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## Consent in forensic genetics as a tool for learning human rights.

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### Abstract

Informed consent is an ethical and legal requirement in research involving human beings. It includes the expression of the subject's autonomy upon the donation of biological material. The authors had previously recognized the high level of vulnerability of subjects referred for DNA testing at the Forensic Genetics Research Institute. In this work, they looked to improve the readability of the Informed Consent Term (ICT) and supported the donors' comprehension process with the use of a comic strip, seeking for the expression of the information presented by the ICT. It was possible to present the donation process as an instrument for learning human rights.

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### 1. Introduction

Overvaluation of DNA examinations has led to an increased search for and acquisition of legal evidence that such examinations do not always respect personal consent (Gomes, 2009; Medeiros, 2009). In fact, informed consent (IC), community consultation, and the subjects' benefits have always been cited as causes for delaying research on DNA (Cho & Sankar, 2004). Nonetheless, to avoid procedural discussions and possible revocation of proof, criminal agencies have called for the use of consent forms for forensic DNA analysis (Medeiros, 2009).

It has been recognized that obtaining or using biological material without consent violates a person's *fundamental rights, mainly, physical integrity and protection of privacy* (Gomes, 2009). Thus, an informed procedure aims to ensure the research subject's autonomy (Almeida, 2010). Providing an understanding of the protocol, discomforts, benefits, risks, and rights by the subjects is a central objective when dealing with research involving human beings (Goldim, 2003).

In the forensic area, ethical concerns should start with obtaining of biological samples and following the steps of processing, using, and storing genetic data. This would be consistent with the International Declaration on Human Genetic Data recommendations, what aimed at respecting human dignity and protecting human rights and fundamental freedoms (UNESCO, 2003).

The objective of this work was to make effective the IC process used at the Forensic Genetics Research Institute. Authors looked for improvements in the readability of the Informed Consent Term (ICT) and in the

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method of information regarding the process that the donors and their genetic material would pass through, The proposal was to enhance comprehension of the methodology. After that, a comic strip was chosen to be an attractive instrument to make learning more effective. It seemed to be a universal language, given the gap between donors and DNA sampling. Readability analysis and the suitability of the informed consent form (ICF) to the rules were emphasized. The authors tried to determine the donors' ability to understand the procedures, in order to verify that they were autonomous when they agreed to forensic DNA trials.

## 2. Material and methods

Data on the donors' educational attainment were extracted from 191 registration forms filed at the Institute involving trials carried out in 2008. Compliance of the ICT with the standards of the 196/96 National Health Council Resolution (Brasil, 2012) and the International Declaration on Human Genetic Data (UNESCO, 2003), which summarizes the current ethical standards, was also verified.

### 2.1. Readability

The consent process was analyzed, especially the ICF used since 2005 by the Forensic Genetics Research Institute of the General Department of Technical and Scientific Police of the Civil Police of Rio de Janeiro for forensic DNA samples obtained for trials.

Readability was evaluated by Flesch Reading Ease (FRE) calculated using Microsoft Office Word 2007®. This index used word length and sentence length, according to the following equation:  $FRE = 206.835 - 1.015 (\text{total words} / \text{total sentences}) - 84.6 (\text{total syllables} / \text{total words})$ . The values obtained were transformed into educational degree, necessary to understand texts in Portuguese, according to Martins et al. (1996).

### 2.2. Comic strip

A didactic comic strip was proposed to support the informed consent process. In fact, with this comic strip, interpretation of the collection process may be made by the donors themselves, instead of it depended exclusively on an spoken information. For several years, the collection process had been explained in such spoken form.

## 3. Results and discussion

A new ICT was built within a pattern that fits the educational level of donors. Most of the interviewed donors had never accessed the Internet or read books and newspapers. Moreover, on average, they had 8.1 years of formal study, which means they had attended elementary school (Garrido & Garrido, 2013). Furthermore, most people who seek services for reassurance e them, they are likely to use any tool, especially when these people are socio-culturally vulnerable (Annas, 2009; Kottow, 2003). This is the reality of the Forensic Institute.

About 45% of donors had not read the ICF (Garrido & Garrido, 2013). However, reading the form ensures the best understanding of this term, whatis the most efficient way to guarantee someone's autonomy. Thus, to make consenting free of doubts and with the aim of ensuring people's autonomy, a comic strip was constructed (Figure 1). People who come to the institute now receive this material, and someone will accompany these people to explain the process and collect their biological sample.

Since 1946, the Nuremberg Code has viewed consenting as an important part of respecting human rights (Annas, 2009). Nowadays, several international declarations, deontological codes, laws, and resolutions determine or

recommend ICF use. Thus, the IC doctrine has achieved the status of international human rights standards, as demanded by courts around the world.

In the forensic area, ethical concerns should start with the biological samples obtained and with the steps to process, use, and store genetic data. This would be consistent with International Declaration on Human Genetic Data recommendations, in order to respect human dignity and to protect human rights and fundamental freedoms (UNESCO, 2003). It may avoid the use of genetic information despite the donor's knowledge and agreement.



Figure 1 – Proposed strip to illustrate (a) consenting; (b) DNA sampling; (c) DNA extraction; (d) DNA amplification; (e) data analysis; (f) reporting.

Tuncel and Ayva (2010) used comics to successfully teach human rights concepts. Comics are considered an instrument that can be easily built up in the teaching-learning process. They are less expensive than other methods and are associated with a regression into childhood pleasures (Williams, 2008). Comics break through the worries about hard moments, which transform the donation opportunity into a complex and disgusting process.

In fact, with comics donors might interpret the collection process themselves instead of depending exclusively on spoken information. For several years, it had happened in such spoken form.

The present work showed the richness of learning. Moreover, ethics and dignity are ensured in the donation process. Despite the dependence of people on this service and their low educational levels, which may have turned the term into an instrument that is difficult to understand, the language of DNA sample processing has been modified. In this case, such modification presents a chance to practice respect for human rights and ethics.

Above all, the proposed ICT was tested and showed to be better understood than the original. Furthermore, this recent instrument will be tested and improved, in order to represent the subject's empowerment. After changes in the

consenting language, a comic strip was constructed to explain DNA sampling and processing. This must be considered permanent material to be used with donors at the Institute, to ensure respect for human rights and ethics.

#### 4. Conclusion

In fact, with the new instrument, interpretation of the collection might be done by the donors of biological material, instead of depending exclusively upon spoken information. Despite people depended on this service and they presented low educational levels, which may have turned the term into an instrument that is difficult to understand, the process of DNA sampling as shown in a comic strip may respect the subjects' autonomy. Above all, it is a chance to practice respect for human rights and ethics.

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