



# Direct-To-Consumers Genetic testing: a medicalisation new facet ?

Henri Jautrou

## ► To cite this version:

Henri Jautrou. Direct-To-Consumers Genetic testing: a medicalisation new facet ?. Sharing science, sharing values: the challenge of diversity., Dec 2015, Toulouse, France. . hal-02535638

**HAL Id: hal-02535638**

**<https://hal.science/hal-02535638>**

Submitted on 7 Apr 2020

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Copyright

# Direct-To-Consumers Genetic Testing : a new facet of medicalization ?



Henri Jautrou  
PhD candidate in sociology  
Doctoral school: TESC (UT2)

Co-directeurs de thèse : BES Marie-Pierre (LISST, UMR 5193)  
DUCOURNAU Pascal (CUFR Champollion)



UMR 1027 INSERM (UT3) / UMR 5193 CNRS (UT2)

## Background :

Our study deals with Direct-To-Consumers Genetic Testing (DTCGTs) sold on the Internet, and more specifically with the ones for health, physiology, performance and behaviour. The products of this booming sector (since 2000) don't require a medical prescription, and health professional consultancy for results access is not systematically needed, which is sales modality not allowed by some national legislations. DTCGTs is an innovation that spark off controversies which are rooted in multiples scientific and medical uncertainties ("missing heritability", informed consent, third parties, etc.).

## Issue: DTCGTs, sign of a new medicalization ?

Medicalization is partly defined as an extension movement of medical jurisdiction, which means interventions in a growing number of human problems (i.e. obesity, child/adult hyperactivity, etc.), both medical and non medical problems. If DTCGTs looks like a de-medicalization movement of genetic and its practice, *"it is essential to remember that demedicalization does not occur until a problem is no longer defined in medical terms, and medical treatments are no longer seen as an appropriate solution"* (Conrad et Schneider, 1980). Conrad (1980, 1992, 2007) make out two occurrences:

- « institutional medicalization » perceives physicians as « formal supervisors in organizations that adopt a medical definition of a problem, yet the routine everyday work is accomplished by non-medical personnel »,*
- « conceptual medicalization » turns up when « a medical vocabulary (or model) is used to "order" or define the problem at hand ».*

DTCGTs are paradoxical. From on side (institutional medicalization), the withdrawal of the medical corps (due to the free access selling) can be identified as demedicalization. From an other side, (conceptual medicalization ) DTCGTs are an extension of medical vocabulary. Our hypothesis is that they are a sign of new actors in the medicalization process.

## Methodology :

To understand this market, we set up a double database which informs the features of DTCGTs companies (inventory and exploration of web-sites, national commercial registers, media sources, etc.), and of theirs entrepreneurs (qualification, entrepreneurial experiences, number of scientific publications or patent registrations, etc. ). We listed 130 web-sites, then focalized on specific web-sites that we called "Incomers" (n=82; whose 56 was created by 86 entrepreneurs).

## It looks like de-medicalization...

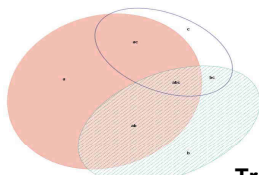
- Genetic testing go out of the medical profession : petitions asking access to the genetic data in order to « *empower the users* », contestation of « *medical paternalism* », « Do It Yourself Biology », political lobbying/militantism against what is call the « *medical power* » and the « *nannies* », etc.
- Few physicians are part of the companies: among entrepreneurs, medicine diplomas (n=15) represent 15% of all diplomas (n=103) ; only 24% (n=19) of the companies are joined by medical counsellors.
- In reaction, the medical regulation is rising :
  - « cease and desist letters » sent to the companies (from FDA, California and N.Y states).
  - sovereign power in USA/UE (i.e. UE: sales are forbidden; France: clients are liable to a 3 750 € fine).
  - medical associations incline to be opposed to DTCGT, and ask for physicians to be involved in the process (it could be « *medical conceptualisation* »).

## ...but it is also a conceptual medicalization.

- Adoption of a medical and genetical vocabulary in order to solve or define human problems (medical, social, cultural, or environnemental) :
  - of daily life: behaviour traits transformed in psychiatric diseases (i.e. violence and warrior gene, bipolarity), cleverness (born gift for such or such discipline), psychology (i.e. love compatibility between to persons, even homosexuality predispositions), physical performance (i.e. alcool endurance, sportive endurance, injuries risk, etc.), nutrigenetic (i.e. cardiac diseases, cancer, obesity).
  - medical (eventually, problems linked to « *diseases of civilisation* »): cardiac diseases, cancer, pharmaco-genetics and « *companion diagnostics* ».
- Creation of a new epidemiological categorie: people said « *at risk* » are « *neither healthy, neither sick* », but susceptible to medical intervention such as:
  - prophylactic mastectomies (in a letter sent to a companie, FDA called attention on risk of over-medicalization)
  - medical follow-up , etc.

## Motors of this medicalization

- Distribution, inside the companies (n=50), of founders' diplomas :



- Pink: biology (i.e. genetic), n=32
- Blue: medicine, n=12
- Turquoise: management (of scientific activities), n=28

Combinations can concern persons who have several diplomas (i.e. such as somes single founder companies).

## -Traditionnal Actors (More or less) -

- NIH: research grants (GWAS or bioinformatic).
- University : « *spin-offs* » and business incubators.
- 35% of the companies (n=28) develop active links with research or scientific industrial world (research collaborations, publications, economical partnerships, etc.).
- Companies out of our specific sample selection are scientific actors (expert of informatic, pharmaceutical, biotechnologies, etc.).

## - New actors -

- Investment funds (often in companies which have a scientific activity).
- Experts of (bio)informatic/NTIC, and marketing « 2.0 » : 4 « Big Five » are localized in the Silicon Valley.

## Specific role of physicians

- Entrepreneurs are higly diplomed (87%) and part of an elite (53%): academic prestige, high number of publications, postes à responsabilité (professors, institut/companie directors, CA, etc.).
- Physicians who fund a companie and got several diplomas (in genetic, law, management or administration) are 67% (n=10) of all « *physicians entrepreneurs* ».
- Medical counselors for the companies have the same profil than « *physicians entrepreneurs* » (i.e. several diplomas and professional elites).

## Perspective

Clarke and al. (2000, 2010) propose to use the term « *biomedicalization* » instead of « *medicalization* », specially to underline the diversity of actors which now produce medicine. Our work shows the TGALs business is based on a « *medicalization without physicians* », but is populated by non medical actors. In addition, the physicians profil is relatively homogenous, and linked to research. A deeper insight in this medical presence would help to describe DTCGT market.

**Rencontres Internationales. Partager la science, partager les valeurs : le challenge de la diversité / International meeting. Sharing science, sharing values: the challenge of diversity.**

**03/12/2015.** Plus de détails [ICI](#).

H. JAUTROU

**INSERM (Unité 1027);** Université Paul Sabatier - Toulouse III: "Epidémiologie et analyses en santé publique: risques, maladies chroniques et handicap", Equipe 4 : "Génomique, biothérapies et santé publique : approche interdisciplinaire".

**LISST (UMR CNRS 5193);** Université Jean Jaurès - Toulouse II, Composante: Centre d'études des rationalités et des savoirs (CERS).

### **Direct-To-Consumers Genetic testing : medicalisation new facet ?**

#### **Les tests génétiques vendus en libre accès sur l'Internet : nouvelle facette de la médicalisation ?**

##### English

Our study deals with Direct-To-Consumers Genetic Testing (DTCGTs) sold on the Internet, and more specifically with the ones for health, physiology, performance and behaviour. As a booming sector since 2000, this market doesn't require medical prescription, and is built without health professional consultancy for test data and results. From a sociology perspective, we used theories of medicalisation (Conrad & Schneider, 1980; Conrad, 1992) and biomédicalisation (Clarke et al., 2000). From an empirical perspective, we explored the DTCGTs market dynamic. We listed 130 web-sites and 152 entrepreneurs, then we used a double database to inform their identity. The market territorial localisation changed, and european web-sites are finally as numerous as theirs north-american counterparts. Database analyses show that biomédicalisation actors are mainly scientific geneticists, biostatisticians, and graduated of MBA which work in scientific industry. These individuals, which sometimes hold more than a single diploma, or which tend to hold hierarchical positions, use Internet as an independent commercial way from medical practitioners. The occasional physicians which start a business can be categorized as *insiders* or as *outsiders* of *scientific field*. On the institutional dimension, DTCGTs are a sign of new actors incursion in *medical field*. Companies are the locus for institutional interactions which can count clinics, research institutes, and investment funds which are specialized in science and relatively new because they are, more or less, independent of industrial groups. Furthermore, one must notice the presence of informatics and Internet companies which, till now, didn't really explore the health field in terms of conception *and* distribution of technical devices.

### French

Notre étude porte sur les tests génétiques vendus en accès libre sur l'Internet, et dédiés à la santé ou à la physiologie, aux performances ou aux comportements. En pleine expansion depuis la fin des années 1990, ce marché se construit en l'absence de prescription médicale lors de la vente, et d'accompagnement par un professionnel de santé lors de l'accès aux résultats. D'un point de vue théorique, nous discutons des théories de la médicalisation (Conrad, 1992) et de la biomédicalisation (Clarke et al., 2000). D'un point de vue empirique, nous avons cherché à comprendre la dynamique de ce nouveau marché. Nous avons répertorié 130 sites-web et identifié 155 entrepreneurs, puis avons étudiés l'évolution de ces profils. La localisation du marché évolue dans le temps, les sites-web européens étant au final aussi nombreux que leurs homologues nord-américains. En matière de *conception* et de *distribution* de dispositifs techniques, les auto-tests marquent une progression de l'autonomie des *outsiders* du champ médical, voire leur intrusion dans ce champ. En outre, ces outsiders peuvent être relativement nouveaux. Sur le plan institutionnel, par exemple, il faut noter la présence de fonds d'investissement spécialisés en science, et plus ou moins indépendants des traditionnels groupes industriels. Il faut par ailleurs constater la présence de firmes de l'informatique et de l'Internet qui, jusqu'à présent, ne s'étaient pas vraiment intéressées au champ de la santé en termes de conception *et* de distribution de dispositifs techniques.