French Republic

PARLIAMENTARY OFFICE FOR SCIENTIFIC AND TECHNOLOGICAL ASSESSMENT

The Personal Medical Record (DMP): what status update for what prospects?

Report of the public hearing of 30 April 2009

The Parliamentary Office for Scientific and Technological Assessment (OPECST), on the initiative of Mr Pierre Lasbordes, a deputy and Vice-Chairman of OPECST, organised on 30 April 2009 a public hearing on the Personal Medical Record (DMP - dossier médical personnel). The creation of the DMP has been scheduled since the adoption of an Act in 2004 and its issues are essential, both for the quality of healthcare and the protection of personal health data.

This public hearing was aimed, on the one hand, at taking stock of the experimentation as conducted to date, by examining the advances achieved and the difficulties encountered, and on the other hand, at studying the project's future prospects, in the light in particular of the relaunching plan announced by the Ministry of Health and Sports and by taking account of the technological solutions available in this field.

By convening, for a single day, the main players of the project, authors of reports assessing the status of its advancement, the CNIL (National Committee on Information Technology and Liberties), representatives of the ministry, health professionals and users of the health system, as well as companies from the sector, the hearing set out to compare analyses on the conditions in which the project has been conducted, and also to compare the recommendations made following this feedback of experience.

Framework of the debate

The creation of the Personal Medical Record was decided by the Act of 13 August 2004 on health insurance, as a follow-up to the provisions introduced by the Act of 2002 on patients' rights.

To achieve this goal, a public interest group (GIP) was set up in 2005. The GIP-DMP grouped the State (the Ministry of Health and Sports), the Health Insurance Fund (CNAMTS), as well as the Caisse des dépôts et consignations (a public financial institution). It was tasked with acting as the contracting authority for the DMP.

The DMP was initially planned to be rolled out in 2007. However its roll-out has experienced many delays and difficulties, which have given rise to several experts' reports. On the basis of these reports, the Ministry of Health and Sports has again taken on responsibility for the DMP and drew up a relaunching plan for the DMP and shared health information systems which was presented on 9 April 2009. The flagship measure of the relaunching plan consists in the creation of a structure with widened competences, the ASIP (Agency for Shared Information Systems in Healthcare) which will group the GIP-DMP (Personal Medical Record), the GIP-CPS (Healthcare Professional Card), and the interoperability part of the GMSIH (Hospital Information System Modernisation Group).

The aim of the hearing was therefore to bring together the main DMP players so as to determine whether the conditions for the success of the project were now present and whether all the obstacles had been removed.

It therefore appeared necessary to take stock of the previous stages of the project and analyse the causes of the observed dysfunctions. Then, in a second stage, it had to be ensured that the new teams tasked with the project were fully aware of the expectations and concerns of future DMP users and had the wherewithall to provide satisfactory solutions.

Therefore the public hearing aimed at shedding as much light as possible on the challenges to be met so that the project can come to fruition by the deadline (mid-2010). During the public hearing, the determination of the various partners to discuss the issue and the quality of the interventions led to an in-depth debate

with due hearing of the parties. This debate underscored the priority for the new teams tasked with the project to overhaul the latter by defining a clear framework based on a broad consensus so that the DMP can form the modern and effective instrument improving the healthcare received by our citizens.

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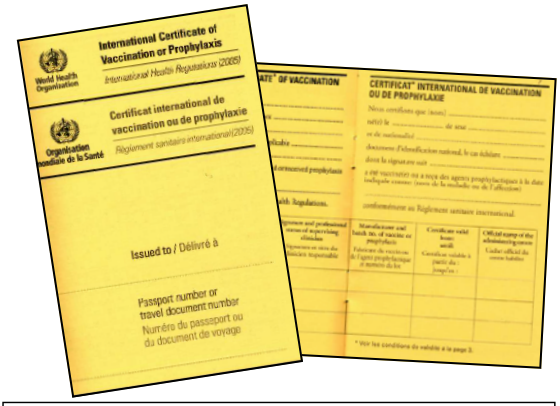
Defining the DMP

From the outset, the imprecision surrounding the definition of the DMP was an obstacle to the development of the project and uptake by the various players. At the time of the announcement of the relaunching plan by the Ministry for Health and Sports on 9 April 2009, it was stated that the **electronic medical record** was meant to be **both personal and shared**. Its aim is indeed to strengthen the role of the patient as a player of his health, by facilitating his access to his healthcare data, and also improve the



International vaccination or prophylaxis certificate

coordination and quality of healthcare, by promoting data communication between healthcare professionals.

The uncertainties as to the manner of addressing the DMP partly arise, beyond the organisational problems emphasised in the various experts' reports, from this twin goal since it is designed as a data processing instrument at the service of patients and also healthcare professionals. However, if it is considered that the patient is at the heart of the system, the question arises as to control by the latter over the content of the DMP, with in particular the right of concealment (the patient himself deciding which information he wants to see appearing in his e-medical record) and collection of the patient's consent whether it be a matter of entering data into the record or consulting it. On the other hand, if the DMP is designed mainly as a healthcare coordination instrument, admittedly for the patient's benefit but not intended to be managed by the latter, then healthcare professionals will be led to be the main users of said record.

It is therefore essential to clarify the nature of the DMP and especially to agree on the definition of the P (Personal, Shared [Partagé], Professional?) in order to demarcate respective fields of competence and the uses assigned to the DMP, even if the latter are designed to be capable of evolution.

Reconciling the various requirements (patients' right to the protection of sensitive data and access of healthcare professionals to the information they vitally need to take care of patients) forms a prerequisite for defining the content of the DMP and the information that will appear in it, as well as for its creation for which its internal structure must be determined.

Lessons to be learnt

The operation of the GIP-DMP has underscored the importance of the choice of personnel and their qualifications. As complicated jobs are entailed, it was suggested, during the hearing, to call in specialised recruitment agencies so as to attract the skills necessary to pursue the project. A more effective human resources management policy is therefore a prerequisite.

The fact that the new structure set in place, the ASIP, is recruiting teams geared to conducting the project, so as to fully exercise its mission as the contracting authority, would also help limit excessive interventionism on the part of ministerial advisers. Overall governance and a clearly affirmed political determination will constitute guaranteed success for the project to a greater degree than daily control.

The governance deficit was underscored in all the reports on the DMP. After legislative decisions which had not perhaps fully grasped the complexity of the project, the lack of strong political support and follow-up on the part of the government did not allow this far-reaching data processing project to be dynamised. However, **governance plays an essential leading role**. Indeed, effective conduct of the project depends closely on the power of governance, the quality of its decisions and compliance with the latter. Project management and contracting must therefore be permanently combined throughout the project.

From right to left : Mr Jean-Claude Étienne, senator, First Vice-Chairman of OPECST, Mr Pierre Lasbordes, deputy, Vice-Chairman of OPECST, and two speakers.

Motivating future users

To date the DMP project has not given rise to strong take-up on the part of future users, whether healthcare professionals or patients. A certain indifference can even

be observed, or even more or less pronounced hesitations. As a matter of priority the interest of the DMP should therefore be demonstrated both for healthcare professionals, whether in private practice or hospital practitioners, and patients.

As for healthcare professionals, the DMP must not be seen as making administrative tasks more cumbersome at a time when these are already time-consuming and medical time is limited. That's why it is essential to stress respect for medical time devoted to patients. Also, the workstation of doctors in private practice is to be ergonomic, and hospital establishments must be equipped with the necessary communication instruments so that consulting the DMP and adding data to it is simple, rapid and reliable. For healthcare professionals the DMP represents a change in daily practice, with more systematic use of data processing and the sharing of medical data on the same patient.

Healthcare professionals will not accept to alter their medical practices and develop DMP uses unless they can *draw an advantage from it in exercising their profession: saving in time, increased security of the diagnosis and therapeutic prescription*. In this respect,

healthcare professionals appear to be particularly interested by exchanges between doctors in private practice and hospital practitioners because the sharing of medical data via the DMP would strengthen care coordination, thereby helping to avoid superfluous examinations and optimising the therapeutic strategy. Hospital practitioners, including those at emergencies, need to know the medical history and the current medical situation of patients they must treat, in order to *combat iatrogenicity* - medical errors that are always possible and the repetition of pointless procedures (iatrogenicity is the causing of complications due to the administration of medicines, like so many negative effects). In the same spirit of cooperation between the various medical personnel treating the same patient, it is essential that the family doctor should have direct access to the main biological and hospital data (results of analyses, reports on hospitalisations and surgical operations, anatomopathological examinations, radiological examinations...). The issue of the traceability of legal responsibility must be better addressed and a clear and fair solution must be proposed in a concerted manner, especially with regard to the ever greater access of patients to medical information on the Internet, which information should be of better quality, if not certified, as certification is a source of disputes of a legal nature.

For their part, patients must be convinced that the DMP will help to focus on prevention, ensuring better quality healthcare and therefore improving their health. In this respect, it could be beneficial to test out the DMP on patients suffering from a chronic disease. By taking a practical case, for instance diabetes, a disease lending itself to involvement on the part of the patient and which requires coordination between the various healthcare personnel owing to the risks of complications and the management cost, the interest of the DMP for patients would become clearer and the strengthened surveillance achieved with it would help improve the efficacy of treatments. The benefit of sharing medical information could also be seen more rapidly.

Security and confidentiality requirements

The lack of enthusiasm with regard to the DMP project is partly due to the questions and concerns it raises, which have not all received satisfactory answers to date.

Advances have been noted. For instance, common ground appears to have been found regarding the identifier since the CNIL, which had taken a stand in favour of an identifier different than the NIR (INSEE code for the identification of individuals) is not opposed to the use of a calculated INS (National Health Identifier) pending the roll-out of a random INS. The issue of the collection of the patient's consent, whether it be for the opening of, consultation of or adding of data to the DMP, must also be rapidly settled. The various stakeholders agree on the principle of explicit consent, the procedures of which must be identical for all present and future health records (DMP, pharmaceutical record, '*web médecin* - doctors' web' whereby doctors can access electronically the history of the prescriptions and reimbursements of patients who have consulted them in the last twelve months. ...).

Other essential points nevertheless appear to present more difficulties, either because of their complexity or owing to the lack of consensus. These points are first of all related to the infrastructures set in place for the roll-out of the DMP. It is a matter on the one hand of the CPS card authenticating the practitioner and therefore ensuring that only authorised

persons can access the patient's record. However, the roll-out of the DMP is presently very insufficient, especially in hospital settings (85% of the 650,000 cards in use are used by doctors in private practice). Similarly, the workstation of healthcare professionals is at the heart of the debate, both regarding its ergonomics

(software allowing user-friendly use, interoperability of all workstations) and its security (choice of the data host, definition of the protection profile of the workstation). Last, the recurrent issue of the right of concealment has still not been settled, healthcare professionals considering it as dangerous, whereas patients are concerned about preserving their private life. Between these contradictory aspirations for exhaustivity and selectivity, only in-depth analysis with mandatory participation of the various stakeholders will lead to the development of practical solutions meeting this twin requirement. Medical secrecy is highly respected by healthcare workers as a whole, so perhaps this conflict is merely apparent.

These issues in suspense concern sensitive topics concerning the security and confidentiality of healthcare data. Providing answers to them is therefore a prerequisite to get all the players mobilised in the project.

A global strategy

The DMP is a highly strategic national health project. However it has been rolled out to date in the form of regional trials or specialised records, without any precise guidelines as to the technical procedures and even fewer directives as to the purposes. Many players in the field have acted with conviction and determination in these various projects. A return must be secured on these major human and financial investments by drawing on the encountered difficulties and successful initiatives so as to develop a national model that can become a major component of health information systems.

The DMP project must therefore fit into a global strategy as it is highly marked by its interdependence with other e-health fields and will be increasingly so in the future. The setting in place of the ASIP, whose field of competences groups the DMP, the CPS card and the thorny issue of interoperability, represents the first time the global context has been taken into account into which the DMP fits. The DMP is indeed set to become the keystone of a vast set-up creating a genuine revolution in the healthcare system, so as to make the most modern means available to improve the quality and security of the healthcare provided to our citizens as a whole, while respecting patients' rights.

Conclusions

1. Better explain the purpose of the DMP
   - Give precise meaning to the 'P' in DMP;
   - Mobilise healthcare professionals and patients;
   - Assess the expected benefits for organisation and management;
   - Identify the constraints in terms of security and confidentiality;
   - Study the possibility of drafting a charter binding the various stakeholders.
2. Determine everyone's responsibilities as part of the governance of the project
   - Clarify the responsibilities lying respectively with the political power and with the governance bodies;
   - Provide the governance bodies with the competences required to exercise the missions assigned to them;
   - Formalise everyone's responsibilities with a precise mission statement based on clear options.
3. Organise the roll-out process
   - Give better chronological, budgetary and organisational visibility;
   - Ensure manufacturers are involved;
   - Ensure that a centre is set up to raise the awareness of players and provide their vocational training.
4. Ensuring coherence of the project with the related legislative and regulatory provisions
   - Provide an overview of the legal infrastructure in force, in order to identify measures remaining to be taken and those that should be modified if applicable.

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