



## From policy making to service use. Down's syndrome antenatal screening in England, France and the Netherlands



Carine Vassy<sup>a,\*</sup>, Sophia Rosman<sup>b</sup>, Bénédicte Rousseau<sup>a</sup>

<sup>a</sup> Université Paris 13, Sorbonne Paris Cité, IRIS, EHESS, CNRS, UMR 8156, INSERM U997, 74 rue Marcel Cachin, F-93000 Bobigny, France

<sup>b</sup> Inserm U750-Cermes, Site CNRS, 7 rue Guy Môquet, F-94801 Villejuif Cedex, France

### ARTICLE INFO

#### Article history:

Received 15 April 2013

Received in revised form

20 January 2014

Accepted 24 January 2014

Available online 31 January 2014

#### Keywords:

Policy

Screening

France

England

Netherlands

Down's syndrome

Informed consent

### ABSTRACT

In industrialised countries, certain biomedical innovations have come into general use, but the ways they are used vary considerably. Prenatal screening techniques for Down's syndrome are a perfect example of this. In 2010, screening rates stood at 61% in England and 84% in France; the previous year the rate was 26% in the Netherlands. The objective of our research, which took place in these three countries between 2008 and 2011, was to explain these differences. In these countries, public authorities focus on women's free access to innovations and on receiving their informed consent. But other aspects of screening policy vary, as do the health systems in which they are implemented. Our study shows that the sociotechnical settings which vary from country to country affected the interactions during the consultations we observed and thus impacted the decision of whether or not to screen.

© 2014 Elsevier Ltd. All rights reserved.

Healthcare innovations are legitimised only when rules have been established to govern their use and when public authorities have created a regulatory framework (Baszanger et al., 2000). Such innovations raise specific issues where screening is concerned. They make it possible to calculate whether a given person runs a significant risk of developing a health problem, and then where necessary to offer diagnostic tests which are generally more expensive and/or dangerous. They are aimed at persons in good health, with a view to preventing problems for which they have no symptoms. When public authorities assess the benefits of screening to decide whether or not to introduce a policy which offers easier access to the service, they face a difficult choice because part of the population can demand access to these innovations as a right, whereas others will consider them to be an additional form of monitoring (Armstrong and Eborall, 2012).

In Europe, programmes for prenatal screening for Down's Syndrome (DS) illustrate the dilemma facing public authorities. National policies have been developed only after considerable hesitation. In several European countries, a small number of obstetricians – who worked in university hospitals and who held

positions in professional associations – were a driving force behind the introduction of innovations in prenatal diagnosis (foetal karyotyping following amniocentesis or trophoblast biopsy), and then screening (markers in the maternal blood and foetal ultrasound) (Reid, 1991). These obstetricians proposed experimental innovations to their patients, to allow them to see whether or not their fetuses had DS and thus to have an abortion should they so wish. Public authorities only intervened at a later date, in response to criticisms from obstetricians who highlighted their patients' requests for said innovations and demanded an end to the inequality of access to these tests. Public authorities feared that because it would lead to abortions, the generalisation of screening would be criticised by electors as a eugenic approach (Petrogiannis et al., 2001; Vassy, 2006).

In the majority of European countries, public authorities opted for screening accessible to all and asked practitioners to obey two principles: that of informing all pregnant women of the existence of these tests, so as to counter inequalities of access, and that of providing said information without influencing their patients, leaving them free to choose whether or not to have the tests. The discourse on freedom of choice and neutrality is essential to the legitimisation of public policy. The notion of choice can be considered as an ideology which justifies the development of numerous healthcare policies (Alaszewski and Brown, 2012).

\* Corresponding author.

E-mail addresses: [c.vassy@iname.com](mailto:c.vassy@iname.com) (C. Vassy), [rosman@vjf.cnrs.fr](mailto:rosman@vjf.cnrs.fr) (S. Rosman), [benedicte.rousseau@yahoo.fr](mailto:benedicte.rousseau@yahoo.fr) (B. Rousseau).

This ideological framework for prenatal diagnosis and screening is criticised in social science works which believe freedom of choice and decision-making on the basis of objective and neutral information to be fiction. The fact that tests are proposed within a medical context gives immediate legitimacy to the objective of abortion (Green and Statham, 1996). The unfavourable situation of disabled persons in western societies means that many women prefer to avoid their birth (Asch, 1999). Other women have no opinion on the matter and prefer to delegate this type of decision-making to professionals (Rapp, 2000). Under the guise of giving pregnant women greater choice and freedom, the State is introducing a new form of government in terms of controlling the quality of fetuses (Schwennesen et al., 2010).

Other social science researchers have conducted empirical studies of the gap between professional practices and the official discourse on informed consent.

In England, Marteau et al. (1992) observed that practitioners present the tests during consultations in such a way as to encourage pregnant women to have them. They provided little information on the test, the disease that they were looking for or the significance of the future results. Presented as one of many other tests recommended for maternal and foetal health, prenatal screening thus becomes routine: women do not always understand that they must choose whether or not to accept it, nor that it can lead to a termination of pregnancy. In another study practitioners in England say that they are unable to be non-directive when they provide information on this screening (Williams et al., 2002). Other observations of consultations in England show that the information given to women is often very limited, and that the test is presented in a favourable light (Pilnick, 2008; Tsouroufli, 2011). The same observation is made in the USA (Press and Browner, 1997) and a study in France shows that practitioners do not always ask for consent for ultrasound screening (Champenois-Rousseau and Vassy, 2012). In other European countries, surveys confirm that certain pregnant women do not realise that they have a decision to make (Schwennesen et al., 2010; Favre et al., 2007).

Some of this research looks at how organisational factors affect interactions between pregnant women and healthcare professionals; for example, having all the tests in a single day in a one-stop clinic in England (Tsouroufli, 2011), or the financial interests of the managers of a health maintenance organization in the USA (Press and Browner, 1997). Yet we know little about the role of national screening policies. This topic is often neglected, even in studies on the decision-making processes of pregnant women with regard to prenatal screening in various countries (Crombag et al., 2013; Reid et al., 2009). Whilst in many European countries these policies have the same conceptual framework, in other aspects they are different; furthermore, they are implemented within specific healthcare systems, where standards governing pregnancy management existed before the introduction of this screening, were embedded in professional practices and could orient the implementation of public policies.

## 1. Studying how public policy is implemented

We propose to analyse the way screening consultations are organized and conducted as a means of implementing public policy within a health care system. We chose to not restrict ourselves to a study of the communication between healthcare workers and patients, but rather to analyse from policy making to service use and to draw attention to the organisational aspect so as to understand healthcare delivery (Griffiths, 2003).

Our international comparison bears upon both the characteristics of public policies and health systems, and upon the practices observed during consultations. We make the hypothesis that the

former affect the latter, by creating specific sociotechnical settings. The concept of sociotechnical setting places the accent on the flexibility of the technical object, which may be used in different ways, depending on the network of actors in which it is embedded, whilst at the same time placing constraints on relations within said network (Akrich, 1992). Within these settings are embedded scripts, i.e. implicit expectations regarding the roles of users and care providers. We will show that settings vary and that they affect interactions between healthcare professionals and pregnant women.

The three countries compared are: England, where medical initiatives favouring the generalisation of screening must work alongside the institutions in charge of public health and which might be resistant to imperative screening (Faulkner, 2012); France, where innovations are driven by a relatively autonomous medical profession which must cope with a multitude of health organisations and a fragmented governance of the health system (Benamouzig, 2010) and the Netherlands, where medical initiatives have led to public controversy and to conflict with Parliament and the Government (Stemerding and Van Berkel, 2001). The choice of these countries can also be justified by significant differences in screening uptake rates: 61% in England in 2010, 84% in France in the same year, and 26% in the Netherlands in 2009 (Blondel and Kermarrec, 2011; Schielen, 2011; Ward, 2011a).

## 2. Method

Our comparison relates to macro and microsocial qualitative data, which is a tried and tested methodology in sociology (Hantrais and Mangen, 1996). In all three countries we analysed official documents from public authorities and professional healthcare associations, along with press articles and social science documents relating to prenatal policy. We also conducted fieldwork.

### 2.1. English fieldwork

In February and March 2011, Bénédicte Rousseau and Carine Vassy working separately but in the same places, observed and recorded 16 consultations given by 6 midwives. These midwives were employed in the National Health Service (NHS) and worked at three consultation sites in socially mixed districts of an average-sized town in the East Midlands. The sociologists observed initial consultations with pregnant women with midwives presenting the first-trimester combined prenatal screening for DS. This combined test calculates a single estimation of risk, based on three variables (maternal age, serum markers and ultrasound measurement of the fetus's nuchal translucency).

In accordance with the recommendations of the NHS research ethics committee, who authorised this study, the sociologists prepared an information letter explaining their research, which was sent to pregnant women prior to their consultations. Just before the consultation, the sociologists asked whether the women agreed to the recording and to their being present, and received their written consent. There were a few refusals from the pregnant women, but the midwives agreed to the presence of the researchers. The consultations were then fully transcribed and anonymized.

### 2.2. French fieldwork

Bénédicte Rousseau and Carine Vassy worked successively in a university hospital in the Paris region between October 2008 and December 2009 with the permission of the Head of the Obstetrics Department. The hospital is located in a working-class district and used by a relatively high population of immigrants. The sociologists

Download English Version:

<https://daneshyari.com/en/article/7335488>

Download Persian Version:

<https://daneshyari.com/article/7335488>

[Daneshyari.com](https://daneshyari.com)