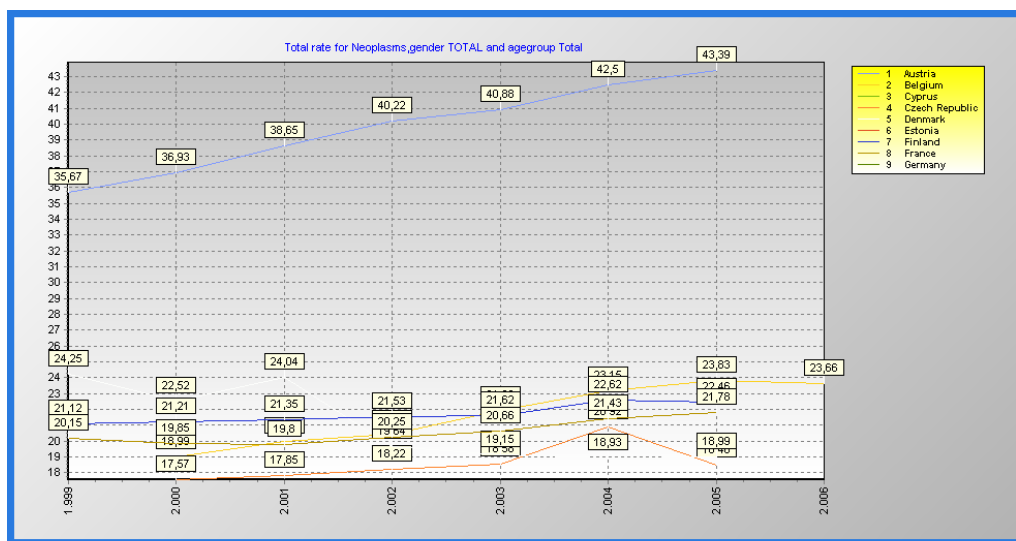
Recommendation

For the future the validation rules may be further developed and closer aligned with those of Eurostat. Also it is recommended to investigate whether countries can be provided with the appropriate soft ware. This would be in line with the urgent request of Eurostat to increase the accuracy of the data as much as is realistic.

2.8. Time Series

It is feasible to collect time series data. One should not expect that all participating countries can submit data over all the (same) years concerned. Here, together with the metadata, valuable information can be derived. Therefore it is important that the collection of data is on a continuous basis and with a proper frequency. The responsible organisation should find a way that countries can submit their national data collection at a time in conjunction with their national collection while comparison between the countries at a practical level remains possible.

An example of a time series analysis is shown below. The example is on neoplasms. Differences in rates may be due to differences in health care systems or registrations but comparing trends sets these differences aside. A rising trend in one member state can be very well compared with a declining trend in another member states. These differences in trends might be even more valuable than differences in rates. Consistent trends also show the reliability of the data collection. In Annex II.8 more examples are given.



Conclusion

The set up of time series require a time series of years and of course regular data collection. Time series are an important element for comparative analysis.

2.9. Comparative analysis

The comparative analysis of HDP2 data on diagnoses is aiming to further evaluate the functioning and usefulness of ISHMT as a tool for international comparison of hospital activities. The emphasis in this presentation will be more on methodological issues than on the content of the statistics reflecting differences in morbidity or health services organisation. Thus, other reasons for variance among countries such as registration and coding differences are of special interest as well as differences due to clinical traditions and policy.

The presentation will illustrate some of the differences found in the analysis of the diagnosis pattern reported from 17 countries. The results were presented and discussed at the Full Group meeting in Madrid in March 2008 (Annex II.9.a). Questions were distributed to the countries about the results (see Annex II.9.b/c). The following includes information based both on the original metadata (Annex II.3) and on the responses to the questions on the results (Annex II.9.b/c.). It has to be emphasised that HDP2 has only collected information on the main diagnosis reported for each hospital stay. In most countries more than one diagnosis is reported nationally but additional diagnoses have not been reported or analysed internationally.

The outcome variables being studied are hospital discharge rates in relation to the population for ISHMT diagnosis groups. Discharge rates have been calculated for all cases (both inpatients and day patients) as well as the proportion of day patients and the average length of stay for inpatients. These outcome variables have been studied with breakdown by age and sex. In this section mainly differences in discharge rates will be exemplified and discussed.

Differences in discharge rates

The total discharge rate, calculated as the rate for all diagnosis groups combined, varies between 200 and 300 per 1000 population among the countries. The highest rates are found for Austria and Belgium and the lowest for Spain (due to known underreporting). Differences among the other countries are less pronounced.

Generally, much greater differences are found for specific groups, both at a higher level, such as the chapter level of ICD, and at a more detailed level, illustrated by specific ISHMT groups.

Austria has a higher rate than any other country for the whole group of *malignant neoplasms*. Otherwise this rate is fairly similar among countries (with the low rate for Spain as an exception). Austria has more hospital beds than most other countries, but a main reason for the high Austrian rate seem to reflect more readmissions during investigation and treatment of cancer patients in Austria than in other countries and coding differences (see below). Morbidity reasons seem unlikely.

Discharge rates for the whole group of *mental and behavioural disorders* vary among countries, mainly reflecting the differences in coverage (mental hospitals not included in some countries).

Discharge rates for the whole chapter *symptoms, signs and abnormal clinical and laboratory findings* are very low in Latvia and Lithuania and relatively high in England and Scotland. There are similar differences for specific symptoms such as *pain in throat and chest* and *abdominal and pelvic pain*. A policy not to use this type of diagnoses, partly connected to lower reimbursement rates for symptoms than for more definite diagnoses, seems to be one possible explanation for the low rates in the Baltic countries. The high U.K. rates could mainly reflect a clinical diagnostic tradition.

There is great variation in discharge rates for the whole chapter *Factors influencing health status and contact with health service (Z-codes)*. There are very high rates for Belgium, France and Ireland. Consequently, this will result in lower rates of other, disease oriented diagnoses. National coding advices seem to be the main reason for the high use of Z-codes. The high rates for Belgium and France are partly due to the inclusion of healthy new born babies in the group (see 2.4). For Ireland which does not include healthy newborn babies, coding rules seems to be a reason.

Denmark sticks out with a very high discharge rate for *medical observation and evaluation for suspected diseases and conditions (Z03)*. A national policy for using this code instead of symptom codes seems to be the explanation.

France, Ireland, Italy and the Netherlands have the highest rates for *other medical care (incl. radiotherapy and chemotherapy sessions)(Z51)*. For Ireland this corresponds to the same discharge rate as for the whole group of malignant neoplasms (for which radiotherapy and chemotherapy are most often provided). It is obvious that different coding praxis exists for care of diagnosed cancer patients. ICD-10 actually advises the use of Z-codes for this type of patients, a rule that is not followed in many countries.

In France the discharge rate (mainly day patients) is high for *other factors influencing health status and contact with health service* (the remainder group within the Z-chapter). This group is mainly composed of follow up and control visits.

Examples

Some examples of different discharge rates for specific diagnoses may also be mentioned here. High discharge rates for *tuberculosis* in Latvia and Lithuania reflects known morbidity differences. Inpatients are mainly middle-aged and elderly men. A policy to keep these patients as inpatients to secure rational drug therapy may be an explanation. Finland shows higher discharge rates for children with *diabetes mellitus* than nearby Denmark. Discharge rates for elderly males are much higher in Denmark, however. These differences seem to reflect morbidity differences.

There are high discharge rates for *hypertensive disease* in Austria, Latvia, Lithuania and Poland. Hypertension is thus reported as the main reason for hospital investigation and treatment in these cases. Probably other countries do more often register the resulting complications to hypertension (cardiosclerosis, heart insufficiency, nephropathy etc) as the main reason for hospital care. Thus, this could it be a matter of coding difference.

A very high rate for *angina pectoris* in Lithuania sticks out and may be a matter of coding difference. There are very low rates for this group in Belgium, Ireland and Spain. The low figure for Ireland 2004 (before the change of its classification) can be explained by the absence of a specific ICD-9-CM definition in the shortlist (mentioned under the ISHMT section above).

Hospital care for *acute upper respiratory infections* is most common in Latvia and Lithuania and also for *pneumonia*, especially in Lithuania. Most of these cases are in the age group under one year. There are marked differences to nearby Finland in these respects. They seem to reflect very different treatment traditions.

There are big differences in the rates for *diverticular disease of intestine*. The high rates in Belgium, France and Ireland may be due to the frequent use of colonoscopy in these countries (shown in the procedure reporting) resulting in detection of (sometimes asymptomatic) diverticulae.

Italy sticks out with high rates for *congenital malformations etc* (mainly registered among children under one year of age). There is no known explanation for this; morbidity differences are unlikely.

Examples of day care differences

Some countries have not been able to report on day care at all or only to a very limited extent. This is true for Czech Rep., Greece, Hungary, Latvia and Lithuania, This also influences some of the comparisons presented above, of course.

For countries that have been able to report on day care, the proportion of day patients (as percentage of all cases) differ quite a bit.

In 2005 it was highest (above 40%) for Belgium, Ireland and Netherlands, 30-35% for France, Italy, England and Scotland and about or below 20% for the other countries.

For all of them there is a clear increase of the proportion of day patients over the time period (1999-2005) for which data is available (see also 2.8).

Which the diagnosis groups with very high proportion of day patients are, differs somewhat among countries. Some groups have very high figures for all countries, however, such as benign neoplasm of colon, cataract, medical abortion, contraceptive management, internal derangement of knee, as well as other medical care including radiotherapy and chemotherapy sessions (code Z51 mentioned above).

High discharge rates (mainly day patients) for *disorders of teeth* are found for Belgium, France, England and Scotland. This is contrary to most other countries. Dental surgery seems to be a task for hospitals in these countries. It seems to be based on tradition but could also be explained by health insurance reimbursement rules.

The variation in discharge rates for *medical (legal) abortion* reflects differences in the legal regulation. The high rates (mainly as day care) in France, Italy, Slovenia and Scotland could possibly be influenced by the abortion method, with readmission of patients treated with non-surgical methods.

France and Ireland both have a high proportion of day patients for *diabetes mellitus*. However, day care is more common in young patients in France but more common among the elderly in Ireland. This may reflect different ways of caring for diabetes.

Differences in average length of stay

The overall average length of stay for inpatients, calculated for all diagnosis groups combined, falls between five and ten days for most countries. The shortest length of stay is found for Denmark, Finland and France. Ireland shows the longest stays, which may be influenced by the high proportion of day care, mainly provided for less severe cases. However, France, reporting the shortest stays, has also a high proportion of day care.

There are only slight differences in the overall figures for length of stay for males and females. In almost all countries men have slightly longer stays than women. Valid and meaningful comparisons have to take both diagnosis and age of patients into account, however. Such studies have been made on the HDP2 diagnosis data but will not be presented here. Mostly, the greatest differences between countries are found for length of stay among older patients.

2.10. Lessons learned

The shortlist of diagnoses (ISHMT) has shown to be a valuable tool for data collection on hospital use. The extensive use of the list by international organisations and by HDP2 has led to detection and correction of some, mostly minor, inconsistencies and errors in the list. A shortlist for international comparison should be kept unchanged for a relatively long period of time to facilitate data collection and dissemination and for time series analyses. ISHMT has the potential to stay as long as ICD-10 is the major classification to be used. Should there be a need for any further changes to the list, an agreed decision process has already been established giving WHO/Geneva the final responsibility for this.

There are several reasons for statistical differences in hospital use between countries. A main purpose with international comparisons is the perspective they can give countries on their own system and possibly stimulate discussions on reforms. Differences in organisational structure, treatment traditions and clinical practice are of special interest for this. One important lesson learned is the necessity of being aware of the many other methodological problems involved, such as differences in registration and reporting rules and in coding practice which have a major influence on the statistics produced.

International hospital statistics are always based on the main diagnosis for the hospital stay, thus not taking additional diagnoses into account. It is therefore important to understand how the selection of main diagnose is done. The international rules for this selection are not always followed and not quite clear. This fact emphasizes the need for WHO and its Network for International Classifications (WHO-FIC) to proceed with work on clarifying this issue.

Metadata that describe national systems and routines for the production of the statistical data are of utmost importance. The collection and analysis of metadata has been an integrated part of HDP2. A major problem for an effective use of hospital statistics is, however, to make such metadata easily available for users of the data and get users to understand the necessity of using them.

One issue for which the problems were not fully understood from the beginning is the different ways of registering newborn babies. HDP2 has helped understanding this issue better.

2.11. Conclusions and Recommendations

Conclusions

There is a need for establishing or finding an institutional base for continuous data collection on hospital use by diagnosis and the management of such a database. Metadata on definitions, content and coverage are the basis for interpretation of the statistics and must accompany all data collection on hospital use. Much effort is required to get the metadata up to date and keep it that way. There is a need for continuous management of data and the relevant metadata.

The ISHMT has proved to be a good instrument for collecting and analysing data on hospital use by diagnosis. The broad international use of the list has resulted in improvement of the definitions of some groups, increasing the comparability between the ICD-9-CM and ICD-10 definitions. There is an agreed process for changes to the ISHMT if needed. The list has the potential of staying as a stable shortlist for hospital diagnoses for the foreseeable future.

It has been possible to collect time series of data on statistics by diagnosis, of value not only for comparing trends between countries but also for the countries themselves. Since the availability of national data from different years differs among countries the improved software has incorporated a function of comparing countries by latest available calendar year.

Countries differ with respect to the registration and coding of healthy newborn babies. How they are handled has an impact on the overall statistics on hospital use.

Countries that do not include them in their hospital discharge database should estimate the number of healthy newborn babies from other sources and report them separately.

Recommendations

Only a few countries are able to report reliable data on external causes of injuries using data from routinely collected hospital discharge databases. Data on external causes are important for injury prevention programmes but are better collected and analysed through special data collection and exchange such as the IDB. Therefore, it is not recommended to broadly collect external cause data through the HDP2 methodology. The HDP2 can provide data on the nature of injury, however, which is part of the ISHMT statistics, also of value for injury prevention.

In order to improve data quality data validation routines have been used aiming at reducing as many obvious reporting errors as possible. This work has to be done in close collaboration with the participating countries and it should continue, making use also of the experience of Eurostat and other international organisations.

Therefore more capacity for the management of (meta)data as well for the data collection should be there to support the MS.

3. Procedures

Overview of HDP2 work on procedures

- Establish a short list on procedures;
- In this connection collect metadata;
- Organise pilot data collection;
- Evaluate pilot results;
- Start data collection on procedures;
- Analyse results from data collection;

3.1. Methodology for development of the list

As already mentioned it was not possible within the scope of HDP1 to conduct a thorough exercise with respect to procedures performed on hospital patients. The HDP1 project did collect data on 18 selected procedures, however, based on some existing shortlists for surgical procedures. The procedures were defined with codes from one of the common classifications (ICD-9-CM part 3) and the participating countries had to translate their national codes into these groups. This pilot data collection was a way to gain experience for further development work, which HDP1 emphasised the need for.

Thus, one major objective of HDP2 was to develop a shortlist of procedures for international comparisons. It was envisaged that a common list of procedures could be used not only for HDP2 but for regular data collection by several organisations at the international level, just as had been the case with the HDP1 diagnosis shortlist.

Professor Björn Smedby was asked to chair an Expert Group, as he did on the development of the diagnosis shortlist. The assignment was to investigate the feasibility of developing a procedure shortlist suitable for international comparison and, if feasible, to develop such a list for the HDP2. The participants of the Expert Group and other international experts whom the group consulted are presented in the report of the Expert Group (Annex III.1). A detailed description of the mode of work is also given there.

A basic decision of the Expert Group was to go for a selected list of procedures and not for an exhaustive list. There is no commonly used international classification of procedures, instead different national classifications have to be used. These do not comprise the same universe of medical and surgical interventions and the number of patients with at least one registered procedure may thus differ among countries due to characteristics of the classifications. Neither is there consensus on how procedures should be grouped in broader groups corresponding to the organ system based chapters of the ICD. For these reasons the Expert Group chose to propose a short list of carefully defined, selected procedures that are able to reflect hospital activity for both inpatients and day patients.

For selecting procedures to be put on the list the following criteria were applied. They were not formally ranked by order of importance but intuitively combined.

Criteria for selection procedures

- Common procedures that are of reasonable volume;
- Potentiality for day surgery;
- Changing techniques over time;
- The economic burden/expensive procedures;
- Public health importance;
- Speciality coverage;
- Continuity with existing international lists.

Other basic considerations of the Expert Group were whether procedure statistics should be based on all procedures reported for a single hospital stay or only on the principal or main procedure. The decision was to go for all procedures. For pilot data collection, the experts recommended statistics based on all procedures, to be compared with principal procedure statistics for countries that could provide such data.

The main steps in the work of the Expert Group were:

- A questionnaire survey among all the participating member states;
- Reviewing a number of available shortlists for procedures;
- Constructing a comprehensive candidate list;
- Discussion of this candidate list in view of agreed principles/criteria for the selection of procedures;
- Analysis of pilot data on procedures collected by HDP1 and from some other countries;
- Mapping the candidate list to several existing procedure classifications;
- Agreeing on a selected list of procedures to be tested in the data collection of HDP2.

The proposed list contained 30 (mainly) surgical procedures with 6 subgroups. The list is found in the report of the Expert Group delivered to HDP2 in June 2007 (Annex III.I). The definition of the procedures were not based on any specific classification but expressed verbally, using the common English term and notations for the chosen procedures. Mappings to the list from several classifications used in Europe were presented together with the list in order to facilitate correct grouping of national data.

After the HDP2 Full Group had received and considered the Expert Group report the following steps were taken:

- Drafting format for data request;
- Collection of specific metadata on procedures;
- Pilot data collection (7 countries);
- Analysis of the results;
- Preparation of broader data collection (17 countries);
- Conclusions and recommendations.

3.2. Metadata

Metadata that refer to all the data collection in HDP2 (such as hospital coverage, registration of day care and private hospital care) has been dealt with above. In addition, extensive metadata on national registration of procedures, classifications used, coding and mapping problems encountered have been collected from the member states.

Seventeen countries have reported metadata on procedures (Annex III.2). All of which collect national data. Half of them record a primary (principal or main) procedure. Almost all of the countries record additional procedures; the total number of registered procedures thus varies from one to unlimited. The countries that assign a primary procedure have different definitions for the selection, however.

Half of the countries use a national procedure classification, some based on the original WHO classification ICPM from 1978. France has a modern classification of its own (CCAM). Four countries use the American ICD-9-CM (different editions however), two countries use the Nordic NCSP and two the Australian ICD-10-AM. National guidelines for the registration of procedures are available in many countries. About half have a national shortlist for the publication of statistics.

Several procedures on the list are performed not only on inpatients but also on day patients (day care or day surgery). In face, one if the selection criterion was used potentiality for day care, primarily. Therefore, the coverage with respect to day care and the definition of a day care case is of certain importance for procedures. Some countries do not register day care at all at the national level (e.g, Spain). For others there is no clear registration of day care cases and they could be hard to differentiate both from inpatients and from hospital outpatients. If lacking a formal registration of day care, countries were advised to count patients discharged on the same day as admitted as day patients (providing they did not die or were referred to another hospital). These circumstances have an influence on the statistics on those procedures that often are performed on day patients. Special metadata was collected on which procedures this applies to (this is expanded on below).

Countries were also asked about problems encountered in mapping the verbal definitions of the procedures on the list to their national classifications. Due to lacking specification in the national classification it was in some cases difficult to get an exact correspondence to the definitions but an approximation could be made. Some of the five subgroups for laparoscopic intervention could not be defined due to lacking codes in the national classification. In these cases, however, comparable statistics can be presented on the main group which the subgroup is part of. (annex III.2.e).

As mentioned earlier, the Expert Group had provided mappings to six of the procedure classifications being used. Metadata indicate that this was helpful for these countries but also for those who had to perform their own mapping from national classifications. Metadata on the problems in mapping has been used to formulate caveats for interpretation of statistics on certain procedures (this is expanded on below).

Most of the countries reported procedure data only for one year – one of the years of the period 2004-2006.

Therefore it is reasonable to present statistics based on latest available year rather than exactly the same calendar year. Differences between years for one country are generally much smaller than differences between countries.

3.3. Data collection and validation

The data is collected using the procedure shortlist that was the work of the Expert Group list. The shortlist can be found in annex III.1. As discussed in paragraph 3.1 the collection took place in two stages. First there was the pilot collection of 7 countries. In the second stage 17 countries delivered data, in annex III.2.a the countries that collected data can be seen. To manage the data collection, a request for data was made (to be seen in annex III.2.b). In the request document the data format is described (annex III.2.b). Problems with the metadata are summarised in annex III. 2.e. An example for a mapping (ICD-9-CM) is in annex III.2.f. (All relevant mappings are on the data CD ROM).

It is important to mention that the data collection is based upon:

- All procedures and not only principle procedure, because the concept of principle procedures only exist in a few countries;
- Both inpatients and day care patients.

Validation

Concerning the validation there are 3 levels:

- At the basis in the hospitals, this is impossible to influence
- At collecting the national data, here some checks can be done, in close cooperation with the data management centre (HDP)
- At the Euro/HDP level, also some checks are carried out in close cooperation.

The validation process of the procedures is described in more detail in Annex . In the annex the guidelines for validation of procedure data are described. Although the quality of the data is the responsibility of the countries concerned, support by data management is required, as is also already stated in the previous part on the diagnosis. (Annex III.2d)

3.4. Comparative analysis

The comparative analysis of HDP2 data on procedures is primarily directed to test and evaluate the functioning of the proposed selected list. This is natural for a project with an emphasis on methodology.

The main purpose for international comparisons in the health field is to give the countries a perspective on the functioning of the health services of their own. Key variables for the comparisons are hospital discharge rates in relation to population by age and sex, percentage of day care and average length of stay for inpatients. Analyses of hospital use for certain procedures make the comparisons more specific and may also involve differences in surgical approach such as laparoscopic interventions versus open surgery.

Differences among countries may serve as an eye-opener and start critical discussions of the functioning and cost-effectiveness of the health services and the hospital activities. There are many reasons for statistical differences between countries such as:

- The coverage is different;
- Real differences in morbidity;
- Clinical treatment traditions;
- Health services organisation;
- Economical aspects;
- Payment system incentives;
- Registration problems (day care vs. outpatients, underreporting of private care);
- Procedure classification differences (including mapping problems);
- Coding practice;

Examples

Below an illustration of some of the differences found for procedures among the 17 countries that had reported data on procedures in September 2008. The data used are from the latest available year in the period 2004-2006; most of them from 2005. (The examples mentioned below are illustrated in a series of diagrams in Annex III.4)

Similar population rates but different surgical approach

Some procedures on the selected list show great similarity with respect to discharge rates in the population. This is true for *cholecystectomy* and *appendectomy*. Also *colectomy* and *inguinal hernia repair* show similar population rates in all countries.

However, there are differences in surgical approach for these common operations. *Laparoscopic cholecystectomies* are done at about the same ratio in all countries (70-90%), while there are marked differences for the other common procedures. Belgium and France have the highest proportion of *laparoscopic appendectomies* (half or more). (See slide 14) There are also great differences for *inguinal hernia repair* with high proportions of laparoscopic approach in Czech Rep., France and Austria. A notably high proportion of *laparoscopic hysterectomies* is reported for Finland. Some of the reported low proportions of laparoscopic approach are due to difficulties in identifying this approach in the classification being used, but there are also clear differences in surgical treatment policy.

Differences in treatment practice and tradition

Thyroidectomy is much more frequent in women than in men in all countries. Ireland and Netherlands have the lowest population rates. A possible explanation is that radioiodine and drug therapy are more common in the treatment of thyrotoxicosis in these countries than in the high rate countries.

The *tonsillectomy* rate is highest in Luxembourg, Netherlands and Belgium and lowest in Czech Rep., Poland, Slovenia and Spain. In Belgium tonsillectomies are very common in the age group 1-4 years compared to Czech Rep. with a very different age-specific pattern (maximum in 15-19 year old). About two-thirds of the tonsillectomies are performed as day surgery in Belgium and Netherlands. This proportion is much lower in all other countries. Could different perceptions of the risks for postoperative complications explain this?

Discharge rates for *coronary artery bypass graft (CABG)* are higher in Belgium, Finland, Netherlands and Italy than in other countries. This is not explained by lower rates for *transluminal coronary angioplasty* for which Belgium and Netherlands have among the highest rates as well. Only for Finland there seems to be a possible explanation in CABG being performed instead of transluminal coronary angioplasty.

The highest rates for *carotid endarterectomy* are found for Austria, Belgium, France and Italy. Definition and registration problems could possibly explain the difference to other, low rate countries. Are differences in clinical policy for the use of this somewhat controversial procedure a more probable explanation for the great country differences?

Rates for *partial excision of mammary gland* are highest in Austria, Belgium, France and Italy. A great proportion of these are done as day care in Ireland but an astonishingly low proportion as day care in France. Except for Greece partial excision is much more common than *total mastectomy*. The greatest difference between the two rates is found for Austria, France and Italy. (See slide 27)

Importance of age structure

Belgium and Denmark are the two countries with the highest discharge rate for *discectomy* but the age distribution of the patients obviously differ (See slide 29). One might ask if there are differences in the clinical indications for discectomy or if there are definition problems for this procedure.

Cochlear implantation is an emerging technology with low discharge rates in all countries, highest in Belgium and Denmark. Age-specific rates for Denmark show that this procedure is mainly performed in the youngest age groups, but cases are also found in the high age groups. It is of special interest to follow the future trend for this procedure and its age related pattern.

There are marked differences between the age specific *cholecystectomy* rates in Denmark; females are operated at much younger age than males. Differences between Denmark and France are found in age-specific female rates for cholecystectomy; females being operated at higher age in France (See slide 33).

Given the great difference in discharge rates for *repair of inguinal hernia* between Ireland and Italy, it is of interest to compare the age-specific rates. It was thought possible that the overall difference could be explained by different age composition (with younger population in Ireland). There is no such explanation, however, since the same relationship between the two countries is found for all age groups (See slide 36).

Length of stay is related to age and comparisons of average length of stay have to take the age structure of populations and patients into account. Overall average length of stay for evacuation of *subdural haematoma end intracerebral haemorrhage* differ not so much between Austria and Denmark but when analyzed by age a clear difference is found with longer stays mainly among elderly Austrian inpatients. Average length of stay for *thyroidectomy* is longer in France than in Denmark for all age groups but the differences are greatest in the oldest age groups. For *coronary artery bypass graft* average length of stay is longer in all age groups in France compared to Netherlands. (See slide 64).

Procedures with registration or definition problems

Discharge rates are very high in almost all countries for *cataract surgery*. However, there are well known problems with registration of these procedures. One may ask to what extent the low rates for cataract surgery in Ireland and Poland are due to underreporting. The proportion of cataract day patients differs among countries, showing very high percentage for Belgium, Finland, Italy and Spain. The very low percentages in some other countries could mainly reflect registration problems or could be explained by real differences in how cataract surgery is handled.

There are high discharge rates for *diagnostic bronchoscopy* in Belgium and France in relation to other countries. There may be known differences in clinical policy or registration problems could explain low rates. There are high proportions of bronchoscopy as day care in Finland, France, Ireland and Netherlands but low proportions in other countries.

There are well known problems with underreporting of *colonoscopies* which may be done on an outpatient basis and as day care. This may at least partly explain the big differences among countries, e.g. high population rates in France but low in Finland, Italy and Spain. In France colonoscopies are performed more frequently in younger age groups than is the case in Belgium and Denmark.

There are some difficulties in defining *infrarenal aortic aneurysm repair* consistently, so part of the country differences may be due to this. There are high rates for Denmark, France, Italy and Netherlands. High rates in Denmark may be due to start of population screening of males for aortic aneurysm. This may be reflected in the fact that Danish patients are operated at a lower age.

There are differences in discharge rates for *femoropopliteal bypass* for which definition and coding problems have also been reported. High rates are found for Belgium, Czech Rep. and Luxembourg.

Gender issues

Most of the sex differences observed are due to morbidity (biological) sex differences such as higher female population rates for thyroidectomy, cholecystectomy, mastectomy and higher male rates for pulmectomy, CABG, and inguinal hernia repair. Although there may be gender differences, i.e. sex differences that cannot be understood as biological differences.

In all countries except Luxembourg and Slovenia (both with small populations) there are higher discharge rates for males than for females for *kidney transplantation*. Without valid information of the prevalence on chronic renal failure (end-stage renal disease) for the two sexes, it is hard to say, however, if this might reflect less access to transplantation for women.

Both for *cholecystectomies* and *appendectomies* there are consistent sex differences with higher proportions of laparoscopic operations among females than males. It may be possible that this could be interpreted as a gender based selection of operation methods. There are age-specific sex differences in operation method, but no greater sex differences in younger age groups as would be expected if cosmetic reason was an important factor.

3.5. Final consideration and suggestion for the selected list

In August 2008 the Expert Group again reviewed the list on the basis of the results of the pilot data collection, including metadata, to consider the need for changes of the list. The main conclusion was that the list had functioned well and provided interesting results.

For some procedures, differences between countries are partly explained by differences in national registration and reporting rules, especially with respect to registration of day care. The blurred border between inpatients and day care patients and between day care and non-registered outpatient care and private care is a problem in several countries. According to the metadata this is true especially for cataract surgery, diagnostic bronchoscopy, colonoscopy and arthroscopic excision of meniscus of the knee. For the latter one there are also difficulties in mapping to some of the procedure classifications. The Expert Group therefore especially considered if any of these four procedures should be excluded from the final list.

Colonoscopy is the only procedure on the list with clear relevance for preventive aspects (i.e. screening for colon cancer) and it is also the most common hospital procedure beside cataract surgery – in spite of underreporting for both. They constitute a normal and important part of hospital activity, even if hospital statistics will not give a complete picture of the extent to which they are performed in the population. Diagnostic bronchoscopy is also a common procedure and arthroscopic excision of meniscus of knee seems to be a somewhat controversial procedure which makes it interesting to follow its development. Therefore, these four common procedures should be kept in the list in spite of some data collection problems. The resulting statistics has to be interpreted with care using information in the metadata that always should be published with the statistics. It is well known, however, that relevant metadata is not always consulted by users of the statistics. Therefore, the Expert Group suggested that some important caveats should be integrated as part of the final list.

Not all countries have been able to report on the five subgroups for laparoscopic interventions due to lack of specification in their procedure classification. Given the great interest in following the introduction and further development of this new technique, these groups should also be kept on the list. It is probable that national classifications without specific codes for laparoscopic approach will introduce such codes before too long.

In its report the Expert Group recommended that procedure statistics should be based on all procedures reported for a single hospital stay and not only be based on the principal or main procedure. HDP2 has primarily collected data on all procedures but a few countries have been able to also report on principal procedure. Comparisons of statistics from the two alternatives have shown that for most of the procedures on the list there is little difference between the two measures, which implies that the procedures on the list usually are principal procedures. There are some obvious exceptions from this, however. Diagnostic bronchoscopy and colonoscopy are often performed together with another, more resource demanding procedure during the same hospital stay, such as pulpectomy and colectomy. Therefore, average length of stay for inpatients for bronchoscopy and colonoscopy will be misleading, since it mainly reflects the influence of the more extensive procedures.

The recommendation of the Expert Group was that future statistics on procedures should be based on all procedures. This calls for rules for double counting and how to avoid it, as specified in the report of the Expert Group. Classifications have different granularity and it is sometimes possible to use more than one code for a single procedure.

If several codes in the definition for a single procedure are registered for the same patient during the same stay, this case should be counted only once for that procedure. But if more than one procedure of those on the selected list is performed during the same stay this case will be counted for both procedures, e.g. one for colonoscopy and one for colectomy.

Only few countries have reported procedure data for more than one year to HDP2. Therefore, the experience with trend analysis is very limited. But it should of course be possible to collect data for trend analysis also for procedures as it was done for diagnoses. The need for maintenance of a procedure list is greater, however, than for a list of diagnoses that could be expected to stay more stable. Surgical development is very rapid, which calls for an agreed process for making future changes to the procedure list. There must be a balance, however, between flexibility and statistical stability.

It is important to decide who should be responsible for the necessary maintenance of the list. If the list becomes a common international list in the future, it seems reasonable to place the formal responsibility for making changes to the list with WHO, just as is the case for the shortlist of diagnoses (the ISHMT). Decisions on changes should be made in consultation with the other international organizations using the list. In Annex III.2.f the mapping ICD-9-CM is as an example included, all mappings can be found on the CD ROM.

Even if the selected list is not changed there may be a need for change of mappings due to updating and changes of national classifications. Therefore, responsibility for maintenance must also fall on national authorities.

In summary, the selected list of procedures has shown to serve the purpose of providing meaningful and interesting comparative statistics of hospital use. The Expert Group recommended that the list should be kept unchanged with thirty groups and six subgroups. The list should be presented with the most important caveats for interpretation of statistics derived from it. The final list has such caveats together with definitions and the main reasons for selection of the procedures. It is presented below.

Final selected list of hospital procedures as recommended by the HDP2 Expert Group

Procedure	Reason for inclusion	Caveat
1. Extirpation, excision and destruction of intracranial lesion Excludes evacuation of haematoma and operations with skull base approach and stereotactic interventions	Specialty coverage	Some national classifications are not able to match the definition exactly
2. Evacuation of subdural haematoma and intracranial haemorrhage Includes evacuation of spontaneous intracranial haemorrhage. Excludes evacuation of epidural haematoma	changing technique, specialty coverage	Some national classifications are not able to match the definition exactly
3. Discectomy Includes intervertebral discectomy for decompression of spinal cord and nerve roots (rhizolysis) with or without excision of bone (laminectomy). Includes microsurgical technique. Excludes chemonucleolysis and discectomy as part of major reconstructive surgery	specialty coverage	Some national classifications are not able to match the definition exactly
4. Thyroidectomy Includes total excision and partial excision of any part of thyroid gland	changing technique, continuity	
5. Cataract surgery Includes secondary implantation of lens and removal of lens	common procedure, day surgery potentiality, public health importance, continuity	Many procedures are performed as day care for which registration completeness varies. Underreporting may also result from non-registered operations in outpatient facilities and private care.
6. Cochlear implantation Includes replacement of cochlear implant	changing technique (emerging technology) expensive procedure, specialty coverage	
7. Tonsillectomy Includes total and partial tonsillectomy with or without adenoidectomy. Excludes adenoidectomy without tonsillectomy	common procedure, day surgery potentiality	Some procedures are performed as day care for which registration completeness varies..

Procedure	Reason inclusion	Caveat
8. Pulmectomy	Speciality coverage	
9. Diagnostic bronchoscopy with or without biopsy Includes bronchoscopy through artificial opening of trachea	common procedure, day care potentiality, specialty coverage	Many procedures are performed as day care for which registration completeness varies. Underreporting may also result from non-registered procedures in outpatient facilities.
10. Transluminal coronary angioplasty Includes percutaneous transluminal interventions (PTCA, PCI), with or without insertion of stent	common procedure, changing technique, continuity	Underreporting is a problem in some countries
11. Coronary artery bypass graft	changing technique, expensive procedure, continuity	Underreporting is a problem in some countries
12. Carotid endarterectomy Includes with or without insertion of stent	changing technique, specialty coverage	
13. Infraarenal aortic aneurysm repair Includes endovascular insertion of stent	changing technique, specialty coverage	Some national classifications are not able to match the definition exactly
14. Femoropopliteal bypass Bypass from femoral to popliteal artery above or below knee	Specialty coverage	Some national classifications are not able to match the definition exactly
15. Stem cell transplantation Applies to recipient only. Includes bone marrow transplantation	changing technique (emerging technology), expensive procedure (process)	
16. Colonoscopy with or without biopsy Includes colonoscopic interventions such as polypectomy. Includes colonoscopy through artificial stoma. Includes sigmoidoscopy. Excludes proctoscopy and rectoscopy	common procedure, day surgery potentiality, public health importance, continuity	Many procedures are performed as day care for which registration completeness varies. Underreporting may also result from non-registered procedures in outpatient facilities and private care.
17. Colectomy Includes partial and total colectomy, excision of ileocaecal junction and colosigmoidectomy and coloproctectomy Thereof: 17a Laparoscopic colectomy Includes "combination of laparoscopic and open techniques (laparoscopic assisted). Excludes conversion from laparoscopic to open surgery	specialty coverage changing technique	

Procedure	Reason inclusion	Caveat
18. Appendectomy Includes incidental and appendectomy “en passant”. (This group includes group 18A) Thereof: 18A. Laparoscopic appendectomy Excludes conversion from laparoscopic to open surgery	common procedure, continuity changing technique	
19. Cholecystectomy (This group includes group 19A) Thereof: 19A. Laparoscopic cholecystectomy Excludes conversion from laparoscopic to open surgery	common procedure, continuity changing technique	
20. Repair of inguinal hernia (This group includes group 20A) Thereof: 20A. Laparoscopic repair of inguinal hernia Excludes conversion from laparoscopic to open surgery	common procedure, day surgery potentiality, continuity changing technique	
21. Transplantation of kidney Applies to recipient only. Includes autotransplantation of kidney	expensive procedure	
22. Open prostatectomy Includes radical and transvesical prostatectomy and excision of adenoma. Excludes transurethral procedures	Continuity	
23. Transurethral prostatectomy Includes transurethral laser resection, electroevaporization and microwave therapy	common procedure, changing technique, continuity	
24. Hysterectomy Includes partial and total hysterectomy (with or without excision of adnexa) by laparotomy or vaginal or laparoscopic methods. Excludes evisceration (exentration) of pelvis and caesarean hysterectomy. (This group includes group 24A) Thereof: 24A. Laparoscopic hysterectomy Includes combination of laparoscopic and open techniques (laparoscopic assisted). Excludes conversion from laparoscopic to open surgery	common procedure, specialty coverage, continuity Changing technique	

Procedure	Reason inclusion	Caveat
25. <i>Caesarean section</i>	common procedure, continuity	
26. <i>Arthroscopic excision of meniscus of knee</i> Includes total and partial excision	common procedure, day surgery potentiality, specialty coverage	Some national classifications are not able to match the definition exactly. Many procedures are performed as day care for which registration completeness varies. Underreporting may also result from non-registered operations in outpatient facilities and private care.
27. <i>Hip replacement</i> Includes total and partial replacement (This group includes group 27A) Thereof: 27A. <i>Secondary hip replacement</i> Includes revision of arthroplasty of hip		
28. <i>Total knee replacement</i> Excludes partial knee replacement Reason: common procedure, changing technique, continuity	common procedure, changing technique, continuity	
29. <i>Partial excision of mammary gland</i> Includes wedge excision and other partial excision with or without lymph node excision. Excludes biopsy and breast reduction surgery.	day surgery potentiality, changing technique	
30. <i>Total mastectomy</i> Includes radical mastectomy and mastectomy with preservation of skin and nipple (subcutaneous mastectomy).	specialty coverage, continuity	

As an example of the mapping provided by the Expert Group the mapping to ICD-9-CM part 3 is presented in Annex III.2.f

3.6. Lessons learned

The thorough work of the Expert Group was a good basis for the selected list of procedures. The initial review of existing shortlists revealed a need for additions to the list in order to gain a broader picture of hospital activity. Through frequency studies of available statistics and after consultations with specialists from different medical fields the candidate list was complemented with some other procedures, e.g. from neurosurgery and vascular surgery. A few emerging procedures and especially new surgical techniques were also added. The comprehensive candidate list was then revised and reduced in light of smaller pilot studies, discussions of definitions and a series of mapping exercises to several procedure classifications. This resulted in fewer ambiguities about the procedures kept on the list.

Lessons from HDP1 had shown quality problems for the mappings to the procedures on the HDP1 short list because they were sometimes done by non-medical persons. Therefore, the mappings performed by the classification experts have served to secure better quality and standardisation in the HDP2 data collection.

All countries may not be able to present reliable data on all the procedures. Comparisons among the remaining countries may still be of value and useful. As mentioned previously, one lesson learned is that differences in organisational structure, registration rules and coding practice are as likely to explain statistical differences between countries in health services use as real differences in morbidity or clinical practice.

Thus there are problems with the comparability of the statistics based on the list. A carefully defined and standardised selected list of procedures may, however, become an instrument for achieving more comparable international statistics.

Nationally collected routine data on hospital use cannot be expected to be perfect. International comparisons based on them, however, can reveal important differences between countries that may help to improve not only future statistics but also – in the long run – the functioning of hospitals through demonstrating alternative ways for organising and running health services.

3.7. Conclusions and recommendations

Conclusions

Registration problems are found in some countries for procedures that are performed on both inpatients and day patients, due to difficulties in differentiating inpatient care from day care and day patients from hospital outpatients. Procedures for which such problems are often found are cataract surgery, diagnostic bronchoscopy, colonoscopy and arthroscopic excision of meniscus of knee. These procedures are very common, however, and constitute a normal and important part of hospital activity.

They should therefore be kept on the list in spite of data collection problems. Some countries have not been able to report on the five subgroups on laparoscopic interventions due to lack of specification in the classifications used.

The subgroups should be kept on the list, however, due to the interest in following this growing technique and the likelihood of future changes in the classifications.

Exact correspondence to the definitions is not possible in some countries for a few other procedures. In spite of this they should be kept on the list. It is not necessary that all countries are able to report on every procedure as long as the majority of countries can do so.

Recommendations

The selected list should thus be kept with the proposed 30 procedures with 6 subgroups. For the interpretation of international comparisons it is important that users are aware of possible comparability problems. In order to stimulate users to read relevant metadata, the list should always be accompanied by the caveats attached to some of the procedures.

Procedure statistics should be based on all reported procedures for a single hospital stay and not only on the principal procedure. The rules for avoiding double counting have to be followed.

The selected list of procedures has been functioning well and statistics based on it have provided interesting and useful results. An important and necessary by-product to the data collection is metadata describing the national registration of procedures and its coverage, the classifications being used and coding and mapping problems related to the list.

Not all countries were able to submit the required data (see Annex III.2.b). It is recommended that there will be an implementation project which assist member states to solve their problems and get the best possible results.

The list has been developed in close contact with international organisations collecting data on hospital use (OECD, Eurostat, WHO/Euro, WHO/Geneva). It is therefore possible that the list may develop into a common international short list of procedures.

Surgical development is rapid, which calls for an agreed process for future changes of the list. Maintenance is needed with respect to content, definitions and mappings. It is important to arrive at a decision on who should be responsible for future maintenance. If it becomes a common international list, it seems reasonable to give the formal responsibility for making changes to WHO, as is the case for the shortlist of diagnoses (ISHMT). Decisions on this should be made in consultation with the other organisations using the list.

4. Special issues

4.1. Outpatients and day-care

Here definitions are very important. About 80% can follow the relevant definition. It is also clear that there are differences between the countries which can not easily be overcome. Day care and outpatients can be the same but that is not always the case for each country. It is also important to consider what the “border” of the hospital is, since this project is about hospital use. Private clinics’ data are collected by some countries, but not all, which again is another difference in the data. This is often dependent on the public funding of health care in particular countries. (See Annex IV.1). It can not be emphasised enough that in spite of the problems and differences the collected -data is of importance. Knowing the differences through the metadata still leaves ample possibilities for analysis.

Day care is (in most cases) included in the data collection. It is an important aspect, for instance, in the analysis of the procedures as it can affect the interpretation of the data (see Annex IV.1).

Outpatient data also have the following issues:

- Less than half the member states collect this data.
- There are large differences in definitions and collection methods.
- Comparability is very difficult.

Conclusion

Collected data on outpatients have not enough meaning. At present Out patients are too difficult to analyse and compare within Europe.

4.2. Cross border hospitalisation

Health systems and health policies across the EU are becoming more interconnected. This is due to many factors, including movement of patients and professional staff. On 2 July 2008, the Commission adopted a draft Directive on the application of patients' rights in to cross-border healthcare, which provides a Community framework for safe, high quality and efficient cross-border healthcare, by reinforcing cooperation between Member States and providing legal certainty over the rights of patients to seek healthcare in another Member State.

Data on cross border patient is also included in the Eurostat data collection. If data on cross border patients is going to be more important in the future, there needs to be more harmonisation and standardisation on procedures.

Cross border treatment of patients is thus clearly an important political and health issue. The HDP projects have their focus on hospital discharge data. It is not a patient data set. This distinction is crucial in understanding the limitations but also the possibilities of the HDP project for information on cross border patients. Most member states do not have information

on which country their citizens go for hospital treatment, so this topic has to be tackled from the perspective of the hospitals. With respect to whether the hospitals registers indicate the country of residence of their patients, the metadata shows that:

- Member states have different methods of coding patients treated in hospital living outside of the country;
- Not all the residents are citizens so there is a definitional issues around 'nationality' and 'non-residents';
- Depending on the health systems in the countries concerned "cross border" patients are (in principle) not registered;
- These issues are not applicable to all countries - only a small number have cross-border activity.

It is possible for some countries to make an analysis where their patients come from. In Annex IV.2.b an example based on a Belgian case is given. This example shows that it is possible, using data from HDP2, to make an analysis on cross border patients but the overall conclusion is that the comparability is poor due to coverage, and that completeness and reliability of the data needs to be improved. In Annex IV.2.a/c metadata specific to cross border is presented.

Recommendation

To accomplish a more valid and reliable picture of cross border patients it is recommended to follow a more exogenous approach and to start with the present data collection on migration as a basis.

4.3. Collaboration and harmonisation with international organisations

During the project there was close cooperation with WHO, Eurostat and OECD. Their representatives were involved in the project activities, present at most Core group and Full Group meetings. Also the Expert Group consulted a specialist, as is described in the Expert Report.

Recommendation

It is obvious that the more a short list is applied internationally, in one way or another, data collection will become more valuable. Therefore the use of the data with related metadata should be harmonised internationally as much as possible, without hampering the build up of a European database as such. The amassing of the data as well as the international harmonisation will be a gradual process. It also means that it is not an absolute matter. Differences, for instances with the applied short list may exist, but this will not be an issue as long as the differences are well documented and do not change the fundamentals of the data collections concerned.

5. Management of (meta)data and data collection

5.1. Metadata, shortlist and mappings

The metadata were built upon and developed from HDP1. It is essential for metadata to be used alongside the data to allow useful analysis and comparisons to be made. Even if comparisons can not be 100% statistically correct (due to collection of administrative data from a wide range of countries) they are the most accurate as is realistically possible and available at this time. A continuous management of the data collection and metadata together, is essential. This should be carried out by an institution and not on project basis. The data collection at national level is already in place for each participating country which means that continuing with this data collection will require minimal resources for contributing countries. For the institution which will carry this forward on a European level, this will become a routine exercise after implementation. Of course this is still to be organised, but will be along the lines of the already existing data collections. Furthermore, the different data collections the member states perform at this moment will be harmonised, which means an improvement in effectiveness as well as efficiency.

Management of metadata is time consuming but essential. Otherwise no comparison is possible. Data are not always absolutely accurate, but with the metadata you can understand what the differences are and what is possible to compare. It is vital to invest time in collection and continuous management of the metadata.

5.2. Database and software

The specialist software developed in Ireland for HDP1 was further enhanced to cater for its role in HDP2. The system is written in Delphi – a rapid application development tool widely used for the development of Microsoft Windows applications and which is particularly powerful tool for generating stand-alone database applications. A major benefit for using this product is that the resultant compiled application is royalty free for distribution on the compact disk (cd). Also the ability to access many types of databases, from local databases to network SQL server databases, will enable the smooth up scaling of the HDP2 database.

The underlying storage and retrieval database used is Paradox. The database tables are indexed to enable fast access to the data. Paradox allows for the use of Structured Query Language (SQL) for data extraction which in turn helps to create a very flexible system for data manipulation. The software which supports a wide range of mapping and graphic features has been improved with the inclusion of standard reports which augment the data comparisons with new graphic features. These features also help support the data validation process. The software facilitates the export of data into Microsoft Word, Microsoft Excel and ASCII files. This in turn allows for the import of the data into a variety of alternative software packages including SPSS, SAS, etc..

The HDP2 software was designed to allow the user to select and create data subsets and graphically view trends across the supported indicators for comparison and for validation purposes. The system was designed in the nature of a database tool. The simplicity of design hides the power of its ability to subset and displays the huge datasets with ease. It is expected that users can exploit the systems functionality with little training. A comprehensive HELP manual which incorporates a step by step user guide is available from within the system. The help manual gives detailed information on how to use the system and explains thoroughly its functionality. The metadata pertaining to the data which in all cases should be consulted when examining the data can be viewed through the system's metadata display feature.

Data Processing

The data was processed and validated by Prismant – Netherlands using SPSS. The raw data was received from each participating country and run through a thorough validation process. After validation the data was then exported to SAS datasets and sent to Ireland. Here the data was further processed and validated for duplicates. The processed data was then converted to Paradox datasets and loaded onto the HDP2 system. HDP2 system CD ROM's were created and issued to each country. Countries were asked to carry out validation checks on their data using the software. A simple process of data validation is included in the system manual and the methodology was explained to all participating countries.

5.3. Availability and use of HDP2 data

All the metadata and data are on the CD ROM, which is easily accessible, not only for the participating countries and concerning institutions but also for other institutions and third parties. In the latter case certain rules must ascertain a proper use of the (meta)data.

Physical availability

The data comes on a CD ROM which includes the application, data and a manual. The system can be loaded onto a single stand alone computer or onto a local area network with little assistance. The system functionality allows for the extraction of the data to files which can be processed by a variety of software applications including SPSS and SAS.

CD ROM

The CD ROM provides the system for easy access to the database. Included on the CD ROM is a user manual which gives step by step instructions on how to use the system. Built into the system area a number of reporting features and a dynamic standard reporting system which enhances the data comparison facilities. The data is displayed in tabular format which can be graphed and mapped for the graphical visualisation of the data. The metadata is also easily accessible within the system.

Age and gender groups are also included. The age groups can be normalised.

Use of the data

In principle the participants are all in favour that the data is properly used. Therefore the participants recommend the usage of the data by interested parties.

This should be carried out under the conditions that the source of the information is properly recognised, the metadata is addressed and the approval of the participant member states is obtained via the managing institution. This is to ensure that a (minimum) number of rules are applied and that the risk of 'abusing' the data is small.

The participants can use the data freely with the restriction that the source is also mentioned with the concerned metadata.

5.4. Future data collection

The participants are convinced that the products of these HDP projects are valuable and that a proper data collection is eminent and necessary; Not only to build up a broad database on diagnosis and procedures with the related metadata and required mappings, but also to extend over the years to obtain more time series. Also use of the data brings evaluation of the applied tooling along. A future data collection should be organised and institutionalised as soon as possible. To wait too long will diminish the usability of the data present at hand.

It is envisaged that a special Project Group spend some more time to formulate ideas for the way the real data collection is to be pursued and how the organisation, management and maintenance of particular products of HDP(2) can be transferred to an institution.

The use of the data with related metadata should be harmonised internationally as much as possible, without hampering the build up of a European database. This amassment as well as the international harmonisation will be a gradual process. It also means that the matter it is not completed. Differences, for instance with the applied short list, may exist but as long as the differences are well documented and do not change the fundamentals of the data collections concerned.

5.5. Lessons learned

The effect of clear and extensive metadata cannot be stressed enough. Without metadata one might be inclined to find the results of the data collection insufficient to be comparable, but with the metadata at hand this is found not to be true. Explanations bring learning, especially of the differences there are. It is certain that the data collection performed in the way it was done will never be accurate enough for everyone's liking. The validation process is on going and improvements will always be sought and required, however, there comes a time when the effort should also be put into the gathering of better metadata, maintenance of mappings and collecting as much as possible. Comparability does not come automatically, but must be analysed into. Therefore do not seek proof and clarity of the statistics, but look for a reasonable insight using the data.

5.6. Conclusions and Recommendations

Conclusion

Short lists are the proper tools for data collection. The collected data is valuable, especially when good metadata is at hand. The data collection when properly organised does not cost exorbitant effort. The software is equipped for data dissemination and analysis. The CD ROM is a useful tool for distributing and using the data.

Recommendations

- Organise an institutional data collection and distribution of the (meta)data;
- Take care of responsible maintenance on (meta) data and methodology;
- Harmonise, where possible, the data collection;
- Organise that other institutions as well as other interested third parties can under strict regulations use the data.

6. Conclusions and Recommendations

6.1. Conclusions

HDP (2) has been a project on methodology. It has addressed how data on diagnosis and procedures can be collected for evaluation and policy making. This also includes how to achieve maximum comparability for member states. The data shown should also be viewed and analysed alongside the metadata.

The project has achieved its objectives but its success will really only show when the collection of the data becomes “institutionalised”. It is now necessary to organise the management of data collection as well as the maintenance of the metadata, mappings and shortlists. The organisation which carries this work forward must collaborate with other European organisations to reduce the burden on member states, so that data is collected only once. Data definitions between organisations need to be agreed between organisations in order for this to be a realistic target.

There are many questions which can be answered using the available data. However it is not possible to anticipate all questions that will be asked. Also the data collection is dynamic and will be subject to changes over time. Therefore for analysis and policy making it is important to formulate the research question carefully in order to use the data effectively.

Aspects of cross border and out patient data are not to be included in a hospital data collection. Due to definitional problems and large differences in the organisation of the care sector, collected data is too amorphous to be of reliable use.

The regular data collection on procedures and diagnosis should be on an annual basis. A decision needs to be made as to whether the data would be collected at a particular set date each year or whether member states would send their most recently available data, which would be at different times throughout the year.

One should bear in mind the reliability of these statistics. Of course the higher the reliability the better the information and the research based upon this data will be. As discussed in sections 2 and 3, validation is also important.

Time series are very useful to see the development in Europe and in the member states concerned. The data is not only of interest to create an overview over the collective member states but also for the individual member states themselves. Further more it is a source for institutions, policy makers and scientists.

6.2. Recommendations

We have learned enough through HDP1 and HDP2 and obtained a good picture on hospital data. Although there is always room for improvement, it is time to push forward and really start to organise the relevant data collection. Improvement will then be yielded (while busy) to collect and especially use the (meta)data.

It is recommended that a special Project Group spend some more time to formulate ideas for the way the real data collection is to be pursued and how the organisation, management and maintenance of particular products of HDP(2) can be transferred to an institution.

The use of the data with related metadata should be harmonised internationally as much as possible, without hampering the build up of a European database as such. The amassing of the data as well as the international harmonisation will be a gradual process. It also means that not all of the issues are resolved. Differences, for instance with the applied short list may exist, but this is acceptable as long as the differences are well documented and do not change the fundamental of the data collections concerned.

The participants recommend the usage of the data by interested parties. This should be carried out under the conditions that the source of the information is properly recognised, the metadata is addressed and that approval of the participant member states is obtained via the managing institution. This to ensure that a (minimum) number of rules are applied and that the risk of abusing is small. It is suggested that the working group begins to formulate such rules (also quality assurance). See Annex VI: Justification.

In this context, the data should be submitted with examples, guidelines, and more over organise seminars, news letters, handy summary of this project to motivate concerning parties to follow up and use the data.

6.3. Conclusions and Recommendation per objective

The following conclusions and recommendations in line with the basic objectives of the project HDP2 are mentioned.

1. Extension by new Member States

The new member states were “absorbed” rather easily. There were no separate sessions required (or desired). Metadata formed the ‘bridge’ between the member states. Thereby metadata and mappings for the various code systems are felt sufficient and member states were given the freedom of which years to supply according to their possible options (1999-2005).

2. Time series

Time series were possible and they are certainly very interesting, not only over the collective member states, but also for the member states themselves. This project was a project on methodology. Therefore it was good to discover that it is indeed possible to collect time series. Also it was learned where attention should be focussed upon: to not only ensure that the data is 100% comparable but to also to learn what can be analysed over the member states in close connection with the metadata.

The results should always be viewed with the metadata at hand.

Time series are important; also therefore a regular integral data collection is to be started, while the existing data base forms an interesting data base already.

3. New topics

- Out patient

The possibilities to collect data for this issue were discussed profoundly. However a general solution is not realistic, as the metadata shows (see also 4.1). It is recommended not including out patients in the epidemiological hospital sphere.

- Cross border

The possibilities to collect data for this issue were discussed profoundly. However a general solution is not realistic, as also the metadata shows (discussed in 4.2). Since this subject is highly important for policy making it is recommended to start a separate study, whereas the Belgium analysis may be used as a start.

Analysis on this topic is also possible with the metadata at hand.

4. Diagnosis HDP2, possible analyses

- External causes

Some analysis on the collected data on comparability. Incomparability due to differences in organisation of the care and hospital systems, although not saying anything about external causes, can be of interest (see 2.5).

- The collected data, also the time series data, makes valuable analyses and evaluations possible. For the member states separately, but also over the member states. See 2.7, 2.8).

- Within in the frame work of the methodology of both HDP projects Gender issues can be further analysed. The data is in the data collection and on the CD ROM.

- Within in the frame work of the methodology of both HDP projects age issues can be further analysed. The data is in the data collection and on the CD ROM. More over if required the age groups can, for certain analyses, be normalized (see manual of CD ROM).

For all of these issues, viewing of the metadata is important so that analysis, even based on incomplete data, can be of interest.

5. Short list Procedures

The relevant objectives are fully achieved. See chapter 3 as well 6.1.

6. Data collection

It is important to bear in mind that the data collection concerns statistical data. A perfect data collection in the sense that there are 'water tight' definitions and validations may be desirable but is not realistic. Of course a certain minimum reliability is required. It is imperative to institutionalise an annual data collection (diagnosis and procedures) to yield the results of HDP (1 and 2). WHO, who is already occupied in the data collection, seems a logical choice. See 6.1.

7. Management of shortlist, metadata and data, CD

Quite a substantial part of the spent time and attention was focussed on the metadata and the mappings as well as the shortlists. At this stage of this project on methodology there is a valuable set of documents, more or less the describing back bone of a possible data collection. It is imperative that these documents should be keep up to date as to enable further data collection. Management of these documents should be organised. Data collection and with it the management of the methodology and concerning (meta)data should be institutionalised. This is not for recommendation by the project. The logical institution to do so is WHO in close connection with Eurostat. But cooperation with OECD can be useful, in spite that this latter organisation is not European. DG Sanco might play a directors role.

This should be explored in detail, but is not within the scope of this methodology project. Data come from the participating member states in csv file format (Excell). Up load to the CD ROM via Paradox to free format distribution. That means that "conversion" to SPSS and SAS is possible. See chapter 5.

8. Recommendations

In each section there are recommendations. In the summary the major ones are summarised.

9. Extension after the project

There is not a real extension recommended for the project but it is envisaged that a special hospital data work group spent some more time to formulate ideas for the way the real data collection is to be pursued and how the organisation, management and maintenance of particular products of HDP(2) can be transformed to an institution. It could be of big help to formulate a temporary implementation project to help countries with specific problems.

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