WHO meeting on the National Health Information Systems (NHIS) project: lessons learned from the pilot phase

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ABSTRACT

The Czech Republic, Denmark, Finland, Hungary, Poland and Romania completed the pilot phase of the project launched by the Health Information and Evidence unit in 2003. Its aim is to develop and test a methodology which could then be made available to all Member States that want to engage in assessing and strengthening their National Health Information Systems. The tools were discussed, and some changes will be brought to them in light of the national reports, due in December.

A draft of the evaluation paper was discussed, with special focus on the preparation steps before the interviews take place, the role of interviews vs. legislation and documentation review, the template for the report, and the role of WHO’s visit to the country.

Follow-up challenges, once the assessment is completed, were discussed in light of experiences from Romania (with the WHO Regional Office for Europe’s methodology) and Finland (based on a self-initiated Reform process). Partnerships in funding and training are essential, as well as the creation of guided dialogue spaces between decision-makers and the producers of information.

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Scope and purpose

The Health Information System (HIS) should be seen as a full part of the health system, offering the basis for its stewardship function. Ministries of health are in the best position to lead the process of reinforcing, or even reforming, the National Health Information Systems (NHIS), while mainstreaming the population data and health-related data from other ministries and disseminating health data to other sectors. The WHO Regional Office for Europe has the responsibility to support Member States to strengthen their Health Information Systems.

The scope of the Regional Office’s project called “Assessment of National Health Information Systems (NHIS)” is to analyse the national health information system and identify areas for improvement. The final goal is to enable the Member States to improve the quality and relevance of the information for decision-making processes. The project consists in producing national reports based on (a) semi-structured interviews with key-informants, and (b) a review of the legislation and background documents pertaining to health information.

The objectives of this meeting were:
- to present the results of the assessment in each of the four pilot countries and the way the report was used in Romania;
- to evaluate the strengths and weaknesses of the methodology (tools and process), before it is offered to other countries;
- in light of the Finland experience in HIS Reform, and of examples from Denmark: to explore the possible next steps of the project, that is the follow-up on the reports’ recommendations, taking advantage of the momentum created by the NHIS assessment and the publication of the reports.

Proceedings

Dr Anca Dumitrescu (Director, Division of Health Information, Evidence and Communication) opened and chaired the meeting until 2.00 p.m.; Ms Véronique Addor (Adviser, Health Information and Evidence) led the discussions.

Dr József Vitrai has been appointed Deputy Head of Department, Office of Titular Secretary of State. He is replaced by Ms Csilla Kaposvari, Head, Department of Health Monitoring and Epidemiology, National Centre for Epidemiology. We are thankful to Dr Vitrai for his significant contribution to the NHIS project, and for hosting the meeting. We look forward to further collaboration with him, and welcome Ms Csilla Kaposvari into the group.

Representatives of the four 2004 pilot countries – the Czech Republic, Denmark, Hungary and Poland – first presented the outline of their reports with the main findings and recommendations suitable for their NHIS. They also described how the methodology has been used and adapted to their country’s situation. Presentations from the meeting are attached ( ).

Ms Addor offered a preliminary evaluation of the tools and process used in the pilot phase, the details of which can be found in the main background paper for the meeting.
Concrete results are already visible in terms of capacity-building in the countries. National teams have gone a long way from the launch meeting of the pilot phase in Prague a year ago: they gained more specific and comprehensive knowledge of the NHIS, enlarged/reinforced their network within the country and internationally, were empowered by the exercise, and strengthened their analytical capacities. Discussions are lively and specific.

The objectives for the pilot phase have been reached, which were (a) to test and refine the methodology for use by other countries; (b) to exchange experiences across pilot countries in assessing the NHIS; and (c) to strengthen Regional Office network of key-informants (public health institutions and decision-makers). The methodology was considered globally appropriate for use by other countries. Minor adjustments will be made to the tools, and participants in the pilot phase were invited to make additional comments by mail if needed.

The main added value of the project is its innovative nature, which brings together producers and users of information (including decision-makers) to discuss not only problems, but also possible solutions. Heads of institutes of public health or institutes of statistics become interviewers of their target audience, through a direct interaction around the main goals of each other’s activities. Such a global viewpoint over the NHIS is unusual. Another major asset of the project was its extension to the district level, getting away from an exclusively national focus. These professionals were honoured and volunteered crucial information about the processing and use of data and information. Their information products and their decision-making process have a lot to contribute to national institutions.

The project was very well received by national teams and by interviewees. Heads of units, even after years of experience in the field and regular meetings with the other actors of the NHIS, reported that they made interesting “discoveries” about their country’s system and the functioning of even well-known partner institutions. This NHIS assessment was timely regarding current national and international preoccupations: documenting health interventions and outcomes in a more efficient way, accessing evidence-based information at the right time in the decision-making process, and understanding where the bottlenecks are for the production of timely and appropriate information. Recognizing the other factors influencing decision-making was an opening to policy-makers.

WHO’s understanding of country-specific HIS problems is clearly enhanced by working closely with national teams, beyond the usual statistical counterparts. The project has good visibility, as indicated by requests for the reports from other countries, presentations of the reports and recommendations at national conferences (Hungary, Romania), articles in local and international journals to be published, and WHO headquarters’ interest through the Health Metrics Network (HMN).

New international exchanges are taking place as a result of this project. The Hungarian team visited the Danish team in August 2004. Dr A. Poustrup (Denmark) participated in a round table discussion at the Hungarian National Conference on Health Information, held on 16 November. Dr Mika Gissler presented the Finnish experience at the Hungarian seminar for policy-makers (see below). The names of more contacts and resource persons were exchanged through e-mail. Dr Irma Csiki is acting as a consultant for Moldova, and Dr Pavla Lexova and Dr Jana Brozova have been contacted by Slovakia, two new countries starting the NHIS assessment.

Challenges include the relative difficulty for the teams to grasp, at first, the scope of the assessment exercise and the unusual process (in the HIS context) of interviewing: who should be
interviewed, why, how should the interviewees be approached, how do interviews complement the documents which are publicly available, were among issues raised several times in the process by all teams. For new countries wishing to use these tools, the examples provided by the pilot countries’ reports should be a significant help to start the project. The visit of a WHO adviser, which was possible in Denmark, Hungary, Poland (and Romania in 2003), was also considered an asset.

- WHO’s presence/support adds to the visibility of the project and of the topic of health information in the country, opens doors to some high-level decisions-makers.
- It helps put in place local collaboration paths which are unusual for statistical offices; e-mails and phone are not sufficient.
- WHO adviser acts as a facilitator, contributes to empower the national team and their institution in front of decision-makers (a key element of the project).
- Helps refocus when the interview goes off track.
- Significantly improves understanding of the country’s situation by the Regional Office, allows for a much closer follow-up and participation in reports’ content, including the elaboration of appropriate recommendations for improvement.
- Extends WHO’s network in the country, allows advertising other activities in health information (e.g. Health Evidence Network, Health for All Database).

However, a country visit is expensive and time-consuming at the scale of 52 countries, and it was recommended to make most use of WHO liaison offices where available.

Other challenges included:

- finding the right team leader and interviewer (thus the importance of a balanced and complementary team);
- an appropriate and seasoned use of the “questionnaire” (renamed “interview guide” to avoid a systematic mailing to interviewees or a rigid questioning session);
- managing qualitative analysis (integration of documentation/legislative review with material from the interviews), and writing a report which truly exemplifies the type of information products we are trying to promote, with the right level of recommendations.

Tools should be considered as one means, among others, to initiate the movement of rethinking and reviewing the NHIS, as well as to exchange within the country and internationally around this issue. However, regular assessments are needed to monitor changes and reforms which are brought to the HIS. Tools can be adapted for this purpose too. The idea is to seize all opportunities of improving the use of information and evidence in decision-making, using the tools as aids.
Sample findings from the NHIS assessments in one or more of the four pilot countries

- A historical practice of data collection exists in all four countries, but the match is often poor between the data produced and the information actually needed; Denmark and the Czech Republic have the most favourable situation in this regard.

- A too restrictive interpretation of the legislation originally intended to ensure confidentiality, in all countries except Denmark, is an obstacle to modern analyses of health services utilization, in particular when studying the seamless chain of care; breaks in confidentiality are still happening though. In Denmark, the linkage system to a population registry is possible through strict respect of databases utilization rules, adequate salaries, “pride” of the staff in charge, and demonstration of the usefulness for all users, including the population itself. Emphasis should be on use rather than misuse (non-existent in Denmark) of personal identification data.

- Long delays to pass and also to implement new laws pertaining to the HIS lead to inefficiencies.

- Fees for data, even between public institutions, can be major obstacles to their full use and accessibility (except in the Czech Republic).

- Quality checks on primary data could be improved and performed in a more systematic manner (need for definitions and standardization, e.g. for hospital-based care), together with a simplification of the data collection procedures; underreporting, coding and reliability in general could be improved.

- Paper is still a support for data transmission, and could/will be reduced by appropriate IT technologies; compatibility of software is an issue.

- Preventive interventions are less thoroughly documented than other areas of health, and data are scarce on the effectiveness of interventions and large programmes’ outcomes.

- Data gaps or limitations exist for some important public health areas, such as minorities, health inequalities in general, or utilization of health services.

- Surveys are scarce in some countries, and their full potential as a complement to routine statistics could be further explored (better integration of routine, register and survey data as in Finland and Denmark).

- Feedback to data providers and users at intermediate levels in the chain of data processing is scarce; it could be seen as leverage to enhance quality through motivation.

- Publication deadlines are too long (decisions are already made), except in the Czech Republic.

- All countries increasingly use web sites to display data and information, which allows for more flexibility and quicker updates.

- There is insufficient focus on interpretation and forecasting.

- The reliability of some hospital data and coding of death is questionable (Hungary, Poland).

- Data are rarely aggregated and analysed at the level where the decision is made.
The data flow between ministries is insufficient, often non-existent; the lack of communication with, and integration of, Insurance Funds data, is also problematic.

Information requests are rarely expressed clearly by decision-makers, and it is difficult for institutions to anticipate issues which will be on the political agenda (except in the Czech Republic).

Establishing personal contacts with the decision-makers is crucial, and this project enabled this.

There is a tension between the need for stability and sustainability in the NHIS, and the need for quick answers and frequent changes in the government, as exemplified by Hungary at the time of the meeting.

Institutions chosen to conduct the project are in a good coordinating position to ensure governmental support and leadership.

Except in Denmark, there is a lack of awareness and purposefulness at all levels about what an efficient HIS can actually bring to both data and health care providers, and even to decision-making; this results in inaction and underfunding.

Among recommendations, the following have a high potential for bringing about real changes:

1. Create an interface structure between information producers and decision-makers, most efficient if based within the ministry of health, with a mandate across ministries.
2. Train and “educate” both information producers (and more generally public health professionals and researchers) and decision-makers together, possibly through the creation of a specific school or curriculum.
3. Focus on targeted analysis and interpretation of findings.
4. Formulate national programmes and health care reform plans in measurable terms; have community indicators at the disposal of policy-makers, to monitor their policies.
5. Stimulate partnerships for HIS funding and for specific training programmes.

Follow-up of the project

Implementing the report’s conclusions and recommendations is a major challenge of this project. Sustainability at country level was among the conditions of success, but funding and interest are not straightforwardly and naturally directed into the area of HIS.

Questions were raised by the participants concerning the type of support WHO was willing to provide for the follow-up at country level. Given limited resources and possible reorientation of priorities at the Regional Office, it is pretty much left at this point to the countries’ authorities and institutions, although expert advice will remain available either at the Regional Office or at WHO headquarters.

For new countries engaging in the assessment, WHO expertise will be available at the Regional Office and within the network of the test countries. Participants from Finland and Romania shared their experience in the follow-up, Finland through an independent process initiated by the government, and Romania through the present project, complemented by an initiative by the National Insurance Fund and two new PHARE projects (see ). It was clear from the Finnish
experience that the difficulty of forecasting all the financial implications of a NHIS Reform and reflecting them in the budget for the next year was underestimated. As a result, budget corresponding to new commitments are not always secured, and may preclude implementation of the solutions, even after large consultation and governmental approval. In Finland, needs for new data collection were estimated at ten persons-year; monitoring the implementation of the new health care reform is the most costly part. Provisional estimates indicate that the Danish HIS, quite exemplary, costs about €70 million in its current form.

Choosing from and assessing the impact of the changes in the NHIS, following the recommendations made in the national reports, would be the next step of the project in pilot countries. This could be conducted by a representative council of all stakeholders at national level. Financial and technical partnerships will be crucial for the implementation phase, and WHO can assist in that. The Health Metrics Network (HMN) at WHO headquarters is one possible avenue.

Lessons learned from the Hungarian seminar for policymakers (held on 17 November)

The whole group participated. This seminar was seen as part of the follow-up process in Hungary. However, less than 10 decision-makers attended the seminar held on a boat from 06.00 to 10.00 p.m., consisting of formal presentations by WHO, a practical exercise on children and road pollution, and a buffet. Among explanations for the low turn-out were recent political and staff changes, the fear of decision-makers to be asked for active participation, not being offered the possibility to stay overnight for representatives from the provinces, lack of a precise definition of the target group, concurrent events (meeting of district HIS services), appropriateness of formal presentations as the right format for decision-makers, and having an English-speaking facilitator with translator instead of a native speaker. It seems desirable to concentrate on one sub-topic (e.g. primary health care, e-health) instead of presenting the whole HIS.

However, it was an opportunity for the Hungarian team to meet again with some of the interviewees and strengthen links for future action.

Decisions

- Deadline postponed to 6 December for reports from Hungary, the Czech Republic and Poland (end of December for Denmark).
- Instruments will be updated according to reports’ content and participants’ comments during the meeting and then circulated among participants for comments (by mid-January).

Proposals

1. (Denmark): organize a meeting on the topic “Personal data for health planning and research: why not?” under WHO’s umbrella about data/information confidentiality in link with the seamless chain of care and health care reforms. Only WHO has the authority,
credibility and neutrality to play this kind of role as a networking facilitator, and it should continue to do so; bilateral contacts are not sufficient. This would be an important contribution to the current debate about data confidentiality which arises in many European countries. Also, WHO should work more closely with the European Union and other international organizations, such as the Organisation for Economic Co-operation and Development, to obtain a strong statement supporting NHIS in Member States.

2. (Hungary): print small brochures for each national report, summarizing the finding in an attractive way.

3. (All): have a web page for the NHIS project, with all the national reports (after January 2005).

4. Pilot countries may be consulted as experts for new countries starting on the NHIS assessment.
Annex 1

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