

## **Sacred secrets broken. Threats to the confidentiality of medical records. The case of Osabide, the centralized data base of Osakidetza (Basque Health Service) in Spain**

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### **Introduction and summary**

The Basque Health Service, Osakidetza, has established a centralized data base, Osabide, with two millions medical records in full without asking permission or even notifying patients or the public (in some case against the written opposition of a few patients who know about the initiative). Two general practitioners who rejected Osabide and prepared a piece of paper to inform patients in the waiting room has been punished with a penalty of two years without working and salaries.

I invite you to participate in a global initiative of e-mail Osakidetza managers to demonstrate that physicians over the world are against this kind of initiative which threatens the confidentiality of medical records and contradict guidelines by the World Medical Association.

### **The confusion between megabytes and mega data bases**

We live in a time when information is valued more highly than action so the collection and analysis of data seem to have become ends in themselves. Nowhere is this more evident than in health services. Now it is technically possible to build up mega data bases with the whole medical records of millions of patients. Collecting and using large bodies of information centrally in a health care system is very expensive and clinically useless. And what about privacy?. What about sharing sacred secrets when patients have not given written consent?. What about the general question of protecting confidentiality?

Politicians in the Basque Country (Spain) and managers in Osakidetza built up a huge medical data base with the whole information of two millions medical records (total population of the Spanish Autonomous Region) updated every day with any piece of information (SOAP, episodes of care, list of problems, prevention activities, tests results, imaging, etc) from any patient-physician and patient-nurse encounter. The official reason is “to offer continuity of care”. The initiative, Osabide, has now more than a year of implementation and in any way considers anything about consent by patients or at least notification to patients. Because Osabide is not illegal *sensu stricto* according to Spanish laws, attempts to stop it have been not successful.

Osabide is against common sense and medical ethics in Spain and elsewhere. The World Medical Association (WMA) declaration on ethical considerations regarding health databases adopted by the WMA General Assembly, Washington, 2002, is very clear about it ( <http://www.wma.net/e/policy.html> ). Central to the question are articles 12 (physicians' responsibilities for the confidentiality of the personal information they hold) and 10 and 16 (patients rights to be informed and to decide that their personal health information is to be stored in a database).

### **Punishment**

Spain has a public health system funded by general taxation covering the whole population. Professionals are public employees paying by salary (and capitation in primary care). In

primary care they work in groups (“teams” according to the legal jargon) in public health centers [general practitioners plus pediatricians plus nurses]. General practitioners have a patient list and they do home visits.

Two general practitioners, Dr. Ángel Ruiz Téllez and Dr. Paz Pérez Gortari, working in Sansomendi Health Centre (Vitoria, Basque Country), opposed Osabide (in March 2002). But the whole electronic medical records (18.000) were transferred to the central data base. They have the opportunity to label an episode as confidential but how to review eighth previous years of work?. And Osakidetza strongly recommended not to use the label “confidential” because the objective of Osabide, “continuity of care”

Osakidetza did not ask permission to patients nor notified them of the new situation (migration of electronics medical records from the health center to a central database, free access to more than 2.500 professionals, and more). So they wrote a note notifying patients in a piece of paper an put it in the waiting room. The note said, *verbatim* “*Estimados pacientes: con motivo del cambio de programa informático, Osakidetza ha traspasado los datos clínicos de los pacientes de este centro de salud a una base centralizada, fuera del centro. Considero mi deber informarles de que dicho cambio se hace sin mi autorización, ni con la suya, por lo que yo no asumo los perjuicios y molestias que esta medida pueda suponer*”. [Dear patients: with the new informatic program Osakidetza has transferred clinical data of patients of this health center to a central data base, away form the centre. I consider my duty to inform you that the tranfer has no my permisson nor yours, and I cannot assume the damage and trouble this initiative can produce to you]. Because this advise and because they did not change their own daily practice from the old informatic system to Osabide, in March 2003 they has been punished with a penalty of two years without working and salary.

I must say that after working almost 30 years in the Spanish National Health Service I have never heard about a such hard penalty (even going drunk to work has not been so severely punish;).

### **What to do?**

My suggestion is:

- 1.- to send a postal card to Dr. Ángel Ruiz Téllez and Dr. Paz Pérez Gortari supporting them, to their postal address: Honduras 5, 1º, E. 01009 Vitoria, Álava (Spain)
- and 2.- to send an e-mail about a/ the problem of confidentiality, b/ the need of asking patients consent when transferring data to a central database, and c/ the opportunity of canceling the punishment to

Mr. Josu Garay [jgaray@sscc.osakidetza.net](mailto:jgaray@sscc.osakidetza.net) (General Director of Osakidetza)  
with copies to:

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[iberraondo@sscc.osakidetza.net](mailto:iberraondo@sscc.osakidetza.net) (Subdirector of ATP, Osakidetza)

[adeblas@apar.osakidetza.net](mailto:adeblas@apar.osakidetza.net) (Manager, Comarca Araba, Vitoria)

[alatorre@apar.osakidetza.net](mailto:alatorre@apar.osakidetza.net) (Medical Director, Comarca Araba, Victoria)

[artotxiki@euskalnet.net](mailto:artotxiki@euskalnet.net) (Coordinator, Sansomendi health centre, Vitoria)

### **Conflict of interest**

**None.**

I have no friendship with Dr. Ángel Ruiz Téllez nor with Dr. Paz Pérez Gortari, although I know Dr. Ángel Ruiz Téllez because he is an expert in medical informatics and leader in this field in Spain. I have no ill-will, antagonism or animadversion to managers of Osakidetza though their decisions could and should be criticize from a scientific point of view when they conflict with a better clinical or ethical option.