

METTRE EN BANQUE L'ADN

Enquête sur une biopolitique du consentement

La mise en banque de l'ADN est devenue un enjeu stratégique central pour la recherche médicale dans le but d'étudier le rôle des gènes dans la survenue des maladies et de pouvoir proposer à terme une médecine dite prédictive. Dans un souci de régulation éthique, cette mise en banque se voit fermement encadrée, tant au niveau national qu'international, par une mobilisation active du principe du consentement des individus. Faisant de cette activité un domaine exemplaire d'une nouvelle biopolitique fondée sur l'assentement des personnes, leur information et même leur participation à la définition de l'acceptabilité des finalités de la recherche, portant dans ce cas sur les gènes. Comment les usagers se positionnent-ils face à ce gouvernement du corps et de ses éléments ? Au-delà du fait classiquement observé que ces derniers rencontrent diverses difficultés à pouvoir exprimer un consentement éclairé, une enquête empirique conduit à signaler aussi l'existence d'oppositions voire de résistances pour certains à actualiser cette biopolitique du consentement et à y adhérer pleinement. Cette distance critique se comprend notamment au regard de la perspective que cette biopolitique les amène à devenir, pour partie, « banques » des finalités d'une recherche qui, sous certains aspects, leur échappe.



Pascal DUCOURNAU est maître de conférences en sociologie au Centre universitaire de formation et de recherche J.F. Champollion d'Albi et sametel, dans le cadre d'un contrat d'interface, à l'Unité INSERM U556 « Épidémiologie et analyses en santé publique : risques, maladies chroniques et handicaps ». Il est par ailleurs enseignant-chercheur associé au LIEST (UMR-CNRS) Université de Toulouse Le Mirail.

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