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INTRODUCTION

Genetic information is often considered as specific, among other biological information, because of its personal and family dimension. When a person is diagnosed with a serious genetic anomaly, the disclosure of this information can be relevant for other family members. For this reason, patient has to inform his relatives when prevention measures or treatment, including genetic counselling, exist. This information can be delivered directly by the patient or indirectly through a legal procedure involving the geneticist responsible for the index case.

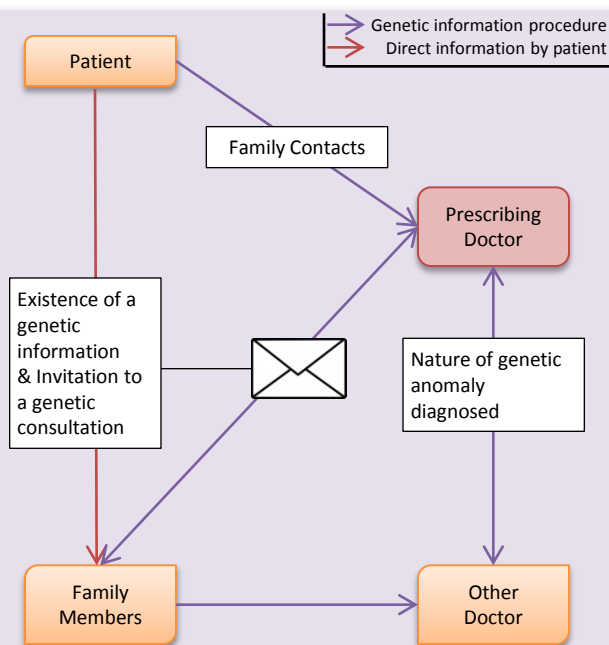
QUESTIONS

Both transmissions of this information raises **legal issues** :

- For **professionals** : how to preserve confidentiality and privacy of personal medical information ? How to ensure the right to know of the relatives when the information to be disclosed can be of interest for their health ?
- For **patients** : what, why, to whom, when and how genetic information should be disclosed to minimize adverse outcomes ?

GENETIC INFORMATION TO FAMILY MEMBERS

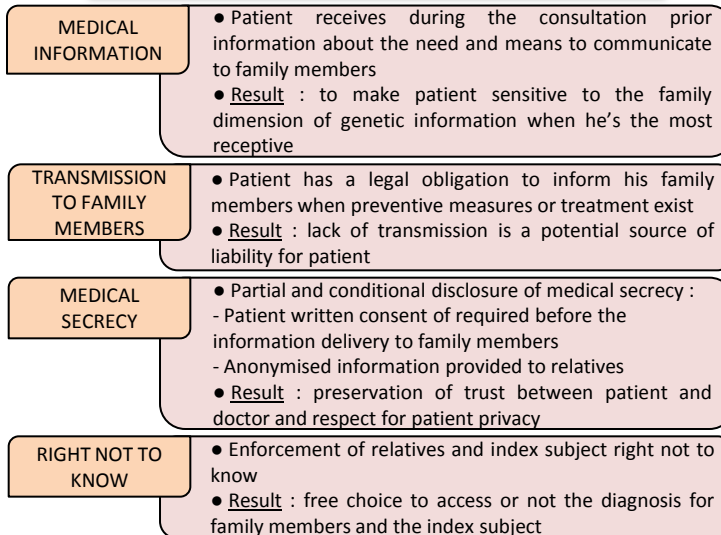
French Public Health Code : L.1131-1-2



Conditions to enforce the legal procedure to disclose the information :

- Diagnosis of a **serious** genetic anomaly susceptible of **preventive measures or treatment, including genetic counselling**
- In case the **patient doesn't want to inform his family members himself or doesn't want to know the diagnosis**

Equilibrium of principles protecting patients' rights



MEDICAL INFORMATION

- Patient receives during the consultation prior information about the need and means to communicate to family members
- **Result** : to make patient sensitive to the family dimension of genetic information when he's the most receptive

TRANSMISSION TO FAMILY MEMBERS

- Patient has a legal obligation to inform his family members when preventive measures or treatment exist
- **Result** : lack of transmission is a potential source of liability for patient

MEDICAL SECRECY

- Partial and conditional disclosure of medical secrecy :
 - Patient written consent of required before the information delivery to family members
 - Anonymised information provided to relatives
- **Result** : preservation of trust between patient and doctor and respect for patient privacy

RIGHT NOT TO KNOW

- Enforcement of relatives and index subject right not to know
- **Result** : free choice to access or not the diagnosis for family members and the index subject

Remaining unclear points - Discussion

- **On the conditions of enforcement :**
 - Notions of "**seriousness**" and "**preventive measures or treatment**" : what is their meaning ?
 - "**family members potentially involved**" : who are exactly the family members to be informed according to the law ?
 - "**shall inform**" : what are the nature and basis of the patient's responsibility ?
- **On the scope :**
 - The addition of "**genetic counselling**" among preventive measures : what is the impact on the scope of the procedure ?
 - Regarding **minors** : does the procedure is applicable to them ?
 - Regarding **prenatal diagnosis** : does the procedure is applicable when a genetic anomaly is diagnosed in prenatal period ?

CONCLUSION

This procedure, revised by the new bioethics law (2011), tends to favor information of relatives by creating a primary legal obligation for the index subject to inform his family members. It draws an effective balance between legal principles (medical secrecy and right to know). Regulatory texts published in 2013 have enriched the procedure (such as the meaning of some terms). However, even if the French legal system is currently almost complete, some difficulties still persist and news ones have emerged (doctor's responsibility who is now in a core position regarding the procedure, addition of genetic counselling) leading to an heterogeneity of practices among medical doctors. Should we need in the future to contribute to the elaboration of professional standards ? In that sense, a set of recommendations will be produced by the end of the current project.

References : Loi relative à la bioéthique n°2011-814 du 07 juillet 2011, parue au JORF n°0157 du 08 juillet 2011 ; T. Herran, Quelle réforme pour l'information génétique familiale ? In. La révision des lois de bioéthique : Loi n°2011-814 du 07 juillet 2011 (V. Larribau-Terneyre, J.-J. Lemouland), Editions l'Harmattan, novembre 2011, p. 65. ; C. Dupras, V. Ravitsky, Disclosing genetic information de family members : the role of empirical ethics. In eLS 2013, John Wiley & Sons Ltd.

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